

# Investigating familial, intimate and personal networks of lesbian, gay and bisexual elders towards the end of life

*Kathryn Almack and Jane Seymour*

Sue Ryder Care Centre for Palliative and End of Life  
Studies, **University of Nottingham**

(on behalf of the Peer Education Project Team)

## Peer education project (funded by the Burdett Trust)

- ▣ Wider aim: To understand the range of older people's concerns about the end of life.
- ▣ Reporting on data from the first phase of this project: series of focus groups in a range of settings to discover views, concerns and experiences about end of life care and to gather opinions about information and education needs.
- ▣ Total of 173 participants.
- ▣ Four focus groups were carried out specifically for older LGB people in the north and south of England with two follow up groups to feedback discussions and prompt further discussions. 15 participants.

# Some background

- ▣ Lesbian, gay men and bisexual (LGB) elders face many of the same issues as heterosexual elders in terms of end-of-life care, but have additional concerns and needs linked to their sexual orientation.
- ▣ Consultation carried out for the End of Life Strategy in England revealed that sexual orientation is one of the most likely areas for inequality and discrimination to occur in end of life care (DoH, 2008).
- ▣ There remain gaps in the research evidence available.
- ▣ There have been significant social and legal changes in the lifetime of the oldest generations of LGB people.

# Demographics

- ▣ No official UK demographic statistics on LGB individuals of any age group.
- ▣ The UK Department of Trade and Industry (DTI Women and Equality Unit, 2003) cite an estimate of 5 – 7% nationally.
- ▣ Price (2005) suggests an estimate of between 545,000 and 872,000 LGB people over the age of 65 in the UK.

# Context of discussion

- ▣ Set in the context of debates about broader changes to family forms within late modernity, alongside social change and demographic shifts.
- ▣ Highlights neglected issues around LGB ageing, end of life care and bereavement alongside wider topic of care and support within 'non-traditional' intimate relationships and personal networks which are brought into sharp focus in the arena of end of life care.

# Families of choice

*I had a partner, Sue, for 15 years, that was 17 years ago but she's my best friend, her partner too. I've no other family, they are my family and they sorted out my moving so I was closer to them. They both look after me if I have to go into hospital, they do everything for me, she tells me off, leaves me notes on the wall. Sue even calls me sis sometimes (Eileen).*

*My family would be my partner and my cat, then my gay friends and then it would extend on to my siblings but some I don't get on with so I wouldn't include them in sorting out my affairs or anything (Andrew).*

# Disenfranchised grief

*I knew he wanted burial and he wanted to be buried next to his mother. He ended up being cremated the other side of (city) and cremation was totally against his religion ... I couldn't stop them but it was like strangers organising his funeral; I was his family. ... but he never wanted it to be known that he was gay. And I respected that, so he wasn't out, I wasn't out then either. I couldn't talk to my family... they thought David was just a friend. I was a right mess. I had no-one to turn to (Jeremy).*

# New relational configurations

*Colin: I don't have a partner. And so my blood relations do play an important part in that. But unfortunately, two of my siblings have died, so there's just my brother left. But of course, my sister had a family, and so I've got nephews and nieces, and now got great nephews and nieces. And I've sorted out an enduring power of attorney, which is now called lasting power of attorney, and chosen someone generations younger.*

*Norman: I don't have blood relations but my late partner had children and his daughter in particular I'm quite close to, and I'm godfather to two of the grandchildren. So there is a closeness there, and I've actually got a younger generation that might be of help to me as an older person, because most of us have got nobody younger that they would consider to be close.*

# Civil partnerships

*A few years ago on holiday, I nearly drowned, and I remember my real concern wasn't about myself, but about my partner, how my family would treat him. And I thought crikey, I must do something about it. I was fished out obviously! It opened up my mind to the discussion and we talked about it and he said yes, I am sort of concerned about your sister interfering. And so we have done the civil partnership, which really has helped to bring things together. And I've warned my sister, if it does happen, in light of the civil partnership, don't you hassle him, there is a will that has got to be honoured (Andrew).*

# Fears and concerns

*I do know many lesbians and gay men who are partially out ... they're not really out, and you just wonder how they're going to cope, isolation is a big thing as we get older. If we haven't got families or younger people around us and most of our friends are like the peer group, you need those people there, but we won't all live forever, it's quite frightening ... some people are not, you know, it's up to them how they are, but because they're not out, they can't express themselves, only within their own circle. It's going to make life so much more difficult for them (Ken).*

# Research questions

Small data set - conclusions necessarily tentative and can not be widely generalised.

- ▣ Explore how sexual orientation may impact on LGB older people's experiences and concerns about end of life care and planning and on bereavement within a same sex relationship.
- ▣ Explore important social relationships and networks in relation to end of life – who counts?
- ▣ Examine the negotiations of roles, responsibilities and commitment towards end of life.

## Concluding comments:

- ▣ Parallels between heterosexual and LGB experiences of growing old, end of life care and bereavement but also issues specific to the LGB population.
- ▣ Insights into a range of configurations of social and biological families, friends and kin that are also, for some, inter-generational.
- ▣ Changes experienced within personal networks in relation to care and support available to older LGB people as they age.
- ▣ Questions: ways in which access to economic, social and cultural resources shape later life experiences of LGB people – and more widely the possibilities of care and support towards and at end of life for and between individuals in non-traditional relationships.