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The Highs and Lows of Caregiving for Chronically Ill Lesbian, Gay, and Bisexual Elders

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Abstract

This study examines informal caregivers' and LGB care recipients' "best" and "worst" experiences of care within their relationship. Communal relationship theory guides the research. The work uses qualitative interview data from a sample of 36 care pairs ($n=72$), divided between committed partners and friends, to understand the similarities and differences in the care norms employed in varied relationship contexts. Findings from the study show that relationship context influences the experiences that caregivers and care recipients identify as "best" and "worst," but often focus on the relationship and needs met at bests, and conflict and fear of worsening health as worsts.

Keywords

caregiving; GLBT populations; GLBT issues; qualitative; chronic illness

Caregiving, which includes hands-on personal care, instrumental assistance with household needs, and emotional support (Wrubel & Folkman, 1997), has been the focus of many academic studies. Typically, studies that address the significance of the relational contexts of care focus on spousal dyads, adult child-parent relationships, and neighbors (Barker, 2002). Little of the existing research, however, has addressed the relational context in caregiving for lesbian, gay, and bisexual (LGB) adults age 50 and older, an understudied population that differs from other populations due to its invisibility, marginalization, unique types of support systems, and lack of legal protections. Both sexual orientation and the context of the caregiving relationship (i.e., relationships between committed partners and friends, straight and LGB) are expected to have an influence on the perception, experiences, and quality of care.

This study focuses on the care experiences indicated to be the "best" and "worst" informal care experiences according to both care recipients and caregivers and contextualizes these experiences within the theory of communal relationships. The evaluation of best and worst instances in the contexts of caregiving by the study participants in both committed

partnerships and friendships serves as a vehicle for attaining a deeper understanding of the ways that individuals experience care within the relational context. Asking the participants, both caregivers and care recipients, to identify and describe the best and worst experiences of care revealed a wealth of thematic material which serves as a basis of the present study. Our work uses interview data from a sample of 36 pairs of older LGB care recipients and their informal (unpaid) caregivers who consist of either a committed partner or a friend (N = 72) to understand how the care recipients and caregivers differently perceive and experience noteworthy moments in the caregiving process. Theoretically, the authors engage theories of reciprocity and social exchange and conclude that Clark's (1981) theory of communal relationships provides the optimal framework for understanding the dynamics that occur in these informal care relationships. The article concludes with a discussion of implications for practice, given our findings.

There are more than 62 million caregivers providing unpaid care in the U.S., at an estimated economic value of more than \$450 billion (Feinberg, Reinhard, Houser, & Choula, 2011). There are likely more than 2 million U.S. older adults that self-identify as lesbian, gay, or bisexual (LGB) (Cahill, South, & Spade, 2000; Fredriksen-Goldsen, Kim, Emler, Muraco, Erosheva, Hoy-Ellis, Goldsen, & Petry, 2011). The exponential growth of the 50 and older population in the next two decades suggests the number of LGB older adults may more than double by 2030 (Fredriksen-Goldsen, et al., 2011), yet, the informal caregiving of sexual minority adults 50 and older has received limited attention.

The existing research on LGB caregiving illustrates that formal services are less often utilized than in other populations; additionally, the duration of the care provided by friends or extended kin relationships may be shorter (Coon, 2003; FCA, 2002; Fredriksen-Goldsen, 2003). The relational aspect of informal caregiving, which is the relational context in which the care occurs, affects the perceived quality and challenges inherent in the care context. Informal caregiving, for the purposes of this study, is defined as hands-on personal care (e.g., assistance with dressing or bathing), instrumental assistance with household needs (e.g., housekeeping, transportation and coordination of care), and emotional support (e.g., emotional reassurance) provided by a committed partner or spouse, friend, or community member who is neither paid nor a volunteer affiliated with a service organization.

Review of Literature

Much research on caregiving has been built on the theoretical foundations of stress and coping theories or on sociological theories of work. When studies focus on the relational contexts in which care takes place, they typically address heterosexual spouses and adult child-parent relationships (Adams, McClendon, & Smyth, 2008; Guada, Hoe, Floyd, Barbour, Brekke, 2012) and tend to focus on either caregiver or care recipient perceptions, not both. When care recipient characteristics and outcomes have been examined, the care recipient and caregiver outcomes and burdens tend to be viewed as separate from their relational interactions (Coeling, Biordi, & Theis, 2003; Cox & Dooley, 1996; Lyons, Zarit, Sayer, & Whitlatch, 2002; Pruchno, Burant, & Peters, 1997). Often, studies fail to consider the recipient of care as an active participant in the dyadic care process (Lyons, et al., 2002;

Sauter, 1996), which ignores a primary player in the care relationship and limits our understanding of the relational context of caregiving.

