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“That’s what friends do”: Informal caregiving for chronically ill midlife and older lesbian, gay, and bisexual adults

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Abstract

This study examines the relationships between friends; a caregiver who provides care to a care recipient, who is a lesbian, gay, or bisexual (LGB) adult over age 50 in need of assistance due to chronic physical or mental health conditions. Using a sample of 18 care pairs ($n = 36$), this work examines qualitative interview data. Findings from the study include: (a) both the care recipient and the caregiver receive benefits from the friendship; (b) caregiving alters and challenges the friendship; and (c) friends assume differential levels of commitment and responsibility in providing care. Studying this population of LGB adults expands our knowledge about the diversity of care arrangements and needs within a relational context.

Keywords

caregiving; chronic illness; friendship; gay; informal caregiving; lesbian; gay; and bisexual; midlife; older adult

The present work focuses on friends as caregivers (CGs) for older lesbian, gay, and bisexual (LGB) adults. While some prior research addresses the importance of friendship in the lives of older adults and LGB populations (Felmlee & Muraco, 2009; Nardi, 1999; Weston, 1991), we lack a clear understanding of the roles of friends in caregiving for aging LGB adults. This topic is significant for older LGB populations because the work of caregiving typically is expected to be the responsibility of family members; there is an implicit assumption by policy-makers that the elderly will have a network of CGs, comprised of family members (Cohen & Murray, 2006; Wolff & Kasper, 2006). Yet, an increasing number of studies show that caregiving is often undertaken by friends, neighbors, and other community members, rather than by biological or legal family members (Barker 2002; Himes & Reidy, 2000; Stoller & Earl, 1983). Because current cohorts of LGB elders have experienced marginalization over the life course, which may include intense stigma,

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rejection by family members and laws that prohibit same-sex headed families (Fredriksen-Goldsen & Ellis, 2007), they may not have available networks to provide instrumental support as they age (Rook, 2009). As such, the current cohort of aging LGB adults may be more likely to rely on non-kin to provide care than straight persons.

This article examines the relationships between a friend who provides informal (unpaid) care to a gay, lesbian, or bisexual friend, who needs assistance due to chronic physical or mental health conditions. The focus of this work is on the ways in which the research participants experience their caregiving relationships as both the source of caregiving and friendships. In particular, we examine the participants' own experiences of caregiving (and receiving care), the aspects of caregiving that are consistent with definitions and expectations of friendship, and the way that caregiving alters friendship bonds and may present challenges to the relationship. Studying this population of LGB adults expands our knowledge about the diversity of care arrangements and needs within a relational context.

Non-kin caregiving

Some friends provide the bulk of care for chronically ill older adults; in other cases, non-kin care is supplementary, but may increase over time if primary CGs become unable or unwilling to provide the needed level of assistance (Himes & Reidy, 2000). For older adults without children, friends who undertake significant caregiving responsibilities often are the most important element of an older adult's support network (Barker, 2002; Stoller & Earl, 1983). Friends may assume caregiving responsibilities even when other potential CGs can be identified; one study showed that one-third of chronically ill individuals being cared for by a friend had children, some living nearby, who did not provide help (Nocon & Pearson, 2000). According to prior studies, friends who provide informal caregiving are most likely to live alone and to be female, and unmarried or widowed (Barker, 2002; Burns, Abernethy, Leblanc, & Currow, 2010; Himes & Reidy, 2000). The average age of non-kin informal CGs ranges from 55 to 64 (Burns et al., 2010), although in Barker's study the total age range of the sample was 22–87 and she found that 47% of non-kin CGs were aged 65 or older, 12% were aged 80 or older, and 31% were age peers (within 10 years of each other).

The expected duration of care also shapes caregiving, in that friends are more likely to provide care in situations that appear to have a clear termination point and shorter perceived duration of functional disability (Himes & Reidy, 2000). Yet, one study found that nearly one-third of friends who provided care did so for more than a year, with half of the sample performing caregiving duties for up to six months (Burns et al., 2010). Other research found that over one-quarter of non-kin CGs provided care for over five years (Barker, 2002).

Some studies have concluded that once a person assumes the role as an informal CG, irrespective of her or his status as romantic partner, friend, or biological family member, these individuals serve congruent functions (Fehr, 1996). Indeed, the care provided by a friend ranges from assistance with transportation to the provision of personal care (Barker, 2002). Yet there are distinct ways that informal caregiving by friends affects the care experience. On the one hand, the care provided by friends to terminally ill individuals may lead to different outcomes than caregiving by family members, such that those receiving

care from friends were more likely to receive palliative care services, allowing the recipient of care to die at home (Burns et al., 2010). On the other hand, elders who had help from informal sources were more likely to report unmet needs than elders whose spouse was the sole form of help (Stoller & Pugliesi, 1988). Some of these shortcomings may be associated with the formal and informal limitations on non-kin CGs. Unlike formalized marital relationships and biological family ties, friends who do not have power of attorney privileges are not privy to medical information and cannot make health care decisions, which may limit their ability to provide care (Fredriksen-Goldsen & Ellis, 2007). Moreover, friends who provide care have reported that they have been hesitant to help with various tasks, fearing that the care recipient's (CR's) family of origin may take offense due to the social norms that view family as having the official responsibility for providing care (Nocon & Pearson, 2000). Additional challenges that may accompany caregiving include feeling strain and stresses, experiencing increased time commitment and a dwindling social life, getting too involved, getting too attached, and feelings of guilt when the CR needs more care than the friend can provide (Barker, 2002; Nocon & Pearson, 2000). Research on caregiving and reciprocity found that some of the negative effects of caregiving to be decreased by reciprocal warmth between the CG and recipient of care (Reid, Moss, & Hyman, 2005).

