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Privacy, sexual identity and aged care

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PRIVACY, SEXUAL IDENTITY AND AGED CARE

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ABSTRACT

Privacy is a key quality indicator in aged care and is acknowledged in the Australian Government's Quality of Care Principles 1997. The promotion of individuals' rights to privacy is also used to advocate freedom of sexual expression and was used as a rationale for the decriminalisation of homosexuality. This paper examines issues facing older gays and lesbians in the public expression of their sexual identities in aged care settings. It focuses on privacy practices that facilitate or limit identity expression. It is argued that aged care providers and workers need to construct relatively safe environments that enable older gays and lesbians to disclose and express their sexual identity. Failure to do so may mean that some gays and lesbians are forced back into the closet in their older age: a form of institutionalised homophobia.

INTRODUCTION

Of all that is considered private, the most private is sex. Our sexual genitalia are indeed our private parts. When we hear of individuals' private lives, it is of their sexual lives that we imagine. And when in 1973 then Prime Minister, John Gorton, moved in the House of Representatives that homosexuality should be decriminalised, he saw individual freedom as being enacted through a respect for individual privacy.

> We are concerned with one question and one question only. That question is, I repeat: Should homosexual individuals who are adults, who both wish a homosexual relationship with each other, who do not flaunt it but who act in private, withdrawn from the public gaze, be dubbed criminals and be subject to punishment by the criminal law? I suggest to the House that they should not be treated in that way (House of Representatives 1973: 2327).

The promotion of freedom of sexual expression through a commitment to privacy signifies only a limited acceptance of gay and lesbian identities and seeks to restrict them to a private realm (MacKinnon 2000). Johnson (2002) argues that Gorton's sentiments are still very much part of the political discourse in Australia, where many continue to self-regulate public displays of their homosexuality, such as same sex couples refraining from holding hands in

public. However for those gays and lesbians who were in their 20s in 1973 and who are now in their 50s, homosexuality is unlikely to exist solely in a private underworld. Public representations of homosexuality have increased considerably and for many the flaunting may now be accompanied more by pride than shame. As more of those who publicly identify as gay or lesbian approach older age, aged care providers and workers will need to respond to the importance of the public expression of older people's sexual identities. In this paper I discuss the construction of public and private issues for older gays and lesbians and consider some implications for aged care.

THE PUBLIC AND THE PRIVATE

In western societies the concepts of the public and the private occupy the centre-ground of the social sciences, including public policy analysis. According to Mills (1959: 22) the value of the social sciences lies in the development of the sociological imagination: the capacity to see 'the intimate realities of ourselves in connexion with larger social realities.' Similarly, feminist scholars have exhorted us to see the personal as political. What were once private and unspoken matters, such as domestic violence, are reconstructed as public problems (MacKinnon 2000).

The concepts of the public and the private seem to hold a mythic power for many people, not least politicians. Bailey (2002) identifies three locations or

containers of the public in western societies: the state, civil society and community. All three are changing: the role of the nation-state is shifting due to globalisation and the influence of supranational organisations; increased participation in civil society is promoted by both sides of politics (e.g. Harris 2002); and the expansion of global communication suggests that communities of identity are likely to be just as important as communities of locality in the future. Despite the value of these publics, arguably it is the private realm – characterised by solitude, intimacy, anonymity and reserve (Westin 1967) – that is even more valued in western societies. For Bailey (2002: 16)

> The modern sensibility undoubtedly accords a very high value to what it takes to be the moral qualities of the private… It sees the private as historically and ontologically prior to the public in some way (quite wrongly in my view), and that the private is a shield and protector or refuge from a public world of danger (Bailey 2002: 16).

In the risk society, where the individual is exposed to global forces (Beck 1992), the private realm offers a moral haven. The ascendance of the private, as with individualisation, has accompanied the globalisation of liberal capitalism and the promotion of individual human rights as a means of achieving social justice.

While the notions of the public and private shift in relation to each other, they are not necessarily mutually exclusive. The public world is rarely public to everyone: some public matters, such as national security, are kept intensely private or secret. Conversely, privacy involves not simply the internal experiences of the self. Privacy also involves the extension of the self into the social world (Rykwert 2001). Thus, the expression of an individual's privacy (e.g. the marking out of personal territory) is a public act. Similarly privacy can be seen to apply not just to a sole individual, but to two or more individuals connected through intimacy (Solove 2002).

