WHEN A PARTNER DIES: LESBIAN WIDOWS

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Death of a life partner and the subsequent bereavement are profound experiences for an individual. By far, the majority of bereavement research reported is focused on heterosexual couples, primarily married and often in the later years of life. The purpose of this study was to describe the bereavement experiences of lesbians whose life partners have died. The study used a descriptive, qualitative design informed by feminist scholarship and phenomenology to access the depth of personal experiences, as well as internally interpreted meanings of those experiences, among lesbian widows.

Death of a life partner and the subsequent bereavement are profound experiences for an individual. Literature in gerontology and other health-related disciplines on loss of spouse is plentiful and widowhood has been well studied. What is known about bereavement, however, is less than what is not known; specifically, there is lack of an integrative theory of grief and bereavement, lack of standard approaches to grief assessment, and our knowledge of the interactions of risk factors for poor outcomes of grief and bereavement is obscure (Benoliel, 1999; Streobe, Hansson, Stroebe, 1993).

By far, the majority of bereavement research reported is focused on heterosexual couples, who are primarily married, and often in the later years of life (Fry, 2001; Lopata, 1996; McCorkel, Robinson, Nuamah, Lev, & Benoliel, 1998; Pasacreta & Barg, 1998; Scannell-Desch, 2003).
Research on loss of a homosexual partner is limited. Literature in this area includes several recent studies of gay men who have lost partners or good friends from HIV-related illness (Klein & Fletcher, 1986; Oerlrmans-Bunn, 1988; Siegal & Hoefer, 1981; Sowell, Bramlett, Gueldner, Gitzmacher, & Martin, 1991; Weiss & Richards, 1997).

The gay and lesbian community is broad and diverse, comprised of many smaller, cultural communities. Life experiences of gay men and lesbians differ in many ways, especially in terms of relationships and partnering patterns. The experience of lesbian widows is not well understood and cannot be extrapolated from the male experience with HIV-related deaths. Therefore, the purpose of this study was to describe the bereavement experiences of lesbians whose life partners have died. We additionally hope to identify potential interventions to link research to action to meet recognized needs.

BACKGROUND

Cowles and Rodgers (1991) identified culture as a part of both individual and normative aspects of bereavement. While lesbian sexual orientation is very diverse (Institute of Medicine; IOM, 1999), lesbian culture is generally hidden within mainstream society (Barrett, 1989; IOM, 1999; Krieger, 1983; Lewis, 1979; Lockard, 1985; Wolf, 1979), thus little is known about mortality, bereavement, and interventional support in the lesbian community. Lesbian communities are not geographically bounded, but rather, throughout the United States many individuals self-identify as lesbian women who belong to a lesbian community (Barrett, 1989; Krieger, 1983; Lockard, 1985; Wolf, 1979). Within these communities, lesbian kinship networks, determined by symbolic or practical ties, choices, and love, differ from those in the traditional nuclear family and will determine who is bereaved by the death of a lesbian woman (Deevey, 1997; Riley, 1988; Weston, 1991). Literature about lesbian bereavement is lacking.

Many lesbian women have long feared abuse by health care professionals (Stevens, 1994a, 1994b, 1995; Stevens & Hall, 1988). When a lesbian woman dies, her survivors may not be recognized at all by health care providers who have limited knowledge of lesbian culture and kinship networks (Deevey, 1997; Penelope & Wolfe, 1993). Only recently have lesbians received recognition in mainstream health care literature as a vulnerable population (IOM, 1999; Stevens & Hall, 1991; Stevens, 1992). Doka (1987) identified specific problems of disenfranchised grief among non-traditional relationships; knowledge of lesbian bereavement is enriched by the writings of lesbian women describing personal
experiences with terminal illness (Butler, 1989; Butler & Rosenblum, 1991), but to date, only two research sources address bereavement among survivors following a lesbian woman’s death (Deevey, 1997; Jones, 1985).

Jones (1985) investigated social support following the death of a lesbian partner and found that the unpredictability of caregiver and family responses during periods of bereavement was a source of stress and fear in the daily lives of many lesbian women. Deevey (1997) studied lesbian cultural variation in kinship patterns and the expression of mourning; she identified mixed experiences of bereavement with the strongest factors of disenfranchised grief being lack of social support and intense negative feelings. Deevey’s findings also suggested that aspects of risk of complicated grieving and health problems in lesbian bereavement are related to disenfranchised grief, but also reflect themes common in heterosexual populations, including sudden death and ambivalent relationships.

Understanding the lived experiences of loss of a life partner for lesbian women will help facilitate the development of appropriate and specific interventions by nurses, social workers, and other professionals working with this population. Recommendations from women who have lived this loss and told their stories point to the depth of grief and loss and ways women can be supported through this difficult situation. While the bereavement support system may be strong for heterosexual survivors and widows, many community services have excluded or overlooked lesbian widows in need of support. This study will provide information to bridge this gap in knowledge and indicate needs for services to improve healing and mental health in this population.

