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JAMES C. MCPARLAND BSc Hons

THE EXPERIENCES OF LESBIAN, GAY AND BISEXUAL
PEOPLE WITH DEMENTIA.

Section A: The impact of psychosocial factors on the ageing of
older lesbian, gay and bisexual people: A review of the literature.

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dementia?

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Doctor of Clinical Psychology

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SALOMONS CENTRE FOR APPLIED PSYCHOLOGY
CANTERBURY CHRIST CHURCH UNIVERSITY

CANTERBURY CHRIST CHURCH UNIVERSITY
Doctorate in Clinical Psychology (D.Clin.Psychol.)

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Portfolio Summary

This portfolio investigates the experiences of lesbian, gay and bisexual people with dementia.

Section A reviewed research literature in order to develop understanding about the psychosocial influences on ageing for older lesbian, gay and bisexual individuals. This section provided a summary and critique of these studies. A number of psychological factors were explored including those relating to mental health and adjustment to an ageing identity. Social factors included caregiving and receiving in older age, and responses from professionals when accessing services. It was suggested that these psychosocial influences might shape experiences of ageing for older lesbian, gay and bisexual people. These included challenges brought about by stigma and discrimination, suggesting that although social attitudes towards non-heterosexuals in Western Countries have improved, the development of resilience and coping skills when ageing remains important for this population.

Section B examined the experiences of lesbian, gay and bisexual people with dementia, including how this is experienced within relationships. To elucidate these experiences, interviews were conducted with these individuals and those with whom they had a significant relationship. Verbatim transcripts from 10 interviews were studied through an interpretative phenomenological analysis. It was suggested that many aspects of dementia, including the important role of relationships in maintaining identity, were similar to published studies involving heterosexuals. There appeared to be distinct and additional aspects for these individuals that related to their sexual orientation. These results are discussed in relation to existing literature and their clinical and research implications.

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Section A: Literature Review

**The impact of psychosocial factors on the ageing of older
lesbian, gay and bisexual people: A review of the literature.**

Word Count: 8244 (249)

Abstract

Research suggests there may be specific psychological and social factors relevant to ageing for individuals with a non-heterosexual identity. The current review synthesises and evaluates the extant literature investigating the psychosocial influences on ageing as a lesbian, gay or bisexual person. It focused on empirical research involving older non-heterosexuals to develop understanding about these influences and guide future research in this area. The Cochrane Database, PsychINFO, MEDLINE, Web of Science and Google Scholar were searched for relevant findings and studies were chosen for review based on specific inclusion criteria. The search identified 42 papers suitable for review. The majority of these had not been reviewed in earlier review papers. Findings were within two domains: psychological, consisting of sub-themes relating to identity, mental health and body image; and social, consisting of relationships, social support, discrimination, caregiving and receiving, community, accessing services and housing. Methodological issues identified with these studies related to sampling procedures and lack of control groups, although most studies used appropriate measures and acknowledged inherent limitations. Future research could explore how older non-heterosexual identities intersect with other aspects in later life, such as couple relationships and cognitive difficulties.

Keywords: Ageing, lesbian, gay and bisexual, older adults, sexuality, psychosocial.

Older Age

Older age is a developmental life stage theorised to begin around the age of 60 years old (Erikson, 1950; Levinson, 1978, 1996). Additionally, the majority of adults consider 60 to be the age they reach 'later life or old age' (Humphrey, Lee, & Green, 2011). The UK National Health Service (NHS) typically defines older people as those aged 65 or above; this links to the traditional retirement age and 'older adult' services are largely provisioned for those over 65 (Department of Health, 2001). This life stage involves challenges including role loss, the death of loved ones, threats to independence and chronic health conditions (Hash & Rogers, 2013). The UK has an ageing population; there are 11 million people aged 65 or over and by 2086 one in three people will be over 60 (Age UK, 2015). There will be increased numbers of older people and it is important health and social services are able to meet their needs, particularly the National Health Service as two thirds of service users are 65 or over (Philp, 2007).

Older people experience age-related discrimination and most feel services do not pay sufficient attention to their individual needs (Age Concern and Help the Aged, 2009). This includes acknowledging diversity in ageing, such as sexual orientation, and identities beyond the "white heterosexual majority" (Northmore, Ball, & Smith, 2005, p. 5). There is growing appreciation of diversity in ageing experiences, but minority sexuality issues are largely not on the mainstream research agenda (Newman & Price, 2012). However, between 5% and 7% of the UK population are non-heterosexual, so it is estimated there are between 600,000 and 840,000 lesbian, gay and bisexual people over 65 (Stonewall, 2012). In this paper, 'non-heterosexual' refers to individuals who identify as lesbian, gay or bisexual (LGB). Please see glossary of terms in Appendix A.

Lesbian, Gay and Bisexual Context

Historically, non-heterosexual sexual orientations have been pathologised as representative of mental illness, with the American Psychiatric Association (APA) first listing homosexuality as a sociopathic personality disturbance in 1952 (American Psychiatric Association, 1952). In 1973, the American Psychiatric Association removed homosexuality as a pathological disorder and issued a statement of support for gay rights, followed in 1974 by the American Psychological Association (American Psychiatric Association, 1973; Lamberg, 1998). Within the UK context, male homosexuality was illegal until the Sexual Offences Act of 1967 when same-sex acts between men were decriminalised (UK Parliament, 1967). Legal rights for LGB people have continued to improve, with the recent introduction of equal marriage (UK Parliament, 2013). These changes are important in reducing health inequalities; more socially integrated relationships, such as through marriage, are related to better health outcomes for gay adults over 50 (Williams & Fredriksen-Goldsen, 2014).

Even though socio-legal conditions are improving, health and social inequalities remain for LGB people (Hunt & Minsky, 2007). These include social exclusion, stigma and discrimination due to homophobia, and heterosexism, the assumption of heterosexuality, ingrained in social structures. Such factors continue to influence the lives of LGB people as they age, and they report greater ageing concerns than heterosexual peers when approaching older age (Stonewall, 2011). These include needing care, independence, mobility, health, housing and mental health. However, there may be adaptive factors that help to mediate these social influences, such as individual resilience, or the creation of “families of choice” for non-heterosexuals, who may be estranged from biological families (Weeks, Heaphy, & Donovan, 2001, p.9).

Hash and Rogers (2013) outline how traditional models of ageing may apply to older LGB populations. Erikson (1950) suggested older adults attempt to resolve a conflict between ego integrity and despair. This involves reflecting on and evaluating their lives, to move towards a position of acceptance; self-acceptance may be challenging for LGB individuals that have experienced societal stigma. Humphreys and Quam (1998) suggest successful transition into older adulthood in line with Levinson's (1978, 1996) "seasons of life" theory may involve acceptance and openness about sexual orientation for LGB individuals.

Beyond traditional models there is little theory specifically conceptualising older age for LGB individuals (Hash & Rogers, 2013). Kimmel (1978) suggested LGB individuals experience identity conflict early in life as they reconcile their sexual orientation. He proposes that those who resolve this crisis develop a sense of "crisis competence", which is useful in terms of losses and changes in older age (Kimmel, 1978, p. 117). Friend (1990) theorised that older LGB individuals build ageing identities based upon socially constructed meanings. The current cohort of older adults may have lived through heterosexist and homophobic contexts; if they resisted internalising such messages they might be able to adapt to ageing effectively. Overall, psychosocial factors are central to models of ageing.

Psychosocial factors can be defined as influences that act between the social and individual levels (Martikainen, Bartley, & Lahelma, 2002). These are not fully individual or fully social, but are an interaction between these two levels that influence an individual's mind or behaviour in relationship with the broader social context. Given the potential social challenges that non-heterosexuals face, it would be reasonable to imagine that these would interact with individual development in older age, to create psychosocial influences that shape the ageing process. A number of

review papers have considered this interaction and begun to explicate the psychosocial influences on ageing for this population.

Previous Literature Reviews

The earliest review discussed the historical emergence of research in this area (Cruikshank, 1991). It concluded that social issues such as discrimination impact ageing, but acknowledged the weaknesses of an evidence base that relies on small-scale unrepresentative samples. One review relating to gay male gerontology and one to older lesbians outlined the shifting focus from debunking pathological stereotypes towards quantifying the challenges such stereotypes provoke (Gabbay & Wahler, 2002; Wahler & Gabbay, 1997). A small-scale review of ten studies involving gay men over 45 years old described how older gay men may conceal their sexual orientation in healthcare settings due to fear of discrimination (Kean, 2006). Haber (2009) proposed upcoming generations of older lesbians and gays lived through gay liberation, so will have higher expectations and advocate for responsive policies.

Fredriksen-Goldsen and Muraco (2010) took a lifecourse perspective on ageing and sexual orientation amongst 58 studies conducted in North America from 1984 to 2008. The review outlined psychosocial factors in ageing, the challenges of identifying with a marginalised population and the importance of creating ‘families of choice’ to provide support. It included research involving participants aged 50 or over; it is slightly unclear how this inclusion criterion was applied as studies included participants under 50 whose results were not disaggregated. The most recent review focused solely on gay men (Fenkl, 2012), concluding that feeling threatened when accessing services may rekindle earlier discrimination fears, so services need to be culturally appropriate.

The majority of published reviews had unclear or relaxed inclusion criteria. For example, most reviews considered research involving those over 40 to represent older age. Throughout the present review, ‘older age’ refers to adults aged 60 or above; this is considered a useful definition when investigating an international population (United Nations, 2012), and is in line with psychosocial developmental models (Erikson, 1950). Search strategies are missing from some of the previous reviews, they are mostly relevant to a North American context, and aside from widespread acknowledgement of study sampling limitations, designs and methodologies have largely not been critically appraised.

Current Review

The present systematic review aims to:

- Gain understanding of the psychosocial influences that may contribute to ageing as an LGB person
- Summarise the empirical research in this area
- Review the methodology of these studies and critically appraise and synthesise their findings
- Outline the research and clinical implications

Methodology

Search Strategy

To identify relevant studies, a systematic review of empirical papers published up to December 2014 was conducted (Grant & Booth, 2009). PsycINFO, MEDLINE, Web of Science and Cochrane databases and Google Scholar were searched using broad-based terms. The search terms were: [*lesbian or gay or bisex* or homosex* or sexual orientation or sexual minority or sexual preference*]; *and* [*ageing or aging or*

older adults *or* elder *or* gerontology *or* gerontological]. Across all databases, the strategy yielded 745 references (Appendix B, Table B1).

Inclusion/exclusion Criteria

Studies were included if: (a) all participants were 60 or older, or (b) the results for LGB adults aged 60 or above were disaggregated. The review focused on ageing and sexual orientation specifically, so studies were excluded if a majority of participants identified as transgender. Articles focusing on HIV/AIDs were excluded, as this area has a well-reviewed literature base (e.g. Martin, Fain, & Klotz, 2008). See Table 1 for full inclusion and exclusion criteria and PRISMA flowchart of search process in Figure 1 (Liberati et al., 2009).

Table 1. *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
English language	Case studies
Peer-reviewed journal	Majority of participants were
Participants at least 60 years old	transgender
Participants identifying as lesbian, gay or bisexual	HIV/AIDs focus
Presents original research findings	

Data Extraction and Analysis

Data extraction was conducted on each study meeting the inclusion criteria to facilitate the process of reviewing the papers and synthesising the data. Consideration was given to sample characteristics, methodologies used and main results. Studies adopted a range of heterogeneous methodologies so various evaluative frameworks

were required. Most larger scale studies were cross-sectional and the STROBE checklist was employed as an evaluative tool (STROBE, 2007). Qualitative studies were appraised using Yardley's (2000) criteria. These include: commitment and rigour, transparency and coherence, sensitivity to context, and impact and importance. For all studies, Meltzoff's (1998) suggestions for critically evaluating research were considered.

Structure of review

Psychosocial factors explored in the retrieved studies were diverse. As such, the review has been organised into broad domains of psychological and social functioning, similar to Fenkl (2012). Within these domains, the literature has been further grouped into themes related to specific psychosocial aspects. Some studies presented results across both domains, touching on several themes. Where this is the case, the same study may be included in more than one section.

Findings

The final sample included 42 studies summarised in Table 2. The majority had not been covered in previous reviews.

Figure 1. PRISMA flowchart

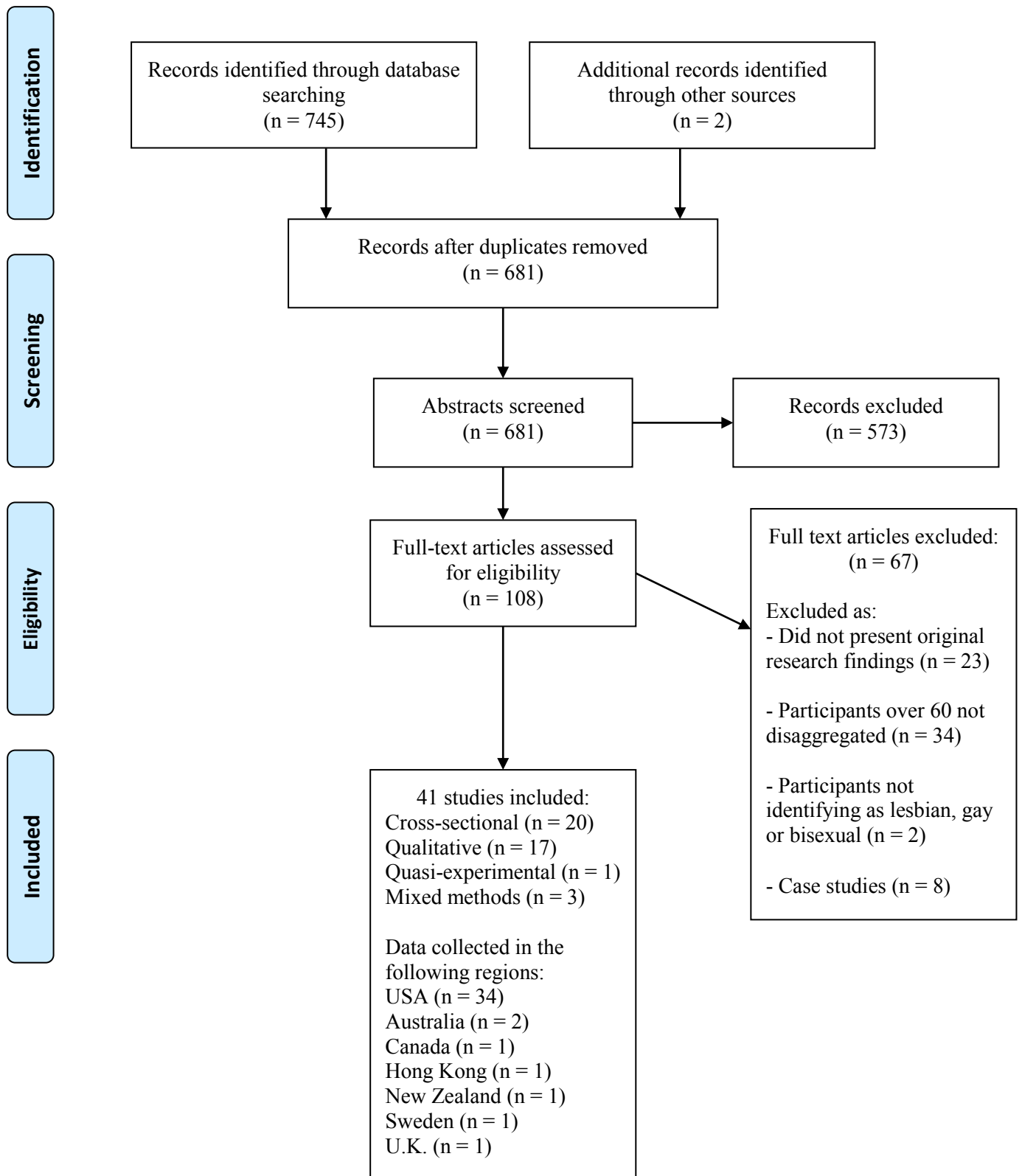


Table 2. *Main features of the reviewed studies*

Author/Date	Country	Sample	Gender/ Sexual Orientation (SO)	Methodology and measures	Main results
Kelly (1977)	USA	N=30 (of 241 total) Age: 65+	Gender: Male SO: Gay	Mixed-methods, investigator- designed questionnaires and interviews with content analysis.	Social stereotypes of older gay men as odd, closeted and disconnected from the LGB community are inaccurate. Older gay men were sexually satisfied.
Minnigerode & Adelman (1978)	USA	N=11 Age: 60- 77	Gender: Female (45%) and male (55%) SO: Lesbian and gay	Qualitative interviews, unclear analytic framework.	Self-acceptance may be a life-long struggle for older gay men and lesbians. Gay men evaluated body changes negatively more often than lesbians.
Kehoe (1986)	USA	N=50 Age: 65- 85	Gender: Female SO: Lesbian (86%) and bisexual (14%)	Cross-sectional, investigator- designed questionnaire.	Older lesbians were mentally and physically healthy, coping with ageing. 44 of the respondents considered themselves well adjusted to ageing.
Kehoe (1988)	USA	N=100 Age: 60- 86	Gender: Female SO: Lesbian (91%) and bisexual (9%)	Cross-sectional, investigator- designed questionnaire, including the Life Satisfaction Inventory.	Majority of older lesbians were in good or excellent health, felt positive about ageing and their lesbian identity. 86% scored in middle or top range on a measure of adjustment to ageing. Sex was less important after the age of 60 and 43% were in relationships. A sub- sample of women over 75 had no less interest in sex than those who were younger. 61% of lesbians had exclusively lesbian female close friendships.

