

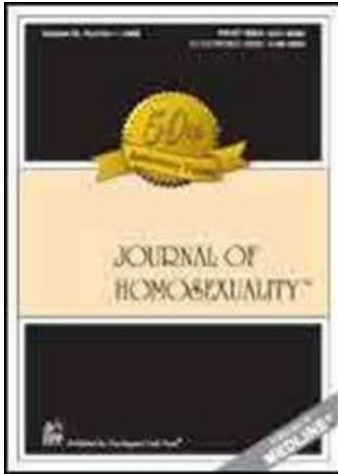
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An Exploration of the Experience of Lesbians with Chronic Illness

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An exploration of the challenges facing lesbians with chronic conditions and their coping strategies was investigated by examining the experiences of participants who were clients of a volunteer organization serving chronically ill lesbians. This article reports the results associated with those challenges, with its ultimate goal being and to assess the effectiveness of current services. Using the participant observation method, as employed by O'Toole (2000), the analysis was based on multiple data sources and 10 years experience within the volunteer organization, including 3 years in direct client support. A qualitative method served as the primary focus for the study. The quantitative method preceded the qualitative method and provided limited supporting data. The total number of participants included all past and current clients, but the number participating in each data source varied. Qualitative sources included archival structured interviews ($n = 69$), taped interviews ($n = 5-6$), and extensive comments written in response to the quantitative surveys ($n = 14$). The quantitative measures ($n = 14$) included the researcher-developed Chronic Conditions Challenges Checklist (C4) and the Short Form of the McGill Pain Questionnaire (SF-MPQ; Melzack, 1998). A content analysis of all data sources found a number of challenges that met the criteria of being identified in at least two data sources and across multiple participants. Challenges included those related to the disease process (i.e., pain, fatigue, and decreases in mobility) to impacts of the condition (financial security, ability to participate, support from family of origin and independence, loneliness, and issues related to mental health). Challenges were discussed in terms of

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those that are similar to and different from other women suffering from chronic illness, as well as their relevance to related literature.

KEYWORDS *lesbians, chronic illness, disability, challenges, mixed method, fatigue, mobility*

In 1996, a group of lesbian women came together to develop a plan for helping other seriously ill lesbians and their families. They spent the three previous years helping two of their friends deal with cancer and another struggle with a severe mental disorder. Several in this group had been an integral part of the community support of gay men during the AIDS crisis and recognized that the physical, emotional, and social support needs of the ill women were very similar to those of their gay male friends. They also realized that the care team concept used to organize the support of AIDS sufferers could be employed in an analogous fashion to assist chronically ill lesbians. Thus began SisterSupport (a pseudonym), which now in its 11th year, has provided care teams and other services to approximately 80 chronically ill women and their families.

The aim of this study was to explore the experiences of lesbians who were living with chronic illness and disability. The study was based on a participatory approach, similar to that used by O'Toole (2000) whose 25 years of experience within the world of lesbian disability culture provided the basis of her investigation into the identities of lesbians with disabilities. The current research is based on the author's 10-year experience within SisterSupport, as one of the original "founding mothers" of the organization, serving in various capacities over the years, and providing direct support of clients over the past three years as Vice President of Client Services (VPCS). The researcher is also a lesbian, active in the gay and lesbian community, and, having raised a disabled son (now 37 years old), is well versed in dealing with the myriad issues related to chronic illness. The method for this exploratory study evolved as the researcher explored her clients' needs and investigated ways in which SisterSupport might more effectively serve them. It began as a simple objective study of the challenges and coping strategies used by 14 current participants and evolved into a qualitative analysis of the experiences of SisterSupport participants as reflected in multiple archival and current sources.

The initial quantitative assessment was based on an a priori hypothesis that insight into the day-to-day challenges faced by these women and the coping strategies that they developed to deal with them might help her determine the appropriateness of current SisterSupport services, as well as how they might be improved. Results were limited to the options presented in the questionnaires and there was no way to assess the pervasiveness of

particular challenges in women's day-to-day lives, or the relative usefulness of one coping resource or strategy over another.

Despite the limitations, the questionnaires provided the starting point for the subsequent qualitative analysis, as most participants had taken the opportunity to write copious comments under the category of "other." Other qualitative sources included the numerous resources available within the archives of SisterSupport (e.g., intake interview records), informal face-to-face interactions with participants and audio-taped interviews with the members of the client support group.

This study reports the results associated with the challenges that SisterSupport participants face as they deal with chronic illness on a day-to-day basis. The coping strategies and resources that participants use will be the subject of a separate report. The present research used a mixed methods approach, with the qualitative method of data collection and analysis as the primary focus.

The subject of lesbian health has, until recently, received little attention. Prior to the 1970s, related research reflected the medical community's belief that lesbianism was pathological, hence requiring an understanding of etiology, diagnosis, and treatment (Stevens & Hall, 1991, p. 300). In a review of relevant literature from 1970–1990, Stevens (1992) found that health care providers often expressed negative attitudes toward lesbians, but believed that their negative attitudes did not compromise their services to lesbian patients. Lesbians reported that their health care providers often assumed that they were heterosexual, and when they attempted to correct this misimpression by disclosing their sexual orientation, were treated negatively. Fear of disclosing their sexual identity combined with lack of access to affordable health care often resulted in lesbians' putting off or avoiding needed medical assistance (Stevens, 1992), especially of a traditional nature (Reagan, 1981); and, if they sought care, disclosure of sexual orientation was avoided (Stevens & Hall, 1988).

During this same period, a number of studies addressed specific health issues faced by lesbians. Several researchers suggested that lesbians may be at higher risk for breast cancer due to fewer than recommended mammograms, clinical breast exams, and breast self-exams, as well as higher rates of nulliparity, delayed child-bearing, alcohol consumption, and body mass index (BMI; Bradford & Ryan, 1987; Johnson, Smith, & Guenther, 1987; Kehoe, 1986; McKirnan & Peterson, 1989; Robertson & Schacter, 1981; Stevens & Hall, 1988). On the other hand, lesbians were much less likely to suffer from typical sexually transmitted diseases (STDs), such as gonorrhea, syphilis, and herpes (Johnson, Guenther, Laube, & Kettel, 1981; Johnson et al., 1987; Robertson & Schacter, 1981; Zeidenstein, 1990).

