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OLIVER HAWTHORNE BSc Hons PGDip MSc

UNDERSTANDING THE SOCIAL SUPPORT OF  
OLDER LESBIAN AND GAY PEOPLE

Section A: What is currently known about the social support of  
older lesbian, gay and bisexual people?

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Section B: A grounded theory study of the informal care and  
support of older lesbian and gay people with long-term health  
conditions.

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A thesis submitted in partial fulfilment of the requirements of Canterbury Christ  
Church University for the degree of Doctor of Clinical Psychology

APRIL 2017

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

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And to the family I was gifted: Leo, Susie, Mum and Dad, for all the different ways that you have supported me, and for allowing me to delay birthdays and national holidays until I was finished.

### **Summary of Major Research Project**

**Section A:** This section explores the existing literature around the social support for older lesbian, gay and bisexual people. The literature suggests that compared to heterosexual people, lesbian, gay and bisexual people receive more support from friends and less from family, whilst maintaining a similarly sized support network. It is suggested that the different role of friends in comparison to families may contribute to reports that lesbian, gay and bisexual people receive less support from their networks. Recommendations for research and clinical practice are made.

**Section B:** This section comprises a grounded theory study of what determines how older lesbian and gay people receive informal support from their networks when they experience long-term health conditions. Fourteen mid-later life lesbian and gay people were interviewed who had experience of providing care, receiving care, or running groups for these populations. It was identified that living arrangements largely determined who gave care and support. Choices around care and support were informed by past experiences of managing being lesbian or gay in a sometimes-unsupportive society. These results are discussed in relation to clinical practice and avenues for future research.

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**OLIVER HAWTHORNE BSc PGDip MSc**

**Section A: What is currently known about the social support  
of older lesbian, gay and bisexual people?**

Overall Word Count: 7935(362)

APRIL 2017

### **Abstract**

Research has highlighted the importance of social support for older people. The social context of lesbian, gay and bisexual (LGB) people means that the social support older LGB people receive is likely to differ from heterosexual people. The present review aimed to synthesise and provide a methodological critique of the research literature on the social support of older LGB people. Nineteen papers (nine qualitative and ten quantitative) were reviewed.

The literature suggested that although older LGB people report having similarly sized social support networks to the older heterosexual population, a significant proportion of older LGB people reported not receiving certain types of support. One possibility is that a greater reliance on friends over family may account for this. Experiences of discrimination were commonly reported and one study suggested the possibility that older LGB people might be more likely to experience abuse or neglect.

The implications of these findings are discussed in relation to clinical practice and suggestions for future research are made. There is a particular need for research looking at how the support networks of older LGB people adapt to provide care to people with long-term health problems.

**Key Words:** Social support, lesbian, gay, bisexual, older age

### **Introduction**

Social support has been linked to a wide range of beneficial effects, including reducing the risk of mental health difficulties (Thoits, 1995), improved overall quality of life (Helgeson, 2003) and reducing the likelihood of developing physical health problems (Uchino, Cacioppo and Kiecolt-Glaser, 1996). Social support is of particular importance for older people due to the greater likelihood of developing health problems at this time in life. Amongst older people, having relatives or friends able to provide support has been shown to be associated with an overall satisfaction with life (Gabriel & Bowling, 2004), a longer period of time living in their own home, and a greater life-expectancy (Rolls, Seymour, Froggatt & Hanratty, 2011).

Two main theories have been proposed as to how social support leads to better health outcomes, these have been termed the “buffering hypothesis” (Cassel, 1976; Cobb, 1976) and the “direct effect hypothesis” (Cohen & Ashby Wills, 1985). The “buffering hypothesis” proposes that social support functions as a means of coping with stressful life events; it is suggested that when we experience a stressful life event the availability of social support that “matches” a need (e.g. an emotional or instrumental need) partially ameliorates the physical and emotional stress of the event (Cassel, 1976; Cobb, 1976). In contrast the “direct effect hypothesis” proposes that the social contact from participating in a network makes people feel happier and less stressed regardless of what is going on in their lives (Cohen & Ashby Wills, 1985). Alongside this, it is suggested that people who participate in a social network are more likely to make decisions which support good health (e.g. diet and exercise) both due to the direct effect of the influence of those around them, as well as the indirect effect of being less stressed and less in need of physically unhealthy strategies to manage anxiety (Umberson, Crosnoe & Reczek, 2010). In a comprehensive review of recent research in social support, Nurullah (2012) found evidence for both theories, suggesting

that social support both “buffers” against the effect of stressful life events and leads people to lead generally happier, healthier lives.

Although social support has received a great deal of attention from researchers, (a search on Medline for “social support” returned 44122 papers published in the last ten years) there is still no single agreed operational definition. Definitions variously focus on structural aspects (e.g. the presence or absence of different types of relationships), functional aspects (e.g. the presence or absence of different types of support provision) or perceived potential (e.g. the extent to which someone perceives that they have access to a supportive network) (Nurullah, 2012). This paper adopts Thoits’ (2010) definition of social support as “emotional, informational, or practical assistance from significant others, such as family members, friends or co-workers; support may be received from others or simply perceived to be available when needed” (Thoits, 2010, p. 46). As noted in a recent review (Nurullah, 2012), this definition recognises that social support is a distinct concept from social integration or a social network. A social support network will be made up entirely of people from someone’s social network, but not all members of someone’s social network will be people who could be said to be available to provide social support.

### **The Context of Social Support for Older LGB People**

Before considering why we might expect social support to be different for older LGB people, it is useful to briefly consider the social context of LGB people in the UK across their lifespan. LGB people born in the UK prior to 1967 (people aged 50 and over) were born in a context where sex between two men was a crime, there was no legal recognition of same-sex sexuality between women (including no legal age of consent) and there was no organised gay rights movement (Stonewall, 2016). Other than the introduction of Section 28 in 1988 (a law banning local councils and schools from mentioning “homosexuality”), social and legal changes

since then have generally moved towards giving a foundation for equality for LGB people and their relationships: “homosexuality” was removed from the “Diagnostic and Statistics Manual of Mental Disorders” in 1973 and the World Health Organisation’s “International Classification of Diseases” in 1990, an age of consent for sex between women was introduced in 2000, Section 28 was repealed and same-sex couples were given access to adoptions in 2003, sexual orientation was recognised as a protected characteristic in the Equality Act in 2007 and most recently, in 2014, same-sex marriages were given legal recognition (Stonewall, 2016). Along with this, public attitudes towards same-sex sexuality have changed: the earliest opinion poll in the UK on public attitudes towards “homosexuality” suggests that 62% of people thought that same-sex relationships were “always” or “mostly” wrong in 1983, compared with 28% believing the same in 2012 (Park, Bryson, Clery, Curtice & Phillips, 2013).

This brief history suggests that older LGB people are likely to have faced not only negative attitudes about their sexual orientation but also criminalisation or lack of legal recognition of their relationships. In line with this, nearly two-thirds of older LGB people report experiencing verbal or physical abuse relating to their sexual orientation over their life-time (D’Augelli & Grossman, 2001). These forms of stigma, discrimination and victimisation are likely to have had direct and indirect effects on the social support networks of older LGB people. Many LGB people report experiencing rejection from families and existing support networks when their sexual orientation was first made known (Guasp, 2010). Early experiences of rejection from families are likely to have an impact on the way people form attachments (Bowlby, 1969), making it more of a challenge to form supportive relationships in later life. At the same time as impeding access to support networks, experiences of discrimination may increase the need for social support. Experiences of abuse related to sexual orientation unsurprisingly increase the risk of people developing mental



health difficulties (Meyer, 2003). Some of the ways that people manage this stress can be physically harmful and LGB people have been shown to be at increased risk of drug and alcohol use, smoking and obesity (Northridge, 2001), meaning that the physical health needs of older LGB people are also likely to be greater than the general population.

### **Why is it important to understand this difference?**

The current generations of older LGB people are the first generations to be in their later life during a context where services have an explicit responsibility to provide them an equitable quality of care. Critical histories of the development of health and social policies have highlighted how the current British welfare state developed around meeting the needs of heterosexual people (Williams, 1992) and services have only had a responsibility to ensure their employees are competent in working with LGB specific issues since the introduction of the Equality Act (2007). Considering the relatively short length of time that health and social care organisations have had to adapt to these changes, it is perhaps unsurprising that LGB people in the UK report having a worse experience of health and social care services (Elliott et al., 2015).

In the UK, the government has placed a much greater emphasis on informal care in recent policies (Care Act, 2014). With the increased emphasis on care provided by friends and family, it is of particular importance that health and social care services are able to work with the social support networks of all older people. A first step towards supporting this would be gathering together what is currently known about these networks and the provision of social support to older LGB people.

### **Previous Reviews**

There has only been one previous review of the social support needs of this population (Barker, Herdt & De Vries, 2006). This review (focusing only on lesbian and gay people) described ways in which the socio-political circumstances of the lives of lesbian and gay people had affected their social support networks in later life. They identified a larger role of friends in comparison to family, and suggested that much of the social support of older lesbian and gay people may come from “family-of-choice” relationships (i.e. a group of close friends who are identified as being like family). Criticisms of the literature were made in terms of the lack of diversity amongst the participants recruited, as well as on the lack of research focusing on the social support of older lesbian and gay people in specific circumstances, including those with long-term health problems. However, this review did not include any information on how the literature search was carried out and had unclear inclusion criteria. Additionally, since this review eleven years have passed during which new research has been published, along with notable changes to the circumstances of LGB people. There is therefore a gap for a systematic review of the literature surrounding the social support of older LGB people.

### **Aims**

This review aimed to provide a synthesis of what current research tells us about the social support networks of older LGB people. The review aimed to provide a methodological critique of the research as well as exploring implications for clinical practice and future research.

### **Method**

A full list of the inclusion and exclusion criteria for this review can be found in Table 1. As the only previous review of social support for older LGB people did not appear to be systematic, the scope of this review is intentionally broad and aimed to explore studies with either quantitative

or qualitative methodologies. Using Thoits (2010) definition of social support, studies of social networks were only included if they explicitly explored the provision of emotional, informational or practical support within these networks.

For the purpose of the review “older LGB people” was defined as people over the age of 50 who identify as being lesbian, gay or bisexual. Whilst 50 is a younger age than is often used in the general older age literature, this reflected the youngest cut-off that was commonly used in the literature referring to “LGB older adults”. LGB people over the age of 50 can be thought of as a distinct cohort, in that anyone currently older than this was born before the emergence of any kind of organised gay rights movement (Stonewall, 2016).

As the social context of older LGB people has changed so much over the previous decades, for this review to meaningfully reflect the experiences of older LGB people today it was important that the context of the research was sufficiently similar to the present day. The removal of “homosexuality” as a mental health diagnosis from the World Health Organisation’s International Classification of Diseases (1990) was chosen as a cut-off, any research carried out before this time was not included.

Studies focusing on transgender people (or which grouped transgender people into the same category of analysis as LGB people) were also not included. Transgender identity is related to gender identity rather than sexual orientation (i.e. as well as being transgender, a person will also be heterosexual, lesbian, gay, bisexual or another sexual orientation).

Table 1: *Inclusion Criteria for Literature Review*

Inclusion Criteria
Published in English in a peer-reviewed journal.
Contained original research.
All participants were lesbian, gay, bisexual or another non-heterosexual sexual minority (this does not include trans people as gender identity is distinct from sexual orientation) or the results of these participants were reported separately.
All participants were over the age of 50 or the results of people over the age of 50 were reported separately
Focused on informal rather than formal supportive relationships (i.e. friends or family rather than professionals).
Focused on supportive relationships (i.e. relationships that provided emotional, informational or practical support) rather than just social relationships.
Published after 1990 (the year of the removal of "Homosexuality" from the ICD-10).

ASSIA, Psycinfo and Medline were searched for any articles containing a combination of the following terms (ageing or aging or “older people” or “older adults” or “later life” or elder or gerontology or gerontological) and (“social support” or carer or caregiver or “informal care” or “informal support” or network) and (lesbian or gay or bisex\* or homosex\* or “sexual orientation” or queer or LGB\* or GLB\*), the search was limited to studies published after 1990. Titles and abstracts were read and any articles which were clearly not related to the theme of this review were

excluded. The full texts of the remaining articles were retrieved, read and assessed against the inclusion criteria. The reference lists of articles meeting the inclusion criteria were then hand-searched for relevant articles, along with a search of the articles citing these papers on Web of Science. Finally, Google Scholar was searched for any remaining relevant papers. A diagram showing this process is displayed in Figure 1. Overall, there were 19 articles that met the inclusion criteria for this review. Ten of the studies were cross-sectional quantitative studies and nine were qualitative.

All papers were read in full and the key findings were extracted. Each paper was scored on the appropriate version (qualitative or quantitative) of the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (SQAC) (Kmet, Lee & Cook, 2004; Appendix A). For each criteria of the SQAC, papers were scored “0” if the criteria was not met, “1” if it was partially or unclearly met and “2” if it was definitely met, an average score was then calculated. The key findings of all papers were then grouped into shared themes. Finally, links between different findings were hypothesised. Commonly, this meant using the qualitative literature to understand possible explanations for differences identified by the quantitative literature. Brief summaries of the method and key findings for each study as well as scores on the critical appraisal tools can be found in Table 2.

Figure 1: *Prisma Diagram*

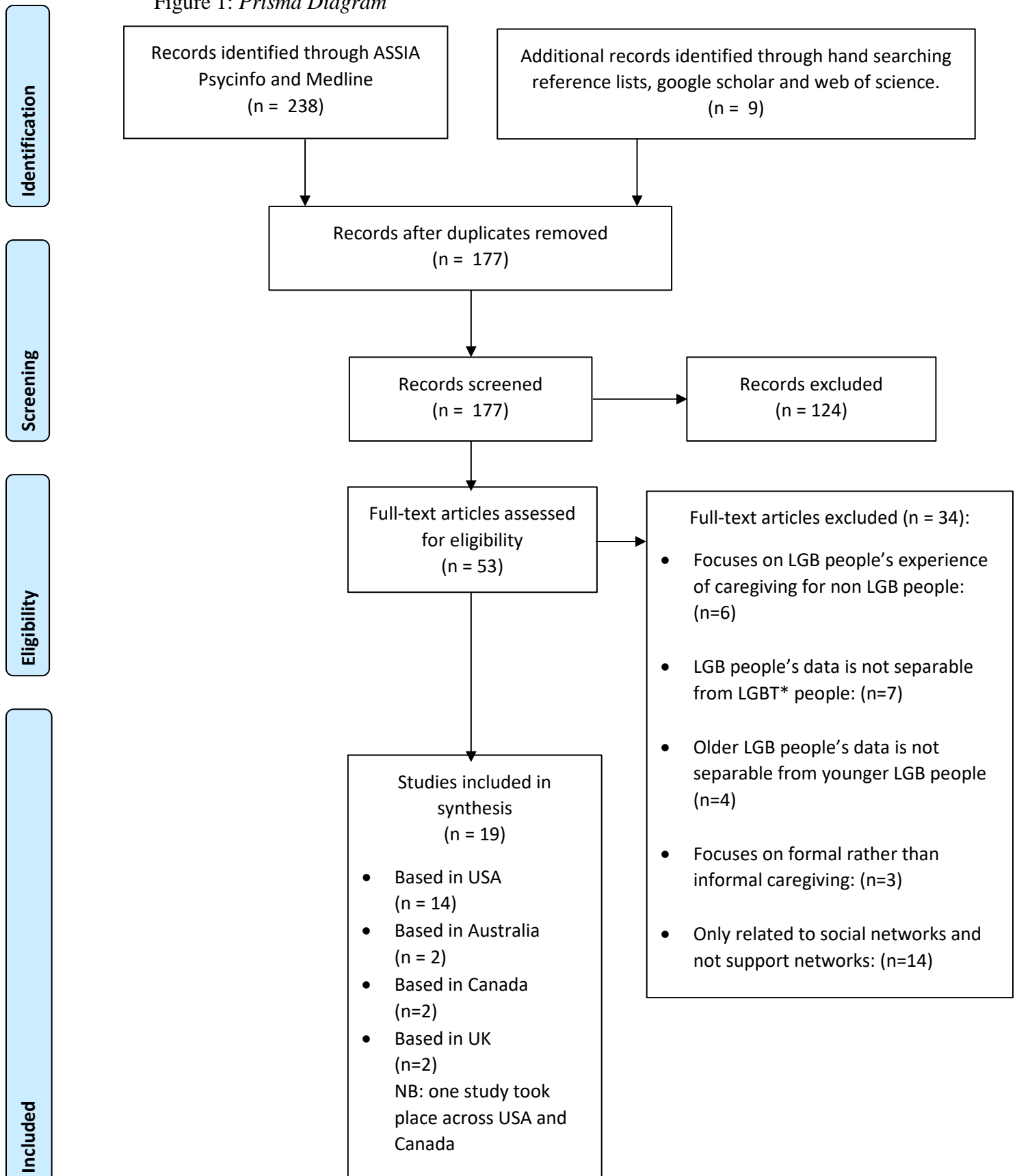


Table 2: *Overview of Studies***Qualitative studies:**

<b>Authors</b>	<b>Year Published</b>	<b>Location</b>	<b>Number of Participants</b>	<b>Sample</b>	<b>Recruitment methods</b>	<b>Methods</b>	<b>Findings</b>	<b>SQAC Score</b>
Hash	2001	USA	4 (3 men, 1 woman)	People over 50 who currently or previously had provided care to a same-sex partner	Advertisements in: LGBT newspapers, bulletins of LGBT groups, LGBT bookstores, social groups, HIV/AIDS support groups and hospices. Personal contacts of the researcher.	Grounded theory study using semi-structured interviews to explore experiences of caregiving.	Experiences of homophobia were common and participants avoided professional support because of this. Homophobia influenced choices about the disclosure of the relationship and lack of formal legal support meant that partners had to draw up living wills.	1.2
Richard and Brown	2006	USA	25 women	Women over 55 who identify as lesbian who spoke English, were not legally married and not "institutionalised"	Advertisements in LGBT mailing lists. Discussions in lesbian social groups. Snowball sampling.	Thematic analysis study using semi-structured interviews to explore experiences of aging.	Configurations in support network were constructed as varying along two different spectrums: the extent to which the configuration was planned or intentional and the extent to which the person was connected to others. Two participants described having a planned, connected configuration; 14 described having an unplanned, connected configuration; 3 described having a planned, unconnected configuration and 6 described having an unplanned unconnected configuration.	1.6

Brotman, Ryan, Collins, Chamberland, Cormier, Julien, Meyer, Peterkin and Richard	2007	Canada	17 (10 women, 7 men)	Caregivers of gay and lesbian "seniors"	"Snowball sampling" No other details given.	Grounded theory study using semi-structured interviews to explore experiences of caregiving.	Caregivers experienced fears about homophobia from services. Some caregivers felt there was a need for a support group specifically for caregivers of gay and lesbian people	1.8
Heaphy	2009	UK	266 (102 women, 164 men)	Lesbian and gay people over the age of 50	User groups, personal networks, advertisements in printed media and the internet, snowball sampling	Focus group with older lesbian and gay people to find issues of concern, questionnaire to all participants using these ideas	Being able to choose the people who provide support is important for older lesbian and gay people. Choice is limited by access to various resources.	1.4
Gabrielson	2011	USA	4 women	Women over the age of 55 who chose to live in a LGBT continuing care retirement centre.	Friends of the people who ran the care organisation being explored.	Collective case studies using semi-structured interviews about their concerns around support.	Participants reported experiences of exclusion from their biological families, expectations of homophobia from mainstream formal services and a recognition that they couldn't cope alone.	1
Muraco and Fredriksen-Goldsen	2011	USA	18 (13 men and 5 women) and their friend caregiver	People over the age of 50 who identified as being LGBT, having a long-term health problem and having a "caregiver" who was a friend	Emails, flyers and presentations in locations where target populations were expected to frequent (e.g. health clinics, support groups, buddy programs, community-based churches and social groups). Participants were paid \$25.	Simultaneous but separate interviews with LGB person and their friend caregiver. Participants were also given measures of physical and mental health and measures of relationship quality for another study.	Friends provided a range of caregiving tasks. Friends spoke about getting personal benefit from the relationship. Dyads described the relationship as being like family. Challenges included that care receivers expressed concerns about not wanting to burden their friends and friends chose not to take on some responsibilities associated with caregiving.	1.9



Muraco and Fredriksen-Goldsen	2014	USA	36 people (19 men, 17 women) and their informal caregiver	People over the age of 50 who identified as being LGB, having a long-term health problem and having a "caregiver"	As above	As above	Relationship was often the best experience of care, worst experience of care often related to not being able to provide all the support needed. There were differences in the best and worst experiences of care between friend and partner caregivers.	1.9
Barrett, Whyte, Comfort, Lyons & Cramer	2014	Australia	11 (6 women and 5 men)	Lesbian and gay people over the age of 65	A recruitment flyer was circulated amongst LGBT* groups	Semi-structured interviews exploring participants experience of discrimination	Experiences of discrimination affected the way that people formed relationships and made getting social support more important and difficult in later life.	1.9
Traies	2015	UK	418 women	Lesbian women over the age of 60	Snowball sampling through lesbian networks	Women asked about their experience of aging through a mix of surveys, individual interviews and autobiographical writing. No details given of analysis.	Friendships, families-of-choice and ex-lovers were all important parts of the support networks of older lesbian women.	1.1

**Quantitative Studies:**

<b>Authors</b>	<b>Year Published</b>	<b>Location</b>	<b>Number of Participants</b>	<b>Sample</b>	<b>Recruitment methods</b>	<b>Methods</b>	<b>Findings</b>	<b>SQAC Score</b>
Dorfman, Walters, Burke, Hardin, Karanik, Raphael and Silverstein	1995	USA	133 (55 women and 53 men)	People over 60 who identified as lesbian or gay	Gay and lesbian organisations, gay and lesbian events, churches, senior citizens' centers and church organisations. Snowball sampling.	Participants were asked to complete a pen and paper questionnaire returned via post.	No significant differences between heterosexual and lesbian and gay people in terms of size of social support network. Gay men and lesbian women had more friends and less family members in their network compared to heterosexual people.	1.5
Grossman, D'Augelli and Hershberger	2000	USA and Canada	416 (297 men and 119 women)	People over 60 who identified as lesbian or gay	Organisations for older LGB people. Snowball sampling. Each participant was paid \$10	Participants were asked to complete a pen and paper questionnaire returned via post. Questionnaire assessed demographic details, social support, loneliness, alcohol use, drug use and a self-rating of overall mental and physical health	Participants averaged 6 people in their support network. Men had more men in their networks and women had more women. Bisexual people had more heterosexual people in their network. Most people in their network knew their sexual orientation. The more satisfied people were with their network the less lonely they felt and the better their physical and mental health.	1.8

