Research paper

Hidden lives: the importance of recognising the needs and experiences of older lesbians and gay men within healthcare practice

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What is known on this subject
- To date, only a limited number of studies of older lesbians and gay men have been undertaken in the UK.
- There has been a lack of awareness and training regarding issues of diversity in ageing for many healthcare professionals.
- Older LGB people may be discriminated against because of their age and sexual orientation, and may experience heterosexism and homophobia from care providers.

What this paper adds
- It considers the concerns and fears that older LGB people have about accessing healthcare, including fear of disclosure and 'coming out.'
- It discusses the importance of providing an atmosphere that is inclusive of diversity, and which emphasises validation and unprejudiced acceptance.
- It considers the importance of person-centred approaches within healthcare that value individual difference.

ABSTRACT

If they are to meet the diverse needs of the ageing population, healthcare practitioners require a greater understanding of the experiences of older lesbians and gay men. The provision of respectful, compassionate, accessible healthcare is as important to them as it is to anyone else. However, to date only a limited number of studies of older lesbians and gay men have been undertaken in the UK, and therefore their experiences and needs have remained largely hidden. This paper reports on the findings of a participative research project, involving older lesbians and gay men, which was one of the first to use this methodology within the UK. Key themes include issues of 'coming out' and concerns about heterosexism in care. These are discussed in terms of the need to adopt a more person-centred approach within healthcare that promotes an emphasis on valuing individual identity and diversity.

Keywords: ageing, healthcare, heterosexism, older lesbians and gay men, sexuality

Introduction

Little is known about the numbers of older people in the UK who may be lesbian, gay or bisexual (LGB) (Musingarimi, 2008a). A conservative estimate suggests that there are currently between '545 000 and 872 000 lesbians and gay men over the age of 65 in the UK' (Price, 2005, p. 16). This lack of knowledge is in part due to research methodologies that use convenience samples (Grossman, 2008), but may also be due to an

absence of questions concerning diversity in sexual orientation in population-based surveys (Musingarimi, 2008a). Despite the absence of statistics, there are significant numbers of older lesbians and gay men within the population, and their experiences and needs have been largely invisible to health and social care providers, even though there have been recent shifts in policy towards recognising diversity and supporting dignity in later life (Heaphy *et al*, 2004; Price, 2005; Pugh, 2005). A recent review of lesbian and gay experience of healthcare suggests that numerous barriers exclude people from healthcare services. These barriers include homophobia, heterosexism, lack of knowledge, poor confidentiality, and the absence of lesbian- and gay-friendly resources (Meads *et al*, 2009: p. 5).

Lack of awareness and training regarding issues of diversity in ageing for many healthcare professionals has been reported in the literature (Hinchliff *et al*, 2005; Price, 2005). This is an international phenomenon, and research in Australia suggests that lesbian and gay people are concerned that their identities will not be properly recognised in later life, particularly when they are accessing health and social care services (Hughes, 2009). This may result in services failing to respond to individual need, which can have a negative impact on both identity issues and dignity in later life. It has been suggested that health and social care practitioners overlook sexuality in their dealings with older service users (Ford, 1998), and that heteronormative assumptions are made about older adults (Cronin, 2006). This paper builds upon the growing literature and policy that inform healthcare practice with older lesbians and gay men, and discusses these in the light of findings that emerged from a participatory research project conducted in the south of England.

