

Chapter 11

'I Didn't Come Out to Go Back in the Closet': Ageing and end of life care for older LGBT people

Kathryn Almack

"You matter because you are you, and you matter to the end of your life" Dame Cicely Saunders (1918 - 2005) (Saunders, 1976)

Introduction

This chapter addresses a particular gap in knowledge concerning the end of life care needs and experiences in the lives of older LGBT people. This adds to a more general body of research which has focused on ageing and the broader health and social care issues for older LGBT people (albeit this has primarily focused on gay men's and lesbian health and social care needs).

The chapter provides a brief overview of end of life care in England and Wales and then addresses issues relating to end of life care for older LGBT people and the gaps in our knowledge in this area. We then draw on findings from the first major UK study of end of life care needs and experiences in the lives of older LGBT people. Our main focus here is to highlight and discuss concerns identified relating to care at home and support from family and friends that respondents envisaged being able to call upon towards the end of life in the UK. Our findings suggest that diverse needs are not being met or not offering adequate provision for older LGBT people. However, we are also able to highlight positive examples to suggest ways forward to develop equitable service provision that addresses core principles of dignity and respect for all.

Introduction to end of life care in England and Wales

Rapid demographic changes (which include ageing populations and more people living with the effects of serious chronic illness towards the end of life) present a pressing public health challenge related to the care and quality of life of older people (Hall et al, 2011). There are 14.9 million people in the UK aged 60 and above (ONS, 2015); using a commonly cited estimate that about 5 – 7% of the population identify as LGBT, that suggests an estimated population of between 745,000 and 1,043,000 LGBT people aged 60 and over in the UKⁱ.

In the UK, there is general agreement that the definition of 'end of life care' means 'the last year of life'; although it is acknowledged that the period in which such care is needed ranges from a few years to a matter of months, weeks or days, and into bereavement (NHS England, 2014). The UK is an acknowledged leader in palliative and end of life careⁱⁱ. In 2008, the first ever English End of Life Care Strategy was launched (DoH, 2008a). This sought to promote high quality care for all adults at the end of life in England by providing people with more choice about where they would like to live and die. Similar strategies for the end of life have also been developed in Wales, Scotland and Northern Ireland. Consultation for the English End of Life Care Strategy Equality Impact Assessment (DoH, 2008b) noted that in terms of quality of end of life care, LGBT people were most at risk of discrimination. The Strategy and the National End of Life Care Programme (2008 –13, charged with the implementation of the Strategy) generated significant momentum and improvements in end of life care (Kennedy et al., 2009, NHS England, 2014). Actions for End of Life Care: 2014-16, (NHS England, 2014) reviews these achievements and set out NHS England's commitments to 'align it with current needs of the population and the changing health and social care landscape' (p5). This document identifies that inequalities in end of life care for certain groups of people remain; however LGBT people are conspicuous in their absence in this document – those named are homeless people; black and minority ethnic populations; people with learning disabilities and people with dementia. Most recently, the English Care Quality Commission (CQC, 2016) published a report highlighting continuing inequalities in end of life care for people from certain groups including LGBT people. The report suggests that LGBT people may sometimes experience poorer quality care at the end of their lives because providers do not always understand or fully consider their needs.

Background to LGBT palliative and end of life care research

Both evidence of and identifying ways to address inequalities facing LGBT people has been hampered by the dearth of research with a specific focus on older LGBT people's end of life care needs and experiences; both as people coming towards the end of life and as carers of partners or friends coming to the end of life.