<p>Shippy, Cantor and Brennan</p>	<p>2004</p>	<p>USA</p>	<p>233 men</p>	<p>Men over 50 who identified as gay</p>	<p>Mailing lists from all major LGBT organisations, articles in community publications. Face-to-face recruiting through health clinics, senior centers and major LGBT events. Snowball sampling</p>	<p>Participants were asked to complete a pen and paper questionnaire returned via post. Questionnaire assessed demographic details, experiences of giving care, experiences of receiving care, social support network, preferences for who would give care, wellbeing and openness about sexual orientation</p>	<p>Participants reported having friends and family in their support network but were more often in contact with friends than family. Participants were most likely to choose partners to receive support from if they were present. Friends or "myself" were commonly selected if partners were not present, biological family were rarely selected. 60% felt they needed more emotional support with 14% saying the needed more instrumental support.</p>	<p>1.8</p>
<p>Masini and Barrett</p>	<p>2008</p>	<p>USA</p>	<p>220 (141 men and 79 women)</p>	<p>Lesbian, gay or bisexual men or women over the age of 50</p>	<p>E-mails to agencies serving LGBT adults, e-mail lists, websites, distributions of palm cards at local venues and word of mouth. Snowball sampling.</p>	<p>Participants completed a questionnaire online. The questionnaire included demographic measures of social network and social support, psychological and physical functioning and lifestyle.</p>	<p>Participants reported having an average of 2.5 people in their network. Support from friends but not from family were significant predictors for "mental quality of life".</p>	<p>1.2</p>

Fredriksen-Goldsen, Kim, Muraco, & Mincer	2009	USA	36 people (19 men, 17 women) and their informal caregiver	People over the age of 50 who identified as being LGB, having a long-term health problem and having a "caregiver"	Emails, flyers and presentations in locations where target populations were expected to frequent (e.g. health clinics, support groups, buddy programs, community-based churches and social groups). Participants were paid \$25.	Simultaneous but separate interviews with LGB person and their friend caregiver. Participants were also given measures of physical and mental health and measures of relationship quality for another study.	Discrimination and relationship quality were associated with depression among both older LGB adults and their caregivers. Relationship quality may moderate the impact of discrimination as a risk factor for depression in LGB adults with a long-term health problem.	1.7
Lyons, Pitts and Grierson	2012	Australia	1179 men	Gay men over the age of 40 (data separated out for people older than 60)	Advertisements places on social networking websites and websites that specifically targeted gay men	Nationwide online survey exploring various aspects of men's wellbeing	Gay men over the age of 60 reported having more social support than younger gay men.	1.4
Gabrielson, Holston and Dyck	2014	USA	50 women	Lesbian women 55+	Investigators professional contacts and snowball sampling	Asked to fill in the Lubben Social Network Scale and an exploratory factor analysis was carried out on the results.	Lubben social network scale contains ambiguous items for some lesbian women and does not fall into the same factor structure as for heterosexual people.	1.6

Ramirez-Valles, Dirkes and Barrett	2014	USA	182 men	Gay and bisexual men over the age of 55	Not stated, data taken from an unreferenced prior study	Structured interview on perceived health, depression, health care providers knowledge of sexual orientation and number of sources of emotional and instrumental support.	Emotional support was positively correlated with perceived health. Depression was negatively associated with instrumental support. Those living alone and those who were single had less sources of support. Older people and those from ethnic minority backgrounds had less sources of support	1.6
Grossman, Frank, Graziano, Narozniak, Mendelson, Hassan and Patouhas	2014	USA	113 (76 men, 30 women, 6 trans women, 1 trans man)	LGB people over the age of 60	12 community-based agencies and groups for older LGB people	Completed survey posted in. Participants were asked about their own and others' experiences of abuse from caregivers, as well as demographic, self-esteem, personal mastery and general wellbeing.	22% of participants had experienced abuse from a caregiver and 25% knew an older LGB person who had experienced abuse	1.6
Gabrielson and Holston	2014	USA	36 women	Lesbian women 55+	Investigators professional contacts and snowball sampling	Asked to fill in a modified electronic version of the Lubben Social Network Scale. Exploratory Factor Analysis carried out to understand more about measure	Adding a "family of choice" section increased the validity of the Lubben Social Network Scale for older lesbian women	1.6

## **Results**

Three main themes of findings were identified: the structure of older LGB people's support networks (the size, frequency of contact, composition and any differences in these factors within the older LGB population), the types of support that these networks do and do not provide and particular challenges within these relationships.

### **Structure of Older LGB People's Support Network**

#### **Size of network.**

Two USA studies looked at the average number of people in the support networks of older LGB people, using the same measure for gaining a description of social networks (Grossman, D'Augelli, & Hershberger, 2000; Masini & Barrett, 2008). Grossman et al. (2000) found that participants listed an average of 6.3 people in their support network with more than a third saying that they had 10 or more, whereas Masini and Barrett (2008) found that participants listed an average of 2.5 people with only 3% reporting 8 or more and 45% naming only one member. Looking at the differences in these studies reveals possible explanations for these differing estimates. Firstly, although both studies used the same measure of social support, Grossman et al. (2000) capped the maximum number of people respondents could list at 10 and Masini and Barrett (2008) capped it at 8. As social isolation can be associated with shame, it may be that participants felt pressured into giving a socially desirable response and listing more people when presented with the suggestion of a higher maximum number of people in their network. Secondly, Grossman et al. (2000) recruited people in person through community groups and asked people to complete a paper questionnaire, whereas Masini and Barrett (2008) recruited people online and asked them

to complete the survey on a website. An online method of recruitment may have partially removed the socially desirability bias through the degree of anonymity offered by an online survey.

Only one study identified any older LGB people who reported having no support network. This Australian study found that only 1 of 223 men reported having no “elements” of social support, with the number of elements defined as the number of different types of supportive relationships (friend, partner, child, parent, sibling and other family member) in their network (Shippy, Cantor, & Brennan, 2004). However, each of the studies used a method of recruitment that was biased towards people with more social connections (e.g. recruitment through LGB agencies, word of mouth or advertisements on online social networks) meaning that it was not clear whether it would actually be possible for someone with no social connections to be recruited.

The only study to investigate whether the sizes of support network differed for older LGB people and older heterosexual people found no evidence of a “clinically” significant difference (Dorfman et al., 1995). They used the Lubben Social Network Scale (LSNS) (Lubben, 1988) to assess the social support of “heterosexual” and “homosexual” people aged over 60 and found that the mean score on the LSNS of both groups was over 28 (classified as “high social support”), they do not report the actual score of the two groups or information about statistical significance. However, two articles draw into question the validity of the LSNS as a measure of social support for older lesbian women (Gabrielson & Holston, 2014; Gabrielson, Holston, & Dyck, 2015). The first of these two articles carried out an exploratory factor analysis of the LSNS for older lesbian women. They found that a two-factor structure (friends and family) did not fit the results of lesbian women as it did not adequately reflect family-of-choice relationships and the questions used meant that there was some ambiguity as to whether same-sex partners would be classed as friends or family (this study was carried out prior to marriage equality in the USA) (Gabrielson & Holston,

2014). The second of the two studies found that an amended version of the LSNS with an added “family-of-choice” category alongside a qualitative response field increased the validity of the LSNS (Gabrielson, Holston & Dyck, 2015). There were no studies which explored the validity of the LSNS with older gay men.

Although there were very few people who reported having no access to a support network, there were three studies which found a significant proportion of people who reported having a support network but not receiving sufficient support. An online survey of 840 gay men living in Australia, (Lyons, Pitts, & Grierson, 2013) found that 21% of the men between 50 and 59 and 14% of the men over 60 reported that their network gave them “a little or no” support rather than “some or a lot”. One study (Ramirez-Valles, Dirkes, & Barrett, 2014) looked at the proportion of older gay men who reported receiving different types of support: 21% reported receiving no emotional support, 47% spiritual, 51% daily living activities, 62% transportation, 68% financial and 69% health care related support. Perhaps most strikingly, one study found that 60% of older gay men felt that they needed more emotional support (Shippy, Cantor & Brennan, 2004), double that reported by the heterosexual population (Cantor & Brennan, 1993). Although there were no quantitative studies exploring the same question with lesbian or bisexual women, in a qualitative study exploring lesbian women’s description of the configuration of their support network, 6 of the 25 women gave descriptions of their support network that the author coded as being “precarious” meaning that whilst they may have had many people in their support network, there was no consistency in the provision of support, networks could be scattered across the country and there were times when participants felt like they had to manage major life events alone (Richard & Brown, 2006).



One study looked at how much contact older LGB people have with the people that they view as being in their support network (Green, 2016). This study found that older LGB people reported having significantly less contact with people in their support network than older heterosexual people (Green, 2016). This study used data from a national survey, in which households were randomly sampled across the UK, meaning that it escaped some of the recruitment biases of the aforementioned studies. Unfortunately, this study combined the responses of lesbian, gay and bisexual people with those that responded “other” to the sexual orientation questions. Evidence from qualitative research carried out by the Office of National Statistics (Haseldon, Joloza & Household, 2009) suggests that most people who respond “other” are heterosexual people where language and cultural barriers prevented them from understanding the question. This interpretation is supported by the very high proportion of people who responded “other” who reported having been turned down for a job due to language barriers (Understanding Society, 2016). The “other” group was larger than the gay, lesbian and bisexual groups combined and no separate analysis was carried out of each group drawing into question the extent to which these results can be usefully interpreted.

There was a suggestion that some older LGB people may prefer not to receive social support, for reasons that are unclear; one study found that a high proportion of gay men had a preference for relying on “myself” for different types of support (Shippy, Cantor & Brennan, 2004). Additionally, Richard and Brown (2006) identified three lesbian women who were coded as having “independent” configurations of social support. However, they described this group as being conflicted about not receiving support, with the authors feeling that they needed support but did not want to access it.

**Composition of support networks.**

Across studies, there was a consistent finding that older LGB people had fewer family members in their support network than the older heterosexual population but more friends (Dorfman et al., 1995; Grossman et al., 2000; Shippy et al., 2004; Green, 2015). The proportion of LGB people with a partner in their support network varied between 36% (Shippy et al., 2004) to 50% (Massini & Barrett, 2008). There was a suggestion that gay men may be less likely to have a partner than people in the general population, but the study which made this comparison was also the study with the lowest proportion of people with a partner (Shippy et al., 2004). One study found that 15% of gay men had a child but only 60% of those with children remained in at least monthly contact with them (Shippy et al. 2004). In a qualitative study 11 of 25 lesbian women (44%) reported having a child (Richard & Brown, 2006). For the purpose of comparison, a large UK survey reports that of 214 LGB people interviewed, 32% reported ever having a child (31% of men and 33% of women) (Understanding Society, 2016). Qualitative accounts suggest that ex-lovers were a significant source of social support for some lesbian women (Traies, 2015; Richard & Brown, 2006) but no studies reported on how common this was.

Although there were no studies which explicitly looked at why older LGB people may have more friends and less family members in their support network, there were several themes in the literature which may account for this difference. A qualitative study using thematic analysis to explore how “homophobia” influenced the social support of 12 LGB people in Australia, gave descriptions of many participants’ accounts of being rejected by their parents, siblings and children on account of their sexuality (Barrett, Whyte, Comfort, Lyons & Cramer, 2014). Similarly, in a survey of 266 LGB men and women over the age of 50 in the UK, 34% of women and 22% of men described finding that they had become less close to their family of origin due to their

sexuality (Heaphy, 2009). The second theme is the possibility of friendship meaning something different amongst older gay and lesbian people. A common theme across all the qualitative studies was the concept of “families of choice”: a network of close relationships often made up largely of gay or lesbian friends. Participants in qualitative studies commonly described their friends as being “like families” (Massini & Barrett, 2008; Traies, 2015, Heaphy, 2009; Gabrielson & Holston, 2014; Gabrielson, Holston, & Dyck, 2014; Barrett et al., 2014) and several authors spoke of how friendships amongst LGB people might go beyond a heteronormative understanding of that word. One study exploring the experiences of older lesbian women described how the boundary between partner and friend was blurred, with people sometimes sharing homes with ex-lovers or adopting children together after romantic relationships had ended (Traies, 2015). Friendships were also highlighted as having an extra importance for older LGB people due to the need of having people who affirmed your identity and intimate relationships when living in a society that did not (Barrett et al., 2014). The lower proportion of older LGB people with children (Shippy et al., 2004; Richard & Brown, 2006; Traies, 2015), is also likely to be an important factor in the prevalence of friendship over family support. It may be that not having children increased the motivation and ability to maintain friendships over time.

#### **Differences in support network structure within the LGB population.**

One study looked at how social support differed between older and younger gay men (Lyons, Pitts & Grierson, 2012). This study found that men over 60 were significantly more likely to feel supported by friends than men in their 40s and 50s, they also reported more close friends and feeling more connected with the gay community (Lyons et al., 2012). This study used an online method of recruitment for each age group, which may have created a bias towards recruiting well-connected people in the over 60's: compared to younger people, older people who use the internet

are on average wealthier and report better psychological wellbeing and physical health (Chen & Persson, 2010). A study which did not use an online method of recruitment found that for gay/bisexual men the number of sources of social support varied negatively with age (as well as ethnic minority status) (Ramirez-Valles, Dirkes and Barrett, 2014). There were no studies that investigated whether the support of lesbian or bisexual women differed across the life course.

Two studies looked at some potential differences between the support networks of older gay/bisexual men and older lesbian/bisexual women. Grossman et al. (2000) found that the networks of gay/bisexual men were predominately male (67%) and the networks of lesbian/bisexual women were predominately female (75%), however there was no significant difference in the number of heterosexual men in the networks of the men and women in the study with both reporting low numbers (13% and 9% respectively). Women had significantly more people in their networks than men, there were no differences between men and women in the proportion of LGB people in their network or in terms of the proportion of their network that knew of their sexual orientation (Grossman et al., 2000). Dorfman et al. (1995) found that lesbian women had more family members in their support network than gay men, lesbian women also had slightly more friends in their network than gay men but this difference was not significant. Only one study carried out any analysis of differences between bisexual people and lesbian/gay people. This study found that bisexual people had significantly more heterosexual people in their support network (Grossman et al., 2000).

Two studies identified that being in a relationship or living with a partner meant that people had more sources of social support and reported greater satisfaction with the support they received (Ramirez-Valles, et al., 2014; Grossman et al., 2000). Grossman et al., (2000) also reported that 2% of the LGB people in their study lived with a friend and 2% with a sibling; Ramirez-Valles et

al. (2014) reported that 13% of the gay men in their study lived with someone other than a partner. Neither study reported if living with someone other than a partner had a similar effect on social support.

### **Types of Support Provided by Networks**

LGB people were most likely to receive emotional support from partners and close friends rather than family members (Grossman et al., 2000; Masini & Barrett, 2008) but where family members were present in their support network they were also likely to provide emotional support (Grossman et al., 2000). One study, which looked at gay men's preference for support, found a preference for partners and close friends to provide emotional support over family members (Shippy et al., 2004). Instrumental support was most often provided by partners for both gay men and lesbian women (Grossman et al., 2000; Massini & Barrett, 2008). When asked to list who they would want to provide instrumental support if they needed it, gay men were most likely to select a friend if they did not have a partner (Shippy et al., 2004). These figures for instrumental support should be interpreted with caution as participants across these studies reported good physical health so were likely to be in need of less significant instrumental support than is normally considered in the caregiving literature. There were only three studies which explored the support of older LGB people with physical health difficulties (Brotman et al., 2007; Hash, 2001; Fredriksen-Goldsen, Kim, Muraco & Mincer, 2009). These three studies focused largely on experiences of discrimination and this is explored in the following section. However, these studies may also give some suggestion as to who provides care to older LGB people with health problems. Of the 36 caregivers recruited to the Fredriksen-Goldsen et al. (2009) study, 18 were partners, 17 were friends and 1 was a sibling. Of the 17 recruited to the Brotman et al. (2007) study 7 were

partners, 3 were friends, 4 were children, 1 was a sibling and 1 was a neighbour, the final study (Hash, 2001) targeted their recruitment towards same-sex partners and recruited 4 people.

Two secondary analyses of the interview data from Fredriksen-Goldsen et al., (2009) study explored the experience of those older LGB people with health problems who were supported by their friend (Muraco & Fredriksen-Goldsen, 2011) and differences between the best and worse experiences of caregiving between friends and partners (Muraco & Fredriksen-Goldsen, 2014). Both studies scored high for methodological quality on the SQAC, only losing one point for the reflexivity of the account. They found that both friendship and partner dyads described a diverse range of support, from picking up laundry to supporting with intimate personal care tasks. Mutuality was particularly important in the friendship relationships in a way that was viewed as distinct from the experience of partners, and friends described some of the benefits they received (e.g. a sense of being a good person) as being part of the reason they provided care (Muraco & Fredriksen-Goldsen, 2014). Although both partners and friend dyads commonly described arguments as being part of the “worst” experience of care, some partners said that arguments were the “best” experience of care because it deepened their empathy and brought them closer together, this was not true of the friends (Muraco & Fredriksen-Goldsen, 2014). Friends sometimes experienced challenges dealing with the bureaucracy of health and social care organisations due to their lack of legal relationship to the person they were caring for. Finally, although the friendship dyads spoke of being “like family” many friends were able to talk about a limit to the amount of time they would be willing to give and were unwilling to take on some of the roles that might traditionally fall to a partner (e.g. taking on legal power of attorney) (Muraco & Fredriksen-Goldsen, 2011). Care receivers were also aware of not wanting to be a burden to their friend and this restricted the help that they would ask for or allow to be given. This challenges the view that

these relationships fully compensate for less support from families of origin and may partially account for the fact that many older LGB people reported not consistently receiving support despite having similar sized support networks to older heterosexual people.

### **Particular Challenges**

#### **Experiences of discrimination.**

Older LGB people and those caring for them reported experiences of discrimination or expectations of discrimination from health services across qualitative studies. It appeared that in earlier studies, experiences of discrimination were more common, with fears about the potential for discrimination being more common in later studies. The earliest study explored the experiences of one woman and three men who had provided care to their (now-deceased) same-sex partner (Hash, 2001). In this study all four participants described experiences of discrimination from professionals: being denied access to services for relatives, not being allowed to plan a shared burial plot, inappropriate questioning from healthcare professional and one professional who “made no bones” about not liking gay people. Similarly, in a 2007 study (Brotman et al., 2007) all 17 caregivers of Canadian older LGB people participating in the study reported a range of experiences of discrimination from health professionals. In a later study looking at the experiences of four Australian lesbian women who had chosen to live in care home for older LGB women, no experiences of discrimination from professionals were noted but there remained a frustration with government policies that meant that same-sex partners would not inherit their partner’s social security benefit or be able to visit their partner in an intensive care unit (Gabrielson, 2011). Fears of general older people’s services were also described with participants concerned that they would have to hide their sexual orientation if they were to go into a nursing home. In the most recent study, no experiences of discrimination from health professionals or government policies are noted

but the fear of discrimination remained (Barrett et al., 2014). These fears meant that caregivers described continuing to provide care beyond what they felt able to, due to reluctance to access formal support services.

One quantitative study looked at the relationship between experiences of discrimination and depression amongst LGB older adults with health problems and their caregivers (Fredriksen-Goldsen, Kim, Muraco & Mincer, 2009). They found that half of care recipients and 43% of caregivers reported experiencing discrimination on the basis of their sexual orientation. Experiences of discrimination were linked to depression for both caregivers and receivers, with the perceived quality of their relationship with their caregiver having a protective effect amongst those receiving care (Fredriksen-Goldsen, Kim, Muraco & Mincer, 2009).

#### **Abuse in caregiving relationships.**

One study reported potentially troubling findings in relation to the number of older LGB people who had experienced abuse from those providing them support (Grossman, Frank, Graziano, Narozniak, Mendelson, El Hassan & Patouhas, 2014). They found that 22% of people reported having experienced abuse or neglect from their caregiver and 25% said they knew another older LGB person who had experienced this. The authors describe these results as being “within the estimates of elder abuse in general” but the review they compare these results to put 25% as being at the very highest end of the range of estimates, with the only studies giving results around this figure looking at abuse of older people in China (Cooper, Sellwood & Livingston, 2008). A more recent review suggests that amongst studies looking at the general population of older people living in the USA, the highest reported rate of abuse of older people is 14% (Dong, 2014), suggesting that older LGB people may be more likely to experience abuse from a caregiver than the general population. This finding is complicated by the fact that the study did not clearly



differentiate abuse from health professionals (potentially leading to the inclusion of experiences of institutional discrimination which have been commonly reported elsewhere) and the fact that people were recruited from LGB community centres rather than the likely more representative samples recruited in other studies of abuse of older people (e.g. via random-digit dialling or mail surveys).

### **Overall Methodological Issues**

One of the clearest questions around the literature is the extent to which these results can be generalised to the wider LGB population. Across studies, participants were largely white, university educated and younger, and reported higher incomes and better physical health than is average for the general older adult population. Although it may be expected that the older LGB population would in fact differ from the general older adult population in this way, as those in socially privileged positions may find it easier to occupy an LGB identity; evidence from large surveys carried out in the USA suggests that the group of people who self-identify as LGB do not differ demographically from the general population in terms of ethnicity, gender or income (Gates, 2014). Although there was some evidence that older LGB people are more likely to be university educated and younger (Gates, 2014), it seems likely that the method of recruitment introduced possible bias.

Studies consistently recognised the method of recruitment as a limitation and were appropriately cautious in not overstating their claims. Almost all studies used a range of the following methods of recruitment: advertisements in the LGBT press and in LGBT social spaces, recruitment through LGBT organisations, recruitment through social networking sites and LGBT websites and recruitment through “snowball sampling” (asking participants to pass on details of the study to other potential participants). Of the different methods, studies which only recruited

through the internet appeared to have the most educated, affluent and white samples, this may be related to access and previous use of the internet. Recruitment through LGBT organisations and snowball sampling appeared to allow recruitment of a more diverse population. However, these methods are particularly problematic for the purpose of researching social networks as they mean that the sample is biased towards people who are connected to other LGB people. It may even be possible that the higher than average number of friends that older LGB people reported across studies could be partially attributed to this bias.

The SQAC checklist highlighted the challenges of recruitment across the quantitative studies. A common weakness was that studies did not report how many people were invited to take part versus how many people did actually end up taking part. Many studies suggested that this was not possible due to using a convenience sample. Whilst this would certainly be more difficult using a convenience sample, studies could report the number of people who were recruited through each source when using a mixture of different recruitment strategies. This would enable readers a better understanding of what part of the LGB population is being reflected by these studies.