Pope & Schulz (1990)	USA	N=21 (24% of total) Age: 60+	Gender: Male SO: Gay	Cross sectional, investigator-designed questionnaire.	83% of both men over 60 and those between 50 and 59 considered themselves sexually active. Overall, 38% of men aged 60 or over had sex once a week. Older gay males maintain both an interest in sex and the ability to sexually function.
Adelman (1991)	USA	N=52 Age: 60+	Gender: Female (48%) and male (52%) SO: Lesbian and gay	Mixed methods, structured interviews and questionnaires, including the Life Satisfaction Index, Symptoms Index and Self-criticism Scale.	Higher satisfaction with being gay in later life was related to higher life satisfaction and lower self-criticism.
Galassi (1991)	USA	N=15 Age: 60+	Gender: Female and male (Gender % unstated) SO: Lesbian and gay	Quasi-experimental. Investigator-designed questionnaires and unclear analysis.	An intergenerational group workshop increased pride and wellbeing. The majority had fears about coming out to services.
Quam & Whitford (1992)	USA	N=31 (38.8% of total) Age: 60+	Gender: Female (67.7%) and male (32.3%) SO: Lesbian and gay	Cross-sectional, investigator-designed questionnaire.	Older lesbians and gay men were mostly accepting of the ageing process, scored highly on life satisfaction and participated in some form of lesbian or gay specific community organisation.
Dorfman et al. (1995)	USA	N=56 (52 heterosexuals in control group) Age: 60-93	Gender: Female (57%) and male (43%) SO: Lesbian and gay	Cross-sectional, Questionnaire including the Geriatric Depression Scale and Lubben Social Network Scale.	No differences found on depression scores between homosexuals and heterosexuals. Lower depression associated with higher social support.
Hamburger (1997)	USA	N=9 Age: 60+	Gender: Female and male SO: Lesbian and gay	Cross-sectional, investigator-designed questionnaire.	The majority of respondents wanted to live in a community where sexual preference is irrelevant and non-heterosexual culture is

					planned for.
Whitford (1997)		N=21 (of 41 total) Age: 60+	Gender: Male SO: Gay	Cross-sectional, investigator-designed questionnaire.	Gay men over 60 were more accepting of the ageing process than those between 50 and 60. Acceptance related to involvement in gay social groups.
Rosenfeld (1999)	USA	N=37 Age: 65+	Gender: Female (54%) and male (46%) SO: Lesbian and gay	Qualitative, semi-structured interviews analysed with phenomenological maps.	Social context at time of gay identity development affected discourses available when constructing a gay identity. This could lead to inter-cohort differences related to the enactment of homosexuality in older age.
Grossman, D'Augelli & Hershberger (2000)	USA and Canada	N=416 Age: 60-91	Gender: Female (29%) and male (71%) SO: Lesbian, gay and bisexual	Cross-sectional. Battery of questionnaires including a modified version of the Support Network Survey, the UCLA Loneliness Scale, the Alcohol Use Disorders Identification Test and the Drug Abuse Screening Test.	Older people had around 6 people in their support networks. These were predominately close friends, but also included partners, siblings or relatives that provided emotional support.
Pollner & Rosenfeld (2000)		N=49 Age: 65-89	Gender: Female (49%) and male (51%) SO: Lesbian and gay	Qualitative, semi-structured interviews with an unclear analysis.	Older people related differently to the heterosexual 'other'. Heterosexuals were found to be portrayed as threatened by older gays and lesbians. These responses impacted their sense of self and identity.

D'Augelli & Grossman (2001)	USA and Canada	N=416 Age: 60-91	Gender: Female (29%) and male (71%) SO: Lesbian, gay and bisexual	Cross-sectional. Battery of questionnaires including a modified version of the Revised Homosexuality Attitude Inventory and an investigator-designed measure of sexual orientation victimisation.	65% had experienced at least one type of victimisation (verbal abuse, threat of violence, sexual assault, physically attacked, threat of disclosure, discrimination at work or in housing). Lifetime rates of victimisation included 29% threatened with violence, 16% physically attacked and 7% sexually assaulted. More suicide attempts were reported amongst those who had been physically attacked. 44% of gay men had been physically assaulted compared to 16% of the lesbian respondents.
D'Augelli, Grossman, Hershberger & O'Connell (2001)	USA and Canada	N=416 Age: 60-91	Gender: Female (29%) and male (71%) SO: Lesbian, gay and bisexual	Cross-sectional. Battery of questionnaires including investigator-designed measures of older adult mental health, physical health and cognitive functioning.	84% of the sample reported their mental health was good or excellent. Correlates of better mental health included higher self-esteem, less loneliness and lower internalised homophobia.
Grossman, D'Augelli & O'Connell (2001)	USA and Canada	N=416 Age: 60-91	Gender: Female (29%) and male (71%) SO: Lesbian, gay and bisexual	Cross-sectional. Battery of questionnaires including the Rosenberg Self-Esteem Scale.	Most older lesbian, gay and bisexual older adults reported fairly high self-esteem, with no differences due to gender or sexual orientation.
Orel (2004)	USA	N=26 Age: 65-84	Gender: Female (62%) and male (38%) SO: Lesbian, gay and bisexual	Qualitative, semi-structured focus groups with content analysis.	Older lesbians, gays and bisexuals were well prepared for the psychological challenges of ageing. 50% had accessed mental health services

Drumm (2005)	USA	N=9-12 (varies each group) Age: 60-80	Gender: Female SO: Lesbian	Qualitative analysis of a group using a Record of Service.	A social support group was useful for older lesbians in terms of empowerment, fostering a sense of universality and developing their relationship skills.
Hall & Fine (2005)	USA	N=2 Age: 73-85	Gender: Female SO: Lesbian	Qualitative, semi-structured interviews with narrative analysis.	Having lived lives of activism, two older lesbians were able to create positive environments that transcended traditional categories (e.g. ethnicity, class, gender) when ageing.
Clover (2006)	UK	N=10 Age: 60-75	Gender: Male SO: Gay	Qualitative, semi-structured interviews, 'successive approximation' analysis.	Previous experiences with homophobic healthcare staff and current heterosexist practices meant that health needs went unmet.
Drasin et al. (2008)	USA	N=144 (of 2402 total) Age: 60+	Gender: Male SO: Gay	Cross sectional, investigator-designed questionnaire.	Compared with an older cohort, younger gay men were reaching psychological and social milestones, such as identifying as gay and taking part in the gay community, at earlier and earlier ages.
Hughes (2009)	Australia	N=23 (6.2% of total participants) Age: 66+	Gender: Female and male (Gender % unclear) SO: Lesbian and gay	Cross-sectional, investigator-designed questionnaire.	Older lesbian, gay and bisexual people were more concerned about cognitive decline than a younger cohort. Across all age groups, gay men expressed higher concerns about body image as they age than lesbians.
Rosenfeld (2009)	USA	N=28 Age: 64-89	Gender: Female (50%) and male (50%) SO: Lesbian and gay	Qualitative, semi-structured interviews with inductive grounded theory analysis.	Older lesbians and gays employed heteronormative strategies, such as gender conforming, in the interests of personal safety, respectability and collective gain.

Smith, McCaslin, Chang, Martinez & McGrew (2010)	USA	N=38 Age: 60+	Gender: Female (39.5%), male (55.3%) and intersex (2.6%) SO: Lesbian, gay and bisexual	Cross-sectional, investigator- designed questionnaire.	Many felt that senior services could be unfriendly towards lesbian, gay and bisexual older adults. Areas of greatest unmet needs for these individuals were LGBT-friendly legal advice, social events, grief counselling, social workers and assisted living.
Stein, Beckerman & Sherman (2010)	USA	N=12 (community focus groups) Age: 60-84 N=4 (care setting focus group) Age: 64-88	Gender: Female (33%) and male (67%) SO: Lesbian and gay Gender: Male SO: Gay	Qualitative, semi-structured focus groups with thematic analysis.	Participants reported fears around accessing care, including rejection from healthcare providers and having to hide their sexuality in residential care. Older gay men in care experienced fears around open disclosure, so may have hidden their sexuality.
Slevin & Linneman (2010)	USA	N=10 Age: 60-85	Gender: Male SO: Gay	Qualitative, semi-structured interviews with 'narrative enquiry' analysis.	Older gay men drew on resources to counteract the stigma of corporeal ageing, at a time when masculinity is compromised.
Jonson & Siverskog (2012)	Sweden	N=276 Age: 60-81	Gender: Female (32%), male (59%) and transgender (9%) SO: Lesbian, gay, bisexual and queer	Quantitative content analysis and qualitative content analysis of online dating profiles.	Dual content analyses revealed how self-mocking comments about bodily appearance can serve to give older age problematic status, or display marketable characteristics of older people.
June, Segal, Klebe & Watts (2012)	USA	N=30 Age: 60-81	Gender: Female SO: Lesbian	Cross-sectional. Battery of questionnaires including the End-of-Life Care	Both older and younger lesbians had positive beliefs about holistic and alternative medicine.

				Questionnaire, the Health Care System Distrust Scale and the Holistic Complementary and Alternative Medicine Questionnaire.	
Kong (2012)	Hong Kong	N=14 Age: 60+	Gender: Male SO: Gay	Qualitative. Analysis of oral histories based on a 'post-structuralist power-resistance paradigm'.	A changing sociocultural context shaped how older men could use LGB spaces. They worked to resist the unwelcoming 'homonormativity' of contemporary queer culture, e.g. through LGB voluntary work or 'quitting' the scene.
McIntyre and McDonald (2012)	Canada	N=Unclear Age: 60-84	Gender: Female SO: Lesbian	"Qualitative research", methodology unclear.	Sexuality was often relegated to the 'private realm' for older lesbians, particularly in settings governed by heteronormative ideals.
Jihanian (2013)	USA	N=3 (interviews) Age: 64-74 N=4 (focus groups) Age: 61-79	Gender: Female and male (Gender % unclear) SO: Lesbian and gay Gender: All male SO: Gay	Qualitative, semi-structured focus groups and interviews with 'standpoint theory' analysis.	15 domains of responsiveness were identified, relating to awareness of partner relationships, preferred gender expression, diversity, knowledge of HIV/AIDs, non-stigmatising HIV/AIDs, understanding of social challenges, the impact of religion, alienating language, openness, unconditional caring, inclusive services, gay-friendly literature and creating safe environments.
Kushner, Neville & Adams (2013)	New Zealand	N=12 Age: 65-81	Gender: Male SO: Gay	Qualitative, semi-structured interviews with thematic analysis.	Older men had ageing concerns relating to homophobia and accessing care, and being with others, as social support was seen as central to successful

ageing.

Lyons, Pitts & Grierson (2013)	Australia	N=86 (40-49) N=523 (50-59, N=231) Age: 60+	Gender: Male SO: Gay	Cross-sectional, investigator-designed questionnaire.	Men over 60 years old more likely to be poorer and live alone than those in their 40s and 50s. However, they were just as likely to be in a relationship and drew greater support from friendships. Reports of discrimination dropped between those in their 40s, 50 and 60s ($\chi^2(2, N = 838) = 11.55, p < .01$).
Van Wagenen, Driskell & Bradford (2013)	USA	N=22 Age: 60-80	Gender: Female (50%) and male (50%) SO: Lesbian, gay and bisexual.	Qualitative, semi-structured interviews with grounded theory analysis.	Four levels of coping with ageing amongst older LGBT adults were reported. Overall, most participants demonstrated resilience in the face of ageing challenges. 16 participants were on the “surviving and thriving” and “working at it” gradations of coping. 6 participants were “ailing”.
Croghan, Moone, Rajean & Olsen (2014)	USA	N=123 (24.8% of total) Age: 65+	Gender: Female and male (Gender % unclear) SO: Lesbian, gay and bisexual	Cross-sectional, investigator-designed questionnaire.	Compared to the general population, these individuals were less likely to have traditional sources of support, i.e. a family member, and more likely to care for someone not related to them. Similar rates of caregiving were reported amongst those between 65 and 74 and those over 75, of 22.1% and 23.8% respectively. For all participants, 74% would rely on non-biological kin for support.

Gardner, de Vries & Mockus (2014)	USA	N=281 (221 < 60 years old) Age: 60+	Gender: Female and male (Gender % unclear) SO: Lesbian and gay	Cross-sectional, investigator-designed questionnaire.	There was a trend for those under 60 to use LGBT-specific services more regularly than older people. Across all ages, many respondents reported their sexuality would make them uncomfortable accessing services and they may fear open disclosure.
Grossman et al. (2014)	USA	N=113 Age: 60-88	Gender: Female (33%) and male (67%) SO: Lesbian, gay and bisexual	Cross-sectional, investigator-designed questionnaire.	Almost a quarter of the participants had experienced at least one type of harm from a caregiver (physical harm, psychological harm, verbal harm, sexual harm, financial exploitation, or neglect). 25.7% knew other LGB older adults that had experienced at least one type of harm from a caregiver. 26% rated their ability to think clearly and concentrate as having decreased over the preceding five years.
Jenkins Morales, King, Hiler, Coopwood & Wayland (2014)	USA	N=33 (118 < 65 years old) Age: 65+	Gender: Female (49%), male (45%), transgender (4%) and other (2%) SO: Lesbian, gay, bisexual and other.	Cross-sectional. Battery of questionnaires including the Patient Health Questionnaire-2 and the Revised UCLA Loneliness Scale.	More older women than men were in relationships, but these differences were not significant. 41% of over 65's were in relationships and were less likely to be lonely. Older people felt there were not enough health professionals with understanding of their specific issues.
Orel (2014)	USA	N=26 (focus groups) Age: 65-84	Gender: Female (62%) and male (38%) SO: Lesbian, gay and bisexual	Mixed methods. Semi-structured focus groups with content analysis and cross-sectional investigator-designed questionnaires.	Older adults experienced stigma and discrimination based on their sexuality and age. Seven areas of concern were: healthcare, legal, institutional, spiritual, family, mental health and social.

		N=1150 (surveys) Age: 64- 88	Gender: Female (64%) and male (36%) SO: Lesbian, gay and bisexual		Older adults anticipated and experienced discrimination when using senior social care services and health care. Over half felt their needs went unmet.
Putney (2014)	USA	N=12 Age: 65- 80	Gender: Female SO: Lesbian	Qualitative, semi-structured interviews with grounded theory analysis.	Pets provided companionship relationships. These involved love and caregiving, which attenuated loneliness, encouraged personal growth, fostered self- acceptance and gave purpose.

Psychological Factors

Identity. Monika Kehoe conducted two of the earliest studies into the identity of ageing lesbian women (Kehoe, 1986; Kehoe, 1988). In the first study, a large majority perceived themselves as well-adjusted to ageing (Kehoe, 1986).

Furthermore, many participants rated their self-image as 'good' or 'excellent' with only one rating it as 'poor'. Kehoe concluded older lesbians have a positive self-image and proposed they are better equipped for the ageing process, as they have previously negotiated challenging life transitions. This concept reflects Kimmel's (1978) theory of LGB ageing which suggested that reconciling sexual orientation earlier in life develops useful "crisis competence" towards challenges of ageing.

However, as no comparisons with a control group are provided, such as heterosexual counterparts, it is unclear if older lesbians are any better prepared for ageing. Kehoe hypothesised that reliability was affected due to a generational effect, whereby respondents were resistant to discuss intimate matters, so biased towards positive self-

representations. Additionally, as the questionnaires were not validated and possibly subject to this respondent bias, it is not possible to conclude older lesbians have positive self-identities.

These investigations were extended when 50 additional women completed a version of the aforementioned survey (Kehoe, 1988). The majority felt positively about their lesbian identity and 86 scored in the middle or top range on a standardised measure of adjustment to ageing. For both studies, recruitment involved adverts in gay bookstores, feminist/lesbians newsletters and gay academic organisations. Thus, the self-selected and homogeneous sample consisted of well educated, connected and 'out' lesbians from white, middle-class backgrounds. This is a significant limitation to external validity and it is unclear if these findings would extend to more diverse, disadvantaged or hidden populations.

Two other early studies attempted to destigmatise older gay and lesbian identities (Kelly, 1977; Minnigerode & Adelman, 1978). Kelly (1977) reported a content analysis on interviews with older gay men, suggesting being gay itself did not cause problems for ageing, but societal stigma was an issue. A small-scale pilot study interviewed older lesbians and gay men, and compared adaptations to ageing (Minnigerode & Adelman, 1978). Dimensions of self-concept were investigated including age-status identification and self-acceptance. The study does not report how this qualitative analysis was conducted, but proposed that gaining self-acceptance was a lifelong process. For both studies, the reporting of the qualitative analysis was poor quality by contemporary standards (Yardley, 2000); there were no details around analytical process or quality assurance. Overall, these studies were historically significant, as they provided counter-evidence to prevailing negative

stereotypes that all older LGB individuals experienced maladjustment to ageing (Berger, 1984).

A higher quality mixed-methods study, that comprehensively reported a discriminant analysis and used standardised measures, reported high life satisfaction and low self-criticism were significantly related to high satisfaction with being gay or lesbian (Adelman, 1991). Conversely, low life satisfaction and high self-criticism were related to low satisfaction with a gay identity. In relation to ageing, Whitford (1997) reported a significant relationship ($p = .018$) between age of respondent and acceptance of the ageing process. Gay men over 60 were more likely to be very accepting of the ageing process than those between 50 and 60. Also, acceptance of one's ageing process was related to participation in gay social organisations for those in the older age group. These findings suggest self-acceptance of one's sexual identity helps adjustment to ageing; this relationship may be mediated by increasing age and involvement in gay organisations.

Aspects of identity were explored in three qualitative studies by Dana Rosenfeld (Pollner & Rosenfeld, 2000; Rosenfeld, 1999; Rosenfeld, 2009). Across these studies, interview transcripts were drawn from the same sample of 49 participants, dependent on the focus of the study. Rosenfeld (1999) explored the production of identity amongst a sub-sample of older gay men and lesbians. A distinction was made between those that identified as homosexual prior to gay liberation and whose identities were shaped through stigmatising discourses, and those who began to identify as homosexual throughout the era of gay liberation. The available discourses appeared to shape and inform identity for these two cohorts in older age. The first cohort viewed presenting a homosexual self in rejecting environments as incompetent, as it would not be self-protective. The second cohort rejected hiding sexual

orientation, as it would mean internalising heterosexist depictions of homosexuality as shameful rather than positive and “revolutionary” (Rosenfeld, 1999, p. 133). Pollner and Rosenfeld (2000) further elucidated differences in response to the “heterosexual other”, who were portrayed as threatened by older homosexuals. To mitigate this threat, older people engaged in two responses: “passing” as heterosexual; or sexual orientation disclosure. While the first group feared exclusion, those who disclosed felt concealment was duplicitous and threatened self-identity.

