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End of Life Care Considerations for Gay, Lesbian, Bisexual and Transgender Individuals Deb Rawlings

Abstract

Negative social attitudes, discrimination, and homophobia affect gay, lesbian, bisexual, and transgender (GLBT) individuals during their lifetimes. These experiences can affect how these individuals access health services and interact with health professionals, resulting in adverse outcomes compared with their heterosexual counterparts. End-of-life experiences can also be shaped by these factors. There are implications for health professionals in terms of equity of access to targeted health care, preventive screening, and visibility in policy, as well as in principles of inclusiveness, dignity and respect, and competence in care. This article takes a brief look at some of the issues specific to the end-of-life care of GLBT individuals, using a case study as an illustrative example. Holistic care at the end of life is a familiar concept to palliative care nurses, but it is important to place greater emphasis on considering competence in aspects of care relating to sexuality.

Keywords: Gay, lesbian, bisexual, transgender (GLBT) / Equity / Discrimination / Homophobia / End-of-Life care

Introduction

The health decisions that people make are influenced by the environment in which they are born, raised, and live their lives, and therein lie considerations for some gay, lesbian, bisexual, and transgender (GLBT) individuals (see *Box 1* for definitions) (Woodward and Karachi, 2000). Health is a mirror of social circumstances, requiring health care to be inclusive and equitable for all individuals, without barriers based on lifestyle choices. This discussion paper highlights some of the issues that GLBT individuals may face at the end of life, such as the long-term effects of negative social attitudes and overt discrimination and homophobia (Fish, 2010). If unaddressed these issues can ultimately lead to inequity in access to health care, compromised health-care delivery, and disparities in quality of life and health outcomes (Buffie, 2011).

General Health Considerations for GLBTI individuals

Global population estimates of GLBT persons range between 4 and 10% (Meyer and Wilson, 2009). However, there are limitations inherent to data collection strategies that require self-identification of sexual orientation, as some people may not admit to their lifestyle choices. Such difficulties go beyond population censuses: for health professionals non-disclosure of sexual orientation has implications for the visibility of patients' health needs, e.g. in engagement with certain symptoms eg, engagement with patients regarding symptoms that could be indicative of early disease, and for ensuring that those people who are important to the patient are included in the patient's care (Almack et al, 2010).

GLBT individuals cite many reasons why they might not necessarily 'come out' to health professionals. They may fear discrimination, stigmatization, or poor care; may feel threatened by health professionals; or may simply decide that their sexual orientation is not relevant to a particular visit (Schilder et al, 1999). However, non-disclosure can mean that the health issues of GLBT individuals may go unrecognized. Hence, as for any other individual or group with potentially compromised care outcomes, health professionals need

to be aware of the issues that may be of relevance (Rosenstreich et al, 2011).

There are specific health considerations for GLBT individuals. Indeed, sexual orientation can have an independent effect on health behaviours and care (Diamant et al, 2000). For example, GLBT individuals have higher reported rates of alcohol consumption, smoking, substance abuse, and obesity, as well as a higher prevalence of childhood sexual abuse than their heterosexual counterparts (Mulé et al, 2009). Historical events have left a legacy of distrust for many older GLBT individuals. For example, Jay describes how homosexuality was classified as a mental illness until the 1970s, with electroconvulsive shock therapy advocated for years.

Negative social attitudes as well as overt discrimination and homophobia are thought to have contributed to greater mental health problems in GLBT individuals, such as anxiety, depression, and increased suicide risk (Cochran and Mays, 2009). For some GLBT individuals, lifelong physical victimization has resulted in post-traumatic stress disorder (D'Augelli et al, 2006). Owing to their sexual behaviour or lifestyle choices, GLBT individuals also have a propensity toward certain illnesses, such as human papillomavirus (HPV)-associated anal cancers and breast and ovarian cancer in some lesbians and bisexual women—probably due to null parity (Frisch et al, 2003). Particular health issues that can affect the transgender community include issues relating to the management and use of hormone therapies and sometimes to illegal drug use, HIV infection, and participation in the sex trade (Gay and Lesbian Medical Association, 2001). HIV/AIDS has long been an issue for GLBT groups: much of the early literature focused on gay men, and to date they remain the group most affected (van de Laar, 2009). Many factors affect the higher rates of HIV/AIDS among sections of the GLBT population, including non-disclosure of sexual orientation (such as bisexuality) and high-risk sexual behaviour (such as unsafe sex practices) (Melendez et al, 2005).