Background

Recent policy and practice in relation to ageing in the UK have begun to focus on diversity (Office of the Deputy Prime Minister, 2006), and have emphasised the promotion of 'dignity' in later life (Department of Health, 2001). This has been complemented by legislation that addresses equality and sexual orientation within UK government policy. Such legislation includes the Civil Partnership Act (2004), which gave same-sex couples the rights and responsibilities available within marriage, and the Employment Equality (Age) Regulations Act (2006), which prohibits discrimination on the grounds of sexual orientation in the provision of goods, facilities and services in the exercise of public functions. In the NHS, the Darzi Report (Department of Health, 2008a) set a target of achieving high-quality care for all through a more personalised approach intended to overcome persistent and significant variations in quality. The aim was to improve services for people who are traditionally less likely to seek help, or who experience discrimination when they do so (Department of Health, 2008a). A focus on personalisation and the individual, it was argued, might highlight the needs of marginalised groups and promote more inclusive policy and practice. Policy is being developed by the Department of Health to identify gaps in practice knowledge, particularly in terms of the healthcare needs of older lesbians and gay men and the experiences of healthcare providers (Fish, 2007a). Guidance has also been produced with the aim of reducing health inequalities for lesbian, gay, bisexual and transgendered (LGBT) people (Fish, 2007b). These developments help to promote good practice, thus enabling practitioners to challenge assumptions about heterosexuality and the resulting heterosexism that it fosters, However, despite these efforts, ageing and sexuality remain an emerging focus of research and practice, and the needs and experiences of older lesbians and gay men have been largely disregarded by the majority of healthcare institutions (Addis *et al*, 2009). Such invisibility has a major impact on the needs and experiences of older lesbians and gay men, and leads to marginalisation and discrimination in the provision of health and social care services. In turn, this may directly affect the health and well-being of members of these diverse groups.

The experience of marginalisation and discrimination

All older people are subject to the impact of ageism and ageist attitudes which lead to age discrimination, invisibility and disempowerment. Ageism is 'a process whereby older people are systematically disadvantaged by the place that they occupy within society' (Lymbery, 2005, p. 13). For older lesbian and gay people, ageism is compounded by heterosexism and homophobia (Heaphy *et al*, 2004; Johnson *et al*, 2005; Price, 2005). Heterosexism is the assumption that all individuals are heterosexual and that heterosexuality is more natural and normal than same-sex orientation. The experience of heterosexism may undermine individual lesbian and gay identities and sense of self-worth. Heaphy *et al* (2003), in their study of people over 50 years of age, identified a belief that health and care service providers operated according to heterosexual assumptions.

Gender assumptions may also influence the ways in which healthcare practitioners assume heterosexuality, for women in particular, and in a study undertaken in New Zealand, more women than men reported that

their healthcare provider usually or always assumed that they were heterosexual (Neville and Henrickson, 2006). Concerns about misrecognition of their sexuality have prompted older lesbians and gay men in Australia to frequently disclose their sexuality to healthcare providers (Hughes, 2007).

Homophobia among healthcare staff, including nurses, is a well-documented phenomenon (Evans, 2000). The negative impact of homophobic threats, intimidation, verbal abuse and physical assault on lesbian and gay identity and self-esteem has already been established (Flowers and Buston, 2001). Fear of homophobic discrimination and stigma prevents many older lesbians and gay men from seeking appropriate care and services. Concerns about confidentiality may mean that individuals are reluctant to disclose their sexuality to healthcare practitioners, who themselves may avoid the topic and find it difficult to discuss sexual health issues. This may in turn make treatment decisions difficult (Hinchliff *et al*, 2005). The importance of recognising diversity and the need to combat possible discrimination will be explored in the following section, which considers the findings of a participatory action research project undertaken with older lesbians and gay men.

The Gay and Grey project

This section addresses a number of issues related to promoting understanding about diversity within the ageing population, which emerged from a participatory action research project into the needs of older lesbians and gay men in South-West England. The Gay and Grey Project was undertaken by Bournemouth University and a local voluntary agency working with older people and their carers, and the findings were written up in the *Lifting the Lid Report* (Gay and Grey in Dorset, 2006). Before the project commenced, ethical approval was granted by the local Research Ethics Committee. The project was funded for three years by the Big Lottery Fund, and adopted a participatory action research (PAR) methodology (Bradbury and Reason, 2003), which included both a quantitative survey and qualitative interviews. The age range for participants was 50 years or over, and the oldest participant was 90 years of age. A participatory methodology was chosen as it was felt to offer an inclusive approach to exploring the needs of minority groups. This approach also required the older volunteers to be active in all aspects of the project from the beginning to the end. The volunteers were supported in undertaking the research by a university researcher and a full-time project worker. This included designing, piloting, distributing and analysing a quantitative

questionnaire ($n = 91$), and undertaking qualitative in-depth interviews ($n = 30$).

