

Chapter Four

FINDINGS

Respondents

The study sample consisted of nine women and ten men. Tables 4.1 and 4.2 provide a summary of their characteristics. An overall summary of respondent demographics can also be found in Table 4.3. The names, provided in the tables and findings below, are all fictitious. It is important to mention that a few respondents did not use the term “partner” to describe their relationship with the care-receiver. One female respondent referred to this person as her “friend” and another male respondent referred to the care-receiver as his “lover.” The term “partner,” however, will be used throughout the remaining text for the sake of uniformity.

Table 4.1

Characteristics of Female Respondents

Name	Age	Race	Education	Employment status	Care/relationship duration	Primary health conditions (partner)	Locale
Anna	69	Caucasian	MA	Retired	3 yrs/33 yrs	Lymphoma	S
Barbara	52	Caucasian	BA	Not employed	1.5 yrs/2.5 yrs	Diabetes Hepatitis C	S
Carie	54	Caucasian	BA	Disabled	4.5 yrs/4.5 yrs	Parkinsons	MW
Jane	62	Caucasian	AD	Retired	22 yrs/26 yrs	Diabetes Heart Disease	S
Lynn	53	Caucasian	HS	Employed	2 yrs/10 yrs	Brain Tumor	MW

Name	Age	Race	Education	Employment status	Care/relationship duration	Primary health conditions (partner)	Locale
Maria	74	Hispanic	MA	Retired	1.5 yrs/4yrs	Breast Cancer	S
Marjorie	77	African American	3 yrs of college	Retired	20 yrs/20 yrs	Diabetes Obesity	W
Sally	52	Caucasian	JD	Employed	5 yrs/12yrs	Breast Cancer	S
Ursula	67	Caucasian	2 yrs of college	Retired	10 yrs/17 yrs	Heart Disease Breast Cancer	NE

Note. All names are fictitious

EDUCATION: HS-High School; AD-Associates Degree; BA-Bachelors Degree; MA-Masters Degree

LOCALE: MW-Midwest U.S.; NE-Northeast U.S.; S-Southern U.S.; W-Western U. S.

Female Respondents

The female respondents share a common experience of providing care for a chronically ill partner. Many of their experiences will be detailed in the pages that follow. These women ranged in age from 52 to 77. Majorie, who was 77 at the time she was interviewed, was the oldest respondent in the study sample. Six of the female respondents had provided care to partners within two to five years of the time they were interviewed. Sally and Anna were the only study respondents to have last provided care within fifteen years of the time they were interviewed.

Many of these women were in long-term partner relationships and a few also provided care for several years. Six were in relationships that had lasted over ten years before caregiving ceased. Jane, Marjorie, and Ursula had provided care to their partners for ten years or more. There were also large age differences between some of the female respondents and their partners. Barbara had been twelve years older than her partner and both Sally and Ursula had been almost twenty years younger than their partners.

Some of the female respondents had been in heterosexual marriages prior to the partner relationship and some have also begun new partner relationships since the cessation of care. Five of the women had been previously married to men and Carie, Marjorie and Lynn each had adult children from their marriages. Three of the female respondents' partners had been married and Maria's partner also had an adult child from a previous marriage. Following the cessation of care, four of the female post-caregivers had entered new partner relationships.

The majority of the female respondents resided in the Southern United States. Only

Ursula resided in the Northeast and Marjorie was the only female from the Western United States. Barbara and Marjorie were the only study participants to live in areas with populations under 20,000. In addition, Barbara was the only study participant to not live in or adjacent to a major metropolitan area.

Although they tended to reside in the same area of the country, in other ways they account for most of the diversity in the study sample. For example, Marjorie and Maria are the only cultural minorities in the study and Carrie exists as the only respondent who is currently a caregiver. Although all but one of the study respondents are “post-caregivers,” most ceased caregiving when their partners had died. Jane, Marjorie and Sally, on the other hand, ceased caregiving when they ended the partner relationship. Maria ceased caregiving when her partner’s cancer went into remission. They are still together and recently had a commitment ceremony.

These respondents also cared for partners with diverse health conditions, including Parkinson’s Disease, heart conditions, diabetes, and cancer. Sally, Ursula and Maria, however, all provided care to partners who suffered from breast cancer. The women were also diverse in terms of their level of education and their employment status. Lynn and Sally were the only female respondents who were working full-time at the time they were interviewed. The women were currently and had been previously employed in various occupations including positions as a lawyer, teacher, college professor, social worker, counselor, business woman, systems analyst, and home repairer. Despite the differences in their level of education and employment statuses, all but one female respondent appeared to be middle class in terms of income.

Table 4.2

Characteristics of Male Respondents

Name	Age	Race	Education	Employment status	Care/relationship duration	Primary health conditions (partner)	Locale
Ben	64	Caucasian	BA	Retired	4 yrs/32 yrs	HIV/AIDS	NE
Brian	61	Caucasian	BA	Employed	3 yrs/16 yrs	HIV/AIDS	S
Don	60	Caucasian	MA	Employed	1.5 yrs/5 yrs	HIV/AIDS	W
Edward	57	Caucasian	Ph.D.	Employed	10 mos/5 yrs	HIV/AIDS	NE
Jeffrey	67	Caucasian	Ph.D.	Employed	2 yrs/34 yrs	Diabetes Heart Disease	NE
Jim	59	Caucasian	MA	Employed	1.5 yrs/7 yrs	HIV/AIDS	W

Name	Age	Race	Education	Employment status	Care/relationship duration	Primary health conditions (partner)	Locale
Lenny	64	Caucasian	MA	Retired	2 yrs/6 yrs	Lou Gehrigs (ALS)	MW
Mike	50	Caucasian	MA	Employed	4 mos/5 yrs	Colon Cancer	S
Paul	53	Caucasian	BA	Employed	7 mos/18 yrs	Lung Cancer	NE
Ted	50	Caucasian	Some College	Employed	10 yrs/17 yrs	HIV/AIDS	S

Note. All names are fictitious

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LOCALE: MW-Midwest U.S.; NE-Northeast U.S.; S-Southern U.S.; W-Western U.S.