The literature of the 1990s was marked by a growing awareness that lesbians were a unique subgroup, with potentially unique health behaviors, needs, and risks (Rankow, 1995a; Solarz, 1999; White & Levinson, 1995).

Several studies focused on the role of the medical community in pathologizing lesbians (Harrison, 1996; Stevens & Hall, 1991; Wilkerson, 1994), while others investigated lesbians' experiences within the medical community (Robertson, 1992; Schwanberg, 1996; Stevens, 1994b, 1995; Trippet & Bain, 1992; White & Levinson, 1995) and/or provided recommendations for more sensitive and inclusive treatment to caregivers and training for health care professionals (Gentry, 1992; Harrison, 1996; Matthews, 1998; Rankow, 1995b; Robb, 1996; Roberts & Sorensen, 1995; Robinson & Cohen, 1996). Research confirmed the finding that lesbians, especially older lesbians (Deevey, 1990), felt invisible within the health care system due to assumptions of heterosexuality by health care professionals (Peterson & Bricker-Jenkins, 1996; Bybee, 1991; Jackson, 1994; Robertson, 1992; Roberts & Sorensen, 1995; Stevens, 1992; Wilkerson, 1994) and that they were more likely than other women to postpone or avoid health care (O'Hanlan, 1995; Robertson, 1992; Smith, Heaton, & Seiver, 1990; Solarz, 1999; Stevens, 1992b, 1994a, 1995; Trippet & Bain, 1992; White & Dull, 1997; Zeidenstein, 1990). Several studies investigated ways in which lesbians attempted to manage the health care experience by, for example, turning to alternative forms of care (Harrison, 1996; Matthews, 1998; Moran, 1996; Rankow, 1995a; Solarz, 1999; Trippet & Bain, 1992; White & Dull, 1997), controlling information about themselves and screening health care providers (Matthews, 1998; Stevens, 1992a, 1994a).

During the same period, several studies found significant economic barriers to health care in lesbians (Lauver & Karon, 1999; Rankow, 1995a; Rankow & Tessaro, 1998a). Lesbians had lower incomes than other groups of women (Bradford, Ryan, & Rothblum, 1994; Rankow & Tessaro, 1998a), and were less likely to have health insurance coverage (Bybee, 1991; Rankow, 1995a; Rankow & Tessaro, 1998a; Solarz, 1999). Other studies confirmed earlier findings related to lesbians' elevated risk for breast cancer. They were less likely than other women to undergo breast screenings or examine their own breasts than other women (Ellingson & Yarber, 1997; Moran, 1996), had higher levels of alcohol consumption and alcohol-related problems than heterosexual women which did not decrease as they aged (Abbott, 1998; Bradford, et al., 1994; Hughes & Wilsnack, 1997; Lehman, Lehman, & Kelly, 1998; Moran, 1996; Rankow & Tessaro, 1998a), elevated BMI (Roberts, Dibble, Scanlon, Paul, & Davids, 1998; Sievers, 1994), and a higher incidence of nulliparity or late parity (Bybee, 1991; Bradford, et al., 1994). Some studies also found that lesbians had higher rates of illicit drug use (Bradford et al., 1994; Bybee, 1991). Findings related to the use of tobacco were mixed, with some showing higher levels in lesbians than a comparison group (Bradford et al., 1994; Moran, 1996) and others showing similar or lower levels (Roberts & Sorensen, 1995; White & Dull, 1997). Finally, lesbians were found to suffer higher levels of stress associated with discrimination, which likely produced or exacerbated a variety of symptoms

(Bybee, 1991; O'Hanlan, 1995; Rankow, 1995a; Solarz, 1999), and were less likely to be supported by their families of origin, more often depending on their partners and friends for social support (Moran, 1996; White & Dull, 1997).

Suggestions that lesbians might be at an elevated risk for cervical cancer were based on their higher levels of smoking, engaging in unsafe sexual practices (Rankow, 1995b; Rankow & Tessaro, 1998b), and lower levels of receipt of regular gynecological care and Pap tests than other groups of women (Bradford et al., 1994; Buenting, 1992; Ellingson & Yarber, 1997; Ferris, Batish, Wright, Cushing, & Scott, 1996; Moran, 1996; Rankow, 1995a). Several studies also found evidence of woman-to-woman transmission of STDs that required only skin-to-skin contact, including herpes simplex virus (HSV), human papillomavirus (HPV; O'Hanlan, 1995; Rankow, 1995a), and bacterial vaginosis (Berger et al., 1995); according to White (1997), the risk and prevalence of transmission of the HIV virus between women is low.

Research related to lesbian health published from 2000 to the present has supported and expanded previous findings. Studies confirmed that lesbians were less likely than heterosexuals to be insured (Cochran et al., 2001; Diamant, Wold, Spritzer, & Gelberg, 2000; Harris Interactive, 2005; Marrazzo & Stine, 2004), more often delay seeking health care (Sinding, Barnoff, & Grassau, 2004; van Dam, Koh, & Dibble, 2001), and more frequently used alternative medicine (Saulnier, 2002). Lesbians also had a more negative perception of the health care system and were less likely to be satisfied with the care they received and the lack of inclusion of their partner in discussions with physicians (Barbara, Quandt, & Anderson, 2001; Fobair et al., 2001; Saulnier, 2002). Disclosure of sexual orientation to health care providers was found to be related to the consistent use of medical care (Bergeron & Sinn, 2003; Steele, Tinmouth, & Lu, 2006). Earlier findings related to higher levels of stress experienced by lesbians were corroborated (Gruskin, Hart, Gordon, & Ackerson, 2001), and lesbians were found to be more apt to depend on friends and partners, rather than family of origin, for support (Fobair et al., 2001).

