



CREaTE

Canterbury Research and Theses Environment

Canterbury Christ Church University's repository of research outputs

<http://create.canterbury.ac.uk>

Please cite this publication as follows:

McParland, James C. and Camic, Paul M. (2016) How do lesbians and gay men experience dementia? *Dementia: The International Journal for Social Research and Practice*. ISSN 1471-3012.

Link to official URL (if available):

<http://dx.doi.org/10.1177/1471301216648471>

This version is made available in accordance with publishers' policies. All material made available by CReaTE is protected by intellectual property law, including copyright law. Any use made of the contents should comply with the relevant law.

Contact: create.library@canterbury.ac.uk



How do lesbian and gay people experience dementia?

James McParland & Paul M Camic*

If citing this article, please cite the published version:

McParland, J. & Camic, P.M.* (2016). How do lesbians and gay men experience dementia? *Dementia*. Advance access: doi: 10.1177/1471301216648471

*corresponding author: paul.camic@canterbury.ac.uk

Abstract

Introduction: The subjective experience of dementia for lesbian and gay individuals is largely absent from the extant literature. This study aimed to explore what it means to experience dementia in this context given the documented psychosocial influences facing this population. A second aim was to develop understanding of these experiences within dyadic relationships. **Method:** Ten semi-structured interviews were conducted with lesbian and gay individuals with dementia and people with whom they had a significant relationship and analysed using interpretative phenomenological analysis. **Results:** Three superordinate themes, reflecting characteristics of participants' experience, were identified: *duality in managing dementia, giving yourself away vs. holding onto yourself*, and *relationships as sheltered harbours*. Ten subthemes indicated the processes that were adopted to adjust and make sense of the experience of dementia. These included decisions around concealment, ensuring safety and the promotion of personhood and couplehood. In line with findings for heterosexual couples, partners had an important role in maintaining the identity of the person with dementia. **Conclusions:** Results suggest additional and distinct challenges, including experienced and perceived discrimination and heterosexism. In response to these conditions, interviewees worked to resist a 'double stigma' of dementia and sexuality. Findings indicated areas of improvement for dementia services, including training in inclusive practice.

Keywords: Ageing, caring, dementia, relationships, sexuality.

Older Lesbian and Gay Adults

The current generation of older lesbian and gay (LG) adults have lived through historical times in which their sexual orientation has often been pathologised and criminalised (Ward, Pugh, & Price, 2010). Homosexuality was listed as a pathological disorder by the American Psychiatric Association until 1974 (American Psychiatric Association, 1973), and a criminal offence in the UK until 1967 (UK Parliament, 1967). “Treatments” for homosexuality involved aversive procedures such as electro-therapy and conversion therapy (Smith, Bartlett, & King, 2004). Activism and shifting societal attitudes have led to socio-legal improvements for LGB individuals, such as workplace anti-discrimination legislation, enhanced equality law and equal marriage (UK Parliament, 2003, 2010, 2013).

Despite these improvements, social and health inequalities remain, including stigma and societal prejudice (Dinos, 2014; Williams et al., 2010). Gay men and lesbian women are more likely to report experiencing psychological distress than their heterosexual counterparts, perhaps due to living with a socially stigmatised identity (King et al., 2003). Older LG individuals are at additional risk of marginalisation due to ageism (Ward, Jones, Hughes, Humberstone, & Pearson, 2008). Perceived stigma extends to healthcare contexts and around half of LG people aged 60 or above would not feel comfortable to be “out” to health providers (Ellison & Gunstone, 2009). Fredriksen-Goldsen and Muraco (2010) have suggested the need to explore the interaction of factors such as age, health and healthcare access, stigma and cognitive impairment as they affect LG ageing.

Dementia in a Lesbian and Gay Context

In 2012 one in 14 people over the age of 65 in the UK were living with a dementia and estimates suggested there were 800,000 people with dementia (PWD) (Alzheimer's Society, 2012). A dementia diagnosis often becomes a primary identity, obscuring other elements such as sexuality. Issues related to minority sexuality are largely absent from the mainstream dementia research agenda (Newman & Price, 2012). However, it is estimated between 5% and 7% of the UK population are gay or lesbian (Stonewall, 2012), so there may be up to 56,000 gay or lesbian people with dementia currently in the UK; this is a population that is under-represented in research. These individuals may experience a triple marginalisation due to their age, cognitive impairment and sexuality (McGovern, 2014). **As yet, little is known about how the specific psychosocial aspects of ageing for LG individuals intersect with cognitive difficulties in older age (McParland & Camic, 2016).**

Kitwood (1997) characterises “personhood” as the specific attributes an individual possesses that make them a person. He uses this term in a theory of dementia care that advocates maintaining people with dementia's personhood through appreciating their unique biopsychosocial circumstances, such as their sexuality. Important psychological components of personhood include safety and comfort, inclusion, occupation and a valued identity. Research is needed to assess how personhood is maintained for lesbian and gay individuals whose sexuality may be obscured by their diagnosis, as person-centred dementia care involves the acknowledgement of sexual orientation (Mackenzie, 2009). Other issues related to being gay or lesbian may further challenge personhood such as social exclusion, personal isolation, stigma, and/or familial estrangement (Stonewall, 2011).

Within residential settings, older LG individuals have identified that care staff, administration staff and other residents can all be sources of discrimination (Johnson,

Jackson, Arnette, & Koffman, 2005). In these contexts, within which institutional homophobia or perceived discrimination is encountered, psychological safety in relation to personhood may be under threat. This is concerning as LG individuals are often more likely to require community and residential care but less likely to have their identities affirmed than heterosexuals (Westwood, 2014). The process of sexuality disclosure can thus be extremely stressful for someone with dementia and may exacerbate anxiety around “who knows what” (Price, 2008).

Relationships and Caring

Evidence suggests couples work together to promote the personhood of the individual with dementia (Hellstrom, Nolan, & Lundh, 2005, 2007; Merrick, Camic, & O’Shaughnessy, 2013). This research has also looked at how couples work to maintain their sense of a relationship or couplehood, as attachment is a component of personhood and secure attachments are associated with couple wellbeing (Nelis, Clare, & Whitaker, 2012). Findings indicate that adjusting to dementia within relationships involves flexibility and changing roles. Little is known about how these findings extend to LG partnerships where there may be additional psychosocial influences. It is important to note that LG individuals are more likely to be single and live alone than their heterosexual counterparts (Musingarimi, 2008). These individuals, who may be estranged from biological families, often rely upon friendships and “families of choice” (Dorfman et al., 1995; Weeks, Heaphy, & Donovan, 2001). Although not unique to LG people, Baylis (2010, p. 176) proposes the term “significant other” to indicate non-biological kin providing support and care in this context. Again, it is not known how relationships and attachments with significant others work to maintain personhood for LG people with dementia. Price interviewed 21 gay men and lesbian women caring for someone with dementia (Price,

2010, 2012) and many reported experiences of heterosexism. These experiences led to fears that carers themselves may develop dementia and have their sexuality negatively perceived when accessing support. Also, the response of health and social care staff to sexuality disclosures mediated caregiving experiences and affected their ability to manage the demands of caring. A telephone support group was found to reduce feelings of isolation among LG caregivers of partners with dementia, many of whom had confronted prejudice in health and social services (Moore, 2002).

Aims

The present study aimed to explore how LG individuals experience dementia and maintain their personhood, including the role of “significant others” in this process, and secondly, to explore how couplehood is maintained and how this is experienced by “significant others” themselves. The intention of the research was to develop understanding of these experiences in order to positively influence clinical practice and enhance service provision for LG individuals with dementia and their carers. The research was thus intended to advance practice and advocate for inclusive services. The research questions addressed were:

- What is the experience of dementia for LG individuals and their significant others?
- How is this experienced relationally, within partnerships and other significant relationships?

