Caring for Mum and Dad: Lesbian Women Negotiating Family and Navigating Care

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Abstract

This article reports on findings from a qualitative study that explored the experiences of twenty-one gay men and lesbian women who care, or cared, for a person with dementia in England. The aim of the study was to explore how a person's gay or lesbian sexuality might impact upon their experience of providing care in this context. Analysis of the data identified a number of consistent themes—carers' experiences of the early signs and symptoms of dementia, of receiving the diagnosis, becoming a carer and their hopes and fears for the future in light of their care-giving experiences. The article reports on one theme that emerged from the wider study—the strategies lesbian carers used to negotiate the complex and contested category of the 'family' in the context of their care-giving experiences. The findings highlight the variety of ways in which families, of both biology and choice, were central to respondents' experiences of providing care for parents with dementia and of receiving support for themselves.

Key words

Lesbian dementia family caring

The invisibility matrix

Much of the care given to older people generally, and to those with dementia in particular, is provided within 'the privileged category of family' (Aronson, 1998, p. 518). It is generally acknowledged, therefore, that providers of informal care are to be found primarily within the biological family unit; a number of studies suggesting that, for older people in particular, the primary care-giver is most often a spouse in whose absence adult children often undertake the primary caring role (Collins and Jones, 1998; Hirst, 2004). The gendered nature of this 'family' care is also well documented (Dahlberg *et al.*, 2007; Foster, 1996; Manthorpe, 2003; Tester, 1996; Twigg and Atkin, 1994; Ungerson, 1997), with the adult daughter being cited as the archetypal care-giver—an issue mirrored in the gender profile of carers of people with dementia (Levin *et al.*, 1989; Wenger, 1994).

The woman referred to above is framed within what Manthorpe (2003) refers to as the 'spinster model', in which an unmarried daughter is left at home to care for her ageing parent(s), and by Hash (2001) as the 'woman in the middle' phenomenon. The woman in question is in the 'middle' by virtue of her (customary) generational position (the adult child) and because of her particular personal circumstances—being perceived as torn between the demands of mother, spouse and worker (Hash, 2001, p. 17). As Manthorpe (2003) notes, 'the family is the linking relationship between all such models' (Manthorpe, 2003, p. 753) and it is suggested that a woman's familial situation and her gender (as a daughter, wife or sister) provide a culturally sanctioned frame of reference for working out 'the best thing to do' when it comes to negotiating caring responsibilities (Finch, 1989, p. 142).

Whilst gender is, then, one of the primary determining factors in care-giving relationships, the *sexuality* of female care-givers appears to be only a peripheral consideration (Manthorpe, 2003). The adult daughters referred to above, for example, if not part of a heterosexual partnership, tend to be classed simply as 'single' or 'never married' (Manthorpe, 2003). The neglect of lesbians' lived experience of providing care is, Manthorpe (2003) suggests, 'in contrast to the broad recognition the community care is largely reliant on women and linked to gendered patterns of relationships, employment and welfare supports' (Manthorpe, 2003, p. 755). The possibility that carers may be lesbian women is seldom, if indeed ever, addressed. As such, in the context of dementia at least, the care-giving contributions of lesbian women have been largely overlooked, having been constructed within a limited heteronormative (the presumption that everyone is heterosexual) framework.

This framework is one of the critical foundations of the biological family, the bedrock of which embodies 'a whole conglomerate of linked institutions', including gender, love and reciprocity (Plummer, 1992, p. 19). These notions all are centrally implicated in the giving and receiving of care and those whose caring experiences occur outside, or in contravention of, the heteronormative family may be seen to transgress expectations of how, and by whom, care is ordinarily provided. Lesbian carers may thus be seen to operate at the margins of conventional care-giving contexts and discourse. Consequently, other than in the context of HIV/AIDS, information about the care-giving experiences of lesbian (and gay) people is rare. Whilst there is, of course, much to be learned from the HIV/AIDS literature about the experience of caring for a person with the condition, there is little in this body of work that relates to the ways in which care-givers are required to negotiate relationships with their biological families in the context of providing, rather than receiving, care.

