PERSON-CENTRED CARE AND RELATIONSHIP CONTINUITY IN SPOUSAL RELATIONSHIPS

By

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A thesis submitted to the University of Birmingham for the degree of

DOCTOR OF PSYCHOLOGY

School of Psychology

University of Birmingham

August 2023

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ABSTRACT

Objective: The purpose of the thesis was to explore the applicability of the concept of person-centred care (PCC) to the care provided by spouses/partners to people living with dementia and to explore whether perceptions of continuity within the relationship influence how person-centred the care is. With a view to laying the foundations for future interventions aimed at enhancing PCC within the home setting, the thesis also provides a systematic review of evidence about the effectiveness of educational interventions in enhancing PCC.

Methods: A mixed-methods approach was used, including a qualitative study exploring the variations across spousal carers in terms of how person-centred their care is when supporting their partner with everyday tasks and a mixed-methods study investigating whether spousal carers' experiences of relationship continuity is associated with providing a more person-centred approach to care. In the systematic review, few studies involving family carers were found and so the review focused on educational interventions for staff working in dementia services.

Results: Overall, the findings from the systematic review found that there was little evidence that educational interventions alone can provide reliable and substantial improvements in the delivery of PCC in staff. Study 2 suggested that the ideas of PCC are applicable to spousal carers and that there is a significant variability in the degree to which they exhibit PCC. Participants reported little awareness of the concept of person-centred care and little guidance and support from services about how best to provide care. The mixed-methods study (Study 3) found that perceptions

of continuity in the relationship were associated with significantly more frequent references to a person-centred approach to care (rho=.39; p=.04).

Conclusion: Spouses/partners do not always provide care that is person-centred and there is scope for improving their understanding of best practice and for providing better support and guidance about how they can best provide care. The systematic review suggested that educational interventions alone may not be adequate for improving the quality of care, and the provision of information needs to be supplemented with other interventions. Focusing on the quality of the relationship, and specifically perceptions of continuity within the relationship, may provide one way forward.

ACKNOWLEDGMENTS:

I would like to express my sincere gratitude and appreciation to all those who have supported me throughout the completion of this thesis.

First and foremost, I extend my deepest thanks to my supervisor, Dr. Gerard Riley, for providing me with the invaluable opportunity to undertake this research and for their continued guidance and support. Their expertise, insightful feedback and encouragement have been instrumental throughout this journey.

I am also grateful to my second supervisor, Dr. Jan Oyebode, for their valued collaboration and contribution. I would also like to extend my heartfelt appreciation to the Alzheimer's Society for granting me the opportunity to pursue this research.

I would like to express my profound gratitude to my family for their love and support. To my parents, Catherine and Ottavio, and my brother, Hadrien, thank you for providing the encouragement I needed to persevere. I would also like to acknowledge my beloved cats, whose playful antics and comforting presence provided a much-needed respite during challenging times.

Finally, I want to express my deepest appreciation to Saba for his continuous encouragement and unwavering support.

PUBLICATION OF RESEARCH REPORTED IN THE THESIS:

During the course of my PhD within the School of Psychology, University of Birmingham, the following article, based on research conducted for this PhD, was published. I took charge of all aspects of the review including its design, execution, analysis and the preparation of materials for publications. While secondary authors primarily contributed feedback on study design, data analysis, and paper editing, the overall direction and decision-making were under my purview. Chapter 3 describes this research and includes a copy of the paper as published.

Carparelli, C., Jones, C., Oyebode, J. R., & Riley, G. A. (early online). A systematic review of the effectiveness of educational interventions in promoting person-centred care in dementia services. *Clinical gerontologist*. https://doi.org/10.1080/07317115.2022.2152515

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CHAPTER 1: Overview of thesis

How good is the care provided by family members to a spouse/partner who is living with dementia? Evidence about levels of physical and emotional abuse in this context (Selwood & Cooper, 2009; Cooper et al., 2010) suggests that the standard of care does sometimes fall below an acceptable level, but there is little evidence about less extreme shortfalls in the quality of care.

Person-centred care (PCC) is widely promoted in institutional settings and is considered by many to be the gold standard against which institutional care should be evaluated (National Institute for Health and Clinical excellence, 2016). This thesis explored whether PCC is a useful way of evaluating the care provided by spouses/partners, and whether carers vary in how person-centred their care is.

Given the ethical value of PCC and its potential benefits for the well-being of both the person giving and the person receiving care (Li & Porock, 2014; Brownie & Nancarrow, 2013; Kim & Park, 2017; Olsson et al., 2013; Barbosa et al., 2014; Rajamohan et al., 2019), evidence that family carers do not always provide person-centred care would suggest the importance of understanding the reasons for this variation. Earlier research indicated a link between the quality of the relationship (specifically whether the spousal carer perceives continuity in the relationship) and the degree of PCC evident in how the carer responded to challenging care needs such as aggression (Riley, Achiampong et al., 2020). This thesis extended research on this issue by exploring the link in the context of providing care and support for the tasks of everyday living.

The value and benefits of PCC also suggests the importance of developing interventions to support family carers in providing more person-centred care. As a

contribution to this development, the study also reports a systematic review of evidence for the effectiveness of educational interventions in improving the person-centeredness of care. Few studies addressing this issue in the family context were found, and so the review focused on paid carers working in dementia services. However, it was anticipated that the findings of the review would have at least some applicability to considering how best to support family members to deliver high quality care.

The thesis is comprised of the following chapters:

- Chapter 2 introduces the key concepts included in this thesis and provides an overview of the relevant literature. This chapter briefly covers dementia and its prevalence as well as the prevalence of family carers in supporting people with dementia. It also provides an overview of the concept of PCC, the literature highlighting its benefits and its implementation in practice. Furthermore, it discusses the concept of relationship continuity and the existing literature suggesting a link between relationship continuity and PCC.
- Chapter 3 presents a systematic review of the effectiveness of educational programmes in promoting the delivery of PCC by staff in dementia services. Given that PCC has been predominantly applied in dementia services and that the majority of these services rely on educational programmes to promote the implementation of PCC by staff, this chapter focuses on evaluating the impact of educational programmes on the delivery of PCC by staff. Several databases were searched and eighteen studies were identified for this review.

- Chapter 4 qualitatively explores how spousal carers conceptualise and describe the nature of the support that they provide. It also examines the differences across carers in the extent to which the care provided is person-centred. 30 spousal carers participated in interviews on how they support their spouses with everyday tasks and the factors influencing their caregiving approach. This study also sheds light on the barriers encountered when delivering PCC in spousal settings.
- Chapter 5 expands on the previous study by exploring the relationship between relationship continuity and variations in the person-centredness of the care provided by the spousal carers. Employing a mixed-methods approach, this chapter utilises the participants' interviews from the previous study and their results in the Birmingham Relationship Continuity measure (Riley et al., 2013) to investigate the hypothesis, supported by existing literature, that continuity contributes to a more PCC-oriented approach.
- The final chapter summarises the thesis's main research findings, reflects on the limitations of the current work and suggests directions for future research. The results from the studies may aid dementia services to further understand the current limitations of existing educational programmes being delivered and inform the further development of interventions aimed at enhancing PCC in spousal relationships, potentially by increasing perceptions of continuity within the relationship.

For a visual presentation of the aims and chapters of the thesis detailed above, please refer to Figure 1.

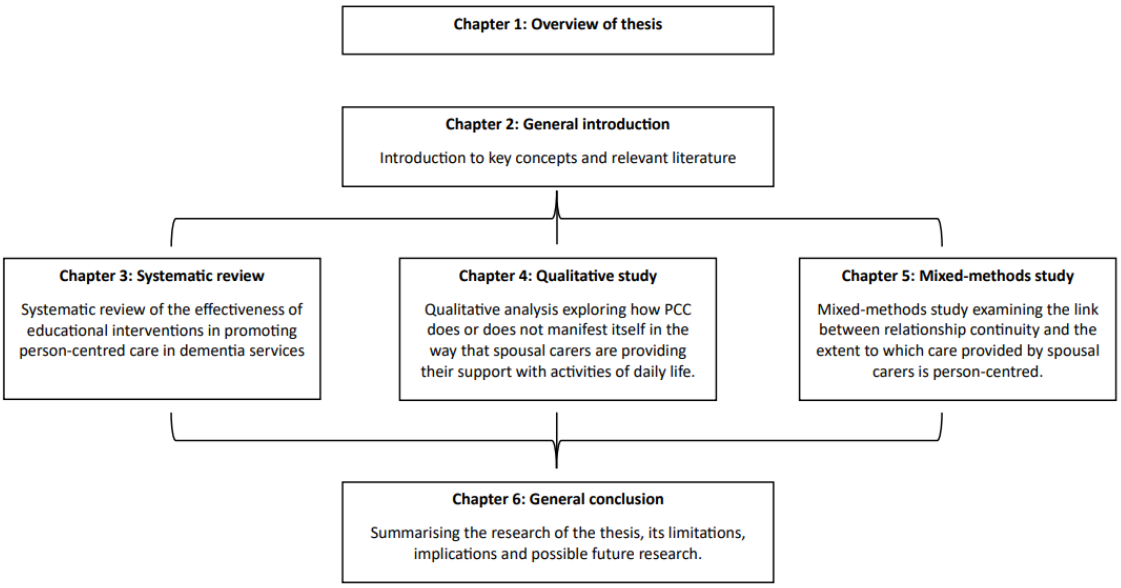


Figure 1. A visual representation of the current thesis chapters and aims.

CHAPTER 2

Introduction

Dementia:

Dementia is a syndrome characterized by a general decline in cognitive function, often accompanied by memory problems that progressively worsen, impairing the ability to perform daily tasks (Husain & Schott, 2016). Dementia is typically associated with underlying neurodegeneration, which can be caused by a variety of reasons including various diseases or damage to brain tissue. The most common type of dementia is Alzheimer's disease, marked by an insidious decline in memory, followed by a loss of other cortical functions and the ability to perform daily tasks (Quinn, 2013). Other common types of dementia include vascular dementia (characterised by a sudden onset, a stepwise course, and an association with strokes), Lewy body dementia (characterised by Parkinsonism, neuroleptic sensitivity, visual hallucinations and fluctuations) and fronto-temporal dementia (characterised by personality changes, disinhibition and/or expressive language impairment) (Quinn, 2013).

While there is currently no cure for the underlying neurodegenerative conditions causing dementia, there are medicines and treatments available to help alleviate symptoms. Most licensed medications are aimed at treating Alzheimer's Disease and have been suggested to slow the degenerative process, at least in the early stages (e.g., Donepezil). Although these are not aimed at helping the person cope with its impact, these treatments can help relieve some symptoms or slow down their progression (Tisher & Salardini, 2019). Other medicines targeting related conditions (e.g., heart problems), may also alleviate some symptoms of dementia, particularly in vascular dementia (Tisher & Salardini, 2019). Non-pharmacological interventions like cognitive stimulation therapy, cognitive rehabilitation, and reminiscence and life story

work have shown promise in slowing the progression of symptoms in the early stages of the disease, improving cognitive, mood and quality of life (Tisher & Salardini, 2019).

Dementia is more prevalent in older people, and as life expectancy continues to rise, so does the incidence of dementia. According to Prince et al. (2015), in 2015, over 46 million people were living with dementia worldwide, and this number is projected to rise to 131.5 million by 2050.

Family carers:

Family carers, particularly spouses, provide the majority of care for people with dementia, especially in the early stages of the disease. According to a report by the Alzheimer's Society (2014), there were around 670,000 informal carers of people with dementia, the majority of whom were spouses (Lewis et al., 2014).

Although this allows people with dementia to have a higher quality of life than they would otherwise and typically need institutional care less quickly (Brodaty & Donkin, 2009), caring for someone living with dementia has been shown to have negative effects on carers' well-being (Donaldson et al., 1997). Caring responsibilities have been linked in the literature with increased stress and psychological and physical strain (Lieberman & Fisher, 1995; Poulin et al., 2010). In fact, a meta-analysis found that compared to non-carers, carers of frail older adults showed higher levels of depression and stress and lower levels of well-being and physical health (Pinquart & Sorensen, 2003). There is also a significant body of research that highlights the impact of dementia on family relationships and the spousal relationship in particular. Several reviews have synthesized the available evidence, including Ablitt et al.

(2009), Evans and Lee (2014), and Wadham et al. (2016). These reviews consistently find that dementia can place significant strain on family relationships. Spousal relationships are often affected the most, with partners of people with dementia experiencing high levels of burden, stress, and depression. Caregiving responsibilities can also strain relationships, with partners often taking on the majority of caregiving duties and feeling overwhelmed and isolated as a result.

Although the majority of care is being provided by family carers, there is very limited research on the quality of care provided by partners and spouses and the factors that influence it. Some research has investigated levels of abuse of people with dementia by family carers and has found evidence of abusive behaviour being common (Cooper et al. 2009), showing one way in which the quality of care can fall below what should be provided. Another study did include a measure of the quality of care being provided by spousal carers by developing a measure of PCC in spouses and did find evidence of less person-centred behaviours in some of the participants (Ellis-Gray et al., 2014).

The quality of care given by family carers is likely to have a major impact on the person with dementia. Studies of paid carers have found that a higher quality of care (specifically, more PCC) is associated with improved psychological well-being on the part of the person with dementia, reduced frequency of behavioural and psychological symptoms of dementia, and decreased need for medication (Poulin et al., 2010; Li & Porock, 2014). The research also suggests that higher quality of care provided by paid carers, is associated with benefits for the well-being of the carer as well, i.e., increased job satisfaction, reduced stress, reduced burnout, reduced turnover and increased confidence in their ability to provide care (Barbosa et al.,

2014; Brownie & Nancarrow 2013; Rajamohan et al., 2019). It seems very plausible to suggest that better quality of care provided by family members may have similar benefits.

There is currently a lack of research looking into the association between quality of care provided and outcomes for the person with dementia and the carer in home settings, however. A systematic review (Hazzan et al., 2014) looked into studies examining the relationship between quality of care provided and caregiver quality of life and only found one study that was relevant which showed that higher quality of care provided was related to higher caregiver quality of life (Gitlin et al., 2003). However, it should be noted that although the study indirectly touched upon this relationship, it was not specifically designed to examine it.

Given the findings about the benefits of high-quality care in institutional settings and the limited evidence about its benefits in home settings, it is crucial to investigate the quality of care in spousal carers of people with dementia and to identify the factors that influence it. A framework very often used in assessing the quality of care is provided by the idea of PCC.

Person-centred care:

Overview of Person-centred care

Person-centred dementia care is an approach widely recognised as the best approach to care for people with dementia (National Institute for Health and Clinical Excellence, 2016). This approach to care has been accepted in many countries as an important guiding principle of the provision of care and aligns with the ethical values of these countries (Health Foundation, 2015; Paparella, 2016). For example, the

importance of PCC is evident in UK legislation and policy. One specific aspect of PCC, involving people in decisions about their care, has been set as a requirement for services by the Health & Social Care Act (2012) and the National Institute for Health and Clinical Excellence (NICE) in 2018 highlighted that good practice dementia care is underpinned by the principles of PCC.

The concept of PCC was developed by Kitwood (1997) who disagreed with the medical approach of focusing on the diagnosis and treatment of the disease and suggested that, as dementia varies from person to person, care should be individualised (Fazio et al., 2018). Kitwood believed that the experience of dementia is not determined by neurological impairment alone, but by the interactions between neurological impairment, physical health, personality, biography and what he termed 'social psychology'. He emphasises that we are all supported by those around us, but that those with dementia rely more heavily on others due to their neurological impairment. Because of this, the type of support received is crucial as it may undermine (i.e., malignant social psychology) or promote (i.e., positive person work) the personhood of those living with dementia (Brooker, 2004). Kitwood emphasised the importance of the relationship between the care-giver and care-receiver in promoting personhood, which he understood in terms of a positive status or standing with others as an individual deserving of recognition and respect. The notion of personhood, as proposed by Kitwood, is advanced by offering comfort, fostering attachment, ensuring inclusion and nurturing a sense of identity and continuity with the individual's past experiences (Kitwood & Bredin, 1992). It is undermined by care that fails to acknowledge the person as an individual with their own unique history, their own unique perspective, and their own needs, wishes and goals, and by care

that fails to provide an environment in which the person feels respected and valued. Kitwood's work was heavily influenced by Carl Rogers (1995) and the concept of "unconditional positive regard", which he believed was necessary for individuals to develop to their full potential. The application of this concept to dementia care emphasized the importance of the relationship between the care-giver and care-receiver in promoting personhood and enhancing the quality of life for people with dementia.

Brooker has provided a framework for understanding and applying PCC: the VIPS framework (Brooker, 2004; Brooker & Latham, 2015). The principles of the framework are: Valuing people with dementia and those who care for them (the 'V' principle), treating people as Individuals (the 'I' principle), taking on the Perspective of someone with dementia (the 'P' principle) and creating a positive Social environment for people with dementia (the 'S' principle).

Benefits of PCC

Numerous studies have explored the impact of providing PCC in health and social care contexts. These have highlighted benefits for both people with dementia and paid carers. For people with dementia, the benefits include decreased behavioural 'symptoms', decreased use of medication, improved emotional well-being and improved quality of life (Li & Porock, 2014; Brownie & Nancarrow, 2013; Kim & Park, 2017; Olsson et al., 2013). For paid carers, the benefits include increased job satisfaction, reduced stress, reduced burnout, reduced turnover and increased confidence in their ability to provide care (Barbosa et al., 2014; Brownie & Nancarrow 2013; Rajamohan et al., 2019).

Additionally, although there is a gap in research into using the concept of PCC to understand the care provided by family members, some studies have identified benefits of individual aspects of a person-centred approach. For example, on the basis of qualitative interviews with family carers, Perry and O'Connor (2002) suggested that maintaining personhood in the person with dementia is also beneficial for the carers as they were able to maintain their identities as husbands and wives.

PCC in practice

Although PCC is widely accepted as the standard to which services should aspire, everyday working practices in residential and nursing units often fall short of the standard, even when the unit explicitly endorses the principles of PCC. Clisett et al. (2013) observed ward practices and found that although there were instances of good care practice, staff were not utilising all opportunities to promote personhood for people with dementia. They found that good care practices happened at the individual level with some staff members exhibiting more PCC behaviours than others, but there was no consistency at the organisational level in applying PCC.

The reasons for this failure to deliver PCC in everyday practice are unclear. Some have attributed the lack of application of PCC to its ambiguous definition and the numerous interpretations of the concept (Clisett et al. 2013; Higgs & Gilleard, 2016; Edvardsson et al., 2008). Kogan et al. (2016) carried out a review to identify the definitions for PCC and the elements required for quality PCC in the existing literature and found 15 definitions presenting 17 different principles and values. Another reason is likely to be that staff are not being effectively trained or supported in providing PCC. There is considerable uncertainty about the most effective way to

provide such training and support. Although various training packages and interventions have been developed, evidence for their effectiveness is mixed, with some studies failing to report any benefit (Buron, 2010; Bateman et al., 2016; Dichter et al., 2017). There is a clear need to understand which strategies are successful in promoting PCC (Epp, 2013).

To date, PCC and the VIPS framework have mostly been employed in institutional and nursing home care settings. A systematic review conducted by Kim and Park (2017) found that most research was conducted in these settings, with only two studies focusing on home-based care. Furthermore, these two studies focused on the care provided by professional therapists in the home setting rather than family caregivers. However, the principles of PCC can be applied equally to care provided by family members in the home setting. Kitwood's (1997) concept of PCC was not initially specific to institutional care but encompassed care generally and emphasised the importance of the personal relationship between the care-giver and the care-receiver. In effect, many have suggested that the relational aspect of PCC should be given greater emphasis, advocating for "relationship-centred" rather than person-centred care (Beach et al., 2006; Nolan et al., 2004). If the personal relationship between the caregiver and care-receiver is central to the quality of the care provided, then the concept of PCC should have equal relevance to the care provided by family carers.

Previous qualitative studies have shown that the degree to which the care provided by spouses is person-centred, differs from couple to couple. In an observational study, Ellis-Gray et al. (2014) recorded instances of spouses providing support to their partner on everyday tasks. These observations were rated according

to how person-centred they were, using the VIPS framework as a guide. The findings showed variation across spouses in terms of how person-centred their care was. Qualitative research has indicated that some spouses try to promote individual aspects of PCC, specifically the sense of agency, through for example maintaining their involvement in decision-making or helping them maintain their competencies (Hellstrom et al., 2007; Perry & O'Connor, 2002). However, research has revealed that many clearly struggle to maintain a PCC approach and tend to exhibit higher rates of verbal and physical abuse as a result (Selwood & Cooper, 2009; Cooper et al., 2010). In care lacking a person-centred approach, the diagnosis of dementia often takes precedence over the individual, hence the carer's responses become depersonalised and the person with dementia becomes devalued and almost dehumanised. Due to the potential benefits of PCC on the well-being of both carers and people with dementia, it is important to find a method that can help promote PCC behaviours in caregiving spouses. As most interventions to increase PCC have been designed for institutional settings, it is thus paramount to design an intervention specifically for caregiving spouses as it is estimated that one in three people will eventually care for someone living with dementia (NHS England, 2021).

Interventions involving family carers have often focused on providing information about dementia and on improving the emotional well-being of the carer (Kishita et al, 2018; Selwood et al., 2007; Cheng & Zhang, 2020; Schoenmakers et al, 2010; Gilhooly et al., 2016; Alves et al. 2020). Where the focus is on developing specific caregiving skills, these are typically not focused specifically on making the care more person-centred (Cheng & Zhang, 2020; Alves et al. 2020). When both the carer and the person with dementia are included in the intervention, the focus has

been on enhancing various aspects of relationships (Gilbert et al., 2023, Moon & Adams, 2013), cognitive function and emotional well-being (Bielsten & Hellstrom, 2019a, 2019b; Moon & Adams, 2013; Rausch et al., 2017).

A systematic search was carried out to identify family interventions that have specifically targeted making care more person-centred. Guest and Smith (2021) reported on a training programme designed for African-American caregivers that they described as 'person-centred'. However, the paper provided no discussion of the concept of PCC or evidence that the intervention was informed by the principles of PCC. It is possible that the term 'person-centred' was used loosely to mean involving the participants more in the process of care. *iSupport* is an online intervention for informal carers of people living with dementia (Pot et al., 2019). It is sponsored by the World Health Organization and is particularly targeted at carers in developing countries, and reports of its use relate to these contexts (e.g. Baruah et al., 2021). The programme includes five themes covering the nature of dementia, what is involved in being a carer, looking after oneself, providing everyday care, and dealing with challenging behaviour. The authors state that "The content of iSupport is based on the ground-breaking Kitwood's model, in which the personhood of someone with dementia is central, and in which care is essentially thought of as interaction, according to each individual's needs, personality and ability." For example, the advice relating to food includes suggestions about including the person with dementia in food preparation rather than doing it all for them.

Studies that have evaluated *iSupport* have reported limited benefits. For example, in a randomised controlled trial conducted in India, Baruah et al. (2021) found no difference between the treatment and control groups on measures of

depression, perceived burden, self-efficacy, mastery and self-rated health, with the only difference occurring on the Attitudes to Dementia Questionnaire which assesses whether a person's attitudes to dementia are person-centred or not.

These modest findings do raise questions about how such an intervention could be improved. The intervention involves the provision of information only and there is no interactive element or other kinds of training. The systematic review reported later in this thesis does suggest that simply providing information may not be sufficient to ensure that care is more person-centred. Another issue is that it is unclear how well the intervention is based on research about providing person-centred care in the home context. Other aspects of the thesis address issues about how person-centred family care is and what factors may influence its provision. A better understanding of these issues may enable the development of more effective interventions.

Relationship continuity:

Some studies have suggested a link between PCC and the concept of relationship continuity. Relationship continuity refers to the carer's perception of the relationship with the person with dementia (Riley et al., 2013). Continuity occurs when the carer feels that the relationship has remained essentially the same post-dementia compared to pre-dementia despite the changes brought about by dementia. On the other hand, discontinuity occurs when the carer perceives the person with dementia and their relationship as fundamentally different post-dementia compared to pre-dementia (Riley et al. 2013; Riley et al., 2018). The experience of relationship continuity lies on a spectrum and spouses differ, and may even fluctuate, in how continuous they view their relationship over time (Walters et al., 2010).

Several qualitative studies have explored the link between relationship continuity and PCC, suggesting that discontinuous perceptions of the relationship may be associated with more controlling and restrictive ways of coping from the carer, resulting in less PCC-oriented behaviours. In contrast, continuous perceptions of the relationship have been associated with more tolerant and empathic responses from the carer, resulting in more PCC-oriented behaviours (Walters et al. 2010). A study by Riley, Achiampong et al. (2020) specifically aimed to investigate the association between continuity of the spousal relationship and PCC in spousal carers of people with dementia. The study compared the outcomes of spousal carers on the Birmingham Relationship Continuity Measure (Riley et al., 2013) with the attributions obtained from interviews regarding the factors underlying their partner's challenging care needs. The results showed that higher levels of continuity in the relationship were associated with higher levels of PCC. In addition to the work in dementia care, there is also evidence linking relationship continuity and PCC in the context of acquired brain injury. A review by Riley, Keeble et al. (2020) summarises earlier qualitative studies and reports an additional study on the link between relationship continuity and PCC in this population. The study compared outcomes of spousal carers on the Birmingham Relationship Continuity Measure (Riley et al., 2013) with their reported responses to their partners' challenging behaviours during interviews. The study showed findings consistent with those in dementia care, with greater continuity perceptions being associated with more empathic and person-centred behaviours from carers.