For heterosexuals, marital spouses are most commonly selected to provide care when needed due to norms of intimacy (Allen, Goldscheider, & Ciambone, 1999), care, and commitment (Cancian, 1987) within marital relationships. LGB adults' ability to marry a same-sex partner has been legally limited (or prohibited), though relationship norms consistent with marital relationships appear to govern same-sex partnerships in that when asked to whom they would turn to for caregiving needs, older LGB adults would first turn to partners, then to friends and other family members (Cahill et al., 2000).

Perceived reciprocity or mutuality in the relationship as a pattern of exchange characterized by the giving and receiving of assistance affects relationship quality. In a dyadic relationship the caregiver and care recipient agree, over time, upon a mutually, generally unspoken, defined set of rules or norms that govern their interactions (Coeling et al., 2003; LeBlanc & Wight, 2000). Mutuality can exist even if both dyad members do not contribute "equally," since caregiving conditions change over time. Norms of obligation and generalized rules of reciprocity are more salient in spousal and parent-child relationships than among extended kin or friends (Call, Finch, Huck, & Kane, 1999; Coeling, et al., 2003). On the other hand, level of perceived support, rather than actual support, may be salient among the extended friendship network of lesbian, gay, and bisexual older adults (LeBlanc & Wight, 2000).

Communal Relationships

Some studies about caregiving for older adults have framed the discussion using exchange theories of relationships (Ingersoll-Dayton & Antonucci, 1988; Walker, Pratt, & Oppy, 1992), which focus on the importance of power and reciprocity in dyadic relationships. With respect to caregiving relationships, the receipt of help perpetuates a power dynamic where the caregiver has more power vis-à-vis the care recipient even when the care relationship occurs among committed relationship partners. Such power relations may extend to decision-making about the provision of care in covert ways (Pyke, 1999) and affect the everyday interactions within the care dyad (Beel-Bates, Ingersoll-Dayton, & Nelson, 2007).

A theoretical framework related to exchange theory that elucidates the dynamics in caregiver-care recipient relationships, especially in the case of LGB older adults, is the communal relationships theory. According to Clark (1981), communal relationships constitute an implicit agreement to take care of one another to the best of their ability, with less significance placed on how much any one person expects reciprocation from the relationship. In the case of committed partners, care recipients may use the expression of vulnerable emotion (i.e., anxiety, fear, sadness) to communicate their needs, rather than to defer power, to the caregivers. Expressing gratitude to a partner enhances perception of the relationship's communal strength (Lambert, Clark, Durtschi, Fincham, & Graham, 2010). Prior findings show that in communal relationships, expressions of vulnerability may signal: 1) a need and desire for care, 2) a lack of need or the success of care, 3) appreciation of care, or 4) love and care for the partner (Clark, Fitness, & Brisette, 2001; Graham, Huang, Clark, & Helgeson, 2008). Among married couples expressing vulnerable emotions, reports of less caregiving stress and greater sensitivity to the care recipient's needs by caregiving spouses

led to greater feelings of being mutually cared for by both spouses (Clark, et al., 2001; Graham, et al., 2008; Monin, Martire, Schulz, & Clark, 2009).

In the case of LGB older adults who need care, communal relationship theory explains why friends, neighbors, and community members step up to provide care for others with seemingly little to gain from the interaction. Clark explains the dynamics of communal relationships: “Since at any given time, the needs and preferences of members of a communal relationship are unlikely to be exactly the same, members should be unlikely to give and receive exactly comparable benefits within a short period. Indeed, members may actively avoid giving benefits directly comparable to benefits they may have recently received since doing so might imply a preference for a different and less valued type of relationship” (Clark 1981: 375).

In LGB older adult populations, committed partners are cited as the most common caregivers followed by friends as the second more common relational type (Cahill et al., 2000; Cantor, Brennan & Shippy, 2004), yet the balance of exchanges may vary when chronic illness and caregiving are involved.

Based on the literature, the authors decided to explore the relational aspects of the caregiving relationships for older LGB adults and elucidate the norms, both formal and informal, that regulate these relationships. We asked our sample a range of questions about their caregiving experiences, which ranged from the challenges they faced to the day-to-day actions that comprise caregiving. Here, we focus on the events that participants identified as “best” and “worst” in their interviews because these questions address some of the challenges and rewards that both care givers and care recipients experience in the contexts of care. Moreover, these questions illuminate the often unspoken norms employed by caregivers and care recipients in navigating informal care relationships.