It has been argued, for example, that, in the context of potentially life-limiting health conditions such as HIV/AIDS, people who have been rejected by their families of origin may wish to resolve the problems associated with their biological family relationships (Patten and Walker, 1989). There are, therefore, parallels with the study reported here, but the critical difference between the two contexts (HIV/AIDS and dementia care-giving) is the notion of choice and the fact that, in the context of dementia care-giving, it is the carer, as opposed to the person being cared for, who is required to revisit sometimes fractured family relationships, whilst providing care for the person who may have been the impetus behind the original relationship difficulties and/or breakdown.

Despite the apparent dearth of information already noted, however, there is some relatively recent work that does suggest that lesbian women (and gay men) are centrally implicated in caring roles in the context of both families of origin and families of choice (see, e.g. Cantor et al., 2004; Fredriksen, 1999; Hash, 2001; Hoctel, 2002; Manthorpe, 2003; Manthorpe and Price, 2006; Price, 2008; Reiter, 2003). This body of work has highlighted a number of themes that are consistent with the general 'care-giving' literature, including the extent of care-givers' responsibilities, the psychological and physical strains inherent in care-giving, the problems associated with maintaining employment status through the care-giving process and conflicts that may occur in relationships in a wide variety of contexts. These issues do, of course, extend far beyond the boundaries of sexuality—they affect all care-givers in varying ways. This paper does not, therefore, set out to suggest that the experience of caring is mediated solely by a person's sexuality, but, as Coon (2003) suggests, the multiple barriers and obstacles faced by lesbian carers on account of their sexuality suggest that this particular feature of their identity may, in profound ways, shape the experience of providing care to family members or friends. These

obstacles on individual, interpersonal, organisational, community and policy levels have one common thread: 'that of hatred, discrimination and intolerance' (Coon, 2003, p. 6)—binding threads that link lesbian carers in a way that would be difficult to imagine for their heterosexual counterparts.

Cantor et al. (2004), reflecting on the experiences of both gay and lesbian people, observed that what we know about the experience of providing care from the general care-giving literature may not necessarily be generalisable to the lesbian or gay population. As Coon (2003) argues, until gay and lesbian people: ... no longer experience the discrimination and social isolation that create barriers to receiving competent care, service providers and other professionals need to increase not only their understanding of the issues LGBT caregivers face, but also their competence in service provision to these family caregivers (Coon, 2003, p. 1). The barriers to which Coon (2003) refers were a prominent motif evident in many of the experiences recounted by participants in the study reported here. Moreover, to underline Coon's (2003) argument, participants also suggested that shared experiences of oppression and marginalisation gave them a sense of community with other lesbian women and had, in fact, a positive impact on their abilities, and sensibilities, as carers of people with dementia. As such, they suggested that they are able to approach care-giving with an acute awareness of how issues of exclusion, oppression and discrimination inform the need for, and provision of, care, particularly in the context of dementia—a condition in which stigma, discrimination and exclusion are well-documented consequences of the diagnosis.

In the context of their biological families, no respondent reported the now classic post-coming-out narrative, whereby lesbian and gay children are demonised and rejected by their families of origin. Rather, many people had experienced troubled and difficult relationships with parents and siblings who struggled to accept their sexualities and, for many respondents, it was in the context of providing care for a parent that the problems they had faced earlier in life were exposed anew. Many respondents turned to their social families—their 'families of choice' (Weston, 1991)—for the support they required in their caregiving roles, but their new responsibilities also presented them with opportunities to revisit biological family issues and, in so doing, they were able to reflect upon these sometimes difficult and broken relationships in light of the changes wrought by the diagnosis of dementia and its myriad implications. As such, families of both biology and choice were significant elements of these carers' care-giving experiences.

Methods

The study explored the care-giving experiences of ten gay men and eleven lesbian women whose care-giving relationships occurred within a range of familial and social contexts. Of the eleven female respondents, eight were caring (or had cared) for a parent with dementia, two for other relatives, whilst one woman cared for a partner with a diagnosis of dementia.