A third study extended these ideas and uncovered the strategic use of heteronormativity, such as gender conforming (Rosenfeld, 2009). This provides personal safety and ‘respectability’ in the eyes of heterosexuals, which is threatened by socially undesirable ‘flaunting’ of homosexuality. Generally, these studies were of a good quality, reported with openness and transparency. In terms of analysis, the first study described using phenomenological maps and the third study used inductive grounded theory. However, there was no stated analytic framework for the second study, which is a limitation to methodological transparency. Also, it is unclear how the author arrived at the sub-sample in the third study, i.e. if they were the sub-sample that preferred passing as heterosexual. The results usefully indicate ways that identity is experienced; this includes potential threats to self-identity and positions that can be adopted in relation to sexuality disclosure, heterosexuals and gender performance.

Mental health. Studies have explored aspects of psychological and mental health. The aforementioned Kehoe (1988) study found a majority of older lesbians reported they were in good or excellent emotional health. However, the measures used were not standardised, limiting internal validity. Dorfman et al. (1995) found 15% of a sample of older gay men and lesbians scored clinically on a standardised measure of depression. These scores were compared with a heterosexual control

group and a multiple regression revealed no significant differences after controlling for demographic factors. Higher social support scores were significantly associated with lower depression scores ($R^2 = 0.17$, $F_{(1,106)} = 22.432$, $p < .001$), indicating an influence on mental health. Drawing on Kimmel's (1978) theory, it is hypothesised painful coming out experiences have prepared individuals to cope with ageing challenges. The authors connect to Friend's (1990) theory and suggest role losses associated with ageing are easier for homosexuals whose gender roles may have been more flexible throughout life.

These notions were endorsed by Orel's (2004) focus groups; the majority of participants felt that the psychological resilience needed to 'come out' prepared them for the psychological issues of ageing. Even so, half had used mental health services, and discussed the importance of "gay-friendly" therapists. Also, there appeared to be differences for those not "out" to family, who felt this non-disclosure limited their emotional support. This was a well-described qualitative study using content analysis, limited slightly by a self-selected, mostly out convenience sample recruited through LGB organisations.

A research team in North America conducted a large cross-sectional study into ageing, presenting results in four separate papers (D'Augelli & Grossman, 2001; D'Augelli, Grossman, Hershberger, & O'Connell, 2001; Grossman, D'Augelli, & Hershberger, 2000; Grossman, D'Augelli, & O'Connell, 2001). The sample consisted of 416 older LGB adults recruited through gay organisations and snowball sampling. The reports score highly on the STROBE checklist, including clear rationale and stated hypotheses, tested using appropriate measures and statistical analyses. Sampling limitations were acknowledged in terms of generalisability and the potential for bias with self-selected participants. Two papers focused on mental health.

D'Augelli et al. (2001) investigated predictors of mental health, including the influence of participants' attitudes towards their sexual orientation. Most reported good or excellent mental health and low levels of Personal Homonegativity, a measure of internalised homophobia based on the Revised Homosexuality Attitude Inventory (RHAI; Shidlo, 1994). Men scored significantly higher than women on the RHAI, indicating they felt less positive about their sexual orientation. Bisexual participants scored significantly higher than gays and lesbians on the RHAI, again suggesting discomfort with sexual orientation. D'Augelli and Grossman (2001) found older men experienced significantly more internalised homophobia, alcohol abuse and suicidality related to their sexual orientation. However, Grossman et al. (2001) reported fairly high levels of self-esteem amongst the whole sample, with no differences related to gender or sexual orientation.

Overall, it was found that better mental health was significantly correlated with more positive views of one's sexuality, feeling less suicidal due to one's sexuality, higher self-esteem and better cognitive functioning. They looked specifically at cognitive functioning as one aspect of mental health. Of the sample, 20% felt their cognitive functioning had worsened over the preceding five years. This had a significant relationship with age, as older participants reported decreased cognitive functioning ($r(407) = -0.16, p < .001$). In particular, almost one third of the sample reported that their memory had worsened over the preceding five years; again, this was significantly related to increasing age ($r(407) = -0.16, p < 0.001$). Diminished cognitive functioning was found to predict both poorer current mental health and worse mental health over the preceding five years. This relationship can also operate in the opposite direction, as poor mental health impacts cognitive functioning (Goodwin, 1997). In line with Kitwood (1997), diminished cognitive functioning for

LGB individuals may additionally relate to negative social environments, stigmatised identities and social isolation. There may also be individual differences in reporting or perception of cognitive difficulties.

A higher percentage of people knowing about one's sexual orientation predicted a smaller decline in mental health over the preceding five years. These results suggest that generally, older LGB individuals report good mental health, with openness about sexuality a possible protective factor. However, there are certain vulnerable groups and risk factors for poorer mental health. Gay men and bisexuals may be more likely to feel uncomfortable with their sexuality and such feelings may be associated with poor mental health. Also, those who are older might be at risk of poorer mental health due to diminishing cognitive function, or at risk of declining cognitive functioning due to poor mental health or their wider social context.

Grossman et al. (2014) presented comparable findings with 80% of older adults rating mental and emotional health as good or excellent, indicating consistency over the changing social context of the past decade. A slightly higher proportion of participants, 39%, felt their memory had worsened over the preceding five years. Another cross-sectional study reported concerns about declining cognitive ability were common amongst older lesbians and gays (Hughes, 2009). Aside from these mentions, age-related memory issues or cognitive decline were not explored in the reviewed papers.

A transparent and high quality study adopting a grounded theory approach developed a model of successful ageing for older LGBT adults (Van Wagenen, Driskell, & Bradford, 2013). The authors attended to ethical issues and provided information regarding the interview procedure and grounded theory analysis. Quality assurance and methodological rigour involved analytic triangulation and peer

debriefing. Although few participants could be described as experiencing ‘problem-free’ ageing, optimistic attitudes played a determining role in successful ageing. Such positive attitudes could perhaps explain the generally good mental health self-reports in the aforementioned studies. The authors propose ability to cope with problems determines successful ageing. Four levels of coping along a continuum were proposed; these were “traditional success”, “surviving and thriving”, “working at it” and “ailing”. Most participants were in the “surviving and thriving” and “working at it” gradations, indicating some worries about ageing, challenges with staying connected to others and possible mental health conditions. A smaller number were classed as “ailing”, indicating struggles to cope and dissatisfaction with life. As the authors acknowledged, the lack of a comparison group makes it impossible to conclude these ageing experiences are unique to LGBT older adults. However, these results suggest that although older LGBT adults may experience challenges in ageing, they demonstrate resilience and beneficial optimism.

Body image. Psychological adjustments to changing bodily appearance have been explored as an aspect of ageing. In an early small-scale study (Minnigerode & Adelman, 1978), older gay men expressed greater concern about age-related physical changes than lesbians, suggesting that dissatisfaction with physical self in older age may vary between these groups. A large-scale cross-sectional study reported similar findings, in that gay men across all ages, including over 65s, expressed significantly higher concerns about ageing body image than lesbians (Hughes, 2009). However, in a solely lesbian sample, even though 72% self-rated physical health as being good or excellent, 46% of the sample considered themselves “too fat” (Kehoe, 1988). These statistics indicate it may be pertinent to elucidate psychological experiences of ageing

bodies, as the meanings made of ageing bodies are central to making sense of ageing (Laz, 2003).

Slevin (2008) proposed that maintaining “youthful manhood” is challenging in older age, as men lose job roles, power, and begin occupying traditionally feminised spaces, such as domestic environments. Both older gay and heterosexual men were found to “discipline” their bodies, through dieting and exercise, to conform to normative notions of masculinity. This study did not meet inclusion criteria, but Slevin and Linneman (2010) further explored the experiences of ageing bodies during interviews with 10 gay men. A well-described narrative analysis examined how they discuss the masculinities of their ageing bodies within a social context that stigmatises being old and gay, and exalts youthful, heterosexual masculinity. Some older gay men resisted and counteracted stigmatised identities through drawing on material resources to appear youthful and distancing themselves from similarly aged homosexual peers. Stigma extended to the gay community, where most felt ageism can be more pronounced, as one participant explained, “gays are much more ageist than straights” (Slevin & Linneman, 2010, p. 15). It is suggested that having learned to live with one stigmatised identity (being gay), older men are well-positioned to adapt to a second such identity (being old). However, they suggest acceptance of sexual orientation may be easier than acceptance of corporeal ageing, when masculinity and independence may both be compromised. The authors acknowledged their sample was privileged through being well-educated, white and middle-class. It is unclear how potentially less-resourced populations, such as those with socioeconomic disadvantages, may adjust to ageing bodies.

Jonson and Siverskog (2012) investigated self-mocking comments regarding age-related appearance amongst those using a dating website. Two separate content

analyses on dating profiles gave rise to dual perspectives on age-related body changes. One perspective viewed self-mocking comments as subverting age-appropriate behaviour, but ultimately contributing to constructing old age as problematic. The second perspective viewed such comments, about grey hair and impotence, as displays of marketable characteristics, such as humour and honesty. These dual perspectives illustrate the variety of positions that can be adopted in relation to bodily appearances and their construction, and the problems and opportunities these afford.

Social factors

Relationships. A number of studies have explored sex and relationships. Pope and Schulz (1991) investigated whether sexual behaviour decreases among gay men as they age. This high quality cross-sectional study had a meaningful rationale, to extend the limited understanding in this area. The authors provided clear hypotheses and a comprehensive methodology, including sensitivity to participant fears around how data could be used. Age group comparisons were made and the authors concluded that older gay men maintain an interest in sex and the ability to function sexually. A study of similar quality, which provided information regarding procedure, settings and participants, found a satisfying sex life was related to subjective wellbeing and scores on a validated self-esteem measure for older gay men (Lyons, Pitts, & Grierson, 2013). The analysis was conducted using a well-described hierarchical multiple regression. Men over 60 were just as likely to be in a relationship than those in their forties and fifties, with 56% in an on-going relationship. Being in a relationship was a psychosocial factor related to wellbeing.

For older lesbians, 43% defined themselves as being in a relationship that was both emotional and sexual (Kehoe, 1988). Sex was reported as less important after

the age of 60, with a Pearson's product correlation of 0.18, although 66% considered themselves sexually active. In terms of partnerships, a large cross-sectional study found slightly higher rates of older lesbians were partnered than gay men, but these differences were not significant (Jenkins Morales, King, Hiler, Coopwood, & Wayland, 2014). For all participants aged 65 and older, 41% were in relationships and those who had partners were less likely to be lonely. Companion relationships with animals have been explored in a recent qualitative study (Putney, 2014). Pets attenuated loneliness and fostered self-acceptance through unconditional love; one participant who had lived through a homophobic context, stated, "They don't care if I'm a lesbian. They never have" (Putney, 2014, p. 7). In the only comparison study, Dorfman et al. (1995) found older gays and lesbians were significantly more likely to not have a partner than heterosexuals.

Social support. Grossman et al. (2000) presented a high quality cross-sectional study with a clear objective to investigate the nature of support networks for older LGB individuals. They found older LGB adults had an average of six others in their support networks. These were mostly close friends, who provided social support, and partners, siblings and relatives who provided emotional support. Those who were living with partners were less lonely, as measured by the standardised Loneliness Scale (Hays & DiMatteo, 1987), and reported better mental health. This corresponds with findings that loneliness is higher amongst older gay men who live alone (Whitford, 1997). Grossman et al. (2001) reported larger support networks were related to higher self-esteem ($r = 0.15$, $p < .01$). Dorfman et al. (1995) also found social factors influenced mental health, predicting 17% of the variance in depression. There were similar rates of social support regardless of sexuality, but while heterosexuals primarily garnered this from family, homosexuals drew on friendships.

Similarly, Lyons et al. (2013) reported that gay men over 60 drew greatest support from friendships. Furthermore, thematic analysis of interviews indicated that strong social networks supported the ageing process for gay men (Kushner, Neville, & Adams, 2013).

Both Kehoe (1988) and Quam and Whitford (1992) reported mixed sexuality networks for older LGB individuals, although the majority of lesbians had almost exclusively lesbian close friendships. A well-reported narrative analysis of the stories of two older lesbians suggested their friendship provided an anchor through the ageing process, which enabled them to create safe and positive environments. One participant commented, "If you've got one good friend, you've got it made" and the other agreed, "You've got the world" (Hall & Fine, 2005, p. 186). Group work was helpful in creating intimate friendships for older lesbians, as their circle of friends decreased due to death and relocation (Drumm, 2005).

Discrimination. Over their lifetimes, two thirds of those in a large cross-sectional study had experienced verbal abuse in relation to sexual orientation (D'Augelli & Grossman, 2001). Overall, 65% had experienced at least one kind of victimisation and males were more likely to have been physically assaulted. This compares with the Jenkins Morales et al. (2014) study, whereby males were most likely to have been physically or sexually assaulted. However, women who had been physically attacked reported the poorest mental health. Compared to those who had not been victimised or solely experienced verbal abuse, those who had experienced physical attacks were lonelier, had significantly lower self-esteem and higher internalised homophobia. Through their working lives, 72% of older lesbians and 79% of gay and bisexual males had experienced discrimination due to their sexuality (D'Augelli & Grossman, 2001; Kehoe, 1988).

Lyons et al. (2013) found the percentage of men reporting recent discrimination relating to their sexual orientation significantly decreased between those in their forties, fifties and sixties. Studies have reported that those over 60 were less likely to disclose their sexuality than those who were younger (Jenkins Morales et al., 2014; Lyons et al., 2013). This lack of open disclosure could mean they are less vulnerable to discrimination. Another study found no correlation between sexual orientation disclosure and victimisation or violence (Jenkins Morales et al., 2014). However, as feelings of safety in the wider community increased, so did disclosure ($r = 0.231$, $p < .01$). This may indicate older men make the decision that their contexts are not safe in terms of receptiveness to a non-heterosexual identity, so do not disclose.

Age-related discrimination increased between men in their forties, fifties and sixties, and any discrimination was a key factor in self-esteem and wellbeing, indicating the ongoing challenges for this population (Lyons et al., 2013). Also, for all gay men over 40 in the study, only 43% considered the general public felt positively towards them. This compares with earlier findings that 28% of older lesbians felt discriminated against due to their sexuality and 34% due to their age (Kehoe, 1988).

Caregiving and receiving. For those aged between 65 and 74, and those over 75, Croghan, Moone and Olson (2014) discovered similar rates of caregiving responsibilities. The majority of these individuals were caring for a friend or neighbour, with a substantial minority caring for a partner. No research elucidating the qualitative nature of caregiving experiences was identified in the search. For all LGBT adults aged 48 or over, there was lower availability of a caregiver compared to the general population, increasing risk of residential placement (Croghan et al., 2014). For those over 65, almost three quarters would rely on a partner, friend or neighbour

to be their primary caregiver, not a family member. Notably, almost double would primarily rely on a friend or neighbour rather than a partner. The three quarters figure is higher than Kehoe (1988), where 59% reported that a non-family member would care for them. However, these findings indicate the consistent importance of a chosen family for this population. In terms of receiving care, Grossman et al. (2014) found 22% had experienced at least one type of harm from a caregiver. They found 63% of participants reported self-neglect and two thirds lived alone, comparable with other findings that a majority of those over 65 live alone (Croghan et al., 2014).

Community. Involvement with the wider LGB community has been explored in the research. Quam and Whitford (1992) found 70% of older people accessed lesbian or gay social groups; however, this may be due to a selection bias, as participants were primarily recruited through such groups. Older gay men were more likely to participate in social groups than younger men, and more likely to participate in senior social organisations than older lesbians (Gardner, De Vries, & Mockus, 2014; Whitford, 1997). All older lesbians in a focus group expressed the importance of LGB community membership (Orel, 2004). Older gays and lesbians participating in an intergenerational workshop reported an increase in wellbeing and collective pride (Galassi, 1991).

However, ageism in the gay community has been noted in two qualitative studies (Slevin & Linneman, 2010; Kushner et al., 2013), posing a challenge for older gay men. Also, older men may feel a generational divide with a younger cohort that has reached psychological and social milestones at earlier ages and in more tolerant sociocultural conditions (Drasin et al., 2008). A Hong Kong-based project explored how a changing societal context had influenced older gay males' experiences of LGB community spaces (Kong, 2012). The participants reported that contemporary spaces

were less tolerant of age diversity, as they were youth and physical image obsessed, and often inaccessible without financial capital. To resist this ‘homonormativity’, some older gay men became LGB community volunteers.

Accessing health and social care services. Concerns around accessing health and social care services have been widely documented in the literature. Even though evidence suggests older adults are more satisfied with support received from people who know their sexuality (Grossman et al., 2014), a majority expressed fears about coming out to service providers (Galassi, 1991; Clover, 2006). Recent findings suggest older LGB adults remain cautious about being out to healthcare providers, partly because of fears around not being accepted and respected (Stein, Beckerman, & Sherman, 2010). Participants felt this was more likely to be a problem when receiving personal or nursing care and that they may be neglected if they were openly gay. Furthermore, older adult services may be perceived as unfriendly or even hostile to LGB individuals (Smith, McCaslin, Chang, Martinez, & McGrew, 2010), which is problematic as needs go unmet. A large cross-sectional study reported 53% of respondents were dissatisfied with senior services, feeling they did not meet their unique needs (Orel, 2014). Participants were asked what factors affected their use of services and 32% responded “discrimination or fear of discrimination”. In terms of health care, 42% reported negative experiences related to sexual orientation.

Clover (2006) proposed that a “one size fits all” approach to healthcare does not meet older people’s needs well and sought to elucidate the specific barriers for older gay men when accessing services in the UK. The high quality and transparent qualitative analysis explored experiences of health and social care, revealing that although anticipation of discrimination was more common than actual experiences, there were issues. For example, one participant described a historical negative

experience with a homophobic doctor who was reluctant to examine him, that led to service avoidance despite unmet health needs. Another participant was reluctant to ask his doctor questions about gay sex as he felt they had a limited understanding of gay sexuality and “what gay men actually do” (Clover, 2006, p. 47). Such shared feelings amongst interviewees meant partnerships and relationships were rarely discussed with healthcare professionals. This is problematic as a lack of open discussion means emotional and mental health needs, such as bereavement, social isolation and life changes could remain unaddressed. Positive experiences were reported when workers were empathic, respectful and demonstrated interest.