Method

Participants

When exploring lived experiences through in-depth interviews a sample size of between 4 and 10 is considered to be appropriate (Smith, Flowers, & Larkin, 2009). Recruitment efforts were widespread and included an advert in the Alzheimer’s

Society (UK) magazine, a guest article by the first author for the ‘Young Dementia UK’ website, contacting older age organisations such as AgeUK branches and LGB community organisations to display posters. Inclusion criteria: an LG person with a diagnosis of a dementia, *or* were in a lesbian or gay relationship where one partner had a diagnosis of dementia *or* they had been in a relationship with an LG person with a diagnosis of dementia. Snowball sampling reached further potential participants. Following screening, ten interviews were conducted. Seven of these were with couples living together (four females and three males with dementia and their same-sex partners), two were with individuals with dementia (one gay male and one lesbian female interviewed with a close friend), and one was a lesbian that had previously cared for her same-sex partner with dementia. (Table 1). The mean age of PWD was 74.1 years (range 57 - 83) and the mean age of significant others was 69.3 years (range 43 - 83).

Table 1 here

Procedure

Participants were interviewed on one occasion either in their own homes, over the Internet using Skype or in a community venue. Interviews lasted between 60 to 100 minutes and followed a semi-structured interview schedule containing open-ended questions relevant to the research aims (Kvale, 1996). The schedule was piloted on a gay couple. Questions included involvement with the LG community, experiences of accessing support, and the impact of living with dementia (Table 2). There was a range of severity of dementia; most individuals functioned relatively independently, but one individual was physically immobile and mostly communicated non-verbally, which impacted their participation. Where possible, couples were interviewed

together; dyadic interviewing is useful in creating a shared narrative and demonstrating role interactions (Eisikovits & Koren, 2010).

Table 2 here

Five couples were interviewed together in their homes and one couple was interviewed over Skype. Two individuals with dementia were interviewed at home, one with a friend and one with a home-help present. Two Skype interviews were conducted only with partner of the person with dementia, due to illness of one partner and the other individual's partner having died a number of years previously.

Ethics

The study was subject to review with XXX University ethics panel and full ethical approval was attained; this meant the project details could be shared online, facilitating snowball sampling through word-of-mouth. Those who were able signed a consent form or gave verbal consent over Skype. Principles of Dewing's (2007) process consent method were used to further determine interviewees with dementia's consent. Process consent is used with individuals who have limited capacity for informed consent, but can be observed to communicate and express their wishes. This pathway involved gathering information about how these individuals usually made choices, such as what they would like to eat, monitoring consent throughout the interview, and paced experiential involvement for those unable to communicate verbally.

Data Analysis

Interpretative phenomenological analysis (IPA) is specifically concerned with how humans understand and make sense of experiences (Lyons, 2007). Such an approach lent itself well to the research questions, which related to exploring human experiences, identity and sense-making (Smith & Osborn, 2007). Interviews were

transcribed verbatim and analysed using the method described by Smith et al. (2009). Transcripts were read and re-read, and descriptive, linguistic and conceptual comments were made. Emergent themes across interviews were listed and clustered to form subthemes, then grouped and abstracted into three superordinate themes.

Epistemological position. IPA sits within a critical realist epistemology as it suggests discourse relates to the “actuality of which it speaks” (Coyle, 2007, p.28), while acknowledging the data produced may not have access to this reality (Willig, 2008). The researcher attempts to make sense of lived experience through a process of interpretation. This is termed a “double hermeneutic” (Smith & Osborn, 2003, p.51), as interpretation is a process occurring between the researchers and the participants, as researchers attempt to make sense of participant experiences. IPA theorists suggest that through such interpretation it becomes possible to explicate an individual’s inner world and explore how meaning is given to their experiences. The analysis was thus informed by the researchers’ positions and findings explored in light of existing theory.

Quality Assurance

The researchers were engaged in a number of reflexive practices (Ahern, 1999), including a bracketing interview prior to conducting the interviews and keeping a reflexive journal (Fisher, 2009). During analysis original transcripts were repeatedly consulted to ensure developing themes were relevant to participants’ experiences. In line with Yardley’s (2000) guidelines for qualitative research, which include transparency, credibility is sought through grounding interpretations in direct quotes. The viability of themes and interpretations were discussed with the second author who read about twenty per cent of the transcripts. An independent researcher read two anonymised interviews to check interpretations, helping to ground themes in

participants' words. Final themes were discussed with an individual who had cared for a partner with dementia (non-participant); he felt themes accurately captured and reflected aspects of his own experience.

Results

The analysis resulted in ten subthemes, which were subsumed under three superordinate themes: 'duality in managing dementia, 'giving yourself away vs. holding onto yourself' and 'relationships as sheltered harbours' (Table 3). These are illustrated with quotes.

Table 3 here

Duality in Managing Dementia

This superordinate theme relates to dual aspects of managing dementia. All participants spoke of choices they made between managing alone or connecting with others. A second duality existed between challenges shared with heterosexual counterparts and those distinct to LG individuals. Participants responded to challenges by "passing" as heterosexual or taking action to educate others. The majority of the quotations representing this theme are from "significant others". This appears to reflect the significant and active role of these individuals in managing the experience of dementia.

Isolation or reaching out while negotiating a "double stigma". The choice to either manage alone or reach out and seek support was shaped through internal and external processes. For some, internal processes included motivation to lead a "normal life", whilst others felt this **meant difficulties were not acknowledged**. It seemed to connect with internal stigmatised attitudes towards others with dementia:

"I want to avoid the situation of him mixing too much with people who are in the same situation as him. I prefer him to lead as normal a life as possible." (Stephen)

Such internal attitudes may have been shaped by external responses. For example, Stephen described the loss of Gus's gym friends when dementia meant he stopped exercising. Furthermore, aside from one friend at church that demonstrated support:

“No one else even telephoned to ask.” (Stephen)

Others' responses seemed to shape interviewees' willingness to share. This extended to friendships, where Eleanor expressed possible risks attached to discussing dementia with friends:

“I don't want them to say ‘oh well, perhaps they're not well enough’, and stop asking us to come over or something.” (Eleanor)

Responses included denial strategies, which were experienced as invalidating and unhelpful. Alice and Jean's family found it harder to accept Alzheimer's than their relationship:

“Family's also pretty safe.” (Alice) “As long as the family is OK.” (Jean*)

“Yeah, the family has a little more trouble with the Alzheimer's than they do with our relationship.” (Alice)

These quotes suggest that dementia invokes stigma and the potential for negative reactions or feelings of being ostracised. Bill's mother had 'played down' Bill's diagnosis and Jack's sister 'didn't want to know'. For them, the stigma of dementia was compounded by their LGB identity. Jack experienced this when he and Bill attended a group for people with dementia.

“You get one or two older folk, who perhaps come from a different era and I get that, you know, um, that don't agree with it, that don't like it.” (Jack)

He described this situation as a “double stigma”, related to both their position as LG individuals and the dementia diagnosis and associated difficulties, which affects their relationships and connections with other people.

“... so you’ve got this double stigma. We’re a gay couple and then you’ve got memory problems. Wherever we meet anybody/they’re the two hurdles that you’ve got to get over before you can even think about having any sort of relationship with that person.” (Jack)

This talk indicates that reaching out to other people may involve confronting this double stigma, but is necessary to facilitate connection. Jack describes how if confronted by homophobia it would not bother him, as he’s built a defensive wall. However, he feels vulnerable to dementia stigma:

“At the moment, because it’s all relatively new, my wall isn’t very high when it comes to this particular subject.” (Jack)

Sadie hypothesises that many LG people of her generation have lived closeted lives in relation to sexuality, and dementia could become another hidden and stigmatised identity. This points towards the complexity of navigating two such identities and the challenging decision-making involved.

Laurie felt talking to others in the same situation would be normalising and “ease things”, as she would “probably see that they’re in exactly the same boat”. While for Stephen, the process of talking during the research interview enabled him to sense-make.