Although a PAR approach was adopted because it offers an inclusive approach that embraces new types of knowledge (Bradbury and Reason, 2003), it was important for the research team to remain vigilant with regard to assumptions of conformity of experience, which may have overlooked the nuances and variant voices that emerge from within communities (Healy, 2001, p. 100). It was therefore important to monitor the roles of the volunteer researchers, and any potential bias that may have developed. A more in-depth critique of the methods used in the study can be found elsewhere (Fenge, 2010).

A snowball sampling technique was used to recruit participants to the study. This included raising the profile of the project through local and national gay and lesbian networks and media, through local resources such as libraries and GP surgeries, and through contacts of the older volunteers themselves. Snowball sampling was chosen as it had been found to be useful in identifying older lesbian and gay people for research purposes (Warner *et al*, 2003). However, despite efforts to be as inclusive as possible within the geographical remit of the project, participants from ethnic minorities were unrepresented in the sample. In part this reflects local demographics, but it also reflects the complexities of sampling hard-to-reach groups where there may be particular barriers to disclosure (Grov *et al*, 2006).

An interpretative methodology was adopted as a basis for interviews that explored the meanings that participants attributed to their situation (Guba and Lincoln, 1989). The aim was to obtain their own perceptions of their world, rather than those of the researcher. Thematic analysis and codes were used to analyse the data (Miles and Huberman, 1994), and this was undertaken as a group exercise by four of the volunteer researchers.

A number of key themes that have relevance for healthcare practitioners were highlighted by the project. These included issues about 'coming out' and disclosing identities, and concerns about the experience of heterosexism in care provision as people get older (Gay and Grey in Dorset, 2006). A number of recommendations were developed from the project. These included the need for specific anti-discriminatory policies to be enshrined within codes of practice by health and social care providers, and for education and awareness training in sexuality, addressing homophobia and assumptions about heterosexuality.

Disclosing identities to service providers

The Gay and Grey project found that only 14.3% of people had made their sexuality known to their health

or care workers (Gay and Grey in Dorset, 2006, p. 16). This appeared to be due to an underlying fear of being treated differently, highlighting the constant dilemma of who and when to tell, or when to 'come out.' The anxiety caused by this dilemma cannot be underestimated, and has the potential to be detrimental to long-term health, well-being and quality of life. The stress involved in disclosing one's sexuality has been observed within social work literature (Bayliss, 2000; Hughes, 2007), and confirmed by statements such as the following:

> 'I'm not out ... and I wonder if that's me, being ashamed of being gay, and sort of my defence, self-defence, not wanting people to know – I don't want them to think I'm a mess ...'
>
> (Gay and Grey in Dorset, 2006, p. 60)

Such statements illustrate the complexity of 'coming out', and show the extent to which heterosexism and negative experiences affect people's perception of themselves, their sexuality and their position in society. They also show one of the concerns about discussing their sexuality with healthcare practitioners. The dilemma involved in coming out is clearly described by another respondent:

> 'Although I think it is important to be open about my sexuality, I still find it difficult. I do not like to have to make a public statement about an aspect of myself which is intensely personal.'
>
> (Gay and Grey in Dorset, 2006, p. 20)

Previous experiences of coming out are also important. In Australia, attitudes towards identity disclosure in later life are greatly influenced by earlier experiences of coming out, and the perceived risks attached to such disclosure (Hughes, 2007). Within the Gay and Grey research, some individuals spoke of having no problems disclosing their sexual orientation to professionals, because of previous positive experiences:

> 'I can only say that it is because I am comfortable with myself I do not fear discrimination from them. ... My experiences have all been positive.'
>
> (Gay and Grey in Dorset, 2006, p. 30)