Opinions regarding specific LGB services have been explored and seem to vary depending on age. In one cross-sectional study, higher rates of those aged between 50 and 64, than those 65 or over reported they would be comfortable using specific services (Jenkins Morales et al., 2014). Over 65s perceived more barriers to healthcare, reported greater fears they would be treated differently and felt more unsafe than the younger group. Generally, as age increased disclosure of sexual orientation to healthcare providers decreased, perhaps due to feeling unsafe. Overall, both age groups felt there were not enough mainstream health professionals adequately trained in LGB health issues. This compares with other cross-sectional findings that those over 60 are less comfortable using specific services (Gardner et al., 2014). In relation to mainstream services, a third of participants across all ages indicated fear about disclosing their sexual orientation and this was highest amongst lesbian women. Similar rates of general health service distrust have been found amongst older lesbians and heterosexual women (June, Segal, Klebe, & Watts, 2012), suggesting this may not be unique to non-heterosexuals.

Residential accommodation. Concerns and preferences around residential accommodation have been explored. Older lesbians have reported anticipatory dread about going into mainstream residential care, as they fear their sexuality will be erased due to heteronormative services (McIntyre & McDonald, 2012). However, an unclear analytic framework is a limitation to the methodological transparency of this study. In a more clearly reported thematic analysis, which followed published analytic guidelines and provided detail around this process, older gay men were similarly wary of going into residential care and some expressed preference for LGB facilities (Kushner et al., 2013). A small-scale survey of older lesbians and gays indicated most would not actively desire to move into such facilities, but would be interested in the development of LGB senior residences or assistance to find understanding accommodation (Hamburger, 1997). Some older studies reported that the majority of lesbians would prefer lesbian, rather than mixed gay and lesbian housing (Kehoe, 1988; Quam & Whitford, 1992). However, a mixed sample of older lesbians and gays mostly wanted to live in a community where sexuality is largely irrelevant and non-heterosexual culture is acknowledged, such as units for same-sex couples (Hamburger, 1997). A majority of LGBT older adults felt that traditional nursing homes were not LGBT-friendly (Smith et al., 2010), and one fifth of a large sample felt they faced discrimination when seeking housing in traditional retirement communities (Orel, 2014), suggesting that this ideal has not yet been reached.

A number of older gay men currently living in residential care reported concerns around being ostracised by other residents and having to hide their sexuality (Stein et al., 2010). They also feared being neglected or abused by staff due to being gay, felt alone due to being unable to talk about their lives, partners or grief, and had the greatest anxiety around daily care providers. Suggestions for improved residential

care included staff not assuming heterosexuality, appreciating the individual lives residents had lived, promoting acceptance, and training staff to acknowledge gay people and support intimate relationships. This study is unique as it is the only identified study reflecting the views of those in residential care. Similar issues emerged in interviews and focus groups to identify ways in which long-term care providers need to be responsive to LGB older adults' needs (Jihanian, 2013). The identified domains of responsiveness involved the development of knowledge, skills and attitudes for staff. These included awareness of the central importance of partners, avoiding heteronormative language and creating safe environments for LGBT older adults. When these are missing and environments are homophobic or heterosexist, individual resilience has been suggested as a significant factor in coping (Kushner et al., 2013).

Discussion

Summary

The studies reviewed have suggested that LGB individuals mostly adjust well to ageing identities, with mediating factors that include acceptance of a bisexual or male homosexual self-identity, and increasing age. Specifically, when gay men and bisexual individuals reported higher levels of discomfort with their sexuality, this was linked with poorer mental health. Self-acceptance appears to be a lifelong process, which may relate to involvement with the LGB community; this involvement appears to differentially impact ageing. For some, being around other non-heterosexuals helped adjustment to ageing, while some gay men chose to distance themselves to maintain notions of masculinity.

Experiences of ageism and financial barriers within the community seem to be challenging for older gay men. This fits with findings that higher LGB community

involvement corresponds with increased concern about ageing (Hostetler, 2004). However, intergenerational workshops and voluntary work were shown to create cohesion within the LGB community. Intimate friendships and social support in general plays a key role in successful ageing, reducing loneliness and increasing self-esteem. These relationships are important as older lesbians, gays and bisexuals are more likely than not to live alone, and less likely than heterosexuals to be partnered or garner support from their biological family. 'Families of choice', including friends and neighbours, are often positioned as caregivers, while LGB individuals may adopt these roles for others.

The context in which someone first acknowledges their sexuality appears to be important, as it shapes the discourses available to older people in producing their ageing identities. These disclosures give rise to positions such as 'passing' as heterosexual or open disclosure of sexuality. 'Passing' may be motivated by an attempt to keep safe in stigmatising or discriminatory environments, although doing so may threaten self-identity. This includes caution around sexuality disclosure when accessing health and social services or residential accommodation, which may be perceived as heteronormative or hostile. In these contexts older people make a judgement about responsiveness to non-heterosexuality. Unfortunately, this may mean that needs go unmet in older age, perpetuating health inequalities (Hunt & Minsky, 2007). Moreover, there are indications that those who are not "out" have less access to emotional support and maintenance of good mental health is predicted by a higher number of other people knowing one's sexual orientation. Furthermore, those who have come out may have developed psychological resilience that prepares them for the second stigmatised identity they inhabit in older age.

Methodological Issues

Control groups. Only one study included a heterosexual control group (Dorfman et al., 1995). This is a limitation to the internal validity of the research base as a whole, making it harder to conclude influences are unique to LGB individuals. A number of studies elucidated shared or divergent influences through making comparisons between age groups, genders or sexual orientation. Some studies included only lesbian and bisexual women, or gay and bisexual men. This means certain psychosocial influences are less understood in relation to gender differences. For example, only qualitative experiences of gay males living in care were identifiable (Stein et al., 2010).

Follow up. No studies included follow-up measures, which is a limitation of the extant literature. It is therefore unclear how psychosocial influences may interact with the ageing process at different points. Longitudinal research is considered most useful when investigating relationships with long-term effects, as the same individuals are reassessed at later ages (Meltzoff, 1998).

Quantitative methodologies. Almost half of the studies adopted cross-sectional designs, which are limited in that they cannot infer a causal or reciprocal relationship between LGB identities and the psychosocial influences outlined. However, many of the studies scored well on a relevant evaluation tool, with clear objectives, study designs and methodologies, and fair appraisal of the strengths and limitations of results (STROBE, 2007). Appropriate statistical analyses and standardised measurement tools were used in most studies, indicating a number of significant relationships. However, measures were self-report which could have introduced respondent bias.

Qualitative methodologies. Qualitative studies adopted a variety of methodologies, including content, narrative and thematic analyses. These studies were well evaluated, as they clearly described the analytic process and presented quotes and themes accordingly. Such high quality studies add depth to understanding of psychosocial influences. However, two studies lacked this quality assurance and presented an unclear analytic process (Minnigerode & Adelman, 1978; McIntyre & McDonald, 2012). Similarly, the one quasi-experimental study adopted an unclear analytic framework for qualitative outcomes (Galassi, 1991).

Sampling. Most studies used non-probability sampling procedures due to recruitment challenges with this population, but purposive sampling incurs bias and limits the external validity of the findings. Evidence suggests gay males recruited through the LGB community are significantly different to those identified through random sampling as they have lower internalised homophobia and greater social contact (Meyer & Colten, 1999). As a result, those who are less connected or do not openly identify as LGB may be absent from the literature. Most studies were conducted in predominately white, Western countries, with only one exception (Kong, 2012), which further limits generalisability.

Research Implications

The literature is currently limited due to methodological issues; however, the scope and range of psychosocial influences identified indicate that future research is warranted. Most studies lacked a heterosexual control group and samples largely consisted of white, self-selected, “out” participants, limiting ecological validity. Furthermore, there may be risks inherent in grouping lesbian, gay and bisexual people into one homogenous category. This could obscure important differences related to gender, ethnicity or socioeconomic status (Institute of Medicine, 2011), which would

be worthy of deeper consideration. Future studies could adopt controlled population-based sampling methods to access a more diverse population thus increasing internal validity and representativeness. Older adults are becoming more comfortable answering survey questions regarding sexual orientation (Fredriksen-Goldsen & Kim, 2014), indicating potential for larger-scale population-based studies. Only one study was UK-based (Clover, 2006); further UK-based research would establish how, and if, findings apply to this context.

Other areas for further investigation include qualitative experiences of caregiving and receiving, and experiences of corporeal ageing for lesbian and bisexual females. Additionally, although some studies discussed findings in relation to existing LGB ageing theories, no studies did this in depth or tested theories empirically. It may be useful to assess their validity with upcoming cohorts of older LGB individuals, given the evolving social context within which identities have formed and ageing is experienced. The socio-legal and political context has markedly shifted for LGB individuals over the past few decades; it is important to remain sensitive to the context within which reviewed studies were conducted and acknowledge the impact on results. The earlier papers were historically significant, but may have less relevance in terms of contemporary experiences. Continually updating the evidence base would help establish psychosocial influences on ageing for current older LGB individuals.

Another under-developed area is LGB experiences of cognitive difficulties in older age, where the intersection of LGB orientations and cognitive difficulties, such as dementia, may compound social marginalisation (Westwood, 2014). Experiences of cognitive difficulties may be shaped by the other psychosocial influences outlined in the review. For example, discriminatory social environments are theorised to have a detrimental effect on psychological and cognitive functioning within the context of

dementia (Kitwood, 1997). Research with these individuals would develop understanding about these experiences and how to maintain good mental health for those with diminishing cognitive abilities (D'Augelli et al., 2001).

Clinical Implications

Although socio-legal conditions are improving for older LGB individuals, even the most recent studies indicate that challenges remain (Gardner et al., 2014; Grossman et al., 2014). Also, having disclosed their sexuality more openly throughout their lives, current and upcoming cohorts may have experienced higher levels of harassment and abuse (Jenkins Morales et al., 2014). Such traumatic experiences could have had a negative impact on older LGB individuals' mental health, leading to symptoms of anxiety or post-traumatic stress, which may require specialist psychological intervention (Laugharne, Lillee, & Janca, 2010). However, having experienced these challenges, some older people may have developed useful resilience (Orel, 2004; Kushner et al., 2013). Clinical psychologists could help these individuals connect with this resilience to assist with the challenges of ageing. Those who have not come out may not have had this opportunity, so struggle more in later life (D'Augelli et al., 2001). Van Wagenen et al. (2013) developed a framework of coping in older age, which could be useful in assessing older LGB individuals and determining how best to intervene and enhance their coping ability.

The majority of participants experienced barriers to health and social services, and felt services did not meet their specific needs (Smith et al., 2010; Orel, 2014). This may be due to largely heteronormative services (McIntyre & McDonald, 2012), where older people are primarily seen as heterosexual or asexual (Ekdawi & Hansen, 2010). Such implicit homophobia can mean gay men hide their sexuality if they fear receiving substandard care or being refused service (Neville & Henrickson, 2010).

Individuals may pass as heterosexual if this is perceived to be safer (Pollner & Rosenfeld, 2000), or avoid services altogether, which may perpetuate health disparities between heterosexuals and non-heterosexuals (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013).

Training could improve understanding around LGB issues in mainstream health services, as older people may be less likely to access LGB-specific services (Jenkins Morales et al., 2014). This includes the importance of partnerships and engaging with families of choice. Also, evidence suggests those without partners or contact with relatives are a particularly vulnerable population that may lack emotional support and require more intensive help (Grossman et al., 2000). Furthermore, it is important services gather data regarding sexual orientation; this would send a message of tolerance and inclusivity, and establish population demographics. Other ways to promote tolerance would be through gay-friendly imagery or incorporating LGB perspectives into service planning.

Conclusion

Research has developed an understanding of the psychosocial influences on gay, lesbian and bisexual ageing. These influences include the challenge of societal stigma and discrimination, and the resilience individuals demonstrate in response to ageing challenges, through optimism and a positive attitude. This includes older LGB people that have lived their lives more openly in a changing social context, yet still experience difficulties related to their sexual orientation. It is important these factors continue to be investigated if services are going to best meet their needs.

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Section B

How do lesbian, gay and bisexual people experience dementia?

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Dementia

Abstract

The subjective experience of dementia for lesbian, gay and bisexual 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. Ten semi-structured interviews were conducted with lesbian, gay and bisexual individuals with dementia and people with whom they had a significant relationship. Interpretative Phenomenological Analysis of transcripts identified three superordinate themes reflecting characteristics of participants' experience: *Duality in managing dementia; Giving yourself away vs. holding onto yourself*; and *Relationships as sheltered harbours*. Ten subthemes indicate processes these individuals adopt to adjust and make sense of their experience of dementia. This 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. 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, Gay and Bisexual Adults

The current generation of lesbian, gay and bisexual (LGB) older 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 LGB 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 LGB people aged 60 or above would not feel comfortable to be “out” to health providers (Ellison & Gunstone, 2009). Fredriksen-Goldsen and Muraco (2010) suggest that future studies need to explore the interaction of factors like age, health and healthcare access, stigma and cognitive impairment as they affect LGB ageing. It would seem reasonable to suggest that these psychosocial factors may influence the experience of cognitive difficulties, such as dementia.

Dementia in a Lesbian, Gay and Bisexual 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).

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. Kitwood argues this is a central determinant in the progression of dementia and positive social environments can decelerate deterioration. 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, gay and bisexual 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 LGB may further challenge personhood such as social exclusion, personal isolation, stigma, and/or familial estrangement (Stonewall, 2011).

Within residential settings, older LGB 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 LGB 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). The lack of research means little is known about these experiences and how professionals can respond appropriately to this community (Ward, 2000).

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 LGB partnerships where there may be additional psychosocial influences. It is important to note that LGB 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 lesbian, gay and bisexual individuals, 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 lesbian, gay and bisexual people with dementia.

The limited research indicates that being an LGB carer in itself provides unique challenges, such as being confronted with heterosexist or heteronormative attitudes (Willis, Ward, & Fish, 2011). These attitudes extend to a dementia context. Price interviewed 21 gay men and lesbian women caring for someone with dementia (Price, 2010, 2012); 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 LGB caregivers of partners with dementia, many of whom had confronted prejudice in health and social services (Moore, 2002).

The Present Study

Existing research indicates that being a gay man or lesbian woman caring for someone with dementia presents challenges, but the experiences of lesbian, gay or bisexual people with dementia themselves are absent from the research literature (Peel & McDaid, 2015). The present study had two aims: firstly, to explore how LGB individuals experience dementia and maintain their personhood, including the experiences and role of “significant others” in this process; and secondly, to explore how dementia is experienced by LGB individuals in relationships with partners and “significant others”, including how couplehood is maintained and how this is

experienced by “significant others” themselves. The research questions were as follows:

- What is the experience of dementia for LGB 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). With this in mind a purposive sample of LGB individuals and couples affected by dementia was recruited. There are documented challenges in identifying these largely invisible populations (Peel & McDaid, 2015; Price, 2012). Therefore, recruitment efforts were widespread and concentrated on dementia-related organisations, including an advert in the Alzheimer’s Society (UK) magazine, a guest article by the researcher for the ‘Young Dementia UK’ website, contacting older age organisations such as AgeUK branches and LGB community organisations to display posters (Appendix D).

To elucidate experiences in line with the research questions, individuals were eligible for inclusion if they were an LGB person with a diagnosis of a dementia (e.g. Alzheimer’s disease, vascular dementia), were in a lesbian or gay relationship where one partner had a diagnosis of dementia, *or* they had been in a relationship with an LGB person with a diagnosis of dementia. Interested individuals contacted the researcher and snowball sampling reached further potential participants, all of whom were sent a study information sheet (Appendix E).

Eleven people contacted the researcher to express interest. A brief telephone call was conducted with either the person with dementia or their significant other. During the call, they were asked if a formal diagnosis of dementia had been received. One individual with “memory problems” did not have a diagnosis, so was excluded to ensure homogeneity. 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 3). No participants explicitly identified as bisexual. 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).

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 that reiterated the need to be clear about the hopes for the project, i.e. to contribute to understanding and benefit clinical populations. Questions included involvement with the LGB community, experiences of accessing support, and the impact of living with dementia (Appendix F). There was a range of severity of dementia; most individuals functioned relatively independently, but a couple were physically immobile and/or 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 3. *Participant demographics*

Name¹(s) (* indicates person with dementia)	Ages	Ethnicity	Diagnosis	Years since diagnosis	Details about relationship
Eleanor and Lucy*	72 and 83	White British	Vascular Dementia	2 years	Together for 54 years
Sadie and Kate*	71 and 79	White Irish and White North American	Dementia	1 year	Together for 37 years
Patrick*	78	White British	Dementia	2 years	Patrick's partner of 40 years died a few years prior to the interview.
Stephen and Gus*	83 and 72	White British and White European	Vascular Dementia	5 years	Together for 48 years.
Louis and Frank*	70 and 81	White European	Vascular Alzheimer's	2 years	Together for 47 years.
Laurie and Rose*	77 and 74	White British.	Alzheimer's	10 months	Together for 44 years.
Yvonne (and Teresa*)	65	White British	Alzheimer's	Diagnosed 4 years at time of death	Yvonne's partner of 14 years, Teresa, died a few years prior to the interview.
Alice and Jean*	73 and 69	White British and White North American	Early onset Alzheimer's	6 years	Together for 32 years.
Jack and Bill*	43 and 57	White British	Early onset Alzheimer's	18 months	Together for 25 years.
Carol* and Anne	74 and 55	White British	Alzheimer's	9-12 months	Carol was interviewed with her friend of three years, Anne.

¹ All names are pseudonyms

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 with partners of LGB people with dementia. For one of these significant others, their partner was unwell so could not participate. This individual had previously participated in a media interview discussing their experience of dementia, i.e. not primary data. As the discussion topic related to the research aims, this interview was considered appropriate for inclusion.

Ethics

Ethical approval was attained from the Salomons Ethics Panel, Canterbury Christ Church University (Appendix G). Those who were able signed a consent form or gave verbal consent over Skype (Appendix H). Principles of Dewing's (2007) process consent method were used to further determine interviewees with dementia's consent. This person-centred method does not exclude PWD from research if they lack the cognitive competence required for informed consent. It involves gathering background information and monitoring consent throughout interviews (Appendix I).