The tensions between the public and the private are particularly evident in aged care where intimate caring work – often provided by women in both paid and unpaid capacities – routinely crosses public/private and formal/informal boundaries (Ward-Griffin and Marshall 2003). In Australian aged care policy privacy is given considerable importance and is a key indicator in the Quality of Care Principles 1997, an instrument of the Aged Care Act 1997. To achieve accreditation residential and community care providers must demonstrate to the Commonwealth Government how they meet privacy and dignity standards. The importance of privacy in aged care is also emphasised by the Privacy Amendment (Private Sector) Act 2000 through which the privacy principles of the Privacy Act 1988 are extended to private sector providers. However, there are concerns that a focus on privacy to the exclusion of other rights, such as lifestyle and identity expression, may limit the ability of older people,

particularly older gays and lesbians, to be open about their sexuality (Harrison 2001, Hughes 2004). Following a discussion of the concept of sexual identity and the value of representing such an identity publicly, a range of privacy practices that facilitate or limit sexual identity expression will be examined.

SEXUAL IDENTITY

Sexual identity is a complex and frequently contested concept. Some hold that it is an innate and immutable part of human nature (an essentialist view); while others argue that it is shaped through the performance of social roles (a constructionist view). In psychosocial research on gay and lesbian ageing, sexual identity takes on an Eriksonian form (e.g. Erikson and Erikson1997) as the progression towards successful ageing is seen to have involved the resolution of earlier life crises, such as deciding to be open about one's sexuality (e.g. Brown et al. 2001). This approach affirms gay and lesbian identities as positive and normal in pluralistic societies: it affords such identities due recognition. In contrast, queer theorists, drawing on post-structural ideas, challenge rigid identity constructions, arguing that there is not one sexual identity but many shifting identities that are defined by the acting out of ritualised norms (Butler 1990). The queer potential lies in an awareness of the constructedness of these norms and a celebration of transgression, although it is not possible to stand outside of the norms (Butler 1993, Roden 2001). In queer politics the emergence of a queer identity that embraces a myriad of sexual

outsiders (Stychin 1995) suggests for some an essentialist drift, which, like gay, is easily consumerised (Bell and Binnie 2000). Others argue that political and pragmatic reasons mean that it is necessary to form a strategic identity despite increasing awareness of the fluidity of sexuality and dissatisfaction with gay and lesbian constructs (Green 2002, Smith and Windes 1999). For the purposes of this paper, it is recognised that while there are contested notions of sexual identity and for some such an identity is far from fixed, gay and lesbian identity constructions are important to many people and should be seen as a legitimate expression of one's self and agency.

While there are varying representations of sexual identity, one element that emerges is the sense that sexual identity relates to a minority or deviant sexuality. Thus although all people could be seen to have a sexual identity (in their identification with the cultural representation of their sexual behaviour and feelings of attraction), the concept is most commonly employed when talking about people whose sexuality is different and marginalised from what is considered normal or mainstream. So it is common to talk of the sexual identity of gay and lesbian people, but unusual to talk of the sexual identity of heterosexual people. Similarly, in Australia, when we talk about ethnicity we are often talking of non-Anglo or indigenous ethnicities, rather than of the ethnicity of white-Anglo Australians. Thus in using the term sexual identity, we not only recognise the cultural dimensions of sexuality, but also its politicised nature.

As with gender, sexual identity is both a public and a private matter. However, unlike gender and ‘race’, sexual identity is often invisible. When meeting people for the first time, it is rarely possible to tell if they are lesbian, gay, bisexual or heterosexual. For sexual identity to become apparent it is necessary for an individual to take action to present their identity to another. For gay, lesbian and bisexual people this is usually done by talking: disclosing to the other person this aspect of their identity (Hughes 2003). Other action can be taken to reveal one’s sexual identity. A gay man might dress in a manner that represents their commitment to their identity label and may appear stereotyped. Similarly a heterosexual man might dress in a manner that conforms to male heterosexual codes. A lesbian might attend an all-women event where the visibility of lesbian issues may be higher. In this context, the likelihood that she is a lesbian may be greater and more publicly accepted. Similarly a gay man attending a gay bar is representing his sexual identity in a more public manner. However, these other strategies are potentially ambiguous and for most it is through talking that sexual identity becomes visible.

Gays and lesbians who do not make their sexual identity visible are said, particularly by those who affirm gay and lesbian identities, to be in the closet or to be passing as heterosexual. According to Chekola (1994: 70)

> ‘The closet’ is an institution, a set of practices occurring within the context of a culturally or morally negative view about homosexuality, which has at least two functions. One is to provide a means of protection and survival; the other is to provide a means for hiding something about which one feels shame.