Male Respondents

The male respondents have in common the experience of providing care for as well as losing a partner to a chronic illness. All of the male respondents were post-caregivers and had ceased caregiving because their partners had died. Several of these respondents had cared for and lost their partners to HIV/AIDS. For the majority of male respondents, the duration of this care was under two years. Ted, however, provided care to his partner for ten years. Seven of the male respondents had provided care within five years of the time they were interviewed. Don, Jim and Lenny had provided care within the last ten years of the time they were interviewed. Jeffrey had been widowed for less than a year when he shared his experiences with me.

Even though the male respondents were all Caucasian, three had partners who were cultural minorities. Mike and Jim's partners were both African American and Don's partner was from Laos. Jeffrey and Ben had been with their partners for over thirty years. As with the female respondents, age differences between partners were also apparent among the male respondents. Lenny and Paul had both been much younger than their partners, 12 years and 20 years respectively. Edward, Don and Jim had all been over ten years older than their partners. Also like the female respondents, a few of the men had been married to women prior to the partner relationship. Paul, Edward, Ben, and Lenny all had been previously married to women and each had adult children from those marriages. Mike and Paul's partners had adult children from a heterosexual marriage. Four of the male respondents had begun new partner relationships since the cessation of

care. Two of these respondents have had two or more relationships since the death of their partner.

The male respondents were very diverse in terms of where they resided in the country, although all lived in or adjacent to a major metropolitan area. The majority of the male respondents were working full-time, as Ben and Lenny were the only male respondents who were retired at the time they were interviewed. The men were currently and had been previously employed in various occupations including positions as a businessman, teacher, college professor, dentist, chaplain, counselor, fund-raiser, and archivist. All of the male respondents had completed at least a few years of college and several had also completed graduate degrees. All had also appeared to be at least middle class in terms of income.

Table 4.3

Summary of Respondent Demographics

Gender	9-female, 10-male
Race	17-Caucasian, 1-African American, 1-Hispanic
Age	range: 50-77, average: 60
Education	1-HS, 1-AD, 3-some college, 5-BAs, 6-MAs, 3-PhDs/JDs
Employment status	10-employed, 7-retired, 1-not employed, 1-disabled
Care duration	range: 4 months-22 years, average: 5 years
Relationship duration	range: 2.5 years-34 years, average: 14 years
Primary health conditions (partner)	6-HIV/AIDS, 6-cancer, 4-diabetes, 3-heart condition, 1-brain tumor, 1-Parkinsons Disease, 1-Lou Gehrig's Disease (ALS)
Locale	8-S, 5-NE, 3-W, 3-MW

EDUCATION: HS-High School; AD-Associates Degree; BA-Bachelors Degree; MA-Masters Degree

LOCALE: MW-Midwest U.S.; NE-Northeast U.S.; S-Southern U.S.; W-Western U.S.

Historical Context

It is important to keep in mind that many of the respondents have lived through a similar historical period. This particular period has seen both negative societal attitudes towards gay men and lesbians (including considering them mentally ill and unfit to serve

in the military) to the beginnings of gay liberation and somewhat more positive societal attitudes toward gay men and lesbians (Miller, 1995). Eight respondents also resided in the Southern United States, which has tended to hold more negative attitudes towards homosexuality (Sears, 1991).

Figure 4.1 shows the historical time period through which the respondents have lived. Certain historical events, which either positively or negatively affected the gay and lesbian community, are noted on the timeline. Because the respondents belong to different age cohorts, their ages during these time periods varied. The extent to which they were each aware of, involved in, and affected by the periods and events also vary.

The 1930s saw the beginning of gay men and lesbians socializing in gay bars in large U.S. cities. This time period also saw the enactment of several municipal laws that restricted movies and plays from portraying homosexual behavior and bars from selling alcohol to gay and lesbian customers. During this time in Germany, homosexuals (mostly males) were identified and sent off to concentration camps to die. World War II also marks the first time when military recruits were asked about their sexual orientation and many were turned away for being homosexual. In the field of psychiatry, the 1940s and 1950s progressed the image of the gay man and lesbian as mentally “sick.” It was not until 1973 that the American Psychological Association removed homosexuality from its Diagnostic Statistical Manual (DSM) of psychiatric disorders (Miller, 1995).

The Kinsey studies in the late 1940s and early 1950s also combated the image of homosexuality as a mental illness when it reported on the diversity of sexual orientation. Around this same time the McCarthy era fostered in an “anti-gay hysteria” and expunged

gay men and lesbians from federal jobs. The 1950s through the 1960s saw the emergence of urban gay and lesbian societies and organizations as well as newsletters. During the 1960s police raids and violence on gay bars became routine in many metropolitan areas. As a reaction to this treatment, the Stonewall Rebellion of 1969 witnessed the uprising of gay men and lesbians in New York City. This rebellion marked the start of the gay liberation movement (Miller, 1995).

The AIDS epidemic (beginning in the 1980s) has taken the lives of countless gay men. In the face of this crisis, the gay community has become stronger and more organized in its efforts to combat society's homophobia. The decade that followed (1990s) heated up the debate as to whether gays should be allowed to serve in the U.S. military. Despite the tremendous strides in the advancement and acceptance of gay men and lesbians in this country, individual as well as institutionalized homophobia and heterosexism are still alive and well. As a result, the present years have seen a great public struggle for equal rights and protections for gay men and lesbians, including marriage rights and the inclusion of sexual orientation in hate crime legislation. Although being gay or lesbian can no longer guarantee an individual the classification of a mental illness, it can still deny and obstruct their most basic human rights.