Although such positive previous experiences can have a protective effect on self-esteem, there is a considerable emotional cost incurred by non-acceptance or homophobia, which can be damaging to both individuals and relationships. Some older lesbians and gay men live with the constant fear of disclosure, having grown up at a time when homosexuality was illegal. Some will have experienced 'imprisonment, beatings, expulsion from family or community, loss of children or loss of livelihood' (Hicks, 2008, p. 33). The emotional cost can have a direct impact on long-term health and mental health. Concerns that healthcare

assumes heterosexuality can prevent older lesbians and gay men from feeling comfortable about disclosing their sexuality. Experience of homophobic discrimination within a healthcare setting, or unauthorised inappropriate disclosure by a professional to a third party, can lead to feelings of fear and distrust. However, for a healthcare provider to make an accurate and complete assessment of an individual's personal history, risk factors and health-related needs, it may be necessary to know the sexual orientation of that individual (Musingarimi, 2008b). It is therefore essential to develop an atmosphere that encourages openness and trust. Failure to do so can perpetuate heterosexism and deprive lesbians and gay men of equality of access to health and social care. Fear of being discriminated against may prevent older lesbians and gay men from accessing the services that they need to support their health and independence in later life (Cohen *et al*, 2008).

It is important to acknowledge that older people who come into contact with healthcare services often do so at times of vulnerability and crisis. This may make it even more difficult for them to share information about their sexual orientation and life choices, particularly in terms of 'coming out' to professionals at a time when they are vulnerable. One respondent described this as follows:

> 'I would feel the need to come out to every service provider. ... This requires emotional energy that I may not have if I become more frail.'
>
> (Gay and Grey in Dorset, 2006, pp. 35–6)

Health and mental well-being

The fear of disclosing their identity, coupled with a fear of discrimination or homophobia, can have a major impact on the health and well-being of an older lesbian or gay person, and contributes to a fear of discrimination in health and long-term care settings (Jackson *et al*, 2008). Fear of disclosure and secrecy about identity have been found to lead to relatively low psychological adjustment levels and low morale in later life (Friend, 1990). As one Gay and Grey respondent stated:

> 'it's absolutely appalling, it is just soul destroying. ... To spend years and years constantly denying your natural nature, the way that you naturally are, to just constantly deny that and pretend otherwise and never let your guard down. I mean, put it in its simplest terms, I wouldn't think it's very good for your blood pressure, would you?'
>
> (Gay and Grey in Dorset, 2006, p. 53)

Although little specific research has been undertaken into the mental health needs of older lesbians and gay men, it has been suggested that LGB people are at a

higher risk of developing mental disorders, and of self-harm and suicide (King *et al*, 2008). The experience of stigma affects mental well-being, as it generates stress and can compromise an individual's ability to cope with stressful circumstances, which in turn can contribute to illness (Link and Phelan, 2001). Concerns about care in later life, and specifically about what might happen if a move to residential or nursing care was to become necessary, were also highlighted in the Gay and Grey research project. This links to the perception that health and social care settings may not embrace diversity, and that sexual orientation would need to be hidden. As one respondent suggested:

> 'You've always got to watch what you say, so that people that go into homes have to go into the closet and self-censor themselves. ... I may be pessimistic, but I think it is back to the closet.'

> (Gay and Grey in Dorset, 2006, p. 69)

Providing an atmosphere that is inclusive of diversity rather than stigmatising of difference is therefore a key target for healthcare settings, particularly as this positively supports mental well-being. Gay-related stressors linked to internalised homophobia, stigma and openness about sexual orientation have been found to be predictive of depressive symptoms (Lewis *et al*, 2003), whereas lower levels of internalised homophobia have been found to be linked to better mental health in older lesbians and gay men (D'Augelli *et al*, 2001).

The Gay and Grey research showed that the strongest preference was for 'gay-friendly' homes (Gay and Grey in Dorset, 2006, p. 29). It is therefore incumbent upon wardens and care home managers and providers to ensure that they promote an atmosphere that is welcoming and inclusive, and that gives people confidence that individuals will not experience any discrimination, homophobia or heterosexist attitudes (Musingarimi, 2008a).

