



Prifysgol Cymru
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Trinity Saint David

Caring for Individuals with Dementia: a qualitative exploration of the importance of person centred care and how well it is understood

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2017

Declaration

This work has not previously been accepted in substance for any degrees and is not being concurrently submitted in candidature for any degrees.

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Acknowledgements

Firstly, a massive thank you to my dissertation supervisor Dr. Ceri Phelps. Thank you for all you have taught me during my MSc this last year and a half and all of what you taught me previously in my undergraduate degree. You have assisted me to develop my knowledge, skills and understanding throughout Psychology. I appreciate all the guidance and support you have given me and could not have asked for anything more. Thank you for pushing me to do and be the best I can be and for your commitment and enthusiasm as my dissertation supervisor. I now believe in myself a lot more. Thank you.

I would also like to thank Dr. Paul Hutchings for his continued support over the last few years in my undergraduate degree to my MSc. Thank you for all the skills and knowledge you have provided me with through your teaching and your feedback and comments throughout my MSc journey that have stuck with me during the formation of this dissertation.

I would like to thank the University of Wales Trinity Saint David as a whole and the School of Psychology faculty at the Swansea Campus for providing me with the opportunity to continue as a master's student on the MSc Applied Social and Health Psychology course. Thank you to all who have taught me as well as Dr. Ceri Phelps and Dr. Paul Hutchings who have been mentioned previously as well as having a place to plan, develop and get continued support for my work.

Thank you to all those who have participated in my research and have taken the time to be interviewed. Without you this research would not have been possible.

Lastly, a big thank you to my family and friends who have supported me in this journey and believed in my ability to get as far as I have come.

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Chapter one: Executive Summary

1.1 Research summary

Dementia is on the rise in the UK (Ferri et al., 2005) and person centred care is the best practice of care for individuals with Dementia (Edvardsson et al., 2010). Following this, the British Psychological Society (BPS: 2016) created a policy document called '*Psychological dimensions of Dementia: putting the person at the centre of care*' which discusses the diversity of Dementia, the importance of each individual and how to move forward with person centred Dementia care.

1.2 Social research

- A qualitative exploration into the perceived importance of person centred care and how well it is understood by paid professional Dementia carers was carried out. Alongside a systematic literature review to see the prevailing research past and present in the area. Semi-structured interviews were used, and transcriptions were analysed using thematic analysis.
- Overall, there has been past and present research into person centred Dementia care, how it is used, how it needs to be and is being developed in the care industry. In conclusion, this research has indicated person centred care is known by most but there are contradictions to its provision for individuals with Dementia. Barriers obstructing the provision of person centred care have been identified and the perceived solutions of these barriers.

1.3 Key findings

1. Analysis of interviews showed person centred care as a term is known by most but all aspects of it are not acknowledged. It appears there is a common misunderstanding of what the provision of person centred care entails, which is resembled in the

inadequate training of person centred care provided, if any. This suggests, whilst the concept is known, it is not fully understood, and knowledge levels are relatively low for most.

2. The second predominant theme demonstrated what carers perceive as important does not always represent itself in the real day to day practice of the care they provide and what person centred care they do provide, is done in minimal actions. There seems to be aspects deemed more important in an individual's care than providing some of the main aspects of person centred care: giving choice and allowing an individual's voiced to be heard.
3. Analysis furthered, evidencing several predominant perceived barriers as to why person centred care is not fulfilled for individuals with Dementia. These included, time pressures, staffing issues and inadequate training. Following these perceived barriers were the perceived ways to resolve them to overcome the obstructions to the provision of person centred Dementia care.
4. Overall, the results obtained from analysis demonstrate the misconceptions around person centred care for individuals with Dementia. These results resonate with and enhance results from previous research around person centred care. In conclusion, for person centred care to be fulfilled and executed effectively for individuals with Dementia, the misunderstandings, knowledge levels, training and perceived barriers need to be worked on and overcome. The importance of person centred Dementia care has been reinstated by the BPS (2016) in their policy document which pulls upon the recommendations for better practice.

Chapter two: Systematic Literature Review

A Systematic literature review exploring paid professional carers' perceptions of and awareness about person centred care for Dementia patients

2.1 Abstract

The importance of person centred care for individuals with Dementia has been reiterated by the British Psychological Society (BPS: 2016). The purpose of this review was to (1) explore the perceptions of and current awareness levels of person centred care amongst paid professional carers, (2) explore whether paid professional carers feel they have sufficient knowledge, understanding and training on person centred care and (3) explore how person centred care is being used, developed and promoted in the care industry for individuals with Dementia. This systematic literature review included qualitative and quantitative studies published since 2007 which reported findings on paid professional carers' perceptions and awareness of person centred care for individuals with Dementia and its use and development in the care industry. Within the 12 studies included, perceptions and the awareness of person centred care was identified amongst paid professional carers (Baillie et al., 2016; Edvardsson et al., 2010; Edwards et al., 2014; Kirkley et al., 2011; Smythe et al., 2015; Smythe et al., 2017) and the majority of the studies demonstrated the use and development of person centred care (Baillie et al., 2016; Benbow et al., 2011; Hunter et al., 2013; Kirkley et al., 2011; Kontos & Nagile, 2007; McKeown et al., 2010; Surr et al., 2016). While the studies in this review exhibited evidence person centred care is recognised by paid professional carers and is being used and developed, the review recognised contradictions and limitations throughout the studies.

Key words: Person centred care, Dementia, paid professional carers, perceptions and knowledge.

2.2 Paragraph of context

Dementia is one of the main illnesses in the world (Alzheimer's society, 2017), it is a disease causing cognitive, behavioural and physical impairments resulting in decreased brain function, impairments in language, reasoning and memory and changes in personality and behaviour such as mood swings, agitation and withdrawal (McKhanna et al., 2011). Ferri et al. (2005) explains Dementia as a progressive disorder with no cure. There are 850,000 individuals in the UK living with Dementia, statistics are increasing worldwide, and one person every three minutes develops the illness (Alzheimer's society, 2017; Ferri et al., 2005).

Within the UK there are various care facilities available to individuals with Dementia; care homes, residential or nursing homes and community care (NHS, 2015). Paid professional carers within the UK provide important factors to the lives of individuals with Dementia, such as increasing their autonomy and quality of life, opportunities to socialise, engage in activities and a sense of companionship (Bramford & Bruce, 2000). In the UK, carers provide palliative and end of life care and carry out domestic and personal hygiene tasks (Bramford & Bruce, 2000; Thune-Boyle et al., 2010).

The British Psychological Society (BPS: 2016) created a policy document about the care of individuals with Dementia called '*Psychological dimensions of Dementia: putting the person at the centre of care*'. The document discusses the diversity of Dementia, how receiving a diagnosis can completely change an individual's life and how the care individuals receive is of upmost importance as they need to feel supported and respected, have their voice heard and maintain their autonomy and identity. The document provides several recommendations to move forward with Dementia care, to ensure an individual's needs and

care are tailored specifically to them. Training is recommended to improve the provision of person centred care and how using psychological approaches and research to see further into the requirements of Dementia care can provide explanation how to increase the quality of life of each individual, highlighting the gaps in the provision of person centred Dementia care (BPS, 2016).

Person centred care is a way for carers to embrace an individual's choice and autonomy (Kogan, Wilber & Mosqueda, 2015). The term person centred care was first developed in the 1940's from techniques used in therapy to ensure a person was viewed as a whole (Rogers, 1951). The definition has evolved, though the main points still exist; respecting an individual, their values and preferences, involving friends and family in an individual's care, communicating effectively and providing information about an individual's illness, allowing them to take control of their life (Morgan & Yoder, 2011). Person centred care is seen as the best practice for individuals with Dementia (BPS, 2016; Edvardsson, Fetherstonhaugh and Nay, 2010; Kim & Park, 2017; Mitchell & Agnell, 2015, Manthorpe & Samsi, 2016). However, this may have not always been the case as person centred care has only been fully focused on, promoted and developed within the last two decades for individuals with Dementia (Edvardsson, 2010; Nolan, Davies, Brown, Keady & Nolan, 2004; Ross, Todd & Clarke, 2015). The BPS (2016) discusses the above points emphasising the need for high standards of person centred care.

Literature has evidenced person centred care being used for individuals with Dementia (Chenoweth et al., 2009; Nolan et al., 2004) and its promotion throughout psychological research (Edvardsson et al., 2010; McKeown, Clarke, Ingleton, Ryan & Repper, 2010). This research has been the reasoning behind the creation of frameworks for the implementation of person centred care (McCormack, 2003). However, the literature recognises a common requirement for greater knowledge, guidance and training (Clissett, Porock, Harwood &

Gladman, 2013; Edvardsson, Sandman & Borell, 2014; Edvardsson, Watt & Pierce, 2016; Kim & Park, 2017).

