

Lesbian and Gay Elders: Connecting Care Providers Through a Telephone Support Group

Wayne R. Moore

ABSTRACT. Health and community support services for patients with Alzheimer's disease and their caregivers are primarily structured and provided from a heterosexist perspective. These services are often insensitive to the needs of lesbian and gay caregivers. This article reports on the development of a telephone support group for rural lesbian and gay elders caring for their life partners with Alzheimer's disease or related dementia in northwestern North Carolina. Issues involved in the establishment of the group, along with the structure, content, membership, and evaluation of the six-week group are presented. Six specific themes, which emerged from the personal experiences of these caregivers, are discussed. *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2002 by The Haworth Press, Inc. All rights reserved.]*

KEYWORDS. Lesbian and gay elders, Alzheimer's disease, rural services, support group

Approximately four million Americans suffer from Alzheimer's disease and related dementia. This condition is estimated to affect 10% of the population over the age of 65 and as many as 47% of those 85 and older. With no available treatment to slow its progress, Alzheimer's dis-

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Journal of Gay & Lesbian Social Services, Vol. 14(3) 2002
<http://www.haworthpressinc.com/store/product.asp?sku=J041>
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ease is significant because of its profound effect on the lives of family members, friends, and the community of the sufferer (Alzheimer's Association, 1995; Evans et al., 1989). Available research over the last two decades has indicated that caregivers and families experience considerable psychological, emotional, physical, and financial stress as the patient's condition progressively deteriorates. Support groups for caregivers and families are important as they seek to lessen the physical, emotional, and financial strain of caring for a person with dementia. They can offer information, education, reassurance, and problem-solving opportunities.

The benefits and various types of support and mutual aid groups for Alzheimer's caregivers and their families have been well documented by professional practitioners and organizations (Begany, 1996; Cummings, 1996; Donaldson & Burns, 1999; Knight, Lutzky, & Macofsky-Urban, 1993; O'Connor & Prothero, 1987; Rankin, Haut, & Keefover, 1992; Toseland & Rossiter, 1989; Zarit, Reever & Bach-Peterson, 1980). Steuer (1984) synthesized earlier research by noting: "what members valued most in support groups for Alzheimer families were insight and understanding (cognitive change processes), a sense of belonging (group cohesion), finding others with similar problems (universality), and that these persons were coping and surviving (hope)" (p. 57). Today, care providers and families have access to a broad range of evaluative, educational, and professional services specifically focused on dementia: geropsychiatric assessment programs, adult day care programs, specialized Alzheimer's programmatic units in long-term care settings, special services, and education programs through chapter offices of the Alzheimer's Association. Special educational and support efforts have addressed the impact dementia has on young children and teenagers whose parents or relatives must redirect attention to caring for a grandparent or relative. (Arshonsky, Adelstine, & Stauber, 1988; Frank, 1985; Guthrie, 1985). Multicultural outreach programs, including educational and support groups, have been established to respond to needs of underserved minorities, including African Americans, Hispanics, Asian Americans, and those living in rural areas (Coogle & Churcher, 1996; Henderson, Gutierrez-Mayka, Garcia, & Boyd, 1993; Welsh et al., 1994).

However, one group in our society continues to be underserved in these respects and still encounters barriers when seeking help. Lesbians and gay men caring for their life partner with Alzheimer's disease or other dementia also have challenges and needs, but these are not always the same as those confronting heterosexual couples. During the past two

decades, the number of people over the age of 65 in the United States has been increasing twice as fast as the rest of the population. Within this diverse group, there also exists a large population of older lesbians and gay men. Available data estimate the number of lesbians and gay men over the age of 60 to range from 1.75 to 3.5 million (Jacobson & Grossman, 1996). Changing demographics further illustrate the need to develop more sensitive and informative services for those whose life partners will develop Alzheimer's disease or other dementia. According to Richard Bannin, executive director of the New York-based Senior Action in a Gay Environment (SAGE)(Mann, 1999), every year an estimated 400,000 lesbians and gay men in America turn 50. An even more dramatic increase in the senior gay population will occur over the next decade as new drug and treatment protocols extend the lives of people with AIDS.