From a theoretical perspective, the link between relationship continuity and PCC behaviours makes sense as the relationship between the carer and the person

with dementia is at the centre of the concept of care. When spouses view their relationship as discontinuous, they believe that the person with dementia is no longer the same individual fundamentally. Hence, it makes sense that the knowledge and schema the caring spouse used for understanding their partner no longer seems relevant or appropriate to them. Consequently, they may abandon the use of their in-depth knowledge of that person as an individual, and instead switch to applying a more generic approach, relying on a broad understanding of how dementia affects people and their needs (Riley et al. 2020; Villa & Riley, 2017). Having discontinuous views of the relationship may cause the carer to be less likely to respond to the person with dementia's individual needs as they apply a more generic understanding of caring; which directly contradicts the 'I' principle of the VIPS framework: "treating people as individuals".

Summary and rationale:

Caring for people with dementia often falls to the family and specifically to their partner/spouse (Lewis et al., 2014) and the quality of care provided by these family caregivers is likely to have a significant impact on the well-being of both the caregiver and the care-receiver, as well as the progression of the decline in the care-receiver's abilities (Brodaty & Donkin, 2009; Poulin et al., 2010; Li & Porock, 2014). However, despite the critical role of family caregivers, there is little research focusing on the quality of care they provide and how it might be optimised.

The current thesis applies the concept of person-centred care to explore the quality of care provided by spouses/partners for the completion of tasks of everyday living. It investigates whether carers vary in terms of how person-centred their care is, and explores some of the issues that may explain this variation. Specifically, it

investigated whether there was a correlation between person-centredness and the carer's perceptions of continuity within the relationship (Study 2). The qualitative study (Study 1) also provided participants with the opportunity to describe reasons why they sometimes did not apply, or found it challenging to apply, a more person-centred approach.

Given the value and potential benefits of PCC, interventions to promote more person-centred care in a family context are needed. A systematic search revealed only one such intervention, the *iSupport* programme (Pot et al., 2019). Evaluations of this intervention have reported only modest benefits (e.g. Baruah et al., 2021). A better understanding of the reasons for variation in the person-centredness of family care, as outlined in the previous paragraph, may enable the improvement of such programmes. The programme is also focused primarily on the provision of information in an educational format. Because of cost, this has been the primary method of trying to enhance PCC in institutional and dementia service settings (Hunter et al., 2016a; Surr & Gates, 2017) but questions have been raised about whether simply providing more information is sufficient to bring about real change (Aylward et al., 2003; Hunter et al., 2016b; Surr et al., 2020b). This thesis therefore reports a systematic review of educational interventions to enhance PCC in dementia services. Although this does not directly address the effectiveness of interventions in the home setting, lessons from service settings are likely to have at least some implications for the development of interventions intended for family carers. It was considered preferable to review this body of evidence rather than the PCC-related interventions for family carers because of the very limited number of family studies, particularly at the time at which the review was completed.

CHAPTER 3: A Systematic Review of the Effectiveness of Educational Interventions in Promoting Person-Centred Care in Dementia Services

Abstract

Objectives: To review evidence about the effectiveness of educational programmes in promoting the delivery of person-centred care by staff in dementia services.

Methods: Several databases were searched, and the methodological quality of identified studies systematically evaluated. A summary mean effect size was calculated for several types of outcome (direct knowledge, applied knowledge, attitudes, self-reported and observed working practices).

Results: Eighteen studies were identified. Results were mixed, with findings of no change, significant improvement, and (in attitude) significant deterioration. Effect size was modest for direct knowledge (standardized mean difference = 0.6), but small or negligible for applied knowledge (0.29) and self-reported (0.06) and observed (0.25) working practices. There was a negative effect for attitudes (-0.17).

Conclusions: The quality of evidence was poor. Apart from attitudes, the effect sizes are likely to be overestimates. There was little evidence that education programmes can reliably produce substantial improvements in working practices.

Clinical implications: Education alone is unlikely to be sufficient for establishing high standards of person-centred care in services. It needs to be supplemented by steps to ensure that staff develop skills in delivering such care in practice, and by organizational support to ensure staff have sufficient motivation, cues and opportunities for implementation.

Key words: dementia, person-centred care, residential care, caregivers, education, training, intervention

Introduction

Person-centred care (PCC) has been adopted in many countries as an important guiding principle in the provision of care for people living with dementia (Chirico et al., 2021; Harding et al., 2015; Paparella, 2016). The concept was originally developed by Kitwood who emphasized the importance of valuing and respecting the person with dementia as an individual (Fazio et al., 2018; Kitwood, 1997; Kitwood & Bredin, 1992). PCC focuses on the provision of comfort, attachment, inclusion, occupation, and a sense of identity and continuity with the past. It emphasizes that care must be individualised, taking account of each person's unique history, perspective, needs and wishes; and highlights the importance of creating a social environment in which the person feels appreciated and valued.

Research has highlighted the benefits of PCC in health and social care settings. For people living with dementia, the benefits include decreases in medication and 'behavioural and psychological symptoms', and improvements in emotional well-being and quality of life (Brownie & Nancarrow, 2013; Fossey et al., 2014; Kim & Park, 2017; Li & Porock, 2014; Olsson et al., 2013). For formal paid carers, the benefits include increases in job satisfaction and confidence in their ability to provide good care (Barbosa et al., 2014; Brownie & Nancarrow 2013; Rajamohan et al., 2019), and reductions in stress, burn-out and staff turnover (Barbosa et al., 2014; Rajamohan et al., 2019).

To promote the implementation of PCC by staff, the great majority of dementia services rely on educational programmes that explain the principles and practice of PCC (Hunter et al., 2016a; Surr & Gates, 2017). The programmes are typically delivered in workshops or online, sometimes with follow-up booster sessions.

Although there may be some experiential components (e.g. role play), the emphasis is on didactic learning. The popularity of the approach is very probably due to its low cost relative to more complex interventions (Ballard et al., 2018; Hunter et al., 2016a).

Doubts about the effectiveness of this approach have been raised (Aylward et al., 2003; Hunter et al., 2016b). The programmes focus on increasing staff knowledge about PCC and enhancing attitudes towards the people they provide care for. Although such change might be necessary to bring about improvement in working practices, evidence suggests that it is often not sufficient and it has been argued that it needs to be supplemented with organizational change (Aylward et al., 2003; Hunter et al., 2016b; Surr et al., 2020b). Even in terms of improving knowledge and attitudes, it is unclear how effective educational programmes are, with some intervention studies reporting a lack of significant change on some outcomes or for some participants (Conway & Chenery, 2016; Elpers et al., 2017).

Given the value of PCC and the popularity of the educational approach, it is important to know how effective the approach is in promoting PCC. Previous systematic reviews on the topics of PCC and education have focused on the benefits of PCC for staff and people living with dementia (Barbosa et al., 2014; Brownie & Nancarrow, 2013; Fossey et al., 2014; Kim & Park, 2017; Olson et al., 2013); on the effectiveness of general education and training in dementia services (i.e. not specific to PCC) (Aylward et al., 2003; Rapaport et al., 2017; Surr & Gates, 2017); or on a broader review of PCC interventions (i.e. not specific to education) (Mohr et al., 2021). This review focuses specifically on the effectiveness of education in improving staff understanding and application of PCC. The focus on education stems

from its widespread adoption, attributed to its simplicity and cost-effectiveness as an intervention method, relative to more complex interventions.

Although the current thesis focuses on exploring PCC in home settings, the review has relevance to this issue. The outcome of a systematic literature search, described in Chapter 2, revealed only one intervention, *iSupport*, that specifically focused on enhancing PCC for family carers (Pot et al. 2019). Studies that have evaluated *iSupport* have reported limited benefits (e.g. Baruah et al., 2021). This programme is an educational intervention of the type included in this review. It involves the provision of information only and there is no interactive element or other kind of training. Reviewing the effectiveness of educational interventions in dementia care services may provide some lessons for how interventions may need to be developed for the promotion of care in the home setting.

Method

Literature search

A systematic search of articles published between January 1988 (which predates Kitwood's introduction of the term 'person-centred care') and January 2022 was carried out using the following eight databases: CINAHL Plus, Web of Science, Applied Social Sciences Index and Abstracts, PsycINFO, International Bibliography of the Social Sciences, PubMed, Medline and SCOPUS. The initial search was restricted to titles, abstracts and key words. Exact search terms varied according to the database searched, but they always included 'dementia' and 'Alzheimer', terms related to intervention (specifically, variants of 'intervention', 'education', 'training' and

'therapy') and terms related to person-centred care (specifically, different spellings of this term). These three blocks of terms were combined using the AND operator.

The initial search resulted in 3102 papers, 1401 of which were duplicate papers. The titles and abstracts of the remaining 1701 papers were then screened by the first author (CC) using the inclusion and exclusion criteria listed in Table 1. Following this screening, 314 articles remained. The full texts of these were obtained, and the inclusion and exclusion criteria reapplied by the first author. In cases where there was uncertainty about whether the article met the criteria, these were discussed within the research team and a decision made about inclusion. Seventeen articles met the inclusion/exclusion criteria. The reference lists of these articles were also examined, resulting in one additional paper (Conway & Chenery, 2016). The PRISMA diagram in Figure 2 illustrates the selection process in more detail.

Table 1. Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
– Study evaluated effectiveness of an intervention intended to increase PCC. – Educational methods were the primary component of the intervention. – Participants were staff working in services whose main purpose was to	– Study only used measures of the assumed consequences of PCC (e.g. reduced use of medication) rather than a measure of PCC itself. – Participants worked exclusively in services that were not specific to dementia (e.g. acute hospitals).

provide care for people living with dementia. – Study used quantitative measures of PCC. – Measure of PCC was completed before and after the intervention.	– Study was not in a peer-reviewed journal, was not available in English or did not report original data (e.g. reviews).

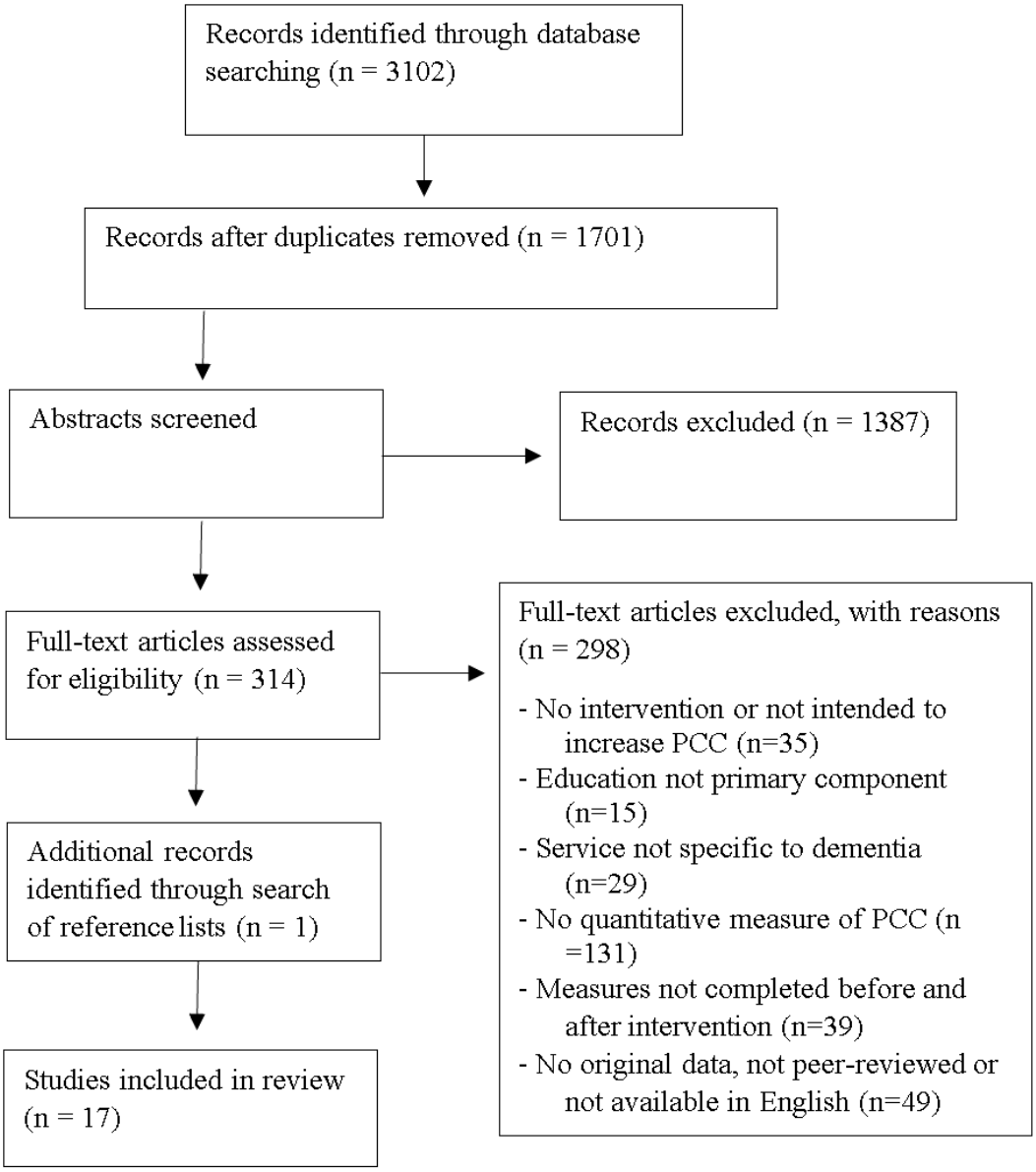


Figure 2. Prisma flowchart

The nature of some of the excluded papers merits comment. Many papers reported on interventions that included an educational component designed to enhance PCC, but they did not include a measure of whether PCC increased. Instead, they measured the potential beneficial consequences of PCC, related to the wellbeing of either the staff providing care (e.g. Isaac et al., 2021) or the person with dementia (see Mohr et al., 2021 for a review). Given the concerns about whether

educational interventions are an effective way of increasing PCC (Aylward et al., 2003; Hunter et al., 2016b), it is important to establish this before making the assumption of these studies that such interventions are effective in this respect. Accordingly, this review focused exclusively on studies that directly measured PCC.

Other exclusions should also be noted. Some studies were excluded because they used an outcome measure that included items relevant to PCC, but only a total score was reported and no specific score related to PCC was provided (e.g. Inker et al., 2021). The interventions were required to be conducted within dementia services. Some excluded studies reported using an educational intervention in other settings such as general hospitals (e.g. Chenoweth et al., 2022). Education was conceptualised in the traditional sense of involving the explicit communication of knowledge. Some excluded studies described more creative approaches to increasing PCC such as using simulation as a way of helping participants appreciate the experience of people living with dementia (e.g. Kimzey et al., 2021). Finally, studies were excluded if the measure of PCC was not taken before as well as after the intervention. Some excluded studies used measures that made no reference to pre-existing knowledge and skills relating to PCC, and so it was unclear if the intervention was associated with an improvement (e.g. Kemeny et al., 2006). This criterion also excluded studies (e.g. De Souza et al., 2020) that involved asking participants how useful they had found the intervention in terms of PCC, but did not collect any pre-intervention data.

Quality assessment

Following Higgins et al. (2011), factors undermining the quality of the study were divided into risks to internal validity (i.e. factors that undermine confidence in

attributing any difference in the outcome measure to the intervention), risks to external validity (i.e. factors that hinder generalization of the findings to other situations) and risks to precision (i.e. random non-systematic errors that decrease the accuracy of the estimates of a summary statistic).

External validity was assessed in terms of how representative the participants were likely to be of the population of staff working in dementia services (based on sample size, method of selection and drop-out rate); and precision in terms of the adequacy of the sample size and the psychometric properties of the measures of PCC that were used. Internal validity was assessed using the Cochrane Collaboration Risk of Bias Tool (Higgins et al., 2011). The authors suggest supplementation of this tool with other criteria considered particularly relevant to the studies being reviewed. In the present case, criteria relating to treatment fidelity and measurement bias were added. In terms of design, studies either used a control group (i.e. randomised or non-randomised controlled trials) or just used one group (i.e. before-and-after design). These two types of design were evaluated separately in the assessment of internal validity because the selection bias item in the Cochrane Tool only applies to studies with control groups. This means that ratings of internal validity bias across the two types of design are not comparable. In terms of minimising the risk to internal validity, controlled studies are, in general terms, more effective because they control for variables unrelated to the intervention that may have led to changes in outcome.

Instructions for applying the quality assessment tool are contained in Appendix 1. For each paper, each criterion was rated as being low (scored as 0), moderate or unreported (=1) or high (=2). Higher scores indicated higher internal

and external validity and precision. Ratings were completed independently by the first and fourth author. Cohen's kappa indicated a high level of interrater reliability, K = .933, p <.001.

Estimating the summary effects

The studies measured PCC using different types of outcome and different measures within each type of outcome. To avoid comparing dissimilar outcomes, summary effect sizes were calculated across each of these different types (specifically, direct knowledge, applied knowledge, attitudes, self-reported working practices and observed working practices). To allow comparison across the studies within each type, the standardised mean difference (Cohen's d) was calculated. In calculating the summary effect, each mean difference was weighted according to the precision of the estimate it provided. Analysis was conducted using the 'Meta' package in R studio (R Core Team, 2018; Schwarzer et al., 2015) and a random-effects model was used to calculate the summary effects.

Four of the 18 reviewed papers were excluded from calculations of the summary effects. Brooker et al. (2016) and Passalacqua and Harwood (2012) provided insufficient statistical data. Elpers et al. (2017) was excluded because of the small number of complete data sets (n=7). The two papers by Barbosa and colleagues (2016 and 2017) reported two different measures of the same type of outcome (observed working practices) from the same study. The 2017 paper was preferred for use in calculating the summary effect because it used a more robust outcome measure that had been previously evaluated. Although some studies reported data from follow-up measures, only the immediate post-training measures were included in the analyses.

In relation to calculating Cohen's d for studies with a control group, only one paper (Ballard et al., 2018) provided sufficient data to enable a comparison between the change scores of the two groups. Accordingly, the difference between the post-intervention means of the training and control groups, and the pooled standard deviation, were used. This method does not account for baseline differences between the two groups and will tend to reduce the effect size if the control group scores are better and inflate it if the control group scores are lower. However, for all but two of the papers (Conway & Chenery, 2016; Hattink et al., 2015), the baseline difference between groups was relatively small (<0.3 standard deviations). For the before-after studies, following the recommendation of Morris and DeShon (2002), the difference between the baseline and post-intervention mean, and the standard deviation of the baseline scores, were used to calculate the standardised mean difference. Further details about the calculation of Cohen's d are available in Appendix 2.

Results

Quality assessment of studies

Tables 2 and 3 provide a summary of the ratings of validity and precision for the before-after and the controlled studies respectively. Internal validity was generally poor. Inevitably, all studies received a zero rating for performance bias because it was impossible to blind researchers or participants to the intervention received. Only two studies explicitly reported that the outcome data were collected by researchers unaware of group allocation (or in the case of before-after studies the nature of the intervention). In all but four studies, levels of attrition were high (over

10%) and not addressed with appropriate intention-to-treat or missing data analyses. Only four studies assessed treatment fidelity. Measures of attitude and self-reported working practice were considered more liable to social desirability bias. As noted earlier, before-after studies offer no control over variables unrelated to the intervention that may have caused a change in the outcome measure (i.e. maturation and historical bias – Schweizer et al., 2016).

Studies generally fared better in terms of precision, although the precision of some was weakened by using measures whose psychometric properties were unclear. External validity was promoted by the selection criterion that participants were required to be working in dementia services. However, it was compromised by high levels of attrition, the fact that participants were volunteers rather than selected at random, and the failure to compare the sample composition with data about the workforce in the services involved in the study. It is thus unclear whether samples were representative of the general workforce, or had an over-representation of participants who were particularly interested or engaged in the training.

Table 2. Quality ratings for before-after studies

	Barbosa (2016)	Barbosa (2017)	Brooker (2016)	Coleman (2015)	Edvardsson (2014)	Elpers (2017)	King (2011)	Passalacqua (2012)	Pleasant (2017)	Williams (2018)
Internal validity										
Performance	0	0	0	0	0	0	0	0	0	0
Detection	1	1	1	1	1	1	1	1	1	1
Attrition	1	2	0	0	0	0	1	0	0	1
Reporting	2	0	2	2	2	2	2	0	2	1
Fidelity	1	1	1	1	1	1	1	1	2	1
Measurement*	0	2	0	2	0	0	0/2	0/0	2	2
External validity										
Participants	0	0	0	0	0	0	0	0	0	0
Drop-out	1	2	0	0	0	0	1	0	0	1

Precision										
Sample size	1	1	2	2	2	0	2	1	2	2
Measures*	0	1	1	0	1	1	0/2	1/1	2	2

* Some studies included more than one outcome measure

Table 3. Quality ratings for controlled studies

	Ballard (2018)	Chenoweth (2014)	Conway (2016)	Hattink (2015)	Jacobsen (2017)	Lood (2020)	Torres-Castro (2021)	Williams (2021)
Internal validity								
Selection	2	2	1	2	1	0	2	1
Performance	0	0	0	0	0	0	0	0
Detection	2	2	1	1	1	1	1	1
Attrition	1	1	0	0	0	0	2	0
Reporting	2	2	0	2	2	2	2	0
Fidelity	1	1	1	2	1	1	2	2
Measurement*	0	0	0/2	0	0	2	0	2/2
External validity								

Participants	0	0	0	0	0	0	0	0
Drop-out	1	1	0	0	0	0	2	0
Precision								
Sample size	2	2	0	0	2	2	2	2
Measures*	1	1	1/1	1	1	2	1	2/2

* Some studies included more than one outcome measure

Characteristics of the studies

Key details about the studies are presented in Table 4 (before-after studies) and Table 5 (controlled trials). Some studies addressed a broader range of issues, but only the information relevant to evaluating the effectiveness of educational training on PCC is included in the tables.

Table 4. Summary of before-after studies

Author and setting	**Participants**	**Intervention**	**Measures**	**Results**
Barbosa (2016) Portugal 2 care homes Only information about the control	31 provided baseline data, 29 provided post-intervention and follow-up data Baseline sample: 100% female, all	Eight 90-minute sessions at weekly intervals. Training focused exclusively on PCC	*Observed working practices*: Video recordings made of morning care routine. Verbal and non-verbal communications rated on 26 dimensions for how PCC they were.	Mean score improved on some dimensions but declined on others, both at post-intervention and follow-up. No

group from this study is reported here.	direct care workers, all without professional qualification	Multi-component: After each session, teachers supervised participants individually during morning routine making suggestions about implementing a PCC approach.	Collected at baseline, post-training and at 6 months follow-up.	statistical analysis of overall change.
Barbosa (2017) Same study as Barbosa (2016) but reported a different outcome measure	See Barbosa (2016), but all 31 provided complete data set.	See Barbosa (2016)	*Observed working practices*: See Barbosa (2016). Video recordings rated using Global Behaviour Scale which evaluates how person-centred the care is	Significant improvement on ratings at post-intervention. Follow-up ratings not reported.

Brooker (2016) UK 106 care homes involved at start and 67 involved throughout	100 recruited; 66 completed the programme; but only 51 provided complete data set. No data about gender or qualifications provided. It was recommended that participants were 'a care assistant, senior care assistant, registered nurse or activity co-ordinator'.	Ten days of training delivered over the course of 3 months Participants were trained to become 'dementia care champions' in their care home, focused on the delivery of PCC; training also focused on how to identify issues within the home and how to cascade learning to others. Multi-component: After training, participants	*Attitude*: Person-centred subscale of Approaches to Dementia Questionnaire Collected at baseline, post-training and after supervision period.	Significant improvement on PCC subscale between baseline and post-training and between baseline and post-supervision.

		attended monthly supervision sessions for 6 months.		
Coleman (2015) USA 15 care homes Compared online with onsite delivery of intervention – so no control group that did	211 participants from 8 homes took part in the online training; 327 from 7 homes took part in the onsite training. Not stated how many provided complete data set, but degrees of freedom for ANOVA implies it was 360.	Three sessions, one per week over 3-week period; unclear how long each session was. Training focused on person-centred communication. No additional interventions .	*Applied knowledge*: Participants rated videos of staff-resident interactions on person-centred dimensions. Data collected at baseline and post-intervention	Onsite training group showed a significant improvement in identifying person-centred communication; but online training group did not.

not receive the intervention	Demographic data only provided for a subsample of onsite training group (n=45): All were direct care workers, with 4% being registered nurses; 82% were female.			
Edvardsson (2014) Sweden	171 took part and 143 provided full data set. Baseline sample: 84% female, 14% registered nurses and	Two day-long seminars Training covered national care policies (including PCC) and how the unit	*Self-reported working practices*: Participants completed the Person-Centred Care Assessment Tool, rating how person-centred they considered	Scores on the Care Assessment Tool showed significant improvement, but scores on the Climate Questionnaire did not.

1 care home containing 24 residential units	remainder not professionally qualified; all direct care staff	matched up to these policies Multi-component: Following training, there were 10 2-hour seminars focused on developing and evaluating a unit-based practice improvement. There was also a day on which units shared information about their improvements. Whole intervention delivered over 10-month period.	the care provided on their unit; and the Person-Centred Climate Questionnaire, rating how person-centred the physical and social environment were. Data collected at baseline and at 12 months.

Elpers (2017) USA 1 care home	23 took part and 7 provided complete data set. Sample providing complete data: 6 females; all direct care staff, 2 of whom were registered nurses.	Three 30-min training sessions Training covered understanding of dementia and managing behaviour, with emphasis on improving attitudes and provision of PCC. No additional interventions	*Attitude*: Person-centred subscale of Approaches to Dementia Questionnaire Data collected at baseline and post-intervention	Because of low number, reliable change index used. Only 2 participants showed reliable improvement on PCC subscale of ADQ, 3 showed no change, and 2 showed a reliable deterioration.
King (2011) USA	1782 completed at least 1 module, varying numbers	Four one-hour sessions delivered by staff trained by the researchers.	*Direct knowledge*: Knowledge tests about each session.	*Knowledge*: Significant improvement on all tests.

