Using Life Story Boards to Engage Clinical Support Workers in Person-Centred Care with People Living with Dementia in an NHS Inpatient Dementia Care Unit:

A Thematic Analysis

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Abstract

Person-centred care (PCC) is the recommended model of dementia care however there are challenges regarding how care staff implement PCC principles in practice. Life story work is one way for care staff to enact the principles of PCC in a structured way with people living with dementia. Life story boards are a less researched method of gathering and recording a life story but may provide a more visual and immediate impact on staff in their everyday clinical practice. Underpinned by elements of technical participatory action research (PAR), this study used life story boards to engage clinical support workers (CSWs) in PCC with people living with dementia in an inpatient dementia care setting. The study explored how these care staff reported their experiences of the process of creating life story boards and experienced PCC via this process. Semi-structured interviews were completed with seven CSWs pre and post-life story implementation to gather this data. Inductive thematic analysis identified four themes: the unit culture as a barrier to valuing PCC and the personhood of patients; 'Us versus them': CSWs positioning of their role; an altered view of the patient with dementia; and a sense of hope: getting past the barriers. Implications for clinical practice involve the importance of collaborative input and leadership from services, empowerment and support of CSWs, as well as commitment to PCC values at all levels of organisational structures so that the organisational culture does not impede life story work implementation for care staff such as CSWs. Using PAR elements and practice development approaches encourages these important clinical implications to be achieved. Recommendations for future research include maintaining focus on the more severe end of dementia in inpatient care and more research of the life story board format due to the boards not getting completed and displayed on the unit.

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Acknowledgements

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1. Introduction

1.1 What is Dementia and What is the Nature of the Problem?

United Kingdom (UK) health services face significant challenges, with a population increasing in size and in life expectancy (Kennedy, 2005). Characterised as an age-related progressive illness, Dementia is a "global epidemic" (Prince, Prina, & Guerchet, 2013, p. 12); as people live longer, the number of people affected by dementia grows. More than 46 million people are said to be living with dementia worldwide and this number is estimated to more than treble by 2050 (Prince et al., 2013). Dementia is an umbrella term used to define a set of symptoms encompassing progressive memory loss, problems in language, communication, problem-solving, concentration, planning, and orientation and there are several different types (Alzheimer's Society, 2014). People with dementia (PwD) typically lose their independence as the disease develops and approximately one third move into residential care once family carers stop being able to manage their needs (Department of Health (DoH), 2009). Within the UK there are over 850,000 PwD (Alzheimer's Society, 2014a) and one in three people over the age of 65 will develop dementia at some point (DoH, 2009). Dementia has a significant economic impact, costing the UK over £26 billion (Alzheimer's Society, 2014a), with major implications for health and social care systems (Wimo & Prince, 2010). In response, the UK government devised a national dementia strategy for England aiming to achieve better awareness of dementia, early diagnosis and high quality treatment (DoH, 2009). This strategy moved away from discussing pharmacological interventions as although the development of drug-based therapies is advancing, there are still no curative treatments (Gonzalez, Mayordomo, Torres, Sales, & Meléndez, 2015). Therefore, the most effective interventions are in the development of services to support PwD and their carers (Nolan, Davies, Brown, Keady, & Nolan, 2002; Pearlin et al., 2001) so to improve

the wellbeing of those who experience the condition now (Algar, Woods, & Windle, 2014). Care as opposed to cure is said to be seen as a "low hanging fruit" (Brown, as cited in Gallagher, 2013, "Work Out the Best Care", para. 5) which offers a more achievable target for research to improve the quality of life of PwD. The provision of such services is therefore one of the most significant issues facing policy makers and care providers today (Mckeown, Clarke, Ingleton, Ryan, & Repper, 2010). In 2012 the UK Prime Minister built upon this strategy, setting a national challenge to push forward the delivery of major improvements in dementia care and research by 2015 (DoH, 2012). The deadline of this has since passed and although there have been changes the government is still focused on keeping dementia a priority (DoH, 2015).

Whilst the private sector plays a primary role in providing continuing care for PwD in advanced stages of the illness, National Health Service (NHS) inpatient dementia units are typically used for patients with high levels of behavioural disturbance and complex physical and psychiatric problems, where the individual is seen to need containing within a clinical environment for the safety of themselves and/or others, for example when showing aggression (Schneider, Scales, Bailey, & Lloyd, 2010). Therefore, these inpatient care settings provide a proportion of care (National Collaborating Centre for Mental Health, (NCCMH), 2007; Schneider et al., 2010). The role of the inpatient unit is to provide a safe environment, staffed by clinicians who are trained in the care of PwD and the assessment and management of those with behaviours that challenge (such as aggression and violence) (NCCMH).

Research into how to improve care in these settings specifically is essential, especially as reports of the experiences of family members of those with dementia have suggested that NHS services were "failing to respond to the needs of older people with care and compassion" (Abraham, 2011, p. 5) and failed to look beyond a patient's

clinical condition and respond to the social and emotional needs of the individual (Abraham). Furthermore, Clissett, Porock, Harwood, and Gladman (2013) argued that most research has focussed on dementia care in long-term care settings as opposed to hospitals which is problematic as there are factors in these settings that can make the delivery of good quality care challenging because the priorities are rapid diagnosis and intervention with short lengths of stay.

1.2 The Biomedical Model of Dementia

The dominant understanding of dementia has been biomedical, framing PwD as suffering from a neurodegenerative brain disease characterised by intellectual deterioration and gradual loss of mental and later physical function, eventually leading to disability and death (NCCMH, 2007). However, the way that dementia affects an individual varies, so there is no defined care pathway to follow by relying solely on this understanding. This model, which underpins institutional psychiatry and places health professionals as the experts, locates the disease within the person with dementia (Kinnaird, 2012) and focusses on damage caused to the brain by the disease and the symptoms that result in the body. Although this approach allowed the development and use of drug interventions which hope to treat the medical symptoms (Moore & Jones, 2012) it also led to PwD being positioned solely as patients, sufferers, or victims of the disease (Twigg & Atkin, 1994). Due to the dominance of the biomedical model and the absence of a cure for the disease, PwD in the past were perceived as being untreatable. They were taken away from their home, family, and society and were 'warehoused' in hospital institutions (Miller & Gwynne, 1972) for indefinite periods of time until a cure was hoped to be found (Adams, 2008). This led PwD to be seen by nursing staff as just a body with physical care needs (Kitwood & Bredin, 1992) which often led to the depersonalisation of the individual (NCCMH) and led to many PwD spending many

hours emotionally distressed and alone due to the resulting neglect of any other needs (Chenoweth et al., 2009).

1.3 Organisational Culture Shift in Dementia Perspectives

During the 1980's and 1990's a cultural shift in perspectives regarding dementia care occurred. This moved away from the biomedical model to a more psychosocial/interpersonal approach. Additionally, a focus on cultures of care also occurred. These shifts were partly due to the work of Thomas Kitwood and colleagues (1990; 1995; 1992; 1997). Kitwood perceived culture as being a way of giving meaning to the world, encompassing social norms such as standards for behaviour, and beliefs and attitudes about what is and what ought to be and he said that people became immersed in the culture they worked in (Kitwood, in Kitwood and Benson, 1995). Consequently, it was seen as important to consider the culture of care units in which dementia staff work and care for PwD as it has consequences for all staff and patients (Luff, Ferreira, & Meyer, 2011). It impacts on the sense of purpose of the unit, organisational systems and processes, and the degree of flexibility within the unit (Dewing, 2009), which may impact on the feasibility of implementing new approaches to care.

Kitwood and his colleagues (1990; 1992; 1997) challenged the biomedical dementia perspective as being reductionist due to only seeing dementia as a disease caused by physical changes within the individual with dementia and nothing more. He instead focussed on a person with dementia's subjective experience of the disorder, rather than on the disorder itself or abilities they may have lost. Kitwood reformulated the view of dementia as a social creation which encompassed both neurological and social-psychological factors. This was supported by the fact that he found a lack of research showing a strong correlation between the severity of organic brain damage and

the severity of dementia symptoms (Kitwood, 1997), for example PwD often experience excess disability over and above that which can be accounted for by their neurological impairment when investigated after death (Brody, Kleban, Lawton, & Silverman, 1971). Consequently, Kitwood presumed that despite organic changes, the progression of dementia must be related to other factors as well. From this perspective looking for the person behind the dementia was encouraged (Kitwood & Benson, 1995; Kitwood, 1997) and PwD could be cared for as individuals with a unique identity and biography, and with greater understanding. This influential perspective, called the enriched model of dementia care (Kitwood, 1997), now coexists alongside the biomedical model and broadens understanding. Good practice that serves the needs of PwD and their carers is respectful of both the biomedical and psychosocial model (NCCMH, 2007).

1.4 First person perspectives in dementia

PwD are viewed as having a subjective experience of their dementia, whether mild to severe, and there is a growing literature base offering insights into these subjective experiences (Clare, Rowlands, Bruce, Surr & Downs, 2008a) such as those of Lee (2003), Snyder (1999) and Taylor (2006). This body of literature evidences there being a psychological and social impact of dementia diagnosis and development on PwD (Clare, 2002a, 2003; Husband, 2000). This view is grounded within a biopsychosocial model of dementia that, while acknowledging the impact of progressive cognitive impairment, maintains a view of the person with dementia as an active agent in forming their own sense of identity, and emphasises in line with Kitwood's approach that this process occurs within a social context (Robinson, Clare, & Evans, 2005).

The experience of living with dementia has been shown to fundamentally be one of experiencing difficult and distressing emotions such as sadness, frustration, and anger

related to issues such as loss, isolation, uncertainty, fear of the unknown, communication difficulties, and a sense of worthlessness (Husband, 1999; Clare et al., 2008b; Aggarwal et al., 2003; Barnett, 2000). Harman & Clare (2006) and Husband (2000) stated that dementia continues to be a socially stigmatizing condition, due to its links with weakened mental capacity, loss of independence, and through its association with aging. As dementia involves changes in memory and other areas of cognition, with implications for social interaction, it is particularly likely to disrupt the sense of self (Clare, 2003b). An individual's sense of worth may be diminished, and it is likely that social context, as expressed for example in the reactions of others, will impact upon a PwD's sense of identity (Kitwood, 1997; Whitlatch, 2001).

1.5 Personhood and Person-Centred Care

PwD present challenges to the nursing ideal of personalised care (Schneider et al., 2010) which is a way of caring that is individualised to the person with dementia and focussed on their specific issues (Suhonen, Valimaki, & Leino-Kilpi, 2002). This ideal requires care staff to understand a person's subjective experience and respond appropriately (Suhonen et al.) however as dementia progresses, a person with dementia may not be able to interact with others and communicate their needs clearly (Kutzleben et al., 2012) and so the first challenge for staff in trying to meet the needs of PwD is to learn how to connect with them and build relationships, often in the absence of verbal communication (Bailey, Scales, Lloyd, Schneider, & Jones, 2013). It is also difficult for care staff to treat PwD, isolated from their normal environments and social circles, as individuals (Schneider et al., 2010). Kitwood (1997) suggested that there were a cluster of important psychosocial needs in all PwD that centred on the need for love. These consisted of: comfort, attachment, inclusion, occupation and identity. However, he felt that these were difficult to meet. In line with the challenges in the literature outlined

above, Kitwood (1997) observed residential dementia care settings where the culture and social environment, such as poor staff practices and attitudes (see below about malignant social psychology), could dehumanise PwD. From this he developed the idea of personhood which defines that every person has an ethical status as a human, given by others in the context of relationships and social being. It implies recognition, respect, and dignity for one another. He stated that PwD have a sense of self that remains intact underneath the neurological losses and that social and interpersonal psychological factors: the social psychology that an individual is surrounded by, were integral to the process of decline in dementia, either increasing the damage or lessening the impact of neurological impairment. This is felt to be an important aspect of a person with dementia as some still debate whether dementia causes personhood to gradually be lost until there is nothing left of who the person was (Davis, 2004) or whether personhood is progressively changed and hidden, but not lost (McCormack, 2004; Kitwood, 1997; Kontos, 2005) and this position has important implications for how and if care is given. If people caring for those with dementia believe that the person is lost, then the ethical demand to take care of them also disappears and can be reduced to basic physical care at the expense of investing energy building relationships with the person. The care role may also be seen as meaningless as there is a risk that the person with dementia's life is now seen as lost. Alternatively, if carers sense that personhood is not lost then it is likely that they will provide care beyond basic physical tasks as the person is still there and staff will ethically feel more duty to provide care to meet their existing needs as a person (Edvardsson, Winblad, & Sandman, 2008).

With respect to literature exploring perspectives of PwD, several studies suggest that although the self is affected by dementia, indicators of selfhood or personhood do persist even in severe dementia (Small, Geldart, Gutman, & Scott, 1998; Tappen,

Williams, Fishman & Touhy, 1999; Cohen-Mansfield, Golander, & Arnheim, 2000; Cohen-Mansfield, Parpura-Gill, & Golander, 2006a, 2006b) which supports the work of Kitwood. The ability of PwD to have awareness of their dementia and their cognitive decline has also been explored. Several studies such as those of Clare, Rowlands, Bruce, Surr & Downs (2008b) and (Mayhew, Acton, Yauk, & Hopkins, 2001) have shown that people with moderate to severe dementia had considerable capacity for awareness. PwD should be viewed as agents trying to make sense of their situation (Clare et al., 2008b). Clare (2002) stated that although some displays of unawareness may be determined largely or exclusively by neurological damage in the brain, for people with early-stage dementia, apparent unawareness must be viewed as the product of psychosocial processes in combination with cognitive impairment., which supports the biopsychosocial approach to dementia expanded by Kitwood in response to the purely biomedical approach.

Kitwood (1997) provided an equation that he believed could make sense of the presentation of an individual with dementia (see figure 1 below).

$$D = P + B + H + NI + SP$$

Dementia = Personality + Biography + Health + Neurological-Impairment + Social Psychology

Figure 1. Kitwood's (1997) equation to explain the presentation of an individual with dementia

Kitwood (1997) found that care staff interactions with PwD such as disempowerment (lacking recognition of a person's abilities and opportunities so to allow them to do what they are able to do) and infantilisation (treating a person as if they were a child or patronising them), which he labelled as malignant social psychology,

threatened PwD's personhood. He acknowledged that these behaviours which defined malignant social psychology were not necessarily because of malignant or hateful intent of carers but were often due to the biomedical focus of care given, resulting in a neglect of psychosocial needs (Brooker, Argyle, & Clancy, 2009) such as that centred around love (Kitwood, 1997). Once neglect of these needs occurs, PwD were said to find it difficult to challenge the dehumanising actions of those around them and re-affirm their own personhood. (Adams, 2008). Brooker (2007), a supporter and developer of Kitwood's work, stated in agreement that a key feature of settings where PwD have their personhood recognised is that they experience a sense of attachment, inclusion, identity, occupation and comfort. Other studies also use the voices of people with dementia and show that they value being able to connect with others, being meaningfully occupied, and having their individuality, sense of self, dignity, choice, and autonomy retained, especially if their levels of self-awareness and awareness of surroundings remain (Aggarwal, Vass, Minardi, Ward, Garfield, & Cybyk, 2003; Train, Nurock, Manela, Kitchen, & Livingston, 2005). PwD report lower levels of psychological wellbeing when these aspects are ignored (Perrin, 1997; Brooker, 2005), and positive relationships and desirable social roles seem central to their preservation of self and wellbeing (Surr, 2006). The positive impact of maintaining personhood has also been shown by several studies in which patients experience reversal of the process of decline in functioning seen in dementia or stability of decline when conditions of life, especially social relationships, are changed (Kitwood, 1997; Martin & Younger, 2001; Chenoweth et al., 2009).

Conversely the negative implications of neglecting psychosocial needs have also been shown and supported since Kitwood's work. Neglect of psychosocial needs has been demonstrated to intensify 'need-driven dementia-compromised behaviours' which are viewed as behavioural and psychological symptoms of dementia likely caused by

unmet needs. These consist of disruptive, agitated, and aggressive behaviours such as wandering, screaming and crying (Algase et al., 1996; Chenoweth et al., 2009) which then in turn lead to loss of independence, social engagement and increased social alienation (Brooker, 2007).

Kitwood believed that the malignant social psychology seen in dementia care could be lessened and personhood preserved (despite declining mental power and inability to communicate) by instilling a framework called person-centred care (PCC). This framework emphasises the therapeutic relationship (interaction) between the individual with dementia and their carer, and how staff can interact in ways that promote a person's sense of wellbeing in the form of their identity, individuality, and autonomy, using 'positive person work' such as recognition (acknowledging and greeting them as a person, knowing their name, and listening to them over a period of time), and negotiation (consulting them on their preferences and needs as and when possible, rather than assuming them) (Kitwood, 1997). So instead of treating the person with dementia as a collection of symptoms and behaviours to be controlled, PCC principles consider the human value or whole of the person regardless of age or cognitive impairment, taking into account their perspective, unique abilities, interests, preferences and needs as much as possible. Therefore, care staff have a central role in PwD's quality of life, having responsibilities in initiating, directing, and maintaining person-centred activities (Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012).

The person-centred model of care is now promoted as the "gold standard" (Peek, Higgins, Milson-Hawke, McMillan, & Harper, 2007, p. 167) preferred model for aged care setting and its principles underpin good practice in dementia care (NCCMH, 2007). The use of PCC has been shown to reduce need-driven dementia-compromised behaviours. For example, Cohen-Mansfield, Libin, and Marx (2007) and Chenoweth et

al. showed a reduction in agitation in PwD in nursing homes via the use of care techniques personalised to individuals' preferences and needs. It is about "a collaborative and respectful partnership between the care provider and user" (Dow, Haralambous, Bremner, & Fearn, 2006, p. 1) and the model necessitates that staff caring for the individual with dementia learn more about them, and understand their experiences, attitudes, and personal meanings (Williams & Grant, 1998), so to better meet their needs (Brooker, 2007).

It is readily acknowledged however that the implementation of the principles of PCC is a challenge for those responsible for the management of care (NCCMH, 2007). For example, Schneider et al. (2010) wrote that given time pressures and the need to manage risk effectively, dementia wards may be kept locked and patient choice may be limited. Attention to basic physical needs may distract from the emotional and person-centred aspects of caring, and impersonal routines may take priority. This tendency has been attributed to a managerial approach to care which emphasises the physical over emotional aspects of care. For instance, one study argued that:

> The rationale of economic efficiency creates a system wherein the measure of care lies with the physical task rather than the quality of human interaction, militating against the individualising of care and the development of relationships between care provider and recipient that is central to a person-centred approach to dementia care. (Kontos, Poland, Mitchell, Cott, & Mcgilton, 2009, p. 133).

In such circumstances indicators of institutionalisation can occur, with negative effects on both staff and patients. Furthermore, care staff have to constantly juggle individual needs against group outcomes which can sometimes mean choosing against PCC, in the
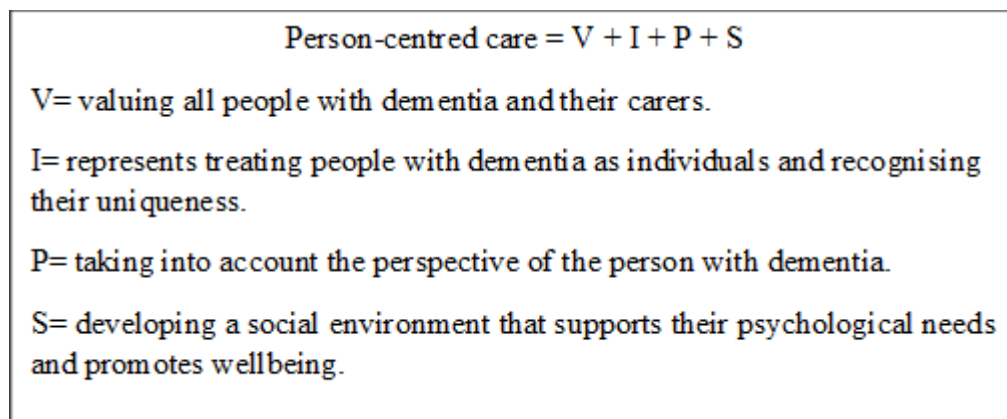
interests of achieving daily routines or maintaining relative stability across the ward. (Schneider et al., 2010).

Other factors that act as barriers to prioritising PCC are financial constraints which can lead to healthcare organisations focusing on meeting financial and productivity targets at the expense of care which is person-centred. A recent example of the negative outcomes of this has been discussed in the high-level inquiry into sub-standard care in Mid Staffordshire NHS Foundation Trust where patient dignity and experience was neglected in favour of meeting standards of performance set by the system around it (Francis, 2013).

In terms of Kitwood's theory about PCC, his approach has been criticised for not providing enough supporting empirical evidence of his claims, for not always explaining his methods transparently and for not using robust enough research methods to collect and analyse his data (Baldwin & Capstick, 2007; Adams, 1996). Dewing (2004), for example, discussed concerns in applying his PCC framework due to a lack of academic rigour in terms of providing no evidence as to the number of people (PwD and carers) he worked with and over what time span. Kitwood's ideas about person-centred cultures of care are also said to be underdeveloped as he does not fully explore the significance of workplace cultures (Dewing, 2008). However, these criticisms are not seen by others to undermine his work overall as Kitwood was at the start of an emerging alternative theory where it is often difficult to support, debate, and critique one's claims and, and since his work many other authors have given support to his ideas and the rejection of the standard biomedical model, being inspired and motivated (Baldwin & Capstick). Furthermore, the psychosocial needs that Kitwood stated were important in order to maintain the personhood of PwD have been shown to be valued by PwD themselves in more recent research exploring their subjective experiences and views (Aggarwal, Vass, Minardi,

Ward, Garfield, & Cybyk, 2003; Train, Nurock, Manela, Kitchen, & Livingston, 2005; Perrin, 1997; Brooker, 2005).

Some researchers have said that Kitwood's philosophy lacks clarity and direction into how to develop positive relationships between staff and PwD, for example Dewing (2004) stated that the utility of positive person work as a framework was judged as not being fully set out despite it being taken on and used widely by practitioners. Dewing therefore recommended that developments were needed around translating conceptual frameworks such as Kitwood's into ones that are meaningful to staff who work with PwD. As a result of these criticisms Brooker (2004) developed the 'VIPS' framework which provided a contemporary view of PCC and a clearer direction on how Kitwood's philosophy might be enacted. She identified that the definition of PCC was not simple, consisting of four elements which she presented as an acronymic titled framework in equation form (see figure 2 below).

Person-centred care = V + I + P + S

V = valuing all people with dementia and their carers.

I = represents treating people with dementia as individuals and recognising their uniqueness.

P = taking into account the perspective of the person with dementia.

S = developing a social environment that supports their psychological needs and promotes wellbeing.

Figure 2. Brooker's (2004) VIPS framework equation to define person-centred care.

Whilst the importance of relationships is implicit within the VIPS model, the focus remains on how relationships impact on PwD's well-being. This carries a risk of not considering fully the issues of other participants involved in care, such as care staff

(Brown Wilson, Swarbrick, Pilling, & Keady, 2013) and informal carers such as relatives. This is also a recurrent criticism of Kitwood's work as he is said to ignore carers and relatives and to some extent staff when talking about PCC (Adams, 2001; Bender & Cheston, 1999). Due to this, Kitwood's view of person-centredness is seen by some as being narrow as it is fixed on the person with dementia. However, his overall purpose is seen as being morally caring towards others (Dewing, 2008) and when critiqued against the traditional biomedical model, his approach to PCC is seen as fairly comprehensive, holistic, and coherent (Baldwin & Capstick, 2007; Whitlatch, 2001). Kitwood's work is also similar to that of dementia researchers such as Linda Clare who made a choice to focus research on the perspectives of PwD to explore their subjective experiences, though Linda Clare and colleagues have expanded Kitwood's work to think more systemically about those around the person experiencing dementia, such as partner carers (Robinson, Clare, & Evans, 2005).

To address some of these critiques Ryan et al. (2008) argued that although "the contribution that PCC has made to improving the quality of services for PwD, and in providing staff with a 'raison d'être' for their work is beyond doubt" (p. 85-86), it is important to consider equally the needs of all participants in care and that a 'relationship-centred care' approach better enables a service to achieve this. Relationship-centred care provides a complementary extension to one existing principle of PCC regarding the importance of relationships with others to the person with dementia, and their potential for promoting well-being. In relationship-centred care all participants mutually appreciate the importance of their relationships with each other. Relationships between patients and clinicians continue to be central although the relationships of clinicians with themselves, with their colleagues and with the community are also emphasised. (Beach & Inui, 2006). Researchers such as Packer (2003, p. 110) have further developed

Kitwood's ideas and have demonstrated how care professionals such as UK community mental health nurses working with carers of PwD could apply a PCC framework in their practice. The model is built on twelve 'core elements', for example recognition, relaxation, collaboration, and play, however this research area is small. Packer's (2003) work also links closely to that of Nolan (1997) and Nolan et al.'s (2001, 2002, 2004) 'Senses' Framework which values both carers and relatives of those with dementia as well as the individual with dementia. This is achieved via a framework of six senses (see figure 3 below).

Security (to feel safe)

Belonging (to feel part of things)

Continuity (to experience links and connection)

Purpose (to have a goal(s) to aspire to)

Achievement (to make progress towards these goals)

Significance (to feel that you matter as a person).
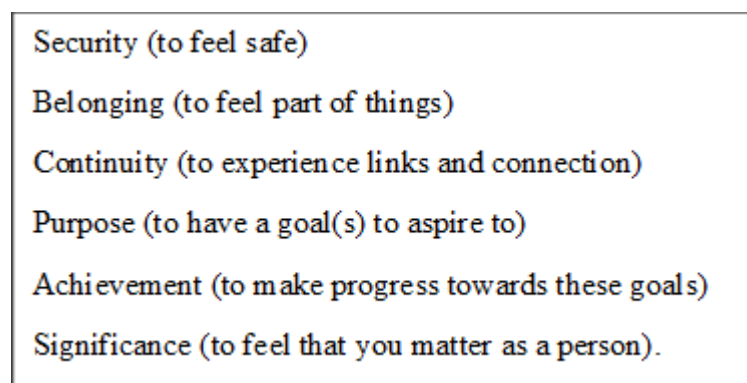
Figure 3. The Senses Framework (Nolan, 1997; Nolan et al. 2001, 2002, 2004)

When these are nurtured they are said to lead to an environment of relationship-centred care which is mutually satisfying to all members. The framework has been subject to extensive empirical testing using a multi-method, longitudinal study design which supported its value in understanding good quality caring relationships (Nolan et al., 2002). Therefore, the literature has moved more to a relationship-centred care ideal though people still tend to commonly use the term 'person-centred care' or use different but related terms interchangeably even when they refer to PCC which emphasises the relational aspects for staff and carers too. This shows that there is no one clear definition of what PCC looks like in practice (McCance, McCormack, & Dewing, 2011). As a result of this ambiguity research has indicated that dementia care staff may still not fully

understand what PCC is, or may believe that the task-based approaches to care they give meet the definition of PCC when in fact they do not (McCarthy, 2006; Skaalvik, Normann, & Henriksen, 2010).

The increased emphasis on the role and experiences of care staff means that it is important to focus on staff experiences of PCC in research. Research supports the effectiveness of person-centred/relationship-centre training approaches in improving quality of working life and job satisfaction for care staff, as well as enabling staff to understand their patients better (Wilkinson, Meyer, & Cotter, 2009; Zimmerman et al., 2005; Nolan, Davies, & Grant, 2001). The experiences expressed by care staff are of importance for the well-being of not only the workers themselves, but also of the patients and families they serve (Zimmerman et al.).

1.6 Life Story Work

One way to enact the principles of person/relationship-centred care is through the use of biographical life-course approaches as they emphasise that the attitudes, interests, and desires of older people are the culmination of a lifetime of experiences. Lives are constructed around many different threads, for example education, work, family and leisure, which shape people's present needs and aspirations (Johnson, 1976; Clarke, 2000). Life story work (LSW) is one specific example of this approach (Clarke). LSW provides opportunities for PwD and those who know them to discuss and review their life experiences: family, friends, work history, achievements and hobbies, using materials like photographs, personal belongings, newspaper cuttings and written recollections about the person's life in their own words or by others as triggers to conversation (Eliopoulos, 1997; McKeown, Clarke, & Repper, 2006). The more structured approach of gathering a life story reveals much more than peoples' past lives in comparison to reminiscence (which involves either group or individual work where

the past is discussed generally, with stimuli such as music or pictures sometimes incorporated, The Institute for Research and Innovation in Social Services (IRISS), 2010). Life story work allows an exploration and critical review of the most recent past, the present, and people's future plans and concerns and this is what sets it apart from just reminiscence (Gibson & Carson 2010).

Through listening to older people's life stories, including their present lives and the circumstances that have shaped them, it is possible to gain a much fuller appreciation of their needs and wishes (Clarke, 2000). This biographical knowledge about a person with dementia "becomes essential if that identity is still to be held in place" (Kitwood, 1997, p.56). LSW involves care staff collaborating with a person with dementia and/or their relatives to gather and formally record this information, and it usually results in a 'product', for example a story book, collage, or board, which displays all the information. In particular, life story collages/boards are usually developed as a shared creative activity, with emphasis placed on the process of developing the board alongside the final 'product', and can be particularly useful in longer-stay settings where visual images can be displayed and accessed easily (Dementia UK, 2011). Life story boards are a method of gathering and recording a life story which has not been explored before in research but may provide a more visual and immediate impact on staff in their everyday clinical practice than the most popular method of a life story book (McKeown et al., 2006; Kindell, Burrow, Wilkinson, and Keady (2014). LSW is an ongoing, dynamic process rather than a task to be completed (McKeown et al., 2006) and can be used therapeutically to enhance communication between staff, PwD, and their families (Wills & Day, 2008).

For the carer engaged in biographical work, locating the 'truth' of the person's life is not the primary rationale for undertaking life stories. Rather, what is important, is

for the listener (carer) to attempt to understand why the person is sharing that particular story, at that particular time and then attempt to determine its meaning from within the person's life course. For some PwD who are more cognitively impaired and /or have communication difficulties it may predominantly be their carer and relatives who complete the LSW. Family members are a valuable source of information and LSW can facilitate involvement as well as offering an opportunity for them to reflect on and celebrate their loved one's life (Dementia UK, 2011). Therefore, in these instances of LSW family carers are encouraged to 'show' the personhood of their relative when the person with dementia is unable to share the information themselves (McKeown et al., 2010).

