Volume I

RESEARCH COMPONENT

BY

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A Thesis submitted to
The University of Birmingham
for the degree of
DOCTORATE IN CLINICAL PSYCHOLOGY

Department of Clinical Psychology
School of Psychology
The University of Birmingham
July 2015

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Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D) at the University of Birmingham. The thesis consist of two volumes.

Volume I

This volume comprises three chapters. The first chapter is a systemic literature review exploring the evidence for meaning-focused psychological interventions for adults in palliative care. The second chapter is an empirical study exploring the experience of men caring for a dying loved one (spouse) and of their experience of seeking help for themselves during this time. The third chapter is a public domain briefing document providing an accessible summary of both the systematic literature review and empirical paper.

Volume II

Five Clinical Practice Reports (CPRs) are presented in this volume. The first report details the case of a 22 year old woman experiencing low mood and self-harming behaviours, formulated from cognitive-behavioural and systemic perspectives. The second report presents a service evaluation, conducted in a Primary Care Mental Health Service, to explore the extent to which a Systemic Family Therapy Service meets local and national standards and guidance. The third report presents a case study of a 47 year old man with Motor Neurone Disease presenting with anger and low mood involving the use of an integrative psychological intervention drawing from social-constructionist systemic and existential approaches. The fourth report presents a single case experimental design evaluating the effectiveness of a doll therapy based intervention for an older adult with a dementia. The fifth is an abstract of an oral presentation given regarding a 17 year old boy with Autism and a Mild Learning Disability who was experiencing feelings of anger, understood in the context of parental separation. An integrative intervention (humanistic, cognitive behavioural, systemic psychology) was used.

All names and identifying features have been changed to maintain confidentiality.

Dedication

This thesis is dedicated to my youngest sister Emma, who was taken from us completely unexpectedly and devastatingly early. I wish you were here to see this.

14/12/1990 – 08/12/2014

Acknowledgments

There have been many people who have walked alongside me during this process and I would like to take the opportunity to acknowledge their part in my journey.

Firstly I would like to thank the participants who kindly took the time to participate in the research and shared their stories with such bravery and honesty.

I would also like to thank both Dr Ruth Howard and Dr Helen Guy for their supervision, encouragement and space to think and develop my work. Ruth, at one point I turned to you and asked if you could "get me through this" and you have done that, I thank-you from the bottom of my heart.

Finally, to my girls, my family and to Ryan, I don't really know what to say words do not seem to be enough. I want to thank-you for the 'care packages', the diet coke, the text messages, the proof reading, the unlimited supply of tea, endless patience and words of encouragement. Thank-you for your unwavering support and belief in me, each and every one of you. I could not have done this without you, any of you.

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Chapter One

What is the Evidence for 'Meaning-Focused' Psychological Interventions for Adult Patients Receiving Palliative Care?

Word count: 7457

Abstract

Background: Patients receiving palliative care experience feelings of meaninglessness, and meaning-focused interventions, which aim to address this need, are emerging in the literature. However, due to a lack of conceptual understanding and a universal definition of meaning, the area is often neglected.

Objective: To explore the evidence for meaning-focused interventions in palliative care.

Methods: Systematic searches of four electronic databases were conducted using a search term strategy specific to palliative care and meaning-focused psychological interventions. These were then screened against inclusion and exclusion criteria. A modified quality assessment (Kmet, Lee, & Cook, 2004) was used to assign quality ratings to each paper.

Results: Eleven papers, describing nine studies, were included in the review. The review found promising yet inconsistent evidence that meaning-focused interventions increase quality of life and meaning for palliative care patients.

Conclusions: The review presents tentatively positive results of the efficacy of meaning-focused interventions in palliative care. However, due to a lack of outcome measures designed specifically to measure *meaning*, an over-reliance on vicarious measurement of meaning, and inconsistency in outcome measures used, the results have considerable limitations. Further research of meaning-focused interventions, conceptual clarity and outcome measurement is needed.

Keywords: systematic review, meaning-focused, psychological interventions, palliative care

1.0 Introduction

Although the exact number is unknown, it is estimated that specialist palliative care is provided to approximately 160,000 - 170,000 people in England each year (National Council for Palliative Care, 2012). Palliative care grew out of the hospice movement in the early nineteenth century and is defined as;

> *" ... an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (World Health Organisation, 2002)*

1.1 Psychological effects

Evidence suggests that prevalence rates of depression are up to four times higher for those receiving palliative compared to the general population (Irwin et al., 2008).Studies also indicate the presence of poor psychological well-being in those receiving palliative care. For example, a meta-analysis identified prevalence of depression in palliative care patients was 16.5%, adjustment disorder 15.4% and anxiety disorders as 9.8% of the sample (Mitchell et al., 2011). These experiences can lead to a desire for hastened death or for 'transience' i.e. to 'not exist' anymore (Hudson et al., 2006; Wilson et al., 2014).

The impact of receiving and living with a terminal prognosis is vast, complex and varies for each individual. It can instigate many feelings including that of existential crisis (Brown, 2003; Henoch & Danielson, 2009) and can result in "considerable psychological, social and existential suffering" (Fegg et al., 2010). Recent studies exploring the lived experiences of patients with advanced cancer reported that participants experienced a series of losses; loss in functioning, sexual relationships and identity (Houldin & Lewis, 2006); they also faced living with uncertainty (Sjövall, Gunnars, Olsson, & Thomé, 2011) and

experienced stigma related to their terminal disease (Kelly & Dowling, 2011). These individuals may experience their world as chaotic, and feel powerless; as one participant described "… I've been given a death sentence; I know I am going to die but it is the unknown. Am I going to get sick, what's going to happen to me?" (Richardson, MacLeod, & Kent, 2010, p. 132). There may also be feelings of anger and disbelief; "I was angry, bloody angry with the doctor when he told me I was going to die … I didn't know where to start with things. There seemed so little time to fix things you know." (Richardson et al., 2010, p. 132).

1.2 Psychological interventions in palliative care

In order to reduce the suffering and improve the psychological wellbeing of patients receiving palliative care, there are a number of psychological interventions which draw from a number of theoretical models of therapy. For reasons of brevity these are not discussed here but a brief overview is included in Appendix A in order to familiarise the reader with the literature and some of the interventions used within palliative care.

Existential / Spiritual Therapies

Existential distress is understood to encompass a number of issues such as questioning 'why me, why now?', a lack of purpose in life, fulfilment, sense of freedom, regret, loss or questioning of faith / spirituality and feelings of meaninglessness. A review of the literature concerning existential distress in palliative care outlined that it is an often neglected aspect due to "…confusion over definition, lack of conceptual understanding, few documented interventions, and the absence of appropriate training for palliative care providers" (Boston, Bruce, & Schreiber, 2011). Furthermore, interventions aimed at decreasing existential suffering often referred to existential distress as a "single concept entity" which overlooks its multifaceted nature. In order to draw more valid conclusions it is efficacious to study a discrete aspect rather than studying them all as a single entity with no delineation between the

different factors. An important component of existential understanding is *meaning*, that is the sense that one makes of their experiences, and is an emerging area of study in palliative care both theoretically and clinically.

1.3 Meaning

Frankl (1962) states that as humans we are both 'meaning seeking' and 'meaning making' beings; that we have an intrinsic drive to make sense of the world, our experiences and of ourselves, that is, to have a sense of *meaning,* purpose and answers to questions which cause conflict when left unanswered such as 'why me?'. Existential questioning often arises in the face of events that question our sense of meaning and purpose in the world, especially those that bring to light one's own mortality. When working towards addressing such questions this can be defined as constructing meaning or 'meaning-making / focused'. The level of meaning an individual holds can also be seen as an outcome of a therapeutic intervention. Thus, it is becoming highlighted as a psychological construct pertinent for individuals receiving palliative care. A brief overview of meaning in palliative care follows.

1.3.1 Meaning in palliative care

A number of studies have found that patients receiving palliative care experienced feelings of meaninglessness (Morita et al., 2014). Lee, Cohen, Edgar, Laizner and Gagnon's (2004) review of theoretical understandings of 'meaning' in the context of cancer commented on the broad and varied understandings of meaning. Interventions aimed at increasing a sense of meaning for palliative care patients are emerging in the literature and qualitative research has explored the patient experience of these interventions. (Nissim et al., 2012) described the intervention (*Managing Cancer and Living Meaningfully*) as providing participants with a safe space to process the experience of their diagnosis of advanced cancer. A study by Hall, Goddard, Speck, Martin, & Higginson (2013) examining the efficacy of *Dignity Therapy*

reported that *hope*, understood in the context of "hopefulness is the ability to find or maintain a sense of meaning or purpose", was a prevalent theme in both intervention and control conditions.

Whilst these interventions have differing theoretical underpinnings including relational theory, attachment theory, and existential psychotherapy, their focus on meaning, whether as a construct for outcome measurement or as a mechanism for psychological change means that they may, for the purpose of the review, be termed as '*meaning-focused'* interventions [1]. Whilst undeniably intertwined with existentialist thinking, this paper proposes that meaning-focused interventions can be seen as an emerging area within palliative care psychology in its own right. As such, a gap in the literature in terms of, the effectiveness of such interventions, has been identified.

1.4 Aim

The aim is to review a number of interventions from varying theoretical backgrounds that are understood to be 'meaning-focused' and examine their effectiveness within palliative care.

1.5 Key terminology

1.5.1 Palliative Care

For the purpose of this review the term 'palliative care' refers to the care individuals receive who have an advanced terminal (non-curative) illness, the term is not disease specific. The onus of classification to determine if a participant was considered palliative was assigned

[1] The term 'meaning-focused' has been used by the author for the purpose of the review and aims to encapsulate the theme of the interventions in the review. The terms draws upon the literature in which the interventions are described and the theoretical underpinnings they cite.

to the authors of each study. That is, if the original study identified the participant as in receipt of palliative care this is accepted unless there is clear evidence otherwise.

1.5.2 Meaning-focused intervention

Within this review meaning-focused interventions are defined as interventions which describe meaning-focused work and / or cite a theoretical basis to support this. It includes interventions which aim to address an individual's sense of meaning, attempt to increase their sense of meaning and/or use meaning-focused work as a vehicle for psychological change.

1.5.3 Intervention

Throughout this review the terms 'therapy' and 'intervention' are used interchangeably. Unless otherwise noted, these are defined as psychological interventions for individuals or groups, and are delivered by a variety of professionals including clinical psychologist, psychiatrists, social workers, nurses and researchers, with training in the specified intervention.

2.0 Methodology

2.1 Scoping Exercise

An initial scoping exercise was conducted via a search of the Cochrane database and Google Scholar. To the best of the author's knowledge there have been no reviews conducted examining the evidence of meaning-focused interventions in palliative care. The scoping exercise suggested psychological interventions considered to be meaning-focused e.g. *Life Review* and *Managing Cancer Living Meaningfully*.

2.2 Literature search strategy

The search strategy was threefold: (1) systematic searches of electronic databases (2) searches through reference lists of the relevant articles and (3) application of relevant inclusion and exclusion criteria.

2.2.1 Electronic database searches

Searches were performed in November 2014 and were conducted on PsycINFO (1967 to November 2014), MEDLINE (1946 to October 2014), CINHAL (1960 to November 2014) and EMBASE (1974 to November 2014). A combination of MeSH and free text searching were utilised with search terms adapted for each database. Search terms related to three main aspects: *meaning-focused* with specific interventions included in free text searching, *psychological intervention* and *palliative care* (see Table 1). In addition, reference lists of retrieved papers were searched for further citations.

Table 1
Search strategy terms

Construct	Terms
Meaning – focused therapy	meaning-focused' OR +'meaning centered' OR 'meaning centred' OR 'meaning making' OR ^'dignity therapy' OR ^logotherapy OR existential OR meaning OR ^'Meaning in Life'^ OR ^'Managing Cancer and Living Meaningfully' OR ^'Life Review'
	AND
Psychological intervention	psychotherap* OR psychologic* OR counsel* OR therap* OR intervention*
	AND
Palliative care	'palliative care' OR 'end of life' OR 'terminal cancer' OR 'terminally ill patient*' OR advanced OR end stage OR severe OR Acute OR 'motor neurone disease' OR +'amyotrophic lateral sclerosis'

* allows for any words beginning with the search term to be identified + American spelling / terminology ^ added into search terms as these were identified as potential meaning-focused interventions through initial scoping

The database search identified a total of 520 records. See Figure 1 for a PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2009) flowchart of the paper selection process (see Table 2 for the review inclusion and exclusion criteria).

2.2.2 Reference list searches

The reference lists of the full text papers were searched for any further relevant articles. This did not reveal any papers meeting the requirements for inclusion in the review.

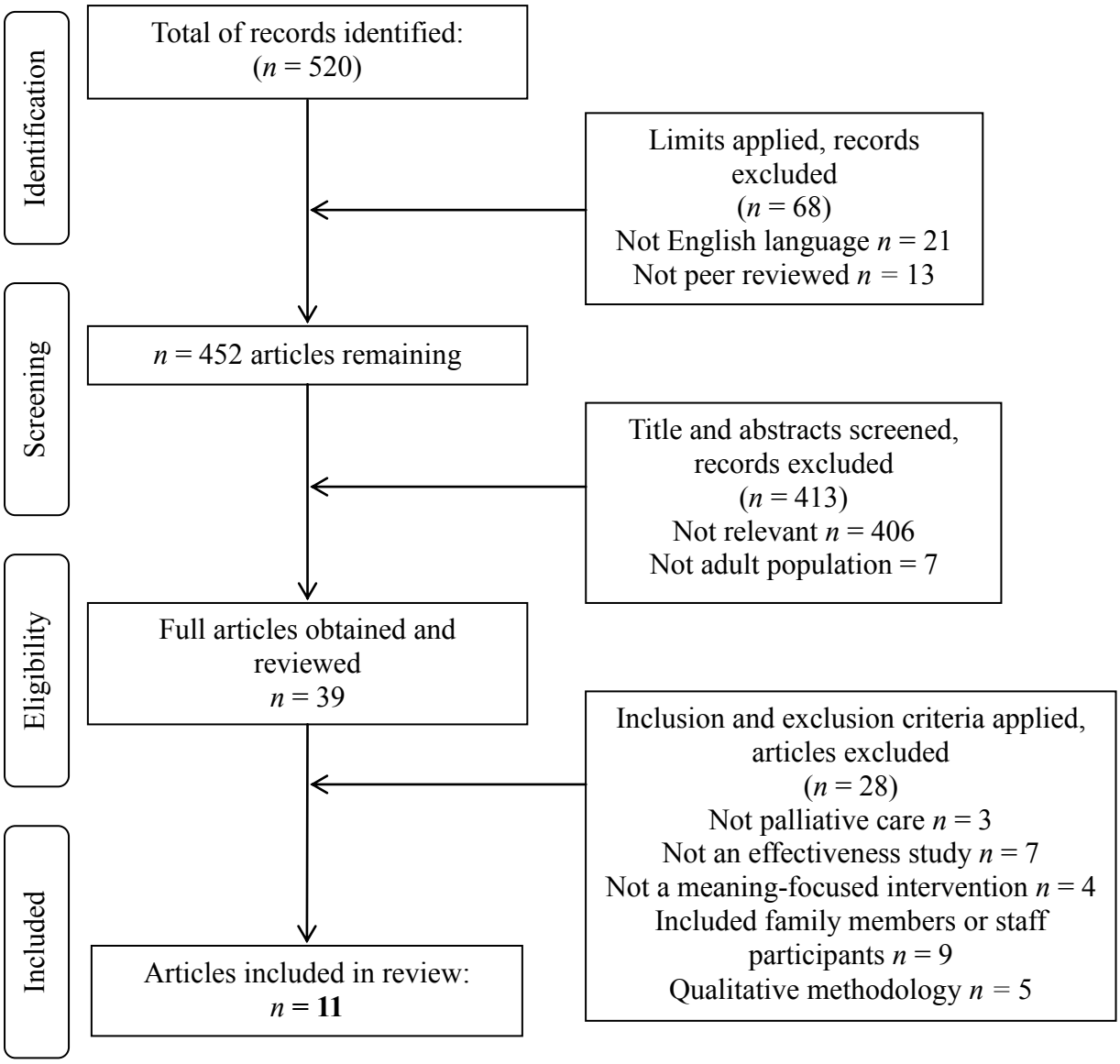


Figure 1. PRISMA flowchart of records included and excluded from the review

Table 2
Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Include if meets all of the following:	Exclude if any of the following are met:
• Peer reviewed journal article, published in English • Adult only participants who were described as in receipt of palliative care by the studies' criteria • Effectiveness study which described a meaning focused intervention for patients receiving palliative care	• Staff participants • Family members and / partners • Bereavement interventions • Case study or cohort study evidence

A total of 520 records were identified, 68 were removed as they were not English language or peer reviewed, or were duplicated leaving a total of 452 records. The titles and abstracts of these were then screened to remove any that were not relevant to the review or did not include an adult population; this removed 413. A total of 39 full-text versions were screened for eligibility against the inclusion and exclusion criteria (Table 2). This removed papers that were not palliative care i.e. 'cancer survivors', not effectiveness studies, did not study a meaning-focused intervention, included staff or family members or used a qualitative methodology. A total of 11 papers were included for the review[2] (see Table 3 for a summary of the studies).

[2] Three papers included in the review cover the same study looking at the effectiveness of *Supportive Expressive Group Therapy* (SEGT); Classen et al. (2001), Giese-Davis et al. (2002) and Spiegel et al. (2007).They were all included as they report different psychological and physical health outcomes. Throughout the review these are referenced to as [Classen et al., 2001; Giese-Davis et al., 2002 & Spiegel et al., 2007] and are referred to as one study, unless stated otherwise i.e. as three individual papers.

2.3 Data extraction

Data were extracted from each paper using a form developed specifically for the review in order to enhance and standardise the information gained, as follows:

- Citation, year and country
- Study design and methodology
- Intervention details (e.g. theoretical framework, session details, format, therapist profession and training)
- Sample characteristics (e.g. sample size, illness, treatment status, control condition)
- Data (e.g. collection, outcome measures, analysis)
- Main findings and author interpretations
- Strengths and weaknesses

See Table 3 (overleaf) for a summary of the studies.

Table 3

Summary of studies

Authors / Year / Location	Intervention / Format	Participants / Disease	Design / Control group	Main outcomes measured	Main findings
Meaning Centred Group Psychotherapy (MCGP)					
Breitbart, Rosenfeld, Gibson, Pessin, Poppito, Nelson, Tomarken, Timm, Berg, Jacobson, Sorger, Abbey & Olden. (2010) USA	8 x weekly group sessions	90 patients with advanced cancer, majority Stage IV (n=57, 63.3%) Most common types of cancer were prostate (n=17, 18.9%), breast (n=14, 15.6%) colorectal (n=8, 13.3%) and lung (n=8, 13.3%).	Pilot RCT Intervention group – MCGP Control group – Supportive group therapy (SGT)	*FACIT-Sp* – Functional Assessment of Chronic Illness Therapy Spiritual Well-Being (total, and two subscales; 'meaning / peace' and 'faith') *HADS* – Hospital Anxiety and Depression Scale *SAHD* - Schedule of Attitudes towards Hastened Death *LOT* - Life Orientation Test	**MCGP** - Spiritual wellbeing improved, effect size larger for improvement at T2 **SGP – FACIT-Sp** improved but greater for MCGP both groups showed some increase on the Meaning/Peace subscale, increases were significantly greater for MCGP patients Modest changes for other measures No change in BHS,SAHD MCGP improved spiritual wellbeing and enhanced sense of meaning, reduced psychological distress
Individual Meaning Centred Psychotherapy (IMCP; adapted from MCGP)					
Breitbart, Poppito, Rosenfield, Vickers, Li, Abbey, Olden, Pessin, Lichtenthal, Sjoberg, Casselith. (2012) USA	7 x 1hr, weekly individual sessions	120 patients with advanced cancer stages III 33.3% or IV 66.7%	Pilot RCT Intervention group – IMCP	*FACIT*- Sp – Functional Assessment of Chronic Illness Therapy, Spiritual Well-Being (total, and two subscales; 'meaning /	Significantly greater treatment effects at T2 (post treatment) across all measures (except HADS-A or D, and BHS)

		Most common cancers were breast (26.1%), colon (16.0%), pancreatic (9.2%), ovarian (8.4%), and lung (3.4%).	Control group – Therapeutic massage (TM)	peace' and 'faith') *MQOL* – McGill Quality of Life Questionnaire *HADS* – Hospital Anxiety and Depression Scale *BHS* – Beck Hopelessness Scale *MSAS* – Memorial Symptom Assessment Scale	No differences in improvement across the different IMCP study therapists. Group-by-time analysis significant differences for FACIT-Sp total score, MQOL, MSAS, but not BHS, HADS, nor FACIT-Sp subscales of 'meaning / peace' and 'faith' IMCP does improve spiritual wellbeing, QoL, meaning and physical symptom distress
Dignity Therapy (DT)					
Chochinov, Kristjanson, Breitbart, McClement, Hack, Hassard & Harlos (2011) Canada Australia USA	3-4 individual sessions over a few days	326 palliative patients with < 6 months to live (according to their healthcare provider) Terminal illness Cancer, most common types were: Gastrointestinal (n= 107, 32.8%), lung (n= 48, 14.7%) 'Other solid tumours (n= 67, 20.6%)	RCT Intervention group – DT Control groups – Standard palliative care (SPC) Client-centred care (CCC)	*PPS* – Palliative Performance Scale *FACIT*-Sp - Functional Assessment Of Chronic Illness Therapy Spiritual Well-Being (total, and two subscales; 'meaning / peace' and 'faith') *PDI* - Patient Dignity Inventory *HADS* - Hospital Anxiety and Depression Scale *SISC* - Structured Interview For	No significant differences were found between the three groups on standardised outcome measures The survey demonstrated that: DT – more likely to report treatment helpful, improved sense of QoL and dignity, changed family perceptions and appreciations of them, and that it had or would be of help to their family. DT – improved spiritual well-being and was

		Non-malignant illness (n=12, 3.6%)		Symptoms And Concerns *QoLS* - Quality Of Life Scale *ESAS* - Edmonton Symptom Assessment Scale Post intervention survey	significantly better than CCC; lessened sadness / depression, more likely to report intervention as satisfactory than those who received SPC Patient longevity post intervention was not significantly different between the three groups Floor effects meant no significant differences between the study arms in primary outcomes
Hall, Goddard, Opio, Speck, Martin, Higginson (2011) UK	2-3 individual sessions in short amount of time (with relative present if desired)	45 advanced cancer patients Most common cancers were: Digestive (n=9, 20%) Respiratory (n=8, 17.8%) 'Soft tissue' (n= 8, 17.8%)	Phase II RCT Intervention group – Dignity Therapy (DT) Control group – standard care	*PDI* - Patient Dignity Inventory *HHI* - Herth Hope Index *HADS* - Hospital Anxiety and Depression Scale *EQ-5D* - Quality of life Two 10-point Likert scales assessing: 1. current quality of life 2. satisfaction with quality of life palliative care outcomes Rate the self-reported	**PDI – dignity related distress** Slight reduction in dignity-related distress in the control group at 1-week follow-up, the groups did not differ in dignity-related distress at any time point **HHI - hope** Reduction in hope in the control group at 1- and 4-week follow-up and a slight increase in hope in the intervention group The intervention group showed higher levels of hope than the control group at both follow-ups. The effect sizes were medium and the

				benefits of dignity therapy or taking part in the study. Response options ranged from 1: strongly disagree to 5: strongly agree.	difference was statistically significant at 1-week follow-up. The groups did not differ on measures of anxiety and depression, quality of life or palliative outcomes. **Acceptability: self-reported benefits** The intervention group was more positive than the control group on all the self-reported benefits ratings
Meaning of Life Intervention (MLI)					
Mok, Lau, Lai & Ching (2012) Hong Kong	1 x 30-60 minute session and 1 x 15 minute session in a 2-3 day period	58 patients with advanced cancer (type of cancers not reported)	Pilot RCT Intervention group – MLI Control group – Treatment as usual (TAU)	*Primary outcome QOLC-E* – Quality of Life Concerns in the End-of-Life single item on global quality of life *Secondary outcome QOLC-E* – all eight subscales	**Main effects were noted between control and intervention groups**: - Single-item QOL score, QOLC-E total score and the mean score of the existential distress subscale of the QOLC-E To a medium effect size - No effects on any other outcome variables
Supportive Expressive Group Therapy (SEGT)					
Classen, Butler, Koopman, Miller, DiMiceli, Giese-	Weekly 90 minute sessions	125 women	RCT	*POMS* – Profile of	**Impact of Event Scale**