Harding et al's (2012) systematic review of peer-reviewed research (published between 1990 and 2010) into palliative and end of life care in LGBT populations identified only 12 relevant papers (the criteria excluded papers not published in English). The majority of papers resulted from studies in the US, and the primary focus of the research was found to be end of life care relating to cancer in populations of lesbian women and gay men. Again, bisexual (and transgender) people's experiences were notable in their absence. However, this is now a burgeoning field of research. Since Harding et al's systematic review which included papers up to 2010, there have been a number of other papers published specifically addressing LGBT experiences and concerns relating to dying, death and bereavement. The bulk of the research comes from Australia, Canada, the US and UK. Examples include: (Almack et al., 2010; Cartwright et al., 2012; Rawlings, 2012, Lawton et al., 2013)

Older people are now the largest group requiring end of life care; the majority of deaths in the UK are people over the age of 65 (Ruth and Verne, 2010). While some of the end of life care issues facing LGBT older adults are similar to all older people, research is now identifying separate issues that need to be addressed for older LGBT people entering their later and last years of life. Overall there is a lack of understanding of the heterogeneous needs of 'older people', particularly those living in non-traditional family forms. Research in the areas of palliative and end of life care have traditionally had a primary focus on family relationships biased towards families (Manthorpe, 2003). An additional consideration for LGBT people is that as LGBT people grow older, there is evidence that they are more at risk of life-threatening conditions where incidence increases with age. These factors can be related to risk behaviours such as smoking or alcohol abuse, which in turn can be attributed to minority

stress. Minority stress is a term used to define chronically high levels of stress faced by members of stigmatized minority groups. This may include experiences of stigma, marginalization or discrimination, now acknowledged as social determinants of health, which may have a significant impact on the health and well-being of LGBT people (Wilkinson and Marmot, 2003). Minority stress may also contribute to reduced social participation and engagement within society, and delaying or not seeking care because of past experiences of or anticipation of facing discrimination. Over their lifetime, LGBT people might avoid preventive health care because of concerns related to both discrimination and insensitivity by health care providers (Almack, 2016).

The Study

The data presented in this chapter are drawn from a UK-wide study The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people (2012-15), funded by Marie Curie Research Programme under a call for proposals addressing the research theme 'variation in care at end of life'. It was a mixed methods study, incorporating a survey (n = 237) and in-depth interviews with a sub-sample of the survey participants (n = 60). The survey was open to people living in the UK aged 60 or over and who self-identified under the umbrella labels of L,G,B and/or T. We also included LGBT people aged under 60 but in a relationship with an L,G,B and/or T person aged 60 or older. To capture the extent and level of engagement with the topic area of end of life care, we asked that participants had some experience of thinking/talking/planning for or receiving end of life care, or caring for a same sex partner or LGBT friend at end of life. We made the survey available online or as a hard copy that we posted out to people with an SAE for return. We recruited participants across the whole of the UK via the research team's extensive LGBT networks; publicity in social and printed media, advertising via generic organisations for older people (retirement organisations, union retirement networks, walking clubs and so on).

The survey had 81 questions (mostly closed questions and scaling of opinions but with some options for further information and some 'open' questions). In addition to demographic and

self-identification data, topics covered included the extent to which individuals were open about their sexual orientation and/or gender identity in different settings; questions about health and wellbeing; about experiences of receiving health and social care oneself or in current or previous caring situations/relationships; ageing; plans and preferences for future care and designating next of kin; on finances and resources. We draw in part of these data in this chapter to provide a descriptive context of the range of circumstances and experiences of participants. The interview data were analysed via thematic readings; as a research team we identified 8 key themesⁱⁱⁱ and a coding framework (74 items) was then developed, tested and then applied to all 60 interviews. In this chapter we draw upon three key themes: accessibility to help and support at current age; experiences within health and social care settings (for oneself or as a carer); preferences for how services should be organised. In returning to these themes, we have examined the data for storied accounts (Plummer, 2007), which sensitises us to the contexts within which stories may emerge as well as the societal context (across a life-course) that enables some stories to be told and widely heard while others are 'weaker' in this sense of being less widely told and heard.

