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BEREAVEMENT EXPERIENCES IN
LESBIAN KINSHIP NETWORKS IN OHIO

DISSertation
Presented in Partial Fulfillment of the Requirements for the
Degree Doctor of Philosophy in the Graduate
School of The Ohio State University

By

Sharon Deevey, B.A., B.S.N., M.S.

* * * * *

The Ohio State University

1997

Dissertation Committee:

Dr. E. Bourguignon
Dr. M. A. Ruffing-Rahal
Dr. P. M. Schwirian, Adviser

Approved by

Patricia M. Schwirian
Adviser

College of Nursing
ABSTRACT

When a lesbian woman dies, her survivors may not be recognized by health care providers who have limited knowledge of lesbian culture. Lesbian kinship networks, including partners, ex-lovers, and friends, are frequently disenfranchised by insensitive health care providers and by the lesbian woman’s family of origin. Disenfranchised lesbian survivors may be excluded from the traditional rituals of mourning and therefore may be blocked in their healing. Because lesbian culture has been hidden within mainstream society, little is known about the experiences of lesbian survivors, following the death of women they have loved.

The objective of this research was to learn about the experiences of lesbian survivors in the context of lesbian culture in Ohio. The three research questions were 1) who are the bereaved lesbian survivors when a lesbian woman dies? 2) what are the experiences of these survivors? and 3) what aspects of lesbian culture are evident in the bereavement experiences of these survivors?

An emergent ethnographic design was used to learn more about the experiences of bereaved lesbian survivors in the state of Ohio. The design included participant
observation, field notes, key informants, artifacts, audiotaped in-person and telephone interviews, demographic data, and kinship network diagrams. Field notes included contextual, methodological, personal self-reflection, analytical information, and a description of participant observation experiences. Seventeen self-identified survivors were located by networking and advertising in Ohio, and interviewed first in person and then for follow-up by telephone. Data were analyzed using field note coding and data summary charts for themes which emerged from the literature and the experiences of survivors. Data interpretation included a discussion of the influence of cultural variations within lesbian communities on lesbian bereavement experiences.
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VITA

1944...................... Born - Glenridge, New Jersey
1967 ....................... B.A. (History) Swarthmore College, Swarthmore, Pennsylvania
1981 ....................... B.S.N., Case Western Reserve University, Cleveland, Ohio
1988 ....................... M.S. (Nursing), The Ohio State University, Columbus, Ohio
1992- 1994 ............. Hospice nurse, Columbus, Ohio
1983- present .......... Psychiatric nurse, Cleveland, Ohio and Columbus, Ohio
1981-83 .................... Public health nurse, Cleveland, Ohio

PUBLICATIONS


FIELDS OF STUDY

Major field: Nursing

Minor field: Cultural Anthropology
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CHAPTER I

INTRODUCTION

Introduction

In this chapter, the nature of the problem faced by bereaved survivors following the death of a lesbian woman will be explored. The relevance of the problem to the discipline of nursing will be discussed. Three research questions will be posed and the major terms of the study will be defined.

Nature of the problem

When a lesbian woman dies her survivors may not be recognized by health care providers who have limited knowledge of lesbian culture (Penelope & Wolfe, 1993). Writing "in memory of the voices we have lost," Morgan Grenwald, editor of the Lesbian Herstory Archives Newsletter, explains (Grenwald, January 1990, p.6):

The Archives is a place to commemorate lost lovers and friends. As a people we have been deprived of the rituals of communal sorrow. Many lesbians have already experienced the pain of silent mourning. Often in newspapers, a euphemism for the death of a lesbian is "There are no known survivors." This is not true. We are each other's survivors.
Because lesbian culture has been hidden within mainstream society, very little is known about mortality and bereavement in the lesbian community. Little is known about what helps the bereaved in lesbian communities manage and resolve their grief following the death of a lesbian woman they have loved. Living in a heterosexist (Neisen, 1990) society where both individual prejudice and institutional discrimination are common, lesbian women often hide their cultural differences in order to protect themselves from violence, job loss, and rejection by their family of origin. Lesbian women often report fear of abuse by health care professionals (Stevens & Hall, 1988; Stevens, 1994a, 1994b, 1995) and fear of being blocked from access to loved ones in health care settings (Thompson & Andrejewski, 1988).

Cultural variation in kinship patterns and in the expression of mourning are of particular interest for this study. Lesbian community writings and recent studies of lesbian kinship by anthropologists (Weston, 1988, 1991, 1993; Riley, 1988) suggest that the "family of choice" for many lesbian women is an extended kinship network that includes "permanent" or current partners, ex-lovers, and close friends, in addition to the more visible members of the family of origin and children.

Individuals who are members of the "family of choice" when a lesbian woman dies may be at risk during bereavement for several reasons. Many are "disenfranchised" (Doka, 1987) as survivors, with neither their relationship to the deceased nor their resulting grief being socially validated. Some are excluded from public mourning rituals like the funeral and bereavement employee leave policies. Lesbian survivors may be at greater risk during bereavement if they have not resolved the earlier grief of losing social status due to lesbian sexual orientation (Ritter & O'Neill, 1989; O'Neill & Ritter, 1992). On the other hand, Schidelman and Schoen (1988) suggest that the "rich experience" of coming out may help cope with bereavement, because coming out as a lesbian woman
"often involves its own grieving process; we lose one identity and forge another, just as one does after the loss of a loved one" (p.114).

Relevance to nursing

Bereavement in heterosexual widows and widowers has been studied extensively in several health-related disciplines during the past fifty years. Health professionals have been particularly interested in the impact of bereavement on physical and mental health in heterosexual survivors. A variety of interventions including bereavement support in hospice programs have been proposed to help those perceived to be at risk for adverse bereavement outcomes. More recently, researchers have raised new questions about how culture affects bereavement and about how disenfranchisement complicates bereavement in hidden survivors whose loss is not validated by those around them. The AIDS epidemic has increased awareness of lesbian and gay issues in health care settings.

Nurse-researchers who have studied anthropology urge the nursing profession to be more aware of cultural diversity (Leininger, 1970, 1985, 1991; Eliason, 1993; Cohen & Tripp-Reimer, 1988). Marginalization of culturally-diverse populations, including lesbian and gay people, has been recognized as a problem in health care (Hall, Stevens, & Meleis, 1994; Stevens, 1992, 1993).

Nurses are sometimes among those health care providers who are uncomfortable providing health care for lesbian women. In a study of nursing educators, Randall (1989) found that half her respondents thought that "lesbianism is not a natural expression of human sexuality" and 28% said they would have difficulty communicating with a woman they knew to be a lesbian. Health care professionals in general know little about lesbian life and less about lesbian death.
After years of medical misinformation (Terry, 1990; Wilkerson, 1994) and public silence about lesbian women, the nursing and medical professions have recently become more aware of the need to provide care to lesbian women in a variety of clinical settings (Deevey, 1995; Denenburg, 1995; Haas, 1994; Rankow, 1995; Roberts & Sorensen, 1995). The American Nurses' Association (1985) acknowledged that "there is continuing discrimination in health care experienced by the gay/lesbian minority population" and that "the gay/lesbian population has the right to quality health care." The American Medical Association formally acknowledged the need for improved care of gay and lesbian clients as recently as 1994. Nurses who have pioneered in making gay and lesbian health issues visible in the nursing profession include John Lawrence (1975), Jeanne Brossart (1979), Andrew Irish (1983), Fred Bozett (1984, 1987), Robert Kus (1985), Carla Randall (1987), Patricia Stevens (1992), Joanne Hall (1992), Judith Saunders (1981, 1988, 1990), and Theresa Stephany (1992).

Nurses have a well-established role in providing care for dying patients and their families, both in hospice programs and in other clinical settings (Rogers & Vachon, 1976; Benoliel, 1983; Demi & Miles, 1986). Bozett (1987) and Irish (1990) argue persuasively that nurses must expand their definitions of family beyond the traditional "nuclear family" which currently is found in only thirteen per cent of actual household configurations. Bozett defines the family as "who the patient says it is" (1987, p.4). In many clinical situations, nurses do not know who the family of a lesbian patient is, either because the patient is not asked or because traditional heterosexual family roles are simply assumed.

In community settings and in a variety of clinical specialties, nurses may provide care for lesbian women who are terminally ill or for their bereaved survivors. Nurses
need accurate information about lesbian survivors, lesbian kinship networks, and lesbian culture in general to provide quality nursing care to this often hidden population.

Research questions

The objective of this research was to learn more about the experiences and needs of lesbian survivors following the death of a lesbian woman. The overall goal was to gather cultural data that will sensitize health professionals to the needs of bereaved survivors in the lesbian community.

The research questions for the study were:
1. Who are the bereaved lesbian survivors when a lesbian woman dies?
2. What are the bereavement experiences of these survivors?
3. What aspects of lesbian culture are evident in the bereavement experiences of these survivors?

Definition of terms

Culture -- the learned, shared beliefs and values of a particular group

Grief -- the emotional and physical response of an individual to loss

Bereavement -- grief specifically related to the death of a loved one

Mourning -- the social or public expression of bereavement in behavior and rituals
Lesbian woman — a woman labeled as "lesbian" or "gay" or "homosexual" by herself, her intimates, or her survivors

Lesbian kinship network — "the kinds of relationships people create and the meaning of these in their lives" (Riley, 1988); individuals identified as the "family of choice"

Lesbian survivor — an individual who self-labels as bereaved by the death of a lesbian woman, and who is not legally related by birth or marriage to the deceased

In summary, health care givers have the potential either to disenfranchise survivors after the death of a lesbian woman, or to provide culturally-competent care to promote healing during the bereavement process. The goal of this research was to gather information to help care givers improve their cultural competency in caring for vulnerable survivors after a lesbian woman dies.
CHAPTER 2

LITERATURE REVIEW

In this chapter the literature related to the study will be reviewed to summarize what is already known that may illuminate the research questions about the experiences of lesbian survivors when a lesbian woman dies. The four major sections of this chapter include 1) an introduction identifying the broad questions which underlie the specific research questions; 2) a discussion of culture and bereavement; 3) a discussion of culture and lesbian communities; and 4) a review of the literature and bereavement and health care. A summary of the sources of literature for the study is included on the following page in Figure 2.1.

Introduction

A preliminary review of the literature related to bereavement in lesbian survivors after the death of a lesbian woman raises several questions which are important to anthropologists and to the culturally-alert nurse researcher: What in human nature is universal? How much of human behavior and emotion are culturally shaped? Asking
questions about how people die raises many other questions about how people live, and how they love: What kinship or interpersonal relationships are recognized and valued?

Figure 2.1. Sources of literature related to lesbian bereavement.
Where do individuals fit in a social group or community? The process of research on bereavement also raises important questions about knowledge: How can emotion and meaning be understood from observation? In what ways does the investigator's own cultural frame of reference determine what is observed? And finally, proposed intervention for bereavement raises more questions: How do people help each other? How does intervention by professionals make a difference?

All of these questions probably cannot be answered by this study. Nevertheless, it is important to remember that such underlying questions contribute to making the study both compelling to the investigator and emotionally provocative to potential participants and reviewers.

Bereavement and culture: The contribution of anthropology

Anthropologists have studied mourning rituals in a variety of communities. van Gennep (1908) is credited with changing the focus of the study of death in nonliterate cultures from an ethnocentric preoccupation with the details of primitive funeral practices to a relative appreciation of the various rites of passage in human life. Gorer's (1965) research in England described different styles of mourning and attributed the "pornography" of death to a shift in prudery from sexuality to mortality in Western cultures. The cross-cultural analysis completed by Rosenblatt, Walsh, and Jackson in 1976 attempted to identify "fundamentally human" emotional responses to death and to
capture the cultural variety in death customs in 76 cultures around the world. Metcalf's 1980 first-hand account of his fieldwork experience in Borneo provided a striking example of how extreme cultural variety in death customs can be emotionally discomforting in cross cultural contact. The reviews of Huntington & Metcalf (1985) and Corcos (1985) clarified how ideology and myth influence a given culture's view of death.

More recently, anthropologists have raised questions about the influence of culture on all aspects of meaning, emotion, and life experience (Geertz, 1973, 1988; Kamerman, 1988; Rosaldo, 1989; Kleinman & Kleinman, 1991; Lewin, 1991). Studies like that by Weiner (1988) in Papua New Guinea continue to stretch our imagination and cultural understanding. Among the Trobrianders she found that “death destroys not only individual lives but also whole complexes of relationships” (p.15).

Bereavement and culture: Disenfranchised grief

The values of cultural groups determine which bereavement experiences are socially validated and which are ignored or disenfranchised. Raphael (1983) acknowledges that "...there may be other dyadic partnerships in adult life that show patterns similar to conjugal ones, among them the young couple intensely, even secretly, in love; the de facto relationship, the extramarital relationship and the homosexual couple" (p.227).
Doka (1989a) describes "disenfranchised grief" in many non-traditional and non-recognized relationships in bereavement. These include bereavement in lesbian and gay relationships, "friend-grievers," pet loss, and the grief of (heterosexual) "ex-spouses."

Pine (1989) describes the contrast between "the 'proper' bereaved" and "the underclass of grievers whose legitimacy may not even be recognized and whose needs are not addressed" (p.13). Doka identifies "the central paradoxical problem [of disenfranchised grief]: the very nature of this type of grief exacerbates the problems of grief, but the usual sources of support are not available or helpful" (p.4). Kollar (1989) discusses how disenfranchised grievers can meet needs for public (or private) mourning rituals when access to communal rituals is blocked. Kauffman (1989) contributes an important observation that grief is sometimes self-disenfranchised due to embarrassment or shame; internalized homophobia could certainly affect grievers in lesbian communities.

A few researchers have studied bereavement in friends. Sklar and Hartley (1990) studied the "hidden population" of "survivor-friends" and report findings that "indicate parallel survivor-friend and family member bereavement patterns" (p.103). Vargus, Loya, and Hodde-Vargus (1989) studied "201 close relatives and intimate friends" surviving sudden or violent death in Los Angeles; however, they do not report numbers of family vs. friends and make no comparisons between the two. Murphy (1986) did compare family members and friends of disaster victims. She concluded that "being a family member of the deceased disaster victim resulted in higher levels of overall mental stress than did being a close friend" (p.424). She argues elsewhere (Murphy and Stewart,
1985-86) for including "linked pairs of bereaved persons," including friends, to help with sampling problems of limited potential sample size and low participation rates. All the "friend" participants in these studies are what Kurdek (1988, p.505) calls "presumed heterosexual."

Meagher (1989) outlines proposed assessment and intervention specifically for disenfranchised grievers, and concludes "the essential task for the grief counselor [with disenfranchised grievers] is to assess the nature of the lost relationship and any apparent deficiencies in recognition and support. In this way the counselor will be able to design more effective counseling strategies to assist the griever in coping with and surviving the loss of a significant other" (p.308).

Bereavement and culture: AIDS

Culture and lesbian communities

Recent lesbian literature provides a glimpse into the often hidden world of lesbian culture, kinship, and grief experiences (Lesbian Revisions Group, 1992). Lesbian women are recognized as a vulnerable population in recent health care literature (Stevens & Hall, 1991). The existence of lesbian communities with a sometimes hidden culture has been well documented (Wolf, 1979; Lewis, 1979; Krieger, 1983; Locked, 1985; Barrett, 1989).

Homophobic or heterosexist values (Neisen, 1990) are common in members of the majority heterosexual culture who are uninformed about, or openly hostile toward lesbian individuals and institutions. Health care providers and family-of-origin members are often experienced or perceived as ignorant and threatening by lesbian women. Lesbian women are by necessity bicultural (Brown, 1989; Haring, 1990). They lead double lives, working among the heterosexual majority but developing hidden networks of support, activity, and resources with their loved ones within lesbian communities.

Lesbian communities are not geographically bounded in the traditional sense of the term community. Research and ethnographic evidence indicate, however, that throughout the United States, many individuals identify themselves as "lesbian women" who belong to a "lesbian community" (Wolf, 1979; Krieger, 1983; Locked, 1985; Whiniest, 1986; Barrett, 1989).

In Ohio, local lesbian publications list many organizations, support groups, religious groups, bars, and businesses. Lesbian Connection, published in Lansing,
Michigan, lists zip code 43202 in Columbus, Ohio as its fourth largest zip code in circulation. Fan the Flames, a bookstore in Columbus, sells many copies of classics in lesbian fiction (e.g. Brown, 1973), lesbian photography (Biren, 1987), and lesbian political analysis (Bunch, 1978). The Ohio State University has a tradition of lesbian scholarship (Painter, 1978; Rupp, 1984; German, 1985), has offered several lesbian studies courses, and currently has both an Office for Gay/Lesbian/Bisexual Student Services and a Gay/Lesbian/Bisexual Faculty/Staff Association. Taylor and Rupp (1993) provided insight into the lesbian feminist cultural activities in Columbus and central Ohio. Despite continuing societal and scholarly debate (Risen & Schwartz, 1988) on the "causes" and legitimacy of lesbian sexual orientation, such rich ethnographic resources document at least the "emic" reality of lesbian culture.

**Lesbian kinship**

Kinship networks in lesbian communities differ from traditional heterosexual nuclear families, and will determine who is bereaved by the death of a lesbian woman. Weston (1988) and Riley (1988) urge the recognition of different definitions of kinship in lesbian communities in the United States. Weston found that lesbian women (and gay men) describe "families we create" that are substitutes for "blood family" (p.153), and "point to the practical services which gay [and lesbian] kin provide for one another, from
cooking dinner to helping out in emergencies and making funeral arrangements —

services that might otherwise be performed by "blood relatives" (p. 154).

Riley (1988) points out the "heterosexual bias" of traditional anthropological
definitions of kinship, and argues that we must look at the "symbolic level of kinship ties
that are not based on biology or affinity ... to bring us to a greater understanding of the
meaning of kinship in contemporary America" (p. 81). "Love," she concludes, "is what
makes a family" (p. 84).

Lesbian community literature supports the Weston/Riley anthropological
research. Clines & Green (1988) in a report on lesbian couples differentiate between the
"birth/biological/adoptive" families of lesbian women and the "chosen family"; they
conclude "the point is that family membership is by selection, not by birth or legal status
alone" (p. 105).

Who, then, is included in a lesbian family of choice? Some writers focus on
lesbian couples and encourage "permanent partnerships" (Bern, 1988) as the basis of
lesbian family. Loulan (1987) suggests, however, that the friend relationship becomes
primary (pp. 72-73):

Probably the most intense passion in the lesbian community is
between friends. Lovers, jobs, and roommates come and go, but
friends can last a lifetime. Our friends often become our chosen
family — the people we trust and cherish above everyone else.
Friendships are sometimes the most important part of our lives.
When our friends are lesbians, we often feel additionally bound to them out of a sense of being 'other'. We each know what it is like being a lesbian in a hostile culture. We shelter each other from the storms created by families of origin, and we nurture each other through bouts of external and internal homophobia. We are mother, daughter, crone, healer, mentor, enemy, and angel for each other. We go through break-ups, illness, childbirth, death, and political upheaval together. Often we are bound by a pact, silent or spoken, to stay together through everything. Our friendships are similar to what we expected from our families of origin but usually did not receive.

Beaker (1988, 1993) interviewed forty lesbian women about their "ex-lover transitions" and concludes that the "unbroken ties" between many (though not all) lesbian ex-lovers are "family-like intimacies." Kassoff (1985) interviewed eight lesbian women in non-monogamous relationships, where the family of choice included two current lovers. The popularity of non-monogamy has varied over time and region in lesbian communities; Jones (1985) reported that one lesbian widow in her study found her deceased partner's "other lover to be the most helpful person to her in terms of providing emotional and practical support" (p. 144).

Kurdek (1988) has used the Saranson Social Support Questionnaire to study the extended networks of gay and lesbian couples. In his data for lesbian women, "most frequently mentioned relationship categories for providers of support" included (in declining order of frequency): friends, partner, family members (mother, sister, father, brother), co-workers, therapist, daughter, son, grandmother, aunt, minister, ex-spouse, neighbor, and ex-partner. Participants also listed a variety of their supporters, including
"ex-spouse's current spouse" and "partner's spouse." In this case, ex-spouse probably refers to ex-lesbian-spouse rather than ex-husband, but research indicates that about thirty percent of lesbian women are heterosexually married before coming out, so confusion in terms can be a problem.

The review of the literature on lesbian kinship therefore suggests that heterosexual models of family relationships cannot be assumed to be universal. Neither the researcher nor the health care provider should make assumptions about the lesbian woman's family structure. In a culturally competent setting, each lesbian participant, each lesbian patient must be asked: Who is your family?

Lesbian grief

Some clues about lesbian bereavement and kinship are found in the personal writings of lesbian women describing their experience with terminal illness. Rosenblum (1988) documented the remarkable support of her partner, who later wrote about her own experience as a survivor (Butler, 1989; Butler & Rosenblum, 1991). Wainwright (1984) details the network that includes her "blood sister", lesbian "friends/family," lesbian "ex-lovers/family," a cousin, a daughter, and the "women of the organizations — Feminist Writer's Guild, Gay Women's Alternative, Lesbian Herstory Archives, and Womanbooks" who were her support in what she calls "this special time" (unpaged).
Some authors suggest that grief in bereavement may be affected by other experiences of grieving related to lesbian culture (Thompson, 1992). Friend (1987) argues that lesbian and gay people are better prepared for the losses of aging because of their gender role flexibility, extended social networks, and the "crisis competence" developed in response to coping with oppression. However, if grief about losing social status due to sexual orientation is unresolved, lesbian women may be at increased risk for poor bereavement outcomes (Ritter & O'Neill, 1989). Schidelman & Schoen (1988) believed that the "rich experience" of coming out into lesbian culture may help cope with bereavement because coming out "often involves its own grieving process; we lose one identity and forge another, just as one does after the loss of a loved one" (p.114).