In some parts of the world, there is no doubt that publicly identifying as gay or lesbian exposes one to real dangers. Amnesty International (2001) reports numerous instances of explicit and implicit state-sanctioned violence against gay and lesbian people, including imprisonment, sexual assault, torture and the death penalty. Homosexuality is a crime in over 70 countries and even where legal those who are more open as gay or lesbian appear to be more at risk than others of physical assault (e.g. D’Augelli and Grossman 2001). The second function of the closet, as Chekola argues, involves hiding not so much from physical violence but from the emotional or psychological assault of being judged abnormal, deviant or immoral. The internalisation of such judgements is experienced as shame. According to Goffman (1968: 8) for the stigmatised ‘shame becomes a central possibility, arising from the individual’s perception of one of his own attributes as being a defiling thing to possess.’

For gays and lesbians, the process of talking for the first time about one’s sexual identity is referred to as ‘coming out of the closet’ or simply ‘coming out’. Coming out is experienced differently depending on the circumstances and

context. Formally, there may be a coming out process that marks the transition to full acceptance of one's sexual identity and a preparedness to present this identity publicly. Cain (1991) refers to the disclosures that accompany this process as therapeutic disclosures. They help the individuals see themselves in a different light and reject their stigmatised identity. Such disclosures are often made to those closest or most symbolic to the individual, often parents, siblings, spouses or children. As Miller and Boon (2000) acknowledge when examining the disclosures of sons to mothers, coming out involves a high degree of risk and feelings of vulnerability, and consequently individuals commonly exhibit some anxiety leading up to these disclosures. However, these formal disclosures are important steps in gay identity formation and many argue their benefit in terms of individuals' self esteem and general mental health (e.g. Elizur and Ziv 2001, Friend 1990).

In addition to formal or therapeutic disclosures, because being gay or lesbian is generally invisible, it is necessary to come out not just once, but continually as one goes through life, such as when making new friends or moving workplaces. These disclosures may be motivated by the desire to build relationships by being open with friends, by resolving or preventing a problem, as well as by a desire to increase the political visibility of gay people (Cain 1991). Openness about one's sexuality and sexual behaviour seems particularly important when receiving health care so that providers can intervene and provide advice with all relevant information at hand. However, gays and lesbians are frequently

reported to be reluctant to disclose information about their sexuality (including HIV status) when in contact with doctors, particularly when their doctor is not necessarily identifiable as 'gay friendly' (Klitzman and Greenberg 2002).

For older gay and lesbian people, the experience of coming out and feelings of connection to the gay and lesbian community is likely to be varied. Rosenfeld (1999) identifies two identity cohorts of older gays and lesbians. These cohorts are constructed not so much by birth and the defining experiences of adolescence and young adulthood, but by individuals' experience of the politicisation of their gay or lesbian identities. Those who formally (or therapeutically) came out before gay liberation's ascendance in the late 1960s, were born (as gay or lesbian) into a discourse of homosexuality as stigma. According to Rosenfeld (1999) gay liberation's rejection of stigmatised identities has been a cause of considerable conflict for some older gays and lesbians. These older people may feel uncomfortable with gay and lesbian visibility, particularly when it is seen to demean homosexuals in the eyes of heterosexuals. Consequently they may feel more comfortable in the stereotyped roles accommodated by heterosexual society, such as the camp queen. Older people who are part of a stigmatised identity cohort may feel discredited both by heterosexual and homosexual society. In contrast, those who came out since gay liberation were born (as gay or lesbian) into a discourse of homosexuality as status. These older people may feel the need to be open about their identity

in all aspects of their lives, believing that not to do so demeans them as people and exacerbates oppression.

As the years go by, the number of older gays and lesbians who identify homosexuality with status is likely to increase and, for aged care providers and workers, being open with older people about their sexual identity will become more important. However, despite this there will remain a number of older people who do not identify as gay or lesbian even though they feel sexually attracted to people of the same gender and may engage in sex with them. This may be because they remain closeted or because they purposefully wish to construct their identity differently. For some, other terms such as bisexual, queer, dyke or camp may be more meaningful. Others may reject the limitations of adopting an identity label. Aged care providers and workers need to be sensitive to generational differences and the different ways in which individuals present their sexuality. The challenge will be to enable them to express their own identity in their own way.

PRIVACY AND IDENTITY EXPRESSION IN AGED CARE SETTINGS

The talking about sexual identity and enabling of older gay and lesbian people to represent their identity publicly is both supported and challenged by a commitment to privacy. The enactment of privacy principles set out in law and policy (e.g. Quality of Care Principles 1997) helps construct environments

where older people may feel able to disclose aspects of their sexuality. It also provides opportunities for older people to engage in sexual behaviour either alone or with others. However, it may also provide health and welfare professionals with a rationale for ignoring sensitive issues such as sexual identity. In a seminar on lesbian and gay ageing, Harrison (2001) noted that a number of students asserted that such private issues should not be a focus for professionals and that everyone should be treated the same: a form of sexual identity blindness. A commitment to privacy above all else may end up constructing environments that lead older people to hide their sexual identity when they might otherwise be open.

