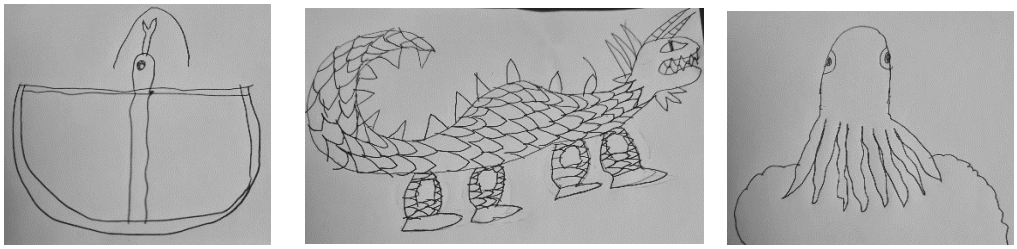
Fighting Imaginary Dragons and Battles with Arrow Snakes and Octopuses

AN EXPLORATION OF THE EXPERIENCES OF CHILDREN'S PALLIATIVE CARE FOR FORCED MIGRANT FAMILIES AND THOSE WHO CARE FOR THEM



Images by Jonah aged 8

by

MARIE ANNE CLANCY

A thesis submitted to the University of Birmingham for the degree of DOCTOR OF PHILOSOPHY in NURSING

The School of Nursing and Midwifery
College of Medical and Dental Sciences
University of Birmingham

April 2023

UNIVERSITY OF
BIRMINGHAM

University of Birmingham Research Archive

e-theses repository

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

Abstract

Background - The aim of this study was to understand the care experiences of forced migrant families from both family and care provider perspectives, in hospital, hospice and community settings. Palliative care for children requires an active, holistic approach to care, with a focus upon improving quality of life. Children's palliative care is complex and multifaceted, requiring multiple specialist and organisation involvement, yet there is limited research to guide practice. Even less is known about the experiences of forced migrant families who encounter a range of additional challenges including the loss of family, belongings, and all sources of familiarity and support. The difficulties of navigating complex bureaucratic systems can confound access and communication difficulties. With acknowledgement of such challenges, a systematic review was conducted which combined existing research from children's palliative care and forced migration. The review highlighted the paucity of literature in this area.

Methodology- Underpinned by a constructivist research paradigm, the Silences Framework offered novel theoretical and philosophical concepts, which helped to situate and prioritise the 'silences' within the marginalised discourses of forced migration and palliative care. Interpretative Phenomenological Analysis methodology was used to privilege participant perspectives and apply an active in-depth cyclical process of reflection and reflexivity. Advisory group members provided expertise in childhood illness, palliative care and forced migration, throughout the study. Through purposive sampling 14 participants contributed to semi-structured interviews, alongside the use of creative research methods of 'draw and talk' to enhance participant expression. Following individual and cross-case analysis, advisory groups

supported the creation of poetic accounts for each participant, alongside interpretative reflective discourse about participant meaning-making. This additional analysis added an extra lens in which to reflexively see, challenge and understand.

Findings - Aspects which optimised families' experiences included compassionate, empathetic, family centred care which valued family belief systems and coping strategies. Two-way learning with and from families was described by all participants, which enhanced understanding and fostered mutual respect. However, barriers to quality care included poor access to services and resources, protocol-led care, limited time with families, communication barriers and staff burnout.

Conclusions – Empirical contributions of this study include the need for a specific educational pathway for health care professionals to include spiritual care provision, cultural humility, and moral reasoning. Interdisciplinary education including the use of lived expert by experience insights, and the arts are also advocated. Implications for future nursing practice include the prioritisation of additional time to build relationships, the importance of interpreter support and the need for better access to hospice care for forced migrant families. Methodological contributions include approaches for enhancing advisory group dialogue and the benefits of creative research methods. Poetry was particularly valuable as it offered a way to understand complex lived participant experience such as faith and healthcare decision making, and also a method for meaningful advisory group dialogue. As such suggestions for how all these aspects might be advanced are also outlined.

Dedication

This doctoral study is dedicated to my wonderful dad John Walters, who was always my biggest cheer leader. I will be forever grateful for his guidance, support and unconditional love.

"She did not stand alone, but what stood behind her, the most potent moral force in her life, was the love of her father" (Lee, 2015, chpt 9, p14)

Acknowledgements

Ode to the PhD

Dear PhD

You have taught me about perseverance

more than any song could

You have etched into my heart a yearning for growth, for better

but you have also stolen many moments, treasured times,

like a labyrinth goblin

you've crawled uninvited into private worlds

stealing peace and persisting in your desire for attention, for completion.

We have battled over sleep, over priorities and time

and yet you have taught me, and nurtured me despite your meanness.

Thank you for the lessons, for showing me my strength and determination

I am grateful for my beautiful children for giving me perspective, my husband for giving me unconditional love, friends to laugh with and my supervisors for their wisdom and support.

I promise to take my passion to improve children and families care with me

and to help others on this journey in the future.

Contents page

Authors declaration form i
Abstract ii
Dedication iv
Acknowledgements v
Ode to the PhD v
Contents page vi
Tables and Figures xiv
Common abbreviations and terminology utilised within this study xvi
Chapter One: Introduction to the study 1
1.0 Introduction 1
1.1 Introduction to Stage One 'Working in Silences' – Background and Contextualisation 5
1.2 Children's Palliative Care Definitions 6
1.3 Prevalence of children requiring palliative care in the UK 7
1.4 Global prevalence 7
1.5 Gaps in access to children's palliative care 8
1.6 Differences between children's and adult palliative care needs 10
1.7 Parental needs when caring for a child with life-limiting or life-threatening conditions 11
1.8 The impacts of providing children's palliative care for health care professionals 13
1.9 Refugee and asylum seeker terminology 14
1.10 Statistics regarding forced migration to the UK 15
1.11 Community hostility 16
1.12 Positive social action 18
1.13 Migration Trauma 18
1.14 The Combination of forced migration and children's palliative care 20
1.15 The Impact of Covid-19 24
1.16 The limited evidence base for care 27
Chapter Two: Study Paradigm and Framework 29
2.0 Introduction 29
2.1 Ontology and epistemology 29
2.2 The Importance of Theoretical Frameworks 30
2.3 Cultural Competence 31

2.4 Cultural Health Capital 33
2.5 Cultural Safety 34
2.6 Cultural Humility 35
2.7 Social Justice Framework 37
2.8 The Silences Framework 38
2.9 Stage by Stage Synopsis 39
2.10 Silences Framework critique 44
2:11 Research Aim and Questions 45
Chapter Three – Systematic Review of the international literature 47
3.0 Systematic Review method 47
3.1 Aim of the Systematic Review 47
3.2 Search strategy 48
3.3 Prospero 52
3.4 Search outcome 52
3.5 Prisma diagram 53
3:6 Quality appraisal 55
3.7 Data Extraction 58
3.8 Synthesis 63
3.9 Results 64
3.10 Recruitment issues 64
3.11 Thematic development 66
3.11.1 Theme 1) Divergence of beliefs and expectations 66
3.11.2 Theme 2) Communication 68
3.11.3 Theme 3) Navigating healthcare systems 69
3.11.4 Theme 4) Burdens and coping strategies 71
3.11.5 Theme 5) Training and knowledge 71
3.11.6 Theme 6) - Perceptions of forced migrant's life world 72
3.12 Limitations, strength and generalisability, transferability of the evidence 75
3.13 Recommendations 76
3.14 Conclusion to the Systematic Review 76
3:15 Conclusion to Stage One 77
Chapter Four Methodology 78
4.0 Introduction to Stage Two – Hearing Silences 78
4.1 Interpretative Phenomenological Analysis 80
4.2 The Philosophical Knowledge of IPA 86

4.3 Phenomenology 86
4.4 Hermeneutics 88
4.5 Idiography 91
4.6 Creative methods, introduction and rationale 93
4.7 Semi-structured interviewing 95
4.8 Funnelling technique 96
4.9 Pilot interview 97
4.10 Draw and Talk method 98
4.11 Poetry 99
4.12 Two methods of poetry creation 104
4.13 Limitations to creative approaches 107
Chapter Five - Positionality and Reflexivity 111
5.0 Introduction to approaches 111
5.1 Positionality and introspection 112
5.2 Gatekeepers within the study and insider/outsider positionality 116
5.3 Power imbalances within the study 118
5.4 A Cultural Humility approach within participant interactions 120
5.5 Peer Correspondence and Letter Writing 120
5.6 Reflexive diary and poetry 121
5.7 Conclusion 125
5:8 Conclusion to Stage Two 125
Chapter Six - Data Collection 126
6.0 Introduction to Stage Three – Voicing Silences 126
6:1 Ethical considerations 127
6:2 Recruitment of participants 128
6.3 Participant Information Sheets 128
6.4 Information giving to clinical teams 130
6:5 Assent and Consent Procedures 131
6:6 Protection from harm 132
6:7 Online interviewing 133
6:8 Sampling processes including inclusion and exclusion criteria 136
Chapter Seven – Data Analysis 141
7:0 Introduction to IPA process 141
7:1 IPA stages of data analysis 142
7:1:1 Exploratory notes 142

7:1:2 Descriptive, linguistic and conceptual notes 142
7:1:3 Experiential Statements or initial theme creation 144
7:1:4 The Creation of Personal and Group Experiential Themes 146
7:2 Rigour and transparency of method 152
Chapter Eight - Findings by theme and setting 154
8:0 Introduction to the section 154
8:1 Group Experiential Themes (GETs) by setting 154
8:2 Explanations of settings 156
8:3 Community setting findings 158
8:3:1 The need for additional carers 159
8:3:2 Lack of financial support 161
8:3:3 Housing 162
8:3:4 Difficulties in accessing resource and services 164
8:3:5 Reluctance to complain 165
8:3:6 A perceived lack of parental proactivity 166
8:3:7 Difficulties in coordinating care 168
8:3:8 Multidisciplinary team working 168
8:3:9 The need for additional time with forced migrant families 170
8:3:10 Judgements, labelling and safeguarding referrals 173
8:4 Hospice setting 177
8:4:1 Relationship building 178
8:4:2 Two-way Education 179
8:4:3 Additional time in the hospice setting 182
8:4:4 Crossing Professional Boundaries and burnout 183
8:4:5 Rest and Respite 187
8:4:6 Difficulties with access and acceptability of hospice care 188
8:5 Hospital setting findings 190
8:5:1 Time spent with families in hospital 191
8:5:2 Lack of caring concern and family centred care 194
8:5:3 Environmental aspects 195
8:5:4 Going the Extra Mile 196
8:5:5 Alienation and Discrimination 196
8:5:6 Divergence of beliefs 204
8:5:7 Gentle Conversations 206
8:5:8 Truth telling and hope 206

8:5:9 Views on Pain 208
8:5:10 Faith and coping strategies 210
8:5:11 Search for normality 213
8:6 Combined across settings findings 218
8:6:1 Parental burdens and gender norms 219
8:6:2 Link and Peer Workers 223
8:6:3 Communication and language barriers 225
8:6:4 Essential nursing characteristics 230
8:7 Summary of findings 235
Chapter Nine - Silences Dialogue ..... **Error! Bookmark not defined.**
9:0 Introduction 237
9:1 Collective Voices Poetry Creation 239
9:2 Dialogue with Collective voices 243
9:3 Dialogue with participants 246
9:4 Conclusion to Stage Three 250
Chapter 10 – Discussion 251
10.0 Introduction to Stage Four – Working in Silences 251
10.1 Summary of study aim and research questions 253
10.2 The factors that optimise or hinder care from the perspective of forced migrant families 253
10.2.1 Building relationships 253
10.2.2 Understanding migration trauma 254
10.2.3 A humane approach to care 255
10.2.4 Reducing discrimination, labelling and stereotyping 256
10.2.5 Engagement 258
10.2.6 Time 259
10.2.7 Social isolation 260
10.2.8 Understanding and responding to family beliefs 261
10.2.9 Difficulties navigating systems and accessing care and resources 266
10.2.10 Cultural Humility in relationships 266
10.2.11 Elements of care combined and illustrated in tree figures 267
10.3 Representing the voices of forced migrant children and their families in research 269
10.3.1 Evaluating draw and talk methodology 270
10.3.2 Evaluating poetic approaches 271

10.3.3 Family photographs and video footage 272
10.3.4 Additional benefits to creative methodology 273
10.4 Children's palliative care professionals' beliefs about factors that optimise or hinder care 274
10.4.1 Access barriers and the challenges of multidisciplinary working 275
10.4.2 Difficult working environments and subsequent HCP burnout experiences 277
10.4.3 Entitlement to healthcare, racism and discrimination 279
10.4.4 Link workers and peer support for families 280
10.4.5 Moral reasoning 281
10.4.6 Two-way education 282
10.4.7 Summary and tree model 283
10.5 Study Limitations 285
10.5.1 Complementary approaches 287
10.5.2 Critique of Interpretative Phenomenological Analysis 288
10.6 Advisory group support with the creation of recommendations 289
10.7 Combined findings in poetic form 292
10.8 Conclusion to Stage Four 295
Chapter 11 Study contributions and recommendations 296
11.0 Introduction to Stage Five – Planning for Silences 296
11.1 Empirical contribution – the need for increased awareness and education 298
11.1.1 The need for improved spiritual care provision 299
11.1.2 The importance of terminology 300
11.2 Recommendations for research 300
11.3 Recommendations for Education 301
11.3.1 Education via lived experience 301
11.3.2 Cultural Humility, Self-Awareness and Moral reasoning 302
11.3.3 Spirituality 302
11.3.4 Interdisciplinary education and pedagogical techniques 303
11.4 Practice recommendations 304
11.4.1 Time and Staff Allocations 304
11.4.2 Prioritising access to hospice care 306
11.4.3 Addressing communication difficulties 307
11.4.4 The provision of further staff support 308
11.5 Methodological contributions 309
11.5.1 Silences Framework suggested amendments 309

11.5.2 Silences Framework amendment recommendations 310
11.5.3 Creative research methods and coproduction 312
11.5.4 Creative research methods and coproduction recommendations 314
11.6 Research Recommendations and summary 315
11.7 Conclusion to Stage Five 316
11.8 Conclusion to the study 318
References 322
Appendix One – Considerations for theoretical framework 362
Appendix Two - Published Systematic Review in Journal of Advanced Nursing 363
Appendix Three – Prospero Protocol 376
Appendix Four - Coding of an individual paper 381
Appendix Five - Dynamic relationships across the codes/themes 382
Appendix Six - Coding across papers 383
Appendix Seven – Advisory group information and study involvement 384
Appendix Eight - Draw and talk mapping utilised with HCP 386
Appendix Nine - Draw and talk mapping for parent/guardian and child (dependent on age/understanding) 387
Appendix 10 – New Lives New Hope – parent advisory poem with direct use of participant quotes (seen in bold) 388
Appendix 11 – Poem from Guardian advisory group member – A Muslim Chaplaincy (with text changes shown in blue) 390
Appendix 12 – Ethical approval documentation 392
Appendix 13 – Participant information sheets for families and children of different ages 394
Appendix 14 – Example informed assent/consent form 403
Appendix 15 – Protocol for potentially distressed participants during research interviews 406
Appendix 16 – Inclusion and Exclusion Criteria for the study 407
Appendix 17 – Family Tessa poem written for their son 408
Appendix 18 – End of Study Information HCP 411
Appendix 19 – End of Study Information Families 413
Appendix 20 – Poem - Notes on my Native Land 415
Appendix 21 - Advisory group thoughts on translating and implementing results to realistic recommendations 416
Appendix 22 – Poem about HCP Marian written by YPAG members 419
Appendix 23 – Poem about HCP Flo written by Marie Clancy 422

Appendix 24 – Poem about HCP Sobia written by Guardians member... 423Appendix 25 – Poem about HCP Clara written by YPAG member..... 425
Appendix 26 – Poem about HCP Holly written by Marie Clancy 426
Appendix 27 – Poem about Family Ahmed written by Parent Champion 427
Appendix 28 – Poem about Family Ahmed written by Parent Champion 430
Appendix 29 – Poem about Family Khatri written by Parent Champion 433
Appendix 30 – Poem about Family Tessa written by Parent Champion..... 436
Appendix 31 - A Kenning poem..... 438

Tables and Figures

Tables

Table One – LLT/LLC Categories 6

Table Two – Inclusion/Exclusion Criteria 49

Table Three – MMAT Results 57

Table Four – Data Extraction Table 58

Table Five – Included studies summarised data extraction table 60-62

Table Six – Methodological approaches and choices for this study 82-84

Table Seven - Example IPA Analysis for individual participant Rebecca 141

Table Eight – Personal Experiential Theme (PETs) One for Kinza 145

Table Nine – Personal Experiential themes (PETs) or individual themes by HCP participant 147

Table 10 – Personal Experiential themes (PETs) or individual themes by family participant 148

Table 11 – Group Experiential Themes (GETs) by family and HCP participant groups 150

Table 12 – GETs across settings 151

Table 13 – Poetry created from participants accounts 240

Figures

Figure One – Stage One Working in Silences 5

Figure Two – Silences Framework and application within this study 43

Figure Three – Key words/search terms 51

Figure Four – Prisma Diagram 54

Figure Five – Stage Two Hearing Silences 80

Figure Six – The Double Hermeneutic Cycle used in IPA Methodology 90

Figure Seven – Case study used with BARA advisory group members 101

Figure Eight – Poem to promote discussion with BARA advisory group 102

Figure Nine – Stage Three Voicing Silences 127

Figure 10 – Advisory group suggestions and changes made to information sheet for participant recruitment 129

Figure 11 – Participant Demographics 140

Figure 12 – All the settings included in the study and their links 156

Figure 13 - The differing factors within this community setting 157

Figure 14 The differing factors within the hospice setting 176

Figure 15 – Flo's drawing to illustrate the family 183

Figure 16 – The differing factors within the hospital setting 189

Figure 17 – Pasban's drawing of Sohail and him in hospital 213

Figure 18 – Drawing by Peroz of Sohail (in yellow) in the hospital bed and then walking out of the hospital 214

Figure 19 – Pasban's drawing displaying positive and negative aspects of his experience 216

Figure 20 – The differing factors which were combined across settings 217

Figure 21 – Rida's drawing of herself as a bridge 221

Figure 22 – HCPs drawings which illustrate sense of self in their caring roles 233

Figure 23 – Timeline to show regular input of advisory groups throughout the study 237

Figure 24 – Images from the website 239

Figure 25 – Stage Four Working with Silences 250

Figure 26 – The tree model to illuminate factors seen as optimising or hindering to care, from forced migrant family's perspectives 267

Figure 27 - The tree model to illuminate factors seen as optimising or hindering to care, from HCPs' perspectives 283

Figure 28 - Venn diagram to show the relationship between Cultural Humility, IPA , the Silences Framework and creative methods in this study 286

Figure 29 – Slides to show research findings from family and HCP perspectives to advisory group members 289

Figure 30 – Stage Five – Planning for Silences 295

Figure 31 – Summarised findings and recommendations for future practice, education and research 315

Common abbreviations and terminology utilised within this study

TfSL	Together for Short Lives (leading children's palliative care charity in the UK)
CPC	Children's Palliative Care
LLC	Life Limiting Condition
LLT	Life Threatening Condition
HCP	Health Care Professional
FCC	Family Centred Care
MDT	Multidisciplinary Team
Collective Voices	Advisory group or Patient and Public Involvement (PPI) in the study
EOL	End of Life
MMAT	Mixed Methods Appraisal Tool
IPA	Interpretative Phenomenological Analysis
PETs	Personal Experiential Themes
GETs	Group Experiential Themes

Chapter One: Introduction to the study

1.0 Introduction

This thesis presents the findings of a qualitative interpretative study into the experiences of children's palliative care for forced migrant families and those who care for them. Approaches to palliative care focus on enhancing quality of life and meeting holistic needs, when families face a problem associated with a life-limiting or life-threatening condition (WHO, 2018). The distinction between palliative and end of life care, is that death is not expected imminently and so palliative care for children may extend throughout months to years of their life. Palliative care is all-inclusive in nature and so may result in health care professionals caring for children with multi-organ interconnected conditions and disabilities. Subsequently, this may require many specialists, within diverse settings such hospital, community and hospice. As medicine has advanced so too has the medical complexity of children's palliative care. These changes have meant an increasing dependency upon expensive medical technology. Intricate and often onerous caring roles for families and children who may live longer, but with increasingly complex needs.

Currently over a 100 million people are displaced due to war, violence, fear of persecution and human rights infringements (UNHCR, 2022). The effects of such displacement are complex but involve social, political and legal dimensions. For many forced migrant families a route into the UK is sought to seek diagnosis, better care or even cure for their children. The circumstances surrounding forced displacement mean that families may have been exposed to conflict and the

disruption of health and social care infrastructure in their country of origin (RCPCH, 2023). Forced migrant families have often experienced long and dangerous journeys, alongside the grief of separation from home and family to reach the UK. Whilst the two aspects of this study; children's palliative care and forced migration are equally important areas of healthcare, they are both neglected in current discourses. This is compounded when they are combined.

My background as a children's nurse alongside experiences of working overseas and within nurse education, have instilled a desire to improve the care for families who are frequently marginalised. My motivation for this study comes from an understanding that the world is not the same for everyone and that with lived experience comes expertise.

Following a review of theoretical frameworks, methodology and methods four inter-connected aspects have been utilised to enhance the findings and analysis. First, the Silences Framework has underpinned the structure and philosophy of this study. With the aim of hearing the 'silences' forced migrant families experience in children's palliative care which may not have been previously recognised or 'heard'. Second, an Interpretative Phenomenological Analysis (IPA) approach has been used to privilege the voices of participants, by combining the psychological, interpretative and idiographic elements of experience. Third, within semi-structured interviews with three families and the health care professionals who care for them, creative methods including 'draw and talk' and poetry have been used. These creative methods helped to enhance expression and create rich detailed examinations of participants accounts. Advisory group members with varied lived expertise, have been involved

in the study throughout to give additional insights and help to readdress power imbalances. Fourth, Cultural humility whilst not a theoretical framework for the study, has been used as a way to offer clear, transparent reflexive research approaches and as a method to limit subjectivity bias. When interviewing participants and working with advisory group members, a Cultural Humility stance also offered an open-minded lens in which the expertise and ability to educate was deliberately transferred. These four complementary approaches have allowed me to give prominence to reflection, equality and empathetic methods, which all aim to enhance relational aspects of understanding and insight.

Analysis of the 14 participant accounts involved individual case by case thematic analysis, followed by group analysis. Group analysis was conducted by family participant, health care professional participant and then through the creation of care setting specific themes. Further analysis and an additional level of interpretation was added through poetic creation and subsequent reflective dialogue with advisory group members and family participants, to aid and enhance my understanding.

The Silences Framework includes five stages which will be outlined in the succeeding chapters. Stage One – 'Working in Silences' includes the background and contextual information of the study alongside a rationale for the study paradigm and chosen theoretical framework. This stage concludes with an international systematic review of the literature to identify the gap in the literature and subsequent need for this study. Stage Two – 'Hearing Silences' includes the methodology, creative methods and my positionality and reflexive approaches within the study. Stage Three – 'Voicing Silences' includes chapters on data collection, findings by

theme and setting and a ‘Silences Dialogue’ for reflective interpretations with the collective voices of this study. Stage Four – ‘Working with Silences’ offers the discussion chapter, and limitations to the study. Finally Stage Five concludes the study with empirical and methodological contributions and recommendations for future practice, research and education.

1.1 Introduction to Stage One 'Working in Silences' – Background and Contextualisation

Throughout this study the Silences Framework (Serrant-Green, 2011) has been utilised philosophically and pragmatically in structuring the thesis. Stage One of the Framework explains the context of the study, including setting out the existing knowledge surrounding children's palliative care and forced migration. The literature has been examined to explore the cultural, clinical, psychosocial and moral arena in which this doctoral research has been conducted. It begins with an acceptance that 'silences' exist and are inherent in a flawed world and follows as depicted in Figure One. Further discussion of the Silences Framework is detailed within the study paradigm and theoretical framework chapter.

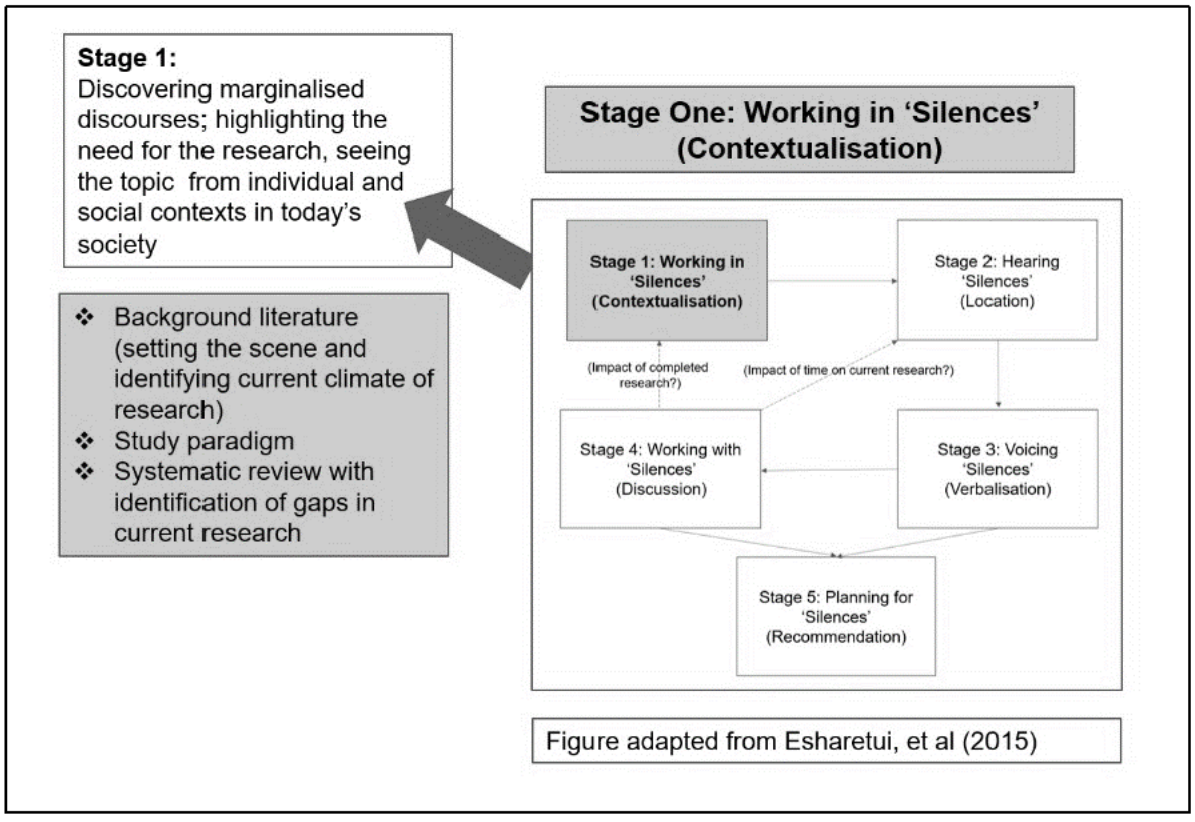


Figure One – Stage One Working in 'Silences'

1.2 Children's Palliative Care Definitions

Children's palliative care (CPC) has been defined as a holistic approach from diagnosis throughout a child's life including symptom control, end of life and bereavement care. The advocates for CPC recommend consideration of the physical, emotional, social and spiritual elements of care, to enhance quality of life and the support of the family (Together for Short Lives (TfSL), 2018a).

Children with palliative care needs have a primary, multifaceted, life-limiting or life-threatening condition. Life limiting conditions (LLC) are said to have no reasonable hope of cure and children will die as a result. Life-threatening conditions (LTC), have viable, curative treatment but this may not always be successful (Thompson, 2015). The definitions for LLC and LTC are quite broad and so within this study the categories encompassing the spectrum of conditions that lead to palliative care needs will be utilised, as described in Table One.

Table One – Life limiting/threatening conditions categories (described by Thompson (2015) and TfSL frameworks)

Group 1	Life threatening conditions for which curative treatment may be feasible but can fail. Examples include cancer, or irreversible organ failures such as heart, liver or kidney
Group 2	Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, but where premature death is still possible or inevitable. Examples include cystic fibrosis, Duchenne muscular dystrophy.
Group 3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples include Batten disease, mucopolysaccharidoses.
Group 4	Includes conditions such as severe neurological disability, where the underlying condition may be static but which may cause weakness and susceptibility to complications leading to premature death. Examples include severe multiple disabilities such as severe cerebral palsy or post severe head injury.

1.3 Prevalence of children requiring palliative care in the UK

In 2012 Fraser et al. estimated there to be 49,000 children and young people (0-18 years) living with LLC and LTC in the UK, with 2,500 deaths from these conditions each year (Sidebotham et al, 2014). Since these figures were produced, the number of children needing palliative care has increased, as has the severity of need due to cutting-edge clinical developments which can prolong the lives of even the most complex children (Thompson, 2015; Mitchell, et al., 2018). Overall the prevalence of LLC has increased 2.6 times since 2010 (Fraser et al, 2020). The highest prevalence of palliative care need was found amongst children of Pakistani origin. However, poor recording and missing data were common problems when analysing hospital data – with a higher prevalence of deprivation in those children living with LLC (Fraser et al, 2020). For the West Midlands region, this relates to 298 child deaths from LLC/LTC in 2015/16, with a 5.3% increase in hospital-based deaths (NHS England, 2017). The 'Make Every Child Count' study predicts a continual increase in LLCs with an expected prevalence of between 67.0 and 84.2 per 10,0000 population (Fraser et al, 2020).

1.4 Global prevalence

The unmet need for palliative care is substantial, an estimated 40 million patients require palliative care annually, with 20 million of these at the end of life. Seventy-five per cent of the world's population live in countries that have no or very limited access to controlled substances for pain relief. Additionally almost 80% of the need for palliative care is in low- and middle-income countries (Clelland et al., 2017;

Connor and Sepulveda, 2020). A recent survey revealed a substantial gap in care provision, with an estimated 170,000 children dying each year in Europe without access to CPC (Arias-Casais et al., 2020). A variety of factors lead to these deficits but predominantly poor health care systems, a lack of specialised training and limited opioid access are key aspects (Brown et al, 2014). Discussions in the Lancet and from international palliative care communities, correlate and advocate for palliative care to become an integral part of humanitarian disaster responses (Powell et al, 2017; Wiseman, 2017). Currently, humanitarian crises prioritise the prevention of communicable disease but the lack of palliative care provision may result in missed opportunities to minimise symptoms and maximise quality of life (Powell et al, 2017; Wiseman, 2017).

1.5 Gaps in access to children's palliative care

There is a growing awareness globally that there are enormous gaps in access to CPC (Institute of Medicine, 2003). CPC is complex and multifaceted with many ingrained misconceptions. Families' belief systems and grief may lead them to focus on futile care, which can lead to denial, a reluctance to engage with specialist services or to give the essential medicines needed to relieve pain. Moreover, CPC is compromised by a lack of specialist staff and resources, a lack of education for health care providers and negative public perceptions (Connor, Downing and Marston, 2017; Collins, McLachlan and Philip, 2018; Friedrichsdorf and Bruera, 2018). Two high profile court cases (Charlie Gard and Alfie Evans) provide examples of extensive negative reporting by the media, which resulted in intense national and

international scrutiny and further confusion regarding CPC. Both of these accounts were brought into the spotlight following prolonged disputes with medical professionals regarding the child's best interests and parental pleas for futile care. In the wake of Alfie Evans death, there were calls for changes to UK law as the conclusions drawn by the Court of Appeal, Supreme Court and the European Court of Human Rights were seen in opposition to a respect for parental autonomy (Wilkinson and Savulescu, 2018). However, lengthy legislative processes are distressing for families and traumatic for health care professionals (HCPs) and promoting ways to reach decisions without such processes would be optimal. Thus, further investment in ethical committees may be necessary to allow for consultations to resolve conflict, or to bring in the need for interdependent mediation in the future (Wilkinson and Savulescu, 2018).

In such cases as Charlie and Alfie where staff motivations regarding care were questioned by the media, more needs to be done to challenge negative perceptions and empathise with the real-life situations faced by both parents and HCPs. TfSL (2018b) following these cases called for fuller understanding of the important and significant roles and work of HCPs in CPC, to enhance the public's understanding. A further consideration within this study is that both Charlie and Alfie's families could speak English and had a good understanding of the roles of HCPs and the wider NHS system. For forced migrant families when both elements of language and health literacy may be missing or limited, ethical decision making in CPC becomes even more complex and potentially traumatic for all involved.

Although parental reluctance to seek and accept CPC can be challenging there are also difficulties relating to a reluctance to acknowledge the need for CPC within the medical profession. This has been documented by Friedrichsdorf and Bruera (2018) in the USA. Four main barriers to CPC were discussed in this article; denial ('we are already very good at symptom control'), palliphobia (fear, particularly surrounding the consequences of implementation or current care criticism), pallialia (a lack of commitment for implementation) and palliactive (regression). These barriers may be precipitated by some common misconceptions surrounding CPC. For example, CPC is only for children with a malignancy, it only begins when curative treatments stop. Further, it can only be provided in a children's hospital, fear of the use of common drugs (opiates), it is too expensive or that involvement in CPC results in the shortening of life or giving up of hope (Friedrichsdorf and Bruera, 2018). All of these misconceptions can lead to inadequate symptom control in children with life limiting disease and a lack of support and coordination of care for families.

1.6 Differences between children's and adult palliative care needs

Furthermore, The World Health Organization (WHO) (2018) state that salient differences between adults and children make children's care more convoluted than that of adults. These differences include a lack of clarity in diagnosis and prognosis with uncertainty, particularly surrounding rare genetic conditions and predicted life expectancy. A greater emotional burden on families and clinicians is associated with CPC, with the need for continual sensitive communication with children and parents. Further, an awareness of ethical challenges is needed as well as understanding regarding the dependence and vulnerability of children. Added to this are the

continual development changes of children and the challenges of age/weight appropriate formulations and drug dosages. It is no surprise that all these factors combine to give a higher degree of difficulty in clinical decision making and care giving (Levine et al, 2013; Weaver et al, 2016; Johnston et al, 2016; WHO, 2018).

1.7 Parental needs when caring for a child with life-limiting or life-threatening conditions

For parents caring for children with LLC/LTC, the complexity of their child's illness and response to interventions may create unpredictability, which may be complicated by long-term grief and unmet need (Carter, 2016; Collins et al, 2016). The significant psychosocial challenges of parents are well documented in the literature (Brehaut et al, 2009; Ward et al. 2015; Kish et al. 2018; Fraser et al. 2021), with many reporting clinical levels of distress, fatigue and below average quality of life (Remedios et al 2015; Fraser et al. 2021). Other stressors are noted, as Connor et al (2010) discusses the life-changing financial and emotional costs to families. The relentless nature of caregiving, responsibility and medical intervention parents are often expected to perform for their child, may also add to the mental ill health of parents (Rallison and Raffin-Bouchal, 2013). In addition to this, dependency on medical technology presents challenges for many families as they may need frequent home adaptions and feel imprisoned by an increasing presence of technology, equipment and carers (Mitchell, 2020). Parental need is varied, but literature reviews in this area have discussed themes of; a need for genuine communication, sincere relationships, respect as an expert and alleviation of suffering for their child (Melin-Johansson et al, 2014). More recently, Mitchell et al, (2020) discussed parental experiences in CPC

and that families often felt like they were ‘fighting’ a fragmented healthcare system which over-focussed on biomedical aspects. In addition is the need for good multidisciplinary collaboration, continuity of care (Van Der Geest et al 2014) and a refocus upon child and family-centred approaches (Mitchell et al, 2020).

Further, long term and community-based trials also include the effects of physical and social isolation for parents, with a frequent exclusion from the workforce and pervasive grief (Collins et al, 2016). Liben, Papadatou and Wolfe (2008) add the challenges of controlling physical symptoms like pain and fatigue, communication difficulties with disabled children and active child involvement in decision making and ethical dilemmas regarding the prolonging of life and minimisation of suffering. A mismatch between the services offered to parents, standards of care and difficulty in gaining or accepting support, are also reported (Collins et al 2016). This is consistent with research from the United Kingdom (Wood et al 2010; Price et al, 2011; Price et al, 2012).

When considering CPC specifically for forced migrant families, poor or limited prognostics, symptom control, resource and accessibility to care in countries of origin, increase need when arriving in a host country. Furthermore, a lack of cultural health capital may mean forced migrant families are not aware of services that exist in their host country and therefore struggle to engage with health care systems and meet HCPs’ expectations (Shim et al, 2010). A lack of medical knowledge, vocabulary and communication skills can also contribute to the inequalities observed (Marmot, 2010).

1.8 The impacts of providing children's palliative care for health care professionals

HCPs caring for children with palliative care needs often describe walking a fine line between professional and personal boundaries, as these become intricately linked through the deep and intense relationships built over lengthy inpatient stays (McConnell, Scott and Porter, 2016). However, most challenging for HCPs appear to be difficulties in making appropriate end of life and symptom management decisions. In a study by Abdin et al. (2021) the complex and emotional strain of such ethical decisions was detailed, including the intense support parents need during periods of decision making. HCPs detailed the stressful nature of this, with experiences of moral distress and anxiety when families insisted on continued interventions against the perceived best interests of the child (McCloskey and Taggart, 2010). Further, is the obvious grief on the loss of a child, with some HCPs reporting depression (Swinney, Yin and Lee, 2007), guilt (Papadatou, Martinson and Chung, 2001), sleep disturbances (McCloskey and Taggart, 2010) and being plagued by painful memories and reoccurring thoughts (Papadatou, Martinson and Chung, 2001).

1.9 Refugee and asylum seeker terminology

This study focussed specifically on forced migrant children and their families. The term forced migrant is a general, open-ended term that covers many kinds of displacement or involuntary movement, across international borders and inside a single country (UNHCR, 2018a). For all forced migrants, pressurised decisions and limited choice mean that they feel compelled to leave their homes to ensure their own and their family's survival (Grove and Zwi, 2006). Conditions of conflict, political unrest and economic challenges are likely to interact and contribute to such decisions (Castles & Loughna, 2005). The term forced migrant includes asylum seekers who have lodged an application for protection from persecution (The Refugee Council, 2013), refugees whose asylum claim has been successful or who have been given refugee status by the United Nations Refugee Agency (UNHCR, 2016). Within this term are those who seek protection and asylum once inside another country, including those who may be unsuccessful (rejected asylum seekers) and those who attempt to remain even though they lack the appropriate documentation (undocumented migrants). Gibney (2000) explains that a fear of repatriation, distrust in government procedures and an unwillingness to be detained contribute to the decision to live illegally. Forced migrants without documentation are often extremely vulnerable as they are susceptible to exploitation and deception by employers, traffickers and members of their own communities (Gibney, 2000).

For undocumented children, their status may have also resulted from being born in the UK to irregular migrant couples, their parents being refused asylum or overstaying their period of legal residence (Gordon et al, 2009). A recent report into the experience of undocumented children in the UK found that children and their

families are often living under the shadow of their immigration status, with a heightened risk of poverty and limited access to healthcare. Barriers to care were noted when primary providers such as General Practitioners (GPs) refused to register undocumented migrants without proof of immigration status (Thomas, Jolly and Goodson, 2018). De Vito et al.'s (2016) systematic review of access to healthcare for undocumented migrants across Europe also identified problems because of differing entitlements and other barriers including language and communication, a lack of knowledge of the healthcare system and a lack of cultural awareness by healthcare providers.

1.10 Statistics regarding forced migration to the UK

In the year ending December 2022 there were 74,751 asylum applications, an increase of more than 50% in 2019 (The Home Office, 2022). However, there are difficulties with the reliability of statistical data as some routes are classed as 'irregular' or 'undocumented' thus limiting data collection (Blinder, 2017). Some authors estimate that this may relate to as many as 674,000 people (Jolly et al, 2020). Of further consideration is the failure of government to adequately process asylum seeker claims, with many living in temporary and unsuitable housing and 40,000 people estimated to be waiting up to three years for an outcome of their claim (Syal, 2022).

The journey to the UK is often difficult, long and dangerous as many graphic media images have shown (Smith, 2015; Sawer, 2020). Estimates suggest 15,000 deaths

have occurred (International Organisation for Migration (IOM), 2017) during the process of migration towards an international destination, with 2331 fatalities in the first eight months of 2018. Many of these deaths happen at sea, with 45, 755 people documented to have arrived in the UK via small boats in 2022 (The Home Office, 2022). However, this remains an imprecise estimate as not all migration deaths and disappearances are reported. For those that do survive the journey, all that was familiar has been lost and upon arriving in the UK, asylum seekers frequently encounter a legal minefield in an intentionally hostile environment (Mind, 2009).

1.11 Community hostility

Resentment and intolerance towards forced migrants has intensified following the Brexit referendum (Kromczyk, Khattab and Abbas, 2021), which gave the public the opportunity to vote to leave the European Union. Allen and Ögtem-Young (2020) found that notions of ‘otherness’ and ‘foreign-ness’ post-Brexit led to increased anxiety, uncertainty and instability for migrants. Access to UK health resources and a moral panic over health exploitation were frequent themes in Brexit campaigns (Fitzgerald et al, 2020). It is thus unsurprising that fears over health entitlement may have heightened apprehension for forced migrants around accessing care.

The hostile environment for asylum seekers and refugees in the UK has been described by some as a web of government policies designed to reduce economic ‘pull factors’ which have been argued, by the Government, to attract disingenuous applicants (Mayblin, 2016). The hostile environment has resulted in policies intended to make life in the UK so difficult for people who are not documented that they will

choose to leave. Perhaps unintentionally, the hostile environment makes life arduous for all people who cannot prove they have the right to live in the UK (Joint Public Issues Team (JPIT), 2018). The Windrush scandal, in which individuals of that generation or their children were asked to prove their British citizenship and detained, deported and/or denied access to medical care when they lacked the appropriate evidence, offers a high-profile example of hostile environment policies.

Further fears about problematising forced migrants have been expressed, following suggestions of using controversial outposts to 'process' asylum seekers as a result of the large numbers of safeguarding cases being processed by Kent Council (Steel, 2020). The often-negative lens of the media may serve to overemphasise problems, place blame upon migrants and negate the positive contributions many refugees bring to the UK (Stewart, 2003; Department for Work and Pensions, 2010). Recent rhetoric that the UK is facing 'an invasion' of migrants is one such example, but one which Sigona (2022) states instead reflects the UK Government's inability to cooperate with European neighbours on vital aspects of safe migration and security. This is further backed by the figures which show that even though small boat crossings and asylum applications are high in the UK, the UK has still received less applications that Germany, France, Spain and Italy (Sigona and Benson, 2022).

1.12 Positive social action

Of further note are the many organisations, which are working towards positive social action and highlighting the need for change. The collaboration of charities, education sectors, the NHS and NGO's to create Refugee Week and World Refugee Day have brought about many, often creative activities to inspire, provoke-thought and raise awareness of the plight of refugees and asylum seekers living in the UK. One such innovation is an artwork, created by Turner Prize nominee Mark Titchner who created large art installations on prominent windows of refugees' experiences (Maxwell, 2018). One message read *"Listen to me. Let me work. Let me pay taxes. I am human. I am scared".* The intention is clear, that communication and empathy is often sparse, difficult but in grave need.

1.13 Migration Trauma

Alongside the acknowledged increased propensity to psychological disorders following trauma for forced migrants, is the common issue of poor access to health and social care in a country of refuge. Most research seems to concur that barriers are extensive and include poverty, administrative problems and communication difficulties (Maffia and Conway 2008; Simonnot et al., 2016).

As a result of some of these combined experiences, families seeking asylum often have complex and diverse needs (Mind, 2009; Zazai, 2015). These may include mental health problems such as depression, isolation and grief following loss of

family and friends. Equally there are traumas related to the asylum process including lack of access to essential resources such as food, accommodation, employment and health services (Children's Society, 2012). Mayblin et al, (2020) reports on what she calls the slow violence of everyday life. She details the intense harms that forced migrants experience at the hands of social policy designed to impoverish every aspect of daily life. Within her research, one participant described having to use food banks due to extreme poverty; *"It is a feeling of death … we refugees were not poor people in our countries, we just had to escape from death to survive. But you do not believe how terrible I felt, standing in the queue in coldness for a bag of food"* (Mayblin, et al, 2020 p114). Mayblin et al. (2020) also refers to the idea of necropolitics, of being 'kept alive but in a state of injury' (Mbembe, 2003, p21). Necropolitics pertains to the idea that systems which appear to help asylum seekers, are actually guilty of an intentional 'gradual wounding', both physical and psychological, including conditions of impoverishment and endangerment for those seeking sanctuary (Mayblin et al, 2020).

Further systemic aspects are those of discrimination and racism within the UK and how they influence both policy and public opinion. The Russian invasion of Ukraine which began in February 2022, has led to mass displacement of approximately 13 million people (Sajjad, 2022a). The high rates of refugee acceptance and the solidarity for Ukrainian refugees has sparked much debate regarding issues of racism in refugee acceptance (Sajjad, 2022b; Reilly and Flynn, 2022). The Ukrainian reception presented a notable contrast to that of Afghan arrivals, with a significant difference seen in the speed of government policies to enable new arrivals to be welcomed and supported even without appropriate visas or passports (Sajjad,

2022a; Reilly and Flynn, 2022). The double standards are glaring and with no calls for the detainment of Ukrainian refugees, the comments of Bulgarian Prime Minister Kiril Petkov appear to echo throughout Europe, *"These are not the refugees we are used to … These people are Europeans … These people are intelligent, they are educated people … This is not the refugee wave we have been used to, people we were not sure about their identity, people with unclear pasts, who could have been even terrorists"* (Majcher, Flynn and Grange, 2020). Further, growing numbers of students and migrants also fleeing Ukraine but of African, Middle Eastern or Asian descent faced racist treatment, obstruction and violence, which compound the differing treatment observed during this crisis (Busari et al 2022).

1.14 The Combination of forced migration and children's palliative care

Forced migrant families with children with palliative care needs are likely to have experienced the trauma of migration and grief, as well as the fear and loss associated with their child's diagnosis. They may have reduced agency and feel disempowered being forced to leave their family, belongings, support and all sources of familiarity. The supplementary distress of uncertainty whilst awaiting diagnosis, experience of critical illness and periods of instability or separation whilst living in fear of their child's inevitable death may also exacerbate trauma (Verberne et al., 2019). Additionally, the resources to provide adequate care and support may be limited or lacking.

The perspectives of forced migrant children and their families are rarely sought and thus under-represented in the literature surrounding children's health (Flanagan and Hancock, 2010). There may be many reasons for this including deprivation, limited agency and low health literacy. Encompassing LLC and LTC, is the term 'disability' and its legal ramifications encapsulate children who have palliative care needs. The Equality Act (2010) explains that disability relates to individuals who have physical or mental impairment, that is substantial and has long term adverse effects on 'normal' functioning.

For many children receiving palliative care their multi-system impairments often result in the need for breathing adjuncts, artificial nutrition, pain and seizure control. Children with palliative care needs, will often utilise special school education provision and require repeat hospital admissions for deterioration, infection or interventions to improve their quality of life (TfSL, 2018a). However, for a child with a LLC or LTC complexity, an urgency to care is needed above disability, with increased support for the family as the child's condition is likely to be unpredictable and at times urgent. It is thus advisable for children receiving palliative care to work between services aimed at LLC, LTC and disabled children, to achieve joined-up provision which enables them to maximise their potential and quality of life (TfSL, 2018a).

Until very recently, disabled asylum seekers were dismissed and disputed, with even those working in the sector claiming disability would make the journey to the UK impossible (Yeo, 2015). However, it has been suggested that the intersecting identities of forced migration and substantial physical/mental impairment, result in

diminished agency. Further, a lack of sufficient numbers, resources or allies makes asserting their needs and rights unachievable (Yeo, 2015, p1). An additional study found that disabled migrants and their carers are often made to feel like a burden on society whilst they suffer significant deprivation, isolation and a struggle to meet basic needs (Yeo, 2017). The UNHCR's criteria for resettlement includes complex medical needs, inadequate access or treatment and for whom sanctuary may mean improvements to quality of life (UNHCR, 2011). For the UK specifically, increasing numbers of vulnerable children are expected as the Government committed to resettle up to 3,000 at-risk children and their families, which includes medical cases (UNHCR, 2018b). The Government are also close to their target of resettling 20,000 refugees under the Vulnerable Persons Resettlement Programme which includes families with children in need of treatment. This becomes of paramount importance to this study, as uncovering more about the needs and experiences of forced migrant families, is important to understanding how care can be optimised.

Some scholars have explored the palliative care experiences for Black, Minority Ethnic (BME) populations. The term BME is often used in public policy and wider society when referring to collective ethnic minority populations including people of colour and racialised minorities (NHS England, 2022). Whilst many of the issues they raise are relevant for forced migrant children and their families, there are also some key differences. From the BME literature, the main themes are a lack of facilities, support and resources particularly for those who do not speak English and concerns about cultural or religious appropriateness of existing services (Kent, 2020). Furthermore, common stereotypes surround the prevalence of large multicultural family networks who are able to provide care. Such assumptions have been seen as

a false justification for limited service provision (Ward, Amas and Lagnado, 2008). However for forced migrant families, missing family networks left behind during displacement create isolation and a lack of physical, emotional and social support. Additionally, negative assumptions in the literature were seen in relation to stigmatising attitudes towards disabilities, with care being viewed as a role or duty of family members only, within some ethnic identities or heritage (Brodaty et al, 2005).

It is also important to consider circumstantial and contextual issues and the relative ignorance of the general population towards disability and its implications (Ali et al, 2006). One study amongst Pakistani and Bangladeshi families found attitudes towards their children were complex and varied and that poor service provision was linked to institutional racism rather than family belief systems (Bywaters et al. 2003). Ali et al. (2006) considers this further by suggesting that negative attitudes may, in fact, result from a complex combination of racism and disablism. Evidence suggests that parents from BME communities, in comparison to white families, are less likely to access care services and disability benefits (Funk et al, 2010) and less likely to be satisfied with care they do receive (Dixon et al, 2015). Yeandle et al. (2007) similarly found that services were underutilised by BME families as they were often unaware of what was available, services were not felt to be sensitive to their needs and service use was restricted due to a lack of information, cost and flexibility. An evidence review by Calanzani et al, (2013) reinforces these findings, adding that a lack of minority doctors and low availability of professional training in cultural competency was problematic for families. In 2020, Kent found that social isolation, negative impacts to parental physical and mental health, an underestimation of the role of religion and culture, all adversely impacted BME families' experiences of care.

1.15 The Impact of Covid-19

In December 2019, a novel coronavirus was identified in China causing severe respiratory disease including pneumonia (Wang et al, 2020). The new variant, COVID-19, was discovered to be highly infectious with a respiratory focus. Spread of infection was via droplets, predominately through coughing and sneezing (WHO, 2020). Worldwide attention and a global pandemic were declared upon the realisation of the intensity of treatment needed (and high risk of healthcare systems becoming overwhelmed). Further considerations included high fatality levels, particularly amongst those who were discovered to be at high risk (NHS, 2020a). For forced migrant families the increased risks associated with ethnicity were particularly apparent. In a large prospective cohort study focusing on Coronavirus in children, it was suggested that South Asian and black ethnicities were disproportionately severely affected (Swann et al, 2020). Further reports highlighted that many forced migrant families were living in such poverty, that they could not afford essential cleaning products (Asylum Matters, 2020) and had to choose between hygiene and food (Phillimore, et al 2022). In addition, a service evaluation by Chidiac et al, (2020) highlighted the suboptimal palliative and end of life care that BME patients received during the pandemic. This was due to poorer access to services, a lack of cultural sensitivity, language barriers, previous negative experiences and conflicting values between family, religion and palliative care (Chidiac et al, 2020).

For children with palliative care needs, families reported that the pandemic had made them feel terrified due to their child's medical complexities and the increased risk of death should they catch COVID-19 (TfSL, 2020a). This meant parents shielded their children as they were initially encouraged to by the UK government,

but this protective response negatively exceeded expectations as some parents avoided any form of medical care or contact (NHS, 2020b). Subsequently, this resulted in delayed or no treatment for underlying or new conditions (which were often not related to COVID-19) and corresponding deterioration and early deaths. These cases necessitated the commencement of safeguarding concerns for some children which was unprecedented (TfSL, 2020a).

With lockdown for the UK becoming mandatory in March 2020, many families became isolated and overwhelmed without their usual support (Hill, 2020; Johnson et al., 2020; TfSL, 2020b). It became necessary for care to be offered in new formats such as the use of video clinic appointments and counselling, food parcel deliveries to the door step, virtual support groups and an increased reliance on community nursing, as other agencies struggled to provide face to face care (Ellis and Lindley, 2020; Royal College of Nursing (RCN), 2020). In addition to these aspects, forced migrant families described inadequate living conditions and intensified poverty during lockdown, with some believing they had been abandoned during the crisis (Phillimore et al, 2022). The shift to online provision of many services had implications for those lacking digital skills, hardware, or data as they became excluded from online support groups, in one report they described *"long days alone … overthinking their past and worrying about their future"* (Phillimore, et al, 2022, p11).

Usual drug supply also became an issue particularly in terms of pain relief, with increased global demand. Brexit changes to supply and stock storages meant some children had to swap medications and manage new challenging side effects

(Studman, 2020). In addition, the evolving nature of palliative care conditions and the associated guidance for those working across settings such as hospitals, the community and within special schools created challenges. Regulatory guidance was particularly contradictory with many variants in the necessary Personal Protective Equipment (PPE) and which procedures were classed as higher risk - aerosol generating procedures (AGP) (Royal College of Nursing (RCN), 2020). Such inconsistencies only served to increase HCPs' frustration, anxiety and fear for themselves and the children they cared for. A further important aspect of consideration was the impact that PPE had on communication, particularly compassionate communication and non-verbal aspects which some children and families may have relied upon. The need for HCPs to enhance 'purposeful expressive' eye contact, enhanced empathy and appropriate touch was discussed, in order to bring comfort and alleviate fear (Groot-Alberts, 2020; Parry, 2020).

For forced migrant families, aspects of the COVID-19 pandemic appeared to mirror the fear and uncertainty of being detained, serving to increase and magnify the intensity of such oppression (Hamid, 2020). Further literature suggests that continued fear of deportation kept many forced migrants from seeking medical help and left them suffering in silence (Parveen, 2020). In the study by Phillimore at al. (2022) enforced isolation, limited freedom and lack of support activated painful memories of conflict and torture and a feeling of having to protect themselves from violence.

1.16 The limited evidence base for care

Within the literature, there remains little evidence or guidance surrounding the care of children at the end of their life and after death. Much of the evidence that is available has been drawn from a professional consensus of clinical practice and from the wider literature on death and dying. Similarly, NICE guidelines (2016), whilst initially welcomed, with a view to standardising care, equitable provision and consistency, have now been criticised. A review of the guidelines in the BMJ discussed that whilst some recommendations are based on systematic reviews, most of these were of low or moderate quality and thus many recommendations fell to expert opinion (Villanueva et al, 2016). The disadvantages to such an approach are the limited evidence base for care and the insufficient research rigor by selecting rationed and often individualistic viewpoints (Villanueva et al, 2016).

When considering the cultural needs for families experiencing palliative care, the report and clinical documentation published by TfSL (2007; 2012) and The RCN (2012) advocates for the importance of communication, religious and spiritual care, with a focus on needs, wishes and beliefs. Looking more widely at adult palliative care guidance, due to the limited clinical documentation specifically aimed at children's palliative care. One review within the BME community, details problems with access to and provision of palliative care, poor monitoring of ethnicity, limited translators, mistrust and poor communication with assumptions and stereotypes permeating (Calanzani, Koffman and Higginson, 2013). A report which examined Muslim family's beliefs with children, families and adult patients also highlighted barriers to accessing care. These included reputation, community expectations, awareness of services, geography, education and confidence (Woolf Institute, 2015).

As a result of such findings and the current absence of literature surrounding forced migrant families receiving children's palliative care, the rationale for this study is stressed. Presently, there is no data on the numbers of forced migrants with CPC needs and no research into their care or experiences of palliation in the UK. However, there is little doubt that palliative care coupled with forced migration is likely to exacerbate already complex problems and impact upon family health and the provision of care.

Chapter Two: Study Paradigm and Framework

2.0 Introduction

The study paradigm and theoretical frameworks for this study were considered early in my doctoral studies to ensure relevance and application throughout the study. The considerations made will thus now be discussed in detail. The paradigm for this study comes from an ontological viewpoint of relativism, the belief that multiple realities exist within individual contexts (Guba, 1990); and an epistemological view that such realities need to be interpreted. My doctoral study explored the views and experiences of forced migrant families and those who care for them, in children's palliative care. As such there was the potential for participants to provide multiple views and experiences dependent upon their individual perceptions and experiences. However, such realities may not be concrete and may be further refined over time, as values may be shaped by evolving influences or changes in knowledge, politics, culture, the economy and by ethnic and gender beliefs (Danks, 2019).

2.1 Ontology and epistemology

The ontology and epistemology together combine to form the research paradigm of constructivism, considering that we construct our realities together with other people (Kivunja and Kuyini, 2017). As a result, an inductive approach to my doctoral research was needed in order to explore these multiple realities. However, such interpretation is heavily dependent on the relationships between researcher, the research subject and participants. Subsequently the study needed to be guided by

processes of reflexivity to ensure previous knowledge and experiences could be reflected upon and their influence to the research process, acknowledged and mitigated (Briscoe, 2013). Chapter five offers further clarification of the approaches utilised.

2.2 The Importance of Theoretical Frameworks

A theoretical framework was needed for my study to inform, guide and underpin the qualitative inquiry (Meyer and Ward, 2014). A theoretical framework helps to construct the philosophical basis for the research (Anfara and Mertz, 2006). Many scholars consider a theoretical framework to be important to a research study, as it can help to enhance criticality and the robustness of evidence. These aspects are enhanced by influencing how evidence is collected, analysed, used and comprehended (Bradbury-Jones et al, 2014). In order to use the most rigorous methods, a theoretical framework to underpin this study was chosen early, in order to drive the entire process and be visible throughout (Anfara and Mertz, 2006). Early utilisation aims to fit with the highest suggested level of theoretical visibility typology; level five. Within level five, the theoretical framework is consistently applied and directs each phase of the research process (Bradbury-Jones, 2014).

The right fit for a theoretical framework with my study was important and so a variety of frameworks were considered. These will now be discussed in further detail and are outlined in Appendix One with relevant details, limitations and considerations particular to this study. Many theoretical frameworks could have been considered here, but I specifically wanted to use a model which acknowledged the cultural

influences upon healthcare, to ensure relevance and sensitivity particularly to the forced migrant participants of this study.

2.3 Cultural Competence

One of the first models considered was that of Cultural Competence. This model dates to the early 1970s when mental and social health services were struggling to practice successfully with East Asian refugees. The new refugees presented with different languages, perceptions and complex and varied needs, which services and HCPs were not prepared for. The focus of the Cultural Competence model is on the individual and based around awareness, knowledge, education, attitudes and skills (McKenzie, 2008). The Cultural Competence model acknowledges that there is a need for individual HCPs to be aware of the impact of culture. Further, is a responsibility, which is both individual and corporate, to ensure patients are respected (The Joint Commission, 2010). Core concepts include cultural desire, which details an individual's motivation to learn and enhance their knowledge about culturally diverse patients. The model states that without cultural desire, further growth may not be possible. However, there appears to be a lack of clarity around the term Cultural Competence, with Jeffreys and Dogan (2012) acknowledging the multifaceted nature of the term and thus of developing competence. Racher and Annis (2007) argue that the term Cultural Competence implies that one knows or has mastered another's culture and has somehow completed a skill set similar to that of learning how to give medications. Racher and Annis (2007) suggest such assumptions have implications for a continued willingness to learn more. Isaacson (2014) further suggests there is thus a potential for an overestimation of personal

cultural competence levels, which may encourage arrogance and further precipitate cultural misunderstandings.

In addition, it also been suggested that the Cultural Competence model could create prejudice or unfair stereotypes towards ethnically diverse groups, which may lead to an exaggerated and simplistic notion of ‘cultural difference’ creating a ‘them and us’ mentality and thus leading to ethnic reductionism and stereotyping (Culley, 2014).

Further problems surround the missing elements of social inequality which is largely ignored by the model, as it is assumed individual knowledge and self-confidence are enough to bring about change (Kumas-Tan et al, 2007). In addition to this is the more pragmatic issue of learning about families from diverse cultures in an evolving, superdiverse environment. Such an environment makes learning and utilising knowledge about different cultures almost impossible, as the diversity of ethno-national backgrounds increase, but also co-exist, with many people having a mixed and thus highly individual heritage (Levi, 2009). Lekas, Pahl and Lewis (2020) suggest that Cultural Competence fails to understand the evolving nature of culture and instead offers a view that a core set of beliefs and values remain unchanged, to be rope learnt. Further criticisms include the realisation that health inequalities have not been reduced despite the introduction of Cultural Competence training in most health and social care institutions (Brach and Fraserirector, 2000; Smedley et al, 2003). As such, further research may be needed to evaluate the benefits of the sustained use of this model (Chang, Simon and Dong, 2012).

2.4 Cultural Health Capital

The second framework examined, Cultural Health Capital, was introduced by Bourdieu in 1977. Cultural Health Capital focuses on medical professionals' interactions with ethnically diverse patients and how the use or absence of shared vocabulary, medical knowledge and information can impact on the care given to patients in a healthcare setting. The model also explores verbal and nonverbal communication skills, interpersonal rapport, attitudes, behaviours, empathy and trust. It details that when these characteristics differ between clinician and patient, problems can accumulate. Conversely, when Cultural Health Capital factors are nurtured by patients and clinicians, they may result in the most ideal health care relationships (Shim et al, 2010). This model also sees Cultural Health Capital as a factor, which may therefore favour the well-educated and so potentially contribute to the accumulation and exercise of power and the maintenance of inequality (Wall, 1995). The advantages of the Cultural Health Capital model however, lie in its potential to help researchers to understand how broad social inequalities operate in patient-provider interactions and shape the content and tone of health care encounters. Cultural Health Capital also recognises that stereotypes should be countered and does this by showing standard markers of social status, structures, agency and health care interactions. Within this premise is also the acknowledgement that there will always be instances of patients who despite being afforded every advantage, struggle; and conversely patients who overcome significant obstacles (Shim et al, 2010). However, limitations include an opposition to the interpretative nature of this particular study, in that Cultural Health Capital contests individualistic notions of culture and instead takes up the concept of culture as a shifting, emergent set of resources which are critical to the pursuit of privilege

and the exercise of power. Further to this, the concepts of habitus, cultural capital and field, which focus primarily on how systems of inequality are reproduced and perpetuated over time, leave little room to consider the processes of structural change (Dubbin et al, 2013).

2.5 Cultural Safety

The third model considered was Cultural Safety. Cultural Safety has been pioneering in Australasia where it was first coined by a medical student who wondered why safe practice, safe knowledge, ethical and legal safety are considered but not Cultural Safety (Waimanawa, 1988). The premise of the Cultural Safety model is that health care needs to be safe for the patient and they thus need to be the focus rather than the health professional. However, in order for this theory to operate, it requires authentic personal reflection on culture, power imbalances and personal preferences which may be difficult to uncover, as often these are subconsciously ingrained. The model also requires grappling with complicated and controversial issues such as inequality, conflict and historical oppression. Cultural Safety has a further emphasis on personal and organisational responsibility in the provision of culturally sensitive care (Pirhofer et al, 2022). Cultural Safety acknowledges the fluidity of culture, however because this model deals with sensitive and threatening issues, it requires creative and sophisticated methods for effective implementation. Wilson et al (2022) analysed Cultural Safety education within indigenous health education programmes and found that even when Cultural Safety approaches are well established, changes to practice still required leadership for a multi-system approach, critical pedagogy

and commitment by nurses. However, Pirhofer et al (2022) found that when quality management processes such as patient feedback, observation, adaptation and personal reflection were utilised within the Cultural Safety model, achieving culturally sensitive care was far more likely.

A study by Arieli (2012) explored some of the key issues associated with the Cultural Safety model, including the ‘ambassador’s dilemma’ here an educational intervention which aimed to increase student’s self-awareness resulted in a fierce battle of each sub-group to represent their own cultural beliefs. The researchers themselves feared this had actually served to strengthen the negative stereotypes that already existed within the society studied. The second theme ‘one big family fantasy’ explored cross conversing resistance. This resulted in limited interactions between groups with uncomfortable dynamics and the denial of conflict and class division by those involved in the study. Further, the presentation of controversial vignettes also led to difficulties in discussions and appeared to result in residual turmoil. Overall, the study presented some honest conclusions and found that when discussing something as sensitive as personal identity, it was difficult to create conditions in which people could respect others but still talk freely about their own identities (Arieli, 2012).

2.6 Cultural Humility

Cultural Humility was the fourth model explored and comes from a Central American philosophy based around providing medical education in a shift away from traditional Cultural Competence frameworks. Cultural Humility offers a framework for lifelong

learning involving a process of self-reflection and self-critique which requires introspection and co-learning (Tervalon and Murray-Garcia, 1998). The framework includes the following attributes; openness, self-awareness, egoless (humbleness), supportive interactions and antecedents (diversity and power imbalance). Positive consequences of utilising the model are discussed as; mutual empowerment, partnerships, respect, optimal care and lifelong learning (Foronda, 2016). However, the poignant descriptors illustrate a grand but possibly unobtainable concept; a belief system of equal human rights with flattening of any hierarchy or power differential, which may be especially challenging within pre-existing medical and health structures. Another element of the model which may challenge medical professionals is the idea of learning from and with patients and being open to a humble, 'I do not know' stance to allow patients to educate them. Equally, the lifelong and thus 'no end' element to the model may also be challenging and different from traditional health care competence-based education. However, Chang, Simons and Dong, (2012) highlight that whilst the mastering of Cultural Humility involves the application of compassionate and humble hearts (which is not always easy), without elements of this philosophy, we run the risk of treating illness and not understanding our patients. Markey (2020) relates Cultural Humility to a need to alter 'hearts and minds', she suggests a solution in closing the gap between definitions and application to practice may lie in exploring the teaching of moral reasoning as a catalyst for culturally responsive care. Such an approach would incorporate teaching through scenarios and simulation, elements of moral motivation, sensitivity, character, judgement and behaviour to better meet the needs of ethnically diverse patients. However, this would need dedicated and risk-free time to reflect, review, discuss and debrief which may prove challenging and time consuming for educators.

At the early stages of my PhD, as a new nurse researcher, the idea of life-long learning which involves a journey of personal growth was appealing and the Cultural Humility framework offered a good basis for personal reflection and reflexivity (Yeager and Bauer-Wu, 2013). The use of Cultural Humility by nurse researchers is also advocated as an essential component in implementing meaningful and ethical research and to better address health inequalities (Yeager and Bauer-Wu, 2013), (practical applications of the Cultural Humility model are seen in the sections on Positionality and Reflexivity (Chapter Five) and Silences Dialogue (Chapter Nine).

2.7 Social Justice Framework

Following Cultural Humility, Nancy Fraser's Social Justice framework was explored. The Social Justice framework discusses commonalities around social injustice in terms of the recognition of cultural difference (the equal acknowledgement of different identities/groups within a society). It also explores the need for economic redistribution (in terms of a more equitable allocation of resources) (Fraser, 2000). A further stage is linked to political representation, with the need for parity of participation for just conditions to be met. For example, objective conditions such as independence and voice, are needed as well as inter-subjective conditions such as equal opportunities for all. Fraser also describes corresponding forms of injustice: maldistribution, misrecognition and misrepresentation. Whilst many of these elements are relevant to the participants of this study, Fraser's model (2003 and 2008) focuses on structures not individuals that produce inequalities, i.e. the ability to vote, international influences. Whilst it is essential to consider societal structures and be able to analyse claims and thus assess and evaluate justice, it has been argued

that Fraser's approach has the tendency to shift the focus away from individual experiences and in so doing negate lived realities (Fraser and Honneth, 2003). Individual experiences are so fundamental to this particular study and my research philosophy, that not considering them fully creates a significant drawback to the model's use herein.

2.8 The Silences Framework

The final model examined, the Silences Framework by Laura Serrant (then Serrant-Green) stood out from the other models as it appeared to fit with both the practical methodological underpinning and my motivation and philosophy for this study. The Silences Framework also appeared a good fit as it focuses on research issues which are under-researched, silent in policy discourse and marginalised from practice. The Silences Framework offers an anti-essentialist approach which suggests that research and experience are both ingrained within context, with the researcher playing a central role at all stages of the research study (Serrant, 2020). As such it correlated well with the Interpretative Phenomenological Analysis (IPA) methodology of this study, which sees interpretation as a fundamental element of how we structure and make sense of our lives.

The Silences Framework describes Screaming Silences, which 'scream out' to the individuals experiencing them but often need to be uncovered by the outside world and researchers (Eshareturi et al, 2015). The 'listener' is therefore the person who identifies priorities or responds to a particular 'silence' (Serrant-Green, 2011). The Silences Framework revolves around marginalised discourses which are so labelled

as they are less prioritised by policy and appear undervalued, absent or invisible (Foucault, 1972; Ifekwunigwe, 1997; Afshar and Maynard, 2000; Serrant-Green, 2011). The relevance of the marginalised discourses debated, owe their importance chiefly to the severity by which they are marginalised and opposed by mainstream views (Tremain, 2008). Individuals described within such discourse often have little power to act and have a 'voice' or say regarding their care or needs and as such experience extraordinary inequalities (French, 2010).

2.9 Stage by Stage Synopsis

The Silences Framework uses a four to five (as individually relevant) stage approach which moves from accepting the values and experiences of the participants in equal measures, to established concepts (French, 2010). Stage One (Working in Silences) highlights the need for both individual experiences and social contextualisation, in order to see the research within the time it will take place. As well as traditional reviews of the literature, Serrant (2020) also advocates for the inclusion of personal experiences particularly of the marginalised, which may mean going beyond academic or published sources. The aim is to work closely within the ethos of intersectionality by valuing lived experiences alongside theoretical debates (Cole, 2019). This means not only reviewing the sources of information but also interrogating the surrounding structures or assumptions in order to expose the social, political, psychological and clinical antecedents to the study. In this way, Rossetto et al (2018), who used the Silences Framework to explore Tuberculosis, and HIV/AIDs co-infection in Brazil, argued that researchers are able to engage with the complexities of societal interplay and challenge the limitations of any dominant

perspectives. Exploring such interplay, gives an opportunity to critique and question past approaches to forced migrant health, whilst still being centred in the reality of present power imbalances. Or as Nyashanu et al (2020) articulate, offering a vision of both the dominant and marginalised views by exposing the multiple realities that exist within a group or society. Such concepts fit well with the interpretative research paradigm of this study, which sees truth as multiple realities that are socially constructed and individualistic in nature. Rosenthal and Lobel, (2016) suggest the approach, offered by the Silences Framework in Stage One, can support simultaneous consideration of theory and practice and the avoidance of fragmented representations.

Stage Two (Hearing Silences) focusses on researcher position or location within the study, including researcher identity, research subject and participants. Serrant (2020) advocates the importance of exposing any silences which may exist in any of these areas. Exposure of silences can allow for a clear consideration of ethnic or cultural sensitivities creating a clearer context and research methodology to be understood and utilised.

Stage Three (Voicing Silences) explores the power structures within the research study with a need to transfer power to participants, to truly value their voices. At the heart of the Silences Framework and this specific stage, is the desire to locate and hear the ‘silent voices’ embedded in a particular issue. The ‘silence voices’ concept aligns well with this study, which focusses on the forced migrant child with palliative care needs and uses creative approaches to enable a greater depth of expression. Stage Three also considers the significance of creating an advisory group to help to

redress power imbalances and inequalities, by further valuing the participant's viewpoints from the beginnings of question formation through to final research dissemination. Within this study different advisory groups have been included in varied aspects and stages, these are summarised in Appendix Seven and further detailed in Chapter Nine – Silences Dialogue.

Advisory group involvement was essential to the philosophy of this study and aimed to increase the participation and influence of different members' areas of expertise (NIHR 2014; Serrant, 2020). Advisory group members thus included children/young people, refugee and asylum seekers, parents, siblings, those who are bereaved and HCPs with specialist expertise in palliative care. The investment and additional time needed for such sustained involvement, comes from a recognition that those who are best placed to inform care are those who have experience of giving and/or receiving such care (Grant and Ramcharan, 2010). As such, advisory group involvement aimed to ensure working together, sharing, negotiating and collaborating in as many aspects of the study as possible (Auckland, 2010; Hogg, 2015). Working with advisory groups provides a distinct move away from research which sees participants as objects of enquiry, towards a view that participants are experts with a unique perspective and insight into their own reality (Shaw, Brady and Davey, 2011; Serrant, 2020).

Stage Four (Working with Silences) focusses on the final discussion aspects including the broader theoretical and philosophical frameworks and broad reflection on the potential contribution of the study. A key element of this stage is to consider the value of the study and how it may have changed understanding of the lived

experiences of forced migrant families in children's palliative care, alongside an acknowledgement of what still remains hidden (Serrant 2020, p7).

Stage Five (Planning for Silences) may not be applicable to all studies, but aims to explore any actions from the research with a focus on recommendations for future service delivery or community action (Serrant-Green, 2011). All of the stages and how they have been applied to this study specifically are summarised in Figure Two.

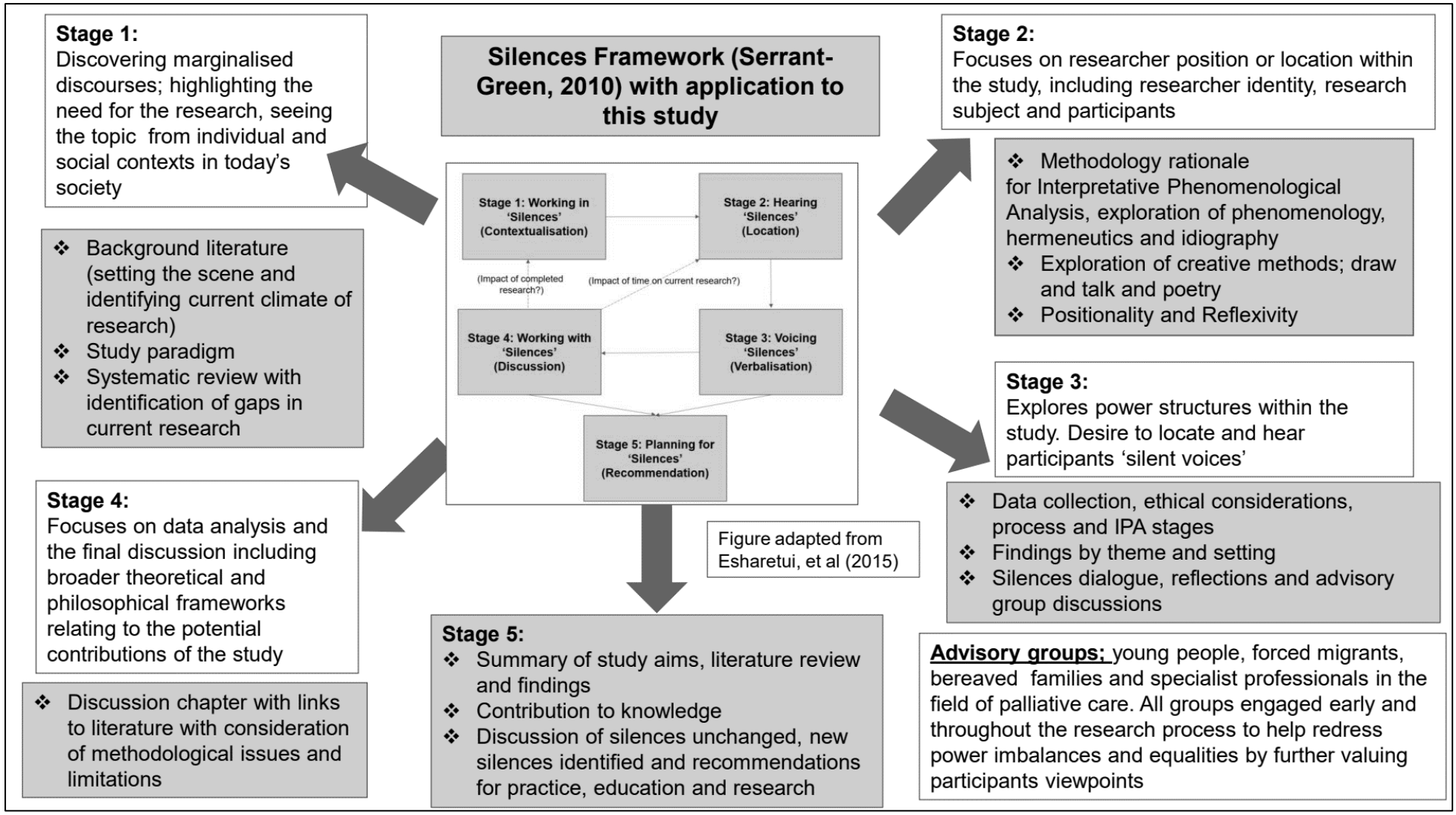


Figure Two - Silences Framework and Application within this stud

2.10 Silences Framework critique

Whilst the Silences Framework appears a good fit for the study, it does have some limitations; the relatively new nature of the framework makes critique of its application narrower. One study which has looked at the applicability of the framework in research practice is that of Janes, Sque and Serrant, (2019). A key discussion in this paper involves the benefit of the Silence Dialogue and Collective Voice's processes. Such a process within the cyclical data analysis phase can be used to stimulate member checking by those independent to but offering potentially important reflections by utilising their lived expertise (Connelly and Yoder, 2000). The use of a Silences Dialogue was also felt to enhance the trustworthiness of Janes' study and was valuable to her as another researcher was not needed for independent analysis (Green and Thorogood 2014).

In my study, the Silences Dialogue stage was helpful in valuing and implementing advisory group feedback, but also because IPA methodology does not advocate traditional member checking, as this is thought to refute the important role of researcher interpretation within the research process (McConell-Henry, Chapman and Francis, 2011). However, Janes et al (2019) state that the Silences Dialogue stage of the framework can lead to confusion. For her, peers assumed this would form part of the data collection process linking it to reviewer feedback, rather than its intention to inform data analysis and interpretation. The careful explanation of this element is thus included to avoid such assumptions. A further limitation of the framework appears to be the multiple ways it has been applied, with some authors showing diagrams of the stages which do not align. Whilst a benefit may be seen in

the flexibility of its application, without the feedback loops suggested between stages (four to one and two to four), the impacts of the completed research and the impact of time upon the current research, respectively could be missed (Figure Two demonstrates the interlink between these stages with two dotted arrows).

My study was closely aligned with the Silences Framework as it explores marginal discourses and how healthcare policy and practice choose to address the health needs of forced migrant children and their families when they experience children's palliative care. By utilising the Silences Framework, it crucially, as per the aim and research questions of the study, helps to seek out the presently unknown and unspoken.

2:11 Research Aim and Questions

The aim and research aims of the study include:

Aim: To understand the care experiences of forced migrant families in the context of children's palliative care.

Research questions are in the context of children's palliative care for forced migrant children and their families and in a range of settings including hospital, hospice and community care;

1. What factors optimise or hinder care for forced migrant children and their families?
2. How can the voices of forced migrant children and their families be best reflected or represented in research concerning their experience?

3. What factors do children's palliative care professionals believe optimise or hinder care for forced migrant children and their families?

The Silences Framework intends to empower researchers to consider the positioning of power within their research. My research questions focus on facilitating a power shift of expertise to forced migrant children and their families, and advisory group members, thus giving voice to their experiences which are often hidden, devalued and thus 'silenced'.

Chapter Three – Systematic Review of the international literature

3.0 Systematic Review method

Following consideration of the background to this study and upon reflection of the Silences Framework emphasis on uncovering marginalised discourses and highlighting the rationale for the study, it was considered important to thoroughly understand and review the literature. As such a systematic review was conducted with the aim of giving a clear and comprehensive overview of the experiences of palliative care for forced migrant families at this time.

Forced migrant families are not currently consulted regarding their care needs in the UK and whilst little evidence base for CPC exists, best practice is varied and inconsistent. As a result, a systematic review on the experiences of forced migrants in children's palliative care was conducted to ascertain the current gaps in the literature.

This chapter will thus give an extended and updated review of the published version found in Appendix Two (Clancy et al. 2020).

3.1 Aim of the Systematic Review

The aim of the systematic review was to explore the experiences of palliative care for forced migrant children, families and those who care for them, alongside present hindrances and examples of high-quality care. It is hoped such exploration may help

to inform future practice for the health care professionals who care for forced migrant families. Subsequently, the review aimed to address the following question:

> ‘What is known about the experiences of children’s palliative care for forced migrant families and their health care providers?’

3.2 Search strategy

Methods included using PEO (Population, Exposure and Outcomes) variables to form a wide-ranging search strategy, clear search terms and consistent inclusion and exclusion criteria (Ten Ham-Baloyi & Jordan, 2016). Seven databases were searched alongside snowballing techniques and searching of the Cochrane Database and Google Scholar to identify any potentially relevant additional or grey literature.

English Language format records were initially searched for peer reviewed empirical primary research for the period covering January 2008 to October 2018 and subsequently from November 2018 to November 2022. Table Two details the inclusion and exclusion criteria alongside their rationale.

Table Two: Inclusion/exclusion criteria and rationale

Included	Excluded
Studies published in English	Non-English language studies due to lack of interpretation skills/resources
Studies written from (2008-2018) and then again from (2018 to 2022) – to gain a clear perspective	Older studies. These limits allow for a focus on up to date evidence (Aveyard, 2014) which is recommended by the NMC when considering evidence-based nursing interventions
Studies which relate to the research question	Studies were excluded when they failed to relate to the research question from either title, abstract or full text. This included many studies which focused on economic migration specifically as this is a very different life choice to the forced journeys made by refugee/asylum seeker families
General articles will be included as HCP's experiences and the experiences of the families discussed may still reveal much relevant and transferrable data to the field of paediatrics.	Studies which focus upon the elderly or such areas as care homes which are very difficult to transfer to paediatric care.
Primary peer reviewed research Qualitative, Quantitative and mixed methods studies have been included as there is a potential for them to help answer the research questions. By using different types of data, a richer picture of the problem should also emerge.	Secondary research, these studies tend to provide less detail about the methodology of studies and thus less rigour and objectivity (Polit and Beck, 2009). In addition, opinion pieces, conference/workshop write-ups and studies which discuss care based upon clinical cases without a clear research methodology were also excluded.

The search strategy involved the initial use of Mesh headings (database taxonomies) to commence the search, with the additional of extra terms to capture additional material. Search terms were refined following each search as terminologies surrounding CPC and migration are wide-ranging and vary internationally. New terms were added with searches rerun and the process replicated until no new articles were identified, all search terms remained consistent when rerunning these searches (Figure Three).

Population (P)		Exposure (E)		Outcome (O)
Refugees including Asylum seeker/seeking	AND	Terminal care/terminally ill patient	AND	Infant
OR		OR		OR
Transient and migrants		End of life care		child
OR		OR		OR
Displaced persons		Palliative care		Pre-school child
OR		OR		OR
Emigration and Immigration		Life limiting		adolescent
OR		OR		OR
Undocumented child		Life threatening		Health care/treatment barrier
		OR		OR
		Death and dying		Health care professional/personnel
		OR		OR
		Disabled child		Parent
				OR
				Health service accessibility
				OR
				Health care utilization

+Some terms relate directly to search fields created on specific databases

Figure Three – Key words/search term

3.3 Prospero

Registering the review in Prospero (Appendix Three) enhanced the rationalisation for the study as it accentuated the gap in the literature, decreased the likelihood of repetition and provided methodological pellucidity. The review protocol was developed iteratively refining processes and transparency as work progressed.

3.4 Search outcome

From 2008 to 2018, 422 articles were retrieved, following the exclusions outlined, 18 studies described in 20 articles were critically appraised using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). 20 articles were produced because authors Kvarme et al. (2016), Kvarme, Alebertini Früh, & Lidèn, (2017) and Wolff, Pak, Meeske, Worden, & Katz, (2010) and Wolff, Pak, Meeske, Worden, & Katz, (2011) used the same data to publish two separate articles.

From 2018 to 2022 a total of 309 articles were retrieved, a vast increase in literature published about migration and refugee health was noted in this period. The increased needs identified during the Covid-19 pandemic and the current conflict in Ukraine, may explain this general increase. In terms of relevance to this study, much of the literature analysed was either not specific to palliative care or forced migrant populations. Also, of note was a significant number of papers which were excluded as they were not primary empirical research, with many reviews and conference

abstracts. Of the articles retrieved, four were critically appraised using the MMAT tool.

3.5 Prisma diagram

The PRISMA diagram helped the appraisal of articles and ensured selection based on sensitivity and specificity (Moher et al, 2009). The original and subsequent search are further detailed in Figure Four.

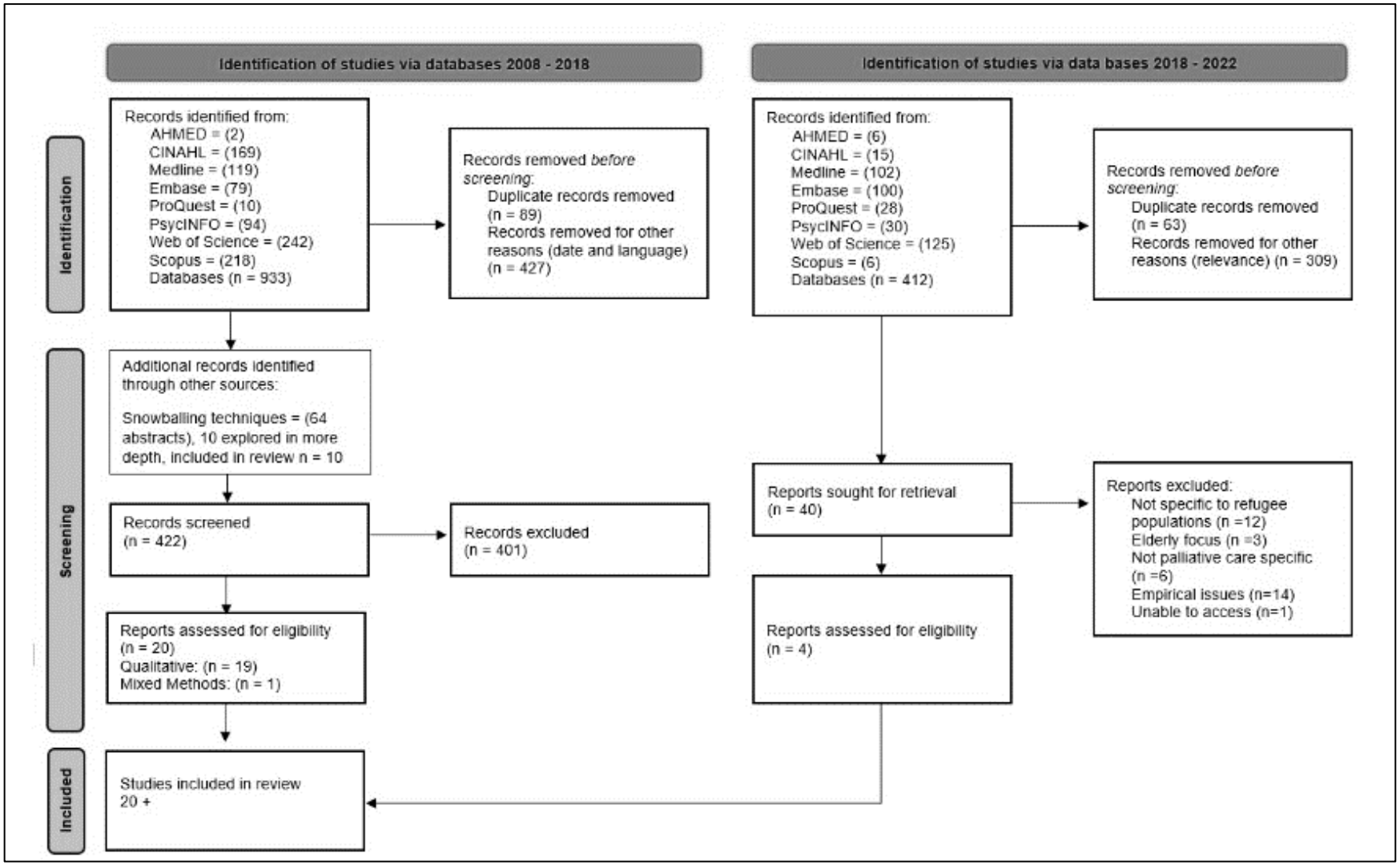


Figure Four – Prisma Diagram (adapted from Page et al. (2021)

3:6 Quality appraisal

Appraising the quality of methods utilised in each study of the review was essential as overstating the effectiveness of interventions is common in studies that are not conducted meticulously (NHS Centre for Reviews and Dissemination, 2009). An appraisal tool to evaluate empirical qualitative, quantitative and mixed methods approaches was required and so the MMAT appraisal tool (Hong et al., 2018) was selected. MMAT gives step by step guidance of the appraisal process and clearly explains how to make objective decisions. All three of my doctoral supervisors appraised each study in the review and two supervisors checked at random for consistency within four papers. This process ensured the review was robust and reliable and that any differences of opinion were reflected upon until a consensus was reached.