“It’s only in talking, only in touching on things that you realise what’s going on under the surface in your own lives.” (Stephen)

Interviewees had various relationships with the larger LG community, including some dementia stigma experienced by Carol in terms of patronising sympathy, which appeared to undermine her personhood. Alice felt the wider community had not really responded, although both her and Sadie emphasised drawing on their networks for support:

“The most important support for us has been queer friends.” (Alice)

Sadie had created a “support circle” of mostly lesbian friends to provide additional care, suggesting a role in maintaining attachments and promoting inclusion, which are both tenets of personhood. Overall, there was a sense the interplay of both dementia and sexuality stigma could leave individuals feeling vulnerable and possibly threaten personhood; taking risks and reaching out despite this vulnerability could be beneficial.

Shared and distinct challenges. The duality in this subtheme encapsulates experiences that are universal in relation to dementia and distinct challenges for LG individuals. This theme particularly relates to the experience of accessing health and social services. Interviewees discussed common frustrations with services, including poor dementia screening and follow-up. When Eleanor first told her GP that Lucy was having memory difficulties, her GP put it down to ‘age’. Eleanor described expressing her frustration:

“I’ve been with her all these years, I know it’s not her age.” (Eleanor)

Other frustrations related to post-diagnostic support. Stephen described a disappointing response from his social worker that informed him:

“the decision has been taken that we are now simply a diagnostic service. We can’t help you in any other way.’ Full stop.” (Stephen)

For Alice, provision of dementia services was so limited, she felt it difficult enough to get any support, “let alone have it considered we’re lesbians” (Alice).

Eleanor emphasised sameness in dementia experiences, irrespective of sexuality. In particular, her talk relates to the emotional impact:

“It would be the same sort of emotions I suppose/ if somebody you love is not well you’re gonna feel just as bad.” (Eleanor)

Similarly, Yvonne explained that although sexuality played a part, dementia dominated when caring for her partner.

“I think the lesbian thing is an added...it’s an added difficulty to an already difficult situation, but it’s not the dominant experience.” (Yvonne)

Jack echoes the concept of sexuality being an added challenge. When revealing his relationship to older adult services it could be awkward:

“...it’s an awkward moment, it doesn’t upset us. But it’s something you could be doing without.” (Jack)

For many participants this awkwardness extended to an uncertainty around whether they were actually experiencing homophobia. Jack and Laurie recalled being treated curtly and wondering if this was connected to their sexuality. Similarly, Sadie described carers turning away when she gives Kate a kiss, but being unsure if this may be to give privacy. For her, this brought to mind previous experiences of rejection due to her sexuality. Louis seemed more certain in his and Frank’s negative experience with one memory clinic doctor:

“...she was really horrible and I think she had a problem with us being gay.”
(Louis)

Louis explained that the doctor focused on medical issues and never asked how they were coping. **For him, this implied she was not interested in them as people, undermining both Frank’s personhood and their couplehood.**

Anticipated and experienced homophobia was also discussed. Yvonne experienced homophobia when someone suggested her partner Teresa’s Alzheimer’s may be linked to her lesbianism. Alice expressed concern that other service users in residential care would be homophobic. Additionally, Alice hypothesised that her partner Jean’s experiences of homophobia throughout life, such as verbal abuse, were

shaping her dementia. This particularly related to current fear that she felt was an expression of earlier traumatic memories.

“...we know it’s coming up in terms of the trauma that we experienced as queers.” (Alice)

Alice, Sadie, Jack and Laurie all described experiences whereby their relationships and sexuality were made invisible when they accessed services. Alice felt Jean’s lesbianism was not acknowledged in respite care. Sadie reflected that language caused invisibility, such as carers calling Kate ‘Mrs.’, and workers sometimes assuming Bill was Jack’s father. Laurie felt her status as a lesbian couple was somehow less than that of a heterosexual couple.

“And there’s a concept that because you’re a lesbian couple, you don’t have the same feelings.” (Laurie)

Taking action to educate. The third subtheme highlights duality between interviewee’s experiences passing as heterosexual or resisting this happening. It connects to the previous subtheme and how LG individuals responded to challenges. Many participants experienced heterosexism, such as assumptions they were siblings; for some, it seemed easier to ‘pass’ as heterosexual. For example, Yvonne explained the presumption her and Teresa were sisters was easier at times. Jack reflected that when others assumed Bill was his father, correcting them did not feel like a priority.

“... you think, do you know what, I can’t be bothered. I’ve got too much on my plate.” (Jack)

Patrick, who lost his partner 6 years ago, suggests it may be easier for single people with dementia, but indicates it has been hard to manage alone:

“It’s easier because they’re less obviously gay and there is still prejudice against gay people and it’s more difficult because they’ve lost their partner.” (Patrick*)

He talks about prejudice that could face visible same-sex couples, connecting to Jack's comments about adding to an already challenging situation. In contrast, some respondents actively challenged heterosexism. Sadie's partner Kate resisted being called a 'Mrs'.

“Oh my god... (Laughs) she doesn't like that at all. 'I'm not a Mrs!' she says. 'I'm a lesbian. And I've been in a lesbian relationship for 37 years!'” (Sadie)

She described needing to be “proactive” and on the “offensive”. Speaking up seemed to be linked to histories of activism for some participants: Stephen and Gus hosted meetings in the early years of the HIV epidemic; Sadie and Kate fought for same-sex partnership rights; and Alice and Jean campaigned for the ordination of lesbians and gays. Some individuals managed the uncertainty of homophobia in the previous subtheme through making complaints. Others made comparisons with heterosexuals to emphasise the validity of their needs. Frank felt service providers need educating:

“To know about gay people and what their needs are, that you should treat them equally/not to think differently about them.” (Frank*)

Yvonne and Jack discussed training in LGB issues, so staff would be respectful, non-judgemental and value individuals irrespective of sexuality. Sadie emphasised isolation in the queer community and the lack of visibility of both older LGB individuals and those with dementia. Many interviewees hoped that their participation would increase visibility and get stories “out there”. Sadie felt this was important to:

“...to bring, so to speak, bring the issue out of the closet.” (Sadie)

Giving Yourself Away vs. Holding onto Yourself

The second superordinate theme relates to the experience of identity for LGB people with dementia and their significant others. It conceptualises identity as something that can be held onto or given away. Giving yourself away has a double meaning; it also refers to unintentionally revealing something about yourself.

Dementia as external, sexuality as internal. Interviewees' talk positioned dementia externally. This involved an unwillingness to accept their diagnosis. Bill, Patrick and Lucy demonstrated this reluctance, with Kate indicating this may be due to an experience of shame:

“But, I just feel like I’m just normal really, and I know I’m not, but you know, that’s it.” (Bill*)

“Well (pause), it’s not a name that I use. I don’t quite accept that I have got a serious memory problem.” (Patrick*)

“I don’t think about it. Life goes on. You know.” (Lucy*)

“Ah, dementia. Before I couldn’t say the word, because, because I was ashamed of it.” (Kate*)

Many constructed dementia as an “it”; Alice and Jean went further, giving dementia the name “Old Stinky”:

“(laughing) How long has ‘Old Stinky’ been around? Um, it’s about 6 years now.” (Alice)

Externalising dementia in this way seemed to make it less threatening, perhaps serving a self-protective purpose for the individual. In addition to this externalisation, participants discussed practical strategies they adopted to resist dementia, such as making lists or other memory aids. Stephen sets distance between Gus’s dementia and their couplehood, linking this resistance to an improved quality of life:

“As a gay couple? Oh (pause), we’ve had a wonderful life together/despite Gus’s condition, we still have a remarkable...quality of life.” (Stephen)

Similarly, Laurie emphasised that challenges due to dementia were:

“...nothing to do with Rose, it’s with this damn illness.” (Laurie)

In contrast, participants’ talk located sexuality internally. They described being “lesbian”, “gay” or a “gay man”, indicating these identities were an internal, stable part of themselves. Also, sexuality was constructed as a valuable identity by interviewees. Jack felt being gay meant you developed valuable self-protection skills, while Bill linked his sexual orientation to a subjective feeling of happiness:

“We’re quite happy aren’t we? I think being our sexuality, I’m quite happy. We both are.” (Bill*)

This extended to valuing being around other LGB people. Stephen described how Gus responded positively to:

“...being surrounded by gay people...” (Stephen)

Holding onto the ‘core’. Interviewees discussed how interests were one aspect of personality that seemed to make up the person with dementia’s “core”. For example, Frank and Rose enjoyed reading and gardening respectively. However, there was an acknowledgement that independent activity was becoming progressively more difficult. Rose explained her frustration:

“I get angry, I get so... When I think what I’ve done and you know, been, you know, (um) people I’ve met and all this... I mean, I can’t do any of that now.” (Rose*)

Similarly, Carol felt her artwork was less free-flowing:

“...I’m losing something; that ability to be correct /to do what I want but to do it in a more flowing way...” (Carol*)

Although getting harder, it appeared that others around the person with dementia had an important role in maintaining interests. Sadie took Kate to the library, even though she no longer read, while at home:

“I try to get her to stay up, and to sit with me, er, on the couch, and we watch the gameshows together.” (Sadie)

It seemed significant others attempted to defy the person with dementia being totalised by their difficulties. This involved various strategies to maintain enhanced and worthy identities. For example, Anne and Carol were planning a joint exhibition of their artwork, while Jack described Bill as a “valued employee” in his café. For many interviewees this involved knowledge of and connections with the past.

Eleanor and Lucy had previously been lounge singers. Eleanor described Lucy as an “amazing singer” that:

“... knows 1000’s of songs and she still does now.” (Eleanor)

This appears to suggest that significant others have a role in promoting occupation and a meaningful life as an aspect of personhood for individuals with dementia. Also, photographs and objects provided a connection to the past. For Sadie and Eleanor photographs prompted reminiscence with their partners, implying this was important to hold onto identity. Holding onto identity through reminding the individual with dementia who they were and what they have achieved also demonstrates the role of significant others in maintaining identity, a further psychological need when maintaining personhood. Alongside connecting to the past, participants spoke of learning to enjoy things more in the present. Jack described how Bill cheerfully danced around the kitchen each morning, and Bill explained his philosophy:

“I can’t help it, I’m just like, you’ve got one life and that’s it.” (Bill*)

Sadie described Kate similarly responding to humour and emotional “lightness”, while Yvonne explained Teresa:

“...was always herself, you know, the core of who she was as a person was always there in spite of the deficits.” (Yvonne)

Concealment decisions. This theme relates to decision-making around sexuality or dementia concealment. Most interviewees talked about previous sexuality concealment; this was often due to anticipated and experienced discrimination. Rose and Laurie described living a “double life” and had experienced workplace discrimination. Often, fear of exposure was linked to concealment. Jack and Bill talked about the risk they could have been arrested and Louis’ stepfather had reported him to the police. Rose discussed how fear affected relationships with others, including the risk her sexuality would be revealed in conversation:

“...you couldn't be open to people ... you had to sort of move back all the time/then if something on that note came you, you sort of erm.. you'd give yourself away.” (Rose*)

This extended to homophobic abuse for some interviewees, including Alice and Jean:

“We both lost jobs, and we both have been attacked.” (Alice).

Alice goes on to explain that despite challenges, living publicly invited support. Other interviewees had felt it necessary to conceal their sexuality at times, but believed they may be doing a “disservice” to others who were often accepting. It was becoming harder to hide sexuality as interviewees were allowing professionals into their lives. This was negotiated in different ways, but most participants were very open, **appearing to indicate the importance of having their couplehood acknowledged.** Stephen, Sadie, Eleanor, Alice and Carol all emphasised that telling people “up front” was important. Jack clarified:

“If you get it out the way straight away, then you know exactly where you are with people.” (Jack)

He and Bill had a similar approach to Bill’s dementia, which appeared to give them some control in reducing gossip or stigma. However, Rose felt differently and explained there were people she would rather not know about either her sexuality or dementia, leading to an ongoing experience of hiding:

“I’ve been hiding the whole of my life.” (Rose*)

Laurie implied Rose had not integrated either identity:

“You’ve never really come to accept it.” (Laurie) “No.” (Rose*)

“And I think it’s the same with the illness, to be honest.” (Laurie)

This expounds the idiosyncrasy of this decision-making process, which may be shaped by earlier experiences of sexuality concealment and/or discrimination.

Safety signals. This subtheme links with concealment decisions, but solely encompasses the process of sexuality disclosure. Safety signals are conceptualised as messages that other people send to interviewees regarding the safety of disclosure. The majority of participants described an experience of reading such signals. For some, this involved appraising others’ attitudes to determine if they were receptive. Eleanor and Jack suggested that their doctor stopping to visit indicated receptiveness. Eleanor explained:

“They said what relationship are you and I said we’re partners and he said that’s fine. He’s so nice to me. When he drives past he stops to talk to me and everything.” (Eleanor)

Yvonne highlighted a temporal aspect to this process, before deciding to reveal her sexuality.

“...If I’m not sure, you know, what the attitudes of the other person is/I would wait until I get to know them and trust them.” (Yvonne)

For Laurie and Rose, verbal acceptance of their sexual orientation from others indicated safety, while for Frank these signals could be non-verbal. He and Louis attended a carers group and continued receiving a warm welcome after revealing their relationship:

“Can you explain that you’re partners?” (Interviewer). “Yes, they’ve been excellent and the organiser is always hugging and kissing us.” (Frank*)

Overall, safety signals indicated that it was OK for LG individuals and couples to be themselves, which is central to maintaining both personhood and couplehood.

Relationships as Sheltered Harbours

The final superordinate theme conceptualises relationships as akin to a sheltered harbour, within which challenges related to dementia and/or sexuality were navigated; these challenges are likened to metaphorical “storms”. In these spaces, relationships and couplehood were required to re-calibrate due to incumbent changes and “tidal shifts”. Such changes related to roles in relationships and the consequent effect on couplehood. Harbours offer protection from extreme weather, but this protection is limited; within the findings, significant others of people with dementia had an important role in maintaining and evolving contexts of safety, to the extent that this was possible.

Navigating storms together. The storms within this subtheme refer to difficulties related to being LG, but also new challenges related to dementia. Overall, the strength of relationships was apparent with the impression that challenges were negotiated together. Initial “coming out” in intolerant contexts had been facilitated by supportive relationships, giving the sense that relationships had enabled interviewees

to become who they were. For example, Louis described familial pressure that led him to deny his sexuality; this changed when he met Frank:

“I was engaged to be married, and I knew I was gay from twelve. It was done for family/I met Frank and I just fell in love with Frank.” (Louis)

Carol similarly lived as heterosexual until her first relationship with a woman:

“... I’d never really considered that aspect of myself before (um) and (err) she kind of blew me over.” (Carol*)

Many couples indicated an experience of being “relationship trailblazers” given the societal context within which relationships had developed. For example, four couples had been amongst the first to have civil partnerships. The duration of partnerships also implied **commitment**, with seven couples having been together for over 30 years. Partners had negotiated such challenges as homophobia, long-term health conditions and immigration issues. Jack and Bill felt overcoming challenges strengthened their relationship, while Alice believed her and Jean’s consistent “togetherness” enabled them to overcome obstacles:

“...there’s a sense of togetherness that’s, it’s just there, it’s never in question. Right?” (Alice). “Mmmhmm.” (Jean*)

Stephen emphasised his and Gus’ togetherness:

“...it’s always ‘we’, ‘we, we, we, we, we’. It’s never sort of just dealing with the one, you deal with him and you deal with me.” (Stephen)

The reported togetherness indicates relationship strength, which helped to sustain couplehood in the face of challenges and ‘storms’. Current storms included arguments arising from dementia-related irritations or broader frustration towards dementia losses and perceived helplessness. Laurie vocalised her anger:

“I can’t make things right for her....that really gets me mad.” (Laurie)

Laurie and Alice emphasised the importance of honesty and connection, while Carol felt discussing the impact of dementia resolved friction with her partner, Josephine:

“I think the more she knows, the more she understands, the better it’ll be for me and for her.” (Carol*)