Davis, Fobair, Carlson, Kraemer & Spiegel (2001) USA	for a year	with metastatic breast cancer	Intervention group – SEGT + education Control group – Education material only	mood states *IES* – Impact of Event Scale	- Intervention group showed a significantly greater decline in traumatic stress symptoms on the Impact of Event Scale (effect size, 0.25) compared with the control group **Profile of Mood States** - No difference in Profile of Mood States total mood disturbance.
Giese-Davis, Koopman, Butler, Classen, Cordova, Fobair, & Spiegel (2002) USA *Reporting on data from Classen et al. (2001) study*		125 patients with metastatic or recurrent breast cancer		*WAI* – Weinberger Adjustment Inventory *CECs* – Courtald Emotional Control Scale *SESES-C* - Stanford Emotional Self-Efficacy Scale – Cancer	**CECs** Suppression treatment condition significant decrease in mean score (site not significant) **WAI** Restraint – defensiveness Treatment group significant increase in restraint over 12 months **WAI** Repressive – not significant different **SESES-C** total score – difference between conditions marginal treatment condition did not decline in self-

					efficacy compared to the control group SEGT can significantly change affect regulation strategies
Spiegel, Butler, Giese-Davis, Koopman, Miller, DiMiceli, & Kraemer (2007) USA *Reporting on data from Classen et al. (2001) study*		125 women with metastatic breast cancer		*Patient longevity (14 years post intervention)* - Patient longevity or death was determined by communication with participants, family members, and/or physicians, or by consulting the Social Security Death Index, and - Deaths were confirmed by death certificate.	No significant effect on patient longevity by treatment when comparing intervention and control group
Kissane, Grabsch, Clarke, Smith, Love, Bloch, & Li, (2007). Australia	Weekly 90 minute sessions for a year	227 patients with metastatic breast cancer	RCT Intervention group – SEGT plus 3 classes of relaxation Control group – 3 classes of relaxation	*MILP* - Monash Interview for Liaison Psychiatry *EORTC* - Quality of Life C-30 questionnaire *IES* - Impact of Event Scale *MMACS* - Mini Mental Adjustment to Cancer Scale *Patient longevity* – Deaths were confirmed via Victorian State	**Patient longevity** - SEGT didn't prolong patient longevity rates, significant predictors of patient longevity rates were treatment, visceral metastases, and advanced disease at diagnosis **QoL and psychosocial outcomes** – SEGT reduced hopelessness, trauma symptoms, and improved social functioning **Appraisals of group and relaxation sessions**

				Cancer, and State Death Registries. *Treatment data* – taken a follow-up or via medical records following death	– group cited particular aspects as useful **Adherence to cancer treatment** Argues it is evidence that therapy should not just go to those already distressed, as it can reduce risk of becoming clinically depressed when facing an advanced cancer
Meaning Making Intervention (MMi)					
Henry, Cohen, Lee, Sauthier, Provencher, Drouin, & Mayo (2010) Canada	1-4 x 30-90 minute individual sessions	24 women with newly diagnosed Stage III or IV ovarian cancer	Pilot RCT Intervention group - MMi Control group – Treatment as usual (TAU)	*FACIT-Sp*-12 Functional Assessment Of Chronic Illness Therapy Spiritual Well-Being (12 items, 'meaning / peace' subscale) *MQOL* - McGill QoL Questionnaire *HADS* – Hospital Anxiety Depression Scale *GSES* – General Self-Efficacy Scale	**FACIT-Sp-12 'meaning / peace' subscale** - increased by group at t1 and t2 with medium effects sizes (Cohens d 0.42 and 0.41 respectively) **MQOL** - existential well-being subscale and total score trend for higher score for EG patients at t2 compared to CG patients at t2 - No effect on distress or self-efficacy

Outlook					
Steinhauser, Alexander, Byock, George, Olsen & Tulsky (2008) USA	3 x sessions	82 hospice eligible patients Terminal illnesses: cancer (n= 48, 58.5%), heart disease (n= 5, 6.1%), lung disease (n= 10, 12.2%) and 'other' (n= 19, 23.2%)	Pilot RCT Intervention group – Outlook intervention Attention control group – met with facilitator three times and listened to a non-guided relaxation CD True control group – treatment as usual	*MSAS* – Memorial Symptom Assessment Scale *ADL* – Assessment of Daily Living *CESD* – Center for Epidemiologic Study of Depression *QUAL-E* – Quality of Life at the End of Life *DSES* – Daily Spiritual Experience Scale (not administered post intervention) Social support – brief measure	Intervention group showed improvement in functional status, anxiety and depression, and preparation for EoL however statistical differences could not be noted due to small sample sizes Outlook intervention was acceptable to patients from varied ethnic and educational backgrounds

Interventions: DT = Dignity Therapy, IMCP = Individual Meaning Centred Psychotherapy, MCGP = Meaning Centred Group Psychotherapy, MMi = Meaning Making Intervention, MLI = Meaning of Life Intervention, SEGT = Supportive Expressive Group Therapy

Outcome measures: ADL = Assessment of Daily Living, BHS = Beck Hopelessness Scale, CECs = Courtald Emotional Control Scale, CESD = Centre for Epidemiological Study of Depression, DSES = Daily Spiritual Experience Scale EORTC = Quality of Life C-30 questionnaire, EQ-5Q = Quality of Life, ESAS = Edmonton Symptom Assessment Scale, FACIT-Sp (FACIT-Sp-12)= Functional Assessment of Chronic Illness Therapy Spiritual Wellbeing [total and subscales of 'meaning' and ''peace/faith'] (shortened version), GSES = General Self-Efficacy Scale, HADS = Hospital Anxiety and Depression Scale, HHI = Herth Hope Index, IES = Impact of Event Scale, LOT = Life Orientation Test, MILP = Monash Interview for Liaison Psychiatry, MMACS = Mini Mental Adjustment to Cancer Scale, MQOL = McGill Quality of Life Questionnaire [existential subscale], MSAS = Memorial Symptoms Assessment Scale, PDI = Patient Dignity Inventory, POMS = Profile of Mood Scale, PPS = Palliative Performance Scale, QoLS = Quality of Life Scale, QUAL-Ep = Quality of Life at the End of Life [preparation scale], SAHD = Schedule of Attitudes towards Hastened Death, SESE-C = Stanford Emotional Self-Efficacy Scale – Cancer, SISC = Structured Interview for Symptoms and Concerns, WAI = Weinberger Adjustment Inventory

Misc: CCC = Client- centred care, RCT = Randomised Controlled Trial, SPC = Standard Palliative Care, SGT = Supportive group therapy, TM = Therapeutic massage, TAU = Treatment as usual

2.4 Quality assessment

All 11 papers (describing nine studies) were assessed using the framework developed by Kmet et al. (2004; see Appendix B). The framework assesses specific aspects of a study, such as design, methodology, analysis and conclusions. In order to assess the quality of the interventions a further four items were added by the author as these were not covered in the original framework. These criterion were 'the intervention is well described'; 'adherence to intervention is monitored and described'; 'therapist is trained to appropriate level to deliver intervention' and 'there is a well matched control group'. These were created to fit the format of the existing criteria and were scored in the same way and included in the summary scores. Each criterion was scored on a scale: "yes" = 2, "partial" = 1 and "no" = 0 (see Appendix C). Items which were not applicable to a study were recorded as "n/a" and were excluded from the calculation of summary score. Total scores were calculated for each paper giving a maximum of 36. Summary scores were calculated by dividing the total score by the total possible score (i.e. total score minus any items deemed non-applicable). Cut off scores for a 'poor', 'moderate' or 'good' summary score have been created by the researcher and these have been assigned a "traffic light" colour code to provide the reader with a 'quick reference' (see Table 4).

Table 4
Quality Framework summary scores

Cut off summary score	Quality	Traffic light
0 – 0.39	'poor'	red
0.4 – 0.69	'moderate'	amber
0.7 – 1	'good'	green

All papers were assessed by one researcher, however a randomly selected paper was also assessed by an independent rater and the quality assessment tool was found to have good inter-rater reliability as there was a high level of agreement. The overall quality of the studies ranged from 0.58 (moderate) to 0.88 (good), and therefore were all included in the review. See Table 5 for the quality assessment scores of all studies.

Table 5: *Quality assessment of all 11 papers included in the review*

Authors / Year	Strengths (score of '2')	Weaknesses (score below '2')	Quality score
Breitbart, W., Poppito, S., Rosenfield, B., Vickers, A.J., Li, Y., Abbey, J., Olden, M., Pessin, H., Lichtenthal, W., Sjoberg, D., & Casselith, B.R. (2012)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Analysis described and appropriate • Adherence to intervention measured • Therapist adequately trained in intervention	• Recruited via outpatients only • Sample size was only half required for power • No estimate of variance for main results • Results were not reported in sufficient detail (misses negative results) • Conclusions were not supported by the results • Description of intervention provided in another publication • Control was not well matched (therapeutic massage)	**24/34** **0.71**
Breitbart, W., Rosenfeld, B., Gibson, C., Pessin, H., Poppito, S., Nelson, C., Tomarken, A., Timm, A.K., Berg, A., Jacobson, C., Sorger, B., Abbey, J., & Olden, M. (2010)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Sample size appropriate • Analysis described and appropriate • Results reported in sufficient detail • Conclusions supported by the results • Adherence to intervention measured • Therapist adequately trained in intervention • Well matched control group	• Recruited via outpatients of hospital only • Estimate of variance for main results not provided • Description of intervention provided in another publication	**27/34** **0.79**
Chochinov, H.M., Kristjanson, L.J., Breitbart, W., McClement, S., Hack, T.F., Hassard, T., & Harlos, M. (2011)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Sample size appropriate • Analysis described and appropriate • Results reported in sufficient detail • Conclusions supported by the results • Clear description of the intervention • Adherence to intervention measured • Therapist adequately trained in intervention	• Estimate of variance for main results • Not a well matched control group (treatment as usual)	**31/36** **0.86**
Classen, C., Butler, L.D., Koopman, C., Miller, E., DiMiceli, S., Giese-Davis, J., Fobair, P., Carlson, R.W., Kraemer, H.C., &	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly	• Method of group selection was not described (reported in another paper) • Estimate of variance for main results was not	**26/36** **0.72**

Spiegel, D. (2001)	• Random allocation described • Outcomes measures robust • Sample size appropriate • Analysis described and appropriate • Controlled for confounding • Results reported in sufficient detail • Conclusions supported by the results • Therapist adequately trained in intervention	provided • There was no clear description of the intervention • Adherence to intervention was not measured • The control group was not well matched	
Giese-Davis, J., Koopman, C., Butler, L. D., Classen, C., Cordova, M., Fobair, P., Benson, J., Kraemer, H.C., & Spiegel, D. (2002)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Analysis described and appropriate • Results reported in sufficient detail • Conclusions supported by the results • Therapist adequately trained in intervention	• Method of group selection was not described / appropriate • Estimate of variance for main results • There was no clear description of the intervention • Adherence to intervention was not measured • The control group was not well matched (educational control, intervention group also received this)	**23/34** **0.68**
Henry, M., Cohen, S., Lee, V., Sauthier, P., Provencher, D., Drouin, P., Gauthier, P., Gotlieb, W., Lau, S., Drummond, N., Gilbert, L., Stanimir, G., Sturgeon, J., Chasen, M., Mitchell, J., Huang, L.N., Ferland, M.K., & Mayo, N. (2010)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Sample size appropriate • Analysis described and appropriate • Controlled for confounding • Results reported in sufficient detail • Conclusions supported by the results • Therapist adequately trained in intervention • Adherence to intervention measured	• Estimate of variance for main results • There was no clear description of the intervention (reported in another paper) • Estimate of variance for main results not provided • The control group was not well matched (treatment as usual)	**30/36** **0.83**
Kissane, D. W., Grabsch, B., Clarke, D. M., Smith, G. C., Love, A. W., Bloch, S., Snyder, R.D., & Li, Y. (2007)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Analysis described and appropriate • Sample size appropriate • Controlled for confounding • Results reported in sufficient detail	• Estimate of variance for main results not provided • The control group was not well matched • There was no clear description of the intervention (provided in unpublished manual)	**28/32** **0.88**

	• Conclusions supported by the results • Adherence to intervention measured • Therapist adequately trained in intervention		
Mok, E., Lau, K.P., Lai, T., & Ching, S. (2012)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Analysis described and appropriate • Sample size appropriate • Controlled for confounding • Results reported in sufficient detail • Conclusions supported by the results • Clear description of the intervention • Therapist adequately trained in intervention	• Estimate of variance for main results not provided • Adherence to intervention was not reported • The control group was not well matched (treatment as usual)	**25/36** **0.69**
Spiegel, D., Butler, L. D.,.Giese-Davis, J., Koopman, C., Miller, E., DiMiceli, S., Classen, C.C., Fobair, P., Carlson, R.W., & Kraemer, H. C. (2007)	• Clear objective • Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Outcomes measures robust • Analysis described and appropriate • Sample size appropriate • Includes estimate of variance • Controlled for confounding • Results reported in sufficient detail • Therapist adequately trained in intervention	• Conclusions not supported by results • There was no clear description of the intervention (described elsewhere) • Adherence to intervention was not reported • The control group was not well matched	**27/36** **0.75**
Steinhauser, K.E., Alexander, S.C., Byock, I.R., George, L.K., Olsen, M.K., & Tulsky, J.A. (2008)	• Clear objective • Study design evident and appropriate • Outcomes measures robust • Results reported in sufficient detail • Clear description of the intervention	• Subject characteristics described • Random allocation • Sample size was underpowered • Analytic methods were not described • No estimate of variance • Conclusions not reported by results (acceptability) • Adherence was not reported • The control group was not well matched (treatment as usual) • No information on therapist profession or intervention training	**21/26** **0.58**
Hall, S., Goddard, C., Opio, D., Speck,	• Clear objective	• The control group was a treatment as usual condition	**26/32**

P.W., Martin, P., & Higgingson, I.J. (2011)	• Study design evident and appropriate • Subject characteristics described clearly • Random allocation described • Analysis described and appropriate • Sample size appropriate • Includes estimate of variance • Results reported in sufficient detail • Conclusions supported by the results • Clear description of the intervention • Adherence to intervention measured • Therapist adequately trained in intervention		**0.81**

3.0 Results

3.1 Study characteristics and quality

3.1.1 Methodologies and research designs

All 11 papers (describing nine studies) reported use of a randomised control trial (RCT) design, with five of the studies being pilot trials and one described as a Phase II RCT[3] (Hall et al., 2011). Four papers provided further detail of method randomisation, (Breitbart et al., 2010; Breitbart et al., 2012; Classen et al., 2001; Spiegel et al., 2007). Researcher and participant blindness to condition allocation were reported for four of the studies (Chochinov et al., 2011; Henry et al., 2010; Mok, Lau, Lai, & Ching, 2012; Steinhauser et al., 2008).

Using a modified version of the Kmet (2004) criteria, the majority of the papers were defined as strong (n = 8), with three papers being found to be of moderate quality. The proportion of studies being defined as strong increases the reliability of the results found within this review. For the studies which scored moderate levels of quality the weaker aspects related to poor descriptions of the intervention, lack of intervention adherence measurement or an ill matched control group. However, these studies were included as they scored an overall moderate level of quality.

3.1.2 Setting and recruitment

Of the nine studies reviewed, four were conducted in the United States of America (USA; Breitbart et al., 2010; Breitbart et al., 2012; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007] ; Steinhauser et al., 2008); one in Canada (Henry et al., 2010);

[3] A Phase II trial is defined as "Exploratory Trial – Described as the constant and variable components of a replicable intervention AND a feasible protocol for comparing the intervention to an appropriate alternative" (Campbell et al., 2000).

United Kingdom (UK; Hall et al, 2011); Hong Kong (Mok et al., 2012); Australia (Kissane et al., 2007) and one in a combination of USA, Canada and Australia (Chochinov et al., 2011).

3.1.3 Sample sizes

The total number of participants across the 11 papers was 1097; sample sizes ranged from 24 to 227 participants.

3.2 Participant characteristics

3.2.1 Participants

Six studies included both male and female patient participants (Breitbart et al., 2010; Breitbart et al., 2012; Chochinov et al., 2011; Hall et al., 2011; Mok et al., 2012; Steinhauser et al., 2008). Three studies included female participants only ([Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007] Henry et al., 2010; Kissane et al., 2007). The mean ages of participants ranged from 53 to 65 years of age. Five studies reported the majority of participants being of a White ethnicity (54% – 86%; Breitbart et al., 2010; Breitbart et al., 2012; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Hall et al., 2011). Eight studies reported marital status with most participants reporting that they were married or cohabiting (Breitbart et al., 2012; Chochinov et al., 2011; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Hall et al., 2011; Henry et al., 2010; Kissane et al., 2007; Mok et al., 2012; Steinhauser et al., 2008). Seven studies reported education level; in three of these participants had spent an average 16 years in education (Breitbart et al., 2010; Breitbart et al., 2012; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]). Three studies reported data on religious affiliation; Chochinov et al. (2011) and Henry et al. (2010) reported between 26% and 86% of participants held Catholic beliefs and Mok et al. (2012) reported 53% of participants as having a ‘religious affiliation’.

3.2.2 Disease

Of the nine studies, three specifically recruited participants with metastatic or recurrent breast cancer ([Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Kissane et al., 2007) or ovarian cancer (Henry et al., 2010). Six studies ((Breitbart et al., 2010; Breitbart et al., 2012; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Hall et al., 2011; Kissane et al., 2007; Mok et al., 2012) recruited participants with 'advanced cancer'; the site of cancer varied, the most prevalent being digestive (Hall et al., 2011). One study provided no further detail about the site of the cancer (Mok et al., 2012). One study (Chochinov et al., 2011) recruited 'terminally ill' participants with the most prevalent disease being gastrointestinal cancer (33%).

3.2.3 Inclusion criteria for palliative care

One of the nine studies utilised an objective measure of disease severity, the ICD-TNM (Bears, Henson, Hutter, & Myers, 1992), to define Stage IV breast cancer (Kissane et al., 2007). Three of the studies used medical doctor determined stage of cancer to assess for palliative care, i.e. Stage III or IV cancer (Breitbart et al., 2010; Breitbart et al., 2012; Henry et al., 2010), and one used the inclusion criteria of metastatic or recurrent breast cancer and at "significant risk of death from breast cancer" ([Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]). The majority of the studies relied on the patient's healthcare provider (i.e. consultant or palliative care team) to determine prognosis and palliative status. Chochinov et al., (2011) and Steinhauser et al., (2008) required participants to be deemed by their physician to have less than six months to live. Henry et al., (2010) required participants to have received their diagnosis of ovarian cancer within the previous two months prior to recruitment as this was defined, by the authors, as the most vulnerable period in the journey.

3.2.4 Attrition

All nine studies acknowledged attrition within the sample groups. Seven of the nine studies provided details of attrition, the most common reason being illness-related factors or death (Breitbart et al., 2012; Chochinov et al., 2011; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Hall et al., 2011; Henry et al., 2010; Kissane et al., 2007; Mok et al., 2012). Of the two studies which did not provide detailed attrition information, Steinhauser et al., (2008) reported "functional decline" or death as reasons for attrition and Breitbart et al. (2010) did not routinely record attrition details.

3.3 Intervention characteristics

3.3.1 Theoretical underpinnings

Across the nine studies, seven interventions were evaluated. Despite all interventions having a meaning focus, the theoretical underpinnings varied (see Table 6 for an overview of the theoretical background of each intervention). *Dignity Therapy* (Chochinov et al., 2005) is empirically based on a model of dignity using qualitative data from hospice patients. The *Meaning Making Intervention* (Lee, Robin Cohen, Edgar, Laizner, & Gagnon, 2006) cites situational, global and existential meaning-making. The *Outlook* intervention (Steinhauser et al., 2008) was developed from life review, health psychology, self-disclosure and spiritual well-being literatures. The remaining four interventions cite Viktor Frankl's Logotherapy (Frankl, 1955; Frankl, 1962) and / or Irvin Yalom's (1980) work in existential psychotherapy (who is heavily influenced by Frankl) along with other broad existential underpinnings.

Table 6: *Summary of theoretical background for each intervention as presented in the papers*

Intervention / Citation	Theoretical background	Intervention aim
Dignity Therapy (Chochinov et al., 2005)	Based on a model of dignity (created by the creators of the intervention; Chochinov et al., 2005) using qualitative data from hospice patients. Key constructs: Meaning-making via reflection on things that matter most or that they would most want remembered in order to increase sense of meaning and of dignity.	• Semi-structured interview questions prompt patients to reflect on things that are most important to them, and how they would like to be remembered • The conversation is transcribed and presented a 'generativity' document which is shared or bequeathed to the patients choice of loved one/s • Aim is to increase sense of meaning, purpose, worth and dignity among terminally ill people • Reduce psychosocial, spiritual and existential distress, and enhance quality of life
Meaning Centred Group Psychotherapy (MCGP) (Breitbart, 2002; Greenstein & Breitbart, 2000)	Grounded in Viktor Frankl's writings on meaning and Logotherapy (Frankl, 1955; Frankl 1962). Logotherapy is based on the premise of meaninglessness causes existential distress, thus the aim of therapy is to increase feelings of meaning for individuals. Draws on the work of Spiegel, Yalom and Kissane (Speigel, Bloom, & Yalom, 1981; Spiegel & Yalom, 1978; Yalom & Greaves, 1977). Key constructs: meaning-making sustains or enhances a sense of meaning, peace, and purpose in their lives.	• Maintain or increase a sense of meaning, peace and purpose, even as they confront death, among individuals with advanced cancer • Focus on spiritual well-being, meaning and reducing psychological distress • Groups uses didactics, discussion and experiential exercises that focus around themes related to meaning and advanced cancer • Each (group) session addresses specific themes related to an exploration of the concepts and sources of meaning, the relationship and impact of cancer on one's sense of meaning and identity, and placing one's life in a historical and personal context (i.e. understanding one's 'legacy').
Individual Meaning Centred Psychotherapy (IMCP) (Breitbart et al., 2010)	Same theoretical background as original MCGP intervention (above) however adapted to an individual intervention to reduce attrition.	Individual sessions uses didactics, experiential exercises, and psychotherapeutic techniques (eg, reflection, clarification, and exploration) that promote the use of sources of meaning as resources in coping with advanced cancer. Sessions address specific sources of meaning as well as themes related to cancer and identity, legacy, hope, and the finiteness of life. Patients are also assigned related readings and homework exercises.
Meaning Making Intervention (Lee et al., 2006)	Existential meaning-oriented intervention that focuses on situational, global, and existential meaning for cancer patients Key constructs: existential, meaning-making increasing situational, global, and existential meaning will increase self-esteem, optimism and self-efficacy.	To facilitate the search for meaning following a cancer diagnosis by: (1) reviewing the impact and meaning of the cancer diagnosis (2) exploring past significant life events and successful ways of coping, as related to the present cancer experience (3) discussing life priority and goal changes that give meaning to one's life, while considering cancer-related limitations With the aim to reduce negative outcomes i.e. depression and anxiety

Outlook intervention (Steinhauser et al., 2008)	Content and structure is based on research conducted by the authors results from research exploring patient spiritual wellbeing in which end-of-life preparation and completion were outlined as important. These 'tasks' form the need for individuals facing end-of-life to both look back to assess their life lived, and forward to prepare for the remaining months / weeks of life. The intervention is also influenced by the evidence from life review and health psychology self-disclosure literatures. Key constructs: existential, meaning-making through completing a set of 'tasks' related to end of life preparation.	Aim is to help patients make sense of their life lived and to prepare themselves and family members for the remaining duration of their life. This is done via life review (sense making) and self-disclosure which facilitates healing.
Supportive Expressive Group Therapy (Spiegel et al., 1981)	The rationale grew out of existential psychotherapy, with a focus on existential concerns of death anxiety, isolation, responsibility, choice, and meaning (Yalom, 1980). As existential thinking supposes that living with a terminal illness amplifies existential concerns of death, meaning, freedom, and isolation. Key constructs: existential, meaning-making reduces existential conflicts	Aim of the group intervention is to give patients an opportunity to discuss these concerns through direct processing, which confronts patients with emotional experiences. This allows them to develop ways of managing and tolerating such negative affect in the moment.
Meaning of Life Intervention (Mok et al., 2012)	Based on Viktor Frankls' Logotherapy (Frankl, 1955; Frankl, 1962). Key constructs: existential, meaning-making facilitates increased quality of life.	Aim is to help participants reflect on their lives based on the sources of meaning of life: creative, experiential, and attitudinal values

3.3.2 Intervention delivery

Of the interventions in the nine studies, six were delivered on an individual basis (Breitbart et al., 2012; Chochinov et al., 2011; Hall et al., 2011; Henry et al., 2010; Mok et al., 2012; Steinhauser et al., 2008) and three were group interventions (Breitbart et al., 2010; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Kissane et al., 2007).