Each study in the review was scored individually for quality (in research design, methodology and rigour) and usefulness (applicability to this study) (Daniel, Taylor, & Scott, 2010, 2011; Taylor and Scott, 2012). When assessing quality, scores of one related to a rigorous study in which any bias relating to the research design or implementation had been addressed; scores of two showed consensus with design and methods and efforts to minimise bias; a score of three was applied when studies showed unsatisfactory criteria of rigour, did not tackle bias or were flawed. Relevance and usefulness to the subject area was scored using: one to show particularly useful and relevant studies; two indirect relevance but some useful information; and three minimal relevance. Studies which scored three for either

quality or usefulness was omitted from the review. Results can be found in Table Three, with studies from 2018-2022 denoted by blue shading.

Table Three – Summary MMAT results

Studies in the review	Q.S1.	Q.S2.	Q.Q1.	Q.Q2.	Q. Q3.	Q.Q4.	Q.Q5.	**Quality**	**Usefulness**
Qualitative studies									
Pergert et al (2008)	√ NT	√	√	√	√	√	√	1	1
Khanlou et al (2015)	√ NT	√	√	√	√	√	√	1	1
Brassart et al (2017)	√	√	√	√	√	√	√	1	1
Green et al (2018)	√	√	CT	√	√	√	√	2	1
King et al (2015)	√ NT	√	√	√	√	√	√	1	1
Lindsay et al (2012)	√	√	√	√	√	√	√	1	1
Pergert et al (2012)	√ NT	√	√	√	√	√	√	1	1
Kvarme et al (2016) and Kvarme, Fruh and Liden (2016)	√	√	√	√	√	√	√	1	1
Gulati et al (2012)	√ NT	√	√	√	√	√	√	1	1
Wolff et al (2010) and (2011)	√	√	√	√	√	√	√	1	1
Fellin et al (2013)	√ NT	√	√	√	√	√	√	1	1
Contro et al (2010)	√ NT	√	√	√	√	√	√	1	1
Davies et al (2010)	√ NT	√	√	√	√	√	√	1	1
Burnes et al (2008)	√ NT	√	√	√	√	√	√	1	1
Beatson (2013)	√ NT	√	√	√	√	√	√	1	1
Sneesby et al (2011)	√ NT	√	√	√	√	√	√	1	1
Pinheiro and Jaff (2018)	√ NT	√	√	√	√	√	√	1	1
Broom et al (2019)	√	√	√	√	√	√	√	2	1
Guo et al (2021)	√ NT	√	√	√	√	√	√	2	1
Sacchi et al (2021)	√	√	√	√	√	√	√	1	1
Mixed Methods									
Periyakoil, Neri and Kraemer (2015)	√ NT	√	x	√	CT	CT	CT	2	1
Gray et al (2021)	√ NT	√	√	√	√	√	√	2	1

Key	Yes	√	Can't tell	CT
	No	x	Not titled correctly	NT
	Shading denotes updated search from 2018 to 2022			

3.7 Data Extraction

It was important to ensure the selection process increased the objectivity of the review by having an explicit inclusion/exclusion criteria which was free from any researcher preferences (or bias) (NHS Centre for Reviews and Dissemination, 2009). Preliminary decisions were based on titles and abstracts, with thorough assessment to aid inclusion and exclusion concurrence. When uncertain the full text of the article was explored to ensure articles weren't excluded inappropriately.

The extraction of information from each article was curated in a table (Table Four), to highlight salient points from each study and ensure a standardised, consistent approach which aimed to improve the validity and reliability of methods (NHS Centre for Reviews and Dissemination, 2009).

Table Four – Data extraction table

Study details (Aims, reference, location, author details, peer reviewed article?)	
Context and participants (Setting, intervention, participants)	
Study design and methods (Sampling, data collection and analysis, theoretical models? Methodologies, methods)	
Findings (Key themes, concepts, recommendations)	
Quality of the study (Limitations, data/reporting)	

At the end of the process a table was produced including all studies, this was divided between HCP-specific and family-specific studies and with studies from 2018-2022 denoted by blue shading (Table Five).

Table Five - Included studies summarised data extraction table

Articles focussed on HCP perspectives						
Article details	**Participants**	**Setting**	**Methodology**	**Methods**	**Analysis**	**Themes**
HP1 Pergert, et al (2008)	HCP N=35	**Sweden** Oncology units; hospital + community	Grounded theory	Individual interviews and focus groups	Constant Comparative analysis	Tools for bridging obstacles (conceptual framework); communication tools, transcultural tools and organisational tools
HP2 Khanlou, Haque and Sheehan (2015)	HCP N=27	**Canada** Rehab; community + hospital	Sandelowski's qualitative approach	Telephone interviews	Thematic analysis	4 supports; structural (language, comm, health capital, access to services/info), instrumental (tangible, financial, care-giving, respite), emotional (family, friends, compassionate HP), perceptive (individuals view on whether support helpful and sufficient). These were different to the values and beliefs of SP.
HP3 Brassart et al (2017)	HCP N=21	**Canada** Rehab centres	?Grounded theory	Interviews	Thematic content analysis	Barriers; limited language skills, divergent beliefs, diagnosis, roles, misunderstanding systems, non-acceptance of treatment, goals and daily stresses. Facilitators; strategies to overcome language barrier, developing shared understanding of child's disability, strategies to understand treatment process
HP4 Green et al (2018)	HCP N=28	**Australia** Palliative care unit (single) Hospital + community	Grounded theory	4 focus groups	Constant Comparative analysis	6; determining rules of engagement (diagnosis and prognosis), navigating challenge of language to patient understanding, understanding migration experiences to establish trust, maintaining balance between patient safety and comfort, good experience through accommodation of beliefs, navigating important role of family while providing patient preferences
HP5 King et al (2015)	HCP N=42	**Canada** X2 rehab centres	Inductive content analysis approach	Interviews	Content analysis	4 strategies used to engage IP; understanding the family situation, building collaborative relationships, tailoring practice to client's situation and ensuring IP understanding of therapy procedures.
HP6 Lindsay et al (2012)	Health Care Prof (HCP) N=13	**Canada** Rehab in community	Qualitative descriptive approach	Interviews and focus groups	Constant Comparative analysis	Challenges; lack of training, language and comm issues, discrepancies regarding understanding of disability, building rapport, gender, keeping with advocacy.
HP7 Periyakoil, Neri, Kraemer (2015).	HCP- doctors N=1040	**America** X2 large training hospitals	Mixed methods	Questionnaire	Grounded theory coding and statistical analysis and regression	85.7% found it very challenging, especially for those patients whose ethnicity was different to their own. Barriers; language & interpretation issues, patient/family religio-spiritual beliefs, doctor's ignorance of patient's culture, diff in truth handling and decision making and patients limited health literacy& mistrust of HC system. Doctors ethnicity and medical sub-speciality influenced barriers
HP8 Brom et al (2019)	HCP N= 57	**Australia** X3 hospitals in 2 states (NSW and QLD)	Qualitative Interpretative approach	Focus Groups	Grounded theory? Purposive sampling with concurrent analysis	1.Culture as merely one aspect of complex personhood 2.Managing culture at the intersection of institutional, professional and personal values 3.Balancing professional values with patient values and beliefs and building trust and respect 4.The importance of time and everyday relations for generating understanding and intimacy and for achieving culturally competent care

HCP 9 **Gray et al (2021)**	HCP N= 294	**USA**	Mixed methods	Web based survey	Free text questionnaire analysis and chi-squared analysis to evaluate associations	A majority of clinicians (68%) perceived that access to hospice was limited or unavailable for undocumented migrants in their location and among respondents who provided data regarding hospice scope. 38% reported that services provided to undocumented immigrants were limited compared to those provided to other patients. Reports of restricted access and scope varied by region, and those in large metropolitan areas were more likely to report restricted scope of care than those in smaller towns (43% vs 28% p=0.03). Qualitative analysis revealed common limitations in hospice scope including reduced access to medications and equipment inability to access inpatient hospice, inadequate translation services, reduced staffing, and restricted duration of services.
Articles focussed on family's perspectives						
Article details	**Participants**	**Setting**	**Methodology**	**Methods**	**Analysis**	**Themes**
F1 Pergert et al (2012)	Parents N=11	**Sweden** Oncology unit; hospital	Grounded theory	Interviews	Open coding approach	Struggling on; in a situation of powerless dependence, protecting family interests. Approaches used in interactions with staff; cooperation, contesting, reluctant resigning
F2 Kvarme et al (2016)	Parents N=27	**Norway** Hospital	Phenomenological	Individual and group interviews	Interpretative	Parents experience their own health and quality of life challenges. Described burden of care which affects sleep, physical & mental health. Single mothers particularly vulnerable.
F3 Kvarme, Fruh and Liden (2017)						Parents resources; attitude to their situation, personality & inner strength are important for coping. Parents used emotion-focused and problem-focused coping. Newly arrived migrants, single mothers who lacked support and those with language difficulties struggle to cope. Stress; personal, social, structural problems, insufficient resources and access to welfare services
F4 Gulati et al (2012)	Parents N=50	**Canada** Oncology centres	Grounded theory	Interviews	Constant Comparative analysis	62% parents no difficulty communicating with HCP, 26% struggled and 12% could not communicate in English. Comm challenges influenced parent's role in caring and made difficult to learn med terminology. Interpreting services problematic. Lack of information and social integration in HC process.
F5 Wolff et al (2010)	Fathers N=15	**America** Hospital	Life story method	Interviews	Narrative analysis	Challenges; child's illness; psychosocial functioning, family conflict, economic challenges. Coping strategies; interpersonal support, coping styles and structural assistance
F6 Wolff et al (2011)						Assumed roles due to; childhood experiences, economic or employment situations, mother's inability, preferences & reinforcement.
F7 Fellin et al (2013	Parents N=5	**Canada** Recruitment via community org.	Grounded theory and interpretative approaches	Interviews	Open coding approach	Barriers; divergent perspectives of IP and SP, language barriers, IP knowledge of systems, financial barriers, experiences of discrimination &gender relations. Facilitators; third person to help navigate the system such as SW.
F8 Contro et al (2010)	Families N=38	**America** Hospital	Grounded theory	Interviews	Constant Comparative analysis	3 aspects characterised experiences; a backdrop of poverty, the absence of traditional community support, facing challenges of caring for siblings. Maintaining connections to homeland was important.
F9 Davies et al (2010)	Parents N=36	**America**	Grounded theory	Interviews	Thematic analysis	3 types of info shared by HCP; info about child's life in hospital, info about parent's daily life in hospital, info about treatment and EOL issues. Four

		Hospital				patterns; no info, basic info, basic info plus implications, basic info plus implications + attention to parent's questions concerns and emotions.
F10 Burnes et al (2008)	Parents N=1032	**Canada** Speciality clinic for SCD	Long interview method	Semi-structured interviews	Long interview 5 stages	Daily caregiving coping; community perceptions of SCD, experience and perceptions of HC system and the effect of insufficient systemic resources on mother's ability to cope
F11 Beatson (2013)	Parents N=6	**America** Community	Grounded theory	Interviews	Thematic analysis	4 themes; native healing, unmet needs, ongoing challenges, helpful helping
F12 Sneesby et al (2011)	Families N=15	**Australia** Recruitment via community org.	Interpretative	Focus Groups	Content analysis	Communication issues; disclosure and consent, concepts of disease and illness, attitudes towards medical treatment, customs, spiritual and religious issues.
F13 Pinheiro, Jaff (2018)	Patients, caregivers for children N=25	**America** Hospital and community	Grounded theory used but not stated	Interviews	Thematic analysis	4 themes; continuity of care/availability of care, perceived quality of care/satisfaction, psychosocial support/support systems, coping mechanisms/tactics employed.
F14 **(Guo et al 2021)**	Patients (n=22) and caregivers (n=7)	**Jordon** X2 hospitals	Qualitative cross-sectional study	Semi-structured interviews	Thematic analysis	1.Psychological distress and sustaining social support which was reported either absent or limited 2.Knowledge and uncertainty. Lack of information and poor communication between healthcare providers and patients caused significant distress due to uncertainty 3.Family anxiety and support roles. Being away from the home country cut patients and caregivers off from their wider social support network, which added increased anxiety and responsibilities to caregivers 4. Compounded trauma and poverty
Articles focussed on family and HCP perspectives						
Article details	**Participants**	**Setting**	**Methodology**	**Methods**	**Analysis**	**Themes**
Both 1 Sacchi et al (2021)	Carers, interpreters, nurses, palliative specialist, health care workers N=27	**Northern Italy** Hospital	Constructivist Grounded theory	Semi-structured open-ended interviews	Thematic analysis	Findings evidenced that professionals feel they were not adequately trained to cope with immigrant cancer patients. Nonetheless they were highly committed to providing the best care they could, rushing against the (short) time the patients had left. Analyses evidenced four main categories; providing and receiving hospitality, understanding each other, addressing diversity and around the patient. These were conceptualised under the core category of achieve the best while rushing against time.

3.8 Synthesis

Following data extraction a thematic analysis was carried out to identify the themes of each study, followed by analysis to identify any relationships between the findings. Braun and Clarke (2022) guidelines were utilised to ensure the themes accurately summarised the documented findings. Initially, this involved reviewing each study individually and coding the author(s)'s themes with simple terms to summarise each findings section (Appendix Four). This was undertaken for each paper separately and codes were then reviewed to see how they integrated together, checking and rechecking to ensure the codes accurately summarised the findings.

Following this, an analysis of the frequency with which themes appeared in different papers was conducted, alongside a reflection of the significance and relevance of each theme (Appendix Five). At this stage, themes that might be amalgamated were identified where they were similar or part of a pattern (Aveyard, 2018). Next, theme names were examined to ensure they best fit the content included. Through 'working back and forth' dynamically within the data, robust themes were created (Lincoln, Guba, & Pilotta, 1985, p. 342). Following this stage was the integration and interpretation of studies within the review, taking account of any similarities and inconsistencies (Braun and Clarke, 2022). This involved looking at the themes across the studies and rather than being a simple tabulated process, it involved the recognition of relationships across the themes and the dynamic processes involved within the research findings (Appendix Six).

3.9 Results

Table Five provides an overview of the 18 + four new studies included. Articles originated from a multitude of countries (America n=7, Canada n=7, Sweden n=2, Australia n=3, Norway n=1, Jordan n = 1 and Italy n =1). Twenty were qualitative, with two mixed methods studies. The qualitative studies offered a variety of research approaches. Whilst some adaptability of research approaches can allow for a certain amount of flexibility (Bradbury-Jones et al., 2017), it can also cause confusion. The diversity in approaches showed broad scoping methodologies which offered little transparency regarding the methods used. It was hard to find a rationale for sample size or know whether the methods utilised were appropriately rigorous to validate the claims made (Kim, Sefcik, & Bradway, 2017). Furthermore, although many studies were interpretative in nature none described reflexive approaches.

3.10 Recruitment issues

When analysing the studies within the review, there appeared to be several issues with recruitment. Two studies (Contro et al, 2010 and Davies et al 2010) used a retrospective design only recruiting families post child bereavement. Whilst this may have been implemented to offer a sensitive and seemingly less traumatic approach to bereaved families, it may have created recall bias (the failure to accurately remember a past event/experience). However, some scholars would suggest the memory surrounding the death of your child is so distinctive, vivid and emotive that any recall bias would be minimal (Bartlett, 1932; Kensinger and Ford 2019). Further recruitment issues included a lack of male respondents with the voice of fathers

being distinctly absent. In addition to this was a lack of children's voices and perspectives.

It is widely discussed in the research literature that forced migrant communities may find it difficult to be involved in research projects. Many reasons must contribute to this, but Emami and Mazaheri (2007) discuss aspects of fear, suspicion and the touching on cultural taboos as being responsible for raising defence mechanisms and a reluctance to participate. A further mistrust of the research community is thought to be significant (Cook and deMange, 1995) and thus overcoming these aspects through active participation in research seems critical in improving the future recruitment and retention of refugee and asylum seeker participants. However accessibility and inclusivity of the systems and mechanisms for valuing forced migrant voices in research are also debateable. This is further reiterated by the limited use of advisory boards or patient and public involvement (PPI) within the studies identified.

The first-person perspective of children who experience palliative care is missing entirely from this review. Whilst this is not uncommon (Ghirotto et al 2019) and may be simply due to the complicated nature of illness which makes communication difficult, other issues may also play a role. A study by Weaver et al (2019) suggests a tension within CPC research to enhance the speciality but also a need to protect potentially vulnerable populations from untoward research inclusion burdens. However, they also highlight that this fear is commonly felt by clinicians rather than the families themselves and so may correlate with the difficulties of obtaining ethical approval for research studies as highlighted by CLAHRC North Thames (2018) or

issues related to gatekeeping and lack of funding or time to conduct research (Peake et al 2018).

3.11 Thematic development

A summary of the articles included in this review can be found in Table Five. Following analysis, five main themes were identified in 2018; 1. Divergence of beliefs and expectations, 2. Communication, 3. Navigating healthcare systems, 4. Burdens and Coping Strategies and 5. Training and Knowledge. Details of each theme and a summarising Cultural Insensitivity Sensitivity Framework, are found in the published systematic review (Appendix Two). To avoid repetition, only aspects relevant to the four new articles will be discussed here. The updated search conducted in 2022 revealed a focus upon oncology, with three out of the four articles focusing on cancer care. Following a thematic review of these articles, similarities to the themes already identified were noted. A new theme - Theme 6) Perceptions of forced migrant's life world, will also be discussed here.

3.11.1 Theme 1) Divergence of beliefs and expectations

Broom et al (2019) described divergence of beliefs and expectations as a difficult balance between institutional, professional and personal values. The reliance on biomedical priorities by many HCPs was tangible and widely documented. Professional and moral conflict was also discussed, particularly surrounding personal ethics, patient autonomy and the use of traditional medicines. A participant

consensus was described, in that failure to recognise or balance competing and conflicting values was potentially damaging to trusting respectful relationships:

> *"There's a lot of that [distrust] as well. Because revealing what (alternative medicine) you're taking has the danger of being told not to use it and perhaps, because it's very much a medical model here, they may not feel there's a sympathy towards that perspective either. So that unfortunately then can set up an adversarial relationship where they're feeling that their beliefs are not being respected and their way of managing health is not being respected and then the gap gets wider"* (Social worker, p6).

For some HCP participants, these challenges appeared unsurmountable as they choose to delegate care to those with more perceived cultural similarities. However, issues of resulting inadequate specialist care were raised in the focus groups by other HCPs.

Converse to this was the importance of time and everyday interactions to generate understanding and intimacy between HCPs and patients/family members. The impact of concealed and often unrecognised 'everyday' encounters, helped participants to see the refugee as a person. These included informal exchanges and reciprocal moments of understanding. Such events were detailed as elusive and momentous, particularly as they often came following many initial confusing encounters. Correspondingly, the significance of time invested in therapeutic relationships was emphasised by all participants in this study:

> *"What you're doing is constantly assessing and shifting your communication and picking up what the issues are usually from the sensitive nature of what you're doing with people. So 2 am chats or when you've got someone in the shower and things like that you get that trust bond"* (Nurse, Broom et al, 2019 p7).

3.11.2 Theme 2) Communication

Communication continued as a dominant theme with all four new articles detailing aspects of communication and language barriers to care. Gray et al, (2021) noted inadequate access to personnel and language resources such as interpreters, with 37.6% of survey respondents detailing that care was restricted or limited in scope for undocumented migrants.

Guo et al (2021) detailed aspects of frustration, sadness and desperation after cancer diagnosis which was compounded by elements of uncertainty. Here, family members actively concealed the truth from their relatives to protect them, particularly relating to diagnosis and prognosis:

> *"He has a malignant mass in his bladder. We did not want to tell him about it because his spirit is really low and he gets anxious and worries about himself and his family … He is always anxious, so we kept it a secret to keep his spirit high"* (Caregiver Palestinian, son caring for his father, p919)

Conversely, patients in this study wanted information regarding these aspects but this was concealed from them, due to the use of family members as interpreters, which limited HCPs ability to share accurate information. Guo et al (2021) does not detail why this was the case, but further explanation of this issue appears to be necessary to ensure patients' rights are respected and the need for truthful information is met. Sacchi et al (2021) further reiterates this, with similar examples:

> *"In the phase in which there were important things to communicate, it was the daughter who was the interpreter; but in fact, I did not understand what she said to her mother. I suspect that she did not tell things as they were"* (Oncologist, p431)

Additionally, Sacchi et al (2021) describes the negative consequences for HCPs when trying to discuss worsening health, side effects and prognosis without professional interpreters. HCP participants described their upset and the challenge such conversations held, but such incidents did not appear to be infrequent. Further detailed by Guo et al (2021) was the importance of timeliness of information giving and the use of incremental steps to prevent further distress:

> *"It's their right to know everything about their condition, but not when they're not in the proper psychological shape. If the patient's mental state improves, their physical state improves too and only then can the doctor talk to the patient honestly about their condition. It is better if the doctor does not break any bad news to the patient when they're depressed" (Libyan Patient, Ovarian Cancer IV, p921).*

Due to the poor communication experiences detailed, both studies discussed the negative consequences for patients of limited information about their disease and treatment. Of subsequent note is the increased anxiety, uncertainty and fear documented, particularly when professional interpreters had inadequate involvement in care (Guo et al, 2021; Sacchi, et al, 2021). However, both of these studies centre around adult care and so some of the specific elements of child-to-parent, parent-to-child and HCP-to-both-parent-and-child information giving, receiving and the potential differences between these subsets is missing from this review.

3.11.3 Theme 3) Navigating healthcare systems

Gray et al (2021) gave American specific examples of restrictions to medications and equipment and reduced staff visits in hospice care. Limited access to

multidisciplinary care and an inability to provide hospice beds, due to lack of entitlement or access to funds to pay for these aspects of care, was also detailed:

> *"Patients have access to service providers but no coverage for meds or procedures … It's rare for undocumented immigrants to be able to stay in the hospice inpatient unit, as they are not inclined to offer charity beds. Sometimes this means patients have to stay in hospital''* (Physician, p1170).

Remarkably, although the Gray study used a mixed methods approach, it appeared not to delve into the rationale behind funding limitations, or for the poor access to hospice services detailed for undocumented migrants. The perspectives of patients and families were not detailed in this study either and so it was difficult to get a clear picture of the issues and barriers forced migrants faced regarding hospice care.

On a similar access to funding theme, Guo et al (2021) detailed patient difficulties in applying for or receiving financial support in Jordan, with many being unable to afford care, medications, treatments or even living costs:

> *"I am afraid that one day I would not be able to buy my pills. . . I wish they would lower the price of the medication or just give it to us for free … National hospitals in Syria provide chemotherapy and radiotherapy free of charge, whereas in Jordan we have to pay for it"* (Syrian, Patient Breast Cancer III, p922).

Whilst these two examples differ due to the differing health care systems to the UK, it is clear that access to resources is notoriously difficult for forced migrants and can result in much stress and anxiety as bills escalate and daily living costs increase.

3.11.4 Theme 4) Burdens and coping strategies

Additionally, to the original review, spirituality and a faith in God was described as being sustaining for cancer patients in the study by Guo et al (2021):

> *"It is all about believing. If you believe the Quran will cure you, then it will. . . We do what we can do and leave the rest to God. I do not believe it is serious because I have faith in God that there is not a disease without a cure. I know a stage 4 cancer is serious, but I know God's mercy exceeds all"* (Caregiver Palestinian, father caring for his son –p921).

Whilst faith and community support were optimising to care experienced by patients in the Guo et al (2021) study, these were understandably limited by the separation of forced migration:

> *"His family calls us from Iraq. They keep telling me not to worry and that I am fine. It makes me optimistic and I do not let despair get into my life. They do not leave me alone for one second. My friends come to my house to visit. . . they support me and comfort me"* (Patient, Iraqi, Breast Cancer III, - p920).

Surprisingly, the responses of HCPs to aspects of patient spirituality and faith practices, despite their high priority for patients and caregivers, was not detailed in this study.

3.11.5 Theme 5) Training and knowledge

Similarly, to the literature within my published review, the study by Sacchi et al (2021) detailed a lack of HCP training and education. Resultant feelings of being ill-equipped to adequately meet the needs of forced migrant families was detailed, with

participant quotes revealing a lack of awareness of important systems and processes:

> *"I do not know. . . We just gave an indication like 'Try that office', in other cases we tried to find out ourselves a way to get solutions. But who knows? Information is here and there"* (Nurse, Sacchi, et al 2021, p433)

3.11.6 Theme 6) - Perceptions of forced migrant's life world

The complexity and individuality of culture was debated in three of the new articles reviewed. In Broom et al. (2019), culture was acknowledged as integral to identity, with recognition of culture frequently discussed as critical to developing quality, caring relationships. A consensus from each of the eight focus groups in this study, detailed the importance of recognising the uniqueness of each refugee patient. HCP participants also identified that culture is not a fixed or discrete notion and that such beliefs could prove negative for HCP and patient interactions.

Within the study by Guo et al. (2021), there was a recognition of migration trauma, with limited availability and opportunity for patients to return home, often as a result of war or persecution:

> *"Of course, I do want to return to my home country, but only when I am cured because the country is still unstable and medications are not as available there as they are here"* (Syrian Patient, Guo et al, 2021, p922).

The recognition of migration trauma was discussed as being positive in this study, as it enabled HCPs to be more holistic, identity problems early and address 'the unique

and multidimensional needs' of forced migrants (Guo et al, 2021). A further aspect discussed was the use of assessment tools such as the Edmonton Symptom Assessment System (ESAS), the Distress Thermometer for all patient encounters and plans to develop a third Integrated Palliative Care Outcome Scale (IPOS) to reflect specific concerns at the Jordanian hospitals under study. Whilst such tools can be helpful in giving consistent care, Ajibade (2021) asserts that assessment tools need clear patient involvement to accurately calculate need. For forced migrant populations, this may be difficult due to the communication barriers and likelihood of poor health literacy as highlighted regarding the use of the Distress Thermometer by Lo et al, (2016).

Further concerns specifically for ESAS, relate to the poor definition of areas such as wellbeing (Hui and Bruera, 2017) and for all scale use, the notion of encouraging a formulaic approach to care. Therefore, the use of such tools appears contrary to Guo et al's (2021) assertion that a person-centred care approach is fundamental to quality care. Subsequently, further explanation of how these two aspects could work mutually, for patient benefit would be valuable.

Conversely to the negative perceptions of forced migrants in the background section of this chapter, in the Italian study by Sacchi et al (2021) a theme of hospitality and correlated trust in the health care system was discussed. Without associated explanations of hostility or resentment from the reporting research team, one HCP participant described:

> *"There is a common culture of hospitality, to the extent that many, even if they are not residents, come here to be cured"* (Sacchi et al, 2021, p430).

Interestingly, Sacchi et al (2021) also details cultural minimisation in this study, with some HCPs describing cultural differences as unimportant or irrelevant and others seeing all ethnicities as alike:

> *"Whether they are Roma or Chinese, anything you can think outside the hospital, I focus on the health problem. . . they had habits like ours." (Nurse, p432).*

The common view described in this study of forced migrants as disadvantaged appeared to lead to feelings of pity and the potential for paternalistic and patronising viewpoints:

> *"I give a special eye on them because they are vulnerable and they totally need our resources and attention"* (Health care worker, Sacchi et al 2021, p432).

> *"I am always a little more careful with them. I see them more and more 'weak' in this situation"* (Nurse, Sacchi et al 2021, p432).

Whilst the commitment to and empathy for forced migrants was apparent from many of the quotes used in this study, it was also evident that there were elements of labelling with refugees seen as 'fragile' (Sacchi et al, 2021). The theme of perception is an important one, as it appears to link to the development of relationships when a forced migrant's lifeworld is understood well, but conversely when cultural factors are minimised or misunderstood, there is the potential for labelling and paternalism.

Overall, the addition of four articles to this review reinforce the issues previously highlighted in both the background section and published systematic review article (Clancy et al, 2020).

3.12 Limitations, strength and generalisability, transferability of the evidence

By restricting this review to include only English Language articles, the data set may have been limited and this may have potentially inclined the findings towards English-speaking nations and their viewpoints and methods (NHS Centre for Reviews and Dissemination, 2009). However the translation of non-English language research was not feasible, during this doctoral study due to a lack of resource and time.

Within the review different terminologies for CPC and forced migration were used interchangeably. CPC and migration were described in varied ways which were often unclear. Subsequently it was not always clear if the subject matter was relevant to this study and so thorough examination of many of the articles found had to be conducted. For CPC this related to the types of illness, disability and for forced migration, terms to describe refugee and asylum seekers were used broadly, without detailed explanation and so full text searching was often necessary. However, by being very meticulous with terminology relevance in each article, the review has been strengthened by providing a methodical approach throughout. The international context of the review provides a further strength as it increased generalisability and transferability.

3.13 Recommendations

From this review it is clear more research is needed about the experiences of children's palliative care for forced migrant families to fill the gaps in knowledge identified. Children and young people did not appear to be involved in the research forming this review. Whilst this is not uncommon and it may relate to the nature of CPC (Ghirotto et al., 2019), children and young people's vital contribution to how care could be improved is currently missing. Further research involving children and young people is thus recommended. A focus upon hospital settings was noticed in this review and so in order to gain further perspectives surrounding care giving in hospice and community settings an expansion across care settings is recommended for future research in this area.

3.14 Conclusion to the Systematic Review

Valuable insights into the experience of children's palliative care for forced migrant families have been offered within the findings of this systematic review. The creation of a culturally sensitive care framework has added a contribution to the existing knowledge in this area. Palliative care service providers often recommend an individualised approach to care, however for forced migrant families, this is particularly important as experiences of migration trauma can result in powerlessness and the need for empowerment. The need for compassion, humility and listening to migration experiences were emphasised by this review. These fundamental aspects of care were seen as imperative to building trusting relationships with mutual respect and understanding. The use of a Cultural Humility

approach to care may be beneficial but further research on its application may be helpful.

The Cultural Insensitivity Sensitivity Framework created from this review (within the published article in Appendix Two) provides a useful tool for HCPs to see how the antecedents and consequences of care relate to families' experiences. The subsequently unique insights offered may thus help to increase awareness, empathy and the facilitation of culturally sensitive CPC.

3:15 Conclusion to Stage One

In summary Stage One has explored the background to this study with reference to the 'silences' which exist for forced migrant families in CPC. These centre around a lack of access, resources, misconceptions and parental burdens in CPC. The literature around forced migration details the impacts of trauma and the hostile environment upon families. Chapter Two explored the study paradigm and theoretical frameworks: Cultural Competence, Cultural Health Capital, Cultural Humility, Social Justice and Cultural Humility to highlight the advantages and limitations for possible use in this study. The chosen framework Silences Framework was also rationalised alongside the fit with the study design, methodology and philosophy. Lastly, Chapter Three described the systematic review which was conducted to highlight the gaps in the research literature. This section details the review which took place in 2018 and the five themes identified as well as an updated review from 2022 which adds four extra articles and an additional theme 'perceptions of forced migrants' life world'.

Chapter Four Methodology

4.0 Introduction to Stage Two – Hearing Silences

When describing this stage of the Silences Framework, Serrant (2011) outlines the importance of recognising how we as researchers 'hear' different 'silences'. She describes the researcher as 'listener' and clarifies the significance of rationalising how the researcher will identify, conceptualise and understand the 'silences' inherent within their research. It is subsequently important within Stage Two to identify the 'silences' inherent in conducting my study, my relationship to these and how I hope to 'hear' these 'silences' via my chosen methodology. Forced migrant families are rarely included in the literature surrounding child health care. They are frequently excluded from policy, practice and research discourses partly due to their marginalised and often tenuous immigration status. Many obstacles exist making it difficult for forced migrant families to participate in research, such as language and communication barriers, coupled with mistrust and fear which may be linked to previous trauma. These barriers were carefully considered and strategies to minimise them and 'hear' forced migrant family's experiences will thus be discussed in detail within this stage.

Stage Two describes the chosen methodology, Interpretative Phenomenological Analysis (IPA), with details of IPA's phenomenological, hermeneutic and idiographical origins and relevance to highlight the 'silences' in this study. IPA focusses upon the individual and values research participants' experience and expertise. Such a philosophy links well to my background in children's nursing,

wherein I used the philosophy of Family Centred Care (FCC) in all interactions with families. FCC concentrates around the ill child and sees the parents as experts in their child's care. Throughout my career, I have seen individualistic approaches such as FCC empower parents and help to readdress power imbalances and the vulnerability that families often experience when their child is admitted to hospital. In a similar way, I hope that my chosen methodology and research methods will centrally position forced migrant families in this study and empower them to voice their experiences.

Stage Two will also detail the value of the creative approaches used in my study, including 'draw and talk' and poetry. Considerations of how such approaches may enhance rapport, articulation and freedom of expression for participants are also discussed here. Finally, there will be a consideration of personal positionality and potential researcher influence on the study and how reflexivity may have benefitted the research process. Further details of Stage Two are detailed in Figure Five.

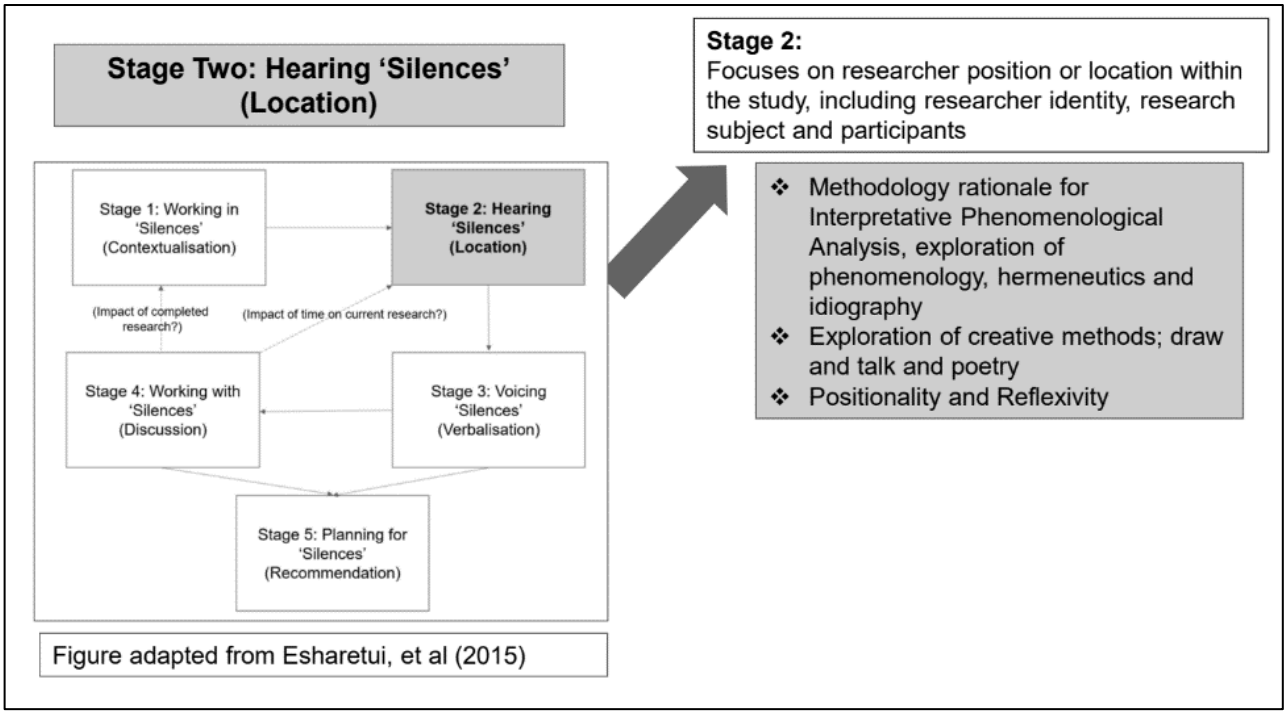


Figure Five – Stage Two Hearing 'Silences'

4.1 Interpretative Phenomenological Analysis

Qualitative research is concerned with the quality of experience, often asking 'what it is like' to experience certain phenomena (Larkin, 2019). Health psychologist Jonathan Smith first introduced IPA in 1996, with the aim of offering an alternative experiential approach to biomedical models of disease and illness (Smith, 1996; Brocki and Wearden, 2006). IPA uses a post-positivist framework and thus rejects the notion that the world is the same for everyone. Instead, IPA values subjectivity and the distinctiveness of human experience (Smith, Flowers and Larkin, 2009). IPA is widely used in health and associated disciplines and particularly to examine personal experiences of health and illness. IPA studies exploring children's palliative care focus on some of the most sensitive aspects of living with illness (Gower, et al, 2017; Griffiths, Schweitzer and Yates, 2011), including experiences of death (Harper

et al, 2011), spiritual aspects to caring roles (Vachon et al, 2012) and difficult decision-making (Kelly and O'Brien, (2015). IPA research exploring forced migrants' experiences similarly includes complex phenomena such as sense and meaning making (Kelly, Nel and Nolte, 2016), psychosocial challenges (Allan et al, 2017), coping and resilience (Iraklis, 2021), trauma (Gilkinson, 2009; Learman, 2015) and pre- and post-migration experiences (Tessitore, Glovi and Margherita, 2019). The use of IPA within palliative care and forced migrant's health points to how valuable IPA is considered in these fields. However, a thorough consideration of other qualitative methods was undertaken prior to selecting IPA and the results are shown in Table Six.

Table Six – Methodological approaches and choices for this study

Methodology	Advantages	Disadvantages
<u>Ethnography</u> Originates from anthropology and sociology. Utilises direct observations to create field notes with direct interviews which may offer 'insider' perspectives	Researchers need to gain entry to the cultural group of interest and immerse themselves in their daily lives. Ethnography offers a holistic perspective viewing all aspects of the phenomenon under study as parts of an integrated whole (Bernard and Gravlee, 2014). It embraces cultural relativism (*cultures must be understood on their terms*) with a focus on cultural systems with identifiable features, such as the physical boundaries of a school or hospital or the shared identities of a gang or football team (Lofland and Snow, 2005).	• Non-prescriptive method • Issues with access to others cultures including ethical issues of crossing personal/professional boundaries and loss of own identity (Creswell, 2013) • May be a laborious and time-consuming process (Elkatawneh, 2016) • Participant and possible recall bias (Padgett, 2017). • Issues with acceptance and normalisation of researcher in the field. Social dynamics between interviewer and participants are complex and deep-seated and movement between 'insider and outsider' positionality may be very challenging particularly in migrant research (Ganga and Scott, 2006), where the negotiated nature of reality and the importance of 'holism' within global contexts are so crucial to understanding (Prentice, 2013).
<u>Grounded theory</u> Central goal to explain a process or action in order to generate a theory or an illustration of how a process works	Useful when no existing theories regarding the process of interest exist as theories are generated solely from the data (Elkatawneh, 2016).	• Some confusion is noted over what precisely constitutes grounded theory with huge variations seen in the literature (Pawluch and Neiterman, 2013) • Challenges to recognising when data saturation has occurred or if this is possible given the uniqueness of human experience (particularly

	Procedural instructions for GT have been said to help demystify and increase accessibility to the method (Oktay, 2012). Major source of data are interviews (typically around 20-30), these are analysed by inductive coding of the data and memo writing to document analytic decisions. Process begins with opened coding and the researcher employs constant comparative analysis across respondents, situations and settings. Concept of data saturation is used to guide data collection and analysis and is achieved when new participants or codes/themes are redundant and no longer revealing new information (Padgett, 2017).	within palliative/end of life care which is regarded as one of the most individual life events (Timmermans, 2013). As such the objectivist assumptions of GT have led some authors to conclude that grounded theorists must be dispassionate, neutral, all-knowing observers of reality (Charmaz, 2008; Clarke, 2005) which is at odds with this study's underpinnings of cultural humility and learning from the participant experts. • Codified procedures and guidance may constrain creativity which are central to this study (Padgett, 2017)
<u>Case study</u> An event, process, activity, single person or several people's activities. Multiple sources of data such as interviews, observations, documents artefacts etc.	In-depth enquiry offered which can often help to explore historical and social changes or rare events/clinical cases (Padgett, 2017). Multiple types; intrinsic (exploratory usually rare topic), instrumental (larger purpose to demonstrate something to develop theory or evaluate/critique), collective case study (multiple case analysis (Stake, 1995)	• Difficulty in determining the case/s, difficulties in defining boundaries (Elkatawneh, 2016) • Can be a messy process of trying to maintain the distinctive process of each case (Padgett, 2017) • Multiple methods require many skills of the researcher which may be more challenging for the PhD student
<u>Narrative approaches (NA)</u> Rooted in literature, history and sociolinguistics.	Useful for studying one or a few individuals and when the topic lends itself to 'narrativizing' of some kind for example life histories,	• Interpretation either by researcher or participant or both is essential • Narratives are retrospective accounts

Derived from the premise that speaking and writing are forms of meaning making (Frank, 2010)	biographies, folk tales. Highlight context and the importance of language in meaning making	• NA may lead to or be confused with conversation analysis or discourse analysis • Requires high level of researcher skill in multi-language linguistic interpretation (Padgett, 2017).
Action and community-engaged research has roots in pragmatism as well as the 1960's liberation movements.	Linked to participatory action research and community based participatory research, this approach has fundamental commitments to community empowerment and partnership (Stringer, 2013). With the notion of active community engagement and mutual respect being central to the methodology. Involves a degree of immersion and mixed methodology.	• Ethics – impact of research methods upon community members • Issues with continued, committed and sustained engagement, substantial time investment needed to build and nurture partnerships • Negotiation, compromise and consensus over method may be difficult to resolve with conflicting priorities amongst stakeholders (Padgett, 2017) • Need for relocation of power, development of sound dialectic and development of shared quality criteria to ensure validity (Wimpenny, 2010). • The researcher must 'know' the community they seek to help, as one study on HIV prophylactic treatment revealed the complexities of community decisions and sexual practices in relation to adherence to treatment regimes, which was misunderstood by the research team and adversely affected the results of the study (Susser, 2015)

The decision to utilise IPA was made as IPA considers participants with lived experience of a topic to be experts in this field and thus encourages the researcher to prioritise and value individual's lived experience. Grounded theory was considered carefully but the idea of data saturation did not readily connect with my desire to collate diverse experiences, or complement my belief that individuals have a unique insight to offer and thus each individual must be valued and considered fully. Whilst aspects of community participation and ethnography were appealing, they posed many ethical considerations, access and time constraints to this study and so were not selected. In addition, IPA appears particularly beneficial when examining topics which are multifaceted, ambiguous, difficult to express and emotional in nature (Smith and Osborn, 2015, p41). IPA is advantageous because of the meticulous attention given by the researcher, to enable participants to recount as full an account as possible of their experience. However, unearthing such accounts requires a high level of skill on the part of the interviewer. Smith and Osborn (2015, p42) state the need for both *"strong empathic engagement and highly attuned antennae ready to probe further into interesting and important aspects"* (Smith and Osborn (2015, p41).

4.2 The Philosophical Knowledge of IPA

IPA is derived from three areas of philosophical knowledge: Phenomenology, Hermeneutics and Idiography. Phenomenology is rooted in philosophy and focusses on explaining the human understandings of experience and the way in which the world appears to the person who is experiencing it (Moran, 2002). Phenomenology aims to explain how we see, perceive, judge, value or remember concepts (Moran, 2002). Phenomenologists describe the importance of exploring and dissecting experiential meanings in order to uncover complex, rich descriptions of lived phenomenon (Finlay, 2009). As such, phenomenological research methods need to be responsive to the subjective interconnection between the researcher and their participants (Finlay, 2009). Individuality and subjectivity are viewed constructively within phenomenological research processes, as researchers are encouraged to be empathetic (Wertz, 2005) and open to many viewpoints, whilst having an attitude of curiosity combined with critical self-awareness (Finlay, 2008). Some of these concepts will be further explored within the reflexivity elements of this stage.

4.3 Phenomenology

Phenomenology contains many different emphases and interests, but two of the major phenomenological philosophers: Husserl and Heidegger, will be discussed here, due to their pivotal role in the development of IPA. Husserl's phenomenology involved a careful dissection of human experience. Famously, he argued we should go back to the 'things' (experiential content of consciousness) themselves by trying

to step outside of our everyday experience ('our natural attitude') to reflect upon them (Smith, Flowers and Larkin, 2009). Reflection (seeing, thinking, remembering and wishing) and a 'stepping away from the activity' was thus seen as critical, as Husserl theorised that it enabled an intentional grasp and additional appreciation to be gained (Husserl, 1927). Husserl suggested the need to consider the consequences of 'taken-for-granted' living, with the familiar and instead put this to one side. By separating out elements of perception, memory, judgements, thoughts and values, Husserl believed it was possible to see such elements through a series of 'reductions' intended to move the inquirer away from assumptions and preconceptions and towards the essence of the experience (Husserl, 1927). However, scholars have criticised Husserl's theories as being too complicated (Tuffour, 2017). Furthermore, the notion that pre-conceived ideas can be 'set aside' is something many scholars struggle to accept, seeing the premise as unachievable (Spinelli, 2005). However, Husserl's work has helped IPA researchers to focus on the central premise of reflection and thus an attentive, systematic examination of the content of consciousness.

Heidegger (a student of Husserl) diverged from Husserl as he believed Husserl's work was too abstract and theoretical. Instead, Heidegger focused on the concept of Dasein ('there-being'), a concern with the ontological question of existence itself and the practical activities and relationships which make experiences meaningful (Heidegger, 1962). Heidegger's view of experience always includes a 'person-in-context' element, as he believed we are always related to the world and that this is a fundamental part of our composition (Larkin, Watts and Clifton, 2006). As such, it is said the IPA researcher needs to embark on studying Dasein by immersing

themselves in the world of the participants (Moran, 2002). However, this may be argued as a naive notion which is difficult to achieve in reality. This is well articulated by C. S Lewis as he says *'for what you see and hear depends a good deal on where you are standing: it also depends on what sort of person you are'* (Lewis, 2008). Heidegger's theories highlight the significance of our relationship to objects, others and language to how we make sense of experiences.

4.4 Hermeneutics

The second element of IPA, Hermeneutics, includes the study, theory and practice of interpretation (Kinsella, 2006). IPA analysis relies upon interpretation because research observations are always made from our own position. Interpretation can be seen as a cyclical process in which everything that is encountered is then interpreted (Kinsella, 2006). Within IPA, through intersubjective inquiry and analysis of each case, a double hermeneutic (two-stage process of interpretative activity) is generated as the dynamics of preconceptions interlink with the 'researcher making sense of the participant making sense of their experience' (Brocki and Wearden, 2006). Gadamer (1975) spoke of interpretative activity as us each having our own horizon of understanding – our own presuppositions, beliefs and predilections. When we meet another, our horizons overlap and we will then make ourselves understood and in turn understand the other (Shaw, 2010). Smith (2011, p10) states that the meaning making process includes *"a chain of connection between embodied experience, talk about that experience and a participant's making sense of and emotional reaction to, that experience."* Figure Six, illustrates a double hermeneutic cycle with the researcher and participant each processing their own meaning based

on their preconceptions and context and meeting together in a ‘fusion of horizons’ during the research interview. The value of the double hermeneutic in IPA is that the researcher and participant can look at the same phenomena from different angles and through interpretation, the researcher can reveal both surface and deeper meaning-making which is context specific (Wagstaff et al, 2014).

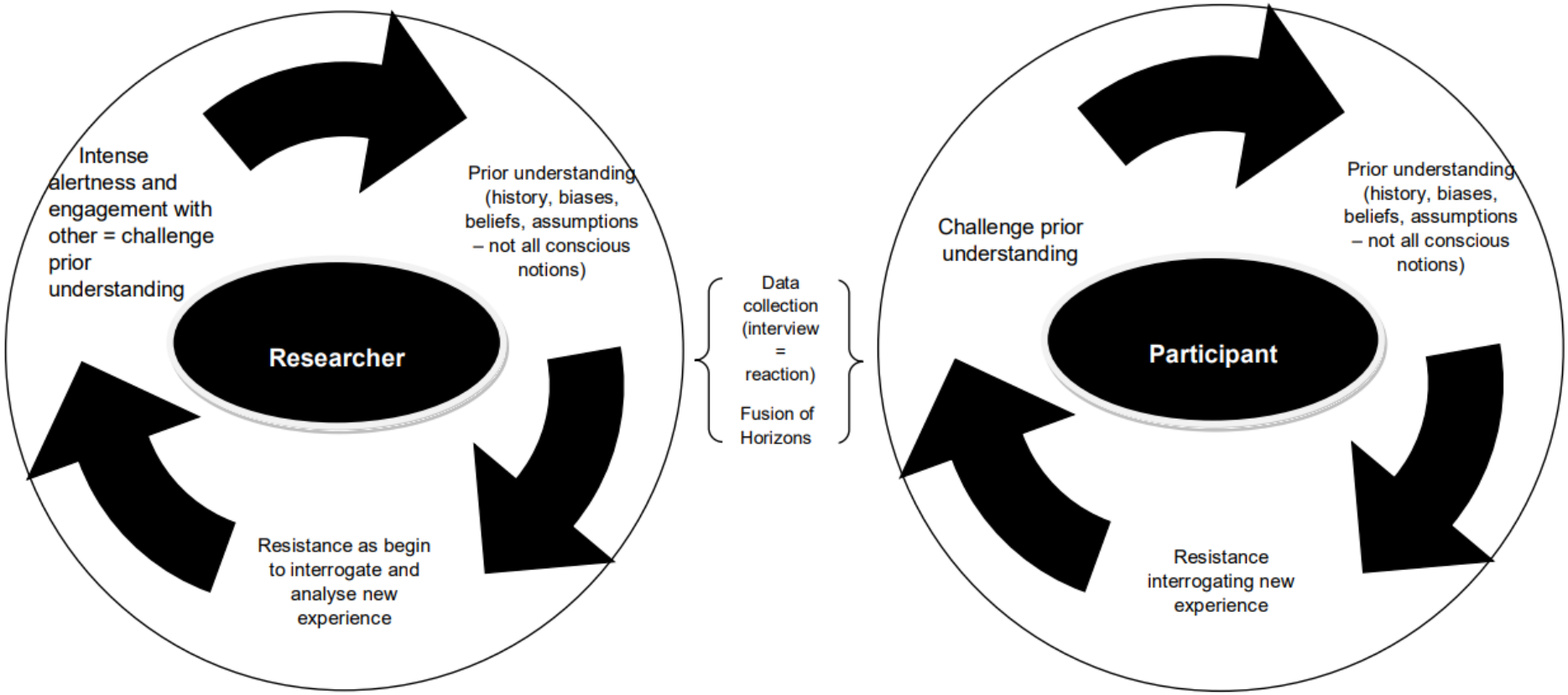


Figure Six - The double hermeneutic cycle used in IPA methodology
Developed from concepts by Shaw, (2011) and Clancy (2011).

4.5 Idiography

IPA offers a ‘bottom up’ approach to research as the cares and concerns of the participant are paramount, with those studied considered the expert (Clifford, 2018). Within IPA, participants are portrayed in their own territory within a natural setting - their world, within their relational self. Thus, the choice of language, context and the significance of the experience for the individual is important in the process of meaning making (Willig, 2000). Whilst IPA aims to emphasise and highlight the individual experience (Idiography) as opposed to other methodology, it pays close attention to each case - offering detailed and nuanced analysis by valuing each participant’s account in its own right, before moving to cross case analysis for convergence and divergence between cases (Tuffour, 2017). IPA does this by seeking to identify commonalities shared by those with a similar experience, by utilising a homogenous sample of participants (Clifford, 2018).

Within my study, the benefits of adopting an IPA approach are that it enabled multiple perspectives of children’s palliative care to be compared, whilst keeping families at the core of the study and preserving the individual contexts of all the participants involved. IPA also allows individual participants’ accounts to receive recognition for the unique learning that they may offer for those who care for forced migrant families in palliative care. Pringle et al, (2011) suggest that only by hearing, reaching and accessing participants’ experiences can we ‘see’ (and I would suggest ‘hear’) those individuals who may be in greatest need of nursing support. However, there are challenges to implementing an IPA approach in a thorough and meaningful way,

while observing both philosophical and phenomenological elements. Within IPA, philosophical insights need to be discussed but also with an acknowledgement of the phenomenological psychology in a live and dynamic way (Smith, Flowers and Larkin, 2009 p33). An example of these intertwining aspects is seen in the lower back pain study by Osborn and Smith (2008), in which the multidimensional aspect of responses were explored. These included the embodied (the active actions of living with pain), cognitive-affective (as they reflected on what they did) and existential (the practical everyday living and consequences of actions). Such multidimensional and technical psychological concepts, may be too abstract or too complicated for many researchers to grasp, summarise and document within their research findings. Subsequently, it is not too surprising that some of IPA's biggest criticisms are the lack of standardisation and the many complex ambiguities which require understanding and conceptualisation (Giorgi, 2010).

In order to draw out the meaning making described, the hermeneutics of empathy (recognising, understanding) and suspicion (inquisitive questioning and exploring the participant's interpretation) were applied to enable me to make the most appropriate decisions regarding meaning (Smith, Flowers and Larkin, 2009). Further reflective questioning aided these aspects such as: *"What is the person trying to achieve here? Is something leaking out here that wasn't intended? Do I have a sense of something going on here that maybe the participants themselves are less aware of?"* (Smith and Osborn, 2007, p53). The emphasis on interpretation was important in order to avoid the analysis being too descriptive, a further common criticism of IPA (Larkin, Watts and Clifton, 2006, p103).

Within this study, forced migrant families, children and those who care for them were encouraged to explain their understanding of their experiences of children's palliative care and I used empathy, humility and inquisitive questioning to fully absorb and appreciate the explanations given. As such, IPA methodology offered a rich data collection method and analysis of both the uniqueness of human experience and what is shared or different between individuals (Flowers, Hart & Marriott, 1999).

4.6 Creative methods, introduction and rationale

Within palliative care, it has long been noted that the circumstances in which a patient or family member may find themselves in can be indescribable. It is thus foreseeable in times of sorrow, grief or perplexity that solace and representation may be found in creative forms such as poetry and art (Brennan, 2020; Gilmour, Riccobono and Haraldsdottir, 2020). Due to an inquisitive and growing understanding of creative methods alongside personal use of creative philosophies, I was keen to use them alongside semi-structured interviewing techniques to help create additional spaces for participant expression. A further rationale for exploring creative approaches in this study was to respond to my third research question 'how can creative approaches be utilised to discuss sensitive topics?'

Creative methods have been thought to draw readers closer to the lived stories of participants by their aesthetic evocation (Casey, Proudfoot and Corbally, 2015). In a study exploring women's experiences of postnatal depression (PND), artwork created

by women appeared to help them to articulate their experiences, as many described a feeling that words alone did not seem to reach the vulnerability and depth of emotions experienced (Liamputtong et al, 2008). Within the PND study, the use of words and drawings together gave enhanced access to lived experiences and thus allowed the participants further freedoms of expression, which may not have been accessible through interview methods alone (Liamputtong et al, 2008).

The use of drawings within IPA interviews has been linked to enhanced data collection, by providing rich, evocative data and encouraging insightful metaphoric verbal accounts (Kirkham, Smith and Havsteen-Franklin, 2015; Cope, Jones and Hendricks, 2015; Boden, Larkin and Iyer, 2018). It has also been suggested that the use of creative methods can support participants, particularly those whose first language is not English, to share otherwise hard-to-reach aspects of their lived experience (Boden, Larkin and Iyer, 2018) and to voice issues of concern that they may never or rarely be asked about. Both elements of sensitivity and accessing challenging experiences are particularly important in this study, making the incorporation of creative methods potentially more valuable (Lawrence-Lightfoot and Hoffman Davis, 1997).

Further, the use of creative methods has been offered by some researchers as a way to address some of the major concerns of IPA; that interpretations offered are only the opinions of researchers and that IPA offers an elite view for the few eloquent participants that have the requisite communication skills to articulate their experiences adequately (Willig, 2008; Tuffour, 2017). However, within this study

creative approaches may have a paradoxical impact of offering additional expression for some participants, whilst also proving difficult for other participants to understand and use. Subsequently the use of more than one creative method was chosen and offered as a voluntary and additional aspect to the semi-structured interview to enhance inclusivity. Further criticisms about creative research methods include the need for a high level of self-directed participant creativity and innovation by the researcher (Knowles and Cole, 2008). Some of these concepts will be further explored alongside methods which were developed to reduce potential limitations.

4.7 Semi-structured interviewing

Interviews were conducted within a semi-structured approach in order to offer open-ended, non-directive questions to participants within a flexible structure. Such an approach has been said to invite rich description and participant narration with minimal researcher influence and additional time for participant rationalisation, reflection and evaluation (Smith and Osborn, 2003; Larkin, 2019). All interviews first began with a discussion about the voluntary nature of taking part in creative aspects such as drawing or later poetry creation. Smith, Flowers and Larkin (2009) asserted the need to facilitate interactions in an IPA interview, which encourages participants to tell their own accounts in their own words. As such, rapport between the researcher and participant was extremely important to ensure that participants felt safe and able to tell their story. Thus, by voicing early in participant interactions, the voluntary nature of the creative approaches, I hoped participants would feel free to try the techniques without pressure or constraint (McAndrew and Warne, 2010).

I felt by being open and approachable about the creative approaches which could be used in my research interviews and allowing participants time to voice their concerns, which was often done through humour and discussions about 'only being able to draw stick men', participants began to feel more relaxed. During initial discussions I was also able to emphasise that no judgements about the quality of artwork produced would be made, in order to further reduce any pressure on participants. I instead highlighted to participants that my focus was upon listening to their discussions and interpretations of their own creations through aspects such as symbolism, picture content and colour (McAndrew and Warne, 2010). Many participants were interested in the creative approaches with four HCP participants and one family participating, in which two siblings drew pictures during their interviews and the parents discussed a poem they had written about their experiences.

4.8 Funnelling technique

Pragmatically, interviews followed a structure similar to that outlined by Boden, Larkin and Iver, (2018) (Appendices Eight and Nine outline my approach). The initial questions for family participants (*'Could you tell me about yourself, your family and how you came to the UK?'*) and HCP participants ('*Could you tell me about your career so far and how you came to work in CPC?*'), were crafted to allow participants to talk about themselves and give context and background to their experience. Subsequently, each participant had time to think about the topic to be discussed before being asked about more specific issues. Burnard, (1991) describe such

questioning as a funnelling technique in which general views are gained first, before moving onto more detailed areas of concern. The funnelling technique has also been said to allow time to build rapport with participants, which is particularly important where trust in HCP, researchers and those with authority may already be diminished (Fang et al, 2015) and where feeling valued may be crucial to the preceding participant responses (Esses, Medianu and Lawson, 2013; Ahmed et al, 2019). The use of funnelling was discussed during a pilot interview with members of the palliative care network advisory group, in which it was recommended as a method to eliminate preconceptions and allow easy first conversations to flow as dictated by individual participants.

4.9 Pilot interview

A pilot interview of the technique, prior to participant interviews, was helpful to discuss questioning strategies and possible prompts for sharing common ground and establishing a trusting relationship (Goodall, 2014). For one family member, this was particularly helpful as I had been to their country of origin (Afghanistan) and simple discussions around the chaos of travelling along the roads there made the participant smile and recount similar experiences. Furthermore, the open-ended line of questioning utilised is backed by IPA researchers Smith, Flowers and Larkin (2009) who state that it allows the researcher and participant *"to engage in a dialogue whereby initial questions are modified in the light of participants' responses and the investigator is able to enquire after any other interesting areas which arise"* (p. 57).

4.10 Draw and Talk method

Initially the draw and talk sessions were scheduled to take place in the hospital or hospice environment (one familiar to the participants). Play services had volunteered to help run sessions with the children, to gain their views and work within their individual abilities and I had hoped to run some sessions separately with parents. Further to this I had hoped to have advisory group members present to work with participants, drawing alongside them to share technique and show them their own drawings. It was hoped (with participant consent) this would create a relaxed atmosphere for participants and allow advisory group members to further get to know the participants they would later potentially write poetry about. Although such plans needed to change due to the pandemic, during my draw and talk interactions (most of which took place online or in the families own home), I felt able to confirm my understandings of the meaning making that participants had verbalised in their interviews. The additional drawing discussions also allowed participants time to add subsequent comments or salient feelings and correct my interpretations as appropriate. This was valuable to my analysis and allowed me to further show my concern and respect for the points which they made.

Through drawing, Todres and Galvin, (2008) found that participants were encouraged to use the aesthetic qualities of language, trying out words to communicate their fuller experience, for example, by switching to more metaphorical and poetic language. Thus, visual methods have been said to improve the quantity and quality of verbal data and illuminate to the researcher the finer points and

nuances of every account, allowing a holistic perspective to emerge (Lawrence-Lightfoot, 1983; Cope, Jones and Hendricks, 2015).

4.11 Poetry

Following interview transcription, a poetic lens to the participants' accounts was introduced. Generally, the utilisation of poetry in any form can have benefits such as dealing with minute particulars, which can reveal a great deal in a small linguistic space (Clary, 2010). Importantly for this study, poetry has been found to be very meaningful to those who seek to understand the meaning of the human experience, particularly in life and death (Rice, 1999). Hahessy (2015: p3) suggests that engaging with poetry can confirm the 'relational connection' and support engagement with others as humans rather than 'patients'.

One concern in the use of poetic approaches in a forced migrant population was that asking participants to create poetry could be off putting or too challenging, particularly for participants who may struggle to express themselves in English. In order to assess the relevance and appropriateness of poetic approaches in this study, a local refugee and asylum seeker association (BARA) advisory group were consulted to gain from their expertise and lived experience insights.

The BARA group participated in an example exercise during one of their in-person meetings to help assess the feasibility, appropriateness and practical application of creative methods in this study. After giving some context to the research, I read aloud

and gave out handouts of a prepared case study (detailed in Figure Seven) and poem (Figure Eight) for the group as none of them had specific experience of palliative care and so needed more details on the background to the study. The group then split into smaller groups of mixed heritage, ethnicity and gender and discussed the questions posed by the scenario and how these might be answered using creative approaches.

Sami has to stay at the children's hospital	
	Sami is staying at the children's hospital with his mum. Sami is 6 weeks old and his brother Ali is 5 years old. Ali fled his war-torn home country with his family and came to Birmingham 18 months ago and his brother Sami was born here. Sami was born with a rare genetic condition which means he may be frequently poorly and not live to adulthood. From your experiences of migration and hospital care what might help the nurses caring for Sami and his family to look after him well? How can the nurses help Sami and his family to feel better whilst in hospital? What things might be worrying or upsetting for Sami's family? What advice would you give to Sami's family as they start their journey?
Turn over the paper to write, draw or create a poem of your thoughts for Sami and his family	

Figure Seven - Case study used with BARA advisory group member

Hidden lives, hidden patients

We clasp onto wishes for hope.
Wishes that wet the dryness of our tongues

Sweat drops from my father's face,
He smells as though time has run out.

We arrive expecting relief but instead claim more fear
He is scooped from his metal cot and rested, his broken heart on mine
Whenever we pray, we weep

Let everything be done we say
But we can't stop it now, like sand collapsing
Back down the hole, dug on a dry part of beach

Figure Eight - Poem to promote discussion with BARA advisory group

The BARA group consisted of a total of 11 male and female members from countries including Zambia, Zimbabwe, Nigeria, Afghanistan, South Africa, Sudan, Turkey, Eritrea and Uganda. I initially discussed with the group how it was likely these activities would take place within interviews or small groups. I asked the group if they would see these as better taking place in family, gender or role-based subsets. The consensus was that this would be of individual preference and best to check at the time of conducting the research.

The responses from the small groups and the discussions generated much interest, with participants engaged in detailed conversations about the use of poetry and art in research interactions. None of the group participants appeared put off by the nature of the task, or by being asked to think creatively when discussing their own thoughts and experiences (or that of the scenario family). I asked the group specifically if they thought families would be happy to write, draw or engage with poetry and if any of these tasks might be too challenging, difficult, offensive or taken as patronising. The group were overwhelmingly positive and did not state any reservations or fears, in fact they liked the variety of methods and that families would be able to choose based on their own preferences, abilities and beliefs. Discussions also linked the creative approaches to the development of empathy. The group highlighted a desperate need for empathy and understanding of the families in my research and the need for others to 'walk in their shoes'. They suggested that the use and creation of creative works might help others to see and understand their plight, difficulties and the specifics of having migrated in often traumatic circumstances. Advisory group input and expertise have been utilised throughout this study and are further detailed in Chapter Nine – Silences Dialogue.

Following the research interviews, participants were asked if they would like to create their own poetic account of their experiences. This was offered with or without support and as with the draw and talk method, as a voluntary option without any additional pressure. The creation of poetry can be very time consuming (particularly for the novice) and so the potential of time pressures, or limited literacy and personal preferences not to partake were considered. Participants were offered the

opportunity to create poetry together with me, with advisory group members or by themselves. For those participants who did not wish to create their own poetry, I asked if they were happy for a member of my advisory group to look at their anonymised interview in order to write a poem about their experiences. I was then able to work with my advisory group members to utilise their experiences of care and/or marginalisation and create poetry from the participants accounts. Initially I asked all my advisory groups if anyone would like to take part in creating poetry, with or without my support and had many offers of help and interest. I tried to match participants with advisory group members, so for example the parent champion from the hospice was asked to explore the parents accounts in more detail, so as to work closely within his expertise.

4.12 Two methods of poetry creation

Poetry creation took place in two ways based on advisory group member preference. For the parent champion who was an established poet and the more confident Guardian members, we had a conversation for context about the participant and then they took away an anonymised version of the participants transcript to work on a poetic account in isolation. The advisory group member sent their initial poem drafts to me and we met again to discuss their thoughts and how they had created the poems. For the YPAG advisory group, we worked together on the poetry creation, with an initial workshop to explore the method before additional meetings to look at progress and explore interpretations, together, prior to the final version and meeting to discuss any additional reflections. These meetings provided a rich opportunity to

share interpretations and gain valuable insights from the advisory group members who were experts by experience within their own domain.

In addition, poems were sent back to participants after creation, to allow time for participants to check and verify the portrayal of their experiences, with space to offer amendments and improvements and thus improve overall interpretation (Kendall and Murray, 2005).

Poetry has been widely used to represent and communicate experiences (Sparkes and Douglas, 2007) and has many benefits in research including the ability to arrange the exact words of participants to make meaningful representations of their lived experience. Appendix 10 offers an example of this method within the poem ‘New Lives New Hope’, which was created by a parent advisory member, who upon my request highlighted the participants’ exact words with bold type, alongside his own interpretations. The creation of poetic accounts can thus result in improved accuracy as the method utilises the participants own pauses, repetitions, alliterations, narrative strategies and rhythms of speech to create pose (Gergen and Jones, 2003).

The use of poetry in research has been said to give freedom to participants to voice their experience in their own style and pose and as a conduit to help articulate their feelings more clearly than with standalone interview techniques (Chan, 2012). Poetry has also been shown to help slow down thinking and allow participants extra time and space, as they consider the most effective way to express themselves (Jack, 2016). The process of poetry creation involves word reduction, but can also add

wholeness and interconnectedness of thoughts and feelings which may help those who hear it to rethink the central concerns in a powerful manner (Richardson, 2000). Poems can thus be an evocative dissemination tool by telling the realistic dimensions of participant's experiences and helping listeners to be moved on a different level and thus respond, engage and listen differently (Kendall and Murray, 2005).

An example of this is seen in work by Killick (1997) in which people with Alzheimer's disease spoke of their confusion and panic. They described what life was like before and after the disease using metaphoric and sensual language. These accounts were translated into poetry which emphasized the participant's resilience, wit, insight and creativity and challenged previous assumptions that people with Alzheimer's lose such characteristics (Killick, 2005). Further, participant poetry about epileptic seizures appeared to help professional's understanding of the condition. The in-depth temporal descriptions within this research poetry, included insightful perceptions of participants actual experiences. Including their awareness, consciousness and bodily sensations during a seizure which may have otherwise been difficult to understand due to their interconnected, sensory and complex nature (Featherstone and Sandfield, 2013). Öhlen, (2003) highlights the importance of poetic configuration which ensures the poetic description does not move too far away from the narrated experiences of the participants, as the narratives need to speak for themselves. However, some authors have argued that consideration of different poetic forms is also essential, as some may condense the data too much, such as the Tanka, thus taking away context and leaving the reader struggling to get a sense of the person and their experience (Furman, Lietz and Langer, 2006). Therefore, within this study

different poetic forms were used to suit advisory group members, but also to allow a range of expressions to be used and understood by different readers (This is further illustrated in Appendix 11 which offers a more jovial approach in the Guardians advisory group members poem – A Muslim Chaplaincy).

4.13 Limitations to creative approaches

The poetic lens in which to see data is a relatively new, alternate and complex way of understanding it (Sparkes et al, 2003; Souter, 2005). In this study, poetry offered an opportunity to avoid using snippets and small portions of direct quotes and instead give a more complete account of the participant's experiences. The benefits of using poetry lie in the ability for more of participants' accounts to be seen and disseminated, which is a fundamental premise of the Silences Framework. However, the creation of poems can be a difficult technique to master. Some scholars have questioned the need for any researcher using poetry to study poetry more formally (Piirto, 2002). Despite the sense in researchers having a deeper respect and understanding of literary forms, research poetry aims to offer accounts which are unintimidating, accessible and may differ from more traditional poetic formats with good reason. In order to improve my understanding of poetry, I conducted extensive reading, writing and studying of poetry, particularly from experts in the field such as Andrew Motion who created verbatim poetry from military personnel's accounts (Motion, 2009).

Further limitations to creative methods are noted by scholars who identified assumptions in their findings with some outputs depicting stereotypes and normative representations in the artworks created (Einarsdottir et al, 2009; Campbell et al, 2010). A further concern to using creative approaches in research is linked to the accuracy in interpretation of findings, with many questioning the validity due to the subjective lens of the researcher (Silverman, 2001; Literat, 2013). The use of advisory group expertise somewhat limited the unequivocal subjectivity described.

Additionally, the relational map technique was instrumental during interviews and involved an interview arc or a draw-talk-draw-talk structure (Boden, Larkin and Iyer, 2018). The relational map technique helped to maintain IPA philosophy as analysis was grounded in the participant's own accounts and **their** interpretations of **their** pictures (Kirkham, Smith and Havsteen-Franklin, 2015).

Opportunities for participants to offer their insights and amendments into any poetry written about them, was also in keeping with a philosophy of this study, that phenomenological research should involve walking together with participants on a journey (of discovery) (Kvale and Brinkman, 2009). An additional limitation to creative approaches is that of a potential for limited creativity in participants (and researchers) and the difficulties in fostering and encouraging this (Knowles and Cole, 2008). Being aware of such limitations and my naivety with creative approaches, I partook in specific study days on the use of creative approaches in research by the National Centre for Research Methods (NCRM), led by an expert in the field Helen Kara. Participating in this two-day course with other academics increased my knowledge

and awareness and offered some pragmatic lessons from those who have used creative methods extensively. Examples included how specific prompts and additional questioning about artworks may be useful to keep participants engaged (Casey, Proudfoot and Corbally, 2015).

Whilst the use of creative methods is definitely not a *'*magical tool' (Søndergaard and Reventlow, 2019) within this study, it was offered as a supplementary method of generating additional information, which could be analysed and understood in conjunction with traditional interview transcripts and for theoretical and contextual awareness and was thus very valuable.

Whilst the advantages to interlinking IPA methodology, interviews, creative methods and advisory group knowledge was felt to be positive, this created complexity at the analysis stage. It was at times difficult to understand participant meaning making, alongside the complexities of needing interpreters and translators for written material and wanting to value the expertise of advisory group members. The potential for segmentation between groups, with the possibility of competing voices and conflict was vast. However, a further beneficial element to this study was the impact of my clinical academic background, alongside qualitative research skills, which enabled me to understand the healthcare relevance and context of the discussions with participants and advisory group members. My background in children's nursing was further advantageous as were my nursing experiences in Far North Queensland, Malawi and Afghanistan. Alongside the reflexive approaches (which are further detailed in Chapter Five) and supportive detailed dialogue with my three supervisors,

I felt able to reconcile and complement the collective voices added to my methodology. I feel that all these elements thus combined to enhance my empathy, insight and understanding and thus the articulation and interpretation of participants accounts.

Chapter Five - Positionality and Reflexivity

5.0 Introduction to approaches

Trustworthiness and validity in qualitative research have been extensively debated by scholars (Long and Johnson, 2000; Sandelowski and Barroso, 2002; Rolfe, 2006; Smith and Noble 2014). The importance of the participant-researcher relationship and the potential that this creates for partiality has been well established. As Alvesson and Skoldberg (2009, p79) state; *"there is no one-way street between the researcher and the object of study; rather the two affect each other mutually and continually in the course of the research process*". Reflexivity is thus essential in qualitative studies as it enables researchers to become aware of their impact upon their research participants and study findings (Shaw, 2010). Reflexive methods can therefore help to identify subjectivity in data analysis and increase the congruency and credibility of findings (Darawsheh, 2014). Reflexivity originated in the fields of anthropology and ethnography, led by writers such as Clifford and Marcus, (1986). They started their reflexive writing with confessionary tales, with the aim of moving away from privileged, authoritative claims to knowledge and towards a postmodern, transparent account of research methods which acknowledged the difficulties of interpretation (Finlay and Gough, 2003).

Reflexive techniques used in this study include the five concepts of reflexivity termed by Finlay (2002b). Within my positionality statement, an introspective account of my own passionate concern for my research topic is highlighted. Inter-subjective reflection and discursive deconstruction have been used to examine myself in

relation to others particularly through my reflexive diary and poetic writing. Mutual collaboration, reflection and social critique were utilised through letter writing, peer correspondence, a Cultural Humility stance in research interviews and through undertaking reflexive dialogue with my PhD supervisors.

5.1 Positionality and introspection

Reflexive research requires a willingness to consider how one's background, personal values and experiences affect our observations and analysis, so that rather than denying or hiding issues, which may arise, they can be tackled and research adapted to bring a clearer realistic version of participants accounts. Uncovering the positionality of the researcher, i.e. 'where we are coming from within our research' is a vital first step to becoming more self-aware (Finlay, 2002a; D'Silva et al, 2016).

Positionality is a statement about the values, beliefs, interests and ambitions of the researcher, which might shape the research interest and thus its focus. Some of the important elements about myself are my female, white, British, working-class background. I am a children's nurse first and foremost but now also a nurse academic and lecturer in a university setting. Personal experiences of working in multicultural Birmingham (UK), Malawi, Afghanistan and Far North Queensland with aboriginal families have influenced me greatly. Examples of untreated pain, babies abandoned by families who struggled to accept a terminal diagnosis and a lack of prioritisation by government bodies to properly fund care, left a legacy for me and

shaped my determination to help those on the margins of society. These elements are considered further in my poem below, ‘Not my legs’.

Not my legs

A recurring childhood dream,
I look down and my little legs are black,
my feet are bare and standing amongst ashes
I know they are my feet but equally they aren’t
A strange affiliation previously unspoken

At 19 Birmingham offered a big exciting escape from small town mentality
So many people from so many places interested but also alarmed me
How would I know what to do?

One little Asian boy with beautiful olive skin, stays in my mind
He had a rare condition, no hope
His family devastated, stayed away,
frightened to get close as they knew he would soon leave them

As a student I stayed
even in my fear
I sang
older nurses peered in,
curious

An elective opened the world for us but I shied away,
preferring adventure and fun rather than self-discovery and harsh realities

But then a chance opportunity led to tropical medicine
Far North Queensland, the only paediatric unit in reach
So many children, so impoverished, underserved, last on any priority list
We fashioned equipment,
no resources for these aboriginal babies

But connections were made for me,
stronger this time
clingy embraces,
soothing pats and strokes to still
missing mothers, pain,
all manner of rashes and ills

But joy too
first tastes of jelly, cake and laughter
nurses so exceptional their faces still shine

Rewarded for my time with a silver nappy pin
new skills learnt and heart changed
I knew I had to care for those uncared for,
or cared for by so few, unseen

Africa loomed
Welcomed me in and held me
in an embrace too tight
to ever set me free

But as death passed so closely
touched so many
It also whispered in this nurse's ear
I choose to investigate
sit still with God
who welcomes all babies home

But oh, to learn about another
to be immersed
to listen
to grasp fresh language
to be welcomed into lives
mud huts so proudly swept
little fishes freshly purchased
lives full of joy, passion
for faith, family and laughter

And then to receive my nurse's hat
brilliant white, starched straight
Florence would be proud

A privilege
long hours worked side by side
trying to teach but mostly being taught
and then to be told
'you are Malawian now Marie'
the tears feel close even now

Afghanistan brought fresh eyes
smells, sights and sounds
guns and fear
chaos on roads with no system to view
but also, beauty,
green eyes like the famous photo
under the brightest blue burkas
colours so vivid
stories to behold in awe,
that one nation could endure so much

And so, on returning I knew I couldn't say goodbye
to those so many miss,
see as different,
challenging
and too difficult to engage

So, for me,
I am learning
learning every day
and encouraging others to listen
as much needs to be told
to be heard

I am also a wife and mother, which brings empathy and understanding for families but also an awareness of how different and difficult it must be to have a child/ren with a palliative diagnosis. Some or all of these aspects can be seen as a paradoxical influence on this study, as it may enhance the study through a greater contextual and relational understanding, or constrain the study by being fixed around personal or professional experiences (Ashworth, 1997). Authors have viewed such a phenomenon differently but many refer to it as an insider/outsider paradigm.

Being a children's nurse and a nurse researcher had many benefits to this study but also added complexity, which needed to be considered carefully. At my main study site, I had an honorary contract within the palliative care team. I also became nursing chair of the local paediatric palliative care network during my PhD, with included hospital, hospice and community settings and many multidisciplinary team (MDT) members. These links were helpful as I was able to get to know specialists in the field well and utilise some of my clinical nursing skills and experience. Working within the palliative care team and network helped me to build rapport and trust and thus increase interest in my research and my search for potential participants.

5.2 Gatekeepers within the study and insider/outsider positionality

Much of the literature refers to problems with accessing participants as gatekeeping, i.e. those with the power to allow researchers access (or not) to potential participants (Holloway and Galvin, 2016; Lee, 2005). Gatekeeping is common in healthcare research, where patients may be seen as vulnerable and at risk of coercion and manipulation by researchers and thus in need of protection (Holloway and Galvin, 2016). My nursing roles and the relationships I built in differing capacities were helpful in recruiting participants and for giving staff the time to understand my motivations, research ethics and the process for potential participants to become part of my research. However, my nursing background also meant I had to consider which role or insider/outsider position I was in when meeting families and even staff members. I discussed this with the lead palliative care nurse in supervision and we decided having two separate identity badges (nurse and researcher) would allow me to be clear in my role and intentions. One benefit of my separate badges was the ability to declare my role to families and staff rather than appearing ambiguous. By taking time to deliberate my badge and the work I was being involved in, also allowed me space to consider how I may shift between insider nurse to outsider researcher within my interactions. Burns et al (2012) discussed a similar issue within her midwifery research in which she struggled between being an unseen observer and with being a midwife who would normally intercede. The author felt this was an impossible and frustrating ‘tight rope to walk’.

The badge system worked well for me when in the hospital environment as when wearing my nurse badge, I did feel the kinship and professional bonding with team members described by Asselin in (2003). However, I was also mindful of staying impartial, in order not to make assumptions if any of the HCPs' I encountered later decided to become participants (McNair et al, 2008; Burns et al, 2012). Aburn, Gott and Hoare (2021) discussed a similar notion when they realised they had started to make assumptions about their participants by seeing them through the lens of their own experiences. By being aware of the potential for such issues in my own research, I was able to keep focussed and steadfast in the knowledge, that every participant would be different and thus must be seen as such. By taking an outsider view, I was thus unable to assume similarity or understanding and instead focus fully upon listening and increasing my understanding of the individual accounts of my participants.

When interviewing families, I was honest about my differing roles and immediate focus. I also discussed this aspect within my ethical review, as families had to be assured any involvement in my research would have no impact upon their care, now or in the future. Due to the pandemic, I had ceased working in a clinical capacity prior to finding my participants and so none of the families were known to me clinically which I think was an important distinction. However, families did respond well to my nursing background and for one family this allowed them space to discuss very personal and emotive elements, such as care of their son after death, which they may not have felt comfortable to share with someone non-medical. Conclusions from the literature on the insider/outsider aspects of nursing research suggest that the

middle ground between insider and outsider needs to be occupied, in order to respectfully negotiate relationships whilst retaining a degree of analytical distance (Burns et al, 2012). Leslie and McAllister (2002) make the thoughtful assertion that the insider/outsider line should not be seen as one of binary oppositions, but more of a dialectic which requires acknowledgement. Within my study I tried to be open and approachable and was happy to discuss my roles, their overlap and any concerns they may generate.

5.3 Power imbalances within the study

Whilst many elements of my personal and professional affiliations were positive, it was important to also acknowledge the power differences between myself and particularly the family participants. Kvale (2002, p9) termed this *"the asymmetrical power relations of the research interviewer and the interviewed subject".* Reflexive consideration of potential asymmetrical relationships and ways in which they may be exacerbated by presumptions surrounding such aspects as age, gender, race or ethnicity was important. D'Silva et al (2016) explored cross-cultural identity, as within her research, the colour of her skin was questioned and debated. Through her realisation of how her participants saw her and links they made to a shared ethos of marginalisation, she realised that *"the truth of who I am was not mine alone to make but rather what my participants made me out to be within their own boundaries"* (D'Silva et al 2016, p98). Similarly, Mangat (2018) talked of changing skin colours.

Mangat described herself as of Indian descent but born in Canada, her PhD focused on Indian women who had been raped. She found her positionality changed depending on where she was and who she was with and she suggested that intersecting identities are context specific and relational, thus she could change from brown to white. The influence of multiple identities is also discussed by Sydor (2019) who found the many layers of influence she had (her strict religious background, lack of sex education as a child and her role as a sexual health nurse), were affecting her decisions with her research analysis. It is clear from such studies that there are many layers of influence, affect and perspective to consider when working cross-culturally.

My positionality highlights my privilege and being aware of this and the notion of social critique theory in reflexivity i.e. the recognition of multiple, shifting researcher-participant positions, was critical to understanding both myself and myself in relation to my participants. However, it is not an easy undertaking to deconstruct authority (Finlay, 2002b). Such a process is not straightforward and requires huge amounts of effort to identify and interrogate personal and professional practices. Subsequently, it can be challenging particularly for professionals such as nurses who may be used to professional distance and objectivity (Finlay and Gough, 2003). I used many different strategies to aid the process of trying to become separate and look at myself as if from the outside, so I could begin to critically analyse my relationships anew, particularly where power imbalances were apparent.

5.4 A Cultural Humility approach within participant interactions

One approach was to utilise a Cultural Humility philosophy openly with participants, as advocated by Yeager and Bauer-Wu (2013). This allowed me to voice my incompetence, show my limited knowledge of their experiences and thus ask questions, encouraging participants to reciprocally educate me. For one family, this centred around the value and importance of their Muslim faith. By acknowledging my limited understanding, I felt a pivotal shift in our relationship as I became the one who needed their education and they relished the chance to be heard. Similarly, a study researching young Pakistani men found a comparable method for addressing power asymmetry, by focusing upon a two-way relationship in their research interviews and the importance of knowledge exchange and rapport (Shivji et al, 2022). Such an approach also fits with the work of Bhabha (2004, p312) on transcultural hybridity where ethnically diverse individuals meet and merge their views to create new knowledge (Manathunga 2013; Lee, 2016).

5.5 Peer Correspondence and Letter Writing

A further method aimed to increase my own self-awareness, especially of white privilege and power, was that of peer correspondence and letter writing with a fellow PhD student working with primary school refugee children and their families. This idea came from the indigenous research conducted by Lira et al, (2019) in which a group of researchers working with indigenous participants used correspondence-

centred methodology (Rautio, 2009), to give space for sharing the complexity of what each member of the team brought to their research. Letter writing in both instances allowed time to share our perspectives about knowledge, academia and our fears, vulnerabilities and positionality. We used our letter writing and subsequent meetings to create a safe and confidential space to discuss our memories, influences and allow time for each of us to be heard and valued. An element which was particularly helpful for me was that of discussing my own oppressive relationship with my brother and how this has affected my own empathy for others' pain and oppression. Within our correspondence, we were also able to question each other on difficult and confronting aspects such as decolonisation of our research methods and how working with advisory groups might help towards this.

5.6 Reflexive diary and poetry

I first learnt about reflexivity during my Master's thesis (Clancy, 2013), particularly the importance of undertaking critical questioning in order to examine myself and reduce any personal prejudices as much as possible (Underwood, Sattethwait and Bartlett 2010). Reflexivity is a dynamic and ever evolving method of continual questioning and personal evaluation. However, it seems important to acknowledge that often our thoughts, motivations and perceptions are partially subconscious and, as such, we may not be aware of them. As such we need to repeatedly engage with difficult and probing aspects of self-discovery and awareness. Self-discovery is not an easy process, but by writing things down at pertinent moments and reviewing them I was better able to see, for example, if my approaches to interviewing were effective and

to look at resolutions if modifications to questioning techniques were needed (Rolfe, 2006).