Care needs at the end of life are often complex, and for the GLBT community there are additional issues about which health professionals must be aware. The rest of this article concentrates on the end-of-life care needs of GLBT individuals, using the case study in *Box 2* as its jumping-off point. This case study illustrates many salient aspects of the end-of-life care needs of GLBT individuals, including issues around living openly, participating in advance care planning, family, and bereavement.

End of Life Care

Once someone has been diagnosed with a progressive life-limiting illness that is not responding to therapy, the focus should be on optimizing function and comfort in physical, emotional, existential, sexual, financial, and social domains. Dying is a human process and there is a need to recognise sexuality as a critical element of humanity—a need that has yet to be fully addressed in the context of the end of life (Moller, 2005; Redelman, 2008). Grace (2005) highlighted that unless a gay person has HIV/AIDS they will be unlikely to find care at the end of life that supports their identity, and this is backed up by the dearth of literature relating directly to the end-of-life experiences of GLBT individuals, although arguably there will be many parallels with the experiences of heterosexuals (Almack et al, 2010).

For patients receiving palliative care, all of the social experiences of their lifetime come together at the end of life to form a network of relationships that provides emotional and practical support. For GLBT people there are issues that are uniquely related to their social experience and identity, such as patterns of resilience, coping, and vulnerability, that determine how they will approach stressful issues throughout life.

Living Openly

Discrimination is an issue for many GLBT individuals, for whom disclosure of sexuality

to health professionals may result in poor care or rejection (Eliason and Schope, 2001). Some older GLBT individuals may have hidden their sexual orientation earlier in their lives, for example because homosexuality was (and still is) illegal in some countries and so living openly as GLBT invited prosecution (Kees, 2000). The social worlds of GLBT people may be dichotomous: individuals may live openly in some circles but not in others. For example, family and friends may not be aware of an individual's same-sex relationship, with long-term 'friendships' perhaps not being recognized for what they really are. For many GLBT individuals, patterns that have been established over the course of their life will form the basis for their engagement with other individuals, including health professionals.

GLBT individuals may seek out health professionals who they regard as 'gay friendly' or more competent in minority sexual orientation issues, but this is generally not possible in the case of health professionals or caregivers providing end-of-life care at home (Cant, 2006). GLBT individuals may feel pressured to come out to caregivers regarding living arrangements that had previously been private; alternatively, they may in effect go back 'in the closet' (Price, 2010), with some choosing to hide their relationship to the extent of putting away photographs and personal belongings. Birch (2009) discussed in the context of dementia the added burden of inadvertently being 'outed' by a confused partner. Carers have also described discomfort at leaving a vulnerable partner in the care of someone who they perceive to be homophobic (Brotman et al, 2007). The stress of potential exposure to discrimination, in the place in which people have the right to feel most safe, needs to be a consideration of those providing care (Eliason and Schope, 2001; Price, 2010).

Advance Care Planning

Advance care planning is a priority area for palliative care and one that has seen investment at policy level on some countries in recent years (Street and Ottoman, 2006). As for Peter in the case study, when someone is no longer able to make their own decisions they will need someone to do so on their behalf. It has been suggested that, in the absence of an appointed surrogate or advance directive, under-treatment or overtreatment may result (Castillo et al, 2011). Discrimination can be a factor in decision making, with the role often falling to the 'next of kin' owing to a powerful legal precedent, in neglect of the position of same-sex partners. In many countries, same-sex partners are not afforded the legal protection that is offered by marriage, although steps have been made regarding their rights in this area (Castillo et al, 2011). Stein and Bonuck (2001) argue that relevant information to promote awareness of the medical, psychosocial, and legal implications of sexual preferences should be included in programmes and policies on end-of-life care.

In cases like Peter's, in which there is discord between the dying person's family of origin and their same-sex partner, the partner may have no or limited rights when it comes to being involved in end-of-life care or even in gaining access to the individual. This may extend to accessing the individual's body following death or being involved in decisions regarding burial or cremation (Grace, 2005). GLBT individuals have highlighted fears around family interference in decision making and fears that their wishes would not be respected when advocating for advanced care planning (Hash and Netting, 2007). Like their heterosexual counterparts GLBT individuals need to document their wishes, but they must do so in the context of their circumstances, such as by recognizing their partners in advance directives or by giving power of attorney. Dying intestate (without making a legal declaration regarding the distribution of one's estate) is problematic if the legitimacy of the partnership is not recognized. Resulting disputes over property can exacerbate the grief of the remaining partner, who then has to provide proof of the partnership (Birch, 2009).