Despite the potential challenges, caregiving friends report distinct benefits to emerge from providing care for a friend. Prior research shows the benefits of providing care for friends include giving the CG a sense of satisfaction, reflecting their nature as a giving person, enjoying the bond with the recipient of care, aligning with religious beliefs, and feeling appreciated (Barker, 2002; Nocon & Pearson, 2000).

Caregivers of LGB older adults

For LGB individuals, friends often fulfill the role of voluntary (Braithwaite et al., 2010) or chosen family members, providing support, love, and instrumental assistance (Weston, 1991), through caregiving. Older LGB adults often turn to chosen family members for care (Brotman et al., 2007), in part due to stigma and lack of acceptance by biological family members (Cantor, Brennan, & Shippy, 2004; Hays, Catania, McKusick, & Coates, 1990; Kadushin, 1996). When asked about who they would ask to help them for caregiving needs, the majority of gay men and lesbians 50 years and older reported that they would turn to their partners first; among those without partners, most would seek help from friends (Cahill, South, & Spade, 2000; Cantor et al., 2004). Still, little is known about the existing informal care relationships for adults over age 50 years in the LGB population.

The provision of care by friends appears to have its roots in reciprocal care within broader LGB communities; according to Weston, over the course of their lives, many LGB individuals have received care from other LGB individuals who are non-kin. Within LGB populations, providing care is viewed as an investment in receiving care (Grossman, D'Augelli, & Hershberger, 2000). Accordingly, of those LGB adults who had received caregiving in the past, 76% had provided care to others; of those who had not received care, 60% had provided care to others (Grossman et al., 2000).

As a demographic group, gay men and lesbians have extensive caregiving responsibilities: 32% of a national sample reported that they provide informal care and of this group, 61% of

these CGs cared for friends (Fredriksen, 1999). Most studies show that gay men and lesbians are particularly willing to provide caregiving support within their own communities. For instance, Hash (2001) found that lesbian and gay male adult CGs for other lesbian and gay male adults valued the caregiving experience as a means to show their strengths and commitment, while Brotman et al. (2007) noted that caregiving reinforces a community identity that preserves a sense of political and social solidarity. Grossman et al.'s (2000) study found that lesbian and gay adults were more willing to help gay men and lesbians than bisexual and straight individuals. Nearly all males (95%) reported a willingness to provide care for gay men and 52% were willing to provide care for lesbians, whereas 95% of lesbians were willing to provide care for lesbians, and 43% for gay men. Again, this study did not take into account the age of the LGB population.

Lesbian and bisexual females gave more help than gay and bisexual males, 73% versus 62%, respectively, although this is not statistically significant (Grossman et al., 2000). This finding varies from the traditional heterosexual community, where women provide a statistically higher amount of care than men (Cancian & Oliner, 2000). Some attribute the difference in caregiving rates between LGB and heterosexual populations to varying gender roles, which are not as rigid for gay and bisexual men (Grossman et al., 2000; Kurdek, 1993). Given that LGB individuals may embody less hegemonic and less rigid gender norms (Connell, 1992), they consequently may be willing to perform different roles in caregiving than their heterosexual counterparts. Another explanation for the differing rates of caregiving for gay and bisexual men is that the human immuno-deficiency virus/acquired immune deficiency syndrome (HIV/AIDS) crisis of the 1980s helped to develop a culture of care in the LGB communities. In examining studies of HIV and AIDS caregiving, the informal CGs for people with AIDS tend to be younger and male, with the relationship between the CG and receiver of care identified as a friend or partner (Turner & Catania, 1997; Turner, Pearlman, & Mullan, 1998). Many friends and partners who provide care to people with AIDS are infected with HIV and have other people with AIDS in their networks (Turner & Catania, 1997; Turner et al., 1998). Moreover, Turner and Catania's (1997) study shows that relationship of the CG to the recipient of care was described as "friend" by nearly 80% of respondents.

While the research on informal caregiving in LGB communities has grown in the past decade, several gaps remain in the literature. One area that needs additional attention is the characteristics of the group providing care for older LGB adults. The existing research illustrates the demographics of non-kin caregiving and HIV caregiving, but provides a less clear picture of those who take on informal caregiving for older LGB adults. Because the support networks of older LGB adults may differ from other populations of older adults, given the legacy of social stigma and legal prohibitions of same-sex partnership and parenting, the current cohort of older LGB adults may be especially reliant on informal CGs, particularly if they are not partnered. It is not clear whether the informal care by non-kin for older LGB adults more resembles the non-kin caregiving group (typically older, female, and single), the profile of HIV/AIDS CGs (gay male, friend, or partner), or some new construction.

A second area that lacks thorough examination is the way that the context of care affects caregiving and the potential health outcomes for LGB older adults. Because LGB adults' experiences of social support, community, and family life are distinct due to histories of stigma and discrimination, their caregiving relationships likely are distinct, as well. Such influences can affect the provision and experiences of care; therefore they need to be more fully explored in social research.

Finally, the current literature does not address the structures of support and care for the older LGB community. Studies of non-kin caregiving have a broad focus that, in the absence of identifiers of the sample members as lesbian, gay, or bisexual, are presumed to reflect a heterosexual population. The existing studies of caregiving for older LGB adults typically combine and summarize the findings for both romantic partners and friends, which in most other contexts are viewed as distinct relational forms. As such, we know little about the lived experiences of relationships that blend both friendship and caregiving for older LGB adults, from both the CGs and recipient of care's perspectives. This study serves as a starting point to address the current gaps in the research.