3.3.3 Therapist profession and intervention training

Professional background of those delivering interventions was reported in six of the studies and included Clinical Psychologists and Trainee Clinical Psychologists, Psychiatrists, Nurses, Oncologists and Social Workers. Two of the studies used the more general terms of 'healthcare professionals' (Mok et al., 2012) or 'therapist' (Steinhauser et al., 2008). One study reported that the authors of the paper delivered the intervention; however their professions were not reported (Hall et al.,2011) The majority of professionals delivering the interventions received intervention training, as reported in seven of the studies (Breitbart et al., 2010; Breitbart et al., 2012; Chochinov et al., 2011; Hall et al., 2013; Henry et al., 2010; Kissane et al., 2007; Mok et al., 2012) although the nature of training varied across studies and included a review of therapy manuals, watching therapy videos, clinical supervision and study days.

3.3.4 Intervention adherence

Adherence or fidelity to the interventions was reported in seven of the studies. Four studies reported adherence being measured via audio or video recording of the sessions (Breitbart et al., 2010; Breitbart et al., 2012; Chochinov et al., 2011; Henry et al., 2010). One study reported fortnightly supervision (Kissane et al., 2007) and one study conducted a random audit of three therapy transcripts (Hall et al., 2011). Three of the studies did not

provide information on how adherence was measured ([Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Mok et al., 2012; Steinhauser et al., 2008).

3.4 Study outcome measures

Across the nine studies a total of 29 standardised outcome measures were used with little consistency in the outcome measures used across the studies (see Table 7 for an overview). No measure explicitly assessing meaning was used in any of the studies, however a number studies used meaning 'focused' measures to vicariously measure meaning, these are highlighted with * in Table 7. Three studies included information regarding longevity of participants after receiving a meaning-focused intervention as an outcome measure (Chochinov et al., 2011; [Classen et al., 2001; Giese-Davis et al., 2002; Spiegel et al., 2007]; Kissane et al., 2007).

Table 7 *Outcome measures*[4] *used in the studies*

Paper	*FACIT-Sp	HADS	SAHD	LOT	*MQOL	BHS	PPS	*PDI	SISC	QoLS	ESAS	HHI	EQ-5D	*QOLCE	POMS	IES	WAI	CECs	SESE	MILP	EORTC	IES	MMACS	GSES	MSAS	ADL	CESD	*QUAL-Ep	DSES
Breitbart et al. (2012)	■	■	■	■																									
Breitbart et al. (2010)	■	■			■																								
Chochinov et al. (2011)	■	■					■	■	■	■	■																		
Hall et al. 2011)		■						■				■	■																
Classen et al. (2001)															■	■													
Giese-Davis et al. 2002)																	■	■	■										
Henry et al. 2010)	■	■			■																			■					
Kissane et al. (2007)																■				■	■		■						
Mok et al. (2012)														■															
Spiegel et al. (2007)																													
Steinhauser et al. (2008)																									■	■	■	■	■

[4] * used as a measure of meaning, FACIT-Sp (FACIT-Sp-12)= Functional Assessment of Chronic Illness Therapy Spiritual Wellbeing [total and subscales of 'meaning' and ''peace/faith'] (shortened version), HADS = Hospital Anxiety and Depression Scale, SAHD = Schedule of Attitudes towards Hastened Death, LOT = Life Orientation Test, MQOL = McGill Quality of Life Questionnaire [existential subscale], BHS = Beck Hopelessness Scale, PPS = Palliative Performance Scale, PDI = Patient Dignity Inventory, SISC = Structured Interview for Symptoms and Concerns, QoLS = Quality of Life Scale, ESAS = Edmonton Symptom Assessment Scale, HHI = Herth Hope Index, EQ-5Q = Quality of Life, POMS = Profile of Mood Scale, IES = Impact of Event Scale, WAI = Weinberger Adjustment Inventory, CECs = Courtald Emotional Control Scale, SESE-C = Stanford Emotional Self-Efficacy Scale – Cancer, MILP = Monash Interview for Liaison Psychiatry, EORTC = Quality of Life C-30 questionnaire, MMACS = Mini Mental Adjustment to Cancer Scale, GSES = General Self-Efficacy Scale, MSAS = Memorial Symptoms Assessment Scale, ADL = Assessment of Daily Living, CESD = Centre for Epidemiological Study of Depression, QUAL-Ep = Quality of Life at the End of Life [preparation scale], DSES = Daily Spiritual Experience Scale

3.5 Study outcomes

3.5.1 What is the impact of meaning-focused interventions on meaning for palliative care patients?

As previously stated no specific measures of meaning were used in any of the studies reviewed. In order to answer the question, conclusions are drawn from the measures which were considered by the author to provide information regarding participants' sense of meaning. With this in mind, there was some evidence that the meaning-focused interventions were found to have a positive impact on patients' sense of meaning.

The results of Breitbart et al. (2010) suggest that the *Meaning Centred Group Psychotherapy* intervention significantly improved participants' sense of meaning, the effects were reported as higher at two months follow-up, suggesting that the positive effects might continue post-intervention. Henry et al.'s (2010) *Meaning-Making Intervention* also indicated a statistically significant main group effect for the intervention for women with newly diagnosed ovarian cancer compared to the control group with a trend towards higher existential well-being for the intervention participants after three months. These findings were similar when the *Meaning Centred Group Psychotherapy* was adapted for individuals (Breitbart et al., 2012). In the individual therapy study, there were greater treatment effects for the intervention group compared to the control group, who received therapeutic massage only. However, unlike its predecessor, this intervention resulted in no differences at the two month follow-up. As both patient groups were a sample of advanced cancer patients, it is possible that this difference in the follow-up findings may be attributed to the *delivery* of the intervention i.e. group versus individual therapy; individual therapy does not have the benefits of being with others also facing and living with advanced cancer (in this case the majority of patients had Stage IV cancer) and of peer support which may continue outside of

the intervention. All three studies were scored as 'good' against the quality criteria, meaning that the results have increased validity and reliability due to the strong study designs, procedures and interventions.

In contrast to these positive findings, Chochinov et al. (2011) found no significant differences between the control and intervention conditions, using the same subscales of the FACIT-Sp as previous studies, when comparing the effects of *Dignity Therapy* to two control conditions: treatment as usual and "client centred care". Although all of the participants had advanced disease, they were at different stages within the disease trajectories; in the Chochinov et al. (2011) study, participants were deemed to have less than six months to live in contrast to those in the Henry et al. (2010) study who recruited participants who had been diagnosed with Stage III or IV ovarian cancer within the last two months. Breitbart et al. (2010) and Breitbart et al. (2012) did not discuss diagnostic information.

When considering non-standardised measures of meaning, Hall et al. (2011) devised a self-report survey with two meaning-focused items; "made life more meaningful" and "heightened my sense of purpose". The intervention group (*Dignity Therapy*) scored more highly than the control groups on these items which directly referred to the intervention, however the difference for the item "made life more meaningful" was not statistically significant at one week follow-up; however, at four month follow-up the differences between groups were statistically significant for "finding that the intervention heightened my sense of purpose". This might suggest that effects take time to appear as participants process the impact of the intervention. Although the study was assessed as "good" in the quality assessment, the use of a non-standardised measures lessens the reliability and validity of the findings.

It is noteworthy that all of the aforementioned studies were defined as being of good quality, suggesting a high level of methodology and clear reporting which increasing the reliability of conclusions. However, no study used a specific outcome measure of meaning, which creates a substantial limitation in this review and although there is evidence that suggests meaning-focused interventions have a positive impact on participants' sense of meaning, these positive findings need to be interpreted with caution.

3.5.2 What effects do meaning-focused interventions have on patient quality of life?

There was little consistency in the outcomes measures used, the results have been organised in terms of positive results, contradictory results, negative results.

Two studies found evidence that meaning-focused interventions improved quality of life; Mok et al. (2012) used the QOLC-E and found significant main effects between the intervention and the control group. Henry et al. (2010) used the MQOL and found a significant time-by-group interaction on the MQOL existential subscale, with participants scoring higher on this scale at three months post intervention follow-up than the control group. Both of the studies used measures with good reliability (Cronbach's alpha of 0.87 and 0.83 respectively). However Mok et al. (2012) scored moderately on the quality assessment due to using a treatment as usual control group, this means that the positive results need to be treated with caution due to the study design.

Breitbart (2012) also used the MQOL and found that whilst the scores improved significantly for the intervention group immediately post-intervention, no statistically significant treatment effects were observed at 2 months follow-up. Although both Henry et al. (2010) and Breitbart et al. (2012) used the MQOL, there were inconsistent results regarding the post-intervention follow-up findings. Due to the two studying different interventions (*Meaning Making Intervention* and *Individual Meaning Centred Psychotherapy* respectively)

with two diverse sample groups (24 newly diagnosed advanced ovarian cancer patients and 120 advanced cancer patients respectively), it is difficult to compare the two studies and draw conclusions regarding the difference in results at post-intervention follow-up.

The following studies found mixed results. Kissane et al. (2007) found a significant improvement on mean social functioning subscale scores of the Quality Life C-30 Questionnaire; however there was no significant improvement on the emotional subscale, as the authors had hoped. As the study was scored as 'good' on the quality assessment for study design, this inconsistency of results may suggest that the effects seen are as a result of the group delivery of the intervention which positively affected patients' experience of wider social interactions, rather than the intervention itself. Therefore the improvement could not be assigned wholly to intervention techniques.

Steinhauser et al. (2008), Chochinov et al. (2011) and Hall et al. (2011) found no supporting evidence that meaning-focused interventions improved quality of life in patients receiving palliative care (*Outlook* intervention and *Dignity Therapy* respectively). However, both Chochinov et al. (2011) and Hall et al. (2011) found intervention effects for self-reported benefits gathered via post intervention survey items regarding quality of life. The inconsistency of results suggests that the quality of life measures were not sensitive to the change that was captured via the self-reported benefits, although both measures report good Cronbach's alphas. This suggests that the outcome measures were not capturing the change rather than that the intervention had no impact on quality of life. Participants' level of distress was not a criterion for inclusion to the study and the authors described how this created a ceiling effect i.e. it would be difficult to improve on an area which the individual did not see as problematic. Furthermore, Hall et al. (2011) outlined poor response rates and high attrition

during the study period, which could account for the null findings regarding quality of life scores. All of these studies were scored strongly on the quality assessment.

In summary, the evidence that meaning-focused interventions improve quality of life for palliative care patients is mixed. Whilst there is good evidence from high quality studies, using reliable measures, suggesting a positive impact on quality of life for these interventions, this is not consistent across the studies reviewed. Issues with attrition, small samples sizes and ceiling effects have all been outlined as possible reasons for this. Further, quality of life as an outcome may not be the best way to measure impact and outcome of meaning-focused interventions, and that a more meaning-focused outcome measure would yield more robust results.

3.5.3 Do meaning-focused interventions increase patient longevity?

Three studies included in this review looked at patient longevity i.e. the length of time a participant lived post intervention (Chochinov et al., 2011; Kissane et al., 2007; Spiegel et al., 2007). Both Spiegel et al. (2007) and Kissane et al. (2007) assessed the efficacy of a *Supportive Expressive Group Therapy* (SEGT) intervention for participants with metastatic breast cancer, with Spiegel et al. (2007) attempting to replicate their original noteworthy findings that this intervention increased patient longevity time for patients with metastatic breast cancer (Kogon, Biswas, Pearl, Carlson, & Spiegel, 1997; Spiegel, Kraemer, Bloom, & Gottheil, 1989) without success. Similarly, Kissane et al. (2007) found no evidence that SEGT prolonged patient longevity rates. Further analysis revealed that the significant predictors of patient longevity were, unsurprisingly, advanced disease at diagnosis ($p = 0.05$), presence of visceral metastases ($p < 0.001$), and treatment with chemotherapy and hormone therapy ($p < 0.001$). Although not a main outcome Chochinov et al. (2011) also reported patient longevity outcome data and no significant differences were found. Overall, none of

the studies, which were scored as strong against quality criteria, produced evidence that meaning-focused interventions increased the length of time participants lived post intervention.

4.0 Discussion

4.1 Aim of the review

The aim of the review was to examine the evidence of meaning-focused interventions for adults receiving palliative care.

4.2 Summary of findings

A total of seven 'meaning-focused' interventions (as defined in this review), based on a variety of theoretical models, were reviewed in nine studies, reported in 11 publications. All of the studies were considered moderate (n = 3) to good quality (n = 8) as assessed against the modified Kmet (2004) quality framework.

4.2.1 Meaning

There were no explicit or standardised outcome measures of meaning; rather this construct was captured using a variety of outcomes. When looking at the results from the studies reviewed, the evidence of meaning-focused interventions on patients' sense of meaning was encouraging, and positive effects were found for the majority of interventions. Four studies (Breitbart et al., 2010; Breitbart et al., 2012; Hall et al., 2011; Henry et al., 2010) found significant treatment effects that indicated the meaning-focused interventions increased participant sense of meaning. Only one study (Chochinov et al., 2011) found non-significant results using the same outcome measure as three of the other studies. As discussed, this may have been due differences in individual participant factors such as stage of disease and

prognosis. Although the results are promising and from good quality studies, the lack of consistency in terms of the measurement of meaning, with two studies omitting to include any form of meaning measurement, limits the strength of the findings.

4.2.2 Quality of life

The evidence of meaning-focused interventions on patients' quality of life was broadly encouraging and positive effects were found for the majority of studies. In total five of the studies found some positive evidence (Chochinov et al., 2011; Hall et al., 2011; Henry et al., 2010; Mok et al., 2012) and two of these studies found significant treatment effects when using standardised measures of quality of life (Chochinov et al., 2011; Hall et al., 2011). However, there was some inconsistency within the findings, with some effects not remaining significant over time (Chochinov et al., 2011) and others only being significant in specific areas (Kissane et al., 2007). A total of eight quality of life measures were used across the seven studies, which may have contributed to the lack of consistency in the findings. Given that the focus of the interventions was meaning, it may also be that the measures used were not sensitive to change in quality of life, as both Hall et al. (2011) and Chochinov et al. (2011) found treatment effects on the self-reported benefits of taking part, but not on the standardised quality of life outcome measure. All but one of the studies, Mok et al. (2012; which was scored as 'moderate'), scored as 'good' against quality criteria, which increases the reliability of the findings of positive intervention effects.

4.2.3 Patient longevity

This review of three good quality studies provided no evidence that meaning-focused interventions increased longevity of palliative care patients (Chochinov et al., 2011; Kissane et al., 2007; Spiegel et al., 2007). Furthermore, Spiegel et al. (2007) was not able to replicate the findings of the original study (Spiegel et al., 1989) which found that the intervention

increased patient longevity post intervention. The factors found to predict patient longevity were physiological, such as disease, presence of metastases and treatment. The exploration of psychological interventions and the possible physiological effects have been the centre of research for a number of decades. Although this review does not support this notion, the debate continues, with new evidence emerging that psychological interventions do influence physiology of palliative care patients (Lutgendorf & Andersen, 2015; Xia et al., 2014).

4.3 Limitations

The largest limitation of the review is the lack of a universally accepted definition of 'meaning-focused' interventions. There are numerous ways in which psychological interventions, with a meaning focus, are described which is reflected in the search terms used for the review. Examples from the literature include 'meaning centred' 'meaning making' or 'meaning of life' interventions and other names which are less obvious to label their intervention, using terms such as '*Dignity Therapy'*, '*Outlook'* and '*Supportive Expressive Group Therapy*', even though meaning (as an aspect of existential therapy) is at the core of them. This was a considerable challenge when searching for relevant studies to review. In order to address this, it is recommended that future research to explore meaning-focused or meaning-centred interventions to strengthen the working definition of this sub group of psychological interventions.

Due to the heterogeneity of the studies reviewed it is difficult to draw firm conclusions regarding the efficacy of meaning-focused interventions for patients receiving palliative care. The lack of standardised measures of meaning in the studies reviewed is a limitation of the studies themselves and this review. Outcome measures need to be valid, reliable and sensitive enough to detect change. There are a number of ways in which an individual's sense of meaning can be captured, as outlined in Brandstätter, Baumann,

Borasio, & Fegg's (2012) review of 59 meaning outcome measures, who stated that there is wide range of reliable and valid measures for researchers to choose from. Inclusion of explicit, standardised measurement of meaning would increase study quality and should be included in future research regarding meaning-focused interventions.

There were differences across all of the interventions reviewed in terms of delivery (e.g. group or individual intervention delivery), duration and the training of the therapists (i.e. profession and specific training in the intervention). Whilst the majority of the interventions were individually delivered (in six out of nine studies), the duration and frequency of the interventions varied greatly. These differences made it difficult for comparisons to be drawn. The three group interventions were more consistent in this way as all were delivered weekly for a period of a year.

The methodological quality of the studies was assessed using the framework described by Kmet et al. (2004), modified by the author for the purposes of this review. The four additional items concerning the quality of the intervention (i.e. clear description, measures of adherence, well matched control group and therapist training in intervention), were added. Whilst the all the papers were of a good or moderate quality, a methodological limitation of the studies is that many of the control groups were 'treatment as usual' and were not particularly well matched to the intervention arm. Appropriate methodology should control for confounding factors; treatment as usual can mean any number of things and therefore variability in treatment impacts the validity and reliability of the study findings.

The statistical test, Cohen's kappa co-efficient which measures inter-rater agreement of qualitative items was not used as the quality assessment did not meet the assumption that each response variable has the same number of categories and that cross-tabulation must be symmetric (Lund & Lund, N.D.), therefore it was not possible to run the test.

None of the studies employed a baseline of distress as an inclusion criterion during recruitment. The main inclusion criteria were cancer type and or stage of advanced disease (malignant and non-malignant) i.e. nothing psychological. This presents challenges as baseline distress can give information about who is more likely to benefit from an intervention, and indeed who did benefit when post-intervention measures are repeated. Finally, there was little cultural diversity represented in the studies, which were conducted in the UK, USA, Australia and Canada; with two studies being conducted in Japan and China.

There are a number of methodological challenges to consider when conducting research in palliative care, and some of these were evident from this review. Attrition in palliative care research is unavoidable due to participants' complex health status and treatment regimes, and was prevalent within all the studies reviewed; however, not all of the studies captured sufficient detail concerning reasons for withdrawal from the studies. This is an important area for consideration when embarking on intervention studies in palliative care: large enough sample sizes need to be achieved for meaningful outcomes, whilst being mindful of the health status and prognosis of individuals participating.

Defining palliative care is inherently challenging. The palliative care status of patients in the studies reviewed was described in an inconsistent way across the studies and some studies did not provide any information on how this was defined. Although the status of participants was presumed by the author to be correct, the samples varied in terms of their disease and prognostic status. Three studies (Breitbart et al., 2010; Breitbart et al., 2012; Henry et al., 2010) included patients with Stage III cancer, which they used to denote 'advanced cancer' and many studies relied on healthcare professionals' opinion to identify palliative status. Whilst it is understood that assessing prognosis is a complex and non-precise matter, the lack of consistency, transparency and over reliance on the staging of cancer as a

measure of palliative status, is a limitation of the studies reviewed and it is recommended that this is addressed in future research in this area.

Alongside methodological issues there are also ethical concerns to address when conducting research in palliative care. Addington-Hall (2002) outlines a number of these; individuals facing a terminal prognosis are considered, by researchers and healthcare professionals, to be especially vulnerable and so extra caution is taken when considering their participation in research. She also cites Raudonis (1992) who suggests that it is unethical to ask them to participate in research. Further, Gordijn and Janssens (2000) put forward the idea that as patients receiving palliative care are unable to see the benefits of intervention studies directly, it is therefore ethically questionable that they should be asked to take part in research that they will not gain from themselves. Although these concerns appear to be in order to protect palliative care patients, it is restrictive and suggests that a whole participant group should be excluded 'en masse' from research – an idea that is in itself unethical. It also neglects to attend to the point that these individuals have something to tell us about their care and their lived experiences and makes assumptions regarding participants' capacity to consent to participation. In a study exploring hospice patients' views on taking part in palliative care research, the participants shared that, for them it meant that they would be using their time *meaningfully* - "it would be a way to give something back now before I die, I would have done something good for the future", to receive a sense of *validation* - "it is good to research, especially when you are dying, you don't want to be forgotten", and *assurance* that comes from knowing research is being conducted to improve the dying experiences such as pain management. Furthermore, some patients stated that they drew the conclusion that " … not doing research in palliative care was equivalent to not being committed to optimizing care for the terminally ill" (Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006). Therefore whilst ethical concerns need to be addressed, particularly in terms of length and

mode of intervention and disease status, in order to make participation as acceptable for palliative care patients as possible, they need not be 'protected' to the point of exclusion.

In order to maintain a clear focus in this review, research conducted with family members and loved ones was excluded. However, there are a number of studies which explore meaning-focused interventions with family members and / or partners of individuals receiving palliative care, including two studies published whilst this review was conducted (Applebaum, Kulikowski, & Breitbart, 2015; Wagner, Johns, Brown, Hanna, & Bigatti, 2015) suggesting that this is an important consideration for future research. For similar reasons, studies conducted with staff were also excluded. The well-being of staff is imperative to enhancing the care of patients receiving palliative care. Therefore, it would be useful to explore meaning-focused interventions for staff; a number of such studies are published in this area, e.g. Fillion, Dupuid, Tremblay, De Grace, Breitbart (2006), Morita et al. (2014) and Vachon, Fillion, Achille, Duval, and Leung (2011).

Qualitative evidence was also excluded from the review for reasons of focus. However, this is also an important area in which further research would lead to a better understanding of the effects and experiences of receiving meaning-focused interventions, for both staff (Leung et al., 2012) and for patients (Hall et al., 2013). This need is highlighted by studies such as Chochinov et al. (2011) and Hall et al. (2011), both examining *Dignity Therapy*, where there were no statistically significant improvements on a number of measures of quality of life and meaning but where participants reported benefits of taking part. Qualitative research will help to increase our understanding of meaning by developing operational definitions and to understand the mechanisms of meaning-focused interventions in palliative care. So both qualitative research and mixed method approaches are recommended.

4.4 Clinical implications

The findings of this review suggest that meaning is an important construct for people receiving palliative care and there is growing evidence that interventions focussed on this can alleviate distress. Opportunities for patients to discuss existential themes such as meaning of life, meaning of their illness and experiences, should be provided. This could be on a more informal level, in everyday conversations with healthcare providers or in formalised meaning-focused interventions. Both of these require that staff receive training, alongside forums for discussion such as peer led and clinical supervision. Interventions should be developed with both individual and group formats considered. Outcome measures should be used which explicitly measure meaning to ensure validity and reliability of findings from any future research. The stage of an individual's disease should be taken into consideration, for example brief therapies such as *Dignity Therapy* would more appropriate for a patient with a prognosis of less than six months than *Supportive Expressive Group / Individual Therapy*, which whilst useful is intended to last for a least year. Ethically conducted research in palliative care is imperative, and patient involvement in all stages of research, is needed to improve care for those facing the end of life.