84 care homes, only 28% of which had dementia-specific units	completed the knowledge test after each module, ranging from 1078 to 1805; and numbers completing each item on attitude questionnaire ranged from 1045 to 1666. Sample completing at least 1 module: 90% female, all direct care workers, unclear if any had a professional qualification.	Training focused on creating a person-centred environment and providing PCC. No additional interventions	Administered before and after the session to which it applied. *Attitude*: Questionnaire developed for study. Administered at baseline and post-intervention.	*Attitude*: Items analysed individually because of poor internal consistency. Nature of analysis makes it difficult to interpret what changes occurred.

Passalacqua (2012) USA 1 care home	50 were eligible, but only 26 provided complete data set. Data provided about sample, but unclear whether it refers to sample of 50 or sample of 26: 89% female, all direct care workers, no information about professional qualification	Four weekly 1-hour workshops, one a week over 4-week period Training focused on person-centred communication No additional interventions	*Attitude*: Abbreviated person-centred subscale of Approaches to Dementia Questionnaire *Self-reported working practices*: Questionnaire developed for study. 14 items about how the participant communicate with residents. Data collected at baseline and 6 weeks following the intervention	*Attitude*: No significant improvement *Self-reported working practices*: Significant improvement on 3 of the 14 items

Pleasant (2017) USA Online	Sample included both formal and informal carers. 144 provided baseline data, 62 at post-intervention and 51 at follow-up. Sample completing the follow-up: 88% female; 71% described themselves as formal carers and 54% as 'licensed' carers.	Four online modules. A minimum of 40 minutes had to be spent on a module before being allowed to progress to the next one. Training provided general introduction to dementia as well as information about PCC. No additional interventions	*Applied knowledge*: Developed for study. Participants watched a video of a carer assisting someone with dementia and rated how person-centred the care was. Data collected at baseline, post-intervention and at 30-day follow-up	No significant improvement on identification of PCC either at post-intervention or follow-up.
Williams (2018)	39 provided data at baseline, 38 post-	Three 1-hour sessions over a period of 3 weeks.	*Observed working practices*: Participants	Significant improvement at post-

USA 11 care homes	intervention and 32 at follow-up, 82% were female and all were 'certified nursing assistants' providing direct care	Training focused on PCC communication. No additional interventions	were videoed during routine care and communication was rated on 8 PCC-related dimensions, using previously evaluated measure. Data collected at baseline, post-intervention and at 3-month follow-up.	intervention on two of the eight dimensions, and this improvement was maintained at follow-up for one dimension. No significant change on other dimensions.

Table 5. Summary of controlled studies

Author, setting and design	**Participants**	**Intervention**	**Measures**	**Results**
Ballard (2018) UK 69 care homes RCT: Care homes randomly allocated to intervention or control group. Control group did	Focus was on outcomes for people with dementia; no details about staff participants provided. In intervention homes, 443 people with dementia at baseline and 296 post-intervention; in control	Training given to 'champions' who cascaded training to other staff. Delivered over 9-month period. Training not exclusively focussed on PCC Multi-component, including on-site	*Observed working practices*: Observed interactions between staff and persons with dementia were coded using the Quality of Interaction Scale. Context of the interactions is unclear.	Improvement in ratings for intervention group were significantly larger than any shown by control group

not receive the training.	homes, 440 and 257 respectively. PCC measure was completed in 62 homes.	consultation sessions, team formulations and goal planning	Data collected at baseline and at 9-months (at point when intervention was concluded)	
Chenoweth (2014) Australia 38 care homes RCT: Care homes randomly allocated to intervention or control group. Control group did	Focus was on outcomes for people with dementia; no details about staff participants provided. In intervention homes, 142 at baseline, 95 post-intervention and 64 at follow-up; in	Five staff from each home received 32 hours of training in PCC, delivered over 6-month period. Training exclusively focussed on PCC, though little detail provided. Multi-component, including on-site	*Observed working practices*: Observed interactions between staff and persons with dementia were coded using the Quality of Interaction Scale. Context of the interactions is unclear.	No significant improvement in ratings for training group, either at post-intervention or follow-up

not receive the training.	control homes, 155, 98 and 64 respectively	supervision in applying principles and telephone support	Data collected at baseline, post-intervention and at 8 months	
Conway (2016) Australia 12 centres providing community care RCT: Centres randomly assigned to intervention and control groups.	Intervention group: 29 at baseline and 19 provided complete data set. Control group, 30 and 16 respectively. Samples providing complete data. Intervention group: 82% female and 5%	No information provided about length of training. Training focused on PCC communication No additional interventions	*Direct knowledge:* Communication Support Strategies in Dementia knowledge test, adapted from a measure used in previous studies. *Attitude*: Person-centred subscale of Approaches to	*Knowledge*: Significant improvement for intervention group at post-intervention and at follow-up, but the improvement was not significantly greater than that shown by the control group at follow-up.

Control group did not receive the training.	had nursing qualifications; for control group, 87% and 6% respectively. All direct care workers.		Dementia Questionnaire Collected at baseline, post-intervention and 3-month follow-up for intervention group, but only at baseline and follow-up for controls.	*Attitude*: No significant improvement in intervention or control groups.
Hattink (2015) Netherlands & UK Online	46 recruited; 10 in intervention group provided complete data set and 14 in control group.	Training delivered online, available for 4-month period. Unclear how long training took.	*Attitude*: Person-centred subscale of Approaches to Dementia Questionnaire	No significant improvement in intervention group, and not significantly greater than control group.

RCT – participants randomly allocated to intervention or control group. Training made available to control group after completion of the research.	Sample providing complete data set: Intervention group – 80% female; for control group 100% female. All described as 'professional caregivers'.	Training covered general issues about dementia and providing dementia care, including person-centred communication. No additional interventions	Collected at baseline and post-intervention	
Jacobsen (2017) Norway 24 care homes	In intervention group, 122 at baseline, 84 at follow-up; in control group, 127 and 120 respectively.	Training was given over 2 full days. Training focussed on a decision-making model to facilitate the use of a	*Self-reported working practices*: Participants completed the Person-Centred Care Assessment Tool (PCAT) rating how	No significant improvement

RCT: Care homes randomly allocated to intervention or control group. Control group offered the training after completion of the research.	Detailed information about participants not provided. Across all 24 homes, the percentage of registered nurses was 40%.	person-centred approach rather than restraint in challenging care situations. Multicomponent: One-hour monthly coaching sessions over a 6-month period, focused on helping staff apply the decision-making model to real situations.	person-centred they considered the care provided by their care home. Data collected at baseline and after the end of the 6-month coaching period.	
Lood (2020) Australia, Norway and Sweden	Data were collected from relatives of people living in the home. Baseline data	Training was given over a 14-month period. No further details given about	*Observed working practices* Relatives completed the Person-Centred	No significant improvement at post-intervention or at follow-up for intervention

6 nursing homes Homes assigned to intervention and control groups, but this was not random. Control group received one lecture on PCC immediately after collection of baseline data.	provided by 459 relatives, with 149 providing post-intervention and 132 follow-up data. Staff receiving training: 90% women and 88% with a professional qualification. All were direct care staff.	number of hours/sessions. Training focused on understanding of PCC and how this translates into caring and the physical and social environment. Additional interventions: Training involved identifying how site-based reflection and evaluation could take place, and	Climate Questionnaire, rating how person-centred they considered the overall service provided by the home. Data collected at baseline, post-intervention, and at 6 months follow-up.	group, with scores showing a non-significant decline.

		follow-up discussions of this reflection/evaluation.		
Torres-Castro (2022) Mexico 8 care homes RCT: Care homes randomly allocated to intervention or control group. Control group did not receive the training.	In intervention group, 57 at baseline, post-intervention and follow-up (i.e. no attrition); in control group, 39 at all three points. 72% female in intervention group and 55% in control group. No details about work role or qualifications.	Participants received 2 full days of training. Training not exclusively focussed on PCC No additional interventions	*Attitude*: Person-centred subscale of Approaches to Dementia Questionnaire Collected at baseline, post-intervention (12 weeks) and follow-up (24 weeks)	Significant decline in scores for the intervention group, for both baseline vs. post-intervention and baseline vs. follow-up.

Williams (2021) USA 7 care homes RCT: Care homes randomly allocated to intervention or wait-list control. Control group received intervention after the experimental group completed the post-	Intervention group: 147 completed baseline communication rating task, 134 completed baseline knowledge task; 67 completed post-intervention communication task and 94 completed post-intervention knowledge task Wait-list control: figures were 72, 64, 64 and 64 respectively, and then 35 completed	Three 1-hour modules delivered online. The modules did not have to be completed in one sitting. Training focused on PCC communication and had similar content to Williams et al. (2018). No additional interventions	*Direct knowledge*: Questionnaire assessing knowledge of person-centred communication. *Applied knowledge*: Participants rated video of interaction between a carer and a person with dementia on four dimensions, including two related to person-centred communication.	*Direct knowledge*: In the first phase of the study (i.e. prior to control group receiving the intervention), participants in the intervention group showed significantly greater improvement than the control group. When scores for both groups were combined, there was a significant improvement in scores from baseline to post-intervention.

intervention measures.	both tasks following receipt of training. Of the 219 participants who completed the baseline communication rating task, 93% were female and 25% were professional nurses. All were direct care staff.	Data collected at baseline and post-intervention	*Applied knowledge*: When both groups were combined, there was a significant improvement on both person-centred dimensions. Separate analysis for each group not reported.

The majority of studies were conducted in USA or Europe (i.e., the UK, Sweden, Norway, Portugal and the Netherlands), with one conducted in Mexico and three in Australia. Baseline sample sizes ranged from 23 to 1782, with a total of 3544 participants. The studies by Ballard et al. (2018), Chenoweth et al. (2014) and Lood et al. (2020) are not included in these figures because they did not provide information about the number of staff who took part in the training.

Except for two studies, participants in the studies were all paid staff working in dementia services. Pleasant et al. (2017) included informal unpaid carers in their sample alongside paid staff and in King et al. (2011) it is unclear whether all the sample worked directly with people living with dementia. Reflective of the composition of the work force, the great majority of participants were female. Not all studies provided information about the job roles of the participants, but, in those that did, all participants had roles that involved the direct provision of care to people living with dementia. In several of these studies, none of the participants had a professional caring-related qualification. The percentage with a professional qualification in the other studies was 25% or less, apart from the study by Lood et al. (2020) in which the figure was 88%.

The characteristics of the training varied. In some studies (e.g. Edvardsson et al., 2014), the educational component addressed other aspects of dementia and there was not an exclusive focus on PCC. Conversely, sometimes the training focused on one particular aspect of PCC such as communication (e.g. Passalacqua et al., 2012). Training also varied in length, from three 30-minute sessions to 10 whole days. Some interventions involved additional components intended to supplement the educational training. For example, Barbosa et al. (2016) followed up

the training with individual supervision during the morning care routine in which the trainers would make suggestions about how a person-centred approach could be implemented.

Five different types of PCC outcome were assessed in the studies. Three studies involved a test of *direct knowledge* in which participants had to answer questions concerning material covered in the content of the teaching. Three studies involved a test of *applied knowledge* in which participants were shown a video of an interaction between a carer and a person with dementia, and asked to rate how person-centred the carer was. Six studies used the same *Attitudes to Dementia Questionnaire* (Lintern et al., 2000) which has a subscale that evaluates *attitudes* related to PCC. Two studies asked participants to rate the service in which they worked in terms of how person-centred they considered it to be, and one asked participants to report on how they communicated with the people they were providing care for. These outcomes were categorised as *self-reported working practices*. Finally, five studies videoed participants providing care to people living with dementia and rated them in terms of PCC and a sixth (Lood et al., 2020) asked family relatives of the people living with dementia to rate the service as a whole in terms of how person-centred it was. These outcomes were categorised as *observed working practices*.

Findings

The findings were mixed. Although many papers reported improvements following training, some reported a failure to improve and some even reported a deterioration. In terms of the *direct knowledge* outcome, two papers reported significant improvements following training (King et al., 2011; Williams et al., 2021).

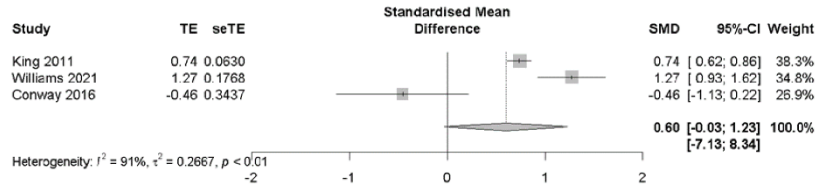
Conway et al. (2016) also reported significant improvement, but this was not significantly greater than the improvement also shown by the control group. For the *applied knowledge* outcome, one study reported significant improvement (Williams et al., 2021) one reported no improvement (Pleasant et al., 2017) and one reported significant improvement for the on-site training but not for the online training (Coleman et al., 2015). Outcomes for the PCC subscale of the *Attitudes to Dementia Questionnaire* were also varied. Only one paper (Brooker et al., 2016) reported an improvement; three papers reported no significant change (Conway et al., 2016; Hattink et al., 2015; Passalacqua et al., 2012); and one paper reported a significant decline following training (Torres-Castro et al., 2022). Elpers et al. (2017) analysed outcomes for individual participants on this questionnaire: Two showed reliable improvement, three showed no change, and two showed reliable deterioration.

The primary aim of training is to change actual working practices. Again, the findings about this were mixed. In terms of self-reported changes in communication, Passalacqua et al. (2012) reported significant improvement on only three out of 13 dimensions. For participants who rated the quality of care provided by the service in which they worked, Jacobsen et al. (2017) reported no improvement, while Edvardsson et al. (2014) reported significant improvement on one measure but no change on another. Observations are more likely to provide a less biased assessment than self-report. Again, findings were mixed. While two studies reported significant improvement (Ballard et al., 2018; Barbosa et al., 2017), two reported no significant change (Chenoweth et al., 2014; Lood et al., 2020) and one reported significant improvement on only two of the eight dimensions that were evaluated (Williams et al., 2018).

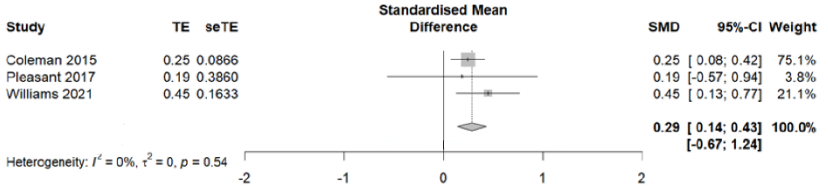
Eight studies included a follow-up evaluation of outcome as well as a post-intervention evaluation, ranging from 30 days to 8 months. Four of these studies failed to observe any significant improvement at both post-intervention and follow-up. Of the remaining four, Barbosa et al. (2016) did not provide a relevant statistical analysis and Williams et al. (2018) reported that there was significant post-intervention improvement on two out of eight dimensions and that this was sustained at follow-up. In Brooker et al. (2016), there was a post-intervention improvement in attitude that was sustained at follow-up (although participants continued to receive supervision during the follow-up period); and in Torres-Castro et al. (2022) a post-intervention decline in attitude was sustained at follow-up.

In terms of effect sizes, Figure 3 provides forest plots for the five analyses. The largest effect was for direct knowledge (standardised mean difference = 0.60). Using the benchmarks suggested by Sawilowsky (2009) (>.1 = very small; >.2 = small; >.5 = medium; >.8 = large; >1.2 = very large), this represents a medium-sized effect. Smaller effects were obtained for the ability of participants to apply what they had learnt to identifying examples of good and bad care practice (SMD = 0.29), and for the impact on working practice, both self-reported (SMD = 0.06) and observed (SMD= 0.25). For attitude change, there was a very small negative change (SMD = -0.17).

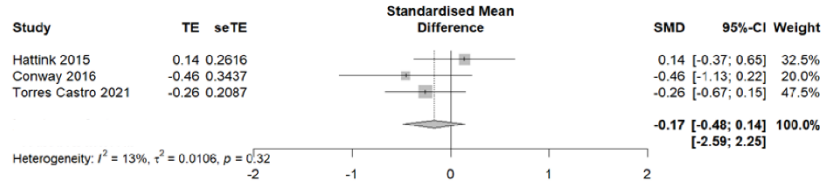
Direct knowledge:



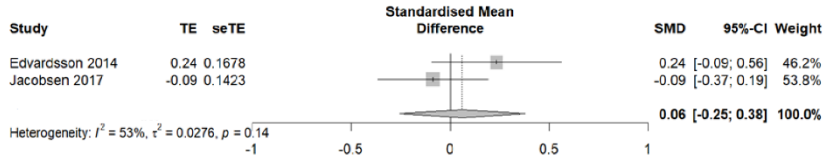
Applied knowledge:



Attitude:



Self-reported working practice:



Observed working practice:

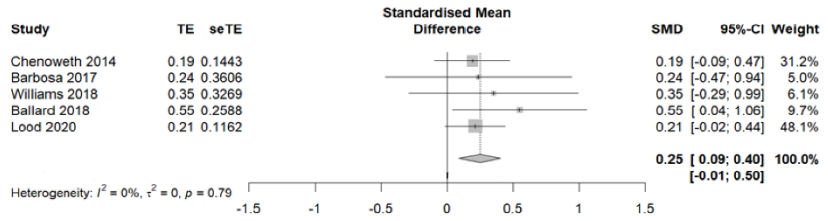


Figure 3. Forest plots for the five different types of outcome

Note: Each of the SMDs from the studies are plotted and shown as a square, with the 95% confidence interval displayed. The size of the square represents the weighting of the study within the random effects model. The vertical line at 0 on the x axis represent the value associated with the null hypothesis; if the 95% confidence intervals for an SMD cross this vertical line then the effect is non-significant. The weighted average of the SMDs (i.e., the summary effect) is shown as a diamond, the centre of which represents the weighted average, and the left and right extremities represent the 95% confidence intervals of the estimate.

Discussion

This review provided little evidence that educational interventions can provide reliable and substantial benefits in terms of ensuring that staff provide person-centred care. Viewed from the perspective of significance testing, results were mixed, with some studies reporting significant improvement, some reporting no significant effect and some that evaluated attitude change even finding a significant decline in outcome following training. The analysis of effect sizes similarly suggested limited benefits. There was a medium effect on direct knowledge but the effect size was disappointingly small for applied knowledge and work practices. The overall effect on attitudes represented a reduction in person-centredness. There was also little evidence that educational interventions can bring about longer-term positive change. Of the eight studies that included a follow-up measure, only two reported sustained positive change. However, in Williams et al. (2018) this change occurred on only two out of the eight dimensions measured, and in Brooker et al. (2016), participants continued to receive supervision during the follow-up period.

These effect sizes need to be considered in the context of the high probability that, because of the failure to control some major sources of bias, the effect sizes exaggerated the effectiveness of the intervention (although, in the case of the studies that evaluated attitude, there were some methodological issues, discussed below, that may have served to reduce the effect size). A range of factors may have inflated effect size. First, there was a high attrition rate in most of the studies that was unaccounted for in the statistical analysis (Tables 2 and 3). Participants who find the training valuable seem more likely to remain engaged with it than those who find it unhelpful. Second, some of the outcome measures (specifically, attitude measures and self-report measures about working practices) were subject to social desirability bias that would increase the apparent effectiveness of the intervention. Another inflationary influence is the fact that the methods of assessing outcome in some studies were likely to result in practice effects such that the repeat of the assessment would result in higher PCC scores regardless of any impact of the training. For example, following a knowledge test, participants can think about their answers, discuss them with colleagues etc., and this is likely to lead to better performance on the second test. This seems a likely explanation of the fact that, in the study by Conway et al. (2016), participants in the control group also showed a significant increase in knowledge scores when before and after scores were compared. Finally, several of the studies included additional components to the intervention (Tables 4 and 5), such as participants being supervised during the provision of routine care to enhance their application of what they had learnt (Barbosa et al., 2016), which seem very likely to have increased the size of the effect.

Developing knowledge and skills

Overall, there was only a medium effect size in terms of improvements in direct knowledge. This is somewhat surprising, given that this simply reflects the participants' ability to understand and remember what they have been taught. Consistent with this finding, studies that involved interviewing staff working in dementia services have found that those who have received training in PCC often struggle to articulate its meaning, and that there are misunderstandings and gaps in their knowledge (Colomer & de Vries, 2016; Skaalvik et al., 2010). In part, this finding might stem from the abstract nature of the principles of PCC that increase the difficulty of understanding them. Indeed, some have gone further and argued that the principles are unclear and ambiguous, further complicating their understanding (Clissett et al., 2013; Kogan et al., 2016). In part, the finding may also reflect shortcomings in the educational methods used. Based on a review of educational provision in dementia services, Surr and Gates (2017) made recommendations about educational methods, such as avoiding independent e-learning, the availability of in-service experts, and providing a minimum of the equivalent of one day's training, preferably in full day sessions or in sessions lasting at least one hour. Similarly, Rapaport et al. (2017) reported greater effectiveness for educational interventions that included individual training and ongoing supervision as well as didactic group learning. These recommendations were not always satisfied in the studies included in the present review.

Limited understanding of PCC may also contribute to the lack of any substantial benefit in terms of applying the principles to rating imaginary and real examples of care provision in terms of how person-centred they were. If staff do not understand the principles, then they will find it difficult to determine how to provide

PCC in particular situations. Consistent with this, participants in qualitative studies have highlighted the gap between theory and practice as a major obstacle to their application of training (Kong et al., 2021). One approach to addressing this issue is to provide more information to staff about how to be PCC in particular aspects of their working practice, rather than expecting them to work this out for themselves (Surr et al., 2021a). For example, in addition to the structured training session about communicating in a person-centred way, Conway and Chenery (2016) provided follow-up sessions in which participants were observed conversing with someone living with dementia and then provided with feedback about how well they were following the principles. Providing more detailed and specific information about how to be PCC in practice is also a feature of *dementia care mapping*, an alternative approach to fostering PCC (Brooker & Surr, 2006). This involves training a small group of staff; these staff then formally observe working practices; and meetings are then held with all staff to discuss the observations, to highlight good and poor practices, and to devise action plans to improve the quality of care.

It may also be helpful to consider this issue in the context of broader research about procedural/skill learning in which people acquire the ability to make specific responses that comply with general rules without necessarily ever knowing what the general rules are (i.e. implicitly) (Reber et al., 2019). Learning occurs not through being taught explicit rules and then learning how to apply those rules in practice, but through frequent exposure to a wide range of different specific situations in which the individual makes a response or observes others responding, and is given timely feedback about whether the responses are compliant with the rules or not. For example, children learn complex grammatical rules of speech not by being told what

those rules are and then working out how to apply the rules in each situation (the inefficient declarative route, which adult learners of a second language usually use), but through frequent exposure to correct application of the rules by themselves and others in a very wide range of specific circumstances and feedback about errors (Cochran et al., 1999; Reber et al., 2019; Smalle et al., 2017). The learning is not explicit: Children learn to apply the rules successfully without ever knowing (in a declarative sense) what the rules are. This is not to say that explicit learning of the rules is never helpful (adult learners of a second language do make some progress), but it is not necessary and not always the most effective method of acquiring a skill.

In the present context, this comparison with procedural/skill learning research suggests that the most effective method of learning how to provide PCC may be for staff to engage in, and observe others in, a wide range of specific care situations, along with timely feedback about whether the care was person-centred or not. In practical terms, this might be achieved by working alongside someone skilled in PCC who models good practice and provides regular feedback to others about their approach. This aligns, in part, with the WHELD approach (Fossey et al., 2019) which involves training some existing members of staff to act as ‘Dementia Champions’ to model and cascade good practice down to work colleagues. Another option would be work placements in which staff from other services work for several months within a service which is known to provide a high standard of PCC. This experience could provide them with more effective opportunities for acquiring the skill of providing PCC.

Changing attitudes

Findings from studies that measured changes in attitude following training were very mixed, with evidence for significant improvement, no significant change and significant deterioration. The summary effect was negative, although this was very small (-0.17). To some extent, this outcome may have been influenced by methodological flaws. The three studies included in the calculation of the summary effect size all involved control groups. In Conway et al. (2016), the control group scored nearly 1 standard deviation higher at baseline than the training group, which would have reduced the effect size. The reverse was the case for the study by Hattink et al. (2015) in which the control group scored nearly 1 standard deviation lower, but the results from this study appear to have been distorted by ceiling effects. Methodological flaws are, however, unlikely to provide the full explanation of the findings about attitude change. The study by Torres-Castro et al. (2022) suffered from neither of these problems (baseline differences and ceiling effects), but the training group still scored lower post-intervention than the control group and showed a significant before-after decline.

Improving working practice

The review suggested that the educational programmes had a minimal impact on improving the working practices of the participants. Although limited understanding and skill may have contributed to this, it is unlikely that this provides a complete explanation. Other studies, focused on aspects of care unrelated to PCC, have measured both knowledge and working practice, and found that staff failed to change their working practices even though they knew what to do (e.g. Cohen-Mansfield et al., 1997). Approaches such as *dementia care mapping* that do focus on providing more specific guidance about working practice have also found it difficult

to make an impact. A recent large scale randomised controlled trial of dementia care mapping found that implementation of PCC did not increase following the intervention (Surr et al., 2020a; Surr et al., 2021b).

Such findings have led many to argue that organizational and systemic changes are required alongside training to create an environment in which staff are supported to apply PCC in practice (Aylward et al., 2003; Clissett et al., 2013; Fossey et al., 2019; Griffiths et al., 2019; Hunter et al., 2016b; Surr et al., 2020b). In qualitative studies, staff have also highlighted that organizational issues prevent them implementing more person-centred care (Griffiths et al., 2019; Kong et al., 2021; Røsvik & Mjørud, 2021; Watson & Hatcher, 2021).

