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Searching for LGBT carers: mapping a research agenda in social work and social care

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Abstract

Tentative efforts have been made in UK Government policy and through pockets of social work and social care research to recognise how sexuality and gender identity shape the experiences of lesbian, gay, bisexual and transgender (LGBT) individuals providing care to others. In this article, we map the literature base of existing research in the field of LGBT care provision and outline themes of LGBT caring developed from a recent eight-month scoping exercise. Themes were generated from a scoping exercise conducted in England and Wales in which we gathered stakeholders’
perspectives, including carers and carer organisations, about future research and problems for LGBT carers through focus groups and semi-structured interviews. We discuss three thematic areas developed from qualitative data: 1) the absent presence of LGBT carers in data collection and monitoring; 2) the heterosexist responses and heteronormative assumptions encountered by LGBT carers from health and social care professionals, and 3) efforts to disentangle the needs of transgender people providing care from LGB carers’ experiences. To conclude, we identify lessons learnt for future social work research and directions for developing a wider research agenda.

**KEYWORDS:** lesbian, gay, bisexual, transgender (LGBT), sexuality, gender identity, carers, social care, heteronormativity

**Introduction**

Support for ‘informal’ carers is a key commitment for the UK coalition government: carers are recognised as fundamental to stable communities (HM Government, 2010) and are included as a protected group from discrimination under the Equality Act 2010. While emphasis is placed on tailoring services around individuals, little is known about how providers meet the needs of lesbian, gay, bisexual and transgender (LGBT) people providing unwaged care to other adults. In 2008 the UK Government published the carers’ strategy which acknowledged that the needs of carers differ depending on their personal circumstances, family structures and community networks. LGBT carers were also identified as one of the hidden groups of carers about who little was known (HM Government, 2008: 19). In parallel, the Carers Strategy for Wales (WAG, 2007) recognises that social services need to consider service provision for individuals on the basis of gender identity and sexual
orientation. Any support mechanism that is ‘fit for the 21st Century’ (HM Government, 2010) must be receptive to diversity in carers’ needs and interests, including diversity in sexuality and gender identity.

Prior to the UK Governments’ Carers Strategy (HM Government, 2008), sexual orientation and gender identity were not explicitly recognised in equal opportunity measures for carers (see Carers (Recognition and Services) Act 1995 and Carers (Equal Opportunities) Act 2004). This omission has been partially addressed by the Carers Strategy acknowledging that carers are a diverse population (HM Government, 2008: 19). Outside the sphere of carers’ rights, anti-discrimination law for LGBT people has strengthened over the last decade in fields such as employment and the provision of goods and services (Employment Equality (Sexual Orientations) Regulations 2003 and Equality Act (Sexual Orientation) Regulations 2007). The Equality Act 2010 streamlined existing legislation and conferred equal protections across the seven equality strands alongside new protection for carers. Carers will now be afforded the same level of protection by law because of their role in caring for children and other adults (Government Equalities Office, 2010). For social workers, these commitments at policy level support principles of anti-oppressive practice by seeking to challenge inequalities in the provision of social care services. A critical awareness of sexual orientation and gender diversity amongst carers and caring relationships will help strengthen practitioners’ responsiveness to carer’s needs and interests. This article seeks to contribute to this critical awareness.

In this article, we intend to map the contours and dimensions of the provision of care by LGBT-identifying adults. Our first objective is to explore existing research in the
field of LGBT care provision, initially, we discuss trends evident in the health and social care literature about sexuality, gender identity and caring. We then present and discuss themes of ‘LGBT caring’ developed from a recent eight month scoping exercise conducted in England and Wales. Through focus groups and semi-structured interviews, we gathered stakeholders’ perspectives about future research directions and problems for LGBT carers. Stakeholders included LGBT-identifying individuals with previous and current experiences of providing care. In concluding, we highlight lessons learnt for future social work research with adult carers. Throughout this article, we avoid references to ‘informal’ carers in recognition that the care individuals provide for significant others is far from informal or illegitimate. Likewise, the term ‘unpaid’ carer does not adequately capture carers in receipt of direct payments. We follow Clements’ (2009: 9) definition of carers as a significant person ‘who provides care to another person and is not paid for providing that care (nor is she or he providing the care as a volunteer placed into the caring role by a voluntary organisation).’