Lesbian bereavement

Only three research or clinical sources addressed questions about lesbian bereavement. In 1985 Linda Jones completed a dissertation on bereaved lesbian survivors' perceptions of social support following the death of a partner. This phenomenological study in the discipline of education included unstructured interviews with 15 lesbian women. Jones compared the ways in which lesbian and heterosexual widowhood were similar and dissimilar. In this study all deaths were from natural causes, and survivors following suicide were intentionally excluded.
In 1990, Judith Saunders published a chapter on gay and lesbian widowhood in Kus's clinical nursing text, *Keys to caring: Helping your gay and lesbian clients*. Saunders is a nurse who completed a 1981 qualitative study of uncoupled identity in heterosexual widows. In this clinical chapter, she described seeking, finding meaning, and balancing activity-affect as the three stages of the bereavement process. She identified several bereavement problems specific to gay and lesbian people, including stigma, internalized homophobia, lack of legal protection, closeting, substance abuse, depression, the possibility of “stalled” grief, and the lack of traditions for aging and dying in gay and lesbian communities. Saunders did not include lesbian widows in her original study (1981). She seems to have combined her knowledge of heterosexual bereavement with her general lesbian research findings (Saunders et al, 1988) in this chapter, without directing studying bereaved lesbian women.

In 1991 April Martin included a case study example of clinical counseling with a bereaved lesbian widow in Silverstein’s text on *Gays, lesbians, and their therapists*. She described both her feelings and those of her client during the process of her interactions with a lesbian widow whose partner of ten years died of cancer after months of caregiving. This chapter provided an unusual insight into the ways in which therapeutic connections help heal both the provider and the client.

In all three examples, only widow-equivalent lesbian survivors are identified as being at risk during bereavement. The close relationships of ex-lovers and passionate friends described in lesbian literature are ignored.
In Western intellectual thought, several pioneering thinkers have added to our understanding of heterosexual conjugal bereavement and its consequences. The classic literature includes Freud's (1917) discussion of mourning and melancholia, Lindeman's (1944) description of the symptomatology of normal grief, Bowlby's (1961) psychodynamic explanation of grief and separation anxiety, and Engel's (1961) consideration of grief as a disease. Kubler-Ross (1969) originally described four stages of grieving in the dying process, but her stages (denial, anger, bargaining, acceptance) have been popularized as bereavement stages. Bugen (1977) was the first to propose a non-stage model for bereavement prevention, and Lofland (1985) reintroduced the importance of social context in grieving.

Health professionals have studied heterosexual widows and widowers in some detail, asking questions about the characteristics of their bereavement experiences, the health outcomes related to bereavement, and the interventions needed to improve physical and mental health outcomes for those at risk (Stroebe & Stroebe, 1987). Stroebe and Stroebe asked in 1981 if the "broken heart" (death following soon after the death of a spouse) was a myth or a reality. These authors and their colleagues (1987, 1988, 1989) have made a significant investment in bereavement research, but conclude that what is known with any certainty about bereavement is less than what is not known.
In a recent comprehensive overview on related scientific research, bereavement chroniclers Stroebe, Hansson, and Stroebe (1993) conclude that "we are still far from an integrative theory of grief and bereavement" (p. 458); that "currently there is no standard approach to bereavement assessment" (p. 458); and that "a frequently overlooked concern is the failure to distinguish between main effects and interactions in the analysis of risk factors for poor outcomes" (p. 461). These authors conclude that bereavement researchers must be aware of "individual and cultural heterogeneity" and the "multidimensionality of bereavement reactions" (p. 462).

Factors which have been acknowledged to complicate bereavement in heterosexual populations include issues related to the death, the relationship, and the social/cultural context. A death that seems in some ways unjustified (due to youth, human cause, or suddenness) is known to be more difficult to accept. When the relationship was in some way ambivalent, from unresolved anger or miscommunication, grieving may be prolonged. The social/cultural context provides permission and rituals for mourning. If the relationship is hidden, or socially condemned, the rituals of mourning may be unavailable to help in the healing process. In all these examples, the normal intense emotions of anger, sadness, denial, and fear may be intensified and prolonged. There is also a growing awareness that social policy decisions can escalate or improve social and health problems related to bereavement.

Many questions remain about the effectiveness, adequacy, and accessibility of the variety of bereavement interventions. Several models of care have been proposed for
intervention. These include individual counseling (Worden, 1991), group psychotherapy (Leiberman & Yalom, 1992), non-professional mutual support groups, and one-to-one widow-to-widow peer support. Hospice programs have offered a variety of programs using these models (Lattanzi-Licht, 1989). In England, the Cruse program offers government sponsored in-home counseling (Parkes, 1987). Cruse was started in 1960 to serve widows, began serving widowers in 1980, and by 1987 was expanded to all bereaved.

Bereavement and health care: Nursing

Nurses have approached the study of bereavement with a variety of questions and research methods (see Table 2.1). Thirty nursing articles published between 1981 and 1995 were reviewed. Eighteen were research articles, three were research reviews, three were theoretical discussions, and the remainder were clinical discussions. Most focused on heterosexual widows, or conjugal bereavement, with an expansion to include widowers in more recent years.

Issues of culture were ignored in research, except for Hoeffer (1987), who oversampled for black participants to obtain a more representative sample. Hoeffer included “never married” women, but if this category included lesbian women, she gave no indication. Lesbian women were not mentioned in any of the articles. Heterosexuality is assumed, except for the mention of gay men in two later discussions of
<table>
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<tr>
<th>Date</th>
<th>Author(s)</th>
<th>Focus</th>
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<tr>
<td>1981</td>
<td>Saunders</td>
<td>Young widows, uncoupled identity</td>
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<td>1982</td>
<td>Valanis &amp; Yeaworth</td>
<td>Ratings of physical and mental health, older widows</td>
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<td>1983</td>
<td>Benoliel</td>
<td>Review of death/dying nursing research</td>
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<td>Hauser</td>
<td>Lit review, bereavement outcomes for widows</td>
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<td>Murphy</td>
<td>Theoretical review of bereavement</td>
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<td>1984</td>
<td>Demi</td>
<td>Review of hospice bereavement programs</td>
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<td>1985</td>
<td>Brock &amp; O'Sullivan</td>
<td>Relationship of role change to widow adjustment</td>
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<td>Martoccio</td>
<td>Theoretical review of bereavement and intervention</td>
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<td>1986</td>
<td>Demi &amp; Miles</td>
<td>Quantitative nursing critique</td>
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<td>1987</td>
<td>Collison &amp; Miller</td>
<td>Imagery work with dying patients and their families</td>
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<td>Gass</td>
<td>Relationship of coping and health in older widows</td>
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<td>Hoeffer</td>
<td>Comparison of older single women and widows</td>
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<td>Rigdon, Clayton, &amp; Dimond</td>
<td>Interviews for theory to help elderly bereaved</td>
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<td>Warner</td>
<td>Widows vs. widowers perceived social support</td>
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<td>1988</td>
<td>Constantino</td>
<td>Depression related to bereavement intervention</td>
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<td></td>
<td>Oebermans-Bunn</td>
<td>Support groups in AIDS bereavement</td>
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<td>1989</td>
<td>Carter</td>
<td>Themes of bereavement in all types of bereaved</td>
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<td>Kirschling &amp; McBride</td>
<td>Effects of age, sex on experience of widowhood</td>
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<td>1990</td>
<td>Burford</td>
<td>Lit review on health and coping in widows</td>
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<td>Herth</td>
<td>Grief resolution variables in widows and widowers</td>
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<td>Steele</td>
<td>Factors influencing death/surround experiences</td>
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<td>1991</td>
<td>Cody</td>
<td>Lived experience of grieving; Parse theory</td>
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<td></td>
<td>Cowles &amp; Rodgers</td>
<td>Concept analysis of grief</td>
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<td>1992</td>
<td>Aber</td>
<td>Paid work as a predictor of widow health</td>
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<td>Jones &amp; Martinson</td>
<td>Caregiver bereavement after Alzheimer’s deaths</td>
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<td>Davis, Hoshiko, Jones, &amp; Gosnell</td>
<td>Effect of support group on perceived stress</td>
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<td>1993</td>
<td>Glass</td>
<td>Role of CNS in bereavement care</td>
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<td>Houldin, McCorkle, &amp; Lowery</td>
<td>Relaxation &amp; immune status in bereaved spouses</td>
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<td>Pilkington</td>
<td>Lived experience of grieving, Parse theory</td>
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<td>1994</td>
<td>Joffrion &amp; Douglas</td>
<td>Bereavement clinical ideas for CNS’s</td>
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<td>Kerr</td>
<td>Bereaved daughters, meaning</td>
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<tr>
<td>1995</td>
<td>Cody</td>
<td>Grief, meaning, families, AIDS, Parse theory</td>
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Table 2.1. Nursing contributions to bereavement theory and research
AIDS-related bereavement. Carter (1989) was the first to extend her research to include any adult who had “lost a loved one.” Cody (1991, 1995) studied the lived experience of bereavement using Parse’s nursing theory. He acknowledged various types of family structures but did not address the issue of culture directly.

Cowles and Rodgers’ (1991) concept analysis of grief identified culture as a part of both individual and normative aspects of bereavement. Joffrin and Davis (1994) cited a recent letter from Benoliel noting that the expression of grief is “highly dependent on cultural customs” (p. 14).

Nurses studying bereavement may have ignored lesbian culture in part because the primary advocate of transcultural nursing, Madeleine Leininger, does not include gay and lesbian culture in her research agenda. In a 1991 book-length summary of transcultural theory and research, Leininger included 54 national and international cultural groups. Despite her earlier (1978) awareness of cultures as specific and contemporary as nursing and medicine, Leininger has been curiously silent about lesbian and gay culture.

Bereavement and health care: The hospice movement

The hospice movement has changed public consciousness about dying and provided new resources for terminal and bereavement care. Hospice programs usually offer bereavement assessment and support as part of the offered clinical services (Demi,
1984). Despite the inconclusiveness of research on bereavement, many clinical assumptions are made in hospice practice.

In clinical hospice practice, William Worden's (1991) framework has been used as the basis of bereavement risk assessment and follow-up, and thus has influenced this research. Worden described four non-linear tasks of mourning: 1) to accept the reality of the death; 2) to work through the pain of grief; 3) to adjust to an environment in which the deceased is missing; and 4) to emotionally relocate the deceased and move on with life (pp. 10-16).

Worden's description of the manifestations of normal grief included lists of eleven feelings, nine physical sensations, five cognitive changes, and twelve behaviors. These lists are used by hospice professionals and volunteers for anticipatory teaching in families and for supportive counseling and groups for those identified as at risk or in the process of complicated grieving.

Worden identified seven categories of risk to "try to predict how a person would respond to a loss [death]." These include 1) who the person was; 2) the nature of the attachment; 3) mode of death; 4) historical antecedents; 5) personality variables; 6) social variables; and 7) concurrent stressors. Worden's analysis of these bereavement risk factors prompts many questions about lesbian bereavement specified below in Table 4.

In reviewing the multidisciplinary scientific literature on bereavement and health, and the clinical writings of Worden, the focus on widows is glaring. With the exception of pregnancy, no other experience of women has so intrigued traditional male and male-
identified scientists. Why, in an era when death is taboo and women are generally
discounted, have so many investigators examined the trauma caused by a woman losing
her man? What if we learned, as feminists used to claim, that a woman without a man is
indeed a fish without a bicycle? I do not in any way wish to discount the devastation of
losing a beloved, long-time companion. It strikes me, however, that in the study of
widows, grief is only the obvious, clinically compelling issue. Other underlying issues
may include the impact of cultural glorification of heterosexual dependency, monogamy,
and the nuclear family.

The long-term consequences of these societal values are evident in the experience
of widows. Once proud to be helpless in so-called masculine skills, the widow must
confront the gaps in her financial and mechanical knowledge. Once praised for having
only one primary adult relationship, the widow must reach out to others using social
skills undeveloped since adolescence. And once proud to live in the nuclear family
isolation of the city or the suburbs, the widow must face the future without the relational
depth of extended families of kin or choice.

Conclusion

In previous research on lesbian aging (Deevey. 1988), the investigator sought
information about the life experiences and health-seeking behaviors of an "invisible"
population: older lesbian women. On reflection, important issues of bereavement and
culture were overlooked in the first study (see Appendix A: Reflexive Statement). In this study participants are not simply lesbian women of a certain age. Rather, this study examines one of the inevitable issues of aging, the loss of loved ones, in the context of lesbian culture.
CHAPTER 3

METHODOLOGY

Introduction

This chapter describes the research design of the study, the community of study, the research procedures, the strategies for data management, analysis, and interpretation, the precautions, and the limitations.

Ethnography

The design of this study is based on the traditional ethnographic field methods first developed in the discipline of anthropology. Leininger (1970, 1985, 1991) was the first and foremost among nurse-researchers to recommend this method in the study of culturally-diverse communities, especially when little is known about the population of interest. An emergent ethnographic design was used to discover the emic perspective of survivors after a lesbian woman's death. Ethnography is recommended as the research method of choice when little is known about a cultural phenomenon (Ragucci, 1972; Germain, 1986; Leininger, 1985; Lipson, 1989; Hammersly & Atkinson, 1984; Omery, 1988; Parse, Coyne, and Smith, 1985).

The goal of the ethnographic method is to discover how people organize their behavior and attribute meaning to their experiences. The ethnographer seeks implicit as
well as explicit aspects of knowledge in a given culture. Ethnography is an emergent research design which "compels the investigator to negotiate the paradox of planning what should not be planned in advance" (Sandelowski, Davis, & Harris, 1989).

Zaharlick and Green (1991) defined the goal of the ethnographic researcher to "identify and explore the cultural patterns of everyday life and the consequences for participants of being members of particular groups" (p. 206). Ethnography is, according to these authors, a "dynamic-interactive approach" to research with three overlapping and continuing phases: preplanning, discovery, and presentation of findings (Zaharlick and Green, 1991). The discovery phase has traditionally been called fieldwork in anthropology. In this study I have used the term participant observation instead of fieldwork because I have conducted the study in my own community. My role in the study most closely resembles the "observer-as-participant" on the continuum of openness to secrecy described by German (1988, p. 154) in that my research interests were common knowledge among community members during the six years of the study.

Participant observation was documented in handwritten field notes which included description of the researcher's experiences, reflexive self-awareness, commentary on artifacts, ongoing discussion with the key informants, contextual notes on the interviewing process, and an audit trail (Lincoln & Guba, 1985) of the methodological and analytical decision-making process. My point of view switched frequently from the "emic" (insider) to "etic" (outsider) perspective, during both observation and interpretation (Tripp-Reimer, 1984). The presentation of findings and Appendix A include a discussion of this reflexive process.

Ethnographers have traditionally been interested in the cultural aspects of death and bereavement rituals (Corcos & Krupka, 1984; Weiner, 1988). More recently researchers in several disciplines have, as described in Chapter Two, used ethnographic
methods to study various phenomena in a variety of hidden populations, including lesbian and gay communities (Barnhart, 1975; Barrett, 1989; Weston, 1991).

The ethnographic design of the study is outlined on the next page in Figure 3.1, and is described in detail in the following sections.

The community of study

The study focused on lesbian communities in the state of Ohio. Much of the previous research in lesbian communities has been done on the east or west coasts (Almvig, 1982; Wolf, 1979; Bell & Weinberg, 1978; Hedblum & Hartman, 1980). Less is known about lesbian communities in the midwestern United States (Krieger, 1983; Chesnoff, 1990). I lived as a participant observer in the lesbian community in central Ohio from the inception of the study in 1990 until data interpretation was completed in 1997. The lesbian community in Ohio is a somewhat hidden network of love and friendship alliances, community events, publications, and businesses.

Participant observation

The researcher walks a delicate balance as participant observer in ethnography (Powdermaker, 1966; Thorne, 1983; MacPherson, 1988). The researcher's "entire person" is the primary instrument in ethnographic research (Zaharlick, 1992). The researcher must answer the question "who are you to do this?" (Agar, 1980). In this study, the researcher is the author, and will answer this question from the first-person perspective.
Participant observation

Field notes
- Community activities
- Key informants
- Artifacts
- Informal comparison

Interviews
- Audiotaped 1:1
- Audiotaped telephone
- Demographic data
- Kinship data

Data management

Field notes analysis
- Transcription
- Five category coding
  - contextual
  - methodological
  - personal
  - analytical
  - community participation

Interview analysis
- Transcription
- Structured comparison
  - Demographic data
  - Narratives
  - Question summary
  - Doka
  - Worden

Findings
- Community
- Demographic
- Experiences

Cultural interpretation

Implications

Figure 3.1 Sources of data for an ethnographic study of lesbian bereavement in Ohio.
I have lived as a lesbian participant in lesbian communities in Ohio since 1978, and have thought in print about various aspects of lesbian life (Deevey, 1995; Deevey, 1993; Deevey & Wall, 1992; Deevey, 1990; Deevey, 1989). A participant community member has all the advantages of ease of access and greater depth of informant self-disclosure, plus the disadvantages of insider bias and inability to notice familiar data. Suppe (1981) argues that both lesbian and gay male cultures may be inaccessible to heterosexual researchers. He believes that "knowledgeable, trained, well-acculturated members of the [lesbian] subculture" are best qualified to study this hidden population. He urges participant-observer members of the community to be alert to bias, and warns such researchers to expect that their results will be "considered 'soft' by quantitative social science researchers" (p.79).

DeSantis (1990) emphasizes the importance of winning the support of both individuals and gatekeepers in communities where members increase their vulnerability by participating in research. Potential participants must believe that the investigator is doing work that will be more benefit than menace to each participant.

In Ohio, the vast majority of lesbian women are highly secretive, or closeted. Lesbian women like myself who are "out" or intentionally visible to heterosexual people are sometimes threatening to members of the community who are more "closeted," for two reasons. First, a closeted woman may fear being "outed" involuntarily; or she may be uncomfortable seeing someone else so differently manage the challenge of surviving as a stigmatized person. Hiding and confronting are two quite different modes of coping. Those who prefer one method of coping are often uneasy with those who prefer the other. As a result, "out" lesbian women are sometimes isolated within their own communities (McDaniel, 1985).
As an “out” lesbian researcher, I needed to persuade potential interview participants and casual informants that my research may eventually improve the care of lesbian women in health care. Participants needed to be glad I was doing something they might not dare. Closeted participants needed at the same time believe that I would protect their public “passing” (heterosexual) identities and refrain from questioning the legitimacy of their closeted way of coping with discrimination.

Field (1989) emphasize the challenge of differentiating between clinical and ethnographic interviewing, while Janken & Cavalari (1978) stress the problem of limiting intervention when problems are uncovered during the research process. With twelve years experience as a psychiatric and hospice nurse, I knew how to listen at several levels and maintain a balance of involvement and detachment. My experience as a novice hospice nurse during the research project gave me valuable direct experience with death and bereavement.

Field notes

Reflexive field notes of participant observations for this study were initiated in 1990 (Drew, 1990). These described the development of the research questions, first impressions of the process, feelings about mortality and bereavement, responses of community members and colleagues, and description of my initial experiences as a hospice nurse. The reflexive statement in Appendix A is based on selections from both these field notes and my personal journal.

Following the recommendations of Rodgers and Cowles (1993), handwritten notes were kept because this method was familiar and efficient for me. I had maintained a personal journal with two to four entries per week since 1978. For the duration of this
project, the personal journal was used only for personal process unrelated to the research. For several months I practiced switching back and forth between my personal journal and the field notes and eventually found the separation less awkward than at first. I carried two small spiral notepads of different sizes for journal and field notes at all times. As these filled up, I tore apart the little notebooks and stapled the pages into a larger notebook for later transcription.

Four categories of field notes were initiated (contextual, methodological, personal, and analytic), as advised by Rodgers and Cowles (1993). To avoid blocking the flow of recording, no effort was made to separate these categories until coding after transcription as described below. After each interview, field notes were made using categories recommended by Hall (1994), including non-verbal communication, power dynamics, rapport, the interviewer's emotional response, the participant's emotional response, the flow of events, comparison to previous interviews, and the setting.

Key informants

Two individuals served as key informants for this study. Key informants are known leaders in a community whose experience adds focus and depth to the researcher's interaction with community members. The first key informant was a prominent lesbian physician activist in Boston who has also been a close personal friend for the past twenty-five years. She is a bereaved survivor after the death of her lesbian partner in 1981. She was interviewed by telephone before the study began. She was asked for her ideas about the research project, for suggestions for probe questions, and for advice on potentials pitfalls for participants and for the researcher. In follow-up
correspondence and e-mail, she was asked about her perceptions of narratives emerging from the data analysis.

The second key informant was the founder of an east coast organization for lesbians with cancer. She is the surviving partner of a personal friend who died in 1989. Ideas for the research were discussed with her before the proposal was developed, and progress reviewed with her at the fifth anniversary dinner of the organization in 1995.

Artifacts

Community artifacts related to lesbian bereavement were collected during the study. These included first hand accounts (Givens & Fortier, 1992; St. Pierre, 1992; Moran, 1992; Murphy, 1992; Bulter, 1989; Corrine, 1986), obituaries in lesbian and mainstream publications (Klaich, 1991), novels (Lindau, 1989; Donohue, 1995), poetry, and music (Small, 1990; McCalla, 1992). Other artifacts included programs from funeral and memorial services and death certificates. Observations about the death certificates were included in the discussion of demographic data. An in-depth analysis of the other artifacts was beyond the scope of the study, but they provide rich primary sources for later work in this field.