Method

Participants

The interview data that guide this research were collected in 2005-06 in an urban area of Washington State. Trained researchers interviewed a sample of 36 pairs of older LGB care recipients and their caregivers (N = 72). For the purposes of this research, “care recipient” (CR) was defined as a self-identified lesbian, gay, or bisexual adult age 50 or older that requires assistance with daily needs. “Caregiver” (CG) was defined as the person designated by the LGB older adult as the informal helper who assists most with daily needs, and is neither paid nor a volunteer affiliated with a service organization and could include committed partners or friends. The caregiver was required to be age 18 or older, but did not need to be of sexual minority status. Only the primary informal caregiver to the older adult participated in the study.

Participants were recruited through an extensive search of community and health services that cater to older adults or LGB individuals. Specifically, the research team recruited participants by sending email, posting flyers, and making presentations in locations where the 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

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

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 interview, the CG and CR reviewed and signed an informed consent form. At the end of the interview each participant was paid \$25 as a token of appreciation for her/his time and participation in the study.

Open-ended qualitative questions were asked at the termination of a series of quantitative questions, about an hour into the interview period. The interview began with the interviewer asking the participant a series of quantitative survey questions, which are not being addressed in the present study, but have been published elsewhere (see Fredriksen-Goldsen, Kim, Muraco, & Mincer, 2009). The quantitative questions included standard measures of physical and mental health, the types of illnesses and disabilities that required care, and measures of dyadic relationship quality. By the point in the interview when the interviewer asked open-ended questions, the interviewer and the participant had developed a degree of rapport. The open-ended questions addressed a range of topics about the nature of care and the ways that care affected the relationship. The questions for the caregiver that provided the most fruitful data for this study were: "Please describe the best experience you've had providing care for [care recipient]" and "Please describe the worst experience you've had providing care for [care recipient]." The questions for the care recipient that provided the majority of data for this study were: "Please describe your best experience of receiving care from [caregiver]" and "Please describe your worst experience of receiving care from [caregiver]."

The qualitative interview data were transcribed verbatim and then coded by examining responses to a series of questions. The data are exploratory in that they address experiences of LGB care recipients, age 50 and older, and their caregivers, who are either committed partners or friends. Given the difficulty in recruiting this largely invisible population, the researchers established the greatest possible sample that was available at the time of

recruitment; therefore, the standard qualitative benchmark of saturation was not the sampling goal. The experiences of this sample are not intended to be representative of all LGB adults age 50 and over, nor are they generalizable to other populations; rather the findings from this study can help us to better understand the norms that guide the caregiving context of the sample.

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 partners and 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.

Results

The self-identified relationship context of the caregiving pairs ($N = 36$) was 50% committed partners, 47% friends, and 3% other, including neighbors and others. The sample characteristics by age for care recipients was 74% age 50-59, 17% age 60-69, and 9% age 70 and older; for caregivers 69% was under age 50, 17% age 50-59, 8% age 60-69, and 6% age 70 and older. In terms of ethnicity, approximately 50% of both the care recipients and caregivers were Caucasian, 20% of the care recipients and 31% of the caregivers were African American, 17% of care recipients and 13% of caregivers were multiethnic, 9% of care recipients were Latino, 3% of caregivers were Asian, and 3% of both care recipients and caregivers were Native American. The sexual orientation of the care recipients was 67% lesbian or gay and 33% bisexual; the caregivers were 63% lesbian or gay, 17% bisexual, and 20% heterosexual.

The relationship characteristics of the committed partnership portion of the sample by relationship type and gender ($n=18$) are as follows: 50% of the committed partnerships were male/male, 33% of were female/female, and 16% were male/female (one transgender individual and two bisexual individuals were members of these partnerships). Of the dyads characterized as friends or "other" ($n= 18$), 50% were male/male, 44% were female/female, and 22% were male/female. Of the male/female friendship dyads ($n=4$), 25% were comprised of a male care recipient and a female caregiver, while 75% were comprised of a female care recipient and a male caregiver.

Care recipient participants suffer from one or more of the following conditions: mental condition including bipolar, schizophrenia, depression (66.6%); HIV/AIDS (62.5%); arthritis (44%); high blood pressure (37.5%); diabetes (31.5%); Alzheimer's disease (18.5%). Most of the sample of care recipients had three or four of the aforementioned conditions. In a typical week 17% of caregivers provided care for 4 hours or less, 14% provided 5-9 hours, 31% provided 10-19 hours, and 38% provided 20 or more hours.

The themes that emerged from the qualitative data are presented here according to the dyads comprised of committed partners and friends. We make this analytical distinction because there are relational differences between partnerships and friendships, which affect the contexts in which caregiving is performed. In particular, given prior research findings, caregiving in the context of a partnership is an implicit relationship expectation, while caregiving in friendship embodies the norm of caring for each other, but may have limits to the care friends are willing to give over the long term, especially when decision-making is required (Muraco & Fredriksen-Goldsen, 2011).