Studies also continued to find that lesbians were more likely than heterosexual women to be obese (Cochran et al., 2001; Valanis et al., 2000) and to have higher levels of alcohol use and drinking-related problems (Aaron et al., 2001; Cochran, Keenan, Schober, & Mays, 2000; Cochran et al., 2001; Diamant et al., 2000; Gruskin et al., 2001; Valanis et al., 2000); there, however, is some evidence of a decline in levels of abuse in recent years (Hughes, 2003). Again, findings related to cigarette smoking were mixed: Some studies found higher levels of smoking in lesbians compared to heterosexual women (Aaron et al., 2001; Valanis et al., 2000), while others found that lesbians were less likely to be smokers (Cochran et al., 2001) or that only younger lesbians had higher levels (Gruskin et al., 2001);

still others (Koh & Diamant, 2000) found no difference between lesbians and heterosexual women.

Several studies investigated the receipt of mammograms and Pap smears by lesbians vs. heterosexual women (Cochran et al., 2001; Diamant, Schuster, & Lever, 2000), and by lesbians and bisexuals vs. heterosexual women (Marazzo, Koutsky, Kiviat, Kuypers & Stine, 2001). Results indicated that lesbians and bisexuals had lower rates of reception of these medical services than heterosexuals. Yet, other studies found that lesbians' rates of use were similar to that of heterosexuals (Aaron et al., 2001; Valanis et al., 2000), and that that only younger lesbians (<50 years) were less likely to receive Pap smears (Diamant, Schuster, & Lever, 2000).

Findings of woman-to-woman transmission of STDs (e.g., HPV, HSV, BV) put lesbians at increased risk for cervical carcinoma (Hutchinson, Thompson, & Cederbaum, 2006), and underscored the importance of routine screening for lesbians (Marrazzo, 2004; Marrazzo, et al., 2001; Marrazzo, Koutsky, Eschenbach, Agnew, & Hillier, 2002). Again, all documented cases of potential HIV transmission between women found evidence of other risk factors (Moore & Smith, 2001; Sved, 2001), and, in a recent review, Baernstein et al. (2006) concluded "transmission of HIV between women is rare" (p. 91). Despite the fact that there has been no comprehensive research effort regarding lesbians' risk for particular diseases, Sved (2001) suggested that lesbians may be at risk for endometrial and ovarian cancer due to nulliparity and nonuse of oral contraceptives. Additionally, Valanis et al. (2000) proposed that older lesbians may be at risk for reproductive cancers and cardiovascular disease due to higher rates of obesity, smoking and use of alcohol, lower rates of screening and a diet deficient in fruits and vegetables.

In general, it may be concluded that research related to lesbians' health experiences has primarily focused on experiences within the health care system, rather than their lives with chronic conditions. Several recent studies (Boehmer & Case, 2007; Matthews, Peterman, Delaney, Menard, & Brandenburg, 2002; Sinding et al., 2004) investigated lesbians' responses to cancer, but again, the primary focus was on the health care experience. Two studies (Fobair et al., 2001, 2002) investigated their lesbian and heterosexual participants' mood, body image, family relationships, and social support system in response to newly diagnosed and early stage breast cancer. They found that lesbians were more comfortable with their bodies and had more supportive partners and friends, while heterosexuals had more support from families of origin. Lesbians also reported "more intrusive thoughts about their cancer and . . . less fighting spirit" than heterosexual women (Fobair et al., 2001, p. 47).

Two studies have addressed challenges experienced by lesbians with chronic conditions. Axtell (1999) interviewed disabled lesbians and bisexuals and their partners in an attempt to understand the ways in which they integrated their identities of sexual orientation and disability into their identities as individuals, as one of a couple, and as part of the community. Challenges

that were associated with the development of identity on an individual basis included those related to everyday living, such as adjusting to limitations imposed by their condition, “dealing with ableism” (p. 60) in the environment and in others, and recognizing the positive parts of disability. As well, developing a disability identity involved dealing with one’s own internalized ableism and developing a new relationship with the changing body. Axtell found that the chronic illness experience did not factor into the couples’ identities although it did influence and challenge the relationship, both positively and negatively, especially as it related to boundaries. Challenges on the community level included such factors as lack of accommodations, scheduling conflicts, the absence of childcare, as well as discriminatory attitudes and conflicts between the disabled individuals’ priorities and those of the community.

O’Toole (2000), in her exploration of “the intersections between disability, race, and sexuality” (p. 207), also addressed challenges for disabled lesbians. Challenges associated with the development of a healthy identity included ambiguity in the meaning of disability and lesbianism. Dealing with the medical community represented another challenge for disabled lesbians, who are dependent on their physicians for getting services and benefits, but whose help can be compromised if they disclose their lesbianism. At the community level, disabled lesbians were isolated from both the disability and lesbian groups, neither of whom addressed their needs (O’Toole, 1996, 2000). This isolation was exacerbated by the strong emphasis on self-reliance within the lesbian community, which is contradicted by lesbians with disabilities. O’Toole (2000) suggested that challenges associated with prejudice often lead disabled lesbians to align themselves with one group or the other, but at the risk of losing the support of the alternative group. Other challenges included those related to loving and being sexual, finding appropriate role models and being mothers.

Although there have been calls for an organized care response within the lesbian community (e.g., Aronson, 1998; Sinding, Grassau, & Barnoff, 2006), especially from the self-report literature (e.g., Doucette, 1989; Sorella, 1991–1992), large-scale assistance in terms of care teams, buddies, for example, as seen during the AIDS crisis, is missing (Aronson, 1998). There are organizations, such as the Mautner Project (2007), which assist lesbians with a specific class of problems, such as cancer. Also, the literature (e.g., Aronson, 1998; Sinding, 1999) provides examples of informal groups of lesbians who have joined together to assist individuals. Hence, SisterSupport appears to be unique. It is an all-volunteer organization that provides support to lesbians with chronic disabling conditions through care teams of three to six individuals. The care teams perform light housekeeping, yard work, and other tasks, as well as social support and connection to the lesbian community. Additional services include \$100 per month in grocery gift cards, no-cost taxi vouchers for medical appointments, and access to free case management and a client support group.