Diagnosis disclosure. People with dementia may not conceptualise themselves as having dementia, so 'memory difficulties' was used in printed information. At interview, participants were asked about their understanding of these difficulties and most shared their diagnosis.

Anonymity. This population has documented fears around "coming out" (Stonewall, 2011); anonymity has been ensured and some demographic details changed to further prevent identification.

Distress. Participants were advised not to answer questions that made them feel uncomfortable and the researcher checked-in throughout regarding their experience. Signposting to support services was provided.

Data Analysis

In line with the research questions, qualitative methodologies aim to explore the nature of human experience. Various methodologies were considered, including Grounded Theory, which aims to develop new theories (Glaser and Strauss, 1967), and Thematic Analysis, which generates in-depth descriptions of dominant themes (Braun & Clarke, 2006). 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). This would allow a rich exploration of LGB people's 'experiences', through drawing on the phenomenological and interpretative aspects of IPA to generate new understandings possibly informed by existing theories.

The interviews were transcribed verbatim and analysed using the method described by Smith et al. (2009). Please see excerpts from two coded transcripts in Appendix J. 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. Please see examples of within interview theme development in Appendix K (Figures K1 and K2), cross-transcript theme development table in Appendix L and representative quotes in Appendix M.

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 results are a process occurring between the researcher and the participant, as the researcher attempts to make sense of what the participant has made sense of: a “double hermeneutic” (Smith & Osborn, 2003, p.51). The analysis was thus informed by the researcher’s position and findings explored in light of existing theory.

Quality Assurance

When conducting qualitative research, it is important researchers identify how personal experiences and preconceived ideas may come to bear on the data and ‘bracket’ them if possible (Fischer, 2009). Therefore, the researcher engaged in a number of reflexive practices (Ahern, 1999), including a bracketing interview with a colleague prior to conducting the interviews (Appendix N), and keeping a reflexive journal (Appendix O). Throughout the project the researcher reflected on his position as a gay male from a younger generation than most participants. One aspect involved acknowledging and bracketing a sense of responsibility to solely document challenges, while remaining mindful of more positive experiences and resiliencies demonstrated.

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. IPA coherence is demonstrated through a phenomenological focus on the experiences of participants. Upon final completion of the project, participants will be sent a results summary (Appendix P). The viability of themes and interpretations were discussed with the research supervisor, who read about 20% of the transcripts. These discussions moved themes from being descriptive towards more conceptual. Mostly, both individuals

were in agreement around interpretations; discussions helped to resolve a small amount of minor disagreements to the satisfaction of both individuals. An independent researcher read two anonymised interviews to check interpretations; this process helped 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

Interpretative phenomenological 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 4). These are illustrated with quotes.

Table 4. *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)

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 LGB 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 was avoidant. 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)

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", 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 that's new, 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)

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 LGB community, including some dementia stigma experienced by Carol in terms of patronising sympathy. 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. Overall, there was a sense dementia stigma had almost superseded sexuality stigma, but the interplay of both could leave individuals feeling vulnerable; 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 LGB individuals. This theme particularly relates to accessing health and social services. Interviewees discussed common frustrations with services, including poor dementia screening and follow-up. 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.

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 assumed 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 gay couple, you don't have the same feelings.” (Laurie)

Paradoxically, there was the sense an LGB-specific dementia group may contribute to invisibility and perpetrate marginalisation or otherness. Jack explained:

“... I think that's great. But I also think that's sort of isolating you away from everybody else/this is happening to everybody and I think being gay is normal.”

(Jack)

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 LGB 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 services 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. 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)

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. 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. 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 LGB individuals and couples to be themselves.

Relationships as Sheltered Harbours

The final superordinate theme conceptualises relationships as sheltered harbours, within which challenges or “storms” were navigated. In these spaces, relationships were re-calibrated due to incumbent changes and “tidal shifts”. Harbours offer protection from extreme weather, but this protection is limited. Significant others of people with dementia had an important role in maintaining and evolving contexts of safety.

Navigating storms together. The storms within this subtheme refer to difficulties related to being LGB, 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 depth, 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)

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:

"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*)

Making plans for this possibility seemed to be helpful. Louis and Frank discussed funeral plans and Stephen spoke of financial provisions for future care.

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 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 LGB 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. 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. 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 LGB 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’. 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 LGB 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-LGB people if they fear unequal treatment. For some, this was linked to historical experiences of discrimination and homophobia. Current experiences included uncertainty around discrimination and 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 LGB 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-LGB couples (Hellstrom et al., 2005, 2007). This echoes Merrick et al. (2013), where 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 LGB 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 LGB 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).

Relationships and couplehood appeared to be maintained in similar ways as have been documented for heterosexual samples, including similar challenges. As with non-LGB 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 could have introduced bias. 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 researcher, the quality of pre-existing couple relationships and that the researcher did not meet everyone in person. 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.

It is unknown to what extent these findings would apply for bisexual individuals, or those that prefer to keep sexual orientation secret or feel forced to do so (Price, 2008). Individuals were mostly white and middle-class; this is a common sampling limitation in research with older LGB populations (Fredriksen-Goldsen & Muraco, 2010). 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 analysis relied on transcribed speech, which could have limited the quantity of data from PWD compared to “significant others”. As a single interview was conducted, inferences cannot be made about temporal aspects of experience.

Future research could give fuller consideration to specific diagnosis or stage of dementia, while considering methodologies less reliant on verbal ability.

In terms of analysis, IPA developed understanding of lived experiences in line with aims and a phenomenological approach (Husserl, 1975). Relationships were central to maintaining personhood and creating safe contexts. Evidence suggests loneliness may exacerbate minority stress for older LGB 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 LGB 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 LGB people have someone ‘fighting’ for them. LGB-friendly dementia services have been called for and most interviewees felt this was a priority over LGB-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). An LGBT kite mark has been suggested (Price, 2012), as gay-friendly service providers are not easily identifiable (Gulland, 2009). 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 clinical psychologists enable these “preferred versions” to emerge (Ekdawi & Hansen, 2010, p. 146), through enhancing identities and being solution-focused (Camic, Tischler & Pearman, 2014). This could include foregrounding LGB history and culture in reminiscence groups. Interviewees internalised sexuality and externalised dementia. This indicates that narrative therapy involving problem externalisation may be a useful approach (White, 1998). 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 lesbian, gay and bisexual 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, gay and bisexual 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 LGB issues are currently absent (Department of Health, 2009).

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Section C: Appendices of Supporting Material

Appendix A
Glossary of Terms

Bisexual

Men or women who have a sexual orientation that can involve physical, romantic or emotional attraction towards both men and women

Civil partnership

A legally recognised arrangement for same-sex couples, that allows same-sex couples to obtain similar legal rights as a heterosexual couple that have a civil marriage.

‘Coming out’

The process of telling others about one’s own sexuality/sexual orientation. (Or for a transgender person to disclose their gender identity)

Discrimination

The act of making a judgement about somebody, either positive or negative, based on a bias, assumption or prejudice. An example could be to judge somebody based on their sexual orientation.

Disenfranchised grief

Grief that is not openly acknowledged, or is not felt to be openly acknowledged or accepted by society. An example could be the loss of one’s same-sex partner in certain contexts.

Equal marriage

The recent introduction of laws that give LGB couples the same marital rights as opposite-sex couples.

Gay, gay man or homosexual

A man who has a sexual orientation towards another man.

Gender role

Cultural, behavioural and societally perceived rules or norms typically associated with a recognised gender.

Heterosexism

Societal discrimination and bias against same-sex relationships in favour of heterosexual relationships. This can be based on the implicit assumption that heterosexuality is the norm.

Heterosexual

People who have attraction to, or sexual orientation towards people of the opposite sex.

Homophobia

A fear of and prejudice against LGB people. May lead to hostility, violence or aggression, based on actual or perceived sexual orientation.

Lesbian, gay woman or homosexual

A woman who has sexual orientation towards another woman. A woman may also identify as 'gay' rather than lesbian, gay woman or homosexual.

LGB

Lesbian, gay and bisexual people.

Passing

The act of an LGB person passing, or being perceived as a heterosexual person. Can be a conscious or unconscious process.

Sexuality/sexual orientation

A combination of emotional, romantic, sexual or affectionate attraction to another person. Broadly categorised as heterosexual, homosexual, bisexual or asexual.

Transgender

A person whose gender identity or gender expression does not match one's birth sex. This is independent to sexual orientation. May sometimes include the term transsexual, which describes a person who wants to change, or has already changed their physical sex from their birth sex.

Queer community (also known as LGBT community)

Collective LGBT people - used by some LGBT people and groups to identify themselves. More widely, a generic umbrella term for all people that are not heterosexual or cisgender (those whose gender matches their sex assigned at birth).

Created using:

The National LGB & T Partnership (2014).

www.stonewall.org.uk

www.gov.uk

www.citizensinformation.ie

Appendix B
Further Information Regarding Database Searches

Search	Search Term	PsychINFO	MEDLINE	Web of Science	Cochrane Database
1	“lesbian” <i>or</i> “gay” <i>or</i> “bisex*” <i>or</i> “homosex*” <i>or</i> “sexual orientation” <i>or</i> “sexual minority” <i>or</i> “sexual preference”	33305	29678	43691	941
2	“ageing” <i>or</i> “aging” <i>or</i> “older adults” <i>or</i> “elder” <i>or</i> “gerontology” <i>or</i> “gerontological”	82611	309694	1733707	13427
1 & 2	[limit to English language, peer reviewed and NOT(HIV or AIDS)]	188	132	398	27

Table B1: Table displaying search terms used and number of references located.

Additional searches

A search of Google Scholar was also conducted.

Appendix C
Dementia Style Guidelines

This has been removed from electronic copy.

Appendix D
Recruitment Information

Recruitment poster:

**ARE YOU A GAY, LESBIAN or BISEXUAL PERSON
WITH MEMORY DIFFICULTIES?**

**ARE YOU THE PARTNER, RELATIVE or FRIEND OF
A LESBIAN, GAY or BISEXUAL PERSON AFFECTED
BY MEMORY DIFFICULTIES?**

If so, I would like to hear from you.

My name is James McParland and I am conducting research into the unique challenges facing gay, lesbian and bisexual individuals affected by memory difficulties. The project aims to influence support provided and positively impact health and social care.

Participation in the research will involve a one-off interview, between 60-90 minutes, at a location of your choice. All information shared in the study will be kept anonymous.

I hope to interview couples, relatives and close friends as part of a doctoral qualification in clinical psychology awarded by Canterbury Christ Church University.

If you are interested in taking part or have any questions please call me on 079xxxxx, email me on j.c.mcparland675@canterbury.ac.uk or write to me at the address below:

James McParland,
Trainee Clinical Psychologist,
Runcie Court, Salomons Campus,
Canterbury Christ Church University,
Broomhill Road,
Tunbridge Wells, Kent, TN3 0TG.

Many thanks for reading this advert and I very much look forward to hearing from you. PLEASE TEAR OFF A CONTACT NUMBER BELOW:

Advert in May 2014 'Living With Dementia' – The magazine of Alzheimer's Society:

Lesbian, gay and bisexual people and dementia

Lesbian, gay and bisexual people with memory difficulties and their partners, family and friends are invited to take part in research by a trainee clinical psychologist involving a one-off interview.

For more see www.details.co.nf, call 07922 310097 or email j.c.mcpaland765@canterbury.ac.uk



**What are gay, lesbian and bisexual individuals' experiences of memory difficulties?
How do these difficulties impact upon personal relationships?**

Many thanks for considering taking part in this research. Before you decide whether or not to take part it is important that you can understand why the research is being done and also what it would involve.

Please take some time to read the following information and feel free to talk about it with your family, friends or healthcare workers. You can also contact me if you have any questions or would like any further information. Please contact me by writing to James McParland, Trainee Clinical Psychologist, Runcie Court, Salomons Campus, Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent, TN3 0TG. You can also telephone me on xxxxx, or email me at j.c.mcparland765@canterbury.ac.uk

1. What is the purpose of this research?

My name is James McParland and I am a trainee clinical psychologist. I am completing this research project as part of a Doctorate in Clinical Psychology at Canterbury Christ Church University. The research aims to investigate gay, lesbian and bisexual individuals' experience of memory difficulties. The research also aims to investigate how memory difficulties impact upon people's personal relationships. It is hoped that the findings of this research will give services a greater understanding of these individual experiences and be useful in planning services and specific support.

2. What does the research involve?

If you and your partner, relative or friend decide to take part, the research involves meeting with me together for one interview. This will take place somewhere that is convenient for you and could be at your home if you would prefer. I will ask you both questions about your experiences and of how memory difficulties have impacted upon your relationship. The length of the interview will depend upon you, but it likely to be between 60 and 90 minutes. You can ask for a

break at any time during the interview. I will also audio record the interview.

3. Do you have to take part in this research?

No, it your choice whether or not to take part in this research and your choice will be fully respected. You can withdraw from the research at any time, without giving a reason. Your decision will not affect the services you and your partner receive now or at any point in the future.

4. If you want to take part what should you do?

If you decide to take part please complete the form at the end of this leaflet and return it to me, using the stamped addressed envelope enclosed. I will then contact you by telephone to arrange to meet for an interview.

5. What will happen to the information you give?

All the information that you give during this research will be kept confidential. The audio recordings of the interviews will be stored securely and will be destroyed once the research is complete. I will write a report as part of my training. This report may be published in a journal and disseminated to services that support people with memory difficulties.

Your name will not be used in the report and I will remove any other information that may identify you. If you would like me to, I will share the findings of the research with you.

If you decide to withdraw from the study, any information that you have provided will be destroyed.

NB. If you disclose anything that concerns me in terms of risk to yourself or others I will have to contact local support services.

6. How might taking part affect you?

For some people talking about how memory difficulties have impacted upon their relationship may be difficult and upsetting. For some people it may be helpful and useful. At any time during the interview you can take a break and at the end of the interview I will discuss with you how you found it.

7. How can you contact the researcher?

If you have any further questions or would like more information, you can contact me by writing, phoning or emailing, using the details below. Alternatively, you can complete and return the reply slip below, using the stamped addressed envelope and I will contact you.

8. Who do I contact if difficulties arise?

You may discuss any difficulties with myself, or my research supervisor Professor Paul Camic, research director at Salomons Centre, Canterbury Christ Church University. His contact details are:

Prof. Paul Camic

paul.camic@canterbury.ac.uk

Tel: 0xxxxxxx

9. Who can I contact if I have a complaint?

If you have any complaints you can contact Professor Margie Callanan, the Chair of the ethics panel that approved this project in the Department of Applied Psychology at Canterbury Christ Church University. Her contact details are:

Prof. Margie Callanan

margie.callanan@canterbury.ac.uk

Tel: 01892507672

Thank you for taking the time to read this information.

James McParland,

Trainee Clinical Psychologist,
Runcie Court, Salomons Campus,
Canterbury Christ Church University,
Broomhill Road,
Tunbridge Wells, Kent, TN3 0TG.

Telephone number: xxxxx
j.c.mcpaland765@canterbury.ac.uk

.....please tear off.....

Research question: What are gay, lesbian and bisexual individuals' experiences of memory difficulties?

Titles: Mr/Mrs/Ms/Other.....(please delete as appropriate)
Names:.....

We are interested in your research and would like some more information.

Please telephone us. Our contact telephone number is:.....

Appendix F

Interview Schedule

Introduction

Outline purpose for interview – i.e. to hear their experiences whereby one of them is a gay, lesbian or bisexual person with memory difficulties

Briefly explain project's findings may help to influence the support provided to this population and positively impact health and social care.

Remind both that they do not have to answer any questions they do not want to and can withdraw at any point.

Explain length of interview, between 60-70 minutes in total, can have a break at any point.

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 you 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 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?

Support

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?

Individual interviews (where appropriate)

Questions will follow up and expand on areas of interest noted in joint interview.

Interview for PWD's close relative, friend or partner:

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?

Is there anything else you feel it is important to add?

Ending and debrief

Appendix G
Ethical Approval

This has been removed from electronic copy.

Appendix H
Consent Form

**What are gay, lesbian and bisexual individuals' experiences of
memory difficulties?
How do these difficulties impact upon personal relationships?**

Please read the statements below and if you are in agreement with them, please put a tick in each box. Then print your name and provide your signature and a contact telephone number overleaf.

Both people should complete this form.

1. I have read, or have been read, the information sheet regarding the above study. I have had opportunity to consider the information, ask questions and have these answered satisfactorily by the researcher.

2. I understand that I am being asked to take part in an interview together with my partner, friend or relative, and that the interview will be audio recorded.

3. I understand that my participation is voluntary and that I am free to withdraw from this study at any time, without giving a reason.

4. I understand that whatever my decision about taking part in this study, the services that either of us receive now or in the future will not be affected in any way.

5. I understand that the results from this research will be part of a formal submission to Canterbury Christ Church University for the researcher's doctorate degree and may also be included in a published article.

6. Overall, I give my consent to take part in the above study and to be contacted by the researcher.

.....

.....	
Name of Participant	Signature	Date

.....
Contact Telephone Number

It would be very helpful to know if you have memory difficulties.
Have you been diagnosed with a memory problem? If so, please tick
this box:

Please give this form to the researcher.

Thank you.

James McParland,
Trainee Clinical Psychologist,
Runcie Court, Salomons Campus,
Canterbury Christ Church University,
Broomhill Road,
Tunbridge Wells,
Kent,
TN3 0TG.

Telephone number: xxxxx

j.c.mcpaland765@canterbury.ac.uk

Appendix I
Process Consent Pathway

Based upon Dewing's (2007) method of process consent.

1. Background and preparation

- Work with staff, relatives or other people who are of significance to the person with dementia, to seek access to this person
- Be open and clear about my intentions for process consent.
- Work with these significant other people to gain key information for the wellbeing of the person with dementia, for example, the best time and methods for approach.

2. Establishing the basis for consent

- Talk to both the person with dementia, and these significant other people to establish key information, such as their usual process of consent/objection, usual level of wellbeing.
- Highlight how a change in wellbeing could be recognised, for example what symbols or changes in body language could be observed and recognised.

3. Initial consent

- Follow established methods of consent, such as written information, images, other prompts etc.
- Record the process, the information/conversation, any questions, answers, alongside descriptive information such as location, time, tone of interview and changes in wellbeing.
- Ensure critical reflection on process.