Problems that older lesbians and gay men face in receiving services from medical and human service agencies are beginning to be acknowledged. As a specific coping strategy, this paper presents the development of a telephone support group for older lesbians and gay elders caring for their life partner with Alzheimer's disease or other disorders in a rural, 11-county area of western North Carolina. Two proven human service delivery models—support groups and telephone conferencing—are combined to build a means for care providers to reduce their sense of isolation and enhance their abilities to care for their life partner. This group met for six sessions. The group history, development and membership, as well as the major themes that emerged from the sessions, are set forth in this article.

BACKGROUND

The decision to establish a telephone support group was determined by a number of factors, but the nucleus for it was formed as a result of an unexpected telephone call to the author. She had attended the support group which the author had facilitated about fifteen years ago. At that time her purpose was to learn more about Alzheimer's disease, what problems to anticipate, and ideas about care so she could provide relief and support for her family in Virginia, where her mother was an Alzheimer's sufferer. Now, she requested an appointment to talk about someone she knew who currently had the disease. The author enumerated the various groups that were now available in the county for day, evening, and weekend meetings, but she insisted on speaking directly to the au-

thor. After periods of growing silence, sighs, and crying, she suddenly spilled out, "My life partner of forty years has Alzheimer's disease and I need to talk with you."

This call and a subsequent office visit, followed by several more telephone calls from this determined caregiver, increased the author's awareness of the narrow focus on which support groups are structured. The broad generalization is that most of those who are in the major care-giving role are within heterosexual relationships. Facilitators of support groups have not been inclusive or even aware of the issues that lesbians and gay partners struggle in caring for their partners with Alzheimer's disease or dementia. Nearly all services for older adults have been created within a heterosexual framework in which older lesbians and gay men are placed in a position of either denying or concealing their sexual identity. Lesbians and gays are made invisible to health and community service providers through heterosexist and homophobic practices (Eliason, 1996; Harrison, 1996; Quam & Whitford, 1992). One of the recurring "themes" emerging in support groups and the literature is the impact this disease has on the emotional, psychological, physical, spiritual, and financial well-being of the "spouse." The assumption is that all couples are heterosexual.

After this epiphany, the author made reference to "life partners" or "monogamous lesbian and gay couples" in every professional and community workshop presentation. Over the course of a year, approximately fifteen individuals identifying themselves as care providers for their "life partner" contacted the author, who in turn maintained some regular contact through letters and e-mail. The author then contacted the patient service coordinator of the local chapter office of the Alzheimer's Association to discuss developing some type of service for these care providers. The Piedmont Triad Chapter of the Alzheimer's Association was organized to serve the eleven northwestern counties of North Carolina's Piedmont region and the estimated 25,000 Alzheimer's disease patients and families within this area (Piedmont Triad Chapter, 1994). The author proposed the possibility of some type of support group, a special newsletter, or development of more culturally sensitive pamphlets, and handouts. Others suggestions included sponsoring a one-day workshop bringing these caregivers together and securing funds to reimburse prearranged in-home sitters to allow caregivers the opportunity to attend a group or workshop with less worry or concern. In addition, other options were discussed, such as facilitator training to include lesbians' and gay men's caregiving, and encouraging the local

newspaper feature writer to interview and write about caregiver stress, including one story about one lesbian or gay caregiver.

Unfortunately, after several discussions, the chapter's social-work case manager reported the chapter was reluctant to expand its programs to this population group because of concerns about professional appearance, propriety, and fund-raising. Preliminary calls around the region and state to learn what other programs were doing to address older lesbians and gay caregivers yielded equally disappointing responses. No other programs had any formal or informal services to reach this special population.

CHOICE OF GROUP MODALITY

In view of the negative response by the chapter office of the Alzheimer's Association, a decision was made to develop some structured support for these lesbian and gay caregivers. Establishing a support group to provide education and reassurance to this population could be one method. Since these individual couples lived in eleven different counties, the question remained how to develop and organize a group. Telephone groups have been used to provide support and reassurance to various homebound populations in rural areas such as people with visual impairments, the disabled, the elderly, homebound college students, and people with AIDS. Telephone support groups to educate, encourage, and sustain patients or those caring for relatives with AIDS, multiple sclerosis, sickle cell anemia, cancer, and other chronic diseases are well established (Barry & Beaulieu, 1994; Evans et al., 1984; Rounds, Galinsky & Stevens, 1991; Shilman & Gilardi, 1985). Furthermore, application of computer technology to create bulletin boards or support groups offering assistance, counseling, and advice to patients and families living with an illness or chronic disease has increased over the last decade (Brennan, Moore & Smyth, 1995; Brennan, Ripich & Moore, 1991; Moore & Larson, 1993; Sharf, 1997; Weinberg, Schmale, Uken & Wessel, 1996). Either a telephone or computer based support group format appeared to be an efficacious means of supporting this special group of caregivers.