LSW fits within the ethos of Brooker's (2004) 'VIPS' framework and the 'Senses' Framework (Nolan 1997, Nolan et al., 2001, 2002, 2004, 2006) for example the authors discuss a 'sense of continuity' which involves recognition and value of a person's biography and using the past to contextualise the present. Growing interest in the therapeutic use of biographies has occurred as PwD increasingly reside not with their families but in care units with staff that have little knowledge of the backgrounds of the people they are caring for or the person's local social context. To compensate for this unfamiliarity between PwD and staff, knowledge about the patients' past can be systematically collected and assimilated to enable staff to deliver individualised and personalised care (Moos & Bjorn, 2006). For healthcare practitioners the biographical life story approach may help inform assessment, care planning, and evaluation, for example Johnson, Gearing, Carley and Dant (1988, as cited in Clarke 2000) used biographical assessments to inform care planning in community settings. They justified this approach by arguing that the needs of the individual are not only medical or social but are specific to their biography and current circumstances. Since it encourages a

reciprocal relationship, as the person with dementia and the listening practitioner spend time sharing their feelings and experiences with each other, it should also enable the practitioner to better support the older person in decision-making (Clarke).

Biographical LSW and reminiscence are now the most often utilized psychosocial interventions in dementia research and the most widely used non-pharmacological dementia care approaches (Rieckmann et al., 2008; Woods, Spector, Jones, Orrell, & Davies, 2005). Social Care Institute for Excellence and National Institute for Health and Clinical Excellence guidelines for dementia (NCCMH, 2007) include recommendations for the assessment of a person's life history and the use of biography as a psychological intervention, as well as the National Dementia Strategy for England which refers to the use of LSW as "an effective vehicle for care home staff to communicate and develop relationships with residents, based on their unique life experiences" (DoH, 2009, p. 58).

When used specifically with PwD, positive outcomes in the literature have been shown in terms of LSW improving PCC with the person with dementia (Batson, Thorne, & Peak, 2002; Hansebo & Kihlgren, 2000; Thompson, 2010; Gibson & Carson, 2010; McKeown et al., 2010). Life story books were the primary method used in all but one of these studies. They incorporated pen illustrations, photos, and anecdotal writings about the person's life. One specified that they created a computerised book template in ring binder form (Gibson & Carson). Contrastingly, Hansebo and Kihlgren used a standardised assessment instrument which covers physical, psychological, and psychosocial care but also incorporates some life story gathering. These studies all used qualitative methodology and overall the literature seems to be trustworthy though some (Batson et al.; Gibson & Carson; Thompson) lacked rigour in terms of not stating the data analysis methods used or the authors' epistemological position. This is pertinent as

it was mainly the professional carers (healthcare assistants/clinical support workers) who were giving their opinion on whether they felt care had improved as a result of the LSW (though Batson et al. and Thompson also interviewed relatives and/or the person with dementia). The studies used LSW with individuals who resided either in their own home, residential/ nursing care homes, or attended day care services and so it is hard to judge the severity of dementia of the PwD chosen. This is important to know as research suggests that the positive effects of biographical interventions vary depending on dementia severity, with weaker effects for people with more severe dementia (IRISS, 2010).

A quantitative study examining LSW in book form (using a ringer binder format with illustrations, photos, and anecdotes) specifically showed that it was effective at increasing positive mood, cognition, and communication for people with mild to moderate dementia, that it is a low-cost, low-risk intervention, and that staff can administer it with minimal training, accompanied by supportive supervision (Haight, Gibson, & Michel, 2006). However, there were a small number of participants. The fact that the PwD chosen lived in assisted living and did not have more severe dementia is an important point which likely improves the chance of a positive effect from LSW. Conversely Kindell, Burrow, Wilkinson, and Keady (2014), in their review of eleven life story work resources in which they focused on practical written resources in the form of books, life story templates, booklets or 'how-to-guides' that could either be bought from a publisher and/or were available for download on the internet, described how in considering the benefits of LSW in dementia, the focus appears to be within the mid to later stages of the condition, often when services are more heavily involved, rather than in the early stages which contrasts with the literature described above which emphasises LSW use with people with mild to moderate dementia. Therefore, the wider point seems

to be that exactly what LSW comprises of and what the hoped for outcomes are is dependent on the stage of dementia of the individual.

Other studies have demonstrated that LSW has a positive effect on staff understanding and perceptions towards the people they care for and so improves the social psychology surrounding the person with dementia as Kitwood (1997) would describe it. McKeown et al. (2010) used a qualitative approach and interviewed care staff across an assessment ward, intermediate care ward, and a day centre, and found that using life story books helped staff to shift their focus from the disorder and its symptoms/behaviours towards recognition of the person they cared for as an individual. Staff began to use more affectionate language when describing their patients, and appeared to understand the rationale for patients' behaviours more. The study also found that the intervention strengthened the therapeutic relationship between staff and PwD by encouraging communication and listening to the person with dementia's voice. This study appears to be robust in terms of methodological rigour and it used multiple sites and multiple case studies. Clarke (2000) presented a case study which showed that gathering life story information helped challenge nurses' ageist attitudes and assumptions by decreasing the generalisation of the older person based on age, and revealing the diversity of the individual's life. Nurses reassessed their perceptions and became aware of their inaccurate beliefs, which were often primarily based on the person's physical appearance. Though this paper mainly presented the authors in-depth experience of one case study it was rooted in another 22 PwD that they had interviewed in the community as well as care staff teams and so demonstrates a broad level of experience of the impact of LSW on professionals. This study collected life story information without formally recording and using the information to make a final 'product' such as a book. Clarke, Hanson, and Ross (2003) found similar results from their small scale thematic analysis that explored how

biographical approaches might be used to elicit and understand more about the present needs and concerns of older people and encourage PCC. They stated that LSW in the form of life story books (folders made up of patients' and families' written recollections, photographs and/or other memorabilia) helped staff to gain a more dynamic and holistic picture of the person behind the patient they cared for, for example staff saw the person as more than just a 'grumpy person' or 'elderly patient'. They also found that LSW had a positive effect on job satisfaction and the morale of staff involved in the process of creating the life stories.

1.6.1 Implementing life story work.

Studies that do implement LSW well often had extra staff brought in to dedicate their time to the work such as in a project by Clarke et al. (2003), or had to devote more time than expected to achieve the amount of LSW they wanted, such as in Thompson's (2010) project. This demonstrates that although LSW is increasingly being recommended to support improvements in care there are often difficulties implementing this approach (Dementia UK, 2011; McKeown et al., 2010). Staff are often not given a strong enough rationale for investing time in doing LSW (McKeown et al., 2010), and lack of time (for example due to staff sickness and existing schedules of the setting taking precedence), support, resources, limited skill/understanding and confidence in using the approach is often noted (Gibson & Carson, 2010; Kellet, Moyle, McAllister, King, & Gallaher, 2010; Cooney et al., 2014; Batson et al., 2002). Family readiness to help with the process and level of cooperation are also seen as barriers to implementation (Kellet et al.; Chenoweth et al., 2015). Consequently, for LSW to be effective attention needs to be given to how it is implemented and supported. For example, ensuring everyone has an understanding of the evidence and benefits to LSW should be encouraged, as well as staff being supported

to develop skills and confidence in doing LSW whilst having resources to hand. It is also vital to examine the context and culture of the care organisation in relation to these factors, as having identifiable leaders in the clinical area to motivate and disseminate LSW information to the wider staff team has been shown to be important, as well as them providing visible support and encouragement (Dementia UK, 2011; Thompson, 2010). This helps to ensure that the organisation in which care staff work empowers them to implement PCC tasks and that PCC is a concept that is valued at the level of both the individual carer and the organisation/team (Clissett et al., 2013).

Some studies such as that of Clarke et al. (2003) and McKeown et al. (2013) have adopted a collaborative approach called practice development with the staff team where they conducted their research to help ensure a systematic approach to implementation (McKeown et al., 2013) and that LSW is sustained after intervention from researchers (Mckeown et al., 2010). A practice development model fits with the action focussed and participatory style of their chosen research methods (McKeown et al., 2013) and it aims to achieve a "continuous process of improvement towards increased effectiveness in patient centred care" which is "brought about by enabling health care teams to develop their knowledge and skills and to transform the culture and context of care" (McCormack, Garbett, & Manley, 2004, p. 316). This is achieved by making the purpose clear to all who take part, applying research directly to clinical care, supporting learning by offering training and resources, using the latest evidence-base, supporting creativity, and using methods that encourage participation of stakeholders and staff in the planning and implementation of the work (Manley, McCormack, & Wilson, 2008). Under these conditions one can be more encouraged that the LSW implemented remains person-centred and becomes part of an overall philosophy of the care home (McKeown et al., 2010; McKeown et al., 2006).

McKeown et al., (2006) conducted a comprehensive systematic literature review into LSW and concluded that the literature on LSW was largely qualitative using small-scale explorative studies. As already stated, most papers in the area used life story books and most were created collaboratively with the person with dementia, their family or significant people in their lives, and usually through an interview format. Of 51 papers reviewed by the authors, all but one was said to fail to outline their methodology in any depth and many were not transparent about difficulties encountered during implementation of LSW and how these were addressed. There was no attempt to collate research underpinning the use of LSW in health and social care settings. Furthermore, a search for and presentation of conflicting knowledge, and a lack of critical debate about the use of LSW beyond the theory and in practice was also missing. The reviewed concluded that the area was under-developed but that LSW had the potential to be a valuable intervention. This reviews' findings, which underpin the rationale for this thesis, identified a number of gaps for subsequent research, such as the need for assessment of different methods to capture a person's life story (such as the un-researched method of using boards to display life stories) and the advantages of different approaches to books. The impact that a life story approach has upon staff experiences of their role is also noted to be missing and has not been explored in any depth or on relationships between staff, PwD, and family. Wills and Day (2008) supported McKeown et al's literature review and further enhanced the rationale for this thesis, stating that future research is needed in LSW to expand the findings from their qualitative thematic analysis study which used life story books that care home staff and relatives created collaboratively with a person with dementia alongside the person giving an account of this process. They said that in particular, future research should include

health care professionals and elicit their views and experiences on the use of life story books in clinical practice.

1.7 The Dementia Care Staff Role

The increased emphasis on the importance of staffs' role and perspectives in providing dementia care in the person/relationship-centred care approach, and in the LSW process means that it is important to consider research into staff experiences and issues, especially in engagement in research and LSW, as well as in implementing changes in care.

Care staff are known by many terms including: clinical support workers, healthcare assistants, personal support workers and nursing assistants (Lloyd, Schneider, Scales, Bailey & Jones, 2011). Typically, care staff have a high school education or less (Beck, Ortigara, Mercer, & Shue, 1999), are predominantly female (National Institute of Health Research, 2015) and comprise some of the lowest paid workers in health and social care (Noelker & Ejaz, 2005, as cited in Lloyd et al., 2011). The professionalisation of the role of nursing, increasing staff shortages and need for cost-effective NHS healthcare has led to a growth in the reliance on care staff. As qualified nurses carry out more technical duties, care staff have taken on more direct care activities with patients (DoH, 2013). This is a level of responsibility for which care staff are rarely rewarded (Spilsbury & Meyer, 2004) and they are a neglected component of long-term care (Zimmerman et al., 2005). Care staff are found to share a low status as a group as well as low levels of respect from those external to this group and/or more senior (Lloyd et al.). For example Lloyd et al. found that few opportunities were given for care staff to share their knowledge of the patients they cared for with the wider care team such as nurses

and doctors, **(**Spilsbury & Meyer**)** and that their knowledge of patients was often ignored or not recognised, leading care staff to feel disregarded and devalued.

Caring for individuals with dementia presents many challenges to care staff. It is common for care staff to report not having enough time to carry out their work tasks (Brodaty, Draper, & Low, 2003) or to provide adequately for the emotional side of patients' care (Perry, Carpenter, Challis, & Hope, 2003). There are higher levels of behavioural problems on dementia care wards in contrast to most health settings, including violence and aggression, and patients with dementia are not often in a position to express gratitude or appreciation for the efforts of staff due to communication deficits (Schneider et al., 2010). Consequently, the physical demands of the job as well as its emotional impact are high (Schneider et al.).

Evidence suggests that care staff experience high stress levels and low work satisfaction, which can significantly relate to more negative staff attitudes towards patients with dementia (Brodaty, Draper, & Low, 2003). Tension with role expectation has been found to be a key factor contributing to work related stress and job dissatisfaction in this group, where the role itself is not perceived by the public to be prestigious or one requiring much skill due to the implications of the term 'non-qualified' which care staff are commonly known by (Bailey et al., 2015). Contrastingly care staff experience their role as requiring specialised skills and knowledge (Moyle Skinner, Rowe & Gork, 2003) leading to staff feeling unappreciated. Care staff can cope with job dissatisfaction as a result of these different issues by absenteeism and avoiding work tasks primarily (Moyle et al). The challenges of the role outlined above can contribute to the high levels of staff turnover found in this work sector (Bowers, Esmond, & Jacobson, 2003; The Institute for Research and Innovation in Social Services**,** 2005) and are accentuated by understaffing issues (Royal College of Nursing,

2012). A report by the Alzheimer's Society (2007) states that care staff enjoy interacting

and providing activities for PwD and would like to be able to do more, but that staffing

levels can affect the level of engagement and stimulation they provide. Poor staffing

levels due to high staff turnover leads to a lack of staff continuity which is said to impact

negatively on PCC, as research indicates that continuity allows staff carers to get to

know PwD on a deeper level and use this to better inform their work (Edvardsson,

Fetherstonhaugh, & Nay, 2010) which also builds supportive social psychology and

affirms personhood (Downs, Small, & Froggatt, 2006) in-keeping with Kitwood's (1997)

idealised care.

Badger (2005) identified a range of 'maladaptive' coping strategies applied by

care staff in medical intensive care units including: avoiding the patient, emotional

withdrawal, focusing on technical aspects, and denying all feelings. Bailey et al. (2015)

labelled these as 'detachment' and said that at least some of the time, detachment can be

used deliberately to avoid becoming 'burnt out' (Astrom, Nilsson, Norberg, & Winblad,

1990) during engagement with PwD which is defined as physical, emotional and mental

exhaustion due to the intensity of the work over a prolonged time period (Pines,

Aronson, & Kafry, 1981). Bailey et al. further emphasised that not engaging fully can

sometimes be better than engaging negatively. The protective function of these adaptive

psychological strategies are understandable as they can serve to buffer the negative

emotional impact of attaching to someone, bereavement, and the fear/anxiety of ageing

and death which makes staff more aware of their own mortality (Peters et al., 2013). This

literature builds on that by Menzies-Lyth (1988) who studied nurses in general hospital

and how they spontaneously employed social defences to help manage personal anxieties

and intolerable emotions due to stressful inpatient working. These included 'splitting up'

of the nurse/patient relationship by reducing time spent with individual patients by doing

time-limited and ritualised tasks with many different patients, as well as 'depersonalisation' or removal of the individuality of patients such as by referring to them as numbers as opposed to their name. Linking this body of literature back to that of Kitwood's (1997), he theorised that malignant social psychology was rooted in two common human anxieties or fears which dementia encompasses: becoming frail and dependent due to forgetfulness and fear of a slow death (Dewing, 2008). Furthermore, when dementia erodes brain and mind functioning what is left can be considered not only as worthless but also dangerous and to be avoided (Dewing). A crucial skill for care staff is to be able to selectively use these strategies (which can be seen as part of a malignant social psychology in Kitwood's observations), whilst remaining emotionally available for the rewards that can be derived from the work (Schneider et al., 2010) and to be able to maintain the sense of personhood of the patient with dementia (Bailey et al.). Therefore, understanding the staffs' experience is key to understanding implementation of PCC principles.

Each health care profession has a different culture, including values, beliefs, attitudes, customs and behaviours (Hall, 2005) and in response to the lack of recognition care staff receive, they have been shown to form a distinct occupational identity (Kontos et al., 2009). Care staff have been found to act in accordance with the Social Identity Theory (Tajfel, 1978; Tajfel & Turner, 1979) which is a popular theory with a large evidence base (Hogg, as cited in Burke, 2006) that theorises how people form memberships to groups as opposed to defining themselves as individuals to give themselves a sense of pride as a social identity, and that they have a need to see themselves in a favourable light as a group relative to others outside of their group. Lloyd et al (2011) found support for the social identity theory as care staff, as a result of their marginalised low status, were seen to operate as a close-knit 'in-group' using

collective coping strategies (Ellemers, 1993) such as making favourable comparisons to enhance their own superiority in relation to other staff in the 'out-group' (Brown, 2000). This preserves self-esteem and gives care staff necessary support but can also act to distance them from multi-disciplinary staff who do not belong within their idea of 'team' (Lloyd et al). This can have negative implications for collaborative patient care which requires open channels of communication between the multi-disciplinary care team in order to be most effective at operating in a person-centred way (DoH, 2001).

In terms of the organisational culture surrounding the care staff role, Kitwood (1997) discussed the organisational characteristics that support and confound good practice by dementia care staff. He suggested that the way care staff are treated by their organisation will be reflected in the way they treat their patients. Therefore, staff need to feel respected, valued, supported, and free to express their opinions in much the same ways as their patients do. Brooker (2004; 2007) supported this view in the 'valuing people' element of the VIPS framework, and Nolan et al. (2006) in their 'Senses framework' suggested that an enriched environment of care is created when the six senses are experienced by both care staff (met by management and society) and PwD. Ultimately PCC cannot be implemented with a one-off 'quick fix' (Manley et al., 2008) but requires a change in the values of both the care system and individual professionals (Kontos & Naglie, 2007).

Care staff are largely underrepresented in research (Lloyd, Schneider, Scales, Bailey & Jones, 2011; Schneider, Scales, Bailey & Lloyd, 2010) but research highlights the importance of adequate training for the dementia care role. Research on nursing staff found that they showed a significant correlation between stress and inadequate preparation to meet the emotional needs of their patients (Kennedy, 2005). Linking back to Kitwood's (1997) idea of PCC, he stated that to care for staff means to prepare them

sufficiently for their role and Zimmerman et al. (2005) found that workers who perceived themselves to be better trained in dementia care (and better prepared) were more likely to implement PCC and report higher job satisfaction. Lack of staff knowledge or skills is often highlighted as a reason for interventions not achieving positive results in this area (Ballard et al., 2002; Turner, 2005), and ironically the staff barriers that may get in the way of implementing life story boards may be the very issues that could potentially be positively impacted upon by the LSW, such as work stress, low job satisfaction, and lack of training.

1.8 Summary

Based on the literature reviewed, although the value of further exploring the first hand perspectives of those with dementia who engage in LSW is clear, there is a recurrent gap and clear recommendation to choose to focus on care staff as a groups' experiences and perspectives implementing PCC approaches such as LSW, as opposed to PwD, and being able to incorporate PwD's views is heavily dependent on the severity of dementia. This is not to devalue the experience, awareness, and voice of PwD, as an interest to study LSW is evidence that the individuality and personhood of PwD is deemed present and important. This wish to expand the LSW literature on staff experiences in relation to their engagement with PwD fits in line with current person-centred and relationship-centred care approaches which have developed since Kitwood's, which seek to value those who experience providing PCC as much as those who experience receiving it. The literature also states that in particular, using less researched methods other than books is encouraged, and so using the un-researched method of a life story board with PwD is of interest in order to expand the field. There are many factors which seem to contribute to the ability of care staff and the organisational cultures that they work feeling able to implement PCC tools successfully and these have been

explored largely using qualitative research methodology. These factors broadly involve the dementia care staffs' position within the organisational system, the challenges they face in the role caring for PwD and how they manage these, and the values which take precedence within the culture of the organisation. By working in a collaborative way with dementia care staff this study will attempt to address the perceived limitations of the current literature and explore further the factors related to this topic area (as discussed above) by implementing a programme of life story boards (an un-researched but more visually impacting and easily accessed method) as a vehicle to enhance PCC by proxy. Part of the clinical relevance of this research is in generating recommendations for future interventions for PwD using life story boards.

1.9 Research Question

The study aimed to investigate the following question:

What are the experiences of CSWs trying to use life story boards to engage in PCC with PwD in an inpatient dementia care unit and how do CSWs experience PCC via this?

2. Method

2.1 Overview

This chapter describes the research design, the researchers' epistemological positon, the study procedure and the process of data analysis. Methodological rigour and ethical considerations are also discussed.

2.2 Design

2.2.1 Qualitative framework.

Qualitative methods were selected to address the research question as they are consistent with the largely qualitative nature of previous relevant literature and they allowed for detailed exploration of the views and experiences described by participants (Yardley, 2000). Qualitative methods also sought to understand and express the local meaning of participants' experiences from their perspective and within context rather than according to a generalisable framework of understanding (Hadjistavropoulos & Smythe, 2001; Braun & Clarke, 2013). Qualitative methods allowed access and insight into the subjective world of a marginalised occupational group within society (Braun & Clarke, 2013) and facilitated a more inductive approach to the topic, generating novel information about the processes underpinning life story board implementation (Thomas, 2006).

2.2.2 Use of thematic analysis.

Inductive thematic analysis was chosen to qualitatively analyse participant data. Thematic analysis identifies patterns of meaning also known as themes across data (Braun & Clarke, 2013). These themes serve to summarise significant features of the content of the data in relation to the research question (Howitt, 2013). Using inductive

thematic analysis meant that themes were identified from what occurred within the data itself rather than being theoretically driven or with the researcher trying to fit the data into pre-existing themes (Braun & Clarke, 2013). Thematic analysis has been defined as a method in its own right by Braun and Clark (2006) since previously suffering from a lack of clarification about the theory and method underlying how to use it for analysing data. Braun and Clarke (2006) produced guidelines incorporating six steps for carrying out thematic analysis and since these have been published the method has grown in popularity and is now more widely accepted (Braun & Clarke, 2013; Howitt, 2013). Using thematic analysis in this study has several advantages: it is a flexible approach not tied to one data collection method, epistemological or theoretical position, the themes offer rich descriptions of the entire dataset, and the results of interpretation of data using thematic analysis are easily understood by a wide educated audience (Braun & Clarke, 2013).

2.2.3 Use of elements of a participatory action research approach.

Participatory action research (PAR) ideas were attempted to be incorporated into this study. Previous literature in the area encourages the use of a participatory approach (Baum, MacDougall, & Smith, 2006) as such approaches are viewed not to threaten care staffs' strong in-group identity (Lloyd, Schneider, Scales, Bailey, & Jones, 2011). Many studies in the topic area have also used a model of practice development to implement LSW in a collaborative way with service stakeholders and staff which, as stated previously, is about making the purpose clear to all who take part, applying research directly to clinical care, supporting learning by offering training, using the latest evidence-base, supporting creativity, and using methods that encourage participation of stakeholders and staff in the planning and implementation of the work (Manley, McCormack, & Wilson, 2008).

PAR is similar to a practice development approach except that whilst the development of transferable knowledge is the primary purpose of PAR, this is a secondary purpose of practice development (McCormack, Manley, & Titchen, 2013). Meyer (2001) states that PAR is an overarching research approach as opposed to a method in itself and that the strength of PAR lies in its focus on generating solutions to practical problems and its ability to empower practitioners, by getting them to engage with research and the subsequent development of it, or implementation activities. In this study elements of PAR were incorporated to collaboratively engage staff in the unit in attempts to improve PCC practice within their service (action), making the focus of the research the lessons learnt from the process and outcomes of change (Luff, Ferreira, & Meyer, 2001; Meyer 2001). Please see section 2.4 on page 49 for staff reflections on their current practice and their motivation to engage in changing practice.

Due to the context, the current study employed elements of what Carr and Kemmis (2004) reported as the technical model of PAR. This model has been associated with a positivist standpoint that views its purpose as seeking to discover knowledge. This technical model meant that the researcher brought to the research setting their own rationale for initiating the research and study goals, and a pre-designed intervention plan/practice solution to increase PCC in practice, which were the life story boards specifically. However, the researcher still wished to encourage the unit to attempt to take on some ownership and shape the direction of the intervention in terms of how the boards could look and how the findings of the study could be used to improve future care for example. Whilst a great deal of PAR is orientated around the generation of solutions to practical problems, in the context of this thesis such an approach would have been impractical due to time constraints. In this way the participatory focus of the action research is around implementation (action) activities in LSW as opposed to the planning

of how to implement LSW (though the lead co-researcher was involved in some planning). This approach compensates for the constricted, complex and hierarchical nature of the implementation context. It is important to remember that the ultimate aim of PAR is changing an existing situation for the better, which contains the notion of implementation and importance in finding out barriers and opportunities for implementation of solutions. The participatory ethos of the method, the unpredictability of dementia care, and the focus on relationships in PCC and LSW more generally, provided the justification for employing aspects of this methodological selection. Please see section 2.5.2, 2.6 and figure 7 for a fuller account of how PAR ideas were specifically incorporated into this study

The PAR approach is increasingly used in healthcare settings (Loewenson, Laurell, Hogstedt, D'Ambruoso, & Shroff, 2014). PAR concepts offer scope to understand practices within a care setting, to use this knowledge to introduce interventions or influence change, and assess the outcome (Luff, Ferreira, & Meyer, 2001). Clinically, the Plan, Do, Study, Act cycle (see figure 4 below), is a commonly used service improvement tool in the National Health Service (Langley, Nolan, Nolan, Norman, & Provost, 2009) and was used to inform the design of this study to decide which aspects of PAR could be incorporated and by whom. Action is achieved through a reflective cycle made up of four processes which are intertwined, whereby a plan of action (plan) leads to data collection (do) and analysis (study), which then determines what action should follow (act, plan). The resultant action can be further researched and an iterative reflective cycle perpetuates data collection, reflection, and action, or one 'turn' of the cycle can be enough which feeds into study conclusions which are then written up. This cycle allows for service changes/interventions to be trialled on a small scale. One turn of the cycle was to be the extent of this study and the unit staff were to be

involved in the 'do' and 'act' processes primarily as opposed to the 'plan' and 'study' processes, which are specified later in this chapter.
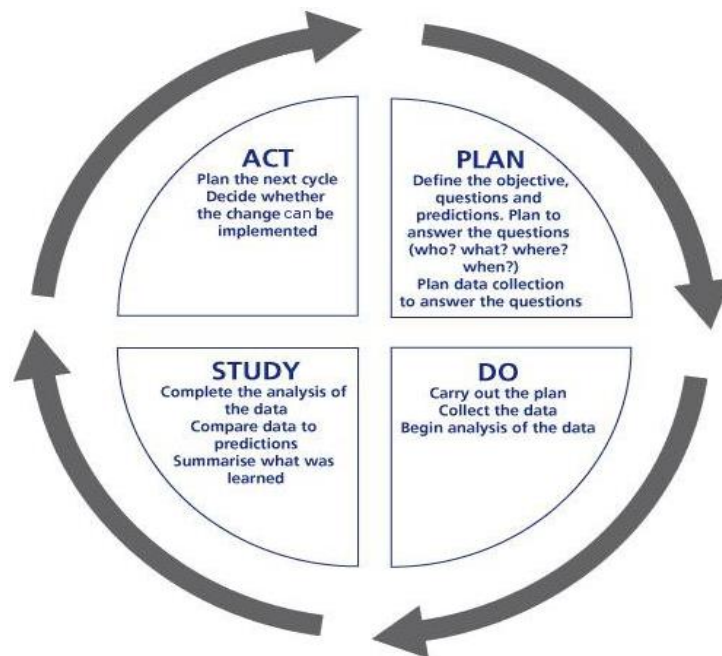
Figure 4. Plan, Do, Study, Act (PDSA) cycle (Langley, Nolan, Nolan, Norman, & Provost, 2009).

As it is often difficult to facilitate change in highly complex environments (May & Finch, 2009) it is common in PAR to use co-researchers. These individuals tend to have an 'insider' status to the research setting and can assist in facilitating change from within. PAR pays attention to power in relationships, encouraging it to be shared between the researcher and the researched (the participants): blurring the line between them until participants become 'co-researchers' (Baum, MacDougall, & Smith, 2006). Using this aspect of a PAR approach hoped to increase the likelihood that the life story board work carried out became part of the overall philosophy of the dementia care unit (McKeown et al., 2010; McKeown et al. 2006). Other hopes when using elements of this approach were to enable the participants to be more honest with the researcher, and to increase the likelihood that the clinical support worker (CSW) participants felt that they

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had some ownership of the study as they would have some say in board design, implementation, and their senior colleagues would be working in partnership with the researcher, acting as co-researchers and shaping the study to fit with the needs of their service (see section 2.5.2).

Ultimately, though it was hoped to use more aspects of the PAR approach, due to the hierarchical workplace culture and barriers related to these, this proved difficult and the methods to improve practice in this implementation context became less participatory and collaborative than had been hoped, in terms of who was and was not assisting with the implementation of the LSW.

2. 3 Epistemological Position

The researcher's epistemological position underpins the qualitative research as it guides the choice of methodology used, so stating the researcher's position aims to increase the trustworthiness and transparency of the study (Mason, 2002) allowing the reader to understand the researcher's theory and assumptions of how knowledge is generated during the research process.

The current thematic analysis was underpinned by critical realism. Critical realism suggests that there is a real, external world that exists independently of one's perceptions, theories and construction of the world (Maxwell, 2011). One cannot have an objective or 'true' knowledge of the world as all theories about it are grounded in one's particular perspective, mediated through models, discourses and narratives, and so all knowledge and understanding about it is fallible and incomplete (Maxwell, 2012; Adams, 2008)
In this study, we have to accept that there is a true form of PCC that exists independently of the interviews and study itself, but one can never directly access this due to our own perspective getting in the way. Therefore, lots of gathering together of, and reflection on

different proposed theories, models, and perspectives of concepts such as PCC is required in order to get as close as able to the reality of PCC as a phenomenon. This has been demonstrated in the introduction chapter. The critical realist approach has been said to correspond well with Kitwood's dialectical understanding of dementia (Adams, 2008) and can be used to explore how and why interventions work in specific contexts (McEvoy & Richards, 2003).

Braun and Clarke (2006) emphasis that it is vital that researchers acknowledge their stance and assumptions when creating themes. Given this the researcher's position in terms of gender, personal experiences, attitudes and expectations about this research will be described. The following section is written in first person to emphasise the perspective/experiences of the researcher which led to and impacted on the development of the research.

2.3.1 Reflexive statement and position as a researcher.

What initially drew me to this study was that I had worked as a CSW with the elderly as well as with other client groups between the ages of 18 and 22 and I felt that I experienced what it was like to be an 'insider' in this CSW group. I remember feeling undervalued by senior staff and management due to not being encouraged to use the academic knowledge and skills learnt at university. I knew that I had more to offer but this did not seem to be recognised as senior staff did not appear interested to hear my opinion on patients. Focus seemed on getting the tasks of the day done as opposed to having an opportunity to reflect on patients as much as I would have liked.

Motivation for carrying out this research in part stemmed from wanting CSWs to feel recognised for what they do and wanting to give them a voice, as I found it to be a challenging job and I wished I had been given a voice or a chance to engage in research to bring more attention to the role. However I was using these roles as work experience

after undergraduate university to go into a more academically advanced level of employment and so there is uncertainty about how on the 'inside' of this marginalised group I actually was in terms of how others viewed me.

In terms of my position in relation to participants, I am a woman undertaking a doctoral level qualification which is salaried at just above the average UK salary (Office for National Statistics, 2014). This stands in contrast to CSWs who, although like me are predominantly woman (Erol, Brooker, & Peel, 2015), typically have a high school education or less (Beck et al., 1999) and comprise some of the lowest paid workers in health and social care (Noelker & Ejaz, 2005, as cited in Lloyd et al.). Therefore I assume there may be a tangible difference between myself and the CSW participants which may impact on how we relate to one another during interactions, more so now that I am training to qualify as a doctor of clinical psychology compared to when I was a graduate CSW when I was younger.