4. Ongoing consent monitoring

- During interview regularly check with the person with dementia as well as their partner if the initial consent still stands.
- Use the symbols/changes in body language etc. established in Stage 2 to look out for and react appropriately to any changes in wellbeing.
- If the wellbeing appears to be decreasing, check with the couple if they would like to pause the interview, and if the interview is causing the decrease in wellbeing, would they like to end the interview.

5. Feedback and support

- Highlight and explain the interview process during the consent process.
- During both consent and interview process reflect critically on the person with dementia's understanding and appreciation of consent. If there is a lack of objection, is that lack valid?
- Debrief (as is outlined in the interview schedule).
- Use supervision for reflection, consideration and evaluation.
- Reflect on my engagement with the couples.
- Consider and analyse any decisions made that relate to consent.

Appendix J
Annotated Transcript Excerpts

These have been removed from electronic copy.

Appendix K
Within Interview Theme Development

Figure K1. Example of theme development for an individual interview (Sadie and Kate*)

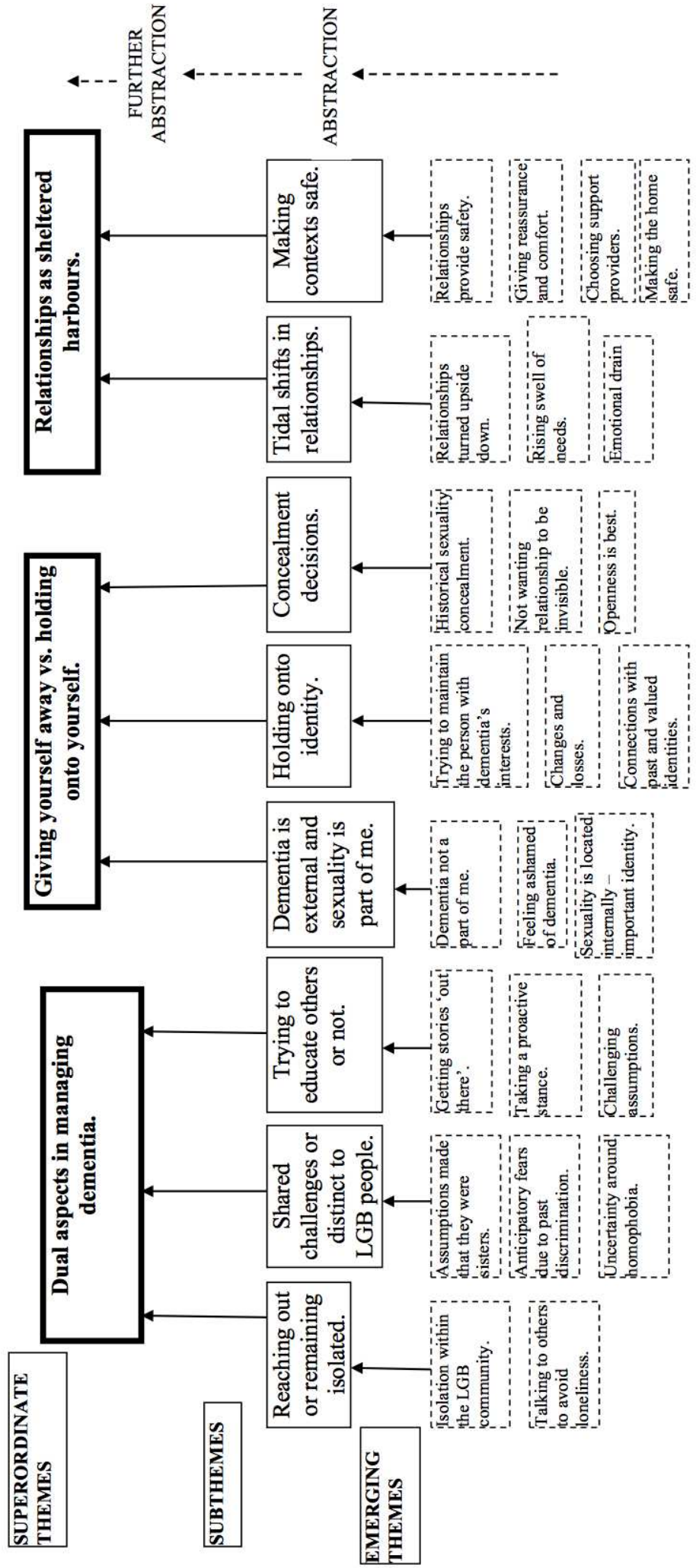
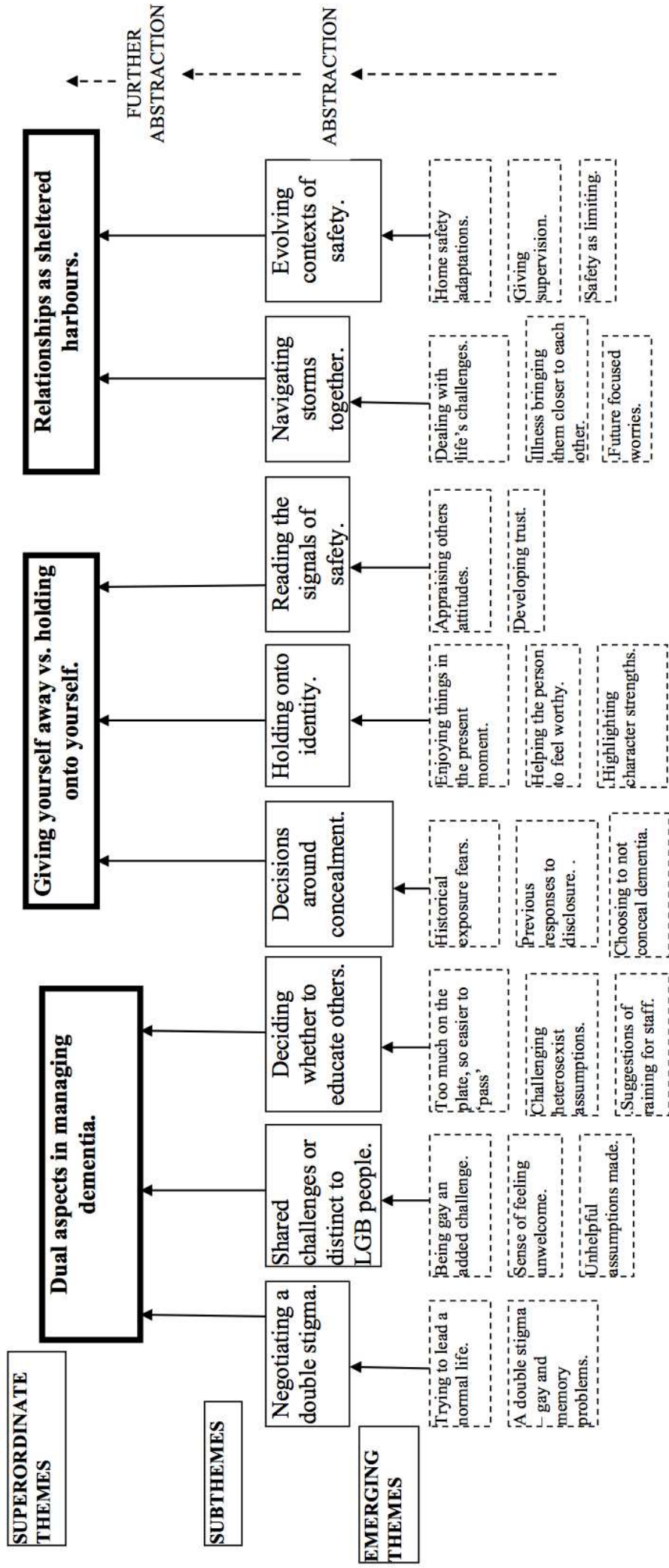


Figure K2. Example of theme development for an individual interview (Jack and Bill*)



Appendix L

Cross-transcript Theme Development Table

Emerging Themes	Subthemes	Super-ordinate themes	
<ul style="list-style-type: none"> - Trying to lead a 'normal life' (4, 9, 10) - Other's responses to dementia (1, 4, 6, 7, 8, 9, 10) - Being LGB is stigmatised (6, 9, 10) - A double stigma? (2, 9) - Relationships with the LGB community (1, 2, 3, 4, 5, 7, 8, 10) - Caring as solitary (4, 7, 9) - Decisions around accepting help (1, 3, 8, 9, 10) - Reluctance to share (1, 7) - Avoiding loneliness (1, 2, 3, 5) - Sharing creates connection (8, 9) - Sharing to sense-make (4, 6, 7) 	<p><i>Isolation or reaching out while negotiating a "double stigma"</i></p> <p>(Interviews: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10)</p>	<p>Duality in managing dementia</p>	
<ul style="list-style-type: none"> - Shared dementia challenges (1, 4, 7) - Sexuality added difficulty (7, 9) - Historical reluctant denial (8) - Unhelpful assumptions made (2, 4, 5, 6, 7, 9, 10) - Distinct experiences (8, 9) - Past trauma shaping dementia (2, 8) - Anticipated and experienced homophobia (2, 5, 8, 10) - Sexuality is invisible (2, 8, 10) - Discrimination experiences: Sexism, racism, ageism (6, 9, 10) - Sense of feeling unwelcome or uncertainty about being treated differently (2, 6, 7, 9) - Managing the uncertainty (6, 9) - Dementia diagnosis and service frustrations (1, 4, 5, 7, 10) 	<p><i>Shared and distinct challenges</i></p> <p>(Interviews: 1, 2, 4, 5, 6, 7, 8, 9, 10)</p>		
<ul style="list-style-type: none"> - Easier to pass (3, 7, 9) - Making comparisons (6) - Challenging heterosexist and other assumptions (2, 7, 9) - Previous activism (2, 4, 6, 8) - Educating others (2, 4, 5, 7, 9) - Getting stories out there (2, 4, 5, 7) - Educating themselves (9) 	<p><i>Taking action to educate</i></p> <p>(Interviews: 1, 2, 3, 4, 5, 7, 8, 9, 10)</p>		

<ul style="list-style-type: none"> - Dementia being an 'it' (1, 6, 8) - Dementia is not part of me (2, 3, 4, 6, 9) - Resisting dementia (3, 9, 7, 10) - Sexuality as internal (2, 4, 9) - Sexuality can be a valued identity (7, 9) 	<p><i>Dementia as external, sexuality as internal</i></p> <p>(Interviews: 1, 2, 3, 6, 7, 8, 9, 10)</p>	<p>Giving yourself away vs. holding onto yourself</p>
<ul style="list-style-type: none"> - Maintaining the person's interests (2, 6, 8, 9) - Less 'free-flowing' and beginning to cease (2, 3, 6, 10) - Knowledge of, and connections with, the past (1, 3, 4, 7, 8) - Enjoying things in the present (2, 7, 8, 9) - The core remains (2, 7) - Feeling worthy (Diminished or enhanced identities) (1, 2, 4, 7, 9, 10) - Fears around losing the self (5) 	<p><i>Holding on to the "core"</i></p> <p>(Interviews: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10)</p>	
<ul style="list-style-type: none"> - Exposure fears (6, 9, 10) - Historical discrimination (1, 2, 6, 8) - Professional hider (1, 2, 6, 9) - Concealment risks? (6, 9) - The necessity of hiding (1, 4, 5, 7, 9) - Unhelpful responses (9, 10) - Becoming harder to hide (3, 6) - Openness is best (1, 2, 3, 6, 8, 9, 10) - Present concealment (6, 7) - Relevance of disclosure (6, 7) 	<p><i>Concealment decisions</i></p> <p>(Interviews: 1, 2, 3, 4, 6, 7, 8, 9, 10)</p>	
<ul style="list-style-type: none"> - Acceptance talk (1, 6) - Appraising others attitudes (1, 4, 9) - Receptive others (1, 5) - Unconscious communication (10) 	<p><i>Safety signals</i></p> <p>(Interviews: 1, 4, 5, 6, 9, 10)</p>	
<ul style="list-style-type: none"> - Unplanned crossing (10) - Clandestine relationships (2) - Strength of relationships (4 5) - Relationships allowing you to become who you are (2, 5, 8, 10) - Negotiating challenges together (2, 4, 6, 7, 8, 9) - Relationship trailblazers (2, 3, 4, 5) - Frustrations and tensions (6, 10) - Travelling alone (1, 4, 6, 7) - Resolving friction (6, 8, 10) - Endings (4, 7, 9) - Staying connected (4, 5, 8) - Future talk (4, 6, 8, 9) 	<p><i>Navigating storms together</i></p> <p>(Interviews: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10)</p>	<p>Relationships as sheltered harbours</p>

<ul style="list-style-type: none"> - Impact on relationships (1, 7, 9) - Losses (2, 7) - Re-calibrating roles (1, 2, 4, 5, 6, 9, 10) - Maintaining partnerships (2, 4, 9) - Memory problems threatening intimacy (4, 5, 9) - Caring rewards /appreciating new roles (2, 3, 4, 6, 9) - Reaching a limit (1, 2, 4) 	<p><i>Tidal shifts</i></p> <p>(Interviews: 1, 2, 3, 4, 5, 6, 9, 10)</p>
<ul style="list-style-type: none"> - Intuition and understanding (7, 8) - Relationships as places of safety (2, 4, 7) - Feelings of security and comfort (2, 4, 7) - Reading others emotions (7) - Not tolerating discrimination (4) - People coming into the home (2, 4, 8) - Making environments safe (1, 2, 4, 5, 6, 8, 9) - Safety as limiting (9, 10) 	<p><i>Evolving contexts of safety</i></p> <p>(Interviews: 1, 2, 4, 7, 8, 9, 10)</p>

N.B. Numbers denote interviews that included these themes.

- 1 – Eleanor and Lucy*
- 2 – Sadie and Kate*
- 3 – Patrick* and Lynne (Home help)
- 4 – Stephen and Gus*
- 5 – Louis and Frank*
- 6 – Laurie and Rose*
- 7 – Yvonne
- 8 – Alice and Jean*
- 9 – Jack and Bill*
- 10 – Carol* and Anne

Appendix M
Table of Representative Quotes

Super-ordinate theme	Subtheme	Emerging theme examples	Illustrative quotation examples
Duality in managing dementia	Isolation or reaching out while negotiating a “double stigma”	Trying to lead a normal life	<p>‘And I keep him as... this is going to sound slightly callous, but I don’t want... 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)</p> <p>‘Because I think we all do that to a certain extent, don’t we? When something’s happening to someone we’re really close to. You don’t really want to accept it at first.’ (Anne)</p> <p>‘It’s so much easier for Bill, I think that part of his coping mechanism is sometimes to bury his head in the sand and just pretend its not happening. By actually going to a meeting, meeting other people and talking about it, he’d have to sort of admit he’s got a problem, so I think that initially is what it was.’ (Jack)</p>
		Others responses to dementia	<p>‘I find it harder talking to people about Bill’s dementia than I do about being gay to be honest. Not that I get embarrassed. It’s just that awkward moment when you tell them and they don’t know, ‘Oh, I’m so sorry’. Don’t be sorry, just deal with it, I think that’s the worst thing someone could possibly say to me, ‘oh I’m sorry’, it’s like, well don’t be sorry, it can happen to anybody, you’ve just got to get on with it.’ (Jack)</p> <p>‘I’ve perhaps not mentioned this, but when Bill first got his diagnosis, I did mention that his mum didn’t take it very well, but my sister, who I was very</p>

very close to, didn't want to know.' (Jack)

'I suppose Anne... she's just great. She just talks to me; she says you know, you're just the same as always. You know, people that are like that but (um) I think she does realise that there's something wrong. But I don't... but I think she kind of plays it down.' (Carol*)

I: And what about family? Kind of, do they know about the memory problems and have they been helpful?

'Yeah, they do but I think to an extent, I don't know, I think they sort of veer between accepting it and being in denial really.' (Carol*)

'And as I say you get worried that people might say, as it happens it doesn't happen with us because we're alright but you think, 'I wonder if people will just sort of drop you' because, you know, it's amazing, you do really find out who your friends are when a situation like this happens.' (Eleanor)

'And people know Gus and have met him socially and met him here and all sorts of things, and it was only really one of the people who actually goes to mass; Mark by name; (um) is one who has actually over this period of time, shown any ongoing support. No one else even telephoned to ask. I found that rather sad because I would've thought... Anyway, I thought and I was wrong.' (Stephen)

'I think we all respond a bit to the stigma attached to dementia, you know, and how you talk about it or how people talk to you about it was it was a problem.' (Yvonne)

Being gay is stigmatised	<p>‘Well, there’s still a certain stigma attached to being gay. Not so much with the young generations, because they’ve sort of grown up with the changes, but the older generation. When we attend these groups and we’re sat there and say ‘this is Bill and Jack, we’re a gay couple, we’ve been together for 25 years. 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)</p> <p>‘Noones left the room, or said anything directly to us, but you can see, perhaps at a table, if we’re all sat round a table and suddenly they realise that you are a gay man, they sit back in their chair. To me that’s a sign that they’re not interested, or they’d rather not, or you know.’ (Jack)</p>
A double stigma?	<p>I think, I think we're impacted because for most people of our, most of the queers of our generation, have been, erm, many have been closeted and so there're not necessarily identifying themselves as queer, or identifying themselves as having, of being queer and having dementia...’ (Sadie)</p> <p>‘You know, it’s, I suppose the first one now is having memory problems, but then sooner or later they want to know who I am. And like I say, it’s not been a massive problem, but it has been a bit awkward on occasions,’ (Jack)</p>
Relationships with the LGB community	<p>‘Like advocating for more supports out in the community that instead of Jean having to go into the first available bed, that because we’re queer there is some validity to that, and they’re not going to just put her in the first available bed. I know that the queer community is working on that, but they have never involved us in what they’re doing, so, what they’re doing just seems to be out there, when we’re already trying to live it.’ (Alice)</p> <p>‘The minute before you just asked me I was thinking to myself well, we’re</p>

all, most of my friends are gay anyway so they're quite understanding of how I feel I suppose. I don't know. We phone up everyday to see if we're all alright you know. I think the gay community are like that. They do tend to stick together a bit you know.' (Eleanor)

'We've never been on the gay scene ever, never. In the 60s we went to a gay pub and a gay nightclub, sometime in the 60s but it wasn't our scene. We found them all a bit cliquey, it wasn't our scene at all.' (Louis)

'I would say what I appreciated was a lot of people in the lesbian community that I wouldn't have been, you know, huge friends with, that I would have been acquaintances with, you know, came to the funeral. I mean, I felt that was supportive.' (Yvonne)

Decisions
around
accepting help

'Everyone one of them said 'if ever you need any help you know where I am', and all that and of course you can't keep phoning everybody, but it is lovely to know that, you know.' (Eleanor)

'You know, when somebody comes round and they try and help in some way, like offer to take Bill out for the afternoon. You think that would be nice wouldn't you, but it's not, because all I'll do is worry and think, do they understand where he's going to go wrong, do they understand that he can't do certain things. Probably not, so it's best he doesn't go, or I'll go with them.' (Jack)

'Because we do have, we do have somewhat of a chosen family. An extended family. And erm, and so, one of them discovered this website on the Internet called lots of helping hands and it's done by an Alzheimer's society we think someplace in the states, and so, there's a calendar, you know, so, so I've asked many of our friends, people that we've known, if

they would, if they're willing to be part of the support circle.' (Sadie)

Sharing to
sense-make

'And in a way, what I'm saying to you is, we often don't realise that we need to re-examine our lives and the way that you can do something of that kind would be... would perhaps with someone who is... and not for a purpose, just to be really helping us to take stock of where we're at. That kind of assessment. I mean I've never talked to anyone the way that I've responded to what you've been asking me.' (Stephen)

'Because I think it's important to... 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)

I: What would that be like do you think, if you did know people?