Ageing inevitably brings more frequent experience of death, and losing a partner in a heterosexual world can cause great anguish, as was highlighted in the Gay and Grey research:

> 'the hardest thing, I think, was [that] people didn't realise ... that bereavement in a gay relationship could be so brutal.'

> (Gay and Grey in Dorset, 2006, p. 65)

Society does not attribute the same level of importance to the loss of a same-sex partner as it does to the loss of a spouse, and this means that the same-sex partner can be denied the rituals and rights that are accorded to marriage partners (Fenge and Fannin, 2009). The disenfranchisement of grief (Doka, 2002) can add significantly to the stress of loss, and can have a radical impact on mental well-being. In terms of end-of-life care, one of the most likely areas for inequality and

discrimination is sexual orientation (Department of Health, 2008b), and therefore it is vital that healthcare providers review their services with regard to their accessibility and appropriateness.

Relationships and isolation

In comparison with their heterosexual contemporaries, a larger proportion of older lesbians and gay men live alone, have no children or familial support, and consequently attach greater importance to 'chosen families' consisting of friends and partners (Heaphy *et al*, 2003; Warner *et al*, 2003; Musingarami, 2008a). This highlights the importance of social capital in the lives of older lesbians and gay men, which has been defined as 'the array of social contacts that give access to social, emotional and practical support' (Gray, 2008, p. 6). Although 39.6% of the respondents in the Gay and Grey sample did not feel isolated (Gay and Grey in Dorset, 2006, p. 22), some respondents did express concerns about loneliness and emotional isolation. One individual suggested that:

> 'In addition to the concerns of all people as they grow older – declining health, strength, independence – there is an increased risk of social and emotional isolation by belonging to a minority group in society.'

> (Gay and Grey in Dorset, 2006, p. 34)

The importance of friendships and social contacts must therefore be recognised and acted upon by professionals, who need to develop sensitivity to the isolation that may be experienced as older people risk losing their social networks as they age (Heenan, 2010). The ability to maintain social networks is essential to continuing health and well-being, especially in the case of older lesbians and gay men. Social networks may be particularly important, and support from friends rather than from family may have positive consequences for mental well-being (Masini and Barrett, 2008). However, the fact that many older lesbians and gay men have never come out will mean that they have no experience of lesbian or gay social groups. Indeed they may have had no contact with others of the same sexuality, other than possibly a partner. This brings further challenges to professionals, who may see the desirability of such contact but be faced with the inability of the individual to acknowledge or express that need.

The Gay and Grey project found that just over 75% of the respondents had sexual needs, and that 42.9% considered that those needs were being met (Gay and Grey in Dorset, 2006, p. 370). This contradicts the assumption that older people become asexual, and as one lesbian respondent has stated:

'none of my identity, none of who I am is amputated, and that includes my sexuality and my sexual needs – from playful flirting, to making love with women.'

(Gay and Grey in Dorset, 2006, p. 37)

The ongoing need for social, emotional and physical contact highlights the importance of appropriate healthcare advice about sexual health. It is also essential that professionals are sensitive in their approach to sexual health needs. If individuals feel unable to come out, their sexual health and well-being could be compromised. The need for social, emotional and physical contact also highlights the need for residential and nursing care providers to develop a positive attitude to 'expressions of intimacy between older gay or lesbian people' (Musingarimi, 2008b, p. 4).

Discussion

The findings from the Gay and Grey project (Gay and Grey in Dorset, 2006) have identified clear implications for healthcare practitioners in terms of acknowledging the diversity of experience within the ageing population. The project emphasised the complexity of the processes of coming out, and the extent to which heterosexism and negative experiences affect people's perception of themselves. Older lesbians and gay men may have specific needs based on their previous life experiences. Fears of discrimination, heterosexism and homophobia are part of this wider social and cultural background. The challenge for healthcare practice is to acknowledge and validate the uniqueness of each individual whose life has been influenced by their social and cultural environment. A person-centred approach that humanises healthcare (Todres *et al*, 2009) may support healthcare practitioners and agencies to focus on the uniqueness of experience, rather than to seek homogeneity within the ageing population. Cooper (2007, p. 11) has argued that the core ethical commitment underlying humanistic practices is 'a commitment to conceptualising and engaging with people in a deeply valuing and respectful way.'