Within this study, a reflexive diary including reflexive poems were useful to collect thoughts particularly at the point of data collection; afterwards and at many points during data analysis for later review and discussion. By keeping a clear record of views and perceptions throughout my data collection and analysis, I have been able to become further aware of my actions, feelings and perceptions and thus any deep, meaningful and difficult questions that needed to be explored further (Freysteinson et al, 2016). Pertinent entries have also been discussed with my PhD supervisors and have been invaluable for ensuring any assumptions are questioned and that my findings were rooted in the accounts of my participants (Fook, 2002; Asselin, 2003; Jootun et al, 2007). By utilising the support of my supervisors, the subjectivity of my data evaluation was limited and the data representation further examined and rationalised leading to enhanced reliability and rigour of my research findings (Mays and Pope, 2000; Smith, 2006; Darawsheh, 2014). Excerpts of my reflexive journey can be found here in the two poems included (‘Not my legs’ and ‘Mothership’) to illustrate method, but also within the Silences Dialogue Chapter - to show how reflexivity has influenced and sometimes changed my analysis and interpretations.

My experiences with poetry have enabled me to gain valuable self-insights and to reflect in a deeper more meaningful way, offering me a cathartic outlet for clinical experiences (Clancy, 2017). With these benefits in mind, I wanted to take my previous learning into my study, in order to promote open and honest reflections as

advocated by Tilley-Lubbs, (2011) and Jack, (2015). Poetry can offer a link between head and heart, a space for dialogue (shared and internal), freedom from academic constraints, help with expression of difficult emotions and increased self-awareness (Leggo, 2008). Redman-MacLaren (2015) discusses reflexivity as a process which enables critical and constant expansion of understanding about research processes and the role of the researcher. She felt that poetry was thus an ideal tool for synthesised, reflexive research practice. Similarly, Finlay (2002b) discusses the use of discursive deconstruction within reflexive practice and the importance of recognising the significance of rhetoric, voice, language and grammatical meanings. Poetic writing is a further method in which I became more aware of my choice of words, terms and their meanings, both for me and others.

In the poem that follows, I share my reflexive experience following interactions during an asylum seeker befriending session, early in my research journey. Within this poetic reflection, I wrestled with my and other's motivations, intentions and the personal, human aspects of my research.

Mothership

Polished skin
Tones gleaming radiantly

Well intentioned? Lottery funded?
Nice to tell others about?
Cynical, hypocritical? me?

Just because my 'ethnic chic' is at the back of the wardrobe,
Aren't I just the same?

This a playgroup but I am looking for philosophical reasoning, anthropology and answers to help me

My motives aren't pure but here I sit with shoes off
Butterfly wings flapping along to a cello beat

Many wouldn't come or would come without their children,
Our precious jewels

But in coming, the humanity of others, our togetherness,
the things we share,
are in sharp focus,

Her beautiful brown African eyes
twinkling with toddler mischief and her mother's love beaming from her proud face
create a lasting imprint

and in her beautiful best pink dress
and ever so slightly too big shoes
her daughter twirls with mine

By reflecting poetically following this encounter, I was able to acknowledge my assumptions and stereotypical views. I have always considered intention to be important within interactions with others but following this experience, I was able to see that our intentions are often internal and thus not visible to others. The organisers of this event may well have had good intentions, most likely they did, as otherwise their time would likely have been spent elsewhere. However, my focus was drawn to the visible - the aesthetic - more so than I realised before and with an intensity and anger I had not previously appreciated. This was helpful as it brought my own views to the forefront, which helped me to reframe them and move forward with a less judgemental stance.

5.7 Conclusion

In conclusion, Finlay (2002b) discusses utilising five techniques (introspection, inter-subjective reflection, mutual collaboration, social critique and discursive deconstruction) in reflexive research approaches. These techniques have collectively helped me to better understand my own role and influence in my research, particularly in the interview and analysis contexts. I have become more insightful by examining my own responses and the interpersonal dynamics in my interactions, particularly where there were potential power imbalances. I have used the learning from these methods to enhance the trustworthiness, transparency and add additional accountability to my research methods.

5:8 Conclusion to Stage Two

To summarise, Stage Two has detailed the methodology for this study IPA, with discussions around IPA's origins and Phenomenological, Hermeneutic and Idiographical roots. Further, in Chapter Four is an exploration of the creative methods of 'draw and talk' and poetry and the potential benefits these offer. Finally to conclude the stage Chapter Five has detailed my personal stance within my positionality exploration and the reflexive approaches used in this study to limit partiality, prejudice and encourage self-awareness.

Chapter Six - Data Collection

6.0 Introduction to Stage Three – Voicing Silences

Stage Three of the Silences Framework incorporates the data collection and analysis phase of this study. The purpose of this stage is to explore the identified 'silences' in context, to highlight the views and experiences of the participants. This stage will rationalise the way that data has been collected, alongside addressing ethical concerns and demonstrating the IPA process followed. Further detailed are the findings by theme and setting, including community, hospice, hospital and combined across setting analysis. Additionally, Stage Three provides an opportunity to discuss how data analysis was reframed and enhanced through a cyclical process - the Silences Dialogue. The Silences Dialogue section details the ways in which the collective voices of this study have been used to enhance data analysis and the accuracy of interpretation. Figure Nine highlights how this stage fits with the other elements of the framework.

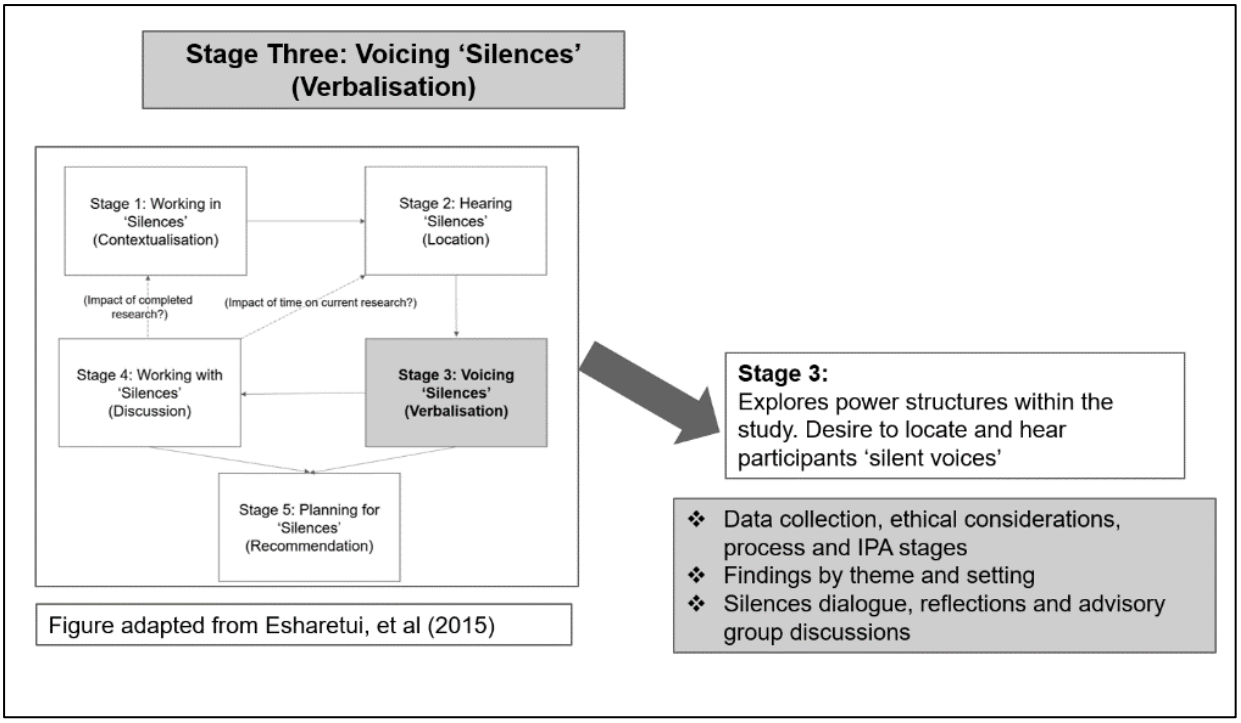


Figure nine – Stage Three – Voicing Silences

6:1 Ethical considerations

The ethical considerations for this study were deliberated with great care to, as far as possible, protect study participants and myself from any harm. I aimed to address both apparent and potentially concealed vulnerabilities and detail here the steps taken to mitigate risk. No data collection took place until ethical approval was received from University Governance and NHS Research Ethical Committee (REC) (Yorkshire & The Humber – Leeds West Research Ethics Committee), approval documents are included in Appendix 12.

6:2 Recruitment of participants

In order to safely and unobtrusively recruit family participants, information about my study was first given to HCPs at my two main study sites; a large in-patient children's hospital and a regional children's hospice. These sites were chosen as they care for many of the children in the region with palliative care needs and have the specialist knowledge and resources available to provide this care. Participant discussion regarding community care was based upon the individual family's utilisation, as this is usually organised in conjunction with either hospital or hospice care.

The recruitment of family members via their usual care teams was undertaken to minimise pressure for families to take part, and ensure they were adequately informed about the project by those with whom they already had a relationship. Recruitment was staged to enable families to be identified (by their usual care team), have time to consider their participation (and read information about the study) and ask me any questions they might have.

6.3 Participant Information Sheets

Participant Information Sheets (PIS) for families and children of different ages were created with advisory group members (details of each advisory group are provided in Appendix Seven) and by following National Research Ethics Service Guidelines (The PIS for the study can be found in Appendix 13). Advisory group input was crucial to the creation of these documents, to ensure they were comprehendible and

addressed potential sensitivities. Amendments to the initial PIS were made following advisory group feedback regarding the initial drawing to be included. The drawing utilised in the PIS and recruitment material was important, as it aimed to attract potential participants and so needed to clearly show the relevance of the study. If the drawing wasn't inclusive, representative or was seen as insensitive or inappropriate this could have negatively affected the recruitment process. Advisory group members suggested the addition of another family, to ensure accurate representation of ethnically diverse families and to be more inclusive of different types of children with palliative care needs. A further suggestion was the removal of one of the red crosses so that families did not consider the project to be linked to one particular faith group (Changes made are detailed in Figure 10).

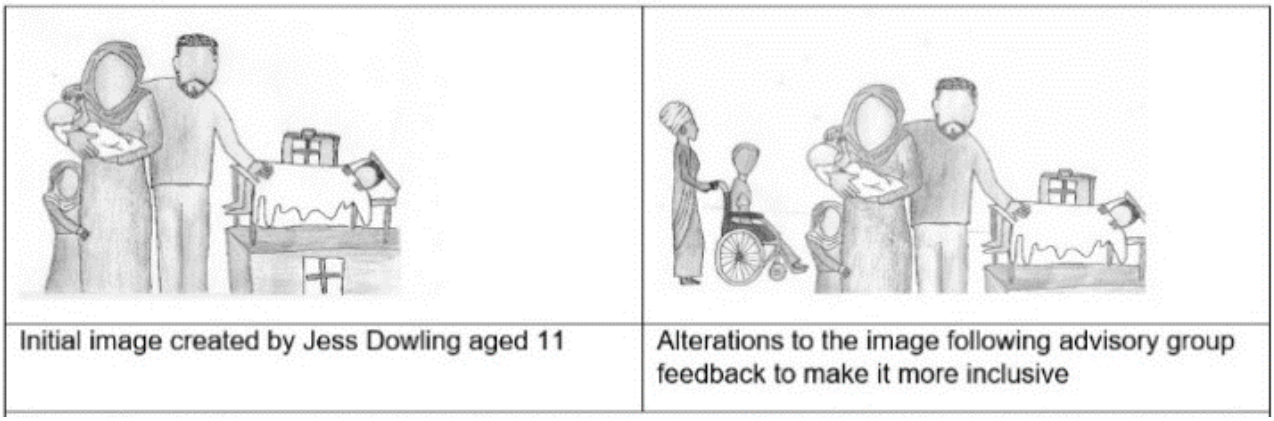


Figure 10 – Advisory group suggestions and changes made to information sheet for participant recruitment

6.4 Information giving to clinical teams

I arranged both formal and informal information-giving sessions for the two study sites, by working with teams during my honorary contract hours and more formally with the use of presentation slides, to inform and encourage clinical teams to help with participant recruitment. Usual care team involvement was also helpful to ensuring any language needs were assessed and met. None of the participants asked for their PIS forms to translated, but two of the families did require interpreters in the interviews. These were organised by the respective care teams so that professional (and where possible familiar) interpreters could be utilised. Care teams were also asked to consider any present physical and mental ill health of the family prior to selection, to help me to evaluate their readiness and ability to participate. A further task carried out by the usual care teams for any potential participant was an assessment of capacity to consent for all adult participants prior to consideration for inclusion in the study. This involved a discussion in which the participant needed to recount and show understanding of the purpose and nature of the research, including any benefits, risks or burdens to taking part following their reflection on the PIS. Once families agreed to take part in the study, the family's care team and I were able to organise interviews to suit the needs of the individuals involved. Additional time at the start of each interview was given, to enable further opportunity for participants to ask any questions and go through the PIS, which was crucial to ensuring participant understanding.

6:5 Assent and Consent Procedures

Assent and consent forms were utilised (detailed in Appendix 14) to ensure all important elements were considered prior to starting the interview. By using a form such as the one in Appendix 14, standardisation and consistency was assured for each interview. For any child participant, Gillick competency guidelines were followed to assess whether they had sufficient maturity to enable them to understand what was involved in taking part in the study (Griffith, 2016). For children under 16 years, assent to participate was taken alongside parental consent. The PIS aimed to be clear and easy to understand for all potential participants and it thus outlined that participants could stop being part of the study at any time, without giving a reason and that they could ask for their data to be deleted up to one month after their interview date. The one-month timeframe was given so as to not delay data analysis but also give a sufficient time for reflection and decision making by families, if upon reflection they did want to withdraw from the study.

Within the consent process, the safeguarding procedures were highlighted to participants. This included when confidential information may need to be discussed with others (if a disclosure of harm to the participant or others or a previous history of abuse of children or adults were disclosed). The consent process was reiterated prior to the commencement of interview. It was important for me to ensure full participant understanding of the safeguarding process in my capacity as researcher but also professionally as a registered nurse. In both capacities I would be duty bound to stop an interview if a safeguarding concern was disclosed and report this information. Participants were also made fully aware that whilst their data was to be anonymised

and confidential, there were exceptions to this in the event of a safeguarding concern. Should any participant have disclosed information about intention to harm others or previous abusive behaviour, participants were made aware that I would need to stop the interview and carefully document and escalate the safeguarding concern to the appropriate channels.

6:6 Protection from harm

Participation in this study was a potential burden on participants' time. Accordingly, the interviews were kept as short as possible, whilst still allowing enough opportunity for participants to share their experiences in a meaningful way. There was also a potential for emotional burden during and following research participation. I thus monitored participants closely during interviews to recognise any distress and to provide appropriate support. Linkages to appropriate services for on-going support were offered to all participants, with the most appropriate sources of support identified with help from the individual health care teams. None of the participants became visibly distressed during their research interviews, but a protocol to manage potential distress was identified and is briefly described in Appendix 15.

My study included discussions surrounding two highly sensitive issues: migration and children's palliative care. Although these discussions were directed by participants, there was a potential for any of the participants involved in the study to experience distress. My experience of investigating sensitive issues and clinical nursing

expertise in caring for sick children and their families was of benefit here, as I felt able to identify mental distress in my participants and act appropriately. I received clinical supervision and support from the Deputy Head Nurse (previous palliative care lead nurse) at the hospital study site. This was valuable to enable me to debrief following difficult conversations, explore challenging decisions and reflect upon the participants, the research and any impact this had on me personally or professionally, in a confidential setting.

6:7 Online interviewing

Following ethical approval and the presentation of recruitment information to clinical teams, participant interviews commenced at the beginning of 2021. The Coronavirus pandemic resulted in a stay-at-home order from the UK government which commenced on the 26th March 2020, following this more localised lockdowns were announced in the summer of 2020 with a second lockdown announced on the 5th November 2020 (Institute for Government Analysis, 2021). By the time interviews commenced most children had returned to school but there were still limits on social mixing. Family fears for children with palliative diagnosis were heightened due to the increased risk associated with Coronavirus infection (as discussed in Chapter 1:15). Subsequently, many families continued to keep their children at home and were reluctant to visit healthcare environments or have visitors to their homes during this time (NHS, 2020b). Interviews were offered to participants via telephone, online or face-to-face. Due to the pandemic one family were shielding during recruitment and

many HCPs' were limiting their contacts, with some study sites not allowing visitors. Subsequently, only one HCP interview and two-family interviews were conducted face to face, with the rest conducted online via Microsoft Teams. Microsoft Teams has inbuilt encryption to protect participants data. Both initial (and the second interview with Family Tessa) were digitally recorded using an encrypted audio recorder or via Teams software and recordings were encrypted within 48 hours and stored on the University Research Data Server (RDS) as per the agreement of University and NHS ethical approval processes.

Prior to organising times and dates for interviews, I asked participants and/or their care teams to consider the location for the interview and any connectivity issues which may impact upon our interview. Engward et al (2022) discussed the need for such pre-interview information with online interviewing, to contribute to risk assessments. Aspects of online safety were important to ensure that participants were able to talk freely without interruption, in a safe and confidential space, where others could not listen in. Engward et al (2022) debate the notion of privacy online as being partial and incomplete, with researchers not always being aware of concealed viewers. As such, a conversation was initiated with each participant to ensure the safety aspects of the online space, such as confidentiality were understood prior to interview commencement.

All participants who conducted their interviews online did so in their own homes. The video function of Microsoft Teams was used for each online interview and this meant many non-verbal cues could still be shared between myself and participants. I feel

this enabled a natural back and forth communication. This included some nonverbal signals such as chronemic (timing and pace of speech), paralinguistic (variations in volume, tone or pitch) and kinesic (eye contact, facial expressions, gestures, postures) communication (Kalman et al, 2006). As Irani (2019) details, I was aware of my inability to observe the full range of body language that participants might demonstrate when face to face but paid full attention to any non-verbal clues offered. Flick (2020) states that an increased attentiveness, noticing and checking can result in a more rigorous shared understanding of the participants' account, which was an important consideration during data analysis. However, the speed of interactions in online spaces have been said to create a distance between researcher and participant, which can reduce the researcher's sense of sensitivity toward the participant (Duggan and Brenner, 2013). Thereby, awareness of such limitations and a focus upon consistently checking my own actions and sense of purpose for the interview, was important in mitigating such aspects.

The timing of the research interviews during the pandemic meant many of the participants had already become familiar and comfortable with online meetings, which was of benefit and minimised user errors often cited as disadvantages to online interviewing (Irani, 2019). Bryman, (2004) and Hanna and Mwale, (2017) suggest benefits to online mediums, in that they may offer a more comfortable environment to share personal experiences, can be more convenient and give more control to participants, whilst also offering easy data capture with built-in recording programmes. Pragmatic limitations to online interviewing may relate to disruptions and problems with connectivity (Hanna and Mwale, 2017) and the need for

infrastructure and finance to support internet activity, which may be limited in the forced migrant population (Latonero and Kift, 2018). However, Kutscher and Kreß (2016) researched internet use for forced migrant populations and found it can have a central role in survival and coping by providing a vital source of contact, orientation and support. Subsequently, internet connectivity may be a priority and much used resource for forced migrant families. Therefore, assumptions were not made and individuals were asked about their preferences and provisions, so interviews could be tailored to each family's needs.

In addition, the online nature of many of the interviews had impacts on the creative approaches offered, as I felt that participants were a little reluctant to try these in isolation but would have been more willing if participating and being shown techniques face to face. This was an unavoidable limitation due to the pandemic, but one which is a learning point for any future implementation of creative methods.

6:8 Sampling processes including inclusion and exclusion criteria

A purposive sampling technique was used in this study, in order to identify and select meaningful perspectives and information-rich cases directly and specifically related to the phenomenon of interest (Boswell and Cannon, 2018; Shackleton et al, 2019). Participants were chosen because they offered insights from a position of shared expertise: parents/guardians of children with LLC/LLT, children themselves and HCP from hospital, community and hospice settings. Inclusion and exclusion criteria

(detailed in Appendix 16) were created to identify the study population consistently and objectively and to ensure the research questions could be answered. One possible benefit to study participation was the opportunity for family participants, all of whom had never been asked for feedback on their care before, to have their opinions heard and respected. Many of the participants shared after the interview that they felt grateful to have the opportunity to share their perspectives. Bogdan and Biklen (1998, p204) described giving voice as empowering people to be heard, who might otherwise remain silent or who have been silenced by others. Mazzei and Jackson (2009, p1) state that researchers need to privilege the voices of the marginalised and to free their authentic voices from whatever restrains them.

A distinctive feature of IPA is the commitment to a detailed interpretative account of participants lived experiences. Thus a relatively small sample size is often recommended to allow for a rich depth of analysis. Brocki and Wearden (2006) conducted a review of 52 IPA studies and found that small sample sizes were common. There are several advantages to undertaking research with small numbers of respondents which include rich insights into specific health experiences (Duncan et al, 2001), gathering clinical implications (Hunt and Smith, 2004) and helping to advance knowledge through multiple small-scale studies (Touroni and Coyle, 2002; Turner, Barlow and Ibery, 2002). Whilst scholars have sometimes criticised the small sample sizes utilised in IPA studies, focusing on a small number of respondents can help to minimise loss of subtle inflections of meaning (Collins & Nicolson, 2002, p626), preserve nuances (Elliott, Fischer and Rennie, 1999) and avoid the researcher becoming overwhelmed by too much data and producing broader, shallow or simply

descriptive analysis (Hefferon and Gil-Rodriguez, 2011). Additional disadvantages to larger sample sizes were the possibility of creating ethical issues, such as a wasting of time or overburdening of participants without adequate research gain (Hennick and Kaiser, 2022). Many of the criticisms of 'small' sample sizes in qualitative research appear to stem from a dominant positivist paradigm with a prioritisation of numerical power (Vasileiou, et al, 2018). For this study the priority was to have data adequacy in which instead of a focus upon numbers, the emphasis was placed on gathering enough data to give rich and nuanced accounts which could be learnt from (Hennnick and Kaiser, 2022). The sample size used within this study gave an additional benefit; the ability to add creative methods to both data collection and analysis. The creative methods utilised added a further level of interpretation and understanding and would not have been possible with larger numbers of participants within a doctoral study timeframe. Subsequently, a sample size of 10 to 15 participants was used to allow rich data to be gathered and to facilitate the inclusion of multiple perspectives to answer all of the research questions (Smith, Flowers and Larkin, 2022). Interestingly, although this recommendation relates to IPA, a recent qualitative study which explored optimal sample sizes for all qualitative studies also suggested 9-17 participants for interview data collection (Hennink and Kaiser, 2022).

My study focussed around three families: two from Syria and one from Afghanistan. A total of seven HCPs from community, hospital and hospice settings were interviewed including three British, one West Slavic national and three of mixed Asian heritage. The HCP participants comprised of social workers, psychologists, hospice team managers, nurses and chaplaincy staff. The profile of participants is outlined in Figure 11 along

with the connections between participants. All names detailed here are pseudonyms to protect participants' real identities.

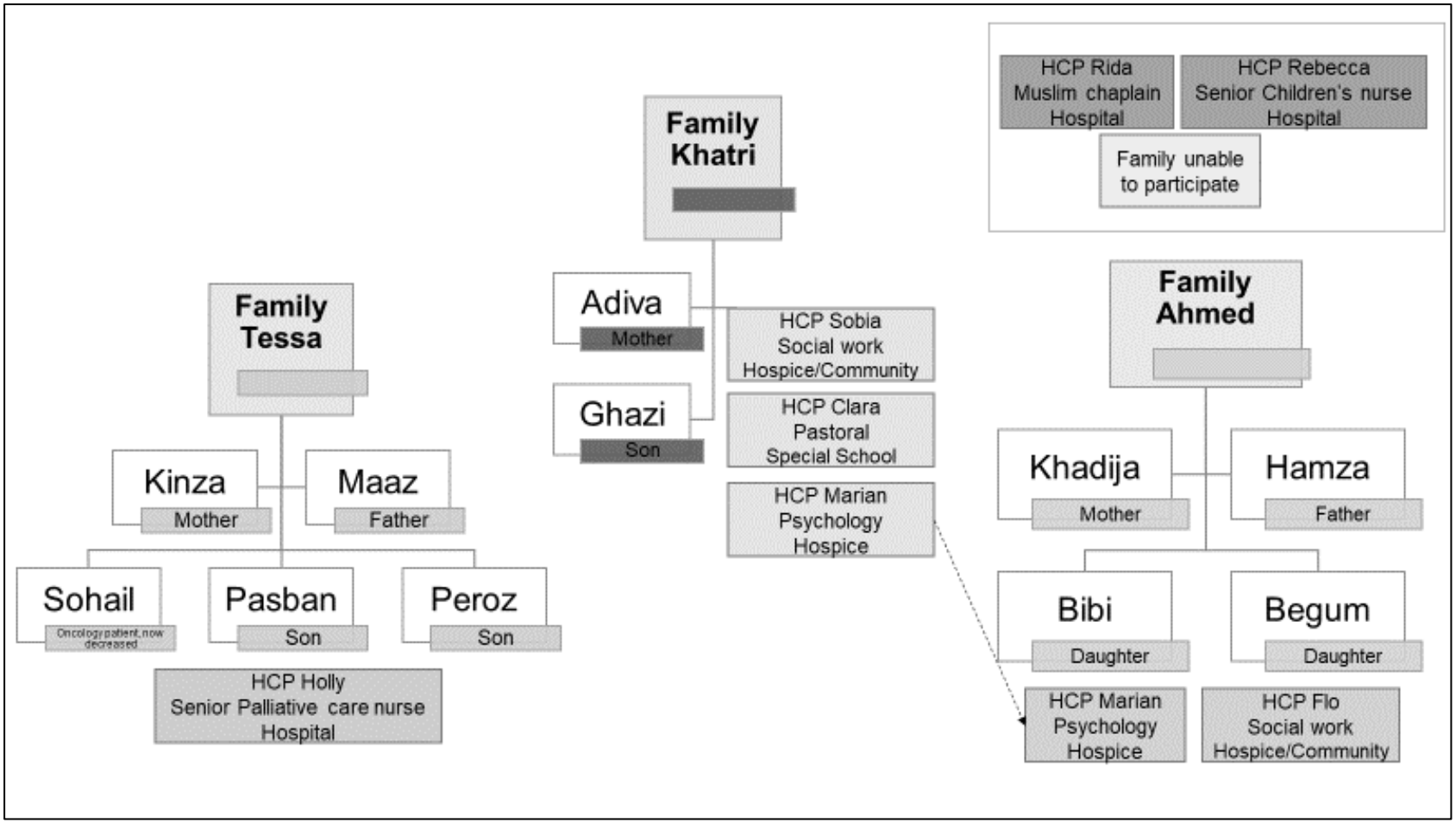


Figure 11 – Participant Demographics

Chapter Seven – Data Analysis

7:0 Introduction to IPA process

A central focus of IPA is a particular emphasis on understanding the participants' individual experiences, thence maintaining an idiographic and inductive approach is crucial when analysing data (Smith and Nizza, 2022). To analyse in alignment with IPA methodology, each participant's account was firstly analysed in a single case by case process, involving interpretation of each interview transcript. Analysis was undertaken line-by-line in order to get closer to the claims, concerns and understandings of each participant (Larkin et al, 2006). For each transcript, the account of the participant was formatted centrally with large margins on each side for initial exploratory notes on the right-hand side (as detailed in Table Seven).

Table Seven – Example of IPA analysis for individual participant Rebecca

Experiential statement	ORIGINAL TRANSCRIPT	**Exploratory notes**
Passion for nursing Generational, family history and expectational	*"So yeah.. so obviously as I said my.. (pause) passion and interest for nursing started when I was about 4 years old and I had my grandma and my aunty that I really wanted to be, who were both midwives, in different.. in fact 2 aunties, I forgot to put the other one".*	L: False start, pauses hesitates D: Passion and interest in nursing started at 4 years old L: Repetition and reiteration of family links to midwifery C: conscious of number of relatives with health professions, is this important? Significant that the number is larger? Is she worried about forgetting loved ones, or not crediting someone important?

7:1 IPA stages of data analysis

7:1:1 Exploratory notes

IPA is notorious for the step by step process it outlines to analysis data. This section will detail the IPA processes I followed with examples to show a transparent method. Initial analysis began after reading and listening to the participant accounts multiple times, I then made notes and used highlighters to detail any words or sentences which appeared interesting and relevant. This initial focus upon creating exploratory notes allowed me to capture significant elements of each participants account, whilst trying to understand what appeared to be important to them. I was also able to reflect carefully on the participants words during this stage, before jumping to any conclusions or making more speculative interpretations. During the initial analysis phase, I was also able to note any similarities or differences in the narrative and any contradictions which may need further clarification. I also found re-listening to recordings of the interviews helpful in remembering the interview context and rekindling the memories of participant' emotions, expressions and non-verbal communication.

7:1:2 Descriptive, linguistic and conceptual notes

Smith et al (2009) distinguish between different types of exploratory notes including descriptive, linguistic and conceptual notes. The understanding of the various types of notes helped me to think in more depth about the contents of the participants account and informed my understanding of the cognitive and affective state of each

participant. Table Seven details an example of how I used these concepts and shows descriptive notes (D:), which were often basic notes to summarise and describe things like objects, events, experiences, processes and locations. Some descriptive notes initially appeared quite self-explanatory or simplistic, but the action of noting them helped me to highlight and reflect on my basic understanding of what was happening in that portion of the transcript. I found this useful as a first step before delving deeper.

The linguistic notes (L:) in the Table Seven example denote the use of language by the participant, including the actual words spoken or how they were spoken. Linguistic comments also included the use of pronouns, verb tenses, pauses, laughter, metaphor use, repetitions, hesitations and tone (Smith and Nizza, 2022). In Table Seven, the term ‘false start’ relates to the hesitation the participant showed when finding it difficult to put her thoughts into words. Considering these elements helped me to reflect on why this might be the case. Lastly, conceptual notes (C:) were added, these were interrogative and often took the form of asking questions about the data, particularly at the start of analysis as I tried to get an overall sense or picture of the data. Some of the questions I asked were left unanswered, but others become clearer as my analysis deepened and my interpretation developed. Overall, I found the use of these three types of notes helpful as I considered the participants and my own understanding of what was being discussed and, as I aimed to maintain an open non-judgemental standpoint in seeing a range of potential meanings.

7:1:3 Experiential Statements and initial theme creation

Following the detailing of initial thoughts in the exploratory notes section, experiential statements (or initial themes) were created. This involved an iterative and fluid process of further engagement within each transcript, including processes of reduction, expansion, revision and creativity. This was frequently multi-directional moving from examining part of the transcript text in its own right but also in the context of the whole interview (Smith, Flowers and Larkin, 2022). Overall, the aim of this stage of analysis was to provide a concise summary of what was important in the transcript, giving a more stable reflection of description, interpretation and understanding. The next stage of analysis involved searching for connections across experiential statements and mapping how these might fit together.

Initially, experiential statements were detailed chronologically and so the links between different portions of the interview could not be clearly seen. To understand the most interesting and important aspects of each participant's account, I found cutting up the experiential statements and arranging them on the floor to break up the ordering beneficial. This also gave me a bird's eye view of the whole account and enabled me to see each experiential statement as equally important. I was then able to move them around and group them together, trying different cluster groups until the patterns between statements appeared to best represent their interconnections (Smith, Flowers and Larkin, 2022). Following this, each cluster of experiential statements was given a title to describe its characteristics, these became the participant's Personal Experiential Themes or (PETs). This can be seen in Table Eight within the example of Kinza.

Table Eight - Personal Experiential theme (PET) one, for Kinza

Theme 1: Feelings of Alienation and Discrimination
Subtheme; Hijab misunderstandings *"Because she wears Hijab so sometimes she feels like, felt like, they do not they are not happy to accept her"* (pg3.10) *"One day they maybe meet her in corridor, my wife was wearing Hijab, she oh like scared from... like this (hides behind hands), silly behaviour"* (pg3/4.10)
Subtheme; Lack of understanding of religious needs *"Sometimes she said while she was fasting so she has to sit without food from the morning until sunset and sunset in the summer was about 9.30 and about 8 o'clock they turned off lights and all the people they try to sleep so it is difficult for Muslims to eat and er everything is switch off electric in the ward, turn off appliances,* So, you cannot switch it on yourself? *"Yes"* *"She has a bad memory sometimes of her first days in the UK of how they dealt with her, she was fasting and she wanted to pray, cannot speak English or understand them or express"* (pg13.39) *"So, when my wife she wants to pray she has to cover her hair to pray, some others maybe they wash their hair like this, they do not like and….we understand them but we wish and hope others understand us. It is our belief and this helps us particularly in this very difficult situation"* (pg12.37)
Subtheme; HCPs Apathy and Anger *"Sometimes I want to go and feed my baby, they told me "you are three days, you can walk", but I cannot walk, I cannot walk, I want help, I want somebody to help me. I am waiting, sometimes I want a cup of water, I want to drink my medicine, a long time to bring and sometimes I feel they was angry, I do not know why, because maybe I think that they thought because I cannot speak English, because I do not know why, so why is this nurse saying, why? When I want to go to our home with my baby, also I want someone help me with my stuff, my bag. "You can". "I cannot, I cannot"* (pg19.61) *"I remember she told me she was not able to ask a nurse to come and bring water so she came and told her 'next time do not press the button' yes you can walk some to reception and ask what you want do not press the button. And all the time I am crying because I cannot be with my husband, I am alone, yes and my baby in intensive care and this day is my son passed away, oh All the time I am crying, I am crying 'what has happened? What has happened? No, you have to go to kitchen/reception do not press another time"* (pg19/20.61)

7:1:4 The Creation of Personal and Group Experiential Themes

The next step of my IPA analysis once all the PETs had been created, was to move onto the next participant's account and repeat the process, treating each new case individually and afresh. Following analysis of all cases (as detailed in Table Nine and 10), the analysis moved to cross case analysis with the aim of showing the shared and unique features of experience across the participants. In order to help with this process, again the PETs were cut up and laid onto the floor to help give a wider view and context of the experiences of participants. This process was similar to the process explained within the systematic review detailed in Chapter Three. Convergences and divergences were noted and it became important to consider particular sub-themes and experiential statements again, to remain grounded in the data (voices of the participants) and ensure my reflections and were clearly representing the participants' experiences.

Table Nine – Personal Experiential themes (PETs) or individual themes by HCP

Holly	**Theme 1:** Individualised care versus protocol led **Theme 2:** Importance of learning/teaching/education (with elements of Cultural Humility CH) **Theme 3:** Expertise, experience and love for the role **Theme 4:** Relationship building and advanced communication skills (links between time spent, trust and understanding of what is important to families) **Theme 5:** Honesty and truth telling tensions and incident
Marian	**Theme 1:** Individualised care **Theme 2:** Learning, education, reflection **Theme 3:** Relational skills and communication **Theme 4:** Health literacy/access barriers **Theme 5:** Personal motivation, experiences, sense of vocation versus challenging nature of the role; burdens (compassion satisfaction and fatigue) **Theme 6:** Strategies to combat challenging role
Clara	**Theme 1:** Own role, characteristics and passion for justice **Theme 2:** Frustration with others passivity and lack of proactivity – links to advocacy **Theme 3:** Barriers to care; Communication, language, finances and access
Sobia	**Theme 1:** Personal history and experience of migration **Theme 2:** Compassion fatigue and elements of burnout **Theme 3:** Relationship building with families **Theme 4:** Parental burdens **Theme 5:** Access, coordination of services, finances and language barriers
Flo	**Theme 1:** Passion for justice, fighting against the system **Theme 2:** Lack of health literacy, awareness and access to services **Theme 3:** Relationship building **Theme 4:** Communication barriers **Theme 5:** Burdens of the role, crossing of professional boundaries versus advocacy **Theme 6:** Parental burdens and coping strategies
Rida	**Theme 1:** Vocational nature of the role **Theme 2:** Migration experience and background (bridge narrative, gender) **Theme 3:** Alienation, isolation and difference **Theme 4:** Cultural reluctance to complain **Theme 5:** Relationship building **Theme 6:** Importance of religious/spiritual awareness to care (education)
Rebecca	**Theme 1:** Background and motivation for the role **Theme 2:** Challenging nature to the role and compassion fatigue **Theme 3:** Entitlement and ethics versus empathy **Theme 4:** Strategies to help families (MDT/Multi agency working, questioning entitlement sooner, deportation, appropriate resource, education, communication, peer/link worker)

Table 10 – Personal Experiential themes (PETs) or themes by family participant

Family Ahmed	
Hamza (dad)	**Theme 1**: Migration journey and purpose **Theme 2:** Lack of family support **Theme 3:** Differences in care between UK and Syria **Theme 4:** Barriers to care – language barrier, misinterpretations (safeguarding referral) **Theme 5:** Facilitators to care (respite, SW relationship, acceptance)
Khadija (mum)	**Theme 1**: Migration purpose **Theme 2:** Parental burdens and responsibility including lack of family support **Theme 3:** Coping strategies; faith, love for children and support of her husband **Theme 4:** Differences in care between UK and Syria
Family Khatri	
Adiva (mum)	**Theme 1:** Migration history and diagnosis (denial, fear and trauma, isolation and alienation) **Theme 2:** Nursing care (lack of care of mum, heart, expectations and differences) **Theme 3:** Relationship building (time, comparison to mum's care) **Theme 4:** Access to resources (carers, housing, respite) **Theme 5:** Parental burdens and gender issues – relationship with dad (fear, stress and despondency)
Family Tessa	
Maaz (dad)	**Theme 1:** Challenges of migration – multiple, lack social support **Theme 2:** School **Theme 3:** Inconsistencies in nursing care (and the rules) **Theme 4:** Communication barriers **Theme 5:** Compassionate nursing care **Theme 6:** Truth telling versus hope **Theme 7:** Faith and coping mechanisms
Kinza (mum)	**Theme 1:** Feelings of alienation and discrimination **Theme 2:** Humanity and compassion of the nurses **Theme 3:** Communication barriers **Theme 4:** Lack of social support and isolation **Theme 5:** Inconsistencies in nursing care
Pasban (Sibling 1)	**Theme 1:** School **Theme 2:** Hospital **Theme 3:** Home **Theme 4:** Nursing care – importance of understanding others beliefs and own attitudes and behaviour over grades
Peroz (Sibling 2)	**Theme 1:** Hospital **Theme 2**: Impact of previous experience on own hospital admission **Theme 3:** Nursing care – importance of kindness

The Group Experiential Themes (GETs) for this study can be seen in Table 11 and are organised by family and then HCP participants. Following further review and in order to analyse and detail what is unique to this study, the GETs were subsequently ordered into themes across settings (as detailed in Table 12). A rationale for this ordering was some of the contrasting findings seen in Table Nine and 10. Here the setting of the care received appeared significant, with family participants detailing a lack of time and short-term view to care in hospital;

> *"The nurses come on shifts obviously, they come and do their bit and go"* (Parent Adiva. 7:55)

Whilst a longer-term approach was described as important in the hospice setting;

> *"It is always crisis centred* (the hospital)*, so for me to actually be in a children's hospice, actually to have that time to actually go in and see somebody build up their rapport … and not actually to be doing something it took me ages to get my head round"* (HCP Sobia. 22.62/3)

Similarly, family centred care was discussed differently in different settings; in the hospital it appeared difficult to achieve;

> *"Nobody can understand her and support her and appreciate our circumstances. I talked with some nurses, please now this day, the memories, we lost our son last year like the same (day), let me support my wife and my baby"* (Dad Maaz (int 1). 19.59)

In the hospice setting the pace of care and time for family interactions appeared to help facilitate family centred care;

> *"We would offer that time and space to understand and to listen and to communicate effectively"* (HCP Marian. 22.71).

Subsequently it was important to also consider my findings by health and social care setting, i.e. where families receive care (as described in Table 12).

Table 11 – Group Experiential Themes (GETs) by family and HCP participant groups

Table of Group Experiential Themes (GETs) for Family Participants
1. Importance of migration stories and other traumatic experiences (past hospitalisation)
2. Communication and language barriers
3. Alienation, discrimination and labelling
4. Coping strategies (faith, truth telling and hope, social support and gender roles, parental burdens, love for child, search for normality)
5. Access to resources
6. Nursing care (optimising and hindering relationships)
Table of Group Experiential Themes (GETs) for HCP Participants
1. Individualised care
2. Importance of teaching, learning, reflection and education
3. Motivation and personal history in relation to role
4. Relationship building
5. Access and health literacy
6. Compassion fatigue, burnout and strategies to overcome
7. Proactivity, passivity and advocacy
8. Parental burdens
9. Coordination of services and MDT working
10. Communication and language
11. Spiritual and religious care

Table 12 – GETs across settings

Participants	Hospital	Community	Hospice	Combined across settings
Families	-Lack of time, short term view of care -Lack of Family Centred Care (FCC) and caring concern -Going the extra mile -Expectations and environmental restrictions (sleep) -Alienation and discrimination -Differing parental beliefs to HCPs -Coping strategies and faith -Search for normality	-Lack of resources (financial and housing) and need for social support -Impact Covid on service provision -Special school rapport, poor coordination of care and HCP reliability -Judgements, labelling and safeguarding referrals -Lack of health literacy	-Relationship building, advocacy, additional time and accessibility of HCP -The struggle to hand over care and lack of attention to detail important to family members -Lack of access to or awareness of hospice care	-Parental burdens and cultural gender roles -Communication and Language barriers -Essential nursing staff characteristics
HCPs	-Protocol led care -Discrimination (experienced and voiced) -Relationship building (non-verbal communication) -Timeliness and consistency in difficult conversations	-Coordination of care (complexity of systems and processes, need for dialogue and rapport) - Passivity, proactivity and a reluctance to complain -Need for extra time to meet needs -Judgements, labelling and safeguarding referrals -Access and health literacy	-Family Centred Care -Relationship building -Time (not crisis centred), long term view to care -Crossing professional boundaries, burnout and compassion fatigue	-Link and peer worker roles -Communication and language barriers -Motivation and love for the role

7:2 Rigour and transparency of method

A further element, to ensure rigour within my analysis, was the detailed audit trail to show transparency of method. This can be traced from transcript analysis to the development of experiential themes (and is shown within the tables provided here). These are examples of interpretation and analysis, however full transcripts are not provided as appendices due to the identifiable elements of rare disease and forced migration detail and the need to protect participant confidentiality (Wiles, et al, 2008).

Whilst semi-structured interviewing is detailed in the literature as offering a powerful tool for data collection, the relational processes and skills of the researcher can be vital in understanding and analysing the thoughts, beliefs and experiences of individuals (DeJonckheere and Vaughn, 2019). To provide a balance of relationship and rigour, I developed tools to aid any difficulties in conversational flow. I also talked through my potential approach in a pilot interview with other experienced researchers, where I was able to voice my concerns and utilise the knowledge of others. I employed a reflexive approach throughout my data analysis which was greatly aided by the expertise of my advisory groups. The process of analysis was further aided by supervision support to aid 'coherence and plausibility' of the interpretation, check my understanding and limit any personal partiality or difficulties experienced during the interview process (Smith, Flowers and Larkin, 2022, p75).

In addition, the advisory groups from this study formed part of the 'Collective Voices' within the Silences Framework application when they reflected upon the study findings with me. Each advisory group had specific expertise and so during this

process I was able to ascertain if my findings fitted with the common experiences of the group/s, allowing me to have a further method of comparison, feedback and cyclical data analysis (Janes, Serrant and Sque, 2019).

Chapter Eight - Findings by theme and setting

8:0 Introduction to the section

This chapter presents the findings from the interpreted data including interviews with HCPs' and their drawings and family members' interviews, drawings and interpretation of video and poetic creations. Following data collection, advisory group members helped to create additional poetic representations and were involved in reflecting with me on the interpretations given, these are discussed in more detail in the Silence Dialogue Chapter Nine.

8:1 Group Experiential Themes (GETs) by setting

Within this study, 14 participants contributed to 12 interviews including two family interviews with Family Tessa (as detailed in participant demographics - Figure 11). The following section presents the themes or GETs interpreted from the interviews conducted with forced migrant family members and HCPs caring for children with palliative care needs. Within this section I have used participants' direct quotes to preserve participant voice and aspire to further offer transparency of method (Corden & Sainsbury, 2006). However, certain identifying features to place or person have been removed to protect anonymity (Wiles, et al, 2008).

Because some families needed an interpreter, some quotes show the interpreter speaking for the family member which alters the tense of the excerpt. Interpreters were used for the interviews with Hamza, Khadija and Adiva. Each interpreter was known to the participant through previous medical interactions within their normal care team and this helped with rapport. Prior to each interview, I discussed with the

interpreter the importance of interpreting the actual words of participant's and their meanings as closely as possible, to work towards 'conceptual equivalence' (Williamson et al, 2011). Conceptual equivalence details the importance of not omitting anything the interpreter might not think of interest (Phillips, 2016). Each interpreter was also briefed on IPA methodology, in terms of the importance of phrases and use of metaphors, as such elements would be important to clarify and include in the interpretation. Within the interview with family participant Hamza, the phrase 'put a torch on the refugee' was used. The interpreter showed her understanding of our prior discussion as she explained this clearly and was able to help with the clarification of meaning for this phrase. A further element of cross checking was undertaken on Hamza's and Khadija's transcripts. I sent the recording of their interview to a second translator to verify the accuracy of the interpretation as recommended by Merry et al (2011) and Clark et al (2017). The translator made very minor grammatical amendments to the transcript but these did not alter meaning or researcher understanding of concepts discussed.

8:2 Explanations of settings

In the following section I address the findings by setting. I identified three settings where families received care or HCPs delivered care to families. These included hospital, hospice and community settings. An additional setting was added - a combined across settings category, for those experiences which either were not setting specific examples or were thought to relate to all of the three settings. Figure 12 shows all the settings together. Structural (S), Relational (R) and Individual (I) factors are also added to highlight the differing aspects of care, caring relationships and organisational factors, which link to how the barriers to care or optimising factors are experienced and often compounded for forced migrant families.

In addition to the direct quotations of participants I have also used my own poetic reflections and the poetic interpretations of participant accounts by advisory group members. These poetic interpretations aim to show how my understanding of participant meaning making were developed and enhanced by poetic interpretation and enquiry.

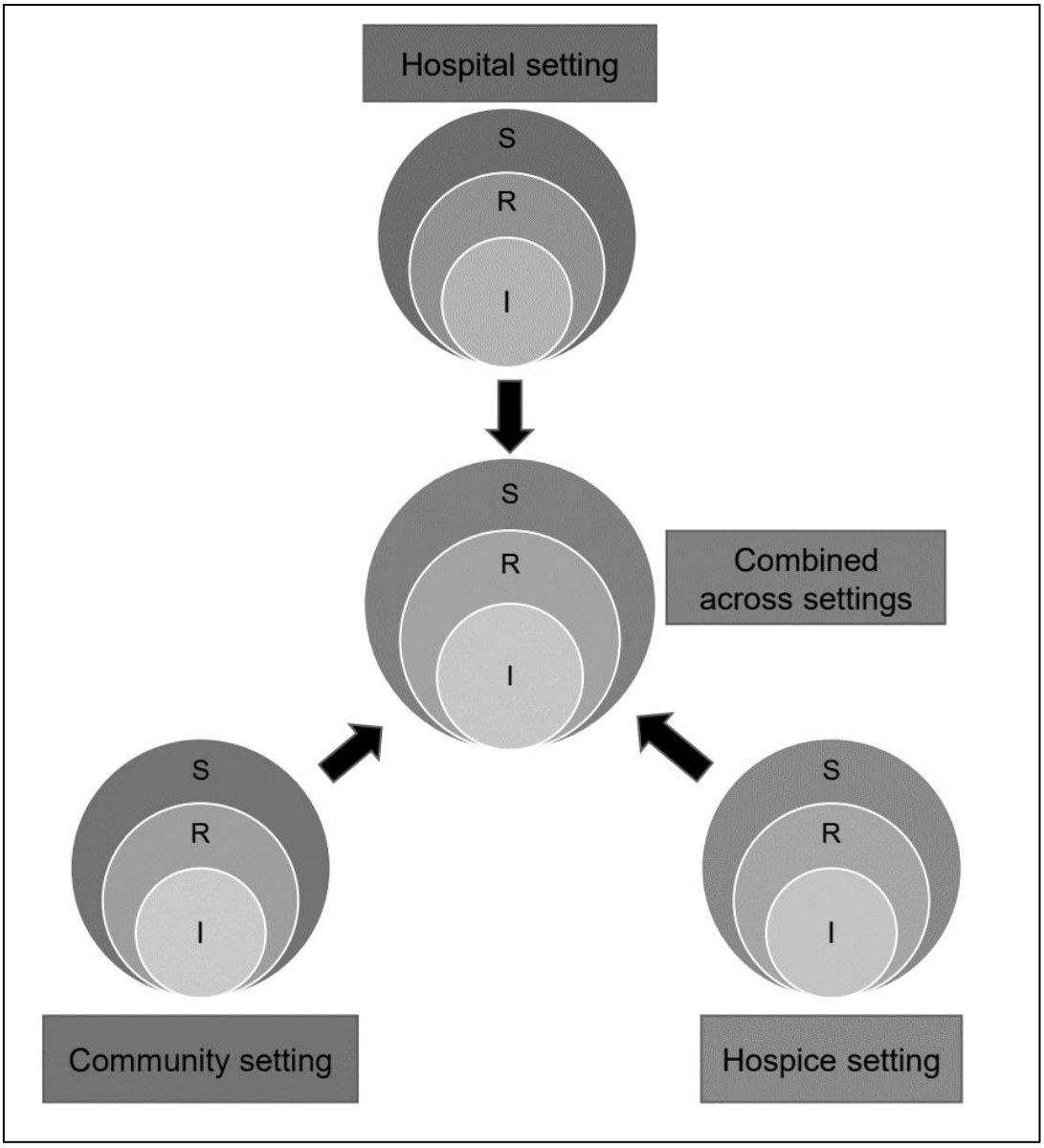


Figure 12 - All the settings included in the study

8:3 Community setting findings

The term ‘community setting’ refers herein to care offered within the home or primary care environment, predominately community nursing, GP services and special school care. The individual, relational and structural factors relating to community care have been detailed in Figure 13 and relate to examples given by the participants of their experiences in this setting.

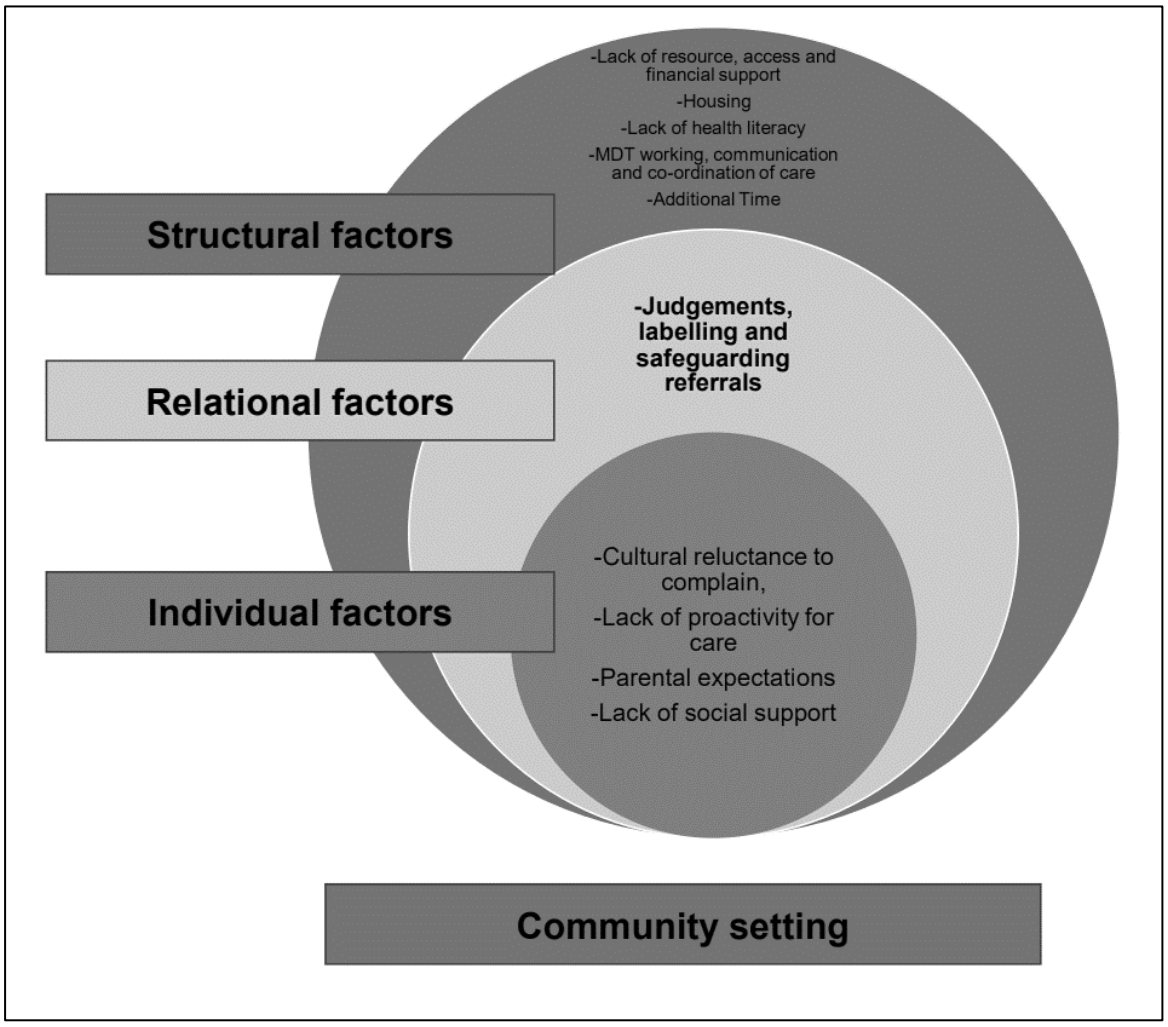


Figure 13 - The differing factors within this community setting

8:3:1 The need for additional carers

When discussing community care, parents and HCPs' described the need for additional care or carers in the home and how difficult it was to organise or fund such care, Khadija mother to two disabled daughters said:

> *"She just needs someone like a carer. For example, if mum busy cleaning the house, cooking, someone to feed her Bibi someone to sit with her"* (Khadija, Mother 16.98)

Nursing care in the home was needed, not only because children with palliative conditions have multiple and complicated needs, but also, as all the families interviewed described, as a result of the additional strain of having no social or family support. The lack of support experienced by participants in this study, related to family participants' forced migration status and the attached grief, isolation and despondency parents experienced as a result of separation from family:

> *"In Syria they used to live as a big family. His mum, dad and his brother lived together. So even though if mum is not free … can get care from Grandma, from Auntie from Uncle from himself. So, it was different than here, here there's no family you have to do everything yourself" (Hamza. Father 6.38).*

> *"The British families, they have relatives, they have families, they may visit them and support them but we are, with us we don't have anybody that lives here" (Maaz. Father 14.41/2).*

> *"Sohail told me many times nobody visits us, we are alone in the hospital, me and you…he told me nobody come to visit us, we are alone here. Other patients they have visitors, they have friends"* (Kinza. Mother 14.41/42).

In addition to typical constraints on funding and access to resources, the Coronavirus pandemic added further pressures to community care with descriptions of the changes and limitations to the services offered during this time given by both parents and HCPs':

> *"When he was going to school obviously then you've got the physios there, you've got the nurses there, so there's other people that can have a look at what's going on … And then they had community nurses, but since the start of Covid, community nurses have stepped back and a lot of them actually started doing different roles, so they've gone back into different work. So, they're not around a lot"* (Adiva. Mother 9.77)

When describing a lack of others to rely on, Khadija illustrated difficulties in asking for support. She was reluctant to ask for help which may have been linked to concerns that she would be judged by others, or be seen as unable to cope with caring for her own children:

> *"She doesn't like someone to feel sympathy/pity for her, she always wanted you know, shouting that she can do it. She's strong. She will be able to support her children and nobody, she won't show that to anybody" (Khadija. Mother 15.94)*

Such concerns likely added additional burdens and further feelings of isolation for the family. Khadija and Hamza had lived through war in Syria and the associated atrocities, when arriving in the UK to safety, they had been accused of harming their daughter Bibi following an accidental burn at home. Bibi their eldest daughter was playing on a beanbag on the floor at home and due to her severe physical disabilities and inability to communicate pain, her toe had been pressed against a hot radiator for some time without her parents realising. By the time they did see the burn it was their daughter's bedtime, as it did not look too bad at this stage they gave her paracetamol and settled her for sleep. Only in the morning had the burn developed

into a nasty blister which they realised needed medical intervention. The GP and practice nurse were quick to attribute blame upon the family and started safeguarding procedures without an interpreter to allow her parents to fully explain themselves. Such experiences may have undermined the parents' ability to trust others to support or help them.

8:3:2 Lack of financial support

Further to a lack of home carers, a lack of financial support was acknowledged by five HCPs' as an area of concern:

> *"They struggled with money because when we are living here, we automatically think these people coming into the country because I've got access to NHS or schools, they're going to have access to everything and that's not true. So, this other mom that I was talking to, they only had £5 per person per day to live on, which was very, very hard"* (Sobia. HCP Social Worker 31.87)

All three families described being constrained in their ability to visit their children in hospital or fully participate in life outside the home due to a lack of finance:

> *"When we came to the UK financially I was unemployed and I don't have any job so I don't have any car, we use buses"* (Maaz. Father 3.8)

> *"We are alone because not all the time my husband can come, he cannot come. He has no car" (Kinza.* Mother 14.41)

8:3:3 Housing

Housing issues were raised by two of the families, notably both of these families have physically disabled children. Housing issues could be split into two categories: 1. inappropriate housing allocation and 2. the need for housing adaptations. Predominately, the need for housing adaptations were due to disability and inaccessibility, however adaptations were difficult to obtain and their omission was said to affect the quality of life for the child/children:

> *"So, if a parent is sitting there saying that they they're struggling to wash and bathe their child, what oh my I goodness, why can't the council just do that? Yeah, why isn't that service there? And a lot of the time it's waiting lists, isn't it? It's funding but when you put yourself in that position, I think it's awful" (Clara. HCP Pastoral Worker 4.12)*

Adiva appeared angry and upset when talking about the housing issues the family faced, as it was clear her son needed adaptations to the home but no one was willing or able to complete them:

> *"They don't help with the housing, they've been under the housing for 5 years and nothing ... we've applied haven't got anything, this house we've rented, you know my husband got that one, otherwise we would've been on the streets. I've left my forefather's country Afghanistan, you know, for a better life … so it's not easy to come to another country so if you do you'd think other people would make your lives easy" (Adiva. Mother 21.163)*

Regarding inappropriate housing allocations, there were two clear examples. Firstly, Marian, an experienced manager and psychologist at the hospice, described a parent who was placed in a housing situation in which they had no choice but to leave one of their disabled children alone, potentially putting their safety at risk:

"Both (children) are wheelchair users and she used to live in the tower block on the eighth floor and ... those two wheelchairs just wouldn't fit in the lift so … the school bus used to come to collect their children, to go to school so she would take one child in a wheelchair and a lift and the other would be on their own in the wheelchair, up by the lift. So, then that became a safeguarding concern. Very, very rightly so, because you can't leave a child in the wheelchair on their own. But what was she supposed to do? So sometimes I think people are put in a situation where it's very difficult to make a right decision or to do the right thing" (Marian. HCP Psychology 18.62)

When arriving in the UK it is common for asylum seekers to be housed by the Government's Immigration department (UKVI) in an asylum hostel. Marian and Adiva described concerns for women's safety in hostel accommodation. Adiva described a threatening atmosphere in a hostel full of men and Marian's example included a mother with a new-born baby who had no access to heating in December. Both examples indicate the hostile environment of asylum hostels and the ensuing fear and withdrawal both women experienced:

"*Hostel that was horrible because she was the only female. I think with six different men ... all the men had their own mental health needs ... so she was the only female with this new-born baby with additional health needs and she was in that room. There was no heating ... I remember the family worker as she offered a lot of practical support; ringing people demanding basically they do something. Because you know this vulnerable woman with this little baby you know and that was in December and she had no heating" (Marian. HCP Psychology 14.49/50)*

"I was the only woman in the hostel, all the rest of them were Muslim men, students, obviously you know you can imagine she's come from Afghani Muslims, so she said somebody said to me go and have food, when I saw all the men there, she said I saw them and just came back into my room" (Adiva. Mother 5.37)

8:3:4 Difficulties in accessing resource and services

Inaccessibility issues in terms of limited resource and service provision were also discussed, in relation to a lack of understanding or awareness of overly complicated UK systems and individual rights and the subsequent helplessness, confusion, missed access to resource and disempowerment of families:

> *"They could be aware of the choices … at least they would be a little bit more in control and they would be able to make decisions and they are not entitled to a lot of things, but what they are entitled to, often they don't know, so they miss out" (Marian. HCP Psychology 20.68)*

> *"They just don't know what's on offer … how systems work there, is very different here, so they might have an expectation of, oh, well, when we were there, x y z happened, here, it's like no, or you've got access to a service or you don't have access to a service" (Clara. HCP Pastoral worker 8.26)*

Flo, a hospice social worker who works in the hospice and community settings, detailed a similar finding discussing how many forced migrants miss out on services or financial help through a lack of knowledge of how to access them. She also raised the question of how much HCPs' understand or are told regarding the systems and entitlements they are advising families about:

> *"If you don't know as an immigrant, you automatically just lose out because nobody's gonna tell you and even us as you know, British citizens or living or born in the UK, we are not told half the stuff sometimes and we've got to do our own research" (Flo. HCP Social worker 5.19)*

8:3:5 Reluctance to complain

Family Tessa initially appeared reluctant to complain about the poor care they received, due to a perceived futility of this, as they discussed the improbability of anything changing. Their reticence about complaining might also relate to a lack of awareness of complaint systems or processes, or how complaints are handled and addressed by the NHS. They were also concerned that complaining would detract from time spent with their children:

> *"Yes, we don't want to complain, we want to spend our time looking after our children, we don't want to spend time to complain to others. And also, we think it does not make any change to complain. There is no any difference" (Maaz. Father 20.63)*

Further dimensions to the reluctance to complain were added by Rida a Muslim Chaplain, who explained that in her experience forced migrant families did not want to complain for three main reasons.; a gratitude for care, respect for HCPs' but also a fear of repercussions. Forced migrant families seem to be caught in a difficult conundrum in which they are thankful for the care they receive (and expected to be so), but also anxious about criticising their care, in case complaining may have effects on the treatment they or their family subsequently receive:

> *"They're already so grateful for what they are receiving in terms of their care, they would not want to make a fuss over something that's been given to them" (Rida. HCP Muslim Chaplain 36.99)*

> *"They will not make a complaint because they the family, are so fearful that if they make a complaint, the staff are not going to look after the family properly, they're going to make life hard for them or ignore them or make them suffer and it's an awful*

thing to think is horrible, but when fear grabs you, your mind goes all over the place" (Rida. HCP Muslim Chaplain 38.102)

Parents Hamza and Khadija described the regime in Syria and the fear that the family lived through. They offered a positive outlook on care in the UK and discussed how grateful they were for all the help they had received. The views they expressed appeared to me, to be at odds with some of the judgemental treatment they had received:

"You have to obey the regime and if you don't or you speak, you speak about you, know your ruler/leader, is above you, so if you do you won't be in life, you will be killed" (Hamza. Father 11.73)

"He doesn't think he's gonna be a discrimination because all the people in this country are lovely, to all the refugees here" (Hamza. Father 10.60)

Much of the discussion on this theme, on access to and understanding of services, highlighted the multifaceted problems forced migrant families face and how differing perceptions and previous experiences can impact upon care.

8:3:6 A perceived lack of parental proactivity

Forced migrant families' low levels of health literacy was raised by some HCPs, but the differing levels of awareness and the implications of not understanding UK systems for parents was highlighted by Clara. Clara is a pastoral worker in a special school supporting children and families in many areas of health and social care. She discussed her perception of a lack of parental proactivity for care**.** Initially Clara appeared knowledgeable about the circumstances Family Khatri were living in and discussed the impact of Adiva's limited language skills, lack of knowledge and low

levels of confidence combined with responsibility for a busy household. Yet Clara was also quite derogatory when she expressed doubts about Adiva's abilities to use her initiative and have more involvement in the organisation and coordination of her son's care:

> *"It's about being proactive. Maybe giving them a call, but do you do you know that? Do you know it? And do you? Are you on it? (clicks fingers) Are you on it like that, or you're just trusting in you've had a letter, your child is on a waiting list and you just wait till you get another letter? And yeah, it is. frustrating, but it's all it's also quiet, like, it's sad, isn't it? I think in a way that some ladies and especially Adiva, I think she just thinks this is just my life, yeah and she doesn't, there is no more she doesn't aspire for more" (Clara. HCP Pastoral worker 13.42/3)*

Clara problematised Family Khatri as she frequently described the need for Adiva and her husband to be more proactive and challenge the care offered, without consideration of the influence of their country of origin. Adiva's Afghani background was likely to have influenced her perceptions greatly, particularly around her acquisition of knowledge and her understanding of relationships with those in positions of authority. Clara's overly simplistic suggestion that the parents should prioritise following up on tasks or referrals to other agencies, may similarly relate to the stark differences between Adiva and Clara's lifeworld's. However Clara's discussions about Adiva did not suggest an empowering relationship, but rather one which was overly critical and without appropriate cultural awareness:

> *"Where my other parents would ... challenge more … she doesn't feel like she can challenge people… like if you've told me, well, it must be me it must be right and I won't, I won't question that, well, no, you must question everything" (Clara. HCP Pastoral Worker 12/13.39/40)*

"If mum and dad were confident to be able to challenge certain things and know what their rights were and weren't and that they could have a more active engaging part in his life" (Clara. HCP Pastoral Worker 27.79)

8:3:7 Difficulties in coordinating care

Social workers Sobia and Flo similarly saw the differences in awareness and understanding for forced migrant families. However they suggested that many of the problems HCPs faced in coordinating community care, related to problems such as different IT systems and organisational locations resulting in communication difficulties. Further to this, they mentioned structural issues in the form of government policies or red tape which made seeking additional resource or financial aid almost impossible. They discussed a possible solution of a central agency, manual or person who could better coordinate a family's care:

"It's a bureaucracy and the red tape and maybe having one place where they were to call someone and then that person or that agency would be able to have a say in in the medical care ... so, parents didn't have different places" (Sobia. HCP Social Worker 29.82)

"In this situation that they're actually given some information on who to access in their language, who to access, who to call where they can go to for support and advice. What facilities are there for them, what charities are there for them, almost like a manual, that when they come into country they given all the resources that is regularly updated as to this is who you need to speak to, that's who you need to call, this is who you are, if you need an interpreter, we have interpreters that are volunteers free of charge" (Flo. HCP Social Worker 22/3.66)

8:3:8 Multidisciplinary team working

Clara suggested that good multidisciplinary team (MDT) communication and better systems were the key to improving the coordination of community care for forced

migrants. Her descriptions of difficulties accessing patient notes, appointment times and the care other MDT members had advised in different settings, highlighted how complicated the linking of different professionals and agencies is for HCPs and parents to manage and understand:

> *"I don't have access to log into xx, so would be able to say, oh, so and so went home this day and the community nurses went here and so and so had rapid response here or, but then that doesn't key up with say like OT's doesn't link up to the hospital, because they're different systems. So, I could, for instance, I asked for Dr Smith to have an appointment, but that's there, but then she had a telephone conversation, consultation sorry, with the (different hospital) for his splints, well, that's been something different yeah, the physio had rang and she made an appointment to speak to Dr Smith" (Clara. HCP Pastoral Worker 7.22)*

Participants with roles in the hospital environment also acknowledged the importance of MDT working across agencies and settings. For Holly and Rebecca, their experiences of close MDT working were positive and highlighted good practice. They discussed that good MDT relationships created a supportive environment and one in which the team could tackle children's multifaceted problems and learn from one another:

> *"We very much buddied up with the adult community team … the GP and the community nursing team, the district nurses, would be really supportive in helping to manage the care of those children"* (Holly. HCP Nurse 2.14)

> *"It's working together, because nobody can fix everything for one child … Very unlikely that it's just one problem with any of these families. You know regardless of whether they've just come in with a cut finger, or whether they've just been hit by a bus, we are still reliant on different professionals, be that in the primary sector which is like your community nurses, your health visitors, your school nurses your GP, or whether you're talking secondary care you know, with your hospitals, whoever that might be … you need them to link up, like your third party agencies which is like your third sector, your charities, or your local authorities, or your schools, or your.. looking at your education healthcare plans, or ... whatever it might be" (Rebecca. HCP Nurse 26/7.145-7)*

8:3:9 The need for additional time with forced migrant families

The additional time needed to support forced migrant families was acknowledged by Clara, Sobia and Marian. Clara suggested that Adiva's perceived inability to be proactive created extra workload for her, as she explained that western parents would often participate in the chasing of HCPs rather than her having to take this on. Sobia and Marian described the additional time needed to support forced migrant families, with the specific difficulties they faced accessing resources, or housing adaptations, alongside the additional time needed when working alongside interpreters:

> *"We have had families staying there for weeks, if not months, because they had nowhere to go, it takes time to support someone with immigration needs and legal aid is very difficult in my experience to obtain for immigration issues and the whole process can take forever. So, we have to work quite closely with (other agencies) but that doesn't always mean that it's a speedy process. It's rarely a speedy process" (Marian. HCP Psychology 9.30)*

> *"I mean, we apply for charities and there's certain places, lots of charities that actually won't actually give to asylum seekers so for them financially it's very, very difficult to actually get anywhere until they've actually got that stay and then other things can start falling into place" (Sobia. HCP Social Worker 31/2.88).*

In my Kenning[1] poem (Appendix 31) I described the differing perspectives of nurse, refugee and the structural assailant. Whilst the nurse and refugee perspectives were

[1] Kenning poems were often found in Anglo-Saxon and Norse traditions such as the classic poem *Beowulf* which is often used to study the evolution of English Language. Kennings use phrases of two words that replace a noun. Kennings are commonly used to describe something without naming it.

relatively straightforward to articulate, I wanted to add a perspective which had been shared with me but appeared difficult to convey – the structural assailant. The development of the structural assailant was intended to show the hostile government and bureaucratic influences on forced migrant health, which are far removed from care but often entangling to many of the care processes HCPs and families have to unpick and work within. The use of the word assailant was chosen to demonstrate the dark undertones of poor access to health and social care, which may at first be invisible or hidden but become overpowering when they are finally seen or 'heard'. A Kenning poem seemed a good fit for describing what was 'silenced' but uncovered by this study.

Adiva related the time HCPs spent with her son to a better understanding of him. She described a feeling that staff at her son's special school were not able to pick up on his unique cues, signalling that he was unhappy or had an unmet need, a particular concern as her son could not communicate verbally. She suggested that HCPs inability to read her son's cues may be due to a lack of time spent getting to know him, or that perhaps sending him home from school if in doubt, was the easier option for them:

> *"This school whenever he goes he's coming back as whinging, so it's like I can tell that he's not happy. And she says also when he whinges or cries they say he's not well, so they're not getting really to get to know him, so if you know him you'd know, because sometimes Mum will say oh she said there's times where he'd be crying, or vomiting and she'd said to them after you know after he's had his feed, he does vomit sometimes, but it's not because he's ill, but for them if a child vomits twice then they're going to send the child home. But if he's whining you know, you change sides, you sit him up a bit, maybe you change his position and (he will) be happy, but she said if you're not going to do that then obviously the child's going to whinge and cry" (Adiva. Mother 13.110).*

Adiva, Sobia and Clara, were linked together by the care of Ghazi a 10-year-old boy who had a traumatic birth in Afghanistan and a subsequent hypoxic brain injury. They all outlined concerns surrounding the coordination of community care for Ghazi. Their accounts offer different perspectives on the complexities of systems and processes, as well as clear variations in understanding of expectations about roles and responsibilities. Clara discussed the complexities of coordinating different professionals in different settings and the need to be persistent and strong when requesting care or equipment, within metaphors of battling and fighting:

> *"Everything seems to be a **fight** and everything seems to be a **battle**"* (Clara. HCP Pastoral Worker 20.63)

> *"It just becomes a norm doesn't it? an acceptance, well this is just what we have to do and these are the **battles** we have to fight and you think they just take it with so much grace"* (Clara. HCP Pastoral Worker 20.64)

Whilst Clara appeared prepared to work hard and 'fight' through the difficulties in accessing care, she often discussed her care as going above and beyond in her role. Adiva's expectations appeared to differ, as she suggested that HCPs' should by virtue of their role, arrange all appointments or discuss disagreeable arrangements. Adiva voiced her frustration with social services and Clara, as whilst she acknowledged Clara's offers of help, she described her as unreliable and inconsistent in her approach:

> *"Mum feels let down by social services in England because you know they heard so many different things when they were in another country. But they're coming and they're thinking what? Is this it? You know, you know the absolutely gobsmacked by getting doors you know shut in their faces"* (Sobia. HCP Social Worker 11.29)

"She doesn't feel Clara is as helpful … Clara will ask and go away with it, but doesn't seem to come to end or conclusion" (Adiva. Mother 10.85)

Interestingly, Clara appeared to see herself quite differently to how Adiva described her and stated that she often goes out of her way to be persistent and consistent in her relationships with families. These differences in perceptions may relate to the nature of the personal relationship and rapport between Clara and Adiva, or a differing view of expectations and roles/responsibilities. These differences, however, may be crucial in the understanding and negotiation of expectations in order to increase parent's satisfaction with care.

8:3:10 Judgements, labelling and safeguarding referrals

Judgements and assumptions by HCPs about forced migrant families appeared common within the interviews conducted. Marian described an African mum who HCPs struggled to understand and because of judgements and assumptions was nearly inappropriately sectioned:

"I would say another thing was that certain cultural practices that as a norm for the woman when they were interpreted by professionals, professionals interpreted them in a way that, um, well from the lack of understanding and she was then judged based on that as well" (Marian. HCP Psychology 14/5.50)

Marian also described an incident of a nurse visiting a forced migrant family in their home and not being adequately prepared for the interaction. In this example the community nurse visited a family who did not understand English well, without an

interpreter. The nurse mentioned concerns for the child's welfare and calling the police, the only word which was fully understood. The father responded very badly and aggressively due to his own traumatic experiences with corrupt authoritative figures in his country of origin – Cameroon.

YPAG members when interpreting Marian's account into poetic form were shocked by how little the HCPs listened to families. They recognised the lack of time, understanding or attention paid by HCPs and detailed the consequential judgements as 'assumptions after assumptions after assumptions'. The YPAG group also expressed sadness that 'no one head the (African mums) international call for help' (from the poem Learning to and fro, Appendix 22).

Flo described from her perspective the safeguarding incident in which Hamza and Khadija were accused of deliberate harm to their daughter by a nurse and GP, when their daughter was burnt in an accident at home**:**

> *"They (GP and nurse) made this prejudgment instead of looking at the information and analysing it and investigating it, they claimed that this child was harmed by parents and this child needs to be safeguarded. So, it's like they were almost labelled and because they and some families are, because they are from a different country, there's an automatic stigma or labelling attached anyway and that's compounded with oh, had you know she had a burn on her foot, so they must have scolded her. They must have done this. They must have neglected her. There must've and it's nothing of the sort, like I'm ready to kind of advocate and intervene to say, well, actually no, this is the situation" (Flo. HCP Social Worker 2/1.60)*

The descriptions of the incident from parent and HCP viewpoints, illuminate the need for any HCP who care for forced migrants to take time to build relationships with families, to aid understanding of their individual needs such as communication. It is

clear from this example how quickly misinterpretations can occur when interactions are rushed, judgements are made and they are potentially allowed to dominate decision making:

> *"The GP has speak quickly English like speaking fast so he couldn't understand what you're saying and when he answered it he was worried himself so he couldn't know what he was saying. And then when he wanted to hospital and they tell him to wait outside and (they) do checks on Bibi I have to wait all day and then he phoned Flo and Flo has spoken to the staff in hospital, then they understand the situation, then after a while then they discharged all the family to go home" (Hamza. Father 9.58)*

> *"He said that they don't know that Bibi is my life, is everything, is my life … I can't live without Bibi and I do everything for her for her safety and to look after her. And he said that after two weeks when he came home he still thinking about it and he had like a, you know, psychology was playing his mind that they will take her. So that fear but is not did not gonna take her, but that's is what he was thinking all the time for two weeks and it was not, you know, not Peace of Mind" (Hamza. Father 8.52).*

In this interaction and the previous examples, there were many misunderstandings that escalated quickly, with the labelling of families as aggressive, non-engaging, unsafe or generally problematic appearing impulsive and not based on any real knowledge of the family:

> *"They haven't been spoken to through an interpreter, so no one really knew this story, or understood and also they were referred with a safeguarding concern where there as this sort of pending investigation, investigating them as potentially neglecting the children, which is sad because I think it was, if again, if those is that their relationship was built and interpreters where there to allow effective communication that wouldn't have happened" (Marian. HCP Psychology 16.55)*

As well as misunderstandings and potentially discriminatory behaviour, Marian suggested that these often-inappropriate rapid referrals of forced migrant families to safeguarding teams, might be an expression of HCPs feeling helpless and not

knowing how to respond in a situation where action is clearly needed. As such further training or awareness of such family's needs appears imperative:

> *"I wonder sometimes whether people are just number one trying to cover their own backs and number two they want to do something about something that they see, so it's kind of almost like an easy way out" (Marian. HCP Psychology 17.57).*

8:4 Hospice setting

The individual, relational and structural factors relating to hospice care have been detailed in Figure 14 and relate to examples given by the participants of their experiences of care in this setting.

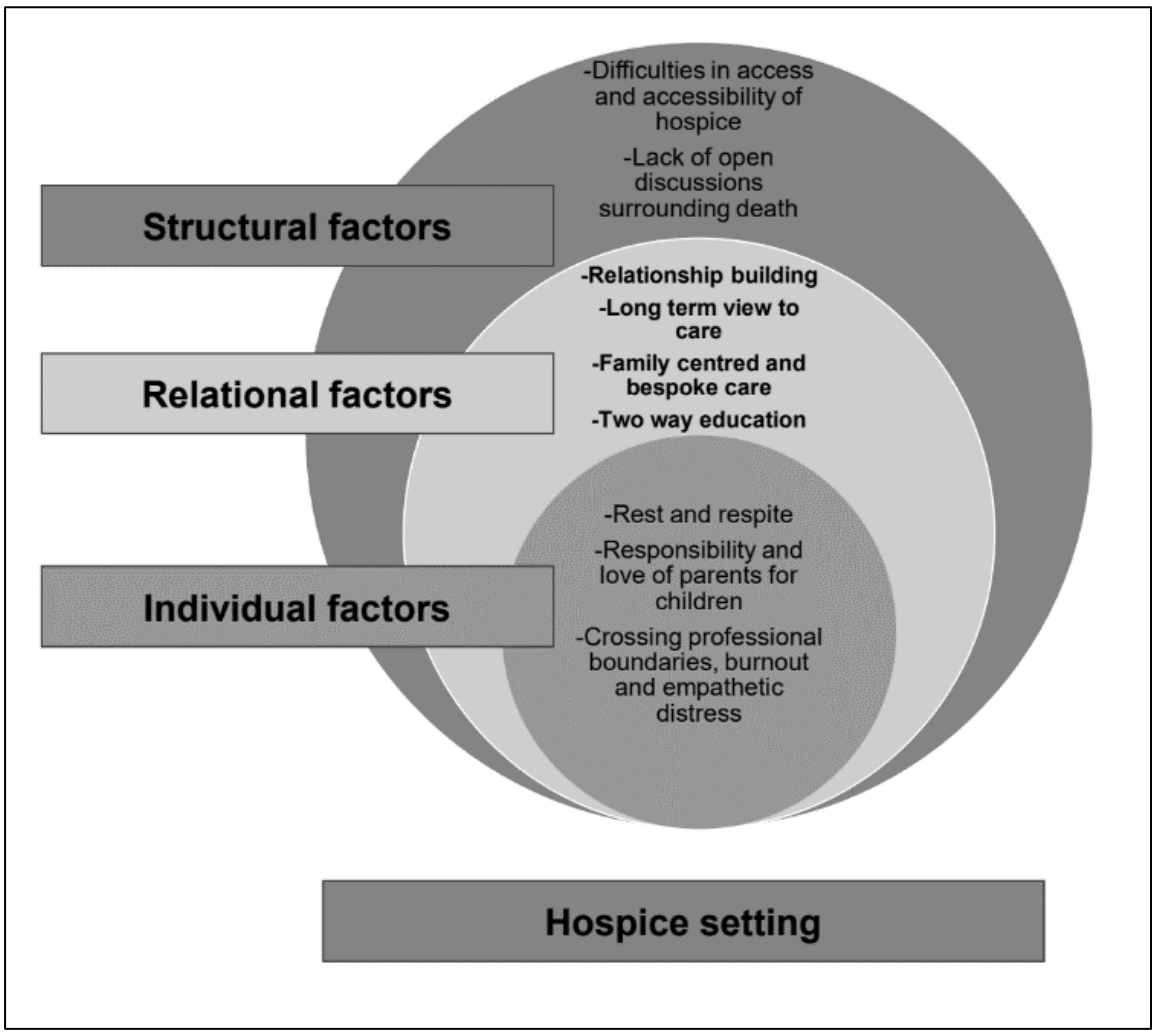


Figure 14 - The differing factors within the hospice setting

8:4:1 Relationship building

Within the hospice setting, participants who received or provided hospice care, outlined that relationship building was very important. Participants discussed that building relationships with families involved listening, empathy and taking time to understand what families were saying to meet their individual needs:

> *"Time and space and being person centred and using all the sort of counselling skills to listen, listen effectively, being able to communicate empathy and then being able to sort of diagnose and support, you know, around palliative care, the nurses often say Marian it's about keeping the patient comfortable and pain free and but often I can see, I observe colleagues at times, you know, communicating that with the family and negotiating certain things with the family is not always straightforward. Given various peoples beliefs, understanding and all that, so I think that it's quite a key to first understand the person where they're coming from and then and being able to have those conversations and sort of almost negotiate around those experiences" (Marian. HCP Psychology 22.72)*

Marian, Clara and Adiva compared the hospital to the hospice environment describing it, as busier and focused upon a short-term view to care. Marian suggested that shift focused work offered less consistency and less time for relationship building with families, which was the opposite of her experience working in the hospice. Adiva and Clara described a speedy flow of tasks and patients within the hospital wherein care appeared rushed and HCPs were eager to leave patients bedsides and move onto the next task:

> *"No one listened. Really no one listened to her. Really no one gave that time and I understand in hospital sometimes you know that it's no time, people, shift change, you know. So, there is that change of people all the time, so it's difficult to build that rapport with someone. I understand that" (Marian. HCP Psychology 13.46)*

"The nurses come on shifts obviously, they come and do their bit and go" (Adiva. Mother 7:55)

"So, they'll see professionals that are very focused on this is what we need to get through and on a time constraint where you've got 45 minutes slot" (Clara. HCP Pastoral Worker 10.32).

A further difference between hospice and hospital care was described by Marian and Sobia, as HCPs being able to take time to spend with families not pursuing active intervention. They described 'taking time' as being present with families, allowing interactions to take place at a pace to suit the individual family and to avoid overwhelming them. The shock of diagnosis or deterioration was described as devastating for families and so the additional time spent with them at such turbulent and sensitive moments, was seen as pivotal to relationship building:

"She just sat there with her without really saying anything and she did that every day for few days and then and then that um started very slowly little steps but started sort of communicating with that worker" (Marian. HCP Psychology 13/4.47)

"I'm at that stage now, about three or four conversations in, when she finally remembers now who I am, because at first there was so many professionals she didn't even know who I was, why am I calling?" (Sobia. HCP Social Worker 21.57)

8:4:2 Two-way Education

An additional benefit of the extra time spent with families was described by Holly and Marian as two-way education and the ability to learn from the families for whom they cared. When YPAG advisory group members created the poem 'Learning to and fro' (Appendix 22), an early interpretation was drawn out of Marian's explanations. YPAG

members created lines of the poem to reflect the importance of Marian's reflections on 'mutual learning' from families. Learn or learning was included four times during the poem for emphasis. They discussed with me how important the aspects of collaboration and negotiation were within their own care experiences. This aspect of Marian's discussion thus took centre stage in their poem with the 'toing and froing' elements of learning forming the title of the poem.

Such aspects were reiterated by HCP Holly and so in the lines of her poem: 'I am teaching, guiding, learning, still learning' and the clarification of the source of much of her learning: 'You learn so much from these beautiful families' was detailed – from 'Sit Alongside, Sit Beside' (Appendix 26). The aspect of working 'alongside' families which Holly described was added to show the levelling of power or authority between nurse and family and how the equalising and prioritising of family's preferences appeared crucial to relationship building, understanding and trust.