To understand why organizational and systemic changes are needed, and what form those changes should take, it is useful to consider the issue from the perspective of models of behaviour change such as the Theory of Planned Behaviour (Ajzen, 2011), the Health Belief Model (Abraham & Sheeran, 2005) and the Behaviour Change Wheel (Michie et al., 2011). Although these approaches differ in constructs and emphasis, common components relevant to the present context include the idea that, if a person is to behave in a certain way, they need to know what to do; they need to be motivated to do it; they need to have the opportunity to do it; and they need to be reminded to do it (or, considered from the perspective of skill learning, they need to be cued to do it). The educational approach to improving PCC addresses knowing what to do and, to some extent, motivation (through its impact on attitudes), but it does not address opportunity, reminder/cues to action and many aspects of motivation. An example can illustrate the importance of these other factors. PCC requires staff to spend more time with residents, and to provide care

and support in a way that is not necessarily the most time or resource efficient way of getting something done (e.g. it is quicker to feed someone than to encourage them to feed themselves). Yet staff are expected to do this in the context of under-resourced services that prioritise quick and efficient task completion (Clissett et al., 2013; Colomer & de Vries, 2016; Cooper et al., 2013; Hunter et al., 2016a; Rapaport et al., 2017). Although the staff member may know they should be encouraging the person to feed themselves (knowledge), there may be other demands on their time that reduce the time the staff member can allocate to mealtimes (opportunity) and create pressure from others to get the job done quickly (motivation). Low staffing levels may also mean the absence of any senior member of staff at mealtimes to provide explicit and implicit reminders of the expected standard of care (motivation and cues to action). Addressing these problems would require organizational change, such as higher staffing levels and shifting to a culture that values quality over the quantity of work completed.

Conclusions

To promote the implementation of PCC by staff, the great majority of dementia services rely on educational sessions that explain the principles of PCC. Evidence from this review suggests that such training may not be sufficient to bring about meaningful change. Staff may struggle to understand the principles because of their abstract nature and may find it difficult to translate the principles into working practice. Education about the general principles should be supplemented by steps to ensure this knowledge is translated into an understanding (not necessarily an explicit understanding) of how PCC should be delivered in practice. Options include clinical supervision, ‘dementia champions’ to model and cascade good working practices to

colleagues, and the provision of work placements in services known to provide a high standard of person-centred care. Furthermore, developing staff understanding of what needs to be done, although necessary, is not sufficient to change working practice. Organizational and systemic changes are also required to ensure that staff are motivated to provide person-centred care and are given sufficient opportunity and cues to action.

The findings of this review also carry implications for the promotion of PCC in home settings. A systematic search for interventions to promote PCC in home settings revealed only one intervention, the *iSupport* programme (Pot et al., 2019). Studies that have evaluated *iSupport* have reported limited benefits (e.g. Baruah et al., 2021). The programme is similar to many of the interventions described in this review in that it involves the provision of information only and there is no interactive element or other kinds of training. The findings of the review suggest that one reason for the limited success of the *iSupport* programme may be this reliance on simply providing information in an educational format. Many of the concerns raised about this kind of intervention seem likely to apply to their use in a domestic setting as well. For example, like paid carers, family carers may also struggle to understand the somewhat complex and abstract concepts incorporated in PCC; they may experience difficulty in translating the concepts into specific care behaviours; and they may benefit more from learning PCC as a skill rather than as a set of facts.

CHAPTER 4: A Qualitative Study of Person-Centred Care in Spousal Relationships

Abstract

Objectives: This study aimed to investigate the differences in the quality of care provided by spousal carers when supporting their partners with activities of daily life, as well as the reasons for these variations.

Methods: 30 spousal carers were recruited and participated in interviews examining the differences across carers in how person-centred their approach to care was when describing how they provided support to their partner on everyday tasks. The VIPS framework was used as a framework for this evaluation. Participants were also questioned about the factors influencing their caregiving approach.

Results: The findings of this study demonstrate that the ideas of PCC can be applied to family settings, with the participants showing variations in the person-centredness of the care they provided. However, it was apparent that many participants were unfamiliar with the principles of PCC and how they could be applied to everyday tasks. Participants reported a lack of information and guidance relevant to their caring role.

Conclusion: While this study suggests that PCC can be applied to family contexts, it highlights the need to address caregivers' knowledge gaps regarding PCC and to provide formal guidance on its implementations when providing support with daily tasks.

Introduction

Research on the quality of care provided for people living with dementia has often used PCC as a framework to evaluate care quality. Despite the moral value and benefits of PCC, research on PCC in the context of care provided by families is relatively neglected. The neglect of PCC research in family care settings is surprising, given that families – spouses in particular – are often the primary source of care for individuals (Schulz & Martire, 2004).

Most research on PCC has indeed focused on professional dementia care settings. For example, Kim and Park (2017) reviewed interventions designed to improve PCC. The review included 19 studies, but only two of them were in a home care setting. Furthermore, both of these studies focused on supporting professional carers working in a home setting, not on the care provided by families themselves. Similarly, Martinez et al. (2016) reviewed various instruments used to assess PCC provided to older adults. They found that most of the available instruments were developed and validated for use in residential care settings and found that there is a lack of tests specifically designed to evaluate PCC in home-care settings with the few identified being for evaluating PCC being provided by paid carers in these settings.

Despite the existing studies aimed at improving the quality of care delivered at home, none have specifically explored the delivery of PCC in these settings. In a recent study, Baruah et al. (2021) described a training package for family caregivers of individuals with dementia. The training package included modules that covered a range of topics designed to improve caregiver knowledge and skills as well as guidance on self-care and improving their mental health. The study mentioned that the training package was based on PCC, but there was a lack of detail into how this

was done, and it did not appear to be a major focus of the training package. Similarly, Guest and Smith (2021) developed a training programme for family caregivers and although the training was said to be focused on PCC, the description of the information provided in the training was vague and the aim of the training seemed to be increasing knowledge about dementia and improving quality-of-life.

Despite the limited existing literature, the application of the concept of PCC to understanding the care provided by families has the potential to provide useful insights. The concept was not originally developed to be solely in relation to paid care. At the heart of PCC is the idea that the quality of the relationship between the care-giver and the care-receiver is what determines the quality of the care provided (Kitwood,1997). Considerations of the quality of the relationship has as much application to family care as to paid care.

Some studies have highlighted the challenges some family carers face when providing care in family settings, showing evidence of quality of care falling below what should be provided, with high rates of verbal and physical abuse reported by some family carers towards the person being cared for (Selwood & Cooper, 2009; Cooper et al., 2010). In their study, Cooper et al. (2010) investigated the longitudinal changes in abusive behaviour among carers from home-care settings and discovered that nearly half of the spousal carers reported abusive behaviour at the beginning of the study towards the person for whom they were caring, which escalated to almost two-thirds after a year. This underscores the insufficiency of current support services in addressing the quality of care provided by family carers and highlights the importance of addressing these challenges and ensuring that family-provided care is also person-centred.

Although research into PCC in home-care services is sparse, some studies have directly explored how family members promote values in their provision of care that map onto the concepts of PCC, and how adherence to these values differs between carers. For instance, Chung et al. (2017) conducted a qualitative study to explore the experiences of family caregivers who provided care for people living with dementia in the community. They found that family caregivers used various strategies to maintain the agency and personhood of the person with dementia, which are central aspects of PCC, including promoting engagement and maintaining their involvement in daily activities e.g., social interactions and household tasks. In their study, Perry and O'Connor (2002) explored how spouses of individuals with dementia can preserve the personhood of their partner. They identified several strategies used by the spouses, including emphasising their past achievements and abilities and creating a positive and supportive social environment for their partner. Hellström et al. (2007) also explored the strategies used by spouses in caring for their partner living with dementia. Consistent with previous research, the study revealed that the primary strategies used by spouses involved providing a supportive environment for their partner as well as maintaining their partner's involvement; again, these are both values associated with PCC.

Rather than focusing on how some carers promote PCC values, two papers have explored differences between family carers (specifically, spousal carers) in how person-centred they are in their approach. One study by Riley et al. (2020) explored differences in how carers made sense of challenging interpersonal behaviours, such as aggression. The study analysed data from semi-structured interviews with spousal carers and found that some carers were better able to interpret and respond to their

partners' challenging behaviours in a person-centred way than others. Consistent with the notion of the relationship being central to PCC, they also found that those who reported the continuance of an ongoing loving relationship were more likely to respond to challenging interpersonal behaviours in a person-centred way. Another study by Ellis-Gray et al. (2014) developed an observational coding system for rating how person-centred partners were in providing support on activities of daily living and was able to demonstrate that the VIPS framework for conceptualising PCC (Brooker, 2004) can be successfully applied to characterising family-provided care. These studies provide support to the notion that quality of care, and in particular PCC, can be quantified and applied to family-provided care in a measurable and meaningful way.

The objective of the current study was to expand upon these earlier studies that used the concept of PCC to investigate the care provided by spousal partners, with a particular focus on support provided for the basic activities of daily life. Thirty participants were interviewed and asked to describe specific instances of how they provide care and support with the activities of daily life, and to reflect on the general aims and considerations that influence the way in which they provide that care. They were also asked about the challenges of meeting those general aims, and about what influenced the way in which they provided the care.

The aims of the study were:

1. To use the VIPS framework of PCC to conceptualise and describe the nature of the support provided, and to explore differences across carers in terms of how person-centred their care is.

2. To gain a better understanding of the barriers to delivering PCC.
3. To gain a better understanding of what has influenced their approach to providing support on tasks of daily living.

Method:

Ethical approval was obtained from the University of Birmingham's research ethics committee and a copy of the approval letter can be found in Appendix 3.

Participants

Carers affected by dementia were recruited through the Join Dementia Research website which is a service that allows people with dementia to register their interest in taking part in dementia research. The research study was posted on the website and an advert was attached that interested members could have a look at, which is included in Appendix 4. The profiles that were matched to the study were then screened manually by the research team. The carers meeting the eligibility criteria were initially contacted either by phone or email depending on the preference listed on their profile. If the carer was interested in participating and confirmed that they met the inclusion criteria, they were then sent written information about the study along with the Participant Information Sheet (Appendix 5). Participants were given at least 24 hours to look through the information and were then contacted again by the researcher. If they were still interested in participating, an interview date and time was set up.

The target sample size was dictated by the quantitative aspect of the study that is covered in the following chapter. The hypothesis was to be tested using correlation analysis. Power analysis was conducted using G*Power (Faul et al., 2007). For a two-tailed test and an alpha level of .05, with power set at 0.80, the

analysis indicated that a sample of 26 would be required for the detection of a large correlation (0.5). As such, a sample of at least 26 participants was targeted.

To be considered eligible to participate, the carers needed to meet the following eligibility criteria:

- participant was the spouse or partner of someone who had been diagnosed with dementia,
- participant must have been living with their partner for at least 5 years before the onset of dementia,
- participant must have no co-existing learning disability, major mental health disorder or other condition that may have an impact on their ability to take part,
- participant must have not provided substantial care to the person with dementia prior to the onset of dementia,
- a minimum of 3 months must have passed since the diagnosis of dementia was given,
- participant was currently providing some degree of care and support for activities of daily living

Procedure

Due to the risks associated with carrying out face-to-face interviews because of the COVID-19 pandemic, caring partners were interviewed either over Zoom or over the phone, depending on their preference, with the interviews lasting between 30min to 90min. At the start of the interview, the researcher went through the participant information sheet with the participant to give them an opportunity to ask any questions they may have. Following this, the audio or video-recording would

commence so that the researcher could obtain recorded verbal consent for the study. A copy of the consent questions asked can be found in Appendix 6. The interviews were audio or video-recorded, depending on whether the interview was conducted over Zoom or over the phone. Once consent was obtained, the researcher then collected demographic information (Appendix 7) and then proceeded onto the semi-structured interview. The interview was structured into two sections. The first section related to questions about how the couples worked together on daily tasks. At the start of this section, carers were asked to think of cooperative tasks that they performed with their partners on a daily basis. If needed, they were prompted by the researcher with examples of typical daily tasks. The carer was then asked to describe how these tasks are carried out, what support they provided to their partner during these tasks, and why they provided support in that way. Questions and prompts were formulated beforehand to facilitate the recollection of particular memories with regards to the execution of the everyday tasks (e.g., *Can you describe to me in more detail what happens?*).

The second section was comprised of open-ended questions examining the influences behind the support that they provided. They were asked questions regarding whether they reflected back on the way they provide care and support and whether this has changed over time. They were also asked whether they had sought out support regarding providing care and support in everyday tasks from professionals, written guidance or friends and family. They were then asked questions about PCC i.e., whether they were aware of the term and its definition, whether they had received support regarding how to apply this in the context of dementia care and whether they felt that this was something they actively applied.

The interview schedule can be found in Appendix 8. The interviews were transcribed through the Zoom software and the transcripts were then reviewed and any identifying details were removed.

After the interview, the participants also completed the questionnaire about relationship continuity and further details about this aspect of the procedure are provided in the following chapter.

Data analysis

Framework analysis was chosen as the most appropriate method as it allows for a systematic approach to analyse and generate themes between interviews and is suitable for large data sets (Ritchie & Spencer, 2002). The main advantage of this approach is that it allows prior research and ideas to form the basis of the analysis. This method allows the researchers to sift and sort the data in accordance with key issues and themes identified from previous research as well as with the themes identified from the data. In accordance with the aims of the study, the framework we developed for the analysis was based on the VIPS framework devised by Brooker (2004) while the sub-themes were developed inductively on the basis of the coding of the first three transcripts, as per the recommendations for using framework analysis (Srivastava & Thomson, 2009). Categories in the original framework also addressed factors that may have influenced how person-centred the participants were in providing support for activities of daily living. A ‘miscellaneous’ category also captured other issues that were raised by the participants. Two members of the research team went through the first three interviews and agreed on the framework for coding them, which is included in Appendix 9, which was then applied to the rest of the interviews by one of the researchers.

Quality assurance

Two members of the research team separately went through ten randomly chosen transcripts highlighting the descriptions of support they believed demonstrated more or less PCC and rating which element(s) of the VIPS framework each description of support reflected. The ratings from the descriptions of support that were highlighted by both raters were then compared and analysed to check for inter-rater reliability.

The Cohen's *K* in relation to agreement between raters about the VIPS categories was 0.84, with a 95% Confidence Interval of 0.76 to 0.90 which showed an "almost perfect" strength of agreement between the raters as defined by Landis and Koch (1997).

Reflexivity

An essential consideration in this study involves an understanding of the researcher's positionality and its consequential impact on shaping the research (Willig & Rogers, 2017). Several potential biases may have influenced both the execution of the research and the subsequent interpretation of the findings. The researcher's personal characteristics, including being in her twenties, female, and of white European background, as well as her professional background as a dementia adviser for the Alzheimer's Society, could have influenced participants' engagement during interviews. For example, the notable age difference between the researcher and participants might have prompted participants to respond more succinctly, assuming a need for efficiency and brevity due to perceived generational differences.

Ethnicity also may have played a role in shaping participant responses. The fact that the researcher did not share the same ethnic background as a participant

who identified as an ethnic minority may have impacted the interaction. It is plausible that the participant might have been less forthcoming, considering the dissimilarity in ethnic backgrounds. The researcher's gender, being female, may have also impacted the level of openness from participants of the opposite gender.

Beyond personal characteristics, the researcher's professional background as a dementia adviser for the Alzheimer's Society also needs to be taken into consideration. While this background likely facilitated rapport-building, it may have inadvertently predisposed the researcher toward a more sympathetic interpretation of the data, potentially affecting their ability to identify instances of suboptimal care.

The introduction of the research to participants, both the researcher's initial contact and the participant information leaflet, could have influenced the information shared. The emphasis on exploring "what matters for a spouse when giving care and support" might have led participants to perceive the research as focused on evaluating the care provided by the participants. This may have potentially resulted in participants avoiding sharing what they perceived as negative experiences of care, creating a potential bias towards more favourable accounts.

The interview format itself may have constrained participant responses, given its focused nature on everyday caregiving tasks. Participants may have felt compelled to be concise, adhering to the interview's structured format, limiting the exploration of nuanced experiences. Furthermore, the virtual nature of the interviews, necessitated by the COVID-19 pandemic, may have inadvertently fostered a more 'business-like' atmosphere, limiting the emotional engagement. The virtual medium may have introduced a barrier to building rapport, potentially hindering participants' willingness to open up and share their experiences fully.

Results:

Participants

Ten men and twenty women who were carers for their heterosexual partners participated in this study. The demographic information collected about these participants can be found in Table 6.

Table 6. Demographic information of the participants

Number of participants	Gender (N)	Mean age (SD)	Age range	Type of dementia (N)	Length of time since diagnosis (N)	Length of time providing support (N)	Length of relationship (N)
30	Male (10) Female (20)	Partners: 74.3 (8.3) years Participants: 72.4 (8.23) years	Partners: 55 – 92 years Participants: 56 – 88 years	Alzheimer's disease (19), Mixed dementia (5), Vascular dementia (5), Dementia not otherwise specified (1)	6 – 11 months (2), 1 – 2 years (9), 3 – 4 years (7), 5 – 6 years (6), 7+ years (6)	6 – 11 months (1), 1 – 2 years (6), 3 – 4 years (7), 5 – 6 years (7), 7+ years (9)	11 – 15 years (2), 16 – 20 years (2), 21 – 25 years (3), 26+ years (23)

Themes emerged from the participant interviews

The themes discussed in this paper that emerged from looking through the coded frameworks can be found in Table 7.

Table 7. List of study themes

Super-ordinate theme	Theme	Subtheme

Occurrence of PCC when providing support with everyday activities	Values people	Agency and control Supervision Respect and involvement Strategies to maintain independence
	Individual	
	Perspective taking	Impact of dementia
	Social	Communication Responding to upset
Influences on the incidence and application of PCC when providing support with everyday activities	Barriers to PCC	
	Conflicting PCC values	
	External sources	Discussion with others Professional support Written guidance
	Awareness and application of PCC	
	Feeling prepared	
	Reflection	
Broader issues	Issues with diagnosis	
	Professional support	
	Relevance of dementia groups	
	Impact of COVID-19	
	Paying for support	

Support with everyday activities

The first part of the interview focused on asking carers about how they provided care and support with everyday activities with a view to determine how PCC manifests or does not manifest itself in the way they are providing this support.

Values people

a. Agency and control

The first element of the VIPS framework, 'values people', relates to treating the person with dementia with the same status as everyone else in society in terms of control and agency. How much agency and control were given to their partner when completing an everyday task was indeed a recurring theme. As the following quote shows, many participants seemed to be aware of the importance of promoting their partner's agency and control in everyday activities and mentioned worrying about managing their partner too closely or taking over too much:

> *"It's been my policy to encourage independence for as long as possible." (P1)*
>
> *"As long as he can do as much as he can do, for as long as possible, that to me is better than starting to do things for him now I think, I don't feel that it's right." (P30)*

Participants reported promoting agency and control in various ways. The most common ways of promoting their partner's agency and control were encouraging their partner to complete the task on their own, giving them choices on how the task or which task is completed and only helping their partner when requested. Partners showed instances of providing more PCC when they described giving their partner a

choice in how an activity or task was completed to make sure their own wishes and preferences were being considered.

> *“I don't want to live her life for her, I don't know what mood she’s in, in terms of what does she fancy doing, what are the things she's interested in, she actually wants to do today.” (P8)*
>
> *“I just say to him like “the news is coming on” or “this program’s on or that program’s on if you want to watch” and he’ll choose if he wants the programme. He’ll say no, usually he likes watching the news channels and things.” (P17)*

Some participants described variations in how much choice and control they allowed their partner. Many participants stated that they only offered help and support on a task when asked by their partner but in other instances during the interview, they stated that for a different task they took over the task completely without waiting to be asked. For instance, one participant stated that they offered support to their partner regarding taking the medication only when their partner asked for help but also stated that they had taken over grocery shopping completely as it is just easier to do it on their own (P3).

> *“She’s just starting to slip with the donepezil now, she forgets to take it and then she’ll come and tell me she’s forgotten, and should she take it now […] I try and check that she’s doing it, but I just look at this spreadsheet.” (P3)*
>
> *“I just take [the shopping] on, I don’t know whether she could shop, she probably could, if she had a list, she’d have to write the list down, take it to the shop and she would probably bring everything back on the list […], much easier if I do it.” (P3)*

Similarly, although some participants highlighted that they make sure to give their partner choices when completing a task, this is then disregarded for certain participants in other tasks. For instance, although one participant mentioned that they find it important to give their partner choices and in fact said that they make sure to ask their partner what they would like to do every day, in another section of the interview, they mentioned that they do not give their partner the choice regarding what programme to watch and instead chooses for them (P2).

Although participants did reflect on trying to promote their partner's independence, sometimes they failed to apply this to certain activities. Specifically, it seemed to be for tasks that the participant found easier or quicker to do on their own (as is shown in the quote below) or if it compromised their partner's safety or well-being, which is discussed later in this paper.

"*I usually take over […] because I'd never get the cup of tea otherwise." (22)*

When the participants who stated they promoted independence were asked why this was important to them, many provided explanations that were not person-centred. For instance, many participants stated that they promoted their partner's independence on tasks because it was easier for the participant as promoting their independence meant they had less to do themselves:

"The more she can do independent with me not having to do things, the slightly easier it is for me." (P1)

"The more she did or the more she continued to do, the less I have to do it." (P4)

Although many participants provided support in a way that was consistent with PCC principles, their reasoning behind these behaviours was not always person-

centred. Although many participants directly mentioned that they encourage their partners to participate in everyday activities or even encourage them to do these activities on their own, the reasoning behind this person-centred behaviour was not always person-centred. For instance, many participants stated that encouraging their partners to engage in a task is important to keep them stimulated and to avoid them losing more skills or cognitive ability:

"Because I'm deskilling him, I don't want to deskill him." (P16)

"Well, I think that it simulates the brain, to a certain extent." (P20)

Other participants however did provide more person-centred explanations for why promoting independence and agency in everyday activities iss important. Some participants mentioned that the reason they find it important to promote independence is because they know that living independently is something that their partner finds important (P6 and P18) and would be upset if it was compromised (P3 and P15). Other participants mentioned that promoting independence and agency in everyday activities is important for their partner's self-esteem and well-being (P6, P10 and P20).

"I think it's important that he can do things and also for his own self-esteem that he can do some things, because sometimes he'll say, "I can't do anything" and that's simply not true, he can do loads and loads of things." (P6)

b. Supervision

Supervising their partner when they are completing a task was another common theme during these interviews. The most common example of having to supervise their partners was when participants reported having to supervise their partners taking their medication to ensure that they remembered to take it. For

instance, one participant was able to promote their partner's independence in terms of when they take the medication but did need to supervise to make sure their partner had taken it.

> *"It gives him a bit of independence, and you know he will take it when he wants it, after his breakfast rather than before his breakfast, or while he's eating whatever but, I have to keep an eye on [it] to make sure that he has an actually taken them." (P14)*

Although this does impede on their partner's independence, it seems that supervision on a task is an alternative to participants having to take over the task completely. Another example of this was demonstrated by a participant who mentioned that although their partner is able to choose on their own, the participant did need to supervise what clothes have been chosen as their partner may otherwise choose to wear the same clothes again:

> *"If we're going somewhere then I have to make sure he's dressed properly, he would just wear the same old things all the time." (P12)*

The manner in which the participants were supervising their partner on these everyday tasks is important. Certain participants recognised this and supervised their partners at a distance rather than in a controlling or intrusive way. For instance, as is shown in the quote below, rather than managing or controlling the way their partner does the cooking, participant 8 just ensured that the appliances were turned off once the partner was finished cooking.

> *"There are certain dishes which she always made, like chili, which she still makes occasionally. She'll do things on her own, but I would then go into the kitchen to check to make sure everything's switched off." (P8)*

On the other hand, some participants reported supervising their partner even when it was not strictly necessary, which is evidence of a less PCC approach in relation to their partner's agency and control. For instance, one participant stated that they will supervise what clothes their partner picks out even though they would probably be able to do it on their own.

> *"He will choose something, and normally I will say, "yes that's fine" or I might say, you know, "maybe that's a bit of a summery one", but if you know, if I let him do it, he would probably do it, but it's something I don't mind doing with him sort of thing" (P14)*

c. Respect and involvement

The element "valuing people", which is a core theme in PCC, encompasses the fact that each person should have an equal right to respect, dignity and involvement in their environment. Indeed, one of the themes raised in these interviews was the idea of keeping their partner involved in everyday activities. Many participants highlighted their effort to keep their partner involved in decision-making and planning, for instance planning holidays, choosing grocery items and managing finances. When asked why this was important to the participants, to determine their reasoning, a few explained that maintaining their involvement was simply a continuation of how they have lived their life together. Again, it seems that some participants were exhibiting PCC in these instances even though the reasons given were not explained in terms of the model of PCC.

> *"Keep this normal life going for as long as we possibly can." (P18)*

Again, some participants described inconsistency in the application of a more PCC approach across all tasks. For instance, one participant stated that they make

the effort to involve their partner in the grocery shopping even though they would rather do it alone, however, when discussing involving their partner in the cooking, the participant said they did not because "*sometimes it's just more trouble than it's worth" (P14).*

The theme of respect and dignity for the person with dementia was also directly brought up by some participants during the interviews. Most notably, a few participants compared their partners to children, which can be a threat to their dignity. Again, however, there was inconsistency in some accounts. For instance, one participant recognised the importance of not treating their partner like a child, but within the same interview, the participant compared their own partner to a child.

> *"He still deserves respect and it's something I've had to drill into the carers. Don't treat him like an old dear, a child, you have to treat him with respect." (P11)*
>
> *"They become like children." (P11)*

Another recurring theme emerging from these interviews was whether the participants took the time to explain things to their partner. Specifically, this issue came up often when discussing medication. Participants differed on whether they chose to explain the medication being taken to their partner. For instance, participant 4 stated that they do not take the time to explain it to their partner because it would take too much time and they feel that their partner would not understand the explanation anyway. Other participants, for instance participant 14, did seem to exhibit a more person-centred behaviour in this scenario as they reported taking the time to explain the medication and why it was necessary to their partner.