Two research questions guide this work.

1. What are the experiences of caregiving and receiving care in an informal relationship between friends, at least one of whom is LGB, chronically ill, and over age 50? How does this context differ from care provided by partners or family members in straight samples?
2. How does caregiving affect the friendship bond, and conversely, how does the friendship bond affect the provision of care?

Method

Participants

The interview data that guide this research were collected in 2005–2006 in an urban area of Washington State. Trained researchers interviewed a sample of 36 pairs of older LGB CRs and their CGs ($N = 72$). This study only focuses on the 18 pairs whose caregiving relationship was designated to be a friendship ($N = 36$), because the goal of the study is to understand the meanings for caregiving in non-spousal relationships. For the purposes of this research, “care recipient” was defined as a self-identified lesbian, gay, or bisexual adult age 50 years and older that requires assistance with daily needs. “Caregiver” was defined as the person designated by the older adult as the informal helper who assists most with daily needs, and is neither paid nor a volunteer affiliated with a service organization. The CG was required to be age 18 years or older, but did not need to be of sexual minority status. Only the primary informal CG to the older adult participated in the study.

Participants were recruited through an extensive search of community and health services that cater to older and lesbian, gay, bisexual, transgender (LGBT) individuals. Specifically, the research team recruited participants by sending emails, posting flyers, and making presentations in locations where our targeted populations were expected to frequent (e.g., health clinics, support groups, buddy programs, community-based churches, and social

groups). Recruiting from various sites minimized biases compared to relying on a sample drawn solely from one site, such as a support group or health clinic. The recruitment materials stated that participants would be paid \$25 each for their time and participation in the study.

Procedures

Face-to-face interviews were conducted with chronically ill older adults and CGs at a time and location of their choice where privacy could be insured. The older adults and their CGs were interviewed in separate rooms, but simultaneously, to insure that dyad members did not influence each other's responses. The interviews lasted between 75 and 90 minutes and were audio recorded with the permission of the participant. Interviewers were trained in the social and behavioral sciences and experienced with working with lesbian, gay male, and bisexual populations. Interviewers were trained in methods and techniques for effective interviewing of adults with functional disabilities and their CGs.

The interviews provided both quantitative and qualitative data necessary to examine the dyadic processes between CGs and CRs. For the purposes of this paper, only the qualitative portion of the data are being examined in order to best understand the meanings of the care relationship to both members of a non-spousal caregiving dyad. The interviews were conducted face-to-face in the location of the participants' choosing. As such, the research team conducted interviews in public spaces, such as libraries and cafes, in private homes, and in the university research offices. Prior to beginning the interviews, the CG and CR reviewed and signed an informed consent form. At the end of the interview, the participants were each paid \$25 as a token of appreciation for her/his time and participation in the study.

The interview began with the quantitative survey questions, which the interviewer asked of the participant. The quantitative questions included standard measures of physical and mental health and measures of dyadic relationship quality. The open-ended qualitative questions were asked at the termination of the quantitative questions, about an hour into the interview. By this point in the interview, the interviewer and the participant had developed a degree of rapport. The questions addressed a range of topics about the nature of care and the ways that care affected the relationship. The questions for the CG that provided the most fruitful data for the study presented here were as follows.

- Can you tell me a little bit about how it has been since you started providing care for CR?
- What difficulties have you encountered when trying to give assistance to CR?
- What causes conflict between you and CR?
- How has your relationship with CR been affected by her/his need for your help?
- Would you characterize this relationship as family?

The questions for the CR that provided the majority of data reported here were as follows.

- Can you tell me a little bit about how it has been since you've needed help from CG?

- What difficulties have you encountered with CG providing care for you?
- What causes conflict between you and CG?
- How has your relationship with CG been affected by your need for her/his help?
- Would you characterize this relationship as family?

The qualitative interview data were transcribed verbatim and then were coded by examining responses to a series of questions. The data were coded through the process of open coding (LaRossa, 2005), where the material was reviewed repeatedly in order to identify common themes or concepts that emerged from the interviews. In particular, the researchers carefully examined the interview data and then created sub-codes for the most common themes related to the relationships between friends who provide and receive care. The researchers conducted the initial phase of open coding; subsequently, an undergraduate research assistant performed a second round of coding according to the themes the researchers had identified. In the final phase of coding, the researchers reviewed the research assistant's coding in order to reach the final analysis of the data. In order to provide structure to the coding process, the researchers used NVivo 8, a qualitative data analysis program.

Findings

Friends who provide care to and receive care from each other represent a diverse group. The demographic breakdown of the participants shows a heterogeneous sample (see Table 1). For the CG group, eight identified as gay male or lesbian, six as heterosexual, and four as bisexual, with a gender breakdown of 13 males and five females. Among the CG group 13 participants were age 49 years and under; in terms of race/ethnicity, seven were white, seven were black, and four were other. The relationship status of the CGs was four married/partnered and 14 other (single, married, or widowed). The total yearly household income breakdown for CGs was 14 participants earned less than \$20K.

Of the CR group, nine identified as gay male or lesbian and nine identified as bisexual; 11 of this group identified as male and seven identified as female. The age breakdown of the CRs was 15 participants aged 50–59 years; two participants aged 60–69; and one participant aged 70 and older; in terms of race, six were white, nine were black, and three were other. The relationship status of the CRs was two married or partnered, while 16 were other. The total yearly household income breakdown for CRs was 15 participants earned less than \$20K.

