The Last Outing: exploring end of life experiences and care needs in the lives of older LGBT people

A Final Report

Project funded by: Marie Curie Research Programme, 2012-14

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ACKNOWLEDGEMENTS

With thanks to the Marie Curie Research Programme not only for funding the project but their ongoing interest in, and support for, this research study.

Thanks to members of the advisory group who helped us with insightful comments at critical moments in the life of the project.

And finally, but not least, our grateful appreciation to all the many organisations and individuals across the UK who have supported us, helping us with advice throughout and in particular recruitment to the study and all those who took the time to take part in this project.

Study Objectives

- To identify particular needs and preferences salient to sexual/gender orientation relating to end of life care (EoLC) as identified by LGBT older people.
- To examine ways in which sexual/gender orientation may impact on experiences of EoLC for LGBT older people.
- To explore LGBT older people's familial and friendship networks and the ways in which these personal networks may influence later life experiences towards and at end of life.
- To identify recommendations for good practice in EoLC issues addressing issues for LGBT older people.

Methods and Sampling

A mixed methods study consisting of three phases:

1. Survey - online and hard copy. 81 questions (mostly closed questions and scaling of opinions with some 'open' questions) covering themes including sources of care; perceptions of accessibility to and satisfaction with services; positive and negative experiences perceived to be connected to sexual/gender orientation; views on the need for specific or mainstream services. We also gathered socio-demographic data from respondents (including gender, age, health status, ethnicity, household/residence information, relationship status).
2. In depth interviews with a sub-sample of the survey respondents. Semi structured interviews including 'eco-mapping'. Themes explored in the interviews were informed by the survey findings and included:
    - Attitudes and beliefs about end-of-life issues
    - Concerns and experiences of caring or receiving care at end of life
    - Needs for information and support

   The 'eco-mapping' technique was used to visually map out respondents' supportive networks, from which they have or envisage seeking support from in end of life care scenarios.

3. Public engagement workshop
   Drawing on models of research practice used in the Sue Ryder Care Centre, we facilitated a public engagement workshop to feedback findings and to collaboratively develop recommendations which will be used to develop outcomes of the study.

Inclusion criteria

- Self- identify as LGB, whether currently in a same-gender relationship or not
- Self-identify as a trans person with an LGB or heterosexual identity, whether currently in a relationship or not
- Aged 60 or over (OR under 60 but with a LGBT partner aged 60 or over)
- Capacity to give informed consent
- Living in the UK

Exclusion criterion:

- LGBT elders unable to give informed consent
- In early stages (first 3 months) of any bereavement

237 survey respondents followed by a survey sub-sample interviewed in-depth (N = 60). Respondents were living in the UK, aged 60 or over (or had a partner aged 60 or over) and identified as LGB and/or T. Appendix 1 provides an outline of key sample demographics for the survey and interview respondents.

Relevant background findings

- The generations of LGBT people in our study grew up at time when coming out could result in serious negative repercussion including job discrimination, family disapproval, psychiatric interventions, criminalisation, and various other forms of prejudice or intolerance. While there have been significant social and legal changes in the lifetime of the oldest generations of LGBT people, this does not totally eradicate past experiences and their impact on the present. 26% of our survey respondents reported having experienced discrimination related to sexual orientation/gender identity from health and social care professionals.
- An important aspect of understanding the lives of older LGBT people is not just about their differing sexual orientation or gender identity but also their differing history. Their past becomes important when exploring hopes, fears, and concerns around later life and end of life care when they may be in a position of receiving care from people who they fear might not respect or even recognise their differing sexual orientation or gender identity. Many may still be very private about their sexual orientation and gender identity and reluctant to disclose important aspects of their identity.

- There is an assumption that younger LGBT generations will feel more able to choose and request services addressing their specific needs. However, we know little about points of transition in older age and the consequences of these. For example, in our study, respondents noted that levels of confidence and assertiveness may change over time and in particular in transitions from leading active and independent lives through to frailty or dealing with conditions that require care and support.
- Our findings reflect findings from a survey carried out by Stonewall (2011)[i] which found that lesbian, gay and bisexual people over 55 are more likely to live alone and less likely to have regular contact with biological family members. They may be more likely to need formal support and care services in later life but the findings also suggest that LGB people over 55 lack confidence that public services will meet their needs.
- A key issue identified by respondents is heteronormativity - an assumption of heterosexuality unless otherwise stated. For example, in a hospital waiting room, a man and woman of similar age sitting together might be assumed to be husband and wife or (heterosexual) partners; for two women of similar age sat together it is less likely they would be assumed to be lesbian or bisexual partners. Disclosure of one's sexual orientation (coming out) is never a one off process. Our qualitative data suggests LGB&T people have to make choices and decisions about what or what not to say on a regular basis and most used differing strategies in differing circumstances ranging from being totally upfront to not saying anything, challenging or not challenging assumptions. For some LGB people, as well as for transgender people, health and care settings often do not represent safe spaces to disclose important aspects of their identity, or to demonstrate affection towards their partner at a time when they may feel more vulnerable. This can present particular difficulties at the end of life.