Interviewing community members

Interviews were conducted with self-selected individuals who identified themselves as a bereaved lesbian survivor after the death of a lesbian woman. Survivors of each death included "permanent" or current partners (also called lovers, spouses, or significant others), ex-lovers, or close friends of the deceased.
Survivors after the death of a lesbian woman may also include individuals legally related to the deceased. These include parents, siblings, children and sometimes former husbands. Because of practical limitations of scope and size, these individuals were not included in the present study. Other survivors like gay male friends or heterosexual coworkers who are "in the know" and say they are "as close as family" were also excluded because the focus of the study is on survivors who identify themselves as lesbian.

It is not possible to sample randomly from intentionally hidden populations (Adler, 1990; Weibel, 1990; Grund et al., 1991; Donovan, 1993) so all those interviewed in this study were necessarily self-selected. Previous research suggests that many people refuse to participate in bereavement research and that non-response rates are high when participants are selected from death records and obituaries (Gentry & Shulman, 1985; Stroebe & Stroebe, 1989-90). Jones (1985) who interviewed lesbian widows and Carter (1987) who interviewed a variety of bereaved individuals reported no difficulty locating participants by networking and word of mouth. Previous researchers in lesbian and gay communities have found participants eager to share their stories once trust has been established (Warren, 1977; Miller & Humphries, 1980). A goal of the study was to include participation that reflects the variety in race, class, religion, age, ethnic origin, and socioeconomic status which I have observed in the lesbian communities in Ohio.

Recruitment

As a participant observer I was initially aware of thirteen lesbian deaths in Ohio in which there were hidden lesbian survivors during the decade preceding the study. Several of these survivors had talked to me informally when first learning of the project. These friends and acquaintances were invited to participate in the study. I initiated a
Participant Record (see Appendix B) and sent an informal note to each when I was ready to begin data collection. I enclosed a copy of the Written Information for Participants (see Appendix D). Two agreed to be interviewed, and no attempt was made to follow-up with those who did not respond.

I continued to talk informally with friends and acquaintances about the research, and initially met all but two of the participants at social or community events. In discussions about the research, I included the content of the Oral Solicitation for Participants (see Appendix D), but several conversations about the study usually took place before the participants decided to be interviewed. I carried business-size cards (see Appendix E) with information about the study with me at all times and gave them to anyone who expressed interest, or who knew someone who might be eligible to participate.

Potential informants for interviews for the study were also recruited by advertising in Ohio, using outreach strategies to those which have been effective in recruiting gay male samples (Martin & Dean, 1990). Short ads were placed in Lesbian Health News (Appendix F) and The Word is Out (Appendix G). An article describing the study was published in the Stonewall Journal (Appendix H). In addition, I presented a workshop on the goals and preliminary findings of the study at the Ohio Lesbian Festival in 1995 (Appendix I) and posted signs there about the study (see Appendix J). I first met one participant at the workshop, and several acquaintances said they called for an interview after being reminded of the project when seeing the advertisements. One participant was referred by a lesbian therapist who had seen information about the study in a lesbian publication.
Informed consent

Each participant was given the "Written Information for Participants" (Appendix B) at the beginning of the interviewing process. After reviewing the form, the participant read a consent statement on to the audiotape at the beginning of both the in-person and the telephone interviews. The consent statement said: "the risks and benefits of this research have been discussed with me. I understand I am free to withdraw from this study at any time. I give my consent to participate."

The in-person interviews

Interview data were collected in two interviews which were both audiotaped (Spradley, 1979). The first interview was in person and concluded with a request for demographic and kinship information. The second interview, by telephone, took place 2-3 weeks later. The first three sets of interviews were viewed as practice to get feedback on the interview guide and to test my ability to cope with the emotional impact of the interview data (Cowles, 1988). As Zaharlick (1991) explained, the ethnographic pilot phase is not a separate study but rather a systematic attempt to determine what theoretical orientations and conceptualizations of phenomena are appropriate and useful, what data need to be collected, what collection tools and strategies are the most appropriate, what roles and relationships are appropriate for the researcher in the particular situation, and what analysis procedures will yield the desired information" (p.219). After consultation with the dissertation advisor, we concluded that, with the exception of hiring a different transcriptionist, no changes in the research procedures were needed. The first three
interviews were therefore included in the study, as part of the evolving ethnographic process.

Each in-person interview (see Appendix K) lasted 1-2 hours, and took place in the participant’s home, my home, or in one case, in a restaurant. The first question, “How has it been for you since your loved one died?” was inspired by the single question bereavement study by Carter (1987, 1989). Four probe questions were developed in consultation with the key informants: What kinds of experiences have you had with other people around ___’s death (other lesbian women, gay men, children, ___’s family of origin, health care providers, employer and co-workers, others)? What kinds of experiences have you had with ceremonies or commemorative events related to ___’s death? In what ways have your experiences around ___’s death been recognized or hidden from others? What would you want health care providers to understand about these experiences? A sixth question, “How has your physical health been since your loved one died?”, was added at the suggestion of one of the funding sources, the Lesbian Health Fund.

At the end of the interview, participants were asked for demographic and kinship information as described below. Many of the interviews were proceeded or followed by fifteen to sixty minutes of social time for trust-building or to establish the researcher’s lesbian credibility or to catch up on news with those I knew but had not seen recently. At the conclusion of the in-person interview, each participant was given a copy of my article “Older lesbian women” An invisible minority.” This article summarizes my master’s thesis research and was the first article about lesbian health issues published in the *Journal of Gerontological Nursing*.
Demographic data

Demographic data were collected at the end of the first interview (see Appendix L). Participants were asked for information about their own and their loved one's age, race, occupation, education, and ethnicity. Questions were also asked about the cause of death, time since death, length of the relationship, and previous experience with loss and death. A numerical scale from 0 to 10 was used to ask the participant about how close the relationship was, and about how self-disclosing the deceased and the participant have been about lesbian issues.

Kinship diagrams

Survivors were asked to draw their place in the kinship network of their loved one (see Appendix M). Gathering information on the kinship network of a deceased lesbian woman offered three challenges, since the person at the center of the network was herself unavailable to describe her "family of choice": Who knows (accurately) who else was in the network? How can the relationships be labeled? How can the information be quantified or summarized in a useful way?

Participants were asked to draw a free-form "family of choice for ______" to allow description of these networks in whatever form they were perceived. Participants were extremely shy about their drawing skills and one declined to draw the kinship network. For this study, the kinship diagrams were used only for illustration, to get an informal picture of the lesbian family or network. Comparison to more traditional genograms may be done at a later time (Richards et al, 1993; McGoldrick & Gerson, 1988).
Telephone follow-up interviews

Fourteen participants were interviewed a second time by telephone (see Appendix N). The purpose of the second interview was to clarify information for the researcher and to provide assessment and support related to the participant's response to the first interview (Swanson-Kaufman, 1986). Two participants did not respond to phone messages and a letter requesting a follow-up telephone interview. I frequently socialized with a third participant after the interview and therefore did not conduct a formal follow-up interview.

Sample Size

The question of when to stop data collection challenges any ethnographer for several reasons. First, the researcher herself continues to generate more data by maintaining her audit trail as she documents the analytic process in the field notes. Second, the participant observation process is rarely quantified, except in more limited spaces like classroom observation.

In this study, three efforts were made during analysis to capture this more elusive aspect of sample size. First, the number of field note entries were counted (n= 149). Second, a chronology of participation in community events was reconstructed from the field notes and calendars. Third, a descriptive summary was made from the “never-mind” folders of personal contacts with women who discussed participating in the interview part of the study but did not. These are described below in Chapter 4 (Findings).
The number of interviews or cases has traditionally been used to specify sample size. In this study, 17 survivors were interviewed once and 14 interviewed a second time after the deaths of 12 lesbian women. One survivor was interviewed per case, with two exceptions. After one death, two survivors who had not known each other well became friends, and both were interviewed for the study. In the second exception, five survivors in a caregiving group were interviewed individually after the death of their loved one.

Most qualitative researchers report stopping their research when they reach information redundancy or theoretical saturation (Finch & Mason, 1990; van Meter, 1990). In this study the participants were more verbal and less homogeneous than anticipated. They were also at least as emotionally distressed as anticipated. The decision to stop participant observation and interviewing was therefore made for practical reasons (Gerrnain, 1986), to stop heaping data; for personal reasons related to emotional saturation; for analytic reasons, to permit some depth in interpretation (Sandelowski, 1995b); and for philosophic reasons, to accept that what is known is always partial.

The last field notes were written in December 1996. Beginning in 1997, all new analytic and interpretive notes were considered rough drafts for the dissertation and included or discarded as deemed insightful. As a wise woman once said, “the difference between an artist and an amateur is that the artist knows where the wastebasket is.”

Data management and analysis

Managing ethnographic data requires attention to detail, careful management of materials, and continuous thinking (Knafl & Howard, 1984; Knafl & Webster, 1988). In ethnographic research, data analysis begins early in the investigative process, with the
researcher’s ongoing self-reflective observations and informal constant comparison
during data collection. Transcribed interviews were initially proofed for corrections and
a sense of the big picture. Sandelowski (1995a) recommends avoiding line-by-line
“empty coding”, and instead, first seeking an overview, “looking at your data to see what
to look for”.

After a trial of two computer programs, Ethnograph and Martin, and a review of
the literature on qualitative computer analysis (Agar, 1991; Siedel & Clark, 1984; Siedel,
1991), I decided not to pursue line by line computer coding. I decided instead to pursue
themes introduced in the literature review and identified as theoretical orientations
during discussion with committee members. In my opinion, much of the line-by-line
coding done in nursing research generates only Parse-like themes using words which end
in “ing”. These gerunds seem to imply new knowledge, but are not useful in cross-
cultural or clinical situations.

Transcription

The analysis began with the transcription of the hand-written field notes and the
interviews (Sandelowski, 1995a). These were transcribed professionally, with the
support of three grants obtained from the Mid-Ohio Nurses Association, the Women’s
Studies department at the Ohio State University, and the Lesbian Health Fund. By the
end of the study, the field note transcriptions produced 84 single-spaced typed pages, and
the combined in-person and telephone interview transcriptions produced 398 typed
single-spaced pages.
The verbatim transcripts were remarkably accurate. Inaudible sections were noted by parentheses, and pauses, as for example when the participant was crying, were noted by ellipses. In proofing the transcripts, two patterns became apparent. In the first pattern, the inaudible material was also inaudible to me. But in a second pattern, the transcriptionist did not recognize a term that I recognized immediately as cultural language. The transcriptionist was a heterosexual single mother and social worker by profession. She was extremely sensitive and supportive in her response to the interviews. Her lack of knowledge of the cultural references provided good clues in recognizing which terms were in fact cultural. Examples of these terms are discussed below in the cultural interpretation in Chapter Seven.

Summary charts

Five data summary charts were developed for structured comparison as the interviews continued. The outlines for these emerged in reviewing the first three interviews, as I tried to discover general patterns, identify theoretical orientations as described above in Zaharlick's description of the pilot phase, and select among the many possible directions for further analysis.

First, a demographic data summary was compiled for both the 12 deceased and the 17 survivors. Next, a summary of the responses to each of the six questions from the interview outline was made for each participant. A narrative theme summary inspired by Sandelowski (1995a) was made, specifying how the death happened, what were the immediate concerns, and what was the long range impact. An effort was made to capture the essence of each survivor's experience, as described in the section on survivors' narratives (Sandelowski, 1995a).
Two themes from the review of literature were evident in the experiences of the survivors. The first is Doka’s (1987) observations about disenfranchised grief. A yes-no summary was made of Doka’s five categories of experience commonly seen in disenfranchised grief: intense negative affect, exclusion from the care and support of the dying, lack of social support, exclusion from funeral rituals, and practical and legal difficulties.

Worden’s (1991) clinical observations about tasks of grieving and risk factors for complicated grief emerged as a second theme in the experiences of these survivors. Worden described survivors on a continuum of completing the tasks of grieving and having certain risk factors for complicated grieving. As described in the review of literature, Worden’s tasks of grieving include accepting the reality of the death, working through to the pain, adjusting to the environment, and emotionally relocating. Risk factors include who the person was, the nature of the attachment, the mode of death, historical antecedents, personality variables, social variables, and concurrent stresses. The data related to this theory was summarized using yes-no categories in an assessment checklist similar to a clinical acuity scale listing Worden’s tasks of grieving and risk factors for complicated grieving.

After the data summaries were completed, each was used as a guide in reviewing the transcripts for examples of the experience of interest. The cut and paste feature of Word for Windows proved sufficient for integrating interview and field note citations into the text of the dissertation.

During discussion of the findings with the committee, two additional issues emerged as areas of interest. The reports of physical health and illness were reviewed, and demographic questions about the age of the deceased and the incidence of suicide were considered.
A discussion of the descriptive findings of survivors' experiences follows in Chapter 4, 5, and 6. The five data summaries provided a path through what was increasingly perceived as heaped and overwhelming data. Field notes on the emerging analytic process continued to be maintained.

Coding field notes

The field notes were initially color-coded into the four categories proposed by Rogers and Cowles: contextual, methodological, analytical, and personal. There were many overlapping areas, and the conceptual distinctions between methodological decisions and emerging analytic insights were at times unclear. More problematical, the majority of the descriptive participant observation experiences did not fit well into either the personal or the contextual categories. The contextual category as envisioned by Rogers and Cowles specifically described participant observations during the interviewing process, not in a community context. The field notes were therefore re-coded with a fifth category for participant observation at community events. The participant observation, personal, and contextual sections were reviewed before beginning the description of findings. The methodological and analytic notes were reviewed with the dissertation advisor and included as needed in the revision of the methodological chapter, the description of findings, and the cultural interpretation.

Cultural Interpretation

After the interviews were completed, and the data summaries were completed, the transcripts of the field notes and interviews were reviewed a second time with an eye to
cultural language and cultural interpretation. The cultural interpretation of findings in this study is from the point of view of the researcher, based on my unique perspective as a participant member of my own community. I am anthropologist as author (Geertz, 1988), nurse as thinker, with the direction of my dissertation committee. In Chapter 7, I use the metaphor of four villages to discuss the ways variations within lesbian communities influence lesbian bereavement experiences. Geertz (1988) has argued that the goal of ethnographic texts is:

> to enlarge the possibility of intelligible discourse between people quite different from each other in interest, outlook, wealth, power, and yet contained in a world where, tumbled as they are into endless connection, it is increasingly difficult to get out of each other's way (p.147).

**Precautions**

The dissertation proposal was submitted to Human Subjects and approved in May 1994. Protection of the privacy of lesbian informants in this study was required for their sense of safety and willingness to share information in what may be perceived to be a hostile environment. The reputation of the researcher as a discrete and reliable lesbian woman may have been as important to the success of the study as any written guarantees of confidentiality. Informed consent was obtained as described above by the participant reading the consent at the beginning of each audiotaped in-person and telephone interview.

Bereaved informants are also especially vulnerable. Precautions to protect bereaved informants included a non-intrusive selection process, referrals to counseling if requested, and a commitment to share results with informants if requested. One
participant was referred for counseling in the telephone interview. Five participants were given copies of their tapes and transcripts at their request.

Participants were offered the option of selecting the pseudonyms for themselves and their loved ones. Two participants requested to use their real names, which I declined. Other lesbian researchers have noted a similar preference, from participants protesting the invisibility of lesbian women (Kennedy & Davis, 1993). All names used in the study are pseudonyms. In the description of findings, slight changes in demographic information were made in consultation with the committee to assure confidentiality.

Limitations

The information in this study was captured at a point in time in Ohio and cannot be generalized to other times and other communities. The intent of the study was neither to measure objective data, nor to construct a theory for bereavement intervention in lesbian communities. The intent was rather to learn about the experiences of informants in order to sensitize health care professionals to what is not known, and to stimulate a desire to know more.

Summary

In summary, an emergent ethnographic design was used to learn more about who are the bereaved survivors when a lesbian woman dies, what are the experiences of these survivors in lesbian communities in Ohio, and what aspects of lesbian culture are evident in the bereavement experiences of these survivors. The design included participant observation, field notes, key informants, artifacts, audiotaped in-person and telephone
interviews, demographic data, and kinship network diagrams. Field notes included contextual, methodological, personal self-reflection, analytical information, and a description of participant observation experiences. Seventeen self-identified survivors were located by networking and advertising in Ohio, and interviewed first in person and then for follow-up by telephone. Data were analyzed using field note coding and data summary charts for themes which emerged from the literature and the experiences of survivors. Data interpretation included a discussion of the influence of cultural variations within lesbian communities on lesbian bereavement experiences.
CHAPTER 4

FINDINGS: THE COMMUNITY

Introduction

In this chapter, I will present the findings about the lesbian community in Ohio which emerged from participant observation, providing the context in which to answer the first two research questions: Who are the bereaved lesbian survivors when a lesbian woman dies? What are the experiences of these survivors? This chapter includes a reflexive summary, an activity summary of annual community events, and a discussion about the community members who expressed interest in the study but were not interviewed.

Participant observation activities: Reflexive discussion

Schwartz (1996) mused about the discipline of anthropology in a recent essay called "Ruined by Reading." "What," she asked, "is anthropology... the enterprise itself, not the exotic data, since ordinary urban life provides enough exotic data. How do you approach the study of 'man' or 'culture'? How do you tilt your head, what angle of
vision? I read enough to find out how the discipline works, which is by accumulation and accretion, making a mosaic. You gather enough pieces, then step back and look” (p.2).

As a researcher in my own community, the participant observation process meant stepping back and looking at the familiar and exotic data of my own ordinary urban life with greater intention, detachment, and commitment than usual. During seven years, I attended annual community events not only for fun and support, but with an eye and an ear open for bereavement narratives and for potential interviewees. Some days, participant observation meant saving my mail as artifacts of a culture unfamiliar to my nursing colleagues. Despite my delight in the privilege of hearing and telling the often hidden stories of my community friends and acquaintances, the researcher role complicated daily life in unforeseen ways.

Nurse researchers have described their struggle to balance the roles of researcher and clinician, especially when interviewing vulnerable individuals (Janken & Cavalari, 1978). In this research, I had two additional roles, as community member, where I need community support to survive, and as friend, with expectations of mutuality and openness. Balancing these four roles has challenged my energy, my perceptions, and, no doubt, my efforts at wisdom. Balancing these four roles also raises somewhat more complex ethical questions than those so carefully delineated for the protection of participants in quantitative studies (Ramos, 1989). For example, in December 1996, I saw and spoke to seven of the 17 women I had interviewed at Wintervisions, the annual winter lesbian craft fair. Three weeks later, four of the 17 participants attended a party
at my home. To my knowledge, none of these women knew the others were participants in my study, and none of the other guests were aware of the multiple roles complicating these friendships. Confidentiality concerns have served to isolate me and to prohibit me from participating fully or naturally in the community I am observing. Of the 17 women interviewed, eleven (64%) were unknown to me at the beginning of the study. Miller and Humphries (1990) encouraged investigators in stigmatized populations to maintain contact with participants after the research project is completed. By the end of the study, I had some ongoing community or personal contact with all but two (11%) of the interviewees. Several expressed ongoing opinions about my analysis, which added to the interpretive process the challenge of having several audiences. The reflexive statement in Appendix A includes some of my personal perceptions and opinions from my journal and field notes related to the study.

Participant observation: Activity summary

In 1997 in Ohio, there is an elaborate array of community events, businesses, publications, clubs, and informal social and kinship networks which constitute a lesbian community. Table 4.1 summarizes my participation in annual public community events and major social gatherings between 1990 and 1997. Sign language interpreting and disability access are provided at all these events.
<table>
<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>Community Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>June</td>
<td>Gay Pride March</td>
</tr>
<tr>
<td></td>
<td>July</td>
<td>Meeting with key informant in Washington DC</td>
</tr>
<tr>
<td></td>
<td>December</td>
<td>Wintervisions</td>
</tr>
<tr>
<td>1991</td>
<td>June</td>
<td>Gay Pride March</td>
</tr>
<tr>
<td></td>
<td>September</td>
<td>Ohio Lesbian Festival</td>
</tr>
<tr>
<td></td>
<td>December</td>
<td>Wintervisions</td>
</tr>
<tr>
<td>1992</td>
<td>June</td>
<td>Gay Pride March</td>
</tr>
<tr>
<td></td>
<td>October</td>
<td>Telephone interview with key informant in Boston</td>
</tr>
<tr>
<td></td>
<td>December</td>
<td>Lesbian wedding, northern Ohio</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wintervisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Teddy Bear Show</td>
</tr>
<tr>
<td>1993</td>
<td>June</td>
<td>Gay Pride March</td>
</tr>
<tr>
<td></td>
<td>September</td>
<td>Ohio Lesbian Festival</td>
</tr>
<tr>
<td></td>
<td>December</td>
<td>Wintervisions</td>
</tr>
<tr>
<td>1994</td>
<td>June</td>
<td>Gay Pride March</td>
</tr>
<tr>
<td></td>
<td>September</td>
<td>To Washington, DC to Mautner Project</td>
</tr>
<tr>
<td></td>
<td>December</td>
<td>Wintervisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Teddy Bear Show</td>
</tr>
<tr>
<td>1995</td>
<td>January</td>
<td>Mr. Ohio Valley Leather Contest</td>
</tr>
<tr>
<td></td>
<td>May</td>
<td>Ms. Ohio Valley Leather Contest</td>
</tr>
<tr>
<td></td>
<td>June</td>
<td>Gay Pride March</td>
</tr>
<tr>
<td></td>
<td>September</td>
<td>Ohio Lesbian Festival</td>
</tr>
<tr>
<td></td>
<td>December</td>
<td>Wintervisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Teddy Bear Show</td>
</tr>
<tr>
<td>1996</td>
<td>January</td>
<td>Funeral for Virginia</td>
</tr>
<tr>
<td></td>
<td>May</td>
<td>Mr. Ohio Valley Leather Contest</td>
</tr>
<tr>
<td></td>
<td>June</td>
<td>Funeral for Sandra</td>
</tr>
<tr>
<td></td>
<td>December</td>
<td>Gay Pride March</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Wintervisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Teddy Bear Show</td>
</tr>
<tr>
<td>1997</td>
<td>January</td>
<td>Mr. Ohio Valley Leather Contest</td>
</tr>
</tbody>
</table>

Table 4.1. Participant observation community event summary, 1990-97
The annual Gay Pride March in June commemorates what is called the Stonewall Rebellion. In 1969, patrons of a bar called Stonewall in New York City fought back against a police raid and thereby sparked a national movement of gay and lesbian self-affirmation and self-disclosure. The local march is sponsored by Stonewall Union, a gay/lesbian advocacy group. It draws a crowd of 3-6,000 and features speakers, performers, and booths for food, crafts, and politics.