Others adopted different strategies such as spending some time apart or accessing respite care. There was a sense that open discussion became challenging as dementia progressed. For these interviewees it seemed they were beginning to weather storms alone **and their couplehood was under threat**:

“I think to me the biggest thing of all is the loneliness because although the persons there, they’re not there really. You know?” (Eleanor)

This connected with future talk, whereby many participants expressed fear that either partner may die, meaning they could no longer navigate together. Rose expressed the weight of this concern through stressing its singularity:

“...the one fear that will always be... What if something happens to Laurie and I’m left on my own?” (Rose*)

Tidal shifts. This theme relates to the ongoing impact of dementia on relationships, including the changes and re-calibrations experienced. As care needs escalated, the adoption of caring responsibilities left partnerships **and thus couplehood** under threat:

“...there’s this constant, constant sea of needs.” (Sadie)

“...it’s hard for me to think of us as in an equal relationship, because it doesn’t feel like that at all.” (Sadie)

Others echoed the experience of caring threatening partnerships. Stephen had arranged additional carers at home, which he felt enabled him to resume his partner role:

“...my relationship with him is of a loving partner, not a carer.” (Stephen)

“...caring kills love.” (Stephen)

Additionally, interviewees spoke of memory problems threatening intimacy and sexual connection. Jack described how caring responsibilities left him too tired to have sex, or feeling afraid to put Bill under pressure to perform, which could undermine his confidence. Louis elucidated that:

“...with the memory problem that’s lost on the agenda.” (Louis)

Louis and Stephen explained that although Frank and Gus had no libido, tactile interaction through hugs and kisses was still important. Alice described connecting to Jean physically when they lay together.

The negotiation of patient and carer identities meant that roles and responsibilities within partnerships shifted. This included tasks around the house that could no longer be completed by the PWD. Stephen hypothesised this may be easier for LG people such as himself, who have less gendered-roles so are:

“...broader spectrums in terms of knowing how to do things.” (Stephen)

It extended to roles in relationships; Jack described how Bill was somewhat of a “father figure” in their earlier years, but this had shifted. Such change reverberated for Sadie:

“...in many ways our relationship has turned upside down.” (Sadie)

Although Sadie experienced the shifts in her relationship as demanding, her talk indicated tenderness towards Kate. Stephen echoed this sentiment, implying self-care was important so as not to reach a limit:

“...it’s my dearest wish that I try to keep myself in a good condition to journey with him as long as I can.” (Stephen)

Evolving contexts of safety. This theme conceptualises relationships as places of psychological and physical safety. Significant others helped create safe psychological

contexts, **which are a basic need in relation to maintaining personhood**. Alice discussed how shared history and joint understandings had resulted in ways of being with Jean that soothed fear. When she felt Jean was afraid:

“I can just say ‘go to your heart, your heart is true’/and she knows what I mean.”

(Alice)

Similarly, Yvonne felt the strength of her relationship with Teresa enabled her to respond intuitively despite her dementia and communication difficulties. Sadie, Stephen and Eleanor all spoke of efforts to make their partners feel comfortable and secure. Sadie had checked out with Kate if she felt safe:

“‘Oh yes’, she said, ‘I, I know that you won’t do anything to hurt me, or won’t let anything happen that will hurt me’.” (Sadie)

Partners also made physical environments safe. For example, Louis and Frank travelled on cruises so Frank did not wander and get lost, whereas Eleanor and Sadie moved bedrooms so their partners’ need not climb staircases. When it came to homecare, Stephen felt he could protect Gus from any homophobic attitudes as he paid for carers so had some control. However, Alice felt less sure of this and reflected:

“They want a job, they’re not necessarily telling the truth. So, how do we know that we’re safe?” (Alice)

Alongside safety being protective, there was a contrasting experience of safety as limiting **and potentially undermining of personhood**. Jack acknowledged that he could be too overprotective of Bill, which could lead to resentment or isolation. Carol felt that her partner “kept her under her wing” and tried to limit her activities, such as swimming. At the time of the interview Carol felt she had independence, but she worried about the future:

“I’m a bit frightened of the day when I can’t stand up so easily for myself.”

(Carol*)

Discussion

The three superordinate themes connect and build understanding of dementia for LG individuals within relational contexts, in line with the research questions. ‘Duality in managing dementia’ was characterised by dilemmas within the three subthemes. The decision to remain isolated or connect with others was mediated by the degree to which dementia was perceived as stigmatised. Stigma included negative or invalidating reactions from those around the person with dementia; this kind of stigma has been documented (Katsuno, 2005). For some, this overlapped with sexual orientation leading to a ‘double stigma’, which could potentially threaten personhood for LG individuals. Price (2010) reported responses to sexuality disclosure mediated LGB caregiver experiences with accessing healthcare. This extends those findings with an indication that responses to dementia disclosure may mediate both PWD and caregivers willingness to reach out, with sexuality an additional factor.

Duality existed between challenges commonly experienced by those with a dementia diagnosis and those seemingly distinct to LG individuals. This resonates with a recent review that found most people with dementia receive substandard care at some point (Care Quality Commission, 2014). It makes sense interviewees would emphasise sameness with non-LG people if they fear unequal treatment. For some, this was linked to historical experiences of homophobia; evidence suggests two thirds of older LGB individuals have experienced verbal abuse in relation to sexual orientation over their lifetime (D’Augelli & Grossman, 2001). Current experiences included uncertainty around homophobia and discrimination, which in itself could limit feelings of psychological safety. This also related to heterosexist assumptions,

which could have made the nature of relationships unclear. The experience of same-sex partnerships not being taken seriously has been well documented (Manthorpe, 2003; Willis, Ward & Fish, 2011). As dementia is a degenerative condition and the loss of a partner is hugely significant, this could be considered to avoid the potential for experiences of disenfranchised grief (Almack, Seymour & Bellamy, 2010).

Some participants did not challenge inaccurate assumptions, while others appeared motivated to 'take action to educate', which linked to historical activism. Through taking action, they attempted to have their relationships acknowledged and make their experiences visible. Evidence indicates carers deploy "fighting discourse", which enables them to get their needs met when faced with the "maze" of dementia services (Peel & Harding, 2014). The findings suggest this may relate to the experiences of LG individuals in this context.

Participants attempted to hold onto the identity of the PWD to avoid an experience of losing core aspects of self or 'giving the self away'. Holding onto the "core" of the person with dementia involved maintaining connections with the past through reminiscence. Also, significant others maintained valued identities through appreciative language and giving PWD occupation, a central tenet of personhood (Kitwood, 1997). Similar experiences are reported amongst non-LG couples (Hellstrom et al., 2005, 2007), suggesting universality to this experience and an important role for the significant others of all people living with dementia. The findings echo Merrick et al. (2013), where heterosexual couples moved between reflecting on what had been lost and holding onto the aspects of self that remained. Merrick et al. (2013) propose this enables integration of dementia into the self while maintaining self-esteem and personhood. One interviewee seemingly struggled to integrate dementia in a similar way to acceptance of her sexual orientation, suggesting

that sustaining personhood may be challenging for PWD that have not integrated aspects of their identity. This may relate to Kimmel's (1978) theory of LG ageing; those whom have not reconciled their sexual orientation might find it more difficult to adjust to the challenges of ageing, such as dementia.

Sexual orientation was located internally, implying it was valued and integrated into identity. In contrast, dementia was externalised, both from individuals and relationships. This resonates with the narrative therapy concept of externalising problems to resist their influence (Morgan, 2000). Molyneaux, Butchard, Simpson and Murray (2011) found dementia was externalised from relationships, promoting both personhood and couplehood. Friend (1990) proposed older LG individuals build identities based upon socially constructed meanings. Those interviewees that had resisted internalising negative messages about their sexual orientation and regarded it positively may have been better able to resist internalising such messages about dementia. However, this did seem an ongoing and far from definitive process.