CRs suffered from one or more of the following conditions: arthritis (11 participants); high blood pressure (nine participants); HIV/AIDS (eight participants); diabetes (five participants); and Alzheimer's disease (two participants); three-quarters of the CRs (14 participants) indicated that they had been diagnosed with a mental health condition including depression, bipolar disorder, or schizophrenia. Most of the CRs had three or four of the aforementioned conditions. Notably, the CG participants also had been diagnosed with one or more of the following conditions: mental conditions including depression, bipolar disorder, or schizophrenia (13 participants); HIV/AIDS (eight participants); arthritis (five participants); high blood pressure (seven participants). Most of the CGs had two or three of the aforementioned conditions.

The number of hours of care provided by the friend to the CR was as follows: 1–2 hours/week (one participant), 3–4 hours (four participants); 5–9 hours (three participants); 10–19 hours/week (six participants); 20+ hours/week (four participants). Friends helped with the following tasks of daily living: bathing (two participants); grooming (two participants); transportation (10 participants); taking medications (four participants); laundry (eight participants); housekeeping (nine participants); food preparation (eight participants); shopping (12 participants); using the telephone (six participants).

The data show how both the CGs and CRs in the study experience the processes of care, highlighting the everyday tasks and extraordinary efforts that occur through caregiving. In so doing, the data show that both the CR and the CG often receive positive benefits from the presence of caregiving in their relationship. Moreover, participants articulated the ways in which these caregiving bonds constituted kinship ties, thus fulfilling the role of chosen family. Finally, the interview data provide explanations of how caregiving altered and sometimes challenged the friendship and how caregiving is implicit in some individuals' definitions of friendship. It also is apparent that friends are willing to assume differential levels of commitment and responsibility and have limits to the help they can be expected to provide.

Types of provided care

Three types of caregiving experiences are most common among the CGs: providing instrumental care, serving as liaisons between the CR and service providers, and helping with intimate care. These experiences vary, as some participants provide all three types of care for a friend, while others' care is limited to instrumental assistance. Regardless of the type of care provided, caregiving friends help with essential tasks that are difficult, if not impossible, for the recipients of care to perform themselves.

Caregiving by friends, like other forms of caregiving, occurs on a continuum, from picking up prescriptions and assisting with laundry, to more personal types of care, such as helping with grooming or bathing, depending on the CRs' impediments. Trent is the CG for Lydie, who suffers from diabetes and other chronic conditions. Trent explains his care for Lydie:

I don't look at it, like I have to go and help [Lydie]. It's not like that at all. I mean – she needs stuff done like everybody else needs stuff done, whether it's laundry, cooking, grocery shopping. She might just need a little more help as far as what bus to catch, or how to get there, or go with her for support. It's just something that I do because - it would be nice if somebody could help me if I need it.

Lydie shares her perception of the assistance:

So [Trent] just started coming around and started doing things for me and stuff like that. Makes me get up if I'm sleeping in or whatever, so that's good and helpful, instead of just sleeping the whole day away and being depressed.

The CG friends provide a range of care. For instance, Turner, who has AIDS and lives in emergency housing, explains that Niles helps him by bringing him food, picking up his medications, and identifying programs that could help him, such as an organization that assists with laundry. The side effects of various AIDS-related illnesses and the

pharmaceuticals taken to manage AIDS, including confusion and dementia, make Niles' assistance desperately needed.

Often times, CGs act as a support to medical professionals in ensuring the CRs follow through with medication and understand their treatment. Dennis, for instance, is the CG and friend to Billy. Dennis helps Billy by making sure he goes to his doctor's appointments and helping him to understand the doctor's instructions. Dennis explains:

I wanted [Billy] to understand what his medications do for him [so that he will take them]. And the physician that we saw at that time when his latest cocktail was being brought up, he didn't really know how to explain things in layman's terms, so I kind of broke it down for him.

Like Dennis, other CGs help their friends to navigate medical care, but encounter limitations due to their role as friend and informal CG. Cole has helped to navigate various governmental offices for services including the Veteran's Administration (V.A.) with great frustration: "the V. A. – just to make a simple phone call takes 30 minutes, and that's – a couple of times I told [Kyle] – you've got to deal with this, I can't." Kyle explains his own limitations:

My memory, my sight, my sense of smell – my nine day coma really messed me up ... I'm barely alive because of that situation, and because of my age and I've got physical problems – foot, back and now the brain thing. Those things together makes me pretty much 100% disabled.

Despite being disabled, Kyle's only CG is his friend, Cole, whose caregiving functions are limited by his status as a friend, rather than family member or designated power of attorney.

In addition to helping friends navigate medical bureaucracies, these LGB CGs are called on to provide hands-on assistance with intimate care, although this type of assistance was infrequently discussed in the data. In one case, Alana described how her friend, Darrin provided assistance with toileting:

The first time I had an accident and my arthritis was so bad I couldn't clean myself, and ugh – so he helped me and we make jokes about it now, it's so funny – when he was cleaning me up, it was messy, but it was funny, it really, really was.

Caregiving within the context of friendship

The friends in this study fulfill necessary tasks for the CRs and they do so within the context of a meaningful friendship. As such, common friendship norms, such as mutuality and support (Felmlee & Muraco, 2009; Grossman et al., 2000), govern the ways these individuals interact on a day-to-day basis and often motivate their care arrangements. In addition, in discussing the tone of the relationship, the participants often identify their friends as chosen family and discuss the ways that incorporating care-giving has altered their friendship.