The Ohio Lesbian Festival takes place on a farm in central Ohio each September. This event is for women and children only, and is modeled on the larger Women’s Music Festival that has been held in western Michigan every August for more than twenty years. The one-day Ohio gathering draws up to 2000 women from Ohio and neighboring states, and features music, workshops, craft sales, and activities for children.

Wintervisions is a lesbian craft fair held annually before the winter holidays. The craft and information fair is followed by a lesbian dance in the evening. Entertainment is provided, and awards given for service to the lesbian community. Usual attendance is 1000-2000 during the day, and the recent fairs have been open to the public. Both Wintervisions and the Ohio Lesbian Festival are sponsored by an organization called the Lesbian Business Association.

The Teddy Bear Show is a drag show sponsored annually by one of the local men’s leather clubs as a fund-raiser for children’s and AIDS organizations. The show typically raises $3,4000 for these groups. The participants and audience are primarily male and transgendered, with a few loyal and well-loved lesbian women involved.
The Ohio Valley Leather competitions are sponsored by local production companies or leather clubs. Contestants vie for the title of Ms. or Mr. Ohio Valley Leather in categories for appearance, clothing, and speaking ability, and go on to participate in similar national and international competitions.

In addition to attending these events with and in search of interviewees, I also continued my usual attendance at more private lesbian and gay social gatherings. These included informal parties, lesbian ballroom dance lessons, pot luck suppers, and First Fridays (a monthly “Oldies” dance evening at one of the lesbian bars), performances of the Women’s and the Gay Men’s Choruses, and meetings of the over-fifty gay/lesbian club.

In 1996 I attended two funerals of lesbian friends. The first was for Virginia, a 33-year old friend known to me from her long-time community activism and more recently from private parties. Her funeral was held in the Italian neighborhood where she had grown up, and was a remarkable, loving interaction between her family of origin and her culturally-diverse gay and lesbian friends. The service used Native American spirituality as its base, and was conducted by Virginia’s friends in the parlor of the funeral home across the street from Virginia’s home. Virginia’s surviving partner is included in the study.

The second funeral was for Sandra, who died of lung cancer at age 43. She had been cared for during the several months before her death by a primarily lesbian caregiving group of twenty-six women. Five of these women were interviewed for the study. The memorial service for Sandra was held in a gay-friendly Unitarian church two
weeks after her death. Sandra’s friends took turns speaking, and her dog sat quietly with her surviving partner at the front of the sanctuary. Sandra’s family of origin had been supportive of her caregiving group before her death, but did not attend the memorial service.

**Participant observation: Non-interviews**

Stroebe and Stroebe (1989-90) describe the difficulty obtaining participants for bereavement studies. During the research process, I did not perceive that I had great difficulty finding women willing to be interviewed. As I began analysis, however, I was struck both by the size of the “never-mind” pile of folders and also by the length of time between my initial discussions and eventual formal interviews. The time between the first contact to discuss the research and the in-person interview ranged from two weeks to 78 weeks with a mean of 25 weeks, or approximately six months.

When I first proposed the study, I knew of 13 potential participants surviving 13 lesbian deaths in Ohio between 1984 and 1992. Eleven of the survivors were acquaintances and two were identified from obituaries in Ohio lesbian publications. Two of the 13 agreed to be interviewed and were included in the study. No effort was made to encourage reluctant participants, and as a result all of the reasons for non-participation are not known.

Some of the community members who were not interviewed did, however, share information about their hesitancy to participate. One of the original 13 potential
participants who did not respond to my note attended a workshop I gave on lesbian bereavement three years later. Afterwards she spoke privately to me and said the topic was "too painful to reopen." Another promised to call me each of several times she saw me at community events, but did not. I located a friend of one of the 13 potential participants and learned that the survivor herself had died of lung cancer less than two years after her partner’s death. Another potential participant whom I knew fairly well discussed her grief with me informally on several occasions but could not schedule an interview because of multiple responsibilities of work, graduate school, coparenting, and caring for elderly parents.

During the course of the research I also met 9 women who initially expressed interest in participating but did not. A friend-survivor of Virginia called to cancel our scheduled appointment. She said, “my stomach is upset and tells me I am not ready to talk about this.” I offered support for her self-awareness and encouraged her to call at a later time, but she did not. In two cases, I had to cancel scheduled appointments due to my health problems. When I called to reschedule, I repeatedly got answering machines with no return call in response to messages. After leaving three messages, no further effort was made to encourage participation. Three other women lived some distance away, and I did not pursue appointments for health reasons.

In addition, two of the participants I eventually interviewed completely forgot their initial scheduled appointment. Both are usually compulsively reliable and were very embarrassed by their forgetfulness. In all cases, I taught briefly about grief normalcy, and made no effort to encourage those hesitant to participate.
In summary, several community members (n=20) discussed their grieving experiences with me informally, but did not participate in a formal interview. Efforts to identify survivors after the death of a lesbian woman may therefore be constrained by the hesitancy of grieving survivors to participate in similar research projects. In the next chapter, I will discuss demographic information about those community members who were interviewed for the study.
CHAPTER 5

FINDINGS: DEMOGRAPHIC DATA

Introduction

Lesbian women are presumed heterosexual in medical records, death certificates, and obituaries. Little is known, therefore, about the incidence of illness and causes of death in lesbian women. In this chapter, I will report the demographic findings on the death and the survivors in the study to provide initial answers to the first research question: Who are the bereaved survivors when a lesbian woman dies?

Demographic data: The deaths

Demographic data about the deceased women (n=12) were gathered from the survivors at the end of the in-person interview. The age of the women who died ranged from 27 to 68 with a mean age of 44. Eleven of the deceased were white and one Hispanic. By occupation 3 (25%) were teachers, 2 (16%) were artists, 2 (16%) were health care professionals, 2 (16%) worked in government or the military, one (8%) worked in sales, one (8%) worked as a housepainter, and one (8%) was disabled. The
time since death ranged from 10 days to 10 years, with one death less than a month before, two less than a year before, seven 2-3 years before, and two more that 6 years before the interview (see Table 5.1)

<table>
<thead>
<tr>
<th>Age</th>
<th>Range: 27 to 68</th>
<th>Mean: 44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>Caucasian n=11</td>
<td>Hispanic n=1</td>
</tr>
<tr>
<td>Occupation</td>
<td>Teacher n=3</td>
<td>Artist n=2</td>
</tr>
<tr>
<td></td>
<td>Health Care n=2</td>
<td>Sales n=1</td>
</tr>
<tr>
<td></td>
<td>Housepainter n=1</td>
<td>Disabled n=1</td>
</tr>
<tr>
<td>Cause of death</td>
<td>Cancer n=5</td>
<td>Auto accident n=2</td>
</tr>
<tr>
<td></td>
<td>Cardiovascular n=2</td>
<td>Suicide n=2</td>
</tr>
<tr>
<td></td>
<td>Heart attack n=1</td>
<td></td>
</tr>
</tbody>
</table>

Table 5.1. Demographic data on the deaths (n=12)

The causes of death included cancer (n=5, 42%), auto accident (n=2, 17%), cerebrovascular disease (n=2, 17%), suicide (n=2, 17%), and heart attack (n=1, 8%). My community observations have noted similar causes of death in lesbian women. Before I began this study, I knew of 13 lesbian deaths in Ohio between 1984 and 1992. The
causes of death in these 13 situations were car accident (n=2), cancer (n=3), multiple sclerosis (n=1), suicide (n=1), accidental drug overdose (n=1), and not known (n=5). In nine obituaries of lesbian activists collected during the study, causes of death included breast cancer (n=4), suicide (n=2), AIDS (n=1), and not mentioned (n=2). Jones (1985) found in her study of lesbian bereavement that 12 of her 15 participants' partners died of cancer, and three of accidents. Jones excluded three volunteers whose partners died of suicide.

In Ohio the top five causes of death for white women ages 26-45 are cancer, accidents, heart disease, suicide, and homicide. For African-American women ages 26-45, the top five causes are cancer, heart disease, homicide, accidents, and cerebrovascular disease. For white women ages 45-65, the top five causes of death are cancer, heart disease, chronic obstructive pulmonary disease (COPD), cerebrovascular disease, and diabetes. For African-American women ages 46-65, the top five causes of death are cancer, heart disease, cerebrovascular disease, diabetes, and COPD (Rozansky, 1995, pp.15-19). Causes of death in this group are therefore typical for age and race in this locale, with no examples of death due to homicide, diabetes, or COPD.

Death certificates

Death certificates were obtained for 6 of the 12 deaths in the study. The category for surviving spouse was blank or marked “N/A” or “none” for all six. Marital status was
marked "never married" for four, and "divorced" for two. In one case where I interviewed a surviving friend, the surviving partner was included as an "informant". In another case, the surviving friend was herself listed as "informant" because she had been the official power of attorney. Informants in other cases were the father or mother. Based on this small sample, death certificates would probably not be useful in identifying bereaved survivors after the death of a lesbian woman.

**Demographic data: The survivors**

Demographic data about the survivors was gathered at the end in the first interview. The age range of survivors (n=17) ranged from 33 to 59 with a mean of 45 (see Table 5.2). Eight survivors identified as the surviving partner, two as surviving ex-lovers, and seven as the surviving friend. The distinction between ex-lover and friend was not reliable, however, as several women reported either sexual experience, affairs, or romance with their loved one but quite vehemently labeled themselves as friends. Fifteen of the survivors were white, one was Native American, and one was African American. By occupation 3 (18%) were teachers, 3 (18%) were health care professionals, 2 (12%) worked in sales, 2 (18%) in law, 1 (6%) in computer programming, and 1 (6%) in social service, two (12%) were disabled, 2 (12%) unemployed, and one (6%) retired.
In this study, the relative youth of the loved ones at time of death (mean=44) is noticeable. The average life expectancy for Caucasian American women is 76, and the typical age of heterosexual widowhood is over fifty, despite the younger ages at which
men die. Suicide and accidents are both higher risk causes of death in younger women and may account in part for the low age of death in this study.

Suicide in gay and lesbian people has been a controversial topic, as explained by Rofes (1983) in his book entitled, "I thought people like that killed themselves". The medical profession at one time considered self-destructiveness an inevitable part of "homosexual pathology". In reaction, gay and lesbian advocates who were defending their mental health and happiness at first denied the impact of societal oppression in contributing to suicide in the community. Bradford and Ryan (1988) reported a high incidence of suicide attempts in the first national lesbian health survey (16% whites, 27% blacks, 28% latinas). Further study is needed to determine how suicide is related to age of coming out, family and regional homophobia, and other measures of physical and mental health. Research on chronic stress (Kiecolt-Glaser & Glaser, 1995) would be relevant for lesbian women in general and for lesbian caregivers for ill loved ones.

Because so little is known about lesbian death, little can be concluded about risks for widowing among lesbian survivors. The relative youth of the survivors (mean=45) may be a factor of self-selection and friendship with the investigator. My age is 52, but most of my lesbian friends and acquaintances are younger. In Ohio older lesbian women have tended to be more private and isolated. I met two of the oldest participants at the over-fifty gay/lesbian club, which is a new and much needed organization in central Ohio.
The majority of participants in the study would not be recognized as lesbian by their physical appearance or their mannerisms. The survivors in this study in many ways appear to be just ordinary folk, working in a variety of jobs, loving their loved ones as long as possible. In the following chapter, I will share the narratives of their bereavement experiences, and discuss some of the patterns in the experiences they share.
CHAPTER 6

FINDINGS: EXPERIENCES

Introduction

In this chapter, I will discuss the experiences reported by the participants in the study. I will begin with a narrative summary of the experiences of survivors after each of the twelve deaths to answer the questions about who are the survivors and what are their experiences during bereavement. Then I will discuss in more general terms three emergent themes of disenfranchised grief, risks for complicated grieving, and health considerations.

Kate and Amanda

Kate was a small town schoolteacher who died of a brain tumor at age 49 after a three year illness. Her survivor, Amanda is a retired schoolteacher and was interviewed eight years after Kate’s death. Kate and Amanda had lived together 24 years and raised three
children together. Amanda said, "initially it was like I had lost half of myself" and said she felt "very alone." Amanda reported that she:

chose to isolate myself afterwards. The hospice woman who came to talk to the whole family about how to deal with dying and so forth to follow up, invited me to come to meetings and I didn't go. I chose not to go and I didn't go because I didn't want to air our relationship in the meeting. I felt intimidated because I knew of the one couple that was there who were an extremely straight couple that I taught with. I didn't want to talk about my feelings and the depth of my feelings with them there (INT4-7).

Amanda said the hardest part of the process was acting on the decision she and Kate had made about the dying process:

the other thing that I think was real hard, is even though she and I had discussed many times that she did not want to be kept alive, when it was time she wanted to die. Well, when it came time to see whether or not I wanted fluids administered, it seemed almost cruel not to. On the other hand, I said what benefit is there and she [the hospice nurse] said, "she will stay alive longer'. I said no. But that was the, and by that point she couldn't swallow and a lot of things, but that was the thing that haunted me after she died. I knew it was what she wanted. I knew if I'd been in her place that is what I would have wanted. I knew all of that cognitively, but it was the hardest thing I have ever done. Just that little piece. (INT4-9).

Amanda said she and Kate could not have survived without being able to laugh:

We used to sit in the kitchen every morning. Some mornings we cried and some mornings we laughed and some mornings we did both. After we talked about this for awhile she would say, okay, okay, okay. She was done talking about it and it was time to get on with the day. One day we were talking about it and I don't know how this got started, this was while she could still talk, I guess. She decided that she wanted to be buried in a Mickey Mouse sweatshirt. So we just took off with it. Yeah, the pallbearers could sing M-I-C-K-E-Y M-O-U-S-E. We just kind of went with that, we had it all planned and it got to be a big thing. That afternoon the teachers came to visit. I thought it was funny and I shared it. They were just, Oh, don't even say that. They didn't want to hear this part of it, they didn't think it was funny at all. In things like that we were in a different place and we both had a sense of humor and that it the only way I could have gotten through it and I think that was the only way she could have gotten through it (INT4-11,12).
BJ and Joyce

BJ died of cancer at age 68 after a nine month illness three years before the interview. She is survived by her “business partner”, Joyce, now age 48. BJ and Joyce had a 23-year marriage-like relationship and were in business together. They raised two nieces and cared for Joyce’s aging parents. They had a few lesbian couple friends who isolated Joyce after BJ’s death because of concern that her single status threatened their coupled socializing. BJ never spoke openly about gay issues. She used harsh names for Joyce so the children would not suspect the true nature of the relationship. BJ told Joyce she loved her for only the third time just before she died. Despite BJ’s reticence on lesbian issues, the hospice nurse recognized the relationship. Joyce explained:

see, I had hospice. I didn't know any way to let them know because BJ didn't speak the words, of what our relationship was. They may have assumed, but they have to make (inaudible ) and it wasn't until almost a week before, the one nurse came in and said it's obvious that you and BJ are gay and it's fine with me. If you want to talk. It was like almost too late. It was like why didn't you let me know you knew when I could talk before that. If sometimes somebody comes out and tells them, I understand your relationship and I know what you are grieving and what you are going through more than, it's not just your friend, it's not just your roommate. That's one of the things...was it your business partner, your friend, your roommate, it's like well, there's no real deep relationship here, so it wasn't like till a week before the hospice nurse came out and said, I understand. I looked at her and said, you do? I said, I've never spoken it. She said, (inaudible). I felt like maybe if I had felt like they had known before it would have helped (INT5-19).
The week before BJ’s death, Joyce’s brother died, and her aunt’s home on the adjoining property burned. Joyce says only her feeling responsible for her cats and dogs kept her from “bailing out.” She is now in a new relationship with a 34 year old woman who says she has been in love with Joyce since she first met her when she was 21. They are more open now about lesbian issues, and their straight coworkers now tell Joyce how worried they were after BJ died, but didn’t know what to say. Joyce said:

and I already had enough going on at least as far as emotional, and I didn't need more rejection from outside people. I think that too I was afraid to discuss my feelings with people I knew at work, I was afraid to be rejected because they knew I was gay. I was fighting those two feelings and then afterwards I found out how they wanted to be supportive but didn't know how because I wasn't open (INT5-20).

Suzanne and Belinda

At age 52, Suzanne had just started a new business after being downsized from a 23-year government position. Belinda, her surviving partner of 23 years, was interviewed ten months after Suzanne’s death. Belinda described what happened: “she was fine, she had a stroke on Tuesday morning and she passed away on Thursday.” By chance Belinda had not gone to work on schedule the morning Suzanne’s symptoms started. Belinda said:

When I called the emergency squad, when I dialed 911 she looked at me and said, no, no. I actually hung up the phone because I thought she had a leg cramp or something and when I looked at her again I thought, this is crazy, I know exactly what it is, and I called her back, in fact I had to call back twice and the second time I told them that it was a stroke (INT8-2). Suzanne was not able to speak at all. Belinda said she and the doctors were trying to make a decision about resuscitation when Suzanne coded and died. Suzanne and Belinda
had arranged all their legal papers in advance. Suzanne’s only other family, her parents, were too ill to protest or to attend the funeral which Belinda arranged.

Belinda described how the physician recognized the relationship:

INT8: From the time we got there real early in the morning, through the day, it was just kind of, well she was in the emergency room waiting to be admitted and that was almost like business. When the doctor got there at 5:00 in the evening, we were outside the room and he was talking to us and there was a lot of people there because my sister was there and my nephew had come up and Suzanne's real close friends had already gotten there and everything and the doctor wanted to know how we were related and I said we were roommates. He said how long? When I told him how long it had been, he said, then I am going to assume that it's just more than just roommates. Well what he didn't know was that I wasn't out with my sister.

SD: And she was standing there?

INT8: Yes, and my nephew. I said, no, we were just roommates. When we went into the room he apologized and I kind of told him he didn't have to apologize because he was right, the only thing is, they didn't know. From that point forward he took care of me, let me stay in the room at night and gave me kind of the same privileges that I think he would have, you know.

Reminiscing, Belinda described meeting Suzanne when she was 19:

INT8: We met bowling. At the bowling alley. The minute I met Suzanne I knew, and back then I didn't even know, you know I just knew. I can't even explain it. I knew that she was the person, that was it, and it happened. You know it was a great relationship, she was a great person. We were so opposite. We always said that God put us together because we were. She was outgoing, she was a partier, you know, completely different than what I was. It was a good match.

SD: You said you knew she was the one but you didn't know, do you mean you had not thought that your match would be a woman, is that what you mean?

INT8: Oh, no. I had no idea back then. Absolutely not...

SD: No idea?

INT8: No, none. But the minute I met her I just knew. You know, I didn't understand it, but it's the only person I've ever felt that way about and she is the only person I've ever been with (INT8-22).
Marie and Judy

Marie died suddenly at age 48, from a ruptured aorta. Her surviving friend Judy was interviewed two and a half years later. Judy and Marie had been lovers when they first met twenty-five years ago, and were again lovers later during their long friendship. But Judy is adamant in labeling her relationship with Marie as her “very best friend.” She said:

Marie and I were very good friends, she was my very best friend. To have your best friend suddenly die like that without any warning one day, she is up and well and talking and the next day she is dead. I think it's almost worse than if you anticipate somebody dying. Still the end result is the same but I think that the effect is very much different. It is a big loss (INT12-3).

Judy said she was glad to avoid the trauma of the emergency room, where Randy, Marie’s lover who is discussed below, waited to find out what had happened. Judy reports there were several services for Marie:

INT12: Oh yeah, I went to the service, I went to the, I mean there were several services. There was one that the family had, there was a wake, there was a funeral service, a service that the community had.
SD: What was that like?
INT12: It was just a combination of friends and relatives. You know that just celebrate her life. That's basically just what it was. That was, I mean all of it was a part of the whole process of saying good-bye, but probably that...well it was all the service with the family and going to the house after the funeral, I mean that was all being part of the whole thing. I mean everything was part of it, the ritualistic stuff that people need to do to say good-bye and it was all a very important part.
Doris and Dana

Doris was a 27 year old teacher who committed suicide six years before I interviewed her surviving estranged lover, Dana. Doris and Dana, both deaf, worked together in a deaf education program in Northern Ohio. Both were active participants in the deaf gay/lesbian softball leagues. Three services were held for Doris, a regular funeral, a silent moment during a sports event, and a memorial tree service.

Doris and Dana had recently separated just before Doris’s suicide. Dana reports that she was extremely depressed and isolated for several years after Doris died in part because the deaf community blamed her for the death. The sign language interpreter confirmed that deaf custom encourages ex-lovers to be friends immediately to preserve harmony in an extremely small community. Doris had been desperately intrusive at Dana’s work and residence, and both had been in counseling to try to negotiate appropriate boundaries.