METHOD

Quantitative

The quantitative analysis preceded the qualitative evaluation, but played a relatively minor role in the overall understanding of the experience of chronic illness. The methods related to the assessment of challenges are presented here briefly; greater detail may be obtained by contacting the author. Participants were recruited via written notice. Of the 22 current SisterSupport participants, the response of 14 was used for the analysis. Participants ranged in age from 38 to 83, with a median age of 56; 9 of the 14 participants reported that they received other financial support such as Social Security, Medicaid, food stamps, etc.

All participants were provided a document of informed consent, a personal information sheet, and five surveys. Surveys measuring challenges included two questionnaires that measured challenges: the short form of the McGill Pain Questionnaire (SF-MPQ; Melzack, 1998) and the Chronic Conditions Challenges Checklist (C4). The self-administered SF-MPQ, derived from the more comprehensive MPQ (Melzack, 1975), is composed of 11 sensory descriptors (throbbing, shooting, stabbing, sharp, cramping, gnawing, hot-burning, aching, heavy, tender, and splitting) and four words (tiring-exhausting, sickening, fearful and punishing-cruel") that reflect the affective aspects of pain. Words that describe one's pain were scored on a scale from *none* (0) to *severe* (3); a tic mark on a visual analog scale (VAS), as well as evaluative descriptors (from *no pain* to *excruciating*) indicated present pain intensity. Reliability of the MPQ has been reported by Melzack (1975) in terms of correlations between rank and scale pain rating index (PRI; all correlations > .9), and between number of words (NWC) chosen and rank and scale PRI (correlations .89 and .97, respectively). Correlation coefficients between pain rating scores obtained with the SF-MPQ and the MPQ ranged from .62 to .90 (Melzack, 1987).

The researcher-developed C4 was designed to assess a wide range of challenges experienced by lesbians with chronic illness, including personal, interpersonal, and environmental. Initial items for the checklist were generated from requests for assistance or concerns expressed by clients or care team volunteers and were then reviewed by three individuals suffering from chronic conditions, one of whom was a former SisterSupport client. The final list of 24 items was associated with a 5-point Likert scale indicating the degree of difficulty (*not challenging at all* to *extremely challenging*) that the item presented. Options for *not applicable* (N/A), for each item, and *other*, for each category, were also included.

Responses to all items, and all categories of items within both questionnaires were summed and means calculated. As one participant reported that she had little pain and did not respond to the SF-MPQ, this analysis was based on 13 participants. The response option of N/A in the C4 was

re-coded to 1 – *not challenging at all* based on the assumption that a nonapplicable item was inherently not challenging. The scores for all C4 categories were based on the responses of 14 individuals, except for the “transportation” item, in which a missing response resulted in the score being based on the responses of 13 individuals.

Qualitative

The plethora of comments written by participants in response to the category of “other” included in the surveys described above provided the first indication that qualitative data might offer a more fruitful source of information for the present study. Hence, the surveys were found to be useful exploratory tools, effective in eliciting a wide variety of challenges and ways of coping over and above the suggested options. Extensive comments written by 9 out of 14 respondents to the C4 were highlighted and categorized in accordance with the C4 (personal, interpersonal, and environmental).

A second source of qualitative data was SisterSupport intake interviews that all potential clients undergo prior to acceptance for services. As part of the interview process, individuals sign a release form allowing anonymous data from the intake to be used for research and fundraising purposes; both interview and release forms are maintained in confidential client folders. As part of her responsibilities as VPCS, the researcher had developed an Excel spreadsheet in which she entered the written responses of the intake interview for all previous and current clients ($n = 69$, including the 14 participants who had participated in the quantitative portion of the study). Of the categories included in the interview, responses addressing “physical health/medical diagnoses,” “mental health/psychiatric diagnoses,” “assessment of needs and priorities,” “chores you are able to do/chores that others do,” and “volunteer services needed” were considered to provide evidence of challenges associated with chronic illness. The intake interview data was reread several times and themes reflecting challenges were highlighted. Identified themes included challenges associated with the condition itself, support systems, participation in activities in the home and outside environment, and emotional impacts. Challenges were first identified in the interviews of the original 14 participants from the quantitative portion of the study. The analysis of the remaining participant interviews found no additional challenges, although considerable evidence for the previously identified challenges was obtained. The categories were then reviewed by a former SisterSupport board member and client to ensure that the themes were present within at least two data sources. Comments representative of each class of challenge were counted. To protect the anonymity of the participants, no identifying information (names, addresses, etc.) was entered into the spreadsheet; individual participants were distinguished by two-letter identifiers.

Preliminary findings from the study were then presented to SisterSupport volunteers at the monthly meeting. Questions asked and comments made during that presentation engendered another review of the original themes. No additional themes were identified; however, one category was renamed and three challenges were collapsed under the single category of "loss."

A final source of information related to challenges involved an interview with the members of the SisterSupport client support group. The initiation of the group occurred at the end of the data-gathering period and was the first significant attempt on the part of the organization to improve services to clients. This small group of individuals provided a convenient forum for directly addressing the notion of challenges and coping. An initial informal interview took place approximately two months after the inception of the group; the purpose was to answer questions related to SisterSupport policy, assess the progress of the group and familiarize the researcher with the format of the group. Six members of the support group, all of whom had participated in the quantitative portion, as well as two group facilitators (both licensed social workers), were in attendance; the interview lasted approximately 30 minutes. A second interview, requested by the researcher, included six participants and two facilitators. Five of the six members of the group had participated in the previous interviews and the quantitative portion of the study. The interview lasted approximately 45 minutes. The following questions were the focus of this interview:

How do you experience chronic illness?

How has it changed your life?

What was a typical day before your illness vs. what is a typical day for you now?

What effect do you believe your lesbianism had on your experience as a chronically ill woman, and vice versa?

The interview was tape recorded, responses were transcribed, and the transcription was highlighted for common themes related to challenges and solutions. The transcription was read by two independent readers, in addition to the researcher, who provided suggestions related to categories. Themes related to challenges did not change, although additional coping resources were identified.

