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Gay and lesbian carers: ageing in the shadow of dementia

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ABSTRACT
This article reports on findings from a qualitative study, undertaken in England, which explored the experiences of 21 gay men and lesbian women who care, or cared, for a person with dementia. The aim of the study was to explore this experience through the lens of a person's gay or lesbian sexuality. The paper reports two related themes that emerged from the wider study – respondents' hopes, fears and plans for the future and, specifically, the way in which their caring experiences had coloured their views and expectations of how their own health and social care needs may be met. Respondents' narratives reflect a range of pervasive anxieties about the future. First, about the possibility that they might be diagnosed with a condition such as dementia and, consequently, the myriad ways in which their sexualities and lifestyle choices may be perceived and interpreted as they themselves age and, possibly, require health and/or social care and support. In light of these concerns, respondents reflected upon the need for specialist service provision for older gay and lesbian people – an idea that was, perhaps surprisingly, not universally welcomed.

KEY WORDS – gay and lesbian sexualities, future care needs, specialist provision, dementia.

Introduction

Having lived through periods of turbulent political and social change, during which the church, the legal system and the state have attempted to warn and legislate against same-sex relationships, gay men and lesbian women are increasingly becoming a taken-for-granted part of the texture of contemporary life. This shift is evidenced by recent United Kingdom (UK) legislation, such as the *Civil Partnership Act* (2004), the *Equality Act* (2006) and the *Equality Act (Sexual Orientation) Regulations* (2007) that has demonstrated a (arguably rhetorical) softening of public and political attitudes towards sexual difference. Similarly, the field of gay and lesbian studies has ensured that issues of concern to this community (here loosely defined as an

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ideological construct, within which people are able to identify with others, rather than an extant 'group') are studied, commented and acted upon, in the UK at least, by an increasingly sympathetic government and a politically active and vociferous gay and lesbian movement. This broad field of study has, however, largely ignored issues of importance to *older* gay and lesbian people (though there are a small, but growing, number of researchers who are particularly active in this area), a reflection, perhaps, of the sense that ageism is endemic in all sections of society (Healey 1994).

In tandem with this, the field of gerontology, whilst demonstrating an interest in the difficulties associated with ageing as a member of a minority community, particularly ethnic minority communities (Daker-White *et al.* 2002; Manthorpe and Hettiaratchy 1993; McCracken *et al.* 1997; Patel *et al.* 1998; Rait, Burns and Chew 1996; Yeo and Gallagher-Thompson 1996), has similarly, though paradoxically, tended to overlook the experiences of older gay men and lesbian women. Cronin suggests that this particular omission relates, in the main, to the heteronormativity that legitimates 'differential treatment of those who stand outside the heterosexual regime' (2004: 108) and which informs theory and practice in the field. This omission should not be so surprising, however, as the field of gerontology has persistently overlooked the issue of older people's sexuality, other than to reflect older people's experiences in the context of residential care settings where sexuality is liable to be framed within the context of problem and pathology, being viewed as symptomatic of cognitive decline (Price 2006).

Work that does exist, however, reflects a range of persistent, and pernicious, anxieties associated with ageing and/or requiring health- and social-care support as a gay or lesbian person (Barbara, Quandt and Anderson 2001; Beehler 2001; Brotman *et al.* 2007; Eliason and Schope 2001; Cant and Taket 2007; Hash 2001; Heaphy, Yip and Thompson 2004; Price 2007; Moore 2002). These include the fear of facing negative reactions to one's sexuality, being forced 'out', losing contact with gay and lesbian friends and family, and of losing control of one's personal circumstances, leading to isolation and marginalisation. Brotman, Ryan and Cormier's (2002) work, in particular, demonstrated the lengths to which gay and lesbian people might go, first to ensure that their identities remain secret and, secondly, that they should be able to maintain their relationships after the advent of illness or disability:

> I heard a story once that one lesbian couple ... one of the partners changed her name to her partner's last name so that they would be taken for sisters. To be put in the same room. (2002: 6)

Indeed, the existing body of work suggests that the anxieties perceived by gay and lesbian people as they age may be well founded, as their interactions with service providers are demonstrated as being largely characterised by homophobia (irrational fear or aversion to people who are not heterosexual), heterocentrism (the, perhaps unconscious, assumption that everyone is heterosexual) and heterosexism (the privileging of heterosexuality above other sexualities) (Price 2010).