Dana’s mother, her love for her work, a psychiatric hospitalization, and counseling helped her survive the painful years. Dana also reports that she experienced a lot of hostility from other deaf lesbian couples:

I’ve seen people angry, but not only at me but also at Doris. There were several people who were angry at both of us. Especially gay couples. Folks that I played softball with, three of us became friends and we got to know each other more and more and more, and they knew Doris before they met me. I met them through Doris and through playing softball. Before Doris died we would always go out together and do things together, hang around, they would come over, we'd go over. After Doris died, they stopped. I would call them and they would ignore me. I would see that they were angry and it took them a year to finally realize that it was not my fault. It took them a long time (INT12-6).
Virginia and Irene

Virginia died of a heart attack at age 33 after a year on disability for cardiac and asthma problems. She was well known for years of political activism. Her surviving lover, Irene, was interviewed ten months after Virginia’s death. Irene had shared Virginia’s interest in politics and had served as president of the local gay rights organization. Irene still lives with her husband of many years, and she describes a close friendship between Virginia and her husband. The details of the relationship between Virginia and Irene were never discussed explicitly with Irene’s husband, but he was an active participant in Virginia’s funeral and has been very supportive since. Irene is chronically ill with lupus and said that she and Virginia made many of their decisions in the context of both having chronic and life-threatening illness.

Virginia and I, we went through a balancing act. When she didn't feel good I tried to take care of her and when I didn't feel good, she would take care of me. But both of us being so wounded, there was a whole lot that I couldn't do. There was no way I could clean up after her on a regular basis and there was no way she could do my housework on a regular basis, so even in our relationship, we knew in a way that we could never live together anyway, we could never do that (INT17-10).

Irene remembered being very open about her feelings for Virginia in public places:

We never tried to hide anything. We were open. We used to love kissing at Kroger stores and Big Bear. Isn't there a book or something that talks about kissing over frozen food? You know like these little lesbian novels? So we would try to kiss at all the supermarkets in the frozen food wherever we went (INT1712).
Priscilla is a 58 year old African American lesbian woman I first met when she attended the workshop on lesbian bereavement I gave in 1995. She had a rainbow flag sticker on her car parked in front of her house the warm spring Sunday I interviewed her two years after Sue’s death from cancer at age 55. When I asked Priscilla to describe what happened she said:

I was standing in line for chow. She came up there and bumped me on my nose twice and ran. I just ignored it. The next couple of days she did the same thing. Finally, I said, why do you do that? She said, oh, I'm just playing and I said, don't do that anymore. She left me alone for awhile and then one time she did it again. But then she ran, and then she didn't bother me anymore. This was at Ft. (inaudible) Georgia (INT7-1).

Priscilla described in great detail the first few weeks she knew Sue, when both were in the army 39 years ago. After a six month intense but non-sexual friendship, Priscilla and Sue went their separate ways.

Priscilla came out as a lesbian in 1987. She said that after being active in lesbian community events for several years, she realized that it was not just the lesbian community she had been looking for, but it was Sue that she wanted to find. She asked her sister if the FBI could look, and her sister said that was illegal. Then in 1993, she met a woman who worked as a private detective. Priscilla hired her to look for Sue. Two weeks later the private investigator called to say she had found Sue, but that she had died two years before.

In the time since, Priscilla has spent much of her time locating Sue’s friends and family. She said she had always kept a picture of Sue on her bureau and told her own family
and her former husband that was who she loved. She has visited the house where Sue was living and has found her grave. Having lived so long with just the memory of Sue, Priscilla has had difficulty accepting her death. She reported:

I needed to go out to that grave site by myself. I needed to do that, because I was hoping I couldn't find it and I would say to myself, well, I was wrong, she isn't here (TINT7-6).

Priscilla describes Sue as a life-long mental companion:

I was never lonely, even in the marriage that I was in. I was, somebody said, aren't you lonely? I said, no, I'm not lonely, because I had her, knowing that I was going to see her. I was going to be in touch with her, you know, even to, just the friendship. I knew it, I just knew it, but I was just too late. She understands, I know she understands (TINT7-7).

In the follow-up telephone interview I referred Priscilla for counseling because of my concerns about the intensity of her grief and preoccupation. She seemed more receptive and comforted, however, when I told her about my feelings and my experience:

SD: Well, I'm just thinking about you and think it's a tough, very tough situation. And you know, Priscilla, I don't know if I said to you, one of the reasons that I so much wanted you to be included in this project is I think how easily my own life experience could have gone that way. I really do... I think I am the kind of person that could easily like have walked away from those feelings, married because I was supposed to... I just know that I was supposed to be one of those women that had a station wagon and a bunch of kids and I feel like I had a close call. You know, that could easily have happened to me. I know the first woman that I loved was actually a teacher, so she probably was too old, or enough older for me that that would have complicated it. But I just always felt that I could so easily be in your situation, which is a number of years later looking back and wishing I would have done it differently. So, my heart just goes out to you. TINT7: Thank you (TINT7-9,10).
Martha and Anne

Martha died in 1984 in an automobile accident at the age of 31. Her surviving friend Anne was the first to be notified of the accident. When interviewed ten years later, she described the ordeal of identifying the mangled body, notifying friends, "de-dyking" the house, and arranging the community funeral. She also attended the family funeral in Martha's home town and was pleasantly surprised to be welcomed by Martha's mother:

I was very apprehensive about going to New York for the funeral because I knew that me showing up there would be like the sore thumb sticking out. Here was a stranger, a young woman, she must be from Cleveland, is this another lesbian? This is somebody to remind them of their daughter's lifestyle, a total different life than she had. I was very apprehensive about going and on the other hand, somebody had to go. Somebody had to go and I felt responsible and I wanted to, that it was me. So even though I had these fears of what people would think, especially her mother and family, I knew that this was the right thing to do and I needed to be there. I was just tickled when I finally came face to face with her mother who knew automatically who I was and the whole bit and her mother gave me a hug and then proceeded to tell me how glad she was I had come (INT2-7).

Martha had many stressors in her life just before her death and had said that she desperately needed to talk to Anne. Anne found Martha's journal, including a list of questions which seemed to be the last thing Martha wrote. The list identifies many of the questions lesbian women struggle with:

why do relationships break up? Does success equal longevity? Value of friendships, non sexual, lovers becoming friends, making our own families, community, how to be friends with ex-lovers, the future of the old lesbian, the panic, age, how your needs and expectations change with priorities, non monogamous situations, butch-femme roles, sex, separatists and other politics (INT2-14).

Like many survivor's when the circumstances of the death are unclear, Anne still has
many unanswered questions about Martha’s death:

Why did she have this car accident? Was she speeding, was she going too fast? Did she hydroplane, was there ice on the road, was there another car on the road that she needed to avoid for some reason? ... Was she shifting and something happened and she slipped and couldn’t control? Did she get a flat tire first which took her out and onto? Was there a car coming, was there a car that did something she had to avoid? Then the question is, was it suicide?

Anne hopes at some time to have a plaque put on a memorial tree at the Michigan Womyn’s Music Festival. Martha and Anne were both very open about lesbian issues, and Anne commented:

“if not out in life you will be in death”, whether it’s your parents going through photo albums, whether it’s a partner being there to fight for... possessions (INT2-20).

Paula and Pat

Paula was a 30 year old Hispanic lesbian woman who was killed while riding as a passenger in a head-on car crash caused by a new driver who was speeding and lost control. She was survived by Pat, her life-partner of five years who was interviewed two years after the death. Pat is a 42 year old disabled Native American. Paula was also Pat’s attendant to help with her physical disabilities. Both women were very active in the lesbian community. Pat describes attending a “horrible Catholic funeral” and a lovely Wiccan lesbian service before Paula’s body was sent to Puerto Rico for burial.

There were additional complicating factors in this death. Although Paula and Pat had completed advanced directive legal papers, a change in the law made them invalid, and they
had not had time to renew them. When Pat met Paula’s divorced parents, she learned that Paula had distorted many facts about her young life in Puerto Rico. She exaggerated her wealth, with elaborate documentation to support her lies. Pat was devastated, saying “not only did I lose my lover, I lost everything that I knew her to be, the person I needed her to be” (INT3-7). Pat explained the betrayal by saying “Paula created an alternative reality in which she could survive” (INT3-6).

Pat had many financial problems because they had made choices based on the myth of Paula’s wealth. Pat said she survived because of the support she received from lesbian friends and lesbian caregivers:

SD: How did you manage?
INT3: People in the community again. People making out a schedule coming in and doing in-services, learning how to give injections. Having a lesbian family practice doctor who was willing to work with the specialists and was willing to work with me. Having a lesbian therapist, having people who had known me in this community for years (INT3-10).

Jane and Ginger

Jane and Ginger knew each other from their mutual hometown in northern Ohio. They quarreled years before both moved to central Ohio. Ginger heard about Jane’s suicide at age 32 from a friend and was interviewed three years after the death. Ginger describes Jane as her “fearful friend” and “a hell of a ballplayer.” Ginger had been the softball coach on Jane’s team. She said Jane got increasingly hostile, intimidating, and blaming, refusing to play and refusing to leave the team. Ginger still grieves for “unfinished business” between them:
I feel like I had unfinished business with Jane. I wanted to tell her that her anger had nothing to do with me. I wanted to say that for a very long time and I couldn't because she died. I never expected her to commit suicide, I never thought she would...regardless of what she thought of me or what I thought of her, to me it's like whenever a lesbian dies, or women die, I feel like a part of my heart is chipped away, because I feel like we had unfinished business. I am trying my best in this lifetime to clean up my unfinished business with people, because my next lifetime I don't want to come back full of anger and hate and rage, I want to cleanse my soul. Even if you and I had a falling out, I would still want to talk with you about our falling out. Grief is grief, at least we know that we got it out (INT9-6,7)

Ginger also described her grief about the recent death of her cat:

I pray for her to rest in peace wherever she is. She helped me, both [cats] helped me deal with a lot these past nine years. They were with me when I got sober, they helped me through my incest issues, they helped me through my rape issues, they helped me through my rage, they have been there with me through my anger and they have been there with me when I was sick, they have been there with me when I needed a friend. They've just been there for me. I remember when I was really sick one time, they would go and eat, go to the bathroom and come back and lay on the bed, and repeat the process. Why can't I find a woman like that? (INT9-15)

Sandra and the caregiving group

Five of the lesbian women interviewed were caregivers for Sandra, who died of lung cancer at age 43. With the help of hospice nurses, the group of 26 women provided around the clock care for the three months before Sandra died. Gloria, Sandra's partner of two years, coordinated the meetings to plan the schedule, and the others marveled at her generosity in sharing Sandra with the others:

Gloria brought us all together as a very coordinated group of supportive women who were very, very dedicated to Sandra and to one another to take care of this woman and carry all of us through this experience (INT11-10).
Grace was Sandra's former lover of seven years and was interviewed between Sandra’s death and the memorial service. Gloria and Grace clarified their potentially conflicting roles of lover and ex-lover with the hospice nurse. Grace said:

I remember when the first hospice visit they came and sat with Gloria and I and talked to us about how this was and how we were going to do this and I was just very honest. I said, I am really scared. I really want to be here but I am scared because I don't know how I fit. I don't know what my relationship is to you, Gloria, I don't know how you feel about my being here, and I cried. I think just my being able to be honest about that, Gloria just opened her arms to me. She said that she really respected and appreciated that I was that honest and that she really wanted and needed my support and Sandra really wanted and needed my support (INT1-11).

Christine was a close friend of Sandra's for nine years and was the legal power of attorney in the caregiving group. Sandra had made clear arrangements to leave her house and life insurance to her partner Gloria. Christine recalled:

INT13: The morning after Sandra died her sister called at Sandra's house and wanted to talk to me and I wasn't there. When I got there I called her back and she wanted to know when she would be getting the money.
SD: That's how she phrased it, when will I be getting the money?
INT13: Yes. Needless to say I was flabbergasted. I had no idea what she was talking about. She thinks that Gloria and I are in cahoots together and that we coerced Sandra during her confusion with her brain tumor to leave this money to Gloria and that Gloria and I were going to share it and it's a mess. It's sad because it's kind of put a damper on all the beautiful, loving care that went on there at the house and getting along with the family. The family seemed to be so grateful to us for taking care of Sandra, because they had just lost their mother in December, five months previously, and they had lost a brother to cancer two years previously. They seemed to be very grateful to us for all we were doing and then this just hit the day after. They won't speak to us and they didn't come to the service. They had no service for their sister or their daughter, which is amazing to me that if they are mad at us and couldn't come to ours, they didn't even have their own. Anyhow, that was just kind of a shocking thing the day after Sandra died. Plus they showed up at the house and wanted their stuff immediately, that day (INT13-5).
Stephanie was another longtime friend of Sandra’s. As one of the two nurses in the caregiving group, Stephanie helped the others learn caregiving skills, and cooked dinners for the group. Stephanie was the executor and had to deal with financial details. She expressed strong anger, describing her contact with a bank about one of Sandra’s credit cards:

Finally I got this poor receptionist and I said who I was and she said, I am sorry that gentleman is not available right now. would you like to speak to his voice mail? I got to tell you, I said, this is not an easy situation and I can't imagine what people do who lose people suddenly, when they've got no...oh my gosh, how they deal with that kind of stuff then, because I wanted to go ballistic because they gave me a voice mail for the deceased benefits office, you know. It felt so impersonal and so cold, and it's like, how can you treat this thing impersonally and cold. I want to say, this is Sandra! (INT16-6)

Stephanie expressed the pride of all the group at overcoming their fears of caregiving:

I got real nervous and real scared around January or February and was afraid that I wouldn't be able to be there for her when it really got bad. I don't know where that fear came from but I remember after she died feeling so grateful that I had been able to walk that walk all the way through because...I don't know why, but there was this part of me that was so afraid that I wouldn't be able to do it (INT16-11).

The fifth caregiver interviewed was Sally, who described herself as Sandra’s “dearly trusted friend” for 16 years. Sally met Sandra at age 19 when she was first trying to find other women who were lesbian. A male friend had told Sally the Women Against Rape organization was “full of a bunch of queers.” Sally went to volunteer. She remembers:

So I remembered looking at the one woman and I thought, is she a lesbian, and I looked at Sandra and thought, is she a lesbian, you know I was like. wow, you know. Then I realized that I had hit like the jackpot (INT14-14).

Sally later took Sandra to her first 12-step meeting. Sally felt unrecognized by others in the group in some ways:
I think it's been harder for me to express how important Sandra is to me even to my friends, my lesbian friends. Like I mean I tell stories, you know and some of the time I wanted to go like, I've known Sandra longer than anyone else. I'm the one that's known her the longest. That's what I want to do, part of me wants to do that. I don't know why. I don't think that I should stick out any more than anybody else and we all had different in the same sorts of gifts that we brought and gave to her (INT14-20).

Most of the caregivers stayed at Sandra's side during the last 48 hours of her life. Several had what they called a wake during the night before she died, bathing and talking to her about letting go. After she died, five of the caregivers washed her again and dressed her in her most colorful clothes. The entire group took pictures of themselves with Sandra's body before she was picked up and taken to the local medical school where her body was donated for research.

Alice and Jamie

Alice died at age 61 of breast cancer after a three year illness. Jamie, a 36 year old elementary school teacher, was interviewed two years after Alice's death. Alice was Jamie’s first lesbian lover, when Alice was 50 and Jamie was 25. Such a "winter-spring" age spread is not uncommon in lesbian relationships. Jamie heard about the death from a childhood friend and returned to her hometown for the funeral. She went alone to the funeral and said it was difficult because she had no closure and no one to talk to. She had no contact with Alice’s surviving partner. Jamie had her own ceremony for Alice by the lake. Jamie keeps a little bear, a gift from Alice, on her desk at school as a daily reminder of her. Jamie’s grief is complicated by the deaths of several of her male friends from AIDS. She said:
What also made it very difficult was not so much that I was burying her but that I also had buried two of my boys that same summer. In fact, I had in a four week period, I had three funerals that I attended. I think that made the impact so much worse because it was such a tremendous amount of loss in a very short time period. You know, my boys had AIDS and I knew they were going and it was only going to be a matter of time with them two, but it just so happened the way the cards fell, I went through three funerals in four weeks (INT1-3).

Jamie describes her relationship to Alice in this way:

It was probably more of a mentor relationship. In the SM world you might even call it daddy/boy. She was elder, I was younger and I looked up to her very much and respected her, but allowed her to be human (INT1-7).

Marie and Randy

Randy had been dating Marie “three months and eleven days.” They had made a commitment to be life partners when Marie died suddenly of a ruptured aorta, two years before the interview. Randy hadn’t met many of Marie’s friends and family, including Judy, described above, who later became Randy’s friend. Randy cried throughout the interview, repeating the theme “she was my everything at that point and then she died and people didn’t know me” (INT6-5). In the emergency room she had to fight to be allowed to see Marie’s body. She couldn’t get her belongings from Marie’s house. Marie’s friends insisted that she wear a dress to the funeral and take a gay man along as her date, to cover for the sake of the family.

Randy also felt the impact of other deaths from AIDS. She said:

It’s like it’s really hard to make...it’s scary to make a commitment, about the time you do they will die and then with all of this H.I.V. going on it’s like Mike or the president of the Club and Mike had full blown AIDS. Ron didn’t think he had it but now he has H.I.V., a high count that he’s going to die too. It’s just like any time I get attached to somebody they die, you know.
Randy said that initially she turned to gay men for support:

After Marie died, I looked like that song Delta Dawn, what's that flower you have on, you know, can this be a faded rose from days gone by? It was me. I went into bars, the lesbians weren't compassionate. They didn't know what death was about, but gay boys know, but women don't know, they don't know, and I went into bars and they made fun of me because I couldn't focus on a conversation, I couldn't make eye contact. I was drinking too much, I was a mess (INT6-10).

Randy says she thinks Marie would have also been interested in the leather community "because she was totally into fantasies" (INT6-10, 11). Randy said she has a lot of gratitude for what she has learned since Marie died, and concluded "I am a very lucky boy" (INT6-29).

In the following sections, I step back from the narratives of the survivors to discuss patterns in their experiences. Themes which emerged include experiences with disenfranchised grief, risks related to the tasks of grieving, and health complications.

**Disenfranchised grief**

Lesbian experiences during bereavement were expected to provide an example of disenfranchised grief, and this theme emerged from some of the narratives. Doka (1987) identified five specific problems of disenfranchised grief in non-traditional relationships. These include intense negative affect, exclusion from the care and support of the dying, lack of social support, exclusion from funeral rituals, and practical and legal difficulties.
Fifteen (83%) of the survivors presented with intense grief, or intense negative affect, at the time of the interview. These feelings were exhibited in tears, verbal intensity, and direct reports of ongoing grief. The primary negative feelings reported by the survivors were "very sad," "rough," "most horrible experience of my life," "obsessed," "very tough," "unfinished," "hard, awful," "only recently have been able to talk about it," "drained," and "having trouble sleeping." Two of the survivors did not present a negative affect. Both were nurses in the caregiving group who had, with Sandra’s partner, co-ordinated total care with more than 20 other women. Both nurses focused on the courage and satisfaction of providing such care for a loved one. Because these interviews took place immediately after Sandra’s death, it is not known if a delayed negative affect might have occurred later (Gersie, 1991).

Only one survivor was initially excluded from the care and support of her dying loved one. She had to fight to gain access to her loved one in an emergency room. She explained that she was the lover and her demand to view the body was respected. Three who were closeted partners were acknowledged as such by the health care professionals involved despite well established survivals pattern of hiding lesbian issues. Four survivors did not get to provide care for their loved one because of sudden death, or death in a distant location.

Lack of social support was reported by ten of the 17 survivors (58%). The five survivors in the caregiving group provided support for each other. If they are counted separately, then ten of the remaining survivors (83%) experienced lack of social support. Some of the most painful narratives emerged in this category. One woman returned
alone to her hometown for the funeral of her first lover; she did not know the current partner, and faced the ongoing hostility of her mother and sister who had always mocked the relationship. Another was the friend called after an automobile accident; she told no one the extent of the injuries she witnessed and received little support for her prolonged ten-year grief at the loss of “just a friend.” Two reported lack of support for reasons related to closeting, where heterosexual friends compared the loss of a life-partner to “losing a sister.” Two reported active hostility from other lesbians. Another hid the extent of her past involvement with her “friend,” but regretted the lack of recognition for the significance of the relationship.

Four of the survivors reported problems related to attending the funeral, and in most cases, separate ceremonies were held by the lesbian survivors. Two learned of the funeral too late to attend. One attended the funeral, but protested that she was told she must wear a dress (to pass for straight), and hide the depth of her feelings to protect the family of origin. Three reported being surprised by positive experiences with the family of origin and coworkers.

Four informants reported practical and legal difficulties. One friend survivor reported “de-dyking” the house (that is, removing all evidence of lesbian lifestyle) before the brother arrived. One surviving partner had arranged power of attorney, but due to changes in the law, the paperwork was not valid, so she could not be part of a legal suit against the driver whose negligence caused her partner’s death. One survivor reported being unable to get her own clothes from her lover’s house. In the case of the caregiving group, the family of origin supported the group before the death, but became
hostile after the will was read. Four other informants reported having made legal arrangements before the death which were not challenged after the death.

The experiences of these survivors are mixed in terms of the disenfranchised grief, with the strongest factors being intense negative affect and lack of social support. Because several were domestic partners and many were open about their relationships, the complexity of completely secret alliances is less an issue than for the participants in Doka’s study. Several had made legal arrangements in anticipation of potential problems at the time of death. Those survivors who were not primary partners were disenfranchised more in their role as friend (Deck & Folta, 1989; Sklar & Hartley, 1990; Sklar, 1991-92) than because of sexual orientation issues. The intense negative affect of most of the participants may stem from previous lack of opportunity to discuss bereavement experiences. Because the average age of the survivors is only 45, bereavement experiences are not as common a topic as in an older population. In a clinical situation, further assessment of such intense negative affect would be necessary.