'Old' LGBT age and end of life care

The last major academic study relating to LGBT ageing in the UK was undertaken 2001-2003 (Heaphy, 2003). This study found that meanings attached to ageing and 'old age' by lesbians, gay men and bisexuals was as varied and context-dependent as you might expect to find in the wider culture. Nevertheless, the authors suggested that sexual orientation was relevant in shaping how one sees oneself, and is seen by others. LGBT people aged 50 and over were reported to describe themselves as 'older' when referring to their sexual identities and lifestyles. A decade or so later, our pilot work suggested that 50 seemed too 'young' to be included in our study. Stonewall undertook a survey of later life experiences of LGB people in 2011, including those aged 55 and over. Defining later life or old age is problematic and across the developed world, a range of chronological ages from 50 to 70 are used to determine 'old age' (Victor, 2010).

Our study had a greater emphasis on end of life care than Heaphy et al., (2003) or Stonewall (2011) and it is acknowledged that end of life care needs are most common among older age groups (whether as patients or carers) (Ruth and Verne, 2010) and that older age groups were perhaps more likely to have had cause (for example through ill health or through the experience of deaths of people close to them) to reflect more on their own mortality. For the purposes of our study we thus proposed to include people aged 60 or over (but also those under 60 if in a partnership with someone aged 60 or over). Reaching an age where participants or their partners required assistance towards the end of life, or where they had thoughts about an anticipated loss of independence, brought issues about care preferences in later life and towards the end of life into sharp focus.

Home

In relation to end of life care, the most commonly expressed option found in surveys conducted about preferences for place of care towards the end of life, is to be cared for at home (Gomes and Higginson, 2008, Leadbeater and Garber, 2010). As Pollock discusses, such survey findings are problematic for a number of reasons – the context and framing of questions can influence responses; often people do not specify a preference and/or there is rarely an option for 'it depends' or 'does not matter' (Pollock, 2015).

However, given that 'home' is nevertheless a commonly expressed anticipated place of care and was a preference noted by many of our interview participants (regardless of how achievable this might be), this presented particular anxieties for our participants in a number of ways; not least that home may represent a private, most often 'safe' space to totally be oneself. Opening up previously private domestic settings to wider scrutiny can be daunting, yet more often than not, the preference to die at home can necessitate the need to have range of health and social care professionals coming into one's home and 'coming out to care' (Brotman et al., 2007, Price, 2010):

“If people, carers, are coming into your home, just an acknowledgement about your sexuality and your relationships in the past and things like that and like if you've got a

photo of you and your partner out, you don't need to be worried, do you know what I mean." (Trevor, gay man, 54, with older partner)

For many, whose life experiences have included hiding their same sex relationships, these represent considerations that impact on feeling safe in accessing home care services. It includes facing scenarios at times when they are likely to feel particularly vulnerable, such as being faced with decisions about hiding items associated with one's sexual orientation or gender identity; what or how much information to disclose or outing oneself to every visiting professional with associated further loss of privacy. There are also understandable fears about discriminatory attitudes, which individuals may feel too vulnerable or dependent on care services to be able to challenge (see Bristowe et al., 2018).

Trans people can face further dilemmas. Service providers often have even less knowledge about the issues relating to trans people than LGBT individuals and it is important to separate out sexual orientation from gender identity. Trans people can face particular challenges if they have to negotiate intimate care with care-workers who may not be aware of their particular needs:

"I've always been very private. As a male to female trans (person) I still having beard growth, this would be an area of care I'd need and want to continue if I am became incapacitated ... unable to shave and apply hair growth inhibitor myself. And other intimate care - dilation and routine douching to keep the vagina clear of possible infections. Hormone therapy is necessary until death and I'd want that to continue..." (survey response, anonymous).

It is important to be aware of the diversity among trans people; some will have spent most of their lives with a gender identity and body other than the one assigned at birth while for others this may be a relatively recent transition.