Advance care planning can go some way to minimizing the impact on same-sex partners if formal mechanisms are in place (Riggle et al, 2006). However, one US study of 1000 GLBT individuals (aged 50–61) found that, although 73% of the participants had discussed end-of-life preferences with someone, only 42% had gone on to complete an advance directive (Metlife et al, 2006). Many reasons for this were given, including several that are also common among heterosexuals, such as feeling no immediate need for an advance directive or being unwilling to think about the issues. However, GLBT individuals have the added factor of having to disclose their relationship (e.g. to a lawyer) in the course of any decision (Stein and Bonuck, 2001).

Family

Some GLBT individuals develop support mechanisms within exclusive communities (often termed 'lavender families'), perhaps owing to alienation from their family of origin or simply to find acceptance (Neville and Henrickson, 2009). Like for Stuart and Peter, this can comprise members of their family of origin, heterosexual friends, and members of the GLBT community, who will be essential in providing support and taking on aspects of the caring role at the end of life, as with any family group at this time.

For some, entering into a heterosexual marriage and having children can be a way of hiding or ignoring their sexual orientation, with family members varying in their degree of knowledge and acceptance of the individual's true sexual orientation. For older people or those at the end of life this could include spouses and children who are unaware of the individual's sexual orientation, ex-spouses and children who are aware and accepting, or those who are unaccepting and who may prevent access to children or grandchildren. The end of someone's life is often a time for reconciliation with family, old friends, or children who have become estranged, but it may equally be a time when ongoing complex family dynamics come into play.

Informal Caregiving

There are many GLBT individuals, especially older people, who live alone or have caring responsibilities and are isolated, with few practical support networks. These individuals have fewer options in terms of where they can be cared for, as evidenced by many older gay men who lost friends and partners to AIDS in the 1980s and 1990s (Metlife et al, 2006). Large numbers of midlife GLBT individuals also provide significant support, care, and advocacy for older parents and for each other, and are sometimes considered to be 'single' or to have fewer responsibilities by their heterosexual siblings—especially if they have no children (Birch, 2009) The earlier cited study of 1000 GLBT individuals (Metlife et al, 2006) found that one in four participants had provided care for an adult friend or family member within the last 6 months, but at least one in five were unsure who would in turn care for them.

Bereavement

For those in a same-sex relationship, the death of a life partner and subsequent bereavement can be more difficult if the relationship was not openly acknowledged, leaving the remaining partner not able to grieve openly (Bent and Magily, 2006). The consequence of this non-disclosure and what Higgins and Glacken (2009) have termed 'silent mourning' is a lack of potential support from health professionals, from the person's own family, and from their partner's family. Using the case study as an example, if Stuart had been left with only the formal funeral that Peter's family had arranged he would have struggled with the lack of recognition of what he and Peter had shared and what they had meant to each other. The additional ritual and remembrance that Stuart, his family, and his and Peter's friends arranged became an important part of Stuart's recovery process.

For many older GLBT individuals, the impact of early multiple HIV/AIDS-related deaths has resulted in psychological distress, including depressive symptoms and often traumatic stress related to cumulative losses (Mahmood et al, 2004). The impact of bereavement in many of these individuals cannot be underestimated, including for those currently living with HIV who may have cared for (or currently be caring for) partners and friends and may have witnessed difficult deaths that they may fear experiencing themselves.

Implications for care

Multidisciplinary is inherent to palliative care, and approaches to engage with the GLBT community need to embrace this philosophy as well as considering intersectoral involvement with multiple agencies, including non-Government organizations, the public sector, and peak bodies. For example, those with mental illness benefit from partnership approaches to care, such as between mental health organizations or groups, sexual minority clinical programmes, palliative care services, counselling and/or bereavement services, and health and community services (Davie, 2006). Individuals, organizations and advocates could similarly work together to address GLBT issues. Yamin (2005) sees that the recognition of every individual's right to health care must mean equity in access and the removal of systemic discrimination, so multidisciplinary groups could for example look to the provision of privacy on wards and advocate against the separation of families due to residential aged care placements.