Both Marian and Holly appeared to discuss the theory of Cultural Humility in action. A Cultural Humility approach was particularly evident as Holly discussed the need for HCPs to be humble and tell families when they did not know or understand, with the building of rapport helping in the acceptance that families could educate HCPs':

> *"You learn so much from these families, you never stop learning, you're always to hold that because you will always reflect on it and it will help the care that you go on to give to another family, another young person"* (Holly. HCP Nurse 10.42)

> *"We give to families, but we also learn from the families and we are open to that learning" (Marian. HCP Psychology 4.13)*

Interestingly and perhaps unexpectedly families also displayed Cultural Humility in their actions and words, they showed great insight into the different lifeworld's of HCPs' and did not judge or assume universal similarity, even when they were treated unfairly:

> *"I obviously understand there's 5 fingers, not all of them are going to be the same, so you're going to get some people that aren't going to be very nice" (Adiva. Mother 21.163)*

> *"In hospital unfortunately we meet many nurses … but I understand there er different attitudes, different culture, some of them very kind, others no aggressive" (Maaz. Father 2.7)*

Three parent participants shared a desire to educate HCPs and to particularly enhance their insight and empathy towards forced migrant families:

> *"I think it would be a good thing to teach, to tell them stories and listen well, listen well from stories and you have to put yourself in their position of these patients or the family. Nobody wants to be in this sick or to be oncology patient, no, but if this is, so everyone must have support and help them" (Maaz. Father 11.33)*

> *"You have to teach them because they haven't seen it so you tell them, there's people that come from different counties and their backgrounds are different, they might have gone through things that you don't know about, so it's about educating, about different things that are going on in the world" (Adiva. Mother 22/3.176)*

8:4:3 Additional time in the hospice setting

The additional time needed to care for forced migrant families also relates to language difficulties, structural and resource deficiencies. However, within the hospice setting, time was particularly valued to incrementally improve the lives of children and families in their care:

> *"It took perseverance. It took a lot of time and effort and resources, but we were able to persevere" (Marian. HCP psychology 15/6.55)*

> *"When she came to (the children's hospice) she was literally like, you know, zzzzz (buzzing noise) talking to everybody, everybody thinking it's going to be a quick fix and I said … I'm going to help you to do what I can but it will take time because obviously with everything there is processes that you have to go through and you know it takes time or what have you, but we finally got there" (Sobia. HCP Social Worker 7.19)*

During the last five years of living and receiving care in the UK, Hamza had also developed an understanding of the cumulative nature of changes to improve the quality of his daughter's life, with incremental changes such as the provision of financial support, equipment and housing adaptations:

> *"I don't think it's going to be, any change will be the same because he's been five years in this country and his lifestyle has been changed slowly, slowly" (Hamza. Father 11.71).*

The consistency of relationships in the children's hospice was mentioned by Hamza and Flo. Flo was described by Family Ahmed as being accessible and quick to help them in times of difficulty:

> *“She’s a very important person in the family life, because as general life routine, sometimes he don't understand the letter, don't understand message he get confused about something. He, the first person will be in his mind will be calling Flo and ask her and she would never say, she always be there for the family” (Hamza. Father 7/8.48)*

The consistency and accessibility given to this family was something Flo worked hard for, as she detailed how she provided such care, from regular visits, to offering clear explanations and following through on actions and tasks. Flo said this level of attention to detail and responsiveness to the family was important in showing her care and in gaining the family’s trust:

> *“So, we've come from being in the position of like, what do you, what do you do Flo? How can you help us? I'm not sure if I trust you and then it's just been built from there, he'll tell me things I'm, they probably wouldn't tell an average professional ... I was seeing family every week because of the amount of work that I needed to do, if that wasn't going through paperwork, if that wasn't filling out the DLA form, it was something else and then I really got to know the family” (Flo. HCP Social Worker 6.19)*

8:4:4 Crossing Professional Boundaries and burnout

Flo’s overwhelming desire to protect the family was however also indicative of potentially crossing professional boundaries into an emotional relationship**.** Flo described her relationship with the family as unlike any other, which may be linked to the vast amount time spent with them. However, it could also have the potential inadvertent impact of burnout or compassion fatigue and an inability to remain objective:

> *“There's been times where I've, you know, spoken to Dad out of hours, but I just feel for me, this is one, this family is one of the families where you know I don't mind, you know, calling them after the time that I'm working 'cause it's not about, you know. I*

work 9 to 5 and that's it, but it is and it isn't because with this family they need that support, then they need to know that there, they're supported … it can be exhausting" (Flo. HCP Social Worker 7/8.22/3)

The depth of emotion Flo expressed for Family Ahmed, can also been seen in her drawing (Figure 15) and the way she portrayed the family, as she explained her drawing to me:

"OK so one side of the heart is mum, one side, the heart is Dad, I've been having three hearts at the bottom. This family is very, very loving family, they are just the literally one unit and there's roots at the bottom, that kind of moulds and glues them together and it's all about Mum and Dad is all about the best interest of the children" (Flo. HCP Social Worker 12.36)



Figure 15 - Flo's drawing to illustrate the family

Whilst some of the elements of overprotection and all-consuming concern for Family Ahmed may be perceived in different ways; overstepping her role, or taking on too much sole responsibility, the compassion Flo demonstrated to the family, highlighted her motivation to provide the highest level of care, with elements of burnout being an unintentional consequence. The portrayal of these elements in the poem written

about her, ‘Exhausted but fighting on’ (Appendix 23), aimed to highlight the often-hidden impact of care on HCPs, with lines that show the ‘exhaustion’ and constant ‘fight’ to ‘prevent them struggling’, alongside her overwhelming desire to ‘protect’ and advocate for the family.

The strength of feeling Flo described may also link to a distrust or concern over the ways that some HCPs had treated the family poorly in past interactions:

> *This family, almost you know you wanna wrap them up in cotton wool and you wanna support and encourage and nurture and all those things because and empower them because you want them to have the best life experience in the UK as possible” (Flo, HCP Social Worker 21:62).*

Sobia also shared the notion of ‘over-attachment’ to families and explained part of her own burnout experience related to the way that hospice worker’s journey alongside families over months and sometimes even years:

> *“We're carrying those cases with us. We're actually on a journey with them yeah, so for us it's a lot harder to separate the two, you know, even we're on annual leave or when we're not working” (Sobia. HCP Social Worker 24.65)*

> *“We get so attached to them as, yeah, you know 'cause you almost feel like you know you're actually living their life with them really” (Sobia. HCP Social Worker 24.67).*

The close work with families, the difficulties in switching off and nature of the role, appeared to link closely to increasing exhaustion and burnout for some HCPs. For Flo, Rebecca and Marian, an increasing dependency upon their care and role within

the organisation was apparent. All described feeling responsible for families, with Sobia using a metaphor of 'carrying her families' through their difficulties and Rebecca using an analogy of her being a 'one-man band'. Flo's desire to protect Hamza and Khadija resulted in hypervigilance where she felt on call all the time, while Marian appeared fearful of the potential consequences for families, if they did not have her personal support:

> *"It's very rewarding, but it's very hard work at the same time … they've been through so much and they will just want answers, then it's almost like you know you're trying to **carry them** through all that to say you know, just wait until we gotta go through this and you're **carrying them** and I think at the same time, I think sometimes your, our own resilience, sometimes goes as well with it" (Sobia. HCP Social Worker 8.21)*

> *"However, I do feel like I'm on alert, it's as if I'm 999, so when they do call me about right OK, what's going on? (Flo. HCP Social Worker 21.62)*

> *"We sometimes **we're the only people** who have had the time to listen" (Marian. HCP Psychology 7/8.27)*

> *"That was quite difficult, but in the end, I am convinced that **if it wasn't for our support**, I'm not sure what that experience of that end of life would have been for her" (Marian. HCP Psychology 10.35)*

Holly an experienced and senior palliative care nurse in the hospital setting spoke about burnout in the third person, giving examples of other nurses and the reasons that they had become burnt out, exhausted and fatigued. These included the longitudinal and traumatic nature of palliative care work and a lack of ability or desire to empathise with more 'difficult' families:

> *"They're tired, they just want to do their job, they're very task orientated and ... a white British family who are good fun and laugh with the nurses and easy to get along with, they're easy to nurse aren't they, whereas a family who you don't really*

understand, possibly because you haven't allowed yourself to understand, the easiest thing rather than to try and learn, is to just distance" (Holly HCP Nurse 27.116)

"I think there's a weariness often, people don't want to understand, or they're too frightened to ask so they'll be brazen and they'll hide behind it by being ... a little bit callous maybe" (Holly. HCP Nurse 28.120)

8:4:5 Rest and Respite

Within the hospice setting, a large amount of HCP's work surrounds the provision of respite and rest for families from their usual caring role. Two of the families received care at critical periods in their lives, as the families welcomed new babies. These respite stays allowed for parents to rest and recover from the birth and spend time with the new baby without having to care for their disabled child:

"Its (respite stay) very helpful for mum, she can rest a little bit with the new baby and sometimes when they have appointment the hospice will take them and look after them" (Hamza. Father 7.42)

"When I was pregnant I was having the baby, the local hospice kept him when I was having him. She goes that was somebody who actually helped me at the time when I needed, because I had nobody else I could... So, she goes obviously I've got no family and that's the only people I could count on that were going to be there" (Adiva. Mother 12.100)

Whilst the provision of respite care is a traditional way for hospices to support children and families, they do also offer bespoke family centred care around the individual needs of the family, which requires flexibility and 'bending' of the rules occasionally. Marian, in her managerial role, oversaw many of these occasions, such as accommodating 70 members of a travelling community whilst a child died at the

hospice. She also helped create new methods of communicating with and documenting for, them due to their low levels of literacy. Marian further mentioned pragmatic elements of bespoke care such as learning how to cook African foods to tempt a young, traumatised mum into eating again, or ensuring the right products were available and understood, to use on African Caribbean hair.

8:4:6 Difficulties with access and acceptability of hospice care

Whilst hospice care was valued as overwhelmingly beneficial to families by HCPs, they also described some difficulties with access and acceptability. Adiva and Sobia described the struggle for parents to hand over care of their children to the hospice and how a lack of attention to detail led to parents' worries about the quality of the care given:

> *"His mouth was smelling, they weren't doing his hair and he wasn't sleeping ... because they weren't putting him in a certain position" (Adiva. Mother 12.104)*

> *"She says no, I felt that you know his face wasn't clean and maybe the nurses didn't look after him properly" (Sobia. HCP Social Worker 26.73)*

Adiva, Sobia and Clara also discussed the responsibility, love and physical attachment that parents felt for their children and that this compounded the difficulties in accepting care from anyone else:

> *"(She said) I can't feel where my body ends and hers starts. I feel that her body is a part of mine so she needs to be say clean and everything … but mom used to say,*

you know, I feel her body is a part of my limb and there's no differentiation from where hers stops and mine starts" (Sobia.28.79)

"She couldn't kind of let go, but so on one hand you want she wants support, she wants help, but then she doesn't want, she wants the break, but she doesn't want to let go of him" (Clara. HCP Pastoral Worker 15.48).

Whilst the love and attachment parents expressed may be considered universal for all parents of children with palliative care needs, for forced migrant families this may be intensified because they have already lost their families and home. When losing so much already it is hardly surprising that their children may become a focus and result in them clinging a little harder due to the loss and grief they have already encountered.

Further barriers to hospice care were discussed by three participants. Maaz was unable to access hospice care at the time that his son was given a terminal diagnosis and the family was most in need of support. For some families, a negative perception of hospice care as somewhere that children go to die, was discussed:

"She had this ideology of hospices come from this they do that and my daughter's not going to die, that's final. Whereas this family, I think because of and this is not to say and, it's not in a derogatory way at all, but because of the lack of knowledge about hospices, it was this is just another service that could potentially help us, was their view ... because we won't, any family that we have, whether the you know UK born, abroad we never unless the child is seen as an end of life child, we don't mention that side of things. We talk about the here and now" (Flo HCP Social Worker 15.45/6)

Marian was aware of differing opinions surrounding hospice care and that those living in the UK may also view hospice care negatively. Flo related such negative views to the potential impact upon family members' acceptance of hospice care or help from hospice teams. For forced migrant families all three of which in this study had a strong religious faith, receiving care from a hospice which is linked so closely

to death or dying, may be perceived as giving up on their child or the family lacking in faith or hope for a cure.

8:5 Hospital setting findings

The individual, relational and structural factors relating to hospital-based care have been detailed in Figure 16 and relate to examples given by the participants of their experiences in this setting.

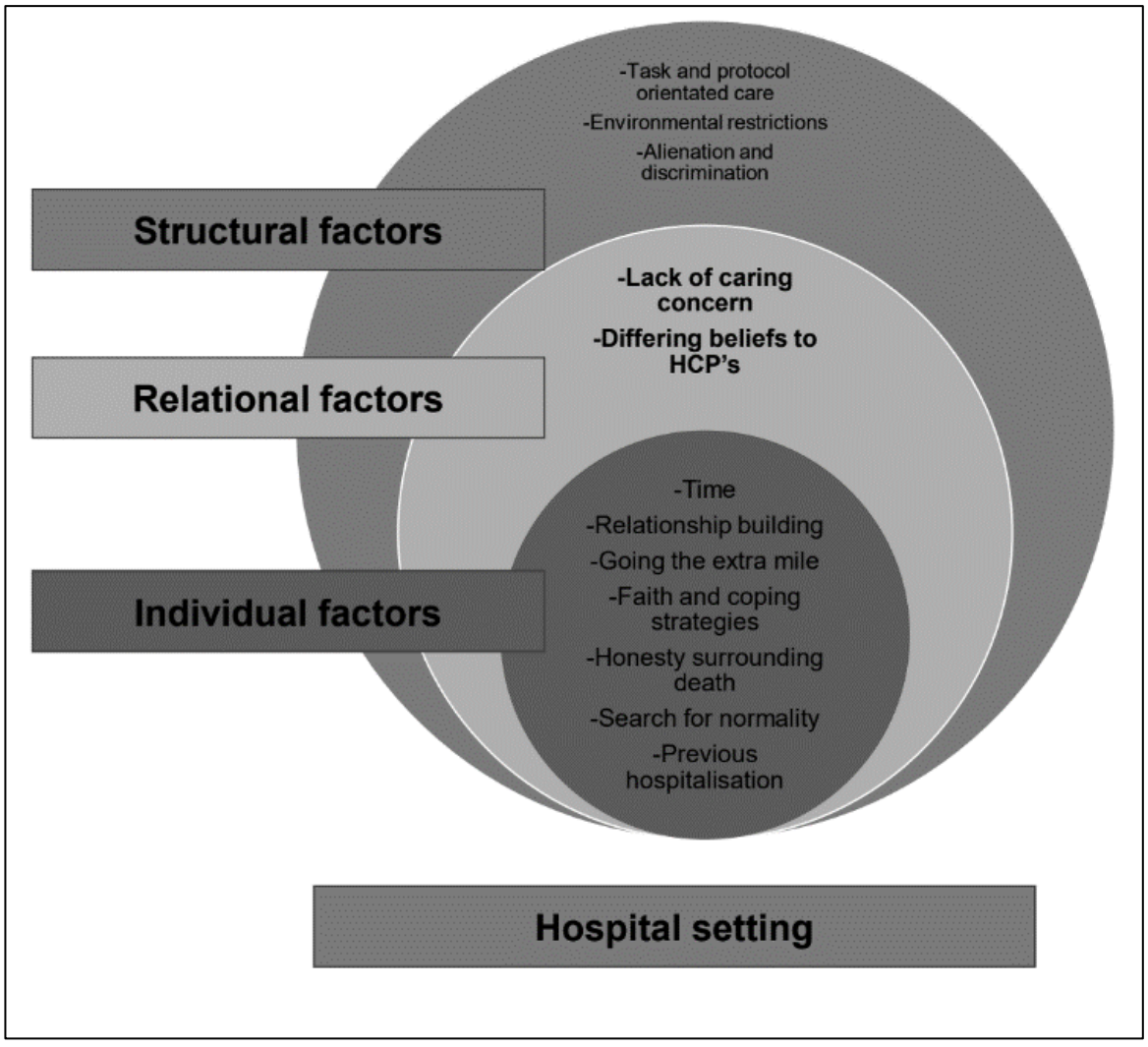


Figure 16 - The differing factors within the hospital setting

8:5:1 Time spent with families in hospital

The amount and quality of time that HCPs spent with families in the hospital setting was described by all the participants who experienced hospital care. Time in hospital was experienced differently to the hospice and community settings, with much of the discussions dominated by a focus on protocols and task achievement. Holly described hospital work in the context of her oncology experience, as protocol led and prescriptive, with staff struggling to give or understand individualised care due to a focus on documentation and task fulfilment:

> *"*[Describing oncology clinic role] *very protocol led, very procedure led, felt wrong for me, I felt like I'd had my wings clipped … we weren't caring for the unique needs of families … it was very task orientated"* (Holly. HCP Nurse 4.21)

> *"It's very much about right you need to do this today, this this and this and report back to me"* (Holly. HCP Nurse 33.150).

Holly viewed ward nursing from her own experiences, but also as an observer, with her current role falling outside of ward routines and being much more autonomous. The specialist palliative care team in which she now works was described very positively by Family Tessa who had much contact with Holly. She was described as a constant presence who was at hand to help and support the family, but who also showed her caring concern and made the family feel understood and listened to:

> *"(Holly) gives you an impression that she understands you and feeling you and wants to help and support and trying to find any way to support and help ... Many times H.. visited my wife in the ward and said 'do you want anything?' 'do you need anything?' I am just coming to say hello" (Maaz Father 8.26)*

> *"I remember once I was with my brother we were going, oh yes and she came in and then she stopped to talk to us and we were having a laugh and talking" (Pasban. Sibling 16 years 16.52).*

Conversely, ward nurses were described by parents as busy and rushed, with Family Tessa describing an incident of a nurse appearing to forget their son between shifts:

> *"So sometimes if there is a nurse looking after my son and she is kind, "oh Sohail", "hi Sohail", you are good boy, you are brave boy" always, so next time it would change to another one, mmm, so he may meet her in the corridor or anywhere he wants to tell her 'hello' because he has a good memory, but she is with him as she cannot understand him or, don't want to say at least hello? Oh, so he's why they? Also, the nurse can't explain like this when nurses are looking after you and they change next time and pretend that they, she, doesn't know who, or they don't say "hello" (Maaz. Father 14.43)*

It was difficult to fully interpret this interaction (or lack of it), as the family did not understand why the nurse might have failed to recognise or speak to their son, when they were not caring for him that day. However, this incident clearly hurt them and left them feeling rejected, confused and worried that his care needs might be ignored. Adiva also described the adverse effect of the busyness of the nurses on her relationships with them and ability to trust them with caring for her son:

> *"She said he's had his teeth removed, he's had his gastrostomy and I'll still stay I've never come home, even though the nurses are there and they'll look after him, but I can't ... she said the first time when they went to hospital for the 2 months when they finally went to the hospital and that, she said in the next room there was another child that was disabled and you know his machines would be beeping, he'd be crying, or the milk would be finished and she said the nurses wouldn't come in and I think that kind of set a precedent for her that you know what I'm never going to leave my child on his own, if anything was to go wrong then the nurses wouldn't be there on time. She goes my heart's not that big so I could leave him on his own" (Adiva. Mother 15.118)*

Holly outlined similar concerns and highlighted the importance of spending time with families, rather than rushing between tasks:

> *"You're really conscious that there's families that are struggling because they're not having that time to share what it is that's important and you've got to have conversations and you don't want to do it quickly or hurriedly or rushed you need to just go and sit with them and have conversations with them and get to know them"* (Holly. HCP Nurse 32.144)

Holly also discussed the difficulty she saw ward staff face in spending time with families, not only in terms of the lack of time during a busy shift, but also emotionally. She discussed the emotional toll of caring for children with palliative care needs and their families and the difficulties of sitting with another's suffering. Holly mentioned that perhaps this difficulty and the comparison to completing a simple task, such as giving a medication, could also be related to HCPs' inability or lack of desire to engage fully with families. For forced migrant families who are isolated and without social support, this may be particularly challenging. However, elements of communication difficulty, 'othering' and a lack of awareness of family circumstance may also play a part in HCP to family interactions and HCPs' willingness to take additional time to understand or meet need:

> *"It's far harder to sit and spend quiet time with a family, than it is to go in with a task and quickly whizz in and whizz out, whether it's to assess clinically or go in and deliver some drugs or take a temperature"* (Holly. HCP Nurse 32/3.146)

8:5:2 Lack of caring concern and family centred care

A lack of caring concern and a poor approach to family centred care during her son's hospital admission was described by Adiva. She spent all day by his side without food or drink. She described assumptions by the nursing staff that her circumstances were similar to western families and that she would use the parents' facilities or canteen, or have her husband bring in food. However, all of these options were problematic, as she lacked money, confidence in her surroundings and her husband's concern, which related to differing gender roles in the family:

> *"She was there on my own with him, for 2 months I didn't eat or drink, I said what about your husband she said he'd come home obviously. She said I'd sit there and hurt myself, physically hurt myself because I was crying just hurt myself. I said surely there would've been a nurse to offer a cup of tea or toast and she said no there was nothing. And she said obviously my husband didn't think let's go home and get her some food" (Adiva. Mother 6.45)*

> *"Obviously it's the first time I was here, I didn't even know the entrance or the exit of the hospital, where one way goes or the other way goes" (Adiva. Mother 8.67).*

When asked if nurses did check on her she said: *"they weren't interested, so they wouldn't"* (Adiva.7.53). The parent champion who wrote about Family Khatri's experiences in his poem 'I am here, I am lost' (Appendix 29) articulated the emotions Advia described of being present but unseen by the HCPs, who failed to see her needs or understand her isolation. He beautifully but painfully described her:

'Drowning in an unknown language,
Disappearing, invisible, ignored.
The only one who talks to me is my child
And he has no voice'

He further related the lack of time and consideration given to Advia, to the HCPs inability to stop and see her desperation. The words of this poem are stirring and difficult to ignore, with the pain of rejection and misunderstanding Advia described clearly pronounced.

8:5:3 Environmental aspects

Correspondingly, environmental aspects sparked a lack of concern over parental comfort in descriptions by Advia and Kinza, as they discussed the lack of provision for them in the hospital, particularly in relation to a bed to sleep in. They also detailed HCPs' overriding focus upon their child without sufficient/any care or concern for his mother. Which was particularly concerning for them as they both endured many weeks by their child's bedside:

> *"All the time I sit in the chair not sleep, pain, yes I have got my son in intensive care and I have to look at him" (Kinza. Mother 20.63)*

> *"Obviously I'm on the sofa and you're not going to get proper rest on a sofa are you?" (Adiva. Mother15.120)*

> *"They had not changed any bed, so just one they would change and she was staying beside Sohail on the chair, they told me this is the side for Sohail yeah was ok, I don't tell them no I don't like this, just this for Sohail you know" (Kinza. Mother 10.31)*

8:5:4 Going the Extra Mile

The experiences recalled by parents may be influenced by differences in care between the UK and countries of origin and differing expectations of caring roles, which may not have been discussed with parents upon admission to hospital. Parents' observations of the ward routine and nursing care were astute so when nurses did take the time to go the extra mile they recognised and valued the extra effort:

> *"A nurse called Jim yes he was busy in his job and work but found free time to play with Sohail (Maaz - Father) yes he was patient in the hospital yes, very kind. Really, yes very kind, very kind (Kinza. Mother 17.52).*

Whilst nurses giving FCC and being seen to go the extra mile would understandably be valued by all, for forced migrant families this extra care was especially important. The significance of going the extra mile is illuminated for forced migrant families when compared to the contrary experiences of hostility, discrimination and trauma, some of which are described by parents within the theme of alienation and discrimination.

8:5:5 Alienation and Discrimination

Parents Adiva, Hamza and Khadija, described their migration journey and subsequent experiences with the Home Office, when discussing the processing of their asylum claims as in-personal, frightening, lengthy and confusing:

"They sent me to the Home Office … I went there and he treated me like a homeless person, he went go and sit over there, you know like a beggar…they came and took me in and questioned me and all sorts you know, have you come here as a terrorist, why have you come here, asking loads of dirty questions as in their implying maybe the sex trade or something like that, who planned it, who sent you here.. so, asked me loads of questions. She said then they fingerprinted me and took pictures and everything and the night time they sent me somewhere. She goes I got really scared then because I thought they were going to sell me (my body) to somebody" (Adiva. Mother 3/4.31)

"A very hard time with the Home Office and every time he seems to try to react on his case, it used to tell him or we have to move, you have to do give you another interview, another interview" (Hamza. Father 4. 21)

Hamza compared his treatment in the UK to experiences in Turkey and Germany, where he felt discriminated against and that help wasn't given to him, as refugees were viewed negatively. Similarly Hamza's wife Khadija, compared healthcare treatment received in the UK, to that in Syria which was extremely limited because of the conflict. Comparisons of this nature which highlight extreme experiences of trauma or poor treatment, may cloud perspectives and make it difficult to give an accurate assessment of discrimination experienced in the UK:

"He felt the difference, the discrimination, it probably in Turkey whereas that they see you as a refugee, I'm Turkish man, this is my country but maybe he feeled that in Germany as well, maybe in his own country, yes, but not in this country at all. He said two country there will be very different, not nice to refugee people is Hungary and Germany. Even though he was not asking for money, he was lost in the country and just asking for directions someone to buy him a ticket to give him the money and buy him ticket nobody will give him any support, nobody, but here in in Britain is differently is very, he feel safe and he feel peace of mind, this country than his own country" (Hamza. Father 10.64/5)

"After the war everything was really hard, really challenging if you are lucky to be seen by the over in the hospital. You are lucky. If not, you would die" (Khadija. Mother 17.104)

Whilst Hamza appeared positive about his and his family's treatment in the UK, he was also quick to offer advice and guidance to nurses about treating refugees fairly and without prejudice. This was contrary to his initial optimism and thus made me question his assertions that the care received had always been non-discriminatory:

> *"As a nurse didn't you know that to not freak like put a like put a torch on the refugee. He wishes future nurses to be reminded to deal with refugees with no prejudice and make sure not to be patronising or controlling" (Hamza. Father 10/1.67).*

When considering Family Ahmed's experiences, a parent champion advisory group member wrote in-depth about the family's traumatic and often horrifying migration experience compared to their experiences of care and welcome in the UK, in his poem – 'We arrived – A refuge for the refugee' (Appendix 27). He articulated the dichotomy and paradoxical aspects the family experienced and how difficult the adjustment and acculturation must have been:

'We arrived, torn by distance and conflict
Separated by memories and time
Isolation and detachment, were quietly soothed
By the words of others, with warmth in their hearts'

The parent champion advisory group member indicated that the extremity of migration trauma may have made the care the family received more meaningful to them, (but not necessary of higher quality), which was illuminating and could have otherwise been overlooked.

Family Tessa described their experiences of discrimination and alienation within the UK health care system, in the form of misunderstandings about Kinza's hijab and the family's religious needs:

> *"One day they maybe meet her in corridor, my wife was wearing Hijab, she oh like scared from ... like this (hides behind hands), silly behaviour"* (Maaz. Father 3/4.10)

> *"Sometimes she said while she was fasting so she has to sit without food from the morning until sunset and sunset in the summer was about 9.30 and about 8 o'clock they turned off lights and all the people they try to sleep so it is difficult for Muslims to eat and everything is switch off electric in the ward, turn off appliances* (so can't be switched back on by individual parents). Yes and her clothes as well, as a Muslim. S*he has a bad memory sometimes of her first days in the UK of how they dealt with her, she was fasting and she wanted to pray, can't speak English or understand them or express"* (Maaz. Father 13.39)

Holly also highlighted similar dismissive practices within the hospital environment:

> *"They don't recognise ... nurses will go in and out regardless, they won't recognise that prayer time is really important and I see prayer mats being taken into the toilet, into the cubicle toilet ... I just think that's ... that shouldn't happen"* (Holly. HCP Nurse 27.114/6)

Rida, who has worked as a Muslim Chaplain for over 20 years, described how alienated she felt in trying to pray during her own hospital admission. She detailed how uncomfortable she felt and how she feared the negative opinions of those around her. Rida used this explanation to highlight how even with her western upbringing, education and awareness of UK healthcare, she quickly felt vulnerable and unsure of herself when she became a patient:

> *"I thought to myself, they're not going to understand me, they're gonna think I'm weird or strange and even if they open the curtain a bit and they say, oh, we just want to whatever and then I'm not allowed to break my prayer and answer them, they're going to think I am so rude and they're not going to understand this that I used to,*

you know, I didn't have the confidence to ask, I would have done that it would give me a peace for 10 minutes, just as if I could have just said can I close the curtain for 10 minutes and just do my prayers please but didn't have so if that's me, yeah then what about a lot of people or already a little bit shy or not confident with their language" (Rida. HCP Muslim Chaplain 40/1.108)

Rebecca a senior nurse working to discharge children with complex care needs home from hospital, raised a different issue as she outlined her thoughts regarding patients born outside the UK and their entitlement to free care. She also discussed the perceived ethics behind parental decisions to bring unwell children to the UK for care, which she often disagreed with. At times during her interview, she muddled forced migration with health tourism which was distracting. Brexit also appeared to be important to her and had clearly increased the complexity of her role:

"Where it becomes complicated is when there's questions about how families have come into the country, whether they've got fraudulent document which does happen, whether they've depending which country they've come from as well as to whether they're.. I mean obviously with Brexit that has added lots of different questions in recent months…. So you know we had a high proportion of those families, where actually when you start to piece their journey together, it has lots of question marks. And because of that, the entitlement to healthcare is then questioned" (Rebecca. HCP Nurse 14.91)

Whilst Rebecca, at times, appeared empathetic to families, she also used some derogatory discriminatory language to describe family's actions such as: "strange", "bizarre" and "suspicious". Rebecca also flippantly described other members of the MDT expressing concerns that her team were heartless, by prioritising legality and the investigation of entitlement issues:

[Discussing a family that were moved from a Birmingham hospital to one closer to their home in Coventry] *"You kind of move one load of baggage from one place to another" (Rebecca. HCP Nurse 28.152)*

> *"Actually if part of that child's assessment is to ask that question of every child, whether you're you know whether you're born and bred Brummy and you've lived in Birmingham all your life, or whether you have just appeared in Birmingham runway" (Rebecca. HCP Nurse 32.165)*

> *"The barriers that are in place are in place for a reason and I think some of it's like self-preservation. Because I think if you don't have those barriers and limitations, there'll never be a.. never be an end point* [to the care or resources allocated]" *(Rebecca. HCP Nurse 33.169)*

Contrary to her discussions regarding entitlement to care Rebecca did seem insightful into the impact of her own limited life experiences. Perhaps most influential was her own perceptive comment about her personal privilege and limited understanding of forced migration:

> *"I suppose I've never lived.. I've lived a very fortunate life I suppose in the sense of.. if I need access to services I get access to services , if I.. you know I've been to university, I'm married I've got a house.. I suppose in that sense I'm kind of quite stereotypical, I.. so for somebody then to come to me and say they've experienced I don't know.. something horrific, you know.. like persecution or whatever it might be, I haven't got the skills or the knowledge to understand them, I can empathise because I'm a human being and I could never imagine.. and that is honestly true I could never imagine what that must feel like" (Rebecca. HCP Nurse 36.188)*

Rebecca discussed a theoretical view that any judgements a HCP may have, should not be imposed upon families. However, it was clear from her discussions and actions that her own values and beliefs did influence her care. Despite the self-awareness she detailed, this appeared to be empty rhetoric as she had not acted upon this and did not detail any intentions to improve her own education, which might have been expected, particularly of someone so senior.

Family Tessa described inconsistencies and inflexibility in the nursing care provided, which hinted towards favouritism of some families, yet alienation or discrimination towards their own family:

> *"In hospital unfortunately we meet many nurses, I don't know how can I say that, but I understand there different attitudes, different culture, some of them very kind, others no aggressive, I can give you an example, Sohail was between 12 and 13 when he enter, was undergoing chemotherapy in Ward, you know in the ward there is many children between months to 12. And there is a ward just for TCT for teenagers. Many times Sohail asked nurses please let me go to other ward because I am young boy who, I have to stay in the bed close to babies crying every time like this, so the nurses they say no you are still below 13 so he proved them that he is in 13, he said oh just there is 10 days left and at the same time he surprised when he entered to the TCT, during a day, he found a boy in 5 or 6 years so you can imagine, how can I answer or reply to my son when he asked me Dad why this 5 or 6 years, staying in TCT, to me just 10 days left to 13, has not allowed me to go, there is no answer and no comment, why are they go"* (Maaz. Father 2/3.7)

Maaz a father to three boys, also described an incident of the family having to use hospital transport following a month-long admission to hospital. Whilst the nurse had explained only Sohail and his mother could travel in the hospital taxi, the weather was particularly cold and Maaz had many buses to catch to get his other children home. He asked if Peroz (Sohail's youngest sibling who was only six at the time) could ride in the hospital taxi with Sohail and Kinza and was met with hostility and a firm commitment to strictly adhering to rules. Maaz commented that whilst the family respected and understood the need for hospital rules, it was clear from their observations that these were frequently bent or changed for other families or when nurses felt inclined to do so:

> *"The rules change, change as they want because we living with them for a long time so you can watch and see what they give others. Sohail sometimes he was saying why they are dealing with us like this? Just because we are not British or we are Muslim so we, at this time we try Sohail you know it is because nurse not good or like*

this, there's other no this one is very kind, very good, so there's characters of people and their background and their culture and how they give out" (Maaz. Father 10.32)

In addition, the family also discussed how the actions of people who cared for Sohail changed when the staff realised their son's care was now palliative. The family sensed an increase in compassion during the last month of Sohail's life prompted by his impending death:

"The last month before he passed away the nurses were very kind, with us and with Sohail but before not so, (did you feel a change then when his condition got worse?) *Yes" (Maaz. Father 8.24).*

Furthermore, three of the HCPs described their and/or their family's experiences of discrimination, alienation and migration in their interviews - these appeared to prompt them to want to provide better care:

"That's giving you a kind of example of the trauma in my life… I grew to becoming, unaware and urm, shy, embarrassed to ask about things that everybody else seemed to know about, for fear of looking like I didn't know or being different from everybody else" (Rida. HCP Muslim Chaplain 10.33)

"Somebody said, oh, you're very into immigration, you know, a lot about immigration. And that's the one I would open up. I said, you know what? This is all about, eight years of being, you know, taking my husband through the immigration system and you know what I went through, so absolutely, when you know people are struggling or you know people don't know where to turn to or feel like you know I'm kind of the ambassador for them because I've been there myself and I really, really do not want other people to go through that… feel so helpless" (Sobia. HCP Social Worker 6.18)

8:5:6 Divergence of beliefs

The lack of understanding of family beliefs including truth-telling, hope and pain relief, are linked to the theme of differing beliefs between HCPs and parents. Specifically, for Family Tessa, there were incidences in which the HCPs and family differed in their approaches to telling Sohail about his palliative diagnosis and preparing him for death. The HCPs appeared to focus upon truth telling and transparency and were keen to swiftly and directly inform him of the situation. They appeared to lack understanding of the family's desire to preserve Sohail's faith and hope:

> *"In the last month of his life when he was in the hospital and the doctor came, Dr Jones and he said sorry Sohail you are dying. You can't imagine this statement to anyone and what about a young boy who is 15, its very, very shock and cannot imagine it. So, this thing I wish to reconsider the NHS that young children or children, not tell them all this bad news … Give them hope. It will not change anything, let them, last few days with hope. So, it's difficult. I am not talking about this, now the doctor he did that that time his duty and he has to tell the truth to Sohail. It's another thing, I wish this to be changed. In our culture, in my country, we never ever tell children this like this, mmm, so the issue of course Sohail replied, do you know what Sohail replied to the doctor? he said nobody knows when he will die, you may die before me" (Maaz. Father 5.14/5)*

During these conversations, the family tried to tell the doctor that it was important to them to remain hopeful of a cure from God and allow Sohail to gain comfort from his faith, but it seemed that their voices and priorities were ignored in favour of a medicalised approach. Holly detailed a medicalised precedence for seeking quick solutions and indicated that in Sohail's case the family were described as being in denial of the truth, rather than following their faith and family belief systems. Holly went on to mention the need in palliative care, for gradual and incremental difficult conversations over time and within trusting relationships, to ensure families are ready to discuss complicated aspects such as prognosis:

"It's important that we recognise that eventually, the family will get to the place that's needed, but we need to be patient and that's what's difficult to share with the clinical team I think, particularly with the nursing team who are seeing him every day, because they want it to be acknowledged straight away, they want to be able to have those conversations … the Advance Care Plan's (ACPs) are lovely and they're fantastic, but often as soon as the word palliative is mentioned, they want the ACPs signed, within a day and in place straight away and actually ... that's not appropriate, because ... you have to do these things in a timely way" (Holly. HCP Nurse 9.38)

The parent champion who wrote about Family Tessa's experience in his poem 'Patience Patients' (Appendix 30), detailed the two perspectives of this incident, both nurse and family. By doing so he showed the opposing priorities and difficulties encountered. He highlighted the busy shift of the hospital nurse and the obstacles in her understanding through an inability to relate to the family's lifeworld. In contrast he describes Family Tessa's simple desire for a humane and holistic approach to care:

'Because no one seems to care …
To see the person inside the patient,
The one who needs the human touch
The presence of kindness …
To treat not just my body, but my soul'

When I discussed the inclusion of treating the soul here, the parent champion felt the HCPs in this encounter were seeing care on a very superficial surface level – 'checking the meds (medication) and the sats (oxygen saturations)', rather than on a human, individual level, which the family desired. The comparison of these two aspects of care, made me reflect further and highlighted the need for HCPs to take time (and patience) to understand the human in front of them rather than the task they represent.

8:5:7 Gentle Conversations

When considering difficult aspects of palliative care, Rida mentioned the need for 'gentle conversations' and being led by family members rather than pushing an agenda:

> *"I probably didn't go into that conversation immediately I never, ever want to seem like I'm pushy and I never want to feel, make allow people start feeling that they've got to think about something that they might not want to, or something that really throws things for them and causes some kind of trauma, you know and so I, I, I just wanted to be able to allow her to discover that that might not be the only way, so whether it was on that occasion or not, so everything is always played by ear, certainly with me anyway" (Rida. HCP Muslim Chaplain 23.63/4)*

Holly also acknowledged the need for prior family involvement and consensus, particularly regarding agreement in sensitive or challenging topics:

> *"I understand Dr Jones in his need to be honest with the teenagers, but I don't share his belief that you do it as soon as the question is asked. I think ... you need to deflect that question back ... So, I will say if someone asks that outright question, turn it back on them if you don't know. If you haven't already had that conversation away from the bedside with family, to get to a level of understanding where you know what your response will be if that question is asked, but more importantly they know what your response is going to be if that question is asked unexpectedly, when you're in the room and they're in the room, or if the question is asked when they're not in the room, we still absolutely owe it to our families to report in to them first and to check in with them and to share potential conversations before they happen, to give them the ownership of how those conversations may go" (Holly. HCP Nurse 24/5.102)*

8:5:8 Truth telling and hope

The narrative of telling the truth to Sohail continued throughout the family interview, as Maaz told me of a nurse who gave Sohail pain relief whilst he was playing his PlayStation in the week before his death. Maaz described how the nurse was very

graphic in her descriptions surrounding death and even used Google Images to aid her descriptions of coffins and graves for Sohail and his mother:

> *"So, he asked her how long I have to use this device (morphine syringe driver)? She said forever. He said what do you mean forever? She said because you will er will die after a week. He was playing and his mind with a game didn't like this, what you are saying? She said tell me in your religion what do they do with the bodies? She said. He said uh I think it is shocking, she told him in my religion as a Christian we put them/bodies in boxes and she started to open her mobile and she Googled and showed him some boxes and graves and a graveyard like this so this is, it was very, very difficult situation we meet at that time. Sohail very brave and positive and we found him like collapsed" (Maaz. Father 5/6.16)*

> *"How you show the boy, a child, a grave and the box and like this and tell him its a few days and bye like this? Sohail just start crying and held his mum's hand over the night, over the night, Kinza told me over the night he held my hand and don't, he was very frightened. So, when I meet him in the morning, the next day he hugged me, dad, crying, crying, he didn't want to let me go out. Very scared" (Maaz. Father 6.17)*

Whilst a transparent approach is intended to follow current guidelines on End-of-Life (EOL) care, for being open and honest, it was contrary to the family's desire for Sohail. After Sohail became distressed, the family asked Holly to visit to try to calm him down and reassure him. When describing the incident during her interview, she was visibly upset and disturbed by the nurse's actions and its impact upon the family:

> *"It's barbaric, you know. Absolutely (pause), disgraceful behaviour. I feel so passionately about it I think that's the kind of thing you strike someone off for ... I know you wouldn't but that's the passion it evokes in me" (Holly. HCP Nurse 24.98/100)*

> *"We should remember that everyone needs to be able to wake up every morning with some hope and go to bed every night and more importantly with dignity. They just straight away they destroyed the dignity of the family. That family was a close family, someone completely stripped them bare, of them dignified approach to Sohail's end of life, no one has the right to do that, no one. We all have the right to be honest, we all are accountable for being honest, but we can do it in a way that's kind" (Holly. HCP Nurse 26.110).*

Holly described nurses as advocates for families. Following this incident she concluded that HCPs had not understood and subsequently not protected or respected Family Tessa's beliefs. I tried to reflect the emotions Holly described to me within the poem I wrote about her 'Sit alongside, Sit beside' (Appendix 26). Within this poem I aimed to convey her anger and how she felt the family were let down, with their trust betrayed as they were 'stripped bare' in a 'callous' and 'brutal' way, which was completely unnecessary.

8:5:9 Views on Pain

Family Tessa were further misunderstood when it came to their views on pain. When discussing elements of a family video with me, in which Sohail appeared to be crying out in pain, the family explained that these videos were taken to show Sohail's faith and resilience. Family Tessa explained that Sohail's faith helped him to cope, particularly with pain and painful procedures and that he saw his pain as a test from God and that by enduring pain he would be granted reward in the afterlife:

> *"We also believe that if someone touches the rose and feels the pain this person gets the reward so when he is suffering from cancer, chemotherapy and all of this he knows that he is receiving a lot of rewards from this, so he is happy to feel the pain. Also, when the doctors say to him to take Morphine and he is feeling unwell and tired he says to us that he is feeling so much pain and he is tired but he doesn't want to take the morphine because he wants to feel the pain and get the reward, if he takes the morphine he won't feel the pain. So, he wants to feel that pain and get the reward so he was happy about this, about God's will"* (Pasban, Sibling 16 years interview 2.40:38)

Similarly, Khadija from Family Ahmed described rewards for good deeds in caring for her children accruing, to be received in the afterlife:

> *"Our God said that whenever I give you, you should be, you know, pleased with it and you should like he's gave Bibi as a as a condition that you have a condition or Bibi has a condition is always she's gonna have a good deeds because you're looking after them and you know God given her that, is that that she is she gaining rewards then from God not from people, she's doing it for her faith and for the love for her children, but is for her faith as well because that's what our you know Islam said to just take whatever is there and look positively to things" (Khadija. Mother 15.96)*

Holly appeared to be understanding and respectful towards Family Tessa, but also aware that other HCPs were often dismissive of differing beliefs and thus failed to see the important role faith planned in the family's ability to cope:

> *"When professionals just don't have that same level of belief. And ... when families say God will cure him God will cure her and they're like well ... it's not going to be ... what do we do about this and they're so dismissive, of even trying to understand and we say well this is another part of their care. We have to build this into his treatment plan, because if that's what they believe, why should we take that away from them, we just have to work alongside it" (Holly. HCP Nurse 20.80)*

For some HCPs, forced migrant families and those with different beliefs to their own, seemed to confront them and highlight the inadequacy of their strategies for example to relieve children's pain. The resultant feelings of inadequacy appeared to result in HCPs' becoming defensive, families being problematised and an increased desire to make the family fit with everyday practices. For other HCPs, such as Holly, the divergence of belief systems led her to consider the individual needs of the family and offer bespoke care.

HCPs perhaps underestimated the difficulty Family Tessa experienced in making decisions for their son and the depth of love and pride they had in their son. The family created a video and poem which they shared with me. Pasban elaborated on why the poem was created:

> *"Because when he (Sohail) was suffering he also said that he wanted, he said that when he recovers he wants people to know his story and so he wants the poetry but different to this so like a good poetry that he recovered so he was suffering at the start and then he got recovered so like a poetry for this. But then he passed away so we couldn't do this as he wanted but then we made one as he passed away"* (Pasban Sibling 16 years Interview 2. 09:42) and Maaz concluded that it was written with *"words coming from mine and my wife's hearts"* (Interview 2.16.20)

The poem written for Sohail was particularly important to the family, as they hoped it might help to educate others and so they were keen to get the poem translated from Arabic into English to enable me to understand it fully. They had the poem translated three times before they felt happy with the translation and shared these with me (Appendix 17). Within the poems, the depths and the importance of the family's faith, was demonstrated not only within the descriptions given but also within the content. Of the three poem interpretations, content relating to faith was 70%, 80% and 80% retrospectively for each poem (see highlighted sections in Appendix 17). Exchanges surrounding the interpretation of this poem are further detailed in the Silences Dialogue chapter.

8:5:10 Faith and coping strategies

All three families interviewed mentioned their faith and how it helped them to cope with the palliative care needs of their children:

> *"God will help her, because as soon as she got married and you have a husband and kids, that's it. You know your life is your children, you know and God will always be with you if you be good with your children and look after them" (Khadija. Mother 13.88)*

The parent champion who wrote about Family Ahmed's experiences in his poem 'The leaver' (Appendix 28), drew attention to the family's faith and recognised that trusting in the goodness of God was important to restore balance, compensate migration trauma and give them hope for the future:

'In the name of God
The most gracious, the most merciful
In God you trust'

In the case of Family Tessa, some of the HCPs involved in Sohail's care saw the family's faith as a challenge and at times in opposition to western medicine. Interestingly when discussing the family's beliefs with them, it was clear they felt it incredibly important to be honest and open with their children about death. Both siblings were with their brother in his final moments and were involved in his funeral. The family talked openly about Sohail in their daily lives following his death:

> *"We talk about him every time, every hour in our life in our house, yes every time we talk about him" (Maaz. Father interview 2.17:44)*

During both interviews with Family Tessa, they showed me images of Sohail post-death. Firstly, a photo from Sohail's father of Sohail in interview one and in the

second interview, pictures and a short extract of video of Sohail. These images when described by the family, related to their love for him, but also his and their faith:

> *"This is Sohail we put blurring on his body because before washing his body is covered by white sheet, because it's not good to, because some people feel scared by the dead body but the photo of his face smiling it was good" (Maaz. Father Interview 2.51:11)*

Pasban, Sohail's 16-year-old sibling, was keen to explain the care of his brother after his death to me alongside his father. Pasban was knowledgeable and without fear when discussing such graphic elements of death:

> *"In our religion we believe that if there is a good picture like this, if there is a smile, it's like a sign of this person going to heaven, but if the face was scary and not really beautiful they prefer not to take pictures or show it to other people"(Pasban, Sibling 16 years) "because we believe that when anyone dies he saw angels and the place he would reside in the next life, so you can notice maybe some people you can notice that they are happy and others no, angry or scared or like this because at this moment they see where they have arrived in the next life" (Maaz. Father Interview 2.30:53)*

> *"I think if people know when they are young that there is death and their parents talk about death with them then they are going to understand it more and when they get older they aren't scared that much of death. Life is part of death, everyone in this life will taste death. I remember my parents saying to me and S and my younger brother when we were young that a strong believer will not fear death only the weak believers so that will give us strength and we know that we will all taste death so we are not scared of it"* (Pasban, Sibling 16 years interview 2.1:13:49)

In the HCPs' pursuit of truth, it seems that they missed seeing the individualised way that Family Tessa wanted to deal with their child's death. Consequently, the family were left with traumatic experiences, which they are still struggling to deal with years following their son's death.

Holly summarised the trauma the family had been through, as she shared with me the differences that forced migrants may experience in palliative care. She explained how HCPs' need to be aware of forced migrants' social isolation and the challenges they have in sharing their religious beliefs. She also described the consequences of forcing western ideals of facing death, highlighting that HCPs' have one chance to get end of life care right and that the decisions which are made, can have negative consequences for families:

> *"They are already isolated from sharing much of what's happening to them as a family … like Sohail's family gosh, it's just ... like another layer of tragedy on that family" (Holly. HCP Nurse 18.69)*

> *It's absolutely unforgivable because ... they will die with that vivid thing in their heads wont they, that will never ever go away, that will never be less blurred, it will never be less painful to remember" (Holly. HCP Nurse 30.130).*

8:5:11 Search for normality

Both siblings from Family Tessa described the hospital environment as one that evoked mixed emotions. Pasban described hopelessness at not being able to help Sohail with his treatment, but relief in a sense of normality brought about by being able to play with Sohail at the hospital. When describing his drawing (Figure 17) Pasban told me:

"This is my brother and this is like me, I am looking kind of sad because I see my brother lying on the bed, I can't do anything and then we feel happy when we play together like we do games in the TCT (Teenage Cancer Trust) room" (Pasban. Sibling 16 years 21.68)

The need for normality, stability, security, respite, social support and integration may be particularly important for forced migrant children as these may have been lost or weakened during their migration journey or as they settle into life in the UK.

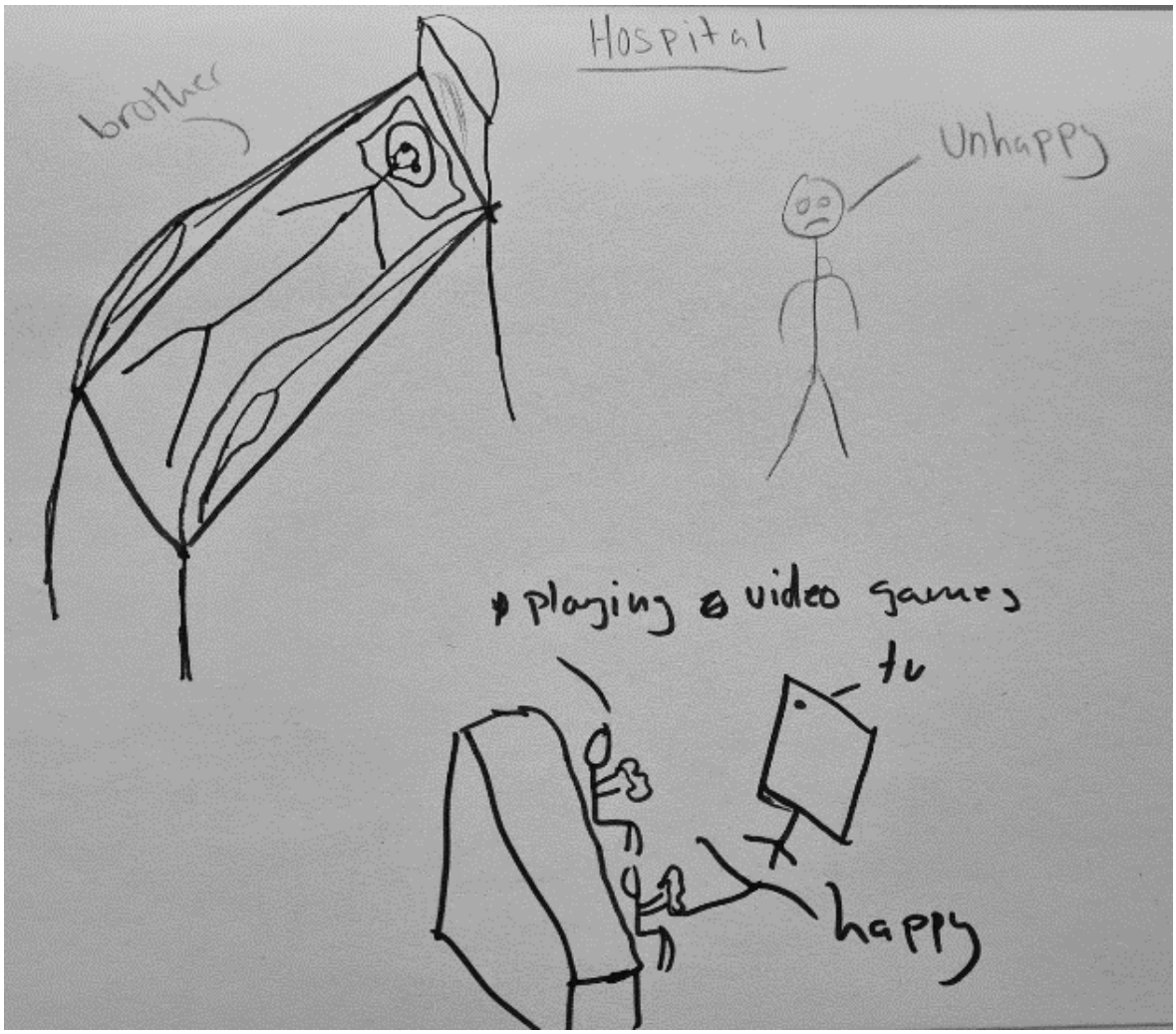


Figure 17 - Pasban's drawing of Sohail and him in hospital

For both siblings the hospital bed was pivotal and restrictive in terms of access to their brother (Figures 17 and 18 detail these aspects).

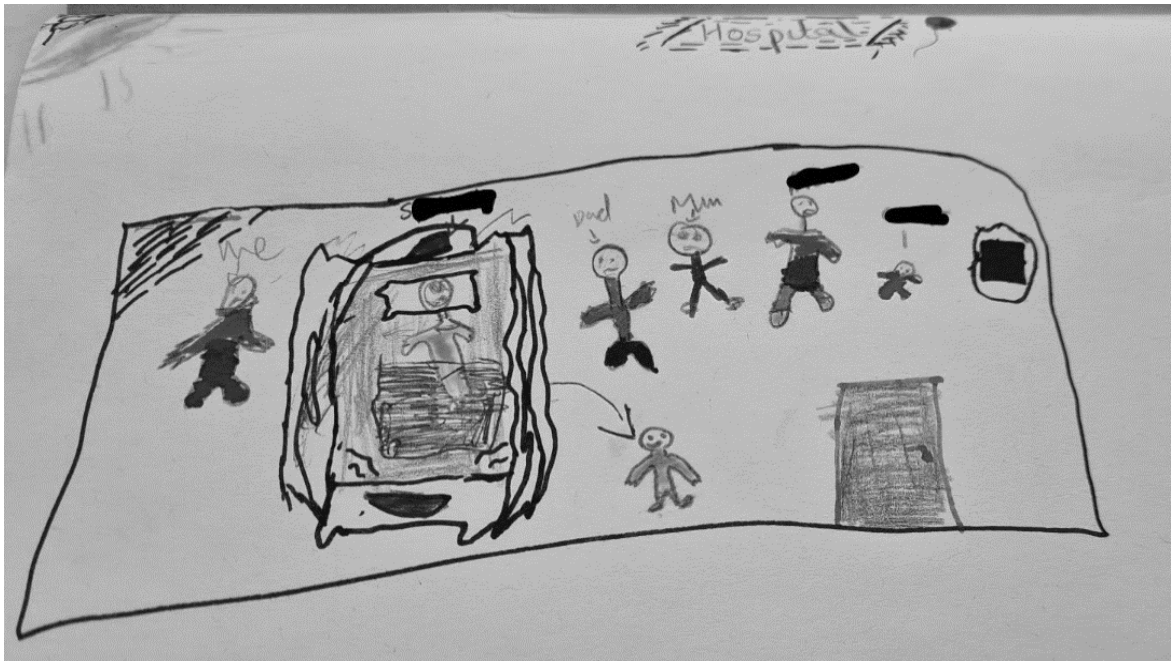


Figure 18 Drawing by Peroz of Sohail (in yellow) in the hospital bed and then walking out of the hospital.

Although family Tessa described a lack of understanding about their religious needs and difficulties in meeting those needs in the hospital, they did recount an example of good practice in which they were able to break their fast in a special palliative care facility and how this created some normality which was helpful to them:

> *"Also they, we thank them, they provide (special facility for palliative and bereavement care at the hospital) yes, sometimes we are sitting with Sohail to like, change the environment, there was Ramadan, our fasting month, we are Muslim fasting from morning to sunset so we were sitting (in special facility) with Sohail and having our breakfast, yeah so it was good to change the environment and atmosphere like out of hospital. Yes, out of the hospital, so it was helpful" (Maaz. Father 9.29)*

A further element, which offered some normality for the family, was when Sohail was briefly able to return to school. However, the limitations inflicted by his cancer and changes to his appearance and abilities were described as heart breaking by Maaz

and Pasban. Pasban described the joy of having his brother at school with him and as they played with friends and the joy at being able to help Sohail by pushing his wheelchair. However, Pasban also acknowledged the difficulties and sadness in realising that Sohail could not join in with a game of football and the embarrassment and shame Sohail felt when his bald head was laughed at by one of his peers:

> *"My brother felt happy sometimes at school because school was like a joyous thing for him, because when he was like making relationships more than studying, he was like meeting friends and talking to friends, so I was feeling like heartbroken at times when I see my brother on the wheelchair, he looks at people playing football, he wishes to play with them but he can't ... and here so like when we are as a family he feels happy and positive, yes and when he talks to friends in school or at the park he also feels happy playing with them. Here I talk about you know chemotherapy side effects, mmm, the loss of hair, some people sometimes laugh at him. I always remember a story, somebody in year 11, he was in year 9, he took his hat off and he started laughing because he doesn't have any hair, this time he was so sad and I was also angry and sad to see this. (The boy responsible) got in trouble but like my brother still remembered this and he talks to us about this, he doesn't like, it's in his memory and he keeps sad he says because people don't like him, so after what happened here and he feels embarrassed because everybody looked at him in the class and that is embarrassing"* (Pasban Sibling 16 years 22.69)

The conflicting elements of joy and sadness are further detailed in Pasban's drawing in which elements of normality brought joy for him and his brother but also in which elements of Sohail's cancer diagnosis brought sadness to them both (Figure 19)

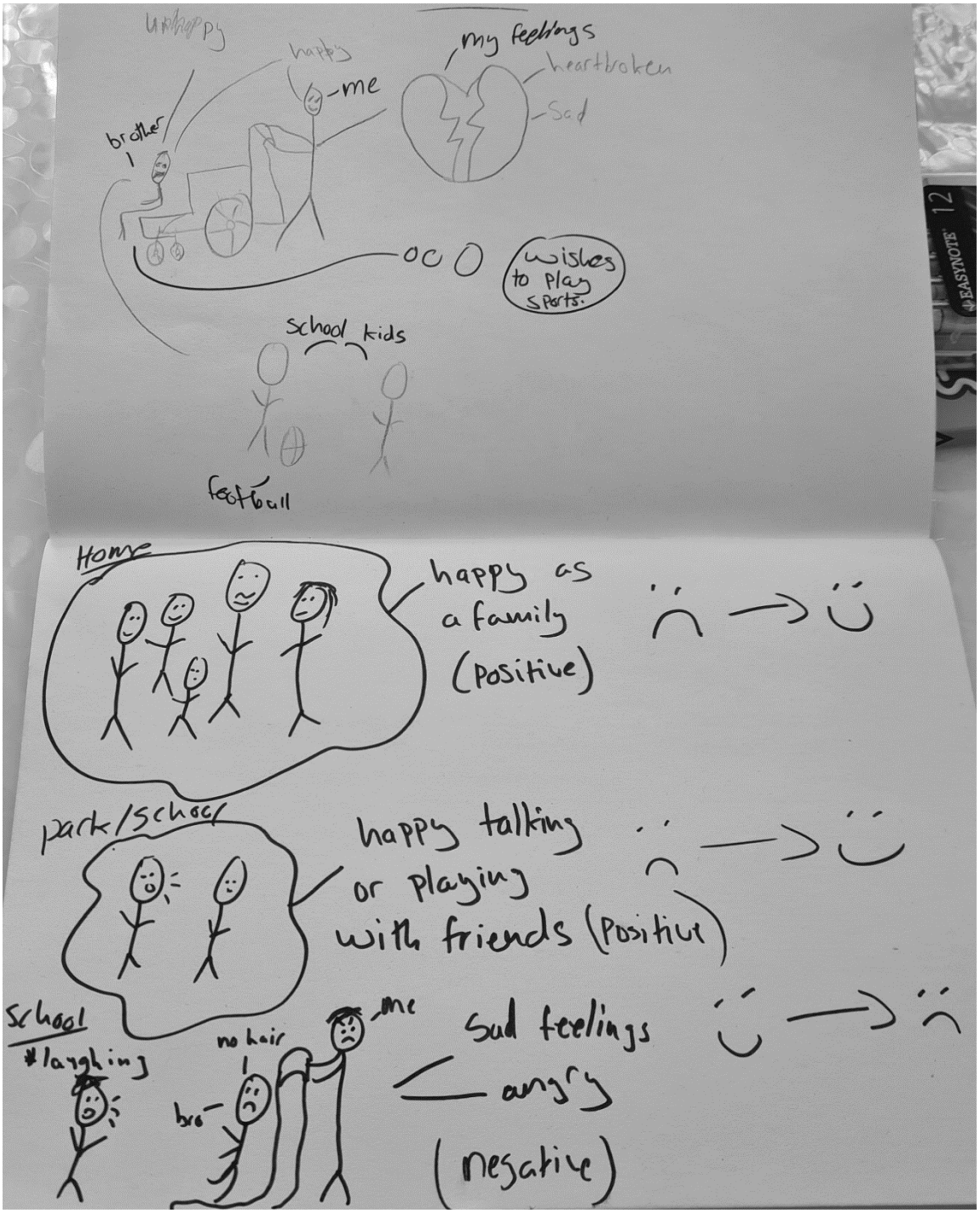


Figure 19 Pasban's drawing displaying positive and negative aspects of his experience

8:6 Combined across settings findings

Some of the themes described by participants crossed settings or were not setting specific and so they have been outlined separately here, as shown in Figure 20.

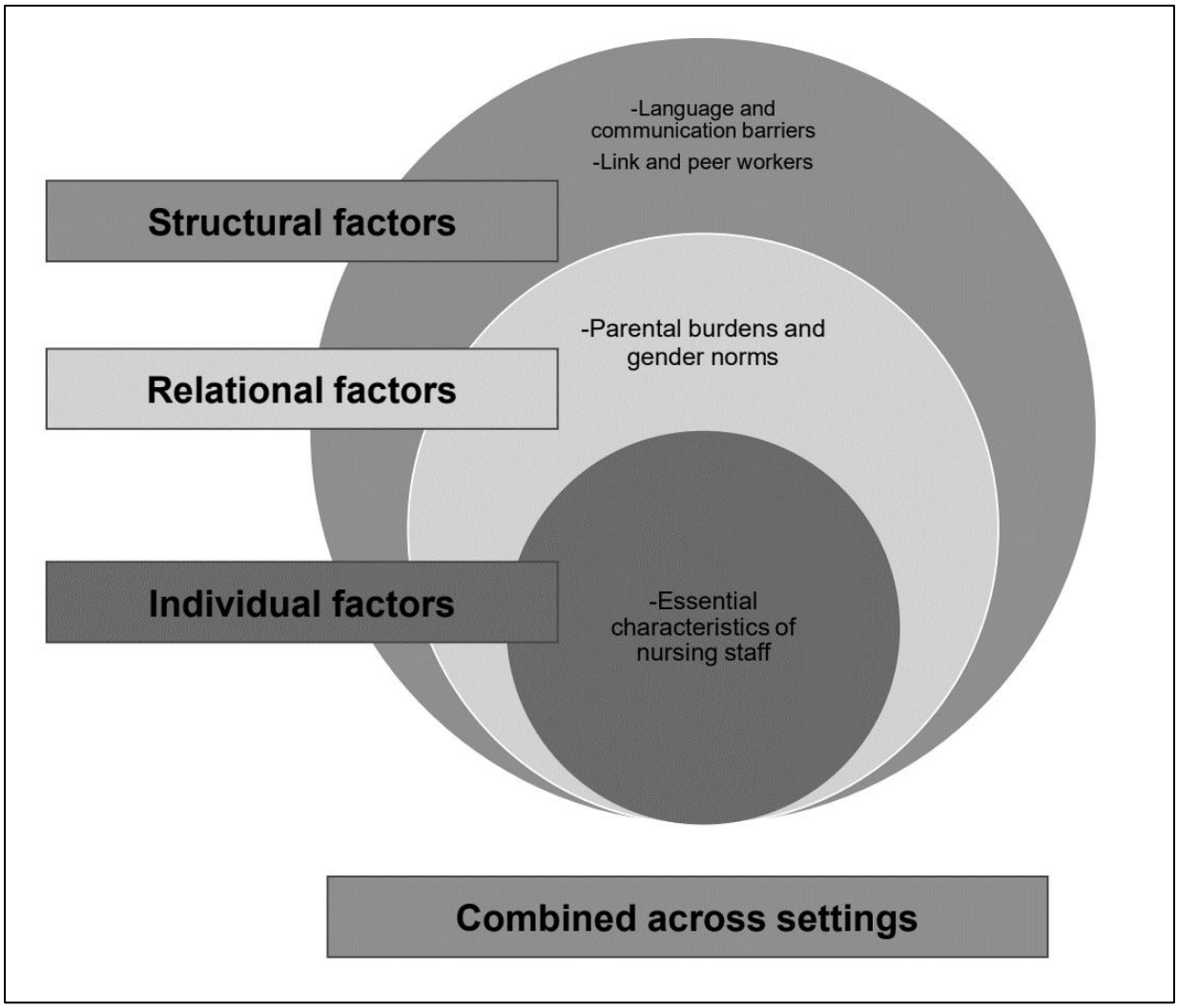


Figure 20 - The differing factors which were combined across settings

8:6:1 Parental burdens and gender norms

All the parents in this study encountered many burdens, both physical and emotional due to their child's palliative care needs. Fear was a strong aspect, which dominated the parents accounts of family life. Adiva described a fear of her son becoming acutely ill with an infection, this fear was obviously exacerbated during the pandemic. For most parents, childhood illness elicit feelings of fear, but for parents with children with LLC, this fear may relate to the child's clinical vulnerabilities and knowledge that even a simple illness could have devastating effects for a child who has a complex multi-system condition. Fear of worsening a child's condition or hastening their death also appeared to limit family's abilities to lead a normal life and often led to them reducing any activities which could bring additional risks for the child:

> *"She said even originally when he used to go to school in the week he'd catch something and he'd get ill for a while, so she doesn't want to take the risk" (Adiva. Mother 9/10.81)*

Parents appeared to be 'on watch' and hypervigilant to the needs of their child/children all the time, with constant worries for their child and little rest or time off. For forced migrant families their fear was worsened by a lack of social support, with caregiving seeming continuous and relentless. For Adiva, the exhaustion, uncertainty of her child's condition and constant worry, led to depression which Sobia described as an inevitability given Adiva's circumstances. Flo also acknowledged the physical stresses of caring for a disabled child, by describing the physical and psychological toll on Khadija of caring for her growing children without the support of her extended family:

> *“At the moment their adaptation is still in its process, so they have to carry Bibi and Begum up and down the stairs, which can be a lot for mum, so that's Dad's role. Urm and usually when mums really exhausted, he takes on that, that role in supporting her with the children” (Flo. HCP Social Worker 11.32)*

The difficulties and uncertainties parents faced in caring for a child with complex needs was also acknowledged. For forced migrant families this may be compounded by language difficulties in understanding children’s symptoms, diagnosis, or deterioration. For two families the arduous journey to the UK was undertaken to seek a cure for their child, but ultimately this was not a possibility. A lack of understanding of their children’s diagnosis prior to coming to the UK was evident. As such the realisation of both families that a cure was not possible may have led to further anger, frustration and despair:

> *“They thought they were going to come here and they were going to make their son better” (Sobia. HCP Social Worker 15.41/2)*

> *“The reason why they came to this country is for her daughter to have the care to be, you know, to get cure to know that her in as she know about it before she doesn't know clearly know anything about her, her condition. Now she understand it” (Khadija. Mother 13.84).*

For Adiva, the parental burdens she experienced were worsened by gender roles which placed her as the sole care giver for her children and her husband as the bread winner. Having to care for her son on her own increased her isolation and the physical stresses upon her body such as back pain and a lack of sleep. Adiva discussed the expectations and misconceptions of the nursing staff that her son’s care would be shared between her and her husband:

"When he had his gastrostomy I think he had his (nasogastric) tube first, they trained both of us, you know and he passed it, but up to this day he's never done it, I'm the only one who actually does it. And the other thing is she goes the second time when he went for his teeth and we were in the hospital, first time I didn't know anything, but the 2 times after when he's gone and the nurses would actually fill up a syringe of his medicine and they'd leave it there for me to actually give it to him. So, they were expecting him there as well, you know you're the mum you will give it" (Adiva. Mother 17.130)

Gender roles within some traditional Asian families were also discussed by Sobia and Rida from their own perspectives. For these HCPs, their own experiences of inequality affected their self-esteem and vocational opportunities, as well as negatively impacting upon how others in their communities viewed them:

"I'm from a typical Asian family where my parents didn't think girls should study" (Sobia. HCP Social Worker 1.2)

"In my community where women were being, we're second class citizens in many cases" (Rida. HCP Muslim Chaplain 15.43)

Clara acknowledged the role of gender in terms of education and a questioning mindset and saw what Adiva described as the differences between her and her husbands' roles in the home, as distinctly different to her own upbringing, which increased Clara's frustration:

"I don't think she'd be fussed about learning better English or because she just sees her role in the house, yeah, no more, no less. So as long as I do what's expected of me, then that's, then that's it, isn't it? Which is but again, I that's not how I see the world and that's not how I was grown. So, it's a, yeah, I think culture is a massive part to play in it" (Clara. HCP Pastoral Worker 14.43/44).

Rida described how her own perspective and background enabled her to become a bridge to those of similar ethnicity and background (as shown in her drawing - Figure 21, which was done following the quote below). Whilst Rida was connected to the British community, having arrived in the UK as a toddler, she also understood the Asian communities' values and beliefs and had additional language skills to help others:

> *"They saw me as a religious figure who was very connected with the British Community that they were living in. So, in a way, it was a kind of a bridge, yes and people put their trust in me to help guide them in the British context, yet still also within their own cultural context and certainly within their religious context" (Rida. HCP Muslim Chaplain 4.13)*

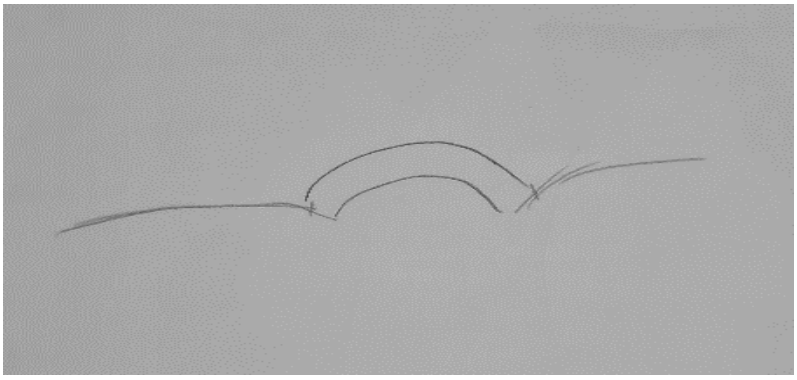


Figure 21 Rida's drawing of herself as a bridge

Sobia, described a kinship with Adiva as she saw similarities in their backgrounds, particularly surrounding the role of men. Conversely, she also described her own experience of having counselling with a white person who did not understand her perspective (or culture) well at all:

"I've actually been to counselling myself years ago and being counselled by a white person, they don't really get the ins and outs of how my family works or how my culture works and how I can't do that, you know so absolutely, absolutely, you know, you really have to know the ins and outs" (Sobia. HCP Social Worker 19/20.54)

"I completely understand where she's coming from because my family, my culture is exactly the same" (Sobia. HCP Social Worker 19.52)

Sobia linked the 'mutual' understanding she and Adiva had to an enhanced ability to build rapport and understanding. Sobia's desire to help families and take the time to get to know them and their needs was clear in her interview account. When the Guardian advisory group member created Sobia's poem 'Perseverance' (Appendix 24), she told me she wanted to stress Sobia's compassion and empathy. The Guardian member told me she found wisdom within Sobia's transcript and that she wanted to convey the commitment she saw in Sobia, over her 17 years of working in hospice social work. The title of the poem 'perseverance' aimed to give further prominence to Sobia's tenacity and determination, despite and perhaps because of her own adversity.

8:6:2 Link and Peer Workers

Rida's personal knowledge and experience of migration helped her to explain often confusing aspects of British healthcare to families. As such, the use of link workers was something she suggested as a way to navigate the health and social care systems and for forced migrant families to gain in their understanding and ability to understand life in the UK. One example she gave of her own chaplaincy work, was of

caring with a forced migrant family whose baby was expected to die imminently. The family had declined memory making activities such as taking handprints of the baby, in fear of creating an idol or image which was seen as unholy (Islamic Idolatry). Rida was able to explain the scriptures surrounding this and ease their concerns. Rida described the link worker role as one in which those of similar ethnicities and backgrounds could help with acculturation and with language, dialect and understanding. Clara also picked up on the challenges of fully understanding families with differing dialects and how often an assumption is made that Arabic is a universal language. She was supportive of a link worker role, having seen it work well in the special school setting and watching link workers build relationships with families more easily:

> *"In an ideal world if we had professionals in their own right in their own setting that had the language skills of that person or of that patient, wow, that's a massive thing" (Rida. HCP Muslim Chaplain 32.86)*

> *"There's lots of different dialects, yeah, so again, if you're Somali is different to if you're Bengali, because you use a different dialect. So, you can again, you can have a language, you can have a conversation in Arabic, but you couldn't pick on everything"* (Clara. HCP Pastoral Worker 10.33)

Similarly, Rebecca suggested peer support as a strategy for supporting families and the use of a hub to bring resources and families together:

> *"Family support hubs, that sort of thing, that you bring people to get there because peer support there's always an argument around peer support and actually if you put families together that feel safe together, they can help each other as well and actually you may even find that you ... especially families that have kind of come into the country in those situations, actually you may even find that you're reuniting people that are ... that have come from the same place that they didn't know" (Rebecca. HCP Nurse 38.193).*

For forced migrant families, the isolation of being separated from their extended families is often associated with feelings of grief and loss. Similarly, having a child with a life-limiting condition can result in families becoming outsiders from 'normal' healthy family interactions. The use of peer workers with similar experiences may thus be important, to share understanding and build new supportive community relationships.

8:6:3 Communication and language barriers

All participants mentioned that communication and language barriers impacted upon care. HCP participants recounted that language barriers affected their abilities to understand and be understood by forced migrant families and thus the relationships they could build, which they found frustrating and restrictive. Family participants talked about the inability to communicate with HCPs' which they said led to further feelings of diminishing confidence, alienation and separation from their care teams. Adiva described this as feeling less valued due to not speaking English:

> *"If you don't speak the language it's like you're not valued as a person" (Adiva. Mother 22.168)*
>
> *"We are new in the country so, my English is not good and I can't explain, I can't talk. She was not able to express and explain to others what she is feeling and answer to their question or queries like this"* (Family Tessa.4.10)

Hamza described the hard work required to learn English, as he discussed a two-year period of being immersed in the language, when he worked in a coffee shop before his confidence increased:

> *"He tried to learn the language you went to college to learn basic English and he started working in a coffee house. It's been two years and this was all in, you know, like all English people working there, they speak the English with us to make him confident. He learned the language making meet other people, speak to other people, which take his confidence up" (Hamza. Father 5.31)*

The difficulties in learning English were not always acknowledged by HCPs. Clara linked her own frustrations at parents not learning English to their limited education or gender restrictions, rather than acknowledging the time commitment and pragmatic challenges of learning a language. Misunderstandings relating to language differences were discussed by Flo and Rida, who realised that ensuring understanding was not as simple as having a family member nod or say yes. They referred to the importance of checking that family members had really understood what was being said:

> *"About ensuring that the communication is being understood, because sometimes when it comes to language, we use a word that we think is right, but actually means something different to others and we were always got to be aware of that" (Rida. HCP Muslim Chaplain 29.79)*

Marian outlined an example of her own role in not checking understanding and how this led to children not receiving the treatment they needed for head lice. Within this example, the parent was blamed when she had simply not understood the instructions the hospice staff had given her. From the hospice staff perspective, the

parent had nodded and smiled her agreement, but unfortunately her understanding had not been checked or confirmed by questioning her further:

> *"We've got the mom from one of the North African countries and she's got children: two children with additional needs and children had head lice … we gave treatment home to mum ... we explained everything in English but mum couldn't speak English and she was nodding and saying yes, but we didn't check her understanding and then she didn't follow that treatment plan ... then again it became a safeguarding issue. But when we actually invested the time and resources and effort and that meant the family worker, myself an interpreter we spent, we did a home visit or a few home visits...it actually transpired that she could not speak English and she didn't understand what we were saying. Urm, so we've learned from that, that always we not only do we need to have interpreter, but we also need to check that if we are communicating, we need to check the understanding. Even if the person saying yes" (Marian HCP Psychology .18.60/1)*

Whilst there was a consensus amongst participants that interpreters were needed and essential, there was also an awareness of financial, gender or dialect restrictions in gaining access to their services. The awareness that interpreters could not, but should be part of more interactions was acknowledged by HCPs and parents:

> *"Yes (they did have interpreters) and sometimes there is doctors they speak Arabic so can help but because there are so many hours, you know sometimes the consultant come in different times of the day, interpreter is difficult to bring the interpreter" (Maaz. Father 10/11)*

Interpreters were regarded as expensive and consequently, were often used sparingly; reserved for the 'important' conversations. The nature of palliative care means that many sensitive and challenging conversations are needed, such as around the use of advance care plans to ascertain needs and wishes, as end of life approaches. Such conversations are not one-off events which are limited to one

discussion, which added to the difficulties experienced. However, for parents Hamza and Khadija, their interpreter experiences within the hospice setting were described positively, as they were able to frequently have the same interpreter and build a relationship and rapport with her, which positively impacted their care experience:

> *"The interpreter, she has made a huge difference, to their lives because, it's not just that she's the interpreter, but she takes a lot of time and I think it's part of her personality to get to know the family" (Flo. HCP Social Worker 16.48).*

Whilst their experience did seem exceptional, it was perhaps one which could be used to illustrate the importance and power of consistency and relationship building with interpreters, because of the positive outcomes that a good relationship with the interpreter had for the family. Difficulties in communicating meant, for most HCP respondents, that they tried many different approaches to aid communication with families including Google Translate, Language Line and electronic mobile translator units, all of which had limitations. Marian used more creative means as she found preparing, cooking and eating one another's traditional food, a method which appeared to cross language barriers and bring together a sense of community:

> *"I found that communicating through the food just cooking together, being together, eating together, what was a great start to build that relationship with people" (Marian. HCP Psychology 5.22)*

Another element of communication outlined by Holly and Family Tessa, was the importance of non-verbal communication. Holly deliberated the significance of sitting or kneeling, the use of silences, touch and eye contact with families. Her approach was perhaps of particular importance for forced migrant families, who may not be

able to rely on language cues and so had to utilise other elements to try to fully understand what was taking place:

> *"I think if you go and stand … families are so used to people standing and not.. and engaging just very temporarily and then going. I think you have to sit down. Even if you're crouching down, so you're all at the same level. The minute you go down to their level, they know that you're not going to walk away. So, I think that's probably quite an important element. and you're all at the same eye level and you're not standing above them. And straight away they know that you're not ... you're there ... you've got that eye contact, that you're not going to prescribe by standing over them, or walk away, or just hear what it is the question that you're asking, you're actually investing in them because you've ... you've put yourself in an uncomfortable position, because the minute you sit, you are saying I'm going to be here for a little while longer than people that stand. And that's a big ... that takes a lot of courage"* (Holly. HCP Nurse 16.62/3)

Family Tessa also acknowledged the importance of non-verbal communication, as Kinza described reading other's eyes and body language and the inactivity of hospital stays which afforded long periods of time watching staff and gauging their responses:

> *"I know I can't, speak English but I can read the body language, I can read from your eyes how can, you think about me. I know I can't speak English, I can't understand English but I understand body language and er ... if somebody weaken you or hate you*" *(Kinza. Mother 13.39/40)*

> *"We living with them for a long time so you can watch and see" (Maaz. Father 10.32)*

8:6:4 Essential nursing characteristics

All the family participants outlined the characteristics they thought nurses needed to possess when caring for families with palliative care needs. For Family Tessa, kindness was extremely important. They discussed examples of this in the care they received and described nurses as needing to have a *'gold heart'* and be *'mercy angels',* to deal with both the difficulties of the job but also the sensitivity in caring for the human hearts of their patients.

Both siblings from family Tessa mentioned the need for nurses to be kind and have understanding, particularly towards others' beliefs. Pasban was also keen to say that these aspects were more important than any grades:

> *"I would like to say like grades, GCSE grades, A levels, it doesn't matter. It doesn't mean that this thing or these people, this person can be a doctor or a nurse. I say that beliefs, like understanding beliefs, behaviour, attitudes, is important for someone to be a doctor or a nurse, because if they treat patients in a bad way then the patients will be feeling sad and this will like affect the patient. Yes, that's what I would like to say" (Pasban. Sibling 16 years 22.70)*

> *"So kind, so the nurses to be like kind, so not always like strict and like mean, so they like treat others nicely" (Peroz. Sibling 16 years 2.71)*

Similarly, Adiva and Khadija described a 'heart for nursing' likening it to a vocation, rather than something that is done for the money:

> *"The nurses that have come to look after children they do it with their heart, they don't do it because they get paid lots of money" (Adiva. Mother 14.114)*

"She want to carer who loves caring for children with … condition is she's not her job to doing it just for sake because she's working. She had to do it with her heart, be kind to … and be a be truthful and no cross words" (Khadija. Mother 16.99)

Despite all the family participants experiencing elements of poor care, they remained understanding of the individual differences in practice among nurses. Whilst not quick to label the nursing staff who had cared for them, parents also requested non-judgemental attitudes and appealed for more empathy, humanity and understanding from nurses:

"Everybody isn't going to be the same, some people are going to be good, some aren't going to be good. So, you treat people as they come across to you, rather than painting them with the same brush, or the label, that they're all immigrants and they're all going to be like this and this is how we're going to treat them" (Adiva. Mother 24.185)

"You can find good nurses and bad nurses, I mean there is behaviour as a nurse and so I hope to find an improvement and nurses to be aware of the pain in in patient's hearts and family's hearts, I wish to find without any discrimination because we are all human and the illness and, in this kind of disease can come to any one of us" (Maaz. Father 11/12.35)

When exploring the career choices of the HCP participants, many explained their desire to help others, to make a difference in families' lives and the experience of being drawn into their profession vocationally:

"It sounds really cliched but just try make it make a difference and make an impact" (Clara. HCP Pastoral Worker 3.8)

"When you get it right, it's beautiful, it's lovely and it gives you a sense of being and knowing that you're in the right place and you're in the right role" (Holly. HCP Nurse 11.45)

"So, when I'm asked, how I came into this job? Or how did I find the job? My answer is usually that I think the job found me" (Rida. HCP Muslim Chaplain 3.9)

For HCP participant Clara whilst being asked about herself and her career she drew a circular purple face with long curly hair (Figure 22). I asked why these choices were made in her artwork and she told me how much she liked purple and associated it with happiness. Her desire to be cheerful and help others was perhaps at first overlooked by me as a 'normal' sentiment expressed by many people working in caring roles. However the YPAG advisory group member who created Clara's poem 'Just trying to make a difference' (Appendix 25) emphasised to me how much meaning she felt was attached to Clara's explanations of purpose within her role. She told me that she felt all of Clara's actions seemed to be centred around this desire to 'make a difference' and that those elements of moral desire and intention to do 'good' should be celebrated. These interpretations were helpful as my own role and years of experience in nursing had perhaps meant I did not see the level of emphasis from Clara in the same way the YPAG member did. These interpretations were further echoed as following her reflections I went back to the HCPs accounts and saw that each of them shared a desire to have a fulfilling career with the potential to change children and families lives for the better. Whilst this desire was almost tangible, many HCPs went on to tell me how structural and organisation factors had quickly blunted their desires, particularly as the realities of working in the sector took hold:

"The job was very, very demanding, I felt like it was a conveyor belt system" (Flo, HCP Social Worker 1:2)

> *"I kind of thought I'd be Mary Poppins and change the world. When I first started and the social work degree and then very quickly realised about the system and how it works"* (Flo, HCP Social Worker 4:13)

> *"You come out of social work, your heads are full, you know you're going to change the world and before you know it, you're actually an organization that, you know what there's actually, you know, slammed doors and really small corridors that you can go on and you know it's all about the money, money, money and you know actually kind of squeezes you I think as a person and as a professional, quite quickly"* (Sobia, HCP Social Worker 5:14)

The additional interpretations which came from advisory group/poetic creation were beneficial to my analysis as I was able to further draw out my understanding. The details HCPs gave of motivations at the start of a career and then when working within healthcare over time, highlighted to me that this may have led to cynicism and feelings of powerlessness or helplessness in achieving the initial personal goals they had set. Such elements may also link to the aspects of compassion fatigue and burnout, previously discussed. Further elements of HCP participants sense of self can be seen in the drawings of participants displayed in Figure 22.

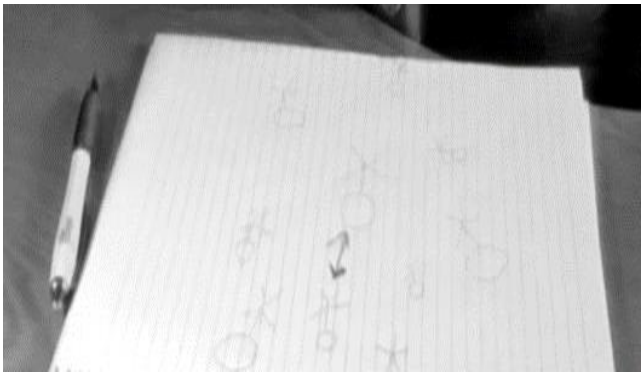


"I like, purple, yeah, I would like to think that I'm a happy, happy girl" (Clara. HCP Pastoral Worker 5.14)

"I do it with a smile I try, yeah, I just think I just want better for people"(Clara. HCP Pastoral Worker 23.71)



"I have that fulfilment, definitely I feel it's my purpose and I think because I am very spiritual, I feel this is my purpose right now, so yes, definitely feel fulfilled in what I do" (Flo. HCP Social Worker 5.17)



"Draw different people around me and some of these people are sort of small, like some of bigger, um, just to sort of represent that the different people in the sense of children as well as adults that, that we work with" (Marian. HCP Psychology 1.6)

Figure 22 HCP's drawings which illustrate sense of self in their caring roles

8:7 Summary of findings

In conclusion, the key findings reported in this chapter relate directly to research questions one and two, question three will be addressed further in the Silences Dialogue chapter. When considering the factors that optimised care for forced migrant families and children, the importance of family centred care and caring concern for all the family was important. Families valued those who went the extra mile and tried to understand their beliefs and values. The building of relationships over a longer period, without focussing too heavily on protocols or documentation was discussed in terms of the differences between hospital and hospice. This linked with the need for additional time to be spent with families to understand their unique experiences and needs. Further to this, was the use of non-verbal communication, a compassionate, kind approach and ensuring that particularly sensitive conversations were both timely and negotiated with families. In order to cope with living with life limiting conditions, many families relied upon their faith yet the value of faith was frequently underestimated by HCPs'. For the siblings interviewed, the importance of normality in terms of their home and school life was described with links to the need for stability, security and respite.

Elements that appeared to hinder interactions were often structural in terms of parents not understanding their rights, or being unable to access resources, including inappropriate accommodation. Consistently for families and HCPs, issues with communication and language barriers were significant. The problems associated with limited interactions and increased the possibility of misinterpretations, labelling and judgements upon parents. For parents, the burdens experienced in caring for their children, were compounded by their migration status,

the uncertainty and anxiety of palliative care conditions, isolation and a lack of social support. Alienation and discriminatory incidents were also described by participants. Difficulties in coordinating care in the community and differing expectations were discussed by HCPs.

The use of link and peer workers to help address some of the challenges described, was suggested in addition to a central migrant hub to provide up to date information. HCPs voiced their passion and motivation for their roles, but that the reality and daily trials encountered in palliative care, affected them negatively and led to expressions of burnout and compassion fatigue.

This study highlights the difficulties in provision of children's palliative care generally, but with a specific emphasis on the needs of forced migrant families. For such families, previous trauma, negative experiences of migration and isolating circumstances when living in the UK, need to be acknowledged and addressed by individual HCPs and organisations to improve the quality of care provided.

Chapter Nine – Silences Dialogue

9:0 Introduction

Throughout this study the inclusion of advisory group expertise has been a vital source of insight, which has enhanced my understanding and perspective. Whilst advisory group inclusion was crucial during analysis stages, I felt their experience and insights were valuable to me throughout my doctoral studies and so I aimed to include them throughout my research process, wherever possible. My study utilised advisory groups which were already in existence and covered many different elements of expertise due to the multifaceted nature of the topic area. By becoming an agenda item within such specialist groups meetings, I felt the power imbalances and undervaluing of PPI expertise often voiced as limitations to PPI (Brett et al, 2014), were reduced. Advisory group chairs led all the meetings that I attended and so they could direct my involvement, time and link appropriate members of the group to different aspects of expertise required.

The incremental and meaningful nature of advisory group input and the building of rapport and relationship which ensued is detailed in Figure 23.