RESULTS

A comparison of the demographics of the 14 individuals who took part in both the quantitative and qualitative portions of the study versus those who took part in the qualitative portion only showed that both groups were dominated by White women (93% in the sample of 14 participants, and 90%

in the remaining 54 participants). The remaining participants in both groups were African American and one Native American woman in the larger sample. Due to the fact that almost all of the women had multiple disabling conditions, it was difficult to determine the number of individuals with specific disorders. The median age of the 14 original participants (56) was higher than that of the remaining group (46.5).

The challenges which follow represent commonalities of experience as articulated by the participants of SisterSupport across the 10-year history of the organization. All challenges were identified in at least two of the three data sources (comments to surveys, archival intake interviews, and client support group interviews) and by several participants within each data source. Direct quotes that illustrate the themes were used with the promise of anonymity, through signed release forms maintained in archival records or put in place as part of the current research project. Two-letter identifiers are used to indicate individuals who wrote comments in response to the quantitative sources and those who participated in the client support group. Quantitative results are presented, where appropriate, as they support or do not support the qualitative findings.

Pain, Fatigue, and Decreases in Mobility

Despite the range of chronic conditions that participants experienced, the most commonly reported challenges associated with the disabling condition itself included pain, fatigue, and impairments in mobility. A simple count of the presence of these challenges in intake interviews found that 27 clients noted moderate to severe pain, 22 complained of fatigue, and 43 described significant decreases in mobility.

JS, in response to the “other personal” category of the C4, stated: “. . . being in constant pain is extremely hard; sometimes I have to choose not to take my meds [so I’m] able to do such things as drive, clean house, and on the meds, I’m not able to function well and have no memory.”

For these women, the challenges posed by the chronic illness were intimately related to changes in the self, and their evolving connection with this new self (Axtell, 1999). During the client support group interview, JS said:

You know, it’s just letting go of what you used to be . . . Because you’re having an attack, so you have to take the medicine. The medicine knocks you out and you are lying down all of the time. You start your life by waking up in the morning taking pills. If you’re feeling good that day, you might not have to take anymore. But generally, you’re taking pills all day long and that’s what you got, is to take pills. And then when you have a real severe attack and you have to take more, then you are not even able to function or able to talk; you can’t drive anymore. I mean you just . . . you feel useless; you really do.

The importance of recognizing the body's experiences of "energy and fatigue, pain, and the changing relationship with the body" is a critical part of the process involved in integrating one's identity as a disabled/chronically ill lesbian into one's identity as an individual (Axtell, 1999, p. 69). O'Toole (2000) described the need for disabled lesbians to "come out twice," as a lesbian and as a disabled woman (p. 215). The ways in which these two identities interact occur on multiple levels (individual, relationship, community) and the process involved in coming out as one identity may interfere with or enhance the other (Axtell, 1999).

The quantitative data also provided some support for the challenges associated with fatigue and pain. Responses to the C4 suggested that fatigue was more challenging (mean = 4.2) than managing pain (mean = 3.6). Mean present pain intensity scores on the SF-MPQ, as measured by the VAS, were 64%, with a range of 0% (no pain) to 91% (worst possible pain), and as measured by evaluative terms, were 56%, with a range of 20% (mild) 100% (excruciating). Results from the SF-MPQ found that the type of pain most often experienced by all participants was "tiring-exhausting" (mean = 2.6). Hence, the suggestion from the qualitative data that pain may be controlled fairly effectively, but at the cost of energy to do other things, finds some support from the quantitative data.

The impacts of pain, fatigue and decreases in mobility were also found in the results of the C4. "Upkeep of home and yard" (mean = 4.5), "using things in the environment" and "doing housework" (means = 4.2) were the highest rated challenges. The effects of the disabling condition combined with lack of accessibility in the environment are perhaps the most obvious reminder that the environment is designed for the able-bodied (Doucette, 1989). JP, who was not part of the participant pool in this study, but was a member of the Support Group, described how her life was affected:

. . . I've had a lot of fatigue so my life is very different in the sense that just to go for a walk with the dogs, I have to take pain medication. And . . . ah . . . to stand up and cut vegetables to make something for dinner, my back starts to tighten up and my neck and all over starts to hurt really bad. So I don't do things very much like things . . . like, if anybody said, "You win an all-expenses trip to Hollywood to meet Scarlett Johanssen, I won't have the energy. That's what I'm saying; the level of fatigue and the level of pain and realizing that it's not something that's going to get better but it's something that's going to get worse. . . .

Loss

Themes of loss permeated all qualitative data sources. Many of these losses, such as loss of economic status, are likely to occur for both lesbians and heterosexual women (World Health Organization, n.d.), whereas others,

such as loss of support from relatives, are more likely to be associated specifically with being a lesbian.

LOSS OF FINANCIAL SECURITY

The SisterSupport intake interviews included general questions related to resources (e.g., topics such as client employment/disability status and client's health care resources). Intake interviews included statements that indicated an overwhelming loss of financial resources. Approximately 52 of the 69 participants had been declared "disabled" and were receiving various forms of support (e.g., Social Security Disability, etc.) or they had not yet been accepted by Social Security and were in a critical state of need. Typical statements of the financial status of participants by intake workers were: ". . . financially supported by her son and other family members . . . lost car . . . sold possessions for money"; ". . . on disability—worker's comp (receives \$587 a month . . . running out in July . . . worried about paying for pain meds after July). . . ."

During the SisterSupport Client Support Group interview, FS described her financial problems: "I'd never had both food and medicine and this now lately is something that . . . I still struggle with, even with [SisterSupport'] help, is to make sure that I have my food and medicine so I won't go through various stages of withdrawal . . . Being chronically ill is tough. That's all I have to say about it."