Therefore, the specific purpose of this systematic literature review is to identify the perceptions of awareness levels paid professional carers have on person centred care and how it is developed and used within the care industry.

2.2.1 Aims

Three aims have been developed for the literature to be summarised around:

1. What are the perceptions of and current levels of awareness of person centred care amongst paid professional carers?
2. To what extent do paid professional carers feel they have sufficient knowledge, understanding and training on person centred care?
3. To what extent is person centred care being used by paid professional carers for individuals with Dementia and how is it being developed and promoted in the care industry?

These aims have been created to answer important questions regarding person centred care for individuals with Dementia.

2.3 Method

2.3.1 Search strategy

A systematic process was used to collect literature about person centred care for individuals with Dementia including the aims of this review. Several electronic databases

were used: Academic search premier, EBSCO Host, ProQuest, ProQuest Central, Education source, Medline, PsychArticles and Science Direct. One other method of identifying literature was from the reference lists of all the included papers. Reference lists were studied to identify relevant published papers.

When searching the databases, dates of papers were narrowed down to only show papers published from 2007 onwards, allowing for ten years of the most relevant articles to appear. When the initial search was carried out, key concepts, abbreviations and synonyms were used and combined (see table 2.1).

Table 2.1

Components and search terms used for the database searches

Components	Search terms
Person centred care	Person centred care, PCC, person focused, Patient centred care
Dementia	Dementia, Dementia patients, Individuals with Dementia, Alzheimer's
Carer	Carer, Carers, Paid carers, Professional carers, Support worker, Formal carers
Perceptions	Perceptions, Views, Attitudes
Knowledge	Knowledge, Understanding, Training, Awareness

Note: All the search terms were combined with 'OR' as well as 'AND' when searching for literature

2.3.2 Review process

Using the above components in the initial search of databases produced 705 papers. From this, a preparatory examination of these papers was carried out by looking at titles of the papers and excluded any irrelevant ones and duplicates. Papers left were examined by reading their abstracts and again any irrelevant papers were excluded. All papers included at

this point were fully examined ensuring their content fitted the specific criteria refining the articles (see Appendix A).

All articles left after this process were examined against inclusion criteria: (1) articles published from 2007 to the present including both quantitative and qualitative studies, (2) articles including psychological studies in common wealth countries, (3) papers reporting perceptions or awareness levels of person centred care, (4) papers reporting the use or development of person centred care for individuals with Dementia (5) sample of paid professional carers (18 years plus). Papers which did not match this inclusion criteria were excluded.

2.3.3 Quality rating of studies

For the quality assessment of the studies the Critical Appraisal skills programme (CASP) was used. The CASP systematic review research checklist was used. Sir Muir Gray (1993) first initiated the checklist using medical literature by Guyatt, Sackett and Cook (1994). The criteria consisted of ten questions about the quality of the studies which are answered by either 'Yes/No/Can't tell' (see Appendix B).

2.4 Results

2.4.1 Overview of studies

Overall, following the inclusion criteria, 12 articles were recognised to fit within this review. An overview of these studies is represented in table 2.2 (see Appendix C), whilst the quality assessment of these studies is represented in table 2.3.

Table 2.3

Quality Assessment of studies included in the Literature review using Critical Appraisal skills Programme Criteria (CASP)

Study	Focus	Paper Relevance	Method Relevance	Sample	Consistent Results	Overall useful results	Application	Benefits/costs	Overall Assessment
Surr et al. (2016)	Y	Y	Y	Y	Y	Y	N	Y	+
Smythe et al. (2017)	Y	Y	Y	Y	Y	Y	N	Y	+
Edwards et al. (2014)	Y	Y	Y	N	?	Y	N	Y	-
Smythe et al. (2015)	Y	Y	Y	Y	Y	Y	Y	Y	++
Kirkley et al. (2011)	Y	Y	Y	Y	Y	Y	Y	Y	++
McKeown et al. (2010)	Y	Y	Y	N	Y	Y	N	Y	-
Baillie et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	++
Benbow et al. (2011)	Y	Y	Y	N	Y	Y	Y	Y	+
Edvardsson et al. (2011)	Y	Y	N	Y	Y	Y	Y	Y	+
Kontos et al. (2007)	Y	Y	Y	Y	Y	Y	N	Y	+
Hunter et al. (2013)	Y	Y	?	N	?	Y	Y	Y	-
Edvardsson et al. (2010)	Y	Y	Y	N	Y	Y	Y	Y	+

Note: Y = Yes; N = No; ? = Can't tell; ++ = High Quality; + = Medium Quality; - = Low Quality

The papers included in this review were published between 2007 and 2017 within the inclusion date requirements. Eight studies were carried out in the UK (Baillie, Sills & Thomas, 2016; Benbow, Tsaroucha, Ashley, Morgan & Kingston, 2011; Edwards, Voss & Llife, 2014; Kirkley et al., 2011; McKeown, Clarke, Ingleton, Ryan & Repper, 2010; Smythe, Bentham, Jenkins & Oyeboode, 2015; Smythe, Jenkins, Galant-Miecznikowska, Bentham & Oyeboode; Surr, Smith, Crossland & Robins, 2016), two in Australia (Edvardsson et al., 2010; Edvardsson, Fetherstonhaugh, McAviliffe, Nay & Chenco, 2011) and two in Canada (Hunter et al., 2013; Kontos & Nagile, 2007).

Most of the 12 studies used qualitative methods (Baillie et al., 2016; Edvardsson et al., 2010; Edwards et al., 2014; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017), three used mixed methods (Benbow et al., 2011; Hunter et al., 2013; Kirkley et al., 2011) and two used quantitative methods (Edvardsson et al., 2011; Surr et al., 2016). The most common qualitative method used was focus groups (Baillie et al., 2016; Edvardsson et al., 2010; Edwards et al., 2014; Hunter et al., 2013; Kirkley et al., 2011; Kontos & Nagile, 2007; Smythe et al., 2015; Smythe et al., 2017) and the most prevalent analysis method was thematic analysis (Baillie et al., 2016; Benbow et al., 2011; Edwards et al., 2014; Hunter et al., 2013; Kirkley et al., 2011; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017).

The smallest number of participants was 11 (Smythe et al., 2017) and the largest 297 (Edvardsson et al., 2011). Four studies recruited participants through purposive sampling (Baillie et al., 2016; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015), two used convenience sampling (Edvardsson et al., 2010; Edvardsson et al., 2011), two recruited through advertisements (Hunter et al., 2013; Smythe et al., 2017) and four studies didn't specify their recruitment methods (Benbow et al., 2011; Edwards et al., 2014; Kirkley et al., 2011; Surr et al., 2016). All the studies participants were 18 years plus and included

healthcare professionals, managers of care homes or staff who encountered Dementia patients (Baillie et al., 2011; Benbow et al., 2011; Edvardsson et al., 2010; Edvardsson et al., 2011; Edwards et al., 2014; Hunter et al., 2013; Kirkley et al., 2011; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017; Surr et al., 2016), three studies involved family carers (Benbow et al., 2011; Edvardsson et al., 2010; Smythe et al., 2015) and two studies involved individuals with Dementia (Benbow et al., 2011; Edvardsson et al., 2010).

2.4.2 Perceptions and awareness levels of person centred care

Eight of the 12 papers in this review fit under this heading (Baillie et al., 2016; Benbow et al., 2011; Edvardsson et al., 2010; Edwards et al., 2014; Kirkley et al., 2011; Kontos & Nagile, 2007; Smythe et al., 2015; Smythe et al., 2017). Two of the eight papers directly identified participants awareness of person centred care (Smythe et al., 2015; Smythe et al., 2017) and all eight directly discuss participants perceptions (Baillie et al., 2016; Benbow et al., 2011; Edvardsson et al., 2010; Edwards et al., 2014; Kirkley et al., 2011; Kontos & Nagile, 2007; Smythe et al., 2015; Smythe et al., 2017).

Smythe et al. (2017) found Dementia nurses had an awareness of the concept of person centred care and some acknowledged it was an important term. However, focus groups identified the perceptions of using person centred care, contradicted the awareness as participants perceived they did not use person centred care and hardly knew their patients (Smythe et al., 2017). Similarly, Smythe et al. (2015) identified participants had good levels of awareness of person centred care but they did not practice it as they perceived it as an add on and not part of their job role. Nevertheless, Dementia staff within a residential setting perceived person centred care to be something that allows individuals with Dementia to have normality and maintain their identity (Edvardsson et al., 2010). However, through further

inspection person centred care was not fulfilled for individuals with Dementia despite the perceptions of staff (Edvardsson et al., 2010).