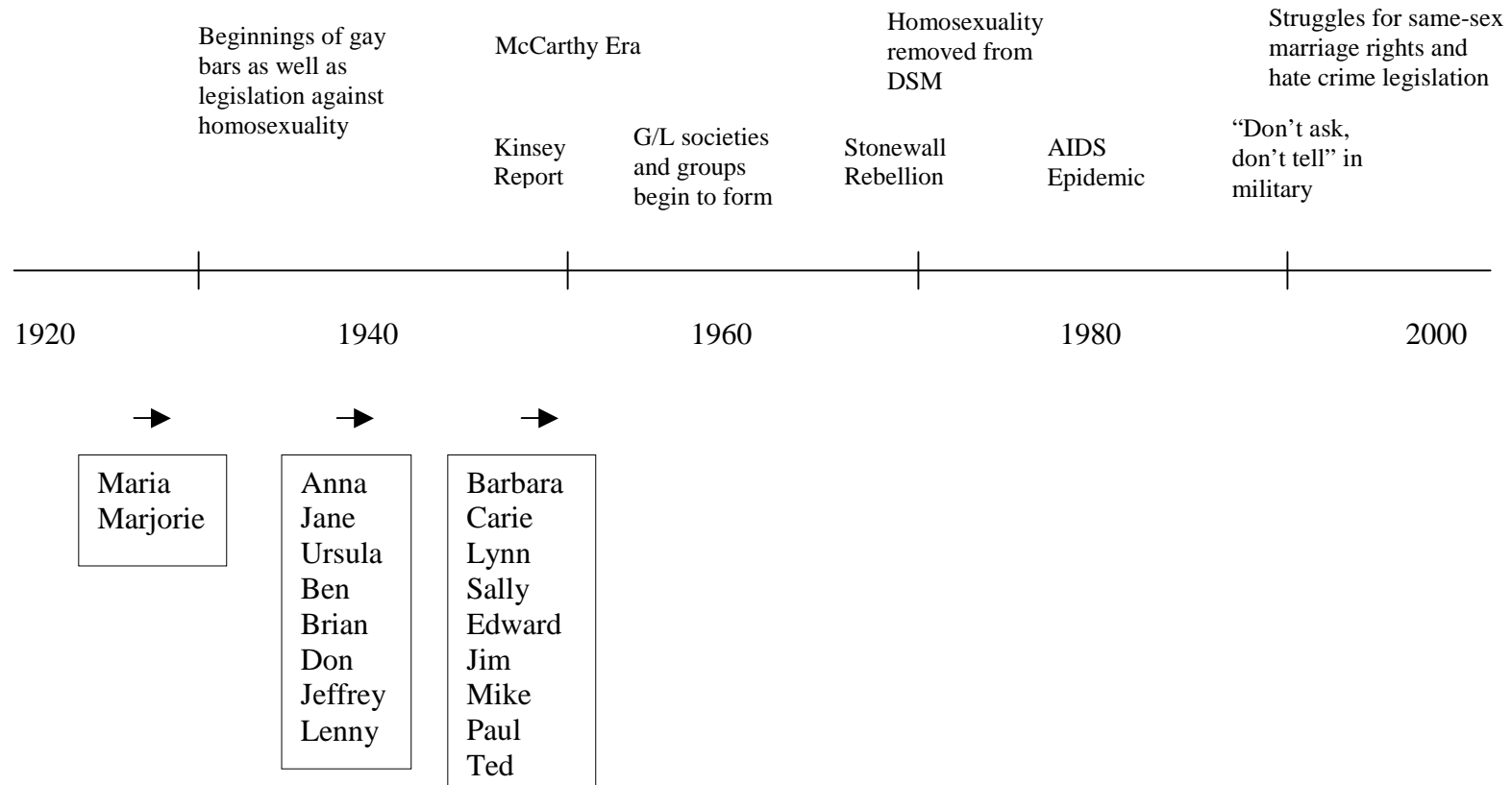


Figure 4.1. Timeline of Gay and Lesbian Historical Events (1920-2000)

Results

In this study, certain categories emerged from the data. The five broad categories include aspects of the caregiving experience, aspects of the post-caregiving experience, interactions with informal and formal support persons and services, long-term planning and decision making, and suggestions for changes to health and human services.

Subcategories will be discussed under each main category (see Table 4.4 for a listing of main categories and subcategories). Although not necessarily related to the caregiving or post-caregiving experience, respondents were also asked to share their suggestions for future sampling and other ideas regarding the study methodology.

Table 4.4

Main Categories and Subcategories

Categories	Subcategories
Caregiving experience	Strains of caregiving Positive aspects of caregiving Commitment to caregiving
Post-caregiving experience	Strains of post-caregiving Positive aspects of post-caregiving Reconstructing lives Outcomes of the experience
Informal and formal supports	Informal supports Formal supports and services Disclosure of the relationship
Long-term planning and decision-making	Decisions regarding the couple Long-term plans of the caregiver
Suggestions for changes to health and human services	Treatment of consumers Education and training Changes to larger systems Responsibility of consumers

The Caregiving Experience

Caregiving, as defined in Chapter One, often involves hands-on care as well as emotional support for a loved one. For the respondents, caregiving entailed personal care, meal preparation, ambulatory assistance, managing doctor's appointments and medications, as well as providing emotional support and comfort to the most important person in their life. Although most of the respondents identified these aspects of the caregiving role, two respondents had a somewhat different definition of caregiving.

When asked when caregiving began, Jeffrey answered, "It's hard to say. I always cared for him." He noted that his partner had always been somewhat dependent on him and caring for his partner had always been a part of their relationship. Brian also noted, "I didn't know I was a 'caregiver', I didn't even know what the word was until a good six months after he was gone. You do what you have to do for a person because you love them."

Although respondents noted different views on caregiving, they all acknowledged strains involved in providing care as well as positive aspects of the experience. The caregiving experience for these respondents, then, can be understood in terms of these strains and positive aspects. In many cases, there was also a very strong commitment to providing care for a partner. Only those aspects that relate directly to the situation as experienced by caregiver and/or the couple will be addressed under this section. Their interactions with and the impact of others involved during this time will be discussed under the section "Informal and Formal Supports."

Strains of Caregiving

Respondents revealed strains or difficult aspects of the caregiving experience (see Table 4.5). These strains were events or circumstances that caused emotional and/or physical hardship during caregiving and may have made the experience even more difficult. Strains of caregiving can be understood in terms of strains related to being the “primary caregiver,” strains related to the illness itself and its progression, strains resulting from changes in lifestyle and partner relationship, and employment and financial issues. The respondents also shared their general feelings regarding the difficulty of caregiving.