“I don’t explain because she has six tablets in the morning, so I’m not going to go through, […] no good explaining to her what they are, because she don’t accept, you know, [that] she got these conditions.” (P4)

“We’re putting [him] back on citalopram to try and raise his mood, which hasn't worked so far, but so I can say to him, […] “we’re trying these out to see if we can make you feel a bit happier or bit better” or something like that” (P14)

d. Strategies to maintain independence

Another sub-theme that came out of these interviews was the fact that many participants have tried to devise strategies to maintain their partner’s independence or ability to carry out a task on their own. Some strategies were unique to that person, e.g., using boxed cake mixes to make baking easier for their partner (P10) or purchasing specific kitchen appliances that are easier to use (P6, P11 and P17), while other strategies were more widespread and were mentioned by several participants. The most common ones were concerning purchasing equipment that would help their partner e.g., dosette boxes (to make taking medication easier for their partner). Another common strategy was maintaining a good routine. Many participants reported that keeping a routine can help promote their partner’s engagement in activities that become familiar to them, as is demonstrated by the below quote.

“I don’t need to remind him, he knows routine. He knows that at breakfast he takes one lot [of medication], and then he knows when he's going to bed, he takes another.” (P13)

Using technology in everyday tasks also allowed participants to promote their partner’s independence while making sure their partner is safe. For instance, many

participants reported that in order to promote their partner's freedom to roam, they were able to use GPS trackers to allow their partners to walk about independently while still remaining safe.

> *"They all now have to be kind of organized on his behalf and supervised, he still does this, but I've a put a tracking app on his phone so that I know where he is on the cycle rides, just in case I need to go and get him." (P18)*

Many participants had also set up strategies specifically around making managing finances easier for their partner so that they could still maintain some independence. Participants reported strategies such as making sure that their partner has the right amount of cash on hand when going to the store, simplifying the PIN number to make it easier to remember, keeping a limited amount of money in their bank account in case the card gets lost or giving them a limited amount of cash on hand in case they lose it, or something goes wrong.

> *"He has to have the correct money to go, he's struggling with money, he struggled with money for a while, but most mornings he's got a little pot to put change in and I make him count the money out that he needs and then he goes to the paper shop and back." (P13)*

Another change mentioned a few times that helped partners maintain independence was moving houses. This came up in a few interviews where the participants explained that downsizing houses and/or moving into a bungalow or a one-bedroom house made it easier for their partner's mobility issues and navigating and moving about the house to avoid getting lost.

> *"V can't get lost in a one-bedroom house, we did have three stories and that was providing difficulty" (P8)*

Moving homes however does present its own challenges. A few participants mentioned that moving homes had however affected their partner's ability to do certain tasks on their own. For instance, a few participants mentioned that as they moved homes, they obtained new appliances for the home that their partner does not understand how to use (P6 and P11). Moving homes also affected one partner's ability to remember their way around the home (P6).

Individual

Another tenet underpinning the VIPS framework of PCC is the idea of providing individualised care. This entails regarding the individual with dementia as a unique person with a distinct personal history, personality, values and objectives, and providing care for them accordingly.

Many participants reported taking into account their partner's personality or preferences when making choices on their behalf. For example, although multiple participants reported choosing TV programmes for the partner without asking what they would like to watch, they choose the programme based on their idea of what would appeal to their partner.

> *"I tend to know what he'll like or most of the time he's happy watching what I'm happy watching." (P19)*
>
> *"In the evening if we're watching together, I would say, maybe 80% of the time I have to prompt for an answer. Sometimes he'll suggest something and then I'll try to go with that, as far as possible, or I'll try to find things that he would like so that we're not always watching things I would have chosen." (P18)*

Another example of providing individualised care that emerged from these interviews was taking into account their partner's personal history when providing

care in the context of everyday tasks. For instance, as is shown in the quote below, one participant showed understanding of how their partner chooses to carry out an everyday task by reference to his past.

> *"Then he goes around with the same sponge and cleans up all the sides, and even if there's something on the floor and you see, this is an interesting one, because I said to his daughters, "why has he started" and she said, "Oh well, his mother used to do this". I don't know about the dishes, but she used to go around with the cloth, so whether that's come back." (P14)*

Another common example of taking into account their personal history was the use of humour during everyday tasks. This seemed to be a common occurrence for participants who reported that they have had a history of using humour in their relationship in the past and want to maintain that positive environment now as well.

> *"I think I have, because I know what makes our relationship work and what doesn't work, so well I've tried to maintain that kind of approach really, you know, we still have a joke about things sometimes." (P6)*

On the other hand, some participants reported less person-centred behaviours when it came to providing individualised care as they showed instances of deliberately ignoring or not taking into account their preferences. For instance, one participant demonstrated a disregard for their partner's preferences regarding clothing choices. When asked if they give their partner a choice of which jumper to wear, the participant responded by saying "*just give him one, because he won't care"* (P12). Similarly, one participant reported often ignoring their partner's wants if their partner said they did not want to do the activity the participant had planned that day:

“If it's something that we might do or have done in the past I’ll say, “would you like to do that?”. Normally, the answer’s no but we might do it anyway, if I decided we’re going to do it, we probably will do it.” (P3)

When asked why giving their partners a choice in how the task or which task is completed is important, many participants provided person-centred reasonings as to why this is important. For instance, a few participants mentioned that giving them a choice is respectful (P11 and P18) and is important as their partner is still able to choose for themselves so the participants feel they should not be choosing for them (P2 and P11).

“Because of the fact that he does understand, if he was lying in bed all day long completely out of it, which he will get like that, then it's different, it's different how you speak with him. But I try and give him the opportunity on the off chance that he understands or fancies going out, I still ask him.” (P11)

Many participants also directly mentioned that they understand that the care provided should be individual and unique to that person’s needs. A few mentioned the fact that this care should be individual as not all dementias present in the same way so a generalised approach to care would not be appropriate.

“Taking, you know, say A as an individual and looking at his needs rather than doing the generic thing of saying “this is what people with Alzheimer’s need”, it’s tailored care because, I mean I have to say, A is like nobody else I know with dementia.” (P12)

On the other hand, many participants made generalisations of people with dementia. Interestingly, even participants that had stated the importance of not taking

a generalised approach to care, such as participant 12, also at other points in the interview made generalisations of people with dementia:

> *"He's very good at preparing large quantities of red wine, but that's another part of the frontotemporal dementia." (P12)*
>
> *"Somebody was explaining to me that if you've got dementia, your brain's working so hard to try and just keep going, you know, trying to remember things, trying to know how to do things, trying to get up in the morning and all of that, that actually you are exhausted." (P12)*

Perspective taking

The third element in the VIPS framework relates to the participant's ability to take on the perspective of the person with dementia and respond with empathy. Many participants exhibited this when reflecting on how their partner might feel about their ability to complete a particular task. For example, multiple participants demonstrated taking on their partner's perspective when showing that they understood how it must feel for their partner to not be able to complete tasks on their own.

> *"Equally I can understand how he could feel humiliated by needing that help, because that's how I would feel if it was me, so I'm constantly trying to help him maintain as much independence as he can, for as long as he can, while not setting him up to fail with tasks I know he's just not going to be able to do." (P6)*

Other participants showed taking on their partner's perspective when discussing how their partners might be feeling more generally. Participants showed understanding of how their partner's past history, personality or mood can affect

them. In fact, many participants mentioned that they were aware that their partner's mood can affect their ability to complete a task.

> *"Her ability to do things for herself is directly impacted by how much stress she's under and some of that is things which are stressful and some of that is things that she perceives to be stressful and get yourself into a state, so it just does depend what mood she's in. So, it can range from I don't have to do anything to I have to help her get dressed." (P8)*

In contrast, some participants showed a lack of taking their partner's perspective when completing everyday tasks. For instance, one participant reported not being able to understand the reasons behind their partner's difficulties in completing a task:

> *"But if you ask him to do anything differently, so like getting him to hang the washing on the line, sort of have to help him now. I just don't know, I have no idea what he doesn't understand about hanging washing on the line, but he doesn't." (P12)*

a. Impact of dementia

The main indication of perspective-taking was when participants showed understanding and awareness of the dementia's impact on their partner. Many participants mentioned that they were aware of the ways in which the dementia affected their partner's personality or abilities. This awareness and understanding of these changes helped the participants provide PCC as it influences the way they provide care and support on tasks or even what activities they choose to complete with their partner. For instance, one participant mentioned that the dementia has affected their partner's ability to follow along or participate in conversation, so they

have sought advice on how to manage this and have found strategies that have been helpful to help maintain their partner's involvement in conversations. As a result of taking on their partner's perspective on how their change in ability regarding participating in conversation affects them, they were able to seek the right assistance and apply successful strategies to support their partner.

> *"When I did phone the Alzheimer's Society, that was very helpful, was when there's a conversation going on, try and stick to one subject so he can follow it and try and slow it down a bit like, you know when we are with a group of friends or family, you know it's like conversation changes, zigzags across and he can't follow it. And that was very helpful, and I did tell my family that." (P6)*

Taking on their partner's perspective seemed to also affect the way that participants communicate with their partner. A few participants explained that their awareness of the impact of dementia on their partner's abilities or personality affects the way they communicate with their partner during a task. For instance, one participant mentioned that because their partner struggles with following instructions, they avoid complexity when communicating with them regarding how to complete a task.

> *"He struggles with anything that's got more than one, you know, if I gave him two things and one's for there and the other's for there, that's too much information." (P10)*

Taking on their partner's perspective on how dementia has affected them, directly helped in being able to set up strategies to maintain their partner's involvement and independence. As mentioned earlier, many participants have found that keeping a good routine has helped maintain their partner's independence. As

one participant reported, this strategy resulted from the ability to take on their partner's perspective about how anxious their partner now becomes without a routine in place.

"She's very settled, she doesn't get anxious really, as long as we're doing what we always do." (P3)

Social

The fourth element of the VIPS framework relates to creating a positive and supportive social environment for the person with dementia. This element was prevalent when participants discussed the way they communicated with their partners and the ways they responded to their partner being upset.

a. Communication

One of the main issues that came up in many interviews regarding communication was whether the participant criticises or corrects their partner when their partner completes a task wrong or when they have said something incorrect. The occurrence of criticism seems to be quite mixed in many participants. Many report that although they know it is wrong to criticise or correct their partner, this can be hard to apply all the time and they occasionally make mistakes.

"Sometimes when I get frustrated and I shout, I think after I shouldn't have shouted, it's not his fault, but you know that's life." (P13)

"And he was on the top floor, so I called him, I said to him "what's all this?", and he said "what?" and I said to him "well, all these shorts". "Well," he said, "what's the matter?", and I said, "G, they're a mess, look". "I didn't do it" and I said, "is it the ghost again?", I said, "G, you must've", I said, "I've come up to

make the bed", I said, "and there's all these shorts everywhere" but he insists that it wasn't him." (P17)

Many participants were aware that this is something that they should avoid but find it difficult to apply at all times. When asked why these participants find it important to avoid criticising or arguing with their partner, although some provided a person-centred explanation e.g., it lowers their partner's self-esteem (P19) or it upsets them (P9 & P12), many provided explanations that were unrelated to PCC. For instance, a few participants mentioned that they do not see the point in criticising or correcting the way their partner completes a task because their partner will not remember it and it will not help them do the task better next time. This seems to be another instance where, although the approach to providing support might be person-centred, the reason for doing it this way was unrelated to the principles of PCC.

"Absolutely no point because he won't remember next time, so I'm just wasting my breath really." (P12)

Some participants also showed more person-centred behaviours when demonstrating that they try to choose their words carefully because they understand that phrasing is important to the way their partner reacts or interprets the information. For instance, one participant identified that phrasing is very important to avoid what they have said coming across as criticism or like an order.

"She's quite sensitive to those because basically anything like that, actually she will view as criticism, and the choice of words, choose words carefully, one of the things that she'll say that's a trigger for her is if you say, "you need to". So, coming here, you know, "we need to do, you need to be ready for 11 o'clock" or whatever it is, that might generate an adverse reaction." (P7)

In fact, a common less person-centred behaviour with regards to communication was that many participants showed instances of giving direct orders or commands to their partners. Although a few participants, like the one mentioned previously, choose their words carefully to avoid instructing their partners on how to do something, many do not recognise the importance of phrasing things as a request or suggestion and often give their partners a direct order.

> *"I usually say, "well go and have a proper shave". He'll say, "I've had one". "No, you haven't". "How do you know?" "Because I can still see your beard." "Oh", and then he'll go and have another go." (P27)*
>
> *"Like today, "are you going to have a shower now?", "no". When she acts out, I'll say, "we're going out, we've got to do this and do that, look I'm having a shower now, you come and have a shower now" and she did. It's sort of a learning curve how to deal with things." (P28)*

Another common theme was the use of humour to create a positive and supportive environment for their partner. As mentioned previously, this usually occurred in couples where humour was used even before the onset of dementia. Many participants in fact recognised the importance of using humour to create this positive environment for their partner:

> "*Yes, because I think sometimes, he feels like, not that he's a burden, he feels that he's sort of having to repeat himself, but it's like I said to him, we're getting old now, so we're both repeating ourselves, we try and laugh about it." (P9)*

b. Responding to upset

How participants responded to their partner being upset was also a point that was raised many times in these interviews. Similarly to avoiding criticism, many participants were also aware that they should be avoiding confrontation as much as possible but again, participants do not always find it easy to follow this. Many participants have devised their own strategies to avoiding confrontation with the most common strategies being leaving and giving their partner space, providing emotional support and comfort, and remaining calm and not engaging. Even with the best of intentions however, participants reported that sometimes they have gotten frustrated or angry with their partner even though they know they should not have. As evidenced in the below quote, this is another instance where taking on their partner's perspective has helped the participant understand how to respond in an empathic manner.

> *"Sometimes I might get frustrated and bark a bit, but generally I'm trying not to do that now and I realise how difficult it must be for her, so I am trying to be more patient, to be honest." (P15*)
>
> *"Sometimes he'll say, "I'm frustrated with myself". […] Sometimes I try and distract him, talk about something else, sometimes I walk away, sometimes I get frustrated and snap back. (P6)*

Influences on the way carers help with everyday tasks:

Barriers to PCC

Although many participants stated the importance of promoting independence, they still showed instances of doing things for their partner without waiting for them to ask for help or, in some cases, actively preventing their partner from completing a

task on their own. While some participants took over completing a task on their own for reasons such as because it is easier to do it themselves, e.g., when grocery shopping or choosing their partner's clothes, many participants stated that there are certain tasks that they do not have a choice but to take over; for example, when it comes to their partner's safety or wellbeing. Many participants stated that they have either had to start supervising their partner taking their medication, or even in some cases getting the medication out for them and putting it back once they have taken it to ensure that the medication is being taken properly.

> *"I have to supervise him taking the medication because he'll just forget. If I said, "go and take your medication", and he'll say, "yes, I will". But then unless I keep saying "go and take it now", and that can, you know, that feels like nagging sometimes, so I guess I just say and I just go and get it and say, "here's your medication" and he takes it." (P6)*
>
> *"I just get everything ready, get it out and give it to him because that's something I can't afford to have go wrong, you know, I don't want him to be overdosing or missing doses." (P18)*

Another example of suppressing the person's independence for safety reasons, was when it came to preventing their partner from driving. Many participants have had to actively prevent their partners from driving or have had to take over driving altogether as their partner is no longer safe to drive.

> *"He's still driving, and I went into the car with him the one day and we were nearly killed so I had to persuade him not to drive so then I had to drive." (P11)*

Finances also seemed to be an area of concern for many participants. A few participants mentioned having to prevent their partner from spending money by, for

example, locking the computer to prevent them from doing online shopping, hiding credit cards, and stopping their partner making unnecessary purchases at the store. Participants have reported that they often need to supervise their partner's management of the finances such as their online banking or have had to take over managing the finances altogether.

> *"He does all the things like online banking. I don't do banking online, but I have to look at my iPad every day [to make sure] that he hasn't done anything daft on the computer." (P9)*

Several participants also mentioned that although they try to encourage their partners to complete tasks independently, they have to intervene in certain instances. For instance, they feel they have to intervene in case their partner does the task wrong e.g., packing for a holiday. Some participants also reported taking over because the task was causing their partner distress.

> *"He struggles to know what clothes to take with him and when we went on holiday, went on a cruise, he got very distressed because he'll just stand and look at the wardrobe and not know what to take, so I did that for him. I took that over and did that for him because if we go to the caravan, if I leave it for him to do, there is a chance, you know, he won't have brought underwear or he won't have brought a jumper or something, or conversely, he'll bring too much of one thing." (P6)*

Similarly, many participants reported that they often had to intervene and complete the task themselves if they are in a hurry and do not have the time to wait for their partner to figure out how to do it on their own. For instance, the quote below shows that one participant sometimes prevents their partner from making them a cup

of tea if they are in a hurry and cannot wait for the time it would take for their partner to figure it out.

“You know if I haven’t got a lot of time, and I’m on the way somewhere, I do want to cup of tea then I’ll say I’ll make it, it's a little bit easier to do that.” (P22)

In summary, other considerations sometimes led participants to provide support in a way that was less person-centred.

Conflicting PCC principles

Another interesting issue that emerged from the interviews was the fact that in certain circumstances, PCC principles seemed to conflict. It seems that in certain instances, by prioritising one PCC value and showing more person-centred behaviour for that value, it can sometimes cause the participant to be less person-centred in another principle. For instance, as is shown in the quote below, by taking over the task for their partner, this participant exhibited less PCC when referring to the “values people” principle, however the participant did this only because the task had become distressing to their partner which shows evidence of more PCC as they were creating a positive social environment (“social” principle). This is also evidence of more PCC when it comes to perspective-taking as they realised how upsetting the task was for their partner.

"Sometimes I encourage him, other times I do it because he gets so distressed that he can’t remember how to do it." (P6)

Another example of this is shown in the quote below. In this instance, the participant showed that they are struggling to find the balance between trying to give their partner a choice in what to wear and not appear too controlling, which relates to the “values people” principles, while also taking into account the pride they have in

their appearance, which relates to the “individual” principle. In this example we can see that the participant acknowledged that prioritising one principle when providing care can lead to not being able to provide care that aligns with the other principle.

> *“You don't want him to still be in his pyjamas so it is something that maybe I don't need to do, but I do have this feeling that - there are two things you want people to understand, what it's like to live with somebody with dementia, so the crazier things he does with them, the better, but for his pride, but you know that it's nice, because he always looks so nice, I mean he's a nice looking man, and so it's a bit of a dilemma really how much to interfere, and how much just to let him and get on with it.” (P14)*

External sources

Part of the interviews focused on whether and where the participants were able to find advice and guidance about how to support their partners with everyday activities. The main sources of support explored were support from friends, family and other carers, professional support and written guidance.

a. Discussions with others

When asked whether participants sought out support or advice regarding how to support their partners, many participants seemed to seek out mainly emotional support rather than practical caring advice. Specifically, when it came to seeking support from dementia support groups, many participants found that they either felt reluctant to go to the groups or reluctant to seek advice from the attendees. Many participants felt that the people attending are older or at a more advanced stage and so the advice would not be relevant. The participants who found these groups helpful,

mainly appreciated the opportunity to have emotional support from other carers who understand what they are going through.

"There's a lot of tears shed at these places, when you're sitting talking with each other, but that is a big plus I think because everybody understands because they're all in the same boat." (P10)

Only a few participants did report gaining some practical advice from these groups. For example, one participant reported that speaking with other carers taught them the importance of eye contact when communicating with their partner (P13). However, it seems that even for those that did obtain guidance, their initial intention when attending these groups was not to seek out advice but rather just a source of emotional support.

Other sources of support mentioned were friends and family. Again, this support seems to be mostly emotional support. A few mentioned that the reason they do not seek support from their family is because they do not want to feel like they are burdening their children with their issues.

"I don't want to burden them too much with the responsibility for, you know, having to care for me or for him." (P6)

A few participants mentioned that the support received from their family and friends was mainly in the form of having discussions about how to proceed regarding their partner's care. For instance, one participant mentioned that the decision for their partner to stop driving was made as a result of having a discussion with their family (P14) and one participant reported speaking to their friend about what services and support are available in the area (P5). A few did however mention specific strategies and guidance they have received regarding everyday activities e.g., strategies on

how to respond to their partner being upset (P14) but this seemed to be a rare occurrence across the participants.

> *"He gets cross with somebody and then he goes out and has what we call a sulk, and his daughter will say "just leave him to it" and that's quite true often he'll come down, and you know, perhaps I try and say "look, you know, I'm sorry if I was cross with you" or whatever like that, but she said just let it go" (P14)*

b. Professional support

Many participants mentioned that they feel that there is a real lack of professional support available. Even participants that mentioned specific advice they found helpful from healthcare professionals still felt that not enough support was available. For instance, participant 6 mentioned that although they received advice from their medical consultant about encouraging independence on tasks for as long as possible, which they found helpful, they still were not happy with the support available. They mentioned that the advice they were given was generic and the healthcare professional did not take the time to get to know them and their relationship. The participant also felt judged and felt that the medical consultant was being patronising. This sense of feeling judged was echoed in a lot of other interviews and in fact was a common reason as to why participants did not seek out support in the first place.

> *"You don't want to be not coping yeah, and asking for help because you failed, like you failed then really, so you do try and plod on really." (P10)*
>
> *"People just don't get it and I think that's true that unless you've got somebody who's been through it, but people just don't really understand […], so [seeking*

support] is something I really need to do but you also feel slightly guilty that you're not coping." (P14)

Another common reason as to why some participants did not seek support was because they felt that they have not needed to yet as they do not feel like they have reached a stage where they would need support or advice. One participant even mentioned that they did not identify as a carer which is why they did not feel as though they have needed advice regarding their caring role.

"Although I obviously, you know talking to you, I can see that I probably do have quite a role in caring for him, I don't look at myself as a carer." (P5)

A couple of participants mentioned speaking with the Alzheimer's Society and receiving some helpful advice. As the below quote shows, one participant mentioned that they found it particularly helpful to speak to the Alzheimer's Society about how to manage the behavioural changes associated with their partner's dementia. Again, however, this was a source of advice or support mentioned by very few participants.

"The behaviour changes, sort of more aggressive, and we talked through that and how you deal with it, you know, how you react is important. Although of course it can change, what works one day, it doesn't work the next." (P2)

c. Written guidance

The majority of participants mentioned receiving printed material from various organisations. This written guidance seems to have been mainly received by the couples at the point of diagnosis. Although practically all participants reported having received these printed materials, no clear consensus could be found regarding whether these are generally considered helpful to the participants. A lot of participants however did report having gained some helpful information through the

written guidance. For instance, a couple of participants reported that they appreciated having the opportunity to get other carers' perspectives (P2 and P15) and a few participants reported that it helped them understand the progress of dementia and what symptoms to expect (P2, P6, P14 and P17).

Interestingly however, even out of those that mentioned helpful advice they had obtained from the written guidance, a few mentioned that generally however they did not find the guidance particularly useful. Many criticisms were raised about these materials such as the fact that the advice provided was too generalised; that it can cause their partner distress if they read the materials; and that the guidance is not appropriate when *"you're in the middle of it"* (P1). Common criticisms were regarding the fact that many participants felt that this guidance was generally unhelpful for younger-onset dementia and was unhelpful for people in the earlier stages of dementia. Participants felt that the perspectives and advice provided in the materials did not reflect what the participants were going through and were not relevant to their situation. This seems to echo the way many participants feel about the groups and services available for people living with dementia.

> *"A great ring binder full of information and pictures of old people with dementia and contact for, I can't remember what it was called, some sort of nurse, admiral nurse, and I thought well, we're not at that stage, early onset dementia, and that was 8 years ago, so it just went in the cupboard, and I think I might even have put it in the bin." (P5)*
>
> *"There was nothing appropriate or relevant for that current situation, it wasn't the right time to give us that." (P5)*

With regards specifically to advice regarding support with everyday tasks, only four participants reported having gained guidance that was helpful. Participant 2 stated that the written guidance they received helped them better understand how their partner processes watching TV and participant 6 and 17 both stated that the written guidance was useful in being able to explain the symptoms of dementia to their partner and showing them that they are not alone in experiencing them. Participant 6 also mentioned they found the information regarding distraction techniques and to avoid correcting their partner useful and participant 21 stated they learned about the importance of routines and being organised as well as communication strategies and useful equipment that could help with everyday tasks.

PCC

The interview also examined whether participants were aware of PCC, their understanding of it and their sources of information regarding this concept. Fourteen of the 30 participants stated that they had heard the term before. Four participants had heard of it in the context of their previous experience in teaching or healthcare rather than in the context of dementia care, and four reported that they had heard the term in passing but did not know what it meant or in what context they had heard it. Out of those that had heard of PCC in the context of dementia care, the majority reported that they had heard of the term through their own personal research rather than through professional external support.

> *"No one discussed it with me, so it would have been something I've read somewhere." (P8)*
>
> *"I think I might have scanned it somewhere, whether I read through something." (P25)*

The participants that reported having an awareness of PCC were asked what their understanding of it was and how they would define PCC. One common explanation was that they believed PCC was about taking into account the fact that every person receiving care is unique with their own individual needs and preferences. A few participants also mentioned that PCC meant considering the person's individual needs when it came to structuring a care package for the PLWD.

> *"Taking, you know, say A as an individual and looking at his needs rather than doing the generic thing of saying "this is what people with Alzheimer's need", it's tailored care because, I mean I have to say, A is like nobody else I know with dementia." (P12)*

Another common explanation was that their partner's needs should come first and be prioritised over the participant's own needs.

> *"It's putting V at the centre of the care and making sure her needs come first and we adjust accordingly." (P8)*

Only two participants stated that they made a conscious effort to provide PCC as a result of what they have learnt about it. However, many participants reported having aims in their provision of care that overlap with PCC principles (e.g., maintaining their partner's independence) even though they did not explain these by reference to the ideas of PCC.