Person centred care is not perceived to be embedded in the organisational culture of care homes, specifically in this case, respite and short break homes (Kirkley et al., 2011), whilst Baillie et al. (2016) reported similar findings, that person centred care was not put into practice due to it not being part of a workplaces culture. Alongside this, Dementia professionals perceived person centred care as innate and not something that can be taught (Smythe et al., 2015). Smythe et al. (2015) furthered this with similar findings from family carers. Furthermore, eight of the studies in this review identified barriers to why person centred care was not carried out despite the awareness and perceptions identified. These barriers included: lack of time, managing staff issues, prioritising other aspects of the job and not knowing how to use person centred care (Benbow et al., 2011; Smythe et al., 2015; Smythe et al., 2017). Other barriers were the negative attitudes held (Edwards et al., 2014). Kirkley et al. (2011) saw the negative attitudes of Dementia staff causing obstructions to the implementation of person centred care within respite homes. With Kontos and Nagile (2007) believing person centred care is not successfully executed as professionals do not perceive patients as individuals but as people with Dementia, distorting their perceptions of person centred care.

2.4.3 Knowledge, understanding and training

Knowledge, understanding and training of person centred care were discussed in ten out of 12 papers (Baillie et al., 2016; Benbow et al., 2011; Edvardsson et al., 2010; Edwards et al., 2014; Kirkley et al., 2011; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017; Surr et al., 2016). The knowledge and understanding of person centred care ties in with perceptions and awareness, as a barrier to person centred care was

not knowing how to do it (Smythe et al., 2015). Kirkley et al. (2011) supported this finding through various interviews and focus groups by discovering a lack of knowledge of person centred care among managers and staff in Dementia residential homes.

Evidence suggests that Dementia professionals understand person centred care (Edwards et al., 2014) although, no definition of person centred care is the same within and amongst care homes (Kirkley et al., 2011). Beside this, Kirkley et al. (2011) identified organisations caring for individuals with Dementia believed they were caring for individuals in a person centred manner but weren't, indicating a lack of knowledge and understanding. Similar to Kontos and Nagile's (2007) results, Benbow et al. (2011) saw carers never saw each individual for themselves but as someone with Dementia. Kontos and Nagile (2007) saw a need for carers to understand them better by taking time to get to know the individuals they care for.

Despite this, Edvardsson et al. (2010) saw Dementia staff have understanding and knowledge on person centred care, they knew to personalise environments and get to know the individuals with Dementia beyond their diagnosis. Nonetheless, whilst this study saw knowledge of person centred care another study saw Dementia care homes based around the staff and not the individuals living there with Dementia (Kirkley et al., 2011). Two of the studies found participants required more improved training, as well as more information for person centred care to be achieved (Edwards et al., 2014; Smythe et al., 2017). Again, this indicates a lack of knowledge, a lack Dementia professionals are aware of.

Three of the ten studies discuss training and how it has improved person centred care (Baillie et al., 2016; McKeown et al., 2010; Surr et al., 2016). During one study, acute hospital staff were exposed to a person centred Dementia care programme at a foundation and intermediate level (Surr et al., 2016). The foundation level had a significant positive change

on attitudes towards individuals with Dementia and the intermediate training had an increased significance for attitude change and significant positive changes for satisfaction and care efficacy (Surr et al., 2016). These findings indicate training can positively change an individual's attitudes towards person centred Dementia care with a significant difference across all time points ($p < .001$), how this training could assist in the implementation of person centred care and provide support for in depth training for the provision of person centred care (Surr et al., 2016).

In a different approach, enforcing individuals to think about how they should provide Dementia care, McKeown et al. (2010) carried out life story work to enhance person centred care. Results demonstrated life story work increased person centred care by increasing staff's understanding and knowledge of the individuals with Dementia (McKeown et al., 2010). Another study used an ethnodrama called 'Barbara's story' and found ethnodrama's to be extremely useful as educational tools when it comes to person centred care, increasing awareness of person centred care and increased understanding resulting in a rapid improvement (Baillie et al., 2016).

Whilst several studies indicate a lack of knowledge and understanding of person centred care (Benbow et al., 2011; Kirkley et al., 2011; Kontos & Nagile, 2007; Smythe et al., 2015; Smythe et al., 2017) and two studies providing evidence for carers acknowledging this lack (Edwards et al., 2014; Smythe et al., 2017) other studies demonstrated contradictory results finding there is knowledge and understanding (Edvardsson et al., 2010; Edwards et al., 2014). Regarding training, it was suggested the barriers to providing person centred care should be taken into consideration when developing person centred Dementia care training (Smythe et al., 2017). Training for person centred Dementia care is an important aspect for individuals with Dementia and is something to be worked on and developed (Baillie et al., 2016; McKeown et al., 2010; Surr et al., 2016).

2.4.4 The use, development and promotion of person centred care

All of the 12 studies discuss the use of person centred care and its development and promotion (Baillie et al., 2016; Benbow et al., 2011; Edvardsson et al., 2010; Edvardsson et al., 2011; Edwards et al., 2014; Hunter et al., 2013; Kirkley et al., 2011; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017; Surr et al., 2016). Throughout the studies, the findings indicated issues to be worked on for the development of person centred care. Two of these issues were identified by Edwards et al. (2014) who found a need for more communication with the individuals with Dementia, as well as negative attitudes staff hold to be challenged. Likewise, it was seen organisations needed to start making changes for a cultural shift (Baillie et al., 2016; Kirkley et al., 2011). Moreover, Dementia homes need to move away from a one size fits all approach as all individuals with Dementia are different and care should be personalised (Kirkley et al., 2011).

Similarly, Edvardsson et al. (2011) found perceived person centred care was significantly associated with job satisfaction (40%; $p < .001$) but staff felt they could not provide person centred care due to following organisational routes. This needs to be resolved for the development of person centred care (Edvardsson et al., 2011). Therefore, staff need to shift their focus from just completing tasks (Edvardsson et al., 2011; Kirkley et al., 2011). Other study's findings show a need for carers to understand the individuals they work with (Kontos & Nagile, 2007). Moreover, Edvardsson et al. (2010) saw research with individuals with Dementia assisted in the development of person centred care as their perceptions provide valid information enabling staff to be successful in person centred care.

As previously mentioned by Smythe et al. (2017), training can assist the development of person centred care, Surr et al. (2016) identified the need for in depth training to develop person centred care and believed a general person centred Dementia care programme was

required. Hunter et al. (2013) believed training should be based around educating staff about Kitwood's (1997) definition of personhood due to finding that staffs beliefs about an individuals personhood can influence the decisions made by health care providers about person centred care.

Life story work was effective for the development of person centred care as it enhanced staff's acknowledgement of the individual behind the Dementia, bringing fulfilment to the individuals as their voice was being respected and heard (McKeown et al., 2010). McKeown et al. (2010) saw life story work as a method to fill a gap in the provision of person centred care. As well as focusing more on the individual themselves, individuals need to participate in more activities of their choice (Benbow et al., 2011). Kontos and Nagile (2007) reinforce this finding.

2.5 Discussion

This review assessed a total of 12 papers exploring the perceptions and awareness of paid professional carers on person centred Dementia care and how person centred care is being used and developed. All the studies discussed the use of person centred care to an extent (Baillie et al., 2016; Benbow et al., 2011; Edvardsson et al., 2010; Edvardsson et al., 2011; Edwards et al., 2014; Hunter et al., 2013; Kirkley et al., 2011; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017; Surr et al., 2016).

A number of results were identified. Firstly, paid professional Dementia carers have awareness of person centred care and its importance for individuals with Dementia, but perceptions held did not coincide with this awareness (Smythe et al., 2015; Smythe et al.,

2017). Further to this, one studies results saw both positive and negative perceptions amongst the same staffing team, causing contradictory results to the study (Edvardsson et al., 2010). Similarly, whilst studies demonstrated knowledge of person centred care, others didn't and where knowledge was identified, person centred care was not fulfilled when caring for individuals with Dementia (Benbow et al., 2011; Edvardsson et al., 2010; Kirkley et al., 2011). Research has suggested when there is a lack of knowledge towards a specific subject, this can distort an individual's attitudes and perceptions towards the behaviour (Almanzar et al., 2014; Fabrigar, Petty, Smith & Crites Jr., 2006; McGlade & Pierscioneck, 2013). This research explains why, even though there is awareness around person centred care, perceptions are negative and person centred care is not carried out.