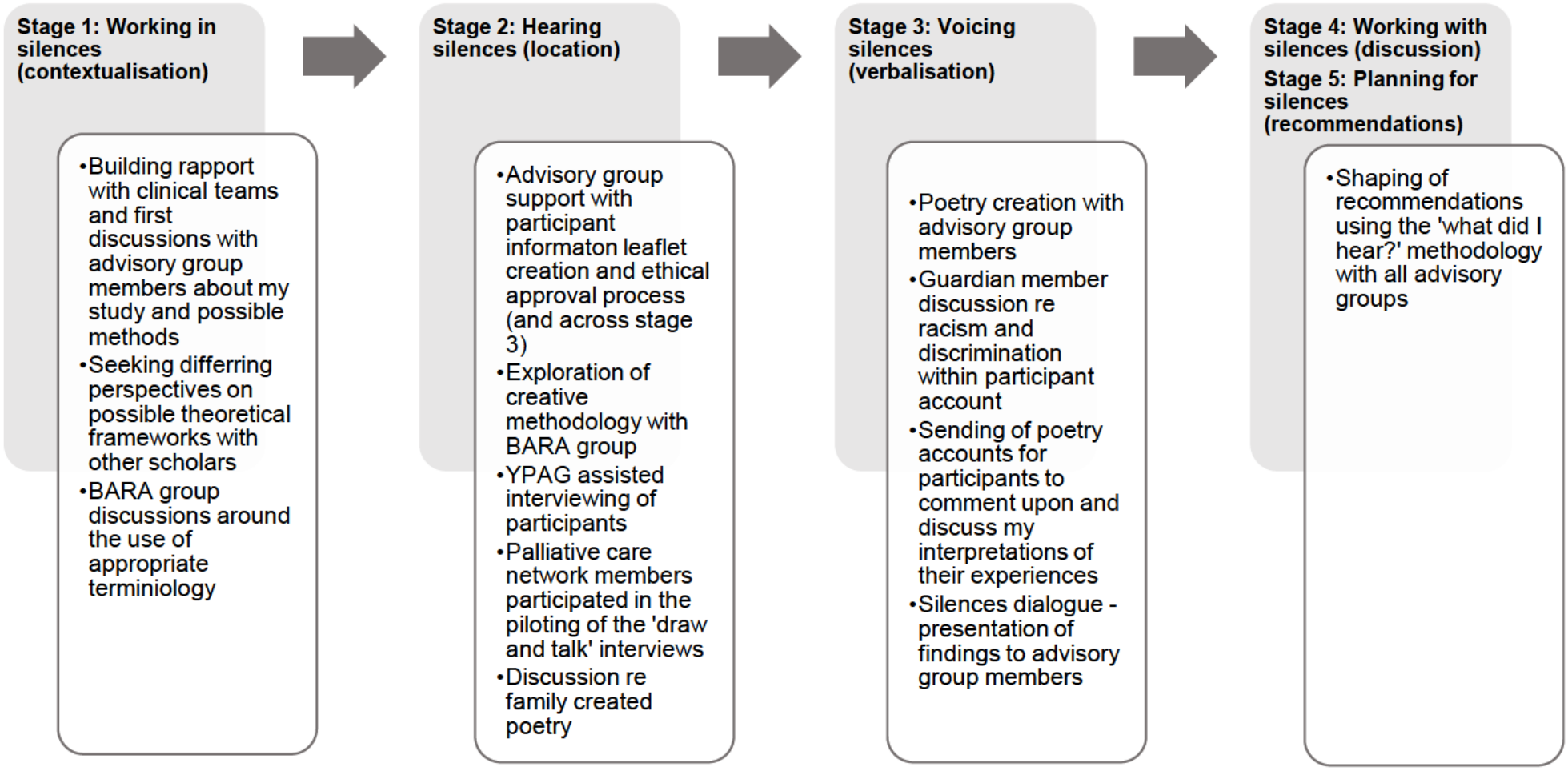


Figure 23 – Timeline to show regular input of advisory groups throughout the study

In order to gain the full benefits of the suggested approaches in the Silences Framework after initial analysis, draft findings were reviewed with the collective voices of this study to include a more detailed level of analysis and insight, as advocated by Serrant-Green (2011). The Silences Dialogue is subsequently an important element herein and particularly to the analysis phases. The Silences Dialogue allows for additional space and time, to be dedicated to reflection. The prioritisation of such dialogue, has thus allowed me to ratify, question, challenge and contextualise my findings with the collective voices of the study; my advisory groups, and participants. Even though the term 'Silences Dialogue' is an oxymoron, this section aims to illuminate how the analysis of the participants' accounts have benefitted and at times changed, as a result of further engagement with the collective voices of the study. Furthermore, this section explores additional reflections based upon research question two; 'how can the voices of forced migrant children and their families be best reflected or represented in research concerning their experiences?'

9:1 Collective Voices Poetry Creation

The use of creative methods in this study had several benefits. One unanticipated benefit was the additional discussions, which took place with advisory group members, during the creation of poetry from participants' accounts. A full list of the poems created by advisory group members and myself, is detailed in Table 13 and within performances seen by authors in the website created for this study (this can be accessed using the QR code). Images from the website displayed in Figure 24.



Figure 24- Images from the website

A poem was not created for Rebecca because of the discriminatory nature of some of the views she expressed.

Table 13 – Poetry created from participants accounts

Participant	Poem title	Created by	Found in Appendix
Marian	Learning to and fro	YPAG members	22
Flo	Exhausted but fighting on	Marie	23
Sobia	Perseverance	Guardians member	24
Clara	Just trying to make a difference	YPAG member	25
Rida	A Muslim Chaplaincy	Guardians member	11
Holly	Sit alongside, sit beside	Marie	26
Family Ahmed	New Lives, New Hope	Parent champion	10
	We arrived		27
	The leaver		28
Family Khatri	I am here, I am lost	Parent champion	29
Family Tessa	Patience, patients	Parent champion	30
	The End's Fragrance	Family Tessa	17
Summary of accounts	A kenning poem including perspectives of nurse, refugee and the structural assailant	Marie	31
	Imaginary dragons, battles with arrow snakes and octopuses	Marie	Page 292

The process of working in collaboration with advisory group members to create poems was quite lengthily, as many had not written poetry since school. I ran a series of workshops for those with interest, during which we explored similar research to poetry techniques including Featherstone and Sandfiled, (2013). We had multiple meetings to discuss progress and any difficulties encountered and advisory group members appeared to enjoy the process and value the opportunity to be actively involved in research outputs, as expressed in the quotes from members:

"The process was different to other projects I have been involved with (which were) *more practical and focussed on the different aspects of hospice care for the child, for example testing a new online booking system. This was the first time I could use my creative ability as a poet. It was a challenge, but one I enjoyed and found positive and useful"* **Parent Champion advisory group member**

"I found it really insightful being able to share someone's journey and experiences through poetry. By reading the transcript beforehand I felt I was learning more about the person being interviewed and really paid attention to what they were saying and took real value in what they shared. Putting their transcript into poetry is a really creative way of being more engaged with research and makes it a lot more interesting" **GUARDIANS advisory group member**

"I loved Marie's project. One of my favourite projects I have ever been involved in. I also had no clue I could write poetry. I look what we did and I wouldn't have believed we could do that. It was really interesting and it felt good to be able to support a topic that is not raised enough in healthcare. Equity isn't really raised. It seems to be often about health outcomes we focus on but what about the care and compassion they receive. It felt so relevant" **YPAG advisory group member (1)**

"This project was definitely different to what we normally do with YPAG, since we get to create our own "material" instead of solely commenting on what's been done. I enjoyed it and found it quite interesting. It also provided me with invaluable insight to the lives of those living in hospices" **YPAG advisory group member (2)**

Further benefits of advisory group poetry creation were the enhanced relational connection between myself and members, but also empathetically between advisory group members and participants (Hahessy, 2011). The active nature of involvement in poetry creation also enhanced advisory group collaboration in the study, which has been shown to help address power imbalances in research (NIHR, 2015; Shaw, Brady and Davey, 2011; Auckland, 2010). In addition, our meetings gave *'space to talk and change,'* elements of PPI Knowles et al (2021) detail as crucial to enhance shared dialogue, value expertise, allow space for tension, feedback and disagreement. During our poetry meetings, we discussed participants' accounts, their motivations, perspectives and the possible meaning making both they and I were making from our interview interaction. Through this dialogue exchange, my analysis and interpretations of participants accounts were discussed and at times challenged and changed, some examples of these interactions are detailed in the following section.

9:2 Dialogue with Collective voices

When discussing Family Ahmed's transcripts with a parent champion advisor, he reflected on their descriptions of language difficulty, misunderstandings and anxiety, their concern for their daughters, but also the relief of now being in a caring society. Through the parent champion's empathy for the family, I was able to more fully appreciate Family Ahmed's fears, but also the love they had for their daughters. This interaction helped me when interpreting the family's accounts, to better reflect these perspectives, particularly when trying to articulate their challenging and traumatic experiences with the Home Office and during a safeguarding referral.

When considering the perspective of HCP participant Rebecca, I initially developed a theme based around ethics and moral decision making, as much of her discussion seemed to focus on entitlement to care. Whilst I wanted to capture Rebecca's views, I also initially struggled to make sense of them. Many members of the advisory groups have supported the study from start to finish enabling the relationships which have been built to be open, supportive and honest. However, a unique aspect of the collective voices in this study, is the addition of new groups as they were needed. By adding new advisory groups and thus new expertise, I was able to gain further insights as dictated by the participant accounts and findings. In order to help me analyse and understand Rebecca's account, I asked for advice from the Guardians advisory group as they specialise in seeking to address and improve healthcare institutions tackling of inequalities. Upon reflection of Rebecca's account with an advisory member from Guardians, we realised that she had confused health tourism and forced migration numerous times throughout our interview:

> *"I think it tests your morals, I think it tests ethics, it tests.. your opinions and views, personally and professionally I think. Because.. you know I don't necessarily always agree with things that people do and* ***the choices*** *that they make" (Rebecca.18/9.111)*

Upon reflection the muddling of health tourism and forced migration distracted me greatly during Rebecca's interview and throughout my initial analysis. Whilst I wrestled with the terminology and her limited understanding of it, I almost overlooked that regardless of this distinction, what Rebecca was describing was discriminatory. This was discussed with the guardians advisory group member as we realised that Rebecca described different attitudes, treatment and judgements for different family circumstance:

> *"Actually questioning the fact of where has this person come from, actually why have they come here?"* (Rebecca, 24.135)

> *"When we unpicked it, we were then realised that actually they weren't eligible for healthcare treatment unless they paid. But obviously we would treat, because that's what we* ***had*** *to do"* (Rebecca, 28.151)

Upon discussion with the Guardians advisory group member we were able to recognise a fresh that Rebecca's job as a nurse was to care and not to judge the choices of parents. It was thus difficult to reconcile some of her comments and discussions without seeing them as discriminatory and alienating. My supervisory team were also helpful in supporting me to further understand Rebecca and my meaning making. I did not, by any means, want to accuse her of being racist without foundation, but I was also mindful of the need to call out such behaviour, rather than ignoring it and becoming part of the problem myself.

Interestingly, some of these discussions led to a personal realisation that I have perhaps overly high and sometimes too simplistic, expectations of staff perfection. I no longer work clinically and so I may miss some of the context behind HCP and family interactions. It was a powerful insight for me and one which helped me to see the need for balance in setting high standards for care, but perhaps in a more realistic light with the context of the pandemic and other stresses as well.

Subsequently following all these reflections, Rebecca's discussions on this subject were placed within the alienation and discrimination theme as it was clear her beliefs had impacted her attitudes and care negatively. It was important to me to reflect Rebecca's comments as accurately as possible, but also with a view to looking at future recommendations and the impact of implicit and explicit bias (preferential treatments or prejudice based upon partiality) when caring for diverse families.

A further example came during reflections surrounding Family Tessa's experiences. One advisory group member reflected on how nurses and doctors manage tasks, *'on a required basis, minute by minute, hour by hour'* which is *'functional and practical'*. Conversely, we discussed that from family Tessa's perspective *'each second, minute, hour and day is precious. Getting though another day, waking the next morning is a profound and important event when time is sadly short'*. This reflection brought home to me the reality of such experiences for the families in this study. Being a nurse but also a mother, I have felt empathy with both the HCPs' and family participants in my study, but the parent champions were able to further illuminate the precious nature of limited time with a child receiving palliative care and of the lasting nature and consequences of caring interactions. Through such realisation, I was able

to add further depth and focus to the interpretation of the family's accounts and to understand their prioritisation. This included drawing out the findings regarding relationship building and nursing characteristics, which were originally incorporated in group experiential themes per participant group (detailed in Table 11) but were subsequently included by care setting (Table 12) to allow greater expansion of family examples and differences between settings around these themes.

9:3 Dialogue with participants

One family, family Tessa had created their own poem for their son after his death. Their initial poem was in their first language (Arabic) and despite many different translations (organised by them at their insistence) they still were not too pleased with the end result (detailed in Appendix 17). They shared their concerns with me and I was able to check my understanding with them after reading the poem. When analysing the poem (interpretation three), the word humiliation was quite startling to me and so I contacted the family to check if perhaps they meant humility (as this did seem to fit better with the tone of the sentence). Maaz was able to respectfully educate me as to why humiliation was exactly what they meant and why. This interaction may seem a simple one, but the poem was connected to the family's faith. The family's faith was central to their and their son's meaning making about their experiences in palliative care, particularly regarding coping with pain. Aspects relating to faith are notoriously quite difficult to gain detailed information about, without such a clear lead in as the poem created. By checking and discussing poetry

after its creation, I was also able to add another layer of interpretation to data analysis.

Traditional member-checking of interpretations (sending transcripts/findings and asking participants to verify if the representation of the account is accurate) is often recommended, as a way to verify the quality and accuracy of a researcher's findings (Janes, Serrant and Sque, 2019). As discussed within the methodology stage, traditional member-checking was not carried out in this study for several reasons. Firstly, sending full transcripts to family participants did not seem ethically appropriate due to the migration and diagnosis trauma which was discussed in some interviews. However, the idea of ensuring a clear understanding of experiences had been achieved during interpretation was important to me and so poetry which had been written about participants was sent to them for feedback.

Interestingly when initially sent out, replies were not received and when one poem was due to be used in a webinar, despite already having HCP participant consent, I felt an additional moral responsibility to check the participant would be happy for me to share it. The participant told me she had not read her poem, but nonetheless she trusted my interpretations and was happy for me to share it. Such dissonance was challenging to manage and quite unanticipated. However, it may have been related to the nature of the material sent out, i.e. poetic form which was unfamiliar, or perhaps the timeliness or personal circumstances of the participant.

One methodological advantage of sharing the poems created, was that they were similar to providing an individual case summary to participants. This enabled me to

firstly give the idiographic level to participants without the potential distraction of the later cross-case analysis. However, in order to also provide a fuller picture and be inclusive to those who may find a poem hard to interpret, an end of study information sheet (Appendices 18 and 19) with the cross-case analysis was sent out alongside each individual poem. By sharing additional information later, participants had another opportunity to feedback if they felt their contributions and perspectives were not well reflected. In contacting the participants again in this way, it also helped me to address the dissonance I felt when initial feedback to the poetic material was not given.

Upon sending out individual poems and end of study information together, the response was much more positive, however HCP Clara was uncontactable and had likely left her post, HCPs Marian and Sobia also did not respond and families Ahmed and Khatri were also uncontactable.

HCP Rebecca responded positively to the summary sheet and was keen to link me to the interpreter group at her hospital to share my findings with them. I had already been in contact with this team, but Rebecca's suggestion did highlight her understanding of the importance of addressing language and communication barriers.

HCP Rida told me that she was *"so happy to have had the privilege of participating in your study. It has been a pleasure working with you. Your summary looks really good and I am sure this work will go a long way in improving the care of forced migrant families*". She also detailed: *"what a surprise for me to read the poem about my*

experiences! I feel so honoured! Please convey my thanks to the advisory group member who so skilfully wrote it and since you asked, I have made just a few minor track changes". The changes made by Rida are detailed in Appendix 11 and were important to ensure that her experiences were accurately reflected in the poem which may be used for dissemination purposes.

HCP Flo was affirming and said that *"the poems are real yet beautifully put together and the findings are interesting. I am glad there is hope for the families that arrive in the UK from such trauma and in need of advice and guidance whilst residing in their new home".* Similarly HCP Holly told me she found her poem *"humbling and I hope so much that with the hard work and investment you have given to your cause, future families will benefit from a deeper insight and research-based approach to the unique and truly important values each individual family holds. Thank you so much and well done. This is amazing for you, for the profession and most importantly for our families…dignity, respect, understanding and kindness should always be part of the care we are so privilege to give and be a part of".*

Family Tessa also responded very encouragingly:

> *"We have read through your summary sheet and we are happy with everything you mentioned. We must admit, the poem is absolutely wonderful! I think it is well written and it clearly highlights our experiences with some of the nurses. Also, thank you for not making things very specific with our personal details and for keeping everything anonymous. My family and I, wish you all the best with the rest of your research and we hope this will have a positive outcome in the future of health care. Please keep us updated with the results and don't hesitate to contact us if you have any questions or queries".*

The dialogue described in this section with advisory group members and participants may be seen as an example of ‘hearing’ the ‘silences’ in this study, as they affected the analysis and interpretations offered. The Silences Dialogue section thus allowed further opportunities to value, respect and fully understand the collective voices of the study. Janes, Serrant and Sque (2019) discuss the importance of such cyclical data analysis as an invaluable strategy for preventing further silencing of participants and enriching the trustworthiness of the study.

9:4 Conclusion to Stage Three

In summary, Stage Three has detailed the data collection methods and IPA process followed, alongside ethical considerations for the study. Chapter Eight has discussed the findings by theme and setting and Chapter Nine - Silences Dialogue has focused upon the impact of advisory group and participant dialogue. Particularly impactful were aspects of poetry creation and participant feedback as detailed in the examples here.

Chapter 10 – Discussion

10.0 Introduction to Stage Four – Working in Silences

Stage Four of the Silences Framework offers an opportunity to present the discussion section of the study. Within this chapter, there will also be a dialogue around how the research aim and objectives were met and consideration of new 'silences' which have emerged as a result of the study. Two tree figure images, created in conjunction with a youth advisory group member, are presented to illustrate the factors which hinder or optimise care from both family and HCP perspectives. Figure 23 details how Stage Four fits within the Silences Framework as a whole and which elements of the study are included herein.

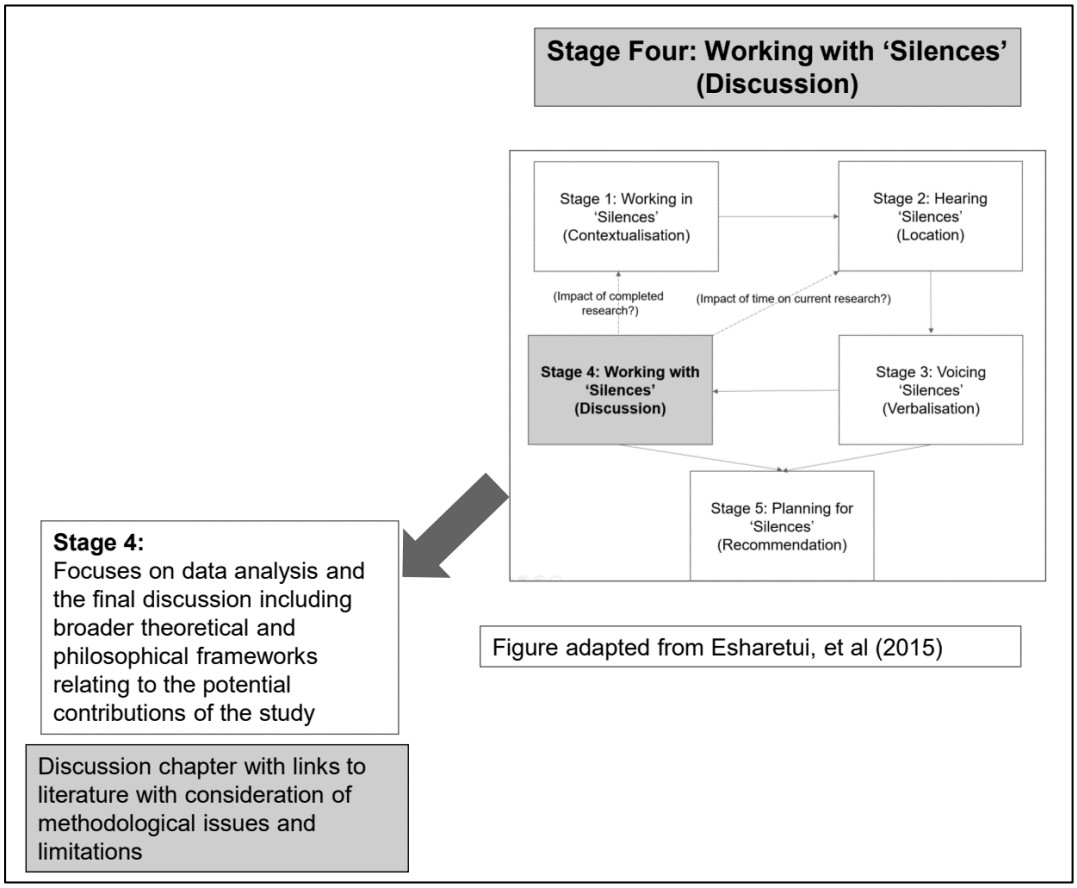


Figure 25 – Stage Four – Working with Silences

Stage Four offers a critical reflection on the contribution of this study to the current children's palliative care literature and policy and considers how I and the collective voices of the study have impacted upon the research field. This stage concludes with a poem, which further aims to summarise the findings from this study.

10.1 Summary of study aim and research questions

The aim of this study was to understand the care experiences of forced migrant families in the context of children's palliative care. Research questions (outlined in Chapter 2:11) aligned to this aim. The discussion chapter is framed around the research questions; exploring and critiquing how they have (or have not) been addressed.

10.2 The factors that optimise or hinder care from the perspective of forced migrant families

The literature surrounding children's palliative care highlights the importance of HCPs' and family relationships (Brykczynska and Simons, 2011). Authors comment on the importance of continuity and consistency in relationships, to help parents cope with the uncertainties of palliative care disease and the complexities of care required (Heller and Solomon, 2005; Brimble et al, 2019).

10.2.1 Building relationships

Within this study families reported that long term relationships with HCPs were crucial to the provision of family centred, holistic and bespoke care and that it took time to develop rapport and trust. For forced migrant families, many of whom had experienced persecution in their country of origin, subsequent difficult migration journeys and UK community hostility, this continuity was crucial. Each family studied had experienced hostility since arriving in the UK. For Adiva, this centred around

poor treatment by the Home Office, whilst Hamza described the regime in Syria, fearing for his life and his hazardous 11-month journey to the UK. After Hamza and Khadija arrived in the UK, they experienced a safeguarding referral which commenced without an interpreter and left them feeling labelled and judged. Family Tessa experienced many micro-aggressions and described feeling alienated and discriminated against.

10.2.2 Understanding migration trauma

Family members described the need for HCPs to understand their migration and resettlement experiences in order to better empathise with them. Other scholars have stressed the importance of listening to migration experiences in order to establish trusting relationships (Kvarme et al, 2016; Green et al, 2018) and create better understanding of past traumas and current family context (Contro et al, 2010; Vukčević et al, 2016). Mechili et al, (2018) also describe the importance of gaining a better understanding and feeling for what refugees have experienced by 'getting into refugees' shoes'. Richard et al, (2019) further reiterate the importance of acknowledging refugee's journeys by 'getting to know them' and offer mutual respect for them as people. However, such conversations may prove difficult and can be challenging for HCPs to pitch correctly, which can lead to avoidance. A further consideration of discussing migration experiences is the likelihood or fear of exacerbating trauma. The risk of re-traumatisation needs to be handled sensitively and with a trauma informed approach, which may be unfamiliar to some HCPs

(Wylie et al, 2018). The rationale for such conversations also needs to be explained clearly to families, so that they are pitched as supportive and informative for meeting health care needs rather than relating to any legal, visa or care entitlement (Dodds and Hunter, 2022).

A ‘silence’ revealed through this study was the clear desire families had to share their individual migration and health journeys. One social worker noted after my interview with Family Ahmed that they had told me more about their previous experiences in our interview than in her two-year relationship with them. As well as the importance of sensitive communication, another consideration concerns the timing of such conversations. My experiences and those of other scholars working with forced migrants lead me to suggest that the sharing of migration journeys occur in the first few meetings to gather context and show caring concern, which Deps and Charlier (2020) cite as imperative to building trusting relationships.

10.2.3 A humane approach to care

Given the multifaceted nature of experiences for forced migrant families of persecution, difficult migration journeys, the feelings of bereavement associated with leaving much behind and with multiple challenges to receiving care for their sick children in the UK, it is unsurprising to see elements which optimised families care such as caring concern, FCC and the desire for kindness and a humane approach. Compassion, kindness, respect, empathy and attention to dignity are all

acknowledged to be important aspects in alleviating pain, disease management and relieving anxiety (Shea and Lionis, 2014; Debs and Charlier, 2020). Mechili et al (2018) found that how forced migrants were approached by HCPs was the most important element in defining their experiences of care. In many different European settings, the study team found that refugees expressed hope for HCPs to be friendly, respectful, have kind words and generate a feeling of acceptance (Mechili et al 2018). Moreover, Bloomfield and Pegram (2015) found that active listening to refugee concerns, appropriate touch and showing care regarding their health concerns was significant.

10.2.4 Reducing discrimination, labelling and stereotyping

Many forced migrants experience discrimination and stereotyping both in healthcare and local community settings. Spencer and Thompson (2022) detail the problems faced by young forced migrants with acceptance, offering accounts of frequent bullying and exclusion. One participant was called a terrorist and another had to sit through a class discussion about what a drain on the NHS refugees were and how they were stealing care from deserving citizens. This labelling unfortunately was also present in teaching staff, one of whom appeared surprised when the young refugee knew what the internet was, let alone how to use it (Spencer and Thompson, 2022). Sampson and Gifford (2010) highlight the critical importance of a sense of belonging within acculturation experiences, with struggles to fit in having a notable effect on mental ill health.

Consideration of the migration trauma and ongoing difficulties often experienced by forced migrant families, may also explain the high impact of feeling cared for and when HCPs went the extra mile to support them (Turnbull, 2015). Often the elements described were subtle, such as smiling and greeting families, spending extra time with them and playing with their children and the value attached to the returning of calls and being accessible when needed. Interestingly, one study noted that while extra time is needed to care for refugee families the lack of insufficient time available, can lead to feelings of professional inadequacy (Dumit and Honein-AbouHaidar, 2019).

The families in my study noticed those HCPs who cared for them, after spending many hours particularly in hospital environments with little to do but watch. Families' insightful recognition of the difficulty of nursing roles and the individual nature of caring relationships even when they were challenging, was surprising particularly given the language barriers. Families were aware when they were being shown caring concern and when this was lacking. HCPs' body language, tone of voice and their authenticity within interactions appeared crucial interpersonal aspects (Brimble et al, 2019). Further to the use of non-verbal communication was the need for additional questioning and checking in on families to show HCP concern. Adiva felt that HCPs' did not 'check in' on her and that a failure to regularly ask how she was resulted in her going without food during her two month stay in hospital. Heller and Soloman (2005) describe the importance of good information flow when aiming to enhance communication between families and HCPs in children's palliative care. They describe the need for regular updates and 'checking in' with families to build relationships and meet evolving needs. For forced migrant families in this study,

these regular check-ins often appeared to be missing, which may be due to communication barriers, or a perceived lack of shared interests/similarities with HCPs, which may make such encounters easier. However, by missing out on regular and integral check-ins, misinterpretations are more likely, as well as the potential for expectations of care to be left undiscussed and misunderstood by families.

10.2.5 Engagement

In order for families to receive family centred care, there is a need for engagement between families and HCPs on an emotional and social level (Allen, Scarinci and Hickson, 2018). Engagement between families and HCPs requires good information sharing, therapeutic relationship building, attentive listening and understanding of the often-complex individual experience of disease (Nilson, et al. 2012). A further aspect of family centred care is the need to enable and empower families to engage in care collaboratively (Serlachius et al, 2018). Forced migrant families in this study found that communication and language difficulties experienced were barriers to this element of family centred care. A further missing element was the engagement between HCPs with families and their children on an emotional and social level. Allen et al (2018) acknowledge that poor communication with families can be disempowering and be linked to feelings of confusion (Rudgeley, 2013), disengagement (Luckstead et al, 2015) and powerlessness (Offord, Turner and Cooper, 2006). They also recognised the need for experienced and knowledgeable HCPs to ensure effective FCC. For forced migrant families, the lack of awareness

HCPs had regarding their individual experiences and circumstances appeared detrimental to caring relationships. Equally, Hendricks-Ferguson et al (2015) describe the experiences of parents of children with cancer, with many facing 'coldness, contradictions and laissez faire attitudes' (Davies & Connaughty, 2002; Hendricks-Ferguson, 2007). Such poor experiences between families and HCPs caused parents to feel abandoned and to question the accuracy of HCP's information. Davies et al (2010) reinforce the notion of abandonment as a consequence of poor communication, as they state that less than optimal patterns of information sharing, due to cultural or communication difficulties can contribute to frustration, anger and sadness for families.

10.2.6 Time

Families in this study were aware of those HCPs who appeared focussed upon 'the shift', compared to those who invested in them and wanted to develop long-term relationships. Davies et al (2017) and Brimble et al (2019) found that parents appreciated HCPs who would take the time to be with them and get to know them. As well as featuring in empirical studies (Steele, 2002), journeying alongside families and a sense of shared history is a common theme in grey literature, such as The Together for Short Lives, (2016), video; *"…making a real difference for families and accompanying them on their journey…for me, is where the reward is..."* Consistency and reliability of HCPs and for Family Ahmed the relationship with their interpreter, were clearly important antecedents of their ability to trust and depend on HCPs. The

use of interpreters for more interactions and not just for medical consultations, was also seen as an optimising factor. However, the literature clearly describes the difficulties in accessing interpreters, in terms of financial implications to organisations but also the unavailability of suitable interpreters sometimes leading to deferred or rearranged care (Robertshaw, Dhesi and Jones, 2017).

10.2.7 Social isolation

The literature around the social isolation of refugees in the UK is stark. Loneliness is linked to poor mental ill health and forced migrants facing stressors around the plight of family members in the country of origin. Alongside an ongoing lack of social and physical support (Gleeson et al 2020), a particular issue when individuals are used to being part of an extended family. A further contributing factor to forced migrant family's social isolation and loneliness are the language and communication barriers, which make even simple interactions difficult (Refugee Action, 2017). The lack of social support and its negative impact upon families described in this study was illuminating but unsurprising, particularly with the additional complexity of the coronavirus pandemic. For forced migrant families, the pandemic meant many HCPs were redeployed elsewhere and the support available for families was reduced or stopped altogether. The absence of social support for forced migrant families may differ to that available for established black ethnic minority families in palliative care, who are reported to often have additional family and faith or community support (Panagiotis et al, 2018). The differences in social support between these two groups

of families with ethnically diverse backgrounds may have created confusion for HCPs and an additional ‘silencing’ or lack of understanding of the desperate need for additional support which forced migrant families in this study described.

The burdens that families endured when receiving palliative care for their children, were eased by normality, such as school life and the utilisation of less clinical areas when possible. Rest and appropriate respite for families were also seen as beneficial. However, the responsibility, duty and intense love parents had for their children needed to be balanced with trusting HCPs to care for their children as they would at home. Kvarme et al (2016) discusses the hypervigilance that parents often experience in CPC, with a feeling of being on duty 24 hours a day. For forced migrant families, this may be compounded by a lack of support and the precious nature of their children which within this study, saw all three families uproot their lives at great personal cost, to better meet their children’s needs.

10.2.8 Understanding and responding to family beliefs

Whilst individualised care was valued by all the participants, the link between cultural practices and health beliefs was not always understood by HCPs. De Haan, Nabirye and Gould, (2020) note that the presence of different cultural practices can influence health practices. Rosenberg et al (2019) observe that the family structure and roles within it can govern healthcare interactions and decision-making processes. Within this study, cultural norms and gender roles made a significant impact for Family

Khatri. Whilst for Family Ahmed and Family Tessa their religious beliefs were an intrinsic part of their understanding of the world and thus influenced all aspects of their lifeworld including their health views. Fowler (2009) argues that, whilst nursing texts indicate that cultural sensitivity is essential within our interactions, our understanding of the implications of aspects like religion for individual families are still limited. More recent work by Harrad et al (2019) describes nurses as having limited education on spiritual care and showing a lack of skill and confidence when providing spiritual care. Timmins (2017) highlights the challenges to providing spiritual care, as nurses' need to communicate and assess the spiritual needs of families by being self-aware and open to different levels of dialogue.

The lack of education of HCPs around faith and religion is emphasised by Fowler (2009) who states that for those with a strong faith, religious obedience is intentional and *'faith is a matter of life and breath'* (p391). Fowler (2009) describes faith as the way in which a person may understand and live life, with religious belief often forming the motive and meaning of life. Religious belief appears to become embedded within an individual's core identity and thus provides the fundamental basis for relationships with others and society. As such, it is unsurprising that when spiritual needs go unmet, spiritual distress may result. Spiritual distress has been defined as the inability to understand the meaning of life and a difficulty in connecting with self, others, or beliefs (Timmins and Caldeira, 2017).

A key contribution of this study surrounds the uncovering of a 'silence' within the provision and understanding of spiritual care to families and the way terminology impacts upon care. Family Tessa's Muslim faith was of paramount importance.

However, they discussed how their spiritual needs were often not valued and frequently dismissed or de-prioritised by HCPs. Their nurse, Holly, described nurses interrupting prayer and a general lack of understanding around the family's desire to allow their son Sohail to practice and live out his faith, particularly towards the end of his life. When examining the literature, it became apparent that some of the problems I identified around faith may relate to how such aspects are commonly termed. For instance, in much of the literature, 'myths' surrounding barriers to accessing palliative care are detailed. One such 'myth' around opioid use is described as a perception by ethnically diverse families that "suffering makes you stronger" (de Haan, Nabirye and Gould, 2020; p168). By using the word myth rather than belief, the language used indicates to HCPs that beliefs about opiates are a falsity which needs to be dispelled, rather than a religious belief to be respected and understood. Challenges around understanding religious belief and enduring pain are thus evident, as the link between suffering, strength and eternal favour is detailed in many religions including Christianity, Islam, Buddhism and Hinduism (Kemp, 2005). Following my new understanding regarding the importance of language and terminology, I reviewed and amended my initial literature review and background sections to ensure I reflected the importance of appropriate and non-judgemental terminology.

Further elements of misunderstanding and minimising of family's beliefs were seen surrounding truth telling and hope. Whilst many HCPs embrace family centred care, a workshop of experts in CPC discussed that FCC became difficult when there was conflict or if family decision-making processes felt 'foreign' (Rosenberg, et al 2019). Kaye et al (2020) describe the conflict between parent hope and disease acceptance

as a ‘pendulum oscillating between antithetical states of awareness’. Rising (2017) discusses the moral distress which may be experienced by HCPs when they perceive nondisclosure or withholding of information, whilst Musto and Rodney (2018) assert the importance of context when considering moral distress. However, Kaye et al (2020) challenge the assumption that hope and realism are opposing spaces and suggest that HCPs need to avoid assumptions that conflate hope as misinterpretation or denial. Rosenberg et al (2019) articulates the need for HCPs to sit with conflict and suggests that perhaps culturally sensitive palliative care necessitates the need to “be more comfortable with messy” (p849). Repenshek, (2009) concurs stating that what has always been considered moral distress may in fact be a difficulty in sitting with the discomfort moral subjectivity brings. Vlachou, (2017) further elaborates on this by suggesting:

> *“We must listen better, look better and not classify, simply and hastily, a person who feels afraid as an ignorant person. In this process, we must also recognise the humanity of those who are worried and uncomfortable with seeing the world around them change. We must also recognise differences, not only as factors that enrich our lives, but also as factors that separate us and create tension. Knowledge, dialogue, tolerance, life in common, in general, are a daily exercise, an exercise in culture”* (Vlachou, 2017, p10).

The difficulties surrounding truth-telling and hope described in this study, may be seen as tensions and often derived from situations where there were no clear answers. Rosenberg et al, (2019) debated that when such differences feel hard to navigate for HCPs, there are often implicit or explicit biases and corresponding assumptions present, which can exacerbate already tense relationships. Often parents can sense HCPs’ discomfort, distrust or disbelieving perspectives and may

thus respond defensively, which may result in further labelling of families as difficult. Holly, within this study, eloquently discussed this as:

> *"I think there's a wariness often, people don't want to understand, or they're too frightened to ask so they'll be brazen and they'll hide behind it by being … a little bit callous maybe and… when people are finding it challenging and difficult and perhaps the family are being a little bit forthright, in expressing what their wishes and desires are, people become more intolerant and less tolerant in meeting those needs" (Holly 28:120-1).*

Rosenberg et al (2019) rationalises that such disparities may magnify over time and only serve to increase differences in care delivery. Parsons and Darlington (2020) concur, as they describe increasing prevalence of conflict in paediatric healthcare settings which is damaging to patients, families, resources and HCPs. They define many examples of conflict between parents and HCPs relating to EoL care, best interests, trust, suffering and spirituality.

Himelstein et al. (2004) describe spiritual assessments as vital within paediatric palliative care. Such assessments can offer crucial information regarding children and families belief systems about the meaning of life, particularly surrounding hopes, values and the role of prayer and faith practices. Himelstein et al (2004) recommends sensitive discussions around past experiences and trauma, to help determine children's views of what occurs following death both physically and metaphysically. Subsequently, the use of gentle conversations around pain and suffering, were seen to help facilitate appropriate spiritual care and early involvement of chaplaincy or faith leaders as needed (Whitman, 2007; Thrane, 2010).

10.2.9 Difficulties navigating systems and accessing care and resources

Final elements, which appeared to hinder the care forced migrant families received, were detailed in a lack of access to services, inappropriate housing, inadequate financial support and a lack of healthcare literacy. Such aspects were also reiterated by HCPs and so these will be detailed in answering research question three.

10.2.10 Cultural Humility in relationships

A further contribution of this study is the emphasised need for a Cultural Humility stance in relationships, this philosophy has been discussed in numerous ways throughout this study. However, when considering the vast need of forced migrant families in palliative care and the unique elements of individual need, it appears of paramount importance to providing high quality care. A benefit to the wider use of this model is the opportunity to improve self-awareness and offer families a more open-minded lens to care. The ability to value individual family beliefs and recognise often deeply ingrained personal beliefs and values which may conflict or damage relationships, appears crucial to reconciliation and collaborative palliative care (Rising, 2017; Alden et al, 2018).

Many of the aspects raised by families in this study relate to the need for compassionate, family centred care which considers individual needs and belief systems alongside the experiences of trauma through both forced migration and palliation. Forced migrant families expressed the need for HCPs to understand their

lack of social support, their struggles to understand and access healthcare systems, the discrimination and hostility faced and the parental burdens and uncertainties of palliative care crisis.

10.2.11 Elements of care combined and illustrated in tree figures

The elements of care described by participants have been drawn together and illustrated by a youth advisory group member, in Figure 26 (and for HCPs in Figure 27). These two tree figures, were developed to both integrate the creative approaches used throughout this study and to bring to life using imagery, a memorable diagram for educative and dissemination purposes. Through the identification and dissemination of both factors which optimise and hinder care for forced migrant families, the findings of this study may be used to provide health care professionals and services, with insights into how they can improve care.

Tree model

Factors optimising and hindering care

Families perspectives

Optimising factors
Sunshine – Long term view to care
Seeds – Family centred, holistic care
Trunk – Beliefs and coping strategies
Fertiliser – Rest and respite
Rain – Normality
Flowers – Going the extra mile
Fruit – Kindness, compassion, humane approach
Roots – Consistency and relationship building with interpreters



Painting by Jess Downing - aged 13

Hindering factors
Rocks – Lack of trust and time
Poison – Judgements and labelling
Stormy weather – Gender and cultural norms
Axe – Lack of social support
Disease – Parental burdens
Rotting trunk – Alienation and discrimination
Sand – Lack of understanding of migration trauma
Decay – Uncertainties in palliative care
Damage by insects – Lack of family centred care

Figure 26 – The tree model to illuminate factors seen as optimising or hindering to care, from forced migrant family's perspectives

10.3 Representing the voices of forced migrant children and their families in research

Research question two concerned a consideration of how the voices of forced migrant children and their families could be best reflected and represented in research concerning their experiences. One answer to this question is the continued and sustained collaboration with advisory group expertise during research studies. Advisory group input into this study has been extremely valuable in helping to shape, understand and respond appropriately to research findings. Ziersch et al, (2019) concur stating that a central aspect of research with forced migrant communities is that of close community collaboration to ensure validity. Advisory group collaboration also helped me to reconcile my interpretations, whilst bringing the voices of forced migrant families to the forefront of my analysis. Without the advisory group's expertise, forced migrant families would not have been represented as appropriately or sensitively and I have learnt a huge amount from the included advisory groups and the families themselves in terms of how they wish to be heard and seen. The use of a Cultural Humility stance within research interactions has further enhanced my learning and helped to foster rapport and trust with forced migrant families (Yeager and Bauer-Wu, 2013).

When I first contemplated this study topic, academic colleagues were concerned about how I would engage with forced migrant families and if we would be able to understand each other enough to have meaningful research dialogue. I began to think about ways to help build rapport and offer different options for expression, particularly considering the likely language barriers.

10.3.1 Evaluating draw and talk methodology

The use of a draw and talk methodology has been beneficial by giving a focus to discussions (Cope, Jones and Hendricks, 2015) and offering siblings additional ways to communicate (Neilson, 2019). Draw and talk methodology was further seen to enhance a sense of shared 'community' in the research interaction (Søndergaard and Reventlow, 2019) with HCP participants. The lack of forced migrant engagement in creative techniques may relate to the limitation of online interviewing for one family and possible embarrassment or lack of understanding of the technique by the other two families. Further, Boden, Larkin and Iyer (2019) detail the importance of how the invitation to draw is given to participants and whether the type of image is detailed, with significance to the level of prompts used. Upon reflection, I did not give very much detail on what or how I wanted participants to draw, as I did not want to appear too pushy or to guide them too rigidly. However, in hindsight more time devoted to this aspect may have been beneficial.

Researchers have also debated whether visual methods really do generate more knowledge and information (Bagnoli, 2009). Further debate surrounds whether it is possible to integrate data collected from various methods (Mason, 2006). As the draw and talk method was additional to interview data, this was an area of consideration. Within this study, any drawings produced were used as complementary data and so set alongside written quotations, however further exploration may be needed if larger quantities of pictures were generated to ensure adequate exploration and use.

After conducting this study, I now have much more confidence in using the draw and talk technique and in the explanation of it, which will be helpful for future research. Meeting families more than once would help to build rapport and trust which may also link to a better uptake (Ziersch et al, 2019). It also seems important to mention that this method was always intended to be optional and flexible, to respect the wishes of participants and not be too forceful in the approach.

10.3.2 Evaluating poetic approaches

Another creative method used was poetry. My initial hope was that participants would create their own poetry of their experiences and talk me through their writings to further illuminate their meaning making. For the HCP participants, this task appeared too time consuming. Whilst many liked the idea, it was clear they did not know where to start and, despite offers of help, they perhaps felt too out of their depth to partake. I would thus be interested in developing future research which would incorporate and help participants to explore the techniques for writing poetry with additional guidance, as I think this might really enhance its use.

Two families did not partake in the poetic approach and similarly, this may be due to a lack of time or confidence in technique. One family, however, offered me a huge learning opportunity in the use of creative approaches as we were able to discuss family photographs, videos and a poem they had written for their son following his death. This was the last family interview I conducted and I think my confidence had increased as well as my ability to develop rapport. I was able to communicate with

this family more freely, which was extremely beneficial, as they were happy to send emails and conduct a second interview to ensure I fully understood the video, photo and poetic medium they had provided. The learning I gained from working with this family was vast, as it helped me to further appreciate the power of a Cultural Humility stance in research interactions, as well as the benefits of giving more choice to the family in terms of how they wanted to tell their story.

10.3.3 Family photographs and video footage

The use of family photographs and video footage as a medium or as artefacts for discussion, was a new concept to me but they worked well at bringing out additional meanings and understandings. The photographs and videos Family Tessa showed me helped them to remember events vividly and recount memories and experiences with many details. Interestingly, much of the literature on the use of photographs in research with migrant communities involves participants taking and then explaining photographs (Fassetta, 2016; Oliveira and Vearey, 2017), rather than the use of treasured photographs as artefacts to discuss, as was the case here. Ziersch et al, (2019) detail the importance of research methods which allow forced migrant participants to 'lead' the direction of their responses rather than following a pre-determined schedule. Such approaches like the one used with family Tessa, are thought to empower participants and allow them to offer broader contexts not conceived by the researcher. Subsequently more research on this topic may be illuminating to evaluate use and relevance, particularly in relation to researching the

experiences of forced migrants or other sensitive populations who may struggle to express themselves through interview alone.

10.3.4 Additional benefits to creative methodology

A further benefit to the use of creative methodology, was an additional way to seeing and understanding migration experiences, which was advocated by family participants. Much of the literature surrounding the use of creative medium such as the arts and poetry suggests benefits for HCPs. Jones, Kumagai and Kittendorf (2019) explains the use of the arts within HCP education, may enhance empathy and perspectives as well as an openness to 'otherness', whilst also stimulating reflection on self, others and the world. McBain et al (2015) state that teaching the art of communicating at end of life is particularly challenging for HCPs and offering creative media to reflect and learn from can be advantageous.

Family participants in this study described the need for HCPs to learn from their (and others) stories and experiences. Crawford and Baker (2009) describe stories as having the power to awaken HCPs observation and communication skills. They detail the power of subtleties and the sub-text of perception, which encourages questioning and a consideration of different perspectives from a truly human perspective. Such benefits are particularly important herein, when considering dissemination of research findings and future teaching strategies. A further consideration of the use of creative medium may be the potential to add a new

dialogue to the current negative media lens surrounding forced migrants. Poems such as ‘Notes on my Native Land’ by David Lazarus (Appendix 20) discuss the benefits of a multicultural society as a kaleidoscope and tapestry of diverse heritage. By offering a conflicting and positive message regarding migration a shift in stigma, labelling and stereotyping may also develop (Danilova, 2014).

Subsequently, when looking to answer question two, giving families the choice of approaches was essential, as it allowed more control to be handed over to participants and a meeting of individual need and preference. Pragmatically, a meeting with a prospective family, to get to know them before an interview might also help to facilitate rapport, alongside explanation of potential creative approaches. Additionally, involving multi-cultural agencies, artists and community members may be advantageous and help with researcher confidence and growing of skill sets (Vlachou, 2017).

10.4 Children’s palliative care professionals’ beliefs about factors that optimise or hinder care

Research question three required an exploration of the factors which optimise or hinder care from HCPs perspectives, this study was based around three families. HCPs who were involved in the family’s care were interviewed to highlight their differing perspectives and offer insights into these care giving roles.

10.4.1 Access barriers and the challenges of multidisciplinary working

At present, there is little research to inform care regarding ethnically diverse family and palliative care workforce experiences. However, problems with access to services and funding are a common problem in the literature surrounding refugee health (Sime, 2014; Castañeda et al, 2015). Much of the literature surrounding forced migrants documents the challenges of understanding and accessing healthcare, particularly surrounding the need to understand complex systems (Nellums et al, 2018). For families in this study, much of this complexity came from poor understanding of entitlement and eligibility. Spencer and Thompson (2022) recognised such issues for forced migrant families, with many describing the NHS as being too complicated and difficult to understand. Further challenges in access and resource came from the different professionals and organisations involved in their children's care. This is a common issue in children's palliative care, where the medical complexity of children's conditions frequently require multiple specialists to work together to care for the child (Aidoo and Rajapakse, 2019). For example, this may include cardiac speciality, renal departments and the paediatric intensive care unit to work together during episodes of severe crisis. However, it may also relate to outpatient, charity sectors and social care as orthopaedics, therapies, special schools, hospice and the child's GP work together to care for the child. Subsequently, such multidisciplinary and multiagency working can be challenging for staff and families to navigate. For forced migrant families, this is compounded by language and communication difficulties, a lack of understanding of roles and responsibilities and how best to contact professionals, as well as missing extended family to help make sense of things with (Spencer and Thompson, 2022).

Hendricks-Ferguson et al, (2015) discuss the importance of multidisciplinary team working to offer support, expertise, role modelling and provide invaluable insights during challenging cases. Multidisciplinary working appeared to offer a sense of comfort for HCPs' in knowing support was available when needed. Within children's palliative care, regional networks have been developed by Together for Short Lives, with such aims in mind, however their remit is currently underutilised, with most networks run voluntarily and many clinical staff unable to attend meetings due to clinical demand.

By interviewing several HCPs in the care of one family, a more detailed representation of the complexity experienced when multidisciplinary and multiagency organisations are needed was shown by Family Khatri. The different narratives of the social worker, special school and mother were illuminating, as they emphasised how misunderstandings and misinterpretations took shape and the frustrations each experienced. This case study may thus prove beneficial in helping HCPs to see differing perspectives as experienced in different settings and from different viewpoints.

A further aspect of difficulty in access was explored within Family Tessa's experience, as they could not access hospice care when needed. In a study by Dixon et al (2015), concerns were discussed in relation to limited hospice capacity. A further consideration was debated in the medically led aspects to hospice care, in which the psychosocial needs of the family may not be given sufficient consideration. The concept of hospice for forced migrant families is often detailed as being a difficult one to accept, with links to death and treatment failure (Dixon et al 2015; Pentaris et al,

2018). For families in this study, the lack of social support meant that hospice care was welcomed and embraced, when it was explained well and explored gently through information and informal visits. The prioritisation of forced migrant families to receive access to hospice care would thus be strongly advocated with a further research exploration of the barriers which may exist for such families.

Considering the access barriers for forced migrant families, HCPs in this study emphasised the brevity of such difficulties and thus the need for additional time and understanding of resource constraints and working with interpreters to fully support families. The additional time needed was also linked to relationship building and ensuring care was individual rather than protocol led, which was felt to hinder care. However, additional time allowances did not seem to translate to workload allocations, staffing levels or working conditions for individuals. Such acknowledgement links to another element which appeared to hinder care from HCP's perspectives.

10.4.2 Difficult working environments and subsequent HCP burnout experiences

Many HCPs in this study, discussed high workloads, poor staffing levels and gave examples of themselves or others experiencing burnout. Pentaris et al (2018) states that even when palliative care services became overwhelmed, HCPs desire to help children and families can see them acting outside of their normal remits, with

associated additional pressure and stress. Further, inadequate specialist knowledge or expertise can also make responding to complex family needs more difficult (Hendricks-Ferguson et al, 2015). Participants in the study by Patraris et al (2018) shared accounts of occasions when the expectations (e.g., provision of social/emotional support) and needs (e.g., respite care, services at home and in the community) exceeded the organisation's resources and capacity to respond because of insufficient staff. A consideration of workload implications with policy makers and commissioners to ensure implementation of additional time and resource in children's palliative care services, specifically for forced migrant families, would thus be advantageous and may fit well with the creation of a policy briefing on this study's findings.

Ling, Petrakis and Olver (2021) discuss how poor working environments within healthcare, can make it hard for HCPs to focus on another's suffering and respond to their individual need. Batson (2017) discussed the concept of empathetic distress and how many HCPs became distressed by another's distress, resulting in a negative, self-focused cycle rather than a focus upon those who require care. Further literature indicates that compassion, which focusses on the other's wellbeing, is a positive state of mind (Klimecki et al., 2013; Nelson et al., 2016). The *wish* for the other to be free from suffering is thus seen as protective against empathic distress, with compassionate approaches leading to feelings of affiliation, care and reward for HCPs (Preckel et al., 2018). Conversely Nolte et al (2017) found that complex demands from overstretched healthcare systems placed extraordinary stress on HCPs, this affected their ability to care for others, leading to compassion fatigue (a state of exhaustion which limits the ability to care), burnout and attrition from the profession.

10.4.3 Entitlement to healthcare, racism and discrimination

Some of the elements raised in this study related to entitlement to healthcare and the alienation and discrimination families experienced in care settings. The literature reiterates that negative reactions to difference and othering of people from diverse cultures often leads to clashes, ethnocentrism, discrimination and stereotyping in healthcare due to the conceptualisation of difference (Almutairi, Adlan and Nasim, 2017; Moorley and West, 2022). Such issues in palliative care have been debated by Hussain, Koffman and Bajwah, (2021) who suggest that the disparities in access, quality and outcomes of care for ethnically diverse patients may pertain to a dominant view of such communities as being 'hard to reach' or 'underserved'. Such a view can reflect an assimilationist perspective to HCPs, in which racial and/or ethnic groups are seen as "deficient, lacking or inferior and in need of services which will enrich their behaviour" (Hussain, Koffman and Bajwah, 2021, p811). It is suggested that whilst using phrases like 'hard to reach' may be well intentioned, they come from an assumption that the dominant ethnicity represents the gold standard (Hussain, Koffman and Bajwah, 2021).

Within this study, Family Ahmed and HCP Marian detailed incidents of safeguarding referrals that whilst well intentioned, were rushed and without appropriate interpretation of both the events or language support, to allow families voices to be heard and understood. The cases detailed appeared to be based upon assumption and negative views of forced migrant parenting, alongside unfamiliar behaviours such as different responses to grief. A lack of awareness was apparent in the cases described, but elements of discriminatory response cannot be overruled. Moorley and West (2022) describe a contributing factor to racism in healthcare is seen in the

dominance of whiteness in current nursing curriculum, which does not reflect the multicultural nature of society. Almutairi, Adlan and Nasim (2017) found that cultural competence was affected by nurse's age, level of experience and country of birth, as these factors were seen to influence their perceptions. Almutairi, Adlan and Nasim, (2017) discussed that gaining cultural awareness thus appears to require exposure to patients from various backgrounds in order to gain the associated cultural knowledge. Many scholars concur and suggest increased contact with those of different ethnic and racial groups can help improve implicit bias (McBide, 2015; Dobbin and Kalev, 2018; Hussain, Koffman and Bajwah, 2021). For HCPs this may link to receiving education from those with lived experience and/or partaking in electives either online (Hyett et al, 2018) or by caring for multicultural communities in different parts of the UK or overseas (Sjögren Forss, Persson and Borglin, 2019).

10.4.4 Link workers and peer support for families

A further element which may optimise care, was the use of link workers and peer support for families. The use of workers of similar cultural backgrounds or peers with similar experiences was advocated by HCPs as a method to provide support but also appropriate understanding, knowledge and meeting of language/communication needs (Spencer and Thompson, 2022). Such an approach may also help to create a more diverse workforce, which is recognised as a strategy to help tackle racism and promote inclusion (Calanzani et al, 2013; Lee, Sulaiman-Hill and Thompson, 2014;

Hussain, Koffman and Bajwah, 2021). However, a further element to consider when aiming to improve cultural sensitivity is that of moral reasoning.

10.4.5 Moral reasoning

Within this study, elements of burnout were discussed by HCPs but there were also elements of indifference and pragmatic acceptance of substandard care, which were hard to untangle but suggestive of disillusionment and emotional blunting. A study by Backlund and Olausson (2021) discuss the concerning long-term effects of intense human suffering on nursing staff. Similarly, in Griffiths et al (2003) nurses felt inadequately trained to deal with the trauma-related, environmental and role-related stressors that they encountered. HCPs in this study were potentially exposed to vicarious trauma from both children's palliative care and migration trauma.

Markey (2020) discusses disengagement strategies used by HCPs when caring for ethnically diverse patients and suggests that HCPs may take painstaking measures to rationalise insensitive care. An inability to challenge moral behaviour and poor care, places HCPs at risk of becoming detached and ineffective (Hunsaker et al, 2015). Markey (2020) discusses the development of moral reasoning as a process of discerning right or wrong ethical action. She ascertains that through using a model such as Rest and Narvaez, (1989) to explore actions and omissions, HCPs may become empowered and able to commit and take courage in providing quality care and challenging associated social injustice (Moorley and West, 2022).

10.4.6 Two-way education

One further aspect which appeared to enhance care for families and the experiences of HCPs, was a two-way education between families and HCPs. Two of the HCP participants discussed the learning that they had gained from forced migrant families and how this had enhanced their practice. All families in the study discussed the value of educating HCPs and how their experiences could contribute to this. Therefore, one contribution from this study may come in the use of family case studies within research and education, to prompt debate and discussion and provide real-life scenarios to work within. Further, the creative approaches used within this study have allowed new perspectives and ways of understanding forced migrant family's experiences to emerge. The flexibility and variety of creative approaches used have thus enabled the development of a toolkit of approaches to enhance research dissemination and future education of HCPs in an empathetic way.

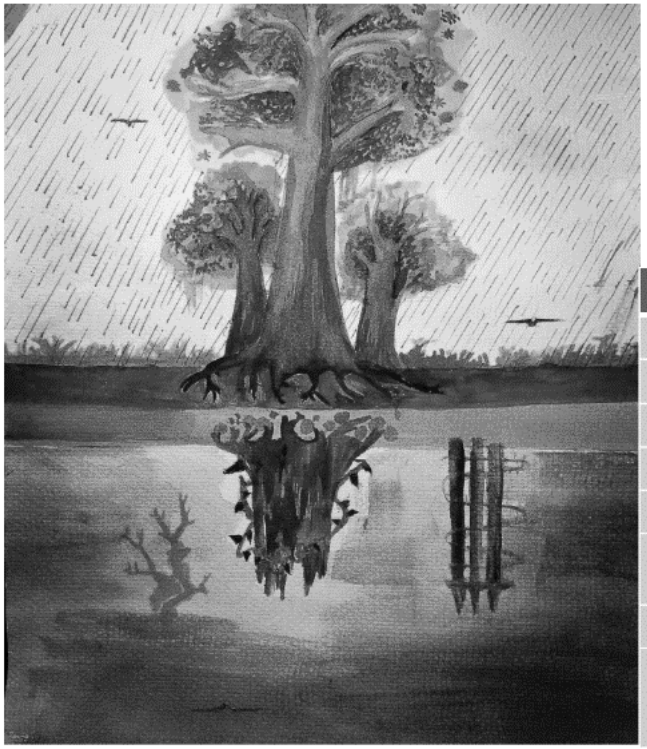
10.4.7 Summary and tree model

Many of the aspects raised by HCPs linked to structural deficiencies particularly in terms of lack of access to services and resource offered to families. HCPs working with forced migrant families face many barriers to facilitating high-quality care, including limited means of communicating and understanding individual family need, which is compounded by infrequent access to interpreters. HCPs are working in time limited and often protocol or documentation focussed organisations. These organisations often do not facilitate the additional time needed to support forced migrant families and work across MDT and multi-agencies. Furthermore, HCPs appear to have little in the way of training or education to help them empathise with migration trauma or facilitate their work with ethnically diverse families. Such education could enhance understanding and limit the divergence in belief systems detailed by family participants. Further to this, HCPs are working at reduced capacity and face staffing shortages in all the settings explored. The detailing of burnout and empathetic distress is thus unsurprising, but needs to be tackled to ensure retention and sustainability of the CPC workforce. All the elements discussed here are summarised in Figure 27.

Tree model

Factors optimising and hindering care
HCP's perspectives

Optimising factors
Sunshine – Link workers of similar cultural background
Seeds – Additional time with families
**Branches* – Relationship building
Rain – Peer support from other families
Flowers – Timeliness and consistency of difficult conversations
Supportive trees – multi-disciplinary and multi-agency working
Roots – Two way education between families and health care professionals



Hindering factors
Rocks – Crossing of professional boundaries
Lightning– Burnout and empathetic distress
Damage – Lack of parental proactivity
Disease – Protocol led care
**Vine* – Communication and language barriers
Thorns – Struggle to coordinate health care teams and multiagency working
**Fence* – Lack of access and health literacy
Crack in the trunk – Divergence of beliefs between health care professionals and parents

*** View shared by families and HCPs**

Painting by Jess Downing - aged 13

Figure 27 – The tree model to illuminate factors seen as optimising or hindering to care, from HCPs' perspectives

10.5 Study Limitations

The initial design of my study centred around forced migrant family participants, with the idea that I would interview those HCPs who they considered important to them, to gain a clearer picture of the care provided from different perspectives. During the pandemic, this became extremely challenging, as I could not visit the study sites to aid this process as originally planned. As such, two HCP participants Rebecca and Rida, did not link directly to a family in the study. This was because a family had to withdraw from the study following serious parental illness after interviews with two associated HCPs had already taken place. Subsequently, whilst Rebecca and Rida offered interesting observations, these were not as specific and thus were less of a focus within the analysis, than the HCPs related directly to the three families included. A further limitation was also created when a medical participant who had agreed to participate was unable to contribute.

A further complication of the pandemic to this study was the difficulty of employing creative methods face to face for some of the participants, due to restrictions at the time and family reticence to meet in person because of the risks to their child/children. The inability to meet in person may have also impacted upon the quality of rapport I was able to build and the ability to interpret body language which was much more difficult online than in person. Additionally, due to the complex nature of the palliative diagnoses of the children included in this study, I was unable to interview the three children whose families I engaged with. I was, however, able to interview two siblings who shared some of their experiences with me. The pandemic and associated social distancing rules rendered my initial plans of working with the

family's usual care teams to try to connect with the disabled children in this study unfeasible. I had hoped to offer sensory based artistic approaches face to face and continue to believe that such techniques offer possibilities for understanding children's experiences in future research.

Inevitably, two interviews with forced migrant families were carried out with the aid of interpreters. The additional voice of the interpreter and issues of interpretation for the family in terms of expressing their thoughts in their native language and then back into English added additional challenges to data analysis. This may also explain some of the hesitancy particularly in Family Khatri's interview. A further missing 'voice' from this study is that of the interpreters who aided each of the families within their healthcare encounters. I had hoped to interview the interpreter, who was described so favourably by Family Ahmed, but this just was not feasible. In order not to miss the important perspectives of children with health conditions, medics and healthcare interpreters, I added representation via the collective voices of the study as advocated by Serrant-Green (2011). Details of discussions with a hospital-based interpreter service, are detailed in Appendix 21 and their guidance is included within the practice recommendations chapter 11.4.1.

10.5.1 Complementary approaches

Finally, this study used a number of approaches which were complementary and helped to further illuminate the silences in this study. However, this also had an impact on time and resources and did at times overly dictate and complicate the study. The Venn diagram detailed in Figure 28 was created to show the inter-connections of approaches used. A thorough understanding of each approach was necessary to understand and take forward the benefits of utilisation in this study. The combination of congruent methodology, methods and philosophy would thus be advocated to other researchers considering researching sensitive areas such as this, but with consideration of number and intersectional complexity too.

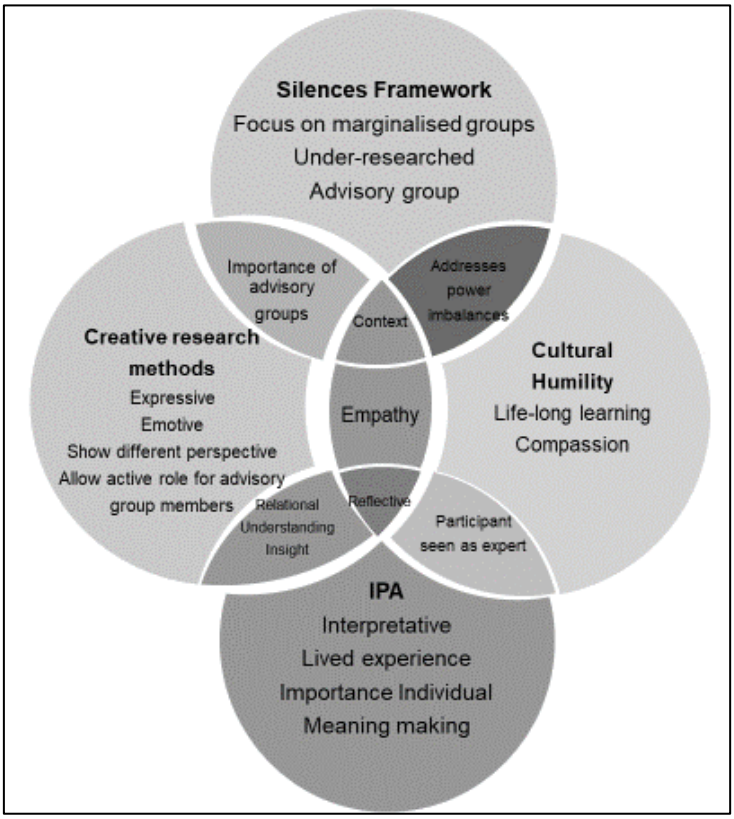


Figure 28 – Venn diagram to show the relationship between Cultural Humility, IPA , the Silences Framework and creative methods in this study

10.5.2 Critique of Interpretative Phenomenological Analysis

IPA has many limitations and within this study the steps involved in analysis were initially appealing as they gave structure and guidance to follow. However, they were also restrictive and extremely time consuming. A sense of being overwhelmed by the processes involved in creating themes, was also expressed by IPA researchers in the study by Wagstaff et al (2014) who compared it to “drowning in a deep bowl of spaghetti” (p8). Nolan (2011) also described feeling hampered by the structure of IPA which she initially craved. She described moving further away from participant accounts as she tried to ‘herd’ her findings into themes. The benefit of reporting on individual case studies was thus advocated (Nolan, 2011).

Whilst it is clear that IPA can help with the creation of rich data and what Van Manen (1990) describe as thoughtfulness, in gathering other people’s experiences to “allow us to become more experienced ourselves” (p62). There are researchers who are dubious as to the existence of unique IPA features (Nolan, 2011). Following this study, I too wonder if despite some of the benefits articulated in the literature, I may have gathered a similar quality and depth of data from a reflexive thematic analysis approach.

A further aspect which is not always discussed in the literature around selection of methodology is researcher confidence. IPA offered a very good starting board, with clear boundaries to work within. When creating new research expertise this was helpful and at times comforting, but also gave a platform for further ideas and how they might be elaborated within differing methodological styles and frameworks for the future.

10.6 Advisory group support with the creation of recommendations

A further method of valuing advisory group expertise was the utilisation of the ‘What did I hear?’ method from Krishnasamy, (2022). This work comes from an awareness of the importance of co-creation of new knowledge in health research with advisory group members. Co-creation aims to move ‘beyond ivory towers’ and deliver dynamic partnerships with the potential for increased relevance, sensitivity and impact of research (Greenhalgh, et al 2016; Redman et al, 2021). Krishnasamy described a method for presenting initial research findings to advisory group members to seek their interpretations and look at recommendations collaboratively to enhance applicability. She used a slide set which starts with ‘what did we hear?’ and presents the current state of experience (research findings) as well as participants’ ideas for an ideal future or improvements needed in care. I used this framework to create the slides detailed in Figure 29.

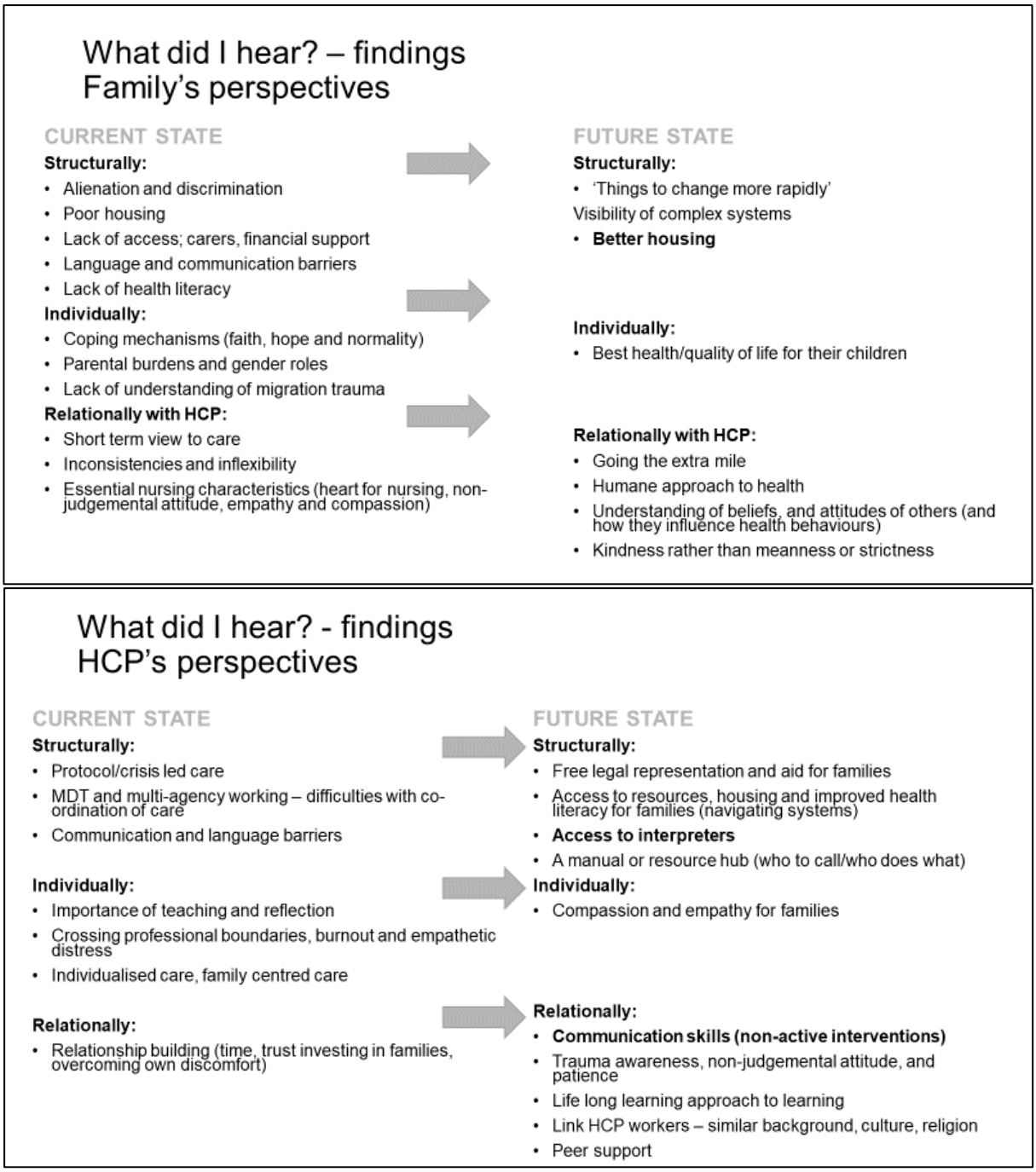


Figure 29 – Slides to show research findings from family and HCP perspectives to advisory group members

The advisory groups who have collaborated throughout this study included; BARA, YPAG, Parent champions, TfSL ethnically diverse support group leaders and Palliative Care network HCP specialists, and an interpreter group. All groups were asked to share their thoughts on how the findings might translate to recommendations for practice and research by being asked, ‘what do you think needs to happen next and why?’.

Discussing my findings with advisory group members was an interesting experience and offered me many practical solutions to my interpretations and in implementing my findings. The value of education was prioritised by all groups. In terms of implementing education into practice, the idea of including faith communities, refugee charities and the importance of lived experiences/case studies into teaching was discussed. The YPAG members felt such training should be mandatory for all HCPs and the specialists in palliative care discussed the benefits of incorporating Cultural Humility into specific modules for existing nursing and medical training. The need for self-awareness within family – HCP interactions and an individual focus to each family’s care was also debated. The use of film and infographics was advocated to help reach and engage different audiences.

Communication barriers were also a focus of discussion, with a need for openness in dialogue with families, better access to interpreters and link workers and the use of health passports to inform interactions. Support for forced migrant families in dealing with migration trauma was recognised by the advisory groups but also for the HCPs who care for them. The expertise shared with me from my advisory groups will be

taken forward into my recommendations section. Further quotations and comments from advisory group members can be found in Appendix 21.

My study brings an additional dimension to the existing literature, in that it explores the experiences of forced migration coupled with children's palliative care through the eyes of three families. This study has used creative methods of art and poetry to further illuminate the experiences of these families, as a way to educate HCPs and highlight the consequences for families when the care they experience is optimised or hindered in different care settings.

10.7 Combined findings in poetic form

In order to fully conclude this stage, the experiences of all three families have been compiled in my poem 'Fighting imaginary Dragons and battles with Arrow Snakes and Octopuses'.

Fighting imaginary Dragons and battles with Arrow Snakes and Octopuses

Gentle, respectful family wounded by cancer, inflicting generational pain
lonely in the oncology ward, no visitors, isolated
a fish bowl to look out of and see nursing actions and behaviours
astute in their accuracy.
Those who went the extra mile, chatted, played, cared and supported
sat down rather than standing over them, like a centurion on duty.
For them hope reigned supreme, faith flowed from every core
but was sharply cut by insensitivity, strict adherence to the rules and guidelines
'You are dying Sohail' shot like an arrow snake, piercing, hissing and tearing such delicate hope
further damaged by graphic images of graves and headstones
A determined nurse, headstrong in her mission to rein back unbelief and denial from their imaged stampede.
But words matter, actions have consequences,
they can be monumental
and leave a family shaking in shock 3 years later.

Love in action, in a journey
in 11 months of hazard and peril
of questioning and disbelief
The burdens of care 24/7 for the voiceless, the unable, the disabled children.
An accidental burn, languishing then growing overnight, masquerading and hiding daily care and vigilance.
Translators not sort, misinterpretation became boundless
then pen to paper in the blink of an eye
Saved by a superhero figure, tired but enduring
called halt and spoke truth over assumption
But now they lay tentative, mole tunnels wait for their diligence
over gracious and thankful but fearful in their passivity

Busy dusty roads
to Home Office interrogation
terror at the possibility of being sold into prostitution
Missing husband, no English and so much uncertainty
a child unable to eat, fitting
mother in a hostel, men of a different faith looming in dark spaces.
Ups and downs of disease progression, crisis in hospital with an overlooked mother.
No orientation, or understanding of western process, hungry and unasked, uncared for
father absent, working, unseeing and unseen
Now back at home she fights a terrifying Octopus, so many tentacles each with its own agenda, its own priorities; to care, to profession, to agency
each becomes baffling, ink drowning out any clarity, desperation and panic for help only make it more impossible to tame or untangle.

Health care professionals battle on, fighting without weapons, resources dwindling and wills broken

without comrades to lean on,
often without understanding their direction
Swords drawn to imaginary dragons
the media, politics and negativity flow like fire from dangerous green nostrils
burning compassion and empathy to cinders.

But when that understanding comes, that moment of connection
it rains in like a waterfall, soothing and reassuring as it quenches those below
their desperation, their isolation, echoing in the caves as the water crashes
kindness filling up and overflowing with authentic compassion

A boat of optimism sails through
Two-way education penned on the side
Humility blazing in defiance and offering up a challenge to potential new farers.

10.8 Conclusion to Stage Four

In Conclusion Stage Four of the study has focussed upon data analysis and the discussion section. Broader philosophical and theoretical frameworks and literature have thus been debated alongside the findings of the study with consideration of methodological issues and limitations**.**

Chapter 11 Study contributions and recommendations

11.0 Introduction to Stage Five – Planning for Silences

Stage Five is often used as a platform within the Silences Framework for discussing the contributions of the study and recommendations regarding future service delivery action planning (Serrant-Green, 2011). Stage Five thus includes empirical and methodological contributions of this study and recommendations for future education, practice and research, further details are included in Figure 30.

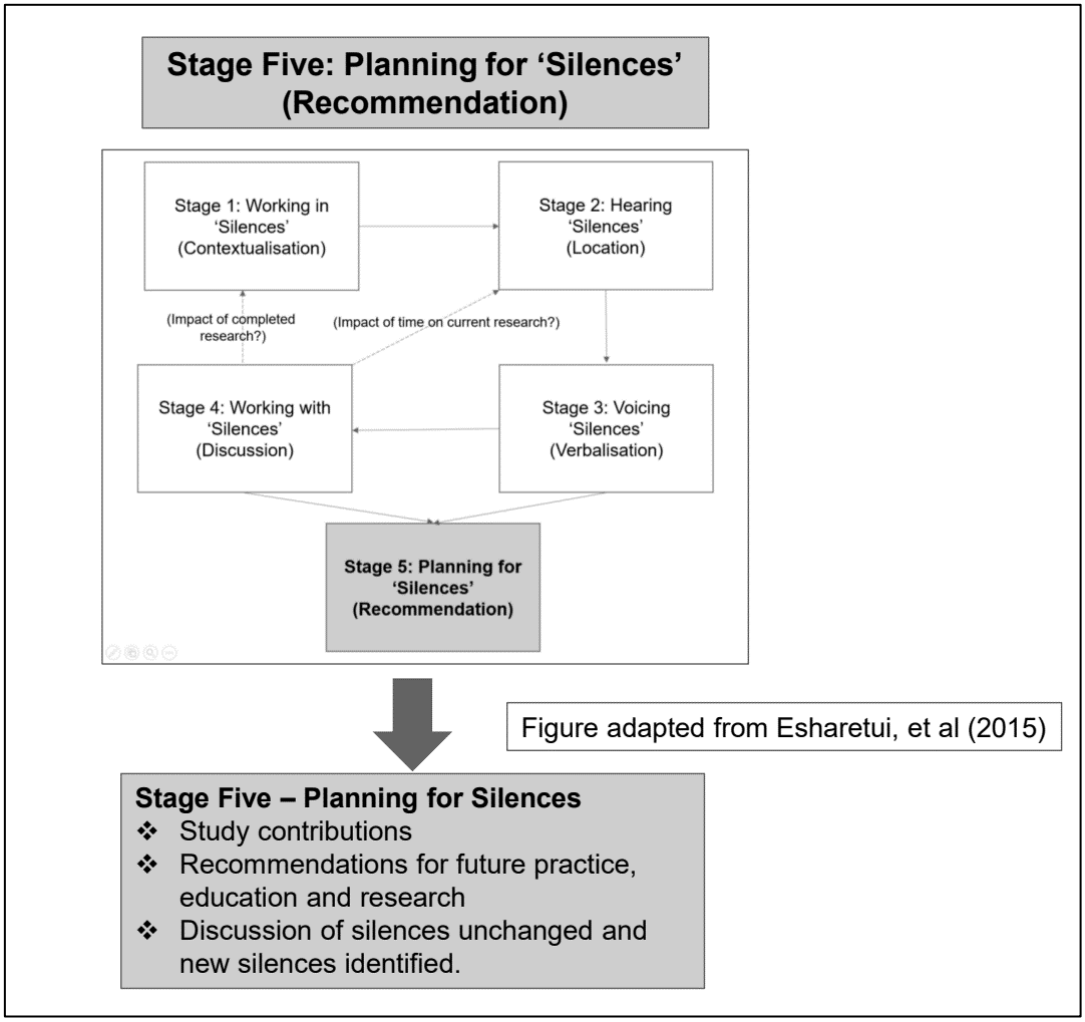


Figure 30 – Stage Five – Planning for Silences

Through this doctoral study, I have made several original contributions to knowledge. The original contribution of this study relates to the addition of new research knowledge by combining two areas of child health missing from current discourse; children's palliative care and forced migration. By combining these two areas, the marginalised voices of families have been given space to speak, be listened to and heard. A further contribution was to reveal five silences relating to distinct aspects of participant experience: 1) the overwhelming loss and grief families endured, 2) communication and relationship building, 3) faith, truth telling and hope experiences as well as the significance of belief/myth terminology, 4) alienation and discrimination experiences and 5) vicarious trauma and HCP burnout.

All these aspects demonstrate the need for the following empirical and methodological contributions of the study. The empirical contributions of this study relate to the need for a new and specific educational pathway for HCPs. Methodological contributions relate to a) the use of the Silences Framework and how advisory group input might be further extended and advocated for, b) the use of creative methods within research with marginalised communities. These will now be discussed in more detail, alongside the important implications for future practice, education and research. Advisory group recommendations have also been added following discussions with each group regarding the practical implementation of study findings.

11.1 Empirical contribution – the need for increased awareness and education

This study is original for its focus on children's palliative care for forced migrant families and is one of the first of its kind to draw together research on palliative care, children and forced migration. In it, I have identified the influence of the media, pressures upon HCP staff and wider palliative care services and resource limitations. Using IPA methods, I was able to explore the 'silences' of burdens faced by families, particularly relating to discrimination, alienation and difficulties experienced when their beliefs differed from HCPs and western families. Findings from this study indicated a lack of HCP insight, awareness and knowledge of forced migration and the potential associated trauma. Similarly, Ormrod (219) in her study about female genital mutilation experiences, discussed a theme of 'silent suffering' in which women were misunderstood, with little acknowledgement of their needs and an overreliance on individual coping strategies.

Linked closely to the need for increased awareness of forced migration, is the need for HCPs to better understand their own implicit and explicit biases. Such awareness is important, particularly as these biases can subconsciously shape the way HCPs' interact and care for families. Self-awareness and bias training links with ethical and moral reasoning for HCPs and the benefits of adopting a Cultural Humility stance in caring interactions with families. Cultural Humility was a concept that I discussed early in this study, but with further understanding of the factors which optimise and hinder care for forced migrant families, the benefits to its use could be substantial. By utilising a Cultural Humility philosophy within cultural education training of HCPs' rather than a Cultural Competence Framework, HCPs' will be better able to

understand themselves, reflect upon their care, attitudes and beliefs about power and privilege and enter a lifelong process of two-way education with families (Kimberg and Wheeler, 2019).

11.1.1 The need for improved spiritual care provision

A further element of HCPs education which appears particularly important, following the findings of this study, is that of spiritual care provision. All three families discussed the importance of their faith in coping with adversity and how their faith influenced their health care decision making. Prior to the study commencing, I was aware of the importance of valuing others' beliefs, but I had not fully understood the interweaving of faith with 'life and breath' as described by Fowler (2009). Families in this study also eloquently described the devastating consequences upon their coping mechanisms when their faith, hope and truth-telling beliefs were dismissed, misunderstood or under-prioritised by HCPs. The significance of faith was 'silenced' by a general lack of insight and understanding on the part of HCPs. Hawthorne and Gordon (2020) rationalise that the dearth of spiritual provision and education for HCPs situates spiritual care as an invisible practice. Many factors may contribute to the lack of attention paid to spirituality, including close affiliation to religion which HCPs may be fearful of misinterpreting or becoming embroiled within (Reinert and Koenig, 2013). The possibility of providing spiritual care appears to incite much fear in HCPs. These fears aware to link to concerns about imposing personal beliefs and as a result being reprimanded and/or a fear of personal spiritual vulnerability (Carr, 2010). Aspects of fear and personal vulnerability appear to combine and may result

in a reluctance to embrace, identify and integrate spirituality into HCPs practice (Hawthorne and Gordon, 2020).

11.1.2 The importance of terminology

A further ‘silence’ which was uncovered during this study, was the importance of terminology, particularly around the use of the term myth instead of belief in the general children’s palliative care literature, which may further ‘othering’ of forced migrants. Gaps in the education of HCPs were vast, with an immense need for improved and specific education to improve the care offered to forced migrant families, as such the related key recommendations for research, education and practice will now be highlighted.

11.2 Recommendations for research

Research recommendations are imbedded within the education and practice sections herein, but also specifically relate to a limitation of this study - the missing perspectives of forced migrant children themselves. Further research that captures the lived experiences of children would be advantageous to understanding more about the factors which hinder or optimise their care. A specific study focusing on children requiring palliative care would need to explore the ways to appropriately

interact and gain the views of disabled children as whilst complex this would be illuminating and extremely valuable to this field.

11.3 Recommendations for Education

Recommendations for an educational pathway involve varied strategies and topics for inclusion which are complementary and detailed below.

11.3.1 Education via lived experience

Ideally, education would focus on pre-registration and early career HCPs, as many beliefs are formed and shaped during this period (Rykkje, et al, 2021). Education strategies would involve those with lived experience of forced migration and receiving healthcare in a host country, in an already established curriculum. Such an approach could help to meet the recommendations of the HCPs and families who participated in this study and outlined a need for better HCP understanding of migration. The inclusion of lived experience of migration in the curriculum was also suggested by the BARA advisory group who advocated for improved empathy and understanding of migration. The YPAG group also suggested education via experts by experience who could share their experiences and potentially have a profound impact upon students.

11.3.2 Cultural Humility, Self-Awareness and Moral reasoning

It is hoped that by using elements of self-awareness and Cultural Humility approaches in the education of all HCPs, alongside increased understanding of forced migration trauma, may result in an increase in the enactment of the essential characteristics for care (detailed by participants in this study). Further benefits may include redressing of power imbalances and an equalising of HCP-family relationships alongside improvements in communication and quality of care, once prejudices are understood and negative judgements dispelled (Prasad et al, 2016; Lekas et al, 2020).

11.3.3 Spirituality

Currently, spirituality education provision for HCPs is sparse and inconsistent, it is therefore a recommendation of this study that spirituality education be prioritised. Present inconsistencies and a lack of direction for spiritual education in healthcare are limiting factors within its implementation (Romeiro et al, 2017), leading to the current workforce feeling underconfident and ill-equipped to provide spiritual care (Keenan and McDermott, 2017). Subsequently, a further aspect which may need additional research is the implementation of spiritual care education guidelines for working with ethnically diverse families, so that consistency can be employed across training institutions and health and social care providers.

11.3.4 Interdisciplinary education and pedagogical techniques

Whilst the educational topics discussed are important, it is equally important to consider how they may be delivered. Many techniques for teaching HCPs were suggested by the advisory groups and participants including the use of stories/narratives (parent participants), film and infographics (network specialist advisory groups) and scenarios, role play and drama. A further element which may enhance the pedagogical techniques suggested is that of an interdisciplinary approach to learning. Advisory group members from YPAG suggested the involvement of play therapy, interpreters and chaplaincy to share their experiences. Whilst the parent champions and BARA advisory groups suggested the involvement of religious/faith leaders from the community, as well as specific refugee charities who could add insights into immigration issues and provide further important links for future working with HCPs following educational activities. There are precedents for such approaches, for example a nursing school in the USA utilised community-based learning opportunities to develop a partnership between the nursing school and two refugee resettlement agencies. Such a partnership was said to improve community engagement and encourage the students to develop their awareness of cross-cultural nursing, social determinants of health and global health issues (Dunlap and Morse, 2018). A similar initiative in the UK would also help HCPs to adopt a holistic approach to care and limit divergences of belief as more awareness and understanding is developed.

Philosophies such as Cultural Humility and moral reasoning and something as existential as spirituality, are notoriously difficult to teach (Arayanasamy, 2014; Nolan, 2018). So, a further insight derived from this study is how a bricolage of

creative approaches may be invaluable in aiding critical thinking, seeing differing perspectives more clearly and supporting the interpretation of complex issues (Elhammoumi and Kellum, 2017; Timmins, 2016).

11.4 Practice recommendations

Recommendations for clinical settings were an important consideration following the findings of this study and will be outlined further herein.

