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Older LGBT people's care networks and communities of practice: a brief note

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Abstract

This paper critically examines literature relating to the care of older lesbian, gay, bisexual and transgender (LGBT) people. It promotes an analysis of the network context of this care and advocates the use of the concept of 'communities of practice' to understand the processes of network participation and identity negotiation.

Introduction

The issues faced by lesbian, gay, bisexual and transgender (LGBT) people as they grow older have largely gone unacknowledged by governments around the world and have only recently been getting attention in the social work literature. Critical issues include discrimination and heteronormativity in the health, social care and aged care industries, and concerns about isolation and lack of supports in later life (Harrison, 2004; Hughes, 2007b). While much of the public discussion in countries such as the United States and Australia relates to the provision of LGBT-specific residential and retirement homes, the reality is that for most older LGBT people – as with other older people – care will be delivered through networks of community-based providers, including informal care-givers (Harrison, 2002). However, actual or anticipated discrimination may block older people's access to formal services (Hughes, 2007b), placing additional demands on care-givers and isolating them from the formal service system (Brotman et al., 2007).

These are critical issues for social workers working both in direct support roles and in case management and assessment activities. This brief note critically reviews key literature on care networks and their implications for older LGBT people. It also

highlights the significance of the concept of 'communities of practice' in conceptualising these networks, and in informing future research.

The paper arises from an ongoing research project on the diversity of older lesbian and gay people's care networks. Treating each care network as a separate case, the project involves qualitative interviews with network participants, including the older lesbian or gay care-receiver, informal carers (e.g. partner, friends and family) and formal care providers (e.g. community health staff, home assistants). The purpose of the project is to analyse the way in which the care-receiver's identities – including but not limited to their sexual identity – are negotiated by these different parties and how network practices impact on the delivery of person-centred care. The project is informed by the conceptualisation of care networks and communities of practice as outlined in this paper.

LGBT older people, carers and care networks

Like heterosexuals, LGBT people are actively involved in providing and receiving care in later life. Emerging research in North America on LGBT care-giving indicates that LGBT people contribute substantial care and support to ageing parents, partners, friends and others (Coon, 2003; Brotman et al., 2007; Shippy, 2007). A survey of 341 LGBT people aged 50 and over in New York revealed that 22% had provided care to a member of their 'family of origin' in the preceding five years and 24% had provided care to a member of their 'family of choice', such as same-sex partners and LGBT friends (Cantor et al., 2004; Shippy, 2007). The importance of a 'family of choice' has particular resonance for many LGBT people and there is evidence that many would like to age – and be cared for – in communities populated by their partners, LGBT friends and like-minded others (Cronin, 2004; Hughes, 2007a).

In western societies care-giving is typically understood as a family activity undertaken by opposite-sex partners and adult children (Manthorpe, 2003). The international literature on family care-giving highlights the complexity of decision-making about care arrangements and the temporal context of care-giving transitions. That is, in the main, care-giving emerges out of pre-existing relationships and takes different forms over time

according to the changes in the relationship and the illness 'career' of the care-receiver (Hughes and Heycox, 2010). Intersecting factors impacting on decisions and motivations to provide care include normative obligations (especially for women), proximity and cohabitation, continuity of relationships and the degree to which support is reciprocated (Carpentier and Ducharme, 2003; Fast et al., 2004; Szinovacz and Davey, 2007).

For LGBT carers (many of whom would be older themselves), recent findings from the United States indicate that they may experience the transition into care-giving – including the factors impacting on decisions to provide care – differently from the general population. A survey by Grossman et al. (2007) of 199 gay, lesbian and bisexual carers suggests that while reciprocity does play a role, normative gender expectations may not be as great as for heterosexual carers. Conversely one-third of those in the New York study caring for a member of their 'family of origin' reported that more involvement was expected of them because they were perceived as having fewer family responsibilities than heterosexual relatives (Cantor et al., 2004). Yet key questions remain. For example, to what extent do reciprocity and continuity of relationships impact on decisions to provide care for LGBT friends, including ex-partners? And what impact does a sense of commitment to LGBT communities have on the provision of care to these people?

In care-giving research and policy, prominence has typically been given to the person identified as a primary care-giver, although in recent years more recognition has been accorded to wider networks of care that provide support and assistance to both older care-receivers and primary care-givers (Fast et al., 2004; Keating et al., 2003; Szinovacz and Davey, 2007). These networks appear to be especially important for older LGBT people given their likely lesser reliance on 'family of origin' relationships as sources of care and support (Cronin, 2004; Heaphy et al., 2004; Langley, 2001; Manthorpe, 2003). In a recent Australian survey (QAHC, 2008), LGBT people reported that they expected to gain emotional, physical and financial support from a wide range of parties, including same-sex partners, LGBT friends, heterosexual friends, community agencies and, to a lesser degree, siblings, extended family members and adult children.

The need for further research into older LGBT people's social, support and care networks – including how friends move into (or resist) care-giving roles – is underlined by the concerns expressed by LGBT people about becoming socially isolated in older age. Social isolation is of particular concern to older gay men, despite the fact that many maintain connections with friends and family (Shippy et al., 2004; Hughes, 2009). Older people living with HIV/AIDS are also identified as at risk of isolation and typically access fewer support services than their younger counterparts (Pitts et al., 2005; Cummins and Trotter, 2008). For carers, there is evidence that many become isolated from their social and work networks after undertaking caring responsibilities, which are typically carried out in the private domain of the home (Russell, 2004).