Thirdly, another prominent result was the reasoning why person centred care is not fulfilled. Barriers varied from not enough time, not knowing how to, the organisational culture of homes, more important tasks and staff not seeing past the diagnosis of Dementia (Benbow et al., 2011; Edwards et al., 2014; Kirkley et al., 2011; Kontos & Nagile, 2007; Smythe et al., 2015; Smythe et al., 2017). These barriers are an issue for individuals with Dementia. One quarter of hospital beds in the UK are occupied by individuals with Dementia (Lakey, 2009), showing the severity of dealing with the identified barriers.

Finally, the studies in this review identified research being undertaken into how person centred care can be used, developed and promoted, demonstrating a move in the right direction for person centred Dementia care. Despite this, numbers of people with Dementia are set to rise to over one million by 2025 and the reviewed studies identified important points such as there being no universal definition of person centred care and the need for a shift from a one size fits all approach (Baillie et al., 2016; Benbow et al., 2011; Kirkley et al., 2011; Kontos & Nagile, 2007). Consequently, these issues need over coming to ensure person centred Dementia care is provided how the BPS (2016) document recommends. Future

research needs to delve further into the individual perceptions of paid professional carers on person centred care, to see how important it is viewed and how to solve the identified barriers. Something this systematic literature review has not done.

2.6 Limitations

This review has provided sufficient evidence answering the questions, set out to explore in the aims. However, several limitations of this review should not be ignored. Firstly, this review was specific to studies involving paid professional carers with most them being UK papers (Baillie et al., 2016; Benbow et al., 2011; Edwards et al., 2014; Kirkley et al., 2011; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017; Surr et al., 2016). This is appropriate when looking at this review in relation to the BPS (2016) document, but results in this review not being generalisable to the world's population. This review was originally going to only include UK papers but due to a lack of UK papers matching the inclusion criteria, it was expanded to common wealth countries, hence the inclusion of both Australian (Edvardsson et al., 2010; Edvardsson et al., 2011) and Canadian (Hunter et al., 2013; Kontos & Nagile, 2007) papers.

Likewise, the samples of the studies were a limitation. Most of the studies either only involved females or had mostly female participants, which could result in gender bias (McKeown et al., 2010). Furthermore, the methods used in the studies were mostly qualitative (Baillie et al., 2016; Edvardsson et al., 2010; Edwards et al., 2014; Kontos & Nagile, 2007; McKeown et al., 2010; Smythe et al., 2015; Smythe et al., 2017). This resulted in focus groups and interviews being used which do not always provide enough

psychological evidence and can involve social desirability bias (Kirkley et al., 2011). Where small focus groups occurred, discussions do not expand enough for results to be reliable (Smythe et al., 2015). However, where quantitative and mixed methods were used (Benbow et al., 2011; Edvardsson et al., 2011; Hunter et al., 2013; Kirkley et al., 2011; Surr et al., 2016) four of the five studies were assessed lower when using the CASP tool for their quality assessment, due to their samples, method relevance, consistency in results or application not fitting in with the reviews purpose as well as it could of, specifically one of the papers (Hunter et al., 2013).

Moreover, when quantitative methods were used the specific behaviours of participants were not seen to acquire information on their involvement with person centred care, so results may not have been directly linked to the review as initially wanted (Hunter et al., 2013). Therefore, results varied amongst papers, though when different methods are used in psychological research it is common for different results to be obtained (Baillie et al., 2016; McKeown et al., 2010). Similarly, where cross sectional studies were used it was seen clear causal interpretations were not acquired (Edvardsson et al., 2011) and content analysis can lack credibility due to falling short of the full picture of the topic being studied (Edvardsson et al., 2010).

When looking at peoples' awareness, perceptions and knowledge a few things need to be taken into consideration. Knowledge levels people have can impact the attitude towards a behaviour and how they perceive it, whether its perceiving whether to carry out the behaviour or a general perception (Almanzar et al., 2014; Fabrigar et al., 2006; McGlade & Pierscioneck, 2013). Therefore, external factors limit the results of the findings. Despite this, it could be said, this makes qualitative research more suited to this review as it obtains in depth information (Baillie et al., 2016; McKeown et al., 2010).

In hindsight, limitations were apparent and future research should take these into consideration. For example, suitable sampling methods and appropriate research methods should be used for higher quality assessment ratings (Baillie et al., 2016; Kirkley et al., 2011; Smythe et al., 2015). Consequently, with these limitations being taken into consideration, research into person centred care for individuals with Dementia can progress through its development and use within the care industry. With all this considered, this review demonstrates person centred care is known to paid professional Dementia carers but not always used due to attitudes, a lack of knowledge and perceived barriers to carrying it out. Additionally, person centred care is being promoted and developed through psychological research. There is sufficient evidence for these developments like training, to be used to enhance person centred care for individuals living with Dementia in the world today.

Chapter three: Research Paper

Caring for individuals with Dementia: a qualitative exploration of the importance of person centred care and how well it's understood

This manuscript has been written for submission to the British Journal of Health Psychology following the Journal's instructions to authors.

Objectives: Person centred care is presently the recommended method of caring for individuals with Dementia. However, research has evidenced person centred Dementia care is underused by paid professional Dementia carers. This study aimed to explore the perceived importance of person centred care for individuals with Dementia and its use by paid professional carers.

Design: In-depth semi-structured interviews were used to explore participants perceptions on person centred Dementia care.

Methods: Ten participants (nine females, one male) were recruited from care organisations and were interviewed. Thematic analysis was used to analyse interviews.

Results: Analysis generated three superordinate themes: (1) variation in knowledge explanations of person centred care; (2) contradictions between the knowing and the doing; (3) perceived barriers of person centred care. These themes represent the misunderstandings around person centred care and how it is not used to the extent it should be, if at all. Results also reflect the perceived reasons and solutions for this, including: better planned time, more staff, colleague support and rigorous recruitment methods and better training.

Conclusion: The importance of person centred care for individuals with Dementia is perceived positively, though the provision of person centred care tells a different story and is not fully executed. To fulfil the requirements of person centred Dementia care and for organisations to deliver it successfully, research needs to build upon and resolve the perceived existing barriers of time constraints, staffing issues and the lack of knowledge due to inadequate training. This will provide a more in-depth look at the surrounding obstructions to the provision of person centred care for individuals with Dementia.

Statement of contribution

What is already known on this subject?

- There is awareness of what person centred care is though it is commonly not implemented for individuals with Dementia.
- There are several barriers to the implementation of person centred care.

What does this study add?

- There is no one holistic definition of person centred care, with explanations varying among organisations and within them.
- Person centred care is being provided in small aspects where it is being provided at all.
- There are specific misunderstandings and obstructions in the way of the provision of person centred care for individuals with Dementia.
- Stereotypes of Dementia are extremely strong.
- Barriers of person centred care go more in-depth than past research has demonstrated down to specifics of recruitment processes of carers and there are several perceived solutions to the problems.

Dementia is a common disease within the UK rapidly on the increase (Ferri et al., 2005). Research past and present is being undertaken to improve person centred care as it is recognised as the most appropriate method for Dementia care (BPS, 2016; Edvardsson et al., 2010) hence the need for vast improvement in its use in Dementia homes and Dementia professionals care practice (Kim & Park, 2017). The concept of person centred care has been around since the 1940's (Rogers, 1951).

Previous studies over the last ten years have started to explore the knowledge and understanding of person centred care and have yielded inconsistent findings. A qualitative study with 11 Dementia nurses identified awareness of person centred care exists, though is not carried out or at least not to the required standard (Smythe et al., 2017). Likewise, a study by Smythe et al. (2015) using community Dementia health teams saw participants identified with person centred care, but did not see it as necessary in their job but an additional aspect resulting in a lack of person centred care. One claim made by several studies is there are

barriers preventing person centred care. Barriers consisted of time constraints, other job roles being carried out first, staff issues and not knowing how to achieve person centred care (Benbow et al., 2011; Smythe et al., 2015; Smythe et al., 2017). Furthermore, findings indicate perceived negative attitudes to providing person centred care (Edwards et al., 2014). One study with 70 participants working with individuals with Dementia in both NHS and social services settings identified organisational culture issues preventing person centred care (Baillie et al., 2016). Moreover, a qualitative study using focus groups pinpointed Dementia staff see the individuals they care for more like a diagnosis than an individual and do not take the time to get to know them (Kontos & Nagile, 2007).