Feeling prepared

The participants were also asked whether they felt well-prepared for taking on the role of helping their partner with everyday activities discussed previously in the interviews. The participants were also asked to expand on what helped them feel well-prepared or what would have helped them feel better prepared for taking on this

role. The majority of participants stated that they did not feel well-prepared for taking on this role. When asked what could have helped them feel better prepared, the responses varied across the participants. Some mentioned that they did not think there was anything that could have helped feel better prepared and one participant mentioned specifically that they did not believe it was possible to be better prepared because everyone is different so will require different care which is something you cannot prepare for.

"No, because I think it's a learning curve for you as well as for them, every person is different, aren't they?" (P2)

"I don't know how I could have been more prepared anyway. I just, I don't know how I could prepare for it." (P4)

A few participants mentioned that their previous personal experience has helped them prepare for taking on this role. Mainly this experience came from past caring for a family member, although a few had professional experience e.g., in healthcare (P6) or working with people with learning disabilities (P16,) that they were able to draw on when having to support and care for their partners.

<u>Reflection</u>

Participants were also asked whether they reflect on how they provide care and support with everyday activities and whether they have changed anything as a result of this. The majority of participants stated that they do often reflect on the way they provide this support.

"Yes, almost continually trying to find the best way to manage the situation." (P6)

A few participants answered that they do not reflect on the way they provide care and *“just get on with it” (P3)*. However, even some of the participants that reported that they do not feel that they reflect on how they provide care, showed evidence of reflection in their interviews. For instance, when asked, one participant stated that they do not reflect on the way they provide support but did show evidence of reflection when they mentioned that they worry about not taking over too many tasks for their partner.

“I worry a bit I could end up doing too much for him” (P5)

Indeed, the most common examples of reflection provided by participants were surrounding how much independence is given to their partners on everyday tasks, worrying about not getting frustrated or angry at their partner and reflecting on instances when they have criticised or corrected their partner.

“Sometimes, you know, I get irritated by things and then I wish I hadn’t very often. And of course, it’s been quite a steep learning, it’s only in the last few months. I’m having to get to grips, stepping back a little bit and thinking before I get frustrated.” (P20)

Participants were asked whether they have changed the way they have provided help with everyday tasks over time and all participants who answered that they had, showed evidence of previous reflection on the way they have provided care and support. For instance, one participant showed evidence of changing the way they help with everyday tasks by reflecting on their partner’s independence on a task and trying to develop strategies of maintaining it.

“What we try and do, is understand what's causing the issue and, if possible, remove it.” (P8)

Broader issues

Due to the open-ended nature of the interview, many broader points and recurring themes emerged throughout these interviews. Although they do not directly relate to the behaviours we were looking into regarding PCC, many themes were mentioned highlighting the lack of support participants feel is available. This general lack of support is an important theme to explore as that may also contribute to the lack of guidance regarding awareness and application of PCC.

a. Issues with diagnosis

A common issue that was raised was surrounding the diagnosis procedure. The main complaint was the length of time it took to get a diagnosis. A few participants even mentioned that they had to pay privately for a diagnosis as it would have taken too long to wait for a diagnosis through the NHS (P11 and P18). Many participants also reported that the diagnosis took a long time because they were told that other conditions, e.g., stress and depression, needed to be ruled out first before assessing for dementia. Many participants in fact reported that they had to push for a diagnosis as their concerns were dismissed as being related to stress because of the age of their partner, as you can see from the quote below.

"It's just easier to diagnose him with stress, but I knew deep down that there was something wrong, so I continued to push forward with it." (P11)

As one participant highlighted, getting a diagnosis early and as quickly as possible is essential as it can provide the carer with an understanding of their partner's behavioural changes, which would help the participant to respond to these changes empathetically and potentially then provide care that was more person-centred.

“It would have made a difference to our relationship, if I understood what was happening and just stopped being, you know, stopped being constantly told that he was just suffering from anxiety.” (P12)

“Once you've got an explanation, makes life so much easier. I mean I’m sure people would say that with dyslexic kids or autistic kids or whatever, just knowing what you're dealing with. Even if there’s no cure or medication or anything just makes your life so much simpler.” (P12)

b. Professional support

The most common issue that was raised was regarding the lack of adequate professional support. Many participants mentioned receiving no support immediately following the diagnosis of dementia and receiving no ongoing support or regular check ins. A few participants also reported that they felt the COVID-19 pandemic impacted the support they received professionally as many services had to shut down. Many participants expressed that any professional support received has been through having to seek it out themselves rather than support being offered to them.

“Nobody at the moment, that’s my big bug bear, there is nothing. Everything that J’s done, or we’ve accessed, it’s all been me that had to investigate, find out.” (P13)

“I think you have to figure it out yourself because you’re on your own, there’s no support, there’s no ongoing care when you’re diagnosed, you know, you can go to a health group and that’s it and literally you are cut adrift.” (P11)

Participants reported that even if they have received professional support, they had issues with the way the support was being provided. The issues with the support they had received varied across the participants. One participant reported

finding the professional support to be patronising and feeling judged (P6), another participant reported the wait for obtaining support was too long (P10) and another participant reported trying to reach out to obtain support but was only signposted to other organisations that could help (P14).

Participants also reported having issues with the support that is provided in the form of dementia and carers groups. Participants felt those groups were not suitable or appropriate for their situation. Participants mentioned a lack of services in their area for people in the earlier stages of dementia and for younger onset people living with dementia. Participants found these services inadequate for their own circumstances as they do not feel that they relate to the people attending and both the participants and their partners will therefore not benefit from and enjoy attending. A few participants even mentioned that they believed the nature of the groups to be patronising.

> *"Everything seemed to be aimed at people who had pretty far on development and didn't want to put P in events with people who were seriously affected." (P1)*
>
> *"It was so demeaning, they were singing the wheels on the bus and handing out little triangles and tambourines. No, no this is far too demeaning." (P13)*

c. Stigma

Another recurring theme across the interviews was the reported stigma experienced by participants. This stigma permeated a lot of different aspects of the caring role. A few mentioned how they felt they could not talk to anyone about the impact dementia was having on the sexual aspect of their relationship. In fact, even when two participants brought it up themselves in the interview, both participants seemed cautious about bringing up the topic. One participant stated, *"I thought about*

whether to say this, or whether this was too much information" (P5) while the other participant stated that this was only the second time that they had spoken about the topic with anyone (P11). Those participants reported feeling that they could not see their partner as a sexual partner anymore.

> *"You no longer see them as a sexual partner, but they don't understand, that was a big problem in our relationship" (P11)*

Another example of the impact of stigma is when looking into why some participants have not sought out further support for their caring role. As mentioned previously, a few participants mentioned not seeking support because they do not want to be seen as not coping with their caring role. Another participant explained that they only want to speak to other carers as they will be able to understand what they are going through rather than judging them.

> *"It's all very hard and if you're speaking to someone who is not in that situation and doesn't realise the limitations that you have on your life and how it altered your life, it sounds a bit as if you're criticizing your partner and you're being disloyal, whereas if you're speaking to somebody who's been in that situation, they understand that you're not being disloyal, you're just trying to get it off your chest." (P20)*

Another participant mentioned that they have also never been able to talk to anyone about their feelings about the changes in their relationship and their partner. They mentioned feeling as though *"people don't want to hear that"* and that in fact this interview was the first time they had been able to discuss this.

> *"They don't want you to be discussing, you know, the fact that actually maybe you don't like this person very much anymore, and all of that, so I did actually*

find that your questionnaire really interesting, first time anybody's ever asked me that many questions." (P12)

It seems that this perceived stigma surrounding their caring role has affected many participants seeking out support and advice regarding how to care and support their partner. Stigma could also therefore be a contributing factor as to why there is a lack of understanding and conscious application of PCC in some participants.

Discussion:

The aims of the study were:

1. To use the VIPS framework of PCC to conceptualise and describe the nature of the support provided, and to explore differences across carers in terms of how person-centred their care is.
2. To gain a better understanding of the barriers to delivering PCC.
3. To gain a better understanding of what has influenced their approach to providing support on tasks of daily living.

Aim 1

Many of the descriptions of specific examples of providing support, and many of the general aims that participants aspired to, mapped on well to the VIPS framework, with examples of the values being promoted and examples of them being ignored or undermined.

The first principle of the VIPS framework centres around the significance of "valuing" the person with dementia during caregiving. A recurring theme within this principle was the extent of agency and control granted to their partner while

completing tasks. Participants showed a clear awareness of the importance of fostering their partner's independence and involvement in tasks, often expressing concerns about overly managing or supervising their partner. Many also shared specific strategies they had developed to uphold their partner's autonomy, which mainly involved purchasing equipment that would help their partner on task. There were instances however where some participants exhibited less adherence to PCC when describing tasks where they actively restrict their partner's involvement. This often seemed to be dependent on the task being completed, e.g., driving or taking medication, or due to external factors such as time constraints on the task being completed.

Another aspect of the VIPS framework is the notion of individualised care, treating each person with dementia as a unique individual with a distinct personal history and personality, and providing tailored care to their specific needs. Many participants reported considering their partner's personal history and preferences when making choices on their behalf, e.g., what TV programme to watch, or when communicating with their partner, e.g., using humour they knew would resonate well with their partner. Conversely, there were instances where some participants exhibited less PCC by disregarding their partner's preferences and as such, providing support that is not individualised.

The third aspect of the VIPS framework relates to the participant's capacity to take on the perspective of the person living with dementia. Many participants demonstrated perspective-taking when reflecting on how their partner's feelings, particularly regarding their ability to perform specific tasks or how their mood might

be affecting them. Notably, participants also exhibited perspective-taking when showing understanding and awareness of how dementia impacted their partner's ability to complete a task, such as following instructions. In contrast, there were instances where some participants showed a lack of taking their partner's perspective. This seemed to occur primarily when participants struggled to comprehend their partner's difficulties in completing a task.

The fourth aspect of the VIPS framework pertains to creating a positive and supportive social environment for the person with dementia. During the interviews, participants frequently discussed the way they communicated with their partners and how they responded when their partner became upset. A prominent topic that emerged in many interviews was whether the participant tended to criticise or correct their partner when they made mistakes while completing tasks. The prevalence of criticism among participants varied, with many admitting that although they understood it was wrong to criticise or correct their partners, they sometimes found it challenging to refrain from doing so and made occasional errors in their approach. Similarly, when describing how they responded to their partner being upset, many participants admitted that although they tried to avoid confrontation with their partner as much as possible, they admitted that consistently adhering to this was challenging and they occasionally struggled to contain their emotions and refrain from getting frustrated or angry.

These findings align with existing literature on how carers promote elements of PCC in other contexts. For example, Hennelly and O'Shea (2022) explored how carers promoted personhood in individuals with dementia, which is a fundamental aspect of PCC. They found that the carers emphasised the importance of maintaining

a good sense of humour, effective communication skills, and avoiding conflict or tense situations. These strategies, which were also reported by participants in our study, contribute to the creation of a positive and supportive social environment for people living with dementia (element “S” of the VIPS framework). Hennelly and O’Shea (2022) also highlighted the significance of respecting and knowing the person, which parallels the strategies reported by some participants in the present study, aligning with the “values people” and “individual” principles of the VIPS framework.

Similarly, Wolfe et al. (2021) investigated what strategies were used by carers and people with dementia to help maintain the autonomy of individuals with dementia, another crucial aspect of PCC. Some of the strategies mentioned in their study echoed experiences shared by the participants in the present study. In Wolfe et al.’s (2021) research, participants emphasised the importance of retaining independence and involving the person with dementia in decision-making to exercise autonomy. They also highlighted the significance of opportunities for connection and the recognition of each individual’s uniqueness to uphold autonomy. These strategies were likewise mentioned by the carers in this study when providing support with everyday tasks.

Aim 2

Although many of the participants aspired to provide care that could be characterised as person-centred, there were challenges to meeting these aspirations. At times, the inability to apply PCC seems to be unavoidable. For example, the interviews revealed instances where carers were unable to prioritise PCC due to concerns for their partner’s safety or well-being. This finding echoes the research by

Sinclair et al. (2018), which explored how couples navigate everyday decision-making. The study showed that the involvement of individuals living with dementia may be affected, depending on the decision being made, particularly if it is considered a “higher risk” decision.

In addition to prioritising their partner’s safety and well-being, participants had other factors that superseded the VIPS objectives. On certain occasions, participants disclosed that they took over tasks either because it was more convenient to do so or due to time constraints associated with task completion. Moreover, several participants reported having to take over specific tasks, such as managing finances or taking medication, where it was important for the task to be completed correctly.

Aim 3

Although much of the care provided could be characterised as person-centred, only 14 participants were familiar with the term “PCC”. Even among those who reported familiarity with the term, it was evident that their understanding of its meaning was not clear. Some participants reported that they were not familiar with its application in dementia care, while others mentioned only encountering the term in passing. In general terms, participants were not explicitly trying to be person-centred in their approach. Indeed, in some cases, although the care could be described as in line with the values of PCC, participants gave explanations of the care in other terms that were unrelated to these values. For instance, when inquired about the importance of avoiding criticism or arguments with their partners – an approach aligned with PCC values – some participants offered explanations that were unrelated to PCC. They mentioned that they refrained from criticism or correction

because they believed their partner would not remember the feedback and it would not aid them in improving their ability to perform the task in the future.

A major reason for the lack of explicit application of PCC was the lack of information and support that the participants had received about their role as a carer. Similarly to the findings of De Poli et al. (2020), most participants in our study emphasised the general lack of formal support and availability of related services for carers. This lack of support emerged as an important theme during the interviews, potentially contributing to the limited guidance and awareness regarding the application of PCC in family settings. Carers emphasised the absence of regular check-ins and ongoing support, which aligns with Clemmensen et al.' s (2021) observation that unmet needs of carers can change over time as dementia progresses. Additionally, several participants reported having to proactively seek support themselves rather than receiving offered assistance, which De Poli et al. (2020) also recognise as problematic since identifying and acknowledging one's own unmet needs can be challenging.

Limitations

In conducting the research, a more structured approach to the interview schedule was adopted, deviating from the typical open-ended nature of qualitative research. Additionally, a framework analysis methodology was employed, informed by existing theories and prior research, to guide our investigation. This deliberate structuring helped to streamline the research focus, concentrating our efforts on specific aspects of carers' approaches to providing care for the partners. Given previous criticism about PCC being too abstract a concept (Clisett et al., 2013; Kogan et al., 2016), the framework analysis was employed, utilising the VIPS framework. This choice offered

a more concrete and specific tool for examining PCC behaviour. Opting for the VIPS framework as the analytical foundation stemmed from the proven success of its application in home settings, as demonstrated in earlier studies. The studies of Ellis-Gray et al. (2014) and Riley, Achiampong, et al. (2020) provide evidence that the VIPS framework can be effectively applied in home settings and can be used successfully as a robust framework for comprehending the caregiving behaviours of spousal carers within the context of PCC.

However, while this structured approach offered advantages, by narrowing the research focus, there is a possibility that some important factors influencing carers' approaches to providing care may have been overlooked. The framework might have inadvertently excluded other significant elements that shape how carers engage in activities of daily living and as a result, the study's findings may only represent a partial view of the broader caregiving landscape.

The data collected during the interviews revealed limited information regarding the underlying reasons behind participants' specific caregiving approaches. It is possible that the participants themselves may not have had clear insights into the factors that influenced their caregiving decisions. Alternatively, although interviews did touch upon participants' caregiving approaches, it may be that the interviews could have pursued this line of enquiry in greater depth. More in-depth questioning and follow-up probes during the interviews might have revealed more information about the motivations and rationale behind their caregiving choices.

One aspect we must reflect upon is the decision to conduct the interviews online, necessitated by the constraints posed by the COVID-19 pandemic. Online and phone interviews offered undeniable advantages in terms of convenience and accessibility for participants, which greatly facilitated recruitment. These remote options provided more convenient conditions, requiring less time from participants and allowing easy rescheduling when necessary. However, it is essential to acknowledge that relying solely on online or phone interviews did also limit recruitment possibilities, as it excluded those who were not comfortable with technology. Moreover, conducting interviews in a virtual setting might have influenced the study's findings, with concerns raised in previous research (Mirick & Wladkowski, 2019; Jowett, Peel & Shaw, 2011) regarding the efficacy of rapport building compared to face-to-face interactions. As a result, this might have affected the depth of the information shared by participants, potentially leading to a less comprehensive exploration of their experiences.

It is important to note that this study relied on participants' accounts of the care they provided for their loved ones. While the narratives offer valuable insights into their caregiving approaches in everyday tasks, it is important to recognise that there could be a discrepancy between what was reported and the actual care being delivered. For instance, a study by Small, Gutman, Makela, and Hillhouse (2003) found that caregivers of individuals with Alzheimer's disease believed they used simpler language when supporting their partners with daily tasks, however objective observations of their interactions revealed that caregivers actually overestimated their use of simpler language in these situations. Originally, the intention was to employ direct observations of caregiving interactions, allowing for a more objective

assessment of participants' behaviours and interactions with their partners. However, this plan had to be altered due to the COVID-19 pandemic, making direct observation unfeasible during this study.

It is also crucial to acknowledge that the study's sample does not fully represent the diverse range of caregivers and caregiving experiences within the broader population. All participants in the study were in heterosexual relationships, and with the exception of one participant, all identified as White British.

Moreover, although inter-rater reliability was high, in line with qualitative research in general, the interpretation of the findings from interview research is subject to a degree of subjectivity. Maintaining objectivity in data interpretation is essential for researchers, which can prompt the need for reflexivity. In the study, the focused nature of the research questions and the specificity of the interview schedule constrained the potential influence of researcher bias ensuring that the findings were not only plausible but reliable as well. The sub-themes discussed in this study were discerned as recurring patterns in the data, however the overarching themes had been predefined before analysis, drawing on established literature regarding the VIPS framework. This deliberate approach to data extraction minimised the possibility of results being skewed by researcher bias. Even in the more open-ended section of the interview schedule, the extracted information closely adhered to the research questions, so identifying which themes related directly to the application of PCC in home settings rather than delving into additional themes that might have emerged from responses in that section. To maintain impartiality, the interview questions, including follow-ups, were intentionally kept as open-ended as possible. This

approach avoided any direct association with specific aspects of caregiving behaviour or opinions, mitigating the risk of leading questions influenced by researcher bias.

Research and clinical implications

Although much of the care described in the interviews was person-centred, there were examples where this was not the case, and it was also evident that the principles of PCC were not always explicitly motivating the type of care that was provided. Many of the participants were unaware of PCC as a principle and it is unclear how many had a thorough understanding of it and how it translates into providing care for the tasks of everyday living. More generally, the participants had received little information or guidance relevant to their role as a carer for someone living with dementia.

This aligns with previous research by Clemmensen et al. (2021) and De Poli et al. (2020), underscoring the unmet needs of carers due to inadequate support for their caregiving responsibilities. These findings underscore the importance of addressing the knowledge gaps among carers regarding PCC and providing formal guidance on its implementation within the context of everyday tasks. Insights from earlier qualitative studies examining various aspects of PCC support the validity of the findings in this study, as strategies employed by participants in those studies align with those used by the carers in this study.

Examples mentioned earlier illustrate this point. Other studies similarly illustrate this point, such as studies by Sinclair et al. (2018) and Chung et al. (2017)

which emphasise the benefits of involving individuals with dementia in decision-making; and Hickman et al. (2020) which highlight the positive impact of maintaining humour in couples' relationships to create a positive and supportive environment. This suggests that strategies identified in this study may be reliable and applicable to other carers as well.

Given the prevalence of challenges and insufficient support identified in previous research, couple with the recurrent strategies used by carers, this study emphasises the need to ensure optimal care and well-being for individuals living with dementia and their spousal carers. It is thus crucial to address these barriers, provide carers with appropriate support, and enhance carers' awareness and knowledge of PCC, and skills in its delivery.

CHAPTER 5: Relationship Continuity and Person-Centred Care in Spousal Relationships

Abstract

Objective: This mixed-method study aimed to investigate the relationship between variations in relationship continuity and the extent to which spouses provide PCC.

Method: 30 spousal carers were recruited and interviewed about how they provide support to their partner living with dementia in everyday tasks. Each passage describing support for a particular everyday task was evaluated according to whether it suggested that the care provided was more or less person-centred. Participants also completed the Birmingham Relationship Continuity Measure (Riley et al., 2013) which assessed their experiences of relationship continuity. Correlation analyses were carried out between these measures.

Results: A significant correlation was found between higher scores on the relationship continuity measure and a greater number of passages suggesting more PCC. Although not statistically significant, a small correlation was found between lower scores on the relationship continuity measures and a greater number of passages suggesting less person-centred care.

Conclusion: This study suggests that promoting greater relationship continuity in couples could facilitate the provision of more person-centred care.

Introduction

For Kitwood (1997), PCC was essentially about the relationship between the care-giver and the care-receiver where good quality care stems from a good quality relationship. More recent authors (Beach et al., 2006; Nolan et al., 2004) have also reemphasised the centrality of the relationship and suggested we focus on 'relationship-centred care' rather than 'person-centred care'. Living with dementia can put a considerable strain on family relationships, and this can in turn change the nature of those relationships (Ablitt et al., 2009; Evans & Lee, 2014; Wadham et al., 2016). This raises the question of whether this could result in a reduction in the person-centredness of the care provided.

Given the ethical value of PCC and the contribution it makes to the well-being of both the care-giver and the care-receiver (Li & Porock, 2014; Brownie & Nancarrow, 2013; Kim & Park, 2017), understanding the changes in the relationship that may influence the delivery of PCC is crucial in improving the care provided to people living with dementia. One potential factor is relationship continuity, which has been suggested to impact how person-centred the care provided is in the context of marriages/partnerships in dementia. Relationship continuity refers to the extent to which a caregiver perceives the person with dementia and their relationship as essentially the same before and after the onset of dementia, while discontinuity refers to the extent to which a caregiver perceives them as essentially different (Riley et al., 2013; Riley et al., 2018). Continuity and discontinuity are at opposite ends of a spectrum, with caregivers varying in where they fall and exhibiting fluctuations over time (Walters et al., 2010).

Previous qualitative research has suggested that spousal caregivers who displayed continuity in their relationship may be more person-centred in their approach to care. For instance, earlier studies found that caregivers who report more continuity tended to respond with greater tolerance and empathy when striving to understand the behaviours of individuals with dementia (Murray & Livingstone, 1998; Walters et al., 2010). On the other hand, those experiencing discontinuity were shown to cope in more controlling and restrictive ways (Lewis, 1998; Walters et al., 2010) and were linked to a more depersonalised approach to care (Chesla et al., 1994; Walters et al., 2010). Additionally, a later mixed-methods study by Riley, Achiampong et al. (2020) was carried out comparing the results of spousal carers on a measure of relationship continuity – the Birmingham Relationship Continuity Measure (Riley et al., 2013) – and the attributions extracted from interviews about the causes of their partner's challenging care needs. The study found that those experiencing discontinuity were less likely to be person-centred in their understanding of behaviours and symptoms of the dementia that were challenging to manage.

Aside from research conducted in the field of dementia care, there is also evidence of the link between relationship continuity and PCC in individuals with acquired brain injury. In a review conducted by Riley, Keeble et al. (2020), earlier qualitative studies were summarised, and an additional study was reported that examined the connection between these concepts in this population. This study compared the results of spousal carers on the Birmingham Relationship Continuity Measure (Riley et al., 2013) and their responses to their partners' challenging behaviours reported in interviews. The study observed that the results were similar to

those found in dementia care, where caregivers who perceived greater continuity were more likely to display person-centred behaviours.

This link makes sense from a theoretical perspective as well. The concept of discontinuity pertains to the perception that an individual with dementia is no longer the same. This may cause the caregivers to abandon their previous knowledge and understanding of the person resulting in a shift towards a more generalised understanding of how dementia affects individuals (Riley et al., 2020; Villa & Riley, 2017). In consequence, they may be less likely to adopt the unique perspective of the person they are caring for and less likely to understand the person in the context of their own unique history.

Currently, the assertion that relationship continuity may impact the delivery of PCC in a family context is supported by a limited number of qualitative studies and one mixed method study. The qualitative studies did not specifically focus on the link between relationship continuity and person-centred care; and the mixed method study (Riley, Achiampong et al., 2020) focused on the link with how spousal carers made sense of challenging interpersonal behaviours. More research is needed to confirm the link and to explore how general it is (i.e., whether it affects other aspects of caring and not just the understanding of challenging interpersonal behaviours). Hence in order to establish a stronger link between relationship continuity and PCC, a mixed methods study was undertaken with the purpose of investigating the claim that continuity contributes to a more PCC-oriented approach to care. To explore the generality of the link, the study investigated the link with the care and support provided on tasks of everyday living. The hypothesis was that spousal carers exhibiting greater continuity would demonstrate a higher level of PCC.

Method

This study used the same sample and data from the previous chapter. As mentioned previously, using the framework, the researcher went through each transcript to pick out passages that were relevant to a consideration of how person-centred the care was that the participant provided to their partner. Conversation about what happened around a particular activity of daily life counted as one passage. When the conversation moved on to another topic, the passage was considered as completed. If the participant returned to discuss that same activity later in the interview, this was counted as a separate passage. As well as being rated in terms of the VIPS system, each passage was rated according to whether it suggested that the care/support provided was 'more person-centred' (i.e., the care/support was judged to promote person-centred values) or 'less person-centred'. If the passage contained both more person-centred and less person-centred components, the passage was rated as both more person-centred and less person-centred. The researcher was thus able to calculate the total number of more and less PCC passages for each participant interview.