Brotman, Ryan and Cormier (2002) go so far as to suggest the fear of discrimination in health and social care services might actually prevent older gay and lesbian people from accessing services that they really need – thus being excluded from appropriate and timely health and social care. Another critical issue for respondents in Brotman, Ryan and Cormier's (2002) work was the fear of having to come out to service providers or, worse, of having to forcibly return to the closet, a familiar theme expressed by the respondents in the present study. Indeed, in the UK context, Heaphy, Yip and Thompson's (2003) study found that only 35 per cent of respondents felt health and social care professionals were likely to be positive towards gay and lesbian service users and respondents suggested that health and social care providers operated according to heterosexual assumptions and expectations.

Moreover, Heaphy, Yip and Thompson (2003) suggested that gay men and lesbian women expressed great anxiety regarding housing and care provision in older age. There was, they found 'notable distrust about respect for their sexual identities and relationships in such contexts' (2003: 50). Unsurprisingly, therefore, respondents' anxieties in my own study allowed for an exploration of the necessity, viability and/or desirability of specialist service provision for older gay and lesbian people. Given the nature of the preceding discussion about respondents' fears for older age, most respondents in my own study explored the notion of specialist services in the context of community and long-term residential/nursing care.

Others have also explored this issue, including Cantor, Brennan and Shippy, whose respondents suggested that the lesbian, gay, bisexual and transgender (LGBT) community were best at 'caring for their own' (2004: 6) and envisioned a developing role for LGBT communities in providing assistance for ageing members.

Thirty-three per cent of Cantor, Brennan and Shippy's (2004) respondents stated that the LGBT community should be a locus for social and emotional support for its members (though the numbers of people actually expressing a *need* for such support was less – 20 per cent). Moreover, 30 per cent of Cantor, Brennan and Shippy's (2004) respondents stated that they would like to have access to specialist LGBT retirement, assisted living or long-term care facilities. These findings, from the United States of America (USA), are broadly similar to those highlighted in the UK context by Heaphy, Yip and Thompson (2003) and Help and Care (2006), who demonstrated the ongoing difficulties faced by LGBT people when they attempt to access services through mainstream health and social care systems.

This article builds upon what is a relatively limited literature base to outline a number of issues related to ageing that may be of concern to gay and lesbian people. It is published as a companion piece to an earlier paper (Price 2010) that focused on one particular theme from the wider study – respondents' experiences of coming out (revealing their sexuality) to service providers. The common thread that links both papers and respondents' narratives is the issue of providing care for a person with dementia and it is through this very particular lens that the data in this paper is presented.

Participants in this study faced myriad challenges in providing support in this context and many of their experiences were characterised by trauma and multiple loss: lifestyle, home, employment status, relationships, social contact, and, for some, their social identity and sense of self. These losses reflect the fact that many respondents had made a variety of major life changes in order to support the person with dementia. For even the youngest of the respondents, then, the experience of providing care in this context permitted them to glimpse, or at least begin to imagine, their own potential futures. In this paper, it is through this very specific 'dementia care' lens that their hopes, fears, plans and expectations for these futures are refracted.

Methods

The study explored the care-giving experiences of 10 gay men and 11 lesbian women who care, or cared for, a person diagnosed with dementia. Of these 21 respondents, 16 cared for parents, two for other relatives, two for friends and one person cared for their partner. All respondents were White British and ranged in age from 23 to 67 years. As a group, they represent a highly educated, politically aware, active and age-diverse population. The data, however, reflect the fact that the study lacked a degree of cultural and socio-economic diversity – a limitation shared with much contemporary research into the lives of gay and lesbian people more generally.

Initial recruitment occurred through a contact within the Alzheimer's Society and the rest of the respondents became involved in the work using snowballing techniques – the majority of the participants through contact with the Alzheimer's Society's Lesbian, Gay, Bisexual and Transgender Carers' Support Group (a national initiative in the UK). The geographic location of respondents was varied, ranging from major urban centres to a remote rural location. The work was promoted using leaflets (distributed at LGBT and dementia conferences), a dedicated phone line, journal articles and conference presentations.