This paper concentrates specifically on those female respondents who cared for a parent with dementia—disaggregating the findings in this way, I would suggest, allows for a specific focus on the biological family context of their caring relationships. Of the eight lesbian participants who cared for a parent, three were in long-term partnerships. Many of the women cared for a parent with little support from other family members. Those who did work closely with siblings and other relatives all reported historically difficult and strained relationships. Partly, this was due to the challenges associated with caring for a person with dementia, partly to the fact that some respondents felt they were under pressure to provide care from family members and, most importantly in the context of the discussion here, the strains carers faced were put down to managing already difficult sibling relationships, some of which are outlined below. The group of respondents was white British, their ages spanned a considerable period (twenty-three to sixty-two years) and they were, on the whole, highly educated—five respondents had a first degree, whilst two had a Ph.D. The limited socio-economic spread represented by this group of participants is a common feature of research with small groups of gay and lesbian people and reflects the difficulties inherent in sampling 'hard to reach' populations. It should be stressed, however, that the potential for generalisation was not an aim of this study. Rather, the intention was simply to explore the experiences of a small group of gay and lesbian people who cared for a person experiencing cognitive challenge and loss.

The sample was recruited with the use of snowballing techniques and data collection took place over a four-year period, though this was not a longitudinal study. Rather, the lengthy time frame was determined by the difficulties associated with recruiting and working with what is a traditionally 'hard to reach' population. Prior to interview, respondents were given an information sheet containing 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/Statement+Ethical+Practice.htm). As a Ph.D. thesis, the work was rigorously scrutinised and examined by internal and external examiners at both upgrade and viva stages. In addition, the research benefitted from the input of peer researchers who ensured that these guidelines were fully adhered to. All data have been anonymised to protect respondents' confidentiality.

Respondents were interviewed using semi-structured interview techniques in the style of what Kvale (1996) referred to as a 'guided conversation' allowing for the development of 'rich, thick, description' (Anastas, 1999, p. 25). Respondents' voices are presented here as a central and very visible presence in the findings in order to preserve the resonance of their experience.

All interviews were recorded (using a digital voice recorder), transcribed in full and read numerous times in order to reveal overarching themes. Following transcription, transcripts were offered to respondents for clarification or alteration. Respondents were assured that any data they were unhappy with would be deleted and used no further. No respondent decided to omit data, but a number of people made additional comments and provided further reflections following the interviews.

Data analysis was undertaken using a constant thematic comparative method (Glaser and Strauss, 1967), though it should be stressed that coding and analysis were undertaken post data collection—an approach that is not consistent with classical grounded-theory techniques (Price, 2010). Themes identified in the data covered the variety of ways in which participants had come to care for a person with dementia; these included analysis of the quality of the relationship they shared with the person they cared for and the extent to which that person, and their wider family systems, were supportive of their sexuality and lifestyle choices.

Participants also related their experiences of formal service provision and whether or not they had felt the need to come out to service providers in the context of their care-giving role—service providers' responses to these disclosures were also explored by those who made them. Many people, in light of their care-giving experiences, also explored their own ageing trajectories and their potential support and care needs as they aged.

Findings

Negotiating care-giving relationships within the biological family

All the respondents in this study were forced to make life-changing decisions when faced with the prospect of caring for a person with dementia. Each person was required to re-think and, in some cases, re-plan their lives in order to accommodate a range of new physical and emotional responsibilities and tasks that most were unprepared for or, at least, had not anticipated or planned. A number of respondents experienced a sense of family pressure to 'care' that some lesbian respondents perceived as being a result of gendered expectations,

whilst others attributed the pressure directly to the fact that, as a lesbian woman, their personal relationships and responsibilities were perceived as being of limited importance when contrasted with those of their heterosexual/married siblings. Others suggested that it was a complex mix of obligation, expectation, love and reciprocity that was distilled into a caring role.