The only study to escape this recruitment bias was Green (2016) which used the results of a national household survey, wherein people were randomly selected for participation by address. Unfortunately, this method of recruitment is clearly not feasible for most studies: the survey on which this study is based identified LGB people over the age of 50 at a rate of approximately four per every thousand houses visited. Although not a perfect strategy, the best approach for smaller scale studies appears to be to use a mix of different methods to try and access as a diverse a section of the population as possible. Studies attempting to gain quantitative estimates of the size of support networks should be particularly cautious about using snowball sampling or other methods which rely on using social connections to access participants.

Only one study used a comparison group of heterosexual people (Dorfman et al., 1995). This means that for the most part the quantitative research literature just provides a description of older LGB people and does not allow us to easily unpick what experiences are particular to older LGB people and what may be universal to all older people. Studies commonly compared their findings against similar studies within the general population to draw conclusions (e.g. Shippy, 2004) but this approach means that differences between the studies (e.g. recruitment strategy, questionnaires used) could explain any differences found.

The qualitative studies shared a common weakness as assessed by the SQAC, in that they did not reflect on the relationship between the researcher and participants. This may be particularly problematic for research in this area as some researchers recruited through their own networks, complicating the boundaries between researcher and participant. Five of the papers used no method to verify their coding (Traies, 2015; Gabrielson, 2011; Heaphy, 2009; Hash, 2001; Richard & Brown, 2009) and three (Traies, 2015; Gabrielson, 2011; Heaphy, 2009) did not describe the method they used to analyse data, drawing into question the validity of the results of these studies.

There were no qualitative papers which focused only on the experiences of gay or bisexual men and the two quantitative papers which focused on lesbian/bisexual women only looked at the validity of a measure. This means that we are missing important structural information about the support networks of lesbian and bisexual women and experiential information about social support of gay and bisexual men. Additionally, there were no papers at all which focused only on bisexual people and where papers did include bisexual people, they made up a small proportion of the overall group. The available social support literature allows us to say very little about the social support of older bisexual people other than that they have more heterosexual people in their networks than lesbian or gay people.

A common strength was the use of participatory methods in designing the research. This was particularly true of many of the qualitative studies which described a process of identifying key areas of concern within the older LGB community before honing the focus of the research question. Some researchers identified as older LGB people themselves (e.g. Traies, 2015) demonstrating the high levels of involvement from older LGB people in setting the research agenda. The fact that social support was commonly arrived at as a key area of concern for people in this population suggests that this remains an important topic of research.

### **Summary of Results**

In summary, although older LGB people report having similarly sized social support networks to the older heterosexual population, there is evidence that a significant proportion of older LGB people are not receiving certain types of support from the people they view as being part of their network. Whilst this may be partially related to some LGB people successfully managing ageing independently by choice, it may be that a greater reliance on friends over legally recognised family means that the availability of certain types of support is lacking for older LGB people. Whilst there are many ways that the friendship networks of older LGB people do seem to fulfil their description as “families-of-choice” there also appear to be important ways in which the support provided by friends differs from that provided by legal-relatives or partners. Friends were more hesitant about taking on some of the roles that might be expected of partners or legal-relatives (e.g. taking on responsibility for financial or medical decision making) and older LGB people reported being more cautious about “burdening” friends meaning that they did not ask for certain kinds of help.

Older LGB people and their caregivers reported experiences of discrimination from health services or fear of discrimination, this motivated some older LGB people to avoid accessing formal

care for longer than they might otherwise, meaning that informal caregivers sometimes ended up taking on more caregiving responsibilities to compensate. Less experiences of discrimination from professionals were reported in more recent studies than in the past but many older LGB people were still concerned about the potential to experience discrimination. Experiences of discrimination were related to depression for both older LGB people and their caregivers and the perceived quality of the relationship with their caregiver had a protective effect against experiences of discrimination for older LGB people. Finally, one study suggested the possibility that older LGB people might be more likely to experience abuse or neglect than older heterosexual people. However, there was only one study which looked at this and differences in its methodology make it hard to compare this against the literature looking at elder abuse in the general population.

Caution is advised in applying these results beyond the population that researchers were able to access. Most studies looked at a North American population, and participants tended to be more likely to be white, wealthier, better educated, have better physical health and be younger than older people in the general population. Bisexual people were also very underrepresented across the papers.

## **Discussion**

### **Clinical Implications**

This review has highlighted the complexity of the supportive relationships surrounding older LGB people. The role of friends, families and partners can all differ from the role that they traditionally play in the care surrounding older heterosexual people. In line with the previous review (Barker et al., 2006) this was seen in the greater involvement of friendships in the support of many older LGB people as well as the lesser involvement of members of their family of origins.

However, since this previous review there has been a greater exploration of the limits of this care. Whilst some studies have suggested these relationships act as replacement for close family ties (e.g. Dorfman, 1995), there appear to be important differences between the role that family plays in the lives of many older heterosexual people and the role that friends play in the lives of many older LGB people. Awareness that social support may be less likely to come from family is important for professionals working with older LGB people in thinking about how best to involve their support networks. Services should be aware of how the names they give to particular services (e.g. “family therapy”) may indirectly impede access for older LGB people.

There was evidence that older LGB people frequently had access to a support network that was of a similar size to the heterosexual population. The “direct effects” hypothesis suggests that access to a support network alone has a positive effect on physical and mental wellbeing (Umberson et al., 2010) and these findings suggest that older LGB people have access to this benefit. However, despite reporting similarly sized support networks to the older heterosexual population, there was evidence that older LGB people were less likely to get support which matched their needs (Shippy et al., 2004; Richard & Brown, 2006). The “buffering hypothesis” suggests that not getting social support that matches needs during periods of stress will lead to stressful events having a greater physical and psychological impact (Nurullah, 2012). It may be that this lack of support matched to need contributes to the high reported rates of physical and mental health problems amongst older LGB people (Northridge, 2001). Although more research is needed to understand more about this reported lack of appropriate support, one possibility is that differences between friendship and family support partially account for this. It was highlighted that some older LGB people felt like they did not want to “burden” their friends and friends were more uncertain about taking on some particular caregiving responsibilities (Muraco & Fredriksen-

Goldsen, 2011). It may be that friendship-caregiver dyads need to have more explicit negotiations about exactly what people are and are not willing to help with due to a lack of visible templates for these kinds of relationships in wider society. Services may have a role in supporting these conversations to happen, either through care co-ordination or in some cases through systemic therapy. Health and social care staff should check whether LGB older people feel adequately supported and assist them to improve existing supportive relationships or cultivate new ones as required.

### **Research Implication**

Whilst the literature gave a good description of how the social support networks of LGB people are configured, there were no studies which directly explored what determines how the networks around LGB people adapt to provide care in response to emerging health needs. This was also a gap identified by the previous literature review in this area (Barker et al., 2006). The literature suggested many LGB people were more disconnected from their families of origin due to experiences of discrimination (e.g. Heaphy, 2009) and that very close friendships akin to family were common amongst older LGB people (e.g. Muraco & Fredriksen-Goldsen, 2011). However, this do not allow us to understand why particular individuals take on caregiving responsibilities for older LGB people. Current thinking around social support in the heterosexual population has suggested that the caregiving system organises itself largely according to the expectations of society as well as each individual's attachment to the person in need of care, the gender balance of the family (females are more likely to provide care) and the family's internal value system (Keith, 1995; Leopold, Raab & Engelhardt, 2014). This does not account for the experiences of older LGB people: there are less societal expectations of friends to take on more extensive caregiving roles, attachments to family-of-choice have developed in a different context later in life and the gender

balance of their networks is generally predominately male or predominately female. Furthermore, it is not clear to what extent a family-of-choice, which is likely to have less clear and more fluid boundaries than a biological-family, can be said to have an internal value system. A theory of how particular individuals come to give support to older LGB people in response to a health problem would allow us a better understanding of which older LGB people may be more likely to need additional support from services. Due to the lack of research in this area, this question would be particularly well suited to a qualitative exploratory study.

More generally, there is a need for quantitative descriptions of the social support networks of lesbian and bisexual women and qualitative studies exploring the experience of social support for gay and bisexual men. Whilst there were some papers that included gay/bisexual men in qualitative studies and lesbian/bisexual women in quantitative studies, these papers mostly did not focus down onto differences between men and women. Additionally, there is generally a need for more studies that look at social support for older bisexual people. Bisexual people made up a very small proportion of the participants across studies. It could be argued that their inclusion in this way contributes to what has previously been described as “bisexual-invisibility” (Hutchins, 2005) as their particular experiences are hidden amongst the much larger data-set of lesbian and gay people’s experiences. Future research should be mindful of previous guidelines that have argued that bisexual people should be separated from lesbian and gay people in academic papers (Barker, Yockney, Richards, Jones, Bowes-Catton & Plowman, 2012). Also, research is required with LGB individuals with additional characteristics associated with discrimination (e.g. those with ethnic or gender minority status or those with disabilities or from more deprived socioeconomic backgrounds), who may require and receive social support differently to other groups. Finally, future quantitative studies should consider the use of a comparison group of heterosexual older



people or older people not recruited on the basis of their sexual orientation. This will allow for a clearer understanding of the particular experiences of older LGB people and, by extension, allow for a clearer understanding of how health and social care professionals may need to adapt their practice to work with older LGB clients.

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**Section B: A grounded theory study of the informal care and support of older lesbian and gay people with long-term health conditions.**

Overall Word Count: 7981(300)

All participant names and locations mentioned have been changed to preserve anonymity.

APRIL 2017

### **Abstract**

Lesbian and gay people are more likely to experience long-term health problems and less likely to have relationships that typically provide informal care. Whilst some researchers have suggested that care is provided by family-of-choice relationships (i.e. a network of very close friendships), there has been no research looking at what determines the organisation of care.

Grounded theory was used to explore what determines the organisation of informal care for older lesbian and gay people with health problems. Fourteen mid-later life lesbian and gay people were interviewed who had experience of providing/receiving care, or running groups for these populations.

Findings suggest that this population experience losses to their network related to their sexuality as well as due to ageing and the impact of their health problem. This means that except for those living with others (partners, ex-partners or housemates), people often experience their care needs being “left to” them. In response, people seek connections or alternatives to support. Support arrangements developed for those living alone tends to be distributed across multiple people. Strategies and attitudes developed from managing being lesbian or gay influence choices and resiliencies in navigating these challenges.

The results suggest that older lesbian and gay people have unique strengths and challenges in accessing care in the context of long-term conditions. Recommendations for research and practice are made, including the need for developing ways of working with distributed care networks and suggestions for supporting clients to use resiliencies developed from experiences of being lesbian and gay.

**Key Words:** Social support, lesbian, gay, older age, long-term health problem

## Introduction

### Long-Term Health Conditions Amongst Older Lesbian and Gay People

In the UK, in 2013 an estimated 38 percent of people over the age of 55 had experienced a long-term health condition (defined as a life-limiting health problem lasting more than twelve months) (Office of National Statistics, 2015). Lesbian and gay people are believed to make up approximately 1.5 to 5 percent of the population (Aspinall, 2009), meaning that a conservative estimate would suggest that there are between 105,000-350,000 older lesbian and gay people with long-term health problems in the UK. This will be an underestimate as this population is at an increased risk of developing physical and mental health difficulties (Fredriksen-Goldsen, Emlet, Kim, Muraco, Erosheva & Goldsen, 2013.) This is possibly related to commonly reported experiences of stigma and discrimination (D'Augelli & Grossman, 2001). Stigma and discrimination can have directly harmful effects on the neuroendocrine system (e.g. Hatzenbuehler, 2009) or be managed in harmful ways (e.g. smoking, drug and alcohol use and obesity) (Northridge, 2001).

Access to social support has been highlighted as one important factor in maintaining physical and mental wellbeing in the context of long-term health conditions (DiMatteo, 2004). Theories of social support have proposed that as well as the direct positive effect on physical and mental wellbeing from participating in a social network, social support can also have a “buffering” effect whereby receiving support matched to need protects against physical and emotional stress during challenging periods of life (Nuruallah, 2012). Studies have shown that social support increases adherence to medical treatment (DiMatteo, 2004), reduces experiences of depression related to chronic health conditions (Penninx et al., 1998) and increases life expectancy (Rolls, Seymour, Froggatt & Hanratty, 2011).

### **Caring Relationships of Older Lesbian and Gay People**

It has been suggested that the caring networks of older people are organised according to a “principle of substitution” (Qureshi & Walker, 1989). Meaning that there is an expected hierarchy of who will provide care, (Qureshi & Walker, 1989). This is ordered such that the expectancy first falls on partners, then children, then other family members, before expanding out into the wider network (Shanas, 1980). In line with this, in the UK, partners and children most frequently report providing care to older people (Health and Social Care Information Centre, 2010). However, as has been highlighted (Barker, Herdt & De Vries, 2006), this order of substitution reflects a heteronormative understanding of family and social relationships. Compared to heterosexual people, older gay/lesbian people are less likely to have partners and more likely to live alone (Guasp, 2010), less likely to have a child (Understanding Society, 2016), and more likely to be separated from their biological family (Guasp, 2010). Current evidence suggests that whilst older lesbian and gay people have similarly sized support networks to heterosexual people (Dorfman, 1995), the support provided may be less matched to need (Shippy, Cantor & Brennan, 2004; Richard & Brown, 2006).

As well as these challenges, lesbian and gay people may show resiliencies which are well suited to the task of managing old age. It has been suggested that LGB older adults have developed “stigma-competence” in that they have successfully navigated the challenge of holding one stigmatised identity (i.e. a lesbian/gay identity) and are more prepared to hold a second stigmatised identity (i.e. an older adult identity) (Friend, 1990). It may also be the case that this “stigma-competence” extends to the provision of support to people in their network. Lesbian and gay people often have larger friendship networks than heterosexual people (Dorfman et al., 1995). Many have

described some of their friendships as being akin to family and within the literature these relationships are often referred to as a “family-of-choice” (Weeks, Heaphy & Donovan, 2001). It has been suggested that these relationships may provide care after developing a health problem (Barker, Herdt & De Vries, 2006).

To date, studies looking at the care of older lesbian and gay people with long-term health problems have all taken place in North America and have largely focused on experiences of discrimination (Brotman et al., 2007; Hash, 2001; Fredriksen-Goldsen, Kim, Muraco & Mincer, 2009). Most caregivers recruited were partners or friends, with some children, siblings and neighbours also providing care. Studies reported that experiences of discrimination were common amongst both carers and caregivers (Brotman et al., 2007; Hash, 2001; Fredriksen-Goldsen, et al., 2009), and that this was linked to experiences of depression (Fredriksen-Goldsen, et al., 2009). Secondary analysis of Fredriksen-Goldsen, et al., (2009) suggested that whilst friends and partners did not differ in the amount of care they provided, the reasons for providing care differed, and some friends were aware of a limit of how much they would do (Muraco & Fredriksen-Goldsen, 2011; Muraco & Fredriksen-Goldsen, 2014).

While these studies give us some suggestions as to who may provide care as well as some of the challenges of this experience, they do not tell us why or how they came to do so. Furthermore, most research that has explored the support older lesbian/gay people receive has come from outside the UK. Only two peer-reviewed studies have explored this issue in the UK (Heaphy, 2009; Traies, 2015). Although both spoke of the importance of a family-of-choice, neither looked explicitly at people with caregiving needs so we do not know to what extent a family-of-choice provides care to older lesbian and gay people in this country.

**The UK care context**

An ageing population and a period of financial instability has meant that the UK government has recently moved to a greater emphasis on informal care (i.e. support by family, friends and the local community) rather than direct professional support (Seale, 2016; Care Act, 2014). In line with this, figures suggest that in the UK approximately 400,000 fewer older people were getting support from formal services in 2013/14 compared to 2009 and the number of people providing informal care to older people has increased from 16.6% of the population in 2009 to 18.9% in 2013 (an increase of approximately 1.7 million people) (Humphries et al., 2016). This means that the role of health and social care services has partially shifted away from the direct provision of care to supporting the networks around people to provide this care.

**Informal care for UK older lesbian and gay people with long-term health problems**

We currently know very little about what determines how informal care becomes organised around older lesbian and gay people with long-term health problems in the UK. UK health and social care services have only had explicit legal duty to ensure their employees are competent in working with the issues this population faces since 2007 (Equality Act, 2007). Lesbian and gay people commonly report feeling less satisfied with the standard of care they receive (Elliott et al., 2015), suggesting that many health and social care staff may lack competency in working with these clients and their support networks.

To improve the quality of care provided to this population, we need a better understanding of how informal care becomes organised around older lesbian and gay people. A fuller understanding of this will enable practitioners to provide more effective support to individuals and their networks, allow us to identify individuals who may be less likely to receive informal care, and allow for further service-related research.

### **Aims**

The main aim of the present study was to develop a theoretical understanding of how the informal care networks around older lesbian and gay people are formed after they develop a health problem. The following research questions were explored:

1. What determines how informal care and support is organised around older lesbian and gay people after they develop a health problem;
2. What support arrangements are developed by this population?

### **Method**

Due to the paucity of literature in this area, a grounded theory methodology (Glaser & Straus, 1967) was used. The study adopted a critical realist epistemological approach, taking the position that there are objective factors that determine how care becomes organised, but that the understandings of this is affected by the cultural context in which the study was situated (Willig, 2013). The overall design of the study was guided by Urquhart's (2013) description of grounded theory which was judged to fit with this epistemology.

As there are multiple participants in a caring relationship, an understanding of these different perspectives was necessary to gain a full understanding of how these relationships are organised. Consequently, the study triangulated the perspectives of older LG people with long-term health problems, those that provided care to them and those running social groups for this population.

As is core to grounded theory (Urquhart, Lehman & Myers, 2010), data analysis proceeded alongside data collection. This allowed the direction of data collection to be informed by ideas emerging from the analysis. Following each interview, memos were made (Appendix B) noting



initial ideas about themes. Theoretical sampling (Glaser & Strauss, 1967) was used to recruit participants likely to have new perspectives on ideas developed from prior interviews. Recruitment stopped once “theoretical sufficiency” (Dey, 1993) was reached, meaning that whilst the interview might have suggested new ideas about individual categories, no entirely new categories emerged nor experiences that could not be understood within the theoretical framework developed.

### **Participant Recruitment**

To enable access to a heterogeneous population, recruitment strategies were employed targeted towards the older adult population, the LGBT population and the older LGBT population. This included advertisements in newsletters for older people and for LGBT people, a website (Appendix C) speaking with group facilitators, attending groups, sharing on social media and using word of mouth. Participants recruited were also asked to forward details of the study to members of their network. Perspectives of three groups were sought:

- Lesbian and gay people, over the age of 50 who had experienced a long-term health condition since turning 50. In line with the Office of National Statistics (ONS), a long-term health problem was defined as a physical or mental health problem lasting over a year (ONS, 2015). The age of 50 was chosen as a cut-off as this reflects the age used by much of the existing research literature around gay and lesbian people in their mid-late life (e.g. Barker et al., 2006).
- Those who had provided non-professional support to the above group. Everyone who responded to the advert were partners of older gay and lesbian people with a long-term health condition.

- One person who had developed a support group for older lesbian and gay people. It was hoped that this person's experience of witnessing relationships form and develop amongst older LG people would allow them a third, observer perspective on the topic of enquiry.

Fourteen people were interviewed (ten individuals and two couples). Pseudonyms and contextual information for participants are displayed in Table 1. Further demographic details and information about recruitment is displayed separately in Table 2 to prevent identification of participants.

Table 1 - *Participant details*

Interview	Pseudonym	Gender	Interviewed as:	Health problem
1(Interviewed as couple)	Julie	Female	Carer	Cares for wife (below)
	Sandra	Female	Person with health problem	PTSD and chronic pain
2	Richard	Male	Carer	Cared for partner who died of multiple health difficulties
3	Lucy	Female	Person with health problem	Chronic back problems
4 (Interviewed as couple)	Adam	Male	Person with health problem	Chronic life threatening health conditions
	Nick	Male	Carer	Cares for partner (above)
5 & 9	Stephen	Male	Carer & Person with health problem	Provided care to an ex-partner who died of dementia, a civil-partner who died and has experienced life threatening illness.
6	Simon	Male	Person with health problem	PTSD
7	Paul	Male	Carer & Person with health problem	Cared for partner who died of a life threatening disease. Experienced “mental health difficulties”
8	Matthew	Male	Person with health problem	Chronic back pain
10	Diane	Female	Person with health problem	Arthritis
11	Victor	Male	Ran support group for older LG people	Ran support group for older LG people
12	Fred	Male	Person with health problem & carer	Cared for partner with neurological disease Has experienced life threatening illness
13	Hannah	Female	Person with health problem	Chronic pain and “mental health difficulties”.

Table 2 – Further details of participants.

Methods of Recruitment (N)	Age Ranges (N)	Ethnicity (N)
Met at coffee morning for older LGBT people (3)	40s (1)*	Caucasian – UK (11)
Word of mouth - connected to LGBT charity (2)	50s (4)	East Asian (2)
Word of mouth - through professional connections (5)	60s (5)	Caucasian – European (1)
Partner of another participants (2)	70s (3)	
Friend of previous participant (1)	80s (1)	
Met at training event on working with older people (1)		

*\*NB the person younger than 50 was interviewed as a carer*

### **Ethical Considerations**

Ethical approval for the study was obtained from a university ethics panel (Appendix D). Participants were given information about the study (Appendix E) at least 48 hours before consent was sought. On the day of the interview, a consent form was completed (Appendix F). Following the interview, participants were offered a list of support organisations (Appendix G) and a follow-up telephone call to check whether there were any issues arising from the interview that the person wished to discuss. During the interviews, one participant shared details of mental health difficulties for which they were not receiving support. A risk assessment was carried out, and with their consent a letter was written to their GP asking them to arrange an appointment. This process was discussed with both supervisors. At the end of the study a summary of the findings was sent to the ethics panel and participants who had requested this (Appendix O).

### **Interviews**

Interview schedules were developed prior to the first interview (Appendix H). In practice, the interview schedules were used as a guide for the interviews, balancing the need to explore particular topics with allowing participants to direct the interview towards their key concerns

(Urquhart, 2013). In line with a grounded theory methodology (Urquhart et al. 2010), questions were developed across interviews to allow for ideas developed from previous interviews to be explored (an example of this development is given in Appendix I).

Interviews ranged from approximately 30 – 120 minutes. One person (Stephen) was interviewed twice, the first time about his experience of caring for his partner and the second time about his experience of being cared for himself. Participants were given the choices over the interview location with one participant choosing to be interviewed at a private room in a university, one in a café, four via telephone and eight in their home.

### **Data Analysis**

After reading the entire transcript to get a full sense of the participant's account, a second close reading of the transcript was carried out. During this reading, short sections of text were coded. Where possible, participants' own words were used for codes (i.e. in vivo codes), Urquhart (2013, p. 96) describes how for "researchers coming from a critical realist position, the use of an in vivo code strengthens the authenticity of data interpretation as it is seen to come from the data itself".