Leino-Kilpi et al. (2001), in referring to privacy issues in health care settings, illustrate four dimensions of privacy - physical, psychological, social and informational - that provide a useful framework for thinking about privacy in aged care. Physical privacy relates to the extent to which individuals are physically accessible to others (Leino-Kilpi et al. 2001). This includes individuals' sense of personal space and their connection to a physical territory, such as a home or office. The lack of physical privacy in residential settings has been widely critiqued for its institutionalising effects and its failure to provide space for and recognition of the need of sexual expression (Minichiello et al. 1996, Nay 1992). As with other older people, older gays and lesbians require private spaces to engage in sexual behaviour by themselves or with others. It is laudable then that in Australian aged care policy considerable emphasis is

placed on providing private rooms and bathrooms (Gray 2001). However, as Bland (1999) argues in relation to the delivery of residential care in Britain, it is likely that social conventions regarding privacy continue to be breached because of the perceived need to minimise exposure to risk by maintaining a close surveillance of residents' behaviour.

In the provision of home care services, providers need to negotiate different territories. Some, such as a living room or kitchen, may be semi-public spaces with visitors easily accommodated. Bedrooms, bathrooms and toilets are clearly more personal territory. Providers will invariably need to request permission to enter these areas and be sensitive to individuals' personal effects in these rooms. Where people have not disclosed their sexual identity or are not obviously living with a same-sex partner, items throughout the home, such as artwork or photographs, may signify or suggest the sexuality of the occupant. This may provide aged care workers with an opportunity to discuss meaningful dimensions of the occupant's life and provide a point where a gay or lesbian identity might be disclosed. As with other older people, maintaining a degree of personal space and having personal territory is undoubtedly important for older gays and lesbians. However, where individuals feel different from the mainstream, the value of a personal refuge from the public world may be greater and any perceived threats to this refuge may be received more anxiously.

Leino-Kilpi et al. (2001) see psychological privacy as the ability of the individual to manage the experience of one's own and others' thoughts and feelings, and to develop personal values. Privacy in this sense relates to the ability to manage the internalisation of others' and society's values and norms. For gays and lesbians, psychological privacy might involve rejecting negative social attitudes toward homosexuality given one's knowledge about oneself and one's own values. Psychological privacy can be enacted by maintaining positive self-esteem and exercising human agency. Strategies that acknowledge older people's diversity and that value gay and lesbian identities would be important in facilitating psychological privacy for older homosexuals. Application of aged care standards focusing on the provision of support for older people's preferred lifestyles (Quality of Care Principles 1997) provides a basis for establishing rights to identity expression. Aged care workers need to be supported and appropriately trained so that they do not fall into the trap of treating older people as homogenous and failing to identify difference apart from variations in care needs (Bayliss 2000). By talking about diversity and providing an environment in which gay and lesbian identities are respected, aged care providers enable older gays and lesbians to identify themselves and to have their sexual identity acknowledged as a valued dimension of their lives.

Social privacy relates to the individual's control over social contacts, including with whom to have contact, and the frequency, length and content of interaction (Leino-Kilpi et al. 2001). Gay and lesbian people have, more than likely,

influenced who enters and exits their social networks depending on their accommodation of their sexual identity. Those who are homophobic may be quickly dropped from a friendship group. However, in older age gays and lesbians may exercise less control over the members of their social networks, including staff employed in aged care settings. Mattiasson and Hemberg (1998: 532) recognise the potential for homophobic responses by staff, although they hardly affirm the value of gay and lesbian identity expression:

> Homosexuality … is something about which we all have individual feelings and moral values that influence both our personal and professional lives. It may be even more difficult to feel intuitively how one, as a carer, should approach the possible homosexuality of a patient compared with the sexuality of patients in general. … The overall aim is that the caring staff should treat all patients with the same respect. It is important to stress that we are not responsible for our feelings as such but we are responsible for how we deal with them and express them.

The possibility that older gays and lesbians might encounter homophobic or barely tolerant workers seems considerable. In residential settings older people are rarely consulted about the suitability of a particular worker (Roe et al. 2001), and in both residential and community-based communal settings, older people have little say in who they are required to engage with. Attention needs to be given to those networks and relationships that limit the expression of gay

and lesbian identities and strategies should be developed to enable gays and lesbians to exercise some influence over such relationships.