**Mapping the literature on LGBT carers**

Beginning the search: What we do know about the needs of LGBT individuals providing care?

To date, there has been a negligible amount of social work and social care research that examines specific issues for LGBT carers in accessing and receiving health and social services. The hopes, wishes and expectations of LGBT carers across health, illness and ability have not been sufficiently explored. Prior research has predominantly focussed on specific healthcare needs such as carers of people with dementia (Price, 2008, 2010), older caregivers (Brotman *et al.*, 2007; Shippy, 2007),
and care provision to people with HIV (Land et al., 2003; Munro and Edward, 2008). Research with LGBT carers overlaps with related fields such as the social care of older people (Hash, 2006; Grossman et al., 2007), the invisibility of LGBT identities in residential settings (Cronin and King, 2010b) and care provision for people living with HIV/AIDS. Research in the field of HIV/AIDS has highlighted difficulties and stressors for carers and same-sex partners with coping, bereavement and loss, and mental health (Park and Folkman, 1997; Reynolds and Alonso, 1998; LeBlanc and Wight, 2000; Land et al., 2003; Cadell, 2007). Fredriksen-Goldsen et al. (2009) argue that research about LGBT carers has tended to focus on either the care recipient or provider in isolation from each other. This is despite research evidence indicating that discriminatory treatment is experienced by both caregivers and care recipients in same-sex relationships (Fredriksen-Goldsen et al., 2009).

Invisibility in social care practice and policy is a prominent theme in the carers’ literature (Manthorpe and Price, 2005; Price, 2009). The anxiety that overshadows the disclosure of same-sex relationships to health and social care professionals is a fundamental concern for LGBT carers that can hamper fair access to services. This anxiety can be exacerbated when carers’ private lives are open to external assessment by social care professionals and care managers (Price, 2009). Price’s (2009) qualitative research with twenty-one lesbian and gay carers illustrates the complexities of managing the disclosure of LGB identities to outsiders. Decisions to disclose can be largely dictated by prior responses from health and social care professionals, demanding a need to continually reassess each new encounter with each professional. These conclusions are supported by Brotman et al.’s (2007) grounded
research which suggests experiences of discrimination and distrust in professional care can prevent lesbian and gay carers from accessing health and social care services.

Changing direction: Tracing heteronormative assumptions about carer identities and relationships

Within the social care literature, there has been little theoretical engagement with the dynamics and pressures of LGBT caring relationships and care-practices. More recently, a poststructural, or ‘queer’, theoretical lens has been applied to critically examine and destabilise normative assumptions about carer and LGBT identities. Like sexual identities, carer identities are a social construct and can be fluid and transitory as individuals move in and out of carer roles throughout the lifecourse or during periods of illness and disability (Cronin and King, 2010b). The concept of heteronormativity has informed discussions about the normative assumptions of family and kinship that frequently inform carer identities and shape service provision. Berlant and Warner (1998) characterize heteronormativity as ‘...the institutions, structures of understanding and practical orientations that make heterosexuality seem not only coherent—that is organised as a sexuality—but also privileged’ (p. 548). An inherent and universal assumption contained within heteronormative logic is the equation of heterosexual experience with human experience (Yep, 2002). Heteronormativity is a pervasive aspect of social and cultural life, including social care policy and practice (Cronin and King, 2010b).