According to the World Health Organization (n.d.), chronic disease and poverty are highly intertwined. Not only are the poorest individuals most likely to suffer from chronic conditions, but living with chronic illness often causes or exacerbates economic decline. There is also a strong ethic within the lesbian community, which puts pressure on lesbians to be self-reliant (O'Toole, 2000) and which may result in their being uncomfortable with asking for help. The self-report literature provides many examples of this emphasis on self-sufficiency, and its effect on disabled lesbians (Brownsworth & Raffo, 1999). An example by Lizard Jones illustrates this point, and the effect it had on her self-esteem. "Not being able to support myself strikes right at the core of my self-image as a dyke. I do my best not to be ashamed that I take handouts, but I often am—ashamed, that is. And then I'm ashamed of being ashamed" (Brownsworth & Raffo, 1999, p. 50).

LOSS OF THE ABILITY TO PARTICIPATE IN ACTIVITIES

Many SisterSupport participants reported that they had been forced to give up activities that were a major part of their lives. Although specific mention in intake interviews of losses in participation was made by only 15 participants, it is likely that the true decreases in the ability to participate, given the mobility problems described above, were considerably greater.

In response to the “other environmental” category in the C4, RJ described the challenges associated with being unable to participate: “. . . not feeling well enough nor able enough to throw parties or go out to eat or go to a movie or go camping or walk on the beach or go horseback riding or sing professionally, etc. . . .” An intake worker described another client as “depressed (‘doesn’t feel like a person’ anymore, can’t do routine things. . . .”

For many of the participants, such as HG, who had received an athletic scholarship in college, the activities that they could no longer engage in defined them as individuals. In response to the questions “How do you experience chronic illness? How has it changed your life?” she stated, “Before; I liked it before when I could do sports—no problem, and everything; play ball—no problem and then I . . . had to quit coaching and quit playing ball because I couldn’t do anything, you know, which was . . . sad.”

Following up on HG’s comment, JS said:

I agree. It’s like . . . I think the hardest thing in the world is to sit and watch somebody else mow your yard. And you used to have your own landscaping company. You used to do all that yourself. You used to have people under you that worked for you and now you have to get people come over to do it for you. And to not be able to go in and sweep your own kitchen or . . . sometimes you can’t even bend over and tie your shoes.

The loss of the ability to participate, due to chronic illness or disability, pervades all aspects of a disabled person’s life. In 1998, a Harris Poll found that disabled people are significantly less likely than nondisabled individuals to work, to take part in leisure activities outside the home, socialize, have adequate transportation, and get access to medical care. Coined the “participation gap,” it has only increased over the years in most areas (Taylor, 1998). Being unable to participate in valued activities contributes to the sense of isolation and reduced quality of life that pervades the lives of chronically ill lesbians, especially older lesbians (Sinding, et al., 2006).

The only other highly rated participatory activity on the C4 was “attending church and religious activities” (mean = 4.1), the result of only 8 of the 14 participants. Interestingly, one of the few participation gaps that appears to have narrowed over the years is in the number of disabled people attending church or religious services (Taylor, 1998).

LOSS OF INDEPENDENCE

Having to ask for help and depend on others was mentioned by at least 10 participants during intake interviews. As a specific challenge on the C4, “dependence” received a mean of 4.3, providing further support for the impact of this challenge. The self-reliance ethic that is endemic to the

lesbian community clearly played a large role in this particular challenge. Common statements made by participants were “. . . it was difficult to ask for assistance . . .,” “I hated to ask for help,” and “I am not used to having other people do things for me.” A remark made by one participant responding to the C4 expressed this loss succinctly. “I was a very active woman until 6 years ago and now have a difficult time as I have always been independent and hate to have to give in to being helped. It’s a very hard pill to swallow.”

In her study of lesbians with cancer, Matthews (1998) found that a “perceived threat to independence” served as an obstacle to their accepting either material or emotional support. The significance of this particular challenge for organizations, such as SisterSupport, is that it points to the importance of the relationship between caregiver and care receiver. The dependency associated with having to be cared for by someone (e.g., partner, friends) with whom they have no culturally sanctioned relationship (Aronson, 1998) is a very real possibility for lesbians with chronic illness. Such caring relationships must “constantly [be] negotiated and affirmed” (Aronson, 1998, p. 509), creating a great deal of stress and uncertainty for these women at a time when their resources are already low. As a 501c3 organization, SisterSupport has attempted to implement a caring relationship that is sanctioned and supported by the larger community, thus ensuring dependable care through the systematic allowances of the organization and the activities of the care team. The relationship between the client and team often becomes a long-term bond of mutual giving and receiving, and over time, participants become involved with supporting the organization in various ways (e.g., providing handmade objects for silent auctions, attending SisterSupport events, etc.). The benefits to the participants are considerable. In a comment to the C4, a client stated: “I realized that I could not go on without my friends and my great team from SisterSupport.” Another client commented, “I would like to say to all of you: Thank you very much for the many things you do and for the things you are doing now like the Food project. I very much appreciate it along with the visits for helping including the extra attention my dogs have gotten as a result! You are all really great.”

LOSS OF SUPPORT FROM FAMILY OF ORIGIN

As with the care teams that arose to take care of gay men with AIDS during the 1980s, SisterSupport was initiated to fill a need for lesbians that was not being assumed by either social services or families (Aronson, 1998). In recognition of the distinctiveness of the chronic illness experience for lesbians, the SisterSupport client intake form includes three questions: “Do [family members] know that Care Teams may be visiting? Is it all right with them? Would you like us to call them and explain our services?” Five participants reported that they were not “out” to their families and seven said that their

relationships with members of their family were strained or nonexistent. An intake worker described one client's relationship with her family with the following: ". . . parents and son don't know client is gay and [client] asks us to humor this. She plans to tell son and parents about sexual preference [*sic*] on son's graduation from HS and then plans to live with partner. Afraid parents will take son away if they know she's gay."

Of another client, the intake worker stated, "client has been apart from family of origin since age 13. She has had no contact with mom for the last 6 years . . ."

Estrangement from family of origin is not necessarily the rule, however. Several participants were found to depend on parents, siblings, or children, for both physical and emotional support. The sister of one client, herself a lesbian, bought a four-bedroom house so that her chronically ill sister could live with her. Formerly in a nursing home, the client was living with her sister, her sister's partner, and their daughter.