Informational privacy involves the control of information about people (Leino-Kilpi et al. 2001). This includes individuals' control over information about their own sexual identity. It could also involve the management of information about individuals by others through, for example, compliance with professional codes of ethics and privacy legislation. Both Commonwealth (e.g. Privacy Act 1988) and State (e.g. NSW Privacy and Personal Information Protection Act 1998) legislation set out privacy principles which need to be addressed by providers through privacy management plans. The proposed National Health Privacy Code will consolidate such legislation in relation to health care and will provide protections for consumers in the development of electronic health records (National Health Privacy Working Group 2002).

Despite these developments the ability of legislation to direct workers' privacy practices is limited. For example, workers employed by Aged Care Assessment Teams (ACATs) exercise considerable discretion over what issues are raised during assessment processes. While the Privacy Act 1988 requires that government agencies only collect information directly related to their functions, ACATs are expected to provide a comprehensive and holistic assessments of clients' care needs (Commonwealth Department of Health and Ageing 2002). Thus the scope for the lawful collection of information on older people seems

broad. However, whether or not enquiring about an individual's sexual identity might be seen as part of this duty is unclear and likely to be variable depending on the client's situation and the assessor's own values and perspective.

Aged care services need to provide gay and lesbian older people with the opportunity to disclose aspects of their sexual identity. In this respect aged care privacy strategies should be concerned with constructing environments where older people are able to make choices about the disclosure of personal information. By not providing opportunities to disclose, services enforce a code of secrecy on the individual. This is potentially damaging to individuals (e.g. by forcing them back into the closet) and represents a form of institutionalised homophobia. The opportunities for enabling the disclosure of sexual identity lie in skilled questioning and the development of professional relationships in which the client trusts the worker enough to be honest. Failure to do this means workers may block the disclosure of information, such as sexual health problems, that may be essential in the delivery of care. In a study of older lesbians' and gays' expectations as they grow older Quam and Whitford (1992: 373) highlighted some of the fears associated with ageing.

> One woman felt she was particularly vulnerable to the homophobia of her lifelong physician, who might provide her with poor quality care or no care at all if he knew she was a lesbian. Many respondents expressed a variety of concerns about discrimination in health care, employment,

housing, and long-term care compounding their expected losses associated with the aging process alone.

According to Langley (2001) agencies also need to examine their procedures to ensure, for example, that the assessment forms used are appropriate to gay and lesbian people's relationships. While many agencies (e.g. ACATs) may be under pressure to conduct one-off assessments of individuals' needs, it seems important that older people are given the space to talk about important dimensions of their lives, including their sexual identity, and to reflect on the relevance of these dimensions for the work at hand. Additionally, aged care providers could develop strategies to appear more 'gay friendly', promoting an active acceptance of diverse sexualities so that older gays and lesbians might feel more comfortable being open about their sexuality.

The issues raised in this paper challenge aged care policy, practice and research in that they question the heteronormativity of the aged care industry, where a (latent) heterosexuality is assumed. Policy and practice strategies could actively promote contexts that support older people to be open about their sexual identities. For example, while there is much benefit from healthy and active ageing programs that emphasise the strengths of the older population, such programs could be extended to promote awareness of the diversity of the older population, particularly in relation to sexuality. Most of the research priorities into ageing and sexuality identified by Minichiello et al. (1996) nearly a decade

ago have yet to be realised. Significantly, there has been a paucity of research on the experiences and needs of older gays and lesbians. On the basis of arguments in this paper, future research might examine how aged care workers and older gays and lesbians negotiate privacy issues in their relationships and how sexual identity is brought into the open.

CONCLUSION

As in other areas of life, in aged care the public and the private are intertwined. Wilcocks et al. (1987) talk about older people's experience of residential care as the negotiation of private lives in public spaces. In the delivery of home-based care private spaces become public with movement of aged care workers in and out of people's lives. Privacy in these contexts is important and, as most acknowledge, one indicator of older people's quality of life. However, privacy strategies should not simply require the hiding of aspects of the self. They should also be about the construction of relatively safe environments that enable the open expression of an individual's identity, including their sexual identity. A failure to provide such environments in aged care means that individuals will be forced to keep important aspects of their identity secret and closeted. Similarly privacy strategies should provide opportunities for the appropriate disclosure of personal information. By not allowing for opportunities for individuals to disclose their identity, aged care workers are not receiving the appropriate information on which to intervene. And by not

providing the opportunity for sexual identity – particularly a non-hetero sexual identity – to move from being a private to a public issue, aged care services are contributing to the marginalisation and invisibility of gay and lesbian older people.

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