Partners: Care Recipients Best and Worst Experiences

One of the most common themes present in the qualitative data was that the care recipients perceived the best experiences of caregiving in terms of the relationship context. In particular, many of the best caregiving experiences were identified as expressions of love and commitment to the relationship. One care recipient noted that the best experience of receiving care is found in the caregiving partner's "love ... the willingness to do anything that's needed." Other care recipients found it difficult to identify one particular best experience:

On the one hand the whole thing's been a good experience, he's seen me through a hell of a lot and he's not walked away. He works to understand. And I guess you do see deeper and deeper [commitment] as time goes on, and I want to be able to return it, too. I can certainly see his commitment to me, you know, that he's stayed with me through some of the stresses that he's had to go through. It helps me understand the depth of the commitment that's there, and I would certainly do the same for him.

Here, we see that to the care recipient, the caregiver's ongoing assistance comprises the best experience because it signifies strength and commitment in the relationship.

Another common experience identified as the best by care recipients was the caregiving partners' recognition and fulfillment of needs, both day-to-day and in crises. One lesbian care recipient said the best experience of receiving care is that her partner cooks her meals. Another gay male care recipient noted that his partner is "very conscious of my likes and dislikes ... He's very considerate and has an eye out for things for me that he thinks I would like. So it's more an ongoing thing than just a single example." Some of the care recipients' best experiences of care were more notable instances when caregivers saw a developing health crisis and responded immediately. One gay male care recipient remembered his best experience, "Probably last month when I had rapid heart beat, because I woke up in the morning and I knew something was wrong but I wasn't sure what it was, but he immediately, when he woke up, just called 911 and that was it. So he just took care of it there on the spot." In part, the care recipients acknowledge the categorization of optimum caregiving is related to fear of managing the difficult circumstances of their illnesses. One lesbian care recipient explained, "I would say there would be times that I was absolutely terrified and she would still be there, and that could be as simple as trying to take a bath when I had parts of me that couldn't have water on them. And she always managed to pull it off."

The most common response to the question of the worst caregiving experience by care recipient partners was that there was “no worst experience.” When care recipient partners were able to identify a worst experience, it tended to either be a pointedly embarrassing situation they had endured (especially those dealing with incontinence) or a feeling of being a burden to the caregiver. One lesbian care recipient explained that the worst experience was, “When I lost control of myself and wet the bed and everything, and that was so embarrassing. And of course she had to take care of me.” A gay male care recipient similarly explained, “Well, it's only been bad when the experience is bad. You know, like when you're incontinent and things are a mess and he'll help me into the shower and then help clean up the bed and everything. That's the – I mean, he doesn't mind doing it, it's very seldom it's happened, but that's like the worst.” Others acknowledge that they worry about being a burden to their partner. One lesbian care recipient explained, “I just feel like sometimes [my partner] wants to give up – and I wouldn't blame her.” Another noted that the most frustrating experiences are when she has to ask her partner for assistance, “Knowing she's going to be irritated, but having to ask.”

Partners: Caregivers' Best and Worst Experiences

Like care recipients, caregiving partners also focus on the best experiences of caregiving in terms of the relationship context. In particular, many of the best caregiving experiences were identified as those that represent the love and commitment they have for their partner. One gay male caregiver said, “I hope it doesn't sound trite, but every day that I wake up with him is the best experience ... it's the fact that he's still here.” Other caregivers identify the best experiences as being able to provide enjoyment by going on trips or outings that the care recipient would not be able to attend otherwise. A lesbian caregiver noted that the best experience was when she was able to help her partner attend a local music festival that she greatly enjoyed by figuring out how to navigate the grounds, setting up transportation, and bringing her food. Other caregiving partners considered the best experiences to be their ability to provide financial and emotional support to their partner. As one lesbian caregiver explained, “OK, the best thing I think that I've done is that I'm in a position where she does not have to work. And so that was the main thing, because she got fired after so many years because of the headaches and not being able to function. So that just caused her a lot of fear – how am I going to support myself? So I stepped in and I was helping her along.” Another lesbian caregiver reiterated that the best experiences occur in the day-to-day actions of caregiving and being a partner, rather than in more grandiose activities: “I think it's just the support that I provide her, overall. I mean you're talking about the best kind of care giving and that kind of thing, but it's just every day. I think it's the overall support that I can provide her and do provide her.”

One of the ways in which the caregiving partners most differed from other respondents was in identifying difficult and conflict-filled moments in caregiving as “best” experiences. Some caregiving partners reported their awareness that their relationship was different because of the illness, yet the couple would survive the challenge. One gay male caregiver explained:

It was one of those cathartic moments; he had come home from the hospital after about a four-day stay, and was on a whole lot of medication which was making him

absolutely stupid as well as nauseous and incontinent. And besides holding down a fulltime job ... and I was just getting so angry and frustrated and we were both that way. And I started to lose it; I just started to scream. He started to cry, and I just realized then that it was OK for another human being to depend on someone, particularly me, and that I could do this and that if given all the choices in the world, he would not ever want to be a 3-year-old again and how hard it was for him to have to ask for help. It was one of those great moments of inner growth, and growth on both parts, where we both let go our expectations that were no longer reasonable in the situation that existed, and became OK with it.