Key findings – addressing the study's objectives

- Preferred choices about how end of life care services should be organised and access to services are complex. The survey data reports a clear preference (almost two thirds of respondents) for specific LGBT services for or run by LGBT people and a similar lack of confidence in mainstream services.
- However, the qualitative data indicates greater ambivalence and suggests a far more nuanced picture of preferred choices with desires expressed for services that are inclusive of all. LGBT people do not have shared and fixed needs and attention does need to be paid to differences within and between these categories. For example, a significant number of women expressed a desire for women only services (heterosexual, lesbian or bisexual women) as a preference. Some men wished to have male carers. Many were hesitant about LGBT services potentially creating segregation; although some people DID want to be ‘segregated’. Key choices noted are for services to:
    - Develop greater inclusivity for all people
    - Reflect the broad diversity within our society
    - Instil confidence that LGBT people could feel validated, understood and safe
    - Be places where one could find 'like-minded' people
- Survey and interview respondents report that advance care planning is important for LGBT people. Motivations to complete advance care plans include some issues similar to those reported for the general population such as not placing burdens on others but also distinct issues such as providing protection for partners and significant others who might otherwise not be recognised.
- 82% agreed that it was particularly important for LGBT people to make and record plans for future care; 40% said that they had talked/informed their partners or friends about their preferences for future care and treatment. Only 18.5% of the respondents had written down and recorded their preferences for future care and treatment. These figures are broadly reflective of the general population.
- One important point made was that LGBT people needed access to advice and advisors to make plans, who would understand something about the diversity of LGBT lives.
- Barriers to completing advance care plans and Lasting Powers of Attorney again include some issues which may be similar to those reported for the general population - such as feeling daunted by the paperwork or costs involved and not wanting to think about or plan for the end of life. Distinct issues identified for LGBT people include not knowing who to nominate in decision making roles due to their personal networks comprising people of the same age or ongoing social isolation.
- Survey and interview respondents want to be able to nominate 'important others' as next of kin, which might mean same-sex partners or significant friends. While there is an absence of legal clarity about who is 'next of kin', in practice the default position reflects heteronormative norms; it is still often assumed to refer to people related by blood or (heterosexual) marriage.
- Respondents want significant others in their lives to be acknowledged, respected and involved in their care (and in some cases keeping family of origin at a distance or explicitly NOT wanting family of origin involved).

- Conditional family relationships are sometimes a barrier which can compromise one's integrity; for example trans people in particular were often estranged from family of origin or had conditional relationships (for example, a trans woman who wants to maintain contact with her daughters and grand-children is only able to do so if she reverts to being their 'Dad' and 'Granddad' in their company).
- Having one's wishes respected after death was a particular concern. Respondents gave many anecdotal stories of LGB people they knew who had died and whose partners and/or friends had been excluded from the funerals by families of origin. For trans people, particular concerns are expressed about being buried by family of origin under their birth gender, despite knowledge of legal protection of one's acquired gender identity – concerns here are not only about being cared for and dying where one wishes but to be buried as one wishes.
- Respondents want to be able to maintain ongoing access to LGBT virtual networks and other links if/when dependent on others for daily assistance. They also felt choice would be enhanced if services demonstrate equal treatment for LGBT service users and instilled confidence that they could offer inclusive and safe spaces. This may include displaying LGBT symbols and images in service materials – but importantly backed up by training to ensure sensitive and appropriate service provision.
- Seeking spiritual and religious support that is accepting of LGBT people is important for LGBT people with spiritual and religious beliefs but not always easy to access. This could present obstacles to being able to feel at peace towards the end of life and in making choices about accessing hospice services perceived to have religious orientations.
- Some respondents spoke of being carers for elderly parents or other relatives. While they might chose to be out in their care settings, sometimes they were aware that elderly relatives would not want to be 'outed' as the parent/relative of a LGBT person, which constrained choices to be out. Another complexity for LGBT people taking on the role of carer is the history of their relationships with their family in the past; they may feel obligated rather than choose to be carers.
- Older LGBT people had a rich variety of personal support networks – some small, some large. 'Richness' is not about quantity: Small networks can hold really effective support; and large networks might be characterised by many acquaintances not necessarily many close friends. One dominant narrative in previous LGBT research -that biological family doesn't figure in LGBT people's lives – was not always borne out in the data. While some respondents were estranged from biological families or had difficult or ambivalent relationships with family of origin, many had close and supportive relationships with members of their biological families.