When starting this study, I assumed I would be perceived as an 'outsider' and someone who had idealistic visions or naïve goals as CSWs may have judged me for not understanding what their role was like. I assumed that this may alienate me from them and affect engagement but I was keen for them to know that I may understand their perspective having worked in similar roles previously, as well as having worked in an older adult dementia service under the current climate of NHS austerity and budget cuts (Durdy & Bradshaw, 2014), though in a more senior role as a trainee clinical psychologist. The 'outsider' assumption stems from my experiences on the 'inside' whereby senior staff such as doctors and psychologists came in and out of an environment that we worked long shifts in (which were also stressful environments) and there was a collective assumption that only we understood what it was like on the ward

and in the role and that others who wanted to make changes to our practice did not understand and so were met with resistance.

I assume that my role as a trainee clinical psychologist impacted on my approach to the research as the role has a socially constructed expectation of social status as by becoming a doctor I will be in a highly qualified profession that has occupational prestige (Shoichet, 2014). My expectations were that I would minimise the social status of the role and adopt a more neutral label for my role such as being a trainee psychologist. I wanted to present as less senior in NHS banding compared to the CSWs (whom I was aware from the literature could feel inferior due to their banding) and reflect that I was wanting to learn from these individuals. I hope this may have helped blur the boundaries between us, in line with elements of a PAR approach, and minimise resistance to change that I assumed I should be aware of due to past experiences and due to my knowledge of the literature on social identity and in-group, out-group behaviours which can negatively impact on communication (Tajfel, 1978; Tajfel & Turner, 1979; Lloyd et al., 2011; DoH, 2001). I attempted to combat these assumptions and concerns so as to avoid CSWs potentially feeling lower in status than me (despite them largely having had significantly more specific experience supporting those with dementia) as this may have impacted on their wanting to participate in the research.

CSWs would have been aware that this study was research tied to the UEA, so this may have positioned me as associated with a university, in a powerful and unfamiliar position in relation to the CSW participants. This risk may have affected CSW participants' ability to take up a more collaborative position with me which is hoped for when using aspects of technical PAR.

In terms of my theoretical position whilst training to be a clinical psychologist, I work within a biopsychosocial model and so was drawn to the theoretical movement away from viewing dementia care within the medical model and instead viewing dementia as a psychosocial phenomenon that can be affected by many factors within and surrounding the individual (such as the care staff around a patient with dementia). Therefore I am motivated to add to this body of literature. Furthermore I value a systemic approach to working in my clinical role, and this study is of value to me as it allows me to work in this approach and to build on my systemic skills to become a better psychologist.

These experiences and reflections have informed the ideas behind the research design, research questions, method of data collection, and will likely impact on data analysis.

2.4 Context for the Research

The partner unit chosen for this study was a NHS funded, purpose-built specialist inpatient dementia care unit in England, comprising of two wards with twelve beds each. They offered 24 hour nursing and care services to adults with severe dementia and complex care needs and the average stay on the unit for a patient was three to four months, where they would often then be moved to a residential nursing or care home.

The multidisciplinary staff team comprised of medical, psychological, nursing, occupational health, and physiotherapy staff. During this study and whilst deciding who would potentially be most suited to act as co-researchers the researcher engaged with band 3 CSWs (the frontline care staff who were the research participants), a band 4 assistant practitioner, band 5 nurses, band 6 charge nurses (in charge and responsible for all nursing duties and rota's on the wards), one band 5 and one band 6 occupational therapist (OT), an activity coordinator, a clinical nurse manager (in charge of the whole

nursing team including charge nurses), and two clinical psychologists (band 8). The staff appeared very busy, with CSWs observed to be with patients on the floor (mainly feeding, 'doing' physical personal care, walking around corridors with patients, and aiding medical tasks) whilst the band 5 nurses were observed to alternate between being on the computer in the ward office and delivering medical interventions on the floor to patients. The band 6 charge nurses appeared to often be sat in a separate office but were the ultimate decisions makers day to day, and were who the band 5 nurses went to for support. The psychology and OT teams appeared quite separate to the medical and nursing team, with the psychologists' office being off the wards and on a different floor. They tended to go onto the wards as and when required to support staff with psychological patient care. The OTs (with support from an activity coordinator) had more of a regular presence on the ward but they also appeared detached from the daily ward routine. The trust as a whole was under financial strain and there seemed to be staff shortages as there were often a large number of agency CSWs on shift.

The unit's clinical nurse manager and clinical psychologists were keen to engage in research and the wards already carried out life story information gathering on a small scale as part of their routine clinical care to promote PCC using a 'getting to know me' poster tool. However this was reported by the team to be too inflexible, focussing mainly on personal and physical care preferences such as how patients liked to be washed. This keenness was vital as participation from participants and stakeholders is said to be fundamental to action research as it demands that participants recognise the need to change and are willing to play an active part in the research and the change process (Meyer, 2001). In collaboration with the unit's clinical nurse manager, consultant clinical psychologist, and two OTs (who were identified as the co-researchers of this study in-keeping with using elements of PAR) this study sought to support the unit in their

initiative to increase the amount of LSW they carried out, in the form of boards specifically.

2.5 Participants

In-keeping with elements of PAR this study had two groups of participants who were purposively sampled. The use of purposive sampling is common in qualitative research (Patton, 2002) and is consistent with previous qualitative studies that want to access and generate insight and in-depth understanding into a particular phenomenon of interest (Mason, 2002; Patton).

2.5.1 CSW participants.

The main group of interest consisted of NHS employed CSWs. More detail on this group will be given later.

2.5.2 Co-researcher participants.

The other group of participants were 'insider' senior non-care staff consisting of the unit's clinical nurse manager, consultant clinical psychologist and both of the occupational therapists. These staff members acted as study co-researchers and in-keeping with some aspects of PAR their roles varied based on how they wished to shape the study but primarily we worked in partnership to:

- Shape the study's implementation strategy to aid interest in the study within the CSW team.

- Provide information on the study (this was not recruitment of staff but creating of interest within the staff team).

- Aid organisation of study information sessions, data collection sessions, and the training session.

- Aid ongoing implementation of the life story board creation process with the CSWs

The co-researchers did not recruit or gather data but facilitated the research exercise. They were not the main focus of interest in this study, their role as participants was to shape and support the study, and no data were taken from them. This formed the only planning element of the plan, do, study, act model and went no further.

2.5.3 Inclusion and exclusion criteria for CSW participants.

The study's inclusion and exclusion criteria were as follows:

- Only NHS employed CSWs who worked regular weekday shifts were eligible for inclusion: due to the active and regular nature of CSWs participation in LSW with patients required, as well as the University of East Anglia's lone-working policy of only carrying out research activities between the hours of 8am to 6pm, Monday to Friday, CSWs needed to regularly work week day shifts.
- CSWs who worked night shifts and weekends only were excluded: these CSWs would not have been available to attend the research activities as these were held during weekdays. They were also unable to create the life story boards during their working hours as patients would have been asleep.
- Only CSWs who were happy to not rotate across both wards on the unit for the duration of the study were eligible for inclusion: CSWs usually worked across both wards and this was not possible for CSWs who wished to participate as they needed to stay on one ward working consistently with the same patients until post-interviews were complete.

- Only CSWs fluent in English were eligible for inclusion: this was a requirement as they needed to understand and engage in the interviews and produce clear and in-depth answers to enable a good quality data analysis.

- CSWs who worked for non-NHS agencies were excluded: these CSWs were unlikely to work on the wards regularly enough to attend the research activities, as well to be able to create the boards in the time given as agency staff worked on an ad-hoc basis. Also they would not be employed by the NHS.

These criteria were agreed with the co-researchers who felt that they were practical, that they did not negatively impact on the functioning of the wards, and left a suitable number of potential participants.

2.5.4 Sampling.

2.5.4.1 CSW participants.

It was hoped that eight to ten CSWs would be recruited based on a systematic literature review on LSW showing a range of sample sizes between five and thirteen (McKeown et al. 2006) to be common. A sample size of seven participants were recruited and interviewed before life story board implementation commenced, within the range of previous studies published in the topic area. Two participants dropped out of the implementation part of the study after their initial interview (but did not withdraw their data) and so five participants were trained in making a life story board, took part in the implementation phase and completed a post- life story board implementation interview. This meant that the study captured twelve separate interview data points in total which is in-keeping with Braun and Clarke's (2013) recommendation of 10-20 interviews for medium sized projects using interactive data collection methods. See figure 5 below for a visual summary of this recruitment phase.
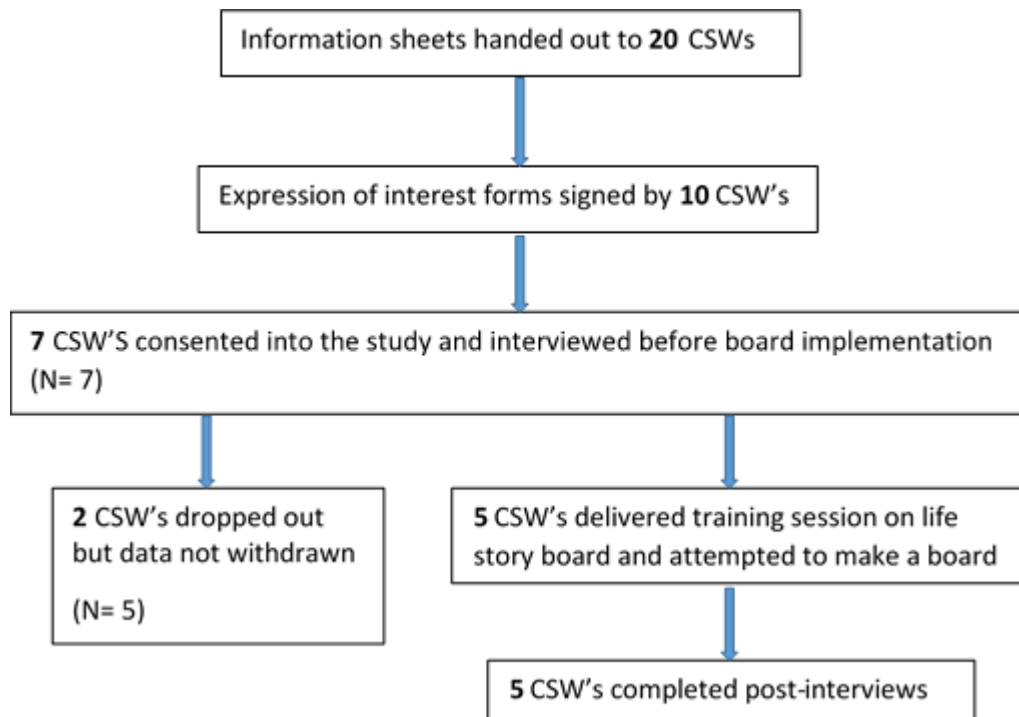
Figure 5. Summary of the CSW participant recruitment phase, accounting for drop-out.

Participant demographic information was collected but is not stated precisely due to the small sample size and local setting of the research leading to risk of violating participant anonymity. However in general terms participants consisted of six females and one male. Five of the CSW participants were White British. The remaining two participant's ethnicity and nationality cannot be stated due to risk of violating anonymity. Six of the participants worked on one ward and one worked on the other ward. One participant worked for NHS professionals on a regular basis (the NHS bank support work resource) whereas the remaining six were employed by the trust. Participants had varying ages and levels of experience in the role but this was not asked specifically.

2.5.4.2 Co-researcher participants.

The sample size for this group was not pre-decided as they were a pre-existing group of senior staff who identified themselves as wishing to co-facilitate this study.

Ultimately three co-researchers were consented into the study: the consultant clinical psychologist and the two occupational therapists on the wards. The clinical nurse manager who originally was keen to act as the lead co-researcher and collaborate with the researcher for this study retired soon after ethical approval was granted for the study to commence, and the band 6 occupational therapist left soon after consenting and initial interviewing of participants had commenced. A band 4 assistant practitioner with experience in carrying out LSW and who had a personal interest in the topic was also approached to be a co-researcher but chose not to participate due to competing occupational demands. The other clinical psychologist working on the ward was not asked to be a co-researcher as the consultant psychologist spoke on behalf of both of them. See figure 6 below for a visual summary of the co-researcher recruitment phase.

1. **Potential co-researchers available in service**: Clinical nurse manager, Two Clinical Psychologists, Two Occupational Therapists (OTs: one band 5, one band 6), Assistant Practitioner.

3. One **Clinical Psychologist** consents to act as lead co-researcher. Two **OTs** consent to act as other co-researchers (N= 3)

2. **Clinical nurse manager** left the service before formal consent given to act as co-researcher.

4. **Remaining Clinical Psychologist** is not required to act as co-researcher so is not asked to consent to participate

5. **Assistant Practitioner** declines to consent to act as co-researcher

6. Band 6 consented **OT** left the service.

7. **Two co-researchers** participating until end of the study (consultant clinical psychologist and band 5 OT) (N= 2)

Figure 6. Summary of the co-researcher recruitment phase, accounting for drop-out.

2.6 Study Procedure and Recruitment

The overall study procedure and recruitment process is outlined in figure 7 (see below). This is presented alongside a descriptive summary of the procedure to aid clarification.

Engaging the Research Site	• Clinical nurse manager and two clinical psychologists (most senior potential co-researchers) sent study proposal before a face to face meeting booked with researcher and supervisor. • Meeting with clinical nurse manager, both clinical psychologists, and band 6 OT. Rapport built. Informal agreement reached about partnering with the unit for the proposed study. Input received on study documentation. • Formal agreement given from service management to host research and to take clinical responsibility.
Recruiting and Consenting	• Four co-researchers consented. • Co-researchers disseminated information to team on their initiative to increase creation of life story work via the study (and the researcher supported implementation of the initiative using boards specifically). • Posters put up in ward offices by OTs to advertise information/recruitment sessions to CSWs • Informal information sessions held with CSWs. Information and expression of interest forms handed out. Signed forms collected back at end of sessions or at a later date. • Ten potentially interested CSWs contacted via text to answer questions and to book in the combined consenting session and initial interview before implementation of life story boards.
Initial interviews	• Seven CSWs responded and were consented/interviewed. The purpose of interviewing was to establish prior to intervention, their experiences of and perspectives on their role in term of person-centred care, life story work, and what the challenges to engaging with patients in this way were in the context of their job roles. Interviewing took place over a period of two months.
Life story board training	• Life story board training sessions designed in face to face discussion with the lead clinical psychologist co-researcher. • Training on how to create boards with people with dementia delivered to five participants. As per PAR they were encouraged to contribute to the design of the boards to be as flexible to their needs. • Participants supported to choose one patient to work with by clinical psychologist co-researcher.
Life story board implementation phase	• Participants supported to start implementation of a life story board over a period of 10-12 weeks, with the unit taking full clinical responsibility. Participants supported and motivated by co-researchers: clinical psychologist helped participants to gather materials, contact family, shared formulation information. OT available to help them make the board by offering to print and type information on computer. • Researcher supported co-researchers in their role to support participants. • Researcher stepped back from the wards allowing participants to continue to attempt to implement life story boards. Researcher visited wards to check on how implementation was progressing less frequently but kept in touch with progress via email with co-researchers. • Boards were kept securely on the unit and they took clinical responsibility for their storage.
Post-implementation interviews	• After a maximum period of 12 weeks surpassed, five participants completed post-interview after attempting to implement life story boards. • Participants asked if they wanted to be emailed a summary of the study findings when written.
Post-study Dissemination	• End of study. Dissemination of study findings to co-researchers and service management

Figure 7. Outline of study procedure and recruitment process

2.6.1 Engaging the research site.

In-keeping with using elements of a PAR approach, conversations with potential co-researchers in the unit were made. The study was summarised in a meeting and the thesis proposal, ethics application, and study documents were collaboratively finalised (see Appendices A, B, C, & D). The service manager reviewed study documents and approved participation (See Appendix E). A3 white boards to make the life story boards with were purchased by the unit.

2.6.2 Recruiting and consenting.

The co-researchers disseminated study aims in ward handovers and team meetings as a way to create interest in the study from within the service, in preparation for information sessions. Information sessions were advertised on posters (see Appendix F). The researcher presented information at the start or end of handovers, with permission granted by the clinical nurse manager. The information sessions informed CSWs about the rationale for the study, what the inclusion criteria were and what their role would be (with information on relevant aspects of PAR to be used, and how/what data the researcher wished to gather from them). These sessions lasted no more than 20 minutes and were repeated to allow for CSW shift patterns/annual leave until the researcher felt they had spoken to all CSWs who met inclusion criteria. Information forms were distributed (see Appendices A & B) and any queries were answered. Interested CSWs who met the inclusion criteria were given an expression of interest form (see Appendix C). Interested CSWs were asked to sign the form to formally express their interest in participating and hand it to the researcher (who stayed on the ward after the meetings to be a visible and familiar presence on the ward) or to a designated administration assistant who was independent of the study and not in a position of power

over the potential participants. The researcher attended the wards to speak to CSWs on a weekly basis over a period of approximately three months.

The researcher contacted potential participants who expressed interest to book their first interview. At this meeting they were given a consent form (see Appendix D) before interviewing took place.

Co-researchers (who were consented before CSW participants) were also given an expression of interest form and consent form and were asked to hand these in via the same procedure.

2.6.3 Initial interviews.

Semi-structured interviews were conducted with each participant before life story board training and implementation began and these lasted approximately one hour each. More detail is provided later.

2.6.4 Life story board training.

After the interview phase, each CSW participant took part in a training session (see Appendix G for PowerPoint slides). Training lasted approximately one hour. Due to shift patterns not all participants could attend together and so two training sessions were conducted, the first with two participants, and the second with three participants (with the two other participants having withdrawn before this stage). Permission had been granted from the clinical nurse manager (before they left the service) for CSWs to take time off the ward during their shift to attend this training in a private room between the hours of 13:30- 14:45. However this did not go to plan as one participant had to leave the session to escort a patient to hospital and so their training session was completed over telephone.

2.6.5 Life story board implementation phase.

Trained participants attempted to implement an increased amount of LSW using board, as part of the 'action' element of PAR. When needed, the co-researcher helped participants to identify a patient as part of routine clinical care in the best interests of the patient. Participants worked individually with a patient. No data were collected from the patients with dementia as they were not the focus of this research.

Participants were increasingly left to work on the study without motivation from the researcher, however the researcher continued to support the co-researchers via email or face-to-face. This stepping back from the unit was with a hopeful view of allowing ownership to develop within the two participant groups, supported by operational commitment from management. No data were collected from the co-researchers.

The boards, if completed, were to be the property of the patient and it was hoped that they would be displayed in patient's bedrooms, which the unit already planned to implement as part of their routine clinical care.

2.6.6. Post-implementation interviews.

Participants were interviewed again using similar questions to the initial interview, though there were more in-depth questions relating to their experiences of the process of board creation. This occurred under the same procedure as the pre-interviews: off the ward during staffs shift and between the times of 13:30 and 14:45.

2.6.7 Post-study dissemination.

Once the thesis is written, all participants who asked to have a summary of the findings will be emailed one. A summary of the findings and implications of the research will also be given to the co-researchers and service management in keeping with the

'study' and 'act' components of the Plan, Do, Study, Act (PDSA) cycle (Langley, Nolan, Nolan, Norman, & Provost, 2009) and the lead co-researcher will collaborate on how best to disseminate the findings in order to improve care in the unit.

2.7 Interview Guide and Procedure

Semi-structured interviews are widely used in qualitative methodologies and healthcare research (DiCicco-Bloom & Crabtree, 2006). Two semi-structured interviews each using a topic guide (pre-life story board implementation and post) were used as aides to allow the use of broad questions to guide the interviews with CSW participants' (see Appendices H & I). The value of having two interviews was to explore participants' experiences both prior to, and after LSW, with time for reflection. Using the topic guide, each interview developed organically and idiosyncratically around a core set of topics (including PCC, LSW, staff familiarity and perception of these approaches, staff roles and barriers to care). The guides consisted of key questions designed to cover main themes which reflected the research question, and follow-up questions to encourage expansion of themes, developed in line with Rubin and Rubin (2005). The questions were not framed in purely theoretical terms (for example: 'person-centred care') but rather, non-academic language was utilised such as: 'engaging with patients in a way which makes you feel like you know them as a person'. Consultation with research supervisors was also utilised to ensure that the interview structure and questions fitted the research questions, were specific, yet broad enough to allow unforeseen themes/topics etc to emerge. The guides were refined in partnership with the co-researchers, in keeping with using some PAR principles. This refining involved the researcher seeking their advice on pertinent issues and questions to ask. The post-interview topic guide was developed based on topics that seemed important from the pre-interviews as well as from the researcher's experiences during time spent on the wards.

At the end of the interviews participants had the opportunity to raise any issues not discussed.

Interview times were mutually arranged with the researcher and the participant when they were on shift, between the hours of 13:30 and 14:45. This time was recommended to ensure that it caused minimal disruption to ward staffing levels as this was when the early and late shift staff teams crossed over. Interviews took place in a private room off the ward. Interviews were recorded on a Dictaphone and lasted up to 60 minutes. Participants were thanked for their time at the end.

2. 8 Data Analysis

Braun and Clarke (2006) produced a systematic six-phase set of guidelines which were used to ensure a good quality analysis. These are: familiarisation with the data through transcription; coding generation; searching for themes based on these codes; reviewing themes; defining themes and finally the writing of the report. They note that the researcher can move back and forwards between these steps increasing the quality of the analysis (Howitt, 2012). Braun and Clarke (2006) also created a 15-point checklist for good thematic analysis which was referred to during analysis and the writing of the research (see appendix J).

2.8.1 Transcription and familiarisation.

Data were transcribed verbatim into Microsoft Word by either the researcher or a paid professional transcriber. The researcher transcribed three interviews. The transcripts were checked against the recordings by the researcher to amend any errors, any identifiable information was anonymised, and line numbers were added. This checking allowed the researcher to familiarise themselves with the data and to become immersed in it even when they had not transcribed it, in line with Braun and Clarke's (2006) recommendations. This

allowed the researcher to start to notice data relevant to the research question. A record of these casual noticings was kept on the transcripts themselves to refer back to when the researcher started initial coding.

2.8.2 Coding.

Complete coding was used which involved identifying in the transcripts anything relevant to the research question using an inductive approach. Relevant sections were highlighted in bold using Microsoft Office and each transcript was worked through one at a time before moving to the next transcript, with the researcher coding extracts of data that they had highlighted as relevant. Extracts referred to anything from individual words to many lines of data, and the same extract could be coded in different ways. Coding referred to the researcher labelling briefly the essence of why an extract seemed relevant to the research question. Codes started off primarily labelling the semantic meaning of the extract which was without interpretation and only described the essence of what was actually said by the participant. As coding progressed it increasingly become more conceptual, encompassing possible theoretical meanings behind the extracts, through the researcher's interpretative critical realist lens.

After the researcher finished coding a transcript they revisited the complete coded transcript as codes became increasingly more concise with time and practice. Codes were amended to fit with the researcher's increased familiarity with the transcript and of the codes commonly used. An extract of a coded transcript is provided as an example in Appendix K

2.8.3 Development of themes.

After codes were revisited across a transcript, all codes were imported into Microsoft Excel. Each participant's codes were grouped in order and using a different

font colour to be easily distinguishable. Line numbers, participant number and whether it was a pre or post interview were also added as labels (a label of 1 was used for a pre interview and 2 for a post interview) to ensure that the researcher could locate the original source of the code. Codes were organised into broader patterns of codes based on their similarity and given a descriptive label and these became the foundation of larger grouping codes.

This bigger view of the 'shape' of the data allowed the researcher to modify the developing grouping codes to either broaden and make them more in-keeping with other codes, or to make some more refined to account for subtle differences in their essence of meaning. Irrelevant codes which did not fit into any broader grouping codes were grouped separately and labelled 'dump'.

This phase then moved to a visual mapping form where the researcher reviewed all grouping codes in one place and started arranging similar ones together, with smaller groups of codes around them. Writing and drawing out ideas in the reflective diary was also done, with the researcher summarising each grouping code and smaller set of codes to see if they were distinct and easily definable as a concept to ensure that they were of good quality (Braun & Clarke, 2013). The researcher spent significant time at this stage until they felt that they had a comprehensive set of grouping codes that captured the patterning and diversity within the data (Braun & Clarke, 2013) and these became the candidate themes. Within the themes certain groups of codes became candidate (provisional) sub-themes as they were refined, reviewed, and some were discarded during analysis and during the writing of the results (Braun & Clarke, 2013). Themes and subthemes were given names and these were refined during the process to ensure they reflected their content. During this phase the researcher returned to the original coded transcripts and the Microsoft Excel spreadsheet of collated codes to ensure that the

developing themes and subthemes fitted with the data in its original context and the codes as a whole.

Coding and theme development was reviewed in research supervision at several stages to aid the refinement of the analysis and to aid reflection. This also ensured that the analysis was a trustworthy telling of the story of the data and so acts as a verification step (Braun and Clarke, 2013). Triangulation of data was carried out as three different theoretical lenses (the researchers and the two supervisors) were used to examine the same data to open up a more in—depth understanding of the data (Tracy, 2010). Member checking with the co-researcher clinical psychologist was also utilised to see if they agreed with the researcher's telling of the story in line with their experience of the service. This aids credibility of the analysis. See Appendix L for an example of the excel spreadsheet with the grouping codes as different sheets, and Appendix M for an example of the use of visual mapping to aid theme development.

2. 9 Methodological Rigour

As the use of qualitative methods is increasingly used, it has become necessary to consider how to assess the value of this method of research (Yardley, 2000). Unlike in qualitative methods where clear concepts such as reliability and validity are often discussed in relation to the quality and rigour of research, these words are not appropriate terminology when discussing the value of qualitative research (Smith, 2006). Instead multiple perspectives have been developed indicating what constitutes a quality or trustworthy piece of qualitative research (Braun & Clarke, 2013). Koch (2006) states that rigour or trustworthiness of qualitative data can be established if an audit trail of the events, influences and actions of the researcher is kept and presented.

Open-ended, flexible quality principles are recommended such as Yardley's (2000; 2008) four validity principles due to the range of qualitative approaches and methods used to address research questions. Yardley's four principles are: sensitivity to context; transparency and coherence; commitment and rigour; and impact and importance. These principles also overlap with guidelines outlined by Elliot, Fischer, and Rennie (1999) which aid quality publication of qualitative research. These include owning one's perspective; grounding the analysis in examples from the data; and providing credibility checks. These guidelines have informed the research process at each stage.

2.9.1 Transparency and coherence.

In line with Yardley, focus has been on ensuring a coherent and close fit between the research question, epistemological stance, and method used to collect and analyse the data and this aimed to ensure clarity of presentation (Elliot et al.). These choices have been justified throughout the method chapter such as the decision to use qualitative methods and thematic analysis. A clear description of the interview process and thematic analysis has been narrated to aid transparency and the themes and subthemes presented in the results chapter are grounded in examples in the form of quotes from the data (Elliot et al.). These quotes have been edited to increase ease of reading: words such as 'um' and repeated words were removed. Quotes which involve data from the same paragraph but have some omitted data in between the start and end of the paragraph in order for the quote to be more relevant and to flow better are signified by three spaced ellipsis points '. . .'. Careful editing has ensured that it does not impact on the overall voice of the participant and the meaning of the quote.

Examples of the research process are provided in Appendices K, L, & M to increase transparency. A rich description of the research setting/context has also been provided (see section 2.4) to aid transferability (Lincoln & Guba, 1985) of the results to other contexts.

2.9.1.1 Reflexivity.

To further aid transparency, consideration of the subjectivity of the researcher and the impact of them on the research was given. This is seen as increasingly important in qualitative research to increase rigour (Smith, 2006). For example, in this chapter the researcher has stated their epistemological position and stance as a researcher which clarifies their values and assumptions which shapes their understanding of the research. Therefore, the researcher has owned their perspective as recommended by Elliot et al. The researcher kept a reflective diary throughout the process which included observations, the capturing of thought processes and decisions made. Entries were also made following each interview to assist in informing potential themes (Yardley, 2000) as recommended by Braun and Clarke (2013).

2.9.2 Commitment and rigour.

Rigour can be demonstrated at all stages of the research process for example by the commitment of time and energy invested by the researcher in engaging with the research site to gather an adequate amount of data at two separate time points in order to represent the sample thoroughly. The researcher spent time immersing themselves in the existing literature as well as the data to aid an in-depth analysis and much time was committed to attending the research site to increase understanding of the culture and role of the participants and co-researchers to shape the study. The attempt to incorporate PAR

concepts also shows commitment to the research as it requires an attempt to achieve a higher level of investment and collaboration with the research site and participants.

Time was spent increasing understanding of the critical realist position, qualitative methods, and thematic analysis by regularly attending and contributing to a qualitative research forum lead by two different tutors each providing a different theoretical lens (Tracy, 2010) which increases rigour of the data analysis. Regular reflective and educational conversations with research supervisors also showed commitment to methodical competence.

Commitment and rigour in data analysis are outlined in sections 2.8-2.8.3 and these steps aid credibility of the results (Elliot et al.).

2.9.3 Impact and importance.

Yardley (2000) states that research is of good quality if it has a practical impact for participant groups, practitioners or policy makers, if it theoretically increases understanding of an issue or creates new understanding. Tracy (2010) also states that research is deemed as important if it is relevant, timely, interesting to the reader, and if it provides a significant contribution to others. The researcher and the research unit (co-researchers and management) felt that the research was relevant to the research site and the research unit wished for the research to be carried out in line with a PAR approach. Clinical justification of the research is also explored in the introduction chapter. It was hoped that the research analysis would offer rich findings that would be interesting to read and have a positive impact on CSWs, other practitioners, and managements' view of LSW with a view to positively influencing future dementia care practice to make it more person-centred and increase future LSW.

2.9.4 Sensitivity to context.

In line with Yardley (2000; 2008) the researcher aimed to promote sensitivity to context by presenting the research in relation to previous literature to justify the need for the current study and research question. At all stages the researcher was sensitive to the perspectives of participants as well as the culture they were embedded in, shown through the use of a critical realist position, and through use of flexible semi-structured interviews to provide a voice for the marginalised group, through the presenting of participant accounts within the context of norms for this group, through use of many participant quotes in the results so to give them a voice, and through consideration of these issues during data analysis. For example research supervision enabled reflection and aided the researcher's openness to alternative interpretations of the data and inconsistencies within it.

2.10 Ethical considerations.

Ethical approval was obtained from the University of East Anglia's Faculty of Medicine and Health Sciences Research Ethics Committee and from the local NHS Research Governance Committee (see Appendices N & O).