There appeared to be interplay between sexuality and dementia 'concealment decisions' mediated by previous experiences of support or discrimination. Individuals read 'safety signals' to determine whether sexuality disclosure was safe. Also, significant others evolved 'contexts of safety', which became challenging as they allowed potentially homophobic workers into their homes. Although paying for care gave a sense of control, most were unable to do this. This may be problematic for those who access home or residential care through a national health service and have less control, as negative interactions in social environments produce a loss of personhood (Kitwood & Bredin, 1992). The findings around 'concealment decisions' appear to be connected to the previous theme of 'shared and distinct challenges'. In particular, uncertainty regarding homophobic treatment would have an effect on how

LG couples decide whether or not to openly disclose. The experience of such uncertainty could have a negative impact on personhood, if couples feel it necessary to hide relationships and aspects of their identity. This is concerning as evidence suggests more people knowing about one's sexuality may be linked to mental health (D'Augelli, Grossman, Hershberger & O'Connell, 2001); perceived feelings of safety in communities appear to have an important role in moderating such disclosure (Jenkins Morales et al., 2014).

Relationships and couplehood appeared to be maintained in similar ways as have been documented for heterosexual samples, including similar challenges. As with non-LG individuals, maintaining couplehood through intimacy and reciprocity in relationships was challenging (Hellstrom et al., 2005). Additionally, for some interviewees with dementia, imposed safety was experienced as limiting and led to concerns around carers' involvement in future decisions. This connects with Molyneaux et al. (2011) who found limiting independence could lead to conflict. Interviewees reflected on lives together and obstacles overcome; this appeared to be important for personhood and couplehood, and is a theme of other dementia relationship studies (LaFontaine & Oyedbode, 2013). Living with dementia may activate attachment feelings, such as a need to seek psychological security (Miesen, 1999); the findings indicate significant others may play a role in meeting such attachment needs. Also, evidence suggests maintaining attachment security is important for caregiver psychological health (Nelis et al., 2013). Generally, relationship strength was apparent and secure attachments appeared to be maintained through honesty and togetherness. Overall, 'relationships as sheltered harbours' offered limited protection from 'storms', but offered a space for retreat and negotiation.

Limitations and Research Implications

The study elucidated experiences of lesbian and gay individuals with dementia, an area where little research has been conducted. However, the sample was self-selected, which may limit its applicability to a wider range of LG people.

Furthermore, although anonymity was safeguarded, participation involved some level of sexual orientation disclosure so attracted mostly visible, “out” individuals. Also, various factors may have shaped the narratives shared, such as the sensitivity of the topic, the age difference between interviewees and interviewer (first author) and the quality of pre-existing couple relationships. Additionally, there were differences in interviewees’ age and relationship contexts, such as length and nature of relationship. These factors could have influenced the stories told and would be helpful to consider in future research. Although individuals were mostly white and middle-class they were drawn from **five** different nationalities, which provided a broader range of perspectives. Participants with dementia varied in terms of verbal ability and engagement level; this could have affected their capacity to articulate thoughts, feelings and experiences. **The interview methodology is thus a limitation to the research and indicates the constraints of one-off verbal interviews for exploring dementia experiences.** Future research could give fuller consideration to specific diagnosis or stage of dementia, **while considering engaging qualitative methodologies less reliant on verbal ability.**

Evidence suggests loneliness may exacerbate minority stress for older LG individuals (Kuyper & Fokkema, 2010); isolated individuals that develop dementia may be particularly vulnerable. This includes those living in residential care where expressions of sexuality may be problematised and LG individuals are at risk of discriminatory treatment (Ward, Vass, Aggarwal, Cybyk, & Garfield, 2005). Future

research could explore how personhood is maintained for single or socially isolated individuals with dementia that lack a ‘sheltered harbour’. The issue of trauma memories related to sexual orientation, such as homophobic abuse, becoming activated when individuals feel psychologically unsafe seems worthy of further investigation.

Clinical Implications

A lack of recognition of same-sex partnerships in the context of caring has been documented and was experienced by some interviewees (Willis et al., 2011). However, the findings demonstrated relationships had an important role in maintaining personhood regardless of sexual orientation. Generally, supporting relationships benefits wellbeing in dementia (McGovern, 2010), and there are arguments for extending the concept of person-centred care to relationship-focused care (Adams & Gardiner, 2005). It is important steps are taken to reduce any invisibility through staff training in inclusive practice and not making assumptions about relationships.

Although significant others took action to educate and created safe contexts, not all LG people have someone ‘fighting’ for them. LG-friendly dementia services have been called for and most interviewees felt this was a priority over LG-specific support (The National LGB & T Partnership, 2014). As personhood involves psychological safety, it could be helpful for services to indicate they are non-discriminatory through “signaling safety” (Peel & McDaid, 2015) through an LGBT kite mark (Price, 2012). Other important issues are histories of homophobia and uncertainty around current discrimination. Again, this highlights the need to send clear, consistent and visible messages of inclusion, particularly given people with dementia’s cognitive challenges.

Significant others maintained personhood through avoiding loss or stigma-oriented discourses. Interviewees spoke about histories of activism and being ‘relationship trailblazers’. It is important that healthcare practitioners enable these “preferred versions” to emerge (Ekdawi & Hansen, 2010, p. 146). This could include foregrounding LG history and culture in reminiscence groups. Another intervention that particularly links to personhood is life story work for those with dementia (McKeown, Clarke & Repper, 2006). In particular, life story work can encourage person-centred care and enable people with dementia to feel proud about their lives and identities (McKeown et al., 2010). This would appear to be especially relevant for LG individuals with dementia, who may find their personhood under threat, and could facilitate positive interactions with service providers. However, there may be a risk individuals unintentionally ‘out’ themselves in unreceptive or unsafe environments through life story work. This emphasises the on-going need for training in non-discriminatory and respectful practice for service providers. Interviewees externalised dementia; this indicates that narrative therapy involving problem externalisation may be a useful approach (White, 1998). There is emerging evidence for adapted narrative therapy with individuals with learning disabilities (McParland, 2015), which may suggest a potential usefulness for those with other cognitive difficulties such as dementia. For those with advanced dementia, emphasising character traits and resources related to sexual orientation could be an alternative to sequential narratives (Young, 2010).

Conclusion

The study aimed to investigate the experiences of LG people with dementia. As predicted in the literature it appears attempts to remain “sexuality blind” and treat people equally are misguided (Cronin, Ward, Pugh, King & Price, 2010, p. 421), as

they can lead to heterosexism, invisibility and exclusionary practices. Such conditions may shape the experience of dementia for some lesbian and gay PWD and their significant others. However, these were not universal challenges as other interviewees experienced respect, understanding and valuable connection. Within these contexts they made concealment and disclosure decisions, attempted to ensure safety and resisted being totalised by stigmatised identities. These experiences are worthy of further investigation and consideration at a policy level, where LG issues are currently absent (Department of Health, 2009).

References

- Adams, T., & Gardiner, P. (2005). Communication and interaction with dementia care triads: Developing a theory for relationship-centred care. *Dementia, 4*, 185-205. doi:10.1177/1471301205051092
- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research, 9*, 407-411. doi:10.1177/104973239900900309
- Almack, K., Seymour, J., & Bellamy, G. (2010). Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual older people. *Sociology, 44*, 908-924. doi:10.1177/0038038510375739
- Alzheimer's Society (2012). *Demography*. Retrieved March 12, 2015, from http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=412
- American Psychiatric Association (1973). *The diagnostic and statistical manual of mental disorders* (2nd ed.). Washington, DC: Author.
- Baylis, B. (2010). The significant other. In L. Whitman (Ed.), *Telling tales about dementia: Experiences of caring* (pp. 176-182). London: Jessica Kinglsey Publishers.
- Care Quality Commission (2014). *Cracks in the pathway: People's experiences of dementia care as they move between care homes and hospitals*. London: Care Quality Commission.
- Coyle, A. (2007). Introduction to qualitative psychological research. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 9-29). London: Sage.
- Cronin, A., Ward, R., Pugh, S., King, A., & Price, E. (2010). Categories and their consequences: Understanding and supporting the caring relationships of

older lesbian, gay and bisexual people. *International Social Work*, 54, 421-435. doi:10.1177/0020872810396261