Influencing future research, policy and practice

This study has been timely to feed into important policy and practice initiatives relating to addressing diversity in end of life care:

- We were commissioned to feed into the Government review of choice in end of life care, undertaken by an independent programme board, chaired by Claire Henry, the Chief Executive of the National Council for Palliative Care. The information gathered will outline the kinds of choices that people would like to be able to make at the end of life and information about the funding, systems and processes that would be needed to enable choices to be enacted.
- Dr Almack is an invited member of an external advisory group that CQC (Care Quality Commission) have set up to provide expert input and critical comment into their 'Inequalities and Variations in Provision of End of Life Care' themed programme
- Dr Almack is an active member of a national LGBT EoLC Advisory Group as one of the research leads (with HospiceUK, St Helena's Hospice, St Joseph's Hospice, Macmillan, Marie Curie, Social Council of Institute of Excellence, National Council of Palliative Care). This is a cross organisational group of specialists in palliative and end of life care who share a vision to improve the experience of those from LGBT communities when thinking about and facing death from living with life limiting and progressive conditions. The group aims to promote awareness of, access to, and delivery of appropriate high quality palliative and end-of-life care for LGBT people affected by life limiting and progressive conditions through research, clinical and care practice, policy and education, liaison and advocacy.
- The Last Outing Research Project has fed into a mapping/reviewing exercise about LGBT public health work for Public Health England (PHE).

Other input into policy and practice

- Ran an information workshop 'Living Now Planning For Later' at the Opening Doors (Camden) - 5th Annual Older LGBT Information Fair for older LGBT people and those who work with them, October 2013
- Invited to run a workshop at a specialist training day for professionals working in the care sector: Making Person Centred care a reality: How to support LGBT older people in care settings. Newcastle, October 2014.

The following activities have also been achieved or are ongoing

- Successful application for funding from the Economic and Social Research Council (ESRC) Festival of Social Science to host a public event: Ageing and care for older LGBT people: Screening of a critically acclaimed US documentary on this subject (Gen Silent) with an introduction about The Last Outing project from Dr Kathryn Almack and a Q&A panel after the film, chaired by Dr Almack with invited expert-by-experience participants.
  This was designed to disseminate our research findings and prompt discussions and action points to take forward.
- Collaboration with a TVN (Technology Evaluation in the Elderly Network, supported by the Canadian Government) Catalyst Research Program Grant: Fostering End Of Life Conversations, Community and Care Among LGBT Older Adults, Profs Gutman and De Vries, Simon Fraser University, Canada, with partners from five other Canadian Universities. When the Canadian study is complete (end of 2015) we hope to do some comparative analysis of our findings.
- Application to the University of Nottingham's new ESRC Impact Acceleration Account. Supported by the agreed collaboration from the National Council of Palliative Care and aimed at practitioners in end of life care. It will involve the development of a training/information resource for diversity training in an end of life context and to raise awareness of the needs of LGBT people
- Dr Almack is a co-applicant on an ongoing Marie Curie Cancer Care Research Programme grant - ACCESSCare: Advanced Cancer Care Equality Strategy for Sexual minorities (2014-16, Harding, R., Daveson, B., Almack, K.)
  This project aims to improve demand for and supply of palliative care for people who identify as lesbian, gay, bisexual and/or trans* (LGB and/or T) and are in the later stages of a life-limiting illness. Findings from The Last Outing will be fed into this project.

Dr Almack and colleagues have presented findings at numerous (N = 20 to date) academic and practitioner conferences, seminars and workshops at international, national and local levels. See Appendix 2.

Dr Almack has drawn upon early findings to inform two publications (one Sage Encyclopaedia entry and one book chapter; both forthcoming 2016) and the research team currently have three key papers under development with a further seven identified for future development.