Given that the gay and lesbian population are traditionally considered 'hard to reach', it was, perhaps, not surprising that data collection took, in total, four years to complete. All respondents were interviewed using semi-structured interviews, conducted in the style of a 'guided conversation' (Kvale 1996). Topics for the interviews were kept intentionally broad, but focused on receiving the diagnosis of dementia, taking on the role of 'carer' and respondents' subsequent experiences of formal and informal service provision. Respondents were also asked if and how their experiences of providing care had influenced their thoughts about their own ageing trajectories.

Prior to interview, respondents were given an information sheet detailing the aims and objectives of the work and each respondent completed a consent form. The study was undertaken in accordance with ethical research guidelines published by the British Sociological Association (http://www.britsoc.co.uk/equality/63.htm). As a PhD thesis, the work was rigorously scrutinised and examined by internal and external examiners. In addition, the research benefited from the input of peer researchers who ensured that these guidelines were fully adhered to. All data have been anonymised to ensure respondents' confidentiality.

Interviews were recorded (using a digital voice recorder), transcribed in full and recurring themes were identified in the data and were coded using NVivo software. Data analysis was undertaken using a constant thematic comparative method (Glaser and Strauss 1967), though coding and analysis was undertaken post-data collection – an approach that is, it should be stressed, not consistent with classical grounded theory techniques (Price 2010).

In the following sections, analysis of the data reflects the course of respondents' narratives, rather than determining the direction of the work. As such, respondents' voices assume a very visible presence in the findings, which focus upon the way in which their caring experiences have influenced their expectations of how their own health and social care needs may be met as they age and their concerns and anxieties about the future in this context.

Living in the shadow of dementia

One of the pervasive effects of caring for a person with dementia, for many respondents in this study, was the way in which being so close to the condition made them consider the range of possibilities for their own cognitive futures. Being diagnosed with dementia was described as 'my worst fear' by one respondent, whilst many of the younger respondents had researched the hereditary nature of dementia in order to assess the risks for themselves.

> One of the things I did, and it was actually quite difficult to do, was that I looked at the hereditary nature of dementia. I went on to the Alzheimer's Society website and looked around what they'd got. Because, I was thinking, you know, is this something that I'm at risk with, and need to know about?

Many respondents weaved issues of sexuality into and through these concerns, as having observed service providers struggle to provide genuinely person-centred services for the people they were caring for, most of whom were heterosexual, anxieties were expressed about the quality of care and support they themselves might receive as a member of a sexual minority. The general sense was that it was unlikely that their diverse sexualities would be acknowledged, respected or, even less likely, celebrated.

One woman focused on the possibility of her being diagnosed with dementia and had concrete ideas about how she wanted her life to be reflected if this was the case:

Respondent: Hopefully, if I've got dementia, my son would hopefully make me my memory books like we made for mum and hopefully he would label them correctly you know: 'Mum with her partner, Julie; Mum with her partner, Debbie'.
Interviewer: Not just with A. N. Other . . .
Respondent: 'With Friend' you know, my unknown 'friend', because that's what would happen if anybody else was labelling them, you know. You know if a stranger was trying to understand the photographs of my life they'd think I had an awful lot of women friends (laughter) . . . it's horrible. So actually I've already started my memory book, it's already started . . . make sure people know who's on those pictures.

This respondent's plans suggest that she has to perhaps look further forward than most people would need to do at the stage she has reached in her life (51 years old). She is making plans to guard against the possibility that others may obfuscate and invalidate her life and lifestyle choices. These possibilities were also explored by a male respondent who also had firm ideas of what he should expect from service providers, should he or his partner require care in the future. His 'wish list' for his hypothetical residential home, for example, included the most basic issues of respect, privacy and personal care that should pertain for any resident. He expected, for example, people to knock before coming into his room, to be dressed in his own clothes and to be able to make choices about the way he lived his life. Additionally, he expected to be able to express his sexual preferences and have the important people in his life acknowledged and validated:

> Like my dad who's got all pictures of his family. I would be able to have all of my pictures, wouldn't I? With my arm round one another . . . And I'm going to take all my books with me . . . And I'd want Living TV because it's wall-to-wall gay programmes on that!

This respondent's specific expectations throw into sharp relief a number of potential management issues in residential care settings where the sexuality of people with dementia appears to be an issue that service providers struggle to recognise and which is, largely dismissed and pathologised (Archibald 1998, 2001, 2002*a*, 2002*b*, 2004).