Table 4.5

Strains of Caregiving

Strains	Characteristics
Primary caregiver	exhaustion; lack of sleep; poor eating habits; physical strain
Illness and its progression	increased doctor appointments, medications, and treatments; managing medications and learning treatments; increased dependence and required care; emotional strain; need to be strong
Lifestyle and relationship changes	relocation or home modification; dietary changes; changes in the division of household tasks; changes in the physical aspect of the relationship
Employment and finances	conflicts with employment responsibilities; decreased finances; increased debt

One of the most difficult aspects of providing care was that one person managed the bulk of the caregiving responsibilities. At times this was due to lack of support from family and friends and in other cases it may have been intentional on the part of the caregiver, who did not trust anyone else to provide care to his/her partner. Other times, this was due to the wishes of the care-receiver. As Maria said of her partner, “She didn’t want anyone to take care of her but me.” In serving as the primary caregiver, the

respondents noted physical strains including exhaustion, lack of sleep, poor eating habits and physical strain related to hands-on care.

It was evident that there were also strains related to the illness itself as well as its progression. Several respondents mentioned the strain of managing their partner's doctor's appointments. As Jeffrey recounts, "We were forever running from one doctor to the other." Not only was keeping up with regular doctor appointments stressful, but unexpected trips to the hospital added even more strain. Jane explains that she and her partner were "constantly running to the ER in the middle of the night." Managing medications and treatments for their partners was also mentioned as being quite difficult. This management often required research (on the different medications) and sometimes even learning to administer a specific treatment such as injections. Some participants found this research and need to keep up-to-date to be very time consuming and stressful.

The progression of a partner's illness often involved an increase in the number of doctors' appointments and medications and treatments. This progression also increased care-receiver dependence that required increased levels of care from the caregiver. This progression, then, added even more strain on the caregiver. Together with the increased need for care and treatment, the progression of the partner's illness caused a great deal of emotional strain for the caregiving partner. Often, this emotional strain was related to their partner's reactions to their increasing care needs as well as their prognosis. As Lynn described, "The most stressful aspect of care was that I could not imagine how she felt...walking around knowing that she was dying." Similarly, others mentioned the difficulty of watching their partner's embarrassment as they cleaned up their bodily

functions. Several respondents also voiced frustration with not being able to make their partners well again through care. As Ursula shared, there was the stress of “knowing no matter how much I did, I could not turn it around.” Many also mentioned that they were in “denial” about the progression of the illness. A few respondents also mentioned that their partners developed dementia in the end stages of their illness. As a result, the caregivers dealt with emotional strain related to their partners’ not recognizing and being suspicious of them.

In the face of dealing with the progression of their partner’s illness, one overwhelming theme was that many respondents noted the need to be strong for their partner and not let their partner see the emotional toll the situation was taking on them. This was also to protect and keep as much stress away from their ailing partner as possible. Jeffrey remembers that, “I cried all the time when I wasn’t near him. I would cry all the way to work and all the way home.” Ursula admits that she tried “to keep it as light as possible...keep stress away from her...not to make everything so negative.” Being strong for their partner and trying to absorb the stress of the situation was a significant strain for many of the respondents during caregiving.

Because of the partner’s illness, there were changes in lifestyle as well as changes in the partner relationship. A few respondents mentioned the need to relocate once their partner’s became ill, moving into homes that were more accessible for physical disabilities. Several respondents also mentioned a change in diet that accompanied the onset of their partner’s illness. This was a major adjustment for some, like Sally and her partner, who switched to a macrobiotic diet when her partner was diagnosed with cancer.

A few respondents also voiced their frustration with their partner's lack of appetite, as food had always been a source of pleasure in their lives.

Caregiving also shifted the division of household tasks. This involved major role changes in the home. Prior to the partner becoming ill, tasks were divided up with regard to the interests and talents of each individual. When the partner became ill, many of the tasks became the responsibility of the caregiver. As Sally recalls, "I assumed responsibility for everything...laundry, cooking, cleaning, shopping...because she couldn't get out of bed."

Several respondents also mentioned a change in the physical aspect of the partner relationship. Maria had only been with her partner for a short period of time before her partner was diagnosed with breast cancer. She claims that there was an immediate change in the style of the relationship when her partner became ill, "from sexual to more compassionate" and she added, "We had to purposefully switch to love and compassion and tenderness because that is what she needed." Similarly, Lynn describes the relationship change as, "They become less your partner and more your roommate." A few respondents also mentioned that when their partner became ill they stopped sleeping in the same bed or even in the same bedroom. This was done to increase the physical comfort of the partner or to accommodate durable medical equipment.

All but one respondent had been employed during the time they provided care to their partner. As many of these caregivers worked full-time while providing care, they experienced conflicts with employment responsibilities. As Jane describes her multiple responsibilities at the time, "I had an office job during the day and a nursing job at night."

Barbara had to adjust her schedule and Ted ended up giving notice. During this time, decreased finances were also mentioned as stressful, as many of the couples went from two incomes to one as their partner's illness progressed. A few respondents were also faced with paying off their partner's debts. For some, this also meant going into a great deal of debt themselves.

As mentioned, there were several aspects of the caregiving experience that caused the caregiver as well as the couple a significant amount of strain. Respondents also offered general statements regarding the difficulty of being a caregiver. Ted described the stress of caregiving as being "phenomenal" and Sally called it "absolute agony." Reflecting on the overall difficulty of providing care, Paul confesses,

No matter who it is, whether they are homosexual or heterosexual, what people really don't understand is that when you agree to do something like that, be a caregiver for someone, when the door closes and clicks it's a whole different game than what you think it is. You have no idea of what you will be called to do for this person.

Positive Aspects of Caregiving

As described above, caregiving involved a great deal of strain on the caregiver as well as the couple. In spite of the many strains involved in caregiving, several positive aspects of the experience were also noted by the respondents (see Table 4.6). For these individuals, caregiving was an opportunity—to convey love and commitment, expand the relationship, and for personal growth.

Table 4.6

Positive Aspects of Caregiving

Positive aspect	Characteristics
Convey love and commitment	making partner comfortable; providing hands-on care; willingness to provide care
Expand the relationship	improved communication; increased physical closeness; increased emotional closeness and intimacy
Personal growth	discovered own capabilities; learned new skills; gained strength

Providing care, for many respondents, was the ultimate demonstration of love and commitment to their partner. This love was shown in many ways, including making a partner comfortable and providing hands-on personal care. Their willingness to provide care was also an act of love. As Ben describes, “It was a payback to him and chance to show him that I really did love him and wanted to take care of him.” Many also found that through caregiving, they really learned what it meant to love another person. As Sally relates, “Clearly, the most positive aspect was discovering what love is...discovering the depths of love...in the face of this horrendous tragedy.”