Quantitatively, a single item on the C4, "lack of understanding from family and friends" received a mean response of 3.1, suggesting that familial support might not be particularly challenging. However, the low rating was due to three scores of 1 (*not challenging at all*) by two participants who indicated that they had no relationship at all with their family and another whose family was deceased.

The literature has consistently found that lesbians are less likely than other women to receive support from relatives, and are more likely to depend on their partner and friends for support (Aronson, 1998; Bradford, Ryan, & Rothblum, 1994; Fobair et al., 2001; Kurdek & Schmidt, 1987; Trippet & Bain, 1990). As a disabled lesbian, having a "chosen family" as one's sole means of support may be associated with problems; her chosen family may not be sanctioned by her family of origin or the medical profession (O'Toole, 1996). One client's chosen family had been a large circle of gay men. She reported:

During the 80s, I lost 27 loving and close friends, who were family to me, to the AIDS pandemic. Like others who worked in the community, I lost hundreds of people I knew and liked, but of my good friends, I lost 27. When I first became ill in 1987/88, there were only about 6 or 7 friends left in "our" circle—who were tired of caretaking by then—and thus there were no good friends left to reciprocate in the taking care of me

Despite the difficulties associated with supplanting the family of origin with a chosen family, the impact on the mental health of lesbians and gay men may not be as severe as expected compared to heterosexuals. Kurdek and Schmitt (1987) not only found that homosexual couples were less likely than heterosexual couples to be emotionally supported by relatives, but that support from friends was more important to them than support from family.

Additionally, the lack of familial support did not negatively impact the mental health of homosexual couples, but did compromise psychological adjustment of heterosexual couples (Kurdek & Schmitt, 1987).

Loneliness

Loneliness and isolation represent a critical challenge experienced by many participants and appeared to be a major factor motivating individuals to contact SisterSupport. Loneliness due to isolation often extended to participants' partners, who were their primary means of support. At least 11 intake interviews made reference to the experience of loneliness or isolation, noting that "[client is] . . . very isolated"; "struggles with isolation issues . . . and would like contact"; "no friends, very isolated . . . partner should be regarded as a partner/client as she is decompensating under stress"; ". . . outgoing yet concerned about partner's depression and health problems and their decreasing quality of life. . . ."

For some participants, there was also a sense that, as time passed and their disease progressed, they were being deserted by formerly close friends. In an intake interview, the intake worker stated: ". . . client and partner are rather isolated. [They] spoke at length about betrayal of friends who persuaded them to move to [a nearby city], then took advantage of them & abandoned them."

O'Toole and colleagues (O'Toole, 1996, 2000; O'Toole & Bregante, 1992) have discussed the fact that many lesbians with chronic conditions feel isolated from the lesbian community. Factors responsible for this experience, their obvious dependence in a community that values self-reliance, limited economic independence for disabled lesbians and the stereotypes associated with both disability and lesbianism prevent disabled lesbians from having a valued role within the community. The particular disabling condition may also play a role in increasing the isolation felt by disabled lesbians. Sinding et al., (2006) suggested that breast cancer may actually evoke avoidance rather than empathy. Other conditions, such as chronic fatigue syndrome, may evoke a skeptical response from other women due to the lack of knowledge about the condition (Aronson, 1998) or due to the periods of reduced severity where the individual appears to be better.

For many SisterSupport participants, visits from their care team represented one of the few opportunities for socialization and connection with the lesbian community. In an attempt to relieve the isolation experienced by SisterSupport participants, a client support group was recently initiated. In addition to providing a social outlet, it was hoped that the group would provide a place where participants could come together with other lesbians who were experiencing chronic conditions and a place where they would not have to "leave part of themselves at the door" (Axtell, 1999, p. 68). That the client support provides such a community is illustrated by the following remark by SJ:

I would like to say, since this group was started . . . and finally ended up being a real group. Not only do we talk to each other here, like when EM is in pain and if I'm in pain I call her. We talk to each other about other things like what we did in the past and everything else not to dwell on the pain. And it's good to have somebody there that you can do that with.

The objective data provided little support for the qualitative findings. Responses to two items, "isolation" and "loneliness" on the C4 resulted in mean scores of 3.2 and 3.4, respectively. It is difficult to understand the somewhat low scores for these items, although the fact that all participants had an active team of volunteers may have been a mitigating factor.

Emotional Challenges

The presence of psychological problems, such as depression and anxiety, appear to be strongly linked with chronic conditions (Livneh & Antonak, 1997). In intake interviews, approximately 27 SisterSupport participants reported psychological problems, primarily depression, and/or anxiety, either as preexisting conditions, perhaps exacerbated by their chronic illness or as a condition brought on by the pain, fatigue, loss, and social isolation associated with their disability. Another 9 participants were described as "sad," "stressed," "struggling," "discouraged," etc., indicating a less severe emotional state. In a comment about a potential client's emotional/mental health, the intake worker stated: "At times . . . overwhelming sense of sadness, hopelessness, helplessness over losses, limitations, general condition. Depression is a side-effect of disease—prior to disease, social, extraverted . . ."

The mental health needs described in intake interviews for some potential clients were numerous and alarming, as described in the following statement from an intake interview: ". . . [client reports] depression—sometimes severe; at times suicidal—gun, meds locked up; sometimes asks partner to take her life; quality of life is low and condition progressive; can think of nothing that can get her out of depression—is very related to pain. . . ."

In a recent review of the literature related to mental health morbidity in gay men and lesbians, Cochran (2001) concluded that lesbians and gay men have an elevated risk for certain psychological disorders, especially depression, as compared to comparable groups of heterosexuals. A number of studies have shown that lesbians, in general, experience higher levels of stress associated with homophobia (Bradford & Ryan, 1998; Rankow, 1995a; Stevens & Hall, 1988). Hence, it might be expected that lesbians with chronic conditions would suffer from more emotional problems due to the combined effects of chronic illness, homophobia and lack of familial support. Few studies have specifically examined the level of emotional distress suffered by lesbians with chronic illness. Fobair and colleagues (2001, 2002)

found that lesbians with breast cancer, as compared to heterosexual women, did not show more emotional distress.