CONTENT AND STRUCTURE

This proposed group was comprised of those caregivers who had contacted the author over the course of a year. The author called each

caregiver to ascertain his or her interest in participating in a support group within a telephone call or computer-based interactive group format. Since several prospective members did communicate with the author by e-mail, a computer interactive group was considered also. The purposes of the support group would be to provide information, to decrease participants' feelings of isolation by increasing support from others, and to enhance coping related to the daily care of managing their partner with Alzheimer's or dementia.

A flyer describing the proposed support group and its purpose was developed and then mailed to each of the prospective participants. Six possible topics were listed to provide a framework for the proposed group: (1) Stressful Emotions and How to Cope, (2) Legal Issues, (3) Managing Disruptive and Repetitive Behavior, (4) Responsive Medical Care, (5) Community and Nursing Home Care Issues, (6) Caring for You the Caregiver. The development of these topic areas was based upon the author's past experience facilitating Alzheimer's disease support groups in North Carolina and Ohio and some of the stories, incidents, and issues these fifteen caregivers had called or written about over the previous year. The flyer also solicited other suggestions, topics, or ideas in the planning and implementation of the group. Prospective participants were asked to provide feedback as to their preference for meeting time—afternoon or evening, weekday or weekend, their access to a nonparty-line telephone or access to a computer, and their commitment to participate. A semi-structured psychoeducational framework was selected to maximize the limited number of sessions. From a literature review and discussion with a group work specialist, it was determined that six sessions would be appropriate.

GROUP MEMBERS

Of the fifteen caregivers contacted, seven expressed interest in participating in either a telephone or computer group experience. Of the seven, two members did not have access to a computer so the telephone format was chosen. The group consisted of five lesbian and two gay male caregivers; all were presently engaged in caring directly for their life partners. Each patient had received a thorough medical, neurological, and functional examination in established geriatric evaluation programs located in North Carolina. Of the seven patients, four had been diagnosed as having a dementia of Alzheimer's type, two with multi-stroke infarction along with cardiac disease, and one patient with

multiple diagnoses of Alzheimer's disease, Parkinson's disease, diabetes, and progressive blindness. The age range for group members was 59 to 71 years; the average length in the care taking role was 4 years. One participant had been the primary caregiver for over eight years. The average length of the relationships represented by the group was 30 years, the longest relationship being 42 years, the shortest 21 years. Each group participant was retired, providing direct daily supervision for his or her partner. Careers of the seven participants before retirement had been schoolteacher (2), accountant, furniture broker, county home economist, high school librarian, and X-ray hospital supervisor.

GROUP THEMES

Prior Experience with Support Groups

During the first session, the primary objective was for members to become acquainted with one another, to become familiar with the telephone conferencing format, and to establish rapport for sharing mutual concerns and issues. At the very beginning, it was pointed out that all participants were in the role of primary care provider.

After introductions and a quick review of the group's purpose and ground rules, one group member immediately expressed her delight in knowing there were others just like her caring for their life partner with Alzheimer's disease. Very quickly during the first session, all members spoke of their experiences with attending or participating in a caregiver or family support group in their area:

You can't imagine how I felt [when they] started introducing themselves. Since most were either married or indicated they were there because either their mother or dad had Alzheimer's, I recognized quickly I was different. I just froze. Should I tell them about my partner? Should I just say I have a friend and want more information about the disease? Should I say my sister had the disease and I wanted to see what the support group was about? I froze. I panicked. I realized it would be my turn to introduce myself soon. What should I do or say? All I knew was how we have tried to be discreet and quiet about our private lives all these years.

She went on to say that was the first and last time she had attended a support group.

This shared incident was the icebreaker. All group members expressed similar feelings or memories about attending their first support group in the role of care provider for their life partner. One group member's comments captured the intense feelings of the others: "I knew I wasn't like the rest, those married or adult children caring for a parent, or even the grand-daughter caring for her grandmother." Group members expressed concern about revealing their sexual identity and concern about the very intense emotional effect this might have on other participants.