4.5 Recommendations and future research

Future research should explore meaning in palliative care through the development and validation of clinically relevant measures of meaning for both patients receiving palliative care and staff; to this end quantitative and qualitative methodologies are recommended. The inclusion of measures which explicitly measure meaning, should be included in any future meaning-focused intervention research. Attrition, and other methodological issues present in the field of palliative care research, should be addressed to ensure high quality of research in this field. It is recommended that participants are recruited

from a variety of settings, employing strategies so that the intervention can commence as close to point of recruitment as feasibly possible to help negate the physical health complications that can impede participation (i.e. deterioration, treatment regime changes or death). Furthermore, calculating sample sizes to negate the effects of high attrition rates and use of a widely agreed definition of palliative care (i.e. the differences between this and end-of-life) would facilitate rigour and standardisation across palliative care research, increasing the generalisability and replicability of results. Finally, although omitted due to the scope of this review, exploration of patients' lived experience of completing meaning-focused interventions using qualitative methodologies is integral to developing a better understanding of these interventions. The impact of meaning-focused interventions for family members and staff working in palliative care settings, is an important consideration for future research.

4.6 Conclusion

This review attempted to define a wide variety of meaning-focused interventions as a *group* of interventions within palliative care. A number of meaning-focused interventions have been considered and despite the limitations of the review and studies within it, the evidence suggests that this type of intervention can increase meaning and improve quality of life. These are promising results, ones which are deserving of further research to explore, define, and improve care for those within palliative care settings.

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Chapter Two

Looking After a Dying Loved One; A Male Experience

Word count: 9139

Abstract

Background: Caring for someone close who is dying, such as a spouse, is an emotive experience; however there is little research in caregiving for a spouse at the end of life and of men's experiences specifically. Existing literature suggests that men who are providing care are less likely to seek help than women, especially when it comes to psychological and emotional support for themselves (Fromme et al, 2005; Ussher & Sandoval, 2008).

Objective: To explore the lived experiences of men caring for a dying loved one and their relationship to help-seeking for themselves.

Methods: Eight semi-structured interviews were conducted with men caring for their partner who was receiving palliative care. Interviews were transcribed verbatim and Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was conducted.

Results: Three super-ordinate themes emerged from the data, 'Illness Questions Everything'; 'Constructing the Caring Role' and 'Help-Seeking at the Limit'. The arrival of a terminal illness is traumatic and whilst it deepens relationships it also creates distance. The carer role is conflicting and much sense-making is done, resulting in the carer role being constructed as a source of purpose or meaning. Finally the idea of help-seeking for oneself during this time is seen as incompatible, unmanageable and can only be considered if constructed as a last resort.

Keywords: male carer, palliative care, spouse, help-seeking, qualitative

1.0 Introduction

1.1 Informal carers

A census by Carers UK in 2011 outlined that there are currently six million adults, including friends, family and relatives, providing unpaid care in the United Kingdom (excluding Scotland; Buckner & Yeandle, 2011). It is estimated that the care provided by informal carers averages 100 hours per week/per person and is worth £119 billion per year (Beesley, 2006; Buckner & Yeandle, 2011). Duties provided by informal carers are vast including personal care, giving medication, managing paper work and financial matters, shopping, laundry and meal preparation (Maher & Green, 2002).

The majority of existing literature concerned with caring, describes caring for individuals with a dementia (a specific health condition with a unique trajectory) therefore it is important to note that the majority of the studies discussed below describe caring for individuals with a dementia. A number of detrimental psychological and physical health consequences associated with providing care have been outlined (Stroebe, Schut, & Stroebe, 2007; Vitaliano, Zhang, & Scanlan, 2003) along with higher mortality rates among carers compared to non-caregivers (Schulz & Beach, 1999). A meta-analysis by Pinquart and Sörensen (2003) found that caregivers, when compared to non-caregivers, scored higher on measures of depression and perceived stress, and reported reduced general well-being (Pinquart & Sörensen, 2003). A further meta-analysis by the same authors (Pinquart & Sörensen, 2007) found that the length of time in the carer role, living with the care recipient, a higher age, and lower levels of social support were related to poorer physical health outcomes for carers.

The picture painted of informal caring is often a bleak one, with an emphasis on the detrimental effects on the carer, as described above. However, as advocated by Roth,

Fredman and Haley (2015) a more "balanced and updated portrayal of health effects of caregiving" (p. 309) should be explored, which accounts for some of the more positive effects of the carer role. For example, a systematic review of informal carers looking after individuals following a stroke found that they reported strengthened relationships, increased self-esteem, and a greater feeling of being appreciated (Mackenzie & Greenwood, 2012). Other benefits reported in the literature include a sense of personal growth (Kang et al., 2013) reprioritisation of values (Li & Loke, 2013) and becoming more empathic towards others (Kim, Schulz, & Carver, 2007).

1.2 Spousal informal carers

Given the already demanding role of caregiving, providing care for a spouse brings a unique experience and set of challenges. The evidence is mixed regarding the nature of the caregiver relationship and its effects on the level of burden experienced by carers (Kim, Chang, Rose, & Kim, 2012). For example, Molyneux (2008) found that burden levels were highest in individuals providing care for spouses when compared to adult child-carers. In contrast, Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch and Lopez-Pousa (2010) found that burden was highest in adult child-carers, followed by spouse carers. Ankri, Andrieu, Beufillis Grand and Henrard (2005) found no significant differences of burden related to relationship with care recipient.

1.3 Male informal carers

The carer role is often constructed as a gendered role in which women are at the forefront. However, men make up 42% of the informal carer population (Carers UK, 2012). Research on male informal carers is limited, often using male participant groups as a comparison for female participants, rather than a group of interest in their own right (Ussher & Sandoval, 2008). Furthermore, Pinquart and Sörensens' (2006) meta-analysis of 229

studies looking at gender differences in caregiver variables found that existing literature provides contradictory evidence of gender differences in experience and impact of caregiving.

Ussher and Sandoval's (2008) mixed method study aimed to address this by examining gender differences in the construction and positioning of caregiving through one-to-one open ended narrative interviews. The quantitative results outlined that women caregivers reported significantly higher levels of anxiety and depression than men. From the qualitative interviews of the same study (Ussher & Sandoval, 2008), clear gender differences were drawn in the ways in which the caring role was positioned. Women gave accounts of being positioned as "all-encompassing expert carers" leading to "over-responsibility" and "self-sacrifice"; and men described the role of caregiving as a "competency task" with positive consequences of self-mastery and the negative consequence of "difficulties in dealing with the emotional side of cancer". These gender positions suggest men take a 'rational' stance to the role, considering any sign of distress or help-seeking as "shameful" or "unmanly". This therefore places men at risk of not seeking help and of being overlooked by services, for example, because women are more likely to express distress and thus more likely to receive help.

1.4 Informal care-giving in palliative care

Caring for someone close who is dying, such as a spouse, is an emotive experience; however there is little research into the experience of caregiving for a partner at the end of life. Reviews of both quantitative (Stajduhar et al., 2010) and qualitative (Funk et al., 2010) research on home based palliative caregiving outline an over reliance on descriptive analysis and a lack of clear theoretical framework application.

1.5 Informal carers help-seeking

An area of interest when considering carers, is how they access support services *for themselves* (i.e. how they 'help-seek' whilst providing care for another person).

1.5.1 Gender differences in help-seeking

Existing literature demonstrates that men are more likely to be reluctant to seek help, especially when it comes to psychological and emotional support for themselves (Fromme et al., 2005; Ussher & Sandoval, 2008). O'Brien, Hunt, and Hart's (2005) qualitative study explored men's experiences of health help-seeking from general practitioners (GPs) and how they made sense of this in relation to their constructions of masculinity. The following themes were derived: 'men's unwillingness to consult their GP with 'minor' complaints'; 'shift from minimising to responding'; 'consulting the GP about depression' (which appeared to be a great threat to masculinity); and 'exceptions to the norm' (i.e. there were accounts from some men of a greater willingness to consult with staff). The results highlighted a resistance to help-seeking, as such behaviour appeared to be in conflict with ideas of masculinity. 'Putting up' with pain was seen as a strength and remaining 'strong and silent' was particularly relevant in relation to psychological and emotional difficulties. Grande et al. (2009) conducted a review of support provided to all informal carers whilst caring for a dying loved one and found that there is a gap in the literature regarding men's experiences and needs whilst in this role.

In summary, a clear gap in the research literature has been identified in terms of the examination of help-seeking behaviours in men providing care for their dying loved one (Dahlberg, Demack, & Bambra, 2007; Grande et al., 2009; Ussher & Sandoval, 2008). There is also a need for in-depth analysis of men's experiences with a clear methodological and theoretical stance (Funk et al., 2010).

1.6 Aim of the study

The aim of the study is to explore men's experience of caring for a spouse receiving palliative care, paying particular attention to their experience of seeking help *for themselves* during this time.

1.7 Key definitions

1.7.1 Male carer

The term *male carer* refers to men who were, at the time of the research, in a spousal relationship with their 'loved one' who was, at the time of the research, receiving palliative care. No measure was taken of the care the men provided (i.e. in terms of duties or amount of hours spent delivering the care).

1.7.2 'Loved one'

The term 'loved one' refers to an adult (aged 18 and over) receiving palliative care, who is in a significant spousal relationship with the participant (i.e. married, cohabiting, common law partner or civil partnership). As the term spouse was considered a formal term it was used whilst discussing the literature and then following the participants own language, the term 'partner' has been used to describe all relationship statuses, within the remainder of the paper.

1.7.3 Palliative care

For the purpose of the research, palliative care was operationalised as any contact with a palliative care team. The understanding of palliative care was taken from the World Health Organisation (WHO; 2002) definition:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2002)

2.0 Methodology

2.1 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is increasingly used within health research (Brocki & Wearden, 2006). IPA takes both a phenomenological and double hermeneutic stance, as it is concerned with the participants' *lived experience* and how they, and the researcher, interpret or make sense of their experience (Smith & Osborn, 2003; Smith, Flowers, & Larkin, 2009). It is idiographic as it focuses on the detail of the individual whilst paying attention to social constructionist ideas of how realities and experiences are constructed and informed. This is important for the current study due to the influences of society on the construction of identities in roles such as caring, gender, and seeking help.

Furthermore, IPA allows for information and an understanding regarding the lived experiences of individuals and how they make sense of them. By gaining this understanding of the underrepresented participant group and their experiences of help-seeking, it is hoped that this will then support professionals and services to offer and deliver the best care for those caring for a dying loved one.

2.1.1 Why not a different qualitative method?

IPA overlaps with other qualitative methods, for example, Grounded Theory (GT; Barney, Glaser & Strauss, 1967). The aim of GT is to create a conceptual explanation based on a larger sample where "individual accounts can be drawn out to explain to the resultant theoretical claim" (Smith et al., 2009, p. 202). IPA works with a small number of participants, paying attention to "convergence and divergence" between participants in order to illuminate the lived experience for a particular focus of study (Smith et al., 2009, p. 202).

The detailed case-by-case analysis of data within the IPA approach provides in-depth exploration of the lived experiences, perceptions and understandings of participants rather

than making more general claims about a population. It is through this idiographic process that the data can move "closer to the universal" (Warnock, 1987 as cited by Smith, 2004 p. 42). Considering the limited research in this area to date therefore, IPA appears to be the most suitable choice of analysis.

2.2 Design

Participants were recruited via purposive sampling in order to produce a small and homogenous sample in line with IPA methodology (Smith & Osborn, 2003). Semi-structured interviews were conducted, audio-recorded, transcribed verbatim, and then analysed using IPA (Smith et al. 2009).

2.2.1 Recruitment

Participants were recruited via local hospices, community palliative care teams, and outpatient day services Healthcare professionals across the recruitment settings acted as 'gatekeepers', identifying potential participants, in line with the study's eligibility criteria, during routine contact. They introduced the research, and provided a leaflet containing an overview (see Appendix, to interested potential participants. Interested participants then gave permission for the researcher to contact them directly to discuss the research further and arrange interviews if appropriate.

2.2.2 Eligibility criteria

Participants were included if they were male, over the age of 18 and currently caring for a partner receiving palliative care. The relationship was deemed to be significant if it was of two years or longer. Partners with dementia were excluded due to the different illness trajectory to those routinely cared for within palliative care in order to maintain homogeneity. Participants were required to be English speaking due to the nature of IPA relying on the

participants' use of language to provide a rich account of their experiences, which may have been lost if an interpreter was required.

2.2.3 The sample

A total of eight participants were recruited and interviewed, which is in line with the recommended sample for an IPA research study (Smith et al., 2003). Although the study did not exclusively recruit men caring for a partner with cancer, all but one of the participant's partners had cancer; with one partner being treated for Motor Neurone Disease. The majority of participants were married to their partner and were in heterosexual relationships. One participant was in a Civil Partnership with his same-sex partner. Pseudonyms were created for the participants and their partners in order to protect confidentiality and anonymity (See Table 8).

Table 8

Participant information

Participant / Age range	Partner / Relationship status / Duration	Partner's illness	Hours spent caring per week (approx.)
Dave / 40 – 49 yrs	Julie / Married / 10 years	Cancer	50hrs
Michael / 50 – 65 yrs	Sue / Married / 40 years	Cancer	50hrs
George / 50 – 65 yrs	Andrew / Civil Partnership / 30 years relationship in total	Cancer	100hrs
John / 50 – 65 yrs	Sandra / Married / 8 years	Cancer	100hrs
Donald / 50 – 65 yrs	Joyce / Married / 40 years	Motor Neurone Disease	20hrs
Bruce / 50 – 65 yrs	Jane / Long-term relationship / 14 years	Cancer	40hrs
Carl / 75+ yrs	Rose / Married / 60 years	Cancer	50hrs
Philip / 50 – 65 yrs	Beth / Married / 33 years	Cancer	100hrs

2.3 Ethical considerations

Ethical approval was granted by both NHS Research Ethical Committee [redacted] NHS Research and Development (see Appendix E), along with approval from the local hospice research and development departments. The research was logged with and sponsored by the University of Birmingham's Science, Technology, Engineering and Mathematics Ethical Review Committee. Standard research procedures were followed in order to ensure ethicality of the research; informed consent was sought, participants were made aware of their right to withdraw at any point during the research including after the interview had taken place. Participants were provided with a participant information sheet prior to taking part in the study; they were required to complete a consent form in order to participate, and were given a debrief sheet following the interview (see Appendices F, G and H respectively). Participants were given a £10 high street gift card as a gesture of gratitude for their participation. Data were stored in password protected files and all personal information were stored separately from the data. Confidentiality and anonymity was ensured by the use of pseudonyms for participants and their partners for all data. Participants were made aware and consented to quotes from their transcripts being used in the research thesis (and that this would be a semi-public document in line with University of Birmingham regulations for the storage of ClinPsyD theses), with a view to publish the findings in a scientific journal (see Appendix I for submission guidance). Participant distress was monitored by the researcher throughout the research interviews and although many of the participants became upset, none of the participants became so distressed that neither they nor the researcher felt the need to stop the interview. Gatekeepers were made aware when participants were taking part in the research and at the request of one of the participants the researcher informed a gatekeeper that he would like to discuss the possibility of access to psychological support.

2.4 Data collection

2.4.1 Setting

Research interviews were arranged at a time and place convenient for each participant and took place at the local hospice or in the participants' home. Where home visits took place, confidentiality and privacy were taken into account and interviews were arranged when their partner was out of the house, or in a room where they would not be able to overhear the interview.

2.4.2 Semi-structured interviews

Each interview lasted between 60 to 90 minutes and one interview took place per participant. Each interview followed the same semi-structured interview schedule (see Appendix J). The interview schedule was developed from the research questions and a review of the literature. The semi-structured interview enabled the researcher to develop rapport with participants through the flexible format, allowing questions to be reflexive and informed by the interaction and the topic area. Interviews were audio recorded, anonymised and transcribed verbatim. Participants were sent a copy of their interview transcript to check for accuracy and to consent to parts of their interview being used as anonymised verbatim quotes in the final report.

2.5 Data analysis

The analysis of the data followed guidance as described by Smith et al. (2009) and Larkin and Thompson (2011). The transcripts were read and re-read, including a re-reading whilst playing the audio-recording in order to engage at an intersubjective level with the interviews. Initial noting was completed, paying attention to ideas, feelings and observations. The transcripts were re-read and a detailed line-by-line analysis of 'objects of concern' was conducted; the participant's meaning or stance to the objects were noted down to develop

emerging themes. This was repeated for each transcript before the emerging themes were then clustered and ordered into ordinate and super-ordinate themes. Transcript excerpts (corresponding to emergent themes) where then given a summary title or explanation and organised under themes in a word document (see Appendix K). Transcripts were the re-read for a final time to check against the internal validity of the themes and supporting excerpts, and to see if the interpreted themes 'fitted' with the participants story at a wide and at an idiosyncratic level.

2.5.1 Validity and quality

Yardley's (2000) guidelines for assessing the validity and quality of qualitative work were followed. The guidelines set out four principles and how to apply these to IPA studies. The principles are; (1) sensitivity to context (2) commitment and rigour (3) transparency and coherence and (4) impact and importance.

Sensitivity to context

Sensitivity to the context of the research was established by becoming familiar with existing literature. In staying close to the participants' perspectives, the semi-structured design of the interviews allowed them maximum opportunity to tell their own story and hold their place as experts of their lived experience. Also the in-depth analysis of the data and using verbatim quotes to support results allows the voice of the participant to be heard and for interpretations to be checked.

Commitment and rigour

In-depth analysis was conducted (see previous section) and triangulation was achieved via peer support from a trainee also conducting IPA research, regular meetings with supervisors (both of whom were working clinically in palliative care and both with experience of conducting or supervising IPA research). Interpretations were checked

throughout each stage of the analysis and final themes (and the supporting data) were checked and agreed with supervisors and the peer. A reflective journal was also kept, see Appendix L for an extract.

Transparency and coherence

The description of the analysis process used for the study, use of verbatim quotes to support themes and the inclusion of an audit trail covering all the themes allows for the study to be considered transparent and coherent.

Impact and importance

In order to provide information for which the clinical relevance and usefulness of the study can be assessed, the discussion section of the study includes a sub-section discussing the study's clinical applications.

Reflexivity

As suggested by Shaw (2010), to elucidate the research processes and in order to demonstrate the reflexive approach which has been adopted throughout the research project, a reflexive account has been included. Alongside this the researcher's position to the study and discussion of context have been included in the subsequent sections. The reflexive account is written in first person prose as a more natural narrative style fitting with the aim of exploring the researcher and their experiences in relation to the research.

I am a 30 year old White British female trainee clinical psychologist with a specialist interest in palliative care. I am currently in a long-term relationship with my partner; we are both healthy and with no health conditions, we are looking forward to a long future together. The research, and in particular the research interviews, put me in touch with my feelings, hopes and desires for both my own and my future with my partner. Being witness to the experiences of the participants who have had their lives turned upside down by the arrival of

terminal illness and whom were losing their loved ones to diseases which would not only take their wives and partners away, but also their hopes for future. This universal experience of love and fear, death and living, allowed for intersubjective moments within the interviews. At times this made it hard to 'stick to the schedule' when I was with them, in that moment of sharing, not just as a researcher or clinical psychologist in training but as a *person*. I believe that these very real moments of connection to the participants, their stories and the research project helped me to commit to the project during a very tough time in my personal life. In early December 2014 (prior to analysis of the data) I unexpectedly lost a young and immediate family member. I can only begin to imagine how this has affected my relationship with the research; maybe this is something that will be uncovered over time. However for me, at the time of writing, my personal experience of loss (and all that goes with it) only heightened my sense of duty to do 'a good job' of this research project. There were many differences within our experiences of losing someone who we love dearly; these allowed a sense of separation, making room for me to take the first tentative steps towards engaging with the data. Whilst hard at times, it quickly became apparent that I was able to complete the research project. The research provided a sense of purpose, something tangible and meaningful that I *could* do and that it might make a difference for future men in similar circumstances to the men who participated in the research. Whilst my own experience of loss informed my feelings towards the research it was the participants and *their* data which led the interpretations and results of the research.

3.0 Results

3.1 An overview

Three super-ordinate themes which emerged from the data, and Table 9 illustrates these. What follows is a narrative account, exploring super-ordinate and ordinate level themes alongside relevant quotes from participants[5]. Following guidance suggested in Elliott et al (1999) the analysis describes wider general idea across participants as we all the more idiosyncratic variations within participants.

Table 9
Superordinate and subthemes

Super-Ordinate Theme	Sub-Theme	Contributors
Illness Questions Everything	*Horror of the illness*	Everyone
	Deepened our relationship	Everyone (apart from Donald)
	Distance in our relationship	Everyone (apart from Philip)
Constructing the Caring Role	*I am not a 'carer'*	Everyone
	You are not a 'carer'	Everyone (apart from Carl)
	Caring as a purpose / meaning	Everyone
Help-Seeking at the Limit	*Incompatible*	Everyone
	Being a 'man'	Everyone
	As a last resort	Everyone (apart from Donald & Carl)

3.2 Super-Ordinate Theme: Illness Questions Everything

Their partner's illness and participants' relationships with their partners were predominant in the descriptions of their experiences. They emerged as relational themes, providing context in which the participants understood their experiences. Throughout the interviews participants would come back to the illness and their relationships almost as anchor points through which they were telling their stories. As their worlds were disrupted by the arrival of existential uncertainty brought by the arrival of terminal illness, the only things

[5] '…' indicates a pause in the flow of a participant's speech and [text] is information added to aid clarity for the reader.

they 'knew' to be certain anymore were the presence of the illness, and their relationship with their partner, everything else was questioned. This is illustrated in Bruce's reflection on the impact of the arrival his wife's terminal illness:

> *"and that literally changed in the in….a blink of an eye and I felt instead of being, looking forward [in my relationship] the only thing I was doing was looking backwards thinking well actually that was … I know it sounds … that was actually a better time because it was actually you know, it was well, you think I I can't see this ever getting any better [the illness], it's not going to get any better so…so that's what I mean by change it was a dramatic hundred and eighty degree change from front looking forward to thinking …" (Bruce, line 697)*

3.2.1 Horror of the illness

The way in which participants' talked about how their partner became ill and the arrival of the illness in both their partners' lives and their own, depicted a great sense of horror. The severity of the impact of the illness is reflected in Bruce's description:

> *"with this I feel like I've fallen of a cliff … I haven't got staircase going down this is going to happen this is going to happen and this is going to happen, it's just boom straight down and it and it I don't know it almost seems to be me the faster I'm digging to get out the deeper I'm going I just can't get out if there's nothing I can do to control it" (Bruce, line 1550)*

The ways in which participants shared how their partners became ill reflect that the re-telling is horror or trauma that needs to be managed. For example Philip, Donald, Carl, Bruce and Michael re-told the *whole* story, in a sequential manner and in descriptive detail, explaining stories within the story. This suggests that the story is too overwhelming due to its traumatic nature. This can be interpreted from the way in which Philip struggled to find or say the words to begin to describe his wife becoming ill "Er and erm, basically what's happened it erm obviously has her condition has deteriorated erm" (line 60). And in the way in which Michael suggested the end of the illness story, but then shared more about his wife's (Sue) terrible symptoms and struggles since the diagnosis of cancer:

"so that is where we are, up-to-date, of course there are things in between, ups and downs, fell upstairs and broke her pelvis, fell upstairs broke her arm, damaged her pelvis again, and a broken hip erm and a lot of bruises and thing because of the sort of medication she is on she's got paper thin skin, she only has to touch herself and it will break through and bleed and she's also in hospitals you get these embolisms lumps on her lungs so she has daily injections to keep her blood very thin but because her blood is so thin the slightest cut bleeds, so I have to do the injection coz you can't see and that's the other thing god, over the last few months she has developed cataracts, really bad cataracts that come on very very quickly, she's due to have an operation we are just waiting for the date on one eye but that has complicated things as she can't see which means she can't eat properly, you know her food goes all over the place and it's really, that's distressing ... what time she does have left it not a very good quality because she can't read or see or anything like that so ... so gradually I s'pose there has been a deterioration, very slow deterioration" (Michael, line 87)

The way in which Michael shared this was comparable with panic and suggests that the illness, and all that goes with it (i.e. symptoms, treatment, deterioration and distress), is relentless, allowing for no-one to stop and catch their breath, including Michael as he spoke and the researcher as they transcribed it.

Dave, John and George gave very brief overviews, punctuated with abrupt endings, reflected by the example of John (who lost his first wife to the same cancer as his current wife, Sandra) who, when describing Sandra's cancer, said "...usual thing...lump...checked into mastectomy and erm...yeah, it's gone on from there really..." (John, line 42). Ending the description of Sandra's cancer in this way illustrates the pain he feels, and how for him the trauma of re-telling is overwhelming and cannot be described. This is compounded by the fact he is going through this *again*.