**DESIGN AND METHODS**

The study used a descriptive, qualitative design informed by feminist scholarship (Gluck & Patai, 1991) and phenomenology (Van Manen, 1990) to access the depth of personal experiences, as well as internally interpreted meanings of those experiences, among lesbian widows. The study and procedures for obtaining informed consent were reviewed and approved by the Colorado Multiple Institutional Review Board.

**Sample**

The purposive sample for this pilot study included six women who self-identify as lesbian. Participants were recruited by word of mouth within lesbian communities. Those women who heard about the study...
and were interested called the investigator to initiate contact and entry into the study. All participants were Caucasian and all were speaking about a life partner who had died. These deaths occurred from one to 36 years prior to the interviews. Participants ranged in age at the time of interview from early 50s to late 70s; the range in ages at the time of the partner’s death was early 30s to late 60s. The duration of the relationship itself spanned from 5 to 35 years. The causes of death for participants’ partners included cancer, diabetes, and myocardial infarction.

Data Generation

Data were generated through audiotaped, in-depth, open-ended interviews that lasted from 45 to 90 minutes. One interview was recorded only in field notes. One of two interviewers conducted all interviews, which occurred in participants’ homes or offices, restaurants, or by telephone. Both participant and interviewer taped the telephone interview, and both parties reviewed and filled in the transcript of the call. Initial questions were broad and asked participants to share their experiences of the death of their life partner. As interviews progressed, questions probed to clarify relationships, chronology, and meanings. Tapes of interviews were transcribed and audited for accuracy and any identifying information was removed. Transcripts and field notes were entered into a word processing program for subsequent coding and analysis.

Data Analysis

Data analysis was initiated with data generation and continued throughout the study. Three investigators were involved in analysis activities (later, one retired from the study team). Analysis began with reflecting, reading, and re-reading the data. Data were first approached holistically (Van Manen, 1990); such that the investigators each attempted to express the meaning of an entire interview in a phrase or sentence. We compared and discussed these meaning statements and came to consensus about a way to express the experience described. Data were subsequently approached selectively (Van Manen, 1990), which is to say that passages or text that seemed particularly essential or revealing about the experience being described by the participant were highlighted, again by each investigator individually. As these experiences were illuminated, we conferred and continued to read interview transcripts to seek commonalities among experiences that could be considered thematic. We studied thematic elements for the dimensions that were present for all participants, though to varying degrees and with different expressions.
We also read interview transcripts from the perspective of narrative, in order to understand the storied aspects of participants’ lives. We were able to distinguish important features of character, plot, and lesson.

Trustworthiness of the findings is supported by member checking activities with the participants themselves, maintaining a decision trail, investigator logs and journals, congruence with experiences of others in the population who were not part of the study, and feedback received by the study team following presentation of results at regional, national, and international conferences. These strategies reflect the criteria of rigor outlined by Lincoln and Guba (1985).

FINDINGS

The thematic structure includes three themes about the experience of lesbians losing their life partner: (1) The Reflected Story, (2) The Complex Factors Related to Support in Bereavement Experiences, and (3) The Interpreted Story. Although themes contain distinct elements and dimensions and are discussed separately, the data from which they are derived are the participants’ direct expressions of and representations of bereavement experiences. Because aspects of human experience overlap, these dimensions are not considered to be exclusive. The convergence of experience illuminates the relationship between and among components of the themes.

The Reflected Story

The theme of Reflected Story has two primary dimensions: personal reflection and reminiscence and memories. Personal reflection describes how participants experienced telling a story of their choice about losing their partner. Reminiscence and memories includes the storied descriptions of the deceased partner, as told during interview. Some stories were chronological, others were told in conceptual chunks, but all were opportunities for participants to reflect on the act of story telling and ways in which talking about the experience differed from living the experience.

Personal Reflection

Pearl (all names are pseudonyms) is in her mid 60s and had been with her partner, Ruby, for over 34 years. Ruby died following a myocardial infarction about a year before the interview. Pearl reflected on her experience of going to the Emergency Department (ED) of a community hospital. When she brought her partner to the hospital, Pearl was barred
from access to her partner in the ED cubicle. “Of course, they wouldn’t let me in the room, but I found a little corner desk where I could at least see her feet, which wasn’t much . . . so I never got to say goodbye.” While actually in the ED, trying to be with her partner, Pearl did not think, “of course they wouldn’t let me in” rather, this was expressed upon reflection. Similarly, Pearl had the opportunity to include the meaning of the experience in telling this story, which was that she “never got to say goodbye.”