Research portrays a lack of understanding of person centred care and how to provide it (Benbow et al., 2011; Kirkley et al., 2011). A study by Edwards et al. (2014) saw Dementia carers provided understanding yet no fulfilment of person centred care, resulting in contradictory results. Reasons for the lack of fulfilment of person centred Dementia care amongst what has been discussed prior includes a need for more training within the area (Smythe et al., 2017). Research has been undertaken into the area of training and significant results were found (Baillie et al., 2016; McKeown et al., 2010; Surr et al., 2016).

With issues behind the lack of person centred care accounted for within research and studies identifying ways to make improvements, it could be said psychological research is exploring and evaluating these issues to provide insight into how to take person centred Dementia care forward. The British Psychological Society (BPS: 2016) identified the importance of providing person centred care for individuals with Dementia through a policy document called '*Psychological dimensions of Dementia: putting the person at the centre of care*' which recommended an increase in psychological research and practice to fill gaps in the provision of person centred Dementia care. This recommendation from the BPS (2016) is

supported by findings from past literature due to research consistently providing insight into why person centred Dementia care is not being effectively executed.

Overall, the claims put forward from the study's findings reiterate the need for more psychological research into the area of person centred Dementia care, so steps can be taken to improve it in the UK and to ensure everyone with Dementia is seen as an individual and their voice is heard. Accounting for support and contradictions from study results, the identified issues, alongside there being no universal definition of person centred care (Baillie et al., 2016; Benbow et al., 2011; Kirkley et al., 2011; Kontos & Nagile, 2007), the main aim of the present research was to obtain in-depth information from paid professional Dementia carers about their perceptions on person centred care, whether they identified with its importance and how well it is understood.

3.1 Method

3.1.1 Participants

Purposive sampling was used to recruit paid professional Dementia carers within the Swansea and Carmarthenshire area in Wales. Organisations within the specified region were contacted to reach out to potential participants and a study information sheet was shared on a Dementia carers forum with the researcher's details (see Appendix D for recruitment materials). A total of ten participants were used and were all paid professional Dementia carers. Participants ranged between the ages of 27 and 51 (mean = 36 years), most of the participants were female ($N = 9$) with only one being male. The rest of the demographics

obtained via a short form (see Appendix E) can be seen in Table 3.1. All identifying information has been changed.

3.1.2 Procedure

The discussed study was assessed and ethically approved by the University of Wales Trinity Saint David's ethics committee (see Appendix F for ethics form). Participants who were interested in participating and met the requirement of being a paid professional Dementia carer contacted the researcher via email to discuss the study further and potentially arrange an interview date and time. The researcher followed a set protocol for the advertisement, recruitment and interviewing of participants (see Appendix G). Participants were emailed 24 hours before their interview to ensure they still wished to attend. Interviews took place at the participants place of work ($N = 9$) or a communal convenient place for them ($N = 1$). Interviews were recorded and lasted between 12 and 35 minutes. Written informed consent was obtained before the interview began (see Appendix H) and participants were verbally debriefed at the end of the interview and provided with a debrief form (see Appendix I).

3.1.3 Interview schedule

A semi-structured interview schedule was created consisting of five main questions with prompts (see Appendix J). Semi-structured interviews were used as they allowed the main research aims this study set out to answer to be discussed, whilst allowing the interviewees to explore these questions and expand on their answers through their own personal perceptions and experiences (Dearnley, 2005; Smith, 2011). To ensure the interview schedule was suitable for the current research a document was created providing validated reasoning behind the questions within the interview schedule from a BPS (2016) policy document on person centred Dementia care (see Appendix K). The interview schedule was

piloted prior to the commencement of the study and feedback forms were acquired (see Appendix L).

3.1.4 Data collection and Analysis

All interviews were transcribed by the researcher from the recording device used. Data was analysed using thematic analysis in line with Braun and Clarke's (2006) six step procedure. Firstly, transcribed data was read several times and initial ideas and thoughts were noted (see Appendix M), then initial codes were generated across the transcripts using the initial ideas (see Appendix N). Thirdly, codes were collated into potential themes using all the relevant data by looking for patterns across the transcripts (see Appendix O). The potential themes were reviewed before being finally defined and named in steps four and five (see Appendix P). Step six was the formation of this research paper. All ten transcripts were analysed using this six-step procedure and were compared to create the superordinate and subordinate themes generated. Table 3.2 was created to identify which themes occurred in which transcripts (see Appendix Q). This process was discussed and oversaw with the researcher's academic supervisor.

3.2 Results

The analysis of the ten transcripts resulted in the generation of three superordinate themes: (1) variations in knowledge evidenced in explanations of person centred care; (2) contradictions between the knowing and the doing; (3) perceived barriers of person centred care. All the superordinate and subordinate themes are demonstrated in table 3.3.

Table 3.1

Participant demographics and experience of working in Dementia care

	Gemma	Casey	Julie	Beverly	Lucy	Bobby	Abbie	Donna	Jennifer	Katie
Gender	F	F	F	F	F	M	F	F	F	F
Age (years)	51	33	31	48	29	39	28	27	36	35
Highest level of Education	University degree or higher	College certificate or Diploma	Left school at 16 (GCSE, CSE, O levels or equivalent)	Left school before I was 16 (no formal qualifications)	College certificate or diploma	College certificate or diploma	University degree or higher	College certificate or diploma	Left school at 16 (GCSE, CSE, O levels or equivalent)	Left school at 16 (GCSE, CSE, O levels or equivalent)
Specific job title	Dementia nurse/carer	Carer	Carer	Carer	Carer	Support worker	Carer	Senior carer	Carer	Senior support worker
Experience of working in Dementia care (years)	30	13	6	20	6	1	1	8	6	13

Note: F = Female/M = Male; The names given throughout this paper and on this table are pseudonyms to protect participants' confidentiality.

Table 3.3

Overview of the thematic analysis results

Superordinate themes	Subordinate theme
Variation in knowledge evidenced in explanations of person centred care	Lack of a standard working definition Providing basic care: lacking person centred care Diversity of person centred care training
Contradictions between the knowing and the doing	Conflicted perceptions of the importance to the specific doing Person centred care in bite size chunks The fight of capacity and safety VS choice
Perceived barriers of person centred care	Time pressures Staffing issues Individual identity VS Dementia diagnosis Perceived resolutions to perceived person centred care barriers

3.2.1 Theme one: Variations in knowledge evidenced in explanations of person centred care

The first superordinate theme was demonstrated among all participant transcripts. It represents the diversity amongst paid professional Dementia carers knowledge on person centred care within the same region and in some instances the same organisation.

Lack of a standard working definition

During the interviews it was evident there was not one standard working definition of person centred care. Person centred care is looking at an individual as a whole, viewing their identity and not the diagnosis they have, allowing their voice to be heard, valuing them and considering all their religious and cultural beliefs, as well as their wishes and preferences regarding their care, whilst treating them with respect and dignity and keeping them within a socialised and personalised environment (Brooker, 2004). Throughout interviews, no one individual accounted for all these aspects when defining person centred care. Though most participants were familiar with the term to some extent:

Casey: 'I am familiar with the term obviously from working in care for so many years

but no one individual has the same needs, all individuals have different needs to another’.

Bobby: ‘Well, umm, I would say it is thinking about the person them self [...] It is getting to know an individual. Someone’s umm, likes and dislikes and their background [...] People sometimes should remember about respect too umm, person centred care can be about dignifying someone’.

Generally, the common responses were like those above, whilst the basic understanding was there, a holistic definition was never given. In contrast, three of the ten participants did not know the term at all and two said they knew the term, but it was not used:

Beverley: Umm, I don’t know [...] so you can’t just go in and have a textbook and know these terms and what to do [...] But I’m not great with the terms used.

Jennifer: I’ve never heard that before. Do you mean just personal care?

This shows the variation amongst paid professional carers and how presently the term is not known, misunderstood or only known in pieces.

Providing basic care: lacking person centred care

When looking further into the perceived explanations of person centred care, a common misunderstanding between what was thought to be person centred care and what was infact general basic care was seen:

Abbie: [...] you have to go in with that sort of approach rather than their a number or a room number something like that which is just awful but also to give them the best quality of care in the industry.

Aspects of person centred care are acknowledged here by recognising individuals with Dementia are not just a number and the best quality of care should be given. However,

providing these things is not essentially providing full person centred care, indicating a lack of understanding. Again, person centred care seemed to be confused with providing basic personal hygiene care:

Jennifer: [...] like you have some residents who are in pads, you know you have to constantly keep checking [...] that's the most important thing I think and make sure they have regular baths, showers and yeah.

Basic care needs are of course important for all individuals. However, by these needs being priorities for the execution of person centred care indicates low levels of knowledge.