One woman stated that she was simply expected to 'just get on with it', suggesting, she said, that, as a single, lesbian woman with no children, she had no other more pressing responsibilities. She was, therefore, simply 'available' to care—an example, perhaps, of the ways in which a lack of heteronormative signifiers allows for a blanket negation of lesbians' own lifestyles and commitments.

Other women experienced gendered expectations from a variety of sources—the family, particularly the older members, and the neighbours in the small village community where her mother lived: My brother, who lived in England, couldn't cope and he opted out really. And my other brother was in America, so it very much fell to us as daughters. It was expected of us, certainly, by the rest of the family. Of the local community's expectations and the pressure this created, she said: Oh yes, oh yes, we should be there. We should give up our lives and move into the village, you know, oh it was awful. Family expectations were a common theme for this group of women: I think we lesbian women pick up the pieces and clear up the crap—to put not too fine a point on it! These views are reflected in other work that has demonstrated the uneven expectations of families in relation to the willingness and availability of gay and lesbian carers (see, e.g. Cahill *et al.*, 2000; Cantor *et al.*, 2004).

Nonetheless, one woman, whilst recognising that providing care was a family expectation, was fully prepared to respond: I was caring for her because I wanted to, and because I was available. Yes, it was expected by other family members. But I would have wanted to whatever they said or did. The complexities of providing care as a result of expectation, reciprocity and/or obligation are exemplified by another participant who had a complex relationship with her mother and said that she took on her caring role because, throughout her life, she had felt an implicit obligation to her mother: I was told early on that I was a big mistake. So I did have this theory that we kind of made a bargain when I was still in the womb that, ok, if she was going to have me, then, you know, I'd better come up with the goods. She did not, therefore, conceptualise the need she felt to care for her mother as pressure from herself or others. She saw the caring role as a conduit for, and a demonstration of, reciprocity: I can't call it a pressure, because I've never known anything else and because, you know, it felt like it was in my veins, that was why it was so hard for me to see mum being so unhappy and so, in some ways, it felt like a

completely self-centred act that I could not deal with that anymore for myself, and, in order to function as a human being, I needed mum to be happy and so I needed that to happen and I knew I could make that happen. All respondents described biological family relationships that were sometimes problematic and challenging, largely because of families' difficulties in accepting respondents' sexualities. When it came to providing care for family members, therefore, the parameters of family relationships often required renegotiation, particularly when it was a parent who required support.

One woman, for example, had to work closely with her sister when her mother required support, despite the fact that her sister had, historically, been unequivocally disapproving of her lifestyle choices: There's a long history, I've had a huge long relationship with my sister about my sexuality. I know she still feels it would be better if I was heterosexual. In her heart she still thinks it's a bit sad. Despite the previously difficult relationship this respondent had shared with her sister prior to her mother's illness, she found that the experience of sharing her mother's care with her sister and brother-in-law brought them much closer together: ... the only thing positive was that me, [sister and brother-in-law] formed such friendships over it and we had such a brilliant time together, surviving it. Similarly, another woman worked with her sister to care for her mother in the early stages of her illness and had to contend with, what the respondents described as, her sister's homophobic views. Given the sister's attitude to her sexuality, contact between the two women had been limited prior to her mother's illness. This respondent described her sister as: Evangelical Christian, so has struggled massively with my sexuality ... has kind of campaigned ... thinks I should rot in hell really. She reads the Daily Mail [a right-wing newspaper] and I did not need to hear anything she had to say to me. Despite their differences, this woman found that her mother's illness, and the necessity to work alongside her sister to help care for her mother, provided a range of possibilities for reassessing the relationship she and her sister shared: So interestingly, the point at which mum went into hospital ... was the point at which we [respondent and her sister] started doing much better together. 'Cos I was doing the sleep deprivation and falling apart thing and she was, she was very supportive actually, and I remember coming away thinking how strange, that something as awful as that should bring us to a place where, you know, it, I mean, it felt like it kind of cut through. Despite sometimes troubled parent/daughter relationships (based, often, upon parents being unable to fully accept their daughters' sexualities), a number of respondents reported that providing care for their parent became a catalyst for renegotiation in this context. One respondent attributed changes in the relationship she shared with her mother to dementia itself and the inexorable changes that occurred to her mother's personality as a consequence. She stated that dementia changed her mother's approach to her and, subtly, but inexorably, altered the nature of their