**Reminiscence and Memories**

Participants spent time telling stories in ways that would make the deceased partner present for us both. By sharing stories and letting interviewers get to know the woman who died, participants were actively using the interview as part of the bereavement process. Some were able to interpret or find meaning in talking about the death experience: “Just listening to myself . . . it is just to the core meaningful,” said Joy, who had lost her partner of 31 years to breast cancer seven years prior. Jodi expressed similar sentiments by saying, “I didn’t think I would be so emotional.”

Others found spiritual meaning in being able to love and care for someone in death or they valued reflecting on their partners’ lives. Susan lost her partner of over 26 years to colorectal cancer. At the time of interview, Susan was in her early 70s and two and a half years had passed since her partner died. Susan expressed sadness that her group of friends did not seem to realize the significance of remembering her partner, Marie, even now. “What gets me,” says Susan, “is people don’t even use her name. They don’t talk about Marie and fun and funny or exciting or sad or angry or frustrating times that we’ve spent together.” The memories were very present for Susan and she wanted her partner to be as present for their friends.

**The Complex Factors Related to Support in Bereavement**

Participants reported both positive and negative experiences of Support of Bereavement from family, friends, and health care providers.

**Positive Support**

Positive support seemed to lead to positive bereavement outcomes, such as, quality of life, moving through grief, or valuing self, other, and the couple. Those participants who had positive support spoke of the
blessings of the relationship, lessons of death and dying, and the honor and gifts found in the process. One participant stated:

I think [our friends] needed support and they needed to be there, so we were just there supporting . . . and sharing with one anothe . . . it was a very good situation for me to be going through and dealing with and actually touching everything that was in that house that belonged to her, and at the same time having two such old and very dear friends there sharing all of that because I could completely be myself . . . didn’t have to guard any feelings.

Other positive outcomes were described, for example, relationships with the partner’s family or being able to handle, or release, business and home affairs in a satisfactory way. One woman described her relief and feeling of support received from the hospice nurse on an initial visit. “The first visit that the [hospice] nurse was out [to the house . . . we asked the question,]” When would this begin? and she said, ‘I can help you now. Why don’t you let me help you now?’” In addition to support, the hospice experience was positive in the staff’s acceptance of these women as a couple.

**Negative Support**

Negative support led to hurt feelings carried into bereavement and beyond. Participants themselves perceive a relationship between negative support and less resolution of their own grief. Examples of less resolution included ongoing legal battles, being shut out of a hospital room, close friends not remembering details of the deceased partner’s life, and lack of recognition of the relationship. Jodi recalled:

There was a memorial service . . . and I was the only one sitting on one side of the church. I was all alone . . . and her family was all on the other side. It was like me and them . . . and I was feeling very embarrassed actually.

Jodi, whose partner died from the complications of diabetes, related many negative experiences following her partner’s death, including a strong lack of support from her partner’s family. Echoed another participant, “I didn’t feel supported after her death the way I would have liked the church to support me. Even if I turned them down, I would have liked an offer from . . . the church. Something as simple as acknowledging me and her family in prayers.” These negative experiences surfaced in the stories told, and reflections on the stories as participants searched for ways to express their difficulty resolving the loss for themselves.
The Interpreted Story

As researchers, we contribute our contextual knowledge to a story-as-told, by developing the thematic structure of Interpreted Story. Within the interpreted story, two dimensions are identified: the context of disclosure/non-disclosure as a lesbian, and the dimension of situational problems. Participants identified family, neighbors, and health care providers as points of disclosure or non-disclosure. Situational problems presented in the death/dying environment, the legal environment, and the social environment of the bereaved.

The Context of Disclosure/Non-Disclosure

The context of disclosure/non-disclosure is one of fear of discrimination or rejection. As one participant said of people surrounding her after her partner’s death: “I was asking them to acknowledge something that I had not acknowledged to them, so could I really blame them? But nevertheless, I did. . . hadn’t acknowledged out of fear of being disapproved of.” She and her partner had not disclosed that they were lesbians (i.e., they were not “out” or publicly acknowledged their relationship). This decision was reflected on by the participant as partly disappointing and partly fear of disapproval. The word we as researchers attach to this theme is hegemony.

Situational Problems

One widow said: “She had it all written out, but under the circumstances of our relationship . . . because of horror stories, I wanted it signed by an attorney and everything official.” Effects of covert or subtle homophobia embedded in society also were part of the context for these women’s experiences of death and bereavement. For example, these were relationships and a love that could not be named and led to situations in which the grief could not be acknowledged or recognized by other heterosexual widows who were commiserating about losses with one another.