A similar type of best experience identified by caregiving partners was when they experienced physical vulnerability, which caused them to better understand themselves and empathize with their partners' limitations. One gay male caregiver explained that he had broken his ankle and was on crutches at the same time his partner was in a wheelchair for his chronic condition. He noted, "I think that's one of the most memorable [experiences], because for the first time I could really understand where he was, I could understand that – OK, you had the mobility really jacked up – I broke my ankle and my mobility was really jacked up, I realized how bad this feels, when something like that's taken away. But I then felt guilt about that, too, because I knew mine was going to correct itself and his wasn't."

The worst experiences acknowledged by the caregiving partners related to their own limitations. Some caregivers focused on fear of being unable to take care of their partner or that their partner's health would worsen. Some of the worst experiences were based on actual events that had occurred; for example, one caregiving partner recalled not being able to lift his partner out of the bathtub, which made him realize his partner had needs that he could not meet. A lesbian caregiving partner admitted that sometimes, pushing her partner's wheelchair is physically exhausting, especially when going up and down hills. Other caregivers' fears centered on worries about their partners' declining health. One lesbian caregiving partner said, "I don't like it that her health is going down hill and I'm afraid for her health, I'm just totally worried." One gay male caregiving partner recalled that it was difficult to see his partner in so much pain during a particularly bad spell.

Partners less frequently, but still commonly reported worst experiences of conflict and feelings of frustration. One gay male caregiver noted that an argument occurred when his partner was feeling like he was not able to fully contribute to the relationship, "And I don't remember how things were worded exactly, but I had said something that made him feel like I had called him stupid ... we slept in separate beds that night. That was the worst." Other caregiving partners described overwhelming caregiving circumstances as being their worst experiences. For example, one lesbian caregiver recalled an instance where her partner fell out of bed and broke both of her feet, "When it gets very bad is when in a period of a week she's got so many conditions that there will be a crisis with this condition, a crisis with that condition, like three different urgent things and I'm trying to be there with her in some way with all of them and it's just absolutely exhausting. That's very hard for me."

Friends: Care Recipients' Best and Worst Experiences

Similar to the partners, those who receive care from friends identify best experiences of care to be related to their relationship, as well as the recognition and fulfillment of needs. One care recipient commented that the best experiences of care by his caregiver occurs when they attend concerts together, “and we're both sort of connected to the event in the same way, she has a way of nudging me that is like a very loving nudge, and a happy nudge, too, that I translate into her openness of being able to do such an act, and also we're not making anything out of it as being a sexual thing it's just – I enjoy your company and I'm very happy that I'm here to have this wonderful time right now.” Care recipients also identified the best experiences as those in which they felt taken care of by their caregiving friend. One gay male care recipient explained that when he was hospitalized, none of his family members came to visit and, “All the things that they should have done, could have done, ought to have done – [my friend] did that.” Another gay male care recipient reported that his caregiving friend is, “Always there if I call him. He calls me every morning ... And if I don't answer, he'll get in the car and just drive here.” The consistent care and connection with the caregiving friend seems to be important in classifying an event as the best. Other care recipients remembered the best experience of caregiving as special efforts taken by the friend. One gay male care recipient identified the best experience of caregiving happened when his friend baked chicken at home and brought it to him while he was in the hospital. Others noted their best experiences occurred when their friends fill prescriptions for them and go to the store and buy groceries for them.

Similar to the care recipient partners, the care recipient friends' most common response to the question about the worst care experience was “none.” The few care recipient friends who identified a worst care experience indicated that there have been conflicts with the caregiver; for example, one care recipient said, “Overall she's been a very positive influence, but on a couple of occasions we've had some blowups. I guess that's the closest thing I can [identify as] a problem.”

Friends: Caregivers' Best and Worst Experiences

Many of the caregiving friends characterized the best experiences of caregiving as related to relatively ordinary interactions within the friendship, such as spending time together or providing emotional support. One caregiver said the best caregiving experiences happen when they are simply “hanging out” together, “When we're just sitting around and laughing and talking about what's going on. But the laughing part, I think it far outweighs any grocery-shopping trip. I mean, when we go to the store, we hop a bus and it's just the company, our company.” Another caregiver noted, “just some normal friendship things that friends do.”