relationship, allowing her to work through, for herself at least, some of the issues that she and her mother had struggled with in the past: I didn't love her, I never loved her ... but I became very compassionate and fond of her as a dementing woman because she changed so much and became really sweet. This is bizarre isn't it, and me and my sister would arrive and we'd gird our loins, you know, and we'd be going to do this and do this and she'd say 'Oh, darlings, oh lovie' and we'd be like 'Who's she talking to?' And it took us ages to realise that this was the changed woman. And for me, my experience of mum and her dementia was actually a lovely time to ... not resolve issues because I could never say, 'Mum, why are you such a bitch?' ... but I sorted it out with myself. Similarly, a young carer found new ways to appreciate the relationships she shared with her mother whilst recognising that dementia had altered the relationship in ways she could not have anticipated: Mum is still very much alive and in there and I know I've got, I don't know how many years ahead of me, of horrible times and although it's hard at the moment, I'm desperately trying to keep it so I enjoy my mum and my relationship ... we've never, we're very close now, we've never been particularly that close, it's important that we keep that. Interviewer: Would you say the diagnosis has brought you closer in a strange sort of way? Yeah, I suppose so. I think it's just because I've been through, I'm the one that's got her to ... I'm the one that got her to go to the doctors, I'm the one whose been around and stayed with her all the time through everything. For another respondent, one of the ironic consequences of her mother's dementia was that her mother had effectively forgotten that she was a lesbian, despite having been relatively accepting of the fact earlier in life: I was out to my mother. However, I think that by the time she was ill enough to need caring she'd forgotten about that. Other respondents acknowledged that changes in their parent's cognitive state were responsible for a softening of attitude towards their sexuality. A female respondent said of her father's relationships with her sexuality: Well, he's known for the last 16 years so, you know, way before getting ill and he wasn't, he wasn't as good, I'd say, as my mum was in relation to that. I remember once, years ago, gosh, when I was about 16, having a conversation with him and saying 'You're going to have to get over your homophobia dad' cos it's no good'. He said 'I've seen a lot of young girls in your position and don't you worry, it's a phase and you'll grow out of it, you'll be alright', you know, that kind of ... you know, I'm sure he thought he was being helpful and that sort of thing, but I didn't interpret it like that at all ... I was very angry with him for quite a long time in relation to that. This respondent, too, felt that her relationship with her father was improved because he had, effectively, forgotten that he was not accepting of her sexuality: I mean, quite often he can't remember my name, but very often he can't remember Helen's name but he'll quite often say 'How's the other one?' which, you know, I appreciate that and I appreciate that he's not, you know, he's fairly, you know, he will include my partner. We pretty much always go together to see him. She always comes with

me and the staff at the home know that she's my partner and you know, he'll give her a hug and he's quite sweet.

Support from within: the family of choice

As some of the respondents quoted above suggest, some lesbian women have been rejected and marginalised by their biological families and thus may have little choice but to fashion their identities and living circumstances in 'varying degrees of diversity' (Oswald, 2002, p. 374) outside the organising framework of the heterosexual nuclear family (Weeks *et al.*, 2001). There is, therefore, a consequent need to link into non-biological, friendship networks for support in a range of contexts. This network, popularly referred to as the 'family of choice' (Weston, 1991), may include ex-lovers as well as friends, forming 'something broader than the traditional relationships based on lineage, alliance and marriage' (Weeks *et al.*, 2001, p. 9).