All members of the group commented on their personal struggle to decide whether to reveal their true personal story because of the intense feelings encountered in a traditional support group. It needs to be recognized that many lesbian and gay elders who may attend regular support groups have dealt with the consequences of homophobia throughout their lives by hiding their sexual identity. Survival in their family, job, career, and community depended upon hiding their sexual identity. This was a major survival strategy for older lesbians and gay men in a homophobic society whose laws and policies have labeled homosexuality as immoral, pathological, and illegal. Nevertheless, members of the group had gathered considerable information about Alzheimer's disease and dementia from their physicians, from attending educational seminars about the Alzheimer's disease, from medical newsletters, and from Internet sources.

Antipathy of Medical and Human Service Providers

Even though physicians do not know how to prevent or cure Alzheimer's disease, proper medical care is imperative to reduce or respond to underlying medical problems that arise during the course of the disease. Not only must proper nutrition and fluid intake be monitored, but also medication for agitation, sleeping disorders, or depression be necessary. Regular routine medical care is important for both the patient and the caregiver. The caregivers must maintain their own physical and emotional health in order to continue to provide daily care, supervision, and assistance for the patient. Studies have shown that care providers are more vulnerable to infectious disease because of the impact of prolonged physical and emotional stress (Barrett, Haley & Powers, 1996; Haley, 1997; Kuhn, 1998). All of the telephone participants had at least one story illustrating the sensitivity and concern by medical and human service personnel—or lack thereof—which they had experienced.

One care provider revealed how she “felt betrayed by the medical care system,” having assumed it would be compassionate and understanding of the needs and vulnerabilities of older people. She related that their physician believed her partner “may have Alzheimer’s” and recommended a thorough work-up at a major university teaching hospital known for its Alzheimer’s disease research and geriatric evaluation program. The care partner recalled the puzzled looks, halting questions, and uncomfortable attitudes of the hospital staff that she encountered when presenting herself as the responsible person during the hospitalization. Before admission, she had completed all the preliminary paper work and was prepared with copies [originals] of the patient’s power of attorney and health care power of attorney. Repeatedly, admissions supervisor, nurses, social workers, and others asked the same question: “Whom should we contact in case of emergency?” or “Are there any family members we should be talking to?” or “How are you related?” with the tone bordering on “icy and accusatory.” “They seemed to be talking at me rather than with me.” At the final evaluation summary, when the neurologist and geriatric team members reviewed findings and recommendations, their subtle message again was: “We really need to go over these with a family member.” She noted that even with legal documents they had drawn up in their careful planning for each other—durable power of attorney, health care power of attorney, and living will—people and institutions would not accept that they had a strong and supportive relationship.

Another group member spoke of a recent experience when her partner was admitted to a hospital for tests after rapid onset of increased confusion, elevated blood pressure, and abdominal tenderness. “We were the side show,” she added, recalling several particular situations. After admission, the caregiver spoke to the patient’s primary nurse case manager about staying overnight since the patient sometimes became more agitated and confused at night. The nurse responded condescendingly, “Honey, you know we can only allow a relative to stay with the patient. We know how to take care of your older friend.” The next morning the same caregiver overheard the nursing students chuckling in the hallway, “In this room we have a pair of old gray lesbians.” Their attitude was that older lesbians shouldn’t be affectionate with each other, as if “after 50, passion, caring, and tenderness dry up.” She noted that being an older lesbian is frightening because “physicians and nurses see us differently.” She shared with the group her own experience during a long postponed physical examination. She was told that a routine pap test was unnecessary because she had no family history of

cervical cancer. In fact, her mother, two aunts, and three sisters had died of either breast or cervical cancer. She felt her case had been devalued and treated carelessly due to the prejudice of the nurse practitioner.

Each of the group participants had one or more anecdotes in which as individuals and as caregivers they have had to confront negative comments, derogatory remarks, prejudice, and insensitivity. One male caregiver provided an example of prejudice in his effort to utilize an adult day-care program in his community. On the day of the appointment, the director of the program was unable to meet him and his partner as arranged. Instead, the program coordinator stepped in to complete the initial screening and application. He noted when it came to discussing information about next-of-kin and emergency notification, she handled these with sensitivity and professionalism. When explaining they had been together for over 30 years, she "even complimented us on our commitment to each other. I genuinely felt she was sincere and was a genuine person." The application was completed, financial and insurance forms were copied, and she took them on a tour, making a special effort to introduce them (using first names only) to various staff members and clients. Without reservation, she indicated openings were available; there was nothing to prevent starting the following week. The program director would call the following week about scheduling a beginning date.