As well as participating in the interview, the participants were also asked to complete the Birmingham Relationship Continuity Measure (BCRM) (Riley et al., 2013) which is the only developed measure of RC. The BCRM measures relationship continuity with 23 items that can be answered on the following scale: agree a lot, agree a little, neither, disagree a little or disagree a lot. These items measure the five dimensions of the relationship continuity construct ('relationship redefined', 'same/different feelings', 'same/different person', 'loss' and 'couplehood'). Higher scores on this measure indicate experience of more continuity in the relationship. The

possible scores that a participant can obtain on this measure ranges from 23 to 115. Some participants felt more comfortable filling out the measure on their own while others, who were less comfortable using technology, preferred filling out the measure over the phone or Zoom. As Riley et al. (2013) reported that a limitation of the measure was that certain questions from this measure (i.e., "*I miss having someone to turn to when I need some comfort or support")* assume that the premorbid relationship was satisfactory, the participants were also asked whether they felt that their pre-dementia relationship was satisfactory (i.e., *"Before the dementia started, were you generally satisfied with your marriage/relationship?"*) to ensure that their relationship was indeed satisfactory and control for that variable.

Results

Descriptive statistics

Two members of the research team separately went through ten transcripts highlighting the interactions they believed demonstrated more or less PCC and rated these passages accordingly. The ratings from passages highlighted by both raters were then compared and analysed to check for inter-rater reliability. Passages that were only rated by one rater were omitted from the analysis. The Cohen's kappa in relation to agreement between raters about whether the passages were more or less person-centred was 0.83, with a 95% Confidence Interval of 0.73 to 0.92 which showed an "almost perfect" strength of agreement between the raters as defined by Landis and Koch (1977).

The internal reliability of the BCRM was also examined and a Cronbach's alpha of 0.97 was obtained which shows high internal reliability given that it is above 0.7

which is generally considered the benchmark for acceptable internal reliability (Kline, 1999).

With regards to the question about whether the participant felt that they were generally satisfied with the relationship before the dementia started, all participants stated that they found their pre-dementia relationship satisfactory.

Descriptive statistics regarding the BCRM scores and PCC passages can be found in Table 8.

Table 8. Descriptive statistics

	Mean	Standard Deviation	Range
More PCC passages	15.97	6.90	6 – 39
Less PCC passages	5.97	4.01	0 – 18
Total PCC passages	21.93	7.39	7 – 47
BCRM score	67.07	27.29	23 – 107

Correlation between BCRM scores and number of more PCC passages

The recommendations of Tabachnick and Fidell (2013) were followed in evaluating the suitability of the data for parametric analysis which involved examining the normality of the distribution and the presence of univariate and multivariate outliers. To interpret the correlation, the scatterplots were also examined to look for non-linear relationships and multivariate outliers.

The normality of the distribution of the data obtained regarding the number of more PCC interactions for each participant and the data obtained from the BCRM scores was examined first. The skewness and kurtosis statistics were divided by the

standard error and if this was larger than 2.58 (p = 0.01), it was considered that there was significant skewness/kurtosis in the data. By this criterion, the number of more PCC passages showed significant skew and kurtosis (Appendix 10). Spearman's non-parametric correlation statistic (rho) was therefore calculated.

Using Tabachnick and Fidell's (2013) recommendation, the data was checked for any outliers and any standard score in excess of 3.29 to search for any univariate outliers. Participant 6 was an outlier in the number of more PCC passages as they had a standard score of 3.34.

Using the mahalanobis distances statistic as recommended by Tabachnick and Fidell (2013) to look for multivariate outliers, participant 6 was also a multivariate outlier, their mahalanobis value was above the cut off of 10.83 with a value of 11.15. This was confirmed by the examination of the scatterplot (Appendix 11).

The presence of this outlier also made it more appropriate to calculate a non-parametric correlation, because the influence of outlier is reduced when ranked data are used rather than raw values. Spearman's rho for the correlation between the two variables was employed, as is shown in Table 9. The correlation was in the predicted direction (i.e., more PCC passages occurred more often in the transcripts of those reporting more continuity in their relationship) and medium in size but was not significant.

Tabachnik and Fidell (2013) suggest that the decision about how to treat an outlier should be based, in part, on a consideration of whether the participant can be considered as an abnormality in terms of the population being sampled rather than just a statistical outlier – i.e., whether there may be something about the participant in

terms of the variables being studied that sets them apart from the population. On closer review, it was decided that the participant identified as an outlier could be considered highly unusual in terms of the population and variables being studied. The participant worked for many years as a professional in caring services and described in their interview that they had been trained in how to be person-centred in their approach to clients. When an outlier is considered to be different in some relevant way from the rest of the sampled population, the recommendation is to re-run the analysis with the outlier removed (Tabachnik and Fidell, 2013). Removal of the outlier from the analysis resulted in a higher correlation that was also statistically significant (Table 9)

Table 9. Spearman's rho correlation between number of more PCC passages and BCRM scores

				95% Confidence Intervals (2 – tailed)	
	Spearman's rho	Significance (2-tailed)	N	Lower	Upper
More PCC passages – BCRM score	0.36	0.06	30	-0.18	0.64
More PCC passages – BCRM score (outlier removed)	0.39	0.04	29	0.01	0.67

Correlation between BCRM scores and number of less PCC passages

As before, the recommendations made by Tabachnick and Fidell (2013) were followed and the normality of the distribution of the data obtained regarding the

number of less PCC interactions for each participant and the data obtained from the BCRM scores was examined.

The skewness and kurtosis statistics were divided by the standard error and if this was larger than 2.58 ($p = 0.01$), it was considered that there was significant skewness/kurtosis in the data. By this criterion, the number of less PCC passages showed no significant skew and kurtosis (Appendix 12).

To search for any univariate outliers, the data was examined to check for any standard score in excess of 3.29. No participant appeared to be a univariate outlier in either data set. Using the mahalanobis distances statistic to search for any multivariate outliers, no participant appeared to be a multivariate outlier with a mahalanobis value above the cut off of 10.83.

Although the data were not significantly differently distributed from normal on the skewness and kurtosis variables, there was a floor effect with bunching values at the lower end which can be seen in Appendix 13. Indeed, half of the participants scored 5 or less on this variable, and all but two scored 10 or below. It should also be noted that this floor effect would reduce the possibility of obtaining any significant correlation.

Following Tabachnick and Fidell's (2013) recommendations we carried out a parametric test to examine the correlation between less PCC passages and BCRM scores, however due to the floor effect shown in the scatterplot, we carried out a non-parametric test as well.

As is shown in Table 10 below, there was a small correlation in both analyses in the predicted direction (i.e., less PCC passages occurred more frequently in the interviews of those reporting less continuity) but this was not significant.

Table 10. Spearman's rho and Pearson's correlation between number of less PCC passages and BCRM scores

				95% Confidence Intervals (2 – tailed)	
	Spearman's rho	Significance (2 – tailed)	N	Lower	Upper
Less PCC passages	-0.11	0.56	30	-0.46	0.27
	Pearson correlation	Significance (2 – tailed)	N	Lower	Upper
Less PCC passages	-0.18	0.34	30	-0.51	0.19

Discussion

As hypothesised, this study did show a significant correlation between higher scores on the relationship continuity measure and higher scores on the number of more person-centred passages observed. Additionally, although it was not significant, there was a small correlation in the predicted direction with less person-centred passages occurring more frequently in the interviews of the participants reporting less continuity. This study extends previous research suggesting a link between the two concepts. Previous research has consisted of some qualitative studies in which this link was not the primary focus of the study (Chesla et al., 1994; Lewis, 1998; Murray & Livingstone, 1998; Walters et al., 2010) and a mixed methods study (Riley,

Achiampong et al., 2020) that focused on the link between continuity and the degree of person-centredness evident in participants' understanding of challenging interpersonal behaviours. The current study supports the claim that there is a link, and suggests the link may be a general one, extending to how spousal carers provide support for tasks of everyday living.

The observed link between relationship continuity and PCC lends weight to the theoretical argument of why continuity and PCC may be linked. As mentioned in the Introduction to this chapter, spousal carers often develop a deep understanding of the spouses they care for throughout their time together, including their unique preferences, personalities and life histories. In the case of continuity in the relationship, this may be extended to how they provide care and support for their partner following the onset of dementia, leading to PCC that treats the other person as an individual with a unique personal history and personality with their own needs and preferences, and that tries to understand the situation from the perspective of the other person. Conversely, in scenarios marked by discontinuity, the person with dementia may not be perceived as the same individual, and the detailed understanding of that person could be perceived as less pertinent in managing the situation. This may result in the carer being less likely to use their understanding of the person that was built up over their life together and more likely to use general schemas about people living with dementia in response to the need to provide care, resulting in less PCC (Riley, Achiampong et al., 2020; Villa & Riley, 2017).

Another potential link between continuity and PCC is suggested by the Hellström and Torres (2021) study when looking into perspectives of spouses on their partner's diminished everyday competence using interviews and observation notes

documenting interactions between spouses. One aspect of relationship continuity is the continuation of the sense of couplehood and togetherness, that they are a couple living their life together and dealing with challenges together; whereas in discontinuity, the carer sees themselves in more individualistic terms (Riley et al., 2013). In the Hellström and Torres (2021) study, when the sense of being a couple was lost, the carer referred frequently to themselves and their partner in oppositional terms (“I” vs. “him/her”). In relation to tasks of everyday living, the person with dementia was viewed as a burden, criticised for not doing things properly and criticised for not trying to do things. By contrast, participants in the Hellström and Torres study who retained a sense of being a couple, expressed more tolerant and less blaming attitudes towards the difficulties that the person with dementia experienced with everyday tasks. For example, one participant, when describing how long it took her husband when washing the dishes, said “it doesn’t matter, we have plenty of time”. It is plausible to suggest that these differences in attitude to the challenges presented by everyday living tasks may give rise to behavioural differences in how care and support for these tasks is provided. The ill feeling associated with discontinuity may create a less positive and supportive environment when providing care (the ‘social’ component of the VIPS framework). Additionally, in contrast to the participants who predominantly discussed their partner’s competence on everyday tasks from an egocentric perspective, the participants who retained a sense of being a couple consistently used inclusive language (“we”), consistently viewed their partners’ needs as a shared challenge that required adaptation as a couple and continuously sought their partners’ perspective. These participants demonstrated a proactive approach to understanding and responding to their

partners' unique needs, which aligns with the "individual" and "perspective taking" components of the VIPS framework.

An additional illustration of how preserving continuity can impact PCC is evident in the qualitative study by Hickman et al. (2020), which explored the role of humour in relationships. A prominent theme that emerged from the study was the recurrent notion of "humour has always been there", capturing the enduring presence of humour as a "natural and spontaneous aspect of their couplehood". The sustained nature of their humour suggests a sense of continuity in their relationship, contributing to the creation of a positive and supportive environment during caregiving (element "S" of the VIPS framework).

Insights from studies conducted in institutional settings further support the potential benefits of relationship continuity in the provision of care. In Wu et al.'s (2020) literature review of 25 papers examining care-giver and care-received interactions, they identified elements reinforcing the plausibility of the connection between relationship continuity and PCC. Notably, the studies by Scerri et al. (2015) and Standroos and Antelius (2017) emphasised the importance of maintaining continuity in interpersonal relations in delivering PCC within institutional care settings. Although conducted in such settings, the underlying principle extends to home care. The literature review advocates for "relationship-centred care", as suggested by Nolan et al. (2004), emphasising the centrality of the relationship between care-giver and care-receiver in delivering quality care and highlighting continuity as a crucial factor in providing relationship-centred care.

Limitations

There are several limitations associated with this study. Firstly, the study focused on a narrow demographic, which may limit the generalisability of the findings to other populations with different cultural backgrounds or relationship dynamics. Indeed, all participants were in heterosexual relationship and all, but one participant identified as White British. This limited diversity within the sample may restrict the applicability of the results to broader contexts.

Second, the sample size was relatively small, which decreases the reliability of the findings. A larger and more diverse sample would enhance the statistical power and strengthen the generalisability of the findings. Moreover, employing a larger and more varied sample could mitigate potential sample biases that might have arisen in this study. For instance, the participants who volunteered might have been content to be interviewed because they applied a more person-centred approach when providing support to their spouse.

Third, the study was observational, not experimental. The correlation between relationship continuity and PCC may have arisen because of their relationship to other confounding variables rather than because relationship continuity has the hypothesised impact on the delivery of care. The extent of the deterioration caused by the dementia is a potentially confounding variable. It may become more challenging to deliver person-centred care in the later stages of dementia. For example, it can be more challenging to involve the person with dementia in everyday tasks and decision-making as their cognitive impairment increases and easier for the carer to complete the tasks and make decisions by themselves (Hellström et al., 2007). Likewise, it may be more difficult to maintain a good relationship and to maintain a sense of continuity in the relationship as the dementia advances.

Although there is evidence that continuity can be maintained even in the advanced stages of dementia (e.g. Chesla et al., 1994), nevertheless there is an association between the stage the dementia has reached and a decline in the quality of the relationship (Forsund et al., 2014; Hyden & Nilsson, 2015; Quinn et al., 2015; Marques et al., 2023). So it could be that the association between relationship continuity and PCC observed in this study occurred because both variables are associated with the stage of dementia that has been reached. When living with someone with more advanced dementia, it may be more difficult for the carer both to perceive continuity in the relationship and to provide more person-centred care. Because of the relatively small sample size, it was not feasible to control this confounding variable by statistical means. Future research involving larger samples could focus on controlling this and other potential confounding variables.

Additionally, the method used to encode the level of person-centredness in the care delivery might have lacked reliability, raising concerns about the accuracy of the measurements. The study also relied on self-report measures rather than direct observation, which was initially planned but disrupted by the COVID-19 pandemic. This reliance on self-report introduces potential biases and limitations in capturing the true nature of the care provided. Direct observation of how carers provided support to their partners on everyday tasks would have allowed for a more objective and comprehensive evaluation of the participants' interactions and behaviours.

Research and clinical implications

Given that this study was exploratory in nature, aimed at validating the relationship between these two concepts, additional research is needed with a

control group and a broader demographic beyond the scope of the current research. Findings from this research and future research into this correlation can be used to assist further development of an intervention to enhance PCC in spousal relationships by increasing perceptions of continuity by the carer within the relationships. Yasmin and Riley's (2020) intervention for individuals with acquired brain injury could serve as a valuable reference for developing similar interventions to promote relationship continuity in spousal relationships impacted by dementia. Increasing perceptions of continuity is probably just one strand of a broader intervention aiming at enhancing PCC in family contexts. For example, other studies have explored how spousal couples try and preserve the person living with dementia's sense of personhood (Chung, Ellis-Hill & Coleman, 2017; Hellström, Nolan & Lundh, 2007; Wadham, Simpson, Rust & Murray, 2016), which is a core tenet of PCC, and evidence from these studies and from how couples are able to do achieve this naturally can also be used to develop interventions for couples where this does not come naturally.

CHAPTER 6: General Conclusions

As discussed in the Introduction, supporting family carers in providing PCC is a significant objective, considering its ethical value and positive impact on the well-being of both the caregiver and the recipient of care (Li & Porock, 2014; Brownie & Nancarrow, 2013; Kim & Park, 2017). The main purpose of this thesis was to gather information to aid in developing interventions focused on achieving this goal.

Chapter 3 aimed to assess the current promotion of PCC in dementia services. Knowing what is effective in promoting PCC may help in further development of interventions to promote it, including interventions to promote its use in home settings. As dementia services seem to rely mostly on educational interventions to promote PCC, to achieve this, a systematic review was conducted to evaluate the effectiveness of educational interventions in promoting PCC among staff. The review revealed that the quality of the papers was generally poor and there was limited evidence supporting the effectiveness of educational interventions alone in successfully promoting the delivery of PCC among staff. It was suggested that the approach needs to be supplemented with organisational changes and interventions informed by an understanding of how people best learn complex skills.

In Chapter 4, qualitative methods were employed to explore how person-centred spouses are in the support they provide for the tasks of everyday living, using the VIPS framework for evaluation, and to identify barriers to its application in home settings. Participants reported frequent instances of caregiving approaches aligned with the VIPS framework. However, the level of person-centredness varied among the carers, both across and within everyday tasks, and many were not explicitly trying to be person-centred in their approach. A major reason for the lack of explicit application of PCC was attributed to insufficient information and support

received regarding their caring role. Consequently, the study emphasised the need to address these knowledge gaps among carers and provide guidance on implementing PCC in everyday caregiving tasks. The review conducted in Chapter 3 suggested that simply giving information to people may not be sufficient and that interventions informed by an understanding of how people learn complex skills may be required.

Finally, in Chapter 5, the focus was on evaluating the claim that relationship continuity contributes to a more person-centred approach to care. Previous qualitative studies (Murray & Livingstone, 1998; Walters et al., 2010; Lewis, 1998; Chesla et al. 1994) and one mixed-method study (Riley, Achiampong, et al., 2020) have already supported this link. This study also found that participants who perceived their relationship as more continuous displayed a more person-centred approach to providing support on tasks of everyday life.

Limitations

It is important to acknowledge the limitations of the current research, considerations that could inform future investigations. One notable limitation is the absence of an objective measure of PCC in the empirical studies conducted for this thesis, relying instead on self-report accounts provided by participants. While this approach facilitated a deeper exploration of variations in care provision and identified potential barriers or facilitators to PCC, it introduces the possibility of a discrepancy between reported practices and the actual care delivered. Future research could enhance methodological rigor by incorporating an objective measure of PCC for a more robust conclusion about the link between relationship continuity and PCC.

To further bolster the link between relationship continuity and PCC, it is essential to delve into potential confounding variables that may exert an impact such as how advanced the dementia is. As discussed in Chapter 5, the correlation that was observed between relationship continuity and PCC could have arisen because those participants caring for someone with more advanced dementia may have found it more difficult to maintain a perception of continuity and to provide more person-centred care. Research on this issue can never be experimental and confounding variables can only be controlled statistically. Larger samples are needed in future research to allow for the statistical control of potentially confounding variables.

Furthermore, the research scope was quite focused, particularly in examining how caregivers supported their partners in daily tasks. This narrowed focus may not fully capture the diverse spectrum of caregiving experiences, for example understanding and coping with behavioural changes. In addition, although using framework analysis allowed for a focused analysis of the data (including a “broader issues/miscellaneous” theme), it may have constrained the exploration, potentially overlooking other factors influencing caregivers’ approaches. The specificity of the research questions, while useful for guiding the investigation towards behaviours relating to everyday tasks, may also have inadvertently limited the scope of inquiry.

Another concern could be the generalisability of the findings, stemming from the narrow demographic composition within the sample. All participants were in heterosexual relationships, with the vast majority identifying as White British. This limited diversity restricts the applicability of the research findings to a broader population. Despite meeting the calculated sample size criteria for a mixed-method study, the relatively small sample size further diminishes the generalisability of the

results. The selection process for participants may have introduced bias, as those who volunteered could potentially be more inclined to adopt a person-centred approach to care. Additionally, participants were given the choice as to which tasks were discussed, potentially biasing the data towards instances where a more person-centred approach was applied. These considerations underscore the importance of future research in diversifying the participant pool and adopting more comprehensive methodologies in future research.

Developing an intervention

The findings from these studies provide valuable insights for developing interventions to promote PCC in home settings. Chapter 4 highlighted the lack of knowledge surrounding PCC delivery in spousal carers, indicating the need for educational efforts to facilitate greater PCC delivery in such contexts. However, the systematic review in Chapter 3, focused on educational programmes in professional dementia services, revealed that education interventions alone may not suffice to ensure PCC delivery in institutional settings. Interventions may need to be informed by our understanding of how people learn and apply complex skills. Drawing from the results of Chapter 5, future studies could also focus on developing strategies to support couples in maintaining stronger relationship continuity, as this may enhance the implementation of PCC in their caregiving interactions.

In the area of acquired brain injury, Yasmin and Riley (2020) described a case study in which they applied a therapy designed to enhance a spousal carer's perception of relationship continuity and examined the impact of this on the carer's experience of the relationship, and on the wellbeing of both members of the couple.

The therapy involved a range of components. One key component involved assessing ways in which the couple bonded before the brain injury, whether these ways were still happening, and the reasons why, if they were no longer happening. Where possible, the couple were supported to re-establish those ways. For example, prior to the injury, the couple had spent some time after the evening meal talking over the events of the day with one another, but they had stopped doing this since the brain injury. They were supported in re-establishing this. Pre/post intervention questionnaires showed increases in the spousal carer's perceptions of continuity in the relationship, along with reductions in stress and increased satisfaction in the relationship. A similar intervention could be explored in the area of dementia to determine if this similarly improved perceptions of continuity, and if this, in turn, led to any improvement in the quality of care provided.

Future efforts could focus on developing other components of a broader intervention that focused more directly on promoting more PCC from spouses. In the qualitative study described in Chapter 4, participants described some practical ways in which PCC can be delivered when supporting people to complete daily living tasks. These could be used in developing information and support for carers. There were some very specific suggestions, such as letting the person with dementia use a debit card but putting a limited amount of money in the account so that the consequences of the card being lost or stolen were minimised; and using cake box mixes to allow someone who enjoyed baking to continue with it. Some ideas from the participants were more general, but still quite concrete and easily understood. For example, some participants described how they would supervise at a distance (and therefore in a way that maintained the dignity of the person with dementia) – for example, one

participant explained how they would wait until their spouse had finished in the kitchen and then go in to check that everything had been switched off, rather than staying in the kitchen to watch her. Some participants spoke about the importance of not making demands on their spouse and instead making suggestions about what to do or how to do it. Other qualitative studies have similarly described how participants try to maintain the active involvement and decision-making of their family member and to sustain involvement (Chung et al., 2017; Sinclair et al., 2018; Hellström et al., 2007; Wadham et al., 2016) as well as the importance of maintaining humour to create a positive caring environment (Hickman et al., 2020) All this evidence of family carers naturally using person-centred approaches could be pooled to develop advice and interventions to support family carers to help them deliver better quality care.

Clinical implications

The findings from the literature review underscores areas in which dementia services can enhance their effectiveness. The review (Chapter 3) highlights the inadequacy of educational interventions alone in fostering substantial improvements in PCC delivery. The review also offers recommendations aligned with previous research (Griffiths et al., 2019; Kong et al., 2021, Surr et al., 2021a; Surr et al., 2020b), emphasising organisational changes, ongoing practical support in PCC implementation, and creating an environment that encourages PCC. These insights and suggestions may have broader applicability to other institutional care services implementing PCC, shedding light on the challenges that staff may be facing in various care settings.

The qualitative study (Chapter 4) highlighted the need for services to take a more proactive role in helping carers provide more person-centred care. Participants reported numerous examples of less person-centred care. They also reported a lack of guidance and support from services about how to provide care. Although there were many examples of person-centred care, nearly all participants were unaware of the concept or its importance. What information participants had received was often perceived as overly generic or delivered at an inappropriate time. In any case, the systematic review (Chapter 2) suggested that the provision of information alone may be insufficient. Family carers may learn more effectively from observing good practice and receiving feedback about their own practice. This suggests a potential role for the provision of online videos of good practice and for staff at Day Centres and other services to model good practice and provide feedback to family carers. Participants in the qualitative study (Chapter 4) also highlighted some of the practical challenges in delivering PCC, such as the clash between considerations of safety and being person-centred. More open discussion about what constitutes an acceptable compromise might help family carers make better decisions when these clashes arise.

Addressing the reported lack of support among spousal caregivers in the qualitative study is crucial, which echoes what has been suggested in previous research (De Poli et al., 2020; Clemensen et al., 2021). This is not only important for promoting PCC but also essential for providing carers with the space to discuss the changes in their relationships and their caring roles, an opportunity many participants expressed they had not previously received.

The findings from both the qualitative and the mixed-method studies conducted in home settings may have applications beyond dementia care, particularly in the field of acquired brain injury. Riley, Keeble et al.'s (2020) study has already established a link between RC and PCC in acquired brain injury, indicating the applicability of the VIPS framework in home settings. Certain strategies employed by spousal caregivers for promoting PCC in dementia care may have similar applications in supporting individuals with acquired brain injury. Other fields where PCC is also applied, such as learning disabilities and end-of-life care, could also benefit from these strategies, and investigating the promotion of RC as a means to enhance PCC is worth exploring.

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Appendices

Appendix 1: Instructions for applying the quality assessment tool

A: Internal validity biases

These headings are taken from the Cochrane paper (Higgins et al., 2011)

Selection bias (applies only to studies with a control group)
2:
Services/participants allocated to conditions using clearly described and appropriate randomization procedures
1:
Services/participants allocated randomly but method of randomization not clearly described **or** of uncertain validity **or** relevant information not provided
0:
Services/participants not randomly allocated

Performance bias
The definition of performance bias given by https://catalogofbias.org/
Performance bias is specific to differences that occur due to knowledge of interventions allocation, in either the researcher or the participant. This results in differences in the care received by the intervention and control groups in a trial other than the intervention that are being compared. For example, participants in the control group might seek other treatments, or researchers/clinicians might treat participants differently depending on which group they are in. This bias may inflate the estimated effect of the intervention, particularly in trials with subjective outcomes.
All studies should score zero on this because it is impossible to blind researchers or participants to the intervention received.

Detection bias
Systematic differences between groups in how outcomes are determined. This is about whether those assessing the outcome are blinded to the allocation of participants to groups or, in the case of uncontrolled before-after studies, the nature of the intervention participants had received.
2:
Control group studies - Researchers administering/scoring the outcome measures did not know which group the participants were allocated to
Uncontrolled studies - Researchers administering/scoring the outcome measures were unaware of the nature of the intervention
1:
Control group studies – Information not provided
Uncontrolled studies – Information not provided
0:
Control group studies - Researchers administering/scoring the outcome measures were not blinded to group allocation
Uncontrolled studies - Researchers administering/scoring the outcome measures were aware of the nature of the intervention

Attrition bias

Bias arising because of drop-out from the study. Drop-outs don't bias the study outcome if an intention-to-treat analysis is conducted.
2:
No drop-out occurred **or** some occurred but appropriate intention-to-treat or missing data analysis was used.
1:
No appropriate intention-to-treat or missing data analysis was reported but drop-out was less than 10% **or** no information provided about this issue.
0:
Drop-out was more than 10% and no appropriate intention-to-treat or missing data analysis was reported.