The first seven interviews were coded using this method. After this, the resulting codes were grouped, with codes sharing close enough features being merged and codes which did not usefully contribute to understanding being deleted. The remaining codes were then used as "selective codes" (Urquhart, 2013) to analyse the remaining transcripts.

A third stage of "theoretical coding" was employed where the relationships between different selective codes were explored by looking for participants' own ideas about causal relationships, or overlapping ideas suggesting links (Urquhart, 2013). In line with the structure

developed from this theoretical coding, “selective codes” were then sorted and arranged into categories and subcategories.

The overall process of analysis was iterative; earlier stages of coding were returned to when later stages of coding led to new insights which were then explored across participants. As described by Charmez (2006, p.154), “the discovery process in grounded theory extends into the writing and rewriting stages”; as ideas developed across the process of writing, the data was returned to in order to reevaluate the coding structure.

Throughout, a variety of methods were used to analyse the data. Nvivo 11 for Windows (version 11.4.1.1064) (a computer assisted software programme) was used to organise coding. Memos were kept (Urquhart, 2013) (Appendix J), and integrative diagrams (Strauss, 1987) were drawn to hypothesise relationships between categories as understanding developed (Appendix K).

### **Quality Assurance**

Yardley’s (2000) guidelines for qualitative research were used to promote quality assurance. A research diary was kept (Appendix L) and preconceptions about the topic were discussed in supervision and with peers. This process helped recognition of hopes to find a substantial role for a family-of-choice related to the researchers own experience of such a support structure. This was bracketed during the analysis. A constant comparative method was used to compare the developing theory with the transcripts to check for consistency with the participants’ accounts, paying careful attention to areas where the researcher held pre-conceptions of what would be found. Coding was checked for consistency with the data by sharing two coded transcripts with the project supervisors. Coding decisions were discussed and coding was amended to reflect these discussions. An example of a transcript at the initial stage of coding is included in

the appendix (Appendix M) as well as a codebook relating to the final selective codes (Appendix N), examples of quotes are used throughout the results.

## **Results**

### **Overview of Emerging Theory**

A total of 46 selective codes were constructed from the data and organised into 5 categories: Managing an Outsider Identity, Leaving and Being Left, Care Within a Household, Left to Me and Support from Within the Circle (Figure 1).

The theory suggests that older lesbian and gay people come into their mid-later life having developed a range of attitudes and strategies for dealing with the challenges of being lesbian or gay that influence choices around help seeking. These experiences can also create strengths and barriers in accessing support.

At the same time, older lesbian/gay people may experience unique losses to their support network related to their sexuality, as well as those shared with heterosexual people such as advancing age and their experience of a health problem. These different factors can interact such that older lesbian/gay people may experience a cumulative loss of connections.

When health problems develop for those sharing a home (with partners, ex-partners or friends), care and support is likely to be given by these individuals. Due to losses to their networks, those living alone often experience a period of their support needs being “left to” them. Because of this, there is a process of actively seeking out connections or finding alternative strategies to meeting support needs. Choices of where to seek connections are often partially determined by experiences of being lesbian/gay. When support is not sought from lesbian/gay people this can

involve overcoming expectations of animosity or less support. Support for those living alone is often distributed across several people with no one person becoming a carer.

### **Category 1: Managing an Outsider Identity**

A central category that came up in all but one interview, was how one's sexual orientation means that one learns specific ways of managing an "*outsider identity*" in sometimes-hostile environments. "Managing an Outsider Identity" had the potential to influence many aspects of seeking informal care and living with a health problem in that it influenced: how people coped with the challenges of having a health problem or providing care, how participants connected with others and where they did and did not seek support. The subcategories describe three different ways this was described.

#### **Subcategory 1: Experiences of successfully navigating challenges related to sexuality**

Most participants described experiences of successfully navigating "*battles*" related to sexuality such as coming out and experiencing discrimination. Participants often spoke of how this made them "*stronger*". Diane described this:

*When you ... therefore decide to take your life in a different direction from what a lot of people are saying... I think it just makes you a stronger person.*

Some felt that this prepared them to handle the challenges of living with a health problem or caring for a loved one. Stephen spoke about this in relation to providing care:

*Interviewer: You said gay people make good carers, what do you think it is that makes gay people good carers?*

*I think it probably is that we bring the baggage of rejection into our present, and I think even people of your age know something about that to a certain extent. Because nobody*



*comes out without it being a costly experience in some way, a demanding experience, and I think that because of that we learn about the trials and the slings and arrows of the world.*

Several participants spoke of how the current (mostly) favourable circumstances of lesbian and gay people bolstered their strength in being able to stand up to or disregard discrimination.

Adam described this:

*That perhaps makes us braver than we would be in the fifties, because half of the people out there would support you if somebody was bigoted against you.*

Although all but one of the participants said that attitudes towards lesbian and gay people had improved, several people spoke of experiencing discrimination from health professionals, suggesting the continuing importance of this ability. Several spoke of experiencing an assumption of heterosexuality from medical professionals, Fred overheard social workers laughing about his relationship with his partner, and Adam spoke about concerns about the perceived likely expectation to “*go back into the closet*” if Adam went into residential care.

### **Subcategory 2: Being guarded**

Some participants adopted an attitude of “being guarded” about their lives which affected their choices as to whether to seek support and who to seek support from. Paul described how he was left to provide all the care for his partner as his partner did not want friends to know he was unwell and would not let “nurses” into their home. Paul partially related his partner’s attitude of not talking about problems with friends, to his experiences of growing up in a society where it would be dangerous to be open about your sexuality:

*He wasn't the type to do that... Because of the society, [being] gay was legalised only 67 isn't it in this country? So now I do understand, because if you were open about it you never know what's going to happen.*

This attitude affected where participants felt safe when seeking support for a health problem, with Stephen talking about how being in a hospital with only heterosexual people made him feel “*psychologically unsafe*”. Because of this, as is explored in “seeking out connections”, participants often sought support from other lesbian and/or gay people, or LGBT organisations.

Simon also suggested that the way homophobia “*leaked out*” into gay people could cause a “*sort of nervous paranoia*” which meant that some gay men didn’t want to associate with anyone (including other gay men). He suggested that this had got worse for those who had lived through the HIV crisis:

*People had the paranoia of having HIV and it was generated and diffused into other people, so other people became tighter and didn't go out.*

### **Subcategory 3: Gay and Lesbian Humour**

Across interviews humour was used frequently. Stephen proposed that humour was a distinctive coping strategy for gay people, developed from a need to get “people on side”:

*If you say what's distinctive about being a gay person, one of the things is our humour, that we know how to laugh about all sorts of things that other people don't... humour was really important, to me, this was the way that you got people on side, by making them laugh.*

Across interviews, participants described and demonstrated a variety of uses for humour. Humour was used to aid coping by “making light” of difficult circumstances, to avoid speaking

about difficult topics (e.g. speaking about sexuality with relatives), to demonstrate a “toughness” in the face of adversity, to ridicule discriminatory attitudes and to connect with others.

### **Category 2: Leaving and Being Left**

The second category related to experiences of having to leave people and being left. Some were experiences that might happen to anyone at any stage of life, e.g. relocating or relationships changing. However, participants related other experiences to ageing, being lesbian/gay, or having a long-term health problem, meaning that some participants experienced a cumulative loss of connections. Some of these experiences happened in the distant past and some happened more recently but all contributed to absences from their present support network. These experiences are described across four subcategories below.

#### **Subcategory 1: You don't want me, then I don't want you. Fine!**

All but one of the participants with living relatives remained in contact with some people from their biological family. Although many participants described these relationships as important and/or loving and had frequent telephone contact, only two participants lived near any biological relatives. Linked to “being guarded”, several participants did not speak to their family about their sexual orientation, limiting the possibility of their involvement in their lives. For example, Matthew spoke about how he has “*never ever discussed it [my sexuality] with my immediate family*”.

Although this was not true for all, several described separations from family, heterosexual friends and religious communities due to discrimination. Fred spoke about his relationship with his sister:

*I mean I have a sister that is left, she lives in <a city> with her children, I don't particularly see them. They have their life, let them have it (Interviewer: Is that related [to being gay] in some way?) My sister wasn't happy when she found out earlier on. But I couldn't care less <LAUGHS>*

### **Subcategory 2: Not Having Children**

Only Sandra and Julie described raising a child together and only one other person (Victor) spoke of having had a child from a previous heterosexual marriage. Sandra and Julie did not currently expect care from their child as he was away at university and Victor's son lived abroad. Richard also spoke of how his (now deceased) partner had children from a previous heterosexual marriage but they had stopped contact after he had come out. Adam and Nick spoke about how not having a child meant that there were extra things for them to think about:

*What I'm talking about is when we think about [your burial] because you don't have kids or anything. We think more ahead of what's coming. I don't know if heterosexuals would be like that.*

### **Subcategory 3: Ageing networks**

Descriptions of friends, relatives and partners who “went and died on them” were common across most people interviewed. This was often related directly to getting older, with participants reflecting that death was something you came to expect with age. Stephen spoke about why this was particularly problematic for older lesbian and gay people in rural areas:

*The thing about being old, is that the people around you die. So the community [of gay friends] that might already be in smaller areas quite a small community of people, as you get older, gets smaller still.*

In addition to loved ones dying, some of the participants had also taken on caring responsibilities for older relatives who had become unwell.

#### **Subcategory 4: Health problems limiting opportunities for connecting**

Constraints arising from health problems, and society's reactions to health problems, were also sometimes viewed as reasons for absences from support networks. Lucy spoke about how her health problem meant that she lost some friends as she could no longer take part in the activities that had bound them together:

*It then became very difficult to do any of the things that I used to do. So I ended up losing a lot of those friendships because the things that we had in common and had bound us had disappeared.*

For Fred, his partner's dementia meant that many of their friends had "disappeared" as their friends could not cope with the impact of his dementia on how he behaved in social situations:

*The other friends sort of disappeared, maybe Christmas time was the only time we really got together and then he could say some very hurtful and very wrong things*

#### **Category 3: Care Within a Household**

The third category related to those sharing a home with others. When a health problem emerged for those who shared a home, most care was provided within those relationships. For most, this was their partner. However, Stephen described separating from his partner then returning when he realised he needed care, Diane spoke of receiving support from her ex-partner and housemates and Matthew shared his home with his partner and a friend.

Not all relationships continued with the partner taking on the role. Lucy described how her partner left her shortly after she developed mobility problems. She related this partially to how she

lost “*confidence*” following the loss of her job and the resulting change in dynamic to their relationship.

Within the category of ‘care within a household’ there were three subcategories, summarised below.

**Subcategory 1: Commitment to relationship as a reason for providing care**

The length and quality of the relationship were spoken of as important factors in why care was provided. Many partners spoke of their level of “*investment*” in the relationship, or their shared history. Diane and Stephen also related their reasons for the supportive relationship with their ex-partner to “*love*” as well as their shared history. Diane describes this:

*Because we've lived in the household now for ten years, so it's like we've got, and we both say this to each other, it's like we've got a relationship but we're not having a relationship.*

Examining one negative case supported the idea that length of relationship and commitment was an important factor in determining care within a household. Michael, the only person living with a friend he had known for a short period of time, said of his friend: “*I don't ask him to do anything but he offers to do things like cleaning*”. Michael instead asked his partner, who was also living with him, for other tasks linked to care such as help with personal care and financial support with medical needs.

**Subcategory 2: Care was “left to us”**

However, as well as their commitment, linked with “leaving and being left” for some there was also a sense that care had been “*left to*” them, in that there was no-one else available to provide this. Although Richard said he “*never ever begrudged it*” and spoke very positively about his relationship, he had experienced a more significant loss of connections than some of the other

participants (due to the process of “leaving and being left”) and described why he was the one to provide care as a “*case of left to me*”.

### **Subcategory 3: Support for carers**

For those providing care to people with more extensive support needs, the challenges of caring meant that some had to make sacrifices. Richard described one example:

*I mean just one example I had injections in my knee one time and normally I would just rest up, but with him needing help and all that, unfortunately that wasn't to be.*

Carers sometimes required their own support to deal with these challenges. For some, this was provided by the person they were caring for as described by Sandra:

*It's down to the relying on each other I think. (Interviewer: So the reliance on each other?)  
Yeah, because she supports me and boosts me up and tells me how fantastic I am.*

The two participants who had cared for someone with dementia both spoke about the difficulties of providing support when they were less able to provide this kind of mutual care. Fred spoke about the brief moments of clarity when his partner was able to provide this:

*He would say something like "I'm sorry, I've really upset you today haven't I Fred" and it would floor me, it was so unexpected, came out of the blue and turned round to answer him and he had gone again*

*Interviewer: What was it like during those times when he came back or he had those moments of clarity*

*It was... why couldn't he be like that all the time.*

This challenge was handled by drawing on support from gay and lesbian friends. Stephen described how he would get emotional support: *“I would ask them if I could go around and talk to them”*. Stephen also sometimes asked these friends to *“keep a watch out”* if Stephen left the house and gave him *“physical support”* when they went out together to avoid difficult situations.

#### **Category 4: Left To Me**

All participants not living with someone experienced a stage of their support needs being *“left to”* them, another category identified here. This often followed experiences of *“leaving and being left”*. Participants handled this using a mix of finding alternatives to support and seeking out connections. The two subcategories of these alternate strategies are outlined below.

##### **Subcategory 1: Alternatives to Asking for Support**

A desire to keep *“friends as friends”* and prevent relationships from becoming unequal meant that some living alone sought alternative strategies to asking for support. Lucy described this:

*They're partners, and they're friends and they're going to be supportive in various different ways but I don't want to turn them into a carer.*

In terms of physical support (e.g. mobility and cleaning), if participants were not living with someone they often used strategies other than social support to get these needs met. Some participants used technological adaptations to make their day to day lives easier. Others chose to use quasi-professional support. Adam paid one of his friends to provide support when his partner was outside of the country and Lucy hired university students to act as personal assistants. Adam described how paying his friend meant that he kept it from feeling like he was in his friend's debt for his support:



*I pay him because ... he's a bit of yap! And I'd rather not have him saying <HIGH-PITCHED VOICE> "oh I did this for you and that for you"*

### **Subcategory 2: Seeking Connections**

All of the people not living with someone else reached a point where they wanted to expand their network. For some this came after realising that they could not do it on their own. Paul described how his “breakdown” brought him into contact with the health service, who then helped him to decide to connect with other people:

*This psychologist who contacted [the older adult LGBT charity] she thought that my problem was that I was shutting myself in to my loneliness and not socialising. So that is [how] the idea to mix with the people [came about].*

For others, this decision followed a change to their situation that raised their ability to connect with others and expectations for how their life could be. Lucy spoke of this:

*The other thing was I got wheels, so I could get about a lot more. And that meant, it kind of lifted my spirits as well as my horizons as well. And so that made me think about getting further afield rather than just within two blocks of my house.*

Participants spoke of a variety of ways of connecting with others including joining LGBT organisations, joining mental health organisations, reconnecting with old friends, using dating apps, meeting at parties and for one person attending a festival.

Where participants chose to seek connections was often informed by a sense that lesbian/gay people “belonged together”. Related to “managing an outsider identity” for many this was related to feeling safer amongst lesbian and/or gay people because of past experiences of discrimination. Others spoke about a desire to be around people with shared experiences. Some

people who were not currently in relationships spoke about their desire for romantic and/or sexual relationships and this was also an instigator for some to seek out connections with lesbian or gay people.

However, some gay men suggested that the introduction of dating apps for meeting sexual partners had meant that many gay men were going out to socialise less, limiting opportunities for connections beyond sex. Several gay men also spoke about feeling like gay spaces were less accepting of older people. Victor, who started a group for older gay men described this:

*In a gay pub with lots of young people, you are either the "old git" or the "dirty old man" and not interesting to be taken care of. That is very very strong.*

Likely related to feeling like lesbian/gay people “belonged together” and at the same time feeling that LGBT spaces tended to be targeted towards younger people, many people chose to seek out (or develop) groups specifically for older LGBT people. Most of the time the spaces that people sought out were specific to one gender, but several people spoke of having same-sex attracted friends of both genders.

It is important to note that those who were not recruited through LGBT organisations had not gone to such organisations to seek support. However, for Hannah, support-seeking outside of an LGBT context involved overcoming an expectation of lower support-provision related to her sexual orientation. Hannah described this:

*My sexual orientation, yes I would say that has been important because the people that I've had more support from are not actually gay people. They are more straight people. Which is quite surprising, it has surprised me.*

Several participants commented that the organisations that they had initially accessed (both LGBT and general) had experienced cuts, reducing the availability of this kind of support.

There was one person who had tried to seek connections but had experienced more difficulties than the other participants. Although Simon had joined a group for LGBT people, he found that they did not share the same interests and conflicts had arisen. He spoke of being at “*a low point with people*” and said “*I've got no support at all. In fact, I've got the reverse. I've got people who don't like me.*” The impact of finding one group unwelcoming, highlights the challenges of seeking support when there are few groups for older gay people even in larger cities.

#### **Category 5: Support From Across the Circle**

The kinds of support that participants got from people who were not living with them was described by one person as “*support from within the circle*”; a final category. This reflected the fact that this kind of support was distributed across several people, with no one person providing enough support to be considered a “carer”. Most participants spoke about getting a large proportion of this support from lesbian or gay friends, but participants did also get support from living family members and heterosexual friends.

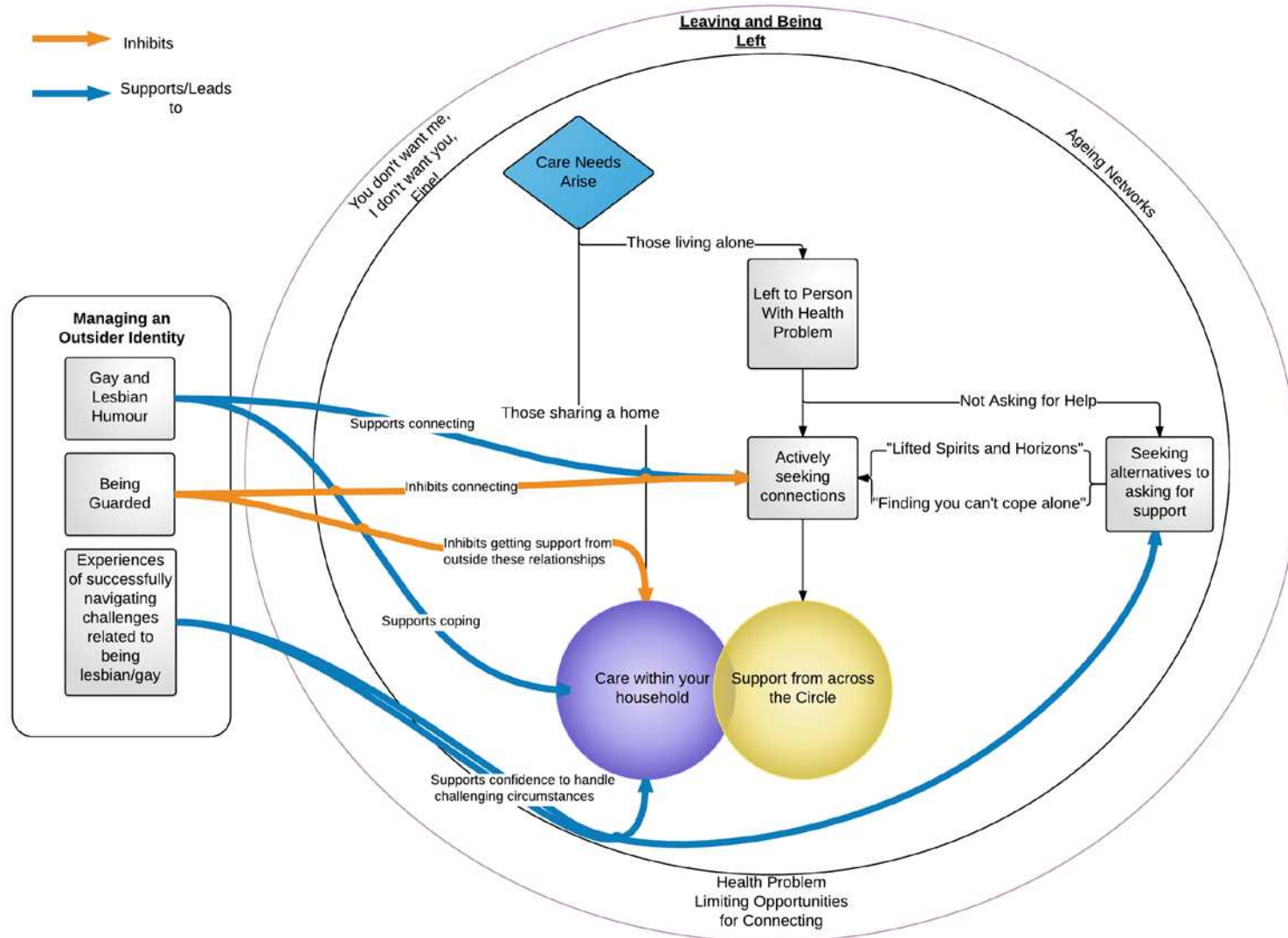
For most this was limited to emotional support or for those with access needs, friends taking account of this when organising activities. Fred described how his network supported him to manage his experience of his health problem:

*James has been very kind, he's rung me on a regular basis, a lot of other friends have either text or rung me, maybe only once a month but “are you okay”, “is everything going alright”, “how are you?” As I say because of the network that I have built up. I feel very lucky in that respect.*

Lucy and Hannah had both experienced some more practical support from a friend (shopping and preparing meals), but this only seemed to happen when it was clear that the support provided was mutual. Lucy described this:

*Because she was around during the day, she needed support to go to the shops, I needed support to go to the shops and I guess it is in my nature that I respond a lot more quickly to someone needing my support than I do to requesting it.*

Figure 1: *Overview of Theory*



### Discussion

In thinking about what determines how informal care and support is organised for older lesbian and gay people, the findings of this study suggest that one of the most important factors is an individual's living arrangements. Those living with partners, ex-partners or housemates largely received their care and support within those relationships. Like the role of heterosexual partners described in the literature (Nolan, Grant & Keady, 1996), partners did not question taking on caregiving responsibilities and gave as much care as it was possible for them to provide. One difference here is the fact that households were sometimes made up of ex-partners and friends and that these relationships also provided a substantial level of support. This appeared to depend on a long shared history and commitment to each other, mirroring research with heterosexual people (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). Previous research has suggested that older lesbian and gay people are more likely than heterosexual people to share a home with someone other than a partner (Ramirez-Valles, Dirkes and Barrett, 2014; Traies, 2015). This study extends this finding to recognise the circumstances where these relationships can take on a caring role when health problems emerge.