The language used by all the participants portrayed a sense of trauma indicating this is how the participants construct the arrival and presence of the illness. For example the use of descriptive words shared a sense of the visceral nature of their experiences. This can be interpreted from Bruce's vivid description of his partner's (Jane) condition after her chemotherapy treatment:

"she would literally, and I know it sounds like an analogy but she would literary be crawling out, she would have that thing on her face, she'd have to have support of either me or of her sister, it would be me, sister and her trying to support her, trying to get her into the car, you couldn't have anything harsh, couldn't have anything cold, couldn't feel her hands then she'd be sick you know" (Bruce, line 516)

3.2.2 Deepened our relationship

The presence of a life changing events such as terminal illness, can bring into question existential concerns such a re-evaluating life, identity and relationships. Having a deeper appreciation for loved ones and feeling a deepening bond was reflected in Philip's words:

"*We've got so much closer … it's errr … it's a peculiar irony, we've had our ups and downs, as everybody does in marriage erm and sometimes it's been very difficult. But since Beth has been diagnosed now, apart from one small little tiff that probably lasted for a few hours, we've errr … and it's wonderful, it really is … it's wonderful and er that is, that is so precious. That is so precious. Honestly" (Philip, line 625)*

The nature of receiving a terminal prognosis allows for individuals to re-evaluate their relationships as they become aware of what they are going to lose. The presence of the illness and terminal prognosis provided the context within which relationships were viewed to be stronger, reflected in Michael's words:

"obviously the … relationship that Sue and I have is probably stronger … erm … not probably is definitely stronger erm … and we value, I value the time I have with her when we have conversations or when we have been able to go on holiday those sorts of things …"(Michael, line 559)

The deepening of relationship was understood in the context of the shrinking of world for George and his partner Andrew "well it has deepened the relationship with me and Andrew as you would expect because we depend on each other so much" (George, line 378).

For many there was also the desire to spend as much time as possible with their partners "I want to hang onto every minute possible. Every minute possible" (Carl, line 60).

At this point Carl became upset whilst speaking, sharing the magnitude of the despair felt having fully understood what it is he will be missing once his wife Rose passes away.

3.2.3 Distance in our relationship

Whilst participants talked about growing towards each other in their relationships there was also a sense of the illness creating distance between them and their partners. George spoke of how Andrew (who at the time of the interview was nearing the end of life) was moving away from him in a more purposive way:

> *"so we both know Andrew is going to go somewhere I am not going to go … and that means that we are both sort of standing off each now? You know … I've been told that it happens that Andrew's focusing on his journey because it is compulsive for him and I am frightened and I am you know … and I have to stay in this world I can't go with him so there is this separation … people talk about a junction coming up … you've been together for years you know you've been together for years and years and years suddenly one of you have to turn back so there is a degree of not wanting to say we don't say it to each other but it's there there is an unwritten saying a slow saying of goodbye …" (George, line 417)*

George gives voice to his fears for the future without Andrew, the ultimate separation is a glimpse into the sense of rejection, abandonment and pain felt by distance that was already happening within their relationship.

Differences in approaches, or proximity to 'acceptance' of the presence of a terminal illness also caused friction and thus distance within relationships. This is reflected in Carl's words "Rose has accepted this much easier than I have. Her view is, 'I've just got to go with it'. I have, in principle, to agree with her, but it's weird" (Carl, line 286).

Feelings of frustration, worries and fears also created distance within relationships as sharing these feelings was not considered to be a reciprocal process by the participants, leaving them feeling isolated. That is, whilst participants felt that it was acceptable for their partners to share their frustrations and fears, it did not feel 'ok' for them to share their feelings with their partner. The participants felt guilt and shame for even having such feelings

of frustration and fear. This is reflected in Donald's experience of his wife's (Joyce) anger towards him. Joyce's illness (motor neurone disease) left her without the ability to communicate, other than grunting. The inability to share thoughts and intersubjective moments with his wife created a sense of distance in the relationship, and the discomfort of Donald voicing his frustrations is interpreted from Donald's use of explaining his pain and frustration as being located within or projected onto visiting friends:

> "*Some people only stay 10 minutes. Some will stay for an hour. Most folks don't last much longer, because it's so difficult. You might as well talk to the television. It's switched off, you won't get any answers. I'm sure she'd just like to see you, because when you go, she will do a lot of grunting and I think she's trying to talk to you, but you've no idea what she's trying to tell you."(Donald, line 1098)*

Loss of sexual intimacy was also experienced in the context of a distance within the relationship created by the presence of a terminal illness. This is reflected in the way George describes the loss within his relationship with Andrew:

> *"we've lost that ability to be tender with each other you know? … erm … that is in part because Andrew no longer sees himself as sexual person … but also I think because we are now both conscious that he is dying … a distance become between us … separation is already starting to happen you know?" (George, line 380)*

3.3 Super-Ordinate Theme: Construction of the Caring Role

This super-ordinate theme reflects the sense-making by participants that occurred through-out the interviews. As the participants were making sense of their care role, the data suggests they constructed this role in the context of perceived societal gendered views of the carer role and its relationship to masculinity, their meaning of their relationship with their partner, and how these influence their experience of the role. The way in which the levels of influence (i.e. societal, personal) and the purpose or meaning they make whilst trying to make sense of what it going on, is reflected in the following extract from Bruce:

I think male carers are called because they … I don't mean this to sound sexist in anyway, there's a belief be it wrongly or rightly that women are carers, that they have a caring nature, whereas men that to some some extent even now that caring nature has to be diminished, and when you're looked on as a carer to some extent by the men that work/school you know but then they think well perhaps you're not you know what you should be doing and all that sort of stuff … (Bruce, line 1358)

3.3.1 I am not a 'carer'

Many of the men did not identify easily with being carers; the participants' doubt in their abilities to cope and to fulfil the role also acted to distance themselves from assimilating with the carer role. Other participants, for example Donald, who was previously heavily involved in his wife's care, rejected the idea he was caring for Joyce:

"Well, at the present I don't really, in that I do visit her every day, but she's actually in the hospice. They do everything. I just, if I go there and she starts to groan because she can no longer speak, I just press the button for her and get somebody to come."(Donald, line 97)

An important aspect of the role for all the men was the sense they made of their relationship with their partner in relation to the care role. Many of the participants did not view themselves as a carer because this appeared to be in conflict with their view of what it meant to be in a partnership / marriage with their loved one. This can be interpreted from the following extract:

"I, I real- yeah, I don't think about that only in that I've...yeah, given up work totally to to care for Sandra...er, the thought of being a male carer or whatever hasn't, didn't, hasn't come into the equation really... it's just there as a name... ... you know I would be with payment or no payment I mean I was here before and I shall be here afterwards...so that that isn't part of it really.. I'm husband, caring for my wife basically..." (John, line 664).

John goes on to share his view by comparing his commitment to his wife (Sandra) to the vows of marriage "you know as the vows say, for better or worse really you're not, no you're [the researcher] not engaged or married or, but as the vows say, for better or worse really isn't it..." (John, line 1435). Caring for their partners as an act of love was at the centre of all the participants' construction of the carer role: "you know Julie is ill she is your partner

she is someone you love so … you … you know… you've got to look after your partner as best you can …" (Dave, line 200). Carl shares his understanding of the role is part of reciprocal care and that there are 'turns taken' -the relationships shifts to accommodate this changing needs:

> *"Life in my opinion, and married life in my opinion, is always and should always be a 50/50 situation. In a situation like this, like we're in now, I would look on it as more of an 80/20, maybe a wee bit more, I don't know. At least 80/20" (Carl, line 457)*

3.3.2 You are not a 'carer'

The participants' experiences of caring for their partners are within a context in which men are not seen as carers, where care is not seen as a 'male' trait, leaving them feeling overlooked and 'invisible' as a group, something that George spoke passionately about:

> *"that is a big thing for me you know you know this whole way in which er … the caring community you know recognise and accept male love and that can be male love between two sexual partners but it could be brothers or any other kind of … uh uh caring that goes on you know … as there are lots and lots of male carers out there but they are invisible" (George, line 172)*

More explicitly, the participants' experiences depicted a sense of feeling overlooked in their individual experiences. This was entrenched in their day-to-day experience as reflected by George: *"they haven't necessarily looked behind the people who've come in … at the guy standing behind and actually seen you as a potential carer" (George, line 210).* He comes back to this point later on in his interview, indicating the importance of this, *"we were just there just to bring them something to clinic … take them back again … and sit there holding hands there was nothing there …" (George, line 653).*

This sense of being overlooked was also related to relationship status, with the participants who are in long-term relationship / civil partnership (but not married) feeling as though they are not taken as seriously as if they had been married and living with their

partner. This is reflected in Bruce's experience of caring for Jane; their caring responsibilities (prior to the illness) prevented them from living together:

> *"the thing and I don't mean to sound childi- if I was her husband I think that might have been slightly different but because I'm not I know I don't live with her supposedly still live with mum umm even though I don't seem to be there any time ummm ... dont know you don't get it's not respect I don't want respect I mean umm" (Bruce, line 1621)*

Bruce then goes on to talk about "the big hole" created in his life by the illness, showing the impact of feeling overlooked and how it is constructed as part of the wider despair he is feeling.

When there is recognition of their role and achievements as a carer this is seen as an 'exception to the rule'. This is reflected in the following two extracts: "it's quite interesting, some of the nurses at the hospice, they've said to me that there's many a man who wouldn't come the way you do" (Donald, line 709) and "no … no I've surprised myself let alone surprising everybody else" (Michael, line 195).

3.3.3 Caring as a purpose and meaning

The caring duties, tasks and role provided a source of purpose and meaning for participants amidst the chaos of the illness, of which George talks explicitly: "yeah yeah its recognition that this role is there and it's a deeply meaningful to me …. it's part of my life and its important part of my life …" (George, line 198).

For some it provided a purpose for example Carl gained a sense of 'ownership' of the duties within the house: "housework is my responsibility. Washing machine is my responsibility. Shopping, if Rose isn't fit enough to go to Morrison's, is my responsibility" (Carl, line 453). Whereas Michael made sense of the role and the purpose it gave, later on his interview, as a replacement of his job which he had to give up in order to care for his wife:

"now I have said so many times 'I got do it coz it's my responsibility' I think it is probably something … I need a purpose, I need a job … I miss my job so I need to have something and caring for Sue has become my job … so I can't do get somebody else to do my job for me …" (Michael, line 482)

The caring role provided a sense of achievement and allowed some participants to feel pride in completing and excelling in the tasks that were challenging, demanding and often new to them "because before when we first started this the toileting business it was a big thing whether I could cope with it or not but it's not a big thing at all now at night …" (Michael, line 509). Or the seemingly 'smaller things':

"she has a microwave she never uses it so she's even doing like toast on the grill under the gas cooker and she and she she never even had a toaster so I said well I went out and brought a toaster I know that seems a small thing but that was like a big thing, erm but even now the house is a mess but I managed to do a bit of it" (Bruce, line 350).

For others, the meaning they took was that the role allowed them to complete an act of atonement, the sense that 'it is my turn now'. The illness questioning everything meant they reflected on their relationships and often taking over the duties of the house was met as a revelation for how much the partners had previously done. This is reflected from Michael's extract:

"… so when we had a son and I changed his nappy once … I'm thoroughly ashamed of this but I could not do it, I couldn't do it …. and Sue did it and so I didn't do it at all … so I am not used to doing these sort of things but because you have got to do it, you do it … it's not something I look forward to or anything like but you've got to do it …" (Michael, line 453)

The carer role duties provided purpose as a distraction from pain of reality: "…I'm finding that I can't sit still. I've got to be doing something all the time and I'm finding it very handy because it's a useful distraction" (Philip, line 226). Philip further reflects and goes on to say that when he was bed-bound due to his own health issues: "that was probably one of the worst times because of the fact that it meant that I had to sit there, start thinking about

things" (Philip, line 264). John spoke about the role in terms of aiding his day-to-day 'survival': "but you know that, I did it yesterday, see and that job's done...and then you think ah well what I'll clean the car today and an, you've got the structure really... I don't think I'd survive without that..." (John, line 1177).

The carer role was constructed as fulfilment of their duties as a partner, and so it connected with them as individuals, giving meaning to experiences which were otherwise overwhelmingly distressing. This can be interpreted from the following two extracts: "… if I make a promise I'll keep it regardless if I am not feeling well I'll keep my promise (Dave, line 745) and "there is no one else could do it … and I've got lots and lots of help but nobody else could take that responsibly" (Michael, line 181)

3.4 Super-Ordinate Theme: Help-Seeking at the Limit

This super-ordinate theme encapsulates the participants' view of seeking help whilst 'at the limit' that is, caring for their terminally ill partner. Seeking help for themselves was perceived as a threatening idea, not only to themselves, as men and as husbands / partners but something that was incompatible with their experiences of caring for their partner whilst at the limit of 'holding it together'.

3.4.1 Incompatible

Seeking help appeared to be 'incompatible' with *everything* for the participants; their experience caring for their dying partners, the carer role, their relationship with their partner, the fact their partners are terminally ill and them as men. The data suggests that it is this incompatibility which prevents men from considering that there could be support for them, that they can access it and that it is 'ok' to do so. In order to begin to recognise a need for accessing help and support for oneself, there is a need to turn *towards* one's own pain,

resulting in turning *away* from others, i.e. their dying partner. The data revealed that this shift in focus was incompatible:

> *"I keep telling myself, "You sir are going to be strong. You've got to be strong. You've got to keep yourself fit, because no way Rose wants to go through this on her own." There's no way I want to let her go through it on her own" (Carl, line 431)*

This perceived dichotomy of there only being the *helped* and the *helper*, the *needy* and the *needed* meant that there was no space for the participants to view themselves as anything other than the coping carer. To be viewed as someone who is also hurting is incompatible with everything they are trying achieve (i.e. being a competent carer):

> *"you do get upset … I will be driving along and a thought will come to me and I will get upset me … and but you get over it you know it's not happening all the time and it doesn't mean I am not safe to drive or anything like that .. but it happens but its hadn't got to the point where I need to talk to someone …" (Michael, line 965)*

When the roles of helper and helped are broken, i.e. when the carer desires to be cared for and turns towards their own pain, there is a sense of guilt as their own pain is considered insignificant compared to their partner's: "you feel guilty as well you know? In your partner's suffering more than you why why complain what do I have to complain about" (George, line 617).

The shift would also require the participants to not only view themselves as vulnerable but to allow for others to see them as vulnerable; again the data indicated that this was not acceptable (or compatible). This is reflected in Carl's description: "outwardly, you daren't show it, but inwardly it's tearing me apart, I can assure you. Outwardly, I still get on to everything in that good-natured way" (Carl, line 232).

The data also reflects that there was a fear that if the needs of the participant as a carer were acknowledged, internally or externally, and if they did turn towards themselves, that these feelings would become uncontrollable: "you supress … you try to get on with the routine I won't think about what's going on … but you can't stop it …. Subconsciously

something is going on …. It's there you know? And it does break through" (George, line 608). The idea that the despair was a 'Pandora's Box' is reflected by Michael's desire to stay away from his emotions:

> *" say I am down the pub, everybody knows Sue is very ill it is quite a closely knit village they all know ... and very occasionally they say 'is Sue ok? Is she alright?' but that is it, we don't engage in a conversation about it and I am grateful for that I don't want to, I go down there to get away from this, I don't want to relive everything down there ..." (Michael, line 764)*

3.4.2 Being a man

Not only is help-seeking deemed incompatible but the data suggests a strong sense of needing to be a 'man' about things. Participants experienced, internalised, and acted out societal views of what it is to be a man - the idea that men are stoic, strong and silent. This, in turn, influenced the construction of help-seeking in relation to this view of masculinity. This is reflected by Bruce and his view that emotions are to be dismissed:

> *"there's a tendency - one not to be emotional, and to not to tell it as bad as it was or is or shall be, so it's like macho thing you know what I mean, I am a bloke and I am coping with it" (Bruce, line 1372)*

This societal expectation for men to reject their own feelings, emotions and fears is also reflected by ideas that men should 'suck it up' and be the 'strong one' in order to protect their partners from their own pain:

> *"I remember cringing in the hospital ... that was er ... didn't cry in front of Julie I waited until I went out and then cried ... and er ... yeah I have teary days I can feel myself feeling tear now ... " (Dave, line 714)*

This was also linked to ideas of burdening their partners if they did share how they were feeling or expressed a need: "no, at the moment, no I mean if, er, yeah, if there's something wrong with me, I don't ... you know I wouldn't normally tell her really, cos I don't want to bur-she's got enough burden without me being..." (John, line 1066).

"yeah, you've obviously don't say 'oh I'm stuck here every day' and 'I can't go down that garden' and 'I can't go out' and... you know, I'm I'm not a moaner really you just... you bite the bullet and do what's necessary don't you really..." (John, line 996)

There is a great deal of stigma attached to 'getting emotional' or upset in front of others, which directly conflicts with the participants' sense of 'being a man' about things. There was a recognition that, for some of the participants, their emotional responses were much more readily available and likely to 'spill over' and how this change distressed them. This is reflected by Bruce when noticing the change within himself over his control of his emotions, between his experience of caring for his mother and his experience of caring for Jane:

"I never felt that emotional as in physically upset or or mentally upset but this has completely changed me now I am just find that I am upset on even the slightest thing I get really really upset umm like stuff on television which is why I've stopped watching things on television erm and just talking to me I found myself I can feel myself starting to get really upset, even now (voice audibly upset) I don't know why that is and I've never done that before" (Bruce, line 1477)

3.4.3 As a last resort

Finally, if a participant was able to navigate the incompatibility, and make sense of help-seeking in terms of his masculinity, help was seen as a 'last resort'. Help is only acceptable when it is presented as the last resort as reflected by George, the only participant who was accessing help at the time of the interview, who spoke about the way in which he allowed himself to access support:

"You get to the point where you think I am gonna crack up here ... you know? erm even to the point sometimes I would be going around Sainsbury's alone and I would start to feel dizzy ... I could just collapse here ... and that doesn't help anybody" (George, line 586)

And for Dave who highlighted his shock and surprise that he was considering counselling:

"yeah ... yeah ... I've had days when felt down ... and at this point where we are even starting to think about counselling because ... you just have days you have days when you feel ... er a little depressed? you know?" (Dave, line 373)

Philip's view that it is better to wait it out, in moments of need rather seek help or support highlights the position of help-seeking as the last resort:

> *"when things are particularly difficult or I'm feeling particularly stressed or anxious about things erm I always think to myself 'right, just get through this. An hour at a time. Take it hour by hour. Just get through…you you're okay, yeah you're okay.' Sort of mentally talk to myself. Talk myself through it. And then erm hoping things are better the next day which errr normally invariably they are" (Philip, line 926)*

There was also a reliance on others to let the participants know that help might be needed and this further distanced the participants in relation to help-seeking for themselves, as reflected by Michael:

> *"no … I don't I don't realise that, I don't think I need it I would expect other people to tell me that I needed it if it become necessary for me to have to have support erm … other people would tell me, I think … I think that people around me would be honest enough to tell me" (Michael, line 912)*

4.0 Discussion

The aim of the current research was to explore the lived experience of men who are caring for their partners receiving palliative care and to explore how they experience seeking help for themselves during this time. This was done by analysing semi-structured interviews using IPA. To the researcher's knowledge there are no other IPA studies which have examined this, hence the current research contributes to the development of a new understanding in the literature. Three super-ordinate themes were interpreted from the data; 'Illness Questions Everything'; 'Construction of the Caring Role' and 'Help-Seeking at the Limit'.

What is the lived experience of men caring for a dying partner?

The arrival of illness was experienced as traumatic, with participants sharing their horror with the researcher. Participants found it hard to know where to start and some did not know where stop in their telling of the illness narrative. Some participants spoke with a great

deal of detail, offering vivid imagery; whilst others could not bring themselves to say more than a few sentences, which resonates with wider trauma literature. For example, Judith Herman's (2010) discussion of a 'remembrance' phase from her studies on recovery from trauma, suggests that there is a point that individuals may reach where they find it useful to share their story of the traumatic event(s) they have endured. This enables the participants to 're-tell' the stories, and to construct and transform their narrative in a way which allows them to connect with and heal from the trauma. The therapist (or researcher in this case) acts as a witness to the story and thus the trauma, acting as an ally to the individual's experience and promoting the healing or 'recovery'.

Whilst the aim of the current interviews was for research rather than therapeutic purposes, this process of re-telling and witnessing fits with the experience of interviewing some of the participants. The way in which a number of participants used large detailed descriptions, with topics seemingly moving from one to the other and back again, illuminated the sense of terror with which they were telling their narrative. Interestingly, one of these participants went on to begin the process of accessing support for themselves, which is in keeping with the ideas of Herman (2010).

The relationship with their dying spouse was a strong emergent theme for all the participants. They spoke of deepened relationships and a re-awakening of their appreciation of the partnership, which is supported by the empirical evidence of caring for a partner (Mackenzie & Greenwood, 2012). However, in parallel, participants spoke of a sense of distance in their relationship in the context of the illness. Their partner being terminally ill meant that it was 'unacceptable' for participants to share their fears, worries or frustrations with their partners as this would create feelings of guilt, further removing them from a shared experience with their partner. Shifts in relationships are also well documented in the literature

for spouse and family carers (Badr & Taylor, 2008; Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000)

How do men experience the caring role?

The participants struggled with how to fit the caring role with their sense of identity or self. There was much sense-making as the men grappled with assimilating the role with who they understood themselves to be. Some of the men felt it was part of their "husbandly duties", a chance to 'give back' to the relationship in picking up the bulk of the housework and other duties, rather than seeing it as the behaviour of a carer. The participants felt invisible at times, overlooked in decision-making processes, seen as a 'hand-holder' and a taxi driver. Colleagues gave platitudes, insincere offers to listen, often asking about their partners but with no real desire to hear the truth about caring. Others felt special and shared how they had exceeded expectations of being a man who cares. This struggle with assimilating societal and cultural views of caring, with internal thoughts and feelings, links with a social constructionist theory as applied via systemic models of psychology. This model suggests that it is the contexts surrounding an individual (e.g. family, social, cultural and wider societal contexts) and the closer personal and family scripts which inform and construct an individuals' meaning of the world, themselves, others, and ultimately their lived experience (Hedges, 2005). Difficulty comes as individuals try to make sense of the often conflicting contextual and implicative influences, for example, when the current participants were trying to assimilate different understandings regarding the caring role, masculinity and their constructed sense of self.

As a result of this process the participants were trying to make meaning from experience and this was evident during the interview. One aspect which was clearly present for all the participants was finding a sense of purpose and meaning in the caring role. This resonates with Viktor Frankl's writings of *Man's Search for Meaning* (Frankl, 1985) in which

he posits humans are meaning seeking and making beings. Frankl's own experience of adversity in surviving his time spent in concentration camps during the Second World War, informed his development of Logotherapy (Frankl, 1955; Frankl, 1962) which suggests that meaning can be found in all circumstances, and that it is our intrinsic desire to seek and make meaning which allow individuals to live life with a sense of meaning and purpose. The participants in this study were experiencing horror and adversity, and although conflicted about the caring role, they actively sought and created meaning within their lived experience of caring for their dying partners.

How do men experience seeking help for themselves during this time?

Seeking help for themselves whilst caring for their dying partner was perceived to be incompatible with their situation and care-giving role. There was tension between the lived experiences of the participants (i.e. pain, fear, despair) and their desire to be good carers. There was also tension between caring and being cared for, the role of helper and of the helped. This fits with the findings of a review exploring family care-givers' experiences of caring at the end of life (Funk et al., 2010). This paper highlights that informal carers view help with a sense of ambivalence, and whilst they recognise the need for support, do not do so due to a number of barriers, such as unwillingness to identify as a carer and concerns regarding the legitimacy of their needs. Alongside this is often a desire to keep a focus on their partner, experiencing discomfort with particular features of accessing the support (e.g., leaving their partner for periods of time, prioritising their needs, and uneasiness with talking about their experiences, emotions and feelings).

This perceived dichotomy created by the ambivalence creates a situation in which it feels impossible to make a choice, causing the participants to 'freeze' in the moment and bring their attention to what is directly in front of them, concentrating on what can be done and avoiding all other thoughts (including that of their own needs no matter how pressing

they are). This resonates with Festinger's *cognitive dissonance* theory (1962) which states there is a strive to maintain cognitive consistency and that when we are presented with inconsistent information / cognitions / experiences (i.e. cognitive dissonance) the reaction is to remove the cause of the distress (i.e. the conflicting experiences) even to the detriment of one's wellbeing, such as the development of unhelpful behaviours, like avoidance.