Jones (1985) also found that support and recognition during lesbian bereavement was more mixed than anticipated. She found that “[i]nteractions with the women’s families, and with their partner’s families, varied from quite supportive to extremely negative. Many of the subjects had been fearful that their families would attempt to interfere with funeral arrangements or the settlement of the estate. The degree of actual interference varied widely. Interactions with doctors, nurse, funeral directors, and clergy also varied” (p. vii). While it is encouraging that lesbian women in both studies had positive as well as negative experiences during bereavement, the unpredictability of
caregiver and family responses remains a source of stress and fear in the daily lives of many lesbian women.

**Risk factors for complicated grief**

From clinical knowledge, it was expected that the survivors’ experiences would place them somewhere on a continuum of completing the tasks of grieving and of having certain risk factors for complicated grieving. Worden identifies four tasks a grieving person must accomplish before mourning is completed. These are 1) to accept the reality of the loss; 2) to work through to the pain of grief; 3) to adjust to the environment in which the deceased is missing; and 4) to emotionally relocate the deceased and to move on with life. The survivors’ experiences were reviewed with these tasks in mind.

None of the 17 informants seemed to have fully completed all four tasks. Four of the 17 had not accepted the reality of the loss, either because it was too recent, or because of wanting to believe in miracles, or because of difficulty accepting a death that occurred during a prolonged estrangement.

Only three of the 17 seemed to have worked through to the pain of the loss. One recent survivor felt she had worked through the pain before the death during her caregiving experiences. One felt she had worked through the pain of her first lover’s death because she had so many later experiences with the AIDS deaths of other friends. One, whose life partner died eight years before the interview, felt that enough time, hard
emotional work, and a sense of humor had helped her work through to the pain, and beyond.

Five of the 17 had adjusted to the environment in which the deceased was missing, but four of these were friend-survivors whose loved one did not live in their immediate environment. The same four had also emotionally relocated their deceased loved one and moved on. The fifth, surviving her life partner, had adjusted to the environment, but had filled her life with friends rather than a new partner. One other survivor reported having started a new relationship, but expressed some concern that she had made the decision so soon.

Worden further identifies several variables which can predict which individuals may have difficulty completing the tasks of grieving. These are 1) who the person was; 2) the nature of the attachment; 3) the mode of death; 4) historical antecedents; 5) personality variables; 6) social variables; and 7) concurrent stressors.

As anticipated, the category of who the person was showed a wide range of kinds of lesbian relationships. These included first lover, best friend, life partner (for 2, 5, 22, and 24 years), fiancee, first love at age 18 and then separated for 39 years, estranged friend, estranged lover, ex-lover still friend, close friend (for 9, 15, 25 years), sober buddy, lover. Ambivalence and estrangement are known to complicate grieving and seem to do so in these narratives.

The mode of death has complicated grieving for four of the survivors. For one, the death was completely unexpected, happening just five days after the newly in love couple had agreed to a life-time commitment. They were talking on the phone when the
loved one felt anxious. She called the squad and died less than an hour later of an aortic aneurysm. One survivor’s partner had a stroke early in the morning. Although she couldn’t speak, she clearly tried to prevent her partner from calling the squad. Her partner was talking about no-code decisions with the doctors two days later, when the loved one coded and couldn’t be revived. In another case, the loved one’s death in a car accident was ruled an accident, but there were no skid marks, leaving the survivor preoccupied with unanswered questions. In a fourth situation, the mode of death was a car accident in which charges of vehicular homicide were successfully brought against the driver that hit the lover’s car.

Several types of historical antecedents that could complicate grieving were mentioned by these survivors. These included estrangement from the loved one, previous deaths in the family of origin, isolation from or abuse by the family of origin, lack of previous experience with death, fear of dead bodies, the suicide of a first lover years before, the deaths of gay men friends from AIDS, and chronic illness.

Personality variables can be another risk factor for complicated grieving. These survivors described themselves, and appeared to me to have a range of personality presentations. These included concrete, difficulty dealing with feelings, outgoing with a strong sense of humor, dependent, a loner, a late-bloomer deeply private, spiritual, abrupt, idealistic, intense, precise, perky, and publicly serene. Several of the survivors identified strongly with 12-step recovery programs.

Several social variables impact on grief resolution in these survivors. One described herself as isolated as a lesbian in a small town, saying she and her partner
“closeted ourselves in our own house” when they raised foster children. One survivor had not met the family and friends of her new lesbian fiancee, so was discounted by the other people closest to her loved one. Two reported hostility from other lesbian women after the loved one’s death because the survivor was now single and therefore a threat to other lesbian couples. One survivor who is deaf reported being blamed by other members of the deaf community when her estranged lover committed suicide.

Concurrent stressors mentioned by survivors include other deaths from AIDS, conflicting responsibilities for members of the family of origin, financial concerns, fear of losing a job in a small town, other emergencies, recent job loss, the death of pets, problems in other relationships, and personal illness. Four of the survivors have chronic health problems, which were exacerbated after the death of the loved one. Three others had cardiac or respiratory problems requiring hospitalization in the year following the death. Two reported psychiatric admissions soon after the death. Two reported an increase in drinking, two reported a concern about weight loss or gain, and three were concerned about their inability to quit smoking.

The initial findings of the study suggest that many of these survivors are at risk for complicated grieving and health problems related to bereavement, but that disenfranchised grief is only one aspect of risk. The risks common in heterosexual populations also appear as themes in this group, including especially sudden death and ambivalent relationships.

Some additional questions to consider when assessing risk factors for complicated bereavement in lesbian women are included in Table 6.1.
Risk factor | Questions
---|---
Who was the person? | Is this the first lesbian relationship? or life-partner? or best friend? Who was the person really and how was she presented to the world?
Nature of attachment | Did homophobia complicate security, self-acceptance, or dependency?
Mode of death | Do secrecy issues interact with this in any way?
Historical antecedents | Previous experience with loss? with counseling? Is there a possible strengthening affect of coping with prejudice?
Personality variables | How are age and geography related to internalized homophobia? How does addiction or recovery impact bereavement?
Social variables | How much support is there from the family of origin? from other lesbian women? What is the impact of AIDS losses?
Concurrent stressors | What is the impact of the stress of managing stigma? What are the most common other stressors (economic, parenting, illness)?

Table 6.1. Questions about lesbian bereavement related to Worden’s risk factor framework

Health complications

Fourteen of the survivors were asked about their experiences with their own physical health during bereavement, as physical symptoms are known to be common in heterosexual bereavement (Stroebe & Stroebe, 1987). Two of the survivors have chronic severe health problems and label themselves as disabled. One has lupus and the other reported a complicated condition I did not recognize. Both these women are at times
confined to a wheelchair. Both reported worsening symptoms after the death of their loved one, and one needed special assistance because her lover had provided much of her care. Three reported new onset symptoms of chest pain, difficulty swallowing, back pain, and respiratory problems; all three were hospitalized within a year of the loved one’s death. Several reported weight gain or loss, increased drinking, and inability to stop smoking despite an intense desire to do so. Two said their health had been “good”, but one of those has been observed drinking heavily on several occasions. One side-stepped the question entirely and talked about the health of her cats.

Research on lesbian health in general has been limited. The first major national study by Bradford and Ryan (1988) did not address experiences during bereavement. Further research is needed to determine the physical and mental health concerns of lesbian women in both daily and crisis situations like bereavement.

**Summary**

The narratives of bereaved lesbian survivors tell us something about who they are and what some of their experiences are. Themes of disenfranchised grief, risks for complicated grieving, and physical health have been considered. In the next chapter, I will address how aspects of lesbian culture are evident in the bereavement experiences of these survivors.
CHAPTER 7

CULTURAL INTERPRETATION

Introduction

In this chapter, the discussion of findings continues with an ethnographic interpretation of the role of culture in the experiences of bereaved lesbian survivors. The goal of ethnography, we remember, is to discover how people organize their behavior and attribute meaning to their experiences. The ethnographer seeks implicit as well as explicit aspects of knowledge in a given culture.

Cultural differences between heterosexual and gay/lesbian (homosexual) culture are briefly addressed. Four cultural groupings within lesbian communities are identified from my perceptions as participant observer. The bereavement experiences of the 17 survivors are then reconsidered within these four cultural groupings. The major cultural issues which impact on bereavement experiences within each group are identified.
Culture: The familiar vs. the other

How then, are we to think about this research in terms of lesbian culture? Culture may be easiest to recognize when most clearly foreign, when the Other culture is apparent from mannerisms, language, dress, or physical appearance that feels unfamiliar to the observer. Gay and lesbian culture is often perceived as Other by observers who assume the universality of mainstream, heterosexual, American culture. Such mainstream observers often perceive themselves as normal and therefore cultureless.

Madeleine Leininger addressed the dilemma of describing familiar cultural habits with the detachment of an anthropologist in her 1976 article “The two strange tribes: The gnisrun and the enicidem.” Using a technique developed by Miner (1956) and elaborated by Spradley and Rynkiewich (1975), she spelled the words “nursing” and “medicine” backwards to poke fun at the un-self-aware assumptions of these two professions. Leininger used humor to comment on aspects of professional life so much taken for granted that they are believed to be natural, real, and inevitable.

Leininger’s article previously inspired me to use a similar technique to describe differences between heterosexual and gay/lesbian (homosexual) culture. In an article published in 1988, I compared “Two other strange tribes: The teh [i.e. het-erosexual] and the moh [i.e. hom-osexual] in America” (Deevey, 1988). This article was published in Cassandra, a radical feminist nurses newsletter. As fugitive literature, it is included in
Appendix O. What I describe as “afbohpomoh syndrome” is the homophobia, or fear and lack of knowledge heterosexual folk often have about lesbian culture.

Mainstream heterosexual nurses often experience homophobia or culture shock when initially confronting lesbian cultural practices which are unfamiliar. Culture shock, however, can be triggered in more than one direction when cultural assumptions are challenged. My field notes reflect my own culture shock in response to renewed contact with heterosexual culture as I tried to understand bereavement issues in my clinical practice and my research (see Appendix A). Lesbian women may also experience culture shock in heterosexual settings, and perceive heterosexuals as Other.

Cultural variety within lesbian communities

The cultural status of gay and lesbian marriage was made officially Other in 1996 by the Defense of Marriage Act. A similar bill (H. B. 160) to prohibit marriage between persons of the same gender was introduced in the Ohio legislature in February 1997. When official government policy forbids lesbian marriage, lesbian widowhood is an impossibility. How will such legislation impact bereaved lesbian survivors, and lesbian culture? It may unite a community that is perceived from the outside as monolithic. What this research shows, in fact, is not the unity of lesbian communities and lesbian experience, but the variety.

What do these 17 survivors have in common? They agreed to participate in a study in which they identified themselves as bereaved survivors after the death of a lesbian woman.
Many were in some way disenfranchised in their bereavement, as discussed above. But how
different their stories are, one from another, in terms of lesbian culture.

I struggled to understand the variety of experiences, using both the specific data from
the interviews and my own experience as participant observer, seeking implicit as well as
explicit interpretation. The boundaries between the roles of partner, ex-lover, and friend
were often blurred, so grouping participants by those categories did not help. One colleague
urged me to drop all but the “real” widows (i.e. the surviving partners), but that would
homogenize and distort my findings, even if making the conclusions more palatable or
comprehensible to heterosexual audiences.

Furthermore, the cultural terms identified as inaudible by my sensitive, capable typist
did not repeat interview after interview. Instead, each interview produced new cultural terms
which she did not recognize. In one of the first interviews, she noted the word heterosexual
as “(?) sexual),” which brought to my attention that heterosexual folk do not use that word to
describe themselves. She did not recognize names of gay places, like Provincetown or
Michigan (referring to the annual festival). Nor did she recognize the names of the many
lesbian organizations, publications, films, and musicians which participants mentioned.
Terms like rainbow, leather, and butch-femme were “inaudible” or misheard. She
transcribed butch-femme as “good friends” and femme roles as “femme rolls.” In my
favorite example, discussing food at the funeral service, she heard “I wondered where you
found a container to dip a cold dike.” The correct cultural language was “I wondered where
you found a caterer to do a typical dyke pot luck.” These transcription “errors” were very
helpful in highlighting cultural terms so familiar to me that I forget they are not universal. I also noticed in reviewing the transcripts that several participants avoided specific cultural language, and used vague terms like “you know” and “people like ourselves” instead of saying the word lesbian.

Only after completing sixteen of the 17 interviews did cultural similarities and differences among some of the individuals begin to become apparent. Thinking about culture, I again remembered Leininger and the Moh and the Teh. Using anthropological imagery, I began to picture villages within Teh and Moh territory, where I and the women in my study live. Instead of seeing just differences between heterosexual and lesbian culture, I saw differences within the lesbian community. There are major differences in the perception of gender and power in different “villages” within the lesbian community, and these differences have an impact on bereavement experiences. First I will describe the characteristics of each village, and then discuss issues related to bereavement for the survivors in each village.

The villages

First there is the Big Village. This is not a metropolitan area per se, but rather the mindset world of heterosexual normalcy. In the Big Village, gender is the defining primary value. Boys must be boys and girls must be girls. Gender is binary: one gender is defined in opposition to the other. Gender is the organizing principle of society, organizing clothing,
work, bathrooms, adornment, and sexual activity. Power is associated with gender, wealth, and whiteness. Clothing styles are "appropriate" to gender, age, role, and class. Cultural language referring to lesbian life in the Big Village is mostly non-verbal, consisting of vagueness about relationships and activity, long pauses, and drifting off or sudden whispering, or phrases like "you know." The elders of the Big Village are unaware of their own culture because they have never left home. The elders often punish or expel anyone who is different. In the Big Village, gay and lesbian folk are called homosexual, and are only visible to other inhabitants if we are swishy (male, too female) or dykey (female, too male) or mouthy (don't ask, don't tell). Lesbian individuals who live in the Big Village may completely share the gender and power assumptions of the majority. They behave differently in private and hide all evidence of their so-called deviance. An American flag flies proudly over the Big Village.

A little ways outside the Big Village is the Rainbow Village. In this cultural mindset, there are many proud and happy gay and lesbian couples, many of whom are raising children. Many Rainbow adults work long hours in the Big Village. Some Rainbow folk discuss their lives with Big Village folk, but most just enjoy their Rainbow weekends and keep a significant emotional distance while in the Big Village. Gender definitions and power dynamics resemble those of the Big Village. Sexual orientation is defined as same gender partner choice. Gender roles are often expanded, so that either partner in a male or female couple may fix the truck, cook the gourmet dinner, or diaper the baby. Clothing styles tend to be less gender-rigid, but more well-pressed than in the Big Village. Cultural language
includes the terms lesbigay, family, and community. The primary symbol of the Rainbow Village is the rainbow flag.

Not far from the Rainbow Village is the Womyn’s Land. Here lesbian couples and a few lesbian communes practice gender separatism, with a celebration of women and rural life as the major values. On the Womyn’s Land, gender is perhaps most intensely the basis of lesbian culture. As feminists, or female separatists, Womyn’s Land folk unite against patriarchy, and often against men, to develop women’s culture, to reclaim women’s history, to celebrate women’s achievements. Power is considered a carry-over from patriarchal oppression. Power differences between individual lesbian women are denied in the promotion of equality and decision-making by consensus. Clothing styles tend toward loose cotton, casual, and the color purple. Cultural terms include birkenstocks, the goddess, and dyke. Symbols of the Womyn’s Land include the respelling of women as womyn or wommin, the labrys (double-headed Amazon ax), the piano insignia from the Michigan Women’s Music Festival, and the linked female gender signs.

Then out near the far left fields is the Carnival Village. The Carnival Village is feared by the majority of people in the Big Village, and by many in both the Rainbow Village and the Womyn’s Land. In the Carnival Village, gender is reversed, or blurred. The binary duotone perceived gender reality of the other villages is replaced by an iconoclastic, multihued spectrum of gender presentations. The gender organizing principles which make the male/female world predictable and reliable are not assumed in the Carnival Village. The terms he and she are not consistent labels, and may be used interchangeably for the same
individual. In the Carnival Village, sexuality is unabashedly kinky. Costume is illusion, exaggerating gender stereotypes, hiding biological truths. The blurring reversals entertain and menace: which pronoun? which bathroom? which partner? which reality? In fact, Carnival folk, though rarely religious, talk often of altered states of consciousness, either in gender role play or in power games. There are many young people in the Carnival Village who create the discourse of queer theory and decorate themselves in metal, leather, and tattoos. Power differences between individuals are explicit, and eroticized. Clothing is fetishized, including metal, leather, and sequins in various combinations. Cultural language includes terms like leather, drag, top and bottom. The primary symbols of the Carnival Village are the leather pride flag, and the theatrical performances called drag shows.

Cross cultural communication among gay and lesbian folk from the different villages can present a challenge. It is not easy for Big Village folk or Womyn's Land folk who only perceive two gender tones of full black and full white to imagine shades of gray. It is equally challenging for Carnival folk who perceive themselves as shades of gray to comprehend being unseen, invisible, unimaginable. Each group may perceive itself as the true, real, or appropriate lesbian folk.

This metaphor of villages has helped me understand the experiences of the bereaved lesbian women. The image of the villages has helped me specify what in the experiences of these survivors relates to lesbian culture, and what it is that goes beyond the variety of experiences to some commonality. The image of the villages of course oversimplifies the various alliances within gay and lesbian communities, ignoring cultural groupings based on
race, ethnicity, and class. Nevertheless, I hope this beginning interpretation will be helpful to nurses who are unfamiliar with cultural variety within lesbian communities (see Figure 7.1).

Figure 7.1. Variety in lesbian bereavement experiences: The villages.
The Big Village survivors

Three of the survivors in the study share similar experiences isolated within the Big Village at the time of the death of their loved one. All lived in small communities some distance from a metropolitan area, and all had lived with their loved ones for more than twenty years.

Amanda, Joyce, and Belinda are the lesbian survivors most like heterosexual widows in this study. They had been in long term relationships and shared a household. At the time of their partner’s deaths, all three shared the cultural values and expectations of the Big Village. All three were deeply closeted, although all describe being recognized as lesbian by health care professionals.

Secrecy, isolation, self-perception, and courage are issues which seem to complicate bereavement for these three survivors. The secrecy of being closeted complicates both the personal and interpersonal experiences of the survivor. A life-long habit of hiding at least suggests some internalization of homophobic values, which Amanda confirms she had. Support from others is either not available or is difficult for those who know the intensity of the relationship, but feel awkward about how to give support without using words and labels that the lesbian women themselves avoid. Self-perception is related to secrecy in two ways. The degree to which a lesbian woman perceives herself as open on lesbian issues depends on what she knows about real options to be open. For example, three years after BJ’s death, Joyce perceives herself as completely self-disclosing on lesbian issues. She is, however,
unaware of local lesbian publications and events, and hid a lesbian publication when the
waitress approached during the interview at the restaurant.

A lesbian woman who lives isolated in the Big Village and has never met lesbian
women who are fully self-affirming and self-disclosing has more limited options available
for how she perceives herself. The impact of this limited perception seems to be primarily
related to reinforcing isolation. In the face of such isolation, what strikes me most is the
courage of these survivors, who made a life with their partners over many years, against such
odds. An example of a kinship network diagram representative of the Big Village is included
in Appendix P, representing an isolated lesbian couple and their cat.

The Rainbow Village survivors

Several of the lesbian women who expressed interest in the research, but did not
participate in the interviews, were the most typical of what I have called the Rainbow Village
within lesbian communities. These are primarily working couples, mid-twenties to mid-
forties, some raising children, who participate in lesbian and gay organizations and
community events. Most have been together a few months to a few years, and many juggle
multiple roles of work, school, parenting, and caring for elderly parents. The four survivors I
perceive to be culturally associated with the Rainbow Village are Judy, Dana, Irene, and
Priscilla. None of the four survivors in this group is completely typical, but each in some
way exemplifies issues related to bereavement in the Rainbow Village.
The strength of the Rainbow Village is the existence of a strong, visible gay and lesbian community with a spectrum of diversity that includes racial and ethnic variety and high levels of disability awareness and support. Lesbian experience provides a bridge that permits communication and support between people that might otherwise have limited interaction with each other. These survivors represent some of the range of life experiences within the Rainbow Village. The risks for bereavement resolution in the Rainbow Village is that community support may be an illusion, and the survivor may feel even more isolated in the context of a community that purports to be inclusive, sensitive, and supportive.

An example of a kinship diagram typical of the Rainbow Village is included in Appendix Q, representing the complex networks of lesbian and straight support common among Rainbow Village folk.

The Womyn’s Land survivors

Eight survivors in the study share a cultural identification with the lesbian-feminist parts of the lesbian community, including Anne, Pat, Ginger, and the five members of the caregiving group. Several of these eight survivors have been active in women-only lesbian organizations and publications, or are regular participants at events like the separatist music festivals in Ohio and Michigan.

The idealism and creativity of lesbian-feminism in the Womyn’s Land is its strength and weakness in terms of bereavement. The caregiving group represents the universal
dream, to be surrounded by selfless, loving friends, lovers, and family at the time of death. But some of these survivors did not respond to requests for a follow-up interview, and an envisioned project to write about their experiences has not materialized. If there is a toll for such a peak experience, then followed by the additional loss as the group goes separate ways, the hidden costs may not yet be evident. The self-blame of survivors who have not been able to resolve conflict to meet the ideal of consensus in the womyn’s community may also be problematic.

The kinship diagram of the caregiving group as representative of the Womyn’s Land is included in Appendix R. In this drawing, the loved one is at the center, with the circle next to her representing the name of the organization where many of the group first met. The complex network of partners, ex-partners, and friends is evident in this example.