The findings highlight the extent to which experiences of managing being lesbian or gay in a sometimes-unsupportive society informed participants' choices about accessing support. These experiences could also give particular resiliencies in managing some of the challenges of caring, living with a health problem and accessing support. This extends the concept of stigma competence (Friend, 1990; Balsam & D'Augelli, 2006) to recognise that resilience and strategies developed to manage stigma can be turned to the tasks of caring, living with a health problem and seeking out support. However, as well as creating strengths, ways of managing discrimination also

had the potential to create barriers. For example, people were sometimes guarded about inviting others into their lives and felt unsafe in certain settings. This connects with previous research which has suggested that many lesbian and gay people pre-screen places from which they seek help for affirmative attitudes towards their sexual orientation (Liddle, 1997). There is also evidence that shame related to sexual orientation leads people to have an ambivalence towards the expression of emotion (i.e. a guardedness about their emotional experience) (Greene & Britton, 2012), which may limit opportunities for help-seeking.

For those living alone, when care needs emerged, rather than getting increased support from their existing network, people largely sought out new connections or found alternatives to social support. In contrast to the existing literature (Brotman et al., 2007; Fredriksen-Goldsen et al., 2009), individual friends were only viewed as taking on a substantial caring role when they were living with the person with a health problem. Whilst it may be the case that friends in these studies were in fact sharing homes (the studies do not discuss their living arrangements), it is also possible that cultural differences between the UK and North America, or pre-conceptions of the prior studies (which both aimed to recruit “carers”) led to these differences. Although there will undoubtedly be circumstances where individual friends living separately do become “carers” (as will also be true of some heterosexual people), the participants in this study did not expect their friends living separately from them to give substantial care in response to a health problem. Instead, new connections were formed and alternative strategies were sought such that support becomes distributed across their network with no one person becoming a “carer”.

The results of this study sheds light on previous findings which have suggested that older lesbian and gay people are less likely to get support matched to their needs despite reporting similarly sized networks to heterosexual people (Shippy, Cantor & Brennan, 2004; Richard &

Brown, 2006); when support was distributed across more people, participants reported only receiving emotional support. More significant support was only received in these circumstances when the support was mutually provided. It may be that there is both an unwillingness to ask for more significant support from less close friends, and a possible “bystander effect” (Fischer et al., 2011) in which everyone in the network leaves the responsibility of providing more costly types of support to someone else. This is significant as the “buffering hypothesis” of social support would suggest that support is only protective against the effects of stressful life events when the support provided is matched to need (Nuruallah, 2012).

In line with previous research (Guasp, 2010; D’Augelli, Hershberger & Pilkington, 1998), many experienced absences from their support network of biological family members. In contrast to previous suggestions (Barker et al., 2006), friends did not appear to replace the care that would normally be provided by these relationships. This suggests that there is not a principle of substitution (Qureshi & Walker, 1989) in the organisation of caring relationships of older LG people, in that for those living alone, existing friendships did not “substitute” for the care that might be normatively expected from a partner or child.

### **Limitations**

Recruitment to the study shared common limitations with other research involving lesbian and gay people: BME people were under-represented, many of the participants were connected to LGBT charities and the oldest participant was in their 80’s. Whilst grounded theory methodologies do not aim for representative samples (Urquhart, 2013), the fact that particular groups could not be theoretically sampled (e.g. those in their 90s and above, and BME people other than East-Asian people) limits the transferability of the findings. The smaller number of lesbian women recruited to the study also meant that it was challenging to draw out differences between the experiences of



gay men and lesbian women. One difference that was found was the fact that gay men spoke about experiences of ageism in the LGBT community and lesbian women did not, this mirrors findings from past studies in the USA (Barker et al., 2006).

In line with previous guidelines which have suggested that the experiences of bisexual people not be merged with that of lesbian and gay people (Barker, Yockney, Richards, Jones, Bowes-Catton & Plowman, 2012), bisexual people were not included in the study. Bisexual people's experiences are likely to differ from lesbian and gay people's in significant ways (e.g. having more heterosexual people in their network) and understanding their experience of caring relationships would require further research.

The fact that the researcher had a non-heterosexual identity is likely to have influenced the study. Whilst this could be viewed as a potential limitation, in that the researcher's own experiences of this community could have led him to impose his own understanding on participant's descriptions, steps were taken to ensure reflexivity. This included supervision and keeping a research diary. The fact that participants were aware of the researcher's sexuality also likely impacted on what was said. For example, some participants spoke of how "heterosexuals are not my people", which may not have been spoken had the researcher identified as heterosexual. In line with a critical realist epistemology (Willig, 2013), the interviewer's identity was kept in mind during the process of interviewing, and careful attention was paid to areas where this might make it harder for participants to say what they wanted (e.g. speaking about ageism from younger LGBT people).

### **Implications for Research**

Grounded theory does not aim to develop a theory or model which is generalizable (i.e. one that can be applied broadly across contexts) but rather, one which is transferable in that it gives

enough rich information for readers to consider how the research may apply in different contexts (Kuper, Reeves & Levinson, 2008). However, the findings of this study can also be used to develop a hypothesis for research that is generalizable. Namely, that the strategies people have developed to manage being lesbian or gay will predict their success at navigating caring relationships later in life.

This hypothesis could be tested through the development of a questionnaire looking at the ways older lesbian/gay people have managed having a marginalised sexual orientation. Interviews and inductive thematic analysis could be used to develop a list of question, and exploratory factor analysis used to develop an understanding of different groupings of strategies and attitudes. As well as being used to validate this hypothesis, such a questionnaire could also be used clinically to identify older lesbian and gay people likely to need additional support from services.

The fact that the participants living alone developed a distributed support network rather than care being left to any one individual suggests limitations with our current ways of working. To more effectively work with these networks, services need to consider developing ways of including the wider network beyond individual carers. We do not currently know to what extent involvement in services would be welcomed by people in these kinds of relationships as some participants spoke about wanting to avoid their friends “becoming a carer”. Further research may be necessary to establish what kind of support from services would be perceived as welcome or helpful for people in these kinds of relationships.

### **Implications for Practice**

As described, many people in this study experienced care being “left to” them or those living with them. This suggests that some older lesbian and gay people may need support from services in building caring relationships. The findings related to stigma competence (Friend, 1990)

suggest a helpful strategy for professionals aiming to provide this support. Professionals working with this population may wish to explore how clients have navigated the challenges of holding a marginalised identity. This may suggest strengths that clients could draw on in developing new caring relationships, as well as supporting thinking about what barrier clients may be likely to face. Strengths-based cognitive-behavioural therapy may be a useful framework for exploring these ideas, in that it focuses on how strategies used to overcome past challenges may be usefully turned to current difficulties (Padesky & Mooney, 2012).

This study has also highlighted that some older lesbian/gay people feel “psychologically unsafe” in healthcare settings perceived as heterosexual. This suggests the continued need for groups and spaces particularly for this population. It may also be helpful for individual organisations to specifically advertise their acceptance of lesbian and gay people or for LGBT staff members to be open about their own sexual orientation when working with these clients. Research has shown that some LGBT people report a better experience of therapy from therapists with the same sexual orientation (King, Semlyen, Killaspy, Nazareth & Osborn, 2007), and it is likely that this finding will hold true across helping professions. This finding also highlights the continued need for services particularly for lesbian and gay people. For some, they are the only places perceived as safe enough to access support.

### **Conclusions**

The findings of this study suggest that older lesbian/gay people with health problems experience losses to their support network related to being lesbian/gay, as well as those relating to ageing and having a health problem. This means that with the exception of those already living with someone, many older LG people experience their care needs being “left to” them before actively seeking connections. The support that these individuals often arrive at is distributed across

multiple people with no single person viewed as a “carer”. Strategies and attitudes developed from managing an LG identity in a sometimes-unsupportive society can create both strengths and barriers in forming these relationships, living with a health problem and providing care.

This study connects with and expands on our understanding of “stigma competence” and the ways in which concealment of sexual orientation may hinder help-seeking. The findings of this study suggest that services should consider how best to utilise these strengths and work with these barriers. In addition, services need to consider how best to work with the wider networks around older lesbian and gay people. Potentially useful avenues for research include looking at how the strategies for managing being lesbian/gay impact on developing support, as well as what kinds of involvement from services would be welcomed by the wider networks around older lesbian and gay people living alone.

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**Appendix A: Standard Quality Assessment Criteria For Evaluating Primary Research Papers (Kmet, Cook & Lee, 2011)**

Quantitative Studies (For each score 2 for yes, 1 for partially, 0 for not met or N/A if not applicable):

1. Question/objective sufficiently described?
2. Study design evident and appropriate?
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?
4. Subject (and comparison group, if applicable) characteristics sufficiently described?
5. If interventional and random allocation was possible, was it reported?
6. If interventional and blinding of investigators was possible, was it reported?
7. Outcome and (if applicable) exposure measures well defined and robust to measurement/misclassification bias? Means of assessment reported?
8. Sample size appropriate?
9. Analytic methods described/justified and appropriate?
10. Some estimate of variance is reported for the main results?
11. Controlled for confounding?
12. Result reported in sufficient detail?
13. Conclusions supported by the results?

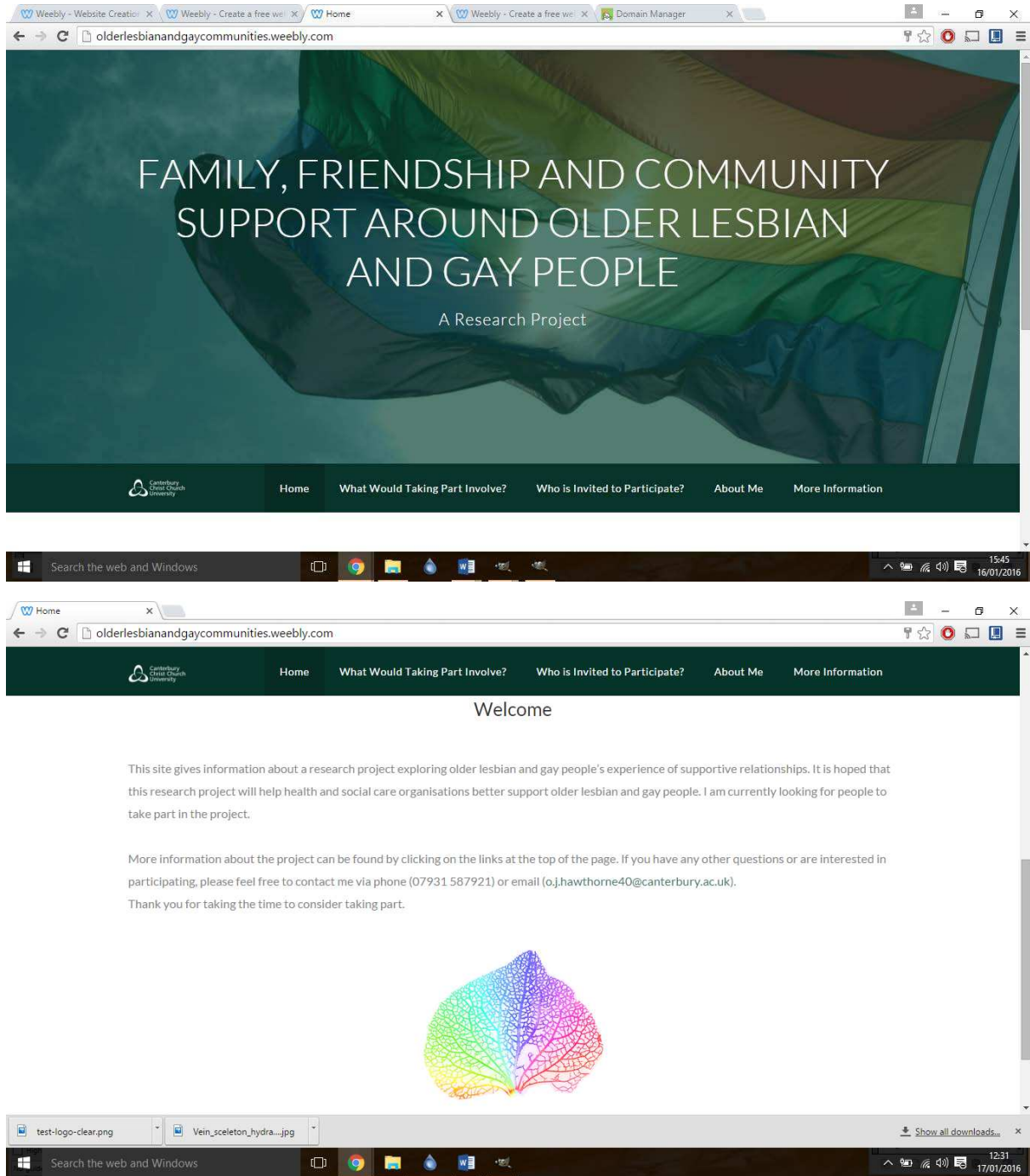
Qualitative Studies (For each score 2 for yes, 1 for partially, 0 for not met):

1. Question/objective sufficiently described?
2. Study design evident and appropriate?
3. Context for the study clear?
4. Connection to a theoretical framework/wider body of knowledge?
5. Sampling strategy described, relevant and justified?
6. Data collection methods clearly described and systematic?
7. Data analysis clearly described and systematic?
8. Use of verification procedure(s) to establish credibility?
9. Conclusions supported by the results?
10. Reflexivity of the account?

**Appendix B: Notes from day of interview**

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Appendix C – Advert and Website



The screenshot shows a web browser window with several tabs open. The active tab is titled 'What Would Taking Part Involve?' and the address bar shows the URL 'olderlesbianandgaycommunities.weebly.com/what-would-taking-part-involve.html'. The website has a dark green header with the Canterbury Christ Church University logo and navigation links: Home, What Would Taking Part Involve?, Who is Invited to Participate?, About Me, and More Information.

The main content area is titled 'What Would Taking Part Involve?' and contains the following text:

After speaking with me on the phone, I'll send you a detailed information sheet about the project. This will give you some time to consider whether or not you want to take part. After this, if you choose to take part I will arrange a time to come and meet with you.

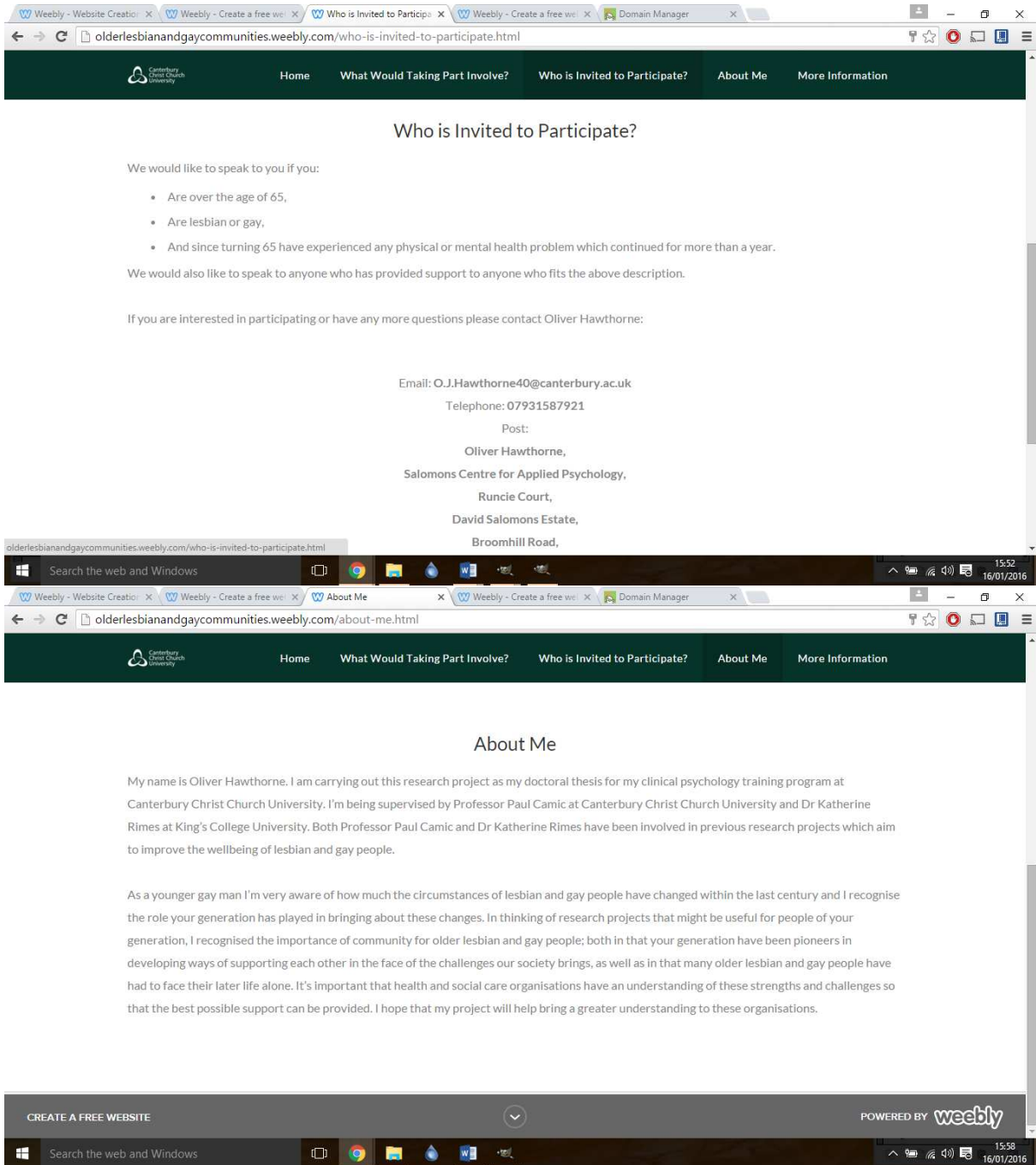
Depending on your preference, this might be at your house but could also be my university. I will ask you to make a list of the people in your life who are important to you. I will then ask you to talk about some of these relationships, thinking particularly about how those people came to offer you support. The conversation will be fairly open and if there are any questions that you don't feel comfortable answering we can skip past them. I will record your responses on a dictaphone and following our meeting will transcribe what you said.

If you are interested in participating or have any questions that you would like to ask please contact Oliver Hawthorne:

Email: [O.J.Hawthorne40@canterbury.ac.uk](mailto:O.J.Hawthorne40@canterbury.ac.uk)  
 Telephone: 07931587921  
 Post:  
 Oliver Hawthorne,  
 Salomons Centre for Applied Psychology,  
 Runcle Court,  
 David Salomons Estate.

The Windows taskbar at the bottom shows the search bar, taskbar icons for Chrome, File Explorer, and other applications, and the system tray with the date and time (15:50, 16/01/2016).





The screenshot shows a web browser window with several tabs open. The active tab is titled 'More Information' and the address bar shows the URL 'olderlesbianandgaycommunities.weebly.com/more-information.html'. The website has a dark green header with a logo for 'Canterbury Christ Church University' and a navigation menu with the following items: 'Home', 'What Would Taking Part Involve?', 'Who is Invited to Participate?', 'About Me', and 'More Information'. The main content area is titled 'More Information' and contains the following sections:

- What are the potential benefits of taking part?  
I hope that the research will help to improve the lives of other older lesbian and gay people. Some people also enjoy taking some time to reflect on their life and those who are important to them, so the interview itself may be beneficial to you.
- What will you do with my data?  
All the information you give me will be treated confidentially. I will include some quotes from our meeting in my final report but I will ensure that these quotes include nothing that could be used to identify you.
- What will happen to the results of the research project?  
You will receive a short report of the findings of the project. Results will also be published in a journal and on my University's website.
- Who is organising and funding the research?  
This study is funded by the Canterbury Christ Church University
- Who has reviewed the study?  
Canterbury Christ Church University Research Ethics Committee reviewed this project.

The Windows taskbar at the bottom shows the search bar, task view, and several application icons. The system tray on the right shows the time as 15:58 and the date as 16/01/2016.

**Calling Lesbian and Gay People Over the Age of 50. We  
Need to Hear Your Experience!**

We are conducting a research project exploring the support provided to lesbian and gay people by their friends, families and local community. We hope that this research project will help health and social care organisations better support lesbian and gay people in their mid to later life. We are looking for lesbian and gay people over the age of 50, who would be happy to speak with a researcher about their experience of receiving, wanting or needing support for a health problem.

Who is invited to participate?

We would like to speak to you if you:

- Are over the age of 50,
- Are gay or lesbian,
- And since turning 50, have experienced any physical or mental health problem which continued for more than a year.

We would also be interested in speaking to people of any sexuality and age who have supported someone who fits the above description.

Who is running the project?

The project is being run by Oliver Hawthorne as his thesis for a doctorate in clinical psychology at Canterbury Christ Church University. The project is being supervised by Professor Paul Camic (Canterbury Christ Church University) and Dr Katherine Rimes (King's College University). Both Professor Paul Camic and Dr Katherine Rimes have been involved in previous research projects which aim to improve the wellbeing of lesbian and gay people.

Where can I get more information?

If you are interested in participating or just finding out more about the project please contact Oliver Hawthorne:

Telephone: 07931 587921

Email: [o.j.hawthorne40@canterbury.ac.uk](mailto:o.j.hawthorne40@canterbury.ac.uk)

Oliver Hawthorne,  
Runcie Court,  
Salomons Centre for Applied Psychology,  
David Salomons Estate,  
Broomhill Road,  
Tunbridge Wells,  
Kent TN3 0TF

[www.olderlesbianandgaycommunities.co.uk](http://www.olderlesbianandgaycommunities.co.uk)



**Appendix D – Ethics Approval**

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## **Appendix E – Information Sheet**

### **Information Sheet**

#### An exploration of the caring relationships around older lesbian and gay people

You are being invited to take part in a research project. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with others if you wish. Please ask if anything is unclear or if you would like more information.

#### Purpose of the project

I am running a research project exploring how older lesbian and gay people are supported by their partners, friends and families in later life. I hope that this research project will help health and social care organisations better support older lesbian and gay people. I am looking for older lesbian and gay people who would be happy to speak with a researcher about their experience of receiving, wanting or needing support for a health problem. I am also looking to speak with anyone who has provided support to someone in this population.

#### Why are you interested in this research project?

As a younger gay man I'm very aware of how much the circumstances of lesbian and gay people have changed within the last century and I recognise the role your generation has played in bringing about these changes. In thinking of research projects that might be useful for people of your generation, I recognised the importance of community for older lesbian and gay people; both in that your generation have been pioneers in developing ways of supporting each other in the face of the challenges our society brings, as well as in that many older lesbian and gay people have had to face their later life alone. It's important that health and social care organisations have an understanding of these strengths and challenges so that the best possible support can be provided. I hope that my project will help bring a greater understanding to these organisations.

#### Who is running the research project?

I am carrying out this research project as part of my doctoral thesis for my clinical psychology training program at Canterbury Christ Church University. I'm being supervised by Professor

Paul Camic at Canterbury Christ Church University and Dr Katherine Rimes at King's College University. Both Professor Paul Camic and Dr Katherine Rimes have been involved in previous research projects which aim to improve the wellbeing of lesbian and gay people.