Diversity of person centred care training

When looking at the variance in knowledge of person centred care and the confusion around its use, one explanation could be the differences in person centred care training. Four of the participants believed they had received person centred care training:

Researcher: [...] Has there ever been a training course you have been put on specific to person centred care?

Donna: Yeah, it's more in some of the jobs I first started in do give you a little course on person centred care [...]

However, two of these four individuals who said they had received person centred care training did not know what the term meant questioning the training they had. Similarly, one individual perceived they had person centred care training, though when explained, it was not training:

Lucy: Yeah...yeah but not...not in depth training. It's just one of them subjects of this is Mary's file, right go and...you go and ask her what she wants if she can answer, what she likes and doesn't [...]

Five of the participants had not received specific person centred care training, though three of them believed the emphasis was in other training they had received:

Gemma: [...] I suppose I have in a way throughout my training [...] the emphasis is there for, for person centred care [...]

Katie: No. I don't think I have.

This subordinate theme demonstrates the diverse levels of person centred care training paid professional Dementia carers receive and could be the initial step for reasoning behind the variation in knowledge.

3.2.2 Theme two: Contradictions between the knowing and the doing

The second superordinate theme demonstrates the contradictions amongst what is perceived as important and what is put into practice.

Conflicted perceptions of the importance to the specific doing

Most participants perceived person centred care as important for individuals with Dementia. Though when it came to explore its use, their appeared to be conflict. This was evidenced by participant five:

Researcher: So how important do you feel all of that is for an individual with Dementia?

Lucy: Really important, super important.

Then when discussing carrying out person centred care, a different story was told:

Researcher: How do you think that impacted the care of the individual?

Lucy: Well they weren't getting the care they needed. Some of them (pause) honestly,

they needed more help than what we could give them and that is a fact and I used to say it all the time [...] I kind of felt like it was, what's the word institutionalised and that's how it was [...] everything was like dududududu and were gonna slot them in dududududu and then in the end your kind of dududududu and you're not giving them person centred care, you're not you know.

Another example is participant ten. Who provided a positive response for the perceived importance of person centred care, though went onto discuss aspects of care which did not follow person centred care principles:

Katie: One hundred percent because they...with Dementia they can't make choice so you've got to [...]

These two extracts from the interviews evidence whilst the perceived importance of person centred care is positive, the specific doing of it is not.

Person centred care in bite size chunks

Person centred care is about providing individuals with choice and allowing their wishes and preferences to be upheld. It was evidenced throughout all interviews, person centred care was only provided to a certain extent:

Researcher: To what extent do you believe the individuals have a say in their care?

Katie: It all depends how far into the Dementia they are, if it was the beginning they would have more input into their care but if they were fully into Dementia it is more the family making decisions or like I said earlier go on how they lived their life before (pause) and try and care for them that way.

Researcher: What about little things like what they're going to wear each day or the time they are getting out of bed and going to bed?

Katie: I put a few little things on the bed and get them to choose what they wanted to wear I would never choose for them but with bedtimes and getting up umm, yeah theres strict routines [...]

Secondly, only two out of the ten participants had seen evidence of long term care wishes and preferences upheld throughout care, with the other eight never seeing it:

Researcher: What about say, an individual has been diagnosed with Dementia and has made choices at the beginning of that diagnosis and has come into care then in the later stages. Have you ever seen evidence of these choices made that have continuously been inputted into their care?

Lucy: Explain better, I'm not sure what you mean, sorry.

Researcher: No that's fine. If an individual has found out they have Dementia and has said right I want to be cared for in this way...

Lucy: [...] I didn't deal with anyone who I saw had notes for an input in their care that way do you know what I mean. Like yes, they had an input in their care in the way as in I like this food, my family do this, and my family do that but not in the way of them saying If I get to the point where I'm I dunno, I can't feed myself I just want to be cared for in this way. I never saw a progression of the care plan no...no.

This was prevalent among the majority of the transcripts. It appeared the only input individuals potentially had in their care was their food and clothes resulting in small chunks of person centred care being provided.

The fight of capacity and safety VS choice

A reoccurring discussion point when it came to individuals having input in their care was to do with the capacity of individuals:

Researcher: Do you think this should be done, or some evidence of choices which have been made by the individual should be seen and upheld?

Beverly: Yeah, they should have a choice, but I don't think there'd...umm have capacity to make the choices would they.

This discussion point occurred in most of the transcripts:

Researcher: That links to the next question, you said you ask the residents themselves, how much input in their own care do they have?

Donna: It depends if they have capacity [...]

The safety needs of individuals were the same:

Researcher: To what extent do you feel the individuals have an important in their own care?

Jennifer: Umm, that's a hard one. Umm (pause) to a certain extent, when it comes to their safety you know umm, sometimes it's...there not always able to make that decision sometimes we have to take over [...].

Nine of the ten interviews portrayed this issue of the individual's capacity and safety obstructing their choices and voice being heard.

3.2.3 Theme three: Perceived barriers of person centred care

Perceived barriers as to why person centred care is not fulfilled were discussed during interviews, with three being more prevalent.

Time pressures

Eight of the participants mentioned the time pressures they have in their job and how they obstruct person centred care:

Casey: Definitely time would be the main one, umm (pause) I don't feel you can implement to a good care standard when you don't have enough time for that individual.

Lucy: [...] your so time consumed with paperwork and stuff that everything's just fobbed over.

The viewpoints above acknowledge the issues time have on person centred care.

Staffing issues

Staff issues were discussed in various ways when it came to providing person centred care to individuals with Dementia. A lack of staff seemed to be a common denominator which in turn impacted the above issue of time pressures:

Researcher: Other than staffing issues did you ever feel there was anything else preventing person centred Dementia care?

Katie: You don't have the time you just haven't got the staff to give one hundred percent care because you don't have enough staff, so you do personal care the best you can and don't always have time to talk because if people aren't in bed you get pulled in and asked why. Just that.

The issue of staffing predominantly appeared in three of the ten interviews and was related to the issues of the types of individuals employed and their perceived lack of concern for the individuals with Dementia:

Abbie: [...] it was so hard to even get them to speak to the residents and it was so

frustrating especially when the residents were trying to speak to them [...] those who think oh well I'm not going to be a solicitor, so I will just be a carer.

Whilst, the perceived issues of staffing only appeared in half of the interviews, where they did appear the emphasis of the barrier they caused to person centred care was large.

Individual identity VS Dementia diagnosis

Thirdly, a main aspect of person centred is maintaining an individual's identity. However, viewpoints among the majority of the interviews perceived a lack of this was what caused a decrease in person centred care:

Lucy: [...] You don't see them anymore as who they are, I mean they are just a Dementia patient [...]

There seems to be a perceived stereotype for all individuals with a Dementia diagnosis:

Julie: Yes, I think a lot of people will just look at Dementia and round them all of as their all the same [...]

Bobby: [...] I think people sometimes think that if you have Dementia you're just going...going one way [...] You know I think Dementia is sometimes, what's the word umm, stereotyped [...]

Individuals are grouped together because of their diagnosis of Dementia causing person centred care to not be executed. The individuals are not being considered, their diagnosis is.

Perceived resolutions to perceived person centred care barriers

Whilst perceived barriers were identified throughout the interviews, participants were also quick to offer what they perceived could resolve these issues to assist in the provision of person centred care:

Donna: I would love more time [...]

An obvious resolution would be more time, and this was demonstrated within participants viewpoints, though it was also evidenced for more time, more staff would be a start:

Researcher: [...] Lastly, in your opinion do you believe there is anything that will improve person centred care for Dementia patients?

Katie: Yeah one to one care or at least one to three so you can actually provide the time and talk to the person with Dementia and it solves the time issues and staff.

Further, participant seven suggested more time to be taken when staff are recruited:

Researcher: Thank you. Is there anything else you believe is important in person centred care?

Abbie: [...] I think more time needs to be taken in recruitment [...] I think there needs to be more restrictions like it is with childcare, you have to have qualifications, have to have more training and it's a lot stricter and I think Dementia residents are just as vulnerable as children if not more [...]

When it comes to the issue of stereotyping individuals with Dementia it was identified this should not be done:

Julie: [...] you shouldn't look at Dementia like that as everyone is different [...]

Further, as a lack of understanding of person centred care is a cause of these barriers to an extent, it was no surprise all participants mentioned the importance of training and how more effective training is needed, as well as support from colleagues and management in the implementation of person centred care:

Casey: Umm, definitely training, umm is very important, you need the understanding behind you [...] umm, and you have to have support off work colleagues and management [...]

Gemma: All training is important [...] I don't think anyone can ever have enough training and it's always good to have.