He was not prepared for what was to come. After two weeks passed with no word, he attempted to reach the program director. However, that same day, a letter from the day care center arrived, signed by the director. The letter said that upon review, the adult day care program was "unable to provide a therapeutic intervention program to best serve the behavioral, cognitive, and safety needs of Mr. XXX." After numerous attempts to contact and schedule an appointment with the program director, it was clear a reconsideration would not be possible. Later the coordinator who had interviewed him sent a note apologizing and expressing her regret about what had occurred. In fact, she wrote she had resigned because of this incident and several questionable ethical actions by the director. When the other group members asked whether he had written to the board or the United Way, the care provider replied, "I just didn't have the energy, will, or stamina to take up another fight."

Given the perceived and subtle hostility of medical and human services, it is not surprising that the number one health risk for lesbian and gay elders is the fear of how professionals and health institutions treat them. This mirrors findings from a recent survey by Schatz and O'Hanlan (1994), where physicians knew of lesbian, gay, or bisexual

patients who had received substandard medical care or had been denied care because of their sexual orientation. Research continues to show lesbian and gay elders encounter bigotry, prejudice, homophobia, and discrimination in our health and medical care institutions (Deevey, 1990; Harrison, 1986; Jay, 1992; Steven & Hall, 1988; Taylor & Robertson, 1994; Trippet & Bain, 1993). Quality of life for caregivers and persons with dementia is dependent upon early diagnosis, consistent primary care, and a supportive and nonjudgmental system of health and human service programs.

Legal and Financial Issues

Older lesbian and gay couples must review and plan carefully to assure their legal and financial affairs, both as individuals and as life partners, are in order. The members of this group were dedicated individuals who had gained respect, admiration, and identity through their work and careers. Each couple had developed interesting work and social arrangements. For example, to maintain their privacy and to lessen intrusion by work associates, five of the seven couples worked in a county adjacent to where their residence was. As one of the retired schoolteachers said, "living in the next county afforded us some protection against nosy colleagues. No one ever decided to just drop in unannounced." The retired furniture broker noted he always preferred traveling positions. "Traveling salesmen can decide how much and to whom to divulge personal information." Social contacts with work associates or involvement in community activities were guarded as well. One member recounted that, even though most of the people at the church she attended "must assume I'm a loner, not a joiner," she only recently decided to talk to the new female associate pastor. Others too realized they had lived very narrow lives with a partner who was their primary social contact. When that partner became ill, they found that emotional and physical support outside the home was limited.

These couples told how significant changes have occurred in the field of employee benefit offerings. For these older adults, there were no employee or domestic partnership benefits; the idea of "gay-friendly employer or business" was unknown. Each faced the necessity for careful financial planning for their retirement and long-term health coverage.

Of the seven couples, three had not initiated any extensive financial estate plan. Of the seven, five represented the range of those who investigated, corrected, or revised their pension allocation, revised property

ownership arrangements, established trusts, or instituted powers of person or property and properly executed living wills. These seven indicated that through reading books, articles, and attending the educational programs offered about estate planning, they had become more aware of the necessity of getting their monetary and legal affairs in order.

This is not to indicate all went well initially. One lesbian couple realized something was wrong when their attorney never returned calls, or the office manager appeared uninterested in pushing their desire to complete their estate and personal plans. The women of the group said that consulting a female attorney or estate planning expert made the process and emotional investment less threatening and overwhelming.

The group became a comfortable medium wherein those who believed their monetary and legal affairs were in order gently pushed and reminded the others of the necessity to get this done. By the third meeting, they had exchanged addresses, phone numbers, e-mail addresses, and the names of attorneys and accountants who they believed were knowledgeable but sensitive to the special financial and legal needs of lesbian and gay couples.