DISCUSSION

This exploratory study has attempted to add another small piece of the puzzle to our understanding of lesbian health by investigating the challenges that are part of the lived experience of lesbians with chronic illness and disability. At the most basic level, the results suggest that the chronic illness experience for lesbians includes challenges imposed by the disease process itself, and a host of challenges resulting from the impacts of the chronic condition.

The primary effects of the disease—pain, fatigue and decreases in mobility—were perhaps the most obvious challenges confronting the participants of this study, and in combination, were often the factor that led participants to ask for assistance from SisterSupport. As well, SisterSupport volunteer activities are most often centered on performing tasks that participants cannot carry out due to these problems. The goal of the care teams is to improve quality of life for participants by freeing up their limited energy reserves for more enjoyable activities.

Further, the results of this investigation suggested that there are ways in which the same challenge, such as dependence, may be experienced differently in the lives of lesbians versus other women suffering from chronic conditions. In her study of lesbians as caregivers and care receivers, Aronson (1998) discussed the impact of dependency on the care receiver and the relationship between the woman giving and the one, receiving. Not only did the care receiver feel “burdensome” and a sense of “relative powerlessness,” the lack of balance in the relationship combined with a loss of social support resulted in the couple being isolated and the former committed relationship changing to one of “obligation” (p. 511). Relevant to the present study, Aronson remarked on the importance of broader “caring arrangements,” such as care teams, to “counter such isolation” (p. 511). The care team approach has been used by SisterSupport for over 10 years to assist lesbians with chronic illness, and the growing waiting list indicates that there is a great need for similar organizations. It is hoped that this concept might serve as a model for other communities who recognize a similar need for support for lesbians with chronic conditions.

Finally, there are challenges, such as the absence of emotional and material support from one’s family of origin, that are uniquely characteristic of the lesbian (and gay male) experience. Rather than receiving support from her relatives, the disabled lesbian is more likely to be supported by her chosen family, usually her partner and friends (Aronson, 1998; Bradford et al., 1994; Fobair et al., 2001; Kurdek & Schmidt, 1987; Moran, 1996;

Trippet & Bain, 1990). However, there are also lesbians with chronic conditions who are not involved in relationships, and thus are dependent on others for assistance. Research has shown that many disabled lesbians, having lost support from their families of origin, find themselves isolated, barely surviving economically, with no dependable assistance that might not be jeopardized by coming out as a lesbian (O'Hanlan, Cabaj, Schatz, Lock, & Nemrow, 1997). SisterSupport began as an extension of chosen family and even now, as new clients are accepted, actively incorporates into the care team, friends who might have been assisting the client previously. Like the care teams that emerged in response to the needs of gay men during the AIDS crisis, SisterSupport inhabits ". . . the social space between families and formally constructed services" (Aronson, 1998, p. 512). Many of the volunteers who are a part of SisterSupport were actively engaged in the care of gay men during the AIDS epidemic and it is their "knowledge about how to make care teams and networks successful" that accrues a benefit to their support of individuals with chronic conditions (Sinding et al., 2006, p. 67).

Both Axtell (1999) and O'Toole (2000) explored the challenges experienced by lesbians with chronic conditions, the former in the context of developing a chronic illness identity, and the latter in terms of challenges that arise as multiple facets of their identities overlap. The present study focused on challenges experienced by chronically ill lesbians with the purpose of improving care giving services. It is proposed that the development of a healthy, integrated identity comprises another challenge, if not the overarching challenge, for disabled lesbians. As a nontraditional form of caring, SisterSupport attempts to liberate chronically ill women from some of the day-to-day challenges of their lives by freeing up time and energy, providing social support, a connection to the lesbian community and meaningful opportunities for participation. It is hoped that such efforts enhance their self-worth and, hence, their whole identities. The implementation of the client support group represents one improvement, and other proposals are being considered.

The author acknowledges a number of limitations with the current study. As the sample was self-selected, there is no way to know the degree to which SisterSupport participants were similar to other chronically ill lesbians in the rest of the population. As most of the participants contacted SisterSupport because they had no other support system, it may be that these women had fewer resources than other lesbians with chronic conditions. It is also possible that this group was more "out" as they aware of the existence of SisterSupport and were willing to have groups of lesbians in their homes on a regular basis. Additionally, the sample was small, the participants were primarily Caucasian and all were from a large urban setting. Due to the small sample that participated in the quantitative portion of the study and the large number of independent variables, only descriptive statistics could be used. Hence, significance related to the results could not be

determined. Additionally, due to the variability of data sources, methods by which data were solicited, and number and ages of individuals participating in each data-gathering method, comparisons across data sources were limited. A further limitation was associated with the differences in power between herself, as a SisterSupport board member and direct provider of client services, and these women, who were the receivers of these services. The researcher sought to establish a relationship of openness and honesty, whereby participants felt comfortable enough to share their experiences of lesbianism and disability. However, the degree to which the researcher's position as Vice President of Client Services within the organization of SisterSupport influenced client responses cannot be determined. In spite of the fact that the researcher repeatedly informed the participants that their participation was anonymous and that their lack of participation would not affect their services, their participation and responses may have been biased.

Despite the limitations, it is proposed that the variability among participants and data sources also permitted the identification of themes that represented the experiences of the broad range of SisterSupport participants, across the entire 10-year history of the organization and through multiple sources. Additionally, the relationship of the researcher to the participants afforded her the opportunity to experience these women's challenges in ways that she could not have expected. Scrambling to find funding for a client's essential medication; rejoicing with another when her disability benefits finally came through; watching a support group discussion suddenly focus on a client in pain, and members reach out to touch her taught the researcher as much about the importance of organizations such as SisterSupport as it did about the experience of chronic illness. That SisterSupport has been successful in providing support for chronically ill lesbians is indicated by the fact that the client based has doubled over the last two years, many volunteers have been with the organization since its inception ten years ago and the funding for the organization has been almost entirely due to the excellent support of the gay and lesbian community. Hence, the true value of this study may lie, as suggested by Aronson (1998), in demonstrating that nontraditional caring concepts, such as SisterSupport, are both possible and effective.

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