D'Augelli, A. R., & Grossman, A. H. (2001). Disclosure of sexual orientation, victimization, and mental health among lesbian, gay, and bisexual older adults. *Journal of Interpersonal Violence*, 16, 1008-1027. doi:10.1177/088626001016010003

D'Augelli, A. R., Grossman, A. H., Hershberger, S. L., & O'Connell, T. S. (2001). Aspects of mental health among older lesbian, gay, and bisexual adults. *Aging & Mental Health*, 5(2), 149-158. doi:10.1080/13607860120038366

Department of Health (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, 6, 11-25. doi:10.1177/1471301207075625

Dinos, S. (2014). Stigma creating stigma: A vicious circle. *Psychiatric Bulletin*, 38, 145-147. doi:10.1192/pb.bp.114.048124

Dorfman, R. A., Walters, K. L., Burke, P., Hardin, L., Karanik, T., Raphael, J., & Silverstein, E. (1995). Old, sad and alone: The myth of the aging homosexual. *Journal of Gerontological Social Work*, 24(1-2), 29-44. doi:10.1300/J083V24N01_04

Eisikovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, 20, 1642-1655. doi:10.1177/1049732310376520

Ekdawi, I., & Hansen, E. (2010). Working with older people in contexts of difference and discrimination. In G. Fredman, E. Anderson & J. Stott (Eds.), *Being with older people: A systemic approach*. London: Karnac.

- Ellison, G., & Gunstone, B. (2009). *Sexual orientation explored: A study of identity, attraction, behaviour and attitudes in 2009*. Manchester: Equality and human Rights Commission.
- Fischer, C. T. (2009). Bracketing in qualitative research: Conceptual and practical matters. *Psychotherapy Research, 19*, 583-590.
doi:10.1080/10503300902798375
- Fredriksen-Goldsen, K. I., & Muraco, A. (2010). Aging and sexual orientation: A 25-year review of the literature. *Research on Aging, 32*, 372-413.
doi:10.1177/0164027509360355
- Friend, R. A. (1990). Older lesbian and gay people: A theory of successful aging. *Journal of Homosexuality, 20*, 99-118. doi:10.1300/J082v20n03_07
- Hellstrom, I., Nolan, M., & Lundh, U. (2005). 'We do things together': A case study of 'couplehood' in dementia. *Dementia, 4*, 7-22.
doi:10.1177/1471301205049188
- Hellstrom, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia, 6*, 383-409.
doi:10.1177/1471301207081571
- Jenkins Morales, M., King, D., Hiler, H., Coopwood, M. S., & Wayland, S. (2014). The greater St. Louis LGBT health and human services needs assessment: An examination of the Silent and Baby Boom generations. *Journal of Homosexuality, 61*, 103-128. doi:10.1080/00918369.2013.835239
- Johnson, M. J., Jackson, N. C., Arnette, J. K., & Koffman, S. D. (2005). Gay and lesbian perceptions of discrimination in retirement care facilities. *Journal of Homosexuality, 49*, 83-102. doi:10.1300/J082v49n02_05

- Katsuno, T. (2005). Dementia from the inside: How people with early-stage dementia evaluate their quality of life. *Ageing & Society*, 25, 197-215.
doi:10.1017/S0144686X0400279X
- Kimmel, D. C. (1978). Adult development and aging: A gay perspective. *Journal of Social Issues*, 34, 113-130.
- King, M., McKeown, E., Warner, J., Ramsay, A., Johnson, K., Cort, C., . . . Davidson, O. (2003). Mental health and quality of life of gay men and lesbians in England and Wales. *The British Journal of Psychiatry*, 183, 552-558.
doi:10.1192/03-207
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing & Society*, 12, 269-287.
doi:10.1017/S0144686X0000502X
- Kuyper, L., & Fokkema, T. (2010). Loneliness among older lesbian, gay, and bisexual adults: The role of minority stress. *Archives of Sexual Behavior*, 39, 1171-1180. doi:10.1007/s10508-009-9513-7
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. San Francisco: Sage.
- La Fontaine, J., & Oyebode, J. R. (2013). Family relationships and dementia: a synthesis of qualitative research including the person with dementia. *Ageing & Society*, 34, 1243-1272. doi:10.1017/S0144686X13000056
- Lyons, E. (2007). Analysing qualitative data: Comparative reflections. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 158-173). London: Sage.

Mackenzie, J. (2009). Working with lesbian and gay people with dementia. *Journal of Dementia Care, 17*, 17-19.

Manthorpe, J. (2003). Nearest and dearest? The neglect of lesbians in caring relationships. *British Journal of Social Work, 33*, 753-768.
doi:10.1093/bjsw/33.6.753

McGovern, J. (2010). Couple well-being and dementia. *Journal of Aging, Humanities, and the Arts, 4*, 178-184. doi:10.1080/19325614.2010.508341

McGovern, J. (2014). The forgotten: Dementia and the aging LGBT community. *Journal of Gerontological Social Work, 57*, 845-857.
doi:10.1080/01634372.2014.900161

McKeown, J., Clarke, A., & Repper, J. (2006). Life story work in health and social care: Systematic literature review. *Journal of Advanced Nursing, 55*, 237-247. doi:10.1111/j.1365-2648.2006.03897.x

McKeown, J., Clarke, A., Ingleton, C., Ryan, T., & Repper, J. (2010). The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing, 5*, 148-158.
doi:10.1111/j.1748-3743.2010.00219.x

McParland, J. (2015). Narrative therapy in a learning disability context: a review. *Tizard Learning Disability Review, 20*, 121-129. doi:10.1108/TLDR-08-2014-0028

McParland, J. & Camic, P. (2016). Psychosocial factors and ageing in older lesbian, gay and bisexual people: A systematic review of the literature. *Journal of Clinical Nursing*.

- Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2013). Couples constructing their experiences of dementia: A relational perspective. *Dementia, Online First*. doi:10.1177/1471301213513029
- Miesen, B. M. L. (1999). *Dementia in close-up: Understanding and caring for people with dementia*. London: Routledge.
- Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2011). The construction of couplehood in dementia. *Dementia, 11*, 483-502. doi:10.1177/1471301211421070
- Moore, W. R. (2002). Lesbian and gay elders: Connecting care providers through a telephone support group. *Journal of Gay & Lesbian Social Services, 14*(3), 23-41. doi:10.1300/J041v14n03_02
- Morgan, A. (2000). *What is narrative therapy? An easy-to-read introduction*. Adelaide: Dulwich Centre Publications.
- Musingarimi, P. (2008). *Social care issues affecting older, gay, lesbian and bisexual people in the UK: A policy brief*. London: ILC.
- Nelis, S. M., Clare, L., & Whitaker, C. J. (2012). Attachment representations in people with dementia and their carers: Implications for well-being within the dyad. *Aging & Mental Health, 16*, 845-854. doi:10.1080/13607863.2012.667779
- Newman, R., & Price, E. (2012). Meeting the needs of LGBT people affected by dementia. In R. Ward, I. Rivers & M. Sutherland (Eds.), *Lesbian, gay bisexual and transgender ageing: Biographical approaches for inclusive support and care* (pp. 183-195). London: Jessica Kingsley.