2.10.1 Informed consent.

2.10.1.1 CSW participants.

CSW participants demonstrated informed consent by reading an information sheet after having also verbally received study information. It was made clear by the researcher and co-researchers that there was no pressure to participate and that they could withdraw at any point until two weeks after their final interview. Participants filled in an expression of interest form before the consenting phase with the option of either

handing the form back to the researcher or to a designated member of the administration team at the unit. Consent forms were given out at the booked initial interview session and consent was re-assessed at post-interview. It was unlikely that this group of participants would lose capacity to consent as they were mental healthcare professionals who were currently employed.

2.10.1.2 Co-researcher participants.

It was stressed in the initial meeting with potential co-researchers that they had as much time as required to decide if they wished to participate, that participation was voluntary and that they could withdraw at any point. These staff were fully informed about the use of aspects of a PAR approach. Potential co-researchers returned completed expression of interest forms after having verbally stated that they wished to take part in the study. Potential co-researchers were then given a consent form.

2.10.2 Coercion.

Steps were taken to lessen the likelihood that participants felt unduly pressurised to participate. CSWs were not singled out to attend information sessions and to participate. Posters were displayed around staff areas on the wards which is a non-intrusive and non-coercive way of raising awareness. Study information was provided to groups of staff and CSWs could leave the information session part of their handovers if they did not wish to attend. It was made clear that taking part or not had no bearing on their employment. Using expression of interest forms before consenting gave potential participants more time to consider their participation and allowing forms to be handed back to an independent member of the administration team who was not in a position of power relative to them also reduced the chances of them feeling coerced. There was also no compensation or incentive to take part in this study.

2.10.3 Confidentiality.

Confidentiality and the limits to this were clearly explained to CSW participants Interviews took place in a private room off the ward so participants could talk freely without being overheard. Participants were explained that all precautions would be taken to maintain their anonymity but that due to the qualitative nature of this study a selection of their verbatim quotes would be used. However, at the point of transcribing interview data any potentially identifiable data were anonymised and replaced with 'XXXXX', and participants were referred to by a number. The researcher and research supervisors had access to participant data and these were stored on password protected computers. In addition, a paid private transcriber was used to transcribe some interviews and so they had access to electronic interview data only. The transcriber was instructed to anonymise all personally identifiable details in the same way as the researcher. As the recordings contained personally identifiable information the transcriber agreed to a confidentiality agreement before files were emailed to them and files were transferred using a secure encrypted system.

Personally identifiable expression of interest forms and consent forms were stored separately from participant data and interview transcripts and only the researcher and research supervisors had access to expression of interest and consent forms. Following submission, data will be destroyed after five years (in line with UEA and NHS policy) having been kept under the custody of the research supervisors and then in an off-site archive used by the UEA medical school.

2.10.4 Risks and avoidance of distress in participants.

It was not anticipated that any harm would come to participants and this was found to be the case. However, CSW participants were being asked to discuss their experiences of caring for vulnerable older adults and this could have been potentially distressing for

them. Participants were informed that they could skip questions and they could take a break or stop the interview if they became distressed. Following interviews, the researcher remained on the ward to talk briefly if necessary but participants did not require this. Good clinical and empathic skills were used throughout all interactions. Participants were informed on the information sheet of potential risks and benefits and were signposted to relevant individuals if they had concerns or complaints but this did not occur.

3. Results

3.1 Overview

This chapter presents a thematic analysis of data elicited prior and following the technical participatory action research (PAR) informed process employed to engage clinical support workers (CSWs) in life story work (LSW). The data provides accounts for how these staff reported their experiences of the process and how they experienced PCC via this process.

3.2 CSWs Progress with Developing Life Story Boards after Formal Training

As expressed in the research question, the primary concern of this study was not about the number of boards created. The boards employed by the technical PAR informed approach were a vehicle to accessing participants talk about wider issues and barriers and as such were facilitators to implementing PCC approaches in this care setting. However, as context to the project themes it is important to understand that of the five participants who attempted to make a life story board, all identified a patient to make a board with, all collected some life story information, and two (participants 1 and 5) began drawing out the design for how they planned to present the information before putting it on the board. No one progressed to the stage of putting any material on a board. Participant 5's chosen patient was discharged from the unit before a board was produced (before the post-interviews) and participant 7's patient passed away before a board was produced.

3.3 Overview of Themes

Four key overlapping themes were created using thematic analysis:

1. The unit culture as a barrier to valuing PCC and the personhood of patients

2. 'Us versus them': CSWs positioning of their role

3. An altered view of the patient with dementia

4. A sense of hope: getting past the barriers.

All themes except theme one are divided into subthemes to identify specific aspects of each theme. Each theme is described fully with excerpts of data presented to illustrate and evidence them. Excerpts of data are labelled with the participant identifier number, whether it was a pre-LSW implementation interview (1) or post-implementation interview (2), and the page and line number in the transcript. The themes and subthemes are shown below (see figure 8). Themes one and two are matched in colour to signify their closer relation to each other, as are themes three and four.
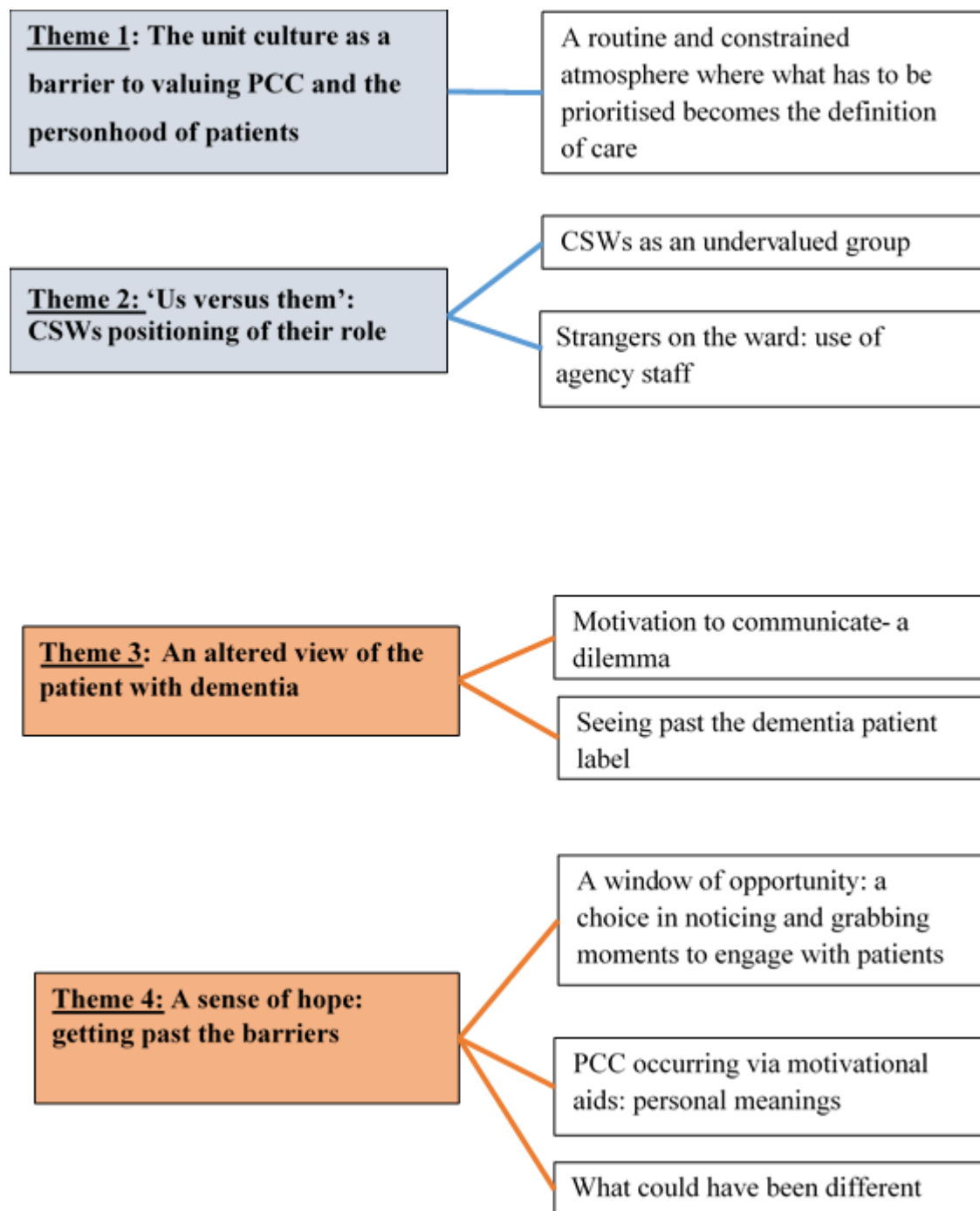
Figure 8. Diagram of themes and subthemes

3.3.1 Theme 1: the unit culture as a barrier to valuing PCC and the personhood of patients.

This theme refers to the context in which LSW took place. There appeared to be barriers to the culture of the unit being able to truly value PCC and the personhood of the PwD. A sense of a routine and constrained atmosphere was perceived where what had to be prioritised on the ward became the definition of care. Participants discussed unwritten rules and expectations of their role which led to a sense of contradiction and uncertainty, where the ward culture seemed to both promote and restrict PCC. These all had implications for carrying out LSW.

Participants spoke about their understanding of what being a CSW meant and in turn what care meant within the culture. Physical and medical focussed tasks were how all participants principally viewed care for patients and this type of care was prioritised as all participants described physical and medical tasks first when defining their role, as well as ensuring ward safety.

> "My job is to care for the patients, provide personal care assistance with personal care…it's also about feeding as well…I think it's also monitoring behaviour, looking at changes in their behaviour…we also do a lot of the physical observations" (Participant 5, interview 1, p. 1, 16-33).

All participants felt that the need to prioritise certain care tasks over others was largely due to staff numbers falling below recommended levels (due to the unit being impacted by financial pressures being felt across the NHS) which led to a perceived lack of time and resources in which to carry out their role.

"Quite often you have just enough staff for your one-to-ones and a little bit, maybe one person left over to swap the rotas round to keep you going" (Participant 4, interview 2, p. 2, 56-58).

"You could do with more people because quite often you are sort of dashing around…you're sort of going from here to here doing this doing that…you're trying to do a lot with very little resources" (Participant 4, interview 1, p. 23, 856-859).

"You get say like this morning we came in and we were short staffed again so that was a case of right what's our priority" (Participant 6, interview 1, p. 22, 454-455).

Participants also spoke frequently about their sense of the environment being "routine-led" (participant 6, interview 1, p. 25, 518), leading them to feel constraint and pressure that tasks had to be done at specific times, within a specific time frame.

"Tasks take time…we have to do them at certain times" (Participant 2, interview 1, p. 24, 472-474).

The rationale for the decision to prioritise physical care and safety seemed to be because these were visually presented as obvious tasks in front of staff which had to be dealt with so to avoid risks to safety (such as injury to patients or staff) which staff would be more accountable for than the less obvious long term detriment of ignoring someone's personhood caused by not focussing on PCC.

"I think it's time 'cause if somebody's presenting behaviour, you have to deal with it there and then and physical health needs to be seen to as well" (Participant 7, interview 1, p. 11, 224-225).

"You do what they want but if you've got another three people demanding or needing attention 'cause they've soiled themselves, urinated, made a puddle on the floor which is then a hazard for somebody else who might come and slip in it, then you have to deal with the task" (Participant 7, interview 2, p. 23, 525-528).

The above quote is one of a number of examples where the participants interpret the patients' soiling themselves in terms of it being a safety issue for others and there is no discussion of the experience of the patient who this is happening to.

The rationale for the culture prioritising physical care and safety also seemed to be because CSWs sensed that these were auditable tasks that senior nursing staff were accountable for them doing. This participant spoke about what they felt senior staff wanted them to do with their time:

"Reading up on policies or doing paperwork and things like that, stuff that's actually monitored and checked and they're accountable for you doing it" (Participant 5, interview 2, p. 11, 411-414).

As a result of this CSWs felt judged by senior staff on what type of work they were doing. PCC tasks such as sitting and engaging with patients were not seen to be prioritised by senior staff, leading CSWs to feel they should prioritise carrying out more visible tasks such as paperwork that can be monitored.

"They'll see staff sitting round in the lounge not doing anything, not realising that you're actually on a one-to-one with somebody …you might have 4 out of the 6 one-to-ones sitting in there and you've got 4 staff sitting in that room not doing anything and if people come in and look and say oh they don't do anything, they're just sitting there, they can't be that busy …the other staff might be

running round like headless chickens down the other end of the ward doing

things" (Participant 7, interview 1, p. 22, 474-481).

"I've got to start ticking some boxes as they call it of things that I've done"

(Participant 4, interview 2, p. 2, 80-81).

The culture of prioritising physical care and the sense of time pressure was

acknowledged by all to be at the expense of PCC with patients to promote their

personhood.

"Medical/physical health side tasks take time and as I see it we've only got some

kind of window of chance to get to know the patient" (Participant 2, interview 1,

p. 26, 483-484).

"A lot of the time everything is so rushed and yes the patients get cared for but

they don't get the person-centred care that they should get because you just don't

have the time" (Participant 1, interview 2, p. 17, 305-307).

The quotes below highlight the complexity of the issue as the unit was viewed as both

promoting and restricting PCC. Participants seemed to feel torn between only doing what

was prioritised and expected of them (which becomes the definition of care) versus also

feeling that there was more to care and that PCC and getting to know patients better as

individuals was important in the role. The use of the term 'normal roles' by participant 7

below suggests that CSWs within the culture may have learnt to view anything over and

above the basic physical care as an addition to their role which has implications for

LSW.

"Oh I think there's a lot more to it" (Participant 3, interview 2, p. 22, 449).

"The normal roles had to come first because you have to keep everyone safe, staff

and patients, so that came first" (Participant 7, interview 2, p. 15, 326-327).

The quote below demonstrates how the concept of patient neglect was perceived in terms of physical care needs not being met and how well staff kept patient care to the ward routine as opposed to the meeting of psychological needs.

"Nobody has been like, well I don't want to say neglected coz they're not, but

nobody's been in bed late or anything like that, they were all up by 10 o clock

this morning and all had their breakfast" (Participant 1, interview 1, p. 24, 526-

528).

However the same participant, as well as others, also contradicted this purely physical view of neglect as they felt that leaving patients alone and not spending time engaging with them meant that they were both missing out on something. The phrase 'left out' used by participant 1 below suggests that patients are positioned as supplementary to tasks carried out by CSWs (the opposite of PCC). This appeared to have a negative emotional impact on participants.

"Unfortunately when there's not enough staff you don't have time to do a lot

with them apart from personal care and stuff like that because you're doing that

most of your shift…so it's like you don't have enough time to be with that person

which is a bit sad really 'cause you feel like they're a bit left out" (Participant 1,

interview 1, p. 11, 226- 230).

"I don't think it's just about doing the personal care and making sure that their

blood pressure is okay and their temperature is okay, I think it is the engagement

with them and showing an interest in them and the things that they like and being

able to do things with them on a more social level…I know that's not what we're here for". (Participant 5, interview 1, p. 27, 570-574).

The quote above by participant 5 voices that senior staff and other CSWs may disagree with their perception that they should be doing more than physical care. This seemed to be why they were cautious to imply that their sense of the role contradicted the believed cultural purpose of the role. This again positions PCC as an additional task. Several participants assumed that some of their colleagues felt that there was no time for PCC which adds weight to this position of PCC not being a core task.

"I think that people don't believe that we have the time to do it sometimes" ['it' being PCC] (Participant 5, interview 2, p. 21, 437-438).

The majority of participants spoke about uncertain boundaries between their role and other professionals such as occupational therapists (OTs), and unwritten rules and confusion about what was allowable within their role. They seemed to want to do more activity-based tasks with patients like OTs and activity co-ordinators but also felt that perhaps the culture would make it harder to do these things.

"I think it seems to be the rule that, but it's probably unwritten, that the activity co-ordinators and the OT's take them to do things like for drinks in the café and the CSW's stay on the ward and do the…personal care, the physical observations" (Participant 5, interview 1, p. 29, 6-7-610).

"I think it's even things like you want to take a patient out for a walk or something, you're not sure if you should do it or not …or you've got to really think about the risks and things like that so then I think you probably end up not doing it but you need authorisation to do it as well" (Participant 5, interview 1, p. 29, 600-603).

Designated hourly 'one-to-one' staff-patient observations were tasks that were prioritised in that they were rota'd time which CSWs had to spend with certain patients. However the purpose of the time was still primarily believed to be for spending on observable basic physical care as opposed to an opportunity for much PCC.

"Just sitting, just keeping them safe, just the basic minimum care" (Participant 2, Interview 1, p. 45, 838-840).

These opportune moments for PCC were often disrupted due to the constraints of the ward routine and to prioritise other tasks or multi-task, indicating that the culture did not value or allow protected staff-patient interaction time.

"I'm talking to him, he starts smiling and I like them holding my hand, I would like to stay with them as long as possible but I have to get onto different jobs and have to be on a one-to-one with somebody else at three o'clock" (Participant 2, interview 1, p. 28, 524-529).

Senior staff were felt to be at the root of this as participants sensed they did not want CSWs to be sat engaging with patients unless on a one-to-one and even then they could be questioned thus leading staff to feeling distracted, detracting from focussed interaction and PCC.

"When someone walks into a room and sees you sitting there next to a patient and you might not even be doing anything, you might just be holding their hand or just talking every now and again, they're probably thinking you're not doing anything and they might say can you get up and go do this, can you do that, what are you doing and it's like well I'm just sitting with the patient reassuring or providing a bit of comfort in some way…that makes you feel quite pressured really because you know the next time when you're going to be sitting down

trying to spend some time with the patient…you're on edge looking around,

you're thinking is this person going to tell me to go and do something else in a

minute" (Participant 5, interview 2, p. 21, 438-452).

This was felt to be a challenge for CSWs who appeared to be stuck in the middle of a

culture where they were rota'd to spend time valuing patient interactions and PCC whilst

at the same time not being allowed time and space to value PCC.

In terms of implementing LSW these embedded cultural factors had a big impact

as care was believed to be about what staff were forced to prioritise and PCC activities

such as LSW did not fit within this. Furthermore it was seen as an additional task and a

"hassle" (participant 3, interview 2, p. 9, 165) because it was not "mandatory"

(participant 5, interview 2, p. 29, 627) like training and did not have to have time made

for it. Participants' views on the units' ability to carry out LSW before the board making

began was often quite pessimistic (though realistic) due to them feeling constrained, and

being allowed protected time was a recurrent topic for many. Participants were also

pessimistic about having time to do LSW with patients unless the person was on one-to-

one observations as often non one-to-one patients were said to be" side-lined" in terms of

staff time (participant 6, interview 1, p. 27, 546). These issues remained the case in the

post-study interviews as well.

"It's just sort of a crazy idea I suppose of making this all work" (Participant 4,

interview 1, p. 47, 984).

"The ones that are not on the one-to-ones, that's where I think you're gonna

struggle unless you have time out to do them story boards, coz I don't know how

you'd find the time to do them" (Participant 1, interview 1, p. 23, 515-517).

"Nobody's really been able to do anything because we're short staffed and we haven't got enough time… If there was allocated time like in a shift and you were allocated no specials that hour and didn't have to do anything but as you can see today we're supposed to be allocated that time and you just don't have time" (Participant 1, interview 2, p. 1-3, 11-54).

A barrier was that staff felt that even patients' basic physical needs as well as staff training needs were not always to be able to be met due to the aforementioned issues and so LSW would not be likely to be achieved. Some staff spoke about the sadness of this and so a need was still felt for basic care to continue to be prioritised. At the end of the study this feeling remained unchanged.

"Some days can be quite upsetting when you go home and you think that person needed changing three hours ago and there weren't enough of us to do it...If you haven't got enough staff you just cannot meet everybody's basic needs let alone anything else" (Participant 7, interview 1, p. 24, 508-512).

"It made me realise that you don't have enough time for patients let alone anything like this" (Participant 1, interview 2, p. 16, 322- 323).

These quotes continue to demonstrate how PCC or finding out about patients' life stories was not seen by staff to be a basic need but that it was viewed as an additional aspect of care. All participants also spoke about the unit culture of routine as a justification for the reduced amount of LSW they were able to implement.

"Well no because we do the same day in day out" (Participant 3, interview 2, p. 20, 409).

This issue of routine meant that all participants seemed to become especially stuck at the point of having gathered some life story information either from relatives, colleagues, or patient files but did not have time to put this onto a board.

> "It's been fine to gather the information but it's just then trying to get the information put down onto paper, really that's where the time restraints have come into it" (Participant 5, interview 2, p. 1, 5-7).

The constrained atmosphere was also used as justification for the LSW not seeming to be able to change how participants viewed the focus of their role as it was inflexible and did not allow time to add in more tasks on top of existing duties.

> Researcher: "did it impact on your day to day job at all"

> Participant: "only trying to fit it in in between all these obs' we have to do, I haven't got time I aint going to be able to add time" (Participant 3, interview 2, p. 19, 381-386).

Several participants also indicated that even if time had been allocated to them for LSW that they would have felt guilty about not being on the ward floor with the other CSWs. These quotes show how even with prioritised and mandatory tasks such as typing clinical notes and training, participants felt guilty about not conforming to the unwritten rules of their role. This is another contradiction as participants were seemingly told to prioritise these tasks but when they did they felt guilty.

> "I feel so guilty…yes guilty to be just sat in an office 'cause I think CSW, it's like we got a kind of law 'we should be on the floor' so yes I don't feel comfortable" (Participant 2, interview 1, p. 37-38, 704-710).

"With protected time for e-learning you try and do that during the day but it's difficult to find half an hour, if you do find half an hour you feel blooming guilty about it because of all the things that are going on…you think I should be out there, I shouldn't be sitting here doing this" (Participant 4, interview 2, p. 24, 528-532).

All participants but one seemed to see a key barrier as being that senior staff viewed their attempts to make a life story board as additional to other prioritised tasks despite there being a superficial and contradictory sense that PCC was "promoted" (participant 7, interview 1, p. 18, 387) within the unit. Participants presumed this as senior staff did not ask them about LSW progress or offer any protected time to work on the boards.

"Even just like them coming up and saying oh I know you're doing this, how are you finding it, how is it going, but there's nothing, they didn't really seem to have any interest" (Participant 5, interview 2, p. 33, 710-712).

As a consequence of this participants did not have a high level of motivation to engage in LSW and it was described as being "pushed into a corner and it's hard to get back into that corner and drag it back out" (Participant 5, interview 2, p. 33, 699-701).

"You'd mentioned in passing oh yes I need some time to do my story board and they'd be like well look at the white board with who's on shift, there's just obviously not enough time for that to happen…and it is a bit disappointing" (Participant 5, interview 2, p. 9-10, 187-201).

"I imagine it would have felt to management, not management more like charge nurses and band 5's, this is not so important, there's more important things you could be doing" (Participant 5, interview 2, p. 19, 403-406).

The quote below indicates that there were differences felt in the priorities within the hierarchical organisation of the unit where perhaps higher level management valued PCC and LSW but that this did not feed down to middle management (for example charge nurses) who may be subjected more to clinical pressures.

"It would be nice if the people upstairs, management know about it" (Participant 4, interview 2, p. 31, 664-665).

The only senior staff support came from the two co-researchers but their support also did not penetrate through the cultural barriers and allow any more protected time for board making to occur. This participant spoke about co-researcher support as if it was a token gesture that would not achieve any change.

"She came back and said I can see if I can get you some protected time but that's very nice to be able to do that but I don't know whether it's these wards or whatever and it's a bit of a staffing moan really but there never seems to be the time for that sort of thing" (Participant 4, interview 2, p. 14, 295-299).

Participants also spoke about how LSW was not discussed in their teams due to having "other things to talk about" (participant 5, interview 2, p. 8, 163). They felt they could not take LSW information to handovers as the purpose of these was seen to be current clinical matters and LSW was not viewed as relevant to this. This culture seems to lead to a sense of PCC skills and aspirations being diminished in staff over their time working there.

3.3.2 Theme 2: 'Us versus them': CSWs positioning of their role

This theme conceptualises participants' sense of their position on the unit compared to other professionals. It also conceptualises the impact of visiting relatives and wider society's perspectives on participants' view of their role and ability to carry

out LSW. This theme has several significant aspects categorised under the following two subthemes:

- CSWs as an undervalued group
- Strangers on the ward: use of agency staff.

3.3.2.1 CSWs as an undervalued group.

Participants commonly spoke about feeling unappreciated and uncared for in their status on the unit by management and other professionals, despite feeling that they knew patients better than other professionals as they spent the most time with them.

"We're the ones that are with them all the time" (Participant 4, interview 2, p. 26, 575-576).

The quote below leads to a sense that senior staff organising a shift did not give much thought to deciding which CSW carried out what task as if the tasks of a CSW were not seen as that important.

"They just don't care…any of them they come on from nights and they just sling anyone in a box saying oh you're going to do this and you do that" (Participant 3, interview 2, p. 20, 397-400).

One participant in particular spoke about negative interactions with the doctor on the ward:

"The doctor, I get angry with him the other week 'cause he done his ward round at one o'clock, I say you can't do it at one o'clock we haven't got the people to do meal times… he still went ahead…and we got fed up with the physios as well 'cause they'd come at 12 o'clock and they'd pull patients about doing this, that and the other and then when they've got them riled up they just cheerio, I say yes

leave us to sort it out…oh I thought I don't believe it… you don't stay and sort

them out, oh no they say that's your job…and we get the hassle afterwards"

(Participant 3, interview 1, p. 16, 302-329).

There is a sense from the above quote that CSWs try hard as a group to maintain a state

of equilibrium but that other senior professionals come briefly onto the ward and disturb

the system and routine and undo the efforts of the CSWs. The sense of wanting to

maintain equilibrium can also help justify why two participants commented on some of

their colleagues not wanting to try new things or accept changes to practice on the ward.

This would cause a barrier to the implementation of the LSW.

"I don't know if its older staff or just people who've worked in the system for a

very long time 'cause some people don't like change they don't like trying

anything new" (Participant 7, interview 1, p. 19, 403-405).

It seemed that CSWs were not informed of why changes occurred on the ward or

what other professionals were doing with patients which led to them feeling left out of

ward decisions, likely impacting on their ability to be person-centred. One participant

(see quote below) felt that they were left out due to boundaries within their role caused

by their lower ranking compared to other staff. Participants also felt that they were

expected to 'sort out' negative consequences of decisions made by senior staff that they

were unaware of (see participant 3, interview 1's quote on the previous page). These

instances occurred on top of an existing heavy workload and these factors all led

participants to feel frustrated and perhaps ultimately disempowered.

"NHS we got ranks haven't we, band 3, band 4, band 5 and yes I think that

sometimes boundaries in the jobs restrict how much we can find out…we don't

as CSW's hardly attend MDT meetings, I think that's a very good place to get to

know about the patient 'cause we get to speak to consultant and OT will be there and social care and the family but because of our rank, band, we don't have the opportunity…we only get to know on the handover that this medication been changed and yes so sometimes, if we could attend a meeting we could know the process and reason why and stuff" (Participant 2, interview 1, p. 23-24, 428-450).

At time participants compared their role unfavourably to other professionals on the unit. This led to a sense of feeling unrecognised.

"It's not recognised is it, people see us perhaps cheap labour …it's very physical, we do physical work and it isn't brainy work…'cause we don't do much paperwork as much as general nurses"(Participant 2, interview 1, p. 46- 47, 874-886).

However this is contradictory to other data as most participants complained about the volume of paperwork in their role.

"Urgh some more paperwork I've got to do" (Participant 7, interview 2, p. 198, 9).

Furthermore others also talked about the "mental stress" (participant 4, interview 1) that the role caused as well as the physical fatigue, which is contradictory to the idea of it being a role demanding more physical than mental skill.

"Sometimes you are talking a lot…and you're thinking a lot, it's quite mental as well so you get really tired" (Participant 5, interview 1, p. 36, 752-753).

Nevertheless CSWs demonstrated beliefs around how others viewed their role negatively which seemed to contribute to their inferior and less valued positioning on the

unit. Participants also spent time reflecting on how those outside of the profession viewed their role such as friends and family, as well as society in general:

"The public don't seem to recognise us that much" (Participant 2, interview 1, p. 50, 941).

They seemed to have to spend time differentiating themselves from nurses to those outside of the profession which led to a perceived distinction between their role as being "unqualified" compared to nurses. This label can be interpreted in an undesirable way as if to dismiss the skills required for their role, impacting on their sense of value within the hierarchical system.

"People don't understand, they ask me what do you do and I explain well I look after people with dementia and they always automatically say are you a nurse and I said I'm not a nurse, I'm not a qualified nurse and I have to explain that kind of yes I'm not a qualified nurse, I'm an unqualified, I'm called a clinical support worker and people don't really seem to know though what the job role is" (Participant 2, interview 1, p. 4849, 910-919).

The most dominant discussion was how CSWs had been asked by others how they were able to do their role and that others felt they would not be able to do the job. Participants felt that this largely stemmed from others having unrealistic and negative views of dementia care and how PwD present, contributing to their low sense of recognition and value. The quotes below lead to a sense of the role being degraded by others.

"I get a lot of people say I couldn't do your job and I say what do you think I do, well you just like wipe peoples bums and well it's not just really that…so I find

that I couldn't do your job is one I get a lot" (Participant 5, interview 1, p. 37, 768-774).

"Most people say how on earth do you do that job, how do you work with them sort of people and that really makes me quite angry" (Participant 6, interview 1, p. 40, 332-333).

The long term consequences of feeling unrecognised and disempowered were that some participants felt greater mental stress, sometimes not wanting to do the job anymore. However most importantly it appeared that participants did not feel able to change practice within the culture in which they worked.

"Some said well we've done this before it doesn't really make much difference" (Participant 7, interview 2, p. 7, 151-152).

Participants also spoke about how past PCC interventions had happened to them and that there was confusion about the purpose of changes and the successfulness of them. This may have impacted on their view of the value of trying to change practice such as by implementing life story boards and perhaps helps to account for the lack of progress with implementation. This participant spoke about the lack of motivation to engage in LSW by non-participating colleagues due to these past attempts:

"I'm probably being very stereotypical here that staff that have been here for a long time will say oh we've done this in the past nothing ever changes things like that whereas I think the younger people or the people who haven't been here that long will say because they haven't experienced it before may find it quite useful" (Participant 7, interview 1, p. 17, 364- 368).

"I wonder if maybe people just think we've had so many things on the walls before in the bedrooms like the flower charts and we've got this new thing now

so I don't know if they just think it's another thing to go on the wall" (Participant 5, interview 2, p. 10-11, 205-213).

Participant 5 above (as well as others) felt that the life story boards were an intervention that felt new and different as it had not been tried on the ward before and yet they perceived that others could be dismissing of it as something already attempted. Perhaps understandably it is easier as a CSW to be dismissing and avoidant of changes to practice as opposed to facing unknown difficulties when they already feel mentally stressed from the role.

As a result of participants feeling unrecognised and undervalued they also seemed to position themselves together as a group identifiable by their role, who understood each other as they felt that those outside of the job did not understand what happened inside the unit. The quotes below highlight a strong sense of participants positioning themselves as insiders and that there are outsiders who lack understanding.