This respondent's expectation that he would have access to gay literature and entertainment would require a radical shift in understanding about the way people in residential care settings, particular those with cognitive difficulties, experience and express their sexuality. It seemed unlikely to him that gay and lesbian sexualities would be afforded the degree of tolerance or understanding that would allow space for the acceptance and/or expression of alternative sexualities that he and other respondents would hope for. His view was shared by a number of other respondents. Another male respondent was, for example, similarly cautious about the possibilities of culturally competent care in residential and nursing home settings:

> . . . if my dad's current service provision was what I was expected to get, I'd be worried, because I just don't think I'd be on the map with it. And from the starting point of, I don't think older people are allowed a sexuality, *per se*, you know, that's irrespective of gay/heterosexual, and I think, if you add sort of LGBT stuff to it, then it just becomes even more increasingly taboo and invisible. So, I don't think I would get a good level of aware care.

This sense of pessimism is mirrored in the small amount of research into the attitudes of residential and nursing care providers. Hubbard and Rossington (1995), for example, reported stereotypical and unsympathetic attitudes to LGBT service users, whilst Opening Doors in Thanet (2003) reported that residential and nursing care providers tended to lack even a basic awareness of the potential needs of LGBT service users.

What became clear through the interviews in my own study was that respondents felt a strong need to mitigate against this by carefully planning for their futures. Like the woman quoted earlier, a number of respondents had made concrete plans for the onset of illness or disability. For some, this involved ensuring that their living circumstances and financial situations protected them from the vagaries of a heteronormative society.

> At the moment, we're going to get [date of civil partnership] under our belts. We're also going to look at will writing as part of that as well... so I think after [civil partnership date] we've got legal recognition of the relationship and I think that becomes a wee bit more straightforward.

Central to this process was the sense that it would be difficult to maintain privacy should health or social care services be required. Privacy was something all respondents valued and strived to maintain and many people feared for a future where such control may be no longer possible. They prophesied a future where the potential for information 'leaks' about their sexualities would be a stressful and anxiety-provoking possibility, where breaches of their privacy and carefully constructed control mechanisms might be compromised should they need more supported accommodation or residential care in future. For these people, the spectre of a disability, such as dementia, in which the possibility for self-advocacy is limited, suggests a concomitant potential for loss of control both of one's cognition and, by virtue of this, control of information regarding one's sexuality.

This point demonstrates the critical nature of the space between the private and public worlds of gay and lesbian people, which may, in fact, span a much greater distance than that which exists for many heterosexual people. For some gay men and lesbian women who are looking toward the future, the legacy of an historical narrative which has demonised, pathologised and criminalised their lives is one which, for some, endures through lasting feelings of shame and the perceived need to conceal their true identity.

The space to which I refer is, however, a paradoxical one. Whilst gay and lesbian identities have been legislated against and forced into the private realm (Fish 2006) by virtue of not being permitted an uncontested visibility in the public arena, gay and lesbian people, used to the invisibility and relative safety offered by this enforced segregation are, sometimes, reluctant to reveal themselves to a potentially condemnatory public gaze. It is this carefully guarded space that may be at risk and might be ineffectively breached by service providers coming into the home, who may fail to appreciate the importance and necessity of maintaining gay and lesbian people's privacy.

It may be hypothesised that younger gay and lesbian people, more accustomed to liberal approaches to diverse expressions of sexuality, would express fewer anxieties about their future care needs than those people who have lived through more trying times. Given that respondents' lived experiences extended over a considerable historical period and, therefore, that they were at varying stages in their own ageing processes, this disparity could, perhaps, be expected to be apparent here. Indeed, Rosenfeld (2003) makes much of the variety of experiences of different gay and lesbian cohorts in her work, which centres upon an analysis of gay and lesbian identity and how this is engendered, maintained and managed through discrete historical periods. She employs the Stonewall uprising (spontaneous opposition from within the gay community to government-backed oppression in New York City, in 1969) as an historical reference point that demarcates 'discreditable' and 'creditable' gay and lesbian identities (pre- and post-Stonewall generations). For those who belong in the 'pre-Stonewall cohort', the amount of energy that concealing their sexual selves consumed may have shaped their existence and, for them, the privacy afforded by the closet may have proved an appropriate social and cultural space and become 'a way to accommodate being the bearer of a polluted identity albeit at a considerable psychic and social cost' (Seidman 2004: 10–39).