Appendix 1

Profile of Participants

	Survey	Interviews
GENDER	%	
Female	50	47
Male	47	48
Alternative identity preferred (examples include pangender; transgender; dual gender life)	3	5
GENDER IDENTITY: 17% of survey respondents and 8.3% of interviewees reported having a different gender to that assigned at birth		
	Survey	Interviews
SEXUAL ORIENTATION	%	
Lesbian	37	45
Gay	43	40
Bisexual	10	5
Heterosexual/straight	3	0
Other (examples given include 'queer'; 'dyke'; 'asexual'; 'not the marrying kind'	7	10
	Survey	Interviews
AGE RANGE	Numbers	
30s - 40s	9	2
50s	12	2
60-64	98	18
65-69	68	20
70s	28	14
80s	7	4
90s	1	0
Notes: 223 out of 237 respondents gave their age. The survey was targeted at people aged 60 and over but also included people under the age of 60 who had a partner aged 60 or over. The overall age range was 37-93 years of age.		
	Survey	Interviews
ETHNICITY	%	
White	87	86
Irish/ other White backgrounds	9	12
BAME backgrounds	4	2
	Survey	Interviews
LIVING ARRANGEMENTS	%	
Living alone	64	65
Living with others (for the majority that meant living with the person they were in a relationship with)	36	35

We made strenuous efforts to widen the diversity of respondents to include LGBT from BAME communities, supported by AgeUK and others but with limited success. While some respondents felt fortunate in being well-resourced and well off financially, others were not. This included gay men living long term with HIV whose working lives may have been disrupted by illness, lesbians who had initially followed a more conventional route of heterosexual marriage and who found themselves less well-resourced later in life.

Appendix 2 – Conference and seminar presentations

Attendee	Conference/seminar	Date	Capacity
Dr Kathryn Almack	Over the Rainbow (AgeUK and Equity Partnership Conference)	Nov 2012	Invited Speaker
Dr Kathryn Almack	Sheffield Death Group Seminar	Dec 2012	Invited Speaker
Dr Kathryn Almack	Marie Curie Annual Palliative Care Research Conference	Mar 2013	Invited Speaker
Dr Kathryn Almack	Social Work Hospice & Palliative Care Network conference, New Orleans, US. Symposium	Mar 2013	Invited Speaker
Dr Kathryn Almack	British Sociological Association Complexities of care for older LGBT people Conference. Leeds, UK	April 2013	Selected Speaker
Dr Kathryn Almack	Panel discussion after screening of the documentary 'Gen Silent' at Fringe! Film Fest. (Explores concerns and experiences of older LGBT people).	April 2013	Invited panel member
Dr Kathryn Almack	Policy Ethics and Life Sciences Research centre (PEALS) Newcastle University Seminar	June 2013	Invited Speaker
Dr Kathryn Almack	British Society for Gerontology	Sept 2013	Selected Speaker
Dr Anne Patterson	National Cancer Research Institute (NCRI)	Nov 2013	Poster presenter
Dr Anne Patterson and Dr Meiko Makita	Equality and Diversity NHS Nottingham workshop	Feb 2014	Invited speaker
Dr Anne Patterson and Dr Meiko Makita	UNISON Conference	Feb 2014	Invited speaker
Dr Anne Patterson	8th World Research Congress of the European Association for Palliative Care, Lleida, Spain. May 2014	June 2014	Poster presenter
Dr Anne Patterson	British Society of Gerontology 2014 Conference. New understandings of old age and the lifecourse. Southampton, UK	Sept 2014	Selected speaker
Dr Kathryn Almack	Making Person Centred care a reality: How to support lesbian and gay older people in care settings. A specialist training day for professionals working in the care sector. Newcastle, UK	Oct 2014	Invited Speaker
Dr Kathryn Almack	British Sociological Association, Social Aspects of Death, Dying and Bereavement Study Group: 'Death, Inequality and Social Difference'. London, UK	Nov 2014	Selected Speaker
Dr Kathryn Almack	Economic and Social Research Council seminar series. Older LGBT people: Minding the Knowledge Gaps. University of Surrey, UK	Nov 2014	Invited keynote speaker
Dr Kathryn Almack	International Association of Gerontology and Geriatrics – European Region Congress: Unlocking the Demographic Dividend. Dublin, Ireland.	April 2015	Invited co-convenor of symposium: LGBT New Ageing
Dr Kathryn Almack	Queer Kinship and Relationships International Conference. Zalesie, Masuria, Poland.	June 2015	Selected Speaker

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[i] Stonewall (2011) Lesbian, Gay and Bisexual People in Later Life.
Stonewall commissioned YouGov to survey a sample of 1,050 heterosexual and 1,036 lesbian, gay and bisexual people over the age of 55 across Britain. The survey asked about their experiences and expectations of getting older and examined their personal support structures, family connections and living arrangements. It also asked about how they feel about getting older, the help they expect to need, and what they would like to be available from health and social care services.