The Carnival Village survivors

Two survivors, Jamie and Randy, now identify so strongly with the leather pride cultural group within lesbian communities that it is not possible to separate their bereavement stories from their self-perception, even though neither was as involved at the time of the death of their loved ones. Both women use traditionally male names and prefer to be considered boys.

The strength of the Carnival Village in terms of bereavement are an awareness of death and the recognition that much of life is theater. Multiple losses from AIDS make death
familiar, particularly to those young enough to be protected from other kinds of deaths. But the difficulty of trusting in life that results from so many losses intensifies, renews, reopens barely healed wounds.

The theatrical nature of the Carnival Village is also a cultural factor which impacts grieving, as a release, as a teacher of illusion and emotion, as a reminder of final curtains. The awareness that, as Randy said, "life is not a dress rehearsal," can increase pleasure and gratitude when bitterness could be the more obvious choice.

A kinship diagram from the Carnival Village is included in Appendix S. This example shows the broken heart of the survivor. The large theatrical tears represent her extreme anguish at the loss of her loved one.

Summary

Minority cultures develop in part in response to hostility from others. Those individuals with a complex sense of identity must struggle to find safety, delight, and a sense of community as cultures grow and change around them. A recent poem by Dragonsani Renteria (Luczak, 1993, p. 38) identifies the many communities and cultures where she has tried to belong. She is currently the director of the Deaf Gay and Lesbian Center in San Francisco. She writes:

Society rejects me for being Deaf.
The Deaf community reject me for being a Lesbian.
The Lesbian community reject me for not being able to hear them.
The Deaf-Lesbian community reject me for being into S&M.
The S&M community reject me for being Deaf.
Society rejects me for being Chicana.
The Hispanic community reject me for being a Lesbian.
The Gay Hispanic community rejects me for being Deaf.
Patriarchal society rejects me for being a woman.
I am rejected and oppressed,
Even by those who cry out readily
Against rejection, oppression, and discrimination.
When will it end?

The 17 lesbian survivors interviewed in this study had a variety of experiences in their bereavement. Cultural differences within lesbian communities described here in the imagery of villages are not always recognized even by lesbian women. Individuals in each village may passionately defend the correctness of only one way of being lesbian.

Heterosexuals who have personal experience with individuals from only one of the villages may assume all lesbian women are exactly like the one or two they have known.

Imagine the dilemma this poses for the caregiver, hoping to be culturally competent and compassionate with lesbian patients who are bereaved or in other clinical situations. The caregiver is challenged first to learn cultural information that has traditionally been hidden, and then to look for variation that may not be recognized by members of the community being cared for. In the next chapter, I will discuss the implications of the findings and the interpretation of this study.
CHAPTER 8

IMPLICATIONS AND RECOMMENDATIONS

Introduction

The observations for this study and the resulting findings and interpretation were captured at a point of time in Ohio, and cannot be generalized to other times and other communities. The intent of the study was to learn about the bereavement experiences of the informants in order to sensitize health care professionals to what is not known about this cultural group, and to stimulate a desire to know more.

In this chapter, I will first discuss nursing implications suggested by the findings and the cultural interpretation emerging from this research. Then I will address the implications from a health policy perspective. Finally I will discuss ideas for future research.

Nursing implications

This study raises more questions than it answers about the experiences of bereaved lesbian survivors: What are the reasons for the intense negative affect expressed...
by participants? What is the impact of unpredictable negative and positive support from family of origin and other lesbian women? What are the reasons for the relatively young age of both the women who died and the survivors? What do we need to understand about lesbian health in daily situations and in times of crisis? How do changing roles and relationships of partners, ex-partners, and friends influence lesbian family structures?

Until more is known about these questions, I believe we should not be too quick to compare lesbian bereavement experiences to the experiences of heterosexual widows. Risk factors for complicated grieving like sudden death or ambivalent relationships may be similar, or not. The surviving lesbian partner may look most like the surviving heterosexual widow, but conclusions about the similarity of their experiences would be premature at this time. Premature comparisons may further obscure cultural differences rather than increase cultural awareness.

The cultural variety within lesbian communities found in this study raises additional questions: Are these differences related to regional or historic factors? Do individual lesbian women move between or remain within these different perspectives over time? How do changes with heterosexual culture impact on lesbian culture? At the present time, it seems impossible to separate lesbian culture, and therefore lesbian health, from issues related to homophobia. Lesbian and gay people will continue to be vulnerable until societal homophobia ends.

So what is the culturally competent nurse to do in order to offer support to lesbian patients who are bereaved? In clinical practice it may be possible to assess cultural variety within lesbian communities with a demographic question which asks: if you are
female and your sexual partner(s) are female, which label do you use to describe yourself (homosexual, lesbian, bisexual, dyke, queer, boy)? Such a question would certainly surprise those of us who sit angry and puzzled trying to decide whether to scream or check single, married, or divorced on more traditional relationship assessments.

Culture complicates grief, but grieving crosses cultural boundaries. I conclude from this study that lesbian women need from nurses what any other grieving folk need: competent compassion. As nurses, we know we are confidant and creative problem-solvers, providing exquisite care to vulnerable individuals in a variety of clinical settings. Occasionally, however, we are forced to confront unknowns that trigger fear, disgust, and anger in even the most skilled and sanguine among us. In an increasingly complex world, we nurses are challenged to know ourselves and our prejudices more than ordinary folk must, in order to provide strangers with consistently competent and compassionate nursing care. We must know our fears and our loathings in order to grow beyond them.

Nurses can also be role models for students. Nursing students in Ohio come to their profession from farms and small towns, from religious families, and from years of watching homophobic news on television. Many have no previous experience with any individuals who differ in race, religion, ethnicity, or sexual orientation. Undergraduate heterosexual nursing students have been open and unapologetic about the rage, disgust, and fear they feel at the thought of caring for lesbian and gay patients. When we advocate culturally-sensitive care for lesbian women like the bereaved survivors described in this study, we ask these young people to make a tremendous leap to grow beyond their assumptions, their fear, and their ignorance.
One of the chaplains at the hospital where I work described homophobia as "an ongoing national spiritual crisis." Despite her traditional Methodist roots, she believed the climate of fear and ignorance on gay and lesbian issues allows individuals and groups to live with a potential for violence that would be addressed and treated if related to any other topic. In this climate, nurses as individuals may have to find their own conscience and develop their own cultural competence with limited leadership in many clinical settings.

Health policy implications

In the same year that Congress passed the Defense of Marriage Act, and gay and lesbian military personnel were reminded never to discuss their sexual orientation, federally funded health projects and health research began to include lesbian women as an at-risk group, especially in breast cancer studies. In August 1996, The Lesbian Health Advocacy Network published a 12-page summary of lesbian health advocacy efforts, health system recommendations, and an overview of lesbian health issues (Plumb, 1996). Bereavement concerns are not among the priority health concerns (which are cancer screening, sexually transmitted diseases, HIV, depression, substance abuse, relationship issues, aging, pregnancy, and parenting). Lack of access to sensitive medical care is identified by the Lesbian Health Advocacy Network as the ongoing most significant health issue for lesbian and bisexual women.
The health system recommendations are therefore needed to indirectly help all lesbian health concerns including bereavement issues. These recommendations with specific goals include guidelines for conducting research, providing services for the prevention and treatment of disease, educating and informing the public, recruiting and training health care personnel, and designing guidance on lesbian and bisexual women’s health initiatives. One helpful resource for health care professionals is a recent curriculum guide on lesbian health and cultural sensitivity (Rankow, 1996).

**Recommendations for future research**

Many questions for future research may emerge from this study. We know so little about how lesbian women live, how they maintain health, which illnesses are common, and what are the most common causes of death. We understand so little about the impact of prejudice on physical and mental health. We are unsure how individual and cultural factors combine in the development of self-esteem, self-awareness, and generosity toward others. We are unclear how to set priorities in a time of cost containment and economic competition. We ponder how spirituality adds comfort and meaning in the face of pain, joy, and death.

My own interest in future research is to learn more about differences within lesbian communities rather than differences between heterosexual and gay/lesbian communities. This study uses the anthropological imagery of tribal villages to begin to describe cultural variation within lesbian communities during bereavement. How do
cultural variations within lesbian communities interact with physical and mental health? How can communication and support develop among lesbian women in different parts of the community?

I am grateful to the women who shared their experiences with me. As one said, "life is not a dress rehearsal," reminding me to savor every moment, knowing that the statistics on death are 100%.
Munhall and Oiler (1986) remind nurse-researchers of the need for "bracketing" in research which requires interpersonal interaction: "one must become aware of personal preconceptions, values, and beliefs. Only through self-awareness of mind-set can the researcher begin to search out and understand another's world" (p. 115). Other researchers call this self-awareness reflexivity (Steier, 1991).

How in the world did I get hooked on lesbian bereavement? When I mention my topic, some people respond, "Yuck, Sharon, you are too weird!" In my earlier research on lesbian aging, I saw straight people squirm when I talked publicly about homosexuality. Now I see them squirm again, confronted unexpectedly by questions of mortality. Since the issues I find so compelling cause discomfort in others, I need to know my own "why?" so that I won't get defensive. Lesbian women have responded more positively, I think: so many start to tell me the stories I hope to collect officially someday in my research.

In the years preceding 1992, I began to see people die. I began to hear of people I knew who were dying; so maybe in part my interest is a coming of age, brutally exacerbated by the epidemic of AIDS that is killing my gay brothers. I saw two lesbian women, whom I respect above all others, completely devastated by the cancer deaths of their ex-lovers. In each case, my lesbian friend served as the co-ordinator, like an older sister, in her ex-lover's dying situation, sparing the current partner the full responsibility for making arrangements, notifying others, confronting institutions. In each case, the surviving ex-lover had even less validation for her loss after the death than did the surviving partner, the lesbian widow-equivalent. I thought often of my three ex-lovers, my closest friends, for whom I would play the same role if needed.

Until recently I knew of only a few lesbian deaths: suicides mostly, or murders I read about in the lesbian press, or the death of an occasional national lesbian leader succumbing to cancer. When I lived in Cleveland, there was M., who died in an alcohol-related car crash; her funeral was a remarkable culture clash of her militant, openly-dyke network and her politely, uncomfortably confused co-workers and family of origin.
In my own family of origin, I have never been to a funeral. My grandparents died far away, and my mother, who detests public weeping, always said, "no, dear, really. I'd just as soon you didn't bother to make the trip." Perhaps I am drawn to learning about that which is taboo or unfamiliar.

I saw my first casket, which was open, in eastern Kentucky, where I had gone to teach in a one-room school after graduating from college. I learned quickly that when someone in the community died, I was expected to close school for the afternoon, expected to lead the children walking single file over two or three hills to the home of the deceased or to one of the many local churches. I loved the twanging, wailing Appalachian questions, that even the youngest first-grader sang so heartily: "will the circle be unbroken? will we meet in the great bye and bye?" It was my first experience with cultural variation in the expression of bereavement.

Of grief, I know a little more. Until recently I have discounted two losses of my own as "not serious," internalizing social sanctions on the relative virtue of categories of grief. For a year in my twenties, I had a foster child named Cassidy. I was recently "out" as a lesbian when my lesbian network made "no children" a condition of continuing group membership. Excluded at that time from my family of origin because of my lesbianism, I complied with the new rules of my lesbian family and sent Cassidy away. It was too late to get her back when the next day I was expelled from the group anyway, for being "too middle class."

For years I couldn't look at toddlers, and drank too much; but I knew nothing about grieving and did not consider my loss similar to any other mother's loss. I got a cat named Nellie, an acceptable child-substitute in the lesbian community. When Nellie died fourteen years later, I could only joke weakly, "it was my longest relationship," discounting both pet loss and the reopened wounds of losing my child.

I started nursing school in 1978, hoping to be thanatologist to the lesbian and gay communities. AIDS had not yet appeared, but many of us dreaded the family interference and theft reported to be universal when a lesbian or gay lover died. Karen Thompson's (1988) nightmare separation from her injured partner, Sharon Kawolski, appalled the community, but surprised no one. On "Sixty Minutes" I had seen Joy Ufema, one of the pioneering "death and dying" nurses, and was inspired by the Hospice Movement beginning to be popular at that time. I had been trained years before in post-mortem care when I worked one summer as a nurses' aide. I remember waking at night, listening in a dream state, to hear if my many cancer patients were still breathing; but none ever died on my shift, so the feared trip to the morgue was postponed.

Even in nursing school, in my mid-thirties, I had little direct contact with death. By sheer grit, I endured the dissection of black-toed human bodies in anatomy lab. Once in my public health rotation I had to accompany my instructor to a home where another
student's patient had died unexpectedly; there she/the body sat, large in her chair, and I was relatively freaked.

After graduation, I did not specialize, as I had planned, in hospice nursing. For some years I thought my previous interest in thanatology was a symptom of unrecognized depression. Am I depressed now? I don't think so; after years of sobriety and therapy, I know better what hurts and what delights. I see, however, potential risk for depression unless I take care of myself while I do this work.

In my ten years of clinical nursing practice, I have only recently again seen death directly, and then not on the job. Other things of course have made me squirm — pubic lice and three-year-olds with gonorrhea in public health clinics, and an occasional knee-deep bed sore on a psychiatric patient. On the locked psychiatric units where I've worked, no one has committed suicide on my shift, and dying patients are usually transferred to medical units as their psychiatric symptoms fade in the last stages of terminal physical illness.

Last year I saw a friend's father die, take his last breath, just when I arrived to offer support during my dinner hour. He had gone off dialysis, and they had been keeping vigil in the hospital where I work. My first AIDS buddy died (so slowly it seemed) of Kaposi's; and my second one died (at last) while I was on vacation: I was glad I had used the excuse of going out of town to say good-bye.

Grief, however, is very familiar in my nursing practice: the grief of lost innocence in incest survivors; the grief of family members about the mental illness of their loved ones; the grief of widows admitted with psychotic depression to the geropsychiatric unit; the grief and bewilderment of battered women; even the grief of the schizophrenic or bipolar patient temporarily intact enough to recognize the loss of normalcy. Much of what I do as a psychiatric nurse is listen to stories of grief.

In my master's thesis research on lesbian aging, I had two goals. I was still looking for role models, someone older and wiser who could help me understand the complexities of lesbian life. And I was [angry] at the homophobic backlash of the AIDS epidemic; I was determined to fight back, to make health care safer for gays and lesbians, for my own sake and for those I love.

But in reviewing my research now, I see I missed important issues of loss and bereavement in aging. Butler & Lewis (1977, p.34) believe that "loss is a predominant theme in characterizing the emotional experiences of elderly people."

I wanted so much to prove that older lesbian women existed, and to show that they were healthier mentally than the hideous stereotypes of isolation and the so-called "perversion" that frightened even lesbian-affirming activists like myself. Like most lesbian women, I struggled with self-hate, fear, and ignorance in my initial self-
awareness. Twenty years after coming out, the opportunity to review the (surprise!)

extensive lesbian literature probably did as much for my own personal growth as for my
goal of increasing lesbian visibility in health care.

When I recently reviewed my aging research, I discovered a silence and

insensitivity on issues of grief. I adapted a questionnaire for the study which had initially

been developed by Chris Almvig in her study of lesbian and gay aging in New York in

the late '70's (Almvig, 1982). She was, I believe, in her thirties when she began her

research, and I was in my early forties when I revised her questions. Almvig and I asked,

"if you are currently in a relationship, how long have you been together?" (Deevey,

1988). In contrast, Kehoe (1989, p.109), who is an older lesbian woman herself, asked

her 60-and-over sample to describe present relationship status as "in a committed

relationship with a woman, separated from a relationship with a woman, widowed from a

relationship with a woman (emphasis added), unattached, in a heterosexual marriage,..."

or separated, divorced, or widowed from a heterosexual marriage.

Almvig and I did ask questions about fears related to aging. Of my 78

respondents, 29.5% feared the "loss of a lover," 47.4% feared "loss of friends," while

only 12.8% feared "death." Renato Rosaldo (1989) explains the need to "recognize that

ethnographic knowledge tends to have the strengths and limitations given by the relative

youth of field-workers who, for the most part, have not suffered serious losses, and could

have, for example, no personal knowledge of how devastating the loss of a long-term

partner can be for the survivor" (p.9).

II. March 1991 (from a paper for Anthropology 810U)

In reviewing my first interview with three older lesbian women and my interviews

this quarter, I see how I enjoy the process. Like Powdermaker (1966), I remember being

curious since childhood about how other people live. I think Peshkin (1972) is correct

that in some ways researchers choose a methodology that suits their personality. Perhaps

from my years of interviewing psychiatric patients, I have learned to be self-aware about

when I push, or self-disclose, or simply listen. I will need more direction and practice,

however, in analyzing initial interviews to develop domains, taxonomies, and follow-up

questions.

I looked through my personal journal for what I remembered as a detailed

description of the setting of that first interview in 1986, but found only two sentences.
The scene seems as fresh as yesterday, though I know that memory and time (and the

temptation to fictionalize) distort. I suspect that my current interest in lesbian

bereavement began in this interview, when my intended topic was lesbian aging.

The interview was arranged by a school friend, with three women in Cincinnati

whom I had never met. I walked down into a basement-level apartment, feeling very

much like an intruder. Before the interview began, we chatted socially, and I accepted

coffee and donuts, which both always give me a stomach ache.
One of the three women, R., had been widowed for two years from her lesbian partner, M., with whom she had lived for thirty years. R. had met the others recently: she said she had known nothing of the lesbian community until a few months before the interview. She and M. had lived in a trailer park, and the only other gay people they knew were two men whose trailer was nearby. More than a year after her partner's death, her two gay male friends had insisted that she start meeting some other lesbian women; for the first time she began to learn about lesbian music, books, support groups.

Suddenly, she jumped up and said to me, "come, I want to introduce you to M." She walked into her bedroom, and I followed her, puzzled but polite. She pushed open a sliding closet door. Inside was a chest of drawers, and on top, a large photograph of a lovely young woman in a World War II uniform. "This is M." she said, with tears in her eyes.

In the interview she said "everyone knew" and she'd "never" had any trouble about her lesbianism. She said quite adamantly that she couldn't understand people who had trouble with their families. My nursing eye saw pain, and the red-nosed tracings of alcoholism, and denial of the cost of being different. Or was I reading into her words what I expected to find?

What would I ask her now, to capture her version, her vision of her life and grieving? What would I hear in her words, and in her metamessages-messages? What would I report, to other lesbian women who face grieving of their own? To caring nurses who can help or hurt grieving lesbian women? To the snickering world at large?

What then, is my role as ethnographer and participant/observer in my own community?

III. 1992-1994

In June 1992 I was unexpectedly laid off from my part-time job as a psych nurse. I applied to work in Hospice, but was turned down because I lacked the high-tech, med-surg, and physical assessment skills I would need for hospice home care. I transferred, with great trepidation and resentment, to a critical care step-down unit where I oriented part-time for six grueling months. In December 1992, I was advised, without warning, to transfer again. At that time I was hired by Hospice and now have worked one year as a part-time on-call hospice nurse managing a caseload of eighty patients.

It has been a difficult and challenging transition. I now know more about morphine pumps and lung sounds, more about dying and dead bodies, more about bereavement. I have seen and smelled the stuff of nightmares. I have consoled myself
that I will do better research on lesbian bereavement because I know more about the
critical care units where many modern folk die, because I have directly confronted the
faces of death, because I have heard the shocked wailing of survivors. I find it painful to
read the eloquent literature of bereavement after weekends when I made four middle-of-
the-night death visits, and talked on the phone to fifteen families who were panicked
enough about their dying loved one to page the on-call hospice nurse.

I struggle with my own aging, trying to distinguish the sleep deprivation of
beeper-jangled night shifts from the insomnia of menopause. I try to manage gracefully
the emotional lability of interacting hormonal change and constant contact with
mortality. I want very much to do the research I envision, one day at a time.

My nursing supervisors at Hospice urged me to give an inservice on lesbian issues
in hospice during my first month on the job. They say they are eager to learn from my
research, to improve the care of lesbian families in our program.

As I begin the study, there is one other issue to own. In the years since 1985, I
have been "out", openly self-acknowledged as a lesbian, in all areas of my life. There
have been many emotionally intense adventures confronting family, co-workers, and
strangers about the lesbian reality they previously denied or despised. I have been
profoundly changed in the process. I feel safer now in the world since I no longer hide
who I am. I have respectful and queer-knowledgeable heterosexual friends and
colleagues. I now feel pain and sometimes anger listening to the profound self-hate and
fear of deeply closeted lesbian women. Yet these are the women I will interview,
because those who are most isolated and most invisible are those most at risk for poor
outcomes in bereavement. I must remember not to blame the victim. I must remember
that they, as I once did, have only internalized the hatred of the homophobic society in
which we live.

IV. 1994-1997

In April 1994 I got sick, and then sicker. I had food disgust, abdominal pain,
nausea, weight loss, dizziness, and relentless fatigue. My initial diagnosis was
gastroparesis, or paralyzed stomach. After three hospitalizations and two surgeries (for
dermatitis), I am finally, almost three years later, feeling better. I have learned more
that I ever wanted to know about the experience of being a patient, the fear of dying, the
stress of illness on one's loved ones, and the financial burden of medical bills and lost
income. I'm sure that the physical, emotional and spiritual experiences of such a
prolonged illness have influenced my research in ways I do not yet begin to understand.
In November 1993, I was fully immersed in hospice clinical work, making routine visits, death visits, and on-call telephone calls to families. I visited upper class mansions, inner city apartments, and the boxlike houses in the suburban area I called the meadow ghetto. When I told my hospice coworkers-workers that I hadn’t been in so many heterosexual homes in years, they looked puzzled, but I wasn’t joking. My culture shock erupted in my field notes, continuing the tribal imagery of the Moh and the Teh from the Cassandra article:

Heterosexual codependency — the "Teh" culture in Twentieth century America encouraged isolated male and female couples to develop only half the life skills necessary for survival, and not only to suppress the other half of life's survival skills, but also to suppress any impulse to reach out to others in love and friendship. This system had its limitations in life, for sure. Heterosexual men and women tended to pride themselves on being bimbos and bullies, both less than the human potential. But the full impact of this damaging cultural aberration became most apparent when one or the other inevitably died first, leaving the other bereft, helpless, isolated. Sickness often followed.