The above quote indicates someone who described themselves as 'private' - possibly guarded and reticent about being open about their particular care routines. Others might not have

undergone any form of gender reassignment surgery. This can lead to feeling apprehensive about revealing one's body to care workers:

"Every time I need bodily care I constantly have to explain my anatomical differences to new people. I'm really worried about going into a care home. My GP, meaning to be kind, said once you go into a care home you become genderless but that is not reassuring ..." (survey response, anonymous)

A trans person's medical records can be inconsistent – one trans woman facing a terminal diagnosis recalled how this was dealt with sensitively by staff:

"I was in hospital and somebody came along and drew the curtains and I thought oh shit what's going on. She was the ward secretary or something and she said 'I'm having problems matching up your file because you say you've had (name of condition) but we've got no record. The nearest we've got is a person of this name'. So I was able to say 'Yes, that used to be me'. So she said 'OK, that's fine I can combine them now'. And I thought that's really enlightened, she hadn't even used the name but treated me for who I am now. A little bit of thought works wonders." (Ivy, 67, trans lesbian)

This is indicative of what good practice looks like in end of life care; Ivy had more peace of mind once she knew that her records had been matched up and also felt reassured that this had been well handled by the staff member.

A further concern occurs for LGBT people who may live in households with more than one partner or have a number of people close to them that health and care professionals need to interact with. This was an issue that arose for a number of participants including a bisexual woman Sarah. Sarah lives with two partners. She lives with a trans woman (Iris) who was previously Sarah's husband before Iris transitioned and a cis-gendered^{iv} man, Damian. Sarah described a period of time recently when she was very poorly with cancer; she had surgery and when she came home she convalesced in a room set up especially for her. She went on to explain:

“It was difficult to explain to anybody coming in why this was a change. They would come in, they would see me in that single bed in that single room, and they would see Damian and Iris, and even if they accepted that we are three, they would see they had the main bedroom, and they wouldn’t realise or understand that actually normally I would have been in there too, and I would be missing it.”

Celia cared for her terminally ill ex-partner Samantha, along with Samantha's ex-husband, Patrick. Celia spoke about some of the health and social care professionals they encountered during this time, who made all kinds of assumptions about the relationships and/or were confused by who was who. At the same time however, Celia felt supported by her GP and by Patrick:

“My lovely GP signed me off with stress, so that I could care for her with Patrick. And every decision was our decision, it wasn't just Patrick who was obviously her next of kin, I was consulted too.”

Sarah and Celia's descriptions of networks of care are possibly, in a normative framework, quite complex to follow. Young et al., (1998) noted a neglect of the role of friendship and informal social networks and this is still a key area to address, where a range of important relationships in relation to end of life care. More recently, Westwood (2013) has questioned the extent to which contemporary law is adapting to take account of changing relationship forms, particularly with friendships becoming more significant in the lives of many, especially in later life and with reference to recognition of LGBT carers within key UK socio-legal policy discourses. The full strength and importance of relationships which may fall under the ‘umbrella’ term of friendships may not be recognized. We do not yet have the language to fully encompass 'short-hand' understandings of these relationships (Almack et al., 2010) in the way that we might have some shared understandings (notwithstanding assumptions) about 'labels' such as daughter-in-law; cousin; partner, spouse and so on. Those involved in non-traditional relationships may be excluded in a number of ways, for example, not being able to have an active role in the care of the dying or by not having their grief acknowledged (Walter, 1999). These are important considerations for the investigation of the

ways in which sexual orientation may impact on concerns and experiences of end of life care, and on bereavement within same-sex relationships.

It is interesting to note from the above quote that although Celia felt supported in her caring role and included in decision making, it was Patrick who was noted as 'obviously' Samantha's next of kin. In the UK, this is an ambiguous term with no legal definition in terms of information sharing and decision making with/for an ill person being cared for. In practice, friends can be nominated as next of kin but this may be questioned and/or overlooked by a default position which often reverts to relationships defined by blood or filial relationships or by marriage (although that can now of course incorporate civil partnerships and same sex marriages). A significant number of participants had anecdotes to tell about people they knew whose family of origin had taken over when the person was dying and/or died, leaving partners and friends without any say in decisions about their partner or friend's care or funeral.