There was a strong sense that to allow these thoughts and feelings about their own needs to be processed and expressed would be to open a 'Pandora's Box', with the fear that if it were opened there would be the potential for them, their coping and ultimately their ability to care for their partner to unravel. This further supported their dissonance to avoid the potential danger of what might happen. Even if the participants attempted to lift the lid and peek into the abyss of their despair, they would be prevented from doing so by their understanding that they need to 'be a man' about things. The participants shared how they felt uncomfortable crying in front of others, noticing how, since their partners had become terminally ill, they were much more emotionally labile and that they were uncomfortable with this change. Following this, *if* they were to consider seeking help for themselves this would be done as a very last resort. This fits with Connell's (1995) exploration of masculinity and help-seeking in which help is only considered once pain, endurance, stoicism and visible injury have occurred. Furthermore, if help is sought, men aim to rationalise or provide a reason for why they have done this and why they have departed from a common view of masculinity, and so help-seeking is neutralised as a last resort (O'Brien et al., 2005).

4.1 Strengths and limitations of the study

A strength of the research was the rigour of the in-depth analysis. A number of strategies were put into place in order to support the analytic process and validity of conclusions drawn, as discussed in the methods section, for example, the way in which the

data were analysed thoroughly and carefully, the triangulation methods put in place, and the care and respect in which the study as a whole was carried out.

A missing voice in the research is that of the care-recipient herself. Whilst this may have been unfeasible for the current research (in terms of time constraints and the remit of a ClinPsyD thesis) this would have allowed for exploration of convergence and divergence between and within couples, and would have been a further source of triangulation (particularly relevant in light of help-seeking).

A further limitation of the research is the lack of direct service-user involvement in the development of the project. Due to time constraints it was not feasible to have the interview schedule reviewed by a relevant individual which would have increased the credibility of the study. However the questions were developed from the literature, with consultation from two Clinical Psychologist with years of palliative care experience, a researcher who specialises in IPA and most importantly with the participant in mind. The participants were given the opportunity to check their interview transcript for errors, and to approve the content, given that verbatim quotes have been used in what can be considered a public document. As stated previously three of the eight participants got in touch following this invitation and all three expressed their gratitude for their involvement in the research. One participant took the time to poignantly share how reading the transcript had moved him. So whilst there was no male carer perspective on the interview schedule development it is believed that the participants' views, at an individual level, have been heard and respected.

4.2 Clinical implications

IPA research does not aim to provide evidence from which global generalisations can be drawn; the following clinical implications are suggested following this research with these

eight participants. Is it hoped that other individuals in similar circumstances mays benefit from the implications.

Men find themselves in a caring role and feel confused by this aspect of themselves, and unsure how this fits with their identity as a man. They make sense of this by identifying as a husband whose duty or responsibility it is to provide care rather than as a man who is caring for his partner. Whilst this is an understandable and protective stance, it also puts them at risk of further emotional, psychological and physiological if their needs are not met.

When considering what may be clinically helpful when engaging with male carers, as illuminated by the lived experience of current participants, a first step may be to continue to demystify this role (for both the carers and staff supporting the patient and carers). It is also pertinent to recognise the barriers which men experience when accessing help for themselves, as they may find it hard to identify themselves as carers, and to seek and engage in such support. Strategies to address this might include teaching and training of staff that explores views of men as carers, which may go towards expanding the view of who cares in palliative care. Focus groups of what support can be useful and more acceptable to male carers again might make support more accessible. This might not result in gendered approaches, but might allow men to take tentative steps towards support without it threatening their sense of masculinity.

Finally, the results suggest that it could be useful to facilitate the meaning-making processes of men caring for their partners. There is an emerging literature supporting meaning-making therapies in palliative care and in particular group therapy has proved useful, suggesting that group therapies which focus on meaning making would also be useful for carers. This could be useful for both men and women however given the results of the study it may be that a male carers group may maintain and protect men's sense of masculinity.

4.3 Recommendations for research

As highlighted previously the use of carer and care-recipient dyad methodology is an interesting and valuable way to explore care giving and receiving in palliative care. It could be used to provide a further source of triangulation when exploring carers lived experience of the carer role and help-seeking during this time, and this could be for both male and female carers.

A systematic review of knowledge and information needs of couples in palliative care suggests a further development of looking at "three-way interactions between patients, service providers and caregivers" (Docherty, Owens, Asadi-Lari, Petchey, Williams & Carter, 2008; p. 2), which again is extremely relevant when exploring help-seeking of carers and therefore is recommended as a topic for future research.

As discussed above, the current area of research is underdeveloped and in need of more theoretical understanding. For example, to conceptualise the experiences of male carers and their relationship to seeking help for themselves whilst caring for a dying partner, in order to inform wider evidence-based service delivery in palliative care. This is recommended to be achieved with the use of Grounded Theory, which employs larger scale qualitative studies with bigger sample sizes to generate "a theoretical-level account of a particular phenomenon" (Smith et al., 2009 p. 201).

4.4 Conclusion

The research findings were interpreted from a rich data set, and provide a contribution towards addressing the gap identified within the literature regarding an understanding of men's lived experience of caring for a partner receiving palliative care and how they experience help-seeking for *themselves* whilst in this role. It is hoped that the findings, recommendations for future research, and clinical implications make a meaningful

contribution, not only to the literature but also towards improving the experience of, and support for men and their partners, whilst facing terminal illness and all that it brings.

> *"Though we try hard to go through life two by two or in groups, there are times, especially when death approaches, that the truth that we are born alone and must die alone breaks through with chilling clarity. I have heard many dying patients remark that the most awful thing about dying is that it must be done alone. Yet at the point of death, the willingness of another to be fully present may break the isolation; as a patient said 'Even when you are alone in your boat, it's always comforting to see the lights of the other boats bobbing by'''. (Yalom, 1989)*

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Chapter Three

Public Domain Briefing Document

Meaning-making in palliative care; reviewing psychological therapies for adults receiving palliative care and exploring what it is like for men caring for their dying partner.

This document provides an overview of the thesis submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. This paper presents a summary of a literature review looking at "meaning-focused" psychological therapies for adults receiving palliative care and a research paper exploring palliative care from the male carer's point of view and how they seek help for themselves whilst caring for a loved one who is dying.

Overall context

Living with a life-threatening illness is life changing for both the patient and the people around them. Research shows that patients facing the end of their lives can experience feelings of 'meaninglessness'. Psychological therapies have been developed to help reduce this feeling; however until now there has not been a review of the literature to examine whether they are effective. Caring for a dying loved one, such as a spouse (e.g. husband, wife or partner) is an incredibly emotive time. Whilst men make up 42% of the carer population in the UK they are often overlooked and are known as the 'invisible carers'. Research suggests that men do not seek help as frequently as women in similar roles. Therefore it is important that research is conducted so that support can be provided for both parties during this time.

Literature Review

Introduction

Patients receiving palliative care can experience feelings of meaninglessness and "meaning-focused" interventions, which aim to address these feelings are emerging in the literature. However, due to a lack of understanding of this area and a lack of a universal definition of "meaning", the area is often neglected. The aim of the review was to address the gap in knowledge and review the evidence for meaning- focused therapies for adults receiving palliative care

Method

A search of the relevant literature identified studies that explored meaning-focused psychological therapies for adults receiving palliative care. A total of 11 papers, studying seven different meaning-focused therapies, were reviewed. These looked at how effective the therapies are in improving quality of life and increasing a patient's sense of meaning.

Findings

There was some evidence that meaning-focused therapies, in particular group therapies (as opposed to individual therapy) are successful in improving individual's psychological well-being when they are facing a life-threatening illness. However, there were a number of issues with the quality of the studies reviewed, including how the researchers measured *meaning*, and a lack of consistency regarding the delivery of the therapies making it difficult to draw firm conclusions.

Conclusion

It is recommended that further research be conducted to explore these therapies further and for future research to include tools specifically designed to measure meaning.

Research study

Introduction

Caring for a partner, who is dying is an incredibly emotional time; however there is little research into the psychological issues faced by people caring for a spouse at the end of life. Men's experiences specifically are neglected. Existing literature identifies that men are more likely to be reluctant to seek help especially when it comes to psychological and emotional support for *themselves*. To address this gap in knowledge, the current study was conducted to explore what it is like for men to care for their dying spouse and to seek help for themselves during this time.

Method

Eight male carers, who were currently caring for their dying spouse, were interviewed. The data were analysed using the Interpretative Phenomenological Analysis (IPA) approach, which allows for an in-depth exploration of individuals' experiences (Smith, Flowers & Larkin, 2009).

Findings

Three overarching themes were created from the data, 'Illness Questions Everything'; 'Constructing the Caring Role' and 'Help-Seeking at the Limit', and each of these themes contained sub-themes which helped create further understanding of the rich qualitative data. For the men who took part in the research, the arrival of their partner's terminal illness was traumatic, and whilst it deepened their relationships with their partners it also created distance between them. The men struggled to make sense of their role as a carer, resulting in them constructing this role as giving them purpose and meaning. Finally the idea of seeking help for themselves during this time was seen as "incompatible" with their role as a man and

husband, “unmanageable” due to the intense feelings it might bring up, only to be considered if as a ‘last resort’.

Conclusion:

Men care too.

However, they can feel confused by this aspect of themselves and unsure how this fits with their identity as a man. They make sense of this by identifying as a husband whose ‘duty’ or ‘responsibility’ is to provide such care. Whilst this is an understandable and protective position, it also puts them at risk of further emotional, psychological and physical distress if their needs are not met. Men need to be supported and their caring qualities need to be destigmatised and demystified so that they can feel more able to identify with this role, and look after themselves whilst caring for their dying loved one.

Appendix A: Summary of other psychological models / therapies used in palliative care

1.2 Psychological interventions in palliative care

Mindfulness

Mindfulness practices and principles form part of many psychological interventions, such as Acceptance and Commitment Therapy (ACT) and Mindfulness Based Cognitive Therapy (MBCT). Mindfulness is described by the Melbourne Academic Mindfulness Interest Group (2006) not as a goal directed activity, but as a tool to increase awareness. Kabat-Zinn, describes it as "paying attention in a particular way: on purpose, in the present moment, and in a non-judgemental way" (pg. 4, Kabat-Zinn, 1994). A recent review of 17 studies examined the evidence for mindfulness based interventions for patients with cancer (*n* = 524*,* Shennan, Payne, Fenlon, 2011). They found that mindfulness based interventions decreased stress and anxiety, and improved sexual difficulties and immune function for cancer patients. However there was conflicting evidence regarding depression and although there was a positive trend in quality of life, this did not replicate earlier findings of similar studies. The review recommended simplified mindfulness based interventions so that individuals who are very unwell, receiving intensive treatment, or who are in the terminal stages of their illness can take part.

Cognitive-Behavioural Therapy

Cognitive Behaviour Therapy, posits that "distorted or dysfunctional … thinking is common to all psychological disturbances" (Beck, 1995, p.1). Difficulties are said to arise when an individual's pattern of thinking no longer functions positively and results in negative outcomes. A review of psychosocial interventions for patients with advanced cancer examined the evidence from 10 studies (Uitterhoeve, Vernooy, Potting, Bensing, De Mulder, & Achterberg, 2004). All but one of the interventions were CBT- informed with additions of

guided imagery, relaxation exercises and skills acquisition. The review found the CBT interventions improved overall quality of life for advanced cancer patients and was particularly efficacious in increasing levels of emotional functioning. However methodological issues such as attrition and participant blinding, affected the quality of the studies, limiting the results of the review. Recommendations were made regarding this to improve rigour of studies in palliative care.

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Appendix B: Quality Assessment

	Criteria	**Met?** *2 = yes* *1 = partially* *0 = no*
1	Question / objective sufficiently described?	
2	Study design evident and appropriate?	
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?	
4	Subject (and comparison group, if applicable) characteristics sufficiently described?	
5	If interventional and random allocation was possible, was it described?	
6	If interventional and blinding of investigators was possible, was it reported?	
7	If interventional and blinding of subjects was possible, was it reported?	
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported?	
9	Sample size appropriate?	
10	Analytic methods described/justified and appropriate?	
11	Some estimate of variance is reported for the main results?	
12	Controlled for confounding?	
13	Results reported in sufficient detail?	
14	Conclusions supported by the results?	
	Summary score (out of 22)	

Appendix C: Additional quality criteria

Additional quality criteria

Bold = item number

15 The intervention is well described

2 = full description of intervention provided

1 = limited description of intervention, or full explanation provided in another publication / source
0 = no description of intervention

16 Adherence to intervention is monitored and described

2 = there is evidence that the investigators have checked adherence to the intervention via described methods such as direct observations, tape recording
1 = limited evidence of adherence to the intervention, or indirect methods such as supervision only
0 = no evidence of adherence checks

17 Therapist trained to appropriate level to deliver intervention

2 = the is clear evidence that the therapist has explicit training in the intervention
1 = the therapist general qualifications are reported (i.e. profession) and is satisfactory, but does not include evidence that they are trained in specific intervention
0 = no evidence that the therapist is appropriately trained in intervention or has appropriate profession

18 There is a well matched control group

2 = an active alternative treatment group has been used that is well matched in terms of structural features of the treatment and its meaningfulness.
1 = an active alternative treatment group has been used but it is not matched for structural features e.g. relaxation, massage
0 = a poor control group has been used that merely controls for the duration of time e.g. waiting list control or treatment as usual

Appendix D: Participant leaflet



Male Carer Study

Are you a male carer?

Are you providing palliative care for a loved one?

Caring for a partner as they near the end of their life can entail, for some, changes in roles and responsibilities such as the 'carer role'. Studies have largely looked at how women experience this thus there is a gap in terms of how *men* experience this.

I am a Trainee Clinical Psychologist studying at **University of Birmingham** for a Doctorate in Clinical Psychology. I am working with two other Clinical Psychologists and we are interested in the experiences of men providing palliative care for their partner. In this study I would like to interview men who are caring for a loved one (i.e. partner / wife) who is receiving palliative care.

Why take part?

Understanding the experiences of men caring for their partner during this time is important. It is important because this knowledge will allow us to better support men at this time. We aim for this research to be used to improve the experiences of both the carer and partner receiving palliative care.

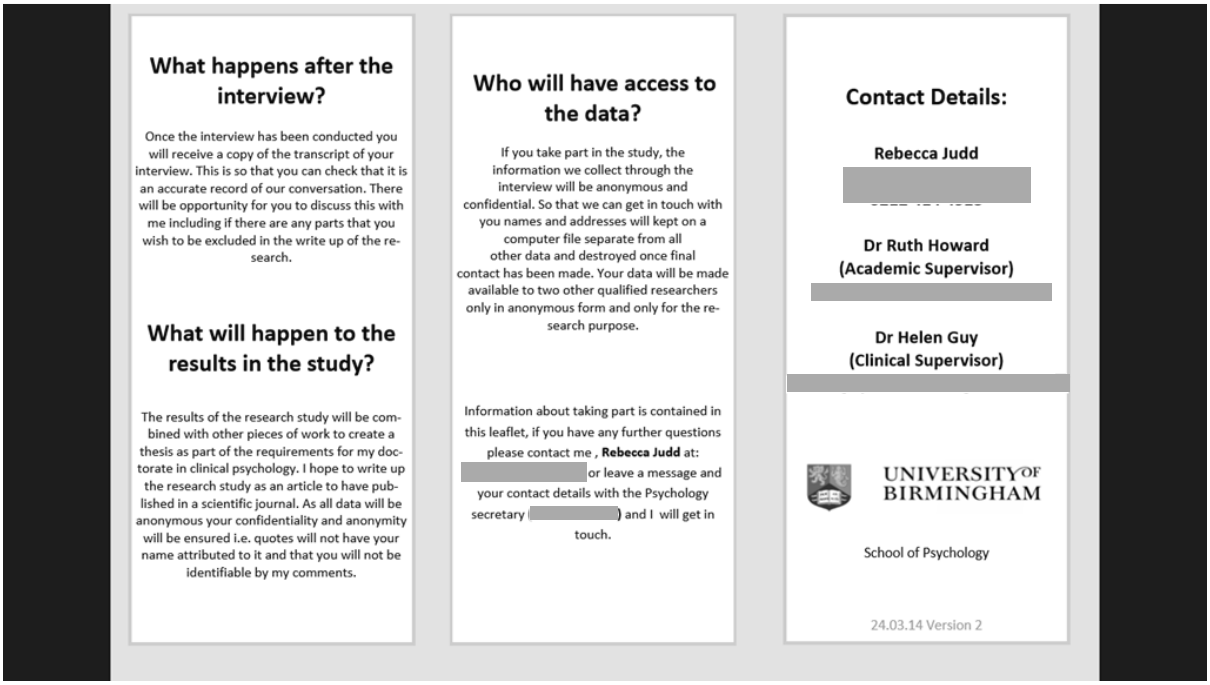
If I take part what can I expect to happen?

If you are interested in taking part then we would like you to tell the person who gave you this leaflet so that they can pass on your details to me. I will then send you a participant information sheet which provides more information about the research.

Once you have received the participant information sheet you will then have two weeks to contact myself (Rebecca Judd) so that we can arrange a time and location for the interview to take place.

The research interview will last around an hour and will be conducted at a location convenient for you i.e. at home, health care facility or at the university. It will be a semi structured conversation covering what it is like to care for your partner and thinking about what support for yourself you access, or would think would be useful for other men in similar situations to yours.

It is understandable that for some, extra support may be required as a result of talking about caring for a partner. Should this happen I can signpost you to relevant organisations or facilitate you meeting with your regular healthcare provider in order to access some further support.



What happens after the interview?

Once the interview has been conducted you will receive a copy of the transcript of your interview. This is so that you can check that it is an accurate record of our conversation. There will be opportunity for you to discuss this with me including if there are any parts that you wish to be excluded in the write up of the research.

What will happen to the results in the study?

The results of the research study will be combined with other pieces of work to create a thesis as part of the requirements for my doctorate in clinical psychology. I hope to write up the research study as an article to have published in a scientific journal. As all data will be anonymous your confidentiality and anonymity will be ensured i.e. quotes will not have your name attributed to it and that you will not be identifiable by my comments.

Who will have access to the data?

If you take part in the study, the information we collect through the interview will be anonymous and confidential. So that we can get in touch with you names and addresses will kept on a computer file separate from all other data and destroyed once final contact has been made. Your data will be made available to two other qualified researchers only in anonymous form and only for the research purpose.

Information about taking part is contained in this leaflet, if you have any further questions please contact me , **Rebecca Judd** at: or leave a message and your contact details with the Psychology secretary) and I will get in touch.

Contact Details:

Rebecca Judd

Dr Ruth Howard
(Academic Supervisor)

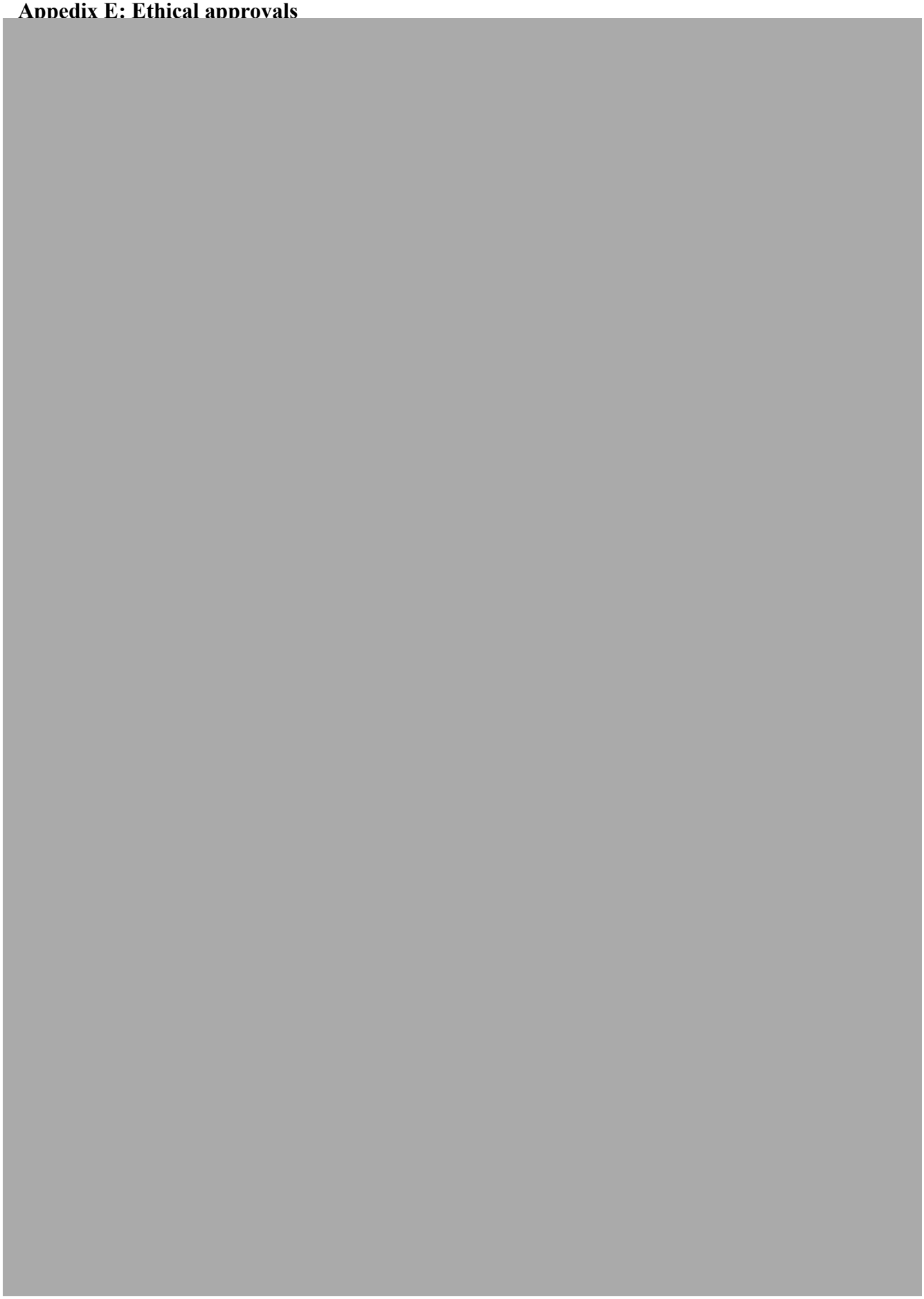
Dr Helen Guy
(Clinical Supervisor)

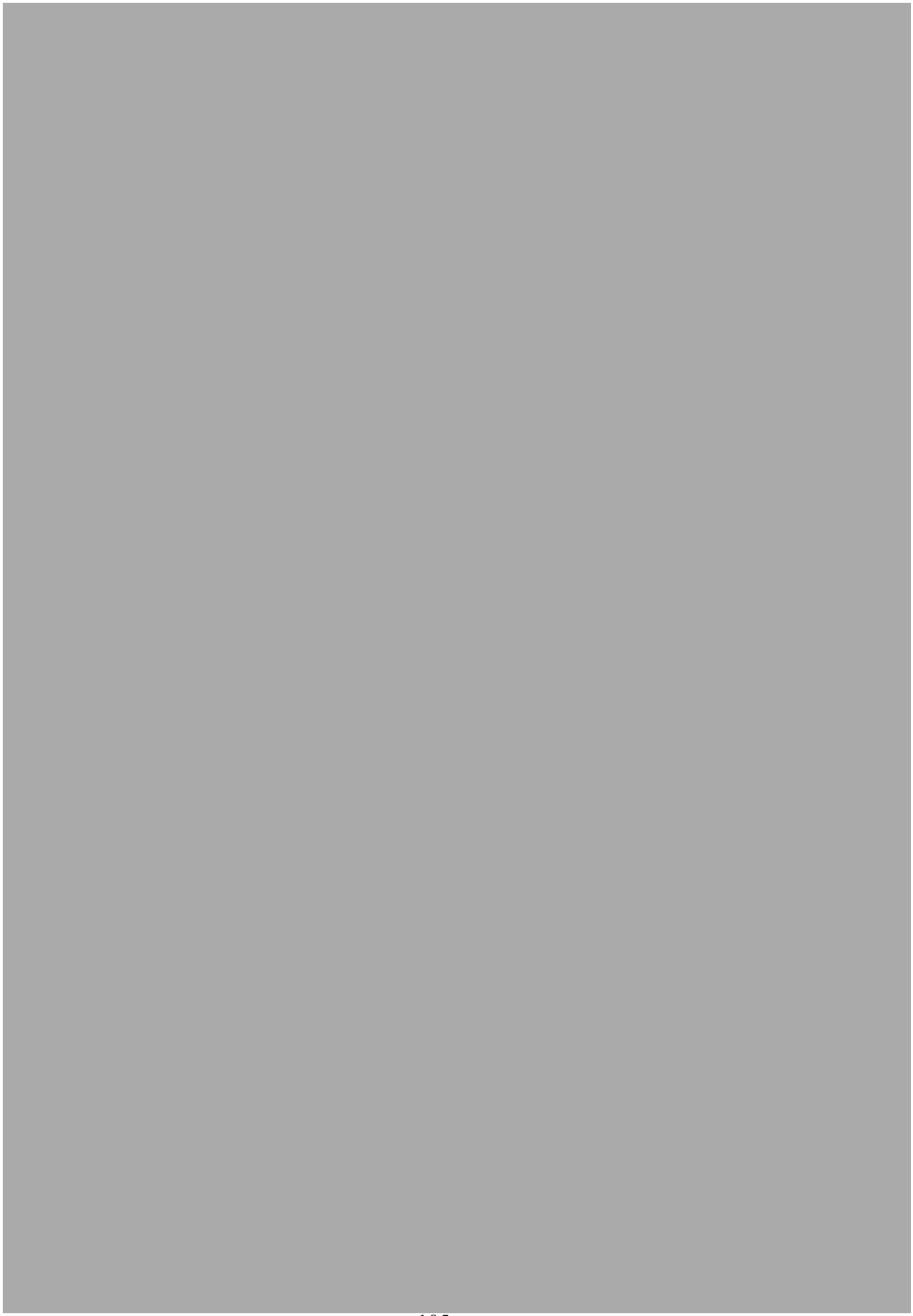
UNIVERSITY OF BIRMINGHAM

School of Psychology

24.03.14 Version 2

Appedix E: Ethical approvals







Appendix F: Participant information sheet



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Participant Information Sheet

Title: *Looking After a Loved One Receiving Palliative Care: A Male Experience*

Researchers: *Miss Rebecca Judd (Chief Investigator), Dr Helen Guy and Dr Ruth Howard (Supervisors)*

Before you decide whether to take part in the study it is important that you understand what the research is for and what you will be asked to do. Please take time to read the following information and discuss it with others if you wish. It is up to you to decide whether or not to take part. If you decide to take part you will be asked to sign a consent form. You can change your mind and withdraw from the study without giving a reason at any time prior to and during the interview and up to weeks after the interview. The standard of care you and your partner receive will not change whether or not you decide to participate in this study. This research study has NHS and University of Birmingham ethical approval.