Conveying this love and commitment had a different kind of meaning for Ben. He was very angry and hurt that his partner had gone outside of the relationship and had contracted HIV. When they discovered that his partner had contracted the virus, he

started going to different agencies to learn more about the disease. He explains, “I heard horrific stories about some of the people there and realized how important it was for someone (with HIV) to have someone...so I stuck with it.” As will also be mentioned in the next section, many respondents were glad to be able to provide care and to affirm their commitment to their partner.

Providing care to a partner did not strictly entail a loss of passion, decrease in physical closeness and other adverse effects on the couple’s relationship. On the contrary, respondents mentioned many positive changes in the relationship as the result of providing care. These changes included improved communication and increased physical and emotional closeness. For many, this experience opened the door for improved communication. During this time couples began to discuss their deepest thoughts and fears. Sometimes these conversations would focus on the process of dying and what the surviving partner would do after the other partner had died. As Ted explains the change in communication, “Knowing that you have a limited amount of time, it gives you the opportunity to open up and really talk candidly about *everything*.”

Caregiving also allowed for increased closeness and often a deeper level of intimacy in the relationship. Although some stated that they had always been close, their partner’s illness and the provision of care clearly deepened the level of intimacy experienced by the couple. As Edward explains, “I don’t think I’ve ever before or ever since experienced a level of intimacy similar to that experience...and I never experienced someone trusting me to the level that he did...even when he was incontinent.” Jim describes the day they

discovered that his partner was HIV positive and how his commitment to stick by him deepened their relationship,

I remember that minute when they told us that John was (HIV) positive and he turned around to me and said, 'Well?' and I looked at him and I said, 'What do you mean "well?" Do you think that I'm going to give up one minute...ya know, I don't know, but we'll deal with it. It's OK.' I was not gonna give up one second with this man. I was just totally, madly in love with him. This commitment brought us a lot closer and he was surprised that I didn't jump ship.

One of the most touching accounts of a positive change in the relationship was provided by Jeffrey as he disclosed that when his partner became ill, they began sleeping in the same bed again. His partner initiated this increased physical closeness because "he wanted to move back into my bed so we could hug and hold each other." Up until this point, he and his partner had not been very affectionate and he admits, "We would only kiss goodnight" and had separate bedrooms for 25 years. After they arranged the bedroom to accommodate his partner's medical equipment, Jeffrey recalls, "When I didn't have to be someplace, I would be in bed with him, even if it was in the middle of the day and I was just reading." Of this heightened closeness he shares, "It was the most beautiful thing I have ever experienced."

Providing care also allowed respondents to learn and grow as individuals. In caregiving, respondents learned a lot about themselves and what they were capable of doing for another person. The experience also taught them skills, including how to be more patient, how to deal with people (including professionals) and be assertive, how to

be more compassionate, and how to manage time and multiple responsibilities. For many respondents this had been their first exposure to caring for someone with a chronic illness. For these persons, caregiving provided an even greater opportunity for personal growth and discovery.

One overwhelming theme was that the experience of providing care gave the respondents a tremendous sense of strength. Managing the multiple tasks of caregiving as well as dealing with the emotional strain of the situation left several respondents with an increased sense of emotional and spiritual strength. It also proved what they were capable of doing for the person they loved. Barbara comments on her acquired strength and discovery of what she was capable of,

I thought, if I could go through this I can go through anything. I had gone for months with hardly any sleep, with working, with driving, with providing care, with battling all sorts of people around us for someone who hardly recognized me half the time. I could get through anything.

Commitment to Caregiving

Although caregiving involved great personal sacrifice for the respondents, many voiced a commitment to providing care for their partner. Interestingly, the level of commitment did not appear to be related to the duration of the relationship. A caregiver who had been with his/her partner for four years had essentially the same level of commitment and desire to provide care as a caregiver who had been with his/her partner for over twenty years. For the majority of respondents there was an unwavering

commitment to stay by their partner's side and not leave him/her during his/her time of need. Several respondents also commented that they have no regrets about caregiving and that if they had the another chance to provide care for someone they loved, without question, they would do it again. As Ursula shares,

For me, it was a total joy to be there for her and I would do it in a heartbeat again...I would do it for any person I loved. I was just very happy that I could do it.

The Post-caregiving Experience

Post-caregiving is defined as the period following the cessation of care. In the lives of these respondents, care ended either because the partner died, because the partner relocated to be cared for by a sibling, because the caregiver left the caregiving situation, or because the partner's illness went into remission. Despite the reason for the cessation of care, the loss of the caregiver role had a significant effect on the lives of the respondents. Respondents noted both the strains related to the cessation of caregiving as well as the positive aspects of no longer providing care. They also faced the challenge of reconstructing their lives following the loss of the caregiver role. During post-caregiving they also recognized the impact caregiving has had on their lives and could identify the outcomes of the caregiving experience (see Table 4.7).

Table 4.7

The Post-caregiving Experience

Aspects	Characteristics
Strains	Emotional distress including loss, loneliness and depression Difficulty adjusting to the loss of the caregiver role
Positive aspects	Improved physical health Increased social interaction Time to attend to own needs
Reconstructing Lives	Getting a “life” or new focal point Redefining oneself Re-entering gay community and dating “Letting go” and “moving on”
Outcomes of the experience	Changes in vocation or career focus Activism Becoming more “out” or open in communications Changes in outlook on life

Strains of Post-caregiving

As stressful as the caregiving experience had proven to be, post-caregiving introduced a new set of strains, described by respondents as a “tremendous transition” and an “on-going process” where the changes are continuous. During this time, most of the respondents were dealing with the death of their partner. These were extremely traumatic experiences even though many knew that the loss was inevitable. As Jeffrey recounts, “In spite of how sick he was and how I prayed that he would go...you could be prepared for the news of somebody dying but there is no way you can prepare for the feeling.” Respondents who had not experienced the death of their partner were still faced with the loss of the caregiver role and the life changes that occur as a result. In post-caregiving, respondents experienced the strains of emotional distress and difficulties adjusting to the loss of the caregiver role.