11.4.1 Time and Staff Allocations

The need for additional support for forced migrant families has been highlighted by this study, as forced migrant participants described their isolation from family and their struggle to interact with HCPs or make friends. The Coronavirus pandemic had a detrimental impact upon forced migrant families. Many HCPs were redeployed from the care of forced migrant children to front line services, and families in many cases, had no social networks to help them during this period. Further, a recent report by the Disabled Children's Partnership (2023) showed additional family impacts post-pandemic of multiple waiting list delays, which are severely affecting physical and mental health as conditions worsen whilst families' wait. As a result, the need for multidisciplinary and multiagency coordination is also further highlighted, particularly for forced migrant families who may struggle to 'chase' appointments. The social isolation experienced by forced migrant families is often due to

multifaceted challenges associated with limited communication skills, fear and mistrust and difficulty connecting with others due to the all-encompassing caring role for a child with palliative needs. A further element which is alienating for forced migrant families is the complexity of UK health and social care systems, with many inaccessible bureaucratic approaches that make accessing and understanding of care pathways and service provision overly complicated and problematic (Green et al, 2014).

With this context in mind, there is a need for additional time and careful consideration of long-term staff to family allocations to allow for consistency, and reliability when HCPs are caring for forced migrant families. Enabling HCPs to spend extra time with forced migrant families would be valuable to enable effective working with interpreters, for building caring, trusting relationships and getting to know families and their individual needs. Additionally, extra time with families would help HCPs to liaise within the multidisciplinary team, but also to access support and advice from experts in the field such as Non-Profit Organisations (NGO's) and legal services to assist with complex aspects such as visa applications and obtaining financial or housing resource. Advisory group members also recommended that HCPs create better links with the charity sector, in order to provide additional support and access to befriending type services for families.

A further recommendation offered by participants and advisory group members, was the creation of a migrant hub or resource manual. This idea could create easily accessible information for families about the NHS care system but also detail resources and agencies locally. However such a recommendation may be difficult to

facilitate given the vast array of languages which materials may need to be translated into and the need for continual changes to information presented to keep it up to date. A possible additional benefit of HCPs learning and working with refugee charities and NGO's during educational activities, may help to bridge this gap in information and ensure advice given to families is up to date and expert led.

11.4.2 Prioritising access to hospice care

Forced migrant families face many challenges including poor and often inadequate housing provision, grief from leaving behind family and loved ones and poor health literacy to understand complex UK health and social care systems. All these factors place forced migrant families at increased risk of further harms. Within this study, families highlighted their need for normality, rest and respite, alongside additional support to limit their isolation and aid them with their caring role. I thus argue that there is a need to prioritise forced migrant families' access to children's hospice care. Prioritisation for hospice services would enable a further network of care providers to help meet complex need and work closely together to support forced migrant families. However, it is acknowledged here that there may be reluctance to access hospice care for some forced migrant families. As such, this area requires further research to fully understand and appreciate particularly in relation to children's palliative care, which is not currently covered by the literature.

11.4.3 Addressing communication difficulties

Communication and language difficulties were a known ‘silence’ from the outset of this study. Limited resource, in terms of interpreter support, was also well documented within the literature. This study has added to the evidence base by illuminating the consequences of limited professional interpreter support, particularly in relation to increased labelling and rapid, often inaccurate, judgement-making of forced migrant families. Utilisation of consistent interpreters was also shown within this study to help to foster rapport and trust with families. For Family Ahmed, their interpreter was seen as another member of staff who could provide care and culturally sensitive family support. When discussing my findings with my interpreter advisory group (see more in Appendix 21), they also gave examples of relationship building, and trust when interpreters had the opportunity to provide consistent support for individual families. The group also used the term ‘cultural mediation’ and described a role which included advanced language skills, but also the ability to see and understand a family’s cultural beliefs and how these might affect healthcare decision making. Further, interpreters in this advisory group gave me examples of them having a positive intermediary role, by helping HCPs to understand different cultural perspectives, but also helping families to understand HCPs expectations. This role and regular interpreter input with both families and HCPs, was thought to improve HCPs cultural awareness, and limit misunderstandings. Subsequently, I propose that interpreter support to forced migrant families is prioritised by service providers. Whilst there are no simple answers to limited financial resource in the provision of interpreters, collaboration with charities and the use of link workers and peer support may help improve access. Additionally, these strategies may help to facilitate better and more regular communication flows, allowing for regular updates

and check-ins between HCPs' and families, to help meet families' multifaceted needs and prevent miscommunications (Heller and Soloman, 2005).

11.4.4 The provision of further staff support

A final 'silence' revealed by this study was the vicarious trauma HCPs were exposed to when caring for families with both palliative and forced migration related suffering. HCPs described elements of burnout with poor staffing levels and limited specialist expertise throughout the three settings, which all appeared to impact on their ability to deliver quality care. A variety of coping strategies have been described in the literature including self-care exercises and self-reflection. Other strategies appear to agree that the development of professional relationships with those of similar clinical expertise is crucial (Liben, Papadatou and Wolfe, 2008). Relationships with other specialist children's palliative care teams can promote debriefing, provide mutual support and peer education, facilitate clinical collaborations and sharing of personal grief whilst meaning-making about the purposes of the role (Papworth, Fraser and Taylor, 2021).

As such, an additional recommendation relates to the provision of adequate support for HCPs' working with forced migrant families, with the notion of developing further national networks of training and support which could be accessed online or face to face. Such education and professional support may also help to tackle the complexities of moral distress which many HCP experience in CPC. Humphrey (2013) describes the difficulties of sitting with uncertainty in clinical practice and the associated feelings of powerlessness that can overwhelm HCPs and affect their

abilities to “serve others, alleviate suffering and support healing” (p92). One strategy suggested to address such distress is the empowerment given to HCPs through gaining additional skills and competency (Mack, 2013). It is thought that expanding HCP’s repertoire of skills to deal with ethical conflict may give them more competence and confidence in proactively addressing any moral distress and in sharing and gaining support as needed (Mack, 2013). However, it is acknowledged that the challenges facing children’s palliative care are also likely to impact on the creation and maintenance of such a network (Papworth, Fraser and Taylor, 2021), so further exploration may be necessary to implement this recommendation.

11.5 Methodological contributions

When considering the methodological contribution of this study, two important elements are proposed: changes to the Silences Framework and the use of creative research methods and coproduction with forced migrant or other marginalised families to enhance findings and interpretation.

11.5.1 Silences Framework suggested amendments

I propose that the role of advisory groups and opportunities for reflection within the framework be extended. Research advances and understanding have seen a drive in the role and need for PPI in research studies (Grant and Ramcharan, 2010; Knowles et al. 2021). Meaningful and authentic involvement and a need to include the expertise of those with lived experience is now promoted routinely by most

research funding and ethical approval bodies (Knowles et al. 2021). Serrant-Green's Silences Framework has been a driving force in promoting the use of PPI or 'collective voices' in research with marginalised groups (Serrant, 2020). At the time of creation, the Silences Framework detailed the need for a Silences Dialogue stage as a key component of discussion with collective voices to help refute or reframe the research findings with the shared expertise of relevant collective voices. However, much focus in the literature surrounding the Silences Framework appears to centre around how the Silences Dialogue stage should be implemented, rather than other aspects of advisory group involvement which may also be beneficial.

11.5.2 Silences Framework amendment recommendations

I recommend that further guidance is offered, particularly to Early Career Researchers (ECRs) on implementing the expertise of advisory group members using a stage by stage approach. Examples such as my own timeline of involvement shown in Figure 23, may be helpful in offering pragmatic structures for ECRs to follow. It is hoped such examples may help to highlight how implementing advisory group expertise and opportunities for shared reflection and feedback incrementally, can be achieved.

Stage by stage advisory group involvement would enable both a cylindrical analysis as currently recommended, but also an incremental and sustained commitment to the collective voices of a study. The collective voices from my study were added to during the seven years of my doctorate and determined by participant findings. Subsequently I felt my utilisation of the collective voices in this study was more

relational than transactional (Foster, 2009). Examples of this include the addition of the Guardian's group to help me interpret elements of discrimination and alienation in the study, the use of additional palliative care specialists' groups to include further medical perspectives and the addition of healthcare interpreters to help shape the recommendations for practice. By adding advisory groups to the study as applicable to the participants' centre of concern and utilising collective voice expertise throughout the study, I feel a higher level of involvement and relevance has been brought to the study. Additionally a two-way benefit was described by advisory group members, where they felt able to showcase their skills and expertise. In addition, examples of co-production and dialogue which have enhanced the study have also been possible.

My study utilised pre-existing advisory groups, I was thus able to become a regular agenda item for many of these groups, by communicating with the advisory group chair. Whilst this had practical benefits as I didn't have to maintain and facilitate my own advisory group, it also meant that I was seen as a contributor to the already important work such groups were doing, which I felt reduced traditional researcher authority. The chair of the group was able to direct my involvement and link appropriate members specifically to the area of need I had, whilst also being mindful of the group's individual needs.

The use of three additional elements to advisory group support within the Silences Framework is thus recommended:

1. A stage-by-stage, incremental utilisation of advisory group expertise, with the possibility of different groups with diverse expertise which may be beneficial to differing elements of the research process.
2. The addition of new advisory groups as determined by participant findings to draw on additional expertise as needed.
3. Utilisation of existing advisory groups to redress power imbalances and allow for several elements of differing areas of concern to be considered. This may be particularly helpful if the study focuses on rarer areas of concern which may not have a distinct advisory group already in existence.

11.5.3 Creative research methods and coproduction

Within this study, poetry creation has formed a unique method for dialogue and collective voice involvement. Through poetry creation advisory group members have had opportunities to share their expertise and meaningfully shape interpretations and recommendations. Tarbi and Morgan (2022) detail the importance of utilising poetry in nursing research particularly as a way to give voice to those underrepresented, especially those with serious illness and to evoke the deeper meaning of narratives. The authors claim poems are a uniquely accessible method of disseminating complex findings as they “relay layered cognitive and emotional meaning” resonant of health experience in a concise and relatable format (Tarbi and Morgan, 2022 p322). Tabi and Morgan’s (2022) research highlights the need for further work in this area, with a particular focus on co-production with advisory group members, as this is an area currently underexplored in the literature.

In order to complement the bricolage of creative approaches developed here, the creation of further artistic works by forced migrant families may also help to reinforce a counter narrative of forced migration to the UK. At the outset of this study, community hostility and negative media perceptions were captured in the background and literature review chapters. As such it appeared that ‘silences’ existed around discrimination and alienation of forced migrant families. Findings from this study confirmed that forced migrant families in children’s palliative care were also exposed to such experiences. However, a further element of ‘silence’ was found in the negative effects of the media lens upon community perceptions of forced migrants and the consequences of this for families.

Interestingly, literature published at the height of the European refugee crisis also makes links between the media portrayal and ‘othering’ of forced migrants and how this has impacted upon community empathy. In her novel ‘Gehen, ging, gegangen (Go, Went, Gone), Erpenbeck tells the tale of Richard a retired professor who is intrigued by the Oraienplatz refugee post. As Richard becomes more acquainted with the refugees, Erpenbeck places emphasis on the universality of refugee suffering and that this acknowledgement helps to flatten difference. However, Butler in 2004 (long before the Ukrainian war portrayed such examples), argues that those in the West are less likely to feel empathy for non-Westerners. She suggests that the lack of attention paid in the media to the vast number of deaths from AIDs in Africa highlight, that whilst some lives are publicly acknowledged by the media and thus grieved, other lives are seen as ‘unmarkable’ or un-mourned (p35). The narratives of refugees’ trauma told by Erpenbeck were seen to have a ‘humanising effect’ on

readers, as commonalities were showcased, producing “an intense identification by arousing feelings of fear and sorrow”, (Butler, 2004, p38).

Counter-narrative artwork is described eloquently in the ‘Colours of a Journey: An Archive of Human Mobility’ project (Anastasiou and Stanivukovic, 2019). The Colours of a Journey project used recording, memorialising and displaying varied everyday experiences of refugees in artistic forms. Such work details the importance of creating artistic opportunities for forced migrants to help them to voice their own stories, experiences and expectations.

11.5.4 Creative research methods and coproduction recommendations

Subsequently my recommendation include:

- The creative approaches used in this study have formed a toolkit of approaches and bricolage of resources such as art works, poetry and case studies, which could be used to help HCPs make sense of forced migrant families’ experiences in children’s palliative care in a different and empathetic way. Dissemination of this creative approaches’ toolkit would be advantageous to share this learning widely and may take the form of a learning event alongside advisory group members to share techniques and experiences.
- The creation of additional creative artworks is advocated to reveal further insights into the experiences of healthcare for forced migrant families. A

similar platform to the ‘Colours of a Journey’ project may be useful, for wide dissemination, with a focus on lived experiences of healthcare in the host country. This study may thus help to form the basis of such a collection with a view to expand and develop this further.

11.6 Research Recommendations and summary

Further research focusing on how creative media may be utilised is important in building the evidence base in this area. Creative media may be used as both a counter-narrative to negative media portrays of forced migrants and also as an educational tool for enhancing understanding and limiting ‘othering’ of forced migrant families. Specific evaluative research may be beneficial in learning more about the potential benefits of creative mediums and methods of co-producing research poetry.

In summary, Figure 31 details the key findings of this study and how they link to the recommendations detailed earlier. Figure 31 was created to indicate the prioritisation of recommendations, as each aspect has the potential to influence those corresponding to it and so cannot be addressed in isolation, this is highlighted with adjoining lines.

11.7 Conclusion to Stage Five

In conclusion, Stage Five has included the contributions of this study to both empirical and methodological dimensions of research. Recommendations for future practice, education and research have also been debated including the ‘silences’ which have been discovered during the course of this study and those which remain unchanged.

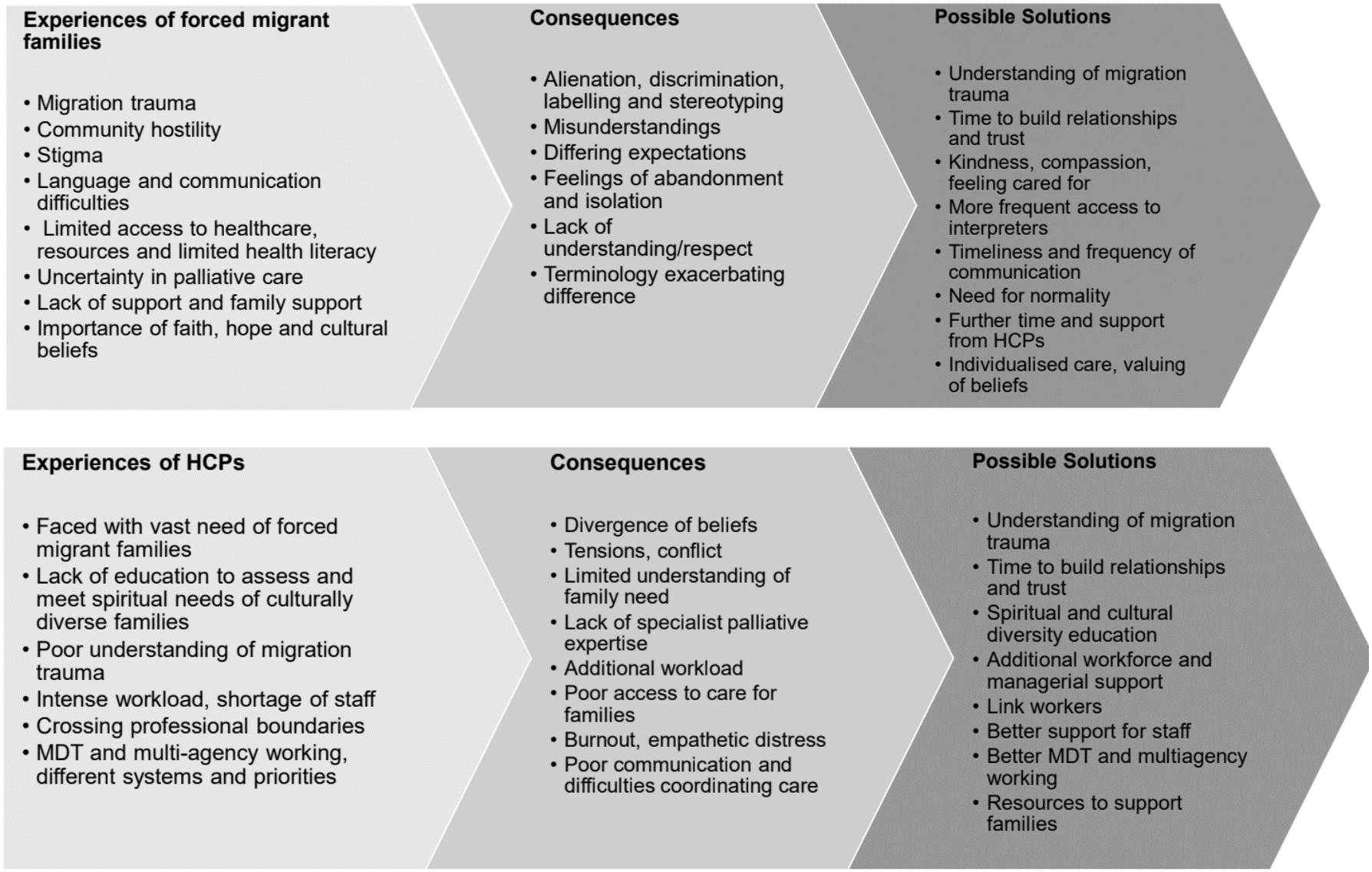


Figure 31 – Summarised findings and recommendations for future practice, education and research

11.8 Conclusion to the study

In conclusion, whilst the literature appraised for this study illuminated many ‘silences’ in both the fields of children’s palliative care and forced migration, this study has brought the two complex fields together to reveal unique insights. The experiences of both family and health care professionals have been analysed, reflected upon and synthesised with a view to improving and informing future practice, education and research priorities.

Solutions to reducing the barriers to children’s palliative care for forced migrant families, whilst optimising the examples of good care highlighted in this study will now be summarised. The empirical contribution of this study indicated limited knowledge and understanding of migration experiences and trauma and so the development of an education pathway is recommended. Including a number of topics within the education pathway, within an established curriculum for undergraduate HCPs would be beneficial. These include the use of lived experiences to increase knowledge and the use of a cultural humility approach with self-awareness and bias education alongside moral reasoning training. These aspects would serve to emphasis the role of lifelong learning in producing humble practitioners who want to redress power imbalances across professions and within their relationships with families. Additionally, the inclusion of spiritual care education is crucial to meeting need and gaining further knowledge of belief systems and their importance to families. Clear spiritual care guidance and expectations which are consistent and standardised to avoid confusion is also advocated across health and social care providers.

Educational techniques to instil such practices/topics include pedagogical approaches such as stories, narratives and participant poetry, film and infographics, scenarios, role play and drama. These aspects may aid critical thinking, offer multiple perspectives for debate and analysis and support the identification and assessment of complex issues. In conjunction with such pedagogy the inclusion of interdisciplinary training with the involvement of faith and refugee specific organisations and charities to share expertise and build supportive relationships for future practice is also recommended.

When considering practice or clinical recommendations additional time and further consideration of staff allocations, to build relationships and offer continuity to families is advocated. If additional time is given to support forced migrant families it may aid HCPs in caring for a range of complex issues, within difficult systems and whilst navigating interactions with interpreters. A further practice recommendation is the prioritising of access to hospice care for forced migrant families with the aim of providing additional support, normality, respite and limiting the isolation often experienced. It is also advised that addressing communication difficulties be prioritised by health and social care organisations, with additional funding for interpreter use and further understanding of their role and ability to provide family support. Lastly the provision of additional HCP support for those working with forced migrant families in children's palliative care, is crucial to addressing the impact of burnout and compassion fatigue described in this study.

Research implications are linked to all of the recommendations described but also include accompanying research which would specifically look at how the perspectives

of often disabled and/or non-verbal children and young people may be included in research about them.

When addressing the methodological contributions to this study an extension to the Silences Framework is suggested to further advocate for the inclusion of advisory group expertise and reflection/feedback opportunities throughout research studies. Such guidance would be particularly aimed at early career researchers and with a practical application focus. Finally, the formation of a bricolage of creative methods and a toolkit of approaches is recommended. A learning event to share the experiences of this study and advisory group members, alongside a website where resources could be widely accessed is thus advocated. Further research into creative methods would also help to strength the evidence base in this area and give a further rationale for their use.

Through the identification of specific family case studies within this study, the identification of constraints and enabling factors for high quality children's palliative care has been possible. By following the collective recommendations detailed here, health and social care organisations, education providers and research funders would assist HCPs in providing the best care for forced migrant children and their families and in limiting the barriers to poor care in the future.

Finally and perhaps most importantly is the need for care which is compassionate and humane, and takes account of individual forced migrant family's needs and experiences. HCP need to remember that each care interaction will have a consequence for family members and within palliative care there is often only one

chance to get things right and make families feel cared for and valued. As each family described within their experiences:

"I know I can't, speak English but I can read the body language, I can read from your eyes how can, you think about me" (Kinza, 13:39).

"Everybody isn't going to be the same, some people are going to be good, some aren't going to be good. So you treat people as they come across to you, rather than painting them with the same brush, or the label, that they're all immigrants" (Adiva, 24.185).

"They [nurses] *have to know they are dealing with a human, not a machine. They are not repairing a machine, this is a human, he has feelings, with heart"* (Maaz, 17.54).

Children's palliative care is a journey which HCPs go on with families as they care for them, one participant shared a very wise summary *'we can't always fix things but we can always be kind'* (Holly).

References

Abdin, S. Heath, G. Neilson, S. Byron-Daniel, J. and Hooper, N. (2021) 'Decision-making experiences of health professionals in withdrawing treatment for children and young people: A qualitative study'. *Child Care Health Development,* 48, pp531-543.

Aburn, G. H. Gott, M. and Hoare, K. (2021) 'Experiences of an insider researcher – interviewing your own colleagues'. *Nurse Researcher,* 29 (3), pp. 22-28. doi: 10.7748/nr.2021.e1794

Afshar, H. and Maynard, M. (2000) 'Gender and ethnicity at the millennium: From margin to centre'. *Ethnic and Racial Studies*, 23 (5), pp. 805–819. doi.org/10.1080/01419870050110904

Ahmed, A. Vandrevala, T. Hendy, J. Kelly, C. & Ala, A. (2019) 'An examination of how to engage migrants in the research process: building trust through an 'insider' perspective'. *Ethnicity & Health*, 27 (2), doi: 10.1080/13557858.2019.1685651

Aidoo, E. and Rajapakse, D. (2019) 'Overview of paediatric palliative care'. *BJA Education.* 19 (2), pp. 60-64.
Ajibade, B. (2021) 'Assessing the patient's needs and planning effective care'. *British Journal of Nursing*, 30 (20), pp. 1166-1171. doi: 10.12968/bjon.2021.30.20.1166.

Alden, D. L. Friend, J. Yein Lee, P. Kong Lee, Y. Trevena, L. Jenn Ng, C. Kiatpongsan, S. Lim Abdullah, K. Tanaka, M. and Limpongsanurak, S. (2018) 'Who Decides: Me or We? Family Involvement in Medical Decision Making in Eastern and Western Countries'. *Medical Decision Making*, 38(1) pp. 14–25.

Allan, J. Williams, G. Charura, D. Cohen, E. Meth, F. Shaw, M. and Taylor, S. (2017) 'The Asylum-Seeker and Refugee Experience - An Interpretative Phenomenological Analysis of Interview Data Elicited Through the Use of Artefacts'. *In: European Community Psychology Association, 10th European Congress, Reflections and Challenges, Community Psychology in the European Context*, 18 October 2017 - 20 October 2017, Newcastle, UK.

Allen, C. and Ögtem-Young, Ö. (2020) 'Brexit, Birmingham, belonging and home: the experience of secondary migrant Somali families and the dirty work of boundary maintenance'. *Safer Communities*, 19 (2), pp. 49-59. doi.org/10.1108/SC-10-2019-0035

Allen, D. Scarinci, N. and Hickson, L. (2018) 'The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review'. *International Journal of Integrated Care* 18 (2):14. doi:10.5334/ijic.3110

Ali, N., Atkin, K., Craig, G., Dadze-Arthur, A., Elliott, E. and Edwards, A. (2006) *Ethnicity, disability and work. Examining the inclusion of people with sensory*

impairments from Black and minority ethnic groups into the labour market. London: Royal National Institute for the Blind, ISBN-10: 1858786919.

Almutairi, A.F., Adlan, A.A. & Nasim, M. (2017) 'Perceptions of the critical cultural competence of registered nurses in Canada'. *BMC Nurs* 16, (47). doi.org/10.1186/s12912-017-0242-2

Alvesson, M. and Skőldberg, K. (2009) *Reflexive Methodology.* London: Sage.

Anastasiou, K. and Stanivukovic, S, N. (2019) *Colours of a Journey: An Archive of Human Mobility*. Available at: https://www.europenowjournal.org/2019/04/04/colours-of-a-journey-an-archive-of-human-mobility/#_ftn4 (Accessed: 1st December 2022)

Anfara, V. Mertz, N. T. (2006) *Theoretical Frameworks in Qualitative Research*. Thousand Oaks, California, Sage Publications Inc.

Arayanasamy, A. (2014) 'The Challenges of Teaching and Learning Spirituality in Nursing'. *Journal of Nursing Care*, 3-5.

Arias-Casais, N. Garralda, E. José Pons, J. Marston, J. Chambers, L. Downing, J. Ling, J. Rhee, J. Y. de Lima, L. Centeno, C. (2020) 'Mapping Pediatric Palliative Care Development in the WHO-European Region: Children Living in Low-to-Middle-Income Countries Are Less Likely to Access It'. *Journal of Pain and Symptom Management Vol*, 60 (4), pp.746-753.

Arieli, D. Friedman, V.J. Hirschfield, M. J. (2012) 'Challenges on the path to cultural safety in nursing education'. *International Nursing Review* 59, pp.187-193.

Ashworth, P. D. (1997) 'The variety of qualitative research: introduction to the problems'. *Nurse Education Today*.17, pp.215-218.

Asselin, M. E. (2003) 'Insider Research; issues to consider when doing qualitative research in your own setting'. *Journal for nurses in staff development,* 19 (2), pp.99-103.

Asylum Matters (2020) *Locked into poverty: life on asylum support.* Available at: https://asylummatters.org/wp-content/uploads/sites/24/2020/10/Locked-into-Poverty-Life-on-Asylum-Support-Nov-2020-Web-Ready.pdf (Accessed: 12th December 2022).
Auckland, S. (2010) BRC Guidance: Involving users in research. Available at: http://www.acprc.org.uk/Data/Resource_Downloads/a_how_to_guide_for_researchers.pdf (Accessed: 12th December 2022)

Aveyard, H. (2018) *Doing a literature review in health and social care, a practical guide.* Fourth Edition. Maidenhead, Open University Press.

Backlund, M. and Olausson, S. (202) 'Nurses' experiences as care providers for refugees in emergency and critical care in Jordan: a qualitative study'. *Glob Qual Nurs Res*, Jan-Dec (8).

Bagnoli A. (2009). 'Beyond the standard interview: The use of graphic elicitation and arts-based methods'. *Qualitative Research*, 9, pp.547–570. doi:10.1177/1468794109343625

Bartlett, F.C. (1932) *Remembering.* Cambridge, Cambridge University Press.
Batson, C. D. (2017) 'The empathy–altruism hypothesis', in Seppala, E. (ed.) *The Oxford handbook of compassion science*. Oxford, Oxford University Press, pp. 27–40.

Beatson, J. E. (2013) 'Supporting Refugee Somali Bantu Mothers with Children with Disabilities'. *Pediatric Nursing,* 39 (3), pp.142-145.

Bernard, H. R. and Gravlee, C. C. (2014) *Handbook of methods in cultural anthropology.* Second Edition. Lanham, Rowman and Littlefield.

Bhabha, H. K. (2004) *The Location of Culture*. Second edition. Abingdon, Routledge Classics.

Blinder, S. (2017) *Migration to the UK: Asylum. The Migration Observatory at the University of Oxford*. Available at: http://www.migrationobservatory.ox.ac.uk/resources/briefings/migration-to-the-uk-asylum/ (Accessed: 12th December 2022).

Bloomfield J, Pegram A. (2015) 'Care, compassion and communication'. *Nursing Standard,* 29(25), pp.45–50.

Boden, Z. Larkin, M. and Iyer, M. (2018) 'Picturing ourselves in the world: drawings, interpretative phenomenological analysis and the relational mapping interview'. *Qualitative Research in Psychology*, 16 (2) pp.218-236 DOI: 10.1080/14780887.2018.1540679

Bogdan, R. & Biklen, S.K. (1998) *Qualitative Research for Education: An Introduction to Theory and Method*. Boston, MA: Allyn & Bacon.

Boswell, C. and Cannon, S. (2018) *Introduction to Nursing Research: Incorporating evidence-based practice*. Fifth edition. Burlington, MA: Jones and Bartlett Learning.

Bourdieu, P. (1977) *Outline of a Theory of Practice*. Cambridge, Cambridge University Press.

Brach, C., & Fraserirector, I. (2000) 'Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model'. *Medical Care Research and Review,* 57, pp.181–217.

Bradbury-Jones, C. Taylor, J. and Herber, O. (2014) 'How theory is used and articulated in qualitative research: development of a new typology'. *Social Science and Medicine*, 120, pp.135-141.

Bradbury-Jones, C., Breckenridge, J., Clark, M. T., Herber, O. R., Wagstaff, C., & Taylor, J. (2017) 'The state of qualitative research in health and social science literature: A focused mapping review and synthesis'. *International Journal of Social Research Methodology*, 20(6), pp.627–645.

Braun, V. and Clarke, V. (2022) *Thematic Analysis, a practical guide*. London, SAGE Publications Limited.
Brehaut J. C, Kohen D. E, Garner R. E, et al. (2009) 'Health among caregivers of children with health problems: findings from a Canadian population-based study'. *Am J Public Health*, 99 (7), pp.1254–1262.

Brennan, F. (2020) *Spirituality, poetry and palliative care.* Available at: https://eapcnet.wordpress.com/2020/02/17/spirituality-poetry-and-palliative-care/ (Accessed 19th December 2022).

Brett, J. Staniszewska, S. Mockford, C. Herron-Marx, S. Hughes, J. Tysall, C. A. (2014) 'A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities'. *Patient,* 7, pp.387–395 DOI 10.1007/s40271-014-0065-0

Brimble, M. J. Anstey, S. and Davies, J. (2019) 'Long-term nurse-parent relationships in paediatric palliative care: a narrative review'. *International Journal of Palliative Nursing*, 25, (11) pp.542-550.

Briscoe, L. (2013) 'Becoming culturally sensitive: A painful process?' *Midwifery*, 29 (6), pp.559–565. doi: 10.1016/j.midw.2011.08.017.Epub 2011 Sep 23.

Brodaty, H., Thomson, C., Thompson, C. and Fine, M. (2005) 'Why caregivers of people with dementia and memory loss don't use services'. *International Journal of Geriatric Psychiatry*, 20(6), pp.537-546.

Brocki, J.M., & Wearden, A.J. (2006) 'A critical evaluation of the use of Interpretative Phenomenological Analysis (IPA) in health psychology'. *Psychology & Health*, 21, (1) pp.87-108.

Broom, A. Parker, R. B. Kirby, E. Kokanoic, R. Woodland, L. Lwin, Z. and Koh, E. (2019) 'A qualitative study of cancer care professionals' experiences of working with migrant patients from diverse cultural backgrounds'. *BMJ Open*, 23 (9) doi:10.1136/bmjopen-2018-025956

Brown, A. E. Howard, S. C. Baker, J. N. Ribeiro, R. C. and Lam, C. G. (2014) 'Reported Availability and Gaps of Pediatric Palliative Care in Low- and Middle-Income Countries: A Systematic Review of Published Data'. *Journal of Palliative Medicine*,17, (12). https://doi.org/10.1089/jpm.2014.0095

Browne, A. J. Varcoe, C. Smye, V. Reimer-Kirkham, S. Lynam, M. J. and Wong, . (2009) 'Cultural safety and the challenges of translating critically oriented knowledge in practice'. *Nursing Philosophy*, 10, pp.167–179

Brykczynska, G. M. and Simons, J. (2011) *Ethical and Philosophical Aspects of Nursing Children and Young People.* Chichester, John Wiley and Sons Ltd.

Bryman, A. (2004) *Social research methods.* Second Edition. Oxford, Oxford University Press.

Burnard, P. (1991) 'A method of analysing interview transcripts in qualitative research'. *Nurse Education Today*, 11, pp461-466.

Burns, E. Fenwick, J. Schmied, V. Sheehan, A. (2012) 'Reflexivity in midwifery research: the insider/outsider debate'. Midwifery, 28, pp.52-60.

Burnes, D.P.R, Antle, B. J. Williams, C. C. and Cook, L. (2008) 'Mothers Raising Children with Sickle Cell Disease at the Intersection of Race, Gender and Illness Stigma'. *Health and Social Work*, 33 (3) pp.211-220.

Busari, S. Princewill, N. Nasinde, S. and Tawfeeq, M. (2022) *Foreign students fleeing Ukraine say they face segregation, racism at border.* Available at: https://edition.cnn.com/2022/02/28/europe/students-allege-racism-ukraine-cmd-intl/index.html (Accessed: 19th December 2022).

Butler, J. (2004) *Precarious Life: The Powers of Mourning and Violence*. New York, Verso.

Bywaters, P., Ali, Z., Fazil, Q., Wallace, M., Singh, G. (2003) 'Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement'. *Health and Social Care in the Community*,11 (6), pp.502-509.

Calanzani, N. Koffman, J. Higginson, I. J. (2013) *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK. Demographic profile and the current state of palliative and end of life care provision*. Marie Curie. Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2013/palliative-and-end-of-life-care-for-black-asian-and-minority-ethnic-groups-in-the-uk.pdf (Accessed on 12th December 2022).

Campbell, C. Skovdal, M. Mupambireyi, Z. and Gregson, S. (2010) 'Exploring children's stigmatisation of AIDS-affected children in Zimbabwe through drawings and stories'. *Social Science & Medicine*, 71, pp.975–985. doi:10.1016/j.socscimed.2010.05.028

Campinha-Bacote, J. (2002) 'The process of cultural competence in the delivery of healthcare services: A model of care'. *Journal of Transcultural Nursing*, 13, pp.181–184.

Carr, T. J. (2010) 'Facing existential realities: Exploring barriers and challenges to spiritual nursing care'. *Qualitative Health Research*, 20, pp.1397-1392.

Carter, B. (2016) 'Perseverance and parents of children with complex health care needs: unsung heroes'. *Journal of Child Health Care*, 20 (3) pp.265-266.

Casey, B. Proudfoot, D. and Corbally, M. (2015) 'Narrative in nursing research: an overview of three approaches.' *Journal of Advanced Nursing*, 72 (5), pp.1203-1215.

Castañeda, H. et al (2015) 'Immigration as a social determinant of health'. *Annual Review of Public Health*, 18 (36), pp.375-392.

Castles S., Loughna S. (2005) 'Trends in Asylum Migration to Industrialized Countries, 1990–2001', in: Borjas G.J. and Crisp J. (ed.) *Poverty, International Migration and Asylum. Studies in Development Economics and Policy*. London, Palgrave Macmillan.

Chan, Z.C.Y. (2012) 'A systematic review of creative thinking/creativity in nursing education'. *Nurse Education Today*. 33 (11), pp.1382-1387.

Chang, E. Simon, M. and Dong, X. (2012) 'Integrating cultural humility into health care professional education and training'. *Advances in Health Sciences Education*, 17, pp.269–278 doi: 10.1007/s10459-010-9264-1

Charmaz, K. (2008) 'Grounded Theory as an Emergent Method', in Hesse-Biber, S. N. and Leavy, P. (ed.) *Handbook of Emergent Methods*, NY, Guilford Press.

Chidiac, C. Feuer, D. Flatley, M. Rodgerson, A. Grayson, K. and Preston, N. (2020) 'The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation'. *Palliative Medicine*, 34 (9), pp.1241-1248.

Children's Society (2012) *'I don't feel human' experiences of destitution among young refugees and migrants.* Available at: https://www.basw.co.uk/resources/i-don%E2%80%99t-feel-human%E2%80%99 (Accessed: 12th December 2022).

CLAHRC North Thames (2018) *CLAHRCBITE - Brokering Innovation Through Evidence. Barriers to Research Access: Voices, Experiences and Solutions (BRAVES).* Available at: http://clahrc-norththames.nihr.ac.uk/wp-content/uploads/2018/11/CLAHRC_NT_-BITE_BRAVES_Final.pdf (Accessed: 12th December 2022)

Clancy, M. (2011) 'The double hermeneutic cycle' used in IPA methodology figure created for Masters in Public Health Dissertation submitted University of Birmingham.

Clancy, M. (2013) 'Is reflexivity the key to minimising problems of interpretation in phenomenological research?' *Nurse Researcher,* 20, (6,) pp.12-16.

Clancy, M. (2017) 'Exploring an autoethnographic stance with poetry in children's nursing'. *Journal of Research in Nursing* 22 (6-7) pp.465-476. doi: 10.1177/1744987117725364

Clancy, M. Taylor, J. Bradbury-Jones, C. and Phillimore, J. (2020) 'A systematic review exploring palliative care for families who are forced migrants'. *Journal of Advanced Nursing,* 76, (11), pp.2872-2884. doi: 10.1111/jan.14509

Clary, P. L. (2010) 'Poetry and Healing at the End of Life'. *Journal of pain and Symptom Management,* 40 (5), pp.796-800.

Clark, L. Birkhead, A.S. Fernandez, C. Egger, M.J. (2017) 'A Transcription and Translation Protocol for Sensitive Cross-Cultural Team Research'. *Qualitative Health Research* 27(12), pp.1751-1764. doi:10.1177/1049732317726761
Clarke, A. (2005) *Situational Analysis: Grounded Theory after the Post-Modern Turn*. Thousand Oaks, CA, SAGE.

Clelland, D. van Steijn, D. Macdonald, M. E. et al., (2017) 'Global development of children's palliative care: the picture in 2017' Wellcome Open Research, 5 (99) doi.org/10.12688/wellcomeopenres.15815.2

Clifford, J. and Marcus, G. E. (1986) *Writing culture: the poetics and politics of ethnography*. Berkeley, University Of California Press.

Clifford, G. (2018). *"Am iz kwiin" (I'm his queen): an exploration of mothers' disclosure of maternal HIV to their children in Kingston, Jamaica: using feminist Interpretative Phenomenological Analysis (IPA) in a resource-constrained context.* PhD thesis. Available at: https://openaccess.city.ac.uk/id/eprint/21213/ (Accessed 12th December 2022).

Cole, E. R. (2019) 'Intersectionality and research in psychology'. *American Psychologist*, 64 (3), pp.170–180. doi.org/10.1037/a0014564

Collins, A. Hennessy-Anderson, N. Hosking, S. Hynson, J. Remedios, C. and Thomas, K. (2016) 'Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study'. *Palliative Medicine*, 30 (10) pp.950–959.

Collins, A. McLachlan, S. and Philip, J. (2018) 'Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion'. *Palliative Medicine*, 32 (1) pp.133-142.

Collins, K. and Nicolson, P. (2002) 'The meaning of 'satisfaction' for people with dermatological problems: Reassessing approaches to qualitative health psychology research'. *Journal of Health Psychology*, 7, pp.615-629.

Connelly, L. Yoder, L. (2000) 'Improving qualitative proposals: Common problem areas'. *Clinical Nurse Specialist,* 14, (2), pp.69-74.

Connor, S. R. Downing, J. and Marston, J. (2017) 'Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis'. *Journal of Pain and Symptom Management,* 53 (2) pp.171-177.

Connor JA, Kline NE, Mott S, et al. (2010) 'The meaning of cost for families of children with congenital heart disease'. *Journal of Pediatric Health Care*, 24 (5), pp.318–325.

Connor, S. Sepulveda, C. (2020) *Global Atlas of palliative care*. Second Edition. Worldwide Hospice Palliative Care Alliance. Available at: https://cdn.who.int/media/docs/default-source/integrated-health-services-(ihs)/csy/palliative-care/whpca_global_atlas_p5_digital_final.pdf?sfvrsn=1b54423a_3 (Accessed: 19th December 2022).

Contro, N. Davies, B. Larson, J. Sourkes, B. (2010) 'Away from home: Experiences of Mexican American Families in Pediatric Palliative Care'. *Journal of Social Work in End of Life and Palliative Care,* 6, pp.185-204. doi.org/10.1080/15524256.2010.529020

Cook, L. S. and de Mange, B. P. (1995) 'Gaining access to Native American cultures by non-Native American nursing researchers'. *Nursing Forum*, 30, pp.5-10.

Cope, V. Jones, B. Hendricks, J. (2015) 'Portraiture: a methodology through which success and positivity can be explored and reflected'. *Nurse Researcher*, 22 (3), pp.6-12.

Corden, A. and Sainsbury, R. (2006) Using verbatim quotations in reporting qualitative social research: researchers' views. Social Policy Research Unit. doi: 10.1007/BF01762869. Available at: https://www.york.ac.uk/inst/spru/pubs/pdf/verbquotresearch.pdf (Accessed: 18th December 2022)

Crawford, P. Baker, C. (2009) 'Literature and madness: fiction for students and professionals'. *Journal of Medical Humanities*,30, pp.237-51

Creswell, J. W. (2013) *Qualitative inquiry and research design: Choosing among five approaches.* Third Edition. Thousand Oaks, CA: Sage Publications, Inc.

Culley, L. (2014) 'Editorial: Nursing and super-diversity'. *Journal of Research in Nursing* 19 (6), pp.453-455.

Danks, E. (2019) *Female Genital Mutilation (FGM): An analysis of the silences in maternity care experiences of FGM survivors and the silences of health care professionals providing maternity care to FGM survivors.* A thesis submitted to the University of Wolverhampton for the degree of Doctor of Philosophy. Available at: https://wlv.openrepository.com/handle/2436/623769 (Accessed: 19th December 2022).

Daniel, B., Taylor, J. S., & Scott, J. (2010) 'Recognition of neglect and early response: overview of a systematic review of the literature'. *Child & Family Social Work,* 15(2), pp.248-257.

Daniel, B., Taylor, J. S., & Scott, J. (2011) *Recognizing and Helping the Neglected Child: Evidence-Based Practice for Assessment and Intervention*. London, Jessica Kingsley.

Danilova, V. (2014) *Media and their role in shaping public attitude towards migrants. UNU Institute on Globalisation, cultured Mobility.* Available at: https://gcm.unu.edu/publications/articles/media-and-their-role-in-shaping-public-attitudes-towards-migrants.html (Accessed: 12th December 2022)

Darawsheh, W. (2014) 'Reflexivity in research: Promoting rigour, reliability and validity in qualitative research'. *International Journal of Therapy and Rehabilitation*, 21, (12), pp.560-568.

Davies B. Connaughty S. (2002) 'Pediatric end-of-life care: Lessons learned from parents'. *Journal of Nursing Administration*, 32(1), p.5-6

Davies, B. Contro, N. Larson, J. Widger, K. (2010) 'Culturally-Sensitive Information-sharing in Pediatric Palliative Care'. *Pediatrics,* 125 (4), pp.859-865.

Davies B, Steele R, Krueger G et al. (2017) 'Best Practice in Provider/Parent Interaction'. *Qualitative Health Research,* 27(3), pp406–420. doi. org/10.1177/1049732316664712

de Haan, M. Nabirye, E. and Gould, L. (2020) 'Social and Cultural Support', in Downing, J. (ed.) *Children's palliative care: an international case-based manual*. International Children's Palliative Care Network (ICPCN). London, Springer, pp.184-193.

DeJonckheere, M. and Vaughn, L. M. (2019) 'Semi structured interviewing in primary care research: a balance of relationship and rigour'. *Family medicine and community health*, 7(2), doi:10.1136/fmch-2018-000057

Department for Work and Pensions (2010) *Working to rebuild lives. A preliminary report towards a refugee employment strategy.* Available at: http://webarchive.nationalarchives.gov.uk/20100405155513/dwp.gov.uk/docs/main-rep.pdf (Accessed: 18th December 2022).

Deps, P. Charlier, P. (2020) 'Medical Approach to Refugees: Importance of the Caring Physician'. *Ann Glob Health,*16,86(1):41. doi: 10.5334/aogh.2779. PMID: 32322539

De Vito, E., De Waure, C., Specchia, M. L., Parente, P., Azzolini, E., Frisicale, E. M., Favale, M., Teleman, A. A. and Ricciardi, W. (2016) 'Are undocumented migrants'

entitlements and barriers to healthcare a public health challenge for the European Union?', *Public Health Reviews*, 37 (13), doi: 10.1186/s40985-016-0026-3.

D'Silva, M. Smith, S. Della, L. Potter, D. Talley, T. & Best, L. (2016) 'Reflexivity and Positionality in Researching African-American Communities: Lessons from the Field'. *Intercultural Communication Studies* XXV: 1

Disabled Children's Partnership (2023) *Failed and Forgotten.* Research by the Learning Hub at the Disabled Children's Partnership. Available at: https://disabledchildrenspartnership.org.uk/wp-content/uploads/2023/03/Failed-and-Forgotten-DCP-report-2023.pdf (Accessed: 26th March 2023).

Dixon, J. King, D. Matosevic, T. Clark, M. and Knapp, M. (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence.* Marie Curie. Available at: www.pssru.ac.uk/publication-details.php?id=4962 (Accessed: 12th December 2022)

Dobbin, F. and Kalev, A. (2018) 'Why diversity training doesn't work: the challenge for industry and academia'. *Anthropology Now*, 10, pp.48–55.

Dodds, H. and Hunter, D. J. (2022) 'Culture as both a risk and protective factor for vicarious traumatisation in nurses working with refugees: a literature review'. *Journal of Research Nursing* 27 (4) pp.357-371.

D'Silva, M. D. (2016) 'Interpreting at the End of Life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency'. *Journal of pain and symptom management*, 51,(3) pp.569-580

Dubbin, L. A. Chang, J.S. and Shim, J. K. (2013) 'Cultural health capital and the interactional dynamics of patient-centred care'. *Social Science & Medicine*, 93, pp.113–120.

Duggan, M., & Brenner, J. (2013) *The demographics of social media users -2012*. Pew Research Center. Available at: https://www.pewresearch.org/internet/2013/02/14/the-demographics-of-social-media-users-2012/ (Accessed: 18th December 2022).

Dumit NY, Honein-AbouHaidar G. (2019) 'The impact of the Syrian refugee crisis on nurses and the healthcare system in Lebanon: a qualitative exploratory study'. *Journal of Nursing Scholarship* 51(3), pp.289–298.

Duncan, B., Hart, G, Scoular, A. and Bigrigg, A. (2001) 'Qualitative analysis of psychosocial impact of Chlamydia trachomatis: implications for screening'. *British Medical Journal*, 322, pp.195 - 199.

Dunlap, R. K. and Morse, E. A. (2018) 'Refugee families and undergraduate nursing service-learning: thinking globally, acting locally', in Slagter van Tryon, P. J. (ed.)

Nursing Education, Administration and Informatics: Breakthroughs in Research and Practice. USA, Information Resources Management Association.

Einarsdottir, J. Dockett, S. Perry, B. (2009) 'Making meaning: Children's perspectives expressed through drawings'. *Early Child Development and Care*, 179, pp.217–232. doi:10.1080/03004430802666999

Elhammoumi, C. V. and Kellum, B. (2017) 'Art Images in Holistic Nursing Education'. *Religions,* 8 (103).

Elkatawneh, H. (2016) *The Five Qualitative Approaches: Problem, Purpose and Questions/The Role of Theory in the Five Qualitative Approaches/Comparative Case Study.* Available at: https://ssrn.com/abstract=2761327 (Accessed: 12th December 2022).

Elliott, R., Fischer, C.T. and Rennie, D.L. (1999) ' Evolving guidelines for the publication of qualitative research studies in psychology and related fields'. *British Journal of Clinical Psychology,* 38, pp.215-229.

Ellis, K., & Lindley, L. C. (2020) 'A Virtual Children's Hospice in Response to COVID-19: The Scottish Experience'. *Journal of pain and symptom management*, 60(2), pp.40-43. doi.org/10.1016/j.jpainsymman.2020.05.011

Emami, A. and Mazaheri, M. (2007) 'Difficulties in Recruiting Participants for a Research Study on Immigrant Dementia Caregiver: Challenges in Conducting Research with a Culturally Diverse Population'. *Journal of Immigrant & Refugee Studies,* 5(4) pp.103-108.

Engward, H. Goldspink, S. Iancu, M. Kersey, T. and Wood, A. (2022) 'Togetherness in Separation: Practical Considerations for Doing Remote Qualitative Interviews Ethically'. *International Journal of Qualitative Methods* 21, pp.1–9. doi: 10.1177/16094069211073212

Erpenbeck, J. (2017) *Go, Went, Gone*. Kindle ed. Translated by Susan Bernofsky. New York: New Directions.

Eshareturi, C. Serrant, L. Galbraith, V. Glynn, M. (2015) 'Silence of a scream: application of the Silences Framework to provision of nurse-led interventions for ex-offenders'. *Journal of Research in Nursing,* 20 (3), pp.218-231.

Esses, V. M., S. Medianu and A. S. Lawson. 2013 'Uncertainty, Threat and the Role of the Media in Promoting the Dehumanization of Immigrants and Refugees'. *Journal of Social Issues,* 69 (3), pp.518–536.

Fang, M. L. Sixsmith, J. Lawthom, R. Mountian, I. and Shahrin, A. (2015) 'Experiencing 'Pathologized Presence and Normalized Absence; Understanding Health Related Experiences and Access to Health Care among Iraqi and Somali

Asylum Seekers, Refugees and Persons Without Legal Status'. *BMC Public Health* 15, 923.

Fassetta, G. (2016) 'Using photography in research with young migrants: addressing questions of visibility, movement and personal spaces'. Children's Geographies, 14 (6) pp.1-15.

Featherstone, V. A. and Sandfield, A. (2013) 'The Coconut Day: A poetic Interpretation of Seizure Experiences'. *Forum: Qualitative Social Research*, 14, (2), Art. 18

Fellin, M. King, G. Esses, V. Lindsay, S. Klassen, A. (2013) 'Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability'. *International Journal of Migration, Health and Social Care,* 9 (3), pp.135-145.

Finlay, L. (2008) 'A dance between the reduction and reflexivity: Explicating the "phenomenological psychological attitude"', *Journal of Phenomenological Psychology,* pp.1–32. doi: 10.1163/156916208X311601.

Finlay, L. (2009) 'Debating Phenomenological Research Methods', *Phenomenology & Practice,* 3(1), pp.6–25. doi: 10.1007/978-94-6091-834-6_2.

Finlay, L. (2002a) 'Outing' the researcher: the provenance, principles and practice of reflexivity'. *Qualitative Health Research*, 12 (3), pp.531-45.

Finlay, L. (2002b) 'Negotiating the swamp: the opportunity and challenge of reflexivity in research practice'. *Qualitative Research*, 2 (2) pp.209-30.

Finlay, L. Gough, B. (2003) *Reflexivity. A practical guide for researchers in health and social care*. Oxford, Blackwell Publishing.

Fitzgerald, D., Hinterberger, A., Narayan, J., & Williams, R. (2020) 'Brexit as heredity redux:Imperialism, biomedicine and the NHS in Britain'. *The Sociological Review*, 68(6), pp.1161–1178. doi.org/10.1177/0038026120914177

Flanagan, S. M. and Hancock, B. (2010) 'Reaching the hard to reach' - lessons learned from the Voluntary and Community Sector. A qualitative study'. *BMC Health Service Research,* 10 (92).

Flick, U. (2020) *Introducing research methodology*. London, SAGE Publications.

Flowers, P., Hart, G. and Marriott, C. (1999) 'Constructing sexual health: Gay men and 'risk' in the context of a public sex environment'. *Journal of Health Psychology*, 4, pp.483-495.

Fook, J. (2002) *Social work: Critical theory and practice*. London, Sage publications.

Foronda, C. Diana-Lyn Baptiste, D. Reinholdt, M, M. and Ousman, K. (2016) 'Cultural Humility: A Concept Analysis'. *Journal of Transcultural Nursing* 27(3), pp.210–217.

Foster, J. (2009) 'Cultural humility and the importance of long-term relationships in international partnerships'. *Journal of Obstetrics Gynaecological Neonatal Nursing,* 38(1), pp.100-107. doi:10.1111/j.1552-6909.2008.00313.x

Foucault, M. (1972) *The Archaeology of Knowledge*. London, Tavistock Publications.

Fowler, M. (2009) 'Religions, spirituality, ethics and nursing'. *Nursing Ethics*,16 (4).

Frank, A. W. (2010) *Letting stories breathe*. Chicago, IL, University of Chicago Press.

Fraser, L. et al. (2012) *Life-limiting and life-threatening condition children and young people in the United Kingdom.* Final Report for Together for Short Lives: Paediatric Epidemiology Unit, Leeds University. Available at: https://www.togetherforshortlives.org.uk/app/uploads/2018/01/ExRes-Childrens-Hospices-Ethnicity-Report-Leeds-Uni.pdf (Accessed: 18th December 2022).

Fraser, L. Gibson-Smith, D. Jarvis, S. Norman, P. and Parslow, R. (2020) *'Make Every Child Count' Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom.* Final Report. February 2020. Available at: https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/research/makeeverychildcount/#:~:text=%E2%80%9CMake%20Every%20Child%20Count%E2%80%9D%20will,of%20need%20in%20the%20future. (Accessed: 12th December 2022).

Fraser, L. Murtagh, F. Aldridge, J. Sheldon, T. Gilbody, S. and Hewitt, C. (2021) 'Health of mothers of children with a life-limiting condition: a comparative cohort study'. *Archives of Disease in Childhood*, 106 (10).

Fraser, N. (2000) *Rethinking Recognition*. New Left Review. Available at: https://newleftreview.org/issues/ii3/articles/nancy-fraser-rethinking-recognition (Accessed: 12th December 2022).

Fraser, N. and Honneth, A. (2003) *Redistribution or recognition? A political-philosophical exchange.* London, Verso.

Fraser, N. (2003) Social Justice in an Age of Identity Politics', in Fraser, N. and Honneth, A. (ed.) *Redistribution or recognition? A political-philosophical exchange*. London, Verso.

Fraser, N. (2008) *Scales of Justice: reimaging political space in a globalizing world*. New York, Columbia University Press and Polity Press.

French, K. (2010) 'Review: the Sound of 'silence' a framework for researching sensitive issues or marginalised perspectives in health'. *Journal of Research in Nursing*, 16 (4), pp.361-362.

Freysteinson W, Lewis Lengelle, R., Meijers, F. and Hughes, D. (2016) 'Creative writing for life design: reflexivity, metaphor and change processes through narrative'. *Journal of Vocational Behavior*, 97, pp.60-67. doi.org/10.1016/j.jvb.2016.07.012

Friedrichsdorf, S. J. and Bruera, E. (2018) 'Delivering Pediatric Palliative Care: From Denial, Palliphobia, Pallilalia to Palliactive'. *Children*, 5, (120) doi:10.3390/children5090120

Funk, L., Stajduhar K.L., Toye, C., Aoun, S., Grande, G.E. and Todd C.J. (2010) 'Part 2: home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008)'. *Palliative Medicine*, 24 (6), pp.594–607.

Furman, R. Lietz, C. and Langer, C. L. (2006) 'The Research Poem in International Social Work: Innovations in Qualitative Methodology'. *International Journal of Qualitative Methods*, 5 (3).

Gadamer, H. G. (1975) *Truth and Method*. London, Sheed and Ward.

Ganga, D. and Scott, S. (2006) 'Cultural 'insiders' and the issue of positionality in qualitative migration research: moving 'across' and moving 'along' researcher-participant divides'. *Forum: Qualitative Social Research*, 7, (3), Art. 7.

Gergen, Mary & Jones, Kip (2008) 'Editorial: A conversation about performative social science'. *Forum Qualitative Social Research*, 9 (2), Art. 43.

Ghirotto, L. Busani, E. Salvati, M. Di Marco, V. (2019) 'Researching children's perspectives in pediatric palliative care: a systematic review and meta-summary of qualitative research'. *Palliative and Supportive Care*, 17, (1), pp.107-118.

Gibney, M. (2000). *Outside the protection of the law; the situation of irregular migrants in Europe.* Refugee studies working paper no. 6. Oxford: Oxford University. Available at: https://www.rsc.ox.ac.uk/files/files-1/wp6-outside-protection-of-the-law-2000.pdf (Accessed 12th December 2022).

Giorgi, A. (2010) 'Phenomenology and the practice of science'. *Journal of the Society for Existential Analysis*, 21, (1), pp.3-23.

Gilkinson, L. J. (2009) *An Interpretative Phenomenological of Refugees" Experiences of Psychological Therapy for Trauma.* PhD thesis. Available at: https://uhra.herts.ac.uk/bitstream/handle/2299/4470/Laura%20Gilkinson%20-%20DClinPsy%20research%20thesis.pdf?sequence=1 (Accessed: 12th December 2022).

Gilmour, F. Riccobono, R. Haraldsdottir, E. (2020) 'The value of poetry therapy for people in palliative and end of life care'. *Progress in Palliative Care,* 28(1), pp6-13.

Gleeson, C. Frost, R. Sherwood, L. Shevlin, M. Hyland, P. Halpin, R. et al (2020) 'Post-migration factors and mental health outcomes in asylum-seeking and refugee populations: a systematic review'. *European Journal of Psychotraumatology*. 11, (1).

Goodall, D. (2014) *An Interpretative Phenomenological Study Exploring Designated Teachers' Experiences of Supporting Looked After Children*. Dissertation. Available at: https://etheses.whiterose.ac.uk/6660/1/DT%20IPA%20Thesis.pdf (Accessed: 12th December 2022)

Gordon, I., Scanlon, K., Travers, T. and Whitehead, C. (2009) *Economic impact on the London and UK economy of an earned regularisation of irregular migrants to the UK*. London, LSE

Gower, C. Higgins, A. Doherty, N. and McCormack, D. (2017) 'Understanding the experiences of fathers of children with congenital heart disease: An interpretative phenomenological analysis'. *Journal of Health Psychology*, 22 (11), pp.1447 –1457.

Grant, G. and Ramcharan, P. (2010) 'User Involvement in Research', in Gerrish, K. and Lacey, K. (ed.) *The Research Process in Nursing*. Sixth Edition. Chichester, Blackwell Publishing Ltd.

Gray, N. A. Boucher, N. A. Cervantes, L. Berlinger, N. Smith, S. Johnson, K. (2021) 'Hospice Access and Scope of Services for Undocumented Immigrants: A Clinician Survey'. *Journal Of Palliative Medicine*, 24, (8).

Green, A. Jerzmanowska, N. Green, M. and Lobb, E. A. (2018) 'Death is difficult in any language': A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. *Palliative Medicine*, 32 (8), pp.1419-1427.

Green, G. Davison, C. Bradby, H. Krause, K. Mejías, F.M. and Alex, G. (2014) 'Pathways to care: how superdiversity shapes the need for navigational assistance'. *Sociology of Health & Illness*, 36(8), pp.1205-1219.

Green, J. Thorogood, N. (2014) *Qualitative Methods for Health Research.* Third edition. London, Sage publications.

Greenhalgh, T. Jackson, C Shaw, S. and Janamian, T. (2016) 'Achieving research impact through co-creation in community-based health services: literature review and case study'. *The Millbank Quarterly*, 94 (2) pp.392-429.

Griffith, R. (2016) 'What is Gillick competence?' *Human Vaccines & Immunotherapeutics,* 12 (1), pp.244-247.

Griffiths, M. Schweitzer, R. and Yates, P. (2011) 'Childhood Experiences of Cancer: An Interpretative Phenomenological Analysis Approach'. *Journal of Pediatric Oncology Nursing*, 28(2) pp.83 –92.

Griffiths, R. Emrys, E. Finney Lamb, C. Eagar, S. Smith, M. (2003) 'Operation Safe Haven: the needs of nurses caring for refugees'. *International Journal of Nursing Practi*ce, 9 (3), pp.183-90. doi: 10.1046/j.1440-172x.2003.00422.x. PMID: 12801250.

Groot-Alberts, L. (2020) *The art of communicating compassion in PPE: Pantomime of Purposeful Expression*. Available at: https://palliverse.com/2020/04/30/guest-post-by-liese-groot-alberts/ (Accessed: 12th December 2022)

Grove, N. J. Zwi, A. B. (2006) 'Our health and theirs: Forced migration, othering and public health'. *Social Science & Medicine*, 62, (8), pp1931-1942. doi.org/10.1016/j.socscimed.2005.08.061.

Guba, E. G. (1990) *The Paradigm Dialogue*. London, Sage Publications.

Gulati, S. Watt, L. Shaw, N. Sung, L. Poureslami, I. M. Klassen, R. Dix, D. and Klassen, A. F. (2012) 'Communication and Language Challenges Experienced by Chinese and South Asian Immigrant Parents of Children with Cancer in Canada: Implications for Health Services Delivery'. *Pediatric Blood Cancer*, 58, pp.572-578.

Guo, P. Alajarmeh, S. Alarja, G. Alrjoub, W. Al-Essa, A. Abusalem, L. Mansour, A. Sullivan, R. Shamieh, O. and Harding, R. (2021) 'Compounded trauma: A qualitative study of the challenges for refugees living with advanced cancer'. *Palliative Medicine* 35 (5), pp.916–926.

Hahessy, S. (2015) 'Reflections on the use of Poetry in Nurse Education: Speaking a Credible Language of Care'. *Nurse education in Practice*, 16 (1), pp140-3.

Hamid, M. M. (2020) *Am I a Number or a Human Being?* Available at: https://www.sounddelivery.org.uk/2020/04/md-mominul-hamid-am-i-a-number-or-a-human-being/ (Accessed: 18th December 2022)

Hanna and Mwale, (2017) 'I'm Not with You, Yet I Am' in Braun, V. Clarke, V. and Gray, D. (ed.) *Collecting Qualitative Data: A Practical Guide to Textual, Media and Virtual Techniques*. Cambridge, Cambridge University Press.

Harper, M. O'Connor, R. Dickson, A. and & O'Carroll, R. (2011) 'Mothers continuing bonds and ambivalence to personal mortality after the death of their child – An interpretative phenomenological analysis.' *Psychology, Health & Medicine*, 16 (2), pp.203-214. doi: 10.1080/13548506.2010.532558.

Harrad, R. Cosentino, C. Keasley, R. Sulla, F. (2019) 'Spiritual care in nursing: an overview of the measures used to assess spiritual care provision and related factors amongst nurses'. *Acta Biomed,* 90 (4) pp.44-55.

Hawthorne, D. M. and Gordon, S. C. (2020) 'The Invisibility of Spiritual Nursing Care in Clinical Practice'. *Journal of Holistic Nursing American Holistic Nurses Association,* 38 (1), pp.147–155.

Hefferon, K. and Gil-Rodriguez, E. (2011) 'Methods: Interpretative phenomenological analysis'. *The Psychologist*, 24, pp.756-9.

Heidegger, M. (1962) *Being and Time*. Oxford, Blackwell.

Heller, K. S. Solomon, M. Z. (2005) 'Continuity of Care and Caring: What Matters to Parents of Children with Life-Threatening Conditions'. *Journal of Pediatric Nursing*, 20, (5).

Hendricks-Ferguson V. (2007) 'Parental perspectives of initial end-of-life communication'. *International Journal of Palliative Nursing*, 13 (11), pp.1-10.

Hendricks-Ferguson, V. L. Sawin, K. J. Montgomery, K. Dupree, C. Phillips-Salimi, C. R. Carr, B. and Haase, J. E. (2015) 'Novice Nurses' Experiences With Palliative and End-of-Life Communication'. *Journal of Pediatric Oncology*, 32 (4), pp.240-252.

Hennink, M. and Kaiser, B. N. (2022) 'Sample sizes for saturation in qualitative research: A systematic review of empirical tests'. *Social Science and Medicine,* 292.

Hill, A. (2020) *'Brink of collapse': parents of disabled children buckling under 24-hour care.* The Guardian. Available at: https://www.theguardian.com/society/2020/may/13/parents-disabled-children-buckling-under-24-hour-care-coronavirus?CMP=share_btn_fb (Accessed: 12th December 2022).

Himelstein BP, Hilden JM, Boldt AM, et al. (2004) 'Medical progress – Pediatric palliative care'. *New England Journal of Medicine*,350, pp.1752–1762.
Hogg, R. (2015) *A Guide to Research for Nurses and Midwives NHS GGC*. Available at: http://www.nhsggc.org.uk/media/234385/beginnersguidetoresearchfinal.pdf (Accessed: 12th December 2022)

Holloway, I. and Galvin, I. (2016) *Qualitative Research in Nursing and Healthcare*. London, Wiley-Blackwell.

Hong, Q.N. Pluye, P. Fàbregues, S. Bartlett, G. Boardman, F. Cargo, M. Dagenais, P. Gagnon, M.P. Griffiths, F. Nicolau, B. O'Cathain, A. Rousseau, M.C. Vedel, I. (2018) 'Mixed Methods Appraisal Tool (MMAT), version 2018 for information professionals and researchers'. *Education for Information*, 34 (4) pp.285-291.

Hui, D. and Bruera, E. (2017) 'The Edmonton Symptom Assessment System 25 Years Later: Past, Present and Future Developments'. *Journal of Pain and Symptom Management*, 53, (3), pp.630-643.

Humphrey, G. B. (2013) 'The Power of Persuasion', in Rushton, C. H. Boss, R. et al (ed.) *The Many Faces of Moral Distress Among Clinicians*. Narrative Inquiry in Bioethics, pp.89–124

Hunsaker, S., Chen, H.-C., Maughan, D., & Heaston, S. (2015) 'Factors that influence the development of compassion fatigue, burnout and compassion satisfaction in emergency department nursing'. *Journal of Nursing Scholarship*, 47(2), pp.186–194.

Hunt, D. and Smith, J.A. (2004) 'The personal experience of carers of stroke survivors: an interpretative phenomenological analysis'. *Disability and Rehabilitation*, 26, pp.1000-1011.

Hussain, J. A. Koffman, J. Bajwah, S. (2021) 'Racism and palliative care'. *Palliative Medicine*, 35 (5), pp.810-813.

Husserl, E. (1927) 'Phenomenology'. Translated by Palmer, R. E. (2014) in 'Phenomenology' Edmund Husserl's Article for the Encyclopaedia Britannica (1927): A new complete translation. *Journal of the British Society for Phenomenology*, 2 (2), pp. 77-90.

Hyett, N., Lee, K. M., Knevel, R., Fortune, T., Yau, M. K., & Borkovic, S. (2019). 'Trialling Virtual Intercultural Learning With Australian and Hong Kong Allied Health Students to Improve Cultural Competency'. *Journal of Studies in International Education,* 23(3), pp.389–406. doi.org/10.1177/1028315318786442

Ifekwunigwe J. O. (1997) 'Diaspora's daughters, Africa's orphans? On lineage, authenticity and 'mixed race' identity', in Mirza, H.S. (ed.) *Black British Feminism: A Reader.* London: Routledge, pp.127–152.

Institute for Government analysis (2021) *Timeline of UK government coronavirus lockdowns and measures.* Available at: https://www.instituteforgovernment.org.uk/sites/default/files/2022-12/timeline-coronavirus-lockdown-december-2021.pdf (Accessed: 15th January 2023).

Institute of Medicine (2003) *When Children Die: Improving palliative and end-of-life care for children and their families.* Washington DC: National Academies Press. Available at: http://www.nap.edu/catalog/10390/when-children-dieimproving-palliative-and-end-of-life-care (Accessed: 12th December 2022).

International Organisation for Migration (IOM) (2017) *Fatal Journeys Volume 3, Part 1; Improving Data on Missing Migrants.* Available at: https://publications.iom.int/system/files/pdf/fatal_journeys_volume_3_part_1.pdf (Accessed: 12th December 2022).

Iraklis, G. (2021) 'Family bonds in the midst of adversity: Insights into refugee children's coping ways'. *Clinical Child Psychology and Psychiatry*, 26(1) pp.222 – 230.

Irani, E. (2019) 'The Use of Videoconferencing for Qualitative Interviewing: Opportunities, Challenges and Considerations'. *Clinical Nursing Research*, 28(1) pp.3–8.

Isaacson, M. (2014) ‘Clarifying Concepts: Cultural Humility Or Competency’. *Journal of Professional Nursing*, 30, pp.251–258.

Jack, K. (2015) ‘The use of poetry writing in nurse education: an evaluation’. *Nurse Education Today*, 35 (9), pp.7-10.

Jack, K. (2016) *Using poetry writing to help students explore empathy.* Nursing Times, 19th May 2016. Available at: https://www.nursingtimes.net/archive/using-poetry-writing-to-help-students-explore-empathy-19-05-2016/ (Accessed: 12th December 2022).

Janes, G. Serrant, L. and Sque, M. (2019) ‘Screaming silences: lessons from the application of a new research framework’. *Nurse Researcher*, 26 (2). pp.32-36

Jeffreys, M. R. and Dogan, E. (2012) ‘Evaluating the influence of cultural competence education on students' transcultural self-efficacy perceptions’. *Journal of Transcultural Nursing,* 23, pp.188–197. doi.org/10.1177/1043659611423836.

Johnson, H. Brighton, L. J. Clark, J. Roberts, H. Pocock, L. Ogden, M., ... Evans, C. (2020). *Experiences, concerns and priorities for palliative care research during the COVID-19 pandemic: A rapid virtual stakeholder consultation with people affected by serious illness in England.* London: King's College London. https://doi.org/10.18742/pub01-034 Available at: https://kclpure.kcl.ac.uk/portal/files/130918874/PPI_COVID_REPORT_PC_25.06.2020_final.pdf#page=2 (Accessed: 12th December 2022)

Johnston, B. Jindal-Snape, D. Pringle, J. Gold, L. Grant, J. Dempsey, R. Scott, R. and Carragher, P. (2016) ‘Understanding the relationship transitions and associated end of life clinical needs of young adults with life-limiting illnesses: A triangulated longitudinal qualitative study’. *SAGE Open Medicine* 4, pp.1 –14.

Jolly, A., Thomas, S. & Stanyer, J. (2020) *London’s children and young people who are not British citizens: A profile*. London, Greater London Authority.
Joint Public Issues Team (JPIT) (2018) *Destitution, Discrimination, Distrust. The Web of the Hostile Environment.* Available at: http://www.jointpublicissues.org.uk/wp-content/uploads/2018/06/Destitution-Discrimination-Distrust.-The-web-of-the-hostile-environment.pdf (Accessed: 12th December 2022).

Jones, E. K. Kumagai, A. K. and Kittendorf, A. L. (2019) ‘Through another lens: the humanities and social science in the making of physicians’. *Medical Education*, 53(4), pp.328–330. doi: 10.1111/medu.13817

Jootun, D. and McGhee, G. (2007) ‘Learning in nursing: the student nurse experience’. *The International Journal of Learning*, 13 (10) pp.57-66.

Kalman, Y. M., Ravid, G., Raban, D. R., & Rafaeli, S. (2006) ‘Pauses and response latencies: A chronemic analysis of asynchronous CMC’.

Journal of Computer-Mediated Communication 12(1), pp.1-23.

Kelly, C. A. and O'Brien, M. R. (2015) 'Difficult decisions: An interpretative phenomenological analysis study of healthcare professionals' perceptions of oxygen therapy in palliative care'. *Palliative Medicine*, 29(10) pp.950 –958.

Kelly, A. Nel, P. W. and Nolte, L. (2016) 'Negotiating motherhood as a refugee: experiences of loss, love, survival and pain in the context of forced migration'. *European Journal of Psychotherapy & Counselling*, 18 (3), pp.252-270, doi: 10.1080/13642537.2016.1214160.

Kendall, M. and Murray, S. (2005) 'Tales of the unexpected: patients' poetic accounts of the journey to a diagnosis of lung cancer: a prospective serial qualitative interview study'. *Qualitative Inquiry*, 11, p733-751.

Kensinger, E.A. Ford, J.H. (2019) 'Retrieval of Emotional Events from Memory'. *Annu Rev Psychol.* 2019 Jul 5.

Kent, W. (2020) *Who supports the families of black and minority ethnic children with life-limiting conditions?* Thesis from Cardiff University. Available at: http://orca.cf.ac.uk/136107/ (Accessed 12th December 2022).

Khanlou, N. Haque, N. Sheehan, S. and Jones, G. (2015) '"It is an Issue of not Knowing Where to Go": Service Providers' Perspectives on Challenges in Accessing Social Support and Services by Immigrant Mothers of Children with Disabilities'. *Journal of Immigrant Minority Health*, 17, pp.1840-1847.

Killick, J. (1997) *You are words: Dementia poems*. London, Hawker Publications.

Killick, John (2005). *You and yours: Dementia.* BBC Radio 4 Interview Transcript, Available at: http://www.bbc.co.uk/radio4/youandyours/transcript_2005_46_fri_02.shtml (Accessed: 12th December 2022).

Kim, H. Sefcik, J. S. and Bradway, C. (2017) 'Characteristics of Qualitative Descriptive Studies: A Systematic Review'. *Res Nurs Health*, 40(1) pp.23–42

King, G. Desmarais, C. Lindsay, S. Pierart, G. and Tetreault, S. (2015) 'The roles of effective communication and client engagement in delivering culturally sensitive care to immigrant parents of children with disabilities'. *Disability and Rehabilitation*, 37 (15), pp.1372-1381.

Kinsella, E. A. (2006) 'Hermeneutics and Critical Hermeneutics: Exploring Possibilities within the Art of Interpretation'. *Qualitative Social Research*, 7(3). doi.org/10.17169/fqs-7.3.145

Kirkham, J. A., Smith, J. A., & Havsteen-Franklin, D. (2015) 'Painting pain: An interpretative phenomenological analysis of representations of living with chronic pain'. *Health Psychology*, 34(4), pp.398–406. doi.org/10.1037/hea0000139

Kish, A. M. Newcombe, P. A. and Haslam, D. M. (2018) 'Working and caring for a child with chronic illness: A review of current literature'. *Child; Care, Health and Development*, 44 (3) pp.343-354.

Kivunja, C. and Kuyini, A, B. (2017) 'Understanding and Applying Research Paradigms in Educational Contexts'. *International Journal of Higher Education*, 6 (5).

Knowles, G. & Cole, A. (2008) *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples and Issues*. Thousand Oaks, CA, Sage Publications.

Knowles, S. Allen, D. Donnelly, A. Flynn, J. Gallacher, K. Lewis, A. McCorkle, G. Mistry, M. Walkington, P. and Drinkwater, J. (2021) 'More than a method: trusting relationships, productive tensions and two-way learning as mechanisms of authentic co-production'. *Research involvement and engagement*, 7 (34).

Krishnasamy, M. (2022) 'Influencing cancer policy and practice through co-design'. Key note presentation from the RCN International Research Conference, Cardiff 5th September 2022.

Kromczyk, M. Khattab, N. and Abbas, T. (2021) 'The limits of tolerance: before and after Brexit and the German refugee crisis'. *Ethnic and Racial Studies* 44, (16).

Kumas-Tan, Z. Beagan, B. Loppie, C. MacLeod, A. and Frank, B. (2007) 'Measures of cultural competence: Examining hidden assumptions'. *Academic Medicine*, 82(6), pp.548–557.

Kutscher, N. Kreß, L. (2016) '"Internet is the same like food" – An empirical study on the use of digital media by unaccompanied minor refugees in Germany'. *Transnational Social Review*, 6, (1-2), pp.200-203

Kvale, S. (2002) *Dialogue as Oppression and Interview Research.* Presented at the Nordic Educational Research Association Conference Tallinn, Estonia, March 7-9, 2002. Available at: https://psy.au.dk/fileadmin/Psykologi/Forskning/Kvalitativ_metodeudvikling/NB32/dialogueopptallinnNB.pdf (Accessed: 12th December 2022).

Kvale, S. and Brinkman, S. (2009) *InterViews: learning the craft of qualitative research interviewing.* London, Sage Publications.

Kvarme, L. G. Alebertini-Fruh, E. Brekke, I. Gardsjord, R. Halvorsrud, L. and Liden, H. (2016) 'On duty all the time: health and quality of life among immigrant parents caring for a child with complex health needs'. *Journal of Clinical Nursing*, 25, pp.362-371.

Kvarme, L.G. Alebertini-Fruh, E. Liden, H. (2017) 'How do immigrant parents of children with complex health needs manage to cope in their daily lives'. *Child and Family Social Work,* 22, pp.1399-1406.

Larkin, M. (2019) *IPA presentation.* Available at: https://prezi.com/clpecwagkvoy/ipa-copy-for-fragmentation-introduction/ (Accessed: 12th December 2022).

Larkin, M., Watts, S. and Clifton, E. (2006) 'Giving voice and making sense in interpretative phenomenological analysis'. *Qualitative Research in Psychology*, 3, pp.102–120. doi: 10.1191/1478088706qp062oa.

Latonero, M. and Kift, P. (2018) 'On Digital Passages and Borders: Refugees and the New Infrastructure for Movement and Control'. *Social Media and Society* ,4 (1).

Lawrence-Lightfoot, S. (1983) *The Good High School: portraits of character and culture.* New York, Basic Books.

Lawrence-Lightfoot, S. and Hoffman Davis, J. (1997) *The Art and Science of Portraiture*. San Francisco, Jossey Bass.

Learman, L. (2015) *A dialogue with three voices: The impact of interpreters on the therapeutic alliance when working with asylum seekers and refugees who have lived through traumatic experiences.* PhD thesis. Available at: https://www.research.manchester.ac.uk/portal/en/theses/a-dialogue-with-three-voices-the-impact-of-interpreters-on-the-therapeutic-alliance-when-working-with-asylum-seekers-and-refugees-who-have-lived-through-traumatic-experiences(8101d34a-a578-4655-a3cc-ba3ec5c65e88).html (Accessed 12th December 2022).

Lee, H. (2015) *Go Set a Watchman.* USA Arrow Publishing.

Lee, P. (2005) 'The process of gatekeeping in health care research'. *Nursing Times*, 101 (32), pp.36–38.

Lee, M, C. Y. (2016) 'Finding cultural harmony in interviewing: the wisdom of the middle way'. *International Journal of Research & Method in Education,* 39 (1), pp.38-57, doi: 10.1080/1743727X.2015.1019455.

Leggo, C. (2008) 'Astonishing silence: Knowing in poetry', in Knowles,,J. G. and Cole, A. L. (ed.) *Handbook of the ARTS in qualitative research.* Thousand Oaks, CA, Sage Publications, (pp. 165–174).

Lekas, H. Pahl, K. Lewis, C. (2020) 'Rethinking Cultural Competence: Shifting to Cultural Humility'. *Health Services Insights*,13, pp.1–4.

Lewis, C. S. (2008) *The Magician's Nephew*. London, Harper Collins Publishing.

Levi, A. (2009) 'The ethics of nursing student international clinical experiences'. *JOGNN*, 38, pp.94–99. doi.org/ 10.1111/j.1552-6909.00314.x.

Levine, D. Lam, C. G. Cunningham, M. Remke, S. Chrastek, J. Klick. J. (2013) 'Best practices for pediatric palliative cancer care: a primer for clinical providers'. *Journal of Supportive Oncology,* 11(3), pp.114–125.

Liamputtong, P. Rumbold, J. Aldridge, D. Alexander, L. Allen, J. Bagley, C. (2008) *Knowing Differently: Arts-Based and Collaborative Research Methods*. New York, Nova Science Publishers.

Liben, S. Papadatou, D. Wolfe, J. (2008) 'Paediatric palliative care: challenges and emerging ideas'. *The Lancet*, 371, pp.852-64.

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic Inquiry*. Beverly Hills, CA, Sage Publications.

Lindsay, S. King, G. Klassen, A. F. Esses, V. and Stachel, M. (2012) 'Working with immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers'. *Disability and Rehabilitation*, 34 (23), pp.2007-2017.

Lira, A. Muñoz-García, A. L. & Loncon, E. (2019) 'Doing the work, considering the entanglements of the research team while undoing settler colonialism'. *Gender and Education*, 31 (4), pp.475-489. doi: 10.1080/09540253.2019.1583319

Literat, I. (2013) '"A Pencil for your Thoughts": Participatory Drawing as a Visual Research Method with Children and Youth'. *International Journal of Qualitative Methods,*12, (1), pp.84-98. doi.org/10.1177/160940691301200143

Lofland, J. and Snow, D. A. (2005) *Analyzing social settings: a guide to qualitative observation and analysis.* CA, Wadsworth.

Lo, S. B., Ianniello, L., Sharma, M., Sarnacki, D., & Finn, K. T. (2016). 'Experience implementing distress screening using the National Comprehensive Cancer Network distress thermometer at an urban safety-net hospital'. *Psycho-Oncology*, 25 (9), pp.1113-1115.

Long T, Johnson M. (2000) 'Rigour, reliability and validity in qualitative research'. *Clinical Effectiveness in Nursing*, 4 (1), pp.30–37.

Maffia, C. and Conway, S. (2008) 'Supporting the health of refugees and people seeking asylum'. Getting it Right. Unite/Community Practitioners' and Health Visitors' Association.

Majcher, I. Flynn, M. and Grange, M.(2020) *Immigration Detention in the European Union: In the Wake of the "Crisis,"* Available at:

https://www.globaldetentionproject.org/immigration-detention-in-the-european-union-in-the-shadow-of-the-crisis (Accessed: 19th December 2022)

Manathunga, C. (2013) 'Culture as a Place of Thought: Supervising Diverse Candidates', in Engels-Schwarzpaul, A. C. (ed.) *Of Other Thoughts: Non-traditional Ways to The Doctorate: A Guidebook for Candidates and Supervisors*. Rotterdam, Sense Publishers. pp.67– 82.

Mangat. S. S. (2018) 'Othering the other: explorations in identity and positionality of the transnational researcher', in Clift, B. C. Hatchard, J. and Gore, J. (ed.) *How Do We Belong? Researcher Positionality Within Qualitative Inquiry.* An Edited Volume of the Proceedings of the 4th Annual Qualitative Research Symposium at the University of Bath.

Markey, K. (2020) 'Moral reasoning as a catalyst for cultural competence and culturally responsive care'. *Nursing Philosophy,* 22. doi.org/10.1111/nup.12337

Marmot, M. (2010) *Fair Society, Healthy lives: The Marmot Review – strategic review of health inequalities in England post-2010*. London: The Marmot Review. Available at: https://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review (Accessed: 4th January 2023).

Maxwell, K. (2018) *Artwork by Turner Prize nominee artist unveiled at two borough libraries.* Available at: http://www.sthelensstar.co.uk/news/16324207.artwork-by-turner-prize-nominee-artist-unveiled-at-two-borough-libraries/# (Accessed: 12th December 2022).

Mayblin, L. (2016) 'Complexity reduction and policy consensus: Asylum seekers, the right to work and the 'pull factor' thesis in the UK context'. *British Journal of Politics and International Relations,* 18(4), pp.812–828.

Mayblin, L. Wake, M. and Kazemi, M. (2020) 'Necropolitics and the Slow Violence of the Everyday: Asylum Seeker Welfare in the Postcolonial Present'. *Sociology* 54 (1), pp.107-123.

Mays, N. and Pope, C. (2000) 'Qualitative research: rigour and qualitative research'. *British Medical Journal*, 320, pp.50–52.

Mazzei, L.A. & Jackson, A.Y. (2009) *Voice in qualitative inquiry. Challenging conventional, interpretive and critical conceptions in qualitative research*. London, Routledge.

Mbembe, A. (2003) 'Necropolitics'. *Public Culture,* 15 (1) pp.11–40.

McAndrew, S. and Warne, T. (2010) *Creative Approaches to Health and Social Care Education*. London, Palgrave Macmillan.

McCloskey, S. and Taggart, L. (2010) ‘How much compassion have I left? An exploration of occupational stress among children’s palliative care nurses’. *International Journal of Palliative Nursing*, 16, pp.233–240.

McConnell, T. Scott, D. Porter, S. (2016) ‘Healthcare staff’s experience in providing end-of-life care to children: A mixed-method review’. *Palliative Medicine*, 30 (10), pp.905-919.

McConnell-Henry, T. Chapman, Y. and Francis, K. (2011) ‘Member checking and Heideggerian phenomenology: a redundant component’. *Nurse Researcher*, 18 (2).

McKenzie, K. (2008) ‘A historical perspective of cultural competence’. *Ethnicity and Inequalities in Health and Social Care*, 1 (1), pp.5-8.

McNair, R. Taft, A. Hegarty, K. (2008) ‘Using reflexivity to enhance in-depth interviewing skills for the clinician researcher’. *BMC Medical Research Methodology*, 8 (73).

Melin-Johansson, C. Axelsson, I. Jonsson Grundberg, M. and Hallqvist, F. (2014) ‘When a Child Dies: Parents' Experiences of Palliative Care - An Integrative Literature Review’. *Journal of Pediatric Nursing*, 29, pp.660–669.

Merry, L. Clausen, C. Gagnon, A. J. Carnevale, F. Jeannotte, J. Saucier, J. and Oxman-Martinez, J. (2011) ‘Improving qualitative interviews with newly arrived migrant women’. *Qualitative Health Research*, 21, pp.976–986. doi:10.1177/1049732311403497.

Meyer, S. and Ward, P. (2014) ‘How to’ use social theory within and throughout qualitative research in healthcare contexts’. *Sociology Compass*, 8 (5), pp.525-539.

Milligan, L. (2016) ‘Insider-outsider-inbetweener? Researcher positioning, participative methods and cross-cultural educational research’. *Compare: A Journal of Comparative and International Education*, 46 (2), pp.235-250.

Mitchell, K. (2020) *The impact of medical technology upon the home and feelings of at-homeness for children and young people with complex health care needs and their family members.* Thesis from Edge Hill University. Available at: https://research.edgehill.ac.uk/ws/portalfiles/portal/36539926/Tracy_Mitchell_Final_Thesis_with_Minor_Amendments_to_upload_to_PURE_5.11.20.pdf (Accessed: 12th December 2022).

Mitchell, S. Slowther, A, Coad, J. and Dale, J. (2020) ‘Experiences of healthcare, including palliative care, of children with life- limiting and life- threatening conditions and their families: a longitudinal qualitative investigation’. *BMJ, Arch Dis Child*, 106 (6) pp570-576. doi:10.1136/ archdischild-2020-320189

Mitchell, S., Slowther, A.-M., Coad, J., & Dale, J. (2018) ‘The journey through care: study protocol for a longitudinal qualitative interview study to investigate the

healthcare experiences and preferences of children and young people with life-limiting and life-threatening conditions and their families in the West Midlands, UK'. *BMJ open*, 8(1). doi:10.1136/bmjopen-2017-018266

Mind (2009) *A civilised society. Mental health provision for refugees and asylum-seekers in England and Wales.* Available at: https://www.mind.org.uk/media-a/4399/a-civilised-society.pdf (Accessed: 12th December 2022).

Moher, D. Liberati, A. Tetzlaff, J. Altman, D. G. Altman, D. Antes, G. and Berlin, J. A. (2009). 'Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement'. *Journal of Chinese Integrative Medicine, 7*(9), pp.889-896.
Moran, D. (2002) *Introduction to Phenomenology*. London, Routledge.

Moorley, C. and West, R. (2022) 'Inclusivity in nurse education'. *Evidence Based Nursing,* 25 (3) pp75-76.

Motion, A. (2009) *The Cinder Path.* London, Faber and Faber.

Neilson, S. (2019) 'Using draw-and-tell methods to inform clinical nursing assessments with children aged 6-12 years'. *Evidence Based Nursing,* 22 (4), pp106.