> The criminalization of sex between men had the result that many gay men maintained aspects of their lives hidden from the rest of society or entered heterosexual relationships in the belief that this was normal and through which they could avoid public scrutiny. (Pugh 2002: 166)

Those who fall, by default, into the 'post-Stonewall cohort' (Cohler 1999) were lucky to have benefited from the feminist and liberationist movements that proliferated in the late 1960s and early 1970s and which 'effectively changed the symbolic and practical terrain on which gay men and women negotiated their past and present lives' (Rosenfeld 2003: 3). Rosenfeld's (2003) analysis would suggest that the need for privacy and the protection of one's personal spaces could be an expected feature of the older carers' experiences, whilst younger carers, used to a more open and accepting society, might be less concerned about issues such as this.

In this study, however, it was the context in which care was given, rather than chronological age or membership of a particular gay or lesbian cohort, that determined the nature of people's fears and anxieties and, whilst many of the older carers in the study did refer to fears of enforced visibility, this was mediated by the context in which they provided care, which differed markedly for each participant. Some provided care for a parent, others for a partner, others still cared for friends and/or other relatives. For some, care was provided within their own home environment meaning that their lifestyle, and thus their sexualities, was more evident to care providers than it would be for those caring outside this context. Others visited residential or nursing care environments and were, thus, caring at a greater distance. These varying contexts within which care was provided often determined the manner and extent to which carers' sexualities were visible and to what extent carers were 'out' to service providers. The age of respondents, therefore, was only one variable among many that determined carers' approaches and responses to providing care and receiving support.

A consistent concern across the age groups, however, was the importance of maintaining links with other gay or lesbian people if they became reliant on support from others. Indeed, Heaphy, Yip and Thompson indicated that lesbian and gay groups or communities were important sources of support for gay and lesbian people and provided a means of maintaining a gay or lesbian identity and ways of living that afforded 'a context for the formation of friendships, and social groups and organisations where individuals can be themselves' (2003: 12).

In the current study, one of the participants explicated this in her argument, suggesting that service providers should understand gay and lesbian-specific ways of experiencing both difference and belonging:

> I do strongly believe that we need to have special acknowledgement that in our society we are not 'the same' and that we need spaces where we can get together for no other reason than that we want to.
>
> For example, I've just been out on my first trip with the Gay Birdwatching Club, a national group of birders who go out at weekends together. Anyone might say well you can birdwatch in any group of like-minded souls – but there's something about being in a majority, sharing a culture, not having to explain, having the same reference points etc. etc., which straight people never even think about because for them it's the norm. We should not have to justify wanting this contact with other gay people other than to say we enjoy it!

North American gay and lesbian groups and academics have, seemingly, understood the importance of gay and lesbian social support networks and appear to have mobilised to manage the needs of their ageing members rather more visibly and, perhaps, successfully, than in the UK. Senior Action in a Gay Environment (SAGE) and The Lesbian and Gay Ageing Issues Network (LGAIN) are vociferous and active advocates for older gay and lesbian people in the northern USA. Both organisations produce well-funded and supported research, online journals and newsletters that raise awareness about the needs of older gay and lesbian communities. Whilst perhaps geographically specific, these organisations do much to promote awareness of housing, health care and long-term care needs of older gay and lesbian people. There are similar organisations in the UK, which appear to lack, however, the focus, funding and support enjoyed by those in parts of the USA.

Specialist provision

It is also in the USA that the notion of specialist gay and lesbian long-term care and retirement housing provision is experiencing an upsurge of interest and some respondents in this study were very much in favour of the development of similar provision in the UK (though they did not explicitly make comparisons between the two national contexts). For these people, the quality of care they might receive as a gay or lesbian person from those who were either gay or lesbian themselves, or who simply recognised and accepted that gay and lesbian service users may have needs that do not fit readily into standard health/social-care or residential and nursing home provision, was an important concern. This was related to broader concerns about the issue of personal identity and a sense of self that might easily be undermined in environments unsympathetic to diverse lifestyles, needs and preferences.