Through a heteronormative lens, carers can be presumed to be heterosexual or it may be assumed that differences in relationships and household dynamics follow nuclear family arrangements. Roseneil (2004) argues that the privileging of familial
relationships can overshadow the recognition of friendship networks and ex-partners as valuable providers of support. Privileging familial relationships neglects difference in caring relationships and ignores the social reality that older LGBT people may not have disclosed their sexual identity to family members and therefore may not regard biological family as potential care providers (Grossman et al., 2007). ‘Families of choice’, including friends, lovers, ex-partners and trusted biological relatives, have more recently been recognised as significant providers of care for LGBT adults (Heaphy and Yip, 2003; Almack et al., 2010; Cronin and King, 2010a, 2010b). Survey research by Grossman et al. (2007) illustrates how reciprocity and care giving are common practices amongst LGBT older people who are not related by kinship. Care for gay men living with HIV has tended to be provided by partners and male friends, with the responsibility for care being fulfilled by other men living with HIV/AIDS (Turner et al., 1994; Irving et al., 1995; Turner and Catania, 1997; Land et al., 2003).

For older people, issues of ageing and frailty need to be taken into consideration when assessing the needs of older carers who fulfil the traditional role of family by providing care for other LGBT people in their social network. The provision of care through friendship networks presents difficulties when peers and partners are no longer able to continue caring or die. These losses in both care provision and relationships heightens older LGBT people’s isolation and exposure to paid carers from outside familiar social networks (Almack et al., 2010). While seeking to understand older LGBT people’s non-traditional caring relationships, we should not dismiss the role of older people in providing care for members of their biological families. Survey research from New York indicates that older LGBT people (aged 50
and over) are equally instrumental in providing support to members from families of origin and families of choice (Cantor et al., 2004).

Locating social differences between the L, G, B and T

While we speak about LGBT carers as a distinct social identity, bisexual and trans people’s issues have often been subsumed within lesbian and gay research and practice. Intersectional theory acknowledges that the failure to distinguish between sexual orientation and gender identity leads to assumptions that their needs are the same (Fish, 2007). The ‘T’ is often included as a token gesture in the title of journal articles, and in studies where the sample includes transgender people, the data are not separately analysed. The distinct issues may be understood with reference to disclosure. For lesbian, gay and bisexual people, ‘coming out’ can be understood as a political act. By contrast, transgender people want to be accepted in their acquired gender and their identities protected in legislation.

Like the overarching term ‘carer’, to discuss LGBT identities as a blanket descriptor ignores differences in life-circumstances based on social characteristics such as gender and ethnicity, and neglects the individual experience of providing care to others. With a focus on women, Manthorpe (2003) has argued that caring practices within lesbian relationships are not explicitly acknowledged in UK social policy and carer literature. Feminist perspectives have raised awareness of patriarchal assumptions about caring as a female attribute however, the social needs of lesbian women as parents and carers of family members have been ignored (Manthorpe, 2003; Manthorpe and Price, 2005).
In parallel, it is difficult to locate research evidence about the needs and interests of carers who identify as transgender or bisexual. More broadly, Alleyn and Jones (2010) argue that transphobia (expressions of hostility towards transgender people) is often reported by transgender clients of social and care services. For the provision and receipt of care, Hines (2007) discusses how transgender communities are invaluable providers of support for individuals undergoing gender reassignment – transgender community members provide social support and educative roles in response to gaps in healthcare provision. The experiences of bisexual people are also under-represented in literature on carers. Fuller attention needs to be given to the expectations bisexual carers may have of health and social care professionals. One example is the difficulty bisexual carers may encounter when having to disclose personal information about past and present caring relationships, which span both different and same-sex relationships (Jones, 2010).