Caregiving plays a role in these friendships and the character or tone of the relationship is influenced by the provision of care; however, rarely do the friendships center entirely on the care tasks, rather, caregiving occurs side-by-side with other friendship activities. Gavin

explains that what he most values in his friendship are the times he shares going to concerts and other activities with his caregiving friend, Elissa. Another CG, Noah, who is the caregiving friend of Aidan comments: “Oh, we’re really good friends. I mean, if I want to, I can tell him anything I want to.” Alvin explains his perspective: “it’s mainly, we’re friends so it’s something that comes out of being friends and not something, that is, I don’t look at it as I’m his CG so much as he’s a friend and I do things for him.” Thus, these CGs viewed the provision of care for their friends to be a natural part of friendship and not an extraordinary act.

Most of the participants recognize mutuality in their relationships, despite one member of the dyad requiring more traditional forms of care than the other. Lydie’s CG, Darrin, explains: “it’s mutual – we need each other. And so, how has it been affected by me? It’s mutual because we both have needs and we kind of care for each other.” Lydie provides greater detail about how she and Darrin provide care to each other:

I think we kind of make each other happy. Make each other look on the brighter side of things. Kind of reinforce and support each other. We have maybe a few things that we both might be having problems with and we talk about it and then we come out with a more positive way of handling things. And we kind of reassure each other.

Thus the caregiving friend may provide necessary instrumental types of support (e.g., helping to do laundry, providing intimate personal care), but both individuals in these care dyads recognize that by being present in each other’s lives and providing social and emotional support, they both benefit from the friendship.

As the borders between friendship and family are blurred in the provision of instrumental support, so too do they blur in the area of financial support. Given the precarious financial situations of most study participants, there are instances where CGs and recipients provide financial assistance to one another. Nadine, the CG for Camila, explains that while she helps with everyday instrumental care, Camila has helped her when she has been in a financial bind: “if I need money, she’s there if she has it and same with me, but for the most part she has more than I do so she’s more of a financial take care than I am.” Darrin also explains that he and the recipient of his care Alana: “share, we share financially. We each have needs, and we see that they are met.” In each of these situations, the CG is the one who mentions the mutual financial care the friends provide each other. It is unclear whether the CGs overlook the financial dimension of their relationship because it is uncomfortable to conceive of the caregiving friend as receiving financial compensation from the friendship, or because the financial element is less significant because the provision of other forms of instrumental care are more meaningful to them. Generally, though, participants emphasize the mutual provision of financial care depending upon who has more resources at any given time.

Personal benefits beyond mutual care also appear to be significant to the caregiving friends in these dyads. One of the most common explanations for why they provide care is that it makes them feel good about themselves. Noah describes his feelings about providing care for Aidan: “sometimes it can be hectic but most times it’s pretty cool because, you know, I

know I'm doing the right thing and I feel good about it." On her caregiving for Lila, Hazel comments: "it feels good knowing that I'm helping someone." Similarly, Andre, Gabe's CG explains:

It has been rewarding for me, because I feel like I'm contributing, I'm doing something—keeping myself busy and he's a friend and I feel like it's my duty, that's what friends do. You know, he was lying on his deathbed and I was there for him.

Here, we see some of the motivations for the provision of care within a friendship. Andre perceives providing care to be a duty of friendship and feels good about his ability to provide assistance to Gabe.

Chosen family and altered friendships

Most of the care dyads between friends consider their close bonds to be a familial connection, extending from their commitment as chosen family. As Gavin said of his caregiving friend, Elissa: "She's there for me. She loves me. I love her. That's family." Nadine, the CG for her friend, Camila, provided this characterization of the relationship they share:

She's my family. She's definitely, she's more of a family to me than my own, except my son. She has my total—she is my daily routine; everything I do centers around her. I mean, I interact with her all of the time. My schedule is according to hers. I do things so that I can either go out to see her or go out and participate in something with her, but she's pretty much the focus of my day.

Here, Nadine identifies Camila as family because she is at the center of her daily life. Interestingly, another common way that participants identify their bond as familial is by comparing it to a known biological family relationship. In fact, a very common characterization of male participants is that they are like a brother. Andrea, for example, characterized Gabe as "a fatherly type. Uncle Joe. Uncle Bob." Others focus on the *chosen* aspect of the chosen family relationship. Noah explains that he considers Aidan to be family because they value and care about each other. He further clarifies: "And you know, a family doesn't always have to come from your gene pool."

While the majority of the participants consider their bond to be a familial one, several participants do not. These individuals made a clear distinction between biological or legal family and friends. Lila, who receives care, explained: "Oh, well, [Hazel] is probably my best friend. I don't consider her family, really, but I guess just members of my [biological] family." Moreover, Niles gave his viewpoint:

I draw a pretty firm line between family and friends. I mean, there's friends, there's close friends ... you can be a friend, a casual friend or a really good friend but a lot of street people say, "oh, this is my family." You what, this is family because you guys share a 6-pack of beer together every day? That's not family.

Here, Niles is critical of the way that “family” is casually tossed around to such an extent that it appears to be meaningless in his eyes. Yet, in most cases, the friends who provide or receive care in these pairs were viewed as having a family connection.

Throughout the interviews, participants indicated various ways that the care aspect of these dyads affected their perceptions of their friendship. In some cases the friendship began by virtue of the provision of care. Darrin, who is the CG, and Alana’s friendship formed while the caregiving relationship was also developing. Darrin and Alana knew each other only as friendly acquaintances before Darrin started providing care to Alana. Alana explains: “Yes, I think we’ve grown closer. We were friends before that, but this is a more trusting relationship because knowing that I have to depend on [him] to help me.” In other cases, longstanding friendships became closer or stronger as a result of adding the caregiving dimension to the relationship. Nadine explained, for example, that while she and Camila have been friends for over 10 years, the tone of their friendship changed and became stronger with the addition of her providing care.