In essence, whilst it is acknowledged there are perceived barriers to person centred care, there are also perceived solutions on how to solve these.

3.3 Discussion

This study aimed to explore the perceived importance of person centred care of paid professional Dementia carers and how well it is understood. The results generated three superordinate themes: variations in knowledge evidenced in explanations of person centred care, contradictions between the knowing and the doing and the perceived barriers to person centred care. All together these themes evidenced there are common misunderstandings around person centred care and whilst it is perceived as important there are various barriers preventing its use for individuals with Dementia.

The three subordinate themes from the first superordinate theme resonate with previous research on person centred Dementia care. The first theme demonstrated person centred care is a term known by most, indicating awareness around it, but like the Dementia nurses in a study by Smythe et al. (2017), despite there being an awareness, person centred care was not used by them, a result replicated by the carers within this study. However, what this theme evidenced is whilst there is awareness of person centred care not one person provided a

holistic view. There was a common misunderstanding among what was perceived to be an act of person centred care, basic personal care being provided was seen as a main aspect, when this is not the case. Previous work by Benbow et al. (2011) replicates this result in a study with carers, seeing a great lack of understanding on what providing person centred care actually entailed and what the most important aspects are. Furthermore, where this research has acknowledged the lack of a holistic view of person centred care, this relates to the fact previous research has identified no universal working definition (Ballie et al., 2016; Kirkley et al., 2011; Kontos & Nagile, 2007). It is recommended for the practice of person centred care to be improved, a standard working definition needs to be accounted for, for Dementia professional carers to follow and abide to. This would decrease the variations in explanations of person centred care.

The BPS (2016) document '*Psychological dimensions of Dementia: putting the person at the centre of care*' sees person centred care as the way forward for individuals with Dementia as well as previous research (Edvardsson et al., 2010). This links into the second superordinate theme of this paper as the importance of person centred Dementia care is acknowledged. However, there was a conflict between what is important and what was carried out. Similar to previous research by Edvardsson et al. (2010) and Smythe et al. (2017), despite the perceived importance of person centred care, it was not provided for individuals with Dementia, or if it was, it was done so in pieces and not to a full extent. This research paper accounted for a potential reason for this. Each individual is viewed in regard to their capacity and safety before aspects of person centred care are provided to them, such as their choice. This result expands on previous literature and for this to be overcome it is recommended person centred care is put before carers views on an individual's capacity and safety, as choice is not something which should be taken away due to another's perception.

Furthermore, perceived barriers were evidenced throughout discussions with participants within this study: time pressures, staffing issues and an individual's identity VS their Dementia diagnosis. Whilst most of these perceived barriers have been identified by previous research (Benbow et al., 2011; Edwards et al., 2014; Kirkley et al., 2011; Kontos & Nagile, 2007; Smythe et al., 2015; Smythe et al., 2017), the perceived barrier of staffing issues has focused solely on a shortage (Smythe et al., 2015). The current research expanded on this, there was a common perception a more rigorous recruitment method needs to be taken when it comes to individuals with Dementia to ensure they are given the respect and care they require. A recommendation for future practice would be to put this in place due to the importance of maintaining an individual's respect, rights and dignity no matter the diagnosis they have (BPS, 2016). Regarding the perceived barrier of an individual's identity VS their Dementia diagnosis, a predominant issue in the present research, there has been similar instances in the past. Kontos and Nagile (2007) identified individuals are sometimes viewed as their diagnosis rather than who they are as a person. This emphasises the need for stereotypes of individuals with Dementia to be removed by paid professional carers and the organisational culture within Dementia homes.

Following this, perceived resolutions to person centred care barriers were identified. Those which appeared obvious and have been mentioned through previous research are more time, more training and a general need for vast improvement (Hunter et al., 2013; Kim & Park, 2017; Smythe et al., 2017). Recommendations for training include organisations considering the research carried out into the successful methods of training: life story work, general training programmes and the use of ethnodrama's (McKeown et al., 2010; Baillie et al., 2016; Surr et al., 2016) and to act and see adequate training as an essential part of practice. Further to this, this study allowed for new suggestions to be made towards the improvement of person centred care as interviews allowed for in-depth data. Perceived

solutions for improvements included, having rules where there must be one staff member to a maximum of three individuals with Dementia and as mentioned before the need for more rigorous recruitment methods. Beside this, a need for support from colleagues and management for person centred care to be implemented was evidenced. This correlates with previous research. It was found amongst various Dementia professionals there was a lack of support from managers and other staff due to the organisational culture, preventing the implementation of person centred care (Baillie et al., 2016). It is suggested future research delves deeper into these perceived solutions to overcome the barriers to the provision of person centred care. Along with organisations to ensure they practice a positive outlook towards person centred care for individuals with Dementia and promote a supportive networking system amongst the staff team.

3.3.1 Conclusion

The present studies results, resonate with previous results from other papers researching the same area. This research has also added to these results regarding the lack of a holistic explanation of person centred care, the misunderstandings, the specific obstructions as well as a more in-depth perception of the barriers and their perceived solutions. It is believed the research implements further support for the required steps forward into the provision of person centred care and also new results that should be considered and built on for the resolution and execution of person centred Dementia care.

3.3.2 Conflict of interest

Researchers declare no conflict of interests.

Chapter four: Reflective Chapter

This reflective chapter will follow Gibbs (1988) reflective framework: reflective cycle. My reflection will be on the process of my Master's dissertation study from beginning to end. My dissertation took place within the university as well as out in society due to my study being applied research. I was the researcher and was supported by my academic supervisor throughout, who oversaw the process. The only other individuals involved were my participants who were recruited due to them being paid professional Dementia carers. The context for my master's dissertation was exploring how person centred care is perceived as important and it's use for individuals with Dementia. I as the researcher went out and interviewed participants, recorded the interviews, analysed them using thematic analysis and wrote a research paper.

Following the description of the event I will now go more in-depth into the processes of my dissertation and the feelings and thoughts personal to me which I had. When I first started my masters, I had always felt dread around choosing my topic, not the process of doing it but the topic itself. This was due to the way I feel comfortable working, whilst it excites me to know I could research a topic area of my choice to potentially identify new results within research, I work better with structure and when initially choosing a topic there is no specific structure which made me a bit apprehensive. When it came to the topic, I believed it would go one way and felt confident I would proceed with my dissertation in mental health, how it is perceived or how it affects individuals. These thoughts did not represent my final work. I was determined to finalise my topic, which was why I was turning to aspects of psychology I believed were obvious for me to research. However, it wasn't until I saw and read a document by the BPS (2016) that clarified in my mind how I would proceed with my dissertation and it was not in the field of mental health like I initially thought but infact was on person centred Dementia care.

Moving further into stage two of Gibbs (1988) reflective cycle on my thoughts and awareness throughout the process, when I had clarified my chosen topic the outcome made me feel enthused about the research I was about to carry out. I had a preconception once the topic was picked that would be it, I underestimated the thought and research I would have to put in despite knowing really what would be required. I learnt things don't just happen at the click of a finger, there had to be reasoning and evidence behind everything I decided for me to provide rationale for my decisions. The training I received earlier in my masters in research methods prepared me for this and I kept reverting to my previous work for pointers and reminders of the way I should be carrying out my research. From the previous training I had received in research methods and reflecting upon my understanding of appropriate research design I recognised a qualitative approach would be appropriate because I was exploring individual's perceptions to a specific subject and qualitative research is seen to be the most suitable method in these instances (Smith, 2011). This was also emphasised by my academic supervisor. Initially, I felt uneasy about carrying out qualitative research as I had always felt confident I would carry out quantitative research for my dissertation. The thought of not being in my comfort zone of obtaining data, putting it in SPSS and gathering my statistical results panicked me but I had previous training in qualitative research which assisted me in the process. I knew for my dissertation to be what I personally wanted it to be, qualitative research was the way forward and I didn't shy away from the challenge, despite never believing this would be the approach I would take. In retrospect I am thrilled I took this stance with my dissertation, evaluating this part of my process I would say I have a whole new outlook on research and insight into the in-depth perceptions and information you can get by using qualitative methods.