In contrast the "moh" people prided themselves on learning the range of so-called male and female skills. They preferred short intense couplings and focused less on the accumulation of mutually owned property. Fewer mohs raised children, and this therefore allowed them to elaborate a rich culture of artistic creativity and self-expression. Of course, they were severely sanctioned for refusing to participate in heterosexual co-dependency. The loss of social status, usually coming quite abruptly with puberty or first love, taught the moh sharp lessons about the fragility of life, prestige, and safety. Some became understandably paranoid and self-destructive: but many others weathered the storms of homophobia, and faced later losses in life with a wisdom and spirituality that were in sharp contrast to the devastation of teh widows. It was not that the mohs loved any less. In fact their ongoing friendships between former lovers amazed many. They often practiced longevity across geographical distance, changing family configurations, and of course, the stress of their devalued status. That seemed unimaginable to heterosexuals locked in what they believed to be the safety of small nuclear boxes (FN93-20).

today is the day that the news has come out that the House of Representatives of the United States has taken the trouble to pass a law that says gays and
lesbians cannot marry each other which of course means many, many things. Among others that there cannot be no lesbian widows legally. I saw on television that Ted Kennedy said, this is mean spirited, legalistic, gay bashing. That's certainly how it feels. It's just crazy to me that so many people spend so much energy trying to insure that "boys will be boys" and as they say "girls will be girls". It makes me angry and very sad. The irony of course is that I am a marriage resister and don't want the state that involved in my affairs, but the implications in terms of not being able to get health care, not being able to get survivor benefits, bereavement benefits and all of those things are enormous. Another irony is that of course the ones that want to marry are the most conservative, the most law abiding, the most materialistic and if the straight people only knew, they should be encouraging those folks, because it's all of us much further out here on the leather and queer fringes, transsexual fringes, transgender fringes, that is what they are really afraid of. (FN96-16).

President Clinton followed either political instinct or his true homophobic heart and signed this policy into law. This law assures that there will be no lesbian widows in the future, and that any who currently claim the status of lesbian widow are in violation of the law. Although I still identify as a marriage resister, I am culturally shocked in a whole new way by this law. As gay and lesbian folk we have been ignored verbally abused, misunderstood, projected onto, vulnerable to hate crimes: these I have coped with.

I wonder how we will respond as a community, now that we are officially defined as Other at the federal level. We are no longer just the weird neighbors who do unthinkable things in the privacy of our bedrooms. It is no longer our private acts that define us. Now we are, as consenting adults, expressly forbidden to love, honor, and obey each other, forbidden to set up nuclear consumer units, forbidden the American dream. Because of the shape of the genitalia of the person we cling to in the night, thousands of law-abiding, hard-working, goods-consuming, responsible voters are shifted outside the option of legality and respectability.

It may unite us as a people. It may make us culturally visible. It may make us the monolithic powerful community more traditional folk seem to fear we are already. For what this research shows is not the unity, but the variety, in lesbian culture.

C. 2/17/97 (Dissertation draft, thinking about the villages). Where do I live? Like most lesbian women, I was born and raised in the Big Village. I discovered my lesbian identity in 1970 when the Rainbow Village and the Womyn's Land were just getting established. I lived many years in the cultural mindset of the Womyn's Land. I began spending time in the Rainbow Village only when gay men started to die from AIDS, and the womyn came to help. I have been a member of the several Rainbow Village organizations for several years. In recent years, I alternate between the Womyn's Land, where my sweetheart lives, and the
Carnival Village, where I am "daddy" to a young boy-woman and the dance partner of Ms. Ohio Valley Leather '95. The Carnival Village frightens and delights me.
APPENDIX C

WRITTEN INFORMATION FOR PARTICIPANTS

College of Nursing
Department of Adult Health and Illness Nursing
1585 Neil Avenue
Columbus, OH 43210-1289
Phone: (614) 292-8222
FAX: (614) 292-7976

BEREAVEMENT EXPERIENCES IN LESBIAN KINSHIP NETWORKS IN OHIO

Written Information for Participants

1. Purpose -- The purpose of this research study is to learn more about the experiences of often hidden survivors when a lesbian woman dies. The investigator is Sharon Deevey, a lesbian hospice nurse who is doing this study as part of her doctoral program in nursing at Ohio State. The faculty advisor for this study is Dr. Patricia M. Schwirian at The Ohio State University College of Nursing.

2. Procedures -- Each volunteer will participate in one audiotaped in-person interview lasting 1-2 hours and one follow-up audiotaped telephone interview lasting 20-30 minutes. The participant will also be asked for some brief demographic and kinship information.

3. Consent -- Participation in the study is voluntary and you may withdraw at any time. Confidentiality is assured. To protect confidentiality, only pseudonyms are used during data transcription and no written consent form is required. You do not need to answer any questions which you do not wish to answer.

4. Risks and benefits -- The major risk of participating in the study is the emotional burden of discussing painful experiences and memories. The major benefits of the study include 1) the opportunity to share important personal experiences that may have to be hidden in other settings, and 2) the opportunity to contribute to making lesbian life experiences more visible without needing to self-disclose individually.

5. Questions -- If you have any questions about the study, please contact Sharon Deevey at 614-488-9520 or the OSU Office of Research Risks, Room 300, Research Foundation Building, 1960 Kenny Road, Columbus, OH 43210.

6. Taped verbal consent -- The risks and benefits of this research have been discussed with me. I understand I am free to withdraw from this study at any time. I give my consent to participate.

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APPENDIX D

ORAL SOLICITATION

Are you interested in participating in my dissertation research study of bereavement experiences of lesbian women in Ohio? My name is Sharon Deevey. I am a lesbian hospice nurse who is a doctoral student at the College of Nursing at Ohio State.

The purpose of this research study is to learn more about the experiences of often hidden survivors when a lesbian woman dies.

I would like to interview lesbian women who are bereaved after the death of a lesbian partner, ex-lover, close friend or other significant relationship. Lesbian participants of all ages, occupations, racial/ethnic identities, and political persuasions are invited to participate in this study. Each volunteer will participate in one audiotaped in-person interview lasting 1-2 hours and one follow-up audiotaped telephone interview lasting 20-30 minutes. The participant will also be asked for some brief demographic and kinship information.

Confidentiality and respect for all levels of closeting are assured. You will be asked for taped verbal consent in lieu of written consent, and you will be free to withdraw from the study at any time. You do not have to answer any questions which you do not wish to answer.
APPENDIX E

BUSINESS CARD

LESBIAN BEREAVEMENT
Are you bereaved after the death of a lesbian woman? Sharon Deevey is a lesbian nurse who would like to interview bereaved partners, ex-lovers, and close friends for her dissertation at Ohio State. Participants must reside in Ohio. For more information, contact Sharon at 614-488-9520.
Lesbian Health News

Florida 33124. It's funded by the Office for Research on Women's Health and the National Cancer Institute.

Lesbian Bereavement
Are you bereaved after the death of a lesbian? Sharon Deevey is a lesbian nurse who would like to interview bereaved partners, ex-lovers and close friend for her dissertation at The Ohio State University. The participants must reside in Ohio. For more information, contact Sharon at 614.488.9520.

HIV in Families, Women & Children
The Families' and Children's AIDS Network (FCAN) has information packets on the following topics: "AIDS in Families, Women and Children," an intro to the unique challenges faced by families affected by AIDS; "Children and AIDS," an overview of the disease process and psychosocial issues; "Adolescent Issues," techniques and tools parents can use to discuss HIV in their home; and "AIDS in the African-American Community," struggles specific to HIV-impacted African-American families. For more information, contact FCAN, 721 N. LaSalle St., Suite 311, Chicago, IL 60610; 312.655.7360.

— WORLD (Women Organized to Respond to Life-threatening Diseases), PO Box 11535, Oakland, CA 94611
Lesbian Bereavement Research
Local lesbian nurse Sharon Deevey is seeking a few more participants for her dissertation research on "Bereavement Experiences in Lesbian Kinship Networks in Ohio." She would like to interview bereaved partners, ex-lovers, and close friends. Participants must be lesbian women who reside in Ohio. Each volunteer participates in one audiotaped in-person interview and one telephone interview. Each participant will also be asked for brief demographic and kinship information. Participation is voluntary and confidentiality is assured. Sharon has a grant from The Lesbian Health Fund to support this research. She hopes to complete all interviews by May 1st. For more information, call her at 614-488-9520.
Lesbian nurse seeking participants for bereavement interviews

Sharon Deevey, a lesbian nurse and frequent writer and presenter on lesbian health issues, is searching for interview subjects for her dissertation: specifically partners, ex-lovers and close friends of lesbians who have died. The project, titled “Bereavement Experiences in Lesbian Kinship Networks in Ohio,” is Deevey’s attempt to chronicle personal experiences often ignored in our society.

Deevey believes the project can have many benefits for participants. “(The interview process) is an opportunity to share important personal experiences that may have to be hidden in other settings,” she said. “It’s also an opportunity to contribute to making lesbian life experiences more visible, especially to health care providers.”

Participation in the dissertation involves an audio-taped in-person interview and one follow-up telephone interview. Deevey also asks for brief demographic and kinship information.

“All participation is voluntary, and confidentiality is assured,” she noted.

Deevey said she received a generous grant from the Lesbian Health Fund to help with transcription of the interviews. Any lesbians interested in being interviewed or getting more information about the project can reach Deevey at (614) 488-9520.
APPENDIX I

WORKSHOP DESCRIPTION

Enrich Yourself Programs

Workshops are 2 hours long unless noted.

1 p.m.  

**Children of Lesbians**  
Sharon Ehrlich  
A children's workshop led by children.

1:30 p.m.  

**Across the Kitchen Table**  
Sheila  
Duel between women of color & white women

**Coming Out in the Classroom**  
for lesbian teachers & students  
Barbara J. Morris, Ph.D.  
A workshop in celebration of our stories at "gay/gay" with comes from Dr. Barr's one-woman play "Revenge of Women's Studies Professor"

**Lesbian Land Movement**  
Dawn and Marilyn  
Come explore with us what lesbians are doing on the land-based communities—will talk about why some lesbians want to move to the land and why others want to but feel they can't.

**Real Estate for the 90s**  
Diana Wilson  
1 hour  
Diana Wilson, Broker of OP/Campus Real Estate  
Resources, answers your questions about buying, selling, investing and exchanging real estate.

2:30 p.m.  

**LivingLIGHTER**  
Michael Langone, Ph.D.  
1 hour  
Body and Soul Fitness  
A body/mind integrated approach to eating and body weight. Learn why NOT to diet, how to eat from inner wisdom and how to love and respect your body.

2:30 p.m.  

**Drumming Circle**  
Joanne  
Bring your drums and play drums, sing, or dance with your hands.

3:30 p.m.  

**Lesbian Bereavement**  
Linda  
A research presentation on the experiences of bereaved partners, ex-lovers, and close friends after the death of a lesbian woman.

**Momazons**  
Kathy Cavanagh & Phyllis German  
David Blevins, Alida Solomon, Dee Parnas  
Beginning in 1979, lesbians choosing children through abortion avoidance and/or adoption have been meeting on a monthly basis, if you are thinking about—though not ready to get pregnant or adopt, or if you become a lesbian mother by choice.

**Lesbians**  
Jan  
Car ou.

Produced by the Lesbian Business Association  
September 8, 1996  
Cincinnati, Ohio
APPENDIX J

SIGN FOR OHIO LESBIAN FESTIVAL

LESGIAN BEREAVEMENT RESEARCH

Your participation is requested for a research study of bereavement experiences of lesbian women in Ohio. The researcher is Sharon Deevey, RN, a lesbian hospice nurse who is a doctoral student at the College of Nursing at Ohio State. Sharon completed her master's thesis on healthseeking behaviors of older lesbian women in 1988 and has presented her research findings to nurses and lesbian groups throughout Ohio since then.

The purpose of this dissertation research is to learn more about the experiences of often hidden survivors when a lesbian woman dies. Sharon would like to interview lesbian women who are bereaved after the death of a lesbian partner, ex-lover, close friend or other significant relationship. Lesbian women of all ages, occupations, racial/ethnic identities, and political persuasions are invited to participate in this study. Each volunteer would participate in one in-person audiotaped interview lasting 1-2 hours and one follow-up audiotaped telephone interview lasting 10-20 minutes. The participant will also be asked for some brief demographic and kinship information. Confidentiality and respect for all levels of closeting are assured.

To participate in the study, please contact Sharon Deevey at 614-488-9520 or c/o The Ohio State University College of Nursing, 1585 Neil Avenue, Columbus, Ohio 43210.
Inperson Interview Guide

(Taped verbal consent — The risks and benefits of this research have been discussed with me. I understand I am free to withdraw from this study at any time. I give my consent to participate.)

1. How has it been for you since ________ died?

2. What kinds of experiences have you had with other people around ________’s death? (Other lesbian women, gay men, children, ________’s family of origin, your family of origin, health care providers, employer and co-workers, others)

3. What kinds of experiences have you had with ceremonies or commemorative events related to ________’s death?

4. In what ways have your experiences around ________’s death been recognized or hidden from others?

5. What would you want health care providers to understand about these experiences?

6. How has your physical health been since ________ died?
APPENDIX L

DEMOGRAPHIC DATA FORM

Interview No. _________
Interview Date _________

Demographic and Kinship Data

How did you learn about this research?
What is your zip code:
How long have you lived in Ohio?
What was your loved one's age when she died? ___ race?___
occupation?___ ethnicity?___
How many years of education did she have? ___
What is your current age? ___ race? ___ occupation? ___
etnicity?___ How many years of education have you had? ___
How did you describe or label your relationship to your loved one?

How long was the relationship? ________________
On a scale of 0 (not close) to 10 (very close), how close was your
relationship to your loved one? ________________
What was the cause of your loved one's death? ________________
How long was she ill? ________________
How long ago did she die? ________________
What other experiences have you had with loss or death?
_______________________________

On a scale of 0 (completely hidden) to 10 (completely open), how
self-disclosing were you about lesbian issues in your life when
your loved one died? ______
On a scale of 0 (completely hidden) to 10 (completely open), how
self-disclosing was your loved one about lesbian issues in her
life? ______
On a scale of 0 (completely hidden) to 10 (completely open), how
self-disclosing are you about lesbian issues in your life now? ______
APPENDIX M

KINSHIP DIAGRAM FORM

Kinship diagram:

Please draw a diagram showing your place in your loved one's kinship network, or family of choice at the time when she died. Consider those she loved, those she spent time with, and those who helped in troubled times. Please label the relationships using whatever terms feel comfortable. Please also note the duration of each relationship, if known. If any other survivors in this network would like to participate in my study, please ask them to contact me.
APPENDIX N
TELEPHONE INTERVIEW GUIDE

Telephone Interview Guide

(Taped verbal consent — The risks and benefits of this research have been discussed with me. I understand I am free to withdraw from this study at any time. I give my consent to participate.)

1. How have you been in the two weeks since we talked about _____'s death?

2. There were a couple of points where I wanted to be sure I understood what you were saying to me...

3. Are there other thoughts and feelings you wanted to add?
Two Other Strange Tribes:  
The "Teh" and the "Moh" in America

by Sharon Deavey

Leininger's amusing and enlightening comparison of the cultures of nursing and medicine has always been one of my favorite short pieces in the nursing literature. Her description of "two strange tribes" uses the perspective of anthropology to comment on aspects of our lives which we take so much for granted that we assume they are "natural" or "real" or "inevitable". In the discussion which follows, I have used Leininger's approach to study the cultures of two other strange tribes which exist in twentieth century Nacirema society - the "Teh" and the "Moh" tribes.

The Teh tribe and the Moh tribe were initially distinguished primarily by their bedroom activity but have developed quite separate cultures within the same region. The Teh tribe claim never to discuss their bedroom activity openly, and indeed, tend to turn pink when bedroom words are spoken aloud. Nevertheless, they have many customs and rituals which proclaim their bedroom activities to other tribes. Teh women drape themselves in white when they are particularly satisfied with their bedroom activity. They also apply pieces of metal to their fingers and change their names and their titles to express their satisfaction. They carry with them paper images of their bedroom partner and of the little Tehs which are born as a result of Teh bedroom activity. Teh chiefs grant satisfied Tehs significant privileges and property rights on one condition: Tehs must agree to pretend that no other tribes exist in the region.

The Moh tribe, in contrast, are much more private about their bedroom activity, and rarely discuss their bedroom partners in public places. They gather in hidden places where they dance and talk with great hilarity about the complexities of life and language, for the Mohs know that things are only sometimes what they seem. Occasionally Mohs will try to copy Teh rituals, especially when they get tired of being ignored. Sometimes Mohs make tentative efforts at cross-cultural communication with individual Tehs who appear more sophisticated than most. However, because Mohs are indistinguishable in appearance from Tehs, Tehs are sometimes frightened and hostile if they discover a Moh in their midst. To prevent this discomfort and danger to themselves, Mohs have learned to avoid communication with Tehs, especially about anything related to bedroom activity. Mohs
do laugh among themselves when Teh chieftains seem so unaware of their own Teh customs which make Teh bedroom activity so apparent.

In many ways the Teh and the Moh tribes are quite similar. They participate in similar tribal survival activities of food-gathering, socializing, creative expression, and travel. But as is true for a number of minority cultures, an elaborate Moh culture has developed in response to exclusion from majority culture. The Moh have created their own churches, music, libraries, boutiques, holidays, and publications. Their language reflects specific customs and assumptions not shared by the Teh culture. Moh people travel on vacation to sections of the region like San Francisco and Provincetown that are known to be Moh-user-friendly.

Like the North American Indian tribes who signaled to each other with smoke, Moh people use several signals (like the labrys, the double gender sign, the pink triangle, and the color purple) to locate other members of the tribe. Moh people refer to each other as "family" or "choir members" or "members of the committee."

In general both tribes accommodate to their different ways without concern. The minority Moh tribe do not, however, control as many resources as the Teh tribe - and in one aspect of their lives the Moh people have particular difficulty. The Moh do not have their own institutions for healing, aging, or dying. They depend during these vulnerable times on the Teh people to provide what are called "health care services."

Often Moh people try to disguise themselves as Teh people if they are sick, or aging, or dying, but such hiding makes their situation worse because they are then separated from their usual customs and their true family. Of course, all Moh people have developed some skills in appearing to be what they are not, just to survive in hostile Teh environments. Most Moh people keep many disguises in their closets. Some disguises are worn when they go to work in Teh factories, and some they wear when they go to visit distant Teh cousins in the land where they were born. Some students of Moh and Teh culture are initially puzzled to learn that most Moh people were raised as young girls in Moh families. The Moh people have accepted that their gods and goddesses had some special reason for making them Moh, in the midst of Teh. They realize that the complex rituals of "coming out" as Moh have strengthened their courage, resilience, and flexibility, both as individuals and as a culture.

A few Moh people specialize in disguising themselves and provide great entertainment for the Moh people. These individuals are called "drag queens". They are Moh who can not only pass for Teh, but sometimes a Moh male can even be mistaken for a Teh female, to the amusement of their audiences. Moh people do not, however, think it is funny then Teh people demand that ALL Moh people pretend they are Teh.

Sometimes in their health care institutions, Teh people experience symptoms of Alibohpomoh Syndrome, which they believe to be a highly communicable problem which develops only in the presence of Moh individuals. Symptoms include rapid circular movements and shortness of breath, similar to those seen in the dance of the whirling dervishes. A few Teh experience even more embarrassing symptoms. Like those afflicted with Tourette's Syndrome (who curse uncontrollably), some unfortunate Teh providers shout out "queer" and "faggot" and "bull dyke" and point emphatically at Moh people who come seeking assistance. In this condition Teh health care providers are of course completely unable to assist Moh people with their problems. The Moh people recognize these symptoms of Alibohpomoh Syndrome, for many of them have
experienced it themselves in their youth. In more isolated corners of the region, some Teh people think that the only reason Moh people ever get sick was because they aren’t Teh. As a result of this ethnocentric ignorance, some Tehs try to change Moh people into Teh copies (also called clones or Xeroxes) instead of taking care of their illnesses. Fortunately this barbaric practice happens only in the least developed parts of the region.

Recently some of the males of the Moh tribe have gotten sick with a virus called AIDS. Some Moh elders, and even some wise Teh leaders, say this tragic epidemic means it is time to confront the denial and cruelty of the Teh tribes toward Moh people. But many of the Moh people are afraid to come out without their disguises. Most of them just pray that they’ll never get sick.

Scholars in many disciplines (1-3) are fascinated by the Moh and the Teh tribes and have begun to document and describe the similarities and differences between these two thought-provoking cultures. Nurses have always been leaders in providing quality care to people of all cultures. As the nursing profession becomes more aware of recent scholarly studies of the Moh and Teh peoples, nurses can incorporate this new transcultural research and theory into their nursing practice.

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APPENDIX P

BIG VILLAGE KINSHIP DIAGRAM

[Diagram of kinship relationships]
APPENDIX Q

RAINBOW VILLAGE KINSHIP DIAGRAM
APPENDIX R

WOMYN'S VILLAGE KINSHIP DIAGRAM
APPENDIX S
CARNIVAL VILLAGE KINSHIP DIAGRAM
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