Challenges and limitations to the care relationship

The friends who participated in the study spoke about their relationship primarily in positive ways, yet they also discussed the challenges that have emerged in providing care to or accepting care from a friend. At times, interpersonal conflicts about caregiving have presented challenges in the friendship, which were discussed by both CGs and recipients of care. Some conflicts arise when CRs have greater needs than can be met by the caregiving friend and others occur when the CRs feel burdensome. Another important topic that surfaced during the interviews was that the growing needs of the CRs, in combination with the CGs’ concerns about the future, create a potentially unsustainable care arrangement.

In general, the participants express positive feelings about both the caregiving and friendship parts of their relationships. Like most relationships, especially ones that involve the stresses of providing care and the difficulties of dealing with chronic illness, struggles and challenges emerge. Dennis, Billy’s caregiving friend, describes one such challenge: “Well, it’s hard to keep him focused on things that need to get accomplished sometimes, and he can get argumentative for no apparent reason.” Another challenge emerges from the tensions in providing what is perceived to be too much versus not enough care. This situation can be especially challenging for friends whose caregiving roles are not clearly defined. Nadine, the CG for Camila, recalls one such situation:

I think sometimes she resents me, sometimes she gets – I assume more than she wants me to or I make decisions that I shouldn’t without consulting her first, I just think it’s the right thing to do and so I do it and she’ll call me on it and say – that’s not what I wanted or that’s not how I wanted it handled and so she’ll let me know if I’ve overstepped my balance.

In addition to negotiating interpersonal boundaries, several CGs express concern that their friend may need more care than they can provide. Elissa who is a CG, explains her concerns about Gavin’s needs for care: “I think that there’s times when I worry that I won’t be able to meet some of the things that he wants from me – there are times when I think he wants more time than sometimes I have.”

CRs also admit sometimes feeling like a burden to their CGs. Indeed, several CRs worried that they may be asking too much of their caregiving friends. As Camila said: “I feel like I’m taking advantage ... Well, [Nadine] spends a lot of time with me and she does have other things to do.” Similarly, Gabe explains that he is aware of the tensions in his care needs from Andre: “sometimes I might depend on him too much ... looks like he’s got something to do and I need something and I get upset.” Conflicts may arise in any relationship, yet they appear to be heightened in situations where one friend is experiencing frustrations due to the pain and difficulty of chronic illness and is simultaneously dependent on their friend for care.

Some potential complications emerge from the CG’s own health issues. In most of the care dyads, both individuals have chronic health conditions, have precarious employment or are underemployed, or are homeless; some participants encounter all three conditions. For example, both Andre (CG) and Gabe (CR) are HIV positive, as are Niles (CG) and Turner (CR). Trent, who is the CG for Lydie, also is HIV positive (Lydie is not). He describes how providing care has affected him: “I’ve kind of put myself on hold, not to the degree where I get sick or anything, but, you know, my health is a life challenge. And some of that’s happened since I’ve helped her. But it hasn’t gotten in the way.” Other participants characterize the difficulty of managing their illness while also being homeless. As Cole, a CR, said: “My situation is just stressful, I mean, I’m in a shelter, a lot of people here have mental problems, me, especially a lot, and then to deal with just surviving – it’s not fun.”

Most of the caregiving participants focus primarily on the friendship as driving their care activities, but also indicated that there are limits to the sacrifices they are willing to make. Hazel explains:

I’m trying to not let it get that way, but [Lila] is becoming very, very needy and I’m afraid that if she doesn’t get some counseling so that she has somebody else to go to with some of the major problems and issues in life, that there might come a time I may have to say – you know, I really don’t have time.

Other CGs place limits on the amount of care they can provide. Nadine, the CG for Camila, characterizes her feelings: “Now [Camila’s] confined so she’s real needy, and like I said, it takes a lot of my time and if I let it, it could be all consuming.” Despite the time demands, both CGs express a desire to stand by their friend, but acknowledge that they may not be able to continue their current levels of attention.

One last and very significant theme in this data is that some CGs acknowledged that there might be a time when they will relinquish caregiving. As Dennis, Billy’s CG explained: “Well, I mean, I was a friend of his before I was ever a caregiver, and I’ll probably be a friend of his after somebody else takes over caregiving.” Here, Dennis’ comment implies that at some point, he may have to bow out of the current caregiving arrangement. Another example emerged with respect to assuming legal rights to make decisions for their friend. Niles, who is Turner’s CG, explains: “[Turner] said well, let’s do the power of attorney thing, I said no. I don’t do that, I don’t want to be nobody’s power of attorney, that’s more responsibility than I want.” Thus, there are limits to the caregiving responsibilities that some informal CGs are willing or able to provide.

Discussion

The data give a fuller picture of providing and receiving care within the context of friendship for LGB elders. Based on the experiences of both members of the caregiving dyad, the findings provide fruitful material for greater analysis about the expectations and limitations of friends as CGs, the reliance on informal support networks from the life course perspective, and the potential implications of many chronically ill LGB adults' reliance on informal support for assistance

In some ways the care in these relationships mirrors what we know about caregiving in general. The caregiving activities encompass a range of needs of the chronically ill CRs, from giving assistance with tasks of daily living to pursuing adequate medical care and services to hands-on help with bathing and toileting. Caregiving does not appear to supercede the mutual enjoyment of everyday friendship for these pairs. In fact, both the CG and recipient of care discuss caregiving as just one of the friendship activities they experience, and an aspect of friendship that has deepened their relationship. Yet, simultaneously, there are challenges presented by caregiving, both to the relationship and to the provision of care. One type of challenge emerges from the stresses of caregiving, which manifests in conflicts between the CG and CR. Another challenge is that the recipients of care worry that they place too many demands on the CG, while the CGs acknowledge that there are limits to how much care and attention they provide.