> "You can talk to someone that knows what you're going through and knows what it's like and knows what your struggles are whereas someone outside they don't know what happens in here" (Participant 5, interview 1, p. 38, 796-799).

> "We can sort of empathise with ourselves, I think we understand each other more I think, we share our challenges and frustration together so we support each other" (Participant 2, interview 1 p. 49, 926-927).

Participants also appeared to employ defensive strategies to off-set negative feelings about their role such as saying that "someone's got to do it" (participant 3, interview 1, p. 31, 613), and comparing their role favourably to nursing staffs who had more office-based work duties to do. This could be seen as way for participants to motivate

themselves to cope working on the unit despite the difficulties, and is perhaps a reason why some staff did feel able to attempt to make a life story board.

> "I do like to be a support worker sometimes cos we got more time to get to know the patient…'cause we do more hands on jobs, we get to spend time, one-to-one time with them…which is perhaps general nurses they sometimes want to have time but they haven't because they got paperwork to do and stuff" (Participant 2, interview 1, p. 48. 893-901).

3.3.2.2 Strangers on the ward- use of agency staff.

Many participants spoke about the high reliance on agency CSWs on the unit and how this was largely seen to be a negative thing despite their presence meaning that overall CSW numbers were increased.

> "It would be nice if we had more regular staff on, you get this morning they're nearly all agency, it's only me and one other CSW what are regular and that is difficult" (Participant 6, interview 1, p.1, 38-40).

The quote below shows how this participant positioned themselves as a 'regular' member of staff compared to agency staff. Other participants also spoke about a sense of belonging for regular staff on the unit, talking about their "own patients" (participant 3, interview 1) and how "it's a lot easier with your own staff" (Participant 6, interview 1, p. 24, 490-491). The reason for the use of the term 'regular' staff and the sense of difficulty using agency staff seemed to be because some agency staff were said to be "strangers" to the ward, not having worked on the unit before and so lacking an awareness of the unit culture, routine, or the individual patients.

> "Today's agency staff are great because they're regulars …they know the patients, they know the routine, they know what to do next so that isn't a problem

but tomorrow I could come in, there could be six strangers in there who'd never been before" (Participant 6, interview 1, p. 43-44, 897-902).

The use of the phrase 'strangers' highlights how they do not seem to belong on the ward and there was a sense that at times many "different people" were coming onto the ward (participant 5, interview 1) which indicates a sense of instability of the environment. This has implications for implementing LSW as agency staff could also likely view the patients they were caring for as strangers.

"They might not then know the history…they might not have read the notes or hear what's happened in all the handovers and things like that and they might not see the relatives" (Participant 5, interview 1, p. 23, 480-483).

"If you're someone who's never been on the ward which happens a lot and you go into handover there's all these peoples' names you haven't got a clue who they are…they could be talking gobbledygook, you wouldn't know what they're talking about" (Participant 1, interview 2, p. 28, 561- 566).

The sense that participants made of the issue of strangers on the ward was that it caused more burden and stress to existing regular staff. There seemed to be several reasons for this. One reason was that agency staff caused them to spend more time typing clinical notes as agency staff did not have computer access which was said to lead to less available time for other tasks like LSW.

"We're the only ones that can do the notes so that's six, seven each and that's going to take a while to do so you find your time then goes" (Participant 5, interview 1, p. 16, 322-323).

The sense of burden also seemed to arise from participants wanting to ensure that agency staff were safe from harm or that they did not cause harm to others due to being

unfamiliar with the ward and the patients. Some agency staff were said not to be trained to effectively prevent and manage aggression (PMA) which seemed to cause frustration and anxiety for staff who then had responsibility to organise the shift rota to account for this and ensure safety for all. This participant gave a sense of this issue:

> "You've got to be on the ball all the while…especially when the agency staff is on and they haven't been here before, you've got to look after them as well as look after yourself and the patients…some of the time that gets pretty hectic… sometimes that can be quite nerve racking" (Participant 3, interview 1, p. 6, 99-103).

> "There's only 2 PMA on and you think god that means we can't do no obs', they'll have to do it all and we'll have to take one and then change them with another member of staff and get these up and that get really ridiculous" (Participant 3, interview 2, p. 23, 471-474).

Some participants also felt that burden arose because agency staff took less initiative with tasks and relied on regular staff to tell them what to do, whereas this did not occur with regular staff as the quote below gives a sense that regular staff worked in sync with one another and with more ease.

> "We had a rare shift, we had regular staff, oh what a difference that make, you've not got to say to anyone can you go and do this, do you mind doing this and you give me a hand because we've all worked together for quite a while and like if two of us went one way the other two would go the other way" (Participant 6, interview 1, p. 23-24, 480-485).

In terms of implementing PCC via LSW on the unit these issues were a dilemma as PCC was said to be harder to make time for due to understaffing and yet when more staff were brought in this also seemed to take time away from PCC tasks seen as 'extras'.

"Then you aren't going to do any extras you only do the basic stuff" (Participant 6, interview 1, p. 44, 902-903).

One participant also recounted that "if they're all agency staff on the ward it's difficult to get off the ward" (participant 6, interview 1, p 43, 896-897) and so staff would struggle to take time off the ward to focus on their life story board. This dilemma is accentuated as participants appeared to view LSW as a helpful tool to reduce the sense of agency staff and patients being strangers to one another.

"If there is the board in their (the patient's) room that's then going to help them (agency) to know they like certain things so that would then obviously benefit the whole ward" (Participant 5, interview 1, p. 23, 483-485).

"Agency staff, people who aren't familiar with that person would be told to look at that board and say this is so and so, this is what they're like, this is what they don't like" (Participant 4, interview 1, p. 32, 671-673).

Participants' apparent perception of a 'regular versus agency' staff divide in their talking also concerned how regular staff positioned themselves together as more superior in their role and at carrying out PCC and how they seemed to spend additional time encouraging agency staff to be more person-centred. This sense of agency staff not being person-centred enough is curious as participants spoke about many regular staff as also not feeling able to be person-centred either.

"Agency…perhaps haven't been trained or they come at it from a different angle, they haven't got that something" (Participant 4, interview 1, p. 22, 463-466).

"You're not just an agency person just sort of sitting there and making sure that they're not doing anything" (Participant 4, interview 1).

"The bank staff, well they just sit there and they look at you as if to say what are you talking about, well I say do a bit yourself don't just sit there with them…no they're just different altogether, that just don't work" (Participant 3, interview 1, p. 19, 403-404).

Perhaps this 'us versus them' divide captured the recurrent pattern of participants' discussions regarding group identity and how agency staff threatened their sense of the ward being familiar, belonging to them, and in a state of equilibrium and so they used strategies like positioning agency staff as strangers or outsiders in order to manage these threats to their role status on the wards and to manage the psychological impact of working in an environment where patients and colleagues changed often.

3.3.3 Theme 3: An altered view of the patient with dementia.

This theme captures how participants reported feeling unmotivated and struggled to engage with patients due to negative beliefs about patients' lack of communication ability due to dementia and due to them wanting to have the engagement process with the patient directly, as opposed to indirectly gaining life story information from others. Conflictingly, LSW is seen as a tool that is helpful to aid engagement with patients via conversations and can change CSWs beliefs of PwD over time to become more positive. The theme is divided into two subthemes to reflect specific aspects and these were:

- Motivation to communicate- a dilemma
- Seeing past the dementia patient label

3.3.3.1 Motivation to communicate- a dilemma.

All participants spoke about their struggles to initiate conversations or to find the motivation to continue conversations with patients. This struggle seemed to stem from a belief that patients could not communicate back or understand them due to their dementia and participants had viewed dementia as being in the way of them being able to engage with some patients.

> "You can't get through anymore to this particular patient, you can't have a conversation anymore" (Participant 5, interview 1, p. 25, 516-517).

One participant spoke in depth about some staff having a view of patients as just 'bodies' or 'shells' with no personality and that this reduced motivation to communicate. This idea of a shell was also mentioned by another participant.

> "Just being this body sitting there that you get up in the mornings and you get dressed and you take them to bed again in the evenings…some of the staff will look at them and just see them as like a shell without the person being there, the person having gone…communication wise so they will sort of sit with them or stand with them and walk with them to make sure they don't hurt themselves…which they do very well…but not really seeing that person…just as no one, the personality having sort of gone….and you know why should I bother to communicate with them because I can't get anything back from them" (Participant 4, interview 1, p. 41-44, 901-922).

Staff spoke about the impact of this belief on their ideas about the worth of investing time trying to communicate. This issue appeared to cause uncertainty: they sometimes felt they were wasting their time engaging leading some staff to just sit in silence with

patients (especially on one-to-one observations) and not make use of tasks to be person-centred and get to know patients. However, at the same time participants seemed to perhaps think that the patients were aware and gaining something from the engagement so it was best to keep trying to engage with them. The reason to keep trying also appeared to come from a PCC approach that one should keep interacting with patients as if they do not have dementia but this did seem challenging at times. This participants' quote indicates that they tried to see the patient as 'normal' like them but that this was perhaps not felt deep down:

> "He probably can't understand a word but I'll still chat to him over lunch or whatever, it probably means nothing and in your mind you think I'm actually wasting my time but it's not the point you still do it…perhaps it's a too harsh a word to put on it cos you're not wasting your time because you're with the person you're doing something with them and you're just talking to them as if they were a normal human being …I don't know what's going on in their head they might well understand it" (Participant 4, interview 2, p. 19-20, 42- 442).

> "If you can't communicate back I'm sure you can still hear what they're saying and even if they can't understand all they can understand bits" (Participant 1, interview 2, p. 24, 486-488).

Participants discussed how engaging with patients who struggled to communicate was much harder when they lacked information about who the patient was as an individual. The quote below seems to reflect a vicious cycle: staff want to find out more about patients, but patients' communication difficulties can reduce motivation to engage due to it being challenging, however finding out more information could help tackle communication difficulties.

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"I try to get to know the person but only I think given the kind of restrictions on how far we can communicate with the patient, we only got a tiny bit of information…some of them have lost that ability to talk…yes so for those people who cannot ever express themselves they must be frustrated, we don't know anything about them really" (Participant 2, interview 1, p. 15-16, 282-295).

"When you go into a room to get somebody up and you've got four blank walls, you've got a patient what doesn't talk to you it's very difficult, you can say hello I've come to get you up or whatever, what else do you then say to someone who's not responding to you is difficult" (Participant 6, interview 1, p. 16, 332-336).

The above quote by participant 6 expresses the difficulty of knowing where to begin conversations with uncommunicative patients who were unknown and in environments that gave no clues to make conversations personalised to the patient. Participant 6 also speaks about the issue of not getting any response back when communicating and so a need for reciprocity during interactions seemed motivating for participants. This was spoken about by others too so to indicate that the person was still present:

"You're looking for some sort of response …I suppose recognition in the mind…or some sort of acknowledgement" (Participant 4, interview 2, p. 20, 432-436).

"Even if I get a raised eyebrow or something it would be nice to see if something is connecting … even if it's just a lift of the eyebrow to say ok I'm listening or I can hear, I know you're here" (Participant 5, interview 1, p. 14, 281-291).

All participants said that knowing more about patients via the use of LSW would have been of benefit to their motivation to communicate. The main benefits were that personal

information would act as a good conversation starter to tailor topics and questions to patients' interests as participants said they ran out of things to talk about. Despite the challenges, some said they felt that life story information they gathered did aid conversations when interviewed post-implementation, though a connection or sense of acknowledgement was not always felt.

> "Sometimes you might just run out of things to say and then you might start blabbering on, you know talking about nothing in the end…so that's I think where the story board will come in to very good hands…because then you'll have, if you can't think of anything to say at the time, you might be able to look at the board and pick something off there and then use that to talk to them about" (Participant 5, interview 1, p. 11-13, 218-272

> "I'd speak to XXXXX about it and although it didn't come across that she was really connecting with me it was still nice to have something to talk to her about so as I said although I couldn't get information from her it was nice to be able to relay the information and make a conversation to her about it" (Participant 5, interview 2, p. 11, 236-237).

One participant reflected on how interacting with a patient about relevant information to their life could be "meaningless" to patients as they felt that the information "didn't register any more" (participant 4, interview 1) which meant that they lacked motivation to continue trying at times. This indicates that staff wanted the patient themselves to be engaged in the LSW process directly and to have a role in maintaining their own sense of personhood, as opposed to others doing this. Other participants also clung to a sense that once a patient lost the ability to communicate that the new life story knowledge would not be of use, which is interpreted to be because the participant wanted

to be able to talk about their life with the patient as opposed to just holding their past in mind when viewing and caring for the patient as they are currently.

"If the patient was communicating yes but because she's not really communicating anymore it doesn't it's not going to make a lot of difference with her case" (Participant 1, interview 2, p. 23, 467-468).

"Everything just seemed to have collapsed inwards so we don't get nothing out of her at all now" (Participant 3, interview 2, p. 1, 25-26).

3.3.3.2 Seeing past the dementia patient label

Participants spoke about their perception of the patients with dementia on the ward. Predominantly patients were seen as having a medical disease or illness of the brain which led to deterioration of functioning and was irreversible. This likely had negative implications for staffs' motivation to see past the disease as they were sometimes viewed as being incurable and unable to be helped. One participant spoke about differences between patients on the unit in terms of their differing triggers to aggression as opposed to differences in their personality which reflected the focus on the medical aspects of dementia and how it can be viewed as taking over the person underneath the dementia.

"I haven't ever worked with any two people that are the same with dementia, they're all completely different, they all have their own triggers" (Participant 1, interview 1, p. 3, 44-46).

"I think it's an amazing illness the way it works, the way it takes over really and there's not at the moment, there's no coming back from it, there's no cure" (Participant 5, interview 1, p. 7, 146-148).

In terms of the dementia taking over the person, there was a sense that patients arrived on the unit as lost behind the dementia as one participant described trying to see who they were as a person "deep down inside" and "getting through to who that person used to be" (Participant 1, interview 1, p. 5, 94-95). This was emphasised more when patients' staff lacked life story information about who the person was. Patients with no personal information known about them were described as a "blank canvas" until staff could "learn stuff and start filling in the spaces" (Participant 1, interview 1, p. 8, 165-170). This was seen as an important task and one that they said LSW could hopefully fulfil as participants spoke about ward handovers as describing patients more like numbers as they did not provide personal information in order to be able to get to know new patients as people.

> "They'll said like 'this man's 89 and he came from a care home and he's an
> absconding risk' but that's not a person, that's a number you're telling me about"
> (Participant 1, interview 1).

The participant below reported after post-LSW implementation that they were able to see the patient differently due to knowing their past.

> "If you have this information you then think of that person more as a person
> rather than just a patient because they're then they've then got a history they're
> then got a past which if you view them just as a patient they're kind of like a
> nobody in a way" (Participant 4, interview 2, p. 17, 365-369).

Participants said that at times patients could be judged personally on their behaviour, especially aggressive and challenging behaviour such as hitting. This seemed to be more likely when staff did not know anything else about the patient and so would use the patient's actions to judge who they are. The quote below demonstrates how

another participant felt that by finding out more personal information they could see past the challenging behaviour as being who the person is, and instead see it more as part of the dementia.

> "If I know the patient more I don't see the patient become agitated or aggressive, I don't put it as the person as just aggressive, I can connect the reason why like what was the trigger" (Participant 2, interview 1, p. 20, 363-367).

Another participant said they experienced a big shift in how they perceived the patient they did the LSW with. This change was also regarding aggression, in terms of them having more empathy to the patient and this quote echoes two other participants' predictions that carrying out LSW would increase empathy towards patients.

> "It's made me look at her differently…because I know more about her and her upbringing and what she's been through it makes you think oh bless her…cos sometimes she can be really horrible, I know it's her dementia… I know that from this now that she's not as hard as she makes out…cos she's quite soft inside and I think you have to look at that part of her and I think that's why they really do help…so you do have the perception they must have always been an angry person but they're not, it's the dementia it's not the person they used to be" (Participant 1, interview 2, p. 8-10, 160-202).

Not all participants felt this way however. One participant in particular felt that challenging behaviour did not impact negatively on how they viewed patients or how they treated patients, and another participant also echoed this.

> "It doesn't really make any difference, I talk to them same way I talk to you…No he's still him he's still there" (Participant 7, interview 1, p. 6, 113-131).

This participant did however feel that learning (even only a small amount) about their designated patient during the LSW process led to them having an altered view of them in terms of having more understanding of the context to their behaviours. They hoped that this would lead to more patience within the wider team when managing possessive behaviours if shared.

> "There were snippets that I had no idea about…he'd had lots of lady friends over the years but they were all fairly short term relationships because he used to get very possessive...which in a way gives you a better understanding 'cause he could get possessive over the staff… things were making sense a little bit, giving you a better understanding of where he was coming from" (Participant 7, interview 2, p. 4-5, 91-98).

Other participants varied in how much they discussed having a changed view of the patient they worked with. One participant felt that they enjoyed finding out the new information but that "it didn't change my opinion of her or anything like that…she always came across quite kind so that never changed" (Participant 5, interview 2, p. 13, 275). Perhaps this was due to the lack of new information found out in the limited time they felt able to gather life story information. Participants did not speak much about a changed relationship with the patient due to any new life story information learnt about them; only two participants mentioned any adaptations to how they or their colleagues behaved because of the process. One participant spoke about offering different diet choices based on information on food preferences and being aware that colleagues had heard them talking to the patient about relevant information to their life history and that the information had been shared in others interactions with the patient allowing others to get to know the patient on a deeper level.

"I found out just a few little things like her food, she liked fish so that was nice to know because then when we had a fish option on the menu I could then say she might like the fish today and it was nice to be able to give her that option 'cause she can't say what she likes to eat" (Participant 5, interview 2, p. 12, 253-257).

"Other members of staff would pick up on what I was saying and say oh really did you do that? Did you do this? So that was quite good in that way, you'd hear that information again coming out from their mouths so obviously something got passed on which is quite good really ''cause I mean it's kind of the idea so everybody knows a bit about them" (Participant 5, interview 2, p. 14, 283-294).

3.3.4 Theme 4: A sense of hope: getting past the barriers.

This final theme encompasses the alternate and more optimistic ways that participants spoke about their work with patients. Despite the challenges perceived in the previous three themes some participants did speak about seizing moments of time to be able to engage in PCC tasks and LSW. This theme discusses the PCC that participants described occurring on the unit in these moments and how staff motivated themselves to provide this and get past the barriers. Furthermore, participants discussed recommendations for what may have made LSW easier to implement if attempted in future. The theme is divided into three subthemes:

- A window of opportunity: a choice in noticing and grabbing moments to engage with patient
- PCC occurring via motivational aids: personal meanings
- What could have been different

3.3.4.1 A window of opportunity: a choice in noticing and grabbing moments to engage with patients.

Participants spoke in ways which suggested that despite the barriers faced to being person-centred and implementing LSW there were chances or moments of opportunity, if looked for, to take and choose to spend on PCC tasks or focussed engagement with patients. The sense was that this was a choice as participants spoke in terms of making time and taking time for PCC as opposed to there being time presented as easily available for such tasks. This has implications for the ability to carry out LSW. The quote below suggests that participant 4 initially felt that they lacked time for tasks but then reflected that they were able to create time for certain tasks which suggests that participants sense of lack of time could be partially subjective. Alternatively perhaps this participant felt the need to say the right thing and present as hopeful to me as the researcher about being able to make time to make a life story board.

> "It's kind of fitting more things in than you really, well you do have time to do, you make time to do them that's right" (Participant 4, interview 1, p. 30, 635-637).

Participant 4 also spoke about an experience of them being able to provide PCC because they decided to take the time to do so and that this was felt by them to have had a positive impact on both them and the patient

> "One morning someone else had got him dressed and they'd put a dreadful pair of trousers on, they weren't his and the poor bloke was trying to hold them up and I said what's wrong…he gave this expression of fed-up-ness and he showed me his trousers and that was dreadful, I said you can't wear them…so I took him down to his bedroom and I took the trousers off him and I sort of hunted around

through our stock and found him another pair, I said try these so he put them on…we put a belt on, he was pleased as punch you know 'cause someone had sat with him and took the time, it was brilliant" (Participant 4, interview 1, p. 8, 162-171).

Other participants reflected on their experiences of providing PCC when they were also busy with other tasks. This seemed to be done through making a judgment on how to prioritise competing tasks with different patients so to be able to grab small moments of time to offer PCC.

"A gentleman…was so angry…something was really bugging him and I was on a '6 in the hour observations' so as long as I'd seen her 6 times in the hour…and I knew she was alright… I knew where the gentleman was so I went and nipped and sat next to him, judged it first and I went what's the matter, I said something's worrying you and he came out with this massive spiel…and I just sat there and went look don't worry about it, your wife will sort it and if she's got any problems then she's got your two lovely daughters and they'll help her. He chilled, I think he just needed someone to talk to about it, get it off his chest, he then sat and ate his tea and was quite pleasant for the rest of the evening but I think it helped him and probably helped the ward to let him just sit and get it off his chest … I'd felt that that 5 minutes with him would be better time spent" (Participant 7, interview 2, p. 23-25, 531-572).

The quote seems to highlight the importance of small decisions that staff make regarding how to spread their time and that these can have a big impact on patient care, as this participant could have stayed on their assigned six hourly observations and ignored the distressed patient's communication of anger and yet they chose to manage both, with

apparent success. Participant 7 below emphasised that this way of working was dependent on the individual CSW in terms of whether they chose to make the most of small opportunities for PCC or whether they used this time for other things such as having a break. Therefore opportunities for PCC do not have to be taken and some staff may not even notice they are there.

> "I think it depends on the individual…some people think well I think I'll go grab myself a cup of coffee now, got five minutes, but to me that was more important to try and get him to calm down than anything else that was going on at that moment" (Participant 7, interview 2, p. 25, 576-579).

A number of participants were able to make use of one-to-one observation time to engage with other patients, who at times were felt to be neglected due to the amount of time that one-to-one's took up. Again this seemed to be a choice but some staff spoke about maximising their engagement with patients not on one-to-ones when their allocated one-to-one patients were asleep.

> "I was on a one-to-one who was sound asleep so that was quite nice, my person was sitting next to me sound asleep so I was talking to this other lady and she was teaching me to knit" (Participant 6, interview 1, p. 34, 641-644).

Participant 1, who got to the stage of writing out their plan for their life story board with the information they had gathered also appeared to be persistent in seeking opportunities to work on their board, which ultimately meant doing it on the ward floor when on a one-to-one. This indicates that flexibility in the approach to implementing LSW seemed to be required if participants wanted to get it done as protected time off the ward was not viable.

"I done that (the rough draft of the board) on an hour that I think I was on a one-to-one with someone who was asleep, so it was like quiet, so I decided to go and get the bit of paper and do it 'cause I thought well I need to write something down, I've got to find some time to do it…I think I managed to get it done because… I made sure that even though I was on the floor that I was actually looking through stuff and doing it…so many times I got the bit of paper out to do it and had to put it back" (Participant 1, interview 2, p. 12-18, 229, 351).

There was also a sense of there being opportunities, if chosen, to make the most of the prioritised basic care tasks and to see beyond the task itself and use these times as a chance to maximise getting to know patients. This contradicts the idea that basic tasks mean that PCC or getting to know patients cannot be carried out so perhaps it is more about how staff use these times and what they see as the purpose of them. Again perhaps this is a more hopeful view as it was said before the participant's attempt at LSW.

"The good times are strangely enough…getting people up in the mornings and putting them to be…meal times are a good time as well to sit with them again because we're all interacting, we're all sitting down round a table" (Participant 4, interview 1, p. 24-28, 510-595).

3.3.4.2 PCC occurring via motivational aids: personal meanings.

The PCC that participants did feel able to carry out seemed to be largely motivated by the sense that they felt that everyone was vulnerable to getting dementia and so many spoke about imagining themselves or others they cared for in the patients' position and giving consideration to what they would want for themselves and their relatives. This seemed to motivate participants to think about different aspects of care

such as meal choices given, waking and bedtime routines, and dressing of patients in a more person-centred and empathic way.

> "It can happen to anybody and you think that could happen to my family, that could happen to me…and you kind of think about then how would you want to be treated and that's kind of something that I like to work off…you know dignity and respect and that's something that I try and sort of, best as I can to put into the way I work" (Participant 5, interview 1, p. 6, 123-128).

> "I always put myself in their place and think that if I was in here and people were talking to me about things that I didn't care about or giving me food that I didn't like… if somebody gave me something I didn't like, you're gonna eat it coz you can't remember but I think that's unfair. I don't like beef burgers so if I came in here and you fed me those and I didn't know, I'd eat them but I wouldn't be happy about eating them. If I'd never eaten them before, why just because you got dementia should you have to do these things" (Participant 1, interview 1, p. 9-25, 181-540)

The quote above illustrates how this participant is also using the positioning of themselves in the patients' situation to understand the impact of PwD having their preferences ignored due to their illness and how this assists their decision that this is not how one should offer care.

Participants imagining patients as their relatives and treating them in line with how they would treat someone they were related to was a recurrent way to describe their approach to care however participants did speak about the challenges of adopting this view despite it being a useful tool to aid PCC.

"That's what I often do I think you know that's my mum so I'll talk to her like I talk to my mum" (Participant 4, interview 1, p. 18, 377-378)

"People here say well you know when you go home you should go home and that's the end of this until the next day but with a job like this you can't do that you're thinking about so and so…you can't help it because you kind of almost become a member of the family" (Participant 4, interview 1, p. 46, 960-986).

The quote above is suggestive of there being a fine line between the use of personal meanings as being helpful to the role and to it making the job harder in terms of adding emotional stress. The following quote also indicates this as the participant talks about how relating to patients (especially if they are a similar age to them) can be emotionally draining.

"There's a lady on our ward, I'm twelve years old than her…and I don't normally take people home in my head do you know what I mean, once I'm out of the door I'm usually ok…I was on the night she was admitted and she got in my head and I keep thinking oh my god twelve year older then her, this isn't right" (Participant 6, interview 1, p. 45, 928-935).

Participants were also seemingly driven to be more person-centred when they made an effort to view patients as people who were valued by their relatives and that they belonged to someone in the same way that staff valued their own relatives. The participant below speaks about viewing their role as important because relatives were trusting them to care for people who were important to them. When this position is enacted it is perhaps easier to work against the barriers to PCC. Another participant also said that imagining the relatives' position of trying to place trust in the hands of care

providers incentivised them to learn more about patients, as they imagined what it would be like if their parent was in hospital and the staff did not know who their parent was.

> "These are somebody's parents…somebody's children, these are probably the most important thing to somebody and they're entrusting them to us to look after" (Participant 7, interview1, p. 23, 478-480).

3.3.4.3 What could have been different.

The last subtheme captures the feedback participants gave when they reflected on what may have assisted them to have implemented more LSW. Predominantly participants spoke about wanting more awareness, support, reassurance and organisation from management and that they could have been encouraged more to see LSW as a target to complete as one participant said that they did not feel as if they were encouraged to do them.

> "I think that management should have been kind of more involved and maybe the four of us that were doing it should have sat in there with (the charge nurses)…so they knew what we were doing… and were in agreeance with the time and actually sat there and sorted out right on a Monday you can have between ten and eleven…and you go off the ward at this time and use the resources you need and do this. I think if we would have had more support that way… I think if we were allowed the time then we could have done it but it wasn't planned properly" (Participant 1, interview 2, p. 32, 650-660).

There were differing recommendations concerning how it would have been best to take the protected time to work on the life story boards, including having an extra CSW to cover their absence off the ward. However other participants' spoke

pessimistically regarding this idea stating that they did not think that would happen and so offered other suggestions.

> "Say they'd have arranged it so all four of us (the participants) were on one shift and got an extra staff member and we all had like two hours out of that shift so there was always one of us missing" (Participant 1, interview 2, p. 33, 668-672).

> "They won't get bank staff in to cover you for two hour…as well looking back on the experience it would have been better I think if I'd have booked a whole day off for it rather than trying to get an hour here and an hour there, if they could have given me a shift of protected time…you could have prior phoned the family and said is there any chance you can come in that day could you bring me some photos, explain what you're doing, could you come and have a chat with me, you could sit and go through his file, you could then gather all the information, go and talk about it and try and produce it" (Participant 7, interview 2, p. 10, 215-222).

<h2 style="text-align:center">4. Discussion</h2>

4.1 Overview

This section provides interpretation of the results to answer the research question of what the experiences of CSWs were who tried to use life story boards to engage in PCC with PwD in an inpatient dementia care unit and how CSWs experienced PCC via this. This research question aimed to capture the whole experience of CSWs implementing PCC via LSW and so the majority of the themes and sub-themes created from the data provide information to explore this research question. The four themes created were: the unit culture as a barrier to valuing PCC and the personhood of patients; CSWs relative to others; an altered view of the patient with dementia; and a sense of hope: getting past the barriers. The results will be discussed in the context of previous literature. A critical appraisal of the study is offered, and implications for clinical practice and future research considered. The extent to which this study was able to fully use aspects of the technical model of PAR will also be reflected upon. To support the discussion excerpts from the researcher's reflective diary are presented in text boxes.

4.2 Discussion of Study Results in Relation to Literature

4.2.1 The unit culture as a barrier to valuing person-centred care and the personhood of patients.

Participants felt that they would have been able to carry out more LSW if the culture of the organisation within which they worked gave an unambiguous message that they valued and wanted to promote PCC and LSW (which are in essence the same things in terms of values). A paradox seemed apparent where the unit superficially promoted PCC as the ideal but then did not or could not provide a culture which allowed staff to use tools such as LSW to implement it. Therefore although PCC is seen as the "gold-

standard" model of care to aspire to (Peek et al., p. 167) and is strongly recommended (NCCMH, 2007), these recommendations are only supported by the organisational culture in a tokenistic way due to other factors getting in the way. Due to this, a focus on the culture and context of the organisation is seen as necessary to understand successful LSW implementation (Thompson, 2010) and to understand factors impeding implementation.

Senior staff such as nurses and management help to set and shape standards and norms for what is valued in an organisational culture (Kane-Urrabazo, 2006) and participants in this study felt senior staff judged or had certain expectations of them as well as a sense that there were unspoken rules of what was acceptable to do within their role. This experience is shown to be a common part of workplace culture whereby there are unwritten as well as written rules (Cox, 2007). LSW was seen as something that was not widely supported or valued by senior staff on the unit. This negatively impacts on implementation of LSW as literature states that it needs to be valued at the level of both the individual carer and the organisation/team in order for it to be effectively implemented (Clissett et al., 2013) and Thompson (2010) stated that all staff should have an understanding of the evidence, benefits and rationale for LSW, so it is not enough for only the CSWs making the boards to be given information and training on the benefits of LSW. McKeown et al. (2010) also supported this as they found that implementation issues occurred when staff were not given a strong enough rationale for investing time in LSW.