### What will happen if I take part?

I will arrange a time to come and meet with you or speak with you on the phone. Depending on your preference, the meeting could take place at your house but could also be my university. I will ask you to make a list of the people in your life who are important to you. I will then ask you to talk about some of these relationships, thinking particularly about what support is provided by these relationships and what support you may still want or need. If you are feeling isolated at the moment, this is also something that I will ask you about in the interview. If you are being interviewed as someone who has supported an older lesbian or gay person with a health problem, the interview will cover the same themes but from your perspective.

I will record your responses and following our meeting will transcribe what you said. If there are any questions that you do not feel comfortable talking about, then you can let me know and we can move on.

### What are the potential benefits of taking part?

We hope that the research will help to improve the lives of other older lesbian and gay people. Some people also enjoy taking some time to reflect on their life and those who are important to them, so the interview itself may be beneficial to you.

### What will you do with my data?

All the information you give me will be treated confidentially. I will include some quotes from our meeting in my final report but I will ensure that these quotes include nothing that could be used to identify you. The only time I would break this confidentiality is if you tell me something that suggests that you or someone else is in danger. In this case I would tell the appropriate people (e.g. your GP or the police) to make sure that you're safe.

### What will happen to the results of the research project?

You will receive a short report of the findings of the project. The full report will be available on my university's website, which I will provide with the brief report; I also hope to publish it in a journal.

### Who is organising and funding the research?

This study is funded by the Canterbury Christ Church University

### Who has reviewed the study?

Canterbury Christ Church University Research Ethics Committee reviewed this project.

### Do I have to take part?

It is up to you to decide whether or not you want to take part. If you do decide to take part, you will be given this information sheet to keep. I will also ask you to sign a consent form indicating that you are happy to take part. If you do decide to take part, you are still free to withdraw from the project at any point.

### Who can I contact for further information, including questions about the research?

Oliver Hawthorne

[o.j.hawthorne40@canterbury.ac.uk](mailto:o.j.hawthorne40@canterbury.ac.uk)

Trainee Clinical Psychologist

Clinical Psychology Doctoral Programme

Salomons Centre for Applied Psychology

Canterbury Christ Church University

Broomhill Road, Tunbridge Wells

Kent TN3 0TF



Supervisors:

Professor Paul Camic

Dr. Katharine Rimes

Who do I contact if I would like to make a complaint about this project?

Professor Margie Callanan (Director of Salomon's Centre for Applied Psychology)

Telephone: 03330117094

Email: [margie.callanan@canterbury.ac.uk](mailto:margie.callanan@canterbury.ac.uk)

**Appendix F - Consent Form for Research Project****“An Exploration of the Caring Relationships Around Older Lesbian and Gay People”**

Participant ID number: \_\_\_\_\_

1. I confirm I have read and understood the information sheet of the above study
2. I have had the opportunity to ask all the questions I wanted about the study
3. I understand that my participation is voluntary and that I can stop at any time
4. I understand and agree that quotations from the interview may be included in a written report
5. I agree to take part in the above study

Participant Name: \_\_\_\_\_

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

**Appendix G – List of Potentially Helpful Organisations:**

Below are contact details for organisations which may be of interest to you. The list of charities has been designed to meet a broad range of potential needs so some of them may not be relevant to your particular situation.

**Services Specifically for Lesbian and Gay People:****Switchboard**

<http://switchboard.lgbt/>

A helpline for lesbian, gay, bisexual and trans\* people. Describe themselves as “here to help with whatever you want to talk about. Nothing is off limits, and we understand how anxious you might feel before you pick up the phone.”

Contact Number: 0300 330 0630

Email: [chris@switchboard.lgbt](mailto:chris@switchboard.lgbt)

**Metro:**

<https://www.metrocentreonline.org>

A charity for LGBT people which offers support around community, mental health and wellbeing and sexual health.

Contact Number: 020 8305 5000

**Services Specifically for Older People****Age-UK**

<http://www.ageuk.org.uk/>

Provides a variety of services to help support the needs of older people.

Contact Number: 020 7820 6770

Email: [general@ageuklondon.org.uk](mailto:general@ageuklondon.org.uk)

### The Silver Line

<https://www.thesilverline.org.uk/>

A free confidential helpline providing information, friendship and advice to older people, open 24 hours a day, every day of the year.

Contact Number: 0800 4 70 80 90

### Independent Age

<http://www.independentage.org/>

A charity which provides advice on issues which may be relevant to older people.

Contact Number: 0800 319 6789

## **Services for Carers**

### Carers UK

<http://www.carersuk.org/>

A charity for people who care for a relative or friend.

Contact Number: 0808 808 7777

### Carers Trust

<https://www.carers.org/>

Further support services for people who care for a relative or friend.

Contact Number: 0844 800 4361

### **Other Helpful Organisations**

#### Mind

<http://www.mind.org.uk/>

Mental health charity offering a range of services.

Contact Number: 020 8519 2122

#### Samaritans

<http://www.samaritans.org/>

24/7 Support line.

Contact Number: 116 123

#### Relate

<http://www.relate.org.uk/>

Low-cost and free relationship counselling.

Contact Number: 0300 100 1234

## Appendix H – Semi-Structured Interview Schedule

### Introduction

First of all I'd just like to take this opportunity to thank you for taking the time to take part in this interview, it's very much appreciated. I've got an information sheet here for you to read through, it's the same as the one I sent you in the post but I just wanted to give you a few minutes to read back over it now before we begin.

*Give information sheet*

Do you have any questions about anything written there? Was there anything that didn't make sense? Just to run over the most important points:

- I'm going to be recording the interview and anonymised quotes from your interview will be used in my write up.
- Whether or not you take part is completely up to you, if you want to withdraw now or at any point up to the end of the interview that is your choice entirely.
- Everything you say to me will be kept confidential. The only time I will break this confidentiality is if you tell me that you or someone else is in danger. Then I'll tell the appropriate people (for example the police or a medical professional) to make sure that you or they are kept safe.

Does that all make sense? Do you have any questions?

If that's all okay can I ask you to sign this consent form.

*Give consent form*

### Semi-Structured Interview

1. To begin with, I'd like to ask you to come up with a list of the people who are important to you now. Please take as long as you'd like to think about this.
2. Is there anyone else who would have been on this list if I asked you when your health problem first began? How about in between then and now? *(If at this point there is no one on their list go to bottom of page)*

*For each person:*

- a. *(If not already stated)* What name would you give to your relationship with x. For example, are they your friend, brother, partner...
  - b. Could you tell me a bit about how you know x *(if applicable)*?
  - c. What role (if any) does your identity as a gay man/lesbian woman play in this relationship?
3. I'd like to find out a bit about the health problem you've been experiencing. Could you tell me when you first began to experience this problem?

4. How has this problem affected your life? (*Prompt: emotional and practical*)
5. Is there anyone from this list who has helped you manage this? Which people? Is there anyone who's not on this list who has helped you?

*For each person they identify:*

- a. How has x helped you manage this?
- b. Tell me about your relationship with x before your health problem emerged.
- c. What is your relationship like now?
- d. Are there any other ways your relationship has changed (*Prompt for positive if only negative and vice versa*)
- e. What do you think it is about your relationship with x that has meant that they are the one to help you with this rather than someone else?
- f. What do you think x would say is their favourite thing about you?

*For each person they don't identify*

- a. Are there any ways that x has helped you manage this? (*If yes return to section above*)
  - b. Do you have any ideas about why it is that x is not one of the people who have ended up helping you manage this?
  - c. What do you think x would say is their favourite thing about you?
2. Is there any help that you do feel you need that you're not getting?
3. Do you have any ideas about what has stopped you from getting the help you needed?
  - a. Would you have wanted any of the people you have mentioned earlier to help you with this? Which particular person?
    - i. (*If yes*) Why would you have wanted help from that person rather than someone else?
    - ii. What do you think has meant that they have not ended up helping you in that way?
    - iii. (*If no*) What has meant that you wouldn't want help with this problem from these people?
    - iv. Is there anyone who you would want help from? What about professionals?
  - b. What about you has enabled you to cope without this help up until now?

*If participant says they don't have anyone:*

1. That sounds like that could feel quite difficult. Could you tell me about the last period of your life when there was someone around who was important to you?
2. Could you tell me what happened between then and now?
3. I'd like to find out a bit about the health problem you've been experiencing. Could you tell me when you first began to experience this problem?
4. How has this problem affected your life? (*Prompt: emotional and practical*)
5. Would you have wanted help from other people?
6. What do you think has enabled you to manage this by yourself for so long?

**Conclusion**

That's actually all of my questions, but before we finish I just wanted to check whether you have any questions for me?

If any questions occur to me about something you've said later on, would you be happy for me to contact you again?

I know we've touched on some emotional topics today so I'm offering everyone who participated a follow-up call a few days after. This would be a chance to speak about any difficult feelings that came up for you so that I can point you in the right direction if you'd like any support. Is this something you'd be interested in?

I also wanted to give you contact details for some organisations that might be useful if you wanted to speak about anything in more depth.

I'd just like to say thank you again for taking part in the project, as I mentioned at the beginning it's very much appreciated.



**Appendix I – Development of Question**

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**Appendix J – Memos from development of selective code - “Gay and Lesbian Humour”****Initial Memo**

Joking is an important way of dealing with losses

Laughter and jokes are used to:

-Distract from uncomfortable subjects (making jokes to avoid talking about the subject of sexuality with family)

-Turn things that used to be painful into something that can be shared and spoken about safely

-Make something frightening seem less frightening

-Deal with the pain of rejection

-Connect with other people

**Second Memo**

I'm interested in how much laughing there has been in the interviews I've been doing. This has come through even though we've been talking about some quite sad and difficult topics: disability, death and aging. X spoke about “our humour” as one of the particular things that gay people bring to help cope and my first interviewee spoke about making light of things to make her partner feel better. Thinking about it now I think that there is a big history of gay people using humour in various ways. “Camp” and “drag” are all ways that gay culture has used humour to either enter a straight world in

an acceptable form (e.g. comedians like Graham Norton) or to challenge (e.g. “Pits and Perverts”, the name Lesbians and Gays Support the Miners gave to their fundraising campaign)

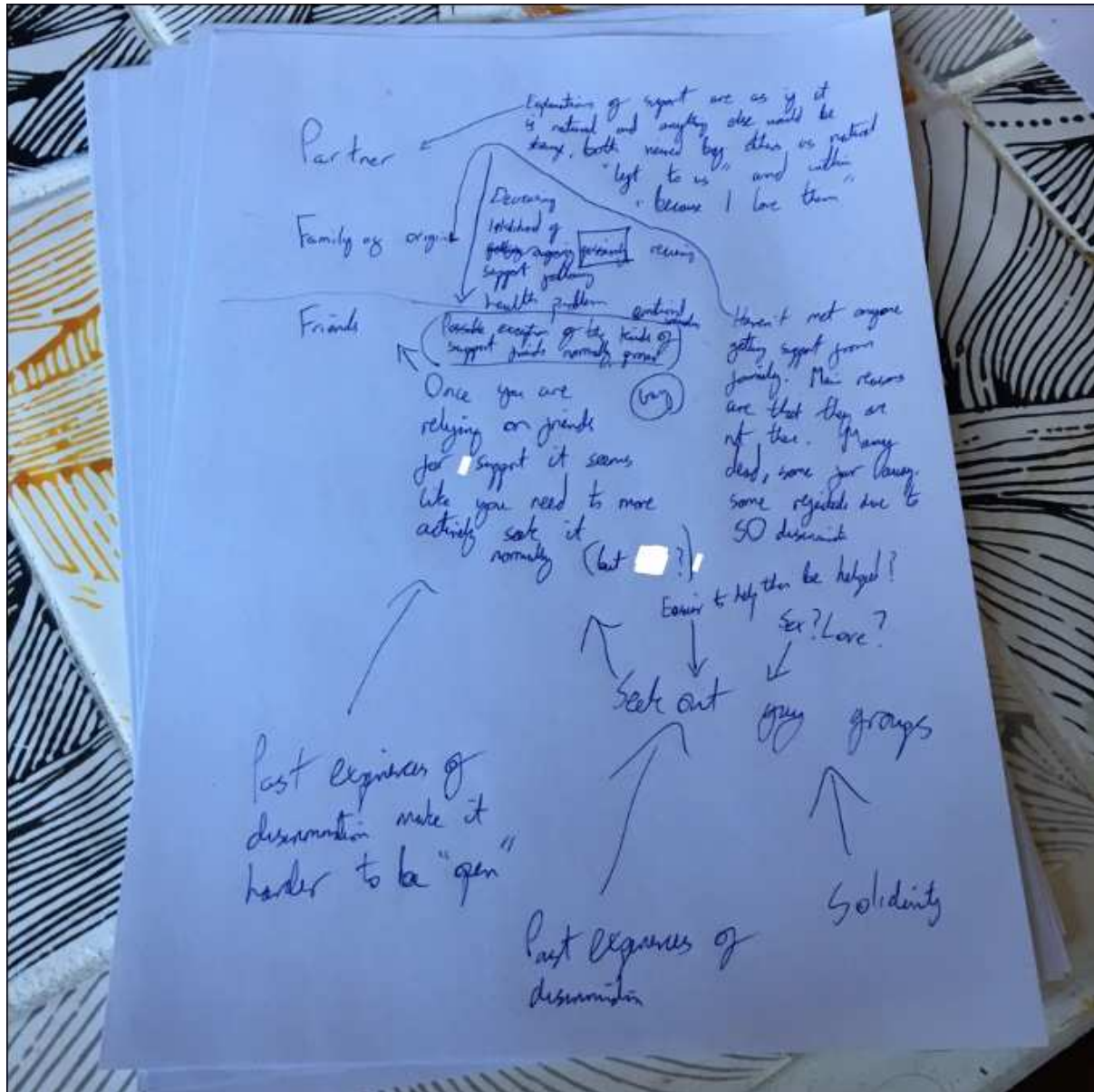
I need to be cautious about making too much of this. In my reflective practice group and in personal therapy the extent to which I use humour to cope with difficulty has been pointed out. It could be that I’m bringing this to the interviews myself, although I don’t think this is a satisfactory explanation alone. Humour takes two to tango, you can’t share a joke if both participants are not willing to engage in it. I need to be careful during coding to attend to the ways that I initiate humour. It might also be helpful to look at the transcripts where participants do not use humour in this way and think about whether this difference comes from the context of these interviews (e.g. my relationship with the participant, how I was feeling on the day) or from the participants themselves.

### **Third Memo**

Yep, I’m much more certain about my ideas about humour now. Although the humour is most evident during the interviews where myself and the participant have a really warm interviewing relationship and both of us seem to be enjoying the process, there is also an interview where I clicked less well with the participant, and an interview where the participant makes jokes that I don’t laugh at. I think this is enough for me to say that it’s not just me who was creating that situation. I’ve also spoken to other trainees doing interviews about whether or not jokes were common in their interviews and paid a little bit more attention to how humour does and does not enter the work I’m doing with my therapy clients.

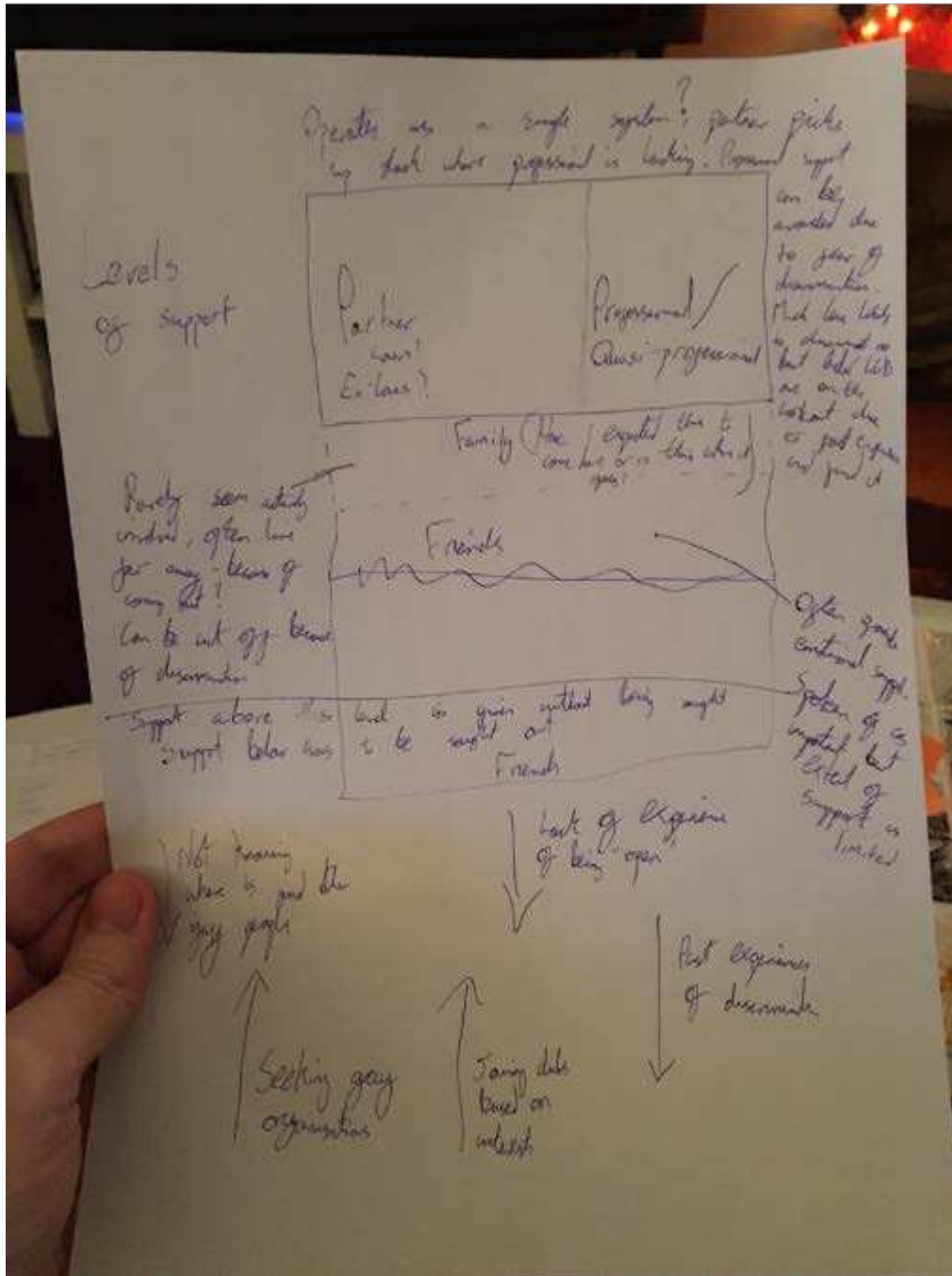


went back and did a closer recoding. As can be seen “active decision to rebuild network” (which became “seeking out connections” in the final-write up) was present at an early stage.



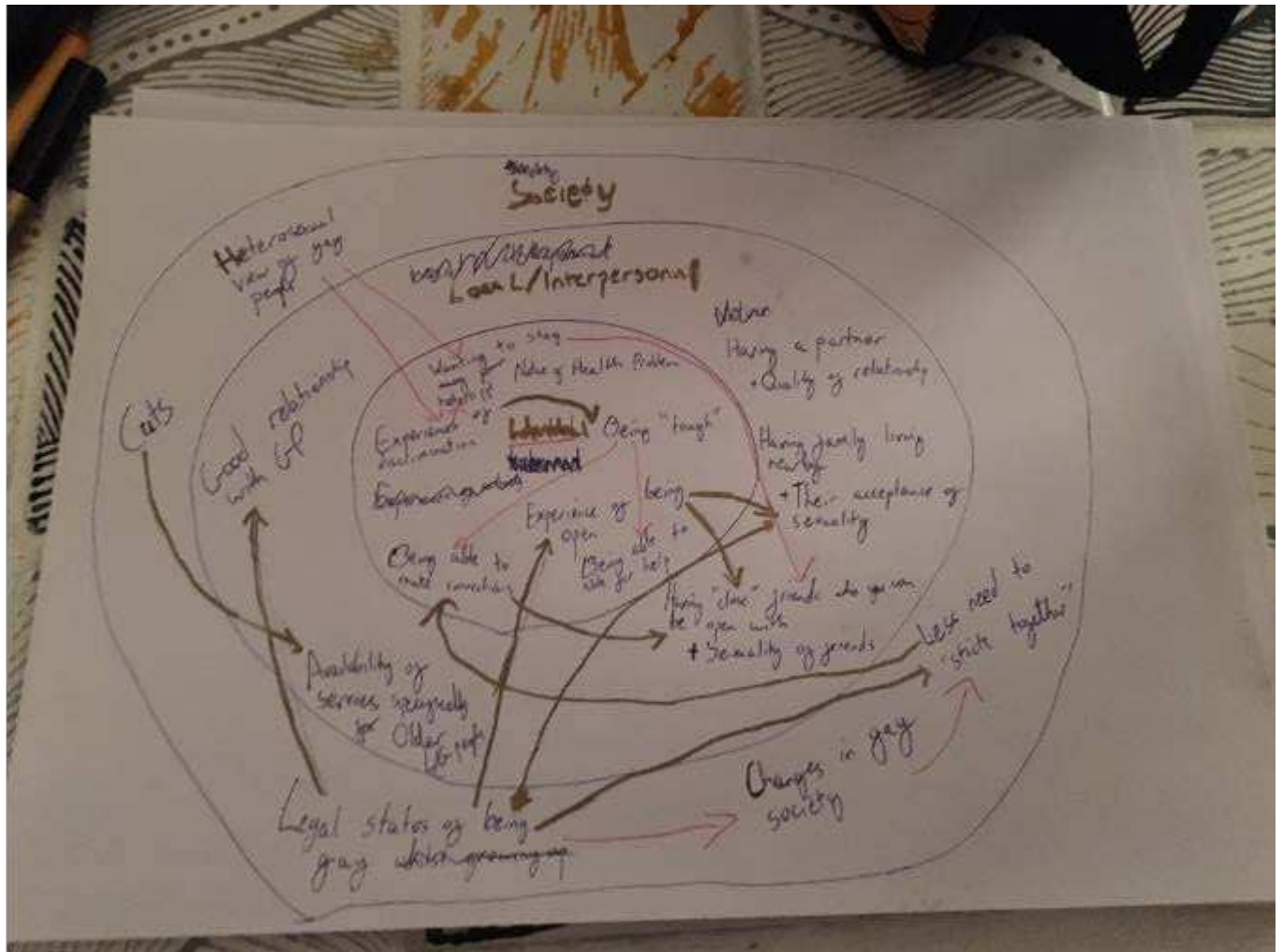
This diagram drawn the same week represents my early ideas about an overall model. Reflecting on it now, it's clear that how I was trying to arrange the data at this stage were heavily influenced by the expectation that there would be a “principle of substitution” (i.e. that there would be a hierarchy of

support with partners expected to provide support, then family if they were not available, then friends). In this diagram you can also see the presence of themes later expanded on including “left to us”, the concept of people leaving across the life-span and how past experiences of discrimination affect accessing support.