With my dissertation idea pinpointed and approved by my academic supervisor, I was excited to proceed and start collating data. The next step was obtaining ethical approval. I felt

self-assured with this process and was aware of the ethical issues surrounding research and working with individuals due to my years in University as well as my work experiences. I felt like ‘what could go wrong, this will be fine and simple’, though I did not realise beforehand the different requirements needed for an ethics form for qualitative than quantitative research. This was initially a shock to me and I kept thinking ‘what am I missing’. However, six drafts later and I got there, my research study was approved by the ethics committee at the first instance. This made me feel amazing, I had overcome my first hurdle to carrying out my research. I have learnt to have more awareness of the differences between ethical issues for different types of research. Specifically, as I carried out interviews, I learnt how thorough and aware you must be to keep anonymity, confidentiality and removing all aspects of identifiable information (Sanjari, Bahramnezhad, Fomani, Shoghi & Cheraghi, 2014). This part of the process would be a positive aspect of the evaluation as I learnt a lot and feel it went well due to there being no concerns with my submitted ethics form.

The second predominant moment through this process which I felt was a hurdle was the recruitment. I felt nervous about going into the real world and having to interview individuals as it was a whole new concept for me. Whereas I felt confident with the recruitment process as I believed it would be quick and easy. Throughout this process I came to the realisation recruiting is not easy, something which has been recognised commonly throughout qualitative research (Trotter II, 2012). The way I first advertised my study, I did not recruit one participant which concerned me. Initially, I could not comprehend why no one would not want to participate and questioned myself, thinking ‘what am I doing wrong’. I remember having a discussion with my academic supervisor at this point about recruitment and was told I had to get myself out there. I knew this was what I needed to do but was anxious at the thought of ringing up care homes or going into them and asking if they would be willing to look at my study information sheet. I came to the realisation, no matter how

scared I was, if I wanted to do the best I can and execute this dissertation I had to just go for it. That was a big step for me and taught me real life research is not as easy as I personally would like to think, and you must be prepared for the time, effort and setbacks you may get.

It took a while, but I got my ten participants which was the maximum number I put on my ethics form. To have put myself out there as a researcher and achieve what I did, I felt truly proud of myself and when I informed my academic supervisor I had interviewed ten participants and they appeared as happy as me I felt accomplished and on top of the world I had done that. It was something in hindsight I wouldn't believe I could have done but also something I did not think would be such a challenge. Evaluating this part of the process, I knew I had achieved a credible sample according to Braun and Clarke's (2013) suitable sample sizes for a master's dissertation as well as previous qualitative research having a similar sample size (Finlay & Elander, 2016; Walton & French, 2016).

When it came to the interviewing of participants, initially I could feel my body shaking especially on the first one but by the third one my confidence grew with each interview. I started to believe in myself as a researcher. Before carrying out the interviews I didn't feel I would ever have an issue with being shocked, or having my own initial opinions or judgements on what people were saying in the interviews despite being fully aware of my own personal views on person centred Dementia care. Again, this was not completely true. Drawing upon work by Frost (2011) on bracketing your own personal feelings, experiences, knowledge and emotions towards a subject to ensure how I interpreted what one of my individuals said was subjective and I did not place myself or my own role within what I was hearing was something I had to account for. As someone who has worked as a carer for individuals with Dementia and currently works with individuals with mental health, jobs I have pure passion for I had to make sure I was taking in what each participant was saying as a researcher and not a carer. Something which has been acknowledged throughout qualitative

research, to remember your place as a researcher (Sanjari et al., 2014; Willig, 2012). Any predispositions I had, were required to be put to the side so the interviews and interpretation which I carried out were accounts of what the participants themselves portrayed ensuring they were not tainted by personal feelings I felt as a researcher (Frost, 2011).

The initial interpretation I had to carry out petrified me, my thoughts were along the line of ‘who am I to interpret this?’ as well as not believing I had the capacity to do so. Although, like it has been said by Willig (2012) interpretations came naturally without me being fully conscious I was doing it. I was convinced the first interpretations I had done were not correct, nevertheless after a meeting with my academic supervisor I realised I did know my data, what I was doing was right and to have a little more faith in myself. When it was finalised, thematic analysis was my method for analysis. I was honestly not prepared for the time I had to put in. In my head my analysis was going to be finished by a certain time point, though in fact it was not the case at all and all I kept thinking was ‘I am never going to get this done’ and ‘I am never going to achieve what I wanted to’.

During the analysis I followed the six-step procedure set out by Braun and Clarke (2006). Following the six steps provided me with some faith in the fact I couldn’t go wrong with my analysis. Again however, I came to the realisation it was not as easy as following six steps in the respect, the analysis I was doing kept changing through my interpretations and how I viewed the participants perceptions to be portrayed. I was dubious personally of my first initial ideas though continued with them and proceeded onto the next stage of the initial coding. The more I was reading the transcripts the more I was seeing further into them and thinking my initial ideas were wrong. Similarly, when it came to my generation of themes, reviewing and defining them I found myself drawing mind maps and making notes of where I thought codes and extracts fitted but in the next read my view would change. At this point I was fretting, I felt a pressure of time. Eventually, I felt it came together after a lot of

rearranging and rubbing out and it made my research paper better. With that, my hope was again restored when drawing upon Sanjari's et al. (2014) work, making mistakes and learning from them in qualitative research is an essential part of the whole process.

Moving on from the specific aspects of the process and fully onto stage three of Gibbs (1988) reflective cycle: an overall evaluation of the process, I would say there was both good and bad aspects of the experience. Making an initial judgement I would say my thought processes and the feelings I felt became more positive as time went on, every time I overcome a new hurdle or achieved something new which I had never done before. The bad aspects for me would be my own personal doubt which I had to overcome throughout the process as well as my lack of insight into the time required for some of the aspects of my dissertation.

Breaking the evaluation down into the analysis of Gibbs (1988) reflective cycle I would say what mainly went well was the result of my analysis and how the themes I generated resonated with past research within the area (Benbow et al., 2011; Edwards et al., 2014; Kirkley et al., 2011; Kim & Park, 2017; Kontos & Nagile, 2007; Smythe et al., 2015; Smythe et al., 2017) and with the BPS (2016) document which was the reason I carried out the study I did. In retrospect I feel my chosen methodology worked exceedingly well and partly accounted for my results relating to those in previous research as the use of semi-structured interviews allowed for exploration into individuals perceptions (Smith, 2011) and whilst thematic analysis can have disadvantages when it has been carried out poorly or is not suited to a research question it was deemed suitable for this research and the correct procedures were followed to ensure these disadvantages did not occur (Braun & Clarke, 2006). I felt what I did well was maintaining my drive and determination. Whilst, I believe I did academic factors well to, like achieving the required participant group and maintaining my identity as a researcher through interviews (Frost, 2011; Sanjari et al., 2014; Willig, 2012)

which were all new aspects of psychological research to me. I feel I achieved what I have due to not giving up, no matter what hurdles I had put in my way personally or academically, I feel I strived to do what I could. What others did well throughout this process was my academic supervisor not letting me slack in my work, pushing me and having more faith in me at points than I did myself. I don't personally believe at this point anything didn't turn out how it should have done but I do believe what went wrong was my inaccurate perception of the time I would need to carry out this research, as well as my lack of knowledge prior to this study on thematic analysis. I believe, had I had a better knowledge or been more self-aware of the time and effort required to be put into qualitative research my whole dissertation could have been improved.

In conclusion, coming onto stage five of this reflective log I would have done a few things differently. Firstly, picking the topic for my dissertation, I wouldn't spend ages dwelling on what to do and then start picking things I felt obvious to me. I would immediately start reading current research and exploring different paths, as if I had done that, I would have found the BPS (2016) document a lot quicker. Secondly, when it came to recruiting participants I would have put myself out there from the offset, I wouldn't have waited for participants to come to me from advertisements, I would make myself heard and people aware of me in an ethical manner to ensure I obtained participants in plenty of time. Lastly, the main other thing I would do differently is ensuring I had read up on and was aware and more knowledgeable on all the aspects of my dissertation from the literature to ethics to the analysis. I know this is part of the process, but I believe having that bit more knowledge would alleviate the time pressures I felt.

With that in mind, when it comes to the action plan of Gibbs (1988) reflective cycle, I believe I have mentioned what I would do differently and what needed to be improved upon in hindsight if I were to do the research again. I would recommend for anyone else who does

qualitative research to take these reflections into consideration as time is of the essence when doing research and is important for every aspect, so any time you can save is key. Thinking about the process I also feel I need to learn to believe in my capability more as I honestly feel I have personally made milestones as a novice researcher and feel my self-doubt I carried throughout this process at times potentially hindered my work. The experience has taught me a lot about both applied research and the commitment required and if I had the opportunity again I would look at this reflection and consider all I have said. All in all, I am happy with taking a chance and carrying out qualitative research as I felt like I was potentially having an input on a real issue within society and like said by Willig (2012) to have the opportunity to interview people on this issue and interpret and conclude their views was a large responsibility, frightening at times but it was also a privilege.

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