Anger: Past, Present, and Future

A frequent theme that arose was how society responds to heterosexual couples in contrast to lesbian and gay couples. The group was complimentary to younger gays and lesbians with the reservation that, as one participant said, "Young gay people don't really understand what we have had to endure." One member captured the group's feelings in a note he sent to each of us after the third session:

We have dealt with fear for a great part of our lives. We feared for our safety; feared our secret would be found out. We feared for our jobs; we feared being discovered. We feared our clients, students, even about our close straight friends. What did they really think of us? We constructed our lives together when we finally found someone who loved and cared about us. Some of our families let us be. Some of our families out and out right disowned us. Our churches and faith cast us out. This group allows me to talk about my fear and anger because others have been there too. I fear tomorrow because I am losing the person who supported and understood me.

A member defused the intensity with humor by saying the group should call itself, "The Thursday Afternoon Survivors' Group."

The group members compared their experiences in coming to terms with their partner's dementia with those of heterosexual couples. They noted that other support groups allowed heterosexual partners to reminisce about how they met their partners, their families, careers, their shared interests, and future plans now robbed by Alzheimer's. What separates homosexual from heterosexual caregivers, one member stressed, is that they had to face their sexuality alone. Coming to terms with who they were as individuals and later developing an identity as a couple took greater emotional investment than heterosexual couples required. Society primarily defines lesbians and gay men by their past and present sexual orientation. Single lesbian and gay elders whose life partner has died, must confront again the loneliness, isolation, and fears they had to wrestle with their youth.

Several times during the life of the group, the members felt they had an opportunity to verbalize their fear and anger about not only what the disease was robbing them of, but also what society has attempted to define about how to react to their past and present situation. Group participation provided others permission to vent their anger and anxiety over the unfair restrictions placed upon them by society, to review their lives, and to verbalize the successes and memories they had made as they built caring and supportive lives with their life partner.

Anticipatory Grief

Discussion in one meeting focused on the daily struggle of managing, supervising, and living with their partner's deteriorating intellect and functions. Each participant had encountered some of the changes dementia brings: problems with wandering, sleeping, agitation, possible violent outbursts, repetitive behaviors or verbalizations, and dilemmas with personal care—dressing, eating, bathing, and incontinence. Members expressed that, even though this forum was limited, it provided a safe medium where they could share their past, present, and future concerns with people who understood and accepted each participant's hope, anger, sorrow, despair, and guilt as being normal.

One group member stated it simply: "Every day we grieve for those who at one time loved us every day." Even though the caregivers expressed hope in their ability (physically, mentally, and financially) to maintain or secure the best care for their loved ones, the group provided participants permission to engage in anticipatory grieving. Caregivers, engaged in the daily role of caring for their partners, confront what Lawrence Rainey (1988) described as "little deaths" along the down-

ward trajectory of dementia. For these members, their grief work begins at the time of diagnosis. Even though their patient may be stable or seem to plateau bringing a sense of reprieve and hope, they confront the eventual death of their partner. The week after our discussion on the multiple dimensions of grief, one member wanted to reflect on the previous week's discussion: "I clearly see with all I've endured, my best friend, my life-long companion, ceases to exist but continues to live." Dealing with the declining intellectual and functional needs of a patient with dementia, caregivers must invest considerable energy—physical, emotional, spiritual—to undertake the tasks and confront choices in providing daily care.

Society's views and responses to homosexuality and grief are social scripts. Aware that not all losses can be openly acknowledged, socially shared, or disclosed, Kenneth Doka (1989) coined the term "disenfranchised grief." Lesbians and gay men have experienced constant fear and dissonance throughout their lives, as single adults confronting individual sexuality, whose life partner now faces death. Participating in traditional support groups may reinforce that lesbian and gay coupling is not socially recognized. Normal sources of support for those facing the death of a spouse—family, friends, health care workers, past work associates, and even funeral rituals—may not be available to lesbian and gay elders where they may publicly acknowledge their losses and grief.

Struggle with Forgiveness and Closure

In his 1907 lecture "Pragmatism," William James wrote, "The philosophy which is important in each of us is not a technical matter; it is our more or less dumb sense of what life honestly and deeply means." The last two sessions of the group focused on past and present relationships with their remaining family members and responses by the faith community to their past and present lives. The underlying theme could be construed as a journey of forgiveness.