The 'family of choice', as referred to by Weston (1991) and Weeks et al. (2001), is of critical importance to gay men and lesbians in the UK. Heaphy et al.'s (2003) study, for example, reported that 53 per cent of women and 49 per cent of men agreed that they perceived friends as chosen family. These findings are, perhaps, a reflection of a number of social developments—the result of which being that family relationships, responsibilities and obligations are in a fluid state of continual negotiation (Finch and Mason, 1993, cited in Weeks et al., 2001). What they also suggest is that, in the absence of traditional, biological, support systems, gay men and lesbian women have embraced the need to develop and maintain diverse and, arguably, unique networks of support (Heaphy et al., 2003; Price, 2006): For many gay people, the 'friends as family' model is a political statement, going beyond the practicality of developing a surrogate family in times of needed social support. It is also a way of refocusing the economic and political agenda to include non-traditional family structures composed of both romantic and non-romantic non-kin relationships (Nardi, 1992, p. 117). It should be stressed, of course, that families constructed beyond the boundaries of biology are not necessarily gay/lesbian-specific phenomena. Rather, they may be a more specific feature of gay and lesbian lifestyles and, for gay and lesbian people who construct their living situations around such arrangements, the family of choice may be the primary relational context of their personal lives (Roseneil, 2004). For many respondents in this study, the family of choice was their principal source of support in their care-giving role a finding that correlates strongly with other research into the lives and living circumstances of, particularly, older, gay and lesbian people more generally (Berger and Kelly, 1986; Heaphy et al., 2003; Kehoe, 1989).

For female respondents in this study, other lesbians and, in some cases, heterosexual friends provided a level of support that they found more functional than the services available from the statutory or voluntary sector: I had fantastic support from my friends, mentally, you know. I'd come back from my mum's completely wrecked and my best friend ... I don't know what I would have done without her. You know, I'd just sort of collapse into her house and have to just sort of like go on and on and on and then she'd pick the pieces up. This woman related the nature of the support she received from friends and ex-lovers as a particular feature of lesbian experience and her analysis of her personal circumstances resonates with the fact that 'for some lesbians and gay men the boundary between friends and lovers is not clear and shifts over time—friends become lovers, and lovers become friends' (Roseneil, 2004, p. 411). These practices, Roseneil (2004) goes on to suggest, 'de-centre the primary significance that is commonly granted to sexual partnerships and the privileging of conjugal relationships' (Roseneil, 2004, p. 411): *Interviewer:* Do you think that's [relying on friends and ex-lovers for support] a specifically lesbian experience? I think it can be, because the scene's small isn't it? If you fell out with everybody, you'd never speak to anybody [laughter]. So we have a vested interest in ... and also, I came from the women's liberation movement. That's where I came out and it was all about passionate friendships and nonmonogamy. The support received from friends and ex-lovers was presented by a number of lesbian respondents as a particular feature of what they described as 'the lesbian experience', suggesting a specifically lesbian 'sensibility' in the provision and receipt of care and support.

For some, this stemmed from a sense that, whilst the biological family continued to be a provider of support, it was inextricably bound up in the often problematic familial relationships referred to earlier: For myself and for a very large number of my gay friends, family is very often a great deal more problematic and, even if there's still the love there, there's the love, but maybe not necessarily the understanding, and so you do, you know, your friends become maybe more central to you than straight people's friends do. This respondent developed a small, intense network of close friends, both lesbian and heterosexual, who were able to provide a support system that allowed her to carefully delineate the perimeters of her support needs, providing social stimulation, which she described as 'real quality' for her mother and offering the respondent respite from her care-giving role. She carefully constructed a system of support that she knew she would be able to rely on at the most difficult points in her care-giving career: So, you know, I was able to see the point at which I'd used everything up and mum needed to go into a home might well be a place that I would find very difficult or impossible. So, I reckoned I would recruit some friends with that brief, to help me look at, every now and then, stand back, look at what was going on, making sure that, you know, mum

and I were both doing alright whether we needed anything else to come into place, with a particular view to keeping an eye on me, and if I'm doing 'It's fine, it's fine, it's fine, it's fine!' and I'm falling apart, to be able to say, you know, permission really, to say to me, '... it's time ...'. For this respondent, being able to turn to her friendship network for this level of insight and understanding was her first choice for the support she felt she needed. It was, she stressed, this group of people rather than her biological family that she would turn to in times of greatest need: There was never any question for me that I'd have gone to blood family to do that, it was absolutely my social family that I was going to do that with. This respondent's position at the hub of her family of choice allowed her to make critical decisions about how she would care and from where her chosen support would come. The creative and carefully selected support system she constructed produced an affirmative, though energy-intense, conduit for care for both her and her mother.