- Peel, E., & Harding, R. (2014). "It's a huge maze, the system, it's a terrible maze": Dementia carers' constructions of navigating health and social care services. *Dementia, 13*, 642-666. doi:10.1177/1471301213480514
- Price, E. (2008). Pride or prejudice? Gay men, lesbians and dementia. *British Journal of Social Work, 38*, 1337-1352. doi:10.1093/bjsw/bcm027
- Price, E. (2010). Coming out to care: Gay and lesbian carers' experiences of dementia services. *Health and Social Care in the Community, 18*, 160-168. doi:10.1111/j.1365-2524.2009.00884.x
- Price, E. (2012). Gay and lesbian carers: Ageing in the shadow of dementia. *Ageing & Society, 32*, 516-532. doi:10.1017/S0144686X11000560
- Smith, G., Bartlett, A., & King, M. (2004). Treatment of homosexuality in Britain since the 1950's – an oral history: The experience of patients. *British Medical Journal, 328*, 427-429. doi:10.1136/bmj.328.427.37984.442419.EE
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method and research*. London: Sage.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51-80). London: Sage.
- Smith, J. A., & Osborn, M. (2007). Pain as an assault in the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health, 22*, 517-534. doi:10.1080/14768320600941756

- Stonewall (2011). *Lesbian, gay and bisexual people in later life*. Retrieved Feb 10, 2015, from http://www.stonewall.org.uk/documents/lgb_in_later_life_final.pdf
- Stonewall (2012). *Sexual orientation – FAQs*. Retrieved Feb 10, 2015, from https://www.stonewall.org.uk/at_home/sexual_orientation_faqs/default.asp
- The National LGB & T Partnership (2014). *The dementia challenge for LGBT Communities: A paper based on a roundtable discussion, 2 December 2014*. Retrieved Feb 10, 2015, from www.nationalcareforum.org.uk
- UK Parliament (1967). *Sexual offences act 1967*. London: HMSO.
- UK Parliament (2003). *Employment equality (sexual orientation) regulations 2003*. London: HMSO.
- UK Parliament (2010). *Equality act 2010*. London: HMSO.
- UK Parliament (2013). *Marriage (same sex couples) act 2013*. London: HMSO.
- Ward, R., Jones, R., Hughes, J., Humberstone, N., & Pearson, R. (2008). Intersections of ageing and sexuality: Accounts from older people. In R. Ward & B. Blythway (Eds.), *Researching age and multiple discrimination: The representation of older people in ageing research* (pp. 45-72). London: Open University.
- Ward, R., Pugh, S., & Price, E. (2010). *Don't look back? Improving health and social care service delivery for older LGB users*. Manchester: Equality and Human Rights.
- Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2005). A kiss is still a kiss?: The construction of sexuality in dementia care. *Dementia*, 4, 49-72. doi:10.1177/1471301205049190

- Weeks, J., Heaphy, B., & Donovan, C. (2001). *Same sex intimacies: Families of choice and other life experiments*. London: Routledge.
- Westwood, S. (2014). Dementia, women and sexuality: How the intersection of ageing, gender and sexuality magnify dementia concerns among lesbian and bisexual women. *Dementia, Online First*.
doi:10.1177/1471301214564446
- Williams, H., Varney, J., Taylor, J., Fish, J., Durr, P., & Elan-Cane, C. (2010). *The lesbian, gay, bisexual and trans public health outcomes framework companion document*. London: Department of Health.
- Willig, C. (2008). *Introducing qualitative research in psychology* (2nd ed.). Berkshire: Open University Press.
- Willis, P., Ward, N., & Fish, J. (2011). Searching for LGBT carers: Mapping a research agenda in social work and social care. *British Journal of Social Work, 41*, 1304-1320. doi:10.1093/bjsw/bcr114
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*, 215-228. doi:10.1080/08870440008400302
- Young, E. (2010). Narrative therapy and elders with memory loss. *Clinical Social Work Journal, 38*, 193-202. doi:10.1007/s10615-008-0146-4

Table 1. *Participant demographics*

Name¹(s) (* indicates PWD)	Ages	Ethnicity	Dementia diagnosis	Years since diagnosis	Years in relationship
Eleanor and Lucy*	72/83	British	Vascular	2	54
Sadie and Kate*	71/79	Canadian and Irish	Unspecified	1	37
Patrick*	78	British	Unspecified	2	40
Stephen and Gus*	83/72	British and Swiss	Vascular	5	48
Louis and Frank*	70/81	South African	Vascular & Alzheimer's	2	47
Laurie and Rose*	77/74	British	Alzheimer's	10	44
Yvonne (and Teresa*)	65	British	Alzheimer's	4	14
Alice and Jean*	73/69	British and Canadian	Early onset Alzheimer's	6	32
Jack and Bill*	43/57	British	Early onset Alzheimer's	18 months	25
Carol* and Anne	74/ 55	British	Alzheimer's	9-12 months	Carol was interviewed with her friend of three years, Anne.

¹ All names are pseudonyms

Table 2. *Interview schedule*

Discussion area	Questions
Background information	Ask both for year of birth, where they were born How did you meet? Where was that? Do you live together? If so, when did you decide to live together?
Memory difficulties	I understand one of you has memory difficulties: How do your understand those difficulties?
Relationship	Can you share with me what it's like being in a couple? (or having a close friendship/relationship, as appropriate) How has life treated you as a gay/lesbian couple? What are some of the things you like to do together? Have these changed in any way? If yes, how have they changed? What has that been like for both of you? Have you noticed any changes in your relationship since the memory problems began? Who do you feel close to? Has your relationship become closer or more distant in any ways? Could you tell me how? Do you have contact with any other family members? What is this like?
Identity	What makes you happy/what do you enjoy? What's important to you? What kind of activities do you do at home? What kind of activities do you do outside the home? Has anything become more enjoyable since you've had memory difficulties? Has anything become easier? Has having memory difficulties changed how you think about yourself? What about your relationship? Is there anything you used to do that has become more difficult? How have you responded to that? Have there been any changes in the way people respond to you? What has this been like?
The gay and lesbian community	Can you tell me about your involvement with the gay community? Has this changed in any way since the memory problems? How do you feel the people you know in the gay community have responded to your experiences? What has this been like for you?

<p>Support</p>	<p>Can you tell me about your experiences of getting support? Have you discussed your sexuality with care providers? Have they asked about yours sexuality? How has this been for you both? Have you felt able to discuss your relationship with services/care providers? What has this been like? What additional support, if any, do you think would be helpful? What extra support would be helpful as a gay/lesbian/bisexual person? Have professional carers been in your home? How has this been? What would be a positive outcome of this interview for you?</p>
<p>Interview for PWD's close relative, friend or partner (where appropriate)</p>	<p>How do you think having memory difficulties has affected the way they see themselves? And the way they see their relationships? (If they have been unable to) - How do you think they would respond to some of the questions I've asked? What kind of challenges do you anticipate for your relationship? What do you think has been useful in helping the PWD feel good about themselves?</p>

Table 3. *Superordinate themes and subthemes*

Super-ordinate Theme	Subtheme	Illustrative Quotation(s)
Duality in managing dementia	Isolation or reaching out while negotiating a “double stigma”	“...so you’ve got this double stigma. We’re a gay couple and then you’ve got memory problems.” (Jack)
	Shared or distinct challenges	“I think the lesbian thing is an added...it’s an added difficulty to an already difficult situation, but it’s not the dominant experience.” (Yvonne)
	Taking action to educate	“...to bring, so to speak, bring the issue out of the closet. Because it's not an issue that gets spoken of easily.” (Sadie)
Giving yourself away vs. Holding onto yourself	Dementia as external, sexuality as internal	“We did, in the early stages we called it ‘Old Stinky’.” (Alice)
	Holding onto the “core”	“She had huge cognitive difficulties, but she was always herself, you know, the core of who she was as a person was always there in spite of the deficits.” (Yvonne)
	Concealment decisions	“I’ve been hiding the whole of my life.” (Rose*) “So I usually tell people very quickly so that they don’t... they’re not under any assumption” (Carol*)
	Safety signals	“He’s so nice to me. When he drives past he stops to talk to me and everything.” (Eleanor)

Relationships as sheltered harbours	Navigating storms together	“You know, it’s always ‘we’, ‘we, we, we, we, we’. It’s never sort of just dealing with the one, you deal with him and you deal with me.” (Stephen)
	Tidal shifts	“So, in many ways our relationship has turned upside down...” (Sadie)
	Evolving contexts of safety	“I do interview them, I do tell them right away, but you can’t always know. They want a job, they’re not necessarily telling the truth. So, how do we know that we’re safe?” (Alice)
		“If I had any sort of untoward reaction, I would just say, ‘Don’t send that person.’” (Stephen)