'I think it would... it would ease things. (Um) I think it would be good just to be able to admit to somebody else you know, 'Oh God, I said this', or I could've killed myself for saying it, why can't I sort of do this, you know?' Not let themselves get irritated and all this sort of thing, you know. To be able to talk to somebody else and probably see that they're in exactly the same boat. (Laurie)

Shared and
distinct
challenges

Dementia
diagnosis and
service
frustrations

'That's another thing. When I realised Lucy had been having difficulties remembering things I took her to the doctor and all they ever say nowadays is your age and I got so angry with him. I said 'it's not her age. I've been with her all these years I know its not her age', and I insisted. He said 'what do you want me to do then?' and I said 'give her a scan and see what's wrong. Something is wrong and I know it is'. (Eleanor)

‘Well, yeah, I’d gone to see the doctor before that and he sent me... he gave me one of these stupid tests like what’s the name of the king or queen or whatever? And what’s the date? That sort of thing. And (um)... which of course, I could answer. So there was no result from that.’ (Carol)

‘But we then... we were told at the beginning that there was no response to people who were in stage one and stage two. And then time passes and we get a visit from the social worker, saying, ‘Stephen, I hate to be here on this mission but 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)

‘... we certainly don’t get very much support for the reality that we are lesbians. The services that, the services are so poor right now for somebody in our situation that it’s hard enough even to get them, let alone have it considered that we’re lesbians. It kind of becomes a non-issue, because there’s so few.’ (Alice)

Unhelpful
assumptions
made

‘Well, they just make assumptions, they make assumptions, like there have been assumptions where they think he’s my father, which does upset him.’ (Jack)

‘They just make assumptions without asking, whereas the younger people tend to ask who he is, or who I am, and that’s what I expect. I don’t expect the red carpet to be rolled out, but I expect someone to say, if they’re unsure, to say ‘and what relationship are you to’, and then it gives me an opportunity to make it very clear, from the outset, that he’s my civil partner.’ (Jack)

‘Then I saw the surgery manager and I explained to him what happened, I

said “I wouldn’t if minded if I was coming to pick up something like a test, I came here for a common cold, a chesty cold and I was coughing and he asked me if I need a HIV test so obviously he linked our names, saw that we both had the same surname’. I have the same surname but I added his onto mine, he obviously saw that and thought ah a gay couple they must have AIDS.’ (Louis)

‘Yeah, I suppose I think some people thought she was my carer and I think sometimes when I first moved here, people thought she was my maid or something (laughs). I mean, how ridiculous. (Um) Or another woman thought she was a gardener.’ (Carol*)

Anticipated and
experienced
homophobia

‘It’s just a feeling sometimes that (um) “well, what are you getting upset about? It’s not like they’re sort of... not your husband or your wife.” I say, “Well, hang on a minute...” And there’s a concept that because you’re a gay couple, you don’t have the same feelings you know.’ (Laurie)

‘There’s never any beds available, and my concern actually in terms of that for Jean and I is, uh, not so much the training that the staff would have had, but the homophobia that the other residents will have.’ (Alice)

I mean, for example, a friend of a friend wondered if Teresa’s Alzheimer’s was linked to the fact that she was lesbian, you know. I think she was coming from a, you know, wrath of God, kind of, perspective, you know.’ (Yvonne)

<p>Uncertainty about being treated differently</p>	<p>‘But, it was very difficult to talk to this doctor, um, about being gay, because he just, I don’t know, call it a sixth sense, but I just felt very uncomfortable that he just didn’t really acknowledge us as proper people.’ (Jack)</p>
	<p>‘And now it’s not the doctors, it’s not the actual medical staff; some of the nurses are a bit iffy.’ (Laurie) ‘Yes. (Rose*) ‘Some of them have been very sort of... haven’t said anything but they’ve been very curt and they’ve looked at the notes and seen next of kin and all this. And they’ve been very oh, you know, I mean... it’s very shall we say, (err) professional and all this sort of... And (um) others have been just the opposite really.’ (Laurie)</p>
	<p>‘I was gonna say the only thing that I've actually noticed is that erm, I do, I do periodically depending on whatever, give her a kiss right? And I have noticed and it, I have noticed that workers turn away. Now that may be because they want to give us the privacy. I don't know. It, it's hard to, it's hard to judge those things. Some years ago I would have said 'Oh yeah they just aren't comfortable but now I don't- now I don't necessarily draw that conclusion.’ (Sadie)</p>
<p>Taking action to educate</p>	<p>Easier to pass</p> <p>‘You don’t, years ago, they were the situations you used to get angry and fight for, you know, no, we’re not brothers, we’re lovers, and you make a real point of it, sort of thing. But, nowadays you think, do you know what, I can’t be bothered. I’ve got too much on my plate at the moment.’ (Jack)</p> <p>‘Now, in a way it would have been easier to have been sisters, you know, and I mean I can appreciate because of the culture of attitudes...I’m sure it’s</p>

a lot easier for two women than it is for two men in that situation. So, presumption that we were sisters would have been easier from my point of view.’ (Yvonne)

Challenging assumptions

‘Of course, we have the experiences of a new worker coming in and calling her 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 thirty seven years!' I mean she's very, very clear about that. Then the worker sort of says 'Oh I'm sorry'.’ (Sadie)

‘But then, with older people, especially receptionists and things, we’ve had a couple of times at our own doctors, when somebody new has started and you know, it’s like, ‘and they are, (pause), your father?’, and you go, ‘no’. And this guessing game goes on for a while and that plays straight into their hands, and they go, ‘well who is he then?’. ‘He’s my gay partner’ and I say it very loudly and then they don’t know where to put their face.’ (Jack)

‘I threw it back at them and I said how would you feel if you went to see your doctor with a cold and the first thing the doctor says to you is do you need a HIV test? Would you feel embarrassed? I said I wouldn’t have minded if I went in and I said I think I might have picked up something, but not for a common cold. I said that he obviously linked our names together and yeah ah a gay couple I think I’ll send them for a HIV test.’ (Louis)

Previous activism

‘When Jean met me I was a candidate for ministry and I was quite surprised that they’d accepted me as a single mum with four kids and then when I came out, that was, they then dropped me for some spurious reasons which I challenged over many years.’ (Alice)

‘...we, we got the legislation changed in 2002. So we were very active, and I was very active in, in, er, both with the bureaucrats in terms of the formation of the legislation, and also politically, in terms of getting the legislation actually passed through parliament.’ (Sadie)

‘I did ten years working at a HIV charity, all of that. I was fully committed to that and Gus was exceedingly supportive. And a lot of the many meetings and things took place actually here in the early days.’ (Stephen)

Getting stories
‘out there’

‘And also, the fact that... to be able to do it in a totally non-judgemental (um) manner, and also (err) to know that maybe in time, this report comes out, maybe it will help somebody else. You know, I think that’s... because I would love it to sort of feel it’s been of some use to somebody, you know.’ (Laurie)

‘In the sense that for us what’s important – and part of the reason why I agreed to this is, erm, that, that it is important for us to be able to erm, somehow get these stories out there.’ (Sadie)

‘I mean many of us have gone through the whole process of coming out about our sexual orientation, or gender identity, but, dementia and Alzheimer’s is another whole area that oftentimes remains invisible, closeted, behind closed doors, so, I certainly hope that being visible around this will also help others to break the silence, to provide support to each other.’ (Sadie)

‘I spoke a couple of months ago, you know, from a personal perspective at the launch, for example, of the LGBT guidelines for health staff.’ (Yvonne)

Giving yourself away vs. Holding onto yourself	Dementia as external, sexuality as internal	Dementia is not a part of me	<p>‘Ah, dementia. Before I couldn’t say the word, because, because I was ashamed of it.’ (Kate*)</p> <p>‘I’ve never felt, I don’t think about it. I don’t think about it. Life goes on. You know. And erm, no I don’t think about it.’(Lucy*)</p> <p>‘I just feel like I’m normal, and that’s how I want to be. Even if I don’t, if other people see the same thing, I don’t know. But, I just feel like I’m just back normal really, and I know I’m not, but you know, that’s it.’ (Bill*)</p> <p>‘My brother and I are very close indeed, you know. We always have been and (um) you know, I sort of... you get to the point where because of Rose’s sort of illness, I don’t know how she would cope with coming with me but at the same time, I can’t leave her. So that stops me from... you know, it’s difficult. And that’s nothing to do with Rose, it’s with this damn illness.’ (Laurie)</p>
		Resisting dementia	<p>I think one is all the time preparing for problems that will eventually appear. I think one has to expect and budget for them getting worse. Otherwise you are going to have a much worse position.’ (Patrick*)</p> <p>‘The only thing I would say that has changed is that we have to be more clever about having our diaries together because otherwise it has happened where we’ve arranged something and then there’s been an element of... did we arrange that yet?’ (Anne)</p>

Sexuality as valued identity ‘I think as a gay man you build up a wall to protect yourself from all sorts of situations. And at the beginning, it’s hard because that wall isn’t very high. But when you’re in your forties that wall is sort of re-inforced several times over, and so you learn that nobody can say anything to hurt you unless you let it.’ (Jack)

‘Particularly we... in a certain sense, as gay men, I think we’re quite... ‘lucky’ is not the word... (err) broader spectrumed in terms of knowing how to do things.’ (Stephen)

‘One of the carers/we’ve had recently; he’s a Spanish fellow and he’s a teensy bit camp. And as soon as he walks in, Gus immediately responds very positively to his presence, as he did with another... two other carers that we have had, one of them we had for about a year and a half, and they got on fabulously well.’ (Stephen)

Holding onto the “core” Maintaining the persons interests ‘Oh, I enjoy gardening. I love gardening; we’ve got a good garden and I’m out there hours, aren’t I? I lose myself completely. Yes, that’s... So I do get help from that, very much. (Um)...’ (Rose*)

‘I guess one of the things that she does do that she does enjoy is going to the library. Erm, and, we have a library within two blocks of our house – two, maybe three – and so, erm, we used to walk to the library together. Now, walking that distance is, is challenging for her so we often will go in the car, er, even though it’s only, like, three blocks, so I know that’s one of the things that she really likes to do.’ (Sadie)

‘I haven’t really got any interests, have I?’ (Bill*)

‘So, you don’t enjoy going on holiday then?’ (Jack)

‘Yes, I like holidays. We just came off one so.’ (Bill*)

‘Oh, where have you been?’ (Jack)

‘On a cruise, yeah, for seven nights. Very nice.’ (Bill*)

Knowledge of
and connections
with the past

‘We sometimes look at our wedding pictures, because we had this massive rainbow wedding with a hundred people at it. And you know, so we, and then we have friends that come over and we can talk about things that we used to do and stuff like that. That keeps us really present in who we are.’
(Alice)

Well, I mean, she was able to...you know, the whole thing of...whatever bit of your brain, you know, stuff like enjoying music or intuition comes from she had that, you know. So, she had a lifelong interest in, for example, classical music or in art or she was always active, so she walked, so she was always able to enjoy that.’ (Yvonne)

‘So there'll be a photograph and I'll see the photograph and then start talking about it you know. I mean it's really hard because I like to say. I want to say 'remember when' But I know that saying remember is, is a bad thing to say to somebody with dementia right? And I can't draw a line very clearly between what I think she's going to remember and what I know she's not going to remember. Right. So. Generally I, I just start talking about the photograph. And about. And I think I do say 'remember this' or 'remember that' and about those, about those years she does remember.’ (Sadie)

‘Gus, what do you most enjoy? (Pause). That’s quite a hard one because his life in many ways was very rich, very artistic, very (um)... he still enjoys music a great deal. A great deal, and is also still really surprisingly knowledgeable, recognising composers, recognising artists who are singing

or playing.’ (Stephen)

Diminished or
enhanced
identities

‘Well I try not to answer for her on things and stuff like that. Um, when its my, I’ve needed to help her, I try to kind of see where she can do what she, give her the opportunity to do what she can do and support her in the things she can’t do.’ (Alice)

‘Yeah, I’m still... that’s my shed up there with Anne in it, and she’s an artist as well, so we’re (um)... we’re going to do a show at a gallery in a couple of weeks. So we’re kind of getting ready for that (laughs).’ (Carol*)

‘So I’ve maybe not got myself organised soon enough but from a point of view of getting organised, I mean you’ve just been nothing but supportive. So you know, from my point of view, I’m doing well out of it and I hope that I’m able to do that for you as well. Although I think at the moment you’re carrying more, probably more than I’m carrying (laughs).’ (Anne)

‘...she’s amazing. I don’t know how she does it. Mind you I used to think she was amazing at the piano bar. I don’t know how she remembered everything. People used to come in with songs I’d never heard of and she’d know the words. But then you’ve always really sang haven’t you Lucy?’ (Eleanor)

‘Always.’ (Lucy)

‘He copes with all the pots on his own, from the whole of the café. He deals with all that. He can clear tables and he takes food down. And there are other odd jobs that he does as well. They’re the same jobs that he does. So

they value him as an employee, because he's very, very good at what he does.' (Jack)

'I guess the other thing is that we, we do reminisce about, particularly about our Chilean years and about our immigration stuff. You know stuff that we were both very active in and politically active in and erm, where it was something that we both shared. And so she, by remembering those things and talking about those things I think it does bring it present to her in that she does sort of feel good about herself in terms of these are, these are really significant things that I have done in my life. And she's proud of them.'

(Sadie)

Concealment
decisions

Historical
discrimination

'It (err)... it affected me a great deal. A great deal. Because they... I was made to feel like it was something not very nice. You know (err), and then in some instances, I mean they would just you know, walk away, sort of thing.' (Rose*)

'Because this was a residential thing, you know, in charge, and (um) it was his way of making sure that nobody ever chose to say anything or do anything or... because in that day, the slightest suspicion of a parent and... You know, the world went up. And (um) so let's put it this way; you become very suspicious of people's motives for the way that they're treating you. His was extremely well-intentioned but I also found it really hurtful, but I understood. You know, it's sort of (um)... That's lived with me for many years, many many years.' (Laurie)

'Well, we both lost jobs, and we both have been attacked, and yeah, we've had a tough time in some ways, yet we've been very public, so we've also had a lot of support.' (Alice)

‘We just never did in showbusiness in those days, its so funny. Now I couldn’t care less. I just say this is my partner and that’s it and its fine. I mean things have changed you know, but it was horrible. Horrible, horrible sometimes you know...’ (Eleanor)

Professional
hider

‘ I think that, erm, us as well as many others were extremely closeted. Erm, I mean many folks that we know were married, erm, and then discovered that they were, that they were gay or lesbian, so initially erm, for many years we were, for a number of years we were very closeted.’ (Sadie)

‘You know people just do not realise ... it's ...you have to put a mask over you and you you get embarrassed if people should ask you oh how is your husband or something like that ...erm ... and you have to quickly makeup ...makeup ...a er... that that was er... the worst part for me I think...’ (Rose*)

‘Oh yes, ...it it comes naturally after a while ...definitely years ago ..erm... and you were never erm... at ease.... never at ease at all...’ (Rose*)

‘Yes, it made me very (um)... very wary of (um) getting involved with people, of making friends, because always you sort of thought hmmm, you wouldn’t be my friend if you knew.’ (Laurie)

‘But if we were going somewhere and I happened to be there, erm, then I would be portrayed as Bill’s friend, because we thought he was only 9, and if you know, it might upset him or people get to know at school and give him a rough ride, you know.’ (Jack)

The necessity of
hiding

‘We said we would only tell him he asked. And he never said a word and we were quite frustrated at the time. But then as he got older and we broached the subject, he said ‘I always knew, and I just didn’t care’. So, you know, again, we were so wrong.’ (Jack)

‘Yeah, we were.’ (Bill*)

‘But our intentions were good.’ (Jack)

‘You know, so really you’re doing a disservice to them as well but of course they couldn’t come out and say,’ Well, are you gay?’ You know, in case you weren’t. (Laughs). You know, its how one person put it to me you know, (um) but basically they just sort of knew, which unconsciously, quite unconsciously, (um) you do give yourself away to people in some respects.’ (Laurie)

‘She was easier about it than I was. I mean, you know, being a psychotherapist she had obviously done an awful lot of work on herself, so she didn’t quite have my hang ups. But, on the other hand, I mean, her personality she was quiet and... I mean, one of her quotes was that, you know, anybody’s who has eyes to see can see the relationship.’ (Yvonne)

Openness is best

‘In a way when you’re open with them, it gives them the freedom to be open as well. You know, so it’s a two-edged sword for what it is... It works both ways.’ (Laurie)

‘I mean sometimes I think I’m a bit too (um) open with people and I think that’s one of my faults really. But (um) that’s how I am and I don’t like secrets. Josephine (partner) probably would be bit more on the wary side.’ (Carol*)

‘I just tell them right up front, and um, most of the responses I’ve had is, ‘I’ve a daughter who is lesbian’, or ‘yeah, I have a cousin who’s gay’, you know. So it’s kind of like it’s a non-issue with them which is really, really nice.’ (Alice)

‘But I think because we have been so public in our lives, and I’ll be damned, you know, I read these things and I hear these things about, about, er, older queers, having to go back into the closet when they go into residential care and I say ‘I’ll be damned, that’s not gonna happen to us’. So I think we take a very proactive stance.’ (Sadie)

Safety signals

Acceptance talk

And we also now have (um) (err) a minister there who is totally accepting, not only accepting but supportive. And (err) he said to me, he said he’s got two little girls; one daughter, I don’t know which is the oldest... I think, I’m not sure... but her godfather lives with a couple of gay men so he’s completely at ease with it. And (um) it comes up very clearly in all his services and in church and so on, he always talks about inclusiveness.’ (Laurie)

‘And that sort of... it’s that really easy total acceptance you know’ (Laurie)

‘There’s a doctor from, he’s from Africa funnily enough and we, we went to see him and he is a darling and they all knew. He 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)

Appraising

other’s attitudes

‘They may be a little shyness sometimes but it just... I can’t see that... They’ve always been very respectful. The whole thing has been quite a respectful support.’ (Stephen)

‘But, I’m a private individual anyway, you know, so I need to trust...you

know, if I know that the...or if I'm not sure, you know, what the attitudes of the other person is, you know, I would wait until I get to know them and trust them.' (Yvonne)

'We trust Dr-----.' (Jack)

'He's really nice actually.' (Bill*)

'Because he works between two hospitals and we're right in the middle, he quite often drops in for a cup of tea to see how Bill is...' (Jack)

Receptive others 'There's no big problem. No big deal at all. Not at all. Especially now I mean its amazing really, and in fact people get quite, get friendly and you know they're intrigued the fact that we've been so long together and we've been all over the world and we have stories to tell and they're quite happy with that so you know its alright.' (Eleanor)

I: What about the carer's group you've been at?