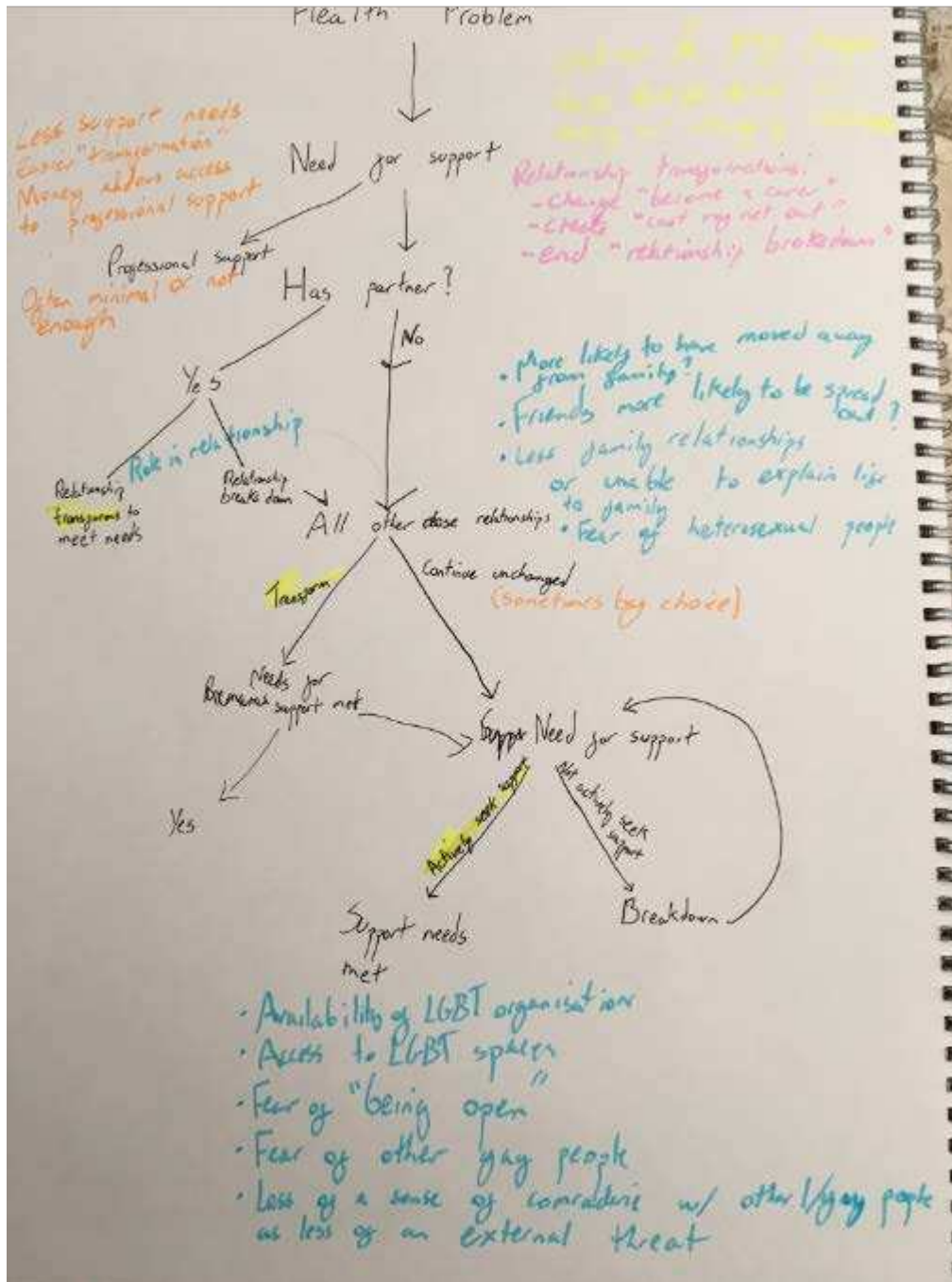


This one is another attempt at a structural model operating on a “principle of substitution”. As can be seen on this diagram next to “family”, at this stage I begin to question whether my expectations of the organisation have influenced the model that I have developed.





This diagram represents an attempt to move away from the structural model I had developed. I'd begun to feel like I was forcing the data to take a shape and this diagram was an attempt to find a different way of organising my codes. I organised what seemed like important or significant ideas into three different categories (society, local and individual) and drew links between them.



This diagram represents my final attempt at organising my data prior to the decision to go back and code closer. This diagram has lost the differentiation between friends and family which I was imposing on the earlier models. However I'm still adopting some ideas from a "principle of

substitution” and placing support from friends and family above the possibility of actively seeking support.

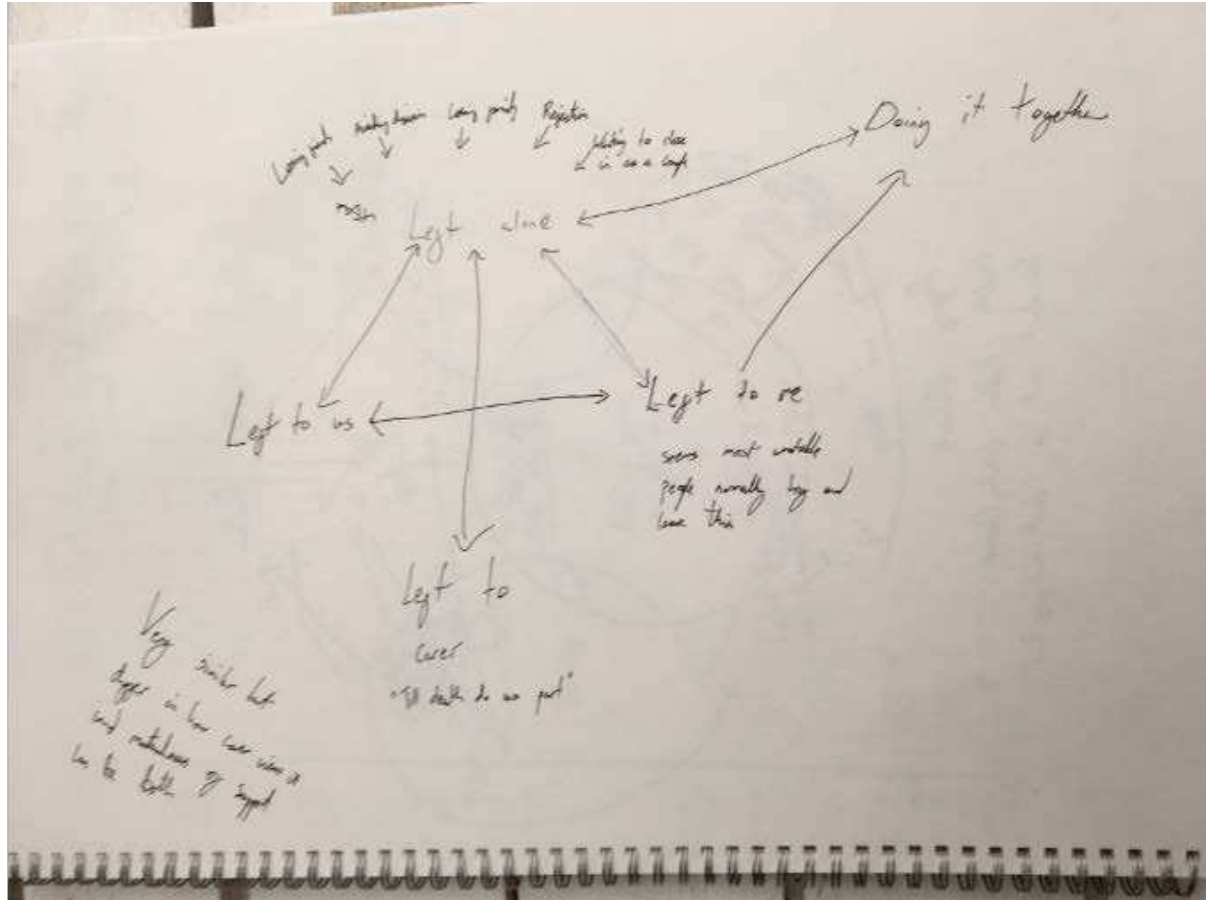
Research Diary Entry from 4th February:

Had a telephone conversation with Paul yesterday and I think something clicked for me with regards to doing grounded theory. We went through my coding and Paul spoke about how we would code for each line and the questions he would ask himself. Paul also agrees that I’m broadly along the right lines with how I’m coding.

I feel like I might go back to recheck where I could code closer. I don’t think these attempts are wasted work. I think what this first attempt at constructing a theory has allowed me to do has been to get a much broader understanding as to what the participants were saying. I constantly had this feeling that I was artificially imposing lines and rules in places where they didn’t fit. One of the things that Paul pointed out was that I was assuming that the person I was investigating needed or would want support. I’d been trying to develop a model of the order in which participants turned to people to ask for support but I’d been assuming that they even looked for support or that there would be an order across participants. I’m excited to see what comes with going back closer to the data.

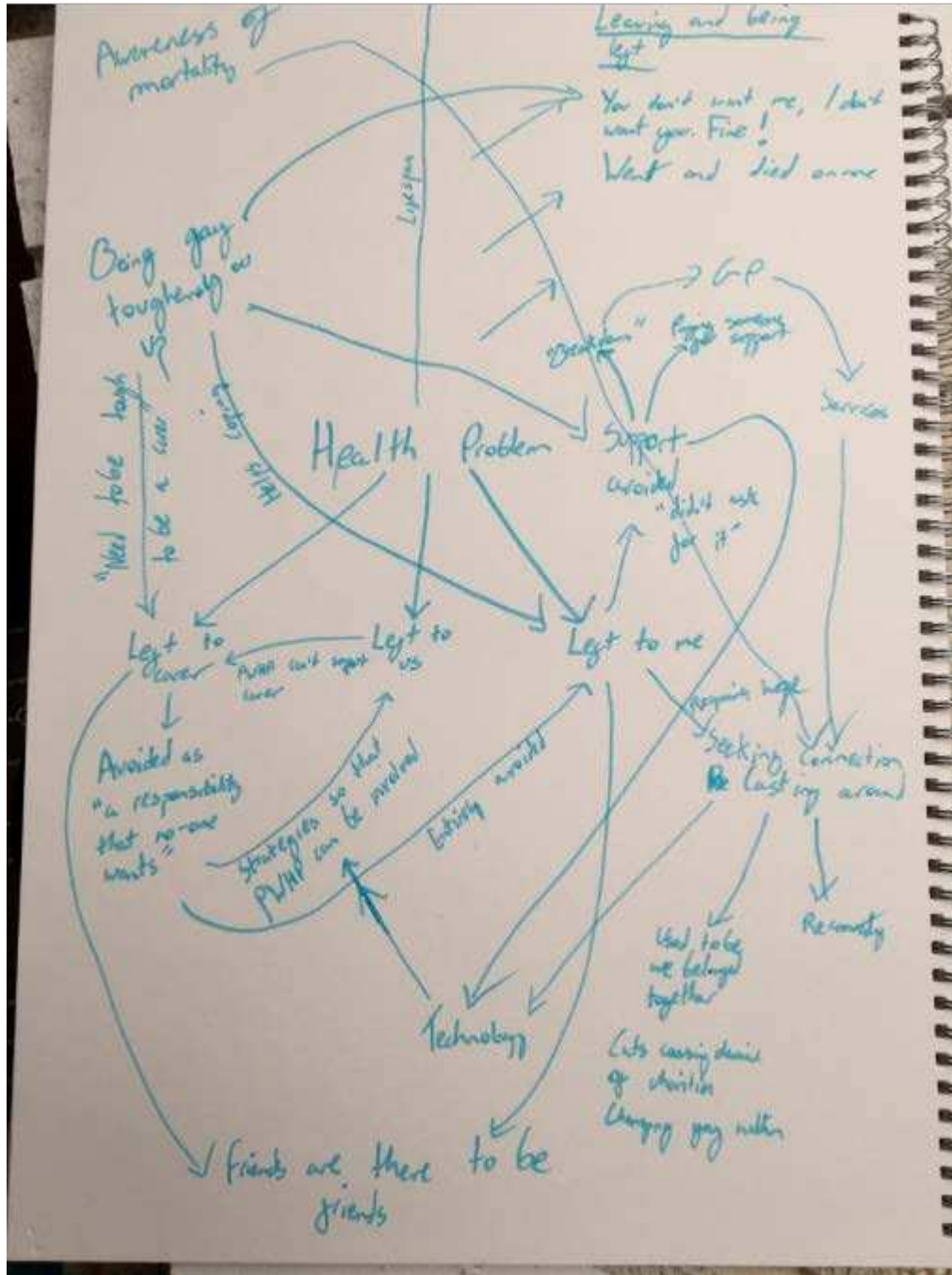
Research Diary Entry from 5th February:

I’ve been working on it throughout today. It’s much more satisfying than and it feels like I’m drawing out something more useful. Feels a bit like therapy, there’s lots of trusting in the process and going somewhere without knowing what the final destination is. I feel quite excited and alive to what I’m doing.



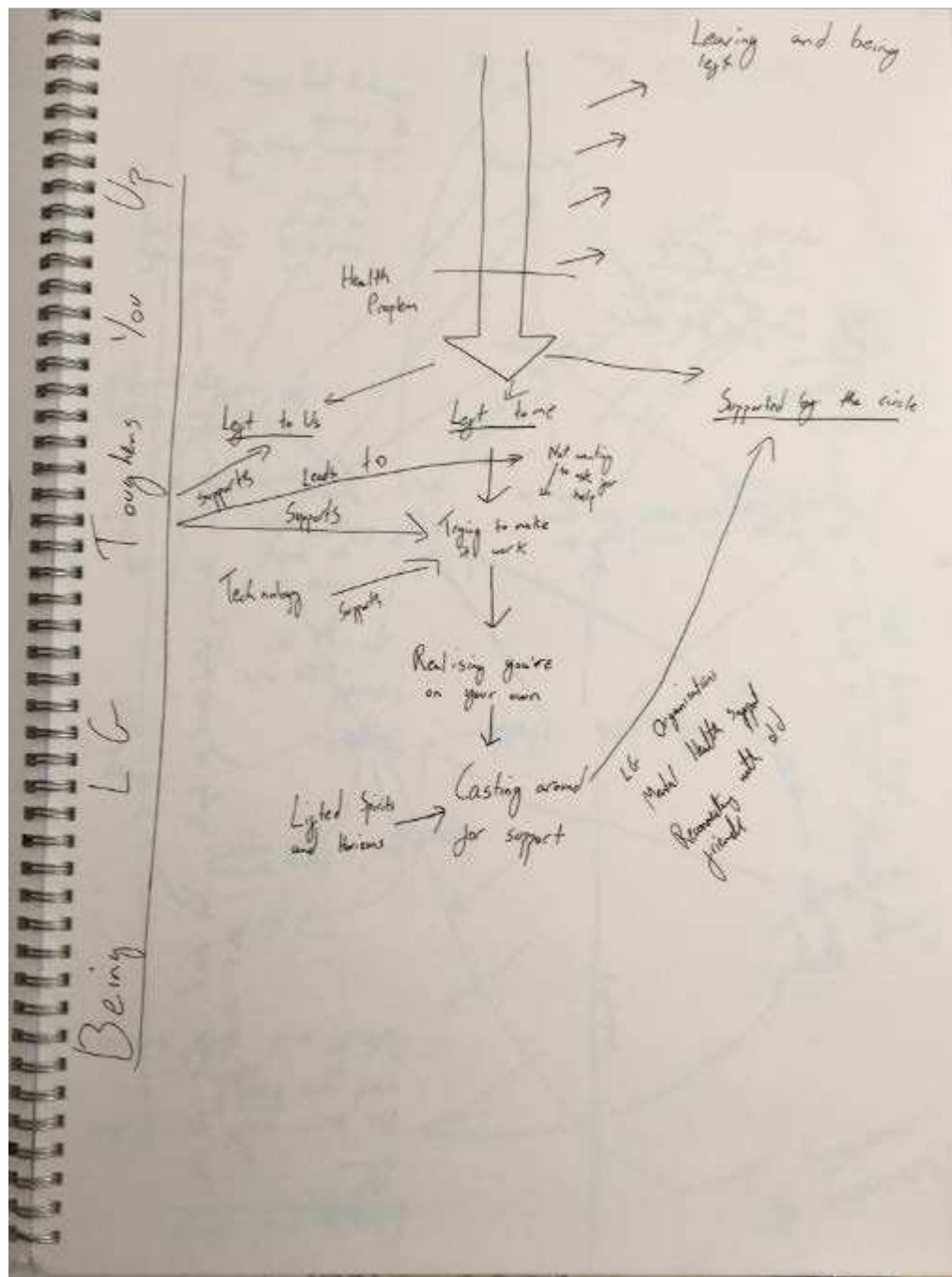
First

diagram after doing a closer coding. The basic structure of this model is quite similar to my final model (“doing it together” was an earlier name for “support from within the circle”). Initially separated out “left to carer” from “left to us” as I felt that the difference between the relationships where mutual support was present was significant enough that it warranted an entire separate category. However, I later realised that this was more of a sliding scale as to how much mutual support was present rather than a binary category.



More fleshed out version of the model. This is now essentially my final version of the theory, for the most part differences between this model and my final version exist only in terms of their names.





From here the actual model does not change, I'm just trying to find a suitable way of displaying it visually.



**Appendix L - Extracts from research diary, emails and timeline of project.**

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**Appendix M – Coded Transcript**

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**Appendix N: Table of Codes**

Category	Sub-category 1	Sub-Category 2	Selective Codes	Quotes
Managing an Outsider Identity				<p>Diane: I think when you make that decision when you're quite young, when you realise that you're different from everybody around you and you want to do something which people really frown on and and think is awful or disgusting and you feel in your heart that there is nothing wrong with it and you therefore decide to take your life in a different direction from what a lot of people are saying. I think it just makes you aware of what. I think it makes you a stronger person being able to go, I want to follow this lifestyle.</p>
	Gay and Lesbian Humour			<p>Stephen: I mean the way that I dealt with it as a teenager, dealt with my sexuality as a teenager which I really didn't understand or would have accepted but humour was really important, to me this was the way that you got people on side, by making them laugh. And if you make someone laugh that's so psychologically valuable</p> <p>Sandra: More as a joke now, it used to get to me originally, but we just joke about it now.</p> <p>Lucy: She had a horse riding accident which had caused brain damage and she was off long-term sick at the time as well. So we were basically a couple of crocs holding each other up &lt;LAUGHS&gt;</p> <p>Paul: Gay as such didn't come into their conversation. How can I put it, you just don't talk about it, or you just make a joke about it when the subject arises.</p> <p>Richard: At least it was till death do us part &lt;LAUGHS&gt;</p>
	Experiences of successfully navigating challenges related to being lesbian/gay			<p>Richard: If there had been any problem I would have dealt with it in my way whereby I would have pointed out that it's against the rules and that nowadays and you know would have insisted on an apology as well</p> <p>Lucy: The experience of having to fight battles. But also the experience that ones confidence not depending on being part of the mainstream and being comfortable with an outsider identity. Because you're going to be an</p>

outsider whether you are an LGBT when I was younger and in terms of being a disabled person now.

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Being guarded

Victor: Second is still problem, particularly with older gay men, because they still live with what they learnt fifty years ago. So they are not outgoing so much as young people now days. So they are holding back, in most cases, in most cases they are conservative, worried about their image, you still hear between older gay men that younger boyfriends or toyboys are regarded as their "nephews". That really still exists and the result of course is mentally in a way they lock themselves up.

---

Leaving and being left    You don't want me, I don't want you. Fine!

Richard: I mean going right back to 2001 thereabouts, 2002, the previous church was a ... church that opened there for forty plus years. I'd introduced Dave to members of the congregation and next thing was we were called into the vestry and told that we couldn't have communion

Interviewer: Gosh

Richard Yeah I know. As it was it wasn't an issue for Dave with him being a lapsed Catholic but at the same time I found it very much judgemental, to put it mildly. So we argued with them for a while and they wouldn't accept our point of view so we just left the church there.

Adam: But a little example is as a student nurse, four of us decided to come up to Scotland. And we had a tent and I would sleep in the tent and the other three would sleep in the car. And I couldn't work this out initially. That's how stupid I was. It was only after I got back from the trip it dawned on me that they were scared to sleep in the tent with me. Which I approached them about and we had a bit of a set-to. And they said "well if you were us would you sleep in a tent with you?" So that sort of finished me all together about mixing with straight people at that time

---

Not having children

Nick: I think one thing that we know that we don't have kids to look after ourselves

	Ageing Networks	Went and died on me	Diane: Well unfortunately in the last few years three members of my family died, which has just been, for me for the the last three years have been very hard
		Caring for family	Adam: We moved her up here because she was all alone, she never saw anybody. I have three neices that were living there but they never went near her. They always had some excuse, so we moved them up, it's only ten minutes by my mobility scooter from here. And she's had quite a lot of problems and recently we discovered she had a stroke
	Everyday experiences	Relationships changing	Laura: I got to know someone in the social network a bit better for a while, probably a couple of people for a couple of years, but lost out on them when they got involved with people and they did that kind of falling in love bit where you end up not seeing them
		Physical distance	Adam: Yeah, I lost touch because one I moved away from Edinburgh and then the other I moved out to the country, so it was you know, it was quite difficult to keep in touch with everybody.
Care within a household	Becoming a carer		Sandra: Well I've more had to become a sort of carer.
Care was left to us		No-one else could	Paul: Because he didn't want anyone else to. He just didn't like the nurses to do anything. I do understand if you are ill you are not thinking straight. You just want someone that you know to help.
		Unprincipled to make an issue of it	Richard: The bottom line is that it was easier that even though it was extra work that I wouldn't have begrudged, and never would to this day, it was a case of left to me really.
Commitment to relationship as a reason for providing care		Wanting to do your best for someone	Stephen: I loved him... I always felt protective towards him
		Ex-partner is family	Diane: I think so. Because we've lived in the household now for ten years, so it's like we've got, and we both say this to each other, it's like we've got a relationship

		but we're not having a relationship. We're very very close, we spend a lot of time together, we work together, we live together, we socialise together but we're not going out with each other but we're kind of sort of going out with each other but not going out with each other.
	Invested in making it work	Stephen: But I did it because we had been together for twenty years at that point... And I felt, I always felt protective towards him and there was, you know, we owned things together and we had joint bank accounts and all this
Support for carers	Making sacrifices	Matthew: <partner> with his problems meant that as soon as he laid down at nighttime meant that his kidneys seemed to start to work and he needed to get up to pass urine. And we'd be up, if I was lucky 4 times a night, and if I was unlucky 7 or 8. The problem was that he could get back into bed and go to sleep, I eventually couldn't and I was getting up early to go and do a job and then come back.
	Holding each other up	Ollie: Are there any ways that Tony supported you during that time.  Richard: Well, good question that. I suppose, emotionally, I suppose again on the emotional side, the fact that we were still together, I think that was really the thing.
	Challenges of absence of mutual support	Stephen: No I think that the problem about dementia is that it's a human thing that effectively caring works when it is a partnership in terms of the giver and reciever where you are able to say thank you, where you respond in ways that the giver feels good about having given. And you don't always get that from someone with dementia, because they've lost all of those skills
	Support from friends	Stephen: My gay friends were hugely helpful in all sorts of ways
Left to me		Simon: I was all by myself you know.