**Seeking directions from stakeholders and carers**

**Methods and analysis**

A scoping project was undertaken to develop a more cohesive agenda for advancing research in this field. Seed-corn funding was received from the University of Birmingham to support the development of ‘think tank’ activities designed to bring together academics with other research partners to scope new research agendas and build networks. In July 2010, two focus groups were facilitated in England and Wales with a number of stakeholders, including LGBT carers, academics and representatives of LGBT support organisations. Qualitative methods were best suited for this exercise because the project was exploratory in nature, and interpretive approaches, such as focus groups, would assist in generating a deeper understanding (Liamputtong and
Ezzy, 2005). Participants were sought through multiple channels including fliers electronically circulated through carers’ organisational lists and networks, postings on FaceBook pages for carers, and information distributed through LGBT organisations, such as the Lesbian and Gay Foundation in Manchester and the Older LGBT Network for Wales.

Ten people took part in focus group discussions and the groups were facilitated by either two or three members of the research team. Table 1 indicates the range of experiences which members brought to the group discussions and also demonstrates the fluid and transitory aspects of carer identities amongst the members with many coming to the groups as organisational representatives or academics but bringing with them experiences of being a carer, both past and present.
Table 1 Membership of focus groups showing each member’s self-elected identity and their professional and personal backgrounds

<table>
<thead>
<tr>
<th>Focus group member</th>
<th>‘Self-elected Identity’</th>
<th>Professional and personal backgrounds</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Focus Group (FG) 1</td>
<td>Lesbian</td>
<td>Organisational representative, previous experience caring for mother</td>
</tr>
<tr>
<td>2 FG1</td>
<td>Gay Man</td>
<td>Organisational representative, previous experience caring for same-sex partner</td>
</tr>
<tr>
<td>3 FG2</td>
<td>Gay Man</td>
<td>Carer, also working for LGBT organisation</td>
</tr>
<tr>
<td>4 FG1</td>
<td>Lesbian</td>
<td>Academic</td>
</tr>
<tr>
<td>5 FG1</td>
<td>Lesbian</td>
<td>Academic, previous and current experience caring for family members</td>
</tr>
<tr>
<td>6 FG2</td>
<td>Trans Female</td>
<td>Organisational representative</td>
</tr>
<tr>
<td>7 FG2</td>
<td>Trans Female</td>
<td>Organisational representative</td>
</tr>
<tr>
<td>8 FG2</td>
<td>Lesbian</td>
<td>Academic</td>
</tr>
<tr>
<td>9 FG2</td>
<td>Gay Man</td>
<td>Organisational representative, previous experience caring for same-sex partner</td>
</tr>
<tr>
<td>10 FG1</td>
<td>Gay Man</td>
<td>Carer - also working for LGBT organisation</td>
</tr>
</tbody>
</table>
Drawing on the literature a topic guide and schedule was developed (Hardwick and Worsley, 2011); both focus groups ran for two hours. The purpose of the focus groups was to identify pertinent issues which inform understandings of care in LGBT communities from the perspectives of social care professionals and LGBT-identifying carers as ‘experts by experience’. Focus groups were followed by semi-structured telephone interviews, using the same topic guide for the focus groups, with four self-selected representatives from carer support and advocacy organisations. In addition one person shared, through email, her narrative about caring for a same-sex partner.

With group members’ permission, focus groups were digitally recorded, transcribed and combined with detailed notes from telephone interviews for the purposes of analysis. Following Bryman (2001), who identifies a series of stages to coding which builds on principles of grounded theory, data was analysed thematically to help make meaning of the information gathered. The three members of the research team collated separate lists of initial codes. These lists were then compared across the team and collapsed into core themes that each told a distinct story about LGBT caring. Cross-comparisons helped to increase the level of trustworthiness of themes by ensuring conclusions reached were accurate and a fair representation of stakeholders’ views. In the following section, we outline three thematic areas and the contribution they make to our understanding of LGBT carers and caring. Quotes are presented below in an anonymised form to prevent identification of individuals or organisations.
Identifying familiar pathways and practices

An absent presence: being counted and recognised as a LGBT carer

Sexuality and gender identity were not routinely monitored by voluntary and independent services. Participating representatives from mainstream service providers identified a gap in their agency’s data collection about issues of sexual identity, same-sex relationships and orientation. A lack of agency recording of this information contributes to the concealment of LGBT carers and prevents the development of a substantial evidence-base for understanding how the needs of carers may differ on the basis of sexuality and gender identity. One point of commonality between LGB-specific service providers and mainstream carers’ support services was a deficit of knowledge about issues for carers and LGBT individuals respectively. This highlights the need to strengthen collaboration across the two sectors as well as improving systems of data collection and monitoring.