Care networks can be distinguished from both support networks and social networks (Keating et al., 2003). Social networks comprise webs of individual relationships, while support networks are made up of those relationships which provide emotional and tangible assistance. Care networks are a further subset and emerge to provide emotional and instrumental assistance to older people because of specific needs associated with their health or disability (Fast et al., 2004). According to Keating et al. (2003: 117) 'fundamental to understanding the caring capacity of the informal sector is to establish the ways in which social networks evolve into care-giving networks when a member has an increased care need'. Understanding care networks better is of particular significance because increased network participation is associated with improved well-being and emotional health, especially for older people (Wenger, 1997; Thomése et al., 2005) and people living with HIV/AIDS (Emlet, 2006). It has also been identified as a key factor in reducing carer burden (Russell, 2004).

Of course a care network may not just involve partners, friends and family, it may also include formal care providers. However, the interaction between formal and informal carers is an under-researched and under-theorised dimension of the international family care-giving literature (Victor, 2005) and there is little understanding of how these interactions impact on the quality of care provided (Piercy and Dunkley, 2004; Clark et al., 2008). Similarly, there is a lack of detailed knowledge about how formal care providers interact with LGBT care-receivers and care-givers, although there is evidence

that past experiences of discrimination and the fear of future discrimination impact on the quality of these relationships and may lead to delays in seeking help from formal providers (Hash and Netting, 2009; Williams and Freeman, 2007). A central issue for many LGBT people – arising from fears of discrimination – is the decision and manner in which to disclose their identity to formal providers. Yet despite the well documented barriers to identity disclosure in the health and aged care sectors (McNair et al., 2001; Hughes, 2007b, 2009), the benefits of disclosure are significant. In US research on older LGBT people's support networks, awareness of the older person's sexuality was a major factor in that person's satisfaction with support received (Grossman et al., 2000). Further, in research on health care use, disclosure of sexual identity is linked to improved help-seeking and better communication with professionals (Steele et al., 2006).

Care networks & communities of practice

So how do care networks affect the way in which care is provided and how identities (such as LGBT identities) are negotiated? Dominant theoretical approaches to understanding older people's support networks include the convoy model based on attachment theory, the exchange approach based on individualised reciprocity, and the individual choice approach which draws upon socio-emotional selectivity theory and theories of social capital (Thomése et al., 2005). While each offers complementary understandings of network relations (Victor, 2005), they lack an analysis of how the socially-situated nature of support and care networks affects identity and network practices (such as the provision of quality care). Conceptualising older people's care networks as 'communities of practice' (Lave and Wenger, 1991) adds another theoretical dimension that draws attention to the learning that can emerge from network relations and practices and the potential to improve the quality of these practices.

Communities of practice are groups or networks of people who regularly interact because of a mutual engagement in a joint enterprise (Wenger, 1998). This can be conceptualised as the provision of care to an older LGBT person. The interaction involves the construction of a group identity and varying levels of network participation by engaging in a shared repertoire of practices: 'routines, words, tools, ways of doing things, stories,

gestures, symbols, genres, actions or concepts that the community has adapted in the course of its existence' (Wenger, 1998: 83). A particular concern is how care networks for older LGBT people help maintain (or challenge) LGBT identities and how other identities (e.g. as a carer or care-receiver) are established through network participation.

Communities of practice are identified as vehicles for expanding confidence and competence in network activities and thus use of the concept also provides a means for understanding how capacity to provide care is affected by network participation. A focus for analysis could be on the way in which network members come to join the network, how they interact with each other, how they learn the common practices and how their sense of personal and group identity shifts through participation. This can provide partial insight into the temporal dimensions of care networks, including the changing experiences of network members, the shifting configuration of and engagement with formal services, and changes in the older person's illness 'career' (Carpentier and Ducharme, 2003; Szinovacz and Davey, 2007).

A key issue which emerges, however, is how power is exercised within these networks and how network members feel included or excluded as they interact with (and within) the network. In his critique of communities of practice, Fox (2000) draws on the actor-network theory concept, translation, to understand the processes of legitimate network participation and the exposure of conflict and power relations in these processes. This gives recognition to diverse and sometimes conflicting identities that are expressed within networks – an approach which appears to have much in common with recent research findings pointing to the complexity and diversity of older LGBT people's identity expression and community affiliation (Brotman et al., 2007; Cronin, 2004; Heaphy, 2007; Hughes 2007a, 2007b). It also has much in sympathy with recent research by Quinn and Evans (2010), based on a reading of Goffman's account of caring and mental health, which draws attention to the conflicts and complexities of everyday care-giving.

Implications for research

While the concept of communities of practice has been applied to an analysis of network relations in the health and human services (Lathlean and Le May, 2002; Payne, 2006) and in relation to knowledge management and innovation in organisations (Swan et al., 2002), it has yet to be applied to an analysis of older people's care networks involving both formal and informal care providers. Research in this area would assist in understanding care networks as a means of learning about and improving capacity to provide care. This has the potential for further development and application. For example, as Gabbay et al. (2003) strove to achieve with an interdisciplinary network of health and social care agencies, it may be possible to identify ways in which evidence-based knowledge can be introduced into care networks and become part of their everyday practices.

Research in this area would also provide insight into the unique configurations of older LGBT people's care networks, including the role played by friends. Of central importance would be the experience of identities – including but not limited to LGBT identities – in the context of these care networks. As Quinn and Evans (2010: 69) argue, 'For social workers, there is a need to work with concepts of identity, which provide a link between how one sees oneself and how others see us and enable carers [and arguably care-receivers also] to negotiate their identity within the dynamics of their culture.' Research into older LGBT people's care networks, utilising the concept of communities of practice, would assist researchers and social workers to move beyond conventional (western) conceptualisations of care-giving and recognise and respond more effectively to the diversity of relationships, identities and network configurations that older people and their carers navigate.

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