A second theme to emerge from caregiving friends' best experiences was instances of help from the caregiver, both in day-to-day and in serious situations. The caregiver's assistance ranged from keeping them company in hospital waiting rooms to taking action that ultimately saved their lives. One caregiving gay male friend noted that he reminds the care recipient to take his medication and helps him to understand his doctors' orders. Another caregiver, a lesbian friend, recalled a very frightening scene with her friend:

I went to see her and she was really cold ... For the most part she doesn't go out or she's confined to her bed, but this time she's in the bed and under the covers with a sweater on just freezing and I called 911 and had her taken to the hospital.... She was in real danger and she could have had kidney failure, they probably could have shut down. She just thought she was cold and she couldn't get warm and I felt good that I could just come and [take care of her] – I thought this is not natural and she said – oh, I'll be all right and I'm like – no, you won't, I'm calling 911.

In these instances, caregiving friends felt good about the assistance they were able to provide to friends in times of real need.

Personal benefit was one final best experience identified by caregiving friends. In particular, friends responded that caregiving makes them feel good about themselves. One lesbian caregiver noted that when her friend came out of surgery, she was waiting for her: “When she came out, she looked up smiling with no teeth; that was my best experience because I felt, I don't know, I felt needed.” Another way that caregivers articulated the best experiences was by explaining how providing assistance to their friend improved their self-esteem. One male caregiver noted, “Now, this is going to sound greedy, but ... it raises my self esteem that I'm helping somebody.”

Some of the worst experiences voiced by the caregiving friends were conflicts brought about by misunderstandings and short tempers. Others' comments reflected concerns about acute or worsening illnesses. One of the caregivers recalled the worst experience as being one where her friend was far sicker than she'd understood, “[The neighbor] called 911 and took her to the hospital and she'd had a heart attack.... She is ill so much of the time that I sort of play it off in my head that it's not quite as bad as she says it is. But when I saw her in that bed with all the tubes and a ventilator on and all the tubes going into her arms and her nose – it was very scary, pretty scary for me.” Fear about the care recipient friends' actions also were designated as some of the worst experiences by caregivers. In particular, one caregiver noted that his hospitalized friend called him to tell him that he was going to pull out all of his tubes and leave the hospital. The friend recalled, “I was trying to talk to him, tell him ‘please don't leave the hospital. If you take the tubes out, you could die.’” Serious past situations also had arisen where the care recipient indicated that they wanted to end their own life. One caregiver said, without hesitation, that the worst situation arose when the care recipient tried to kill herself. She explained, “I didn't know if I should call 911 or not,” which reflects her concern about whether or not she should honor her friend's wishes. Another caregiver encountered a related situation, where her friend told her that she wanted to end her life because no one cared. The friend responded: “I'm here. I care. That's selfish to think that when you at least have one friend. Most people don't even have a friend in life.”

In summary, there were many similarities, but also differences between the experiences that caregivers and care recipients, both partners and friends, identified as the best and worst. The most common best experiences to be identified by all dyad types, that is partners and friends, and by both caregivers and care recipients were related to the relationship itself, rather than any specific act or circumstance. For care recipients, having needs met by either a partner or friend were also commonly expressed as best experiences. Care recipients also

most commonly noted that there were no worst experiences in caregiving by partners or friends. Some differences between partner and friend care dyads were expressed. Conflict was uniformly identified in terms of worst experiences for friend dyads, whereas partners sometimes indicated that conflict was a worst experience, but other times noted that conflict or challenges were best experiences because they drew the partners together or raised the caregiver's level of empathy. Finally, caregiving friends were the only group of participants that identified personal benefit as a component of a best care experience.

Discussion

Approaching the care relationship as a communal relationship rather than an exchange relationship allows for a greater understanding of the expectations of caregiving experiences for both the caregiver and care recipient. While the participants in this study did not address how they define caregiving and the inherent expectations in their own words, we can glean from their evaluations of the most and least optimum care experiences what they view as central or normative to caregiving. As such, this study is exploratory in that we examine what caregivers and care recipients identify as the “best” and “worst” experiences of care that they have encountered in their particular care relationship.

Differences by Relationship Context

Within the partnership dyad, the description of best and worst experiences differs for the caregiver and the care recipient, which is to be expected given the findings of prior studies that address issues such as caregiver stress (Pearlin, Mullan, Semple, & Skaff, 1990) as well as care recipients' emotional strain and deferential actions (Beel-Bates et al., 2007; Newsom & Schulz, 1998). Interestingly, rather than focusing on experiences of care, which was the basis of the interview prompt, a majority of care recipients and caregivers who were partners instead focused on the best experiences of caregiving as representative of relationship commitment. In contrast, when discussing worst experiences of caregiving, caregiving partners were more likely to address their own fears and shortcomings in ably dealing with the needs of their partner. Care recipients typically downplayed the worst experiences of receiving care saying that they had “no bad experiences.” Those who did identify worst experiences of caregiving identified feeling burdensome and embarrassment at the root of the events.