'They've been excellent.' (Frank*)

I: Can you explain that your partners?

'Yes they've been excellent and the organiser is always hugging and kissing us.' (Frank*)

Relationships as sheltered harbours

Navigating storms together

Relationships allowing you to become who you are

'We worked together for a year and in that year I realized that I was in love with her and that I acknowledged who I really was.' (Alice)

'I was engaged to be married, and I knew I was gay from twelve...I knew I was gay. It was done for family, and I was coming home to England in 66' and in 66' I met Frank and I just fell in love with Frank.' (Louis)

'We were both Roman Catholic nuns, so that's kind of the context in which we first met.' (Sadie)

‘Funnily enough, I have a lovely letter from Gus’s father that he wrote me, shortly after they came to the UK for the first time; he was a doctor in Norway; and he said that you know, that he’d... I could show you it actually. He was... how delighted he was to see that Gus was so happy with me and was so comfortable and... that his career and so on was taking very good shape, and he was attributing that to the fact that we had a good relationship.’ (Stephen)

Negotiating
challenges
together

I: I was wondering what strengths you feel you’re both drawing on to cope with these experiences?

‘Well, definitely on our connection and our loving. And the fact that we’ve faced so many obstacles, um, and been, stayed together through all of it. I mean, we’ve had our moments when we wondered, but the fact that we have means that there’s a sense of togetherness that’s, it’s just there, it’s never in question.’ (Alice)

‘I once said that despite his illness, the Meniere’s that he had for 17 years, I believed that it was one of the reasons why we’d stayed together. It sounds a bit odd, that does. But because he couldn’t manage on his own, because some of these attacks were so bad and they used to last for days at a time, and I knew he needed me. That it was one of the reasons he needed me and I wanted to be there for him. So, his illness sort of drew us together.’ (Jack)

‘I think his major strength is that he has such a positive attitude on life and he’s a very strong person. He doesn’t let things get him down for too long. He tends to bottle things up, so periodically he might have a bit of a moment, a wobble, but then he gets back on and everything is fine. It’s that really that carries us through, for both of us I think.’ (Jack)

Frustrations and tensions

‘...we did argue quite a bit soon after I got it. (Um) Because she... I just think she... you know, I do repeat myself quite a lot and I know I do but I don’t know I’m doing it when I do it obviously. (Um) And that got on her nerves quite a bit. I mean, we row; we’ve always rowed, you know, so yeah (laughs), it’s just one of those things.’ (Carol*)

‘I get angry at times.’ (Rose*)

‘This is it; she does, she gets very angry. Of course, I’m in the firing line (um) and I understand that but at that moment in time, it’s difficult. I mean, when you get asked... and you know, what the time is when you’ve got three or four clocks round the wall which she can’t work it out, what’s the time? You tell her. Two seconds later, what time is it now? Five minutes since you asked me the last time (laughs). And when you get that for maybe in half an hour, she’ll have asked me what... fifteen, twenty times what the time is, in the end, you know, you just think for God’s sake, just leave me alone for five minutes you know.’ (Laurie)

Travelling alone

‘The thing with us is we’ve always done everything but everything together which is why I’m finding a bit hard with Lucy not well enough now to do anything really.’ (Eleanor)

‘Occasionally, it goes through my mind, what if anything happened to Laurie? And I would be in a sorry state, I would. I’d have to go... I don’t know what would happen. So that occasionally comes into my mind and

when it does, it's (um) frightening. It's frightening.' (Rose*)

'Yes, I agree with you, totally' (Laurie)

'We're always talking about things, what's happening. We arrange the funeral really; we know it's going to happen one day. We discuss things and we talk about going into the home and what comes after.... if I couldn't cope.' (Louis)

'We're not scared about the future. We know that one of us will go and it doesn't mean the one who is older, it doesn't work that way. I can go first, so we know that.' (Louis)

Tidal shifts

Re-calibrating
roles

'Well the mere fact that I'm doing everything (laughs). She used to be very good at cooking and I do the cooking now. And the money I'm useless at I never even had a purse in my life but now all of a sudden I'm doing the banking and things like that which is you know. It's all going very quickly. You know.' (Eleanor)

'So, when she had to stop driving that was huge/She lost her licence and then over time, she is no longer able to look at any kinds of things that move anymore, anything like that. In fact, is now at the stage where she needs help for her own dressing and things like that. So, it's been huge for me because I've had to take on the things she used to do as well as not only organising our household and our lives and downstairs, now organising her care and her doctor's appointments, and all those kinds of things' (Alice)

'He'd been a chef previously, so he could cook. He could decorate. He'd been, he'd done lots of foreign travel. I'd never even left the country before. You know, I was this very naïve, inexperienced person, who'd just come out the closet, so he was ideal for me. (Pause). And that's all I ever wanted, was

somebody to look after me. But now it's reversed, the roles have reversed, and I look after Bill in many respects. I do struggle with things like cooking, because I've never had to do it (laughs). I'm crap at decorating.' (Jack)

'Everything. I do everything now. He used to do half. Now he's more exhausted and tired, we were speaking to the doctor yesterday; he came round to see us. I said that he's just exhausted he's lost about three stone in weight over the last couple of months. He's just exhausted; he's tired he's got no energy. He used to do the garden and....I just do everything now.'

(Louis)

Maintaining
partnerships

'I don't mean trust as in he'd go and meet somebody else or go and spend money without me knowing, I mean just can't trust him to do things without being a bit of a danger to himself and that's really worrying for me. So then I've become overprotective and sometimes I overstep that mark and become a bit too full on and he gets a bit resentful. You know, he's not a child and I know that, but at the same time I'm just trying to protect him. So that has been difficult.' (Jack)

'Erm. It's certainly become, mmmm, on some level it's become more distant, er, just because we, we can't have those kind of interactions that are part of everyday life and part of living together, right. And, the, it's hard for me to think of us as, as in an equal, in an equal relationship, because it doesn't feel like that at all.' (Sadie)

'I know she doesn't like this analogy but, you know, when, when---I remember, in the earlier days of this disease, that when we crossed the street, I was always, would always take her hand. And I always had the feeling of taking the hand of a child and leading her across the street. And,

erm, that, sort of relationship kind of continues, erm, with, with us.’ (Sadie)

‘...since we’ve had people coming in to do all of the personal things for him and to spend time with him, I’ve actually had a little breathing space. My day is very well structured in terms of what I’m doing at any given time and (err) it also means that (um) my relationship with him is of a loving partner, not a carer. Not... You know, I’m a full time carer because I’m here but I’m not required to do the things that many carers have to do, which in fact can be very onerous.’ (Stephen)

Reaching a limit ‘She, er, because she can’t get out of bed by herself, she constantly is calling me, you know ‘Can you come and help me? I need a glass of milk. I want a cup of hot chocolate. I need to go to the bathroom’, and, you know, ‘I need to go to the bathroom’ is like six or seven times, in, in, in two hours, erm, so, physically, I mean, there’s physically for me that it’s very demanding, in terms of, er, getting—lifting her up, and helping her get out of bed, lifting her up off a chair, er, but emotionally it’s, it’s, it’s hugely draining.’ (Sadie)

‘Where I see what my mother went through. She couldn’t do a thing for herself. My sister used to have a hoist and everything and I think oh my god cus the last thing I want to do is put her in a home and the way I thought at least at a really bad point I could always have someone stay here and help take care. It would be a last resort.’ (Eleanor)

Anyway I thought I’ve got to make it all sorted out here and then even if I cant cope on my own ill just to get someone in help me and I’m sure I’m going to have to because it is very, very tiring. I mean all night she’s waking me up. All night.’ (Eleanor)

‘Bearing in mind that he was at home most of the time and it used to be me

		<p>who went to work. I used to come home, I'd be in a terrible mood, but within an hour or so, with a glass of wine I used to be fine. But I can't do that anymore, I can't take my frustrations out on him, so I have to bottle them up a bit more.' (Jack)</p>
Evolving safe contexts	Feelings of security and comfort	<p>One of the things... I don't want to see big headed or that, but one of the most important things for him is to know that he is with me, I think. He's very happy when... he's never difficult with me at all. (Err) If I'm not in the room, he will quite often call me and I'll come in and see and say, 'Was there something you wanted?' And he'll say, 'Well, no, not really.' But he just wants the reassurance of knowing that he's not alone and I never want him to be alone.' (Stephen)</p> <p>'The only way is I just sort of say are you relaxed and make sure she's comfortable and that. Always teas. You know. Whatever she wants.' (Eleanor)</p> <p>'...I've said to her a few times, so, she said, I said, so I asked her, so, 'What about me, do you feel safe when you're with me?'. 'Oh yes', she said, 'I, I know that you won't do anything, erm, to hurt me, or, won't let anything happen that will hurt me.' She said 'I know, I know those things and yes I feel safe with you'.' (Sadie)</p>
	People coming into the home	<p>'When we have to keep bringing people into our lives that we don't know, and you know, 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)</p> <p>'She used to call them nightmares. The last time the worker came in she called her a terrorist....The ante keeps getting upped.' (Sadie)</p>

‘... I don’t leave the carers hopefully to do things, (err) I keep a watchful eye on what’s going on; not breathing down their necks, but you see it’s not the same people all the time so you have to be watchful and not everyone who comes in is as skilled as the very best.’ (Stephen)

‘If I had any sort of untoward reaction, I would just say, ‘Don’t send that person.’ Plus the fact we’re paying. I feel I have that extra control over who comes in to our home.’ (Stephen)

Making
environments
safe

‘I mean our safety is in having people around us who know our experience themselves.’ (Alice)

‘We were living most of the time upstairs. We love going up there we’ve got a bed sitting room up there and we used to love it but I was a bit worried because Lucy’s eyes are getting worse, and wandering about it at night. So I decided to have the garage done into a bedroom and it’s just literally finished not so long ago, and its wonderful.’ (Eleanor)

‘We are thinking about having something fitted to the house, so that if he needs somebody. Like there was an occasion when you phoned me up at work and I thought, oh god what’s happened, and he couldn’t remember how to switch off the tumble dryer. So I said, just unplug it at the wall, and he was like, oh right, OK, yeah. But for him that was a big issue, and he just wanted somebody to ask sort of thing and you know.’ (Jack)

The bedroom is right behind the living room, cause we had to move our bedroom because we were on another floor in the house, so we had to move our bedroom so that she wouldn’t have to cope with the stairs. (Sadie)

Appendix N
Excerpts from Bracketing Interview

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Appendix O
Excerpts from Reflexive Journal

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Appendix P
Participant Results Summary

Dear [participant's name],

I hope this letter finds you well. I am getting in touch with a final update on my research project looking at the experiences of lesbian, gay and bisexual people with memory difficulties. Over the past months I have been analysing the interviews. I would like to provide a summary of these findings and also invite you to provide feedback.

The questions I set out to answer were:

- What is the experience of memory difficulties for lesbian, gay or bisexual individuals?
- How is this experienced within partnerships and other significant relationships?

I have put my ideas and the themes I found below. I have also used direct quotes from people interviewed in the project (these quotes may be from you). Quotes are used to help illustrate my ideas.

Main Theme 1: Duality in managing dementia.

This theme was about dual aspects to the experience of managing memory difficulties for lesbian, gay and bisexual people. It had three ideas connected to it

1. Isolation or reaching out while negotiating a "double stigma"

Everyone spoke about choices they made between managing memory difficulties alone (either as an individual or within their relationships) or reaching out to others and seeking support. The experience of making this decision seemed to be shaped by other people's responses to memory difficulties. For some, they felt that other people in their lives found it hard to accept their memory difficulties, which meant they were reluctant to 'reach out'. Others spoke about how this was also affected by negative reactions to their sexual orientation, calling it a "double stigma". This wasn't the case for everyone, but it sounded like this situation could leave you feeling vulnerable.

2. Shared or distinct challenges

This was about experiences that may be universal to people with memory difficulties and those that seemed more specific to lesbian, gay and bisexual people. Most of you spoke about seemingly common challenges, such as frustrations with memory services. More specific experiences relating to being gay included uncertainty around discrimination, while others were more sure about their experiences of homophobia. Others spoke of unhelpful assumptions that were made because they were gay, or assumptions that were made about their relationships, such as same-sex partners being seen as siblings.

3. Taking action to educate

When people were confronted with specific difficulties related to their sexual orientation they decided whether or not to make a stand and challenge others. Some people felt they had enough 'on their plate', while others felt they needed to be 'proactive'. This often linked to histories of activism and many of you felt services needed more training in valuing people regardless of their sexuality.

Main Theme 2: Giving yourself away vs. holding onto yourself.

One of my main research aims was to explore the experience of lesbian, gay and bisexual people in terms of how their identity was affected by memory difficulties. In this theme, identity was considered to be something that people could 'hold onto' or 'give away'.

1. Dementia as external, sexuality as internal

I noticed that most of you talked about your sexual orientation as a part of you that was valued and something you held on to. In contrast, many people spoke about dementia as something separate to themselves. This seemed to be helpful in resisting the influence of memory difficulties. I thought that this was a useful idea and something that psychologists could explore when they work with people with memory difficulties.

2. Holding onto the "core"

I was struck by how people with dementia stayed connected to the important things they valued in their lives and how those around them had a special role in helping with this. This seemed to become more challenging if memory difficulties got worse, but involved an understanding of the person's history and an appreciation of their strengths.

3. Concealment decisions

'Giving yourself away' also relates to an experience of unintentionally revealing something about yourself. For some, they preferred to keep their memory difficulties and their lesbian or gay identity private. Oftentimes this seemed to be linked with earlier experiences of rejection or fear related to their sexual orientation being exposed. In the present, it seemed like most of you felt being open around these issues was best. Then you could see other's reactions and know where you stood.

4. Safety signals

As you made decisions about whether or not you would reveal your sexual orientation, you read 'safety signals'. These were signs that it was OK to be yourself and talk about your important relationships as a lesbian, gay or bisexual person. I thought that it would be helpful for services to know that these signs helped you feel at ease, so they could take steps to 'signal safety'.

Main Theme 3: Relationships as sheltered harbours.

The final theme captures the importance of relationships for those with memory difficulties and the impact that those difficulties can have. Relationships as 'harbours'

offered a space for retreat and safety, and a space within which changes could be negotiated.

1. Navigating storms together

'Storms' are challenges related to memory difficulties, but also those related to being lesbian, gay or bisexual. I was really struck by the strength of partnerships and other significant relationships. This strength meant that challenges were 'navigated' together, such as 'coming out' in more intolerant historical contexts and remaining connected to each other despite the influence of memory difficulties.

2. Tidal shifts

It seemed as if memory difficulties were having an ongoing impact on important relationships. For some there was a sense that changes had meant roles and responsibilities had shifted. In some ways, relationships had turned 'upside down'. Such changes are reported in research involving heterosexual couples, suggesting that similar processes occur irrespective of sexual orientation.

3. Evolving contexts of safety

Throughout the interviews I was struck by the important role partners and significant others had in making those with memory difficulties feel safe. This included making the home and physical environments safe, but also providing a sense of emotional protection. As relationships have consistently been shown to be very important in managing the impact of memory difficulties, services could focus more effort on supporting relationships alongside treating individuals. Also, for people with memory difficulties who are isolated and don't have a 'sheltered harbour', services may have to work harder to help them feel safe.

What next.....

I'd like to find out what you think

I would be really grateful if you could have a look at all of the ideas and themes in this letter, then let me know if you think they fit with your experiences of memory difficulties as a lesbian, gay or bisexual person. This includes how these difficulties have impacted upon relationships. Any other feedback from your interview is also very welcomed.

Please email me on j.c.mcpaland765@canterbury.ac.uk

Or call me on 07xxxxx

Finally, I'd like to thank you again for participating in this research project. It was a privilege to hear your stories and you all generously offered incredibly thoughtful ideas and explanations related to your experiences. I hope this research will be used to improve and better understand the experiences of other lesbian, gay and bisexual people with memory difficulties and those who are close to them.

Warm wishes and take care,

James McParland
Researcher/Trainee Clinical Psychologist

cc. Salomons Ethics Panel, Canterbury Christ Church University²

² As requested in the ethical approval letter.