Not asking for assistance	Reasons for	Not wanting to burden one friend	Lucy: I was suddenly down effectively to just one person and that's a responsibility nobody wants, to be somebody else's only friend.	
		Keeping relationships equal	Matthew: I can't just take, I'm not a taker, I like to think of it as more symbiotic, both of us are benefiting. I mean if I'm with somebody, the more I feel them enjoying things with me, the more I'm able to enjoy myself. I get more back with interest, when I give something then they respond in the same way.	
	Alternative strategy	Paying for assistance	Adam: It just makes me feel better, that he can't say to everybody and anybody. You know...(Interviewer: That he's...) He's a bit of a yap. He would do that. Now he doesn't say anything because I would just say "well you get paid for it!"	
		Using Technology	Adam: Yeah, the toilet seat, he's had installed one that basically washes you, you don't have to use toilet paper. And I find that a great struggle actually, because I've got short arms	
Seeking connections	Barriers	Cutbacks cause the demise of charities	Hannah: Yes it has. Unfortunately the day centre, or what we call the service hub, that we go to, no longer. It is still there but the way they run it now is totally different. And therefore we don't have that access and so we don't get out as much as we did.	
	I felt that we belonged together	Perception that LGBT groups are the only place which can be accessed	Paul: Because what I'm saying is without <older LGBT charity> it's a great help to me, I don't know about others but I'm only speaking from my point of view. If we didn't have this sort of organisation when hospital treatment finished, where can I go?	
		Reasons	Campaigning together	Lucy: So from the Thatcher era we'd be on the LGBT marches, anti-racism marches, feminism marches, the whole gamut really



	<p>Heterosexuals are not my people</p>	<p>Ollie: I suppose I'm wondering, I've got it in my mind and it might be completely off the mark, but whether there's something about threat. Because we were speaking earlier about how those men on &lt;gay cruising location&gt; had it in for gay people and I'm wondering if there's something about                  Matthew: Yes, there could be, there could be. I wouldn't deny that at all, I hadn't thought about it at all, but now that you mention it there could be one of the things that make me feel a little bit anti towards them.</p>
	<p>We feel safer together</p>	<p>Stephen: When we formed the LGBT carers group, immediately straight people came in and told us that we couldn't do that, you know "why do you need to, we're all together in this" and you know, ask questions about us, find out what makes us tick because we like to be with each other, we're not saying we don't want to be with you, we're just saying we're more comfortable and we feel safer because of our background.</p>
<p>Barriers</p>	<p>Support offered to gay people all seems to be in the 15-44 age group</p>	<p>Ollie: Okay, so it sounds like there is something about the way that the gay community spaces, is it that they're skewed for younger people so as you get older it gets less easy to make gay new friends                  Stephen: Well absolutely, that's absolutely true</p>
	<p>I haven't been in a gay pub in years</p>	<p>Paul: Therefore I think, lots of other older gay people they are still unable to socialise because they don't want to go into pubs to meet people. Gay pubs and that sort of stuff do they?</p>
	<p>There is no socialisation everything is through computers</p>	<p>Simon: Everyone is all introverted by themselves and going to picking up on the tube                  Ollie: the tube?                  Simon: Not the tube that was before &lt;Laughs&gt; on the</p>

computer. We used to pick up everywhere, on the street corner, but its stopped now.

Methods	Going to a festival	Lucy: Yes, and I think part of that as well was because I got the chair I took myself off to a festival
	Internet dating leading to supportive relationship	Matthew: Anyway one of the people I met was a chap named X... Anyway that was about 8/9 years ago and he's still here.
	Joining LGBT organisations	<p>Ollie: So your network looked a bit different before your disability.</p> <p>Lucy: Yeah, and part of that process was then casting around seeing what groups were there. I setup a group with a friend that went very well for about two or three years and then I became a member of the other big one in &lt;CITY&gt;, called &lt;Group&gt; and I host about three of their activities.</p>
	Joining mental health day centre	Hannah: Obviously I used to go to a mental health centre, a day centre, you know which I was getting some support from. I met some new people there and we found that there would be two or three of us that might, kind of bonded a bit, and we gave each other a bit of support.
	Meeting at a gathering	<p>Adam: Who else have I met that I've been happy to meet? We have a friend in &lt;foreign city&gt; called Y, we call him the madam.</p> <p>Ollie: &lt;LAUGHS&gt; Is that a nickname he chooses or Adam No it's a nickname given to him by X the guy that lives in &lt;CITY&gt;. And we met him at X sixtieth birthday</p>
	Resuming contact with old friends	Richard: A few months after X death I rung Y and ever since then we have regular phone calls once or twice a week.

	Using Social Media	Adam: If like me, although a lot of my friends are spread out, they're there and I can get them spread out. I mean Fred my very first partner ever, we're still together as friends after forty something years. And I speak to him on Skype because he lives in <FOREIGN CITY> now.
Triggers	Finding you can't cope on your own	Paul: Yes, it was really difficult, but I tried to carry on, to make it work. But it's one of those things, you just couldn't go through.
	Lifted spirits and horizons	Lucy: And that meant, it kind of lifted my spirits as well as my horizons as well... And so that made me think about getting further afield rather than just within two blocks of my house which is what my life had been reduced to before.
Support from Within the Circle	They were there to simply be friends	Stephen: And so they were, they were there simply I expect to just be friends and you know, not to run in the opposite direction like his family had.
	Holding each other up	Lucy: Because she was around during the day, she needed support to go to the shops, I needed support to go to the shops and I guess it is in my nature that I respond a lot more quickly to someone needing my support than I do to requesting it.
	Support is distributed	Stephen: I think that the support mechanisms are still there and they are still working and they may be very multifarious but they tend to lack, they tend to lack depth

## **Appendix O: Summary of Study Sent to Participants and Ethics Panel**

Dear <Participant Name>

First of all, I wanted to thank you for the thoughtful way in which you shared your experiences with me. Below is a summary of what I was exploring, what I did, what I found and what I think this means for services.

### **Introduction**

The current UK government's approach to support means that many services are now partially moving away from directly providing support to helping informal carers (i.e. friends, families and local communities) provide support. This may be problematic for lesbian and gay people as we are both at greater risk of many health problems and less likely to have the types of relationship that often provide this support (i.e. partners and children).

We currently do not know who supports mid-later life lesbian and gay people in the UK, or how these support-networks are organised when health problems develop. I wanted to explore these questions to help services better work with the networks around this population.

### **Method**

I interviewed fourteen people; including lesbian and gay people over the age of 50 with long-term health problems, those providing support and those running groups for this population. I aimed to get a variety of perspectives on the topic and the range of issues encountered.

### **Results**

The results suggested that lesbian and gay people come into their mid-later life having developed strategies for dealing with the challenges of being lesbian/gay that create strengths and barriers when turned to the task of accessing social support. Some felt that being gay/lesbian prepared them with the resilience to cope with the sometimes "tough" task of caring and living with a health problem.

At the same time, lesbian and gay people may experience losses to their support-network related to: age, society's response to their sexuality, and experiences of a health problem (and society's response to this).

When health problems develop for those sharing a home with partners or ex-partners most informal care is provided within these relationships. One person noted that being gay meant that they had to do more caring by themselves as their partner was hesitant about inviting others into their lives.

For those living alone, people actively seek out connections or find alternative strategies to meeting their support needs. Many chose to seek support from organisations for gay or lesbian people. When people chose to seek support from predominantly heterosexual organisations this sometimes involved overcoming expectations of animosity or less support. Three participants identified organisations that had experienced cuts during the study.

The support people arrived at tended to be distributed across several people with no single person becoming a carer. Some were keen to keep "friends as friends" which sometimes limited what support they would ask for.

**What Does This Mean for Services?**

- It may be helpful if practitioners take a strength based approach, exploring how lesbian and gay people have overcome past challenges relating to discrimination and think about how these strategies may be turned to current challenges.
- Services need to be aware that some still feel unsafe in services viewed as “heterosexual”. Services should advertise their acceptance of lesbian/gay people and it may be helpful if LGBT staff members were open about their sexuality when working with this population. Arguments need to be made to funders of the need for services specifically for lesbian and gay people.
- Often services just work with a single “carer”. This may exclude the support-networks of many older lesbian/gay people. More research is needed into what kinds of support may be welcome and helpful to these networks.

**What Happens Now**

I will shortly be submitting the project to be marked. As mentioned we are also hoping to publish the research in a journal article. I would welcome any feedback, comments or questions about what I have found.

I would like to thank you again for taking part. Without this, the project would have been impossible and I am enormously grateful for the support you have given me.

Best Wishes

Ollie

Oliver Hawthorne

Trainee Clinical Psychologist

Supervised by:

Professor Paul Camic (Research Director at Salomon’s Centre for Applied Psychology)

Dr Katharine Rimes (Academic Director at the Doctorate of Clinical Psychology Programme, Institute of Psychiatry, Psychology and Neuroscience)

CC: Salomon’s Ethics Panel

## Appendix P: Journal Submission Guidelines

CAMBRIDGE | Instructions for Contributors

### Ageing & Society

#### Submission

Ageing and Society is an interdisciplinary and international journal devoted to the understanding of human ageing and the circumstances of older people in their social and cultural contexts. We invite original contributions that fall within this broad remit and which have empirical, theoretical, methodological or policy relevance. All submissions, regardless of category, are subject to blind peer-review. Authors are reminded of the requirement to avoid ageist and other inappropriate language and to avoid the stereotypical representation of individuals or groups.

All papers must be submitted using Manuscript Central through the Journal's website at:  
<http://journals.cambridge.org/aso>.

All books for review should be sent to: Caroline Norrie and Kritika Samsi, Social Care Workforce Research Unit, King's College London, Strand, London, WC2R 2LS

All submissions must conform to the submission guidelines outlined below. Failure to do so may result in the submission being rejected.

#### Article categories

##### Research articles

Research articles must contain between 3,000 and 9,000 words, excluding the abstract and references. Most papers usually have the following sections in sequence: Title page, Abstract (200-300 words), Keywords (three to eight), Main text, Statement of ethical approval as appropriate, Statement of funding, Declaration of contribution of authors, Statement of conflict of interest, Acknowledgements, Notes, References, Correspondence address for corresponding author. However authors have the flexibility to organise the main text of article into the format that best suits the topic under consideration.

##### Forum articles

In addition to research papers, the Journal welcomes critical/reflective commentaries on contemporary research, policy, theory or methods relevant to the Journal's readers. These articles reflect a viewpoint of the author and they may form part of an ongoing debate. These articles should contain 2,000-5,000 words. There is no preset organisational structure.

##### Special issues

Proposals are invited for special issues that fall within the remit of the journal. Ageing & Society especially looks for proposals that show originality and which address topical themes. Proposals which involve authors from a range of disciplines and/or countries are particularly encouraged and the special issue must demonstrate clear added value in advancing an understanding of ageing and later life that is more than the sum of the individual papers.

Proposals should be submitted by the co-ordinating Guest Editors by email to the Editor, Christina Victor: christina.victor@brunel.ac.uk

Proposals should be submitted by 28 February each year. For further information see the guidelines for special issue proposals available at:  
[http://journals.cambridge.org/images/fileUpload/images/A&S\\_Special\\_Issue\\_Proposals.pdf](http://journals.cambridge.org/images/fileUpload/images/A&S_Special_Issue_Proposals.pdf)

It is Ageing & Society practice that all papers in special issues are subject to blind peer review, undergoing the same refereeing process as all other submissions, led by the Ageing & Society Editor and co-ordinated by the journal's Editorial Assistant. The final decision whether to publish individual papers submitted as part of a special issues remains with the Editor.

## Submission requirements

### Exclusive submission to Ageing & Society

- Submission of the article to Ageing & Society is taken to imply that it has not been published elsewhere nor is it being considered for publication elsewhere. Authors will be required to confirm on submission of their article that the manuscript has been submitted solely to this journal and is not published, in press, or submitted elsewhere. Where the submitted manuscript is based on a working paper (or similar draft document published online), the working paper should be acknowledged and the author should include a statement with the submitted manuscript explaining how it differs from the working paper. Articles which are identical to a working paper or similar draft document published online will not be accepted for publication in Ageing & Society.

### Appropriateness for Ageing Society

- All submissions must fall within the remit of the journal, as described at the beginning of this document.
- All manuscripts must meet the submission requirements set out in this document, closely following the instructions in the 'Preparation of manuscripts', 'Citation of references' and 'Table and Figures' sections below.
- Authors are requested to bear in mind the multi-disciplinary and international nature of the readership when writing their contribution. Care must be taken to draw out the implications of the analysis for readers in other fields, other countries, and other disciplines. Papers that report empirical findings must detail the research methodology.
- The stereotypical presentation of individuals or social groupings, including the use of ageist language, must be avoided.

### Submission documents

All submissions should include:

- A copy of the complete text of the manuscript, with a title page including the title of the article and the author(s)' names, affiliations and postal and email addresses.
- A copy of the complete text minus the title page, acknowledgements, and any running headers of author names, to allow blinded review.

### Named authors

- Papers with more than one author must designate a corresponding author. The corresponding author should be the person with full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish. The corresponding author must confirm that co-authors have read the paper and are aware of its submission. Full contact details for all co-authors should be submitted via Manuscript Central.
- All named authors for an article must have made a substantial contribution to: (a) the conception and design, or analysis and interpretation of data; (b) the drafting of the article or revising it

critically for important intellectual content and (c) approval of the version to be published. All these conditions must all be met. Participation solely in the acquisition of funding or the collection of data does not, of itself, justify authorship.

#### **Peer-review process**

- The corresponding author should prepare (a) a complete text and (b) complete text minus the title page, acknowledgements, and any running headers of author names, to allow blinded review. References to previous papers of the authors must not be blinded, neither in the text nor in the list of references.
- Papers are peer-reviewed. Authors may be asked to submit a revised version of the original paper. In any revised submission, we prefer you to indicate these revisions using track changes where appropriate. An accompanying letter from the corresponding author should outline your changes, and comments on advice that you have chosen not to accept. The corresponding author should confirm that co-authors have agreed to any changes made.

#### **Ethical considerations**

- Where the paper reports original research, confirmation must be given that ethical guidelines have been met, including adherence to the legal requirements of the study country. For empirical work conducted with human subjects authors must provide evidence that the study was subject to the appropriate level of ethical review (e.g. university, hospital etc.) or provide a statement indicating that it was not required. Authors must state the full name of the body providing the favourable ethical review and reference number as appropriate.

#### **Declaration of funding**

- A declaration of sources of funding must be provided if appropriate. Authors must state the full official name of the funding body and grant numbers specified. Authors must specify what role, if any, their financial sponsors played in the design, execution, analysis and interpretation of data, or writing of the study. If they played no role this should be stated.

#### **Copyright**

- Contributors of articles or reviews accepted for publication will be asked to assign copyright, on certain conditions, to Cambridge University Press.

#### **Open Access**

- Please visit <http://journals.cambridge.org/openaccess> for information on our open access policies, compliance with major funding bodies, and guidelines on depositing your manuscript in an institutional repository.

### **Preparation of manuscripts**

All contributions (articles, reviews and all types of review articles) should be typed double-spaced with at least one-inch or two-centimetre margins throughout (including notes and the list of references).

Most research articles usually have the following sections in sequence: Title page, Abstract (200-300 words), Keywords (three to eight), Main text, Statement of ethical approval as appropriate, Statement of funding, Declaration of contribution of authors, Statement of conflict of interest, Acknowledgements, Notes, References, Correspondence address for corresponding author.

The title page should give the title of the article and the author(s)' names, affiliations and postal and email addresses. When composing the title of your article, please give consideration to how the title would be shortened to appear as a running head in final version of the Journal.



The tables and figures should be presented one to a page in sequence at the end of the paper. Black and white photographs may be submitted where they are integral to the content of the paper. Charges apply for all colour figures that appear in the print version of the Journal (see below for further details).

Authors are asked to follow the current style conventions as closely as possible. Please consult a very recent issue of the journal. In particular, please note the following:

- Use the British variants of English-language spelling, so 'ageing', not 'aging'.
- **First level headers are in bold, sentence case and left justified**
- *Second level headers are in italic (not bold), sentence case and left justified*
- Do not number paragraphs or sections. Avoid very short (particularly one sentence) paragraphs.
- Do not use **bold text** in the text at all. For emphasis, use italic.
- In the main text, the numbers one to ten should be written as words, but for higher numbers the numerals (e.g. 11, 23, 364) should be used.
- All acronyms must be expanded on first use, even EU, USA, UK or UN, for those which are commonplace in one country are not in others.
- Do not use footnotes. Endnotes are permitted for technical and information details (including arrays of test statistics) that distract from the main argument. Endnote superscripts should be placed outside, not inside a punctuation mark (so, not<sup>4</sup>).
- Write per cent (not %) except in illustrative brackets.

Authors, particularly those whose first language is not English, may wish to have their English-language manuscripts checked by a native speaker before submission. This is optional, but may help to ensure that the academic content of the paper is fully understood by the editor and any reviewers. We list a number of third-party services specialising in language editing and/or translation, and suggest that authors contact as appropriate:

<http://journals.cambridge.org/action/stream?pageId=8728&level=2&menu=Authors&pageId=3608>

Please note that the use of any of these services is voluntary, and at the author's own expense. Use of these services does not guarantee that the manuscript will be accepted for publication, nor does it restrict the author to submitting to a Cambridge published journal.

## Citation of references

Contributors may follow either the standard conventions: (a) in-text citation of sources (author/date system); or (b) citations in notes.

(a) *In-text citation.* Give author's surname, date of publication and page references (if any) in parentheses in the body of the text, e.g. (Cole 1992: 251). For references with one to three authors, all authors should be named (Black, Green and Brown 2003). For references with four or more authors, the following form is required: (Brown *et al.* 2003). Note that all authors must be named in the list of references, and *et al.* is not permitted in the list. A complete list of references cited, arranged alphabetically by authors' surname, should be typed double-spaced at the end of the article in the form:

Cole, T. 1992. *The Journey of Life: A Cultural History of Aging in America*. Cambridge University Press, Cambridge.

Elder, G.H. and Clipp, E.C. 1988. Wartime losses and social bonding: influences across 40 years in men's lives. *Psychiatry*, **51**, 1, 177-98.

Ruth, J.-E. and Oberg, P. 1996. Ways of life: old age in life history perspective. In Birren, J.E., Kenyon, G., Ruth, J.-E., Schroots, J.F.F. and Svensson, T.(eds), *Aging and Biography: Explorations in Adult Development*. Springer, New York, 167-86.

(b) *Citation in notes.* References should be given in notes, numbered consecutively through the typescript with raised numbers, and typed double-spaced at the end of the article. Full publication details in the same

format as (a) should be given in the notes when a work is first cited; for second and subsequent citations a short form may be used.

For both styles of reference lists, please particularly note the following:

- Authors are requested to minimise the citation of unpublished working and conference papers (because they are difficult for readers to acquire). Where they are cited, complete details of the title of the conference, the convening organisation, the location and the date of the presentation must be given. Papers that have been submitted to journals but on which no decision has been heard must not be cited.
- *Titles of Books and Journals are in Title Case and Italic.*
- Titles of papers, articles and book chapters are in sentence case and not italicised.
- Please note carefully that part or issue numbers should be given for journal paper citations, that page ranges for book chapters should always be given and should be condensed, so 335-64 not 335-364, and S221-9 not S221-229.
- Please use (eds) and (ed.) where required (no capitals, full stop after truncated ed. but not compressed eds).

#### **Citation of Internet pages or publications that are available online**

Give authors, date, title, publisher (or name of host website) as for a printed publication. Then follow with ... Available online at ... full Internet address [Accessed date].

#### **Tables and figures**

There should never be more than ten tables and figures in aggregate, and only in exceptional circumstances more than eight. Please do not use Boxes or Appendices. Present all illustrative material as tables or figures. Please indicate in the text where approximately the Table and Figures should appear using the device < Insert Table 1 about here > on its own line. For figures generated by Excel, please send the original file (rather than a 'picture' version) so that the figures can be copy-edited.

Tables and figures should be clearly laid out on separate pages, numbered consecutively, and designed to fit a printed page of 228 x 152 mm (actual text area 184 x 114 mm). Titles should be typed above the body of the table, with an initial capital only for the first word and proper names and italicised or underlined (for italics). Vertical lines should not be used and horizontal lines should be used only at the top and bottom of the table and below column headings. Authors are asked to give particular attention to the title and to column and row labels (they are often poorly selected, incomprehensible or inadequate). All multiple word labels should be in sentence case. Short titles that concentrate on the subject of the table are recommended. Technical or methodological details (such as sample size or type of statistic) should be described in the labels or in table notes. Spurious accuracy should be avoided: most statistics justify or require only one decimal place.

Figures should also be provided on separate pages and numbered consecutively. For each figure, the caption should be below and in sentence case. Separate lists of captions are not required.

Colour figures can be submitted to Ageing & Society, but charges apply for all colour figures that appear in the print version of the journal. At the time of submission, contributors should clearly state whether their figures should appear in colour in the online version only, or whether they should appear in colour online *and* in the print version. There is no charge for including colour figures in the online version of the Journal but it must be clear that colour is needed to enhance the meaning of the figure, rather than simply being for aesthetic purposes. If you request colour figures in the printed version, you will be contacted by CCC-Rightslink who are acting on our behalf to collect Author Charges. Please follow their instructions in order to avoid any delay in the publication of your article.

Figures should be provided in the following formats:

- For colour halftones: Tiff or Jpeg format at 300 dpi (dots per inch) at their final printing size.
- For line work or line work/tone: EPS format with any halftone element at 300dpi final printing size.

### **Proofs and offprints**

Proofs will be sent to the corresponding author as a PDF via email for final proof reading. The proofs should be checked and any corrections returned within 2 days of receipt. The publisher reserves the right to charge authors for excessive correction of non-typographical errors.

Authors will receive a PDF of the published paper and a copy of the Journal, to go to the corresponding author. If offprints are required, these must be purchased at proof stage.

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