In the present study caregivers in both partner and friend dyads were able or willing to articulate various best and worst experiences with more frequency than the care recipients. In partnership dyads and friendship dyads alike, the care recipients were most likely to respond that there were “no worst experiences” in their caregiving relationship. Viewing the care recipient's inability or unwillingness to name a worst experience through the lens of the communal relationship theory, the assistance they receive fits within their expectations of care from a partner or friend. Because they do not expect any more than the caregiver provides, they do not view any experiences as particularly negative.

Differences and Similarities in Norms and Experiences

Different norms govern the partnership and friendship dyads; this finding is reasonable, given the greater level of commitment between the caregiver and care recipient to their relationship. In particular, caregiving partners tend to identify conflict, and the growth that emerges from the negotiation of conflict, as best, rather than worst experiences. Such an evaluation relates to prior studies' (Clark, et al., 2001; Graham, et al., 2008) identification of vulnerable expressions as barometers of the communal relationship, such that a care recipient's voicing of a need for care or the lack of need for a particular type of care can affect the caregiving dynamic. The conflicts described by the caregivers typically were related to uncertainty that they could effectively meet the needs of their care recipient partner. For instance, one caregiver explained that because of a particularly pointed conflict, he and his care recipient partner both let go of their expectations that were no longer reasonable given the condition of the care recipient's health. In so doing, both the caregiver and care recipient expressed vulnerability, which improved their ability to navigate the new challenges that arose in the care relationship and thus, strengthened their relationship.

Another common theme to emerge from the data is that both the caregivers and care recipients in partnership dyads identify best experiences as connected to the relationship and commitment they share, rather than any singular high point in giving or receiving care. When partner caregivers do identify a best experience, they often refer to a circumstance where they were able to provide a pleasurable event for the care recipient or a time when they felt satisfaction that they could meet a care recipient's needs. The care recipients, on the other hand, point to the day-to-day ways that the caregivers meet their needs and are willing and able to help in a crisis.

Breaches in Relationship Norms

The worst experiences, according to partnered caregivers and care recipients, were those in which the relationship expectations or the care aspects of the relationships were breached. In particular, the caregivers identified the worst experiences as those where they felt that they could not meet the needs of the care recipient and conversely, the care recipients noted the worst experiences as ones filled with embarrassment or where they felt bothersome. The norms of the communal relationship suggest that when a person takes a caregiving role, they make an implicit agreement to provide care to the best of their abilities (Clark, 1981). If a caregiver feels that she was unable to meet the needs of the care recipient, for example, then she may feel as if she has not upheld the agreement, regardless of whether the demands she experienced were too great to accomplish. The communal relationship theory also helps to understand that a care recipient's embarrassment related to her incontinence is a physical, rather than emotional, form of vulnerability that is not accounted for in the normative relationship expectations of care undertaken by adult peers. Were the needs voiced in a vulnerable emotional manner, they would be considered a care recipient's expression of appreciation for the caregiver's actions (Clark, et al., 2001; Graham, et al., 2008). Because the circumstance (incontinence) emerged from an inability to manage one's physical self, it represents a breach of relationship norms and thus, is viewed as a particularly negative experience of care based on the care recipient's, rather than caregiver's failing.

Benefits to Care Recipients, Caregivers

Similar to the findings of the partnership dyads, both caregivers and care recipients in friendship dyads identify the best care experiences as relational, related to everyday support and valued time spent together. In contrast to the partnership dyads, caregiving friends are more likely to articulate their own feelings of increased self-esteem as a benefit gained from providing help to a friend. Perhaps, the self-focus has to do with validation of membership in a communal relationship; by participating in a process that signals a communal tie, the caregiver's own status in a communal system is reinforced. A second way that caregiving friends focus on their own benefit from providing care is in framing the best experiences of caregiving as being able to meet real needs of their friends, which also corresponds with the communal norm of providing care to the best of one's ability.

The care recipient friends most commonly note the best experiences as related to the ability to rely upon the friend as a safety net that stands between them and an unmet need for care. Others point to feeling cared for as a best experience provided by their caregiving friend. Both of these findings illustrate the care recipient reliance upon communal relationship norms, which suggests that when in need, they will find willing community members who will provide care. Unfortunately, there also exists the possibility that the care recipients may have to rely upon different community members to provide care over time, as research shows that there are limits to some friends' willingness or ability to provide unlimited care (Muraco & Fredriksen-Goldsen, 2011).