Gibson and Barsade (2003) describe organisational cultures as multi-layered with the most apparent behaviours of the culture at the top level. Norms and unspoken rules regarding acceptable behaviour are in the middle layer, and the third layer holds the values and deeply held beliefs of what ought to occur in the culture. This may help

explain why some tasks on the surface level appear to be valued by an organisation (such as the need to be person-centred to fit in line with government strategies, policies and research such as this) but are not valued at a deeper level when trying to integrate the tasks as part of routine care, resulting in care staff experiencing contradictory messages and uncertainty about what their role should entail (such as being told there is no time to do LSW) and a tokenistic approach to implementation.

Participants felt that there were no senior staff leading the implementation of the life story boards (except for the researcher) and that band six charge nurses on the unit did not support the study or enquire about progress which led to a lack of incentive to do the work on top of other competing work demands, or to discuss it with colleagues. The current study therefore supports the literature on LSW implementation which advocates having identifiable leaders in the clinical area to motivate and disseminate LSW information to the wider staff team, and to provide visible support and encouragement in terms of helping staff develop skills and confidence in LSW (Dementia UK, 2011; Thompson, 2010). The study also adds weight to Gibson and Carson's (2010) argument that consistent leadership and competent management of even small details such as staff rotas was vital for lasting change, as well as that of Kontos and Naglie (2007) who stated that PCC cannot be implemented with a one-off 'quick fix' (Manley et al., 2008) but requires a change in the values of both the care system and individual professionals. The above factors occurred due to a lack of ability to fully use a PAR approach which aimed to address these known issues in the literature. This meant that this study encountered the same challenges as other studies and the struggle to truly implement PAR demonstrated the barriers within the organisational culture.

In terms of organisational factors impeding LSW progress, all participants experienced the unit culture as being routine-led leading to a sense of constraint and

inflexibility to be able to carry out LSW to value personhood, as only the most prioritised tasks of a physical or medical nature seemed to be encouraged by senior staff and carried out, given time and understaffing pressures. This supports the majority of LSW research in these settings indicating that wards are constrained by routines (Schneider, 2010) and that lack of time (for example due to absenteeism, understaffing and existing schedules) is a main barrier to implementing LSW (Mckeown et al., 2010; Royal College of Nursing, 2012; Kellet, et al., 2010; Cooney et al., 2014; Batson et al., 2002; Gibson & Carson., 2010). Staff spoke about their heavy workloads which supports Clarke et al. (2003) who found that LSW progress was halted due to staff workloads and exacerbated by staff sickness. The LSW in Clarke et al's study was only able to be progressed further with the addition of a paid support worker working on the study which indicates the difficulties of fitting it into existing workloads and routines. Other studies such as by Thompson (2010) took one year (six months longer than anticipated) to achieve the level of LSW completion they expected. This study's results also support the work of Schneider et al. (2010) who spoke about issues implementing PCC due to time pressures and a focus on risk management (which was also the focus for staff in this study). In these situations Schneider et al. said that patient choice becomes limited and a focus on physical basic care and routine dominates at the expense of patients' emotional care. This is also supported by Perry et al. (2003) who found that lack of time impacts on care staff's ability to provide adequately for the emotional side of patients' care. Participants feeling that prioritises on the unit seemed to revolve around physical and medical care also adds weight to findings from Gibson and Carson (2010) and Kontos et al. (2009) who found that care in these settings can often become measured by physical and practical tasks and that a culture of daily routine is established as care staff have to juggle managing group needs versus individual patient needs, with group needs

prevailing. Kontos et al. argued that the quality of individual human interactions can become lost which was supported by the current study when participants felt that they did not have time to engage with patients and that patients became left out due to demands of physical tasks. Participants in this study were felt to be judged negatively when spending time sitting, talking with patients and sensed that this was not the work they should be doing. This adds to Clarke et al's. (2003) findings that care staff were concerned that discussions and personal interaction with patients were often not viewed as proper work. This stands in contrast to the values of PCC as Edvardsson et al. (2008) state that personhood of PwD cannot be maintained unless relationships are valued to the same or greater extent as task-based relationships.

The rationale for prioritising medical and physical care was said to be due to it being auditable and that senior staff were held accountable for tasks that CSWs did. This adds to literature on how these care settings can become focussed on care that is obvious, external, and easily managed (Kitwood, in Kitwood & Benson, 1995). The nature of accountability in the results is also supported in literature on care settings being led by management prioritising the monitoring and meeting of targets and working in line with policies and procedures set by commissioners and regulatory bodies rather than putting patient care at the centre (Francis, 2013; The King's Fund 2013). The financial constraints of the unit where this research took place were also said to contribute to the focus on prioritising auditable care which Kontos et al. (2009) stated leads to a "rationale for economic efficiency" (p.133). This fits with literature showing the negative impact of increasing bureaucracy, constrained budgets and restrictive commissioning on the ability of care staff to provide quality care to service users (Innes, Macpherson, & McCabe, 2006; NHS England, 2013).

The conceptualisation of PCC within the culture of the unit was of it being something additional to basic physical and medical care tasks and that to be person-centred involved doing more and going over and above the role. This idea links to a more medically orientated model of care where PwD are a body with purely physical care needs (Kitwood & Bredin, 1992) as opposed to the psychosocial/interpersonal approach which Kitwood (1997) wished to encourage where PwD have other needs on top of basic physical ones and PCC seeks to holistically meet both physical and psychological needs. This experience supports the idea that providing care is often seen by care staff as a process of delivering the basic requirements of human existence, such as food, fluid and hygiene, and so tasks unrelated to maintaining life are seen as extra work (Age Concern, 2006, as cited in All-Party Parliamentary Group on Dementia, 2009). Due to this it seems that this medical approach still dominated on the unit in this study despite the notion of PCC becoming increasingly discussed in these settings since the 1980's and dementia staff being trained in psychosocial/interpersonal approaches and tools such as LSW. Participants did not seem to have the resources to maintain personhood and in terms of models of personhood such as that of Brooker (2007), Nolan (1997), and Nolan et al.'s (2001, 2002, 2004) 'Senses' Framework' the researchers' interpretation of participants' experiences was that patients did not seem to have their domains of 'inclusion' and 'comfort' maintained or their sense of 'belonging' nurtured. Some participants seemed unsure how person-centred they were and spoke about PCC in relation to physical care tasks often. This supports the ideas of McCance et al. (2011) that the term PCC may not be fully understood by care staff and that there is confusion over what PCC looks like in practice, so they may believe that the task-based approaches to care they give meet the definition of PCC when in fact they do not (McCarthy, 2006; Skaalvik et al., 2010). This is also because there is no one clear definition of PCC and so staff struggle to know how

to implement PCC from theories such as those regarding personhood (Kitwood, 1997; Dewing, 2004).

Most participants experienced guilt about the level of care they were able to give given the constraints of the role and culture, even if they view PCC as something that could be seen as an additional task. This adds to literature showing that care staff often want to be able to do more in their caring role (Alzheimer's Society, 2007) and that they find engaging with patients beyond the basics of task-orientated care motivating, rewarding and satisfying (Bailey et al., 2015). This guilt is also explainable by the multi-layered theory of organisational culture (Gibson & Barsade, 2003) where at the surface level staff are expected to be person-centred, but at the deeper levels of the culture unwritten rules and values exist regarding PCC not being a necessity, which impedes staff from meeting these expectations.

Another explanation for the challenges to carrying out LSW (and the research/PAR elements of the process more generally) was that staff felt overburdened and mentally stressed in the role and so only felt able to do the minimum level of care as going above what is expected is more tiring. This supports literature describing this staff group exhibiting high levels of stress (Brodaty et al., 2003), that staff deal with understaffing issues, time constraints and heavy workloads by feeling burnt out (Astrom et al., 1990), and that staff with lower levels of work strain and stress were associated with higher levels of PCC (Sjogren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2014). This also supports the relationship-centred care approaches by Nolan et al. (2006) and Brooker (2004; 2007) who felt that it was vital for workplace organisations to value staff as much as patients so that staff could offer good care practices. Ultimately participants' perceived some basic care needs as not always being met on time which

meant that additional PCC was unlikely to be implemented. This adds to literature into the standards of nursing care given to older patients in hospitals, indicating that basic needs were not always able to be met as soon as required (Standing Nursing and Midwifery Advisory Committee, 2001). Therefore, it seems that participants had a negative but realistic attitude towards taking on more work tasks on top of what is already expected of them. See figure 9 for a reflective account of this.

Participants keep telling me that they don't have enough time to do their job. I believe their concerns as staff dash around and I struggle to talk to them about the study or I feel like a burden. They tell me they don't have time to even read the information sheet and I struggle to book interviews as I need access to the rota (which requires the charge nurses help now that the clinical nurse manager has left). When I do book in interviews in advance with participants (also informing their senior staff) they can get cancelled as the ward is short-staffed or they have forgotten (even though I double checked to book it in a recommended quieter time in the day). It also interests me that the participants are still included on the rota for the hour they are booked to meet me. When I do manage to take participants off the ward for their interview or for training, a senior nurse will sometimes interrupt saying that they need them to come back onto the ward. Furthermore two participants who initially signed up to the study withdrew due to feeling that they did not have enough time. Interestingly I was able to get participants off the ward in groups of two or three for training despite them saying going off the ward was difficult due to low staffing numbers. Also on the day of the last interview I came to meet with a participant and their colleagues told me that she was stuck on a one-to-one patient observation and that they did not have time or enough staff to let her come off the ward for the interview. I queried this with the senior nurse and they just seemed to click their fingers and made time for the participant to come off the ward. I was left wondering whether there was time or not for this study or whether it just depended on the value that the organisation placed on what the time was needed for. I am also curious about the impact of the loss of the clinical nurse manager and band six OT on the collaborative PAR element of this study which is lacking now.

Figure 9. Reflection on the Sense of Time and Ward Values when Gathering Data

4.2.2 'Us versus them': CSWs positioning of their role

Many participants felt that their role within the culture of the unit put them at a disadvantage to being able to implement LSW. Staff felt undervalued by colleagues, that they were left out of decision-making and that their views were not listened to due to perceived role boundaries and a lower ranking compared to colleagues. This adds to literature stating that care staff are largely unrewarded for the increasing demands within their role (Spilsbury & Meyer, 2004) that they perceive themselves as having a low status in relation to others, that they are often uninformed about organisational changes, are unrecognised in their expert knowledge about some patients and are not included in multi-disciplinary ward rounds and decisions leading to a low sense of autonomy (Lloyd et al., 2011; Schneider, 2010; Firth-Cozens & Cornwell, 2009). They were also said to experience low levels of respect from those external to their group and/or more senior, leading them to feel disregarded and marginalised. Staff felt that their unqualified status on the unit in comparison to colleagues impacted on them feeling undervalued and mentally stressed which supports research showing that care staff negatively interpret the term 'non-qualified' as 'non-qualified' equates to 'unskilled' in many care cultures (Bailey et al., 2015), leading to tension within the expectations of the role as care staff experience the role as complex and requiring a high level of skill (Moyle et al., 2003). Participants spoke about feeling that senior staff did not care which CSW did what task which supports Bowers et al., (2003) who found that senior staff use dismissing styles of management such as minimising and undistinguishing care staff's distinct experience and level of skill, leading them to feel that their role did not matter or that anyone could do it. These factors contribute to feelings of disempowerment stated in this study and that CSWs lacked control to implement LSW or that there was not much point in doing so, especially without senior leadership. As Schneider et al. (2010) also found, this is

unfortunate as some CSWs in this study also felt they knew patients better than other staff and were best placed to carry out LSW and yet may feel that what they do does not make a difference (Moyle et al., 2003). These factors cause concern for the ability of care staff in this unit to adopt PCC as Kitwood (1997) stated that staff need to feel respected and valued within the organisation in order to reflect this back in their care, and Brooker (2004; 2007) argued that the organisation needs to meet the 'valuing people' element of the VIPS framework. This is especially pertinent when applying the principles of relationship-centred care such as the sense of 'significance' in the 'Senses Framework' Nolan et al. (2006). This would have been promoted more if the PAR aspect of the study had been fully implemented.

Participants generally felt undervalued and unrecognised by those outside of the organisation as well, with many saying that people 'outside' did not know or understand what happened on the unit. Participants also discussed being asked how they could do the role. Schneider (2010) supports this idea that important aspects of the care staff role are not widely recognised and that the general public, patients' relatives and colleagues should be supported to be made more aware of care staffs' contribution to care in order to increase their role status. Schneider et al. (2010) said that the question of how staff could do this job was a common one and that it was a form of demeaning the role (Ashford & Kreiner, 1999) as it is an occupational area that is stigmatised and viewed as 'dirty work' (Hughes, 1962) due to it being perceived as degrading. Participants' use of the term 'outside' indicates that they aligned themselves together as a collective identity or group of 'insiders' which is in-keeping with literature that suggests the negative view of the role encourages a strong occupational identity (Kontos et al., 2009; Schneider et al., 2010) and that care staff form a subculture (Ashford & Kreiner). Lloyd et al. (2011) found that care staff positioned themselves as a close-knit 'in-group of frontline experts

in care who shared low status and were distinct from 'outsiders' to the role. Doing this helped participants to feel more supported day to day as they relied on their colleagues. This fits in line with the Social Identity Theory (Tajfel, 1978; Tajfel & Turner, 1979) where care staff's identity is defined in terms of group membership and they strive to maintain a positive identity and increase their self-esteem by making favourable comparisons between their in-group and relevant out-groups. Participants in this study were found to do this as evidenced by their negative comments towards doctors and charge nurses as well as with agency staff, indicating that agency staff were sometimes viewed as strangers and that they knew better than agency staff. This negative dynamic with agency staff has not been focussed on in the previous literature. Despite the negativity related to the role, participants also voiced enjoyment and pride in their role and stated that 'someone had to do it'. This supports the Social Identity Theory as well as the concept of 'dirty work' (Hughes, 1962) whereby a marginalised group are able to secure social affirmation even when it is denied by their organisation or society.

The stress, heavy workloads, and undervaluing experienced by staff in this study can explain why staff feel burdened and burnt out which supports the literature on this and as well as that it can cause low job satisfaction (Brodaty et al., 2003) leading to a negative effect on staffing numbers (Bowers et al, 2003) as dissatisfaction is dealt with by absenteeism (Moyle et al., 2003). This explains the heavy use of agency staff on the unit which is a common occurrence due to understaffing issues (Royal College of Nursing, 2013).

The use of agency staff impacted on regular staff's ability to implement LSW as they had to take on more documenting and risk management (due to new agency staff's lack of awareness of ward risks) which enhanced burden levels. This is a paradox and an

example of a vicious cycle as participants said they could not implement LSW and be as PCC as they wished due to low staff numbers and yet when new staff were brought in this also made implementation hard. Furthermore previous research suggests that LSW reduces burden (Haight et al., 2003). Participants were also concerned about the sense of having strangers on the ward which is a novel perception but is supported by literature that low staff continuity is said to impact negatively on PCC, as staff cannot get to know PwD on a deeper level and use this to better inform their work (Edvardsson et al., 2010) which builds supportive social psychology and affirms personhood (Downs et al., 2006) in-keeping with Kitwood's (1997) idealised care. Participants seemed keen to maintain equilibrium and consistency which supports literature that this keenness is related to higher agency staff usage as this brings unfamiliarity, and care staff seek to maintain relative stability across wards (Schneider et al., 2010). In terms of models of PCC and relationship-centred care such as the Six Senses (Nolan et al., 2006), agency staff make it harder to fulfil the senses of 'continuity' and 'security' on the ward for both patients and regular staff which would lead to an enriched care environment. Also an influx of unknown staff can threaten staff's sense of 'belonging' as the ward may not feel so familiar (Nolan et al., 2006). Bowers et al. (2003) also discussed how organisational reliance on agency staff was seen as a form of dismissing the value of the role to regular staff who had specialist skills due to their experience on the ward. Agency staff were said to lack familiarity with the patient group and regular staff could feel that their organisation viewed them as interchangeable with agency staff and that the organisation only cared about staff numbers and not staff skill. Bowers et al. also stated that new staff could be ill-prepared for the role, as supported by this study as participants felt burdened helping to support unfamiliar agency staff.

Participants spoke about other staff not wanting to engage in LSW due to it being something different. Menzies-Lyth (1988) wrote about an avoidance of change as a defence against anxiety as change is unpredictable. This explains why participants viewed some colleagues as clinging to less PCC practices despite having received training on PCC principles, as their old practices were familiar and less anxiety provoking. Ultimately staff acknowledged the usefulness of LSW on the unit to address issues with unfamiliar staff implementing PCC as it would mean that agency staff and patients would no longer be strangers. This supports LSW literature where LSW is used to compensate for unfamiliarity between PwD and staff (Moos et al., 2006; McKeown et al., 2010; Clarke et al., 2003). See figure 10 for a reflective account of this topic.

I wonder about how honest the CSWs feel they can be with me as their sense of identity as a group means that I am an outsider. Perhaps they think I do not understand their role, which is why I have felt it important to mention that I have worked as a support worker in dementia too. I sometimes feel like I am just another stranger who pops onto the ward, disrupts the routine and leaves again. I wonder how this impacts on the rest of the shift. I sometimes feel guilty interrupting participants even when I have an interview booked with them as they are busy with tasks. Even the remaining co-researchers are outsiders despite them working in the unit, as they are not seen as part of the nursing staff to the CSWs (like the clinical nurse manager was) and lack authority to make nursing management decisions. Perhaps this is why they do not seem to be able to effect much change or are not seen as leaders to the participants.

Figure 10. Reflection on In-Groups and Out-Groups: CSWS versus Co-Researchers and the Researcher

4.2.3 An altered view of the patient with dementia.

Participants expressed a need for LSW on the unit to allow staff to find out more about patients and provide conversation starters, as communication with PwD was seen to be a challenge without knowing anything about the individual. This supports literature stating that the primary challenge for staff in trying to meet the needs of PwD is learning how to connect with them and build relationships, often in the absence of verbal communication (Bailey et al., 2013), as well as that LSW enhances communication between staff, patients and relatives (Wills & Day, 2008; McKeown et al., 2010; DoH, 2009, p. 58).

CSWs perceived engaging with PwD as important, in-keeping with the biopsychosocial model of dementia that psychosocial as well as physical needs are viewed as important, for example core values of inclusion, comfort, and attachment can be achieved through communication (Kitwood, 1997; Brooker, 2007). This would in turn help to maintain personhood. However, participants seemed confused about whether PwD on their unit still had personhood as many said that patients were spoken about or seen as a 'blank canvas' or 'body' (by either themselves or other staff) and that it could seem like wasted time trying to communicate when it was not seemingly acknowledged or reciprocated by patients. This is congruent with the debate in the literature about whether dementia causes personhood to gradually be lost until there is nothing left of who the person was (Davis, 2004) or whether personhood is progressively changed and hidden but not lost (McCormack, 2004; Kitwood, 1997; Kontos, 2005). Overall staff supported the view that patients' identities were not lost which is a common perspective from care staff who attempt to see beyond dementia and the positioning of the individual as a sufferer of an illness (Twigg & Atkin, 1994) to the person (Clarke et al., 2003;). This is said to motivate an ethical duty to provide care beyond basic physical tasks

(Edvardsson, et al., 2008) however when in doubt this has implications for seeing the need to go beyond basic care as they can be seen as just a body, as in the traditional medical model (Kitwood & Bredin, 1992). Another factor which lessened motivation to engage in LSW for one participant was their view on PwD as being incurable due to dementia being seen as a disease. This fits with the medical model and indicates that perhaps some staff still see dementia care as a form of 'warehousing' until a medical cure is found for these untreatable patients (Miller & Gwynne, 1972).

The way PwD were referred to in this study (such as a 'shell', 'body', or 'number') adds weight to literature on care staff depersonalising or detaching from PwD (Menzies-Lyth, 1988) as a way of coping with the emotional challenges of the role. This is interpreted as a form of malignant social psychology (Kitwood, 1997) however participants attempted to combat this and see past the 'shells' of PwD. The occurrence of this was enhanced when there was a lack of biographical information about the individuals to combat this, therefore, LSW can be assumed to help reduce use of these strategies and in turn reduce malignant social psychology. Participants felt that use of these strategies was also enhanced by constraints of the task-based organisational culture, for example in handovers there was little time to talk about individual patients as people and so they were referred to as numbers. This is supported by Badger, 2005, Astrom et al., 1990, and Peters et al., 2013 who said that focus on daily tasks and technical aspects of care can serve as a mechanism to avoid emotional challenges of the role.

The need for reciprocity in communication was important and symbolised presence of personhood. Literature speaks about the relatively unusual levels of reciprocity in PwD and that they are not often in a position to express appreciation or acknowledgement for the efforts of staff due to communication deficits (Schneider et al.,

2010). This poses challenges as care staff are shown both in the literature and in this study to gain satisfaction from small gestures such as raised eyebrows as these are viewed as expressions of the humanity of patients or the human behind the impairment and counters the sometimes de-humanising effects of institutional care (Bailey et al., 2015).

A topic of discussion regarded participants wanting to be able to engage in LSW directly with the patient as opposed to gaining information from other sources. Some felt that unless patients remembered their own biography then discussing it was pointless. This contrasts with Kitwood's (1997) theory whereby those around the person with dementia bestow personhood onto the person using new found life story information (Davies, 2004). It also contradicts other literature where carers are encouraged to 'show' the personhood and worth of their relative and recognise who they are when the person with dementia is unable to share the information themselves (Smebye & Kirkevold, 2013; McKeown et al., 2010). This lack of understanding most likely results from a lack of training on the rationale for LSW.

Only some participants spoke about a significantly altered perception of the patient post-LSW, which supports Batson et al., (2002), Clarke et al., (2003) and McKeown et al., (2010) who also found that staff made allowances for patients' aggression and learnt to see past it due to knowing their past personality and life history. This related to participants having more empathy which also adds to the literature (Egan et al., 2007). Only some participants spoke of a changed relationship or style of care. One participant felt conversations were aided but others ultimately felt that nothing had changed post-LSW implementation. The results therefore partially fit with literature on the benefits of LSW for both patients and staff but are less optimistic. However, the findings support McKeown et al's. (2006) systematic review of LSW literature who

stated that despite overwhelming positivity for LSW there was disparity regarding the impact it had on staff attitudes and practice as a consequence of knowing more about a person's life. For example, Hansebo and Kihlgren (2000) did not find that all care staff agreed that knowing about a person's history had an effect on how they cared for the person in the present, as one participant felt there to be no change. The culture of the unit in the current study was not very person-centred and care staff were part of that, therefore they are more likely to see LSW as less helpful, whereas if the culture shifted in its attitude towards LSW, this would likely change.

A vicious cycle also seemed apparent within this topic. This involved participants holding beliefs about PwD having poor communication abilities, there being a lack of reciprocity in staff-patient engagement, and participants having a lack of biographical information to use as communication tools. This meant that doubts occurred regarding patients' personhood being present, reducing motivation to engage beyond basic care and to implement LSW. However, LSW is found in the literature to enhance these factors (Wills & Day, 2008; McKeown et al., 2010; DoH, 2009, p. 58) therefore it is a paradox that LSW implementation is stopped from being used due to the issues that it could help resolve.

4.2.4   A sense of hope: getting past the barriers.

Despite participants focusing on personal and organisational barriers that stood in the way of implementing LSW and PCC as well as hoped for, all were able to gather some life story information which had a varying impact on them and patients. Participants generally felt they could be person-centred at times, though this was expressed more so before LSW implementation as the study highlighted how hard it was to be person-centred in the role which accounts for the more pessimistic views post-

LSW. Protected time was not available so a need to be flexible and persistent was required. The ability to make a conscious decision to seek out time and maximise free moments to provide PCC seemed the most apparent reason for how this occurred in the face of time constraints. This also involved making the most of basic care tasks, however participants perceived not all CSWs as choosing to do this. This supports Clissett et al. (2013) who worked in line with Brooker's (2007) framework of PCC which encompasses aspects of: attachment, inclusion, identity, occupation and comfort. They found a common theme of missed opportunities where care staff did not maximise chances to connect with patients and PCC appeared to occur in "pockets as a result of individual practitioners" (p. 1502) where some staff seized moments to talk to patients as and when they could to attempt to meet their needs of inclusion. The balance between emphasising the need to complete tasks and the need to develop positive relationships with patients requires reviewing so that it becomes more important for the task to be experienced as positive as opposed to just completed proficiently (Edvardsson, Sandman, & Rasmussen, 2008). This suggests that participants could reframe the purpose of basic care tasks to be more about relationships (and as an opportunity for LSW) as patients need their physical care needs met but not over and above their emotional needs.

Participants were motivated to be person-centred by imagining themselves or their loved ones in the person with dementias' position, or imagining patients as if they were their relatives. This supports recommendations in literature, for example the Alzheimer Society (2013) tells dementia carers to put themselves "in their shoes" (p.93) as this fits the PCC principle of trying to see things from the perspective of the person with dementia. This also supports Tronto's (1993) theory of responsiveness in good care which is a two-way process between the carer and person with dementia, allowing carers to understand the person with dementias' experience (aided by greater biographical

information). The results also support Badger (2005) who found that a cognitive strategy called visualising was used to enhance empathy in nurses which involved imagining patients as if they were their relatives. This idea also links to participants' sense that they felt everyone was vulnerable to dementia. Literature suggests that this belief may cause care staff to utilise psychological strategies to cope with their likely death anxiety as it is a reminder of their own mortality (or that of those they love) (Peters et al., 2013). The consequence of using these is often a reduction in PCC due to staff using detachment strategies (Schneider et al., 2010; Menzies-Lyth, 1988; Badger, 2005) but in this study the reverse occurred as it enhanced care practice. Therefore a balance is required between using strategies such as visualising in order to enhance PCC and then protecting oneself from the emotional burden of attaching to people who are likely to move to other care settings or die, as participants experienced thinking about certain patients when not at work, especially those of a similar age to them. This experience is consistent with literature which discusses how a crucial skill for an effective care staff is to be able to selectively use strategies which could be seen as part of a malignant social psychology in Kitwood's (1997) observations, whilst remaining emotionally available for work rewards (Schneider et al., 2010) and to be able to maintain the personhood of the person with dementia (Bailey et al., 2015).

4.3 Critical Appraisal of the Current Study

A critical appraisal of the strengths and limitations of the current research is offered below.

4.3.1 Use of elements of a Participatory Action Research approach.

The use of elements of PAR were not achieved as hoped for which negatively influenced the amount of LSW carried out. However, this is not seen as a limitation as it demonstrated the influence and strength of the barriers which were identified as

impacting on the researcher and service's ability to implement the life story work. The difficulty in implementing a more PAR informed approach in many ways mirrored the difficulties faced within the context such as it being constrained, leading to the inability to implement the actual intervention of life story work, which is one of the key findings.

The chosen unit was not the preferred site for this type of research (see Appendix P for a description of the processes involved in choosing the research site, the challenges associated with this and how they impacted negatively on the incorporation of PAR elements) and many hierarchical organisational and workplace culture constraints impeded the use of PAR concepts. Once the lead co-researcher (the clinical nurse manager) left (as well as the band six OT) there was no motivated leader of the research from inside the nursing team to promote the LSW from within and no one to liaise with regarding small but important details such as rotas and authorising protected time for LSW. The remaining two co-researchers, despite being enthusiastic about the LSW research, had been slightly less dominant in initial study discussions about ideas for its development, and in reflections about their organisational system and work practices. They were seen by the CSWs as outsiders and more removed from the CSWs, unable to exert management in their role (as this was the role of a charge nurse). The co-researchers also had their own duties and as a result did not have enough time to make up for the loss of the clinical nurse manager, who was the most senior staff member, in terms of promoting the study (and the loss of the band six OT was also felt). Therefore, the LSW was not as collaborative with stakeholders and CSWs creating the life story boards as hoped for when trying to use aspects of technical PAR. LSW was promoted more from outside of the care service and organisational culture (predominantly by the me, as the researcher) and I perceived myself to be viewed by the CSWs and the wider team as an outsider, even more so than the co-researchers chosen (see reflection in figure

10). These issues are a concern in terms of what literature says about what is necessary for organisational culture change so that LSW has a chance of being embedded into normal practice (see section 4.2.1 for literature to support this). The lack of being able to use elements of PAR meant that this study had predictably negative results in terms of being able to carry out LSW, by making many of the same mistakes seen in other studies that attempt and fail to implement LSW without considering stakeholder collaboration and investment. Therefore, one of the key barriers to implementing LSW on top of the organisational culture and specific role barriers discussed in the preceding sections, was the lack of ability to fully incorporate the participatory and truly collaborative concepts of PAR, and it did not seem that participants had true ownership of the LSW.

A strength is that the consultant psychologist co-researcher did collaborate on parts of the study design, training, and analysis (in terms of credibility testing) and the dissemination plans, and CSW participants had some input into board design. Furthermore, the struggles to implement aspects of PAR determined the development of theme one in the data analysis as they were testament to the impact of organisational culture barriers. See figure 11 below for a reflective account of use of the PAR approach.

> *Since the lead co-researcher left the service, as well as the senior band six OT, I have been worried about how motivated the unit will be to carry out LSW. I feel that to adopt PAR is to be collaborative and to have motivation from within the service to want to do the research. I do feel this from the clinical psychologist co-researcher but overall I feel that I am the one driving the research forward as I have more time but I lack authority within the unit. It seems important for the charge nurses to be invested in the LSW as they make decisions about rotas and protected time and I am trying to liaise with them more but this is proving difficult as they are busy and have not seemingly been that aware of the study from the start and do not seem engaged with it (despite having been emailed and spoken to about it by myself and the co-researchers). I am unsure if they know I am the same NHS banding as them and I wonder if this would make them value my opinion more if they knew that I also worked clinically. For now it feels that the CSWs will struggle to feel empowered by this study as there is no one collaborating and leading it who they see as inside their group. I will try to empower them by making the life story board training as collaborative as possible and I will stress that I want to give a platform for their experiences in the interviews.*

Figure 11. Reflection on the Use of PAR

4.3.2 Sampling.

All CSWs on the unit were given an equal opportunity to participate, reducing the chance that only those who were already more person-centred participated, however some were lost before they were consented and so there is a chance that the most motivated and person-centred did end up participating. It would have been of interest to have information regarding why potential participants and other CSWs decided not to

participate. The sample size is not seen as a limitation as it was a challenge to recruit the number of participants necessary to reach an acceptable number and two withdrew, so the researcher would have needed more time if they were to expand the sample. Participants had varying ages and levels of experience in the role which reduces bias as age, level of experience and time in role can affect levels of PCC and burn-out (Brodaty et al., 2003). The lack of demographic information of the group to be able to situate the sample and fully assess transferability of the results to similar research is a limitation but providing this may have jeopardised anonymity of the small participant group. The study recruited six CSWs from one ward and only one from the other ward so having more equal numbers of participants on both wards would be beneficial to feel that both wards were attempting to embed LSW into practice. However more time would have been required. It would have been useful to have recruited more NHS employed agency CSWs as one theme conceptualised attitudes towards agency staff. Only one agency CSW participated and they progressed the furthest with their board so it would have been helpful to see if this was related to being an agency worker. The chosen inclusion/exclusion criteria were necessary as the researcher needed to choose CSWs who were available for all aspects of the study (which proved challenging even for regular CSWs) so recruiting non-NHS agency staff and night shift staff would not have been feasible. The impact of the factors above is limited as the qualitative approach from a critical realist perspective does not intend to generalise results to all CSWs working in inpatient dementia care and data are only intended to represent the experiences and co-constructed understanding of the present sample and the researcher. In terms of co-researchers, a major limitation was that an appropriate replacement for the clinical nursing manager was not found who could be perceived as an insider to the CSW participants, however this was challenging given time constraints.