Some respondents in relationships had specifically taken steps to ensure these kind of scenarios did not arise for them:

“we went to some considerable length and some considerable cost to ensure that we had a level of legal protection. I mean fortunately we never really had to test that but it was reassuring for us, you know, having heard horror stories about people’s partners being denied access to their bedside. So it’s a little bit of protection for each other really when having to deal with each other’s biological families who might potentially have a different opinion. Our civil partnership ... that kind of gives us a whole layer of protection over and above that anyway now.” (Lydia, lesbian, 46, lives with older partner)

At the time of our fieldwork, same sex marriage had not become legal across the UK, although civil partnerships were legal in all four countries^v. Civil partnerships were noted as an important means of 'protecting' a partner's rights to make decisions on behalf of a partner and/or to signal partners taking precedence over any members from families of origin.

A particular concern noted by 2 of the 5 trans interview participants were concerns that when they died, whether their family members would honour their wishes to bury them as a person of the gender they identify with. Shirley (70), who identifies as a trans woman observed:

“... that’s really, really important, because if ... if it’s cancelled out at the time of your demise, that just makes a mockery of your life and you as an individual.”

Later in the same interview she says:

“On my demise, my daughters I’m absolutely sure would insist that I get buried as their dad, and that shouldn’t be allowed, that I feel pretty strongly about. Because that’s them (saying) ‘you’re a little bit crazy, you wanted to live as a female for a while, but it’s over now and you’re dad again’”.

The Gender Recognition Act 2004 states that a person should be legally regarded as their acquired gender in all aspects of life and death. Gender Recognition Certificate. Shirley also had applied for a Gender Recognition Certificate (GRC). Despite these protections however, she was still not confident that this would be respected on her death.

Next, we consider some of the concerns raised about the possibility of not being able to continue to live in one's home; these concerns were heightened for some by a lack of available support networks, especially for those who lived alone or who had no or few close connections with family of origin.

Mainstream environments of care outside the home

There is some evidence to suggest that older LGBT people are often more isolated than their peer group (Stonewall, 2011) or that they are more likely to live alone. These are issues that can affect all older people due to factors such as the loss of friends and family as one ages, reduced mobility or limited income. As the UK’s population ages, the issue of acute loneliness and social isolation is identified as one of the biggest challenges facing our society (Social Care Institute of Excellence, 2012). However, existing research identifies how these

issues may hold particular salience for LGBT ageing populations given evidence that suggests older LGBT people may be less likely to have any children; may be estranged from families of origin and thus lack inter-generational support; more likely to live alone in comparison to their heterosexual counterparts, with the incidence of living alone increasing with age (Brookdale Center on Aging, 1999; Heaphy, 2003). A detailed exploration of our participants' networks of support is beyond the scope of this chapter; instead we highlight some brief considerations of accessing and using mainstream services.

In our survey, 74% of respondents reported feeling 'not very confident' or 'not very confident at all' that mainstream health and social care services provide sensitive and appropriate end of life care services for LGBT people. The reasons why LGBT older people may lack confidence in approaching services are well-documented including the legacy of living through times of being criminalised rather than protected by law, of psychiatric interventions and other forms of prejudice and discrimination from institutions including medicine, the church and the state.

"For myself, I suppose, my fear is that, as either of us gets older or has more health problems to contend with, my fear is that not only will we have to contend with those, but we'll have to contend with the system not being very sympathetic to the fact that we're a couple." (Ron, gay man, 65)

"People of my sort of age who have particularly in earlier years experienced prejudicial discrimination ... you can't predict and rely on a totally integrated service necessarily giving a feeling of safety." (Ian, bisexual, 66)

It is possible that older LGBT people might delay access to health and social care services because of experiences in earlier years of discrimination and/or fears of encountering further discrimination (Ward et al., 2010). Such anxieties mitigate against the dying person and their carers being able to have peace of mind towards the end of life and having a good experience of end of life care. Each new encounter with health and social care staff LGBT people and their carers are faced with a new decision about what to disclose or hide about their sexual

orientation and/or gender identity. Such decisions can be associated with concerns about whether disclosure will impact negatively on the care they receive. Further concerns stem from negative responses from other patients, residents, clients that the older LGBT person encounters in care settings outside the home:

“When my partner was dying she went to a day hospice, mainly to offer me respite. She went three times and then I was invited for the day to see what went on there. The staff introduced me as Josephine’s partner to all the other patients there. The next time after when she went, no-one spoke to her and they made it very very clear why. She just wouldn’t go again. She came home in tears but she wouldn’t tell me why. She was a very strong independent person but obviously ill at that point. She didn’t tell me about it until 3 days before she died. I was so emotional I didn’t do anything about it then ... but I’ve since taken it up with the hospice so some good might come out of it ...” (Liz, lesbian, 65)

“One time Leo was in hospital, he was distressed and said ‘Oh you’re not going to leave me are you?’ and he reached out to hold my hand ... anyway this guy in the next bed, I could see him out the corner of my eye, sort of rear up in bed you know. After I’d gone he rang to tell the nurse, I want to move, don’t want to be here. And I’ve never forgotten that. So, when he went in with the cancer, that was something in our minds you know, you don’t make it obvious you’re a gay couple. I would have loved at times to have hugged him and given him a kiss and I never felt able to.” (Ken, gay man, 70)

Health and social care settings don’t necessarily feel like safe spaces for LGBT people to disclose important aspects about who they are and who they love, or to be able to be affectionate with their partner at a time of heightened vulnerability. Furthermore, feeling unable to access supportive provision (as in Josephine’s case) or for a partner to be able to support a partner by giving them a hug (as in Ken’s case) can place additional burdens on partners and friends to provide informal care, without the support of health and social care professionals.

Our data highlights many further issues to consider here in accessing mainstream services; preferences and ambivalence about the provision of LGBT specific services; experiences of discrimination (but also some positive stories about being treated with dignity and respect); decisions on an ongoing basis about whether or not to disclose information about their sexual orientation; strategies to keep such information hidden. Even those who have been open about their sexual orientation in the past may find they are less confident in doing so if they become frail or need more support from a wider range of people.

A key finding in our data was that forms of discrimination are not always overt but can include more subtle and sometimes unintentional forms of discrimination that are less easy to challenge. One example is 'heteronormativity'; a cultural bias that views heterosexuality as 'normal' and taken for granted in a way that LGBT relationships and identities are not. Examples of heteronormativity include the under-representation of LGBT relationships and people in service promotion leaflets, or assumptions made that someone is heterosexual unless otherwise stated. Heteronormativity can make someone feel invisible, erase a big part of someone's identity, and impact on their ability to involve those closest to them in their care. Some examples we were told by interview respondents include a bisexual woman sat in the waiting room with her female partner; when the nurse called her in she said: "Your sister can come with you." In contrast, if it was a man and woman sat together of similar age, it is more likely that the nurse might check (or assume) first that they are husband and wife not brother and sister. Questions about children and grandchildren may appear friendly attempts at conversation, but for many older LGBT people, having children wasn't a possibility or they might be estranged. This 'pervasive experience of heterosexism' (Cox 2011, p. 194) can render a central aspect of one's identity as invisible. Service providers frequently either do not consider that some service recipients may be LGBT and/or suggest that they provide inclusive services by treating everyone the same (see, for example, (GRAI (GLBTI Retirement Association Inc), 2010).

Conclusions

To be living with a life-limiting condition, to be dying or bereaved can be socially excluding experiences and there are additional layers of exclusion that LGBT people may face at these times. This may include feeling unable to disclose their sexual orientation or their gender identity or other aspects of their lifestyle and culture due to previous experiences or concerns about discrimination from wider society (and sometimes for bisexual people, discrimination from within L&G communities). As a LGB or T person, making decisions about what to say and to whom about your sexual orientation or gender identity is constant and it can be very wearing, especially if you are already feeling ill or vulnerable.