Asked if he felt there was a case for specialist gay and lesbian provision, one respondent suggested:

> Yes there is. And I'll tell you this ... When I'm 75 ... When I'm 75, should I need residential or nursing home care, I am not going back in the closet.
>
> I spent my life fighting to get out of the closet. I'm not going back into the closet. I want to be able to talk to you if you're sitting next to me about how I'm sad because I've lost the man in my life who is important to me. I don't want to have to talk in language that doesn't cause offence.

He went on to stress, however, that stereotypical notions of gay and lesbian identities might be an unfortunate common denominator for care in this context:

> They've all got this idea that all these 75-year-old gay men will all be going round rogering each other ... that's what they're thinking is going to be going on (laughter) ... But they are though, aren't they? 'Cos they define gay male sexuality by the sex act. And that's what it's always about. And that's what they see it as all the time.

Damaging stereotypes were a frequent concern for respondents, who similarly explored the ways in which gay and lesbian sexuality is framed in the public consciousness. Some respondents felt that these stereotypes would inevitably influence the type of care people received and present a façade of homogeneity that was based only on these stereotypical notions, rather than accurate assessments of individuals' needs:

> ... and also one of the dangers is you assume because somebody's gay that they all conform to a stereotype, that they all watch Danny La Rue and all the rest of it.

Others had mixed feelings about the notion of specialist care. One female respondent described the idea of gay and lesbian residential care as 'very cool', and outlined some of the necessary constituents of care in that context:

> I think the important issue ... would need to be the respect and understanding they deserve. Whether that be appropriate privacy with partner, recognition of next of kin

> etc. . . . and obviously yearly trips to Pride in a minibus and monthly visits to the local gay bars to look at the ladies!

On reflection, following the interview, however, and after discussion with her partner, this respondent's view altered, as she recognised the possibility that specialist services may be 'ghettoistic', perhaps generating further distance from the mainstream society. She concluded that 'it is society that needs to change attitudes to include gay people as the norm' and, as such, services should, she suggested, be truly inclusive, rather than specialist in nature.

The notion of the 'gay ghetto' was similarly explored by two respondents whose attitudes suggest a very real disparity in attitudes to this notion:

Respondent 1: I'm not sure about this. My difference is something I celebrate, I am proud of it, it gives me insights, awareness, understanding and joy. To be 'ghettoised' might diminish that.

Respondent 2: Well, I want to go into a residential *gay* home anyway. Because I want to be able to read *Gay Times*, I don't want to read the *Express*.

Interviewer: Some people I've spoken to have said, though, it would be kind of ghettoising us.

Respondent 2: Yes, and I *want* to be!

Others were able to analyse the notion of a 'ghetto mentality' (Roscoe 1988) in more detail. Specialist provision, one respondent suggested, could simply mean a sense of safety and relaxation, knowing that gay and lesbian identities were the norm. Asked what she thought of specialist services for gay and lesbian people, she responded:

> Wonderful, absolutely, definitely . . . Because you're the norm and I do strongly believe that . . . there's something about having a shared culture, and a shared . . . there's just something about that that's different. You know, you don't appreciate it until you stop being a minority, what it feels like to be in a minority . . . You get into the habit, you know, of being guarded.

A sense of shared culture and understanding was a consistent theme amongst those respondents who felt specialist service provision would be a positive development:

> If there were gay services, it would be fantastic. It would just be fantastic. 'Cos there'd be loads of understanding . . . 'Cos I think gay men and lesbians have kind of, we've all gone through a kind of struggle together, you know, just the process of coming out is, I think, just dead hard for everyone. Or it's potentially hard for everyone and I think that makes us into something special as we're sort of older, you know.

The notion of specialist services may, however, be a conceptual luxury born out of confidence in one's sexuality and being a member of a contemporarily visible and vociferous gay and lesbian population. A number of respondents reflected on the experiences of those people who had felt the need to actively conceal their identities throughout their lives and who may, in this context, see specialist provision as threatening to their carefully constructed control mechanisms. The notion of specialist provision for these people would, one respondent suggested, be anathema, but she further stated that this situation is likely to profoundly alter:

> I think what's new is that we've got a generation of older people who've been out and have had an out lifestyle. I mean, I've got two quite good friends who are 75 and 80 and they are a bit reminiscent of that era where you weren't really out . . . But that, I think, is going to disappear, and so there are going to be a lot more assertive gay people around who say 'Well, this is my partner, what are you going to do about it?' You know, 'What kind of care are we going to have?'