4.3.3 Interviews.

The interviews were designed to be sensitive to the perspectives of this marginalised group by being semi-structured and therefore flexible for participants to be able to tell their story. Some participants said the interviews gave them an opportunity to have their experiences heard, making them feel more valued and recognised in their role. This is a strength however some may have seen the interviews as a burden on top of existing duties. To counter this issue the interviews were held at their place of work during their shifts. This allowed the researcher to talk to participants immediately after they had been absorbed in the workplace culture and they were able to reflect on emotional responses to events having occurred during that day. However limitations of this were that it was harder to get participants off the ward for the interview and the interviews were more likely to commence late. Some staff may have been worried about being overheard as they were still at work and this was likely emphasised as senior staff occasionally interrupted the interview. Therefore they may have felt less able to relax and be honest. These limitations however reflect the day to day reality of the role and workplace culture.

It was explained verbally and in writing that the researcher was a trainee clinical psychologist. However there is a risk that not all understood this role and what NHS banding it was and this may have impacted on their accounts in terms of power dynamics and language used when discussing their experiences, as feelings of inferiority related to their NHS banding were common in the themes. There is also a risk that the pre-LSW interview data were more positive as the participants were mindful of wanting to appear enthusiastic to the researcher, despite it being explained that their honest views were sought.

Prominently, a major limitation of this study was that no participants reached the stage of making any boards to put on display so the impact of their presence could not be explored fully in the post-interviews. Participants felt that more time was needed to attempt LSW implementation between the pre and post interviews, as implementation was slow and was affected by staff sickness and annual leave for example. However there was no extra time available for this stage of the study due to factors relating to Appendix P. However, the researcher's hypothesis was that even if more time was given, the barriers to implementing LSW would have remained and so perhaps not much more progress would have been achieved.

Particular strengths were that participants were interviewed on two occasions, giving them time to reflect on their experiences. The interview guides were also refined in partnership with the co-researchers, in keeping with the PAR informed approach.

4.3.4 Training.

A major strength of the study in general was that all participants were trained in a new approach to PCC. After life story board training all participants said they felt equipped with adequate knowledge to start implementation and felt that there was enough structure, whilst it also being flexible as the format of the life story boards was collaboratively decided with them in line with using elements of PAR. A possible limitation is that some participants (with or without guidance from the co-researchers) chose a patient to create a board with that they already had a good rapport with or some life story information resources on, possibly in order to make the task easier. This is understandable if they already felt burdened but meant that at least one participant felt they had not learnt anything new post-implementation and so did not feel that it enhanced PCC or their relationship.

4.3.5 Data analysis.

The study was a small-scale qualitative design taking place in an NHS inpatient dementia setting and so the results cannot be generalised to all dementia settings and care cultures which is a limitation of the study, alongside other qualitative studies. Furthermore, the data are derived from the perspectives of just one group of CSWs on the unit, who may have different views and positions within the organisational culture compared to other CSWs. However, this study has identified the complexity of this topic and the results offer rich descriptions and interpretations into the experiences of CSWs and the organisational context and may also be transferable to other studies which attempt to implement PCC tools such as LSW in similar settings with care staff using elements of PAR (Lincoln & Guba, 1985). The methodological rigour of the study is considered in the method chapter and a strength of the analysis was that it was conducted in line with these plans. Transparency is demonstrated through the focus on clarity of the presentation, through use of data extracts throughout the results chapter to show that theme development is grounded in the data, and through evidence of the analytic steps taken in the Appendices. This helps to achieve coherence. The researcher also moved back and forth between the transcripts and the recordings during coding and theme development to ensure sensitivity to context and coherence. Analysis was thorough as shown by the number of codes generated, however this is also seen to be a limitation as discussions in supervision indicated that the researcher could have coded more broadly and concisely. See figure 12 for a reflective account of the use of supervision during analysis.

> *It is a struggle to make decisions regarding the keeping and rejecting of codes and it is difficult to cluster codes into defined themes without them overlapping as I feel they are interconnected due to the nature of the topic. I wonder if this is because my coding has been too in-depth and not broad enough, which was discussed in research supervision. I felt that I wanted to equally represent every participants experience and not leave out anything as I had been immersed in the setting for a long time, struggled to gain the data, and wanted to give each participant a voice as I knew they felt unrecognised and unvalued. I have also been finding it hard to interpret the data without linking it to existing knowledge of the area. I think supervision is guiding me to balance having an open mind to new information whilst having knowledge of the topic. Also the research question is very open which means that I am not discarding much irrelevant information to the question but this may also be why it is harder to discard codes.*

Figure 12. Reflection on the Use of Supervision during Data Analysis

In line with a critical realist approach, it is accepted that the researcher's perspectives will have influenced the research process and that this interpretation of the data may be different to someone else's. The use of reflexivity is consistent with the critical realist approach and this is a strength as it helps the researcher to own their perspective and get closer to an understanding of the reality of concepts such as PCC. Research supervision aided reflection of the researcher's position, assumptions, and the effects of these throughout the research, especially during the development of understanding during data analysis. A reflective diary was kept throughout and reflective statements informed by this have been interwoven throughout the thesis which aid

transparency and allow the data to be considered within the context of the researcher's perspective.

In terms of credibility, research supervision with two supervisors was used throughout which provided a 'verification step' (Braun & Clarke, 2013) allowing for multiple feedback on the quality of the analysis and also to inform the researcher of where their interpretations made overstated claims of the data. A qualitative research forum was attended throughout the study and member checking with the co-researcher clinical psychologist was also used.

4.3.6 Dissemination.

A strength of the study is the planned dissemination of the research. All participants were offered a summary of the research via email. There are plans to disseminate a written summary of the results of the study and the implications of these to the co-researchers and service managers of the unit. Collaboration with the lead co-researcher as to how best to disseminate more widely is also planned. This is in-keeping with the 'study' and 'act' aspects of the Plan, Do, Study, Act (PDSA) cycle (Langley et al., 2009) on which PAR studies are often based. There are also plans to publish the research in a peer-reviewed journal.

4.4 Implications for Clinical Practice

The results from the present research suggest a number of important implications for how to implement LSW in clinical practice.

4.4.1 Choosing a research setting for life story work-assessing the organisational culture.

This study has demonstrated that there is a clear need to identify what the unwritten as well as written rules and values of the culture of organisations are before

implementing LSW. Having a clear idea about the staff hierarchy, organisational changes, agency staff use, current financial pressures and resource availability is also beneficial as these factors can strongly affect implementing LSW despite it being strongly recommended. The medical model still seemed dominant on the unit chosen in this study despite the unit holding PCC principles and staff having PCC training. Therefore, it was likely to be harder to adopt PCC strategies such as LSW when PCC is seen as the ideal but not always the reality. By identifying the above factors before choosing a research site researchers are better placed to understand organisational readiness to adopt LSW and can assess whether there are senior staff available to empower more junior staff to be person-centred.

4.4.1.1 Choosing a research setting for life story work: the patient group.

This study showed that CSWs experienced difficulty implementing LSW with people with severe dementia and challenging behaviour, and some patients moved to other facilities or died. They suggested using LSW on assessment wards with patients with less severe dementia however they also said that this would not be ideal due to the even quicker patient turnaround on assessment wards. This implicates that there is no ideal inpatient setting to research LSW implementation as there are challenges regardless, and that LSW success is partly about how it is adapted to different stages of dementia. However, research into LSW with severe-end dementia is said to be lacking and there is more research on PwD who live at home, in residential care homes, day care facilities, and with people with mild to moderate dementia.

4.4.2 Stakeholder buy-in and leadership- implications for incorporating elements of PAR.

Consistent with the previous literature it is clear from this research that without buy-in and motivation from stakeholders such as management and senior nursing (who

are willing to act as co-researchers) that LSW will be a struggle to implement as senior staff shape the values of the organisational culture. Researchers need to identify strong leadership/co-researchers from staff who are committed to LSW and PCC values and have the time, authority and resources available. They need to be identifiable staff who are within the unit (and seen as 'insiders' to care staff) for participants to approach for support as and when needed, as this study has clearly shown that there are negative implications if those promoting LSW are perceived as outsiders by those carrying out the research activity of making life story boards. This could be the case if the co-researchers themselves are viewed as outsiders, or if the situation arises (like in this study) where promotion of LSW was done more by an external researcher who is clearly an outsider and stranger to the research setting, despite trying to collaborate on several aspects of the study. Co-researchers also need to be present on the wards, motivating and being interested in the LSW as it progresses. Strong leadership of this kind also increases the likelihood that LSW is something that becomes part of daily conversation during handovers and team meetings, and so participants feel more able to talk about their LSW progress and findings with colleagues and gain more support from them in terms of moral support and help with gathering life story resources and information. Therefore, it is important to take time at the stage of setting up the study to identify reliable leaders/co-researchers and be collaborative with them. Using a practice development approach or aspects of PAR are still recommended as the best way to make these changes, as long as leadership is chosen appropriately and remains in place throughout the research process as these approaches rely on stakeholder collaboration and commitment to want to push forward service development via research, as opposed to having research done to or for them by outsiders. This gives LSW the best chance of

being embedded in routine service delivery and staff carrying out LSW to have some sense of ownership of the work.

Participant accounts post-LSW said that they would have valued a meeting with the researcher, co-researchers, and the charge nurse as participants identified charge nurses as the best leaders for the LSW and felt that a meeting could have ensured that all levels of staff involved had communicated with one another. Recruitment of a charge nurse from each ward would therefore be beneficial to better implement LSW.

4.4.3 The role of clinical psychologists and other healthcare workers in influencing change in healthcare cultures.

This research raised wider questions and implications regarding how best for clinical psychologists and other care professionals to engage with multi-disciplinary teams in order to maximise team working and enable effective change in cultures of care, such as by enhancing PCC. Clinical psychologists (such as the lead co-researcher) are trained with specific skills to improve outcomes for team working such as by thinking about and offering leadership in promoting effective team design, service planning, peer consultation and supervision, reflective practice, teaching, training, research, evaluation and development, and involving service users and carers. Furthermore, I, as a trainee clinical psychologist am in the process of learning these skills. However, we struggled to enact much change in the form of increasing PCC ways of working. The 'new ways of working for applied psychologists in health and social care' document created by the Department of Health (2007) suggests that psychologists need to integrate more within teams so that they have more opportunity to influence others and offer an "authoritative and constructive counter-balance to the medical model" (p. 3). Being in teams can also give psychologists more credibility and thus legitimacy from other professionals. For

example, one study discussed in the document described how psychologists attended

inpatient older adult wards regularly to be available to staff and promoted

psychologically informed practice within person-centred principles. The resource, which

was primarily used by nursing staff, was viewed as an effective and valuable method of

raising the accessibility and responsiveness of psychologists and psychology into

inpatient settings, thus integrating their unique role within the team and raising

credibility (specifically with nurses who hold a powerful position on wards). This full

integration of myself, the co-researcher psychologist, and the OTs was not apparent in

the service in which this research took place, largely concluded by our 'outsider' position

relative to the CSWs. This is described in the new ways of working document, which

states that separation of our role, and of other care professionals who wish to lead on

influencing changes to culture can cause team members to not listen and find it easier to

dismiss and stereotype us. Furthermore, the document outlines how psychologists need

to hold the necessary authority and resources to achieve any defined objectives they set

in dialogue with the teams they are integrated with. These attributes were lacking in the

implementation of LSW in this study which would need to be addressed in future if

psychologists and other non-nursing professionals are to have a chance of being more

successful in promoting LSW.

4.4.4 Training.

This research suggests that some participants and their colleagues were confused

about what PCC was and looked like in practice suggesting that training on LSW should

firstly give a clear outline on PCC before moving onto the rationale for LSW as a tool to

enhance PCC. Alternatively, having an initial training session on PCC to set the

foundation for LSW in the care setting would be beneficial so that the researcher is

firstly targeting any underlying lack of understanding of PCC. Training on the need for

staff to maintain the personhood of the person with dementia as opposed to them doing it themselves is also necessary in severe-end dementia settings, as well as discussion around maximising windows of opportunity to be person-centred and to do LSW (such as during basic care). All levels of the organisation should be trained about LSW as well as participants, for example bringing in senior nursing staff into training sessions so that they are more aware of what participants are expected to do. This would also make senior staff more of a visible and supportive presence to participants. LSW training needs to stress how it is different to other approaches tried so to encourage those who feel that all interventions are the same to participate.

It would be beneficial to encourage participants (and co-researchers supporting this choice) to pick a person with dementia to do a board with that they know less about so greater changes to relationships and PCC may be seen. Encouraging participants to not be too perfectionistic about how they put life story information on the boards should also be done as it may encourage more participants to progress from information collection to board presentation, as some participants in this study said they were waiting until they had enough information so that the board would look good enough (which can then delay other staff benefiting from the board being on display).

Addressing defence mechanisms and coping strategies would be beneficial as the study interpreted some staff behaviours and barriers to be as a result of these. However if staff felt more skilled, confident, less burdened and had more life story information on patients then they may rely on these less.

It is important that boards designed in future research can be flexibly taken off walls and taken apart into smaller pieces to aid their use day to day on the ward by staff and patients.

4.4.5 Factors related to the clinical support worker role.

A clear implication of this research is the lack of empowerment CSWs feel as a group. Skilling up CSWs to be more person-centred and involving them in research increases the likelihood of them feeling valued and qualified in their role. Senior staff need to follow relationship-centred care values by understanding that their staff will struggle to provide PCC when they do not feel that their personhood is being valued. Senior staff should celebrate CSWs role in promoting PCC and LSW which would increase awareness of the role to the public, patients' relatives and other professionals and hopefully enhance role status. Senior staff could make LSW more of central topic during implementation by allowing participants to update the team on progress during handovers and meetings which would also target their feelings of inferiority due to sometimes feeling unrecognised in their knowledge.

The study indicates that it would have been easier to recruit participants once they had completed their mandatory work training to increase likelihood that they had more free time to commit to LSW, as well as encouraging participants to start implementation when they do not have upcoming annual leave. The study also suggests that encouraging more NHS agency employed staff to take part would be beneficial as they have fewer demands placed on them in terms of clinical documenting duties. This may help reduce the in-group, out-group divide between regular staff and agency staff if they are both working on a single project to enhance ward care.

4.5 Suggestions for Future Research

This study offers the following recommendations for future research regarding implementing LSW in inpatient dementia care settings. Primarily, future research should ideally maintain a focus on the life story board format as this is still a less researched

method and one that was prevented from being fully explored in this study in terms of the boards being created and presented on the wards.

Focus on the more severe end of dementia care as well as acute inpatient care is suggested as this is less researched. Staff in these settings often lack life story information for patients which suggests that it is not always carried out before PwD come into their settings. Therefore, research should not neglect this setting as it may be a good opportunity to gather information if it has not been done before.

This study supports the disparities in the literature regarding that although LSW is beneficial, research into LSW is not wholly positive and focussed on benefits to PwD and staff. There are many organisational and personal staffing issues and some care staff do not experience changed attitudes or practices. Therefore, the area needs more studies into these issues as opposed to only evidencing that LSW is useful for PCC, so that practitioners and service developers are more equipped to tackle barriers. Specific focus on how practitioners can shift barriers in healthcare cultures at an organisational level to be more amenable to PCC is also encouraged as this was a key theme from this research.

Future research should rely less on bringing in dedicated staff to implement LSW instead of using existing care staff as this limits opportunity to learn how to get past barriers for existing care staff taking on this task (who know the patients best, are keen to expand the remit of their role and feel more empowered). It also limits learning into how service managers can improve resource management and leadership skills in order to promote recommended interventions within constraints. Furthermore, it also causes a stuck position when services wish to do LSW, look to the literature, learn that they need extra staff, and do not have the resources. Using aspects of PAR or practice development approaches should continue to be a recommended way to carry out future LSW

intervention research, and applying aspects of these approaches when researching how to shift care cultures at the level of the organisation to make them more open to adopting PCC is encouraged. However, researchers need to be clear as to which aspects are in-keeping with these approaches to ensure that there is enough participation and collaboration at both/either the design/planning or action/intervention stages to credit the research as using elements of these approaches.

Further expansion of some of the less developed ideas that have been uncovered by this research would be of use, for example asking more about care staff role boundaries, their sense of their role as being 'dirty work', and the in-group, out-group dynamics of them versus other professionals and agency staff. Future research could include more agency staff (NHS employed who work regular day shifts) to supplement this. Informally interviewing CSWs who did not wish to participate in research would have expanded understanding about barriers and motivators to engaging care staff in LSW, and gaining more demographic information such as age and number of years in service would have allowed the researcher to explore if this impacted on their experiences. Exploring and defining more clearly the relationship between themes would also be of benefit due to their overlapping nature.

If future research allocated more time to LSW perhaps themes regarding an altered view of the person with dementia or an altered relationship could be expanded as this was hindered in this study due to participants feeing that they did not have enough time to see changes. More involvement of patients' relatives may also aid future research as it increases cooperation from relatives to bring in life story resources such as pictures.

4.6 Conclusion

This study offers a rich perspective into how inpatient dementia CSWs experience creating life story boards and experience PCC via this process of implementation. The results demonstrate paradoxes and vicious cycles present within the organisational care culture which act as barriers, maintaining a lack of focus on PCC and motivation to implement service improvement strategies like LSW despite the apparent need and want for LSW to enhance PCC. Despite the barriers explored staff spoke about examples of good PCC occurring on the unit due to an effort to look for and maximise windows of opportunity to engage with PwD. Furthermore, participants managed to gather some life story information which had a varied impact on their view of the person with dementia and on their relationship.

Implications for clinical practice include there needing to be investment from stakeholders in ensuring there is leadership available, commitment to PCC values as well as LSW at all levels of organisational structures so that the culture does not impede LSW for junior staff. A focus on collaboration with stakeholders, empowerment and support of care staff via using elements of PAR and practice development approaches is encouraged once strong leadership from those perceived as integrated insiders to participants carrying out LSW is in place. Training needs to be about setting a firm foundation and rationale for PCC as well as for LSW, as well as about staff support to choose who to do LSW with. Implications for future research include maintaining focus on the more severe end of inpatient dementia care due to the relative lack of research compared to those with mild to moderate dementia, more research of the life story board format in particular as the boards did not get to the stage of being displayed in this study. Use of more NHS agency staff, involving patients' relatives more, and interviewing staff who do not wish to participate in interventions to expand the themes developed is suggested. A continued

focus on carrying out research which builds upon the relatively lacking body of literature that critiques LSW and explores overcoming challenges as opposed to just providing positive evidence for its use is needed. Furthermore, a continued need for research into how LSW can be implemented by care staff within the constraints of NHS organisations as opposed to relying on paid dedicated staff is recommended as this limits opportunities to explore how to get past barriers to normal staff taking on LSW on top of normal duties, as well as how service managers can improve their resource management and leadership skills in order to promote LSW within constraints.

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Appendices

Appendix A: Research Information Sheet for Clinical Support Worker Participants

Appendix B: Research Information Form for Co-researcher Participants

Appendix C: Expression of Interest Forms for Clinical Support Worker Participants

Appendix D: Research Consent Form for All Participants

Appendix E: Letter of Approval to Host Study at Partner Care Unit from Service
Manager

Appendix F: Poster to Advertise Study Information Sessions in the Care Unit

Appendix G: Powerpoint Slides for Life Story Board Training

Appendix H: Initial Interview Topic Guide

Appendis I: Post-implementation Interview Topic Guide

Appendix J: Braun and Clarke's (2006) 15-Point Checklist Criteria for Good Thematic
Analysis

Appendix K: Excerpt of Coded Transcript

Appendix L : Example of Microsoft Excel spreadsheet showing development of
grouping codes

Appendix M: Examples of visual mapping during theme development

Appendix N: Ethical Approval Document

Appendix O: Research and Development Approval Document

Appendix P: Description of processes involved in choosing the research site and
challenges associated with this

Appendix A: Research Information Sheet for Clinical Support Worker Participants

University of East Anglia

Care staff Participant Information Sheet

Introduction

You have been invited to take part in a study exploring how care staff in inpatient dementia care units can use life story boards to participate in person-centred care with people with dementia.

Before you decide whether you would like to take part, please take the time to read the following information, which has been written in order to help you understand why the research is being carried out and what it will involve.

This information sheet should only be read once you have attended the study information meeting.

The researchers

My name is Alex Russell. I am a Trainee Clinical Psychologist and I am carrying out this study as part of a Doctoral qualification in Clinical Psychology at UEA (University of East Anglia). The research is being supervised by Dr Paul Fisher (Clinical Tutor in Clinical Psychology), Dr Simon Hammond (Research Fellow), and Dr Lynne Roper (Clinical Tutor in Clinical Psychology).

What is the purpose of the research?

This study aims to increase the amount of life story work that this care unit carries out (using life story *BOARDS* specifically), in order to gain an in-depth understanding of how care staff report their experiences of creating life story boards with patients and how care staff experience person-centred care via creating life story boards.

It is hoped that this study will promote new ideas and ways of thinking about life story work and person-centred care in dementia care settings.

Why have I been invited to take part in the study?

All NHS employed staff that work in this care unit on regular day shifts and who speak English fluently have been invited.

Do I have to take part?

NO. You are under no obligation to take part, and even after agreeing to do so you may change your mind up until *2 WEEKS* after your final interview without having to give a reason, though you will be offered the chance to give a reason. In making your decision you may wish to seek advice from somebody independent, for example, a friend, family member, colleague, or trusted professional.

If you decide that you would like to take part, please fill in the attached expression of interest form and hand it back to me at the end of the information meeting, or alternatively if you would like some more time to think about it I will return at a later date to collect your form.

If you have any more questions or queries after the information meeting, please email me on the email address below. You can also email my research supervisor Dr Paul Fisher on the details below.

What will my participation involve?

Once you have expressed an interest in participating by signing the expression of interest form, I will contact you via phone or email to answer any questions you may have. If you are still interested in participating I will book in a suitable time/date to meet you at XXXXX to give you a consent form to read. If you are happy to sign this and consent to take part then we will carry out the first of **2** interviews (one before creating the life story boards and one after creation) at this meeting as well. This will be between the hours of 8am-6pm, Monday to Friday, and will last up to 45 minutes. Your manager is happy for you to do this during your normal work shift and this will **NOT** affect your employment or pay.

During these interviews we will discuss your perspectives on person-centred care, life story work, your work role, and later your experiences of engaging in life story work with patients, and how you experienced person-centred care via the life story boards. I will also be interested to hear about any barriers or difficulties during this process. The interviews will be audio-recorded and will **NOT** be shared with your employer. After the interview you will have an opportunity to ask any questions and raise any concerns you may have.

You will be given a brief *TRAINING SESSION* on the usefulness of life story work and how to create the life story boards with a person with dementia. This will be at your place of work and this will **NOT** affect your pay.

What will happen to my information?

The recording of the interview will be typed out so that the information can be looked at in detail. The aim of this is to uncover common themes that are important in understanding the experiences we have discussed. The typed out transcripts will be made anonymous and kept confidentially in a locked storage facility. Your employers will **NOT** have access to any of your information.

Anonymised sections of the information collected from the interview will be looked at by my supervisors, and may also be looked at by representatives from academic and

professional assessment bodies in order to assess the quality of this doctoral research study.

As part of the doctoral programme, I will write up a report of the research. Within this report I will include some anonymous extracts of the interviews to illustrate themes that have been discussed. All names will be changed, including the name of the care unit however aside from this the quotes will be word for word.

I may also write shorter articles for publication, which may also include brief anonymous extracts from the interviews. Your name will never be associated with any published extracts

I will also ask if you would like me to send you a summary of the research findings when the project is complete.

What are the possible disadvantages and risks of taking part?

You will be asked to discuss your experiences of your work with vulnerable older adults. This could be potentially distressing, and every measure will be taken to minimise the risk of distress. If during the interview you are asked a question that you are not happy to answer you can skip it, and if you do become upset, you will be given the option to take a break or stop the interview altogether. Following the interview, I will be available to talk to briefly if necessary, and you will be given details of relevant support agencies.

YOUR WORK ROLE WILL CHANGE SLIGHTLY, with more time spent carrying out life story boards with specific patients. This will *replace* time spent on another task and you will not be expected to carry out this responsibility on top of your normal duties. It is likely that the interviews will take part during your shift so you will be absent from the shift for up to an hour, which your manager will have confirmed with the team. If you choose to take part you will NOT be required to rotate across wards as you will need to work with the same patients for the duration of the study.

What are the potential benefits of taking part?

The information we get from this study may help improve understandings of how life story boards can be used to increase person-centred care in care units with patients with dementia, and how this is experienced from the point of view of staff caring for these people specifically, as research tends to not focus on *YOUR* views enough. The findings of this study will be fed back to *YOUR* care unit to help inform future care practices.

You will receive training in how to create life story boards, as well as information on person-centred care. These will act as transferable skills for caring for people with dementia.

Some people also value the opportunity to discuss their experiences of caring for vulnerable adults with Dementia.

What will happen if I don't want to carry on participating in the study?

If you decide you want to withdraw from the study either before or after your interviews please let me know either face to face or by contacting me on the email address or phone number given at the end of this information sheet.You are not required to state why you have decided to withdraw.. If you have completed the interview you will be asked what you would like to happen to your interview data and you can decide whether you would like it to be used or destroyed. You have the opportunity to do this up until 2 WEEKS after your final interview, at which point your data cannot be destroyed as it will have formed the write-up of a report.

What if there is a problem?

If you have a concern about any aspect of this study, you can contact me and I will do my best to answer your questions. Alternatively you can contact my research supervisor, Dr Paul Fisher (see contact details below). If you remain unhappy and wish to complain formally, you can contact Professor Ken Laidlaw (Director of the UEA Clinical Psychology Course: 01603 593076).

Will my taking part in this study be kept confidential?

YES. All information which is collected about you during the course of the research will be kept confidential. However, if you disclose any information which suggests that either you, or someone else, are at risk of harm then I am obliged to breach confidentiality and inform someone. I will do my best to discuss this with you first.

Who has reviewed the study?

This study has been reviewed and approved by the UEA Faculty of Medicine and Health Sciences Research Ethics Committee.

Contact Details:

Alex Russell:

Email: alexandra.russell@uea.ac.uk. Tel:

Paul Fisher:

Email: p.fisher@uea.ac.uk   Tel: xxx

Appendix B: Research Information Form for Co-researcher Participants

University of East Anglia

Co-researcher Participant Information Sheet

Introduction

You have been invited to take part in a participatory action research study exploring how staff in inpatient dementia care units can use life story boards to participate in person-centred care with people with dementia.

Before you decide whether you would like to take part, please take the time to read the following information, which has been written in order to help you understand why the research is being carried out and what it will involve.

This information sheet should only be read once you have attended the study information meeting.

The researchers

My name is Alex Russell. I am a Trainee Clinical Psychologist and I am carrying out this study as part of a Doctoral qualification in Clinical Psychology at UEA (University of East Anglia). The research is being supervised by Dr Paul Fisher (Clinical Tutor in Clinical Psychology), Dr Simon Hammond (Research Fellow), and Dr Lynne Roper (Clinical Tutor in Clinical Psychology).

What is the purpose of the research?

This study aims to increase the amount of life story work that this care unit carries out (using life story *BOARDS* specifically), in order to gain an in-depth understanding of how care staff report their experiences of creating life story boards with patients and how care staff experience person-centred care via creating life story boards.

It is hoped that this study will promote new ideas and ways of thinking about life story work and person-centred care in dementia care settings.

Why have I been invited to take part in the study?

All NHS employed staff that work in this care unit on regular day shifts and who speak English fluently have been invited. This study is a form of participatory action research meaning that I, as the researcher, want to collaborate with and co-create this study with senior staff within your unit. You have been identified as a potential co-researcher due to

your senior role within the care team, who can help me to develop the study and aid implementation and facilitation of the life story boards with the care staff participants.

Do I have to take part?

NO. You are under no obligation to take part. Even after agreeing to do so you may change your mind up until *2 WEEKS* after your final interview (if you are invited to take part in interviews) without having to give a reason, though you will be offered the chance to give a reason. In making your decision you may wish to seek advice from somebody independent, for example, a friend, family member, colleague, or trusted professional.

If you decide that you would like to take part, please fill in the attached expression of interest form and hand it back to me at the end of the information meeting, or alternatively if you would like some more time to think about it I will return at a later date to collect your form.

If you have any more questions or queries after the information meeting, please email me on the email address below. You can also email my research supervisor Dr Paul Fisher on the details below.

What will my participation involve?

Once you have expressed an interest in participating by signing the expression of interest form, I will contact you via phone or email to answer any questions you may have. If you are still interested in participating I will book in a suitable time/date to meet you at XXXXX to give you a consent form to read and if happy, to sign and consent to take part as a co-researcher in the study.

As per typical participatory action research your role as a co-researcher will vary based on how we wish to shape the study but primarily we will work in partnership to shape the studies' design and to implement the life story boards with the care staff participants. You may be involved in helping to increase interest in the study within the care staff team, providing information on the study, supporting me in organising and facilitating the information sessions, supporting the delivery of training on life story work, and facilitating the design and creation of life story boards with the care staff participants and patients. As co-researchers you will not be recruiting participants or gathering data from them.

You may also be invited to carry out **2** interviews (one before facilitating the creation of the life story boards and one after creation) and this invitation will depend on how much of a role you will have as a co-researcher in the creation of the life story boards with care staff. This will be between the hours of 8am-6pm, Monday to Friday, and will last up to 45 minutes. Your manager is happy for you to do this during your normal work shift and this will **NOT** affect your employment or pay.

During these interviews we will discuss your perspectives on person-centred care, life story work, and later your experiences of engaging in the facilitation and implementation of life story work with care staff and patients, as well as how you experienced person-centred care via the life story boards. I will also be interested to hear about any barriers or difficulties during this process. The interviews will be audio-recorded and will **NOT**

be shared with your employer. After the interview you will have an opportunity to ask any questions and raise any concerns you may have.

You will be given a brief *TRAINING SESSION* on the usefulness of life story work and how to support the implementation of the life story boards with care staff and a person with dementia. This will be at your place of work and this will **NOT** affect your pay.

What will happen to my information?

The recording of the interview will be typed out so that the information can be looked at in detail. The aim of this is to uncover common themes that are important in understanding the experiences we have discussed. The typed out transcripts will be made anonymous and kept confidentially in a locked storage facility. Your employers will **NOT** have access to any of your information.

Anonymised sections of the information collected from the interview will be looked at by my supervisors, and may also be looked at by representatives from academic and professional assessment bodies in order to assess the quality of this doctoral research study.