Most of the respondents experienced emotional distress following the cessation of care. Respondents expressed feelings of loss, loneliness and depression during this time. The loss of a partner was deeply felt and described as one that a person never really “gets over.” Even those who have moved into new relationships admit that they still feel the pain of this loss in their daily lives. This terrific sense of loss was often accompanied by an incredible feeling of loneliness. Respondents noted how this loneliness was compounded by the fact that they continued to live in the home they once shared with their partner. This home often held a lifetime of memories that served as a constant reminder that the caregiver was now alone.

Homes that were once shared with a partner often seemed large and empty in post-caregiving. Several respondents also described feeling a large empty space or void in their lives following the cessation of care. As Ursula shares,

Every so often I will sit in the morning and cry. There is an empty space that I have never, never experienced before in my life...it's a hole. There's a part of me that died that day. There is so much in my life that is missing and nothing fills that void.

Many respondents not only felt a terrific sense of loss and loneliness but also became deeply depressed following the loss of a partner. For some of the respondents, this depression resulted in sleeplessness, loss of appetite, and loss of interest in activities. For others, it resulted in an ambivalence towards living. Lynn confessed that she did not care if she died after she lost her partner as she felt "spiritually and emotionally dead." Mike admits that he was so depressed following the loss of his partner, that he attempted suicide twice.

Respondents also mentioned having difficulty adjusting after the loss of the caregiver role. These respondents provided care for their partners for months and sometimes years and endured great emotional and physical hardship in order to keep up with the daily demands of caregiving. As their partners became increasingly more ill, caregivers continued to meet the escalating care needs. It is not surprising, then, that several respondents mentioned a "crash" following the cessation of care. As Anna recalls, "There's a real crash behind this... You are existing on adrenaline (during caregiving) and when the need for it is gone...oooh." Lynn described a similar feeling, "You are running

90 miles an hour...and all of a sudden you come to a screeching halt and slam into this brick wall and there is this nothingness.” Jeffrey also shared his feelings about the loss of the caregiver role,

I miss the good feeling I had about myself when I was taking care of James. I had devoted myself so completely, using all my mental, physical, and emotional resources, doing something I cared about, believed in and felt was important. Then when he died and the caregiving was suddenly over there was a huge void, the loss of feeling good about myself to which I had become accustomed. I believe there is something about helping other people that gives us all a certain kind of “rush”...People who are long-term caregivers become so accustomed to a steady diet of “rush” that, I believe, it becomes addictive. Now (after 7 months) I realize that I still miss that joy of caregiving.

Positive Aspects of Post-caregiving

Although post-caregiving provided many challenges for the respondents, the cessation of care also involved many positive aspects. In post-caregiving, respondents enjoyed improved physical health, increased social interaction, and more time to attend to their own needs. It was mostly those who had ended care by leaving the situation and/or terminating the relationship that mentioned positive aspects of post-caregiving. Jane, whose partner relocated to her sister’s home, said the cessation of care “felt like somebody really took a load off my shoulders.” Although she felt a great deal of guilt, she also felt relieved. Marjorie left the caregiving situation after it was clear that her

partner was not concerned with her own health or with taking steps to improve her health. Since she left, she has enjoyed more time for travel and volunteer work. Sally, who also left the caregiving situation, says she is “rediscovering peace” now that she is no longer a caretaker. Although he deeply grieved after the death of his partner, Brian found that he looked forward to having some time for himself and to be “selfish” for a change.

Reconstructing Lives

Since the cessation of care, the respondents have experienced many changes and have been faced with the challenge of reconstructing their lives. As caregiving had significantly altered their lives, post-caregiving and the loss of a partner would present its own set of unique challenges. Redefining oneself as an individual (and no longer one-half of the couple or the “caregiver”) and eventually moving on into a new relationship existed as significant challenges for the respondents as they attempted to reconstruct their lives.

Some respondents, as Jane describes it, needed to “get a life” or a new focal point in post-caregiving. For some this involved immersing themselves in their own interests or pursuing new interests. Several respondents also mentioned that they have become re-engaged in the gay community since the cessation of care. During caregiving they had little time to become involved in activities outside of the home. Now, they have the time to become involved again in the gay community and can attend social functions and volunteer for gay and lesbian organizations and causes.

A few respondents had been in a relationship for most of their adult life and were now venturing out into the gay community for the first time. Anna had a younger lesbian friend who introduced her to the lesbian community after her partner died. Anna describes her exposure to the lesbian community for the first time,

I had never been to a (gay/lesbian) bookstore. I didn't know anything about women's music. It was scary at first. I was blown away. I cannot tell you what it was like the first time I walked in (to a Women's music festival) and knew that every woman in that room had to be a sister. Finding community!

Reconstructing their lives not only meant finding a new focal point and pursuing interests but it also meant redefining oneself after the loss of the relationship. Several respondents have struggled with this challenge of re-defining themselves following the cessation of care. Jeffrey, who has lost his partner in the last year, is currently struggling with the questions, "What will my life be without him? Who am I without him? My life was so wrapped up in his and I defined my life around being his partner." Again, for those who had been with their partner for several years, re-defining themselves without this person has been even more challenging.

One of the biggest challenges for the respondents has been to re-enter the dating world and begin new partner relationships. Six of the respondents were in new relationships at the time they were interviewed. Several respondents noted the difficulty of dating and embarking on new relationships. Dating has been frustrating for Mike who claims he has dated eighteen different people in one year and describes those relationships as "sordid." He feels like he is looking for a substitute for his partner. Barbara and Lynn also admit

that they began serious relationships too prematurely as it was just too soon after the death of their partners. Similarly, a few respondents mentioned that they are just not ready to begin dating again and are happy with the company of good friends. A few respondents, like Brian, said they had tried to date but their “heart wasn’t in it.” He continues, “At that point I made up my mind...I’ll just be one of the old, aging queens...Instead of having a partner, I’ll have a lot of friends.” Then,

When you least expect it...BOOM...comes somebody else. Here’s somebody, 30 years younger, considerably more flamboyant and outgoing than Kevin was. In many ways he has outed me more than I have ever been. And that’s the best thing in the world that ever happened. Why hide? And at this age, what difference does it make? It’s wonderful to be a senior gay citizen.