Another respondent furthered this analysis:

> It has to be prepared for now. Because if you introduce gay men's elderly services now, or gay and lesbian elderly services, it might . . . people might not go to it because they're still, people who are that age in 2007 then they still, like they might not even have come out even, you know, for all it's kind of daft that, you know, but that's how it still is for people of that generation.
>
> But I think people who are like me, in their forties now, like my age. In 40 years time, they'll be demanding, you know, like because they'll be used to sort of living together and being together and the idea of civil partnerships and all that'll be more sort of a thing, so, and I think there will be more provision for older gay couples and lesbian couples.

Other respondents commented on their fears about the possible negative reactions they would be subject to in long-term care contexts more generally:

> In residential homes, there's such big issues about homophobia from other residents . . . I think it'll be many years before mainstream services are gay friendly, lesbian and gay friendly. In fact, it will need the whole world to change to sort out homophobia from other residents in the homes.

A measure of the extent of this change is, perhaps, the 'kite mark' (a UK product and service quality certification mark) that is increasingly employed by services keen to advertise their awareness and acceptance of gay and lesbian people. It is an approach recommended by Heaphy and Yip (2006), who emphasised the need for knowledgeable and aware practitioners in health and social care. The kite mark, they suggested, was a visible sign to gay and lesbian people that they were entering an environment that allowed for, and respected, the existence of diverse sexualities. It was also referred to by one of the respondents in this study as a simple, but effective and reassuring, sign that times are changing:

> My dream is to have a kite mark so that LGBT people can see, at once, if a service provider is LGBT friendly. A kite mark that would indicate that staff have been made

aware of LGBT clients, and would indicate that prejudice of any kind would not be tolerated. That would make me feel safe and confident.

Conclusion

This paper began by explaining the context within which the respondents in this study were looking toward their potential futures. The diagnosis of dementia (in another person) and the sexuality of carers have combined to produce what may be a unique experience of caring and of service provision. As such, the specificities of the diagnosis itself undoubtedly mediated carers' experiences and service providers' responses to them and the people they cared for. Understandably, therefore, carers' visions of the future were overshadowed by their experiences of providing care for a person with dementia. For the participants in this study, then, dementia and the context in which they provided care was effectively superimposed upon their expectations, concerns and anxieties about their own ageing processes. As such, many respondents explored the possibility of themselves being diagnosed with a condition such as dementia whilst also linking their predictions for the future to their sexualities. In this context they explored, in some depth, the possible ways in which a dissident sexual identity may be experienced and managed, both by themselves and others, as they aged.

Most evident in respondents' accounts was the sense of fear and anxiety about a future which, it may be permissible to hypothesise, would not be the same for heterosexual people. In response to these anxieties, many participants explored the notion of gay and/or lesbian service provision and some respondents clearly felt that specialist provision provided by services that understood, and respected, gay and lesbian sexualities was the most appropriate response to experiences of, and fears for, services that they felt might not take into account their diverse identities. Others, however, were more reticent about the benefits afforded by specialist provision of this nature. These findings are somewhat at odds with early studies that have explored the health and social care needs of older lesbians and gay men, which suggested that most people were broadly in favour of specialist provision (Hubbard and Rossington 1995; Kehoe 1989; Lucco 1987). It should be noted, of course, that these three studies were undertaken in a different political and social climate than pertains in the twenty-first century and long before civil partnership legislation was enacted in the UK. It remains to be seen, therefore, what effects the *Civil Partnership Act* (2004) and related legislation might have in terms of promoting acceptance and inclusivity in the context of care provision and in social life more broadly. The results of more recent work (though still pre-civil partnership) suggest a closer alignment to the ambivalence felt by respondents in this study to the concept of specialist gay and lesbian service provision (Heaphy, Yip and Thompson 2003).

In the absence of a debatable nirvana in which people's diverse identities (of whatever nature) are genuinely respected and recognised, it is perhaps necessary for providers of services to older people generally to provide spaces, practices, language and symbols that suggest services are provided in genuinely non-discriminatory environments. Service users' responses are then a matter of choice, with the onus upon practitioners to indicate that they enter a practice relationship from a perspective of knowledge and acceptance. Otherwise, issues of sexual diversity are likely to remain significant, but unacknowledged, constituents of health- and social-care interventions.

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