As part of the doctoral programme, I will write up a report of the research. Within this report I will include some anonymous extracts of the interviews to illustrate themes that have been discussed. All names will be changed, including the name of the care unit however aside from this the quotes will be word for word.

I may also write shorter articles for publication, which may also include brief anonymous extracts from the interviews. Your name will never be associated with any published extracts

I will also ask if you would like me to send you a summary of the research findings when the project is complete.

What are the possible disadvantages and risks of taking part?

You will be asked to discuss your experiences of working with vulnerable older adults and supporting care staff. This could be potentially distressing, and every measure will be taken to minimise the risk of distress. If during the interview you are asked a question that you are not happy to answer you can skip it, and if you do become upset, you will be given the option to take a break or stop the interview altogether. Following the interview, I will be available to talk to briefly if necessary, and you will be given details of relevant support agencies.

YOUR WORK ROLE WILL CHANGE SLIGHTLY, with more time spent on supporting the training and implementation of life story boards by the care staff team. This will *replace* time spent on another task and you will not be expected to carry out this responsibility on top of your normal duties. The interviews will take part during your working day so you will be absent for up to an hour if you are invited to be interviewed, which your manager will have confirmed with the team.

What are the potential benefits of taking part?

The information we get from this study may help improve understandings of how life story boards can be used to increase person-centred care in care units with patients with dementia, and how this is experienced from the point of view of staff caring for these people specifically, as research tends to not focus on staff views enough. The findings of this study will be fed back to your care unit to help inform future care practices.

You will receive training in how to create and support implementation of life story boards, as well as information on person-centred care. These will act as transferable skills for caring for people with dementia.

Some people also value the opportunity to discuss their experiences of caring for vulnerable adults with Dementia.

What will happen if I don't want to carry on participating in the study?

If you decide you want to withdraw from the study please let me know either face to face or by contacting me on the email address or phone number given at the end of this information sheet. If you are taking part in interviews you can still withdraw either before or after your interviews. You are not required to state why you have decided to withdraw. If you have completed any interviews you will be asked what you would like to happen to your interview data and you can decide whether you would like it to be used or destroyed. You have the opportunity to do this up until 2 WEEKS after the final group of interviews take place, at which point your data cannot be destroyed as it will have formed the write-up of a report.

What if there is a problem?

If you have a concern about any aspect of this study, you can contact me and I will do my best to answer your questions. Alternatively you can contact my research supervisor, Dr Paul Fisher (see contact details below). If you remain unhappy and wish to complain formally, you can contact Professor Ken Laidlaw (Director of the UEA Clinical Psychology Course: 01603 593076).

Will my taking part in this study be kept confidential?

YES. All information which is collected about you during the course of the research will be kept confidential. However, if you disclose any information which suggests that either you, or someone else, are at risk of harm then I am obliged to breach confidentiality and inform someone. I will do my best to discuss this with you first.

Who has reviewed the study?

This study has been reviewed and approved by the UEA Faculty of Medicine and Health Sciences Research Ethics Committee.

Contact Details:

Alex Russell:

Email: alexandra.russell@uea.ac.uk. Tel:

Paul Fisher:

Email: p.fisher@uea.ac.uk   Tel:

Expression of Interest Form

Study title: Using life story boards to engage care staff in person-centred care with people living with Dementia in an inpatient dementia care units: a Thematic Analysis

Thank you for attending the information session for this research study. This form is provided for you to express your INTEREST in participating in this study. You will NOT be consented to participate in this study at this stage.

Please state your agreement with each of the following statements by *INITIALLING* the boxes. Many thanks.

1) I confirm that I have attended an information session on this research study.

2) I am interested in participating in this study and wish to be contacted by Alex Russell (Chief Investigator) to receive more information about how I can take part.

3) I understand that this form is NOT a consent form to participate in this study and that I will be contacted by the chief investigator before being given the option to sign a consent form to participate in this study.

Please sign and enter your details below for the chief investigator to contact you.

Signed (**potential participant**):..

Date: ....

Print name: ....

Contact telephone number: ……………………………………………………

Contact email address: ……………………………………………………

UEA

University of East Anglia

Consent form

Study title: Using life story boards to engage care staff in person-centred care

with people living with Dementia in an inpatient dementia care units: a Thematic

Analysis

Thank you for agreeing to take part in this study. Please state your agreement with each of the following statements by *INITIALLING* the boxes. Many thanks.

1) I confirm that I have read the information sheet (dated 04/03/2015) about the above study.

☐

2) I have had the opportunity to consider the information on the sheet and ask any questions.

☐

3) I understand that my participation is voluntary.

☐

4) I understand that the interview with the researcher will be audio-taped.

☐

5) I agree to parts of my interview being quoted in reports of the research on the basis that any identifying details are removed.

☐

6) I understand that I can withdraw from the study at any time and that I can withdraw consent for any information collected to be used without giving a reason up until 2 WEEKS after the final interview.

☐

7) I understand that if the researcher is concerned about risk of malpractice or maltreatment that they may be required to break confidentiality.

☐

8) I agree to take part in this study.

☐

Signed (**Participant**): ....

Date: ....

Print name: ....

Signed (**Researcher**): ....

Date: ....

Print name: ....

Appendix E: Letter of Approval to Host Study at Partner Care Unit from Service Manager

NHS

Alexandra Russell
Trainee Clinical
Psychologist
Department of
Psychological Sciences
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

10.12.2014

Dear Alexandra,

Re Study: 'Using life story boards to engage care staff in person-centred care with people with Dementia in residential care homes: a Thematic Analysis'

Please accept this letter as confirmation that I have read the above proposal and approve for this study to take place on ▮▮▮▮▮▮▮▮ at the above mentioned NHS address using our NHS care staff.

Your sincerely,
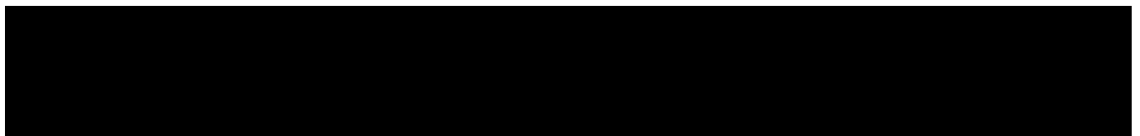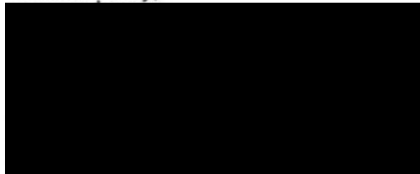
A research study is taking place in this unit

Creating <u>life story boards</u> to engage care staff in person-centred care with dementia patients.

From April-May 2015 a researcher will be attending some weekday staff handovers and team meetings, giving information to regular day-shift care staff about participating in this study.

Further information will be provided at these meetings. Please feel free to raise any questions with ▮▮▮▮▮▮ (Nurse Manager) or ▮▮▮▮▮▮ (Psychologist)

Alex Russell- researcher

(please contact me on: Alexandra.Russell@uea.ac.uk)

Why are we doing this research?

▪ Health services face significant **challenges**, with an increasing population that is living longer

▪ Dementia is an age-related illness and is a "**global epidemic**". As people live longer, the number of people affected grows

▪ There are **over 800,000** people with dementia in the UK and 1 in 3 people over the age of 65 will go on to develop dementia

▪ There are current financial constraints in the NHS and dementia is a financial burden

- **Drugs** can be used inappropriately, aren't helpful for all dementia types, and there is still no medical **cure**

- So...the most effective interventions are the development of care services to support people with dementia and their carers, to improve the wellbeing of those who experience the condition now

"Care as opposed to cure"

Person-centred care

- Person-centred emphasises the **relationship** between a patient with dementia and their carers, and how staff can interact in ways that promote a patients sense of **wellbeing**.

- This can be done by trying to preserve the **personhood** of the patient, which is an 'inner essence' that remains intact underneath the cognitive impairment caused by dementia. It is somebody's status as a human, given by others in the context of relationships. It implies **recognition, respect**, and **dignity** for one another.

- The social environment surrounding a person with dementia has been shown to affect the rate of decline. The environment can be changed to support someone's personhood via person-centred care, by focussing on patients' **identity, individuality,** and **independence**.

- This can be achieved despite a patient's declining mental power and inability to communicate and engage in meaningful activity.

4

Person-centred care

- Instead of treating patients with dementia as a collection of symptoms and behaviours to be controlled, person-centred care considers the human value or 'whole' of the person regardless of age or cognitive impairment, taking into account their **perspective, abilities, interests, preferences** and **needs.**

- **Care staff** have a **central role** in people with dementia's quality of life, having responsibilities in starting, guiding, and maintaining person-centred activities.

- Person-centred care is the '**gold standard'** model. It states that staff caring for people with dementia **learn more** about them, and **understand** their experiences, attitudes, and personal meanings, so to better meet their **needs** in an **individualised** way.

Life story work

- Life story work is a tool to **encourage person-centred care**.

- It provides opportunities for people with dementia to discuss, and review their life experiences: **family, friends, work history, achievements,** and **hobbies**, using materials like photographs, personal belongings, newspaper cuttings, and written recollections about the person's life in their own words or by others as triggers to conversation.

- Through learning about people's life stories, including their **present lives**, it is possible to gain a better appreciation of their **current needs and wishes.**

- Life story work is an **ongoing** process rather than a **task to be completed** and can be used to enhance **communication** between staff, people with dementia, and their families.

Life story work

- It involves **care staff collaborating with a person with dementia** and/or their **family** to gather and record life story information, and it usually results in an 'product', for example a **story board**, which displays all the information.

- Emphasis is placed on the **process of developing the board** alongside the final 'product'.

- **Life story boards** are a less researched method of gathering and recording a life story, but one that may provide a more **visual** and **immediate impact** on staff in their everyday clinical practice than a book for example.

What is a life story board?

An overview of someone's life, including:

- Family history
- School
- Growing up
- Work
- Life achievements
- Their own relationships and family
- Hobbies
- Likes and dislikes
- Other significant information about the person

What is a life story board?

Can include:

- Photographs
- Picture information
- written recollections about the person's life e.g. holidays, events, family
- a time line (mapping a person's life against major historical events)
- Pictures of personal objects
- postcards
- records of achievements
- Copy of birth/marriage certificates
- newspaper cuttings
- pictures from local history department/tourist information offices
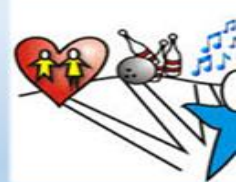
How will it look?

I am Margaret Smith, but most people call me Maggie. I was born in Norwich by the coast in 1932. My mum was called Mary, and my dad was called Bill.

Maggie worked as a nurse all her life. She did night shifts so sometimes she thinks she's working at night now and may struggle to sleep.

She loves dogs and used to have a Labrador named Goldie

Study information reminder

- You will pick **one** patient who you would like to find out more about, to make a board with.

- You will have **2-3 months** to spend gradually making these boards, with support from OT and Psychology.

- Your management know you will be participating and that you will need **time allocated** 'here and there' to focus on gathering life story information and recording it on the board.

- I will pop in regularly to check on how you are getting on.

- You will be **interviewed again** at the end to find out about your experiences of the process of making the board with your chosen patient.

12

How would you collect the info?

- Speak to family members when they come in, telephone them.
- Read their file, formulation work, life story book
- Speak to colleagues: they may know information you don't!
- Spend short bursts of time with the person with dementia using info collected as triggers
- Share your own similar experiences with the patient and family if helpful
- The OT, activity co-ordinator, and psychologist will be on hand to support you with these.
- Find pictures online or in magazines which represent their experiences e.g. if they went to the seaside a lot you could put on a picture of this!

Appendix H: Initial Interview Topic Guide

Topic guide

Pre-interviews:

Thanks for meeting with me. Today I will be interested in learning about your experiences and views on your clinical support worker role, specifically in connection to the relationship you have with patients with dementia who you care for.

I'm also interested in learning about your experiences and views on finding out about a person with dementia's life story/history such as their family, friends, past work, and hobbies etc.

There are no right or wrong answers and you can skip any questions you do not wish to answer. Just to remind you that everything you tell me will be kept confidential except if I have concerns about safety of self/others, in which case may need to stop interview and follow appropriate procedures. Let's get started if that's ok?

- Can you tell me a bit about yourself and your role as a support worker?
- How long have you worked here? Have you seen any changes? *Special measures*

"Thank you for sharing that with me" or "thank you for telling you about that".

Could you tell me little bit more /give me an example/ tell me a bit more about how that felt from your perspective?

- Can you tell me a bit about your experiences of caring for people with dementia?

Can you tell me a bit more about how you feel about this relationship?

- 'Have you come across the term person-centred care before and if so, what does the phrase mean to you? Life story mean? Have you had any training?

- Can you tell me a bit about how knowing a patient with dementia's life history/ story affects how you work with them?

Could you give me an example of what you mean? When was last time that happened and how did you feel about that?

How do you know this? Have you done any training in life story work or person-centred care? Or just personal learning?

- Can you think of any ways in which your work tasks allow you or stop from you engaging with patients in a way which makes you feel like you know them as a person? *rules?*

- How might the life story work/boards assist in your everyday work?

Why is this important, How is it important, How does it help the person, the staff, the ward. Specific tasks eg personal care, feeding?

Could you give me an example of this?

- How might these boards be used by others staff? (who did not create the boards with the person) *agency*?

- In an ideal world how do you think people in your role could use patient's life stories to provide more individualised care?

- How do you think you would get on using life stories (experienced or predicted) in your role?

How might there be challenges? Prompts: professionally, organisationally, personally?

- Have you been involved in anything like life story boards before? (Let them speak and if appropriate ask the following).

How did you find these from your experience?

Within your role/from your perspective, do you see any barriers/issues with these being used?
How could these perhaps be overcome?

- How do people view your care role?

Appendix I: Post-implementation Interview Topic Guide

<u>Post-interview topic guide</u>

Thanks for meeting with me again and for continuing to consent to participate in this final stage of the study. After this interview your participation in the study will end so I wish to thank you for participating! I will be analysing the transcribed interview data and writing up my findings in the form of a thesis after this. I will then feedback the results of my thesis to your service. Do you wish to receive an email copy of this feedback?

Today I will be interested in hearing about your experiences and views on how you got on after our training session with making a life story board with a person with dementia. I'll be asking about the relationship you had with that person during the process as well as the practical aspects of making the board.

I'm also interested in challenges you perhaps had in making the board, or anything related to this and it does not matter how much of your board you got made.

There are no right or wrong answers and you can skip any questions you do not wish to answer.

Although I've come up with these questions it might be that I'm not asking about the right things. So if there's anything about making these boards you want to tell me please do! Just to remind you that everything you tell me will be kept confidential except if I have concerns about safety of self/others, in which case may need to stop interview and follow appropriate procedures. Let's get started if that's ok?

1. **Can you tell me a bit about how you found this life story board study?**
   After the initial interview? After the training session?
   What about before this post-interview? Why did you get involved?

2. **How did you get on making the life story boards?**
   E.g. From choosing a patient. Accessing materials. Time, space, support from colleagues, management.

3. **Can you tell me a bit about how the process of making the board** *(from collecting the info to putting the info onto the board)* **affected the relationship you had with the person with dementia?**
   What? How did it affect it, when did you notice this most, and why do you think it affected it? Different from before? MAIN Q, impact on PCC ideas/principles

4. **Can you tell me a bit about how the process of making the board** *(from collecting the info to putting the info onto the board)* **affected how you viewed them?**

5. **Can you tell me a bit about how the process of making the board impacted on your normal work role day to day, and how you perceived your job as a clinical support worker?**
   In terms of work tasks, time, PCC, ward atmosphere, relationship with other colleagues, view of your job?

6. **Can you tell me about any barriers of difficulties you may have faced whilst making the board?**

   What were they? Why do you think this was a barrier/difficulty? What about professionally, organisationally, personally? Experiences of approaching staff?

   Did you expect these? How much impact did they have? How could they be overcome if you were to do it again?

   What is 'time'?

   You do training and I've noticed it's rota'd, why do you think this is done and not time for life story work and other activities?

7. **Can you think of any recommendations if life story board work was made into normal practice or if another ward was to try and start making some?** *What are they, why do you say that, how could it be achieved? How did you experience the training session?*

8. **Can you tell me what your take home message would be about having participated in this study?**

   Would you take part in anything like this again in future?

   I've asked a lot so is there anything you want to tell me that hasn't been covered or that is relevant that I've missed?

Appendix J: Braun and Clarke's (2006) 15-Point Checklist Criteria for Good Thematic Analysis

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed - interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other - the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done - i.e., described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

Appendix K: Excerpt of Coded Transcript

Ref: participant 5   Date: 26.6.15

341 often. Can be difficult to get to know patients when no info from files and relatives to

342 gather. and although I know he's not going to communicate with me back

343 communication is viewed as primarily verbal because there's only a few phrases he

344 will use it's still nice to be able to you know even if I get a raised eyebrow or

345 something staff notice and positively seek out non-verbal communication it would be

346 nice to see if something is connecting staff wish to see patients connecting with

347 them when they communicate with them. Non-verbal signs can indicate patients

348 connect with staff when they talk. Having no signs that a patient connects with them

349 is difficult,

350 I: yes

351 P: but as I have nothing to really talk about it's a bit difficult you know life story info

352 gives staff something to talk about with patients. If staff don't know patients well

353 they feel they have nothing to talk about and communication is harder. I can ask the

354 question oh do you like this or do you like that but he can't communicate back then

355 there's not really it's quite difficult staff find it difficult when patients can't

356 communicate back, when patients can't tell them about themselves. LS info useful

357 when patients struggle to communicate back.

358 I: yes and kind of how would that effect the relationship even if you just got a lift of the

359   eyebrow

360 P: yes even if it's just a lift of the eyebrow to say ok I'm listening or I can hear I know

361   you're here staff interpret what patient's non-verbal behaviour means. Staff want

362   patients to show that they are listening and know they are with them. I mean if

363   you're sitting looking at someone in silence and maybe your eyesight is not great

364   you might not be able to see them but if you can hear them we know a lot of our

Ref: participant 5   Date: 26.6.15

365 patients can hear then maybe the fact that they know they've got someone talking to

366 them might make them feel a little bit better staff like feel that there is a purpose to

367 their communicating with patients. Having no signs that a patient connects with

368 them is difficult. Patients having someone talking to them is seen as beneficial to

369 them.

370 I: yes yes

371 P: or just a bit that they've got some company really cos I think a lot of the patients can

372 be left um you know alone for like by themselves for a long time just sat in a chair or

373 walking around the ward because staff are busy doing other things staff too busy to

374 give patients company. Patients are left alone for a long time as staff are busy. or if

375 there is a few minutes uncertainty about whether staff have a few minutes to spare

376 and spent with patients to talk where you can sit with someone and talk about things

377 that they might be interesting in or their past then maybe they might not feel so

378 lonely if they do feel lonely Staff think patients may get lonely. Patient company and

379 loneliness is not prioritised over other ward duties. Staff think talking to patients

380 about past or interests may reduce loneliness.

381 I: yes and that brings me nicely to the next question cos you're saying you're off doing other

382 things

383 P: yes

384 I: so what are those other things that get in the way

385 P: they could be um other one to ones um doing personal care on patients I mean we

386 have to do a lot of personal care not just you know once in the morning once in the

387 night it is constantly throughout the day so if a patients maybe get a bit dirty or they

Ref: participant 5   Date: 26.6.15

388   might spill a drink on them we're having to do that personal care is a constant task

389   and takes up a lot of time. um there's also the physical observations which can take

390   a while cos pretty much I think probably 13 of them well the patients we have at the

391   moment are need the full check so that can take a while to do physical and personal

392   care of patients take priority over other patients feelings e.g. loneliness. it could be

393   maybe wiping down the table you've got breaks to cover um notes to do on the

394   system on Lorenzo Tasks that staff spend most time on do not consider patients

395   interests or pasts. I think the problem we've got really is that we don't seem to have a

396   lot of regular staff on so the two like today it's just me and another CWS are the

397   regulars and the rest are all agency workers heavy use of agency staff. Not a lot of

398   regular staff on ward. Time writing patient notes takes away time spent with the same

399   patients. Recording patient wellbeing detracts from patient wellbeing. What gets in

400   the way of spending time talking to patients. Reasons why patients get lonely.

401   I: oh wow

402   P: so we're the only ones that can do the notes so that's six seven each and that's

403   going to take a while to do so you find your time then goes writing patient notes

404   takes up lots of regular staff time when agency staff are on.

405   I: yes

406   P: um if housekeepers aren't here we're making beds so that's 13 beds to do mopping

407   some of the floors if there's been some spillages or something there's just general

408   stuff maybe getting drinks for patients sitting and feeding patients and then we've

409   got a patient who takes quite a long time to eat so you could be there for quite a

410   while you know just feeding feeding patients is not seen as time spent talking to

411   them and getting to know them. feeding is seen as getting in the way of quality time

Appendix L: Example of Microsoft Excel spreadsheet showing development of grouping codes

	A	B	C	D	E	F	G	H	I	J	K	L	M
82	Authorisation by managers does not affect pressure to be there on the floor. . p2.1, p37, 767												
83	guilt due to patients care being affected if spend time off floor doing life story work. . p2.1, p37, 771												
84	Sense of duty to be on the floor. . p2.1, p37,772												
85	Personal care is prioritised- guilt if not done. . p2.1, p37,773												
86	no point in just keeping people safe and not talking to them. p2.1, p40,836												
87	Minimum basic care means just keeping patient safe. p2.1, p40, 836												
88	Sense that minimum basic care isn't enough. p2.1, p40, 837												
89	Patients don't move on a quickly as general hospital. p2.1, p41, 857												
90	Contrast between ward and general hospital. p2.1, p41, 858												
91	feel more encouraged and recognised by NHS recently. p2.1, p45, 936												
92	Staffing levels-short P3.1, pg3, 44												
93	short staffing causes bad atmosphere on ward and issues for staff and patients. P3.1, pg3, 45												
94	negative impact of short staffing on patient care. P3.1, pg3, 50												
95	Patients passed from staff to staff inconsistently and get angrr- trigger for aggression. P3.1, pg3, 50												
96	Positives of the job don't happen often. P3.1, pg8, 161												
97	Staff anger verbalised to doctor. P3.1, pg15, 320												
98	other professions not respecting protected meal times. P3.1, pg16,330												
99	example of change of practice due to care staff telling other roles how they feel. P3.1, pg16,337												
100	Balance ward atmosphere, patient physical care needs, and protected time. P3.1, pg16,338												
101	Staff not wanting ward atmosphere to be unsettled by other roles. P3.1, pg16,347												
102	CSW view other professional input as hassle for the ward. P3.1, pg17, 348												

view of role | **ward cultureISSUES** | 1;1s | relatives | LSW | PCC | comms. | view of PwD | patients position

READY

Appendix M: Examples of visual mapping during theme development

1:1's take up most time and others get neglected

Low staff numbers on ward

The hospital environment – LSW is not what people are here for

WARD CULTURE WANTS TO BE PC BUT STRUGGLES TO BE (need for LSW)

Time is scheduled and routined so lack of time and pressure used as a reason to not do PCC/LSW

Balancing communal vs. individual care of patients is difficult

There is some choice in how to spend free moments if grasp it

There are skills to aid PCC/personhood- already used on ward- IMAGINING SELF IN PATIENT'S POSITION

Us versus them

Others view of the role of CSW = undervalued and is a barrier to adopting PCC

The resources are key- relatives, access to notes

Care is whatever is prioritised/valued by senior staff: physical 'visible' care, risk management, what is mandatory and audited.

Communication and engagement- as a barrier to LSW

How LSW aids communication.

PROCESS AND IMPACT OF LSW

UNDERSTANDING OF WHAT CARE IS (IMPACTS ON PCC AND IMPLEMENTING LSW)

What skills needed for the job and for LSW- there's more to this role than physical care

Making sense of PwD with and without their life story

Recommendations for future

Appendix N: Ethical Approval Document

Faculty of Medicine and Health Sciences Research Ethics Committee

UEA
University of East Anglia

Alexandra Russell
HSC

15/4/15

Dear Alexandra

Project Title: Using life story boards to engage care staff in person-centred care with people living with dementia in an NHS inpatient dementia care unit: a Thematic Analysis
Reference: 2014/2015 - 45

Thank you for your e-mail dated 27/3/15 notifying us of the amendments to your above proposal. These have been considered and we can now confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and also that any adverse events which occur during your project are reported to the Committee.
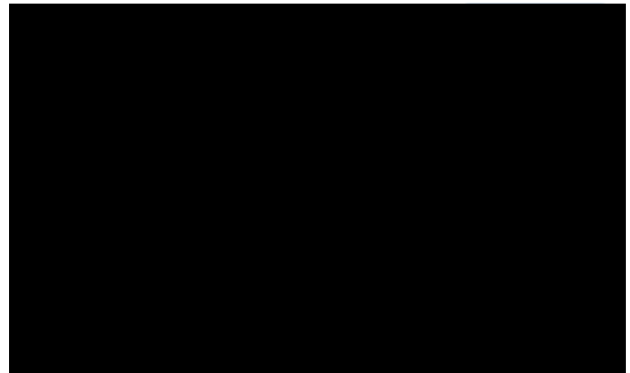
Please can you also arrange to send us a report once your project is completed.

Yours sincerely,

Mark Wilkinson
Chair FMH Research Ethics Committee

Appendix O: Research and Development Approval Document

Miss Alexandra Russell
Trainee Clinical Psychologist
Norwich Medical School
University of East Anglia
Norwich
NR4 7TJ

20th April 2015

Dear Miss Russell,

Re: RD #15 161473: Life story boards with dementia care staff: a Thematic Analysis

Thank you for submitting the above project for local research governance approval. I am pleased to inform you that your project has been given full approval and you may begin your research at the following site:


I have enclosed two copies of the Standard Terms and Conditions of Approval. Please sign both copies returning one copy to the Research and Development office, at the above address, and keeping the other in your study file. Failure to return the standard terms and conditions may affect the conditions of approval. Under the agreed Standard Terms and Conditions of Approval you must inform the R&D department of any proposed changes to this study and submit annual progress reports to the R&D department.

Any researcher(s) whose substantive employer is not the ▇▇▇▇▇▇▇▇▇▇▇▇▇▇▇ must have a Letter of Access or Honorary Research contract and evidence of Good Clinical Practice (GCP) training before coming on site to conduct their research in this project. Please note that you cannot take part in this study until you have this documentation. If a Letter of Access / Honorary Research Contract has not been issued – please contact us immediately.

If you have any queries regarding this or any other project, please contact, ▇▇▇▇▇▇▇, Senior Research Facilitator, at the above address.

The reference number for this study is: **RD #15 161473**, and this should be quoted on all correspondence.

Yours sincerely,
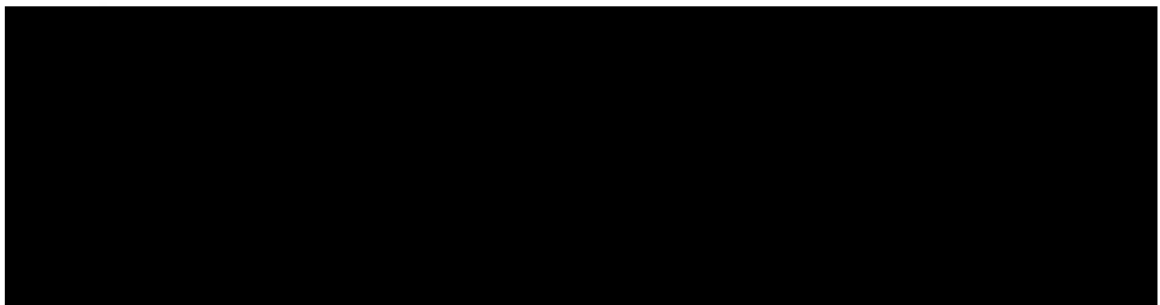
- Several local residential care homes which listed themselves as being keen to engage in research on the 'Research Ready Care Home Network' on the Enabling Research in Care Homes initiative website by the National Institute of Health Research were approached via letter in April 2014.

- The most suitable care home which responded was contacted by the primary supervisors and a meeting was set up between them, the care home manager and deputy care manager in May 2014. The care home was privately owned, providing 24 hour non-nursing accommodation and care services to older adults aged 65 and over, many of whom had dementia (mild to moderate). The home also carried out life story work on a small-scale as part of their routine clinical care as the deputy manager has some training in life story work.

- This care home showed a great deal of interest and enthusiasm in the study and agreed to partner up with the researchers for the study. Agreement from the care home owners was also provided. The deputy manager was keen to act as a PAR co-researcher and increase the volume of life story work carried out in the home. Given this, the home was seen as an excellent choice for PAR.

- The care home pulled out of the research in November 2014 after six months of rapport building and joint planning of the study prior to ethical approval. Whilst the manager and deputy manager had still been keen to do the research, the home owners denied the researchers access to the site and would not engage in conversation with the researcher or primary supervisors.

- A new partner research site was quickly required for the study and so more local residential care homes were approached via letter in November 2014. Unfortunately this did not lead to a new care home to partner with.

- In the interim the researcher, who was on an older adult dementia training placement, heard that the current inpatient dementia care unit's consultant clinical psychologist was keen to implement more life story work. This care unit was approached in November 2014.

- Approval from the service manager of the unit was gained in January 2015 but ethical approval was not gained until May 2015, in part because various logistical matters regarding researching in this NHS context had to be attended to. This delayed being able to start study recruitment which then delayed the interviewing and training process, and reduced the amount of time available for clinical support workers to spend on creating life story boards as the post-implementation interviews had to be completed by October 2015 for it to be viable to complete the project in a timely fashion. This was one of the biggest implications of losing the first care home, as they would have had considerably longer to focus on board-making as ethical approval would have been gained earlier. Recruitment, interviewing and training also took from May until August 2015 despite the

researcher attending the unit two times a week which delayed the start date of board making.

- Several issues were encountered at the current care unit. Primarily, the lead co-researcher (clinical nurse manager) who was the main link between the researcher and the potential participants left the service in May 2015, just as the study gained ethical approval. This meant that the research site lacked drive to proceed with the study compared to the original site. The researcher was encouraged to work with the band six occupational therapist co-researcher for support with liaising with the charge nurses, booking rooms, and arranging rotas to fit in interviews, training and protected time for life story board work but they had no authority to make many decisions as they were not part of the nursing team and were not senior to the charge nurses. This co-researcher also then left the service in June 2015, leaving the remaining occupational therapist co-researcher less available to support the study as they took on additional responsibilities.

- Due to the issues experienced in getting support for protected time for life story work, the researcher approached the deputy service manager in July 2015. They said they would attempt to raise more awareness of the study.

- The researcher was invited to attend a 'safer care pathway' meeting (part of an initiative created to improve care quality) to promote the study with senior level staff such as the deputy service manager, deputy director of nursing and patient safety, modern matron and charge nurses. The researcher attended two meetings (in July and August 2015) and some plans were encouraged for charge nurses to support the study more. Despite this, improvements were not experienced in terms of more time being dedicated to life story work.