NHS Centre for Reviews and Dissemination (2009) *Systematic Reviews: CRD's Guidance for Undertaking Reviews in Health Care.* Available at:http://www.york.ac.uk/inst/crd/SysRev/!SSL!/WebHelp/SysRev3.htm (Accessed: 12th December 2022).

NHS England (2017) *Palliative and End of Life Care Report for Children and Young People in the West Midlands*, The Strategy Unit. Available at: https://www.strategyunitwm.nhs.uk/sites/default/files/2018-04/Final_PPC_Report%20V3_2.pdf (Accessed: 12th December 2022).

NHS (2020a) *Who's at higher risk from Coronavirus?* Available at: https://www.nhs.uk/conditions/coronavirus-covid-19/people-at-higher-risk/whos-at-higher-risk-from-coronavirus/ (Accessed: 12th December 2022)

NHS (2020b) *Novel coronavirus (COVID-19) standard operating procedure – children and young people with palliative and end of life needs who are cared for in a community setting (home and hospice) during the COVID-19 pandemic.* Available at: https://apmonline.org/news-events/apm-covid-19-resources-for-healthcare-professionals/ (Accessed: 12th December 2022).

NHS England, (2022) *Glossary and key concepts.* Available at: https://www.england.nhs.uk/midlands/wrei/glossary-and-key-concepts/#:~:text=Meaning,of%20colour%2C%20and%20racialised%20minorities. (Accessed: 3rd August 2023).

NICE (2016) *End of life care for infants, children and young people with life-limiting conditions: planning and management.* Available at:

https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-pdf-1837568722885 (Accessed: 12th December 2022).

NIHR (2014) *Patient and public involvement in health and social care research: A handbook for researchers.* Available at: https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf (Accessed: 12th December 2022).

NIHR (2015) *Young person's advisory group.* Available at: https://www.nihr.ac.uk/blog/young-people-are-the-future/20148 (Accessed: 12th December 2022).

Nolte, A. Downing, C. Temane, A.Hastings-Tolsma, M. (2017) 'Compassion fatigue in nurses: A metasynthesis'. *Journal of Clinical Nursing*, 26, (23-24), pp.4364-4378.

Nyashanu, M. Nuwematsiko, R. Nyashanu, W. and Jidong, D. E. (2020) 'Lived experiences of stressors and problems of higher education students on teacher education course in the Eastern Highlands of Zimbabwe'. *Pan African Medical Journal,* 36(289).

Öhlen, J. (2003) 'Evocation of meaning through poetic condensation of narratives in empirical phenomenological inquiry into human suffering'. *Qualitative Health Research,* 13(4), pp.557-566.

Oktay, J. S. (2012) *Grounded theory*. NY, Oxford University Press.
Oliveira, E. and Vearey, J. (2017) *MoVE (methods: visual: explore) Examining the use of participatory visual and narrative methods to explore the lived experience of migrants in Southern Africa*. Migrating out of Poverty, research programme consortium. Available at: https://assets.publishing.service.gov.uk/media/5992f170ed915d57479fd306/WP50_Oliveira_and_Vearey_2017_MoVE_methodsvisualexplore_examining_the_use_of_participatory_FINAL.pdf (Accessed: 12th December 2022).

Osborn, M. Smith, J. (2008) 'The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis'. *British Journal of Health Psychology,* 3, (1). p65-83 doi.org/10.1111/j.2044-8287.1998.tb00556.x

Padgett, D. K. (2017) *Qualitative methods in social work research*. Third Edition. London, Sage Publishers.

Page, M.J. McKenzie, J.E. Bossuyt, P.M. Boutron, I. Hoffmann, T. C. Mulrow, C. D. et al. (2021) 'The PRISMA 2020 statement: an updated guideline for reporting systematic reviews'. *BMJ,* 372 (71). doi: 10.1136/bmj.n71.

Papadatou, D. Martinson, I. M. and Chung, P.M. (2001) 'Caring for dying children: a comparative study of nurses' experiences in Greece and Hong Kong'. *Cancer Nursing*, 24, pp.402–412.

Parry, R. (2020) *COVID-19: Evidence-based advice for difficult conversations.* Available at: https://www.realtalktraining.co.uk/app/uploads/2020/03/COVID-19-Evidence-based-advice-for-difficult-conversations-full-citations-1.pdf (Accessed: 12th December 2022)

Parveen, N. (2020) *Coronavirus crisis 'increases suffering of most vulnerable refugees'.* The Guardian. Available at: https://www.theguardian.com/world/2020/may/18/coronavirus-crisis-increases-suffering-of-most-vulnerable-refugees (Accessed: 12th December 2022).

Pawluch, D. and Neiterman, E. (2013) 'What is Grounded Theory and Where does it Come from?' in Bourgeault, I. Dingwall, R. and de Vries, R. (ed.) *The SAGE Handbook of Qualitative Methods in Health Research.* London, SAGE Publications.

Peake, J.N. Beecham, E. Oostendorp, L. J. M. Hudson, B. F. Stone, P. Jones, L. Lakhanpaul, M. Bluebond-Langner, M. (2018) 'Research barriers in children and young people with life-limiting conditions: a survey'. *BMJ Supportive & Palliative Care*, 12, pp.715-721.

Pedersen, P. (1974) 'Cross cultural communications training for mental health professionals'. *The International and Intercultural Communication Annual,* 1 pp.53–64.

Pergert, P. Ekbald, S. Enskar, K. and Bjork, O. (2008) 'Bridging obstacles to transcultural caring relationships – tools discovered through interviews with staff in pediatric oncology care'. *European Journal of Oncology Nursing*, 2, pp.35-43.

Pergert, P. Ekblad, S. Bjork, O. Enskar, K. Andrews, T. (2012) 'Protecting Family Interests: An Interview with Foreign-Born Parents Struggling On in Childhood Cancer Care'. *International Journal of Pediatrics*, Article ID 681301.

Periyakoil, V. S. Neri, E. Kraemer, H. (2015) 'No Easy Talk: A Mixed Methods Study of Doctor Reporte Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients'. *PLoS ONE* 10 (4).

Phillips, D. P. (2016) 'Interpreting and presenting marginalized voices through intersubjective accounts'. *Qualitative Research Journal*, 16 (1), pp.26-38. doi.org/10.1108/QRJ-03-2015-0020

Phillimore, J., Pertek, S., Akyuz, S., Darkal, H., Hourani, J., McKnight, P., Ozcurumez, S. and Taal, S., (2022) '"We are forgotten": forced migration, sexual and gender-based violence and coronavirus disease-2019'. *Violence against women*, 28(9), pp.2204-2230.

Piirto, J. (2002) 'The question of quality and qualifications: Writing inferior poems as qualitative research'. *International Journal of Qualitative Studies in Education*, 15 (4), pp.431-445. doi: 10.1080/09518390210145507

Pinheiro, I. and Jaff, D. (2018) 'The role of palliative care in addressing the health needs of Syrian refugees in Jordan'. *Medicine, Conflict and Survival*, 34 (1), pp.19-38.

Pirhofer, J. Bukki, J. Vaismoradi, M. Glarcher, M. and Paal, P. (2022) 'A qualitative exploration of cultural safety in nursing from the perspectives of Advanced Practice Nurses: meaning, barriers and prospects'. *BMC Nursing,* 21, (178). doi.org/10.1186/s12912-022-00960-9

Powell, R. A. Schwartz, L. Nouvet, E. Sutton, B. Petrova, M. Marston, J. Munday, D. Radbruch, L. (2017) *Palliative care in humanitarian crises: always something to offer.* The Lancet, 389, April 15th, 2017. Available at: http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(17)30978-9.pdf (Accessed: 12th December 2022)

Prentice, R. (2013) 'Ethnographic Approaches to Health and Development Research: the Contributions of Anthropology', in Bourgeault, I. Dingwall, R. and de Vries, R. (ed.) *The SAGE Handbook of Qualitative Methods in Health Research*. London, SAGE Publications.

Price J, Jordan J, Prior L, et al. (2011) 'Living through the death of a child: a qualitative study of bereaved parents' experiences'. *International Journal of Nursing Studies,* 48(11), pp.1384–1392.

Price J, Jordan J, Prior L, et al. (2012) 'Comparing the needs of families of children dying from malignant and non-malignant disease: an in-depth qualitative study'. *BMJ Supportive Palliative Care*, 2(2), pp.127–132.

Pringle J, Drummond J, McLafferty E, Hendry C (2011) 'Interpretative phenomenological analysis: a discussion and critique'. *Nurse Researcher,* 18, (3), pp.20-24.

Purnell, L. and Paulanka, B. (2003) *Transcultural care: A Culturally Competent Approach.* Philadelphia, F. A. Davis.

Racher, F. E. and Annis, R. C. (2007) 'Respecting culture and honouring diversity in community practice'. *Research and Theory for Nursing Practice: An International Journal,* 21, pp.255–270.

Ramsden, I. M. (2002) *Cultural Safety and Nursing Education in Aotearoa and Te Waipounamu.* A thesis submitted to the Victoria University of Wellington in fulfilment of the requirements for the degree of Doctor of Philosophy in Nursing. Available at: https://croakey.org/wp-content/uploads/2017/08/RAMSDEN-I-Cultural-Safety_Full.pdf (Accessed: 12th December 2022).

Rallison LB and Raffin-Bouchal S. (2013) 'Living in the in-between: families caring for a child with a progressive neurodegenerative illness'*. Qual Health Res*earch, 23(2), pp.194–206.

Rautio, P. (2009) 'Finding the Place of Everyday Beauty: Correspondence as a Method of Data Collection'. *International Journal of Qualitative Methods* 8 (2), pp.15–34.

Redman, S. Greenhalgh, T. Adedokun, L. Staniszewska, S. Denegri, S. (2021) 'Co-production of knowledge: the future'. *BMJ*, 372, doi.org/10.1136/bmj.n434
Redman-MacLaren, M. (2015) 'Becoming a researcher: an auto-ethnographic account of a doctoral researcher represented in poetry'. *Journal of Poetry Therapy*, 28 (3), pp.207-214.

Reilly, R. and Flynn, M. (2022) *The Ukraine Crisis Double Standards: Has Europe's Response to Refugees Changed?* Global Detention Project, March 2, 2022. Available at: https://www.globaldetentionproject.org/the-ukraine-crisis-double-standards-has-europes-response-to-refugees-changed (Accessed: 12th December 2022).

Remedios C, Willenberg L, Zordan R, et al. (2015) 'A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions'. *Palliative Medicine*, 29(3), pp.223–230.

Rice, R. (1999) 'A little art in home care: poetry and storytelling for the soul'. *Geriatric Nursing*, 20 (3) pp.165-166.

Richardson, L. (2000) 'Writing: A method of inquiry', in Denzin, N. and Lincoln, Y. (ed.) *Handbook of qualitative research* (second edition). London, Sage Publications. pp.923-948.

Rolfe, G. (2006) 'Reflexivity'. *International Journal of Therapy and Rehabilitation*, 13, (5), pp.215.

Rolfe G. (2006) 'Validity, trustworthiness and rigour: quality and the idea of qualitative research'. *Journal of Advanced Nursing*,53, pp.304–10

Rosenthal, L. and Lobel, M. (2016) 'Stereotypes of Black American women related to sexuality and motherhood'. *Psychology of Women Quarterly*, 40, pp.414–427. doi: 10.1177/0361684315627459.

Rossetto, M. Brand, E. M. Teixeira, L. B. De Oliveria, D. and Serrant, L. (2018) 'The Silences Framework: A method for researching sensitive themes and marginalised health perspectives (English Version)'. *Text and Context for Nursing*, 26 (4).

Royal College of Nursing (RCN) (2012) R*CN competencies; palliative care for children and young people.* Available at: https://www.rcn.org.uk/professional-development/publications/pub-007033 (Accessed: 12th December 2022).

RCN (2020) *Clinical guidance for managing COVID-19.* Available at: https://www.rcn.org.uk/clinical-topics/infection-prevention-and-control/novel-coronavirus (Accessed: 12th December 2022).

RCPCH (Royal College of Paediatrics and Child Health) (2023) *Refugee and asylum-seeking children and young people - guidance for paediatricians.* Available at: https://www.rcpch.ac.uk/resources/refugee-asylum-seeking-children-young-people-guidance-paediatricians#key-practice-considerations (Accessed 27th January 2023).

Rykkje, L. Bakstad, M. Ross, L. McSherry, W. Cone, P. and Giske, T. (2021) 'Educational interventions and strategies for spiritual care in nursing and healthcare students and staff: A scoping review'. *Journal of Clinical Nursing*, 31, pp.1440-1464.

Sacchi, S. Capone, R. Ferrari, F. Sforacchi,, F. Di Leo, S. and Ghirotto, L. (2021) '"Achieve the best while rushing against time": A grounded theory study on caring for low income immigrant cancer patients at end of life'. *Palliative Medicine*, 35(2), pp.426–436

Sajjad, T. (2022a) 'Hierarchies of Compassion: The Ukrainian Refugee Crisis and the United States' Response'. Johns Hopkins University Press. *Georgetown Journal of International Affairs,* 23, (2), pp.191-209. doi: 10.1353/gia.2022.0031

Sajjad, T. (2022b) *Ukrainian Refugees Are Welcomed With Open Arms—Not So With People Fleeing Other War-Torn Countries*, The Conversation, March 9, 2022. Available at: https://theconversation.com/ukrainian-refugees-are-welcomed-with-open-arms-not-so-with-people-fleeing-other-war -torn-countries-178491 (Accessed: 12th December 2022).

Sandelowski, M. (1993) 'Rigor or rigor mortis: the problem of rigor in qualitative research revisited'. *Advances in Nursing Science*, 16, pp.1–8.

Sandelowski, M., & Barroso, J. (2002) 'Reading qualitative studies'. *International Journal of Qualitative Methods,* 1(1).

Sawer, P. (2020) *Sudanese teenager dies in desperate attempt to reach UK from France.* The Telegraph. Available at: https://www.telegraph.co.uk/news/2020/08/19/somali-teenager-16-becomes-first-child-die-desperate-attempt/ (Accessed: 12th December 2022).

Serlachius et al (2018) 'Parental experiences of family-centred care from admission to discharge in the neonatal intensive care unit'. *Journal of Paediatrics and Child Health*, 54 pp.1227–1233

Serrant-Green, L. (2011) 'The sound of 'silence': A framework for researching sensitive issues or marginalised perspectives in health'. *Journal of Research in Nursing*, 16(4), pp.347–360.

Serrant, L. (2020) 'Silenced Knowing: An intersectional framework for exploring black women's health and diasporic identities'. *Frontiers in Sociology*, 5 (1).

Shackleton, N. Randow, M. Von and Greaves, L. (2019) 'Methods of sampling in quantitative health research', in: M. Saks and J. Allsop, (ed.) *Researching Health: Qualitative, quantitative and mixed methods.* Third Edition. London, Sage Publications. pp.227-245.

Shaw, C. Brady, L. and Davey, C. (2011) *Guidelines for Research with Children and Young People.* Available at: https://info.lse.ac.uk/staff/divisions/research-and-innovation/research/Assets/Documents/PDF/NCB-guidelinesCYP-2011.pdf (Accessed: 12th December 2022).

Shaw, R. (2010) 'Embedding reflexivity within experiential qualitative psychology'. *Qualitative Research in Psychology,* 7 (3), pp.233-243.

Shaw, R. (2011) 'Interpretative phenomenological analysis study day'. 24th June 2011. Aston University, Birmingham.

Shaw, C. Brady, L. and Davey, C. (2010) *Guidelines for Research with Children and Young People.* Available at: https://info.lse.ac.uk/staff/divisions/research-and-innovation/research/Assets/Documents/PDF/NCB-guidelinesCYP-2011.pdf (Accessed: 19th December 2022).

Shim, J. K. (2010) 'Cultural health capital a theoretical approach to understanding health care interactions and the dynamics of unequal treatment'. *Journal of Health and Social Behaviour,* 51 (1), pp.1-15.

Shivji, N. A. Meade, O. Watts, K. et al (2022) 'Reflecting on 'insider' and 'outsider' positionality when undertaking culturally sensitive research with young Pakistani men: insights from a female researcher'. *Nurse Researcher*, 30 (2), pp.24-29. doi: 10.7748/nr.2022.e1826

Sidebotham, P. Fraser, J. Fleming, P. Ward-Platt, M. and Hain, R. (2014) 'Patterns of child death in England and Wales'. *The Lancet*, 384 (9946), pp.904-14. doi: 10.1016/S0140-6736(13)61090-9.

Sigona, N. (2022) *Not an invasion, but a self-made policy failure*. Available at: https://www.birmingham.ac.uk/news/2022/not-an-invasion-but-a-self-made-policy-failure?s=03 (Accessed: 12th December 2022)

Sigona, N. and Benson, M. (2022) *The UK's Refugee 'Invasion' is a Brexit-made policy failure.* The Political Quarterly. Available at: https://politicalquarterly.org.uk/blog/the-uks-refugee-invasion-is-a-brexit-made-policy-failure/?s=03 (Accessed: 12th December 2022).

Silverman, D. (2001) *Interpreting qualitative data: Methods for analyzing talk, text and interaction.* London, Sage Publications.

Simonnot, N. Rodriguez, A. Nuenberg, M. Fille, F. ArandaFernandez, P. (2016) *Access to healthcare for people facing multiple vulnerabilities in health in 31 cities in 12 countries.* Médecins du Monde-Doctors of the World. 2016. ffhal-01493906. Available at: https://hal.archives-ouvertes.fr/hal-01493906/document (Accessed: 12th December 2022).

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (2003) *Unequal treatment: Confronting racial and ethnic disparities in health care.* Washington DC, National Academies Press.

Smith J, Noble H. (2014) 'Bias in research'. *Evidence Based Nursing,* 17, pp.2–3.
Smith, J. A. (1996) 'Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology'. *Psychology and Health,* 11 (2), pp.261-271. doi: 10.1080/08870449608400256.

Smith, J. A. and Nizza, I. E. (2022) *Essentials of Interpretative Phenomenological Analysis.* Washington, American Psychological Association.

Smith, J. A and Osborn, M. (2003) 'IPA', in Smith, J. A. (ed.) *Qualitative psychology: a practical guide to research methods*. London, SAGE publications.

Smith, J. A. and Osborn, M. (2007) 'Interpretative Phenomenological Analysis', in Smith, J. A. (ed.) *Qualitative Psychology: A Practical Guide to Research Methods*. London, Sage Publications.

Smith, J. A. and Osborn, M. (2015) 'Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain'. *British journal of pain,* 9(1), pp.41–42. doi.org/10.1177/2049463714541642

Smith, J. A. (2011) 'Evaluating the contribution of interpretative phenomenological analysis: A reply to the commentaries and further development of criteria'. *Health Psychology Review,* 5(1), pp.55–61. doi: 10.1080/17437199.2010.541743.

Smith, J. A. Flowers, P. Larkin, M. (2009) *Interpretative Phenomenological Analysis: theory, method and research.* London, SAGE publications.

Smith, J. A. Flowers, P. and Larkin, M. (2022) *Interpretative Phenomenological Analysis – Theory, Method and Research.* Second Edition. London, Sage Publications.

Smith, H. (2015) *Shocking images of drowned Syrian boy show tragic plight of refugees.* Available at: http://www.theguardian.com/world/2015/sep/02/shocking-image-of-drowned-syrian-boy-shows-tragic-plight-of-refugees (Accessed: 12th December 2022).
Smith, S. (2006) 'Encouraging the use of reflexivity in the writing up of qualitative research'. *International Journal of Therapy and Rehabilitation*, 13(5), pp.209–14.

Sneesby, L. Satchell, R. Good, P. van der Riet, P. (2011) 'Death and dying in Australia: perceptions of a Sudanese community'. *Journal of Advanced Nursing,* 67 (12), pp.2696-2702.
Søndergaard, E. Reventlow, S. (2019) 'Drawing as a Facilitating Approach When Conducting Research Among Children'. *International Journal of Qualitative Methods*, 18.

Souter, J. (2005) 'Loss of appetite: a poetic exploration of cancer patients' and their carers' experiences'. *International Journal of palliative nursing*, 11 (10) pp.524-32.

Sparkes, A. C. Nilges, L. Swan, P. and Dowling, F. (2003) 'Poetic representations in sport and physical activity: insider perspectives'. *Sport, Education and Society*, 8 pp.157-177.

Sparkes, A. C. and Douglas, K. (2007) 'Making the case for poetic representations: an example in action'. *The Sport Psychologist,* 21 pp.170-190.

Spinelli, E. (2005) *The interpreted world: an introduction to phenomenological psychology.* Second Edition. USA, Sage Publications.

Stake, R. E. (1995) *The art of case study research.* Thousand Oaks, CA, Sage Publications.

Steel, M. (2020) *Priti Patel is trying to save asylum seekers from danger – by using wave machines to keep them away.* The Telegraph. Available at: https://www.independent.co.uk/voices/priti-patel-ascension-island-asylum-seekers-ferry-wave-machine-b742236.html (Accessed: 12th December 2022).

Stewart, E. (2003) *A bitter pill to swallow: obstacles facing refugee and overseas doctors in the UK.* UNHCR, Evaluation and Policy Analysis Unit, working paper 96. Available at: http://www.unhcr.org/publ/RESEARCH/3fbb94a32.pdf (Accessed: 12th December 2022).

Stringer, E. T. (2013) *Action research: a handbook for practitioners.* Fourth Edition. Thousand Oaks, CA, Sage Publications.

Studman, A. (2020) *Coronavirus and medicine shortages: what's going on?* Available at: https://www.which.co.uk/news/2020/03/medicine-shortages-whats-going-on/ (Accessed: 12th December 2022).

Susser, I. (2015) *Blame research design for failed HIV study.* Available at: http://america.aljazeera.com/opinions/2015/3/blame-research-design-for-failed-hiv-study.html (Accessed: 12th December 2022).

Swann, O. V. Holden, K. A. Turtle, L. Pollock, L. Fairfield, C. J. Drake, T. M. Seth, S. Egan, C. Hardwick, E. Halpin, S. et al (2020) 'Clinical characteristics of children and young people admitted to hospital with covid-19 in United Kingdom: prospective multicentre observational cohort study'. *BMJ,* 370:m3249

Swinney, R. Yin, L. Lee, A. (2007) 'The role of support staff in pediatric palliative care: their perceptions, training and available resources'. *Journal of Palliative Care*, 23, pp.44–50.

Syal, R. (2022) *More than 40,000 asylum seekers in UK waiting one to three years for decision.* The Guardian, 14th November 2022. Available at: https://www.theguardian.com/world/2022/nov/14/more-than-40000-asylum-seekers-in-uk-waiting-one-to-three-years-for-decision?CMP=Share_iOSApp_Other&s=03 (Accessed: 12th December 2022).

Sydor, A. (2019) 'An interpretative phenomenological analysis of young men's experiences of addressing their sexual health and the importance of researcher reflexivity'. Journal of Research Nursing, (1-2), pp.36-46. doi: 10.1177/1744987118818865.

Taylor, J. S. D., B. Scott, J. (2012) 'Towards an international agenda for child neglect: methodological issues from a systematic review'. *Child and Family Social Work, 17*(4), pp.281-290.

Ten Ham-Baloyi, W. and Jordan, P. (2016) 'Systematic review as a research method in post-graduate nursing education'. *Health SA Gesondheid* 21, pp.120-128.

Tervalon, M. Murray-Garcia, J. (1998) 'Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education'. *Journal of Health Care for the Poor and Underserved*, 9(2), Pp.117–125.

Tessitore, F. Glovi, F. Margherita, G. (2019) 'Pre- and post-migratory experiences of refugees in Italy: an interpretative phenomenological analysis'. *Mediterranean Journal of Clinical Psychology*, 7, (3).

The Equality Act (2010) *Equality Act 2010.* Available at: https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf (Accessed: 12th December 2022).

The Home Office (2022) *Immigration statistics, year ending December 2022*. Available at: https://www.gov.uk/government/statistics/immigration-system-statistics-year-ending-december-2022/summary-of-latest-statistics (Accessed: 21st April 2023)

The Joint Commission (2010) *Advancing Effective Communication, Cultural Competence and Patient- and Family-Centered Care: A Roadmap for Hospitals.* Available at: http://www.jointcommission.org/assets/1/6/aroadmapforhospitalsfinalversion727.pdf (Accessed: 12th December 2022).

The Refugee Council. (2013). *The Truth about Asylum.* Available at: https://www.refugeecouncil.org.uk/information/refugee-asylum-facts/the-truth-about-asylum/ (Accessed: 12th December 2022).

Thomas, S. Jolly, A. and Goodson, L. (2018) *"It was like they cut off all my dreams": Emotional health and wellbeing of undocumented children in London*. University of Birmingham Institute for Research into Superdiversity (IRiS), Barnardo's. Available at: https://www.barnardos.org.uk/research/it-was-they-cut-all-my-dreams-emotional-health-and-wellbeing-undocumented-children-london (Accessed: 19th December 2022).

Thompson, A. (2015) 'Paediatric Palliative Care'. Symposium: Special Needs. *Paediatrics and Child Health,* 25, (10), pp.458-462.

Tilley-Lubbs, G.A. (2011) 'The Coal Miner's Daughter gets a PHD'. *Qualitative Inquiry,* 17 (8) pp.720-722.

Timmermans, S. (2013) 'There's more to Dying than Death: Qualitative Research on the End-of-Life', in Bourgeault, I. Dingwall, R. and de Vries, R. (ed.) *The SAGE Handbook of Qualitative Methods in Health Research*. London, Sage Publications.

Todres, L. and Galvin, K. T. (2008) 'Embodied interpretation: a novel way of evocatively re-presenting meanings in phenomenological research'. *Qualitative Research,* 8 (5), pp.568-583.

Together for Short Lives TfSL (2007) Gandhi-Rhodes, K. and Rose-Odogwu, C. (eds) *The Diversity Toolkit.* Together for short lives. Available at: http://www.togetherforshortlives.org.uk/assets/0000/3648/Diversity_Toolkit_FINAL.pdf (Accessed: 12th December 2022)

Together for Short Lives TfSL (2012) *A guide to end of life care; care of children and young people before death, at the time of death and after death.* Available at: https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-A-Guide-To-End-Of-Life-Care.pdf (Accessed: 12th December 2022).

Together for Short Lives TfSL (2018a). *Children's Palliative Care Definitions.* Available at: https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/introduction-childrens-palliative-care/ (Accessed: 12th December 2022).

Together for Short Lives (2018b) *Remembering Charlie: Why children's palliative care is about never giving up.* Available at: https://www.togetherforshortlives.org.uk/remembering-charlie-why-childrens-palliative-care-is-about-never-giving-up/ (Accessed 12th December 2022)

Together for Short Lives TfSL (2020a) *Coronavirus: Statement from Together for Short Lives.* Available at: https://www.thedonnalouise.org/latest/424-coronavirus-statement-from-together-for-short-lives (Accessed: 12th December 2022).

Together for Short Lives (2020b) *Forgotten families: families feel more isolated than ever under lockdown.* Available at: https://www.togetherforshortlives.org.uk/forgotten-

families-families-feel-more-isolated-than-ever-under-lockdown/ (Accessed: 12th December 2022).

Tremain, S. (2008) *Foucault and the government of disability*. Fourth edition. Michigan, Michigan University Press.

Touroni, E. and Coyle, A. (2002) 'Decision-making in planned lesbian parenting: an interpretative phenomenological analysis'. *Journal of Community and Applied Social Psychology,* 12, pp.194-209.

Tuffour, I. (2017) 'A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach'. *Journal of Healthcare Communications,* 2 (4), pp.52

Turner, A., Barlow, J. and Ilbery, B. (2002) 'Play hurt, live hurt: Living with and managing osteoarthritis from the perspective of ex-professional footballers'. *Journal of Health Psychology,* 7, pp.285-301.

Underwood, M. Satterthwait, L. D. Bartlett, H. P. (2010) 'Reflexivity and minimization of the impact of age-cohort difference between researcher and research participants'. *Qualitative Health Research*, 20 (11) pp.1585-95.

UNHCR – United Nations High Commissioner for Refugees (2011) UNHCR *Resettlement Handbook*, Division of International Protection. Available at: https://www.unhcr.org/46f7c0ee2.html (Accessed: 19th December 2022).

UNHCR (2016). *The 1951 Refugee Convention; Convention and protocol relating to the status of refugees.* Available at: https://www.unhcr.org/uk/1951-refugee-convention.html (Accessed: 12th December 2022).

UNHCR (2018a) *'Refugees' and 'Migrants' – Frequently Asked Questions (FAQs).* Available at: https://www.unhcr.org/news/latest/2016/3/56e95c676/refugees-migrants-frequently-asked-questions-faqs.html (Accessed: 12th December 2022).

UNHCR (2018b) *Country chapters UK – UNHCR Resettlement Handbook.* Available at: https://www.unhcr.org/40ee6fc04.html (Accessed: 12th December 2022).

UNHCR (2022) *Global Forced Displacement.* Available at: https://www.unhcr.org/uk/globaltrends.html (Accessed: 27th January 2023)

Vachon, M. Fillion, L. and Achille, M. (2012) 'Death Confrontation, Spiritual-Existential Experience and Caring Attitudes in Palliative Care Nurses: An Interpretative Phenomenological Analysis'. *Qualitative Research in Psychology*, 9 (2), pp.151-172, doi: 10.1080/14780881003663424.

Van der Geest, I. Darlington, A. E. Streng, I. C. Michiels, E. M. C. Pieters, R. and Van den Heuvel-Eibrink, M. M. (2014) 'Parents' Experiences of Pediatric Palliative Care and

the Impact on Long-Term Parental Grief'. *Journal of Pain and Symptom Management*, 47 (6), pp.1043-53.

Vasileiou, K. Barnett, J. Thorpe, S. Young, T. (2018) 'Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period'. *BMC Medical Research Methodology,* (18), 148.

Verberne, L. M., Kars, M. C., Schouten-van Meeteren, A. Y., van den Bergh, E. M., Bosman, D. K., Colenbrander, D. A and van Delden, J. J. (2019) 'Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study'. *European Journal of Pediatrics,* 178(7), pp.1075-1085.

Villanueva, G. Murphy, M, S. Vickers, D. Harrop, E. Dworzynski, K. (2016) 'End of life care for infants, children and young people with life limiting conditions: summary of NICE guidance'. *BMJ*, 355:i6385 doi: 10.1136/bmj.i6385.

Vlachou, M. (2017) *The inclusion of migrants and refuges: the role of cultural organisations.* Acesso Cultura. Available at: https://ec.europa.eu/migrant-integration/sites/default/files/2017-06/Access-Culture-migrants-refugees.pdf (Accessed: 12th December 2022).

Wagstaff, C. , Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., Senu, H., & Holland, F. (2014) 'The Accordion and the Deep Bowl of Spaghetti: Eight Researchers' Experiences of Using IPA as a Methodology'. *The Qualitative Report,* 19(24), pp.1-15. doi.org/10.46743/2160-3715/2014.1216

Wall, S. (1995) 'Epidemiology for Prevention'. *International Journal of Epidemiology* 24, pp.655–64.

Waimanawa, K. (1988) *Cultural Safety in Nursing Education in Aotearoa: The Hui Waimanawa, Otautahi, Hui Piri Ki Nga Tangaroa, Manawatu*, The Education Officer Maori Health & Nursing Ministry of Education. New Zealand Nursing Council. Available at: https://www.moh.govt.nz/NoteBook/nbbooks.nsf/0/707224BC1D4953C14C2565D700190AD9?opendocument (Accessed: 19th December 2022).

Ward, C. Glass, N. Ford, R. (2015) 'Care in the home for seriously ill children with complex needs: A narrative literature review'. *Journal of Child Health Care*, 19 (4), pp.524-531. doi:10.1177/1367493514538327

Wang, C. Horby, P. W. Hayden, F. G. and Gao, G. F. (2020) 'A novel coronavirus outbreak of global health concern'. *The Lancet*, 395, (10223), pp.470-473.

Ward, K. Amas, N. and Lagnado, J. (2008) *Supporting disabled refugees and asylum seekers: opportunities for new approaches*. Available at: https://www.metropolitan.org.uk/images/Disability-Report.pdf (Accessed: 12th December 2022)

Weaver, M. Carter, B. Keefer, P. (2016) *Essentials 7 book: Pediatric palliative care and hospice*. Glenview IL, American Academy of Hospice and Palliative Medicine.

Weaver, M. S. Mooney-Doyle, K. Patterson Kelly, K. Montgomery, K. Newman, A. R. Fortney, C. A. Bell, C. J. Spruit, J. L. Kurtz Uveges, M. Wiener, L. Schmidt, C. M. Madrigal, V. N. and Hinds, P. S. (2019) 'The Benefits and Burdens of Pediatric Palliative Care and End-of-Life Research: A Systematic Review'. *Journal of Palliative Medicine*, 22, (8).

Wertz, F. J. (2005) 'Phenomenological research methods for counselling psychology', *Journal of Counselling Psychology*, 52(2), pp.167–177.

Wilkinson, D. and Savulescu, J. (2018) 'Alfie Evans and Charlie Gard—should the law change?' *BMJ,* 361: k1891 doi: 10.1136/bmj. k1891

Wiles, R. Crow, G. Heath, S. and Charles, V. (2008) 'The Management of Confidentiality and Anonymity in Social Research'. *International Journal of Social Research Methodology,* 11 (5), pp.417-428, doi: 10.1080/13645570701622231

Williamson, D.L., Choi, J., Charchuk, M., Rempel, G.R., Pitre,N., Breitkreuz, R.S., Kushner, K.E. (2011) 'Interpreter-Facilitated Cross-Language Interviews: Explicating Processes and Assessing Validity'. *Qualitative Research,* 11, (4), pp.381-394

Willig, C. (2008) *Introducing Qualitative research in Psychology*. London, Sage.

Wimpenny, K. (2010) 'Participatory action research – an integrated approach towards practice development', in Savin-Baden, M. and Howell Major, C. (ed.) *New Approaches in Qualitative Research – Wisdom and Uncertainty*. London, Routledge, Taylor and Francis Group.

Wiseman, H. (2017) Calls for palliative care to be included in humanitarian disaster responses. Ehospice. Found online at: file:///E:/palliative%20care%20lit/Calls%20for%20palliative%20care%20to%20be%20included%20in%20humanitarian%20disaster%20responses.html accessed on 26/04/2017.

Wilson C, Crawford K, Adams K. (2022) 'Translation to practice of cultural safety education in nursing and midwifery: A realist review'. *Nurse Education Today,* 110:105265. doi.org/10.1016/j.nedt.2022.105265.

Woolf Institute (2015) *Bridging the gap: strengthening relations between hospices and Muslims of Britain*. Available at: https://www.woolf.cam.ac.uk/research/publications/reports/bridging-the-gap-strengthening-relations-between-hospices-and-muslims-of-britain (Accessed 19th December 2022).

Wolff, J. Pak, J. Meeske, K. Worden, J. W. and Katz, E. (2010) 'Challenges and Coping Styles of Fathers as Primary Medical Caretakers: A Multicultural Qualitative Study'. *Journal of Psychosocial Oncology*, 28 (2), pp.202-217.

Wolff, J. Pak, J. Meeske, K. Worden, J. W. and Katz, E. (2011) 'Understanding Why Fathers Assume Primary Medical Caretaker Responsibilities of Children with Life-Threatening Illnesses'. *Psychology of Men and Masculinity*, 12 (2), pp.144-157.

Wood, F. Simpson, S. Barnes, E. et al. (2010) 'Disease trajectories and ACT/RCPCH categories in paediatric palliative care'. *Palliative Medicine,* 24(8), pp.796–806.

World Health Organization (2018) *Integrating palliative care and symptom relief into paediatrics: a WHO guide for health-care planners, implementers and managers*. WHO publications ISBN 978-92-4-151445-3.

World Health Organization (2020) *Coronavirus.* Available at: https://www.who.int/health-topics/coronavirus#tab=tab_1 (Accessed 19th December 2022)

Yeager, K. A. and Bauer-Wu, S. (2013) 'Cultural humility: essential foundation for clinical researchers'. *Applied Nursing Research,* 26(4). doi:10.1016/j.apnr.2013.06.008

Yeandle S., Bennett C., Buckner L., Fry G. & Price C. (2007) *Diversity in Caring: Towards Equality for Carers.* University of Leeds. Available at: https://www.employersforcarers.org/resources/research/item/download/50_8de774729235968d7e16f53f18eb9a9e (Accessed 19th December 2022).

Yeo, R. (2015) 'Disabled asylum seekers?…They don't really exist': The marginalisation of disabled asylum seekers in the UK and why it matters. *Disability and the Global South*, 2, (1), 523-550 ISSN 2050-7364

Yeo, R. (2017) 'The deprivation experienced by disabled asylum seekers in the United Kingdom: symptoms, causes and possible solutions'. *Disability & Society*, 32 (5), pp.657-677. doi: 10.1080/09687599.2017.1320268

Zazai, S. (2015) 'Wellbeing: the reality for individuals and communities'. Seminar from the Migrant Wellbeing Seminar, as part of the West Midlands Strategic Migration Partnership, Birmingham. 12th November 2015.

Ziersch, A. Due, C. Arthurson, K. and Loehr, N. (2019) *Conducting Ethical Research with People from Asylum Seeker and Refugee Backgrounds*. In: Liamputtong, P. (eds) Handbook of Research Methods in Health Social Sciences. Springer, Singapore. https://doi.org/10.1007/978-981-10-5251-4_50

Appendix One – Considerations for theoretical framework

Theoretical Framework and authors/originators	Interaction premise	Potential benefits of use	Potential limitations in relation to this study
Cultural competency (Pederson, 1974 Campinha-Bacote, 2002; Purnell and Paulanka, 2003)	Orientated around professional learning, education and knowledge	Acknowledges the importance of education and its link to change.	-May lead to an exaggerated and simplistic notion of 'cultural difference' and ethnic reductionism and stereotyping (Culley, 2014). -Need motivation and 'cultural desire' to learn - Contains problematic assumptions about what constitutes cultural competence (Kumas-Tan et al, 2007) -Is may be simply impossible to learn about all cultures effectively in a super-diverse setting
Cultural Health Capital (Bourdieu 1977-1990; Shim et al, 2010)	Cultural health capital is linked to experience and cultural resources which are gained. When used by clinicians and patients it may result in the most ideal health care relationships.	May help to understand wider social inequalities, however favours the well-educated and contributes to inequalities. Aims to counter stereotypes by showing the complicated view of social status and structures and health care interactions	-Contests individualistic notions of culture - Little room to consider processes of structural change -Generalisation from USA
Cultural Safety (Waimanawa, 1988; Ramsden, 1992, Browne et al, 2009)	-Care needs to be safe for the user not the health professional -Power imbalances and personal culture and bias need to be considered	-Requires grappling with issues like inequality, conflict and historical oppression -Acknowledges the fluidity of culture	-Deals with sensitive and threatening issues and thus requires creative and sophisticated methods to implement.
Cultural Humility (Tervalon, and Murray-Garcia, 1998)	A lifelong process of learning including self-reflection and self-critique	-Positive consequences described as mutual empowerment, partnerships, respect, optimal care, and lifelong learning (Foronda, 2016) -Has been applied in many contexts and by varied disciples	- Illustrates a grand but possibly unobtainable concept which needs the flattening of any hierarchy or power differential -Is largely reflexive in nature
Social Justice (Nancy Fraser Recognition and Distribution 2000, 2003, Representation 2008)	Recognition (cultural) Distribution (economic) Representation (political) With need for parity of participation for just conditions	-Focuses on structures not individuals that produce inequalities -Can analyse claims to assess and evaluate justice	-Focus away from individual experiences which can negate lived realities (Fraser and Honneth, 2003) -Generalisation from USA
Silences Framework (Serrant-Green, 2011)	Utilises 5 stages to listen and document the silences which are very apparent to the group experiencing them but currently absent from practice and policy.	Focuses on empowering marginalised groups to be more active in the research process through for example advisory groups	A relatively new model which has few examples of its use or critiques to date, however this study offers the potential to provide this for future researchers.

Appendix Two - Published Systematic Review in Journal of Advanced Nursing

Accessed online at:

https://onlinelibrary.wiley.com/doi/pdf/10.1111/jan.14509

Check for updates

Received: 4 March 2020 | Revised: 9 June 2020 | Accepted: 26 June 2020

DOI: 10.1111/jan.14509

REVIEW

JAN Leading Global Nursing Research WILEY

A systematic review exploring palliative care for families who are forced migrants

Marie Clancy[1,2,3] | Julie Taylor[1,4] | Caroline Bradbury-Jones[1] | Jenny Phillimore[2]

[1]School of Nursing, University of Birmingham, Birmingham, UK

[2]School of Social Policy, Sociology and Criminology, University of Birmingham, Birmingham, UK

[3]School of Nursing and Midwifery, Birmingham City University, Birmingham, UK

[4]Birmingham Women's and Children's Hospital NHS Foundation Trust, Birmingham, UK

Correspondence
Marie Clancy, School of Nursing, University of Birmingham, Birmingham, UK.
Emails: mxc523@bham.ac.uk or marie.clancy@bcu.ac.uk

Funding information
This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Abstract

Aims: To explore the palliative care experiences of forced migrant children, families, and healthcare professionals (HCPs) highlighting successes, challenges, and associated practice implications.

Design: Systematic literature review.

Data Sources: The following search engines were searched from 2008 - 2018: Allied and Complementary Medicine Database, Cumulative Index to Nursing and Allied Health, MEDLINE, Embase, ProQuest, Scopus, Psycinfo, and Web of Science. Extensive reference and citation checking were also conducted.

Review Methods: Systematic review followed PRISMA guidelines with prepared PROSPERO registered protocol #CRD42019129200. English language qualitative, quantitative, or mixed methods studies were eligible for inclusion. Study quality was appraised using the Mixed Methods Appraisal Tool (MMAT).

Results: Eighteen studies (reported in 20 articles) met the final inclusion criteria. Most focused on challenges to care provision. Thematic analysis following methods proposed by Braun and Clarke was undertaken. Five themes were identified: (a) divergence of beliefs and expectations; (b) communication; (c) navigating healthcare systems; (d) burdens and coping strategies; and (e) training and knowledge. A compassionate, collaborative approach with mutual respect crossed themes and was linked to high-quality care.

Conclusion: Forced migrant families have multiple needs including physical and emotional support and help in navigating complex systems. Professional interpreters can ease communication barriers when resourced appropriately. Individualized care is crucial to addressing the intricate mosaic of culture such families present. A cultural sensitivity/insensitivity framework is presented that may help guide future interactions and priorities for those working in children's palliative care.

Impact: This systematic review explored the international experiences of palliative care for forced migrant families. The findings highlight the plight of families who experience multiple traumas and increased levels of grief and loss through their migration experiences and when caring for a child with a life-limiting condition. This

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.
© 2020 The Authors. *Journal of Advanced Nursing* published by John Wiley & Sons Ltd

research has potential to have an impact on professionals working with culturally diverse families in all palliative care settings.

KEYWORDS
children's palliative care, cultural humility, cultural sensitivity, forced migration, nursing, refugee, systematic review

1 | INTRODUCTION

International epidemiological data on child mortality and morbidity highlight an increasing need to focus on children's palliative care (CPC) services as an estimated 20 million children worldwide could benefit from unrestricted access to medical facilities and resources (Institute of Medicine, 2003; International Children's Palliative Care Network, 2019). Connor and Bermedo (2014) estimated that of the children in need of palliative care, 98% belong to low- and middle-income countries and with 83% found in the lower income groups. The African Region covers almost half of this need closely followed by Southeast Asia and Eastern Mediterranean Regions. Children in need of palliative care for progressive non-malignant disease represent the highest proportion for all regions (84.08%), whereas palliative care for cancer (5.69%) and HIV/AIDS (10.23%) is distinctly lower. While the actual numbers of forced migrant children requiring CPC are unclear, the World Health Organization (WHO, 2020) reports higher prevalence of accidental injuries, burns, gastrointestinal illness, respiratory infections, cardiovascular events, nutritional disorders, higher newborn mortality, and other non-communicable diseases. The key issue for forced migrant families appears to be poor access to care in their countries of origin and interruptions to care during migration, which can exacerbate chronic conditions (WHO, 2020).

The philosophy of CPC is to promote the best possible quality of life for children living with severe and incurable conditions through holistic care embracing physical, emotional, social, and spiritual elements (Together for Short Lives, 2018a). CPC is complex, multifaceted, and frequently misunderstood. Taboos surrounding child death can make open and honest conversations between healthcare staff and families difficult. Global CPC is compromised by a lack of specialist staff and resources, negative public perceptions, and limited healthcare provider education and research (Collins, McLachlan, & Philip, 2018; Connor, Downing, & Marston, 2017; Friedrichsdorf & Bruera, 2018).

Forced migrant children and families are under-represented in the literature surrounding children's health (Flanagan & Hancock, 2010). Forced migrant families are compelled to flee their homeland often facing intense physical and mental trauma including imprisonment, torture, violence, and loss. When arriving in a country of refuge, families may experience severe social isolation and be subject to hostility and discrimination (MIND, 2009; Parhar, 2018).

Little is known about the experiences of CPC for forced migrant families, but it is clear that the combination of trauma before, during, and following migration coupled with the complexities of life with a severely ill child results in multifaceted needs. Consequently, this review fills an important gap in identifying the current state of knowledge surrounding the experiences of CPC for forced migrant families and considers how this can inform practice and research priorities.

1.1 | Background

Children's palliative care demands a holistic approach beginning with diagnosis and continuing through life, death, and bereavement (Together for Short Lives, 2018b). The WHO (2018) argue that CPC involves an ethical responsibility for health providers, and that a multidisciplinary, cross-setting, and cross facility-based approach offers the best use of resources.

Children with palliative care needs have a primary, multifaceted, life-limiting, or life-threatening condition (Thompson, 2015). The numbers of children with such needs are increasing as is the severity of need because of cutting-edge clinical developments which prolong the lives of even those with the most complex needs (Mitchell, Slowther, Coad, & Dale, 2018; Thompson, 2015).

Parents' needs may be varied but recent literature reviews highlight the need for genuine communication, sincere relationships, respect as an expert, alleviation of suffering, and support (Melin-Johansson, Axelsson, Grundberg, & Hallqvist, 2014). In addition is the need for good multidisciplinary working and continuity of care (Van der Geest et al., 2014). Community-based trials have identified increased parental physical and social isolation, exclusion from the workforce, and pervasive grief (Collins et al., 2016). Liben, Papadatou, and Wolfe (2008) describe parental and staff challenges such as how to best control physical symptoms, difficulties when communicating with children (who may also be disabled), how to appropriately involve them in decision-making, and ensure that efforts to prolong life do not increase suffering.

This review focuses on forced migrant children and their families. The term forced migrant includes asylum seekers who have lodged an application for protection from persecution (The Refugee Council, 2013) and refugees whose asylum claim has been successful or who have been given refugee status by the United Nations Refugee Agency (UNHCR, 2016).

Poor access to health and social care in a country of refuge is commonly documented. Most research seems to concur that barriers are extensive and include financial insufficiency, administrative problems, lack of knowledge or understanding of the healthcare

Population (P)		Exposure (E)		Outcome (O)
Refugees including Asylum seeker/seeking	AND	Termi nal care/terminally ill patient	AND	Infant
OR		OR		OR
Transient and migrants		End of life care		child
OR		OR		OR
Displaced persons		Palliative care		Pre-school child
OR		OR		OR
Emigration and Immigration		Life limiting		adolescent
OR		OR		OR
Undocumented child		Life threatening		Health care/treatment barrier
		OR		OR
		Death and dying		Health care professional/personnel
		OR		OR
		Disabled child		Parent
				OR
				Health service accessibility
				OR
				Health care utilization

FIGURE 1 Key words/search terms

system, and rights to care and communication barriers (Maffia & Conway, 2008; Simonnot et al., 2016).

Forced migrant families who have children with palliative care needs have experienced the trauma of migration and of grief, fear, and loss associated with their child's diagnosis. They may have reduced agency and feel disempowered. Being forced to leave family, belongings, support, and all sources of familiarity often leaves them feeling displaced. Their child may not have a diagnosis, parents may have to undertake invasive medical care for their child, and they have to deal with uncertainty, critical illness, and periods of instability while living in fear of their child's inevitable death (Verberne et al., 2019). Additionally, the resources to provide adequate care and support may be limited or lacking. For healthcare professionals (HCPs), the diversity and differences in cultural, spiritual, and religious need may be bewildering and confusing.

There are no data on the numbers of forced migrants with CPC needs; however, there is little doubt that palliative care coupled with forced migration is likely to exacerbate already complex problems and have an impact on parental health and the provision of care.

2 | THE REVIEW

2.1 | Aims

The aim of this systematic review was to examine the palliative care experiences of forced migrant children, families, and healthcare providers. A secondary aim was to identify current challenges, barriers, and successes in care provision and to make practice implications for multidisciplinary CPC teams working with forced migrant families. This review addressed the following question: What is known about the experiences of children's palliative care for forced migrant families and their healthcare providers?

2.2 | Design

2.2.1 | Systematic review

This systematic review aimed to identify and appraise all the literature on CPC for forced migrant children, using explicit, rigorous, and transparent methods as outlined by the NHS Centre for Reviews and Dissemination (2009) and Search, Appraisal, Synthesis, and Analysis (SALSA) methods (Grant & Booth, 2009). These frameworks aid the identification, selection, and critical appraisal of existing knowledge, enabling a synthesis of data from included studies (Nicholson, 2007; Ten Ham-Baloyi & Jordan, 2016).

Methods included a broad search strategy using PEO (Population, Exposure, and Outcomes) variables, predefined search terms, and uniform inclusion and exclusion criteria (Ten Ham-Baloyi & Jordan, 2016). The use of the PRISMA tool aided the review process ensuring articles were selected for sensitivity and specificity (Moher et al., 2009). Furthermore, registering the review in Prospero (#CRD42019129200) enhanced the justification for the study as it emphases the gap in the current literature, reduced duplication, and provided methodological transparency. The review protocol was developed iteratively refining processes and clarity as work progressed.

The review research team has a range of skills and experience surrounding systematic review methods, information retrieval, topic/clinical expertise, and methodology, which have enhanced the quality of this review.

2.2.2 | Search methods

The databases searched were: Allied and Complementary Medicine Database (AMED), Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE, Embase, ProQuest, Scopus, Psycinfo, and Web

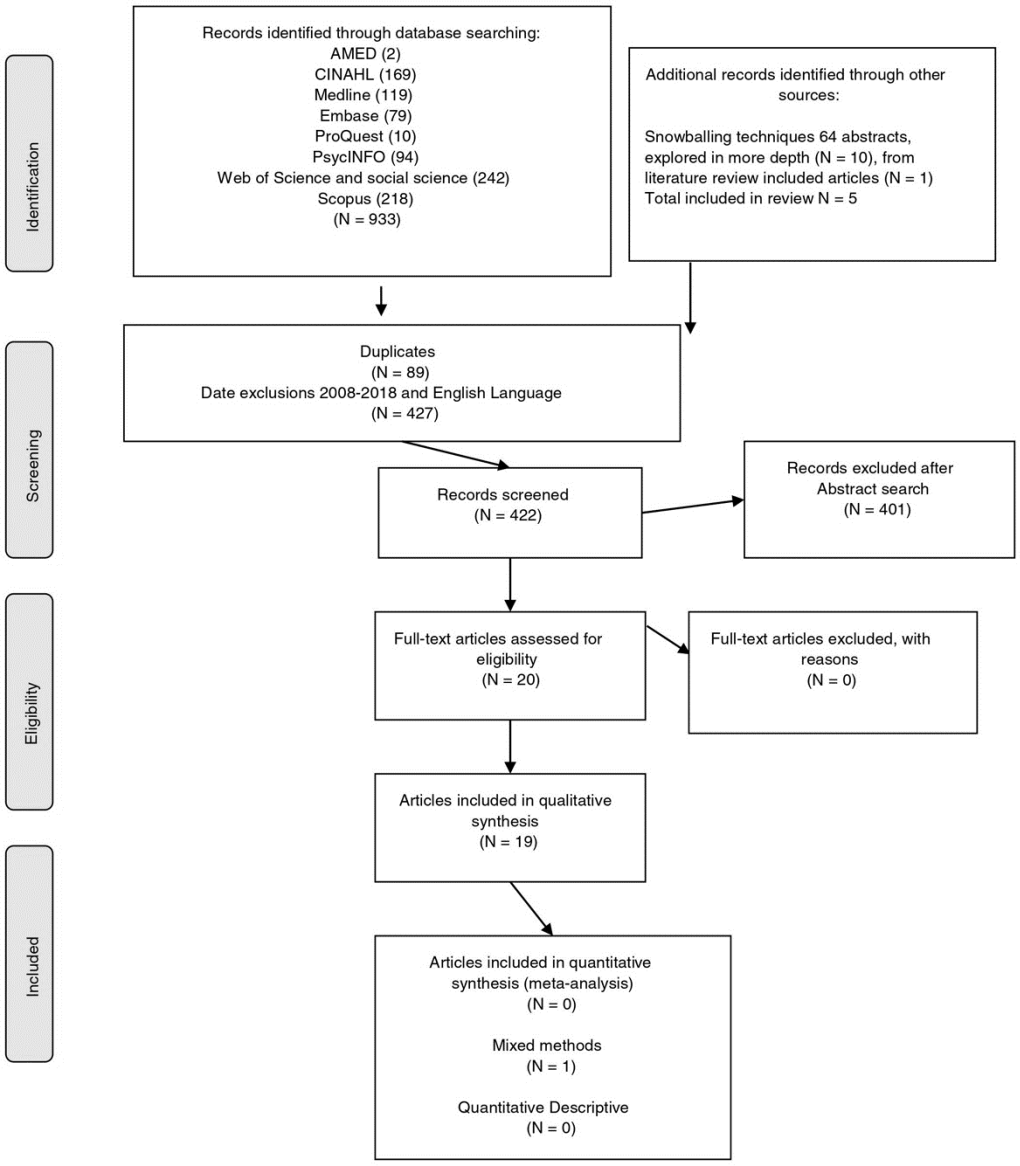


FIGURE 2 Search outcome – PRISMA diagram [Colour figure can be viewed at wileyonlinelibrary.com]

of Science. Snowballing techniques and searching of the Cochrane Database, Summon, and Google Scholar were also used to identify any potentially relevant grey literature. We sought to offer a diverse and comprehensive range of literature from across disciplines, as the topic connects different fields of study, such as the social sciences to health and nursing disciplines.

English language format records were searched for peer-reviewed empirical primary research for the period covering January 2008 to October 2018 (Table S1 for inclusion/exclusion criteria and rationale).

The search strategy involved the initial use of Mesh headings (database taxonomies) to commence the search, adding full-text

terms to capture additional material. Search terms were refined following each search as terminologies surrounding CPC and migration are extensive and differ internationally. New terms were added with searches rerun and the process repeated until no new articles were identified (Figure 1).

2.2.3 | Search outcome

A total of 422 articles were retrieved from the databases with hand searching/snowballing revealing a further five (Figure 2). Following the exclusions outlined, 18 studies reported in 20 articles were critically appraised using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). From the 18 studies, 20 articles were produced because two authors – Kvarme et al. (2016), Kvarme, Alebertini Früh, & Lidèn (2017), and Wolff, Pak, Meeske, Worden, & Katz (2010), Wolff, Pak, Meeske, Worden, & Katz (2011) – used the same data set to publish two separate articles with differing findings.

2.2.4 | Quality appraisal

The use of a quality appraisal tool was important as the effectiveness of interventions can be masked or exaggerated by studies that are not rigorously conducted (NHS Centre for Reviews & Dissemination, 2009). The MMAT appraisal tool (Hong et al., 2018) enabled the appraisal of empirical studies using qualitative, quantitative, and mixed methods. The tool offers clear steps to the appraisal process and explanations which aid decision-making processes. To ensure the robustness and reliability of the review and the MMAT process, all authors appraised each study and two authors (JT and CBJ) randomly checked for consistency in four papers. Differences were discussed until consensus was reached.

All studies were scored separately for quality (judgements regarding research design, methods, and rigour) and usefulness (relevance to the subject area; Daniel, Taylor, & Scott, 2010, 2011; Taylor, Daniel, & Scott, 2012). For quality, scores of 1 indicated that the study was rigorous and bias had been addressed; scores of 2 showed agreement with design and methods and attempts to address bias; a score of 3 was applied when studies did not satisfy basic criteria of rigour, were flawed, or did not address bias. Usefulness and relevance to the subject was also scored using: 1 – to show extremely useful and relevant studies; 2 – some useful information, but not direct relevance; and 3 – very little of relevance. Any study that scored 3 for either quality or usefulness was excluded. Results can be found in Table S2.

2.2.5 | Data abstraction

The selection process aimed to minimize bias over inclusion/exclusion by making this explicit and free from any researcher pre-formed opinions (NHS Centre for Reviews & Dissemination, 2009). Initial decisions were based on titles and, where available, abstracts. The research team examined these to ensure agreement around inclusion/exclusion. Where it was unclear if studies met the inclusion criteria, the full text was assessed to ensure there were no inappropriate exclusions.

A table was used to extract relevant information from each study (Table S3), providing consistency and improving validity and reliability (NHS Centre for Reviews & Dissemination, 2009). At the end of the process, a table was produced including all studies (Table S4).

2.2.6 | Synthesis

The next step in this review was identification of themes from each study followed by an analysis to identify relationships. Braun and Clarke (2006) guidelines were used to ensure that the themes accurately summarized findings. Following this, an analysis of the frequency with which themes appeared in different papers was conducted alongside a reflection of the significance and relevance of each theme. At this stage, themes that might be amalgamated were identified where they were similar or part of a pattern (Aveyard, 2019). Next, theme names were examined to ensure if they best fit the content included. Through 'dynamic working back and forth', robust themes were identified (Lincoln, Guba, & Pilotta, 1985, p. 342). Finally, themes were examined across the studies to look for similarities and inconsistencies.

3 | RESULTS

Table S4 provides an overview of the 18 studies included. Articles originated from a multitude of countries (America $N = 6$, Canada $N = 7$, Sweden $N = 2$, Australia $N = 2$, and Norway $N = 1$). Seventeen were qualitative, with one mixed methods study. A diversity of approaches was evident in qualitative studies. While some research versatility can be helpful and allow for flexibility (Bradbury-Jones et al., 2017), such diversity was confusing as methodologies were broad in scope and offered limited detail about actual methods used. Without clear methodological justification, it was hard to identify sample size or know whether the methods employed were sufficiently rigorous to justify the claims made (Kim, Sefcik, & Bradway, 2017).

3.1 | Thematic development

A summary of the articles included in this review can be found in Table S4; following analysis, five main themes were identified:

3.1.1 | Theme 1: Divergence of beliefs and expectations

A key theme was that of divergence of beliefs between HCP and families. These varied between different perceptions of

parenting (Brassart, Prévost, Bétrisey, Lemieux, & Desmarais, 2017), to conflicting perceptions of diagnosis (Brassart et al., 2017; Gulati et al., 2012; Sneesby, Satchell, Good, & Van Der Riet, 2011), systems (Fellin, King, Esses, Lindsay, & Klassen, 2013), non-acceptance of treatment (Brassart et al., 2017), truth-handling (Periyakoil, Neri, & Kraemer, 2015), and disability (Brassart et al., 2017; Lindsay, King, Klassen, Esses, & Stachel, 2012). Challenges around disclosure and consent were also identified (Sneesby et al., 2011).

Some families seemed to struggle with Western ideals of autonomous parents who advocate for their child and make decisions with HCP (Beatson, 2013; Fellin et al., 2013; Gulati et al., 2012; King, Desmarais, Lindsay, Piérart, & Tétreault, 2015; Pergert, Ekblad, Björk, Enskär, & Andrews, 2012; Periyakoil et al., 2015). One article highlighted a lack of family centred care and instead a reliance by families on medical authority (Fellin et al., 2013).

However, when differing beliefs were acknowledged by HCP, participants shared how an understanding of the child's disability, diagnosis, prognosis, and treatment helped them to prepare for the future and set goals (Brassart et al., 2017; Green, Jerzmanowska, Green, & Lobb, 2018). Collaborative working allowed the development of care that was tailored to fit individual family's situations (Green et al., 2018; King et al., 2015) and enabled accounting for different customs surrounding death, dying, and bereavement (Green et al., 2018; Sneesby et al., 2011).

Families discussed the importance of traditional healing strategies (Beatson, 2013). Physicians incorporating traditional healing were seen as helpful but those who did not, incited anger (Davies, Contro, Larson, & Widger, 2010). Families described the importance of incorporating faith and spirituality into care (Davies et al., 2010) with prayer as a common coping mechanism (Davies et al., 2010; Pinheiro & Jaff, 2018; Sneesby et al., 2011; Wolff et al., 2010).

In Periyakoil et al. (2015), patients' spiritual and religious beliefs about death and dying were seen as challenging, as doctors felt they led to a demand for futile treatments. Clinicians argued that families' hope for a miracle resulted in refusal to engage in end-of-life discussions. Some doctors believed that they had to reconcile religious 'obstructions' with a do not resuscitate status. These findings suggest a lack of empathy, with one study author observing that more collaboration with community spiritual leaders may enhance care.

Gender bias and associated caregiving and decision-making expectations fall within this theme (Burnes, Antle, Williams, & Cook, 2008; Fellin et al., 2013; Khanlou, Haque, Sheehan, & Jones, 2015; Kvarme et al., 2016; Pergert et al., 2012; Wolff et al., 2010). Studies highlighted that mothers were expected to be the primary caregiver, often becoming consumed by the child's illness (Burnes et al., 2008; Khanlou et al., 2015; Kvarme et al., 2016). However, Burnes et al. (2008) argue that fathers may cope by distancing themselves as they struggle to accept the realities of their child's illness, or because they are discounted by HCP who focus on mothers (Wolff et al., 2010).

Some of the gender aspects discussed relate to the lack of fathers' perspectives. The ratio of mother to father participants was 70:30. The studies focusing on fathers detailed actions such as protecting mother's poor physical and mental health, flexibility in sharing care (Wolff et al., 2010), and fathers' increase in self-worth and social status through providing care (Wolff et al., 2011).

The challenges of collaborative care were complex relating to additional time (Beatson, 2013; Pergert, Ekblad, Enskär, & Björk, 2008) and balancing of patient safety versus preference and comfort (Green et al., 2018). Where conflicts were identified, parents reported feeling ignored and unable to make decisions (Davies et al., 2010), fearful of misusing hospital resources (Gulati et al., 2012), cultural misunderstandings, and perceptions of discrimination (Fellin et al., 2013) and racism (Burnes et al., 2008). Pinheiro and Jaff (2018) emphasized the significance of collaborative care as it directly correlated with the perceived quality of care received.

Positive facilitators to good care were described when divergent beliefs were acknowledged, respected (Brassart et al., 2017), navigated (Green et al., 2018), and families helped to advocate for their children (Lindsay et al., 2012).

3.1.2 | Theme 2: Communication

Language and communication barriers were explored by many of the studies from professional perspectives (Brassart et al., 2017; Green et al., 2018; Khanlou et al., 2015; Periyakoil et al., 2015) and those of the family (Gulati et al., 2012; Kvarme et al., 2016; Pergert et al., 2012). Issues identified included medical misinterpretation (Fellin et al., 2013), difficulties in building rapport (Lindsay et al., 2012), and a reluctance to use services. Lack of information meant families expressed feelings of powerlessness, distress, fear, and being overwhelmed (Wolff et al., 2011). In addition, Beatson (2013) comments that no words existed in the native language for the child's condition, so this was increasingly complicated.

Families also reported that they felt abandoned and that staff were sometimes self-interested, not tuned into patients' best interests, and less compassionate and sensitive to their needs than in their country of origin (Periyakoil et al., 2015).

Lack of access to professional interpreters was a key challenge (Brassart et al., 2017; Davies et al., 2010; Fellin et al., 2013; Green et al., 2018; Gulati et al., 2012; Wolff et al., 2010) with some parents unaware of interpreting services (Fellin et al., 2013). An overreliance on families for interpretation was acknowledged as raising ethical concerns around disclosure and accuracy of information (Green et al., 2018; Pergert et al., 2008; Wolff et al., 2011). At times, families elected to use relatives rather than an interpreter given concerns about confidentiality (Green et al., 2018).

Facilitators to good care included strategies to overcome communication barriers such as modifying the language used (Brassart et al., 2017) and using signs, charades, and picture charts (Pergert et al., 2008); however, this offered potential for misunderstandings (Pergert et al., 2008). Non-verbal communication, such as expressive eye contact (Khanlou et al., 2015), engagement (King et al., 2015), or human connection (Contro, Davies,

Larson, & Sourkes, 2010), were linked to empathy, trust (Khanlou et al., 2015), and open-minded, non-judgemental interactions (King et al., 2015).

Two studies described the value of listening to and understanding migration experiences to establish a trusting relationship (Green et al., 2018; Kvarme et al., 2016) and get a better understanding of past traumas (Contro et al., 2010).

Participants shared that when they felt understood, they felt respected and that HCP really cared about their child (Green et al., 2018; King et al., 2015) and this helped to decrease helplessness and uncertainty (Gulati et al., 2012).

3.1.3 | Theme 3: Navigating healthcare systems

Healthcare services were criticized by families and professionals for their limited scope, poor availability and accessibility, and often-dispersed nature (Burnes et al., 2008; Gulati et al., 2012; Khanlou et al., 2015; Kvarme et al., 2016, 2017; Pinheiro & Jaff, 2018). Rigidity and complexity of the system (Brassart et al., 2017; Gulati et al., 2012) were linked to parents' limited understanding of what was available (Fellin et al., 2013; Kvarme et al., 2016) and a lack of knowledge about their child's condition (Beatson, 2013; Burnes et al., 2008). Insufficient systematic resources decreased mother's ability to cope (Burnes et al., 2008). Furthermore, some families appeared to be missing out on services and resources (Gulati et al., 2012) and even struggling to get appropriate diagnosis and treatment (Pinheiro & Jaff, 2018).

Families discussed financial stresses, with limited time and unemployment appearing important factors within the structural challenges to care (Beatson, 2013; Brassart et al., 2017; Contro et al., 2010). Financial stressors sometimes related directly to the cost of medical care or lack of insurance and associated implications (Fellin et al., 2013; Pinheiro & Jaff, 2018; Wolff et al., 2010).

Families and professionals described how a lack of health literacy led to difficulty in navigating the complex healthcare landscapes. Facilitators were linked to an ability to understand healthcare systems which strengthened parents' confidence and reduced anxiety (Gulati et al., 2012). Services such as transport assistance (Beatson, 2013; Wolff et al., 2011) and provision of navigators such as community nursing care (Beatson, 2013; Burnes et al., 2008; Fellin et al., 2013) phone services and paediatricians with specialist knowledge (Burnes et al., 2008) also acted as facilitators.

3.1.4 | Theme 4: Burdens and coping strategies

This theme relates to the challenges faced by parents which result from their care giving responsibilities and was only documented within the family perspective articles.

In terms of physical ill health, parents discuss pain, sleep disturbance, stress, and tension (Contro et al., 2010; Kvarme et al., 2016, 2017; Wolff et al., 2011). Further burdens included a lack of leisure time, marital, and family conflict (Kvarme et al., 2016; Wolff et al., 2010), the unmet needs of siblings (Kvarme et al., 2016; Wolff et al., 2010) and for Mexican parents, a fear of not seeing other children who are left behind with relatives (Contro et al., 2010). These factors contributed to parental exhaustion (Burnes et al., 2008), loneliness, and isolation (Burnes et al., 2008; Davies et al., 2010; Kvarme et al., 2016; Wolff et al., 2010). Parents appeared reluctant to leave their child (Gulati et al., 2012) and struggled with uncertainty and lived in a constant state of fear due to the unpredictable nature of their child's condition (Burnes et al., 2008; Pinheiro & Jaff, 2018).

Forced migrant families suffered from additional hopelessness over the destitution of their country of origin with families detailing the difficulty in seeing their home lands destroyed by war and political injustice (Contro et al., 2010; Pinheiro & Jaff, 2018). Further to this, parents detailed the detrimental aspects of living in poverty (Pinheiro & Jaff, 2018), feelings of powerlessness, shame, and the effects of racism and discrimination on them and their families (Burnes et al., 2008; Pergert et al., 2012).

Coping strategies were undermined by a lack of tangible support including child care, respite services, and psychosocial support (Burnes et al., 2008; Khanlou et al., 2015; Kvarme et al., 2016). Families noted the absence of traditional support from partners, family, priests, and welfare services and struggled without these 'invaluable' support systems (Contro et al., 2010; Khanlou et al., 2015; Kvarme et al., 2017; Wolff et al., 2010). Coping strategies for families included love for the child which kept families going and the use of emotion-focused coping (mostly mothers) and problem-focused coping mechanisms (mostly fathers; Kvarme et al., 2017). Support in a refugee camp was also discussed as being forged by finding extended family and co-national assistance (Pinheiro & Jaff, 2018).

3.1.5 | Theme 5: Training and knowledge

A lack of HCP knowledge in culturally sensitive care was seen as a barrier to good care by HCP themselves (Brassart et al., 2017; Lindsay et al., 2012). Periyakoil et al. (2015) reported that an ignorance of patient's cultural beliefs, values, and practices was linked to a HCP lack of knowledge. A lack of public awareness of conditions was also highlighted and associated with cultural silence and uneducated notions (Burnes et al., 2008). The lack of investment in research and resources was also noted. Burnes et al. (2008) linked low levels of investment to sickle cell being a Black and thus marginalized disease. Conversely, facilitators to good care were linked to good theoretical knowledge, health professionals using reflection and the linking of staff with similar cultures, and ethnicities to families to share cultural expertise and understanding (Pergert et al., 2008).

It appears that the experiences of CPC for forced migrant families predominately relate to aspects which optimize or hinder culturally sensitive palliative care. From the review findings, we have

developed a framework to demonstrate the antecedents and consequences of care when it is seen as culturally sensitive or insensitive by families. The impact this may also have on HCP themselves is also presented (Figure 3). The discussion in the following section centres around the framework.

4 | DISCUSSION

A definition for culturally sensitive care is found in Figure 3, but essentially this relates to an enhanced awareness and deepened understanding of cultural differences with an ability to apply these to



FIGURE 3 The cultural insensitivity sensitivity framework

practice appropriately (Evans et al., 2012). There are three overlapping factors which shape whether or not care is culturally sensitive: individual, relational, and structural aspects.

Individual aspects centre on the burdens to care faced by parents. The unpredictability and uncertainty of CPC lead to anxiety, as parents fear crisis, hospitalization, and their child's death. Anxiety can result in physical and mental ill health. The literature outside of this review details the consequences of caring for a child requiring palliative care and clearly documents the exhaustion, hyper-vigilance, and overwhelming burdens of responsibility (Carter & Bray, 2016; Limardi, Stievano, Rocco, Vellone, & Alvaro, 2016) which were also evident in our findings. Stresses for forced migrant families are compounded by a fragmented cultural identity, loss of belonging, and absence of a support network to provide support (Bhugra & Becker, 2005). Further to this is an apathetic view of migration trauma with the impact of displacement, enforced poverty, and elements of PTSD being frequently missed or minimized by HCPs.

Negative media discourse around migration, community antagonism, and a hostile environment further creates a sense of unease with the potential for forced migrants to be stereotyped or discriminated against (Manstead, Reicher, Greenland, & Nightingale, 2016; Weller et al., 2019). Forced migrant families particularly value those HCPs who offered them compassion, caring concern, affection, and empathy.

Relational aspects of the framework are primarily associated with communication difficulties, with insensitive palliative care being linked to poor rapport and conflicting expectations and beliefs. This is unsurprising as Bergstraesser et al. (2015) state communication is a central aspect of care for parents and linked to high-quality care. When there is a divergence in the views of families and HCP, families observe the cultural ignorance of HCPs, alongside feelings of unease and mistrust. Equally, when HCPs struggle to understand a family's values and practices, especially regarding spirituality, native healing, and gender roles, they feel conflicted.

Conversely, relationships based on mutual respect embodying a philosophy of individualized, collaborative care help parents to feel known and valued. Involving families and creating care pathways which fostered family centred care are linked to increased parental confidence and self-worth and an ability to advocate for their child. Helplessness, anxiety, and uncertainty are experienced when parents cannot have a negotiated caring role.

HCPs who embrace a 'one-size fits all' model move towards the culturally insensitive side of the framework as families feel ignored, stigmatized, and angry. Such 'clinician-directed care' was seen as oppositional to family centred care and linked to limited parental knowledge as their understanding appeared to diminish amid resulting disempowerment.

Individualized collaborative care is not new with NICE (2016) CPC guidelines recommending it and noting that its absence can negatively influence care. Given the traumatic experiences faced by forced migrant families, there is even greater need for collaboration. Their child's illness further removes a sense of normality and diminishes agency (Verberne et al., 2019). The acknowledgement of such factors by HCPs contributes to empathetic, compassionate relationships essential for building trusting relationships, sharing cultural understanding, and meeting families' needs.

The importance of compassion crosses the five themes of this review and seems to relate to a two-way navigation where families and HCPs travel the road of CPC together. Suffering, past traumas, uncertainty, fear, and cultural differences are eased when they are faced together in a trusting, caring relationship (Awdish, 2018). However, being present takes time to listen, understand, and respect each other, acknowledging problems and a lack of knowledge for both parties. Cultural humility exemplifies such a philosophy as illustrated in a palliative case study by Cochran, Saleem, Khowaja-Punjwani, and Lantos (2017), which advocates an acceptance of difference and welcoming of diversity.

Cultural humility aims to address the power imbalances which exist in health care by focusing on egoless dialogue, which is empowering and respectful, and with a commitment to lifelong learning and reflection (Tervalon & Murray-García, 1998). Concepts of cultural humility may enhance traditional models like cultural competence which is said to be limited due to the broad, constantly evolving dimensions of culture (Foster, 2009) and fears too much focus on knowledge acquisition may lead to increased assumptions and stereotypical views (Evans et al., 2012).

Finally, structural antecedents were linked to access to interpreters, language aids, and other services, resources, and information. The link between good communication strategies and navigating access to care is widely reported in studies exploring forced migration and healthcare experiences (Morris, Popper, Rodwell, Brodine, & Brouwer, 2009; Sheikh-Mohammed, Macintyre, Wood, Leask, & Isaacs, 2006). Further to this, Finnström and Söderhamn (2006) suggest a link between a lack of cultural sensitivity and competence among HCP and less access to health care and pain treatment for minority groups. Consistent with the findings of this review, evidence suggests that optimal communication, patient satisfaction, and reduction in errors occur when there is access to professional interpreters and other supporting resources and services (Flores, 2005; Silva et al., 2016).

Families often have limited health literacy and appeared lost in medical jargon and the complex health and social care systems which held the key to accessing care. Families' lack of social support and problems identifying coping mechanisms meant community care, link workers, and respite services were crucial to maintaining their physical and mental health.

The use of link workers or cultural mediators who share language and culture is a strategy to improve communication and access with potentially an additional function of educating staff and supporting the development of trusting relationships (Finnström & Söderhamn, 2006; McGarry et al., 2018). However, the small number of forced migrant families receiving CPC and differences in their culture, language, and country of origin means it is frequently impractical to develop appropriate resources. Thus, collaborative resources may be supported by multi-agency working and shared

across services and settings which would reduce costs but may add logistical challenges.

Our framework enhances and highlights the distinctive insights offered from this review in terms of the experiences of families and HCPs working in CPC. Previous studies (Dewar & Nolan, 2013) have offered models in which to base compassionate relationship-centred care but none have yet focused on empathy and compassion in CPC for families who are forced migrants. These aspects of care were seen as particularly important in our thematic analysis given that challenges faced in accessing, giving, and receiving care are especially complex for forced migrants.

4.1 | Limitations, strength, generalizability, and transferability of the evidence

Limitations to this review include the restriction to only English language articles which have limited the data set and may potentially bias findings towards Western nations (NHS Centre for Reviews & Dissemination, 2009). Translation of non-English language research was not feasible due to a lack of time and resources.

It was never the intention of this review to seek only qualitative studies, but our search and review processes did lead us towards a qualitative analysis. Had we known this in advance, it may have been advantageous to conduct a qualitative meta-synthesis (Sandelowski & Barroso, 2002).

The differences in terminology used in the papers reviewed proved challenging. Both CPC and migration were expressed in different ways which were not always clear from the outset. For CPC, the categories for palliative care were not always used and so examinations of the types of illness/disability had to be conducted to ensure these met inclusion criteria. For forced migration, the word migrant was used very broadly often without further explanations of who these populations were and so often full-text searching was necessary. However, this was enhancing to the study as the thorough approach it necessitated gave further confidence that all appropriate studies had been included in the review. A further strength lies in the international content of the articles included, which ensured generalizability and transferability.

4.2 | Recommendations

Further research is needed to fill gaps in knowledge around CPC and forced migrant families. This review illustrated that child and young person perspectives are lacking. While this is not uncommon in the general population of children in palliative care and may relate to their illness (Ghirotto et al., 2019), other issues may be at play. Weaver et al. (2019) suggests that there is a tension within CPC research between collecting vital data and protecting vulnerable populations.

More work is thus needed to gather the perspectives of children and fathers. A wider range of settings should also be included, such as hospices and respite care, as valuable perspectives surrounding pain and symptom control were missing from this review and research in such settings may aid understanding in these areas.

5 | CONCLUSION

This review has offered valuable insights into the experience of CPC for forced migrant families and contributed to existing knowledge in this area with the creation of a framework guiding HCP towards culturally sensitive care provision. CPC guidelines advise individualized care for all families but for forced migrant families, this is particularly important as experiences of persecution and displacement can reduce agency which needs to be fostered to rebuild self-worth and a sense of belonging. The 'normality' of parenting can be cultivated through a model of family centred care. There is a need for care which focuses on compassion, humility, and listening to individual experiences. This is imperative to building trusting relationships and increasing mutual respect and cultural understanding. Cultural humility may foster such an approach, so further research of its use in CPC would be beneficial.

The framework devised from this review is a useful tool for HCP to see how the antecedents and consequences of care relate to families' experiences. This unique insight into their world may help to improve knowledge, empathetic understanding, and the ability to facilitate future culturally sensitive CPC.

CONFLICT OF INTEREST

We have no conflict of interest to declare in the collaborative writing of this article.

PEER REVIEW

The peer review history for this article is available at https://publons.com/publon/10.1111/jan.14509.

ORCID

Marie Clancy https://orcid.org/0000-0002-0076-5180
Julie Taylor https://orcid.org/0000-0002-7259-0906
Caroline Bradbury-Jones https://orcid.org/0000-0002-5237-6777
Jenny Phillimore https://orcid.org/0000-0003-1213-2302

TWITTER

Marie Clancy @mariecphd
Julie Taylor @bulawayojulie
Caroline Bradbury-Jones @jones_bradbury
Jenny Phillimore @japhillimore

REFERENCES

Aveyard, H. (2019). *Doing a literature review in health and social care: A practical guide*. UK: McGraw-Hill Education.

Awdish, R. (2018). *In shock: How nearly dying made me a better intensive care doctor*. London: Penguin Publishing.

Beatson, J. E. (2013). Supporting refugee Somali Bantu mothers with children with disabilities. *Pediatric Nursing*, *39*(3), 142–145.

Bergstraesser, E., Zimmermann, K., Eskola, K., Luck, P., Ramelet, A.-S., & Cignacco, E. (2015). Paediatric end-of-life care needs in Switzerland: Current practices and perspectives from parents and professionals. *Journal of Advanced Nursing*, *71*(8), 1940–1947.

Bhugra, D., & Becker, M. A. (2005). Migration, cultural bereavement and cultural identity. *World Psychiatry*, *4*(1), 18–24.

Bradbury-Jones, C., Breckenridge, J., Clark, M. T., Herber, O. R., Wagstaff, C., & Taylor, J. (2017). The state of qualitative research in health and social science literature: A focused mapping review and synthesis. *International Journal of Social Research Methodology*, *20*(6), 627–645.

Brassart, E., Prévost, C., Bétrisey, C., Lemieux, M., & Desmarais, C. (2017). Strategies developed by service providers to enhance treatment engagement by immigrant parents raising a child with a disability. *Journal of Child and Family Studies*, *26*(4), 1230–1244.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Burnes, D. P., Antle, B. J., Williams, C. C., & Cook, L. (2008). Mothers raising children with sickle cell disease at the intersection of race, gender and illness stigma. *Health & Social Work*, *33*(3), 211–220.

Carter, B., & Bray, L. (2016). How caring for a child with complex health needs can be both isolating and extraordinary. *The Conversation*. https://theconversation.com/how-caring-for-a-child-with-complex-health-needs-can-be-both-isolating-and-extraordinary-66651

Cochran, D., Saleem, S., Khowaja-Punjwani, S., & Lantos, J. D. (2017). Cross-cultural differences in communication about a dying child. *Pediatrics*, *140*(5), e20170690. https://doi.org/10.1542/peds.2017-0690

Collins, A., Hennessy-Anderson, N., Hosking, S., Hynson, J., Remedios, C., & Thomas, K. (2016). Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study. *Palliative Medicine*, *30*(10), 950–959. https://doi.org/10.1177/0269216316634245

Collins, A., McLachlan, S.-A., & Philip, J. (2018). Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion. *Palliative Medicine*, *32*(1), 133–142. https://doi.org/10.1177/0269216317735247

Connor, S. R., & Bermedo, M. C. S. (2014). *Global atlas of palliative care at the end of life*. Geneva, CH/London: UK World Health Organization/Worldwide Hospice Palliative Care Alliance. https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

Connor, S. R., Downing, J., & Marston, J. (2017). Estimating the global need for palliative care for children: A cross-sectional analysis. *Journal of Pain and Symptom Management*, *53*(2), 171–177. https://doi.org/10.1016/j.jpainsymman.2016.08.020

Contro, N., Davies, B., Larson, J., & Sourkes, B. (2010). Away from home: Experiences of Mexican American families in pediatric palliative care. *Journal of Social Work in End-of-life & Palliative Care*, *6*(3–4), 185–204. https://doi.org/10.1080/15524256.2010.529020

Daniel, B., Taylor, J. S., & Scott, J. (2010). Recognition of neglect and early response: Overview of a systematic review of the literature. *Child & Family Social Work*, *15*(2), 248–257. https://doi.org/10.1111/j.1365-2206.2009.00670.x

Daniel, B., Taylor, J. S., & Scott, J. (2011). *Recognizing and helping the neglected child: Evidence-based practice for assessment and intervention*. London: Jessica Kingsley.

Davies, B., Contro, N., Larson, J., & Widger, K. (2010). Culturally-sensitive information-sharing in pediatric palliative care. *Pediatrics*, *125*(4), e859–e865. https://doi.org/10.1542/peds.2009-0722

Dewar, B., & Nolan, M. (2013). Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, *50*(9), 1247–1258. https://doi.org/10.1016/j.ijnurstu.2013.01.008

Evans, N., Meñaca, A., Andrew, E. V., Koffman, J., Harding, R., Higginson, I. J., … Gysels, M. (2012). Systematic review of the primary research on minority ethnic groups and end-of-life care from the United Kingdom. *Journal of Pain and Symptom Management*, *43*(2), 261–286.

Fellin, M., King, G., Esses, V., Lindsay, S., & Klassen, A. (2013). Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability. *International Journal of Migration, Health and Social Care*, *9*(3), 135–145.

Finnström, B., & Söderhamn, O. (2006). Conceptions of pain among Somali women. *Journal of Advanced Nursing*, *54*(4), 418–425.

Flanagan, S. M., & Hancock, B. (2010). 'Reaching the hard to reach'-lessons learned from the VCS (voluntary and community Sector). A qualitative study. *BMC Health Services Research*, *10*(1), 92.

Flores, G. (2005). The impact of medical interpreter services on the quality of health care: A systematic review. *Medical Care Research and Review*, *62*(3), 255–299.

Foster, J. (2009). Cultural humility and the importance of long-term relationships in international partnerships. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, *38*(1), 100–107. https://doi.org/10.1111/j.1552-6909.2008.00313.x

Friedrichsdorf, S., & Bruera, E. (2018). Delivering pediatric palliative care: From denial, palliphobia, pallilalia to palliactive. *Children*, *5*, 120. https://doi.org/10.3390/children5090120

Ghirotto, L., Busani, E., Salvati, M., Di Marco, V., Caldarelli, V., & Artioli, G. (2019). Researching children's perspectives in pediatric palliative care: A systematic review and meta-summary of qualitative research. *Palliative & Supportive Care*, *17*(1), 107–118.

Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, *26*(2), 91–108.

Green, A., Jerzmanowska, N., Green, M., & Lobb, E. A. (2018). 'Death is difficult in any language': A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. *Palliative Medicine*, *32*(8), 1419–1427.

Gulati, S., Watt, L., Shaw, N., Sung, L., Poureslami, I. M., Klaassen, R., … Klassen, A. F. (2012). Communication and language challenges experienced by Chinese and South Asian immigrant parents of children with cancer in Canada: Implications for health services delivery. *Pediatric Blood & Cancer*, *58*(4), 572–578. https://doi.org/10.1002/pbc.23054

Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., … Vedel, I. (2018). *Mixed methods appraisal tool (MMAT), version 2018*. Registration of Copyright (#1148552), Canadian Intellectual Property Office, Industry Canada.

Institute of Medicine. (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Retrieved from http://www.nap.edu/catalog/10390/when-children-dieimproving-palliative-and-end-of-life-care

International Children's Palliative Care Network. (2019). *Scale of the need*. Retrieved from http://www.icpcn.org/information/the-need-for-childrens-palliative-care/

Khanlou, N., Haque, N., Sheehan, S., & Jones, G. (2015). "It is an issue of not knowing where to go": Service providers' perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities. *Journal of Immigrant and Minority Health*, *17*(6), 1840–1847. https://doi.org/10.1007/s10903-014-0122-8

Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing & Health*, *40*(1), 23–42. https://doi.org/10.1002/nur.21768

King, G., Desmarais, C., Lindsay, S., Piérart, G., & Tétreault, S. (2015). The roles of effective communication and client engagement in delivering culturally sensitive care to immigrant parents of children with disabilities. *Disability and Rehabilitation*, *37*(15), 1372–1381. https://doi.org/10.3109/09638288.2014.972580

Kvarme, L. G., Albertini-Früh, E., Brekke, I., Gardsjord, R., Halvorsrud, L., & Liden, H. (2016). On duty all the time: Health and quality of

life among immigrant parents caring for a child with complex health needs. *Journal of Clinical Nursing*, *25*(3–4), 362–371. https://doi.org/10.1111/jocn.13056

Kvarme, L. G., Alebertini Früh, E., & Lidèn, H. (2017). How do immigrant parents of children with complex health needs manage to cope in their daily lives? *Child & Family Social Work*, *22*(4), 1399–1406. https://doi.org/10.1111/cfs.12358

Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas. *The Lancet*, *371*(9615), 852–864. https://doi.org/10.1016/S0140-6736(07)61203-3

Limardi, S., Stievano, A., Rocco, G., Vellone, E., & Alvaro, R. (2016). Caregiver resilience in palliative care: A research protocol. *Journal of Advanced Nursing*, *72*(2), 421–433. https://doi.org/10.1111/jan.12829

Lincoln, Y. S., Guba, E. G., & Pilotta, J. J. (1985). *Naturalistic inquiry* (pp. 416). Beverly Hills, CA: Sage Publications. $25.00 (Cloth). In (Vol. 9, pp. 438–439).

Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: Challenges and recommendations for healthcare and community service providers. *Disability and Rehabilitation*, *34*(23), 2007–2017. https://doi.org/10.3109/09638288.2012.667192

Maffia, C., & Conway, S. (2008). *Supporting the health of refugees and people seeking asylum. Getting it right*. Unite/Community Practitioners' and Health Visitors' Association.

Manstead, T., Reicher, S., Greenland, K., & Nightingale, A. (2016). *The migration crisis – Psychological perspectives*. Psychologists report from a meeting sponsored by SPSSI-UK and Cardiff University. Retrieved from https://thepsychologist.bps.org.uk/migration-crisis-psychological-perspectives

McGarry, O., Hannigan, A., De Almeida, M. M., Severoni, S., Puthoopparambil, S. J., & MacFarlane, A. (2018). *What strategies to address communication barriers for refugees and migrants in health care settings have been implemented and evaluated across the WHO European Region? Themed issues on migration and health*. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK534369/

Melin-Johansson, C., Axelsson, I., Grundberg, M. J., & Hallqvist, F. (2014). When a child dies: Parents' experiences of palliative care—An integrative literature review. *Journal of Pediatric Nursing*, *29*(6), 660–669. https://doi.org/10.1016/j.pedn.2014.06.009

MIND. (2009). *A civilised society mental health provision for refugees and asylum-seekers in England and Wales*. Retrieved from http://www.mind.org.uk/media/273472/a-civilised-society.pdf

Mitchell, S., Slowther, A.-M., Coad, J., & Dale, J. (2018). The journey through care: Study protocol for a longitudinal qualitative interview study to investigate the healthcare experiences and preferences of children and young people with life-limiting and life-threatening conditions and their families in the West Midlands, UK. *British Medical Journal Open*, *8*(1), e018266. https://doi.org/10.1136/bmjopen-2017-018266

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., Altman, D., Antes, G., Berlin, J. A. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement (Chinese edition). *Journal of Chinese Integrative Medicine*, *7*(9), 889–896. https://doi.org/10.3736/jcim20090918

Morris, M., Popper, S., Rodwell, T., Brodine, S., & Brouwer, K. (2009). Healthcare barriers of refugees post-resettlement. *The Publication for Health Promotion and Disease Prevention*, *34*(6), 529–538. https://doi.org/10.1007/s10900-009-9175-3

NHS Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. Retrieved from http://www.york.ac.uk/inst/crd/SysRev/!SSL!/WebHelp/SysRev3.htm

NICE. (2016). *End of life care for infants, children and young people with life-limiting conditions: Planning and management*. Retrieved from https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-pdf-1837568722885

Nicholson, P. J. (2007). How to undertake a systematic review in an occupational setting. *Occupational and Environmental Medicine*, *64*(5), 353. https://doi.org/10.1136/oem.2006.031153

Parhar, R. (2018). *Distress signals: Unaccompanied young people's struggle for mental health care*. The Children's Society. Retrieved from https://www.childrenssociety.org.uk/sites/default/files/distress-signals-report_0.pdf

Pergert, P., Ekblad, S., Björk, O., Enskär, K., & Andrews, T. (2012). Protecting family interests: An interview study with foreign-born parents struggling on in childhood cancer care. *International Journal of Pediatrics*, *2012*, 681301. https://doi.org/10.1155/2012/681301

Pergert, P., Ekblad, S., Enskär, K., & Björk, O. (2008). Bridging obstacles to transcultural caring relationships—Tools discovered through interviews with staff in pediatric oncology care. *European Journal of Oncology Nursing*, *12*(1), 35–43. https://doi.org/10.1016/j.ejon.2007.07.006

Periyakoil, V. S., Neri, E., & Kraemer, H. (2015). No easy talk: A mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. *PLoS One*, *10*(4), e0122321. https://doi.org/10.1371/journal.pone.0122321

Pinheiro, I., & Jaff, D. (2018). The role of palliative care in addressing the health needs of Syrian refugees in Jordan. *Medicine, Conflict and Survival*, *34*(1), 1–20. https://doi.org/10.1080/13623699.2018.1437966

Sandelowski, M., & Barroso, J. (2002). Reading qualitative studies. *International Journal of Qualitative Methods*, *1*(1), 74–108. https://doi.org/10.1177/160940690200100107

Sheikh-Mohammed, M., Macintyre, C. R., Wood, N. J., Leask, J., & Isaacs, D. (2006). Barriers to access to health care for newly resettled sub-Saharan refugees in Australia. *Medical Journal of Australia*, *185*(11–12), 594–597. https://doi.org/10.5694/j.1326-5377.2006.tb00721.x

Silva, M. D., Genoff, M., Zaballa, A., Jewell, S., Stabler, S., Gany, F. M., & Diamond, L. C. (2016). Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency. *Journal of Pain and Symptom Management*, *51*(3), 569–580. https://doi.org/10.1016/j.jpainsymman.2015.10.011

Simonnot, N., Rodriguez, A., Nuenberg, M., Fille, F., Aranda-Fernandez, P.-E., & Chauvin, P. (2016). Access to healthcare for people facing multiple vulnerabilities in health in 31 cities in 12 countries. Report on social and medical data gathered in 2015 in 11 European countries and Turkey.

Sneesby, L., Satchell, R., Good, P., & Van Der Riet, P. (2011). Death and dying in Australia: Perceptions of a Sudanese community. *Journal of Advanced Nursing*, *67*(12), 2696–2702. https://doi.org/10.1111/j.1365-2648.2011.05775.x

Taylor, J. S. D., Daniel, B., & Scott, J. (2012). Towards an international agenda for child neglect: Methodological issues from a systematic review. *Child and Family Social Work*, *17*(4), 281–290.

Ten Ham-Baloyi, W., & Jordan, P. (2016). Systematic review as a research method in post-graduate nursing education. *Health SA Gesondheid*, *21*(C), 120–128. https://doi.org/10.1016/j.hsag.2015.08.002

Tervalon, M., & Murray-García, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*, *9*(2), 117–125. https://doi.org/10.1353/hpu.2010.0233

The Refugee Council. (2013). *The truth about asylum*. Retrieved from https://www.refugeecouncil.org.uk/information/refugee-asylum-facts/the-truth-about-asylum/

Thompson, A. (2015). Paediatric palliative care. Symposium: Special needs. *Paediatrics and Child Health*, *25*(10), 458–462.

Together for Short Lives (2018a). *A guide to children's palliative care* (4th ed.). Retrieved from https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/FamRes-Childrens-Palliative-Care-Definitions.pdf

Together for Short Lives. (2018b). *Children's palliative care definitions*. Retrieved from https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/01/FamRes-Spiritual-Religious-and-Cultural-Wishes-Factsheet.pdf

UNHCR. (2016). *The 1951 Refugee Convention; Convention and protocol relating to the status of refugees*. Retrieved from https://www.unhcr.org/uk/1951-refugee-convention.html

Van der Geest, I. M., Darlington, A.-S.-E., Streng, I. C., Michiels, E. M., Pieters, R., & van den Heuvel-Eibrink, M. M. (2014). Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *Journal of Pain and Symptom Management*, *47*(6), 1043–1053. https://doi.org/10.1016/j.jpainsymman.2013.07.007

Verberne, L. M., Kars, M. C., Schouten-van Meeteren, A. Y. N., van den Bergh, E. M. M., Bosman, D. K., Colenbrander, D. A., … van Delden, J. J. M. (2019). Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: A qualitative study. *European Journal of Pediatrics*, *178*(7), 1075–1085. https://doi.org/10.1007/s00431-019-03393-w

Weaver, M. S., Mooney-Doyle, K., Kelly, K. P., Montgomery, K., Newman, A. R., Fortney, C. A., … Hinds, P. S. (2019). The benefits and burdens of pediatric palliative care and end-of-life research: A systematic review. *Journal of Palliative Medicine*, *22*(8), 915–926. https://doi.org/10.1089/jpm.2018.0483

Weller, S. J., Crosby, L. J., Turnbull, E. R., Burns, R., Miller, A., Jones, L., & Aldridge, R. W. (2019). The negative health effects of hostile environment policies on migrants: A cross-sectional service evaluation of humanitarian healthcare provision in the UK. *Wellcome Open Research*, *4*, 109. https://doi.org/10.12688/wellcomeopenres.15358.1

WHO. (2018). *Integrating palliative care and symptom relief into paediatrics: A WHO guide for health-care planners, implementers and managers*. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf?sequence=1&isAllowed=y

WHO. (2020). *Migration and health: Key issues*. Retrieved from http://www.euro.who.int/en/health-topics/health-determinants/migration-and-health/migrant-health-in-the-european-region/migration-and-health-key-issues#page-wrap

Wolff, J., Pak, J., Meeske, K., Worden, J. W., & Katz, E. (2010). Challenges and coping styles of fathers as primary medical caretakers: A multicultural qualitative study. *Journal of Psychosocial Oncology*, *28*(2), 202–217. https://doi.org/10.1080/07347330903516902

Wolff, J., Pak, J., Meeske, K., Worden, J. W., & Katz, E. (2011). Understanding why fathers assume primary medical caretaker responsibilities of children with life-threatening illnesses. *Psychology of Men & Masculinity*, *12*(2), 144–157. https://doi.org/10.1037/a0022391

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Clancy M, Taylor J, Bradbury-Jones C, Phillimore J. A systematic review exploring palliative care for families who are forced migrants. *J Adv Nurs*. 2020;76:2872–2884. https://doi.org/10.1111/jan.14509

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

Reasons to publish your work in *JAN*:

- **High-impact forum:** the world's most cited nursing journal, with an Impact Factor of 1·998 – ranked 12/114 in the 2016 ISI Journal Citation Reports © (Nursing (Social Science)).
- **Most read nursing journal in the world:** over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 3,500 in developing countries with free or low cost access).
- **Fast and easy online submission:** online submission at http://mc.manuscriptcentral.com/jan.
- **Positive publishing experience:** rapid double-blind peer review with constructive feedback.
- **Rapid online publication in five weeks:** average time from final manuscript arriving in production to online publication.
- **Online Open:** the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).

Appendix Three – Prospero Protocol

Access online at:
https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019129200

A systematic review exploring the experiences of children's palliative care for asylum seeker/refugee families

Citation

Marie Clancy, Julie Taylor, Caroline Bradbury-Jones, Jenny Philimore. A systematic review exploring the experiences of children's palliative care for asylum seeker/refugee families. PROSPERO 2019 CRD42019129200 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019129200

Review question

The purpose of this review is to explore the experiences of asylum seeker/refugee children and families in receipt of children's palliative care. Further to this will be an exploration of the experiences of the health care professionals who care for these children and families.

This review will thus address the following question:

What do we currently know about the experiences of children's palliative care for asylum seeker and refugee families?

Searches [1 change]

The following sources/databases are to be utilised in this search; Allied and Complementary Medicine Database (AMED), Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE, Embase, ProQuest, Web of Science (core collection) including social sciences, arts and humanities and emerging sources. Extensive checking will also be carried out to ensure all appropriate articles are included and this will also involve the searching of the Cochrane Library Databases and Google Scholar.

The databases utilised aim to give a comprehensive and diverse range of literature and offer a unique perspective within an interdisciplinary network, as this topic has the potential to overarch many different fields of study.

Search strategy; abstract and title search terms;

"Refugees including asylum seeker/seeking" OR "transient*" OR "migran*" OR "displaced persons" OR "emigration" OR "immigration" OR "immigran*" OR "undocumented child*" AND "terminal care/terminally ill patient*" OR "end of life care" OR "palliative care" OR "life limiting" OR "life threatening" OR "death and dying" OR "complex care" OR "supportive care" OR "disabled child*" AND "health behavio?r*" OR "nursing care" OR "health service accessibility" OR "health care utilization" OR "health care adj1 barrier*" OR "treatment barrier*" OR "health seeking

behavio?r*" OR "experience*" OR "health care professional" OR "health care personnel" OR "parent*" OR "child*".

These records will be searched from January 2008 to October 2018 in English Language format and with a restriction on peer reviewed empirical primary research only.

The search strategy will involve multiple testing of search terms as terminologies surrounding children's palliative care and migration are vast and differ internationally. This will involve running searches to check all relevant articles are found and the inclusion of additional/variations of terms until no new articles are forthcoming.

Types of study to be included

Articles will be included which offer primary empirical research evidence that fits with the research questions. Further to this and because of the empirical nature of this review, opinion pieces, conference/workshop write-ups and studies which discuss care based upon clinical cases without a clear research methodology will be excluded.

Qualitative, quantitative and mixed methods studies will be included as there is the potential for them to help answer the research questions by providing different perspectives and insights.

Condition or domain being studied

Children's palliative care within the context of forced migration. Families, children and health care professional's experiences are of paramount significance to this review.

Participants/population

This review will focus upon children's palliative care and as such the review seeks empirical evidence which highlights the experience of children, their families and paediatric health care personnel. Definitions of children's palliative care will follow guidelines from WHO and Together for Short Lives whilst terminologies for asylum seeker and refugee will be taken from the Refugee Council and UNHCR .

Articles which focus entirely upon an adult/elderly population are to be excluded as palliative care at the end of a long life is viewed differently sociologically and attributed specialist care provision which differs vastly to that of children's palliative care. Furthermore the training/education of healthcare staff is also specialised and will thus vary considerably from one specialism such as geriatric medicine to that of paediatrics.

Equally this review will exclude literature which focuses upon economic migration specifically as this appears to be a very different life choice compared to the forced journeys made by asylum seeker/refugee families and thus will highlight different experiences and perspectives than those sought by this review.

However in cases of uncertainty as regards inclusion and exclusion a whole team approach will be adopted in order to achieve consensus.

Intervention(s), exposure(s)

For the purposes of this review the intervention/exposure will be seen as the palliative care service provision given to children and their families. This may take place in the hospital, hospice or home environment which fits with current UK service provision.

Comparator(s)/control

Not applicable

Context

This review is framed within the context of a post referendum Britain on the verge of exiting the European Union. This has ramifications for the general population but also specific consequences for those of differing migration status.

Children's palliative care is still a comparatively new speciality with increasing numbers of children and young people with complex and multifaceted life-limiting and life-threatening conditions. As such service provision is often challenging and resource constrained.

Main outcome(s)

This review aims to provide an explanation of the experiences of refugee/asylum seeker children, families and the health

care professionals who care for them and hopes to highlight current challenges, barriers and successes of care provision. This will then frame practice implications for the multidisciplinary children's palliative care team when caring for children of differing migration status.

Additional outcome(s)

None

Data extraction (selection and coding) [1 change]

Title and abstract screening will be performed by MC, full text articles will then be reviewed by the wider team (JT, CBJ and JP) prior to critical appraisal and quality assessment of the literature.

The main data to be extracted includes; article details (author, title, year, reference for the study), population and participants characteristics and numbers, setting and country of study, methods and methodology applied, analysis methods, themes identified, recommendations and future research implications, limitations and strengths of the study.

Risk of bias (quality) assessment [1 change]

The use of a transparent search strategy and quality assessment using the MMAT and CASP tools (as applicable) of the relevant literature within a research group dynamic will give the review reliability and rigour. Research studies which fail to meet the quality guidelines of these tools will be removed from the review, with a detailed rationale as to why this may be necessary.

The research team will meet regularly for group discussion and the sharing of expertise during the course of the review.

Strategy for data synthesis [1 change]

This review will adopt formal a narrative (descriptive) synthesis in order to provide an analysis of the relationships within and between studies and an overall assessment of the robustness of evidence. This will involve the integration and interpretation of studies within the review taking account of any similarities and inconsistencies.

A thematic analysis including systematic coding of themes within and across papers will be conducted with detailed checking and rechecking within the research team to ensure accuracy. This will then form the basis of results and findings of the review with a discussion of the strengths and limitations of the review and how the research questions have been addressed and any questions which remain unanswered.

Lastly the results will be interpreted within a discussion section and conclusions drawn with recommendations/implications for practice/policy and future research. At least two reviewers of varied discipline/expertise will evaluate all extracted codes and disagreements will be resolved via discussion with a third reviewer.

Analysis of subgroups or subsets

Not applicable

Contact details for further information

Marie Clancy

Organisational affiliation of the review

University of Birmingham

Review team members and their organisational affiliations

Mrs Marie Clancy. University of Birmingham

Professor Julie Taylor. University of Birmingham

Dr Caroline Bradbury-Jones. University of Birmingham

Professor Jenny Philimore. University of Birmingham

Type and method of review

Narrative synthesis, Systematic review

Anticipated or actual start date

01 October 2018

Anticipated completion date

02 September 2019

Funding sources/sponsors

Not applicable

Conflicts of interest

Language

English

Country

England

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Child; Family; Health Services Accessibility; Humans; Palliative Care; Refugees

Date of registration in PROSPERO

30 April 2019

Date of first submission

19 March 2019

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

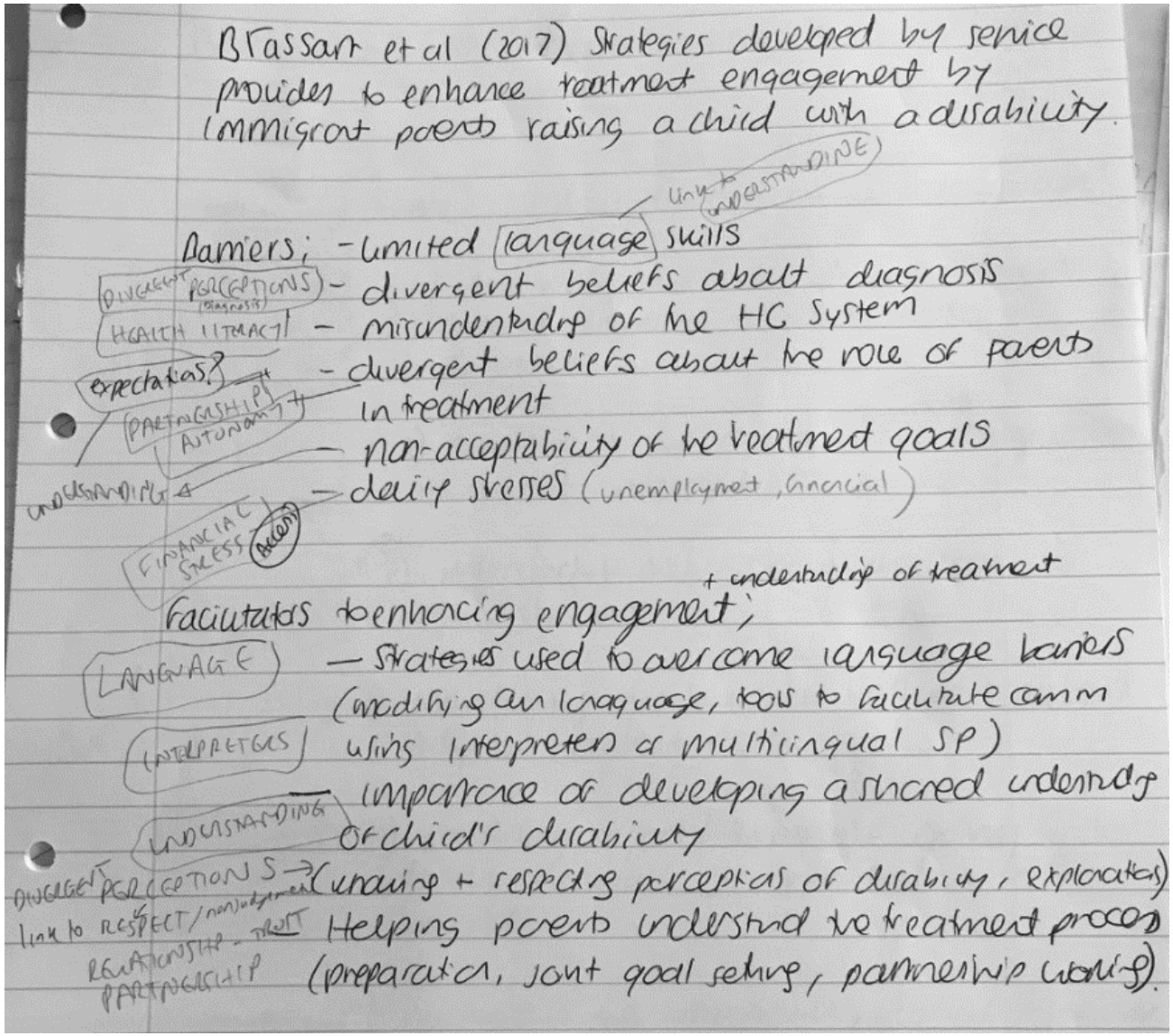
The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

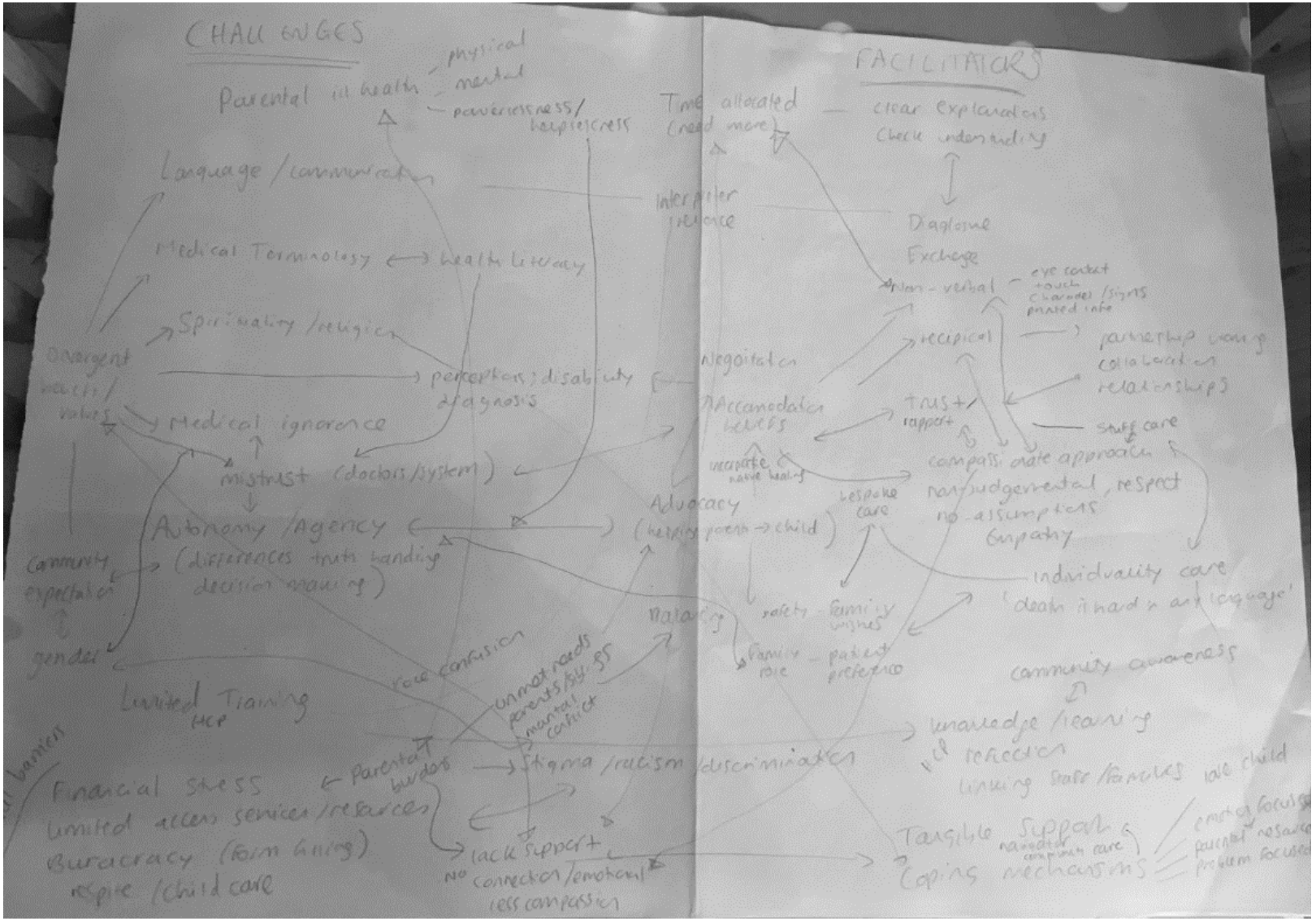
Versions

30 April 2019

Appendix Four - Coding of an individual paper



Appendix Five - Dynamic relationships across the codes/themes



Appendix Six - Coding across papers

Codes	No. times noted	Theme
Parental burdens, unmet needs, conflict	8, 23	Care giving burdens and coping strategies
Family ill health, physical/mental	21	
Lack of family support	5	
Family coping strategies	27	
Tangible support	9	
Perceptions disability, diagnosis, mistrust, medical ignorance, differing beliefs, expectations	14	Divergence of beliefs and expectations necessitating individualised care
Gender differences	8	
Negotiation, accommodation of individualised needs/care	22	
Autonomy, advocacy, agency (differences truth handling/decision making)	7, 5	
Spirituality/religion	4	
Language/communication barriers	6,9	Language and caring communication
Rapport	1	
HCP language and communication facilitators	5	
Non-verbal communication	12	
Compassionate approach; respect, non-judgemental, empathy	10	
Migration experiences/stories	4	
Access services/resources	14	Navigating health care systems
Bureaucracy	1	
Financial stress	3	
Health literacy, medical terminology	13	
Lack training	3	Training/knowledge
Role confusion	1	
HCP training/knowledge	2	
Public awareness	1	

Appendix Seven – Advisory group information and study involvement

Group name	Membership details	Involvement
Birmingham Children's Hospital Young Person's Advisory Group (YPAG)	This group includes patients, ex-patients and local young people's health and youth representatives living in the West Midlands aged between 11 and 18 years old.	One member created pictures and paintings for information sheets and to help disseminate findings Reviewed family information sheets and provided feedback Interviewing of family members/children where possible. This was hoped to help to strengthen trust and aid interpretation/minimise language barriers. Further benefits included helping with contextual and cultural understanding of the responses seen. Individual members helped interpret HCP interviews into poems (when participants either preferred not to do this themselves or did not have the literacy to enable them to do this). YPAG members explored the study findings and helped to shape recommendations
Acorns children's hospice young ambassadors and parent groups	These groups include current carers, bereaved parents and young people, children and siblings who volunteer to support service and health care development	Reviewed family information leaflets and provided feedback A parent champion with special interest helped create poetry from parent participant transcripts (where parents could not or choose not to do this themselves) Parent champions explored the study findings and helped to shape recommendations
Birmingham Asylum and Refugee Association (BARA)	This group includes forced migrant adults who meet regularly to offer each other support and assistance during resettlement and whilst applying for permanent residency in the UK. This group contains parents and a mixture of ages, gender, ethnicities, religions and countries of origin.	Involved in discussions surrounding appropriate terminology Reviewed creative methodology and participated in a workshop looking at the use of poetry and art with potential participants BARA members explored the study findings and helped to shape recommendations
Paediatric Palliative Care Network (West Midlands and South West)	This group contains specialist health care professionals working in the West Midlands including doctors, nurses,	Individual members involved in the review of ethical review documentation and HCP information sheet, informed consent documents and images used

	psychotherapists, play therapists and chaplaincy. The group strives to advocate on behalf of children and their families and have vast experience and expertise in children's palliative care including multiple care settings of hospital, community and hospice care.	Two members from West Midlands Network participated in the piloting of 'draw and talk' interviews Members from the South West Network explored the study findings and helped to shape recommendations
GUARDIANS (Guiding Unity and Advocating for Race, Diversity and Inclusion)	A West midlands-based network for staff aiming to better represent and advocate for staff and families of differing backgrounds in hospital	A member of the group helped create poetry from HCP participant transcripts (where participants could not or choose not to do this themselves)
Interpreter group *West Midlands Hospital*	Interpreters of many different languages and dialects working in paid and voluntary roles at a large West Midlands Hospital	The group was asked to review findings and recommendations to help shape them from their experience and expertise working with families similar to those in this study and ensure the voice of the interpreter was not absent from this study
All groups		Providing a forum for discussion/debate of progress which draws on members' experience and offering valuable insights, priorities and an ability to put the 'jigsaw puzzle' of issues around the topic together. Any members who support the research study will be offered shared authorship or acknowledgement of their work for any conference presentations and article submissions. Encouragement and empowerment will be given for advisory group members to actively contribute as fully as possible based upon their own preference/comfort and availability

Appendix Eight - Draw and talk mapping utilised with HCP

Stage	Intention	Prompts which may be utilised
Mapping process 1	Mapping the self – participants are asked to represent themselves in any way they wish	As you draw yourself, could you tell me about your career so far and how you came to work in CPC? Follow up with observational statements 'you have used black?' 'you are very small?'
Mapping process 2	Map important relationships (to assess quality and texture of relationship) HCP – who cares for this child and how do the relationships work?	How is it sustained (activities/communication) How it has been impacted by life situations (child's condition/HCP external factors) Ask about experiences caring for child (self and others) Positives (what helped to improve care) and negative (what hindered care) elements. Why do you think this was so difficult? Worked so well?
Mapping process 3	Step back from picture to take it all in as a whole	Do you think/feel anything in particular as you see the whole picture together?
Mapping process 4	Consider change – in an ideal world/future (explores how they would like their relational lives to be – their expectations, beliefs, fantasies and hopes) however this stage may also bring new information about how things actually are in the present	Suggest strategies for improving care and aspects related to team working or interdisciplinary care and communication

Appendix Nine - Draw and talk mapping for parent/guardian and child (dependent on age/understanding)

Stage	Intention	Prompts which may be utilised
Mapping process 1	Mapping the self – participants are asked to represent themselves in any way they wish	Could you tell me about yourself and how you came to the UK? How and when did you realise your child was unwell? Follow up with observational statements 'you have used pink?' 'you are sitting on the grass?'
Mapping process 2	Map important relationships (to assess quality and texture of relationship) Ask parent to start with child Parent – who is important in the care of child?	How is it sustained (activities/communication) How it has been impacted by life situations (child's condition/HCP external factors) Can you tell me about your child and their diagnosis? Ask about experiences caring for child (self and others) What things helped to make your care better or what things hindered your care? How did the nurses/doctors help you? What was the environment like? Why do you think your experience as a forced migrant might differ to those who have not experienced migration to another country? Why do you think this was so difficult? Worked so well?
Mapping process 3	Step back from picture to take it all in as a whole	Do you think/feel anything in particular as you see the whole picture together?
Mapping process 4	Consider change – in an ideal world/future (explores how they would like their relational lives to be – their expectations, beliefs, fantasies and hopes) however this stage may also bring new information about how things actually are in the present	Suggest strategies for improving care for future families/children in similar situations

Appendix 10 – New Lives New Hope – parent advisory poem with direct use of participant quotes (seen in bold)

I only want to live a quiet life
With my family by my side
But I'm having a very hard time
With the home office
Trying hard to swallow my pride
And not plead and beg to be allowed to
Stay in a country that does not lock you
Up and throw away the key
For any reason at all
And shells its citizens
And crushes any opposition
With disdain and impunity

The Home Office interviewer
Is asking question after question
Please can you go through your reasons
For wanting to live here again?
Sorry, **we have to move you**
Another interview, another interview
But now I'm in Birmingham
With my family here, safe at last
Relieved, appreciating a reborn-view
And now we can focus on our child
Her illness, her condition, her disabilities
The one who needs the care and attention

And everyone is doing their best
To support and help the family
In a new culture that treats people fairly
Humans rights and dignity
Here we have everything,
All the care that we need from
Doctors and teachers and nurses and
All the other professionals you see,
Take an interest and **do what they can**
Unlike the country we left
Where **we didn't have a chance**
And for that reason we ran

But the reality is that despite help
Kindness and generosity dispelling fears
The language barrier remains so frustrating
And drives a man to tears
It's not just another language, but
Another culture, where everything is different

And every minute is spent trying to make
Heads or tails of this new found freedom in a city
Of new sounds, smells, sights, tastes, experiences
Especially when before, a life before war,
The family was community and all around
Family was extended and extensive, always there to help,

But here there's no family, you have
To do everything yourself.
And when misunderstandings occur you feel
Alone and desperate again, fearful of authority
When you are unable to adequately explain anything
Yet, there are always those who
Do all they can, at a moment's notice,
A few people you can call upon and implicitly trust
A social worker, a charity worker, someone from the mosque
Who listens without prejudice, the minimum of fuss
And offers advice and speaks on your behalf
And says, you are not a refugee, you are all, one of us.

And you are pleased when people greet you
And introduce you by name and ask how you are and
Are you alright, again and again and what
About the little one, is she getting the care she needs?
And you can reply with confidence that she is
Because she is my life, is everything, I can't breathe
I can't live without her, I'd do everything for her for her safety
And to look after her. But lately, life is getting harder
As her needs become more complex and as she has grown,
And again, this new society offers a hand of hope.
A chance for respite, to provide care in a trusted place
While you rest, recover and find some peace, time and space.

And now a future appears, one of hope and freedom
In a land of kindness and sincerity, of tolerance,
Gentle discussions over tea, listened to with patience and dignity.
Nobody will understand what we're going through, what we have to do
But while we can trust in Allah, He will provide a solution
And the best of humanity will embrace us and give us back
A life and opportunity, to be part of a society that values and cares
And shares the same emotions and needs for compassion and
Community, a place where a disabled child can flourish
And live the best life they can
And we can say 'thank you' in our new language
An Arabic heartfelt,
Shukran ja'azilaan. شكرا جذ

Appendix 11 – Poem from Guardian advisory group member – A Muslim Chaplaincy (with text changes shown in blue)

A Muslim Chaplaincy, Who's heard of such a thing
What faith do they follow, what scriptures do they bring
Well I am that person, for over 40 years
Sharing scriptures, laughter, sharing tears

I arrived in the 60's, to this strange Nation
The Who singing 'My generation'
My parents were confused, they arrived first you see
Not understanding the culture, or programmes on TV

I was the first of my siblings, alone with dad and mother
Then at aged 7, along came another
Never allowed to play out, with girls or boys
Playing out with girls and boys stopped at ten
If ever I was caught, wow oh what a noise

Rida commented 'I was allowed to play out in the beginning, but only till I was ten'

My early faith, was a bit of a test
I'd pray occasionally, maybe twice a week at best
I wanted to join, other children, sounds daft
But I also had a passion, for doing needle craft

At first I wanted to be an actress, travel all over the place
But being good at stitching, could I fix a face?
So then It was surgeon, I thought this would be fab
But I ended up on a science course, stuck in a lab

At 22 I found my calling, I had a tendency to share
My religious beliefs, with children in care
Then it grew wider, it felt such a privilege
Connecting with the community, I was their comfort bridge

I spoke to all sorts, from women to males
Some were worried, that their treatment would fail
I gave them hope, each and every day
We would sit and just talk, I would also pray

Explanation of our culture, the things we can do
Explaining to a refugee, the meaning of scriptures too
Like having prints, of their poorly child's hands
Did not go against, Prophet Mohammed's commands

Explanations from nurses, can be different you see
A Muslim Chaplain, can explain to a refugee
Majority are men, who we called the Imam
Often called the Imam
But who do the females have, to keep them calm

Rida commented 'Maybe say 'often called the Iman' (as they are known as Male Muslim Chaplains too)'

So that's where I enter, where my skills can be used
Speaking to females, making sure they're not confused
Being on call, when there's laughter and when there's crying
Reading prayers with families, when children are dying

I remember a patient, fear in their eyes
Thinking nurses were going to kill them, the mask a disguise
Another was worried, about praying on her mat
Wanting the curtains closed, being afraid, she'd be laughed at

Getting over the stigma's was hard to do
Some male **Islamic** parents, wouldn't want to speak to you
Some male **Muslim** parents, wouldn't want to speak to you
But over time, those barriers were broken
I was seen as a religious figure, not just a token

Rida commented 'This should be Muslim but Islamic'

40years of counselling, wow where are all those years
Sharing laughter, prayers, sharing family's tears
It's been demanding, frustrating and also challenging
A Muslim Chaplaincy, who's heard of such a thing??

Appendix 12 – Ethical approval documentation

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mrs Marie Clancy
PhD student
University of Birmingham

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

20 January 2021

Dear Mrs Clancy

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring the experiences of forced migrant families and those who care for them in children's palliative care (CPC)**
IRAS project ID:	**281987**
Protocol number:	**RG_17-066**
REC reference:	**20/YH/0334**
Sponsor	**University of Birmingham**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **281987**. Please quote this on all correspondence.

Yours sincerely,
Alex Thorpe

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Dr B Whitman, Sponsor's Representative*

Appendix 13 – Participant information sheets for families and children of different ages

Information sheet for the parents/guardians of children receiving care for serious illnesses

Research project: 'Exploring the experiences of forced migrant (refugee and asylum seeker) families and those who care for them in children's palliative care (CPC)'

Marie Clancy, School of Nursing,
University of Birmingham

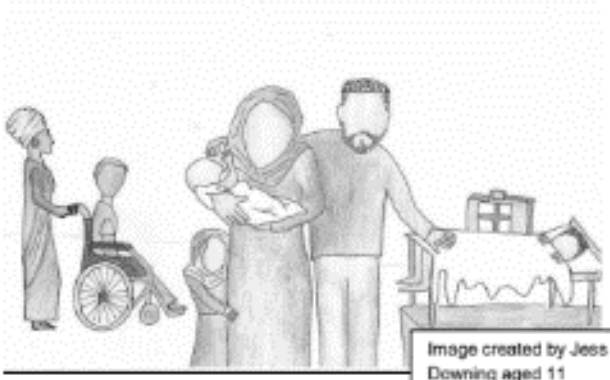


Image created by Jess Downing aged 11

This information sheet is about a research project sponsored by the University of Birmingham being undertaken by Marie Clancy a PhD researcher who is also a children's nurse and lecturer.

Please read this information sheet to help you decide whether you and/or your child want to take part.

What is research and why is it so important? Research is an organised process of solving problems and finding out new information. It can be done in many ways but this project hopes to discover more about you by talking to you during an interview and sharing your experiences with others. Research is vital in healthcare as the information collected can help to teach and guide doctors and nurses about how to improve care.

What is the project about? This project looks at the experiences of care for asylum seeker and refugee families whose children are living with serious conditions, which may or may not get better; conditions which may be considered life-limiting or life-threatening (and thus considered 'palliative'). The project will help us to think about how care may be improved by listening to people who receive and give care. We want to learn about what works well, what doesn't work so well and how services can change to meet the needs of families like yours.

Why have I been asked to take part? We know that for many reasons asylum seeking or refugee families endure lots of difficulties and challenges. Wherever they are receiving care, all families deserve the very best care. This is only possible if families can share their

experiences, needs and beliefs. This project seeks your views of healthcare. We will document your stories and share these with health care professionals, those who help to design services and those who decide what kinds of information is collected to encourage them to make improvements to the care families receive in the future.

What will happen if my child or I decide to take part?

If you would like to share your experiences and take part in the study please send the attached contact details form back to me, you can do this personally or by asking your health care team to send it to me. I will then contact you to answer your questions and arrange a time for an interview. Interviews can be arranged at a time and place you want and if you would prefer face-to-face they can be scheduled around your routine appointments. We can talk by telephone, in person or via online mediums such as Zoom, Skype or Microsoft Teams.

Before the interview you will be asked to read and sign a consent form saying you want to take part and that you have understood the project. If possible, you can support your child to take part too. You may also be asked to attend another follow up interview after the first one; this will be up to you to decide if you want to take part. There will be separate sections on the form for you to consider these aspects. Interviews may last between 20 and 40 minutes but you can talk freely without a time limit. A member of the Young Persons Advisory Group (YPAG) at the Children's Hospital may assist with the interviews however; this is completely your choice and will be discussed with you prior to the interview. This research may use artistic methods to help you express yourself this can include drawing, colouring or painting, if this is something you would like to do. Working in this way can help me to picture your experiences and help you to share your thoughts and feelings as you 'draw and talk'.

What will happen to the information that is collected?

The interview will be audio recorded. The recordings will be typed up and carefully examined. All the information we have collected cannot be connected with you. Your name and that of your family will be removed. Any information gathered will only be seen by Marie and her three supervisors. We will keep all information safe and secure.

The only time Marie would need to tell anyone, what you have said in your interview is if she becomes worried, there is a safeguarding concern (you discuss an intention to harm yourself or others or any previous history of abuse of children or adults). If this happens, Marie would have to stop the interview and she is duty bound to report this information to the appropriate health care teams, and safeguarding leads for further investigation.

If any concerns are raised about the standard of care you have received, this will be referred to the appropriate health care team.

Some of the words or sentences you say may be used to create poems. You can help with this or see the poem written about you to check it and suggest changes. These poems, quotes and any artwork created during the interview may be used in publications, research meetings and to develop educational materials. You will not be able to be identified through the poems. Such material is considered extremely valuable in helping others to understand the experiences of people like you. You will not be able to be identified through the poems.

We know that sharing your experiences may be difficult and you may need extra support. As such, you can pause or stop the interview at any time. We will also ensure you can receive additional support by contacting your health care team if needed.

How will we use information about you?
We will need to use information from your usual health care team for this research project. This information will include your name and contact details. We will use this information to contact you and give you further information about the project. We will keep all information about you safe and secure. We need to manage your records in specific ways for the research to be reliable. People use this information to do the research or to check your records to make sure that the research is being done properly. This means that we won't be able to let you see or change the data we hold about you. You can find out more about how we use your information by asking Marie any questions you may have.

Do I have to take part? Taking part in this study is completely up to you. You do not have to say yes. Whatever you decide to do will not affect the care your child will receive You can stop being part of the study at any time, without giving a reason and you can ask for any information we have gathered about you to be deleted up to 1 month after your interview date.

If a problem arises or you wish to make a complaint about the conduct of this study you may speak to the researcher Marie Clancy, contact the lead PhD supervisor Professor Julie Taylor on [redacted]r via 0121 414 8671 or contact the sponsor sites research governance team on researchgovernance@contacts.bham.ac.uk

You can also contact your PALS team *(details to be inserted accordingly)*

For further information about how research information is used and stored, you can contact the study sites sponsor data protection officer on: dataprotection@contacts.bham.ac.uk

The University has in force a Public Liability Policy and/or Clinical Trials policy, which provides cover for claims for "negligent harm" and the activities here are included within that coverage

Where can you find out more about how your information is used?

You can find out more about how we use your information and how it is stored, by asking one of the research team or by contacting the study sites sponsor data protection officer on: dataprotection@contacts.bham.ac.uk

Results of the study

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.

A one-page summary (in an appropriate accessible format) will be posted to all participants explaining the study findings once the research is complete.

Who should I contact for more details?

If you would like to know more about this project, ask questions or to take part, please contact:

Marie Clancy
University of Birmingham, School of Nursing
Email: [redacted] or Telephone:

Contact details form

I am interested in taking part in the research study *'Exploring the experiences of forced migrant families and those who care for them in children's palliative care'*



Image created by Jess Downing aged 11

Family members details **Name:** **Relationship to child:**		
Preferred contact method (please circle):		
Call	Text	Email
Telephone number:		
Email address:		
Preferred time of day for contact (please add specific times as necessary):		
Morning	Afternoon	Evening

When completed please send this form to Marie Clancy by email (your health care team will help you):

With special thanks to the advisory groups who helped shape this leaflet; YPAG at Birmingham Children's Hospital, Parent and Sibling Ambassadors at Acorns Children's Hospice and members of West Midlands Paediatric Palliative Care Network (WMPPCN).

UNIVERSITY OF BIRMINGHAM

Information sheet for children 11-14 years receiving care for serious illnesses

Research Project; 'Exploring the experiences of care for refugee and asylum seeker children and families'

Hi, my name is Marie Clancy, you can see me in the picture below. I am a PhD student who is also a children's nurse and lecturer. I am working on some research at the University of Birmingham.

This sheet will tell you all about my project so you can decide if you want to take part. You can talk about this with someone you trust too.



Image created by Jess Downing aged 11

What is the project about?

My project is about children (who are refugees or asylum seekers) and what they think about the care they receive.

I want to know what you think is good, not so good and how we might be able to make things even better.

Experiences of forced migrant in CPC
Participant information sheet – children 11-14 years
Version 2 08.01.21 IRAS number: 281987

With special thanks to the advisory groups who helped shape this leaflet; YPAG, Acorns parents and sibling ambassadors and WMPPCN members.

UNIVERSITY OF BIRMINGHAM

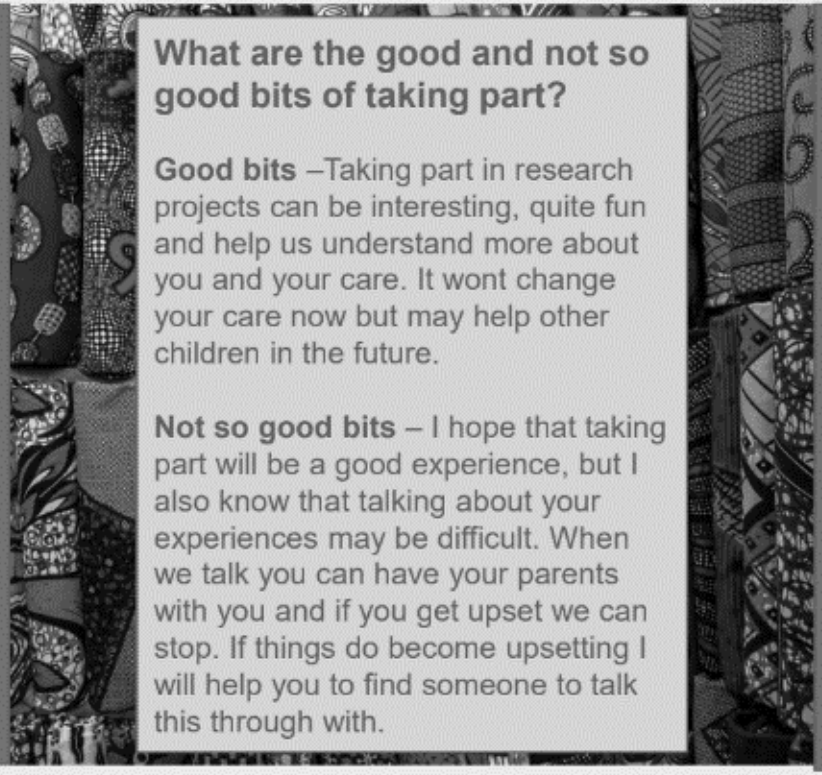
Exploring the experiences of care for refugee and asylum seeker children and families

Why have I been invited to take part?

You have been invited to take part because you have experiences of care which may be different to children who were born in the UK.

I realise that this may be quite hard and so I want to find out about it so I can understand it better and help others to understand it too.

I am also interested in talking to mums, dads and other family members because I think what you have to tell us will be important for improving care for others.



What are the good and not so good bits of taking part?

Good bits –Taking part in research projects can be interesting, quite fun and help us understand more about you and your care. It wont change your care now but may help other children in the future.

Not so good bits – I hope that taking part will be a good experience, but I also know that talking about your experiences may be difficult. When we talk you can have your parents with you and if you get upset we can stop. If things do become upsetting I will help you to find someone to talk this through with.

Do I have to take part?

Taking part in this study is completely your choice. No matter what you choose your care will not change.

If you want to be part of the study, you can change your mind and you do not have to give a reason. You can also ask for any information about you to be deleted up to 1 month after you talk to me.

UNIVERSITY OF BIRMINGHAM

Exploring the experiences of care for refugee and asylum seeker children and families

What would I be asked to do?

You would be asked to have a chat with me (an interview) and during this time (between 20-40 minutes) I may ask you to draw a picture, colour or paint but this will be your choice. Whilst you do this we can talk about what you are doing and what your care has been like for you and your family.

Before your interview I will ask you and your parents to sign a form (a consent form) to say you are happy to talk to me and understand everything about the project.



What will you do with the results of the interviews?

The interview will be recorded and typed up so I can look at it afterwards. All the information I collect will not have your name or your family's name on it. Any information gathered will only be seen by Marie and her 3 PhD supervisors. Marie will keep all information safe and secure.

The only time I would need to tell anyone what you have said is if I am worried you are in danger. If this happened I would have to stop our interview and tell someone who could help make things safer for you.

Some of the words or sentences you say may be used to create poems. You can help with this or see the poem to check it and help make it better. The poems, quotes and any artwork created during the interview may be used in publications, research meetings and to develop educational materials. This is considered extremely valuable in helping others (like future doctors and nurses) understand your experiences of care.

UNIVERSITY OF BIRMINGHAM

Exploring the experiences of care for refugee and asylum seeker children and families

Space for you to write any questions



What do I need to do now?

Have a think about what you would like to do. You can talk about it with your family, friends or anyone else you trust.

I can also answer any questions. I am happy for you (or your parents) to phone, text, or email me about the study – I may not be able to reply to you straight away but I will try to do this as soon as I can.

Once you have decided you can let me know by telling the person who gave you this leaflet. I will then get in touch with you and your parent/s to talk about what happens next.



My contact details

Marie Clancy

University of Birmingham, School of Nursing

Email: [redacted] or

Telephone/text:

Appendix 14 – Example informed assent/consent form

Assent form for young people aged 10 years and under

Exploring the experiences of care for refugee and asylum seeker children and families

Marie Clancy, School of Nursing,
University of Birmingham

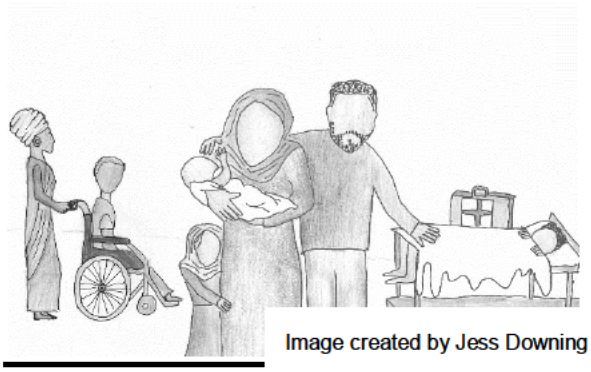


Image created by Jess Downing

Please write or draw in the boxes below to say that you understand:

The information sheet. You have thought about it and had any questions answered.	
That taking part is up to you (you do not have to say yes). You can leave the study if you want to, without having to tell us why and up until the researcher starts to look at everyone's information (up to 1 month after your interview)	
Everything you talk to us about will be kept private unless you or someone else is in danger. No one will be able to tell who you are from the information and it will be kept safe.	
You agree that we can make a recording of us talking and have it typed up taking out your and your family's names	
You agree we can use some of your words, art-work and the poems we make (without your name) as examples	
You agree to a member of the Young Persons Advisory Group being in our interview and helping with this	
OPTIONAL You agree to having a second interview if needed	YES/NO
You agree to take part in the above study	

Child's name	Child's signature	Date
Parent/guardian name	Parent/guardian signature	Date
Name of person taking assent (researcher)	Signature	Date

N.B. Ensure child and family receive a copy of this form

Consent form for Health Care Professionals

Exploring the experiences of forced migrant (refugee and asylum seeker) families and those who care for them in children's palliative care (CPC)

Marie Clancy, School of Nursing,
University of Birmingham

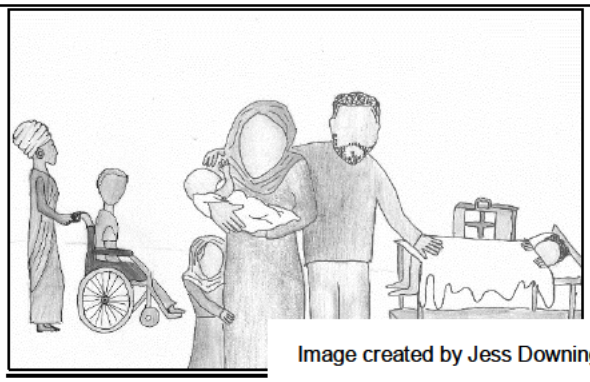


Image created by Jess Downing

Summary of the project

This project has been designed to explore the care experiences of forced migrant families whose children are living with serious conditions, which may or may not get better; conditions which may be considered life-limiting or life-threatening. The aim of the project is to consider how care may be improved in the future by listening to the experiences of those who receive and give care to forced migrant children and their families. We hope to find out what works well, what doesn't work so well and how services can change to meet the varied multicultural needs of families living in the UK.

Voluntary participation in this study

Participation in this study is completely voluntary. If you decide to participate, you have the right to change your mind. You can ask for any information we have gathered about you to be deleted prior to analysis (up to 1 month after your interview date).

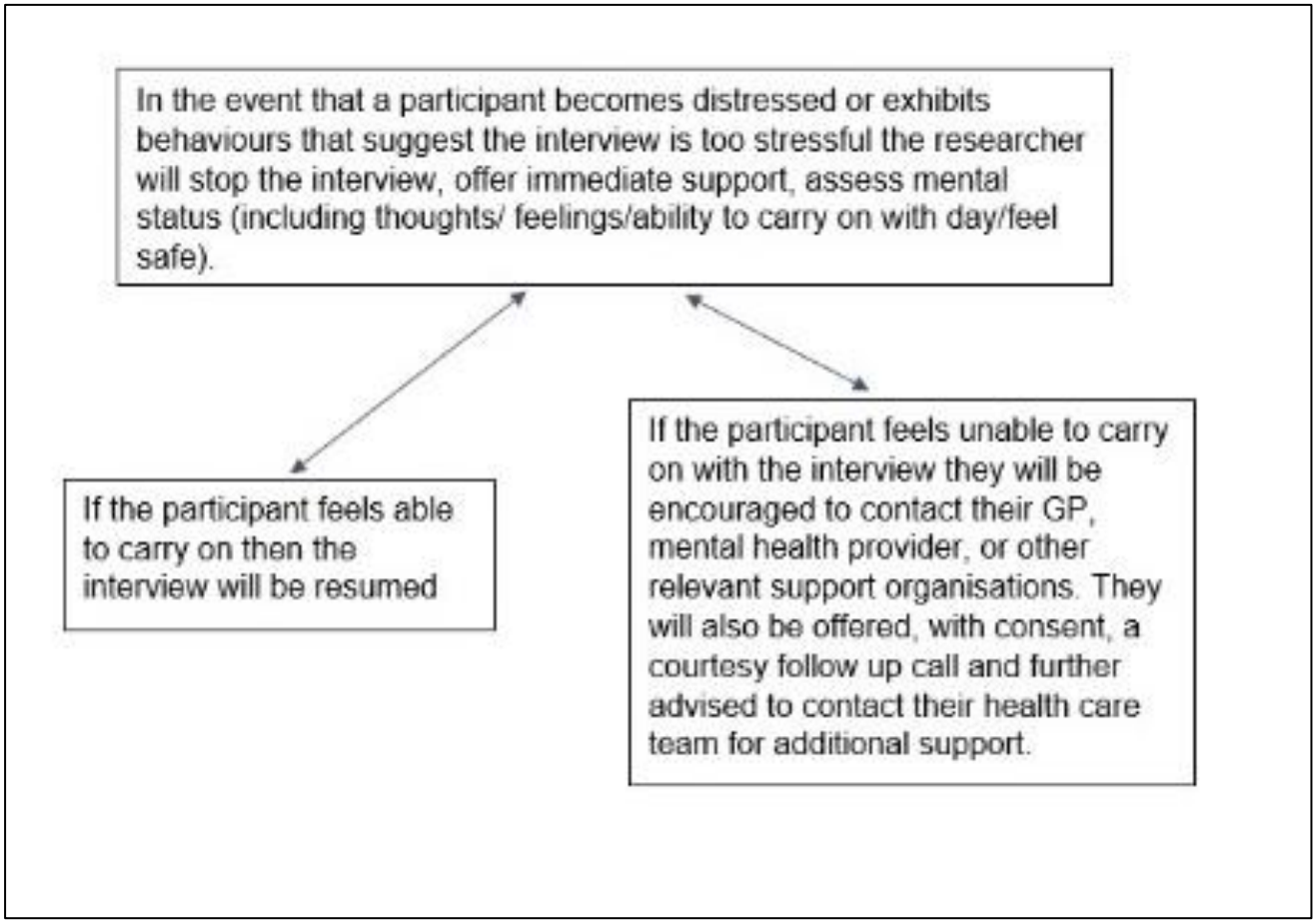
Please indicate below your consent to take part in this study by ticking the boxes to agree to the statements listed

Statement	Please tick below
I have read and understood the information sheet (version number 1 dated 08.01.21)	
I have had the opportunity to ask questions and they have been answered satisfactorily	
I understand that my participation is completely voluntary and that I do not have to take part in this study	
I understand I have the right to withdraw from the study without any prejudice and I have 1 month after the interview to request my data is destroyed	
I agree to take part in an interview in which my discussion will be recorded transcribed and analysed	
I agree to a member of the Young Persons Advisory Group being present during the interview.	
I agree for the researcher to use any artistic outputs from our interview within research articles, conferences and for the purposes of the researchers PhD work. I understand these will be anonymised to keep them confidential	
I agree for the researcher to use quotes from our interview within research articles, conferences and for the purposes of the researchers PhD work. I understand these will be anonymised to keep them confidential	
OPTIONAL - I agree to take part in an additional second interview if invited by the researcher	YES / NO
OPTIONAL - I give permission for my anonymised data to be used in future studies/for further analysis	YES / NO
I agree to take part in the above study	

Participants name	**Participants Signature**	**Date**
Name of person taking consent	**Signature**	**Date**

N.B. ensure participant receives a copy of this form

Appendix 15 – Protocol for potentially distressed participants during research interviews



Appendix 16 – Inclusion and Exclusion Criteria for the study

Inclusion criteria

- Children aged 2-18 years and their family members who are actively involved in their holistic care
- Families 6 months post bereavement
- Children and families who fit the forced migrant definitions outlined and have therefore not come to the UK voluntarily
- Children with LLC or LTC who fall into any of the categories for palliative care outlined by Together for Short lives (2018)
- Health care workers who are actively involved in the provision of care for children and their families and are deemed significant by the families themselves
- Children, families and health care workers within the West Midlands region, who have previously or are actively being cared for by BWCH, Acorns Hospice or a palliative community nursing team
- Capacity to consent

These criteria aim for optimal diversity in important characteristics related to the study population and thus the inclusion of a wide range of perspectives.

Exclusion criteria

- Young adults over 18 years
- Perinatal diagnosis of palliative conditions (as these families will require specialist services and have specific needs which warrant separate research)
- Economic migrant families (as their needs will defer significantly)
- Families whose child may imminently die (as determined by medical staff) or immediately after bereavement
- Children and/or families who do not wish to participate
- Children who are deemed too unwell to be approached for interview, their families may still participate if they wish to.
- Children who are unable to participate for any reason related to their condition, but their families may still participate if they wish to

Appendix 17 – Family Tessa poem written for their son

Poem is sung through the family video of Sohail's life and death

Poem interpretation one -The End's Fragrance

1. May the fragrance of peace scatter upon our dear son S.
2. You were our pride and joy all through our lives.
3. I bear witness to Allah you submitted to his will with great patience and immense gratitude.
4. You have always asked the Almighty for a higher level in heaven after this life
5. With a smile you have always greeted people despite the pain you were going through
6. You asked Allah to heal you and always wished he would be pleased with you
7. Muhammed, the messenger of Allah, approached you in your dreams and said 'peace on you S.'
8. With so much love you have replied 'peace on you too O messenger of Allah'
9. You knew after that moment to submit to Allah's plan and that his plan would be the best for you
10. We ask Allah to heal our wounds from losing you S. we trust he would do so and make your story an inspiration and a reminder for the whole world

Poem interpretation two – The best for last end

1. Greetings with lavender smell for you son S. and be the best for last end
2. A consolation in life is our memory and among people of you we are proud
3. Swear by God, great patient were son, thankful to God and blessings found
4. Satisfied with what God wanted, the generous God asked high stand
5. Greetings with Lavender smell for you son S and be the best for last end
6. A consolidation in life is your memory and among people of you we are proud
7. With cheerful face people you met your patient body in pain suffered
8. God you asked for heal and reward with patience God's satisfaction hoped
9. Greetings with Lavender smell for you son S and be the best for last end
10. A consolidation in life is your memory and among people of you we are proud
11. To you our prophet Muhammed came, peaceful greetings S. he said
12. With passionate heart you answered, with love and longing for him you would
13. Greetings with Lavender smell for you son S and be the best for last end
14. A consolidation in life is your memory and among people of you we are proud
15. May God with love fill the hearts and beloved covered blessings be should
16. Merciful, passionate, generous my God is nice meeting is given for those who would
17. Greetings with Lavender smell for you son S and be the best for last end
18. A consolidation in life is your memory and among people of you we are proud

Poem interpretation three – The End's Fragrance

Peace scatters with the fragrance of Lavender,
Upon you S, and your end's fragrance.
Whose mention is a consolation in our lives,
And our pride amongst all mankind.

Our son, we bear witness to Allah, you were greatly patient.
You thanked the Lord, then received your status.
You trusted His will and were satisfied with His command,
You asked the Generous God for the highest rank.

Peace scatters with the fragrance of Lavender (verse is repeated)

You met people with a cheerful face,
And with a patient body that suffers aches.
Recovery and reward you asked the Almighty Lord,
With patience and humiliation, His satisfaction you hoped.
Peace scatters with the fragrance of Lavender,
Upon you S, and your end's fragrance.
Whose mention is a consolation in our lives,
And our pride amongst all mankind.

Prophet Muhammad, came to you in your dreams and said:
"Salaam S", an honourable greeting that he said.
With a passionate heart you replied: "peace on you too",
With love and longing, you wished to meet again soon.

Peace scatters with the fragrance of Lavender (verse is repeated)

May Allah irrigate our longing hearts,
Generously connecting your loved one's hearts.
Merciful, loving, generous our Lord is,
So will connect your soul to whom he wishes.

Peace scatters with the fragrance of Lavender (verse is repeated)

Poem interpretation four – from Sibling 1

1. The smell of peace, like lavender from S is coming
   We are happy when we talk about him and he makes us feel proud
2. You were patient and we swear by God that you were patient, you thanked God and you went to his will and you accepted what he has given you and you asked him for higher rank (in heaven/eternally/in the next life)
3. With the happy face and great smile you met people, when they visit you, while your body was suffering and you also ask God for healing (for God to cure you) and with patience you asked for his reward
4. The prophet came to you and he said peace on you S
5. We ask God as well to make the relationship with his soul and our hearts close and the same for his beloved ones, as God is merciful and almighty so God will help us and make this relationship stronger with him

Appendix 18 – End of Study Information HCP

Exploring the experiences of forced migrant (refugee and asylum seeker) families and those who care for them in children's palliative care. IRAS no. 281987



End of study information sheet for health care professionals

Thank you so much for your participation in my study, your time and interest has been so appreciated and added a valuable contribution to this research area and the education of future health care professionals. As I am now completing my PhD I wanted to share a summary of my findings with you. You may remember I was very interested in finding out what was working well or not so well within forced migrant families' care, in order to consider any improvements which might be helpful. To summarise my findings, I have detailed the factors which family's and also health care professionals suggested might improve or hamper care.

Family's perspectives	
Things which may improve care	**Aspects which may hamper care**
A focus on long term relationships	A lack of trust and time to understand, assess and treat families
Family centred, holistic care which considers individual need	Judgements, assumptions and labelling of families
Recognition and respect for family's beliefs and coping strategies	Misunderstanding of gender and/or cultural norms
Helping to ensure rest, respite and normality for families	Lack of social support for families
Going the extra mile when providing care	The difficult nature of the caring role affecting parents physical and mental health
Being kind, compassionate and humane	Alienation and discrimination
Being able to have the same interpreter and build a relationship with them	Lack of understanding of migration trauma
Health Care Professionals perspectives	
Things which may improve care	**Aspects which may hamper care**
Link workers of similar cultural background	Crossing of professional boundaries Burnout and empathetic distress
Additional time with families and prioritised building of relationships	Protocol led care
Peer support from other families	Lack of parental proactivity

Timeliness and consistency of difficult conversations	***Communication and language barriers**
Multidisciplinary and multiagency co-ordinated care	***Lack of access to funding, appropriate housing or legal support and poor parental health literacy**
Two-way education between families and health care professionals	Divergence of beliefs between health care professionals and parents

*Aspects in bold where agreed by families **and** health care professionals.

If you would like to find out any more information or share any additional thoughts with me after reading this sheet, please do contact me via [redacted]

Thank you so much again for your time and involvement in this study

Marie Clancy

Appendix 19 – End of Study Information Families

Exploring the experiences of forced migrant (refugee and asylum seeker) families and those who care for them in children's palliative care. IRAS no. 281987



End of study information sheet for families

Thank you so much for taking part in my study, I am so thankful for your time and I hope to share the results of this study to help improve the care of families like yours. I am now completing my PhD so I wanted to share some of my findings with you. You may remember I was very interested in finding out what was working well or not so well within families' care. The table below shows the things which family's and health care professionals suggested might improve or hamper care.

Family's views	
Things which may improve care	**Things which may hamper care**
Working with families over the course of their child's illness	A lack of trust and time to understand families
Caring for each family's needs	Being too quick to judge families
Valuing beliefs and faith	Not understanding the concerns of mum and dad might be different
Helping families get rests from care and can engage in normal customs	The pain for parents of caring for a disabled child without the support of others
Going out of our way (going the extra mile) for families	Discrimination and racism
Being kind, compassionate and humane	Not understanding why someone might need to come to the UK for safety
Using the same interpreter each time	
Health Care Professionals views	
Things which may improve care	**Things which may hamper care**
Staff who understand/try to understand the family's culture	When staff struggle to switch off, say no and become tired in their role
Spending extra time with families	Care which is focused upon tasks rather than people
Refugee families supporting refugee families (peer support)	When families do not or cannot work together with staff
Thinking carefully when talking about sensitive or difficult topics	***Communication and language barriers**
Staff working together even when they have different jobs or work in different places	***Being unable to get funding for carers, appropriate housing or legal support**

Families teaching staff about what is important to them	Not understanding the importance of family's religious faith

*views in bold where agreed by families **and** health care professionals.

If you would like to find out any more information or share any extra thoughts with me, please do contact me via [redacted]

Thank you so much again for being part of this study

Marie Clancy

Appendix 20 – Poem - Notes on my Native Land

To this corner of the world came
people from China and India
from Indonesia and Europe
Some of the people
adopted local ways
They spoke Malay
dressed Malay
but still kept their customs
Others stuck to their ways
while firmly planting
a foot on Malaysian soil
The alchemy worked
And today we have a nation
that is a kaleidoscope
of many things and many people
We all belong to this fabric
having each lent a stitch
to make up a whole
Now we invite the world
To see this tapestry

David Lazarus, 1986

Appendix 21 - Advisory group thoughts on translating and implementing results to realistic recommendations

Parent champions (n=2)

1. Cultural and religious beliefs education, involvement of faith communities. Understanding of cultural attitudes towards HCPs (strict/empathetic etc)
2. An openness in dialogue about feelings towards care of the child

Network palliative care specialists (n=2) + (n=3)

1. Improvements to education and training, specific modules integrated into existing training which draws on your research, creation of a short film and infographics to reach and engage different audiences
2. Importance of a policy brief.
3. Guidance for working with sensitive and ethnically/culturally appropriate.
4. Interpreters to support.
5. More teaching and resources for HCPs to understand the needs of refugee populations.
6. Easy access to interpreters and translated written information.
7. Link workers from marginalised communities employed in hospices to support families and wider communities

BARA (n=4)

1. Communication has to be looked at – if not impossible to understand each other. If asked and do not understand may just say anything and tell wrong answers
2. Involve Iman – discuss such as pain relief and not letting children suffer
3. Relevant brochures, information
4. Awareness – do not understand immigration issues, they are angry because they do not know, so they need to be educated. People come here with so much trauma and if not helped properly can be scared to go to the nurse.
5. Lived experiences, their story resonates with them more. Ca not understand if have not gone through it. People's experience best thing.
6. Place to go, equipment etc. people to speak to about their problems, people do not always speak emotionally strong but they need to know what support is out there
7. Personal interpreter not electronic system .
8. Diverse different link workers – burden on budget but help quality info they can provide
9. Education, they must be advised where to go for their wellbeing, counselling someone to speak to about their past and how it affects them and missing their families
10. Communication between HCP and refugees – improved at all levels.

11. NHS link with refugees via charities and organisations to well understand each other

YPAG (n=6)

1. Better education, maybe training through expert by experience
2. Easier access to interpreters using Dora (iPad on wheels) (like we do at BWCH)
3. Some kind of support group in/outside of a care setting for these families to connect with each other.
4. Cultural awareness/insight being mandatory training for health care staff
5. Maybe a hospital passport for families
6. Support groups available for families to access so they know they are not alone
7. Working with youth workers and play workers to share the information
8. Training/learning for staff on awareness and how to help families in particular situations
9. A support group for staff after dealing with difficult scenarios e.g. with chaplaincy

TfSL ethnically diverse family support group leaders (n=2)

1. Avoid assumptions 'never met a family I could put against another and say their situation is the same'
2. Support needs to be on an individual basis with a benefit to case studies to learn from
3. Need for staff self-awareness – to make sure we get it right and offer support through unique and individual situations. 'Families do not want tick boxes they want to be listened to and connected to the person facing them'

Interpreter group (n=7)

1. Role of interpreter as more than just language – cultural mediator – able to understand cultural roles, expectations and build trusting relationships which can be helpful to gaining more understanding of families' needs. Examples given of judgements from staff regarding controlling dads who are struggling to get medical team to understand their perspective
2. Need for sensitivity
3. Need for staff consistency, to be able to show care, take time to listen and ideally have the same interpreter too
4. Examples of gender roles, nurses prioritises differing from families', i.e. wanting to tick boxes and have speedy discharges
5. Discussed the need for additional time for some decision-making and that staff need to understand not everything is an emergency. Waiting for the right staff member or interpreter to be available to help understand families' fully can be crucial to meeting need
6. Importance of language support from the beginning of treatment/care

7. Present of interpreting team during ward rounds to be able to explain their role and provide support in a proactive rather than reactive manner
8. Interpreter role in improving health literacy – how the hospital works, how to act, get needs met, understand expectations.
9. Talked about different levels of need – non-English and limited-English presenting different stages, cultural challenges, not widely understood by wider healthcare teams
10. Need to raise awareness of value of interpreting team, limited legislation at present so very varied provision across organisations which isn't helpful to families in need
11. Often prioritisation on cost but this and the over use of some remote/electronic interpreting can sacrifice quality of care/relationships

Appendix 22 – Poem about HCP Marian written by YPAG members Learning to and from

I come from far

I came to England 16 years ago

My country had real problems around…

Diversity, equality issues and human rights

So, I didn't like it.

Before England I've never had any contact or friendships with people who are different to me

But I was very open and curious

In my job I have that mutual learning relationship,

Is sort of to and from; to families and from families.

But also in between, families have come through so many different experiences,

Outside the diagnosis of a child's health

Some are sort of small, some are bigger

Family means so many different things to different people

It's about the significant people not who's tied together by DNA

Hospice care is very different to stereotypes

Often c h ao t ic, so many people,

Not just pre and post bereavement care

You get to know the bigger picture, their story, to give the best patient centred care.

I want to learn from the families, not force our way of life upon them

I want to give people empathy

I want to show understanding, through empathic listening

Learn from the families

We need to be holistic

We need to not just touch the surface but reach the core

It's a much wider spectrum

Trauma. Loss. Complex needs.

It’s challenging
Inaccessible communication, no interpreters
Families cannot speak the language, cannot read, cannot write
But we form new communication
Like sharing food; speaking, learning, bonding through food
We can build that togetherness

But it’s difficult
There was a vulnerable woman with this little baby
December and she had no heating.
It was the right thing to do. To offer the room. The help.
She was able to be the mum because we've got nurses 24 hours
But were we taking that room away from someone though?

Two cases so similar
No one listened. No one heard. No one gave their time.
Shouting, screaming
Mum got louder and louder
We communicated very slowly with little steps
We started to understand her behaviour
She was scared
She was angry
She didn't understand

No one heard the international call for help.
There was a lack of understanding
She was quickly judged
Mum’s expression of grief was very different
Mum’s grief took a different shape

Another family labelled as aggressive. Labelled as non-engaging.

Lack of cultural competence from staff

No courage to help

No one gave the benefit of the doubt to families

Assumptions after assumptions after assumptions

Stuck in the cycle

Only eroded when time, resources and effort were invested.

Doesn't always mean that it's a speedy process. It's rarely a speedy process

The week we cared for over 70 members of a travelling family, I must have worked about 150 hours

But it was worth it

To enable families to be together

And hear

“Thank you for your support and thank you are not racist.”

Appendix 23 – Poem about HCP Flo written by Marie Clancy Exhausted but fighting on

I felt like it was a conveyor belt system, my social work job was very, very demanding

I became quite a rebel fighting against all the restrictions for justice, for equality and because I couldn't be responsible for unnecessary deaths due to governmental bureaucracy and red tape

But it was exhausting and so frustrating!

I thought I would be like Mary Poppins and change the world but the systems in social work crushed my dreams

The unfairness of it all is soul destroying

Why should country of birth relate to entitlement to care, why does everyone make it so difficult for those seeking safety?

So, the family I have been working with, for nearly two years now

It's taken time, they weren't sure if they could trust me, but I saw them every week, there was so much to sort out

And then there was an incident, an accidental burn, but the GP and nurse they made an automatic assumption that dad had harmed his daughter. I was so shocked and afraid for them, but I knew hand on heart, this hadn't been a purposeful harm, I knew them so well by now but I had to fight for them. But now it's made me fearful and protective. I want to wrap them in cotton wool, protect them from further harm, further adversity, further labelling

But it can be exhausting

We speak out of hours and I feel like I am a 999 service, always on alert and with Covid at times I become a one-man band, all singing all dancing, just me

And so, I try to be many things, to help them - clear, transparent, consistent and accessible. Giving a little bit extra care, support and understanding

I spent hours, every week, going through everything to prevent them struggling, shouting on their behalf when I need to and they are so grateful and so humble but it's painful for them, emotionally but also physically. Caring their daughter up the stairs mum's poor back and yet they are so dutiful, so faithful and dedicated

There are others too

An interpreter who drops everything for this family, she supports them so well, makes them feel comfortable and they are so disappointed when she isn't there to represent them

And now I am forever learning, forever developing my practice and I feel content, I feel very honoured, very humbled that I'm able to walk the journey with these families in different, very different and diverse circumstances

Appendix 24 – Poem about HCP Sobia written by Guardians member
Perseverance

There's limitations wherever you work, you come out of social work and your head is full of ideas wanting to change the world.

But then you start working in an organisation where doors go slam, slam, slam and it becomes all about money, money, money which ends up squeezing you as a person, as a professional.

Now I work in my local hospice and I get to do real social work:

I get to build rapport,

I get to know them,

I get them to trust me,

I get to build relationships,

I get to take my time and help them understand things,

I can help families with what they need – from access to services, to charities and attending meetings.

The thing is, you have to take the time, to develop trust and respect, which helps to build relationships with families so we can help them the best we can.

One family were surprised at the NHS – the medicines you get, the community nurses, hospital care and support – and it's all free! They feel very privileged because it's not something they're used to.

But that family came here wanting to make their son better but they've learnt to accept it's something they need to live with and they can make his life comfortable.

There's no surprise that it feels like a time bomb ticking for parents who weren't expecting this, finding out there's nothing you can do to make your child better, you never want to wish that on your worst enemy

They have no family here, there's no one from their own family to help them and mum struggles with the cultural expectations that she has to do it all whilst the man goes out to work

That left mum feeling lonely and mentally struggling to see her son the way he is.

Since then mom has had depression, she said "you know, how can I not have depression? I'm the one who's gonna feed him, I'm gonna turn him I'm gonna do everything"

Day by day, day by day I've been able to help Mum to build coping strategies because I completely understand when she tells me about her struggles. I know

about the cultural expectations and pressures, because my family, my culture is exactly the same. I think this helps her to open up, to share and to trust and to get support.

Building trust and helping families get the support they need doesn't happen overnight.

Organisations want outcomes, but they want to see results straightaway.

Our work can take months and years, it takes time and we need to take our time to help families.

We have to remember that we are on a journey with the families we work with, we are carrying that around with us, even when we sign off

Families are so tired, they are completely knackered and haven't got time for themselves.

We get so attached to them living their life with them, we've got so much in our head

Appendix 25 – Poem about HCP Clara written by YPAG member Just trying to make a difference

His needs are very demanding
The services don't line up, they're all different systems
Seeing those children sparks something
Just trying to make a difference

She shares what she needs to share
Communication is a real barrier with so many different systems
We do pastoral care, we do family support
Just trying to make a difference

They have carers every day
She's over the moon because she's able to talk to someone
We can empower parents, they are not alone
Just trying to make a difference

Culturally it's her background, her language
Families from Pakistan and Bangladesh, the African continent, China and Europe
Its madness when there's no means to communicate
Just trying to make a difference

We made waves in the pandemic
So, people don't feel isolated, they don't know what they are entitled to
The future should hopefully be better
Just trying to make a difference

Appendix 26 – Poem about HCP Holly written by Marie Clancy
Sit alongside, sit beside

My career started in oncology and I absolutely loved it

But at times the lack of autonomy was like having my wings clipped

It all became so protocol led, procedure led and task orientated – prescription care

After much hard work I advanced in my career and took on a senior role in palliative care, here I am teaching, guiding, learning, still learning. You learn so much from these beautiful families

Now I get to work alongside so many health care professionals and families, end of life care can be so beautiful and so humbling

Sohail was a very loved boy. His family wanted to protect him from the reality of the truth, that he wouldn't live much longer. We are the advocates, nurses have the families trust and it's important to share stories like this and to respect them.

Sohail had a right to know the truth but his family shouldn't have been pushed to make those decisions before they were ready. They needed a listening ear, good nursing intuition, eye contact and to be heard, to be safe.

I had to invest myself in them, no one wants superficial care. Relationships have to be built by spending that time, sitting down and listening. But it takes courage, its sometimes awkward. I have to get over my own discomfort and keep having little conversations, each day to build relationship, to build trust.

We should never take it upon ourselves to be disrespectful, to assume,

every family is an individual.

By forcing Sohail's family to face the truth of death so brutally they destroyed the dignity of that family, they stripped them bare. Sohail didn't need to see the images of a grave and coffins. The nurse, she was callous. And his poor family their horrible memories of that day will remain vivid, never less blurred, less painful. They will always remember and so we should too.

We have to see the bigger picture, to tailor make our care

But it's harder, harder to sit with, sit beside and journey with families. It's much quicker to whizz in and out, without asking them, without recognising who they are.

We can't always fix it but we can always be kind

Appendix 27 – Poem about Family Ahmed written by Parent Champion

We Arrived
(A Refuge for the Refugee)

We arrived carrying
Our voices and memories,
Bearing our children and
Their hopes and dreams.

We arrived voiceless.
Silenced by language and fear.
Staring wide eyed into
Mouths that spoke in confusion.

We arrived into a torrent of words.
Alien, disorientating, destabilising, yet
Well-meaning and caring, spoken through smiles.
And smiles do not require translation.

We arrived with nervous anticipation
And found care and kindness,
Acceptance, tolerance, friendship
We were not refugees now, but names, people.

We arrived carrying a child
Stripped of the dignity of care and
Compassion, shocked to a shell by
The disintegration of society, riven by war.

We arrived and our child was delivered
Into the embrace of humanity.

Doctors and nurses and social workers;
A language of care and hope and dedication.
We arrived and found dignity and respect.
Afforded the welcome of community.
Afforded our basic human rights
To live in freedom and safety.

We arrived, torn by distance and conflict,
Separated by memories and time.
Leaving behind a family, yet now supplanted
By a new care-family under English skies.

We arrived and bewilderment and misunderstanding,
Isolation and detachment, were quietly soothed
By the words of others, with warmth in their hearts
And gentle words, gratefully received.

We arrived and the daily struggle was not to
Survive bullets and shelling, a desperate search
For medicines and food and a future,
But to ask for help in a foreign tongue.

We arrived and disability was not invisible,
But part of an inclusive society, where equality
And the needs of everyone were met and valued
Where everyone's voice was heard.

We arrived and were accepted, cared for
We arrived and were absorbed into society
We arrived and were allowed to live again
We arrived and were able to feel hope

We arrived from a distant country where

Bombs and fear echoed in our heads
We arrived and discovered that although
We had been forced to flee we had in fact

Arrived home.

Appendix 28 – Poem about Family Ahmed written by Parent Champion
The Leaver

How can you leave,
When the ones you love the most
Have to stay behind?
When the world you know has
Become cruel and unforgiving
Merciless and unkind.
And the last thing you
Wish is to leave
Your family behind.
But you face no
Other choice.

How can you leave,
When to leave
Is akin to grief?
To face uncertainty
And danger at the
Mercy of others.
Shadows that fall
Across a continent
That does not
Want or welcome
You, just wants
To move you on,
Out of sight, forgotten,
Gone.

How can you leave,
When death remains in the

Eyes of your loved ones as
Bombs and bullets fly?
When your children
Desperately cry, for food
For pain relief, for their father.
Where death stalks you
In the black waters
And along every mile that
Punishes sinew and soul.
Destroying your will to go on.
But you must. You must,
Bismillah al rahman al Rahim.
In the name of God
The most gracious, the most merciful.,
In God you trust.

How can you leave,
When the language of hope
Is spoken in a foreign tongue?
And confusion compounds
A sense of aloneness and isolation,
Where every aspect of life
In your asylum home
Is alien and bewildering.

But you know that to leave
Is to search for hope.
And a future and a life.
And security and dignity.
And human rights and decency.
And care and community.
And friendship and humanity.
And compassion and tolerance.

And support and kindness.
And that every mile
And day and month
And year of separation,
Is worth every painful footstep
And moment in fear,
And despair and sadness.
For the possibility,
For the opportunity
Of seeing your family
Reunited and together,
And living in peace again.

And when you listen
The night-silence of a quiet,
Untroubled English street.
And when your wife sleeps
Soundly for the first time in years.
And when you find love and support
And care and concern when
Your children are sick.
And when your children no longer
Cry themselves to sleep hungry.
And when you see your children
Smile for the first time in years.

How can you leave?

How could you not?

Appendix 29 – Poem about Family Khatri written by Parent Champion

I Am Here, Lost

I am here,
Yet I am lost.
Viewed with suspicion, treated with disdain,
Detained for hours and hours at the
Far From Home Office. Is this a refuge
For the refugee, forced to flee, a woman
Of dignity and pride, made to feel like a beggar
In the eyes of those you hoped would help?
Not begging, only asking for some
Humanity and understanding,
Not endless questions demanding answers,
Words, words, words, yet I am here, lost, unheard.
Made to feel wrong for seeking safety
And a life for my son and family in a
Place where disability is treated
With humility and dignity.
I am here,
Yet I am lost.

I am here,
Yet I am lost.
Drowning in an unknown language,
Disappearing, invisible, ignored.
The only one who talks to me is my child.
And he has no voice.
Though his beautiful eyes implore me, bore into me.
Yet they burn bright with love and
It is my comfort, a blanket drawn around me.

A cloak of warmth and hope in the
Chill of a hospital ward.
Where life is a series of checks and beeps
And the cleaner that sweeps and mops is the only one
Who stops and places their hand on my shoulder and
Brings me a cup of tea, stirred with 3 spoons of humanity.
No one else takes the time to stop, sit, sip…stay.
I am here,
Yet I am lost.

I am here,
Yet I am lost.
No money for food.
No language to ask.
Not even understanding which way is in or out,
Entry barred, exit denied, blank stares and people
Who look through you because they are so busy.
So, I sit by my child whose smiles are my only
Nourishment, because still I don't eat or drink.
My husband forgets to bring food, or think to take me home,
Or take my place as the nurses rush past and
They seldom ask if I am ok.
Or why I am not eating,
Or why I am crying.
Or why I don't leave.
They don't notice that
I am here,
Yet I am lost.

I am here,
Yet I am lost.
Waiting for someone to find me.
Someone to rescue me with a hand

Outstretched, warm, strong, supportive.
A hand that pulls me into an embrace of words
That mean more than anything in the world,
‘Are you ok?...
I will help you…
What do you need?...
I’ll make you a cup of tea…
You talk, I’ll listen…
I’ll try to understand…
Don’t worry, I’ll do what I can…’
And then they say the words,
I have longed to hear.

‘I am here,
So, you won’t be lost anymore.’

Appendix 30 – Poem about Family Tessa written by Parent Champion

Patience

Check the meds
Check the sats
Brisk, efficient,
Hurry up,
No time to chat.

No time for questions,
No time for tea.
Let me get on and deal
With you, the patient;
My time's not for free.

Questions, questions.
What do you want to know?
No, I can't explain,
So, settle down, try to sleep.
There you go.

Now, do you know
What happens when you die?
Is your religion different?
Perhaps it is, now
Look, let me explain why

We do things and what
Happens in our belief.
Look, here's a cemetery,
A gravestone, so peaceful
And we all need to grieve

In our own way.
I know you have questions too,
But you'll soon be at peace
And no longer in pain.
I'm only thinking of you.

Oh, the family's here.
Right time to disappear.
It's just so difficult to
Understand them, such poor
English, so hard to hear

Patients

She's always in a hurry.
Always in a rush.
Checking the charts,
No time to talk
And I'm feeling lost.

Telling me to be quiet,
When I cry out in pain.
Not to disturb the others,
Not to upset anyone,
But she never talks the same

Way to anyone else.
Only to me, but
I'm no different.
We all want to feel
Happy, hopeful, cancer free.

Now she sits on the bed.
Pats my hand with a sigh.
'So, in your religion', she asks
'What happens after
Someone has died?'

I stare in disbelief.
I sit silent in profound shock,
When she opens up Google
And shows pictures of coffins.
'In our religion we bury people in a box.'

Then she carelessly repeats
What the doctor honestly said.
'It's so sad you are dying
But you'll be at peace soon'
And my tears start to shed.

I hear my mother, speaking in
Arabic/English – a question. a plea.
Asking what is happening,
Getting upset, distressed
As the nurse turns away to see

And make sense when
They can't communicate,
Through tears and histrionics.
They are always in such
A pitiful state.

Ah, but here's Mr and Mrs Jones.
So brave, their beautiful daughter.
Always a laugh and a smile,
I'll fetch them some magazines
And a fresh jug of water.

Check the meds.
Check the sats.
Sorry I don't understand you
And there's really no
Time to chat.

No time to chat.

The family with an English accent,
The family with the little girl.
She smiles and laughs with her parents
Brings them water, tea, toast
And it feels I am no longer in this world.

Because no one seems to care.
Or looks behind the charts and stats,
To see the person inside the patient.
The one who needs the human touch,
The presence of kindness, a time to chat.

Maybe that's harsh
Not everyone acts in an officious role
Because others here are kind, caring
Sparing time to sit and talk,
To treat not just my body, but my soul.

Which is all I ask.

Appendix 31 - A Kenning poem including perspectives of nurse (N), refugee (R) and the structural assailant (SA)

N comfort maker
R safety seeker
SA hostile and restrictive

N pain reliever
R difficult communication
SA media negativity

N need assessor
R political victim
SA uncompassionate

N system juggler
R persecution fleer
SA tainted by the few

N influenced by background
R family first
SA entitlement focused

N time limited
R frequently misunderstood
SA unseeing and unknowing

N burdened
R exhausted and unheard
SA distanced from reality