As articulate and resourceful women, the women above became central constituents in networks of care and intimacy that constituted their 'families of choice' and their personal circumstances and caring arrangements and activities transcend more traditional notions of the way in which care is provided for and by others. The manner in which these women were able to access and make use of these strong networks of care and support perhaps informs the way in which society more broadly may begin to conceptualise notions of care in a social context in which family forms, a number of theorists have suggested, are increasingly disconnected and unstable and where formal support systems are limited (Beck and Beck-Gernsheim, 1995; Giddens, 1991; Heaphy *et al.*, 2003). Their sources of support are also, perhaps, a reflection of lesbians' traditional commitment to the values of communal living and community networks (Aronson, 1998).

Conclusions

For all the respondents quoted here, becoming a care-giver presented a range of choices and dilemmas in terms of how to manage a changing relationship with the person they cared for and their wider family networks. Whilst any person caring for someone with dementia would, undoubtedly, be required to negotiate changing relationships in the face of the condition, the point here is that the issue of carers' sexualities added a very specific dimension to these reassessments and evaluations of family relationships—issues that it would not be necessary to take into consideration for heterosexual carers.

This paper has outlined a variety of reasons as to why these women came to find themselves caring for a parent with dementia—it is clear that this, as for

any carer, is an issue negotiated by and through a rich mixture of obligation, reciprocity, expectation and love in which issues of women's sexuality are more or less implicated at a variety of levels, depending on the people and relationships involved.

The data have further demonstrated that taking on a care-giving role presented opportunities to revisit and re-evaluate previously difficult and damaged/damaging relationships with family members. For some respondents, the caring process provided a catalyst for renegotiating past hurt and the possibility of perceiving other family members/relationships anew. Other respondents found that they were able to transcend the difficulties in their past relationships by perceiving their parent as inexorably changed by their condition.

This sense of renegotiating the parameters of sometimes damaged, and damaging, relationships was a common experience for respondents and, as suggested above, the changes in quality and type of relationship were often linked to the way in which the person they were caring for had previously perceived and accepted, or otherwise, their sexuality. Indeed, for some participants, this became a critical and defining factor of their caring experience.

For practitioners working with lesbian carers, then, understanding and appreciating the context within which care is provided for family members is crucial. This is particularly so when care is given to parents who may have had a difficult relationship with their lesbian child because of their inability or unwillingness to accept their sexuality. Indeed, the various challenges presented by finding oneself providing care for a person who, earlier in life, has struggled to accept a fundamental constituent of a child's self is a potentially rich field to explore, but one that, to date, has received little research attention.

As a post-Stonewall cohort of gay and lesbian people age, however, the context in which this paper was written will become more familiar and lesbian (and gay) carers' experiences of providing care to ageing parents will inevitably throw service providers' responses into sharp relief. The findings outlined here, therefore, challenge heteronormative, or indeed homophobic, practice (as they do heteronormative family relationships), though it is important to point out that responding appropriately is no simple task, given that lesbian and gay people are not easily identified and may, indeed, go to great lengths to ensure that this remains the case. Similarly, of course, it would be a mistake to presume that all practitioners work within a heteronormative framework or are exclusively heterosexual.

Practitioners should be mindful, however, of the variety and complexity of family dynamics and the expectations placed on lesbian or 'single' care-giver

daughters and the variety of roles these women play in their various familial roles and situations. Moreover, the concept of the 'family' ought to be conceptualised in its broadest possible terms in order to provide culturally informed and competent service provision to carers who may or may not feel able or choose to identify themselves as lesbian (or gay). In this way, we might be enabled to appreciate the complexities inherent in caring for a person whose relationship with the carer may not always have been an easy one and, perhaps more importantly, to recognise and incorporate the vitally important contributions of families of choice into assessment and care provision processes, procedures and practices.

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