When reflecting about this gap in information, two service representatives framed issues of sexuality as a ‘private’ concern that was not the business of care managers and carers’ organisations. To ask questions and record information about intimate relationships, sexuality and identity was perceived as a potential violation of privacy and respect. The turn of phrase ‘none of our business’ signals that issues of sexuality and gender identity have little bearing on the provision of support to carers:

Some boards of trustees have instructed their staff not to do this because they think it’s interfering in people’s personal information…. [If] it does not impact on the care being delivered then why do we need to ask such personal questions?
As LGBT identities are commonly represented as sexualised identities, asking about sexual orientation for many is akin to asking about sex. The legacy of the 1967 Sexual Offences Act which decriminalised sexual orientation in private means that sexuality remains bounded within the private sphere. Consequently, LGBT people lack the right to a public life outside the confines of the private sphere (Fish, 2006: 18). One service provider recognised that this lack of information meant it was difficult to evidence how they provided an anti-discriminatory service:

…the other side of the argument is we are an equal opportunities organisation and how can we prove that we are if we don’t have those statistics. So we are in-between a rock and a hard place.

The expression ‘rock and a hard place’ can denote a form of organisational inertia in which no action is taken to improve practice. This perspective also reflects what Colgan et al. (2006) discuss as a legal compliance approach to diversity management in which organisations seek to abide by minimal requirements specified in equal opportunity legislation. More importantly, this approach negates the need to generate practice-based evidence about LGBT carer’s needs and wishes. Similarly, two service providers echoed the phrase of ‘treating everyone the same’. The ‘colour blind’ perspective conflates sameness with equality and risks the danger of unequal service provision that does not recognise the impact of social divisions based on sexuality and gender identity (Okitikpi and Aymer, 2010). The ‘one size fits all’ approach to equality measures also conflicts with the personalisation agenda of delivering individually-tailored services (Carr, 2010).

Asking carers questions about sexual identity is a difficult discussion to initiate that is morally and politically charged and can lead to encounters with homophobic
responses from the carer or the staff member. However, failure to ask these questions misses valuable opportunities to invite safe and open discussion about social needs within and outside of the caring relationship. Perceiving sexuality as not the business of care managers and agencies creates barriers to disclosure and places the responsibility of disclosure solely on the shoulders of LGBT carers. Failing to record personal information about sexuality and gender identity means that carers’ experiences of discrimination and heterosexism remain anecdotal and difficult to evidence. Maintaining divisions between public and private worlds is also a symbolically powerful means of reinforcing heterosexuality as a normative social marker (Berlant and Warner, 1998).

Caring against the tide of heterosexist responses and heteronormative assumptions

Focus group members who had previously or were currently providing care to another family member or partner described at length their encounters with heterosexist responses from healthcare professionals. Overt experiences of discrimination were considered not worth reporting because of the emotional resources required to challenge discriminatory treatment from healthcare professionals. Furthermore, providing care to partners and family members was a higher priority than challenging non-inclusive practice. One group member, Anthony, recalled the signs of ridicule exchanged between nursing staff about his partner and himself:

But when he [same-sex partner] was discharged from hospital we had to go, I had to pick him up from the day centre… And I went to pick him up and the nurses that were behind the station were sniggering because I went to pick him up and I was holding him up. And [my partner] got really angry, ‘yes he is holding me up and yes he is my partner’ and he got really angry.
In this instance, Anthony returned to the hospital to distribute information about a training programme; however he chose not to take the matter any further through a formal channel of complaint.