That's what friends do

Building upon the scholarship on friends as CGs, most participants in this study indicate that they see providing care as an important part of being a friend. In most cases, a CG willingly assumed the responsibility for taking care of his or her friend without being asked. The recipients of care express appreciation for their friends and accept the assistance with the understanding that they would also help a friend in need, if they were able. Providing help to friends reflects the social norm that friendships meet material and socio-emotional needs (Grossman et al., 2000). Friendship norms explain why individuals assist friends with instrumental tasks, but do not fully explain why individuals take on the full range of informal caregiving when they are not bound to perform such duties. Individuals in the sample who provide care explain that helping their friend raises their esteem. Helping someone else makes a person feel good about her/himself. This finding relates to the norm that friends help other friends in need (Felmlee & Muraco, 2009); in other words, helping is what friends do.

In these friendships, there is also a degree of mutual financial assistance; while none of the individuals who provide care are paid for their assistance, about half of the friends in the sample note that they do pool resources when either is in need. This practice is consistent with the friends' own characterizations of the relationship as "chosen family," wherein people without legal or biological ties enact family relationships. In particular, loaning money and negotiating the feelings in such lending, is typically considered to be kin work, which is a responsibility of family members (Carrington, 1999). The data also provide evidence that some CGs and receivers of care experience their relationship through the lens of family in its current cultural construction. This construction can partly be attributed to the

nature of caregiving as a set of intimate tasks; accordingly, those helpers who undertake these tasks, both paid and informal, characterize their relationships as familial (Karner, 1998; Stacey, 2005).

Most of the friendships in the sample predated their caregiving situations. In such cases, the participants' comments acknowledged that the provision of care was central to the deepening of the relationship in terms of gaining trust, strength, and closeness. Furthermore, the participants note that their relationships have strengthened and deepened due to the inclusion of caregiving in their relationship, as consistent with prior research (Barker, 2002).

This research on LGB caregiving raises some important insights into the unique aspects of care in these communities. While most friends in the study view the provision of care as a natural part of friendship, it is important to note that for most of the individuals in the study who need care, friends are the *only* people currently providing care, which differs from the view that friend CGs provide supplementary help to spouses and biological family members. In this study they provide the support to allow the chronically ill individuals to remain in the community and live somewhat independently. This finding is particularly significant given our focus on chronically ill LGB adults over age 50 years, a population about whom we have scant knowledge with respect to caregiving. Without the care provided by friends, these elders would be without assistance altogether, a finding that is similar to the non-kin CGs who are the most important element of an older adult's support network (Barker, 2002; Stoller & Earl, 1983), but is even more pronounced because in many of these cases friends are the sole source of caregiving and support.

Most chronically ill LGB older adults came of age during a period of severe repression and many have lived their lives in the "closet," hiding their sexual orientation and romantic relationships (Fredriksen-Goldsen & Muraco, 2010). In this study the majority of the participants, CGs and CRs alike, appear to have tenuous ties to family and social networks and therefore are more reliant on these resources of social support (Rook, 2009). The designation of a friend as familial thus may stem from an increased level of intimacy. Yet, a friend's choice to voluntarily provide care and thus, perform duties that are culturally perceived as familial, particularly in light of a lack of support from family of origin, may further invoke the characterization of friends as family (Braithwaite et al., 2010; Muraco, 2006).

None of the participants discussed how gender might influence the care they provide or receive. The finding that 13 out of the 18 CGs in the sample are male, when females typically are more likely to provide care, has interesting gender implications. Because they did not meet the gender norms associated with normative heterosexual life, this cohort may be freer to defy other gender norms, which also may increase their willingness to provide informal care to friends. Moreover, gender norms for gay men do not necessarily abide by norms of hegemonic masculinity (Connell, 1992); this may promote a greater willingness amongst gay men to provide care to loved ones.

Another possibility is that the relationships resemble the findings of research on HIV/AIDS caregiving, in which men are more likely to provide care (Turner & Catania, 1997;

Turner et al., 1998). The legacy of AIDS caregiving may have shaped social norms in LGB circles such that there is a culture of care for community members, which lasts through middle and older adulthood. Indeed, a large portion of the sample is HIV positive (eight out of 18 in the CR sample). Caregiving for chronically ill LGB middle age and older adults seems to resemble the tradition of HIV/AIDS care by friends within the LGB community, both for those living with HIV as well as those with other chronic conditions.

Implications for the reliance on informal care

One final, but very significant point to note is that informal care may have implications for the quality and continuity of care for older LGB adults. Friends do not have the ability to make decisions about medical care or end-of-life issues without a legal power of attorney document or conservatorship in place. However, unlike other care dyads, in this study the data show that there is no implicit expectation that the informal care providers will be willing to take on the legal status to be responsible for the CRs' health and welfare. In fact, the friends' comments often indicate that at some point in the future, they perceive that they will no longer be the primary CG for the recipient of care. In part, this finding underlies the realities that may befall informal care arrangements: the point may be reached where the informal CG cannot solely manage full-time care of a loved one. This is especially significant given that the caregiving friend's own health status may play a role in her or his ability to provide care in the future, as the demographic data shows that most of the individuals who are providing care have two to three chronic conditions of their own. It is unknown how large a role a CG's own health plays in both non-kin and LGB caregiving, although research on HIV/AIDS caregiving often finds that people who provide care in such contexts also may be HIV positive themselves (Turner & Catania, 1997; Turner et al., 1998).