Some health professionals experience discomfort in providing care to GLBT individuals, perhaps stemming from their cultural or religious background, and may be intolerant to that which they do not understand or approve of (Peate, 2009). Timely and effective access to health care is taken for granted by most heterosexuals, but it is unsurprising that some GLBT individuals do not have high expectations of health services (Brotman et al, 2003). For nurses, there is a clear need to identify and minimize the barriers to health care that are faced by such marginalized groups (Equality and Human Rights Commission, 2009; Dysart-Gale, 2010). An example can be found in lesbian and bisexual women's need for breast screening (e.g. due to smoking, obesity, and null parity), which is often not accessed (Hart and Bowen, 2009). Nurses could help to address the ignorance of the need for these procedures with the provision of targeted information, thereby helping to increase preventative screening.

Health professionals need to be aware of the GLBT community's historical stigmatization, specific risk factors, and health needs, as well as being culturally sensitive when working with GLBT individuals (Mayer et al, 2008). Health professionals' reactions to disclosure can have a great impact on care—either positive or negative. The implications of these issues for care at the end of life include the need to respect an individual's sexuality as part of who they are, to become more educated on issues relevant to GLBT individuals, to address barriers to communication, and to advocate for inclusive services (Cant, 2006, Johnson et al, 2005). For example, those services that are more 'gay friendly' can help to relieve some of the burden on partners and informal caregivers who may not otherwise access services because of fears of discrimination (Hughes, 2010). Recognition is also needed of the diversity of the 'lavender families', who need to be acknowledged, respected, and included as family as identified by patients. Civil partnership arrangements or arrangements that recognize same-sex partners as next of kin also need to be considered when addressing who needs to be involved in decision making at the end of life (Birch, 2009; Price, 2010).

Conclusion

GLBT individuals face many potential adverse health and quality of life outcomes. There are still inequities based purely on sexual identity that should not be ignored by health professionals. Palliative care providers frequently do not understand the degree to which GLBT individuals' experiences, such as of hostility, violence, or rejection, can affect how they seek care and their experiences at the end of life. However, by focusing on dignity, respect, and fairness, it should be possible to improve outcomes and quality of life for GLBT individuals and communities.

CASE STUDY

Peter* was a 35-year-old gay man being treated for advanced anal cancer that was diagnosed quite late as Peter did not disclose his sexual orientation to his doctor, being reluctant to talk of symptoms and admit to his lifestyle choices. Peter and his partner Stuart had lived together for nearly 2 years. Peter had no contact with his parents, having been rejected by them as a young man when he disclosed his sexual orientation. Peter had always been wary of who he disclosed his sexual orientation to outside his network of Stuart's family and his and Stuart's friends.

Peter's disease progressed; he was admitted to hospital and was seen by the palliative care service, who initiated discussions around where he wanted to be cared for. On hearing of Peter's deteriorating condition, his parents made contact and started visiting, asking to be included in these conversations. This became difficult, with tension and arguments flaring up between Stuart and Peter's elderly parents, who felt they would not be comfortable visiting Peter at home and wanted him transferred to a hospice for care. Stuart wanted to care for Peter at home with their friends around them. Peter and Stuart never discussed advanced directives, gave each other power of attorney, or made wills, so when Peter started struggling to make his own decisions his parents felt that they could make choices on his behalf.

Peter deteriorated quickly, before any decisions could be made. Tensions continued, with growing animosity from Peter's parents as his friends wanted to see him before he died. Peter did eventually die with his parents present, but Stuart did not get back to the hospital in time. On his return, he found that Peter's parents, who were clearly quite distressed, would not allow him into the room. He had to wait until they went home before he could spend time with Peter. In bereavement, Stuart had support from his own family and friends but was excluded from helping with any arrangements after Peter's death and was made to feel an outsider at the 'family' funeral. He subsequently held a private remembrance service, a forum in which to express his grief openly, with people around him who acknowledged his part in Peter's care and his role in Peter's life.

**Names changed to preserve anonymity.*

BOX 1 TERMINOLOGY

GLBT: gay, lesbian, bisexual, and transgender. This acronym is commonly used to collectively refer to all of these groups of people. Variations to the GLBT acronym exist but are not used or discussed here.

Gay: refers to a person whose primary emotional and sexual attraction is toward people of the same sex/gender. The term is most commonly applied to men.

Lesbian: refers to a woman whose primary emotional and sexual attraction is toward other women.

Bisexual: refers to a person who is sexually attracted to people of both sexes.

Transgender: refers to individuals who do not identify themselves with their gender as determined at birth. This includes transsexuals, cross dressers, and the biologically intersexed, who may be of diverse sexual orientation, from homosexual to bisexual and heterosexual.

**Adapted from Blanch Consulting (2003).*

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