Some participants recounted more subtle experiences of heterosexism in which health care staff failed to acknowledge their same-sex partners. Ellie’s role in providing care as a daughter met the social expectations of medical staff and she was accepted as next of kin. However when Ellie’s same-sex partner, Sam, came to the hospital to visit, they encountered subtle expressions of heterosexism which rendered Sam’s role as illegitimate. This was in stark contrast to the recognition given to Ellie’s brother and his wife:

The situation when I said I was caring for my mum, it was completely different and the only time it was an issue was when my [same-sex] partner was involved. That was about this understanding about who is this person, why should they be involved in this discussion, why should we let them have access… Whereas my brother and his wife there was no question, they understood who this other woman was. So when the four of us were there altogether trying to sort things out, three of us were legitimate and one of us wasn’t …

Ellie’s story highlights how biological family as the privileged source of care can result in lesbian caring not being expected or legitimated. While women are traditionally seen as providers of care, lesbian relationships can disrupt social expectations of heterosexual roles (Manthorpe, 2003; Price, 2011).

Other group members had encountered normative assumptions from healthcare staff about their assumed capacity to provide care for same-sex partners because of their
intimate relationships. Doug shared his experiences of feeling forced into a carer role for a partner in a short-term relationship in which he felt ill-prepared:

I had been dating this guy for a few months and he hadn’t disclosed that he was a very severe bipolar… Then he went into this massive full blown depression, well first there was the manic phase and then the depression followed…The [ward] staff said well he’s ready to be discharged but we can’t discharge him back to his home because we don’t feel that we can discharge him to somewhere where he will be on his own. So I kind of held out for a while but what they were really saying was we would like you to take him in. So I kind of gave in to the idea against my better judgment really. … It was all about this person and getting them well, there was no attention at all on the person who is in the caring role.

Doug’s story is a stark contrast from the homophobic ridicule recalled by Anthony because he was perceived by healthcare staff as instrumental in providing care after hospital discharge. Doug believed this was an unreasonable demand and felt perceived as uncaring by healthcare staff when he attempted to decline this role: And the attitude I got was awful I have to say, they made me feel that big, like I was being selfish, inconsiderate. … They didn’t talk to me, they didn’t even look at me.

One group member Peter discussed the subjectifying assumptions made about his suitability to provide care for his grandmother founded on his identity as a gay man. In this instance, Peter was assumed to be a suitable carer for his grandmother because of his sexual identity:

And what I found was first of all the expectation, it sounds really silly, but how can I put it, the district nurse would say Peter come in and have a look at this, have a look at your Nan because you are going to have to clean her up later. So my Nan is eighty-four [years old] there stark naked which it’s my Nan, so it’s sort of ‘ok’. And it was commented on by a couple of nurses at one point, but you are gay so you are allowed to see it.
Peter’s story raises questions about the implications if he had identified as heterosexual – would heterosexual men be expected to undertake this level of intimate care for older women in their family or be perceived as appropriate providers of care? Both Peter’s and Doug’s stories convey normative assumptions about gender, sexuality and relationships that configure some gay men as appropriate providers of care because of their relationships and sexual identity. In Doug’s story, there is no assessment of the length or quality of his same-sex relationship – his relationship is assumed to be long-term, committed and a source of care. Peter’s story can be read on a number of levels – one assumption may be that his gay identity automatically positions him as a ‘nurturing’ and therefore ideal individual to provide this level of intimate care. An alternative reading may suggest that Peter is perceived to present a low risk to his grandmother’s safety and dignity because of his gay identity. Both assumptions are founded on stereotypes and normative understandings of gay male identities that neglects the needs of carers and may prevent the person being cared for from receiving adequate care.