The tenuousness of long-term abilities and desires to provide care for the CR has implications for CRs. Specifically, CRs who are being cared for by friends may find themselves without adequate support when the caregiving burden becomes too great. This is not to suggest that caregiving friends are not dependable or committed; our sample is comprised of friends, over half of whom provide 10 hours a week or more of voluntary, informal care. Still, friends who want to provide care encounter two strong cultural norms: firstly, that a romantic partner and nuclear legal/biological family lies at the center of one's life (Rubin, 1985), and secondly, that the existing structures of care presume that a CG is a romantic partner or legal family member. Cultural and social expectations fuel the distinction between partners versus friends in providing care such that caregiving is implicit in the definition of a partnership, but not a friendship. For the friend CGs of chronically ill LGB adults, however, providing care is the personification of friendship and chosen family, and an important contribution to their relationship.

In many ways, the dyads resemble non-kin and LGB caregiving, particularly with respect to relying on informal CGs and chosen family members, who typically also are from sexual minority groups, when lacking other sources of support. Yet, another contribution of this research is that it calls into question the idea of a "typical" care relationship for midlife and elder LGB communities, as the friendship pairs in this study are heterogeneous with respect to demographics and health statuses, in unexpected ways. Some of the most notable results

of this study lie in the findings that are less frequent trends, which might be overlooked if relying on statistical measures. Nearly one-quarter of these friends were straight individuals providing care to their LGB friends; a finding that is consistent with prior research about LGB chosen families (e.g., Muraco, 2006), but also one that has rarely been addressed in studies of LGB caregiving. Nearly one-third of the sample is partnered or married (six out of 10 CRs and four out of 18 CGs); a finding that suggests that the CGs have a relationship more typically understood as a traditional family with the accompanying responsibilities, and CRs could have other potential people to provide care. Yet, these friends are the committed CGs.

The findings about the health statuses of both the CG and CR also are deserving of additional attention beyond their potential effects on duration of care. Not only are most of the individuals in the study chronically ill, they are chronically ill with multiple conditions. The individuals who provide care have two to three chronic illnesses, on average, and thus, may benefit from care themselves; yet they spend many unpaid hours per week meeting the care needs of friends. The degree to which mutual caregiving between the individuals in these pairs occurs or has occurred in the past is unknown beyond the pooling of financial resources, but examining caregiving as a process that is not always unidirectional (from CG to CR) is a fruitful avenue for future discussion. In addition, a large portion of the sample, 14 out of 18 CRs, and 13 out of 18 CGs, reported that they had been diagnosed with depression, bipolar disorder, or schizophrenia. Further research that explores whether this finding is consistent across other samples of older LGB CGs and CRs is an important area for future research, as these mental health conditions could have significant effects on the contexts of care.

This research makes strong contributions to the literatures on relationships, older LGB adults, and caregiving, but also has limitations. One limitation is that in the interview, we did not explicitly ask why the CG provides care for the recipient of care. As a result, the study cannot clearly distinguish whether caregiving causes characterization as family, or characterization as family leads to caregiving. This area is ripe for additional research and should be the focus of future work in order to create a better understanding of why individuals voluntarily undertake caregiving responsibilities, in their own words. A second limitation is that the data collected cannot adequately address issues of power between the CG and CR. Given that the recipient of care appears to be more dependent on the caregiving friend than vice versa, we would like to further explore whether or not there is a power imbalance in these dyads that affects the provision of care, the commitment to caregiving, and the quality of the friendship. Because we do not have adequate data to address these issues, we hope to see them pursued in future research.

The findings of this study also point to additional avenues for future research that would help us to better understand the family and caregiving relationships of older LGB adults. One key direction for future research is to perform a longitudinal study that examines the constitution and character of informal caregiving relationships over time. Due to time and budgetary constraints, the majority of research in these areas is cross-sectional. While this is a useful means of gathering data, a longitudinal study would allow us to see, over time, how the care provided within dyads changes and how the relationships between CGs and

recipients of care change and ultimately, will provide a fuller understanding of these dyads. A second area for future research is to more fully examine whether older LGB adults have any greater network of care beyond the dyad, which may include paid help. Such a study would allow us to see the full range of care that is available for this population and would provide a greater understanding of the degree to which older LGB adult caregiving differs or is similar to non-kin and LGB caregiving.

A last direction for future research would be to expand studies to focus on traditionally underrepresented populations. Specifically, there is a dearth of research that focuses on transgender individuals and those from racially diverse backgrounds. Expanding the body of social research to include these populations will allow us to create a fuller picture of lived family experiences. In particular, the findings from this study are not only applicable to older LGB adults, but also to other groups who may face aging with a dwindling social network, for example single women and childless adults. While these populations may not have experienced the same type of historical stigma as LGB adults, they may similarly rely on informal networks of care as they age. Our social structure relies on family to provide care, while we simultaneously limit who can be family and refuse to acknowledge contemporary family experiences. These legal and cultural practices have implications, sometimes grave ones, for caregiving in later life.

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Table 1

Background characteristics of caregivers and their care recipients (percentages).

	Caregiver (n=18)	Care Recipient (n=18)
Gender		
Male	72.22%	61.11%
Female	27.78%	38.89%
Age, M(SD)	46.22 (9.08)	55.17 (5.89)
Race/ethnicity		
White	33.33%	50.00%
African American	38.89%	33.33%
Other	27.78%	16.67%
Education		
High school graduate or less	33.33%	22.22%
Some college or more	66.67%	77.78%
Sexual orientation		
Gay or lesbian	44.44%	55.56%
Bisexual	22.22%	44.44%
Heterosexual	33.33%	0.00%
Relationship status		
Partnered	22.22%	11.11%
Other	77.78%	88.89%