If LGBT people are not confident about services or staff, they may not seek support and/or may not feel able to speak about matters and people who are important to them and crucial to dying well. It is often said about end of life care that we only have one chance to get it right. In caring for or providing services for LGBT people at the end of life this also takes on an additional meaning. LGBT people may have experienced encounters with health and social care staff at some point in their lives where they feel unacknowledged, invisible or in some other way excluded – often against a background of a lifetime of such instances. LGBT people will be adept and alert to nuanced responses on disclosing information about their sexual orientation or gender identity. Every encounter with someone new can be accompanied by concerns about how that individual will respond to information about an LGBT identity. Any points of disclosure can be critical one chance moments – if not met positively this can be a missed opportunity to build up caring relationships and to get to know the whole person which is central to holistic end of life care. However – if LGBT people and those close to them do need care or other services, it is so important that they are able to feel safe in approaching services for assistance and that services are prepared to encounter LGBT people, such that it becomes an embedded part of service provision towards and at the end of life.

References

- Almack, K. (2016) 'Dying, Death and Bereavement', in Goldberg, AE. (ed.) *The SAGE Encyclopaedia of LGBTQ Studies*, New York: SAGE Publications
- Almack, K., Seymour, J., and Bellamy, G. (2010) 'Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual elders', *Sociology*, 44(5): 908-924.
- Bristowe, K., Hodson, M., Wee, B., Almack, K., Johnson, K., Daveson, BA., Koffman, J., McEnhill, L. and Harding, R. (2018) 'Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study', *Palliative Medicine*, 32: 23-35.
- Brookdale Center on Aging (1999) *Assistive Housing for Elderly Gays and Lesbians in New York City*, New York: Hunter College and Senior Action in a Gay Environment (SAGE).
- Brotman, S., Ryan, B., Collins, S., Chamberland, L., Cormier, R., Julien, D., Meyer, E., Peterkin, A. and Richard, B. (2007) 'Coming Out to Care: Caregivers of Gay and Lesbian Seniors in Canada', *The Gerontologist*, 47(4): 490-503.
- Cartwright, C., Hughes, M. and Llenert, T. (2012) 'End-of-life care for gay, lesbian, bisexual and transgender people', *Culture, Health & Sexuality*, 14(5): 537-548.
- Cox, K (2011) 'Sexual Orientation', in Oliviere, D., Monroe, B. and Payne, S. (eds.) *Death, Dying and Social Difference. 2nd ed*, Oxford: Oxford University Press, p. 191-199.
- CQC (2016) *A Different Ending: Addressing inequalities in end of life care (Overview Report)*, London: Care Quality Commission.
- Department of Health (DoH) (2008a) *End of Life Care Strategy: promoting high quality care for all adults at the end of life*, London: Department of Health.
- Department of Health (DoH) (2008b) *The End of Life Care Strategy: promoting high quality care for all adults at the end of life. Equality Impact Assessment*, London: Department of Health.

Gomes, B. and Higginson, IJ. (2008) 'Where people die (1974—2030): past trends, future projections and implications for care', *Palliative Medicine*, 22(1): 33-41.

GRAI (GLBTI Retirement Association Inc) (2010) "*We don't have any of those people here*": *Retirement Accommodation and Aged Care Issues for Non-Heterosexual Populations*. Western Australia: GRAI.

Hall, S., Petkova, H., Tsouros, AD., Costantini, M. and Higginson, IJ. (2011) *Palliative Care for Older People: better practices*, Denmark: WHO Regional Office for Europe

Harding, R., Epiphaniou, E. & Chidgey-Clark, J. (2012) 'Needs, Experiences, and Preferences of Sexual Minorities for End-of-Life Care and Palliative Care: A Systematic Review', *Journal of Palliative Medicine*, 15(5): 602-611.

Heaphy, B., Yip, AKT., Thompson, D. (2003) *Lesbian, Gay and Bisexual Lives Over 50*, Nottingham: York House Publications.

Kennedy, S., Seymour, J., Almack, K. and Cox, K. (2009) 'Key stakeholders' experiences and views of the NHS End of Life Care Programme: findings from a national evaluation', *Palliative Medicine*, 23(4): 283-294.