Additionally, in business matters, decisions about burial or cremation, and access to the body of the partner while dying or after death, these privileges were given to the biological family. Their relationship took precedence over the partner. As one participant told us,

About a month after she died, I was served a subpoena to court . . . he wanted half of that nest egg . . . we finally settled outside of court, which I was glad we didn’t have to have a jury, but it wasn’t really particularly for my favor, but I just couldn’t take it any more. It seemed like things were unfair, but I think that happens a lot.
A climate of fear and ignorance allows persons to live with a potential for brutality that would be addressed under any other circumstances. The interpreted story directs implications for intervening and supporting healthy bereavement among lesbian widows.

**DISCUSSION**

Doka (1987) identified the presence of intense negative affect, display, or feelings in the bereaved as a factor in disenfranchised grief in non-traditional relationships. Deevey (1997) had similar findings and speculated that this may stem from a lack of opportunity to discuss bereavement experiences. These studies are congruent with our findings that this research interview became part of the bereavement process for participating women.

Worden (1991) identified tasks of grieving as well as predictors of complicated grief experiences. She suggested that aspects of the person who died influence the grief experience of the survivor. Although our findings do not give enough evidence of a relationship between the deceased as a person and complicated grief for the survivor, it was extremely important for our participants that we as researchers be able to know the deceased, even if just a little bit. This reflects a different dimension of Worden’s “who was this person” construct, but seems to be similarly important in the bereavement process.

Lack of societal support has been identified as one of five risks or problems of disenfranchised grief for persons in non-traditional relationships (Doka, 1987). Often excluded from the rites and rituals of death and bereavement, these individuals may also face open hostility from families or communities. As Deevey (1997) found specifically within the lesbian community, these now single women may be perceived as a threat to other lesbian relationships.

Jones (1985) and Deevey (1997) both found, as did the current study, that among bereaved lesbians, support from family and friends was mixed. The current study also extended this finding to the realm of support from health care providers. The finding of some positive support is important and encouraging, yet it should not obscure how the unpredictability of support may be stressful in itself for these bereaved women.

Doka (1987) described practical and legal problems and risks of disenfranchised grief, and Worden (1991) included historical antecedents, concurrent stress, social variables, and personality variables as predictive of not accomplishing the tasks of grieving. Deevey (1997) found these to be issues in her study of bereavement experiences in lesbian
kinship networks, as was also the case in the current study. For participants in our study, wills, belongings, homes, social isolation, and health and illness needs among the survivors themselves were all found to be problematic.

**Implications**

A larger sample size and more diverse sample of lesbian widows would increase our understanding of the variations in this experience. Rural women as well as urban-dwelling widows should be included as well as women with varied lengths of time in bereavement. This study was limited to a small sample of volunteers from a large metropolitan community, but the stories told by these women were poignant and fresh, even after years of bereavement. The purposive, word of mouth sampling technique worked well considering the privacy and invisibility of this population. Further research will enrich our understanding of the meaning of this very personal lived experience.

Disenfranchised grief is one important aspect of a risk of complicated bereavement among lesbian survivors. Yet disenfranchised grief is only one aspect of risk. All persons who grieve need competent compassion. Dimensions of culture, including lesbian culture, complicate grief, but grieving crosses cultural boundaries. In the lesbian community lesbian subcultures exist (Deevey, 1997) and differences among them are not always clearly defined. The effects of these differences remain unexamined, so it would be premature to assume comparability between lesbian survivors’ and heterosexual widows’ experiences.

A thorough grief assessment can begin with assessing type of grief, factors that are influencing grief, and self-care practices of the bereaved. A comprehensive bereavement assessment should assess the bereaved and the deceased kinship networks to become aware of others who may experience bereavement. The questions of security, acceptance, fearfulness, or strength from dealing with prejudice and homophobia will be important when evaluating coping resources. What are the bereaved’s previous experiences with loss or with counseling? Had the women disclosed their relationship or lesbian identity to family, friends, and health care providers? What were the positive and negative aspects of support perceived by the widow? These factors would be added to an assessment beyond the typical pattern of assessment used with heterosexual widows.

Implications for nursing and social work practice in end-of-life care and bereavement include a need for developing culturally competent interventions. Leadership is needed in arenas of culturally competent
assessment and clinical care, broadened definitions of home and family, public and provider education, and polity and politics regarding access to care and conduct and funding of research. Education of nurses and social workers practicing in palliative care, mental health, oncology, critical care, cardiac care, and emergency departments must include these culturally influenced issues. Support of the surviving partner during and after the end-of-life experience, as well as support of friends and family, is essential. Advocacy of the partner with the deceased woman’s family may be necessary, or referral to legal or other assistance may be indicated.

Despite growing attention to both widowhood and lesbian health, the experiences of lesbian widows remain hidden within mainstream society. The current study enhances what is known about bereavement among lesbians and about what helps the bereaved in lesbian cultures manage and resolve the grief following the death of a woman they have loved. Understanding experiences and interventions that are facilitators or barriers to successful bereavement is helpful to not only lesbians, but also others who may be part of hidden populations within society.

REFERENCES