Reporting bias
Bias arising because of not reporting all planned statistical analyses (although it can mean other things in other contexts).
2:
Results of statistical tests reported for all outcome measures that were used
1:
Not all results reported, but the reason why one or more are missing is clearly explained and valid
0:
Some results are not reported and no explanation is given **or** the explanation is of questionable validity.

Other internal validity biases: The Cochrane tool (Higgins et al., 2011) suggests the addition of other biases appropriate to the particular research issue.

Treatment fidelity
2:
(a) The intervention was delivered in accordance with a detailed protocol for delivery **and** (b) adherence to intervention was checked and reported to be satisfactory **or** delivery was automated (i.e. online resources)
1:
Criteria (a) was met but no check of fidelity was carried out **or** inadequate information was provided about whether any of the criteria were met.
0:
Adherence was checked and reported to be unsatisfactory.

Measurement bias
2:
Measures of knowledge or applied knowledge **or** observational measures for which inter-rater reliability in the study itself was calculated and this was at least satisfactory (>.7).
1:
Observational measures for which no inter-rater reliability is reported, **or** this reliability was reported in previous research to be at least satisfactory (>.7) but this was not assessed in the study itself.
0:

Measures of attitude and self-reported working practices (assumed to be vulnerable to social desirability bias). Observational measures for which less than satisfactory inter-rater reliability is reported (<.7)

B. External validity

Participants
2:
Participants were randomly selected (N.B. participants within the service should be considered here, not whether the care home was randomly allocated to intervention or control) and either criterion (a) or (b) was met: (a) the residual sample size (i.e. those who completed the study and not including drop-outs) was sufficient to detect at least a moderate effect size (see below) (b) an analysis of their demographic characteristics and relevant work-related details (e.g. length of employment, grade) showed that, in demographic and work-related terms the residual sample (i.e. excluding drop-outs) were representative of the population of care providers from which they were drawn
1:
Participants were randomly selected but neither criterion (a) or (b) were met **or** participants were not randomly selected (i.e. volunteers) but both criteria (a) and (b) were met.
0:
Participants were randomly selected and analysis showed that they were not representative of the population from which they were drawn **or** participants were not randomly selected and either criteria (a) or (b) was not me **or** relevant information not provided.

Dropout rate
2:
No drop out
1:
Some drop out, but less than 10% **or** drop out not reported
0:
More than 10%

C: Precision

Sample size
2:
Sample was large enough to detect at least a moderate effect size (Cohen's d >.0.5) [G*Power: t-test two-tailed, with power set at 0.8, to detect a moderate effect size - for independent samples (between groups), 64 in each group required; for dependent sample (within group), 34 required]
1:
Sample was large enough to detect at least a large effect size [26 in each group for independent samples; 15 for a matched sample]
0:
Sample not large enough to detect a large effect size
Consider only number that provided complete data set – not pre-intervention sample

Measures

2:
Outcome measure has good reliability reported in previous literature or current study (internal, inter-rater and/or test-retest reliability >.8).
1:
Outcome measure has only modest reliability (0.6 to 0.8) **or** paper provides no information about these issues and no studies evaluating psychometric properties could be identified
0:
Outcome measure has poor reliability (<.6), reported in this or previous literature

Appendix 2: Cohen's d calculation for each study

Cohen's d for controlled designs

	Control baseline M (SD) N 1	Control post-int M(SD) N 2	Training baseline M (SD) N 3	Training post-int M(SD) N 4	Cohen's d Control vs training post-int 2 vs 4	Cohen's d Training baseline vs training post-int 3 vs 4	Outcome
Conway 2016	4.4 (0.31) 16	4.4 (0.35) 16	4.1 (0.45) 19	4.2 (0.51) 19	-0.457	0.208	Attitude
Ballard 2018*					0.55*		Observed practice
Chenoweth 2014	78 (31.75) 155	73 (27.78) 98	78 (27.36) 142	78 (24.86) 95	0.190	0.00	Observed practice
Torres-Castro 2021	21.9 (4.3) 39	19.9 (3.3) 39	22.2 (5.3) 57	18.9 (4.3) 57	-0.261	-0.684	Attitude
Hattink 2015	35.57 (14.4) 32	49.36 (4.41) 32	48.80 (2.78) 27	49.90 (3.03) 27	0.141	0.378	Attitude
Jacobsen 2017	47.0 (7.2) 127	48.0 (7.2) 120	46.7 (5.8) 122	47.4 (6.5) 84	-0.087	0.114	Self-report practice
Lood 2020	65.14 (13.67) 459	63.63 (16.00) 149	68.73 (11.10) 459	66.51 (10.91) 149	0.211	-0.202	Observed practice
Williams 2021	58.7 (20.5) 64	63.0 (18.8) 64	63.0 (17.6) 95	83.8 (13.4) 95	1.274	1.330**	Direct knowledge
Williams 2021					0.447***	0.447***	Applied knowledge

* Ballard (2018) reports the Cohen's d for the difference in change scores between the two groups; d=0.55. Will have to use this value since doesn't provide any other relevant information. Ratings were taken at 'care home level' at 62 of the 69 homes. This should be the N entered into the meta-analysis.

**Williams (2021) was a cross-over design. Also report result of combining both groups for a before vs. post intervention analysis involving 130 participants. Before = 61.9 (20) vs After 84.6 (13.5), Cohen's D=1.330 (i.e. same as before-after for the intervention group)

***Williams (2021) was a cross-over design. Only report scores on individual dimensions of video rating task – so the mean of 'recognising elderspeak' and 'recognising person-centred communication' was calculated and used in the analysis. Also, does not provide breakdown of scores by group, only the before-after scores of both groups combined (N=102) (i.e. equivalent to the 3vs.4 comparison). Use this for the 2 vs. 4 comparison as well).

Repeated measures designs

The calculation of the effect size for a repeated measures design either requires the original data set or information about the correlation between the two sets of scores – which none of the papers provide. Also, there is a potential problem with including repeated measures designs (i.e. the uncontrolled before-after studies) and independent group designs in the same meta-analysis (see Morris & DeShon, 2002) because repeated measures designs will typically provide a higher effect size. Morris and DeShon (p.111) recommend that, in the absence of information about the correlation between the two sets of scores, the best option when using both designs in the same meta-analysis, is to use the 'raw score metric' (Table 1 p.114). This involves just using the standard deviation unadjusted for correlations, as one would for independent groups design. However, they recommend using the baseline standard deviation provides a less biased estimate than the pooled standard deviation. This is what is in the following table.

Uncontrolled before-after designs

	Baseline M (SD) N 1	**Post-intervention M(SD) N 2**	**Cohen's d Before vs after 1 vs 2**	**Outcome**
Barbosa 2017	49.64 (13.32) 31	52.79 (15.33) 31	0.236	Observed practice
Coleman* 2015	21.7 (3.46) 538	22.55 (3.53) 360	0.246	Applied knowledge
Edvardsson 2014	PCAT: 31.9 PCQ: 52.9 N=171 (no SDs)	PCAT: 34.2 PCQ: 54.2 N=143 (no SDs)	Report d of 0.34 for PCAT and 0.13 for PCQ	Self-report practice

			Use mean d = 0.235	
King 2011**	Module 1: 1.81 (.87) 1805 Module 2: 1.87 (1) 1078 Module 3: 1.24 (.87) 1087 Module 4: 1.57 (.96) 1150	Module 1: 2.21 (.88) 1805 Module 2: 2.86 (.94) 1078 Module 3: 1.80 (.91) 1087 Module 4: 2.40 (.82) 1150	M1=.460 M2=.990 M3=.644 M4=.865 Use mean d = .740	Direct knowledge
Pleasant 2017***	Correct: 4.6 (0.8) 144 Incorrect: 1.1 (0.7) 144	Correct 4.9 (0.3) 62 Incorrect: 1.1 (1.2) 62	Correct d: 0.375 Incorr d: 0.00 Use mean d: 0.188	Applied knowledge
Williams 2018******	N=39	N=38	d for 8 dimensions in order listed in table: 0.426; 0.600; 0.375; 0.584; 0.588; -0.079; 0.213; 0.104 Mean d = 0.351	Observed practice

* Coleman (2015): These are the statistics for both online and onsite groups combined.

**King (2011): A knowledge test preceded and followed each of the 4 modules. Cohen's d for each module was calculated and the mean of these values used in the analysis. Results from the attitudes questionnaire were excluded because adequate data were not provided.

***Pleasant (2017): Cohen's d was calculated for correct identifications and incorrect identifications and the combined d was used in the analysis.

****Williams (2018): Cohen's d calculated for each dimension (with account taken of whether an increase in PCC meant an increase or decrease) and then mean of these entered into the analysis. For data, see Table 2, p.1022 of article.

Appendix 3: Ethical Approval Letter

Dear Miss Carparelli and Dr Riley

Re: "Person-centred and relationship continuity in spousal relationships"
Application for Ethical Review ERN_18-1795A

Thank you for the above application for amendment, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I can confirm that this amendment now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as now amended, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review. A revised amendment application form is now available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx . Please ensure this form is submitted for any further amendments.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

If you require a hard copy of this correspondence, please let me know.

Appendix 4: Participant Invitation Advert

UNIVERSITY OF BIRMINGHAM

Invitation to take part in a research study looking at how carers conceptualise their caring role

We would like to invite you to take part in a research study being carried out by researchers at the University of Birmingham.

The research is being carried out as part of a Psychology Doctorate course at the University of Birmingham. The study has been approved by the University's Research Ethics Committee.

The purpose of the research study is to study how spousal carers conceptualise their role in providing care and support.

- **You will be required to take part in an interview about your caring role online or over the phone.**
- **Your participation and personal information will be treated with the utmost confidentiality.**
- **Any recording will remain confidential and will only be seen by members of the research team.**
- **You can drop out of the study at any time and ask for your video to be withdrawn from the study.**

UNIVERSITY OF BIRMINGHAM

Appendix 5: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Title of Project: Person-centred care and relationship continuity in spousal relationships

My name is Chiara, I am completing a Doctorate in Psychology at the University of Birmingham and this research study is being carried out as part of my course and is being funded by the Alzheimer's Society. I would like to invite you to take part in a research study. Please read this information carefully before deciding if you would like to take part in this study.
Please remember that taking part in this study is completely voluntary and feel free to contact me if you have any questions or if anything is unclear

What is the purpose of the study?
We are interested in what matters for a spouse when they are giving care and support to someone living with dementia. What do they consider important about the way in which they give that care and support?

Why have we been invited to take part?
You have been invited to take part because you provide care and support for your spouse who has dementia.

Are we the right people to take part?
To be suitable to take part in the study, you need to be able to answer *yes* to all the following statements:

- We lived together for at least 5 years before the onset of dementia.
- I do not have any co-existing learning disability, major mental health disorder or other condition that may have an impact on my ability to take part.
- The person with dementia was not in need of care prior to the onset of dementia.
- At least 3 months have passed since the diagnosis of dementia was given.

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

1. After the meeting at which I explained the research to you, you should take some time to discuss between yourselves and with other people whether you want to take part.
2. I will contact you the next day to see whether you want to take part. If you do not want to take part, that is perfectly fine. If you do want to take part, we will arrange another date to carry out the interview.
3. You will be asked to participate in an interview about your experience of providing support to your partner.
4. The interview will last about an hour and will include breaks. The interview can be carried out at your home, at the University of Birmingham, over the phone, or using the Zoom online service. You can choose whichever you feel most comfortable with. However, I may not be able to travel to your home if you live a long way from Birmingham.
5. Following the interview, I will ask you if you have any questions or concerns and will give you a full explanation of the study.

What will happen to the information I provide for the study?
All the information collected about you during the course of this study will remain completely confidential. It will be accessible only to members of the research team and, if required, to officials authorized by the University of Birmingham to conduct a research audit.

I will need to record our interview so that I can work on it later. I will only record our voices and will not make a video recording. I will initially record the conversation on a recording device or using the online recording service provided by Zoom. As soon as I am able, I will transfer the recording to the University's Research Data Store. This is a secure password-protected storage system and the recording will only be accessible to the research team. Once I have stored a copy on the University system, I will delete the recording from the recording device or Zoom's online facility.

I will also ask you to sign a consent form. When you have signed it, I will make an electronic copy that I will store on the University's Research Data Store. I will then shred the paper copy.

In accordance with University regulations, your data will be kept for 10 years after which it will be securely destroyed.

At the end of the study, a report of the findings will be sent to you if you are interested. This research will also be submitted as part of my doctoral thesis at the University of Birmingham. The research paper may be published in a scientific journal/or presented at a scientific conference. Your name and other identifying information will not be used in any of this.

What are the possible risks of taking part?
Some of the discussions and questions from the questionnaire may ask about some sensitive issues or issues that you may find distressing. You will be offered breaks during the interviews and intervention sessions and you may also reschedule any interview/session if it becomes distressing. If you experience any significant distress, I will direct you to sources of support and may ask for your consent to contact support services such as your GP.

If I am concerned about the safety of yourselves or others, or if you disclose criminal activity to me, I am obliged to inform the relevant authorities. I will tell you before doing so.

What will happen if I want to withdraw from the study?
You are free to withdraw at any point and you are free to leave at any point without explaining why. Any data collected up to that point will be destroyed and the standard of care you and/or your spouse receive will not be affected.

Even after participation in this study, you will have one week after your final session to inform the research team that you would like to withdraw from the study. We will then destroy any data collected.

Expenses and payments
We will reimburse you for any travel costs. Please keep your receipts or tickets so we can reimburse you for the cost.

Contact details
If you would like to discuss any aspect of this study please contact me on:

Email: [redacted]

Post: Chiara Carparelli
School of Psychology,
The University of Birmingham,
Edgbaston,
Birmingham B15 2TT

Or contact the project supervisor on:

Email: [redacted]

Post: Gerard Riley
School of Psychology,
The University of Birmingham,
Edgbaston,
Birmingham B15 2TT

UNIVERSITY OF BIRMINGHAM

Appendix 6: Consent Questions

CONSENT FORM

Title of project: Person-centred care and relationship continuity in spousal relationships
Participant ID Number:

1. I confirm that I have read the 'Participant Information Sheet' carefully; I have had the opportunity to ask questions about anything I didn't understand and have had the questions answered reasonably. ☐
2. I understand participating in the study is entirely voluntary and that I can withdraw at any time, without reason. ☐
3. I understand that the data collected during this study will remain confidential and will only be shared with the research team conducting the study or by officials appointed by the University of Birmingham to conduct a research audit. ☐
4. I agree to the interview being video-recorded. ☐
5. I understand that any information I provide for the study may be published in a write-up of the data, but my name and all other identifying information will be modified to protect my anonymity. ☐
6. I agree to take part in the study. ☐

.....	.....	.....
Print name	Date	Signature

Please fill in your contact details if you wish to be sent a summary of the research findings:

E-mail address: ……
Phone number: …….

Appendix 7: Demographic Information Questions

Demographic information:

1) What is your gender?
(a) Male (b) Female (c) Prefer not to say (d) Prefer to self-describe: ……

2) What is your spouse's/partner's gender?
(a) Male (b) Female (c) Transgender (d) Prefer not to say

3) What is your age (in years)?

4) What is your spouse's/partner's age (in years)?

5) What is your ethnicity?
(a) White: British Other White

(b) Mixed: White & Asian White & Black Caribbean White & Black African

(c) Asian: Indian Pakistani Bangladeshi Chinese

(d) Black: Black African Black Caribbean

(e) Other (please state): _____

6) What is your spouse's/partner's ethnicity?
(a) White: British Other White

(b) Mixed: White & Asian White & Black Caribbean White & Black African

(c) Asian: Indian Pakistani Bangladeshi Chinese

(d) Black: Black African Black Caribbean

(e) Other (please state): _____

7) What is your religion?
(a) Christian (b)Muslim (c) Hindu (d) Sikh (e) Buddhist (f) None
(g) Other (please state): _____

8) What is your spouse's/partner's religion?
(a) Christian (b)Muslim (c) Hindu (d) Sikh (e) Buddhist (f) None
(g) Other (please state): _____

9) How many years have you been married to (together with) your partner?
(a) < 5 years (b) 5-10 years (c) 11-15 years (d) 16-20 years (e) 21-25 years (f) 26+ years

10) What type of dementia do they have?

(a) Alzheimer's disease (b) Vascular dementia (c) Dementia with Lewy-bodies
(d) Fronto-temporal (e) Mixed dementia (f) Don't know (g) Other (please state): _____

11) How long ago was your partner diagnosed with dementia?

(a) < 6 months (b) 6-11 months (c) 1-2 years (d) 3-4 years (e) 5-6 years (f) 7+
(g) Don't know

12) How long have you been providing care for your partner?

(a) < 6 months (b) 6-11 months (c) 1-2 years (d) 3-4 years (e) 5-6 years (f) 7+
(g) Don't know

13) Before the dementia started, were you generally satisfied with your marriage/relationship?

(a) Yes (b) No

Appendix 8: Interview Schedule

Interview Schedule

To start with, get some general background information – both to provide a general context and to allow the person to feel more comfortable about the interview:

- *Complete the demographic questionnaire*
- *Ask some more general questions, such as* What jobs did you have? Any children? What outside help do you get?

Spend no more than 10-15 minutes on this.

A. Setting the context

1. What parts of daily life do you help X with?
    a. Self-care – washing, dressing, eating, drinking, toileting
    b. Moving about at home – getting in/out chairs/bed, moving around the house, using stairs
    c. Moving about outside
    d. Preparing drinks or food
    e. Managing medication
    f. Household tasks – cleaning, tidying, washing or ironing clothes, bed making
    g. Shopping – knowing what they need, managing in shops
    h. Using equipment – phone, TV, hoover, oven
    i. Keeping self occupied
    j. Managing finances, paperwork

Notes: Establish what the participant helps with, not what activities the person needs help with – this may come from other people. There is no need for an exhaustive detailed list of what the participant provides help with – just a broad overview.

B. Detailed discussion of the help provided

Pick out 2-3 of the activities that the participant helps with. Try to pick a range of different kinds of activity and ones in which relatively more help is needed. Discuss each one in turn. Encourage the person to give a really detailed step-by-step account of what each person says and does.

You explained you help X with A. Can you describe to me in more detail what happens? Can you think back to the last time you helped with this? When was that? Can you talk me through it through it step by step. Who does what? What exactly do you help X to do?

As they are going through the description of what happens, ask them at each point questions like – Why do you do it like that? Why do you think that's important? You could do [some alternative] – why do you do it the way you do it?
These questions are a way of trying to get to the decisions that have gone into how the care is provided.

Also, at some point ask: What do you do if X gets into difficulty with something during the task (e.g…..) – how do you deal with that?

What you are trying to get at are the general principles that direct what they do – e.g. giving choice, giving choice in a way that takes into account their limited cognitive abilities, involving the person in how the task is completed, avoiding giving direct orders or commands, asking if the person wants help before giving it, generally how they speak and communicate to the other person during the activity, taking account of what the other person wants, what they like, their preferences, values, how they might feel about needing help with this activity, trying to maintain a positive supportive atmosphere – avoiding criticism, controlling etc. Keep in mind the VIPS summary of PCC: Value their rights of choice, control etc.; Individual – taking account of who they are, their individual preferences, wishes; Person – taking into account the situation from the perspective of the other person; Social – creating a positive social environment in which the person feels valued and cared for.

Some examples: (participant in green, interviewer in blue)

a. *I put the clothes out on the bed first. So, just go back a step. How do you decide what clothes are put on the bed? I get out a few things that I think X might like to wear and ask him what he wants to put on today. Why do you do it like that? Could he not just get the clothes out for himself? No – he would just stand in front of the wardrobe looking at the clothes. He finds it difficult to make decisions – you've got to make it easier for him by saying, do you want A or B? Why don't you just make the choice for him? Why do you give him a choice at all?*
b. *We've got a wet room. So I take her in and sit her on the chair. Do you tell her what is happening – that you are going to help her have a shower? No. Why not? She wouldn't understand – there's no point. Okay. So you've sat her on the chair. What next? I take her clothes off. Do you talk to her while you are doing this – like do you explain what you're doing? No – like I said there's no point. It's easier to do it in silence- it's just distracting if I start talking to her at the same time. And when you're taking her clothes off, how involved is she – like, does she hold up her arms when you take her top off? No – she's just sits there, I do it all. It's quicker if I do it anyway. She'd get cold if I waited for her to make an effort. Do you ever try to get her more involved in what's happening? No – there's no point; she's just in a world of her own.*

C. More general issues

- Reflection: Do you think much about how you provide care and support with these activities we've been talking about? About what's the best way of doing it? About whether you are doing it in the best way? Have you changed anything because of this?
- Conversations with others: Have you ever had any conversations with anyone about the best way of providing help with these kinds of daily activities? with someone in the family? with the carers that come? with other people you've met who are looking after someone with dementia? with a doctor or other professional? Do others around you support the way you provide the care or have they suggested you should do some things differently? Did you change anything about the way you were helping X after that conversation?
- Other sources of information: Were you given an information leaflets or written guidance on how to help with these sorts of activities? Have you looked anywhere for guidance about how to provide help with these everyday activities? Alzheimer's or other websites, books, TV etc. Did you change anything about how you were helping X as a result?
- Being prepared and skilled: Do you feel like you were well-prepared for taking on the role of helping X with tasks like A, B and C (list the activities you've discussed)?
    - If yes: Why do you think that is? What's helped you be well prepared for taking on that role?

    - If no: What is it you find difficult? What would have helped/would help prepare you better for the role?
- Person-centred care: Have you heard the phrase 'person-centred care'? Has anyone mentioned it to you or explained it to you? What's your understanding of what it means? What do you think it means in terms of the things we've been talking about that you help X with? How would you give person-centred care when you are helping X with A? Has learning about PCC made a difference to the way you provide everyday care and support? Do you try to make sure that the care and help you give is person-centred?
- Change: Looking back over the time since you started helping X with these kinds of things, have you changed the way you did this? Why was this?
- General principles:
    - *Only ask these questions if they mentioned some general principles (e.g. trying to include partner in decisions about what they are doing) in Section B and they didn't cover these points in Section B.*
    - You explained earlier how you [*e.g. try to include X in making some decisions about what they are doing*]. Why do think it's important to do it in this way? *Discuss non-person-centred issues that may be guiding the support (e.g. avoiding an argument, getting things done quicker) as well as person-centred ones.*
    - Is it ever difficult to do it this way? What makes it difficult? How do you manage if this happens?

Appendix 9: Final version of the coding framework

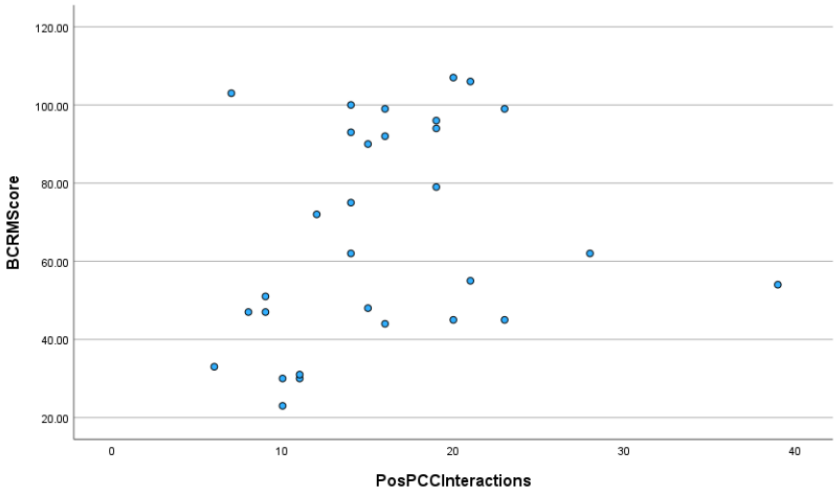
	Examples more PCC	Examples less PCC
Values: **Same status as everyone else in society in terms of control, agency**		
Agency/control/independence	giving choice, involving the person in how the task is completed, asking if the person wants help before giving it, only helping when necessary	doing things for the person without waiting for them to ask for help
Supervision		
Respect/dignity/involvement		
Strategies to maintain independence		
Individual: **Treating the person with dementia as an individual with a unique personal history and personality, and their own wishes, values and goals.**		
Perspective: **Understanding the world from the perspective of the person with dementia, and to respond with empathy.**		
Likes, wants, preferences, goals	Examples of taking account of what the other person wants, what they like, their preferences, values, how they might feel about needing help with this activity.	
Personal history, personality		
Social: **Creating positive, warm and supportive social environment**		
Communication	Avoiding complexity that person cannot deal with	Criticism
Responding to upset		
Other:		

What influences style of helping with everyday tasks?	
External sources – information, conversations, statutory or voluntary services	
Discussions with others	
Printed material	
Professional support	
Awareness and understanding of person-centred care	
Feeling prepared and skilled?	
Changing the way they provided care, and why	
Facilitators/barriers to what they feel they should be doing	
Reflection on what they do and what they should be doing	
Other – why he does things the way he does	

Appendix 10: Normality of the more PCC passages and the BCRM data

	N Statistic	Min Statistic	Max Statistic	Mean Statistic	Std. Deviation Statistic	Skewness		Kurtosis	
						Statistic	Std. Error	Statistic	Std. Error
More PCC passages	30	6	39	15.97	6.896	1.292	0.427	3.014	0.833
BCRM Score	30	23	107	67.0667	27.28513	0.040	0.427	-1.497	0.833

Appendix 11: Scatterplot of more PCC interactions and BCRM data



Appendix 12: Normality of the less PCC passages and the BCRM data

	N Statistic	Min Statistic	Max Statistic	Mean Statistic	Std. Deviation Statistic	Skewness		Kurtosis	
						Statistic	Std. Error	Statistic	Std. Error
Less PCC passages	30	0	18	5.97	4.013	0.884	0.427	1.315	0.833
BCRM Score	30	23	107	67.0667	27.28513	0.040	0.427	-1.497	0.833

Appendix 13: Scatterplot of less PCC interactions and BCRM data