A number of the male respondents have described the dating scene as a “young market,” which can make meeting someone very difficult. Others, like Ted, say that it is difficult to meet a companion unless you are “into the bar scene.” He admits that he has started doing abdominal “crunches” because “as you get older, you have to stay in shape because it is a very young market out there.” Relationships established in this dating scene have been described as being very fleeting. As Ben relates, “In the gay world, everybody eats and runs” and just has sexual encounters. Conversely, Marjorie describes dating among lesbians in her community is like ‘living in a fishbowl’ as she describes it as “an incestual group” who “play musical chairs a lot.” She, on the other hand, is a very private person. She also wonders if her being African American and quite a bit older than other lesbians in her community may create an added barrier to dating.

Those that established new partner relationships have noted the challenge of “letting go” of the former relationship and “moving on.” In some cases this has involved changing their home environment to reflect this new relationship. Edward says that there are a few belongings of his former partner that he does not know how to deal with and says, “I have gone from 25 pictures of him down to 1.” He says this has been difficult for his new partner to deal with. Similarly, Brian mentions an effort to redecorate to be more inclusive of his present partner. Although Maria and her partner are still together and her partner is now in remission, they had difficulty on moving on in their relationship and, as she describes, “begin a daily, normal life” that did not revolve around caregiving and cancer. They have since moved in together and have had a commitment ceremony.

Outcomes of the Experience

In looking at the hardships as well as the joys of caregiving and post-caregiving, it is not surprising that these experiences would have a major impact on a person’s life. For the respondents, there were changes made in life or outlook on life that were influenced by the caregiving experience and, for some, the loss of a partner. This included changes in vocation or career focus, increased activism, and more open communication regarding oneself, and changes in one’s outlook on life.

For some, this involved a change in vocation or a new focus in their career. Sally’s caregiving experience fueled her desire to practice law and protect the rights of same-sex couples. Maria now focuses her therapy on women with breast cancer. Ben has changed careers and is now a chaplain and provides support to patients and families in a hospital

setting. Jim says that the caregiving experience sharpened his desire to pursue a counseling degree and he wants to work in the area of grief and loss because, he says, “These are my issues.” Marjorie has focused her volunteer work on helping caregivers. Because she was distraught with the way that “the patient gets all the pity, sympathy and attention and the caregiver gets nothing but to watch their life go down the toilet.” She now provides respite to caregivers and is attentive to their need to talk.

Although not necessarily changing vocations, Anna and Edward entered into activism as a result of their experiences. After her partner died, Anna was distraught that there were no formal supports for her as an older lesbian. She began to do research and contacted services that cater to older gay men and lesbians. She headed out in her “camping rig” and traveled through an entire state, collecting information on different services. As a result, she founded a support organization for older lesbians in her community. She says it was the beginning of her activism and claims this was,

An effort to try to establish a network of women my age that I could socialize with and kind of have a connection. We have lots of women who are widowed and have found us. Lots of women who were very isolated have found us.

In fact, she met her current partner through this group and says, “we have really become radical dykes.” Edward has become very involved in and “a very strong advocate of the...for lack of a better term...the gay and lesbian agenda in health care education.” He was to present a paper at a national conference that would be the first presentation on gay and lesbian issues in his discipline.

Although not necessarily engaging in activism, many respondents noted becoming more open in their communications as the result of their experience. Some became more out or outspoken about their same-sex relationship. As Edward explains, “That is a consequence...I have understood that it’s important for me to be who I am and part of that is being gay.” Also as a consequence of caregiving and losing a partner, Edward claims that he is much more open in his communications with professionals about “who he is.” When asked if he is “married,” he will now say, “I am not married, I’m in a domestic partnership” and he admits, “Now I set the boundaries where I want them and not where others want them.” Prior to this experience, he claims he would just say, “I’m single.” Anna has also become more open in her communications and admits that she never verbally came out to anyone until after her partner died. Ursula says she is more open as a result of the experience and has now reached a point where, “I don’t need to hide anything from anybody...if you like me, fine, and if you don’t, that’s OK too and I don’t need you in my life if I can’t be myself with you.” Ben also states that he is a little more out as a result of the experience.

As a result of caregiving and post-caregiving, some have changed their outlook on life. For these respondents, this meant becoming clearer about what is important in life and in relationships as well as becoming more spiritually aware. Through this experience, Ted discovered the importance of balance in his life, including time for loved ones. He is no longer interested in “building up a huge retirement account” and says he doesn’t care if he is poor the rest of his life. Jim disclosed that caregiving helped him understand what is important in a relationship and he has become clear about the type of

companion he wants in his life. As a result of the experience, Jeffrey claims that, although he has never been a very “religious” person, he is beginning to explore spiritual issues to try to make sense of his loss. He is reading about afterlife issues and finds this comforting because “he (his partner) can’t just be gone.”

Formal and Informal Supports

As mentioned, the majority of the respondents described themselves as the sole caregiver for their partner, providing the bulk of the hands-on care as well as emotional support. In addition to this primary caregiver, other individuals were also involved in the lives of the couple during caregiving and post-caregiving. These persons were family members, friends, coworkers, and professionals whose interactions (or lack thereof) with the couple impacted the caregiving and post-caregiving experiences. The respondents’ negative as well as positive encounters with these individuals will be detailed. One respondent stressed the importance of sharing the positive experiences. As Jeffrey notes, “There is so much publicity about the difficulties of being gay,” which is why he feels it is so important for people to see that there are family members and professionals who are supportive of these couples. Whether these individuals were supportive or unsupportive, the respondents were also faced with disclosing the nature of the partner relationship to formal and informal support persons. For this reason their disclosure experiences will also be discussed.

Informal Supports

Informal support persons include family members, friends, and coworkers and employers. These persons either provided emotional support or helped with hands-on care or they were less involved and at times, estranged and not accepting of the relationship (see Table 4.8 for a summary of supportive and unsupportive responses). It is important to note that despite the actions of these informal support persons, sometimes it was the caregiver and care-receiver who influenced the support received. Don echoes several respondents' views when he says, "People were generally as supportive as I gave them the opportunity to be. But, when you are so involved in caregiving you don't have time to reach out to that support." Similarly, Lynn says that family and friends were supportive "when I would let them be."