Isolation as a sole carer was amplified for some group members through identifying as lesbian or gay, not feeling safe to ‘come out’ to healthcare staff, and having limited access to social networks and LGBT-specific services. Attempts to access social networks through LGBT communities may be hampered by a felt need to ‘come out’ as a carer. Peter elaborated on the restrictions placed on pursuing personal and sexual relationships outside of his caring responsibilities:

It’s difficult to commit to even want to go on a date with someone because it’s like actually I have really got to be back by 11 o’clock unless I can get someone to stay over … it’s like my last very short relationship of six months was four years ago and even then I was caring for my Nan and it was like actually its far easier to stay at mine than it is to stay at yours. And they [partners] were like well this is my first house and I love having my own independence I don’t want to come to yours, and your Nan’s in
the lounge downstairs and the bed is there and the vibrating mattress is buzzing away in the background… it’s really difficult because I would probably want to be at the other house as well but I have still got that commitment there.

As a wider effect, heterosexist responses and heteronormative assumptions hinder opportunities for providing personalised support to LGBT carers that may counteract feelings of isolation and social exclusion (Ward, 2009).

Disentangling the T from LGB

Across both focus groups, there was collective agreement that gender matters for LGBT carers. However gender mattered in differing ways for different groups. In the above theme we discussed how heteronormative assumptions about gender roles and sexual identities sometimes informed expectations about the capacities and responsibilities of LGB-identifying carers. For the two transgender group members, matters of gender identity and gender transitioning shaped the way in which care was provided for other members of the transgender community.

In seeking to separate issues of gender identity from sexual identity, focus group members recognised there were distinct differences that warranted a separate research focus. Transgender members were concerned that issues relevant to gender identity, gender reassignment and transphobia would be lost or meaningless within a broader ‘LGBT’ inquiry. Previous research was criticised for tagging on the ‘T’ without illuminating distinctive issues relevant to transgender individuals. A preferred model for research was to investigate both issues separately but in parallel and on ‘equal footing’, and to merge findings together to draw out similarities and differences in care. Other members also pointed to the need to be mindful of gender differences in
caring experiences for gay men and lesbian women, as reflected in the literature above.

Transgender group members shared their accounts of providing a responsive form of care to other people within transgender communities who were undergoing gender transition. While transgender members did not explicitly identify as carers, their stories described caring practices where they advocated for other transgender individuals in medical settings, responded to individuals in crisis and set up local communities of care. These roles and practices stemmed from a lack of suitable health and social care services for transgender community members. In this sense, their stories of providing of care differed from other group members’ experiences – the provision of care was exercised across numerous relationships, both family and non-family members, and involved less intimate care and more provision of social support and companionship. These kinds of caring practices resonate with Hine’s (2007) discussion of transgender members as invaluable providers of community-based support for friends and peers undergoing gender reassignment.

One group member Nicole shared her experiences of supporting Grace, a transgender woman who had been sectioned for mental health treatment:

… As a transsexual there was no sense of trying to make her feel comfortable as a transsexual. … Because she [Grace] was sectioned she wasn’t allowed a razor which means ultimately she was growing a beard whilst in there. And I think that sort of atmosphere just made her look in the mirror, feel bad, she got worse, and it was a kind of spiraling thing. I don’t think there was any acknowledgement whatsoever by the staff towards the transgender aspect of it. And I went in there to say hello to her and check she was alright.
Nicole’s story illustrates her pivotal role in advocating on behalf of Grace’s wishes in a complex medical scenario in which health-care professionals need to balance Grace’s risk of suicide (through use of a razor) with her right to dignity and the need to manage her process of gender transitioning and remove unwanted facial hair.

While unable to access support herself at a critical time, another transgender member Ella had instead sought to care for and protect family members by limiting information and alleviating undue stress:

I couldn’t talk to my Mam because although she was fine with everything it was a case of I was always trying to protect her as well from everything I was going through. I was already aware that she was worried about me even when I went through the transition itself, so you feel like you don’t want to pressurise them anymore and you don’t want to cause them any further concerns.