Such an approach is focused upon knowing the patient as an individual by taking a personal interest in the whole person (Seaver *et al*, 2008), and by adopting a humanised approach it is possible to develop an atmosphere that encourages openness and trust. This involves connecting with individual narrative, and developing an understanding of the individual in terms of their biography and uniqueness (Cronin *et al*, 2011). By challenging assumptions and stereotypes it is possible for both agencies and individual professionals to appreciate the person as a unique human being. The development of a safe and trusting

environment that is gay friendly may enable older lesbian and gay people to 'disclose and express their identities, and thus become visible, where they feel it is appropriate' (Hughes, 2007, p. 207). Providing a safe healthcare environment may therefore enable the individual to come out if they feel this is appropriate, whereas an environment that is characterised by 'repeated negative experiences with various providers may cause a person to delay or avoid seeking care' (Saddul, 1996, p. 4).

As well as recognising uniqueness, it is important to ensure that individuals feel empowered rather than disempowered by the care environments in which they may find themselves. This links to notions of agency/passivity (Todres *et al*, 2009), and the importance of a sense of self-worth. Lack of acceptance and fear of discrimination may lead to self-censorship about one's sexuality, and a need to disappear back into the closet (Gay and Grey in Dorset, 2006). Fear and internalised homophobia can therefore have a negative impact on an individual's sense of agency, leading to increased passivity and poor mental health outcomes. This has been clearly articulated by Todres *et al* (2009, p. 70), who suggested that 'a sense of agency appears to be very closely linked to the human sense of dignity. When this is taken away, one's sense of personhood is diminished.' An approach to healthcare practice that is person-centred and that embraces humanisation therefore values the unique individual through dignity, respect and understanding.

The significance of relationships and social capital is also an important aspect of the lives of older lesbians and gay men (Masini and Barrett, 2008). Social support from other lesbians and gay men may have an essential role in maintaining an individual's identity, and is closely aligned with cultural dimensions (Fullmer *et al*, 1999). The provision of services that deny the need to link with a social group or culture can prevent an individual from accessing important positive validation with regard to their social identity (Langley, 1997; Beeler *et al*, 1999). Therefore it is important for healthcare practitioners to remain sensitive to the importance of human connectedness, and the vital role that social capital plays in the lives of individuals from minority groups.

Issues that focus upon maintaining good health, decent housing, companionship and lack of poverty apply to all older people. However, for minority groups of older people, it is important to raise awareness of their different life experiences and the damaging effect that these may have had. Where there is a difference, it is in the need for validation, unprejudiced acceptance by the wider community, and recognition of diverse lifestyles and family situations (Gay and Grey in Dorset, 2006). This supports the assertion by Musingarimi (2008b) that there is a need for affirming environments that embrace diversity and

that positively validate the lesbian and gay lifestyle within healthcare settings.

Conclusions

This paper has suggested that it is important for healthcare professionals to adopt a person-centred approach which humanises care and values individual diversity. At the centre of this approach is an understanding of the unique biographical narrative of each patient, with individual agency being supported and diversity of experience valued and validated. The findings from the Gay and Grey project suggest that concerns about homophobia and heterosexism mean that older lesbians and gay men are particularly vulnerable when they come into contact with healthcare services (Gay and Grey in Dorset, 2006). It is important that they can trust both healthcare environments and practitioners to adopt a non-judgemental and person-centred approach.

As this is an emerging area for research and policy in the UK, methodologies and population-based studies that reflect the diversity within the older LGBT population are needed, particularly with regard to the needs and experiences of older LGBT people from ethnic minorities, rural populations and a variety of socio-economic backgrounds (Grossman, 2008). These can be used to inform healthcare practice, the development of appropriate services, and the training of future healthcare professionals who are sensitive to individual uniqueness and diversity of experience within the ageing population.

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CONFLICTS OF INTEREST

None.

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