Lawton, A., White, J. and Fromme, EK. (2013) 'End-of-Life and Advance Care Planning Considerations for Lesbian, Gay, Bisexual, and Transgender Patients #275', *Journal of Palliative Medicine*, 17(1): 106-108.

Leadbeater, C. and Garber, J. (2010) *Dying for change*, London: DEMOS.

Manthorpe, J. (2003) 'Nearest and Dearest? The Neglect of Lesbians in Caring Relationships', *British Journal of Social Work*, 33(6): 753-768.

NHS England (2014) *NHS England's Actions for End of Life Care*. Leeds: England.

ONS (2015) *Mid-2014 Population Estimates UK*, London: Office for National Statistics

Plummer, K. (2007) 'The Call of Life Stories in Ethnographic Research', in Atkinson, PE, Coffey, A., Delamont, S., Lofland, J., and Lofland, L. (ed.) *The handbook of ethnography*, London: Sage.

Pollock, K. (2015) 'Is home always the best and preferred place of death?', *BMJ*, 10th October, p. 18-19.

Price, E. (2010) 'Coming out to care: gay and lesbian carers' experiences of dementia services', *Health & Social Care in the Community*, 18(2): 160-168.

Rawlings, D. (2012) 'End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals', *International Journal of Palliative Nursing*, 18(1): 29-34.

Ruth, K. and Verne, J. (2010) *Deaths in Older Adults in England*, Bristol: National End of Life Care Intelligence Network.

Saunders, C. (1976) 'Care of the dying: the problem of euthanasia', *Nursing Times*, 72(27): 1049-1051.

Social Care Institute of Excellence (2012) *Preventing loneliness and social isolation among older people. At a glance briefing*, London: SCIE.

Stonewall (2011) *Lesbian, Gay and Bisexual People in Later Life*. London: Stonewall.

Victor, CR. (2010) *Ageing, health and care*, Bristol, Policy Press.

Walter, T. (1999) *On bereavement*, Buckingham, Open University Press.

Ward, R., Pugh, S. and Price, E. (2010) *Don't look back? Improving health and social care service delivery for older LGB users*, Manchester: Equality and Human Rights Commission.

Westwood, S. (2013) "'My Friends are my Family": an argument about the limitations of contemporary law's recognition of relationships in later life', *Journal of Social Welfare and Family Law*, 35(3): 347-363.

Wilkinson, R. and Marmot, M. (2003) *Social Determinants of Health: the solid facts, 2nd ed*, Denmark: WHO Regional Office for Europe.

Young, E., Seale, C. and Bury, M. (1998) "'It's not like family going is it?": negotiating friendship boundaries towards the end of life', *Mortality*, 3(1): 27 - 42.

ⁱ Estimating the size and demographic trends of the ageing LGBT population is difficult. The UK Department of Trade and Industry (DTI, 2003) cite an estimate of 5–7 per cent nationally. To date in the UK, the Census has not included specific questions about people’s sexual orientation/gender identity. Difficulties in collecting such data requiring self-identification are also more complex than simply asking the questions; some people may not want to disclose that information or not want to identify with the categories provided.

ⁱⁱ The UK ranks first in the 2015 Quality of Death Index, a measure of the quality of palliative care in 80 countries around the world (report by The Economist Intelligence Unit).

ⁱⁱⁱ Pathways to LGBT identities; factors impacting on coming out or transitioning; accessibility to help and support at current age; talking about ageing; advance planning for future and end of life care; religion or spirituality; experiences within health and social care settings (for oneself or as a carer); preferences for how services should be organised.

^{iv} Cisgender is a term for people whose gender identity matches the sex that they were assigned at birth.

^v It is now possible for same sex couples to get married in England and Wales (from March 29, 2014) and in Scotland (from Dec 2014) or to convert a civil partnership into a marriage in England, Scotland and Wales. Civil partnerships are legal in Northern Ireland but not same sex marriage.