Who are we?

I am Rebecca Judd, a Trainee Clinical Psychologist currently studying at the University of Birmingham for a Doctorate in Clinical Psychology. I am being supervised by Dr Helen Guy (Consultant Clinical Psychologist) and Dr Ruth Howard (Senior Academic Tutor & Consultant Clinical Psychologist) whilst completing a piece of research looking at how men experience providing palliative care for a partner. We are interested in understanding men's experience of help seeking for themselves during this period, as we know from other research that men seek help differently from women and that men make up a large proportion of people providing care making it an important area to research.

What is the purpose of this research?

The aim of the research is to improve the experience of male care givers when they are providing palliative care for their loved one.

Why have I been invited to take part?

You have been invited to take part as the member of staff at the hospice / health care facility in which you have regular contact, has identified you as someone who is currently providing palliative care for a loved one.

What will happen to me if I agree to take part?

You will be invited to take part in a research interview which will take approximately 1hr to complete at a location convenient to you. The research interview will be a one-to-one conversation between yourself and me, where I would like to ask you questions about what it is like caring for your loved one. In particular about your experience of help seeking, whether

you believe that you sought support for yourself or not. The interviews will be audio recorded and transcribed for the purpose of analysis. All data will be stored confidentially and securely. After the interview has taken place, if for any reason you no longer wish for your interview to be included in the research you can withdraw your data up to two weeks of the interview taking place. Once the interviews have been transcribed you will be offered a chance to review them for accuracy. Small quotes from your interview may be included in the write up of the research and those included will remain anonymous and non-identifiable.

Talking about your experiences may, understandably, be difficult at times therefore you are free to stop the interview at any time to either take a break or to discontinue the interview. If you decide to discontinue the interview your data will be destroyed and not included in the research. Furthermore, if after the interview you feel that you would like some additional support, I will be able to advise you who to contact such as suitable organisations or your regular healthcare professional who is routinely involved in your partners care. I will update your healthcare professional who introduced you to this study that you have taken part so that they can offer further support should you need it. Referrals to further support such as the psychology team will also be offered where necessary.

Expenses and payments

I will endeavour to arrange for the interviews to take place in the most convenient location for you e.g. at your home or at the hospice / health care facility in which you have regular contact. You will be given a high street voucher worth £10 as a way of thanks for participating in the research.

What will happen to the results of the research study?

The results of the research study will be combined with other pieces of work to create a thesis as part of the requirements for my doctorate in clinical psychology. I hope to write up the research study as an article to have published in a scientific journal. As all data will be anonymous your confidentiality and anonymity will be ensured i.e. quotes will not have your name attributed to it and that you will not be identifiable by my comments.

What happens if I have any further concerns?

If you have any further concerns about your participation in this research you can contact the member of staff who provided you with this information sheet who will then get someone from our research team to get in touch with you.

What should I do next?

If you would like to discuss any aspect of this research including taking part, please leave your contact details with the member of staff who gave you this information sheet within two weeks so that I can contact you to discuss your possible taking part in more depth.

NB: To aid efficiency this needs to be done within two weeks of receiving this information sheet.

If you require any further information do not hesitate to get in touch as outlined below.

Miss Rebecca Judd (Chief Investigator) [redacted]

Dr Ruth Howard (Academic supervisor): [redacted]

Dr Helen Guy (Clinical Supervisor): [redacted]

Thank-you in advance,

Rebecca Judd

Appendix G: Informed consent form



UNIVERSITY OF BIRMINGHAM

Study title: *Looking After a Loved One Receiving Palliative Care; A Male Experience*

Participant Identifier Code:.....

Informed Consent Form

Please initial box

1. I confirm that I have understood the information sheet dated 20.12.13 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected. ☐

3. I understand that following the research interview I will have a two-week period for reflection. At any point during those two weeks I have the right to withdraw my interview entirely or in part, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected. ☐

4. I understand that the research interview will be audio-recorded and hard copies of the research transcript will be stored securely for a period of 10 years after the study has been completed. ☐

5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Parts of the data may also be made available to the team responsible for me or my family member's care but only if any previously undisclosed issues of risk to me or my family member's safety should be disclosed. ☐

6. I understand that direct quotes from my interview may be published in any write-up of the data. I understand that any included quotes will not have my name attributed to any such quotes and that I will not be identifiable by my comments. ☐

7. I agree to take part in the above study. ☐

.....	.....	.....
Name of participant	Date	Signature
.....	.....	.....
Name of researcher	Date	Signature

Appendix H: Debrief form



UNIVERSITY OF BIRMINGHAM

Study title: *Looking After a Loved One Receiving Palliative Care; A Male Experience*

Participant Identifier Code: ……

Debrief Sheet

Thank you for taking part in the research.

The purpose of this research is to understand more about the experiences of men providing palliative care for their partner. We are particularly interested in how men seek help for themselves during this time. It is hoped that the research will outline ways in which male spousal carers can be best supported by professionals and services to ensure that they are offered and receive the appropriate care at such a testing time.

Confidentiality

Your interview transcript will be kept anonymous by use of a participant code. If any of your quotes are used in the final research report no personal information will be included; only the participant code will be published alongside the quotes. No personal information will be passed on to other parties, it will be stored securely and seperately from the research data and all personal data will be destroyed after the completion of the research report.

What happens next?

If for any reason you wish to withdraw your interview from the research you can do so at any time up until two weeks after your interview. In addition, you will be sent a copy of your interview transcript for you to check for accuracy. If you are happy with it you do not need to do anything. If there are any issues or concerns you wish to discuss please get in contact via the details below within a two week period of receipt of the transcript. The results will be written up in a thesis held in the University of Birmingham library. The study may also be published in an academic journal.

Further support:

Talking about personal experiences can be upsetting for some people, for different reasons. You may wish to discuss this with the researcher if you feel comfortable to do so via the contact details below. The staff member who put you in contact with this research will be made aware that you have taken part and they will be able to offer further support should you need it. Referrals to the psychology team will be made available where necessary.

Alternatively, we suggest that you contact any of the following services/organisations:

Carers UK

www.carersuk.org/help-and-advice

Phone: 0808 808 7777

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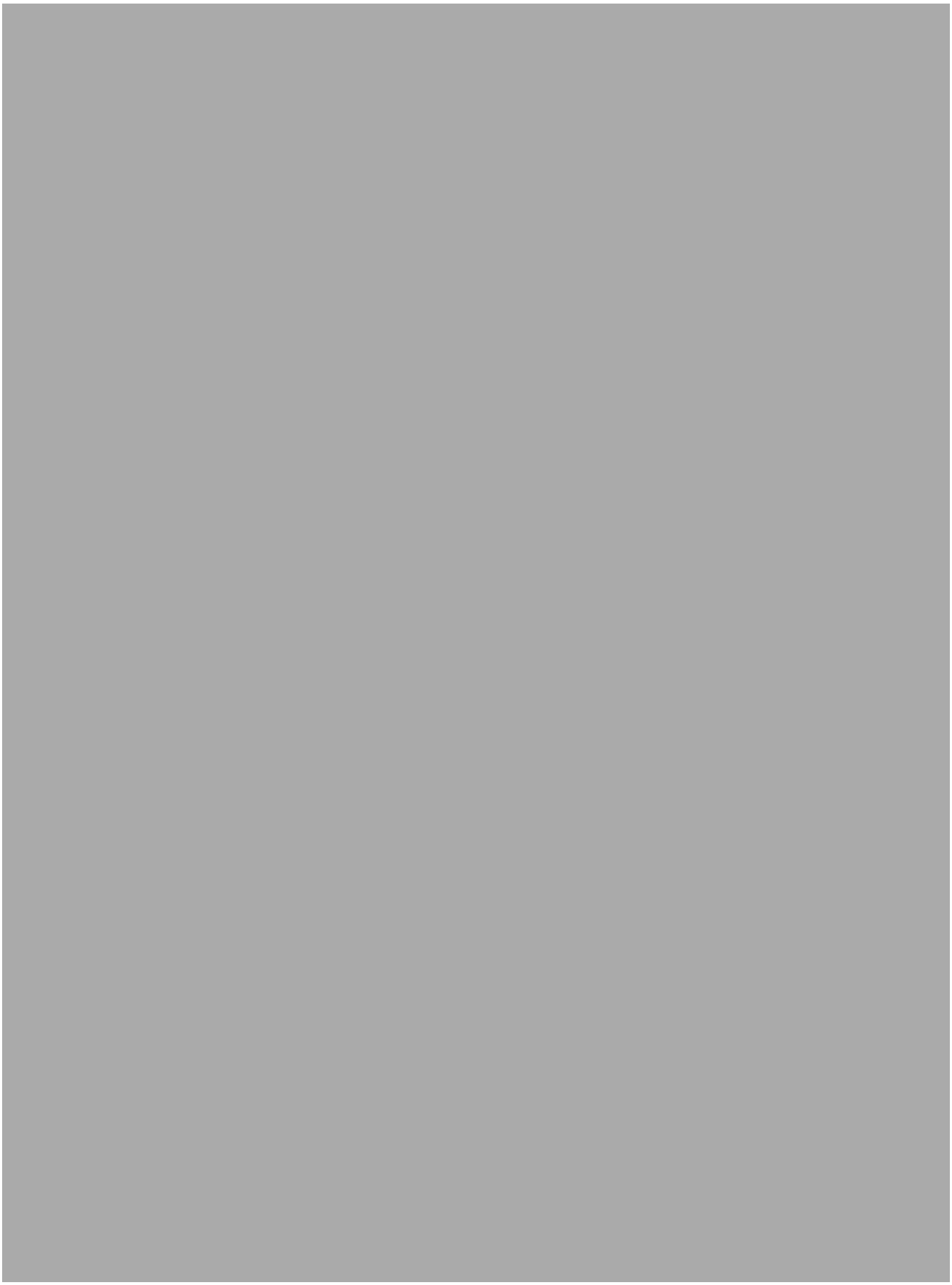
Miss Rebecca Judd (Chief Investigator) [redacted]

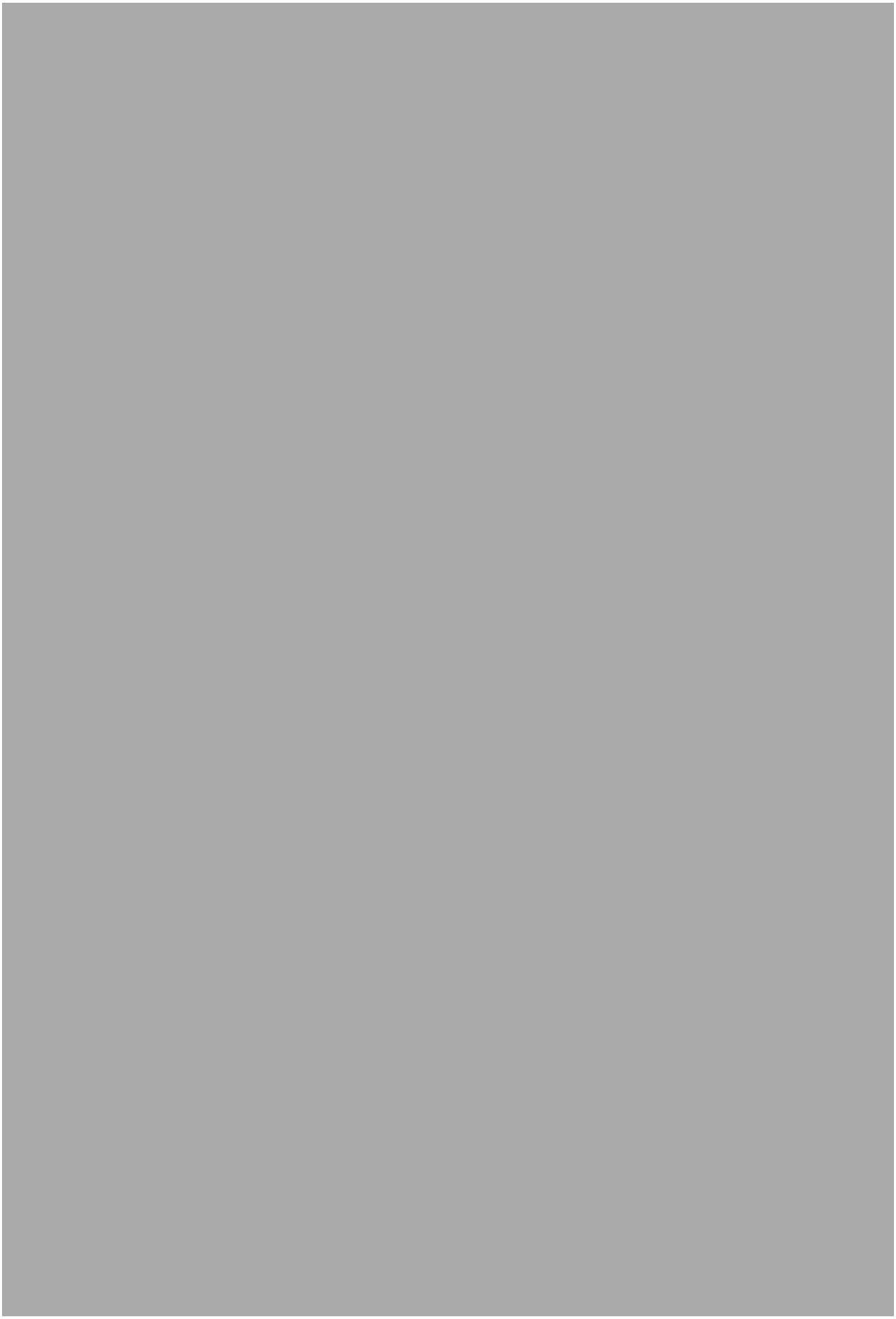
Dr Ruth Howard (Academic supervisor): [redacted]

Dr Helen Guy (Clinical Supervisor): [redacted]

Thank you again for your participation. Yours sincerely, Rebecca Judd

Appendix I: Journal submission guide







Appendix J: Interview schedule



UNIVERSITY OF BIRMINGHAM

Interview schedule

'Ice breaker':

Tell me a little about your partner; how did you meet (use name)?; how long have you been caring for your partner?

Care-giver role:

Can you tell me about how you care for your partner?

- *How would you describe what you do for your partner?*
- *Break it down to tasks / activities*
- *Does it involve different roles?*

Tell me about how you came to be in this role (of carer)?

- *Tell me more about the decision?*
- *Any influences on it?*
- *Tell me about your motivation for doing it*

Tell me about how you experience the carer role….

- What is it like do it?

  Positive aspects

  More difficult aspects

Can you tell me about any impact that the experience of caring for you partner has had for you?

- And what about other relationships in your life? i.e.
  - Partner
  - friends
  - family
  - work colleagues

Tell me about any expectations you had about what the caring role to be like?

- how were these expectations formed? i.e. through media, previous experiences?)
- Does it meet these expectations?

Tell me about any influence or impact being a man may have on your carer role

How being male might affect your experience of caring for your partner?

Help-seeking:

Tell me about your experience of seeking help (for yourself)

- in general
  - *How did you find doing that?*
  - *What response did you get from those who you sought help from?*
- in relation to caring for your partner
  - *How did you find doing that?*
  - *What response did you get from those who you sought help from?*

Tell me about things that do or would make it easier to seek help?

Tell me about things that do or would make it more difficult to seek help?

Tell me about things / support that would help you in your role, caring for your partner?

- *How would you say about how professionals can best support male carers in situations similar to yours?*

Tell me about any impact being male, may have on seeking help

Is there anything you would like to add relating to any of the above?

Care role?

Being a man in a carer role?

Help – seeking as a man?

Appendix K: Audit trail of clustering of themes

	Illness questions everything		
	horror of illness	***Deepened our relationship***	***Distance in our relationship***
Dave	120-121 – slow deterioration exhausting 130-131 - dread 147-148 – life changing 257-259 – painful to see 274-276 – sadness to see partners frustration 290-294 – overwhelming 314-321 - life ruled by chemo treatment, no control 323-327 – unpredictability, tiring and frustrating 382-384 – overwhelming 397-398 – nobody has the answers, frightening 411-412 – reciprocal worry 481-484 – no control 673-676 - outliving prognosis, bittersweet 711-714 – diagnosis terrifying 1061-1064 – living with uncertainty	13-14 – lucky to have met 14-17 – third time lucky 17-19 – soulmate 220-226 – focus on making new memories together 263-283 – admiration for partners determination 354-361 – empathy / sadness for partners frustration 433-437 – pride in partners 'stubbornness' 442-444 – pride in partner 446-451 – disbelief in partner strength (to stay at work) 454 – empathy for her loss (work) 548-549 – pride in how coping as a couple	41-43 – appearance is important 43-46 – loss in their relationship 77-81 – sadness 148-152 – sadness 154-158 – loss of freedom to do 'normal' things 253-255 – increased dependence, overwhelming 307-308 – that's her life, sadness 308-312 – no control 576-585 – it's not the same, sadness loss 960-962 – guilt for talking about it (sex) 962-969 – loss of attraction 969-971 – loss of sexual identity (his) 973-975 – guilt/shame for missing sex 978 – painful to acknowledge 980-982 – embarrassing to acknowledges 982-985 - sex should be 'natural', loss 985-989 - never going to be the same, loss 1009-1013 – lost the person I can trust 384-386 – overwhelming, focus time left 390-397 – panic 391 – loneliness 694-696 – all-consuming 718-721 – overwhelming 1015-1016 – fear
Philip	59-60 – disbelief at duration 60-62 – overwhelming, no words to describe 75-76 – overwhelming (minimises impact) 76-77 – self-conscious of 'moaning' 145-146 – finding hope in improvements 146-149 – hope is given and taken away 149-157 – partners improvement gives hope 159 – medication can restore the status quo 206-207 – pain, no words to describe 232-23 – overwhelming, no words 252-253 - overwhelming, no words	211-212 – "rude awakening" 212-219 – appreciation for what partner did before 229-230 – time together is precious 423-424 – gratitude for time spent together 479-480 – "we are both up and down together" 624-633 – bittersweetness of relationship getting stronger 634-636 – love for partner is precious and it is going (the relationship) 636-638 – "just the little things you know"	

	325-328 – early days were a living nightmare 328-330 – early days walking around in a daze 330-332 – time in between diagnosis and treatment, no man's land 332-336 – no man's land; helplessness 336-337 – no man's land; vulnerable 337-340 – initial treatment relief of distress, something was being done 340-344 – treatment process stressful 344-347 – when treatment stopped so did hope 347-352 – uncertainty distressing 252-354 – regret for not 'doing more' 366-372 – partner nearly dying, frightening cannot say it 372-75 – missed opportunity of surgery, sadness 375-379 – hope taken away (missed opportunity of surgery) 384-387 – new drug gave hope 389-390 – improvements in partner give hope 329-395 – partners improvements provide hope 395-398 – drugs stopped, hopelessness again 398-402 – holding out hope for continuation 405-409 – palliative prognosis unknown territory 409-410 – feels abandoned and helpless (palliative prognosis) 415-416 – dread of what is coming next 418 – thoughts of this are utterly overwhelming 840-850 – you cannot escape it, even on drive to work 855-858 – constant reminders, exhausting 858-861 – unpredictability when it will 'hit' you, anxiety provoking	638-642 – regret for taking partner for granted 650-655 – realising what you have got as it is going, regret, shame 657-662 – re-evaluating what it is important in life 675-678 – re-evaluating relationship little things no longer bother me	
Michael	25 – do not know where to start 26-30 – does not fit with sense of who partner is 33-34 – it won't happen to us 34-39 – not even the doctor saw it coming (comforting) 39-41 – shock of deterioration 42-43 – shock of big the tumour was (guilt / blame)	112-114 – making most of time left 500-502 – reminiscing and planning immediate future 503-509 – time is savoured 553-536 – deepening relationship valuing each other 559-570 – no sexual intimacy replaced with gratitude	70-75 – loss of holidays 120-121 – loss holidays 575-583 – frustration with partner 583-587 – pride in her strength 587-592 – sadness in her denial 196-202 – mourning for past life 205-206 – loss of golden years together 648-689 – pressure of being 'the person' for

	45-53 – trauma / horror of operation 51-53 – trauma I could have lost her 53-61 – disbelief how much partner has been through 61-65 – bittersweet pride outlived prognosis 75-77 – relentless balancing of treatments and side effects 150-154 – cancer is a marathon for both of us 159-160 – success story, one with a sad ending 703-707 – shared impact of illness	570-572 – stronger whilst frustrating relationship shifts 591-596 – ever developing understanding of partner	partner 108-110 – sadness at diminished quality of life for partner
Donald	41-44 – doesn't fit with partners identity, disbelief 48-55 – trauma of early stages 57-58 – partner indestructible 58-64 – relentless 64-66 – partner is strong 67-68 – partner is indestructible 70-75 – guilt for not noticing first symptoms 79-82 – slow and unexplained, scared 87-90 – fast and unexplained, scared 122-130 – frightening 137-145 – uncertainty of what was wrong 146-154 – dead ends, anger 154-162 – incorrect diagnosis, anger 176-177 – diagnosis brought no comfort 303-308 – partner unable to ask for help; frightening 310 – losing ability to speak, distressing 343-344 – heartbroken seeing partner in hospice 365-367 – doesn't fit with partners identity 372-374 – impact of illness shocking 378-382 – MND is unpredictable 369-403 – a living nightmare 520-525 – she is constantly medicated (distressing), this is not my wife 34-36 – hopeless 310-315 – continuing deterioration frightening 317-323 continued deterioration overwhelming 325-328 – continued deterioration distressing 238-331 – how far is this going to go? (terrified) 1056-1059 – uncertain prognosis, distressing		93-98 – abandoned 223-224 – partners anger directed at them 224-226 – partners anger understandable 226-227 – partners anger feels rejecting 509-516 – understands partners anti-medication stance 516-517 – frustrated by partners anti-medication stance 1093-1098 – loss of connection with partner (frustration) 1100-1101 – loss of connection with partner (loss) 1102-1104 – loss of connection with partner (distressing) 362-364 – void in your life 630-632 – too painful to stay in house 632-656 – concerns over own health 657-661 – own aging is worrying 663-673 – own mortality is brought into light (fear) 877-878 – overwhelming