Conflict

One of the most notable differences between partnership and friendship dyads in the study is in the focus on the outcomes for the partnership vs. the outcomes for individuals, which is illustrated in the way that the dyads view conflict. In caregiving and care recipient friend dyads, both groups identify conflicts and misunderstandings as being worst care experiences, a finding that differs from partnership dyads. Whereas in partnership dyads, conflict led to growth, which ultimately strengthened the relationship, none of the friendship dyads viewed conflict as beneficial to their relationship. It is possible that conflict negates the beneficial feelings that caregiving friends feel they gain from providing care, though no existing research about communal relationships addresses the effect of interpersonal conflict. The focus of this interpersonal conflict, however, appears to lie in the individual vs. dyadic outcomes. Moreover, since the communal relationship does not depend on how any care recipient expects reciprocation from any particular caregiver, in times of conflict, caregivers may desire to reallocate their care to another communal member. Lacking the firm commitment toward the care recipient that is present in partnership relationships, conflict may threaten the duration of the dyadic relationship between friends.

One final finding that deserves attention is the caregiving friends' reactions to a care recipient's suicide attempt. While different religious and ethical arguments could shape an individual's response to a suicide attempt, the communal relationship framework interprets such an action as severing a communal tie. An attempt to end one's signals a failure of both the caregiver and the care recipient to abide by the norms of the communal relationship, which places community membership and engagement as the center of informal care.

This study contributes to the relationships, older LGB adults, and caregiving literatures by connecting the experiences that caregivers and care recipients identify as best and worst to the broader theoretical framework of communal relationship theory. In so doing, this work illustrates the differential norms at work in informal caregiving arrangements by partners and friends and helps us to better understand why partners and friends engage in informal caregiving.

The communal relationship framework illustrates the pivotal role of relationship commitment and day-to-day care within LGB caregiving relationships, yet most caregiving services and public policies were not designed to support these diverse caregiving relationships. Most services and policies were developed to assist legally married spouses and other biological family members providing care and often are not accessible to same-sex caregiving partners or to friends, those that typically provide caregiving in LGB communities.

In contrast to most employers, and federal and state leave policies, the National Family Caregiver Support Program (NGCSP), established in 2000 through the U.S. Administration on Aging, broadly defines informal or family caregivers as adult family members, friends, or neighbors who provide care without pay. LGB caregivers and care recipients are able to access NFCSP services such as service information and access, counseling and support, and respite care (Administration on Aging, 2012). The NFCSP provides an example of the significance of defining caregiving broadly. Yet, most existing policies intended to help older adults and their caregivers exclude or limit LGB same-sex partners or friends further increasing the risk for emotional stress and conflict.

Professionals need ongoing training and consultation to increase their understanding of how best to provide services for LGB older adults and their caregivers. Social workers and other service providers need to better understand how the relational context may impact these caregivers and care recipients, and that training needs to be responsive to conflict and changing care situations, especially among caregiving friends when caregiving demands exceed their expectations or abilities to provide on-going care. Such training programs need to address the critical importance of care planning and the use of care teams and other caregiving advocates if needed (Fredriksen-Goldsen, et al., 2011).

While the research makes strong contributions, it also has limitations. One limitation is that we did not ask the caregiving participants why they engage in informal caregiving; thus, our application of the communal relationship theory is based on our interpretations of interview data rather than on specific questions that directly connect the theory to the data. A second limitation lies in methodological procedure we used for this research. At the outset of the study, we opted to interview participants separately, but simultaneously, in order to allow the participants to speak more candidly than they may have, were their dyad mates present. While our methodological choice provided rich data, it also limited the degree to which we can understand the interpersonal dynamics that occurred within the care dyads, since we did not observe the way the participants interacted when together.

The findings of this study point to several avenues that would be fruitful for future research. One area that deserves to be the focus of additional research is a longitudinal study that follows care dyads over time, in order to better understand the duration, character, and quality of the relationships that occurs as the health statuses of these individuals change. Given that our study was cross-sectional, it can only tell us about the dynamics between the care dyads at one point in time. Another study worthy of research attention would place more focus on the existing norms for caregiving and receiving care. While some of these norms emerged from the interview data in our study, making norms of optimal caregiving and care receiving a more central focus of research may help us to better understand existing, but often unstated, expectations.

Conclusion

This work serves as a step toward understanding not only the relational contexts in which caring occurs, but also the expectations that both the caregiver and care recipient have for the care activities. As the older adult population in the U.S. becomes increasingly older and more diverse, it is imperative that we consider experiences of caregiving and care receiving across divergent groups, including within LGB communities. Given their histories of marginalization and invisibility, LGB older adults likely rely heavily on informal care supports, including care provided by partners and friends. By utilizing communal relationships theory to examine the best and worst experiences of caregiving, similarities as well as differences in communal norms by both role and type of caregiving relationship emerge. Communal expectations and engagement have important implications for both caregiving and care receiving in later life.

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