The caring practices described by Nicole and Ella are indicative of care relationships based on notions of reciprocity and interdependence as considered in care ethics (Ward, 2011) which calls into question the boundaries of carer and cared for (Williams, 2001). Their stories also highlights the need for a deeper understanding of how transgender communities exercise care towards others as a vital social resource that is not sufficiently met by health or social care providers.

The politics and practicalities of ‘not knowing’ about LGBT carers

While not a distinct theme in itself, stakeholders shared a number of insights into how future research with carers could be designed to match the needs and wishes of LGBT carers. At the crux of these discussions was an open acknowledgement that information about LGBT carers’ everyday lives was difficult to obtain. Service providers used multiple terms to note the lack of recognition of LGBT carers, such as
‘under-represented’, ‘seldom heard’ or ‘hard-to-reach’. The service gap between mainstream carer organisations and the LGBT voluntary sector was emphasised as a contributing source to unmet needs.

Terms such as ‘hard to reach’ denote an absence from mainstream services and represent LGBT carers as a problematic population that sits in isolation from other carers, lacks a sufficient voice in care provision, and difficult to engage with. One stakeholder reflected on how language use could position LGBT carers in a pathologising light:

Yes, hard to reach, but then you are making it sound like it’s their fault! That’s why I say the underrepresented; across the caring field they are underrepresented. So it’s not pointing the finger at anybody, you are just saying we are aware that we are missing you, how do we help you.

This notable absence is not surprising given the lack of monitoring and information gathering identified earlier and indicates a tension between taking ownership of knowledge generation and seeking further advances in practice-knowledge. The dichotomy between knowing about carers’ needs and not knowing about LGBT carers mirrors Sedgwick’s (1990) theoretical assertion that the heterosexual/homosexual divide is a dominant cultural framework that permeates and informs many areas of knowledge generation in contemporary Western societies. The subordinate location of homosexual subjectivities in comparison to heterosexuality places the needs and interests of LGBT carers as intangible and difficult to grasp, as ‘rocks in hard places’. It is important to acknowledge that participating service providers were dedicated to addressing this knowledge-gap.
On a more pragmatic note, stakeholders emphasised the importance of flexible and accessible methods for engaging carers in research. This included taking into account the need for paid respite services to ensure carer participation, restrictions in travelling long distances away from care recipients, and the importance of utilising communication forums accessed by carers, such as social networking websites. While the Internet was viewed favourably as a platform for gathering narratives of caring, it was also argued that carers may prefer face-to-face contact as a more meaningful mode of participation. Across research methods, researchers need to be sensitive to carers being over-burdened with paperwork and feeling ‘researched out’.

**Consulting the compass: future directions for research**

Through this article we have sought to map some of the different dimensions to LGBT-identifying adults providing care for others by examining the literature and reporting key themes from a recent scoping exercise that included LGBT-identifying carers and representatives from carer organisations. We have not set out to provide an exhaustive list of research problems and the scoping study has not reflected the distinctive experiences of bisexual carers. This is a gap which we hope subsequent work will address. We have identified a number of prominent issues for LGBT carers that generate questions for further social work inquiry. Prime issues include the heteronormative assumptions encountered from healthcare professionals about sexual subjectivities and relationships; the absence presence of LGBT carers in organisational data collection and monitoring; and, the differing kinds of care practices demonstrated within transgender communities in comparison to more traditional understanding of caring relationships.
These issues point to numerous areas for research that encompass wider explorations of the extent and impact of heterosexism on carers, and expanding definitions of caring for understanding how transgender individuals care for friends and peers transitioning in gender identity. In addition, further attention is needed on the extent to which heteronormative assumptions about family, partnerships and gender roles shape caring dynamics and relationships and service providers’ perceptions and expectations of LGBT carers. A resounding conclusion is that more concerted efforts in the generation of research and practice-based evidence are needed to fully appreciate how sexuality and gender identity matters for people with caring responsibilities.

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