	1059-1063 – partner coming home, dread 1063 – duty to care if partner come home 1065-1066 – uncertain prognosis, living in uncertainty 165-166 - no answers for a long time, abandonment 188-190 – distressing to watch partner be cared for		
John	42-46 – history repeating itself 45-50 – surprise at outliving prognosis 50 – living in uncertainty 50-54 – to painful to relive illness story 56-60 – grateful but not hopeful (protecting self) 79-82 – respect of choices 83-98 – helpess 105-106 – there are no 'knowns' anxious 166-180 – better network conflicted (sadness for late wife and relief for current wife) 185-189 - useless 399 – history repeating, anger, scared 403-404 – cruel timing of illness 619-624 – life changed instantly 1273-1283 – useless to help / change anything 1350-1385 – fragility of her body 1326-1336 – changing partners sense of self (sadness) 1333-1334 – useless to change anything (frustration) 1341-1358 – different but stronger	1034-1039 – partner is priority 1350-1385 – gratitude partner is still here, priorities change	60-61 – rejected 453-458 – isolated 1066-1072 – do not burden partner with my concerns (role as husband) isolated
George	58-69 – story of illness is a long rollercoaster 62-65 – learning to live with dying 67-72 – terrifying if new treatment will fit with co-existing treatment 405-409 – go into survival mode 436-440 - life gets tough 444-453 - impacts all aspects of our lives 444-453 – everything is changing	378-380 – co-dependence	23-24 – unsure how to define relationship in traditional way 23-27 – defining relationship impacts on legacy left 28- external description of relationship is important 33-37 - defining relationship impacts on legacy left 37-41 – relationship fitting into societal values

	454-455 – unwelcome change, powerless against it 487-499 – nothing can prepare you for reality of it		41-43 – relationship is left undefined 60-61 – death of our relationship too 97-99 – frustration with partners lack of motivation 122-124 – being partners motivation is exhausting 133-135 – being partners motivation is exhausting 284-291 – losing functioning now is a death for him 291-295 – partners loss of identity is a death now 380-389 – acknowledging partner is dying creates a distance 417 – 418 – separation 419-422 – distance in relationship is inevitable 422-423 – separation is frightening 423-424 – powerless against the separation 425-428 – separation is abandonment 428-431 – saying goodbye is unachievable too painful to even start
Carl	136-193 – the <u>whole</u> story 136-144 – she survived first cancer 151-153 – shared impact of illness 156-165 – illness went undetected 166-170 – relief when someone took action 183-190 – shock of prognosis 192-193 – short prognosis was terrifying 197-200 – reading up on illness 201-204 – missed care opportunities 208-213 – looking for signs partner will be ok 214-220 – changes in doctor treating partner 241-245 – exhausting for both 289-293 - cannot say dying 321-323 – cannot acknowledge what he fears 371 – cannot say 'partner might die' when I am out 459-460 – cannot name the situation as partner is dying	404-407 – brought us closer together 461-465 – admiration for partner 600-601 – time left together is precious 370-371 – partner cannot die alone 603-607 – not wanting to exist without partner 612-614 – wanting to care for them post his death 619-621 – desire to not be here if partner has died 619-621 –does not want to burden his family 621-628 – sad and lonely existence of living in an 'old folks home' 639-640 – nothing without partner 640-647 – his life is a life well lived, the autumn of their lives 652 – 'no way life would ever be the same'	286-289 – partner is closer to acceptance 318-319 – doesn't want partner to be cancer focused 537-543 – dread of 'old folks home'

Bruce	37 – 45 where do I begin? 53 – re-living shock 64 – 78 Have to tell story in sequence 75 - Suffering of loved one *helplessness / powerless* 80 - disease / illness *horror* 80-82 - Doctors missing things *anger* 86-88 – Diagnosis story *Feeling overwhelmed* / shock 95-96 - Constant re-adjustment to new treatment relentless 100-105 - Shared impact of treatment 105-111 - Constant re-adjustment to new treatment relentless 120 - Softening the reliving 'quite' 120 -123 - *Traumatic* story of diagnosis 122 -135 - Cruel timing of illness 156-158 - Doctors missing things *anger* 158-161 - Cruel timing of illness 163-166 - It happened so quickly 171 -172 - *Feeling 'fobbed off'* by medical staff 174-178 - It happened so quickly 177 - Shock / horror 'huge tumour' 184-186 - We had no idea it was there *invasion/attack* 192-200 – shock at speed of deterioration 201 – Horror tumours were that big 203-206 – uncertainty of treatment plan 208-209 – uncertainty why treatment plan 215-216 – shock of first month 216-219 – attempts to understand rapid deterioration 220-226 - comparison of 'old' partner with 'dying' partner – *doesn't fit* 226 - It happened so quickly (illness; deterioration) 228-230 – story of diagnosis is overwhelming 450-470 – *Hypervigilance* re: partner's safety 501-511 – searching for a why 533-537 – how have I survived this so far? 559-570 – no warning signs		264-269 – frustration with partner making it difficult for themselves 273-274 - different approaches 315-317 - *Struggle* with her 'cancer focus' 319-320 - *Frustration* with partner 320-321 - *guilt* for feeling frustrated 328-329 - Partners resistance to change / care 338-339 - *Frustration* with partner 381 – 382 *Struggles* with her 'cancer focus' 390-397 *Frustration* with partner *399 - guilt* for his feelings of frustrated 401-405 - *Frustration* with partner 407-412 - *Frustration* with partner, he wants to protect her 539-555 – loss of hoped for future together 661-666 – loss of hoped for future together 668-710 - loss of hoped for future together 668 – I am going to be alone 698-699 - loss of hoped for future together 702-704 – hopelessness 718-719 – dread of partners end of life *1150-1160 – hoped for future gone* *1160-1163 - future gone hopeless* 1176-1206 – feeling 'outside' of partners experience *1218-1220 – fear of partners further deterioration* 499-501 – needs to tell partner difficult things

	571-580 – discovery of illness embedded in time 585-590 – feeling powerless 595-600 – no previous experience of this to draw on 601 - powerless 603-608 – impact of change on partner – shock 697-708 – hundred and eighty degree change 1005-1009 – I thought she was going to die then 1145-1148 – completely and utterly lost 1163-1172 – treatment restricts their lifes 1302-1314 – blindsided and attacked by illness 1315-1316 – shock from illness is unrecoverable from 1318-1320 – underprepared for illness 1545-1561 – fallen off a cliff 1561-1566 - Lack of prognosis (certainty); *angry* 1568-1585 – anger at the illness 1568-1573 – wards are terrifying 1587-1616 – illness treatment is devastating		
	Construction of caring role		
	I am not a carer	***You are not a carer***	***Caring role offers purpose / meaning***
Bruce	239-244 - shifting view of self as a carer 297-300 – want to improve her quality of life 310-315 – minimises importance of practical support 341-345 - *Justifying* his style / care 400-401 – unsure of his voice as a carer 528-529 – doubting own strength 620-623 – doubting own resilience 778-785 - No conscious decision it is a '*duty'* / responsibility of being her partner 787-789 – revelation that carer role as a <u>'natural'</u> choice 812-836 - Previous caring role for parent duty as a son 838 – 843 - Reciprocal caring role *891-893 - Surprising* revelation of his life-long Carer role	*1395-1411 – truth of caring stops conversations, is isolating* *1416-1418 – you have to protect people from the reality of situation* 1617-1621 – feels overlooked as a carer 1621-1632 - Relationship status not recognised; *feels ignored and de-valued* *1947-1968 – assumption all carers are old and or retired* 1358 – 1379 men as caring / carers does not fit with societal views 1358 – 1379 Woman are better at it / more natural *1379-1388 – lack of peer support is isolating* 1889-1892 - Lack of support offered; *feeling ignored* *1892-1937* - Support for men; *practical challenges*	350-358 - Sense of *achievement / pride* in his care 371-374 - Sense of *achievement / pride* in his care 430-431 - Sense of *achievement / pride* in his care 476-478 - Sense of *achievement /pride* in his care

	1358 – 1379 men as caring / carers does not fit with societal views 1358 – 1379 Woman are better at it / more natural 1359-1379 - My carer role / caring side needs to be hidden *1423-1483 – you have to protect yourself from reality of caring* *1448-1463 – Caring side of me is hidden, but it is the real me*		
Philip	207-210 – natural progression 210-211 – 'obvious' role to step into (purpose) 74-75 – caring for each other (reciprocal)	497-499 – not understood in relation to role 550-555 – stress of autonomy of role 867-868 – isolated (on one to talk to) 868-873 – empty offers of support, despondent, overlooked	79-85 – it has 'slotted in' to lives 139-144 – pride and ownership of his duties 166-169 – pre-occupation with avoiding contamination via house 169-170 – provides meaning and purpose 188-189 – gives him a purpose 223-226 – distraction from horror of situation 227-228 – legitimate distraction 270-272 – reluctant to recede from any roles 272-274 – this is the new 'normal' 298-299 – panic when not able to complete duties 598-599 – universal experience reduced feeling of isolation 1044-1054 – is a coping strategy 1063-1063 – carer role gives purpose 1064-1071 – preoccupied with carer role; exhausting 226-227 – I have got to be doing something all the time 264-266 – I had to sit there, start thinking about things (distressing
Dave	189 – there was no 'choice' 200-204 – caring is a duty of love 204-210 – fit it into life 213-214 – not a duty 745-746 – promise to partner, loyalty	593-595 – underappreciated 940-943 – isolation (some people don't understand how ill partner is)	113-114 – label fits with his experience 213-214 – provides a purpose 277-283 – maintaining partners independence is part of this role 229-235 – prioritising partner is a success 412-420 – useful and with a purpose

			428-431 – maintaining independence, sense of her 546-548 – pride in role 600-603 – protect partners dignity 1024-1030 – continues after their death, purpose 1039-1044 – loyalty continues after their death, purpose
Donald	26-28 – not applicable to my situation 28-29 – hospice provide all care 29-31 – feelings useless / surplus 31-32 – monitors condition from afar 36-241 – household chores not new to me 241-249 – carer role not new to me 219-222 – overwhelming how much to do even with support 252-260 – doing it alone is overwhelming 705-708 – part of marriage (reciprocal) 764-770 – carer role is ethical thing to do 777-778 – fits with sense of identity as husband	440-445 - not feeling heard 709-711 – exceeding societal views of men as carers	1084-1089 – carer role sense of purpose / achievement
John	141-148 – protective 616-655 – financial assistance embarrassment 655-660 – carer role is uncomfortable 664-671 – care role doesn't fit with sense of self 682 – I am here as a husband 687-704 – caring is love 725-729 – responsibility of husband 1034-1039 – partner is priority 1435-1146 – part of vows 1489-1502 – shifting towards identity as a carer	131-135 – isolated and lonely 819-825 – isolated (leaving work) 826-829 – lack of male chit chat 835-838 – loss of contact from other men, isolated 838-846 – excluded no longer needed 849-852 – lost without fulfilment from work 864-869 – misses male comradeship (lonely) 867-872 – constricted 938-941 – undervalued, things go unnoticed 989-992 – little opportunity to say how it how it is, overlooked 1309-1321 – no more regular contact (isolated) 1314-1321 – ever decreasing social contact, lonely	9-10 – different type of busy 223-227 – keeping busy is safety 239-240 – keeping busy means I have a purpose / meaning 347-357 – busy gives a sense of importance and purpose 941-947 – hypervigilant to partners vulnerability 1502-1571 – pride in his efficiency in carer role 1522-1526 – pride in his approach to role 357-360 - structure provides safety 359-360 – pride in achievements (keeping house up) 363-367 – pride and purpose in maintaining house 422-425 – exhausting co-ordinating them 429-431 – the not knowing, biggest problem 431-442 – frustration

			442-444 – anxiety and hypervigilance 446-447 – hide frustration 483-497 – living with uncertainty, anxiety provoking 499-505 – no consistency, anxiety provoking 505-517 – to create structure is exhausting 520-521 – not knowing is frustrating 521-542 - to create structure is exhausting 556-561 – not knowing is very disruptive (worst thing to deal with) 798-808 – trying to make sense by comparing experiences 813-819 – survival 875-881 – it is necessary (practically and emotionally) 890-894 – allow you to switch off (containment) 1177-1186 – part of surviving 1188-1192 – awareness of 'over doing' the structure 1192-1196 – structure provides distraction from real concerns i.e. partners illness 1204-1212 – provides sense of achievement 1248-1258 – uncertainty being fear 1273 – 1283 – trying to seek similarities to help make sense 1422-1427 – being on guard as to who is coming next 1456-1468 – pride in his care for partner 1486-1489 – likening caring to a job, gives purpose structure
George	55-58 – cared for partner before, not a new role 80-81 – dismisses importance of care he provides 86-90 – simplifies carer role 200-204 – is an act of love, not duty 335-340 – it was meant to be (ultimately no choice)	172-178 – male as caring is not recognised 178-179 – male carers are invisible 182-187 – society creates gender divide in who cares 187-192 – frustrated with gender roles, over looks men as individuals 192-194 – painful when you do not fit into society 204-212 – pride in advocating for men 209-212 – male carers are overlooked / invisible	198-200 – provides meaning and purpose 389-394 – prioritising home gives sense of control 398-402 – removing self from outside world creates sense of control 457 – coping is a day to day approach 535-538 – being a 'good carer' doing it all yourself

		215-217 – frustration with caring being seen as a female role 220-227 – advocating gives meaning, a greater cause 268 – they would for a girl 269-270 – fighting for a bigger cause 300-303 – pain at being overlooked 522-525 – hope for future men 650-652 – carers are invisible, hand holders and taxi drivers 672-673 – carer is a carer irrespective of gender 674-677 – stereotypes of genders mean men are overlooked / role not acknowledged 680-682 – men – we do care 683-686 – societal view of men as 'tough' is damaging 704-711 – men as caring needs to be accepted by society	
Carl	457-578 – marriage is a 50/50 situation 478 – caring is a labour of love 479-486 – no decision process, natural thing to do 491-496 – previously cared for partner 509 – duty as husband 510-511 – emotionally painful 530-536 – protects partners dignity		230-231 – jack of all trades 230-231 – present from beginning 407-414 – there's no way (I leave her side) 453-457 – carer roles give a purpose 466-474 – housework is something that I *can* do 393-395 – preoccupied about partner not being alone 513-514 – gives a purpose
Michael	170-172 – embarrassed about praise 174-176 – husbands' responsibility 179-181 – uncomfortable at suggestion decision was made 184-192 - my duty 195-196 – exceeded his expectations as a carer 355-357 – survival mode (do what you have to do) 442-443 – redefining self, sense of disbelief 470-473 – "there isn't *a lot* to do" 550-551 – caring role is specific to partner 596-597 – inspiring and intimidating 672 – minimises changes, guilt for noticing	83-87 – overlooked as a decision maker 306-310 – feeling excluded / overlooked 322-325 – feeling 'fobbed off' 366-369 – anger (change without consultation)	453-459 – toileting, challenge accepted 463-468 – partner prioritised over own discomfort 472-479 – 'owning' housework as his responsibility 482-485 – this is my 'job' 509 -521 – pride in exceeding expectations 520-521 – shame in feeling pride 819 -825 – developing sense of skill in his caring 856-862 – using qualities and skills from job

	losses		
	Help-seeking		
	Incompatible	***Being a man***	***As a last resort***
Bruce	357-359 – wants to be with partner all the time 359-361 – my priorities are my partner 361-367 – time apart needs to be negotiated 367 – being apart from partner is unthinkable 401-403 – make the most of moments left together 431 – 436 – expectation that husbands are strong for their partner 600-601 – wanting to hang on to ever minute possible with partner 933-946 - identity as someone who has had therapy / support *discomfort discussing* *966-979* – there was a (justifiable) physical reason for accessing support historically *978-979 - I manage, I am no longer vulnerable* *979-989* - Support cut *sadness? Relief? Ambivalence / passivity* 999-1009 - Therapy is time away from Partner - *Guilt* 1503-1522 - Expectation of self to be able to 'cope' 1776-1778 – hide feelings from partner 1799 – Crying in front of partner; *shameful* 1019-1027 - Accessing help now; *I am not a priority*	190 - *Minimises* his pain 702-710 - cuts of topic too much to bear 1423-1438 – being emotional is embarrassing (shameful) 1477-1498 – I am now cry, a lot and I don't like it 1523-1526 - Self as vulnerable; *not acceptable* 1542 - Self as emotional; *not acceptable* 1634-1656 – no control over emotions feels weak 1715-1719 – Crying in public; *shameful* 1776-1782 – Crying; *weakness* 1832-1835 - Public crying; weakness *1892-1937* - Support for men; *needs to be 'permission giving' to get emotional*	811-814 – would not know signs that it might be useful 833-834 – stubbornness (pride) gets in the way 846-849 – alien territory, fear 1029-1032 - Self-care; *not a priority (loss)* 1045-1056 - Self-care; *unsure if he does it* 1073 - Recognising need for help; *wouldn't know how* 1075 - His well-being; *minimises (focuses on positive)* 1077-1078 - Recognising need for help; *focus on physical / others telling me*
Philip	66-74 – guilt at the 'added complication' 176-179 – took him away from carer role (helpless) 179-180 – recovery takes him away from carer role (guilt) 180-185 – guilt, there are others worse off 255-259 – conflict of being ill at the same time as partner	234-235 – feelings need to be avoided 301-303 – being alone with thoughts distressing 305-308 - being alone with space to think distressing 419-422 – "got to solider on" 240-242 – predisposition to anxiety 281-286 – facing thoughts is torture 287-288 – dismissing impact of illness	959-960 – unsure if able to recognise signs emotional support was needed 962-969 – best to wait it out 970-974 – unsure how to recognise signs emotional support is required

	260-263 – conflicting demands are impossible to reach 270-272 – regaining normality (recovery) 296-297 – stood in way of carer role 480-483 – frustration at being asked to prioritise own health 692-700 – fear missing a moment with partner 1063-1071 – self-care is indulgent	288-290 – stigma of own mental health 293-296 – sleeping as an avoidance strategy 484-487 – "you can't just cut off from that – I wish you could" 488-491 – impossible to describe how I am feeling, I don't know how I a feeling 497-499 – "I wish someone could give me a magic pill to do that" 507-512 – need to escape from it 507-512 – distraction from them is the best way of dealing with them 541-547 – "and my minds' on all sorts of negative things" 738-743 – my emotions are uncomfortable (for others) 878-881 – emotions in front of others makes you vulnerable 883-884 vulnerability 888-889 – shame 897-904 – feels a burden to others when he does become emotional 903-911 – conflict of whether to share emotions, confusing 909-911 – "they say it does you good, I am unsure about that" 922-928 - women are better at emotions 928-932 – men don't do talking (conflicted) 940-947 – "which men never ask" – isolated 947-951 – men don't know *how* to approach subject	
Dave	750-785 – open to possibility in future (avoidance) 804-806 – hard to 'admit' it might useful (weakness) 698-701 – outward positivity protects everyone 669-671 – protect partner, focus on positives	494-495 – nowhere to direct anger to, lost 497-499 – protect partner from feelings 791-793 – is not 'manly' 714-718 – make you vulnerable, protect others and self-from them 751-755 – it will pass, carry on 753-755 – acceptance of rollercoaster of emotions 848-849 – sign of weakness	373-377 – counselling comes at crisis point 723-725 – when feeling lowest is when I think of counselling 795-802 – is a last resort 726-727 – counselling is a sign of weakness 727-735 – strong willed (sense of self) 744-745 – pride in strength 780-785 – is a last resort

		867-875 – overwhelming, cant voice it 881-885 – too big to put into words, overwhelming 817-820 – does not fit with sense of self 822-826 – not a 'manly' thing to do	
Donald	447-454 – initial offers of help overwhelming (state of shock) 457-464 – offers of help do not come at the right time 467-470 – support so far is partner focused 616-620 - how would counselling help? 620-621 – ambivalence towards counselling 696-698 – help is for the ill (weak)	117 – no dwelling on pain 229-230 – my pain needs to be justified 341-343 – others platitudes. Angry 422-425 – feeling overwhelmed turns to anger 697-698 – you've just got to make the most of a bad job 836-837 - no room for 'moaning' 1107 – sadness hidden by laughter	
John	212-215 – how would therapy help me? 244-249 – therapy is futile in this situation, alone and isolated 253-254 – sharing emotions will burden others 254-256 – therapy isn't going to change my partner dying 386-390 – role as head of family is motivation, purpose 1076-1079 – my problems are insignificant to partners	210 – I'm not really like that 210-212 – self reliant 263-274 – doesn't fit with view of self 289-293 – sign of weakness 321-324 – it isn't for me 996-998 – can't be seen to be moaning 998-999 – 'moaning' is weak 999-1000 – you bit the bullet and do what is necessary 1153-1155 – pride in self-sufficiency	1120-1122 – faith in some HCPs would be able to help
George	90-93 – home becomes epicentre of world 319-327 – world revolves around home 319-327 – guilt for feeling frustrated 532-535 – does not fit with sense of self 540-544 – important to appear to be coping 544 – 547 – biting the bullet 535-538 – being a 'good carer' doing it all yourself 539-540 – protecting partner from true feelings is partners duty 580 – asking for help is a 'sin', shameful admits weakness 646-652- support offered is patient focused	560 – release to talk about himself 'unburdening pain' 572-578 – coping style is part of identity 608-612 – pain of this 'breaks through' grief is overwhelming needs to be caged 617 – 620 – guilt, mustn't complain	586-587 – reaching crisis point 587-593 – physical effects then access support 600-604 – when things reach crisis point

Carl	444-449 – no room for carers' distress, partner is put first 232-233 – cannot show emotions 265-266 – thinking gets you know where 429-431 – emotions need to be hidden	460-465 – having to 'step up' 603 – fear of being considered 'drama queen' 607 – fear of 'going on a bit' 614 – fear of using drama queen language 650-652 – exposed his true inner feelings	
Michael	725-728 – stigma of 'needing' therapy 728-732 – how is this going to help me? 734-739 – distrust 741-749 – ambivalence 954-959 - ambivalence towards help 965-971 – fear of being deemed to be 'not coping'	160 – embarrassment 762-763 – embarrassment of 'being emotional' 764-770 – keep a safe distance from 784-789 – emotions are scary, leaves them with people 959-965 – emotions are to be avoided and 'gotten over'	912-918 – others would tell me if I needed help 823-825 – external symptoms are ok to acknowledge 828-830 - external symptoms are ok to acknowledge

Appendix L: Extract from reflective journal

Thoughts about Philips emerging themes

He tries to take a positive stance throughout, pain too much. Comparing to others situation, allows him to be thankful / grateful for what he does have; the relationship with wife and their time left together

Talks a lot about his wives experience, why did I let this happen? Engrossed in the story, felt rude to stop him talking about what ie wanted to. His experience is wrapped up in partners.

Lots of comparisons, doesn't want to seem to be moaning? Worried what others think? Sense making his own, well at least it isn't as bad, minimises pain?

Interesting absence of how she was diagnosed what let to diagnosis, too painful to re-visit?

Every time he stops, the grief and pain he feels has an opportunity to 'take over'. Maybe this is why the interview was so emotionally charged? He became visibly upset, with tears a few times throughout.

Feels like he uses stories a lot, past events, safer than being in the moment with his feelings? Protecting self.

Partners treatment was appalling, chemo stopping for a surgery that never happened due to Beth being "forgotten", then she nearly dies, 2 days later the surgery is offered, which she can no longer take part it as the tumour had ruptured. This continues with being told she is palliative, given meds she improves, comes to end of course dismay, possibility of extending treatment, up and downs. Oscillates between hope and hopelessness