Group members drew upon the prior discussion centered around anticipatory loss to speak of past and present experiences with immediate family. Four of these caregivers experienced what they called outright hostility and abandonment by immediate family. Two members had tenuous relationships, communicating through holiday, birthday cards, or occasional phone contacts. Only one had what she characterized as a sincere relationship with her younger sister. Those who still had living siblings or some contact with family still expressed feelings of alienation. The group spoke of how families may draw together to support or even provide an emotional outlet for caregivers to ventilate and receive

some message of encouragement. "For me, my life partner was my social world, my primary source of emotional support. My immediate family disowned [me] and closed the curtain to my existence. Here in the group I feel I have found family." Several noted that, even facing the eventual death of their partner, they had found within the group a sense of courage to redefine their life again as a single person. One participant expressed, "Caring for my partner, I've had time to again and again review my struggles and life. It would have been nice to have even a nominal acceptance of family, but the life I have is also a journey of understanding what forgiveness is all about."

In addition, members expressed concerns and shared their unpleasant experiences about how the faith community responded to them both as individuals and as part of the gay community. One caregiver shared how she was dis-invited by the minister; he had sent back her membership card when he discovered "my spouse was another woman." The group's pervasive distress was how some faith communities fail to view lesbian and gay couples as caring, tolerant, and spiritually centered individuals who create a committed life together. From their perspective, some religious communities are continuing to support attitudes that enforce loneliness, isolation, and doubt. Near the end of the session, a member assessed the current debate by offering a compliment about younger gay rights advocates. "They are challenging churches to examine their own values. From our own personal struggles, churches tried to robbed us of our religious identity and self-esteem." This group affirmed that spiritually centered lives and being Christian are not mutually exclusive. Several days later, a member wrote:

Each of us chose to accept ourselves as caring, loving, responsible adults in the face of rejection by family, friends, and churches. We embarked on a journey into the unknown. On this journey we have seen the faces of prejudice, ridicule, hurt, hate, distrust, lies, and self-blame. Our journey now is not self-centered, but self-reflective. We have freed ourselves from the prison of resentment and regret, we know we have the capacity and spirit to again face the unknown journey of each tomorrow.

CONCLUSION

Raymond Berger (1982) called 19 years ago for the social work profession to ignore no longer the needs of older lesbians and gay men. The

collective story of these rural lesbian and gay elders caring for life partners provides an understanding of how they have looked to their partners for primary support and validation as they created authentic lives. This forum allowed members a safe avenue in which to express individual and collective fears, share mutual experiences, and affirm their strength, fortitude, and determination in the task of caring for their life partner.

A post-group questionnaire was used to evaluate the effectiveness of the group. In this, members reported that the experience decreased their sense of isolation and increased their social support system, affirmed their determination to continue in the caregiver role, and strengthened their decision and confidence to maintain their life partner in the home as long as possible. One member wrote, "First I thought the group was going to be about dealing with the death of our partners. The group was about living." Moreover, the following indicators provided evidence of satisfaction:

- All members participated in all the sessions.
- All members were on time and stayed on line for the entire session.
- After the second session, addresses (postal and e-mail) were exchanged.
- Members established a level of rapport where several contacted others between sessions.
- Members maintained regular contact with each other after the six sessions.
- Several members, geographically close to each other, arranged to meet in person.
- They have maintained contact with a group member whose partner required admission to a long-term care facility.

One must be cautious not to generalize that all lesbian and gay caregivers have experienced or confronted the same issues and concerns as those reported by this group. However, the evidence of this group can serve to illustrate the need for more sensitive response to the human reach for support. This telephone support group provides evidence that traditional service programs must understand the special concerns, issues, and needs of alternative groups in order to better evaluate and redesign current models of service delivery. From the experiences reported herein, the evidence is strong that telephone support intervention offered positive reinforcement to this group of lesbians and gays caring for a partner with dementia.

The needs of elderly lesbians and gay care providers often are unrecognized, ignored or minimized by medical care providers, health and long-term care institutions, and community health-related service organizations. The need exists for studies to better understand and serve the emotional and supportive needs of lesbian and gay elder care givers. The challenge facing older lesbian and gay caregivers dealing with life partners' dementia differs from that of heterosexual couples. These care providers, isolated in rural communities and invisible to health and community service agencies, must confront complex medical, psychological, social and legal issues often with little to minimal professional support and understanding.

A dramatic increase in the senior lesbian and gay population over the age of 60 is expected to occur over the next decade. Physicians, nurses, social workers, community-service providers, and community social-service organizations have a professional responsibility to respond to the special challenges and needs of this diverse group.

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