Table 4.8

Informal Support Persons' Responses in Caregiving and Post-caregiving

Support persons	Supportive responses	Unsupportive responses
Family	Provided emotional support and assisted with hands-on care	Did not acknowledge or questioned the legitimacy of the relationship
	Were accepting of and respectful of the relationship	Provided no or superficial support
	Became more accepting of the relationship and reached out to the couple	Had discordant communications with caregiver or care-receiver
	Maintained contact and supported the caregiver in post-caregiving	Were only interested in what they would inherit from the care-receiver
Friends	Provided emotional support and "just listened"	Were too busy to help out
	Provided hands-on care	"Dropped off" because the couple could no longer socialize
	Re-engaged post-caregivers in social activities	"Drifted away" as partner became increasingly more ill

Support persons	Supportive responses	Unsupportive responses
Coworkers and employers	Allowed caregivers to maintain a flexible schedule	Did not recognize the relationship, the caregiver role, or the loss
	Helped caregiver complete their work	Did not provide leave time during caregiving or bereavement
	Gave the caregiver time off even when the organization's policies did not extend to same-sex partner	Did not display the same level of sympathy to the gay/lesbian widow(er) as they had to heterosexual widows(ers)
	Offered legal assistance to caregiver	

Family.

With regard to informal support persons, several respondents mentioned unsupportive family members and the difficulty of dealing with family members who were just not supportive of the relationship. For some, this resulted in total estrangement from families of origin. For many, though, this meant contact but strained relations during caregiving and post-caregiving. Barbara's mother would listen to her but "she refused to acknowledge that it was any sort of relationship...she never accepted it as a caregiving role and she felt that I was being unduly burdened." Later, when Barbara's father died, her mother sought her support. Barbara declared, "You never gave me any support." To which her mother answered, "It's not the same, it was different...we'd been together,

your father and I, fifty years and we were *married*.” Similarly, Brian’s brother and sister-in-law were less than supportive after his partner died. When he called to tell them that his partner had passed his sister-in-law answered the phone and as Brian describes the call, “I told her ‘hi’ and I told her that Kevin had died. She replied, “Oh, I’m real sorry...have I told you about things going down at the church?” Totally uninterested. It was too awkward for them.” Likewise, Ursula notes that although her family provided some emotional support following the death of her partner, “There was no real depth in their support...it was more like ‘the weather, isn’t it nice?’”

A few respondents mentioned that their partner’s families were openly and blatantly unsupportive during caregiving and post-caregiving. Jane, for example, has had great difficulty with her former partner’s family in post-caregiving. Although they did not provide much care or relief while her former partner lived with her, now that she is living with one of her sisters, they are preventing Jane from having contact with her. Jane believes this is unnecessary and says, “After all those years of caregiving and being friends and being in a relationship, we should be able to be friends.” Another incident with a partner’s family became explosive. Ben’s partner’s family did as little as possible to help out but wanted to insure that they would inherit “everything” when his partner died. When Ben confronted them about not helping out, his partner’s brother responded, “Well, my brother was a whore...that’s why he got sick (with HIV/AIDS).” Ben “decked” him and says of that incident, “I completely lost it. I thought I’d kill him when he said that.”

A few respondents noted that either they or their partner had been estranged from their families because of their sexual orientation. Total estrangement from families of origin, though, was very rare among these respondents. Carie, who is currently caring for her partner, feels very isolated and says that her partner's estrangement from her family of origin has put a great deal of strain on the situation and their relationship. Additionally, Carie's adult children have only recently begun to be supportive of the relationship. Other respondents mentioned that their partners had the challenge of re-establishing relationships with estranged family members once they became ill. Although most family members were not estranged from the couple, many did not live nearby and could not assist with hands-on care.

Three of the respondents' partners had been previously married to women and had children from those relationships. These ex-spouses and adult children, at times, made caregiving and post-caregiving even more difficult. These persons were described as being resentful over their ex-husband's or father's "coming out" and leaving the family. Edward's ex-wife had sent him a "mean spirited" letter describing her embarrassment after reading his partner's obituary in the newspaper and she changed back to her maiden name immediately thereafter. Paul's partner's children went as far as not mentioning their father in their marriage announcements, which were published in the newspaper. Similarly, Mike's partner's son was "bitter" about his father being gay and leaving his mother and was only interested in what he would inherit when his father died. Mike's partner's son came down after the funeral but was only interested in "what he could get" from the estate. Paul also experienced problems with his partner's children. He shared,

“At the funeral when it came time to cover him up...they asked his daughter to cover him up and she refused...they asked his son to cover him up and he refused.” Paul was very upset and he went ahead and covered up his partner. He explains, “I figured it would be the last thing that anyone would ever do for him.”

Despite the lack of support some respondents experienced with family members, a common theme was that they did not blame them for their feelings or actions and were not really surprised by their actions and reactions. As Ursula confesses, “I don’t fault them for it...that’s where they are.” Edward asserts that he didn’t really want the support of his partner’s family. Jim shared that his partner’s mother had difficulty with her son having HIV/AIDS, so she was not emotionally able to assist with care and be completely supportive. Instead of being angry with her, he admits, that part of his growth was to come to an understanding that “people do the best that they can and they do what they are able to do. Sometimes it is not what I would like but it’s what they are able to do.”

There were also family members who were supportive in the caregiving process. Relatives of the respondents often reached out in support and acceptance to their adult child’s ill partner. For example, Paul’s mother would come to the house and help out and would also write his partner letters and call him on the phone and offer her support. Ted’s family also helped out and even purchased a family plot in a mausoleum with Ted and his partner. It was also found that a care-receiver’s family reached out to the caregiver. Mike shared that he became closer to and received great support from his partner’s mother. This was unusual, as he did not have much contact with her prior to his partner becoming ill. They shared caregiving duties and even became allies in many

negative dealings with nursing home staff. As Mike explains, “Many times, as you know, in same-sex relationships, when one of the people gets sick the family steps in and pushes out the partner, but she and I actually partnered in his care.”

Four respondents mentioned that they remained in close contact with their partner’s family after their partner had died. Brian reports receiving far more support from his partner’s family than his own family following his partner’s death. Mike even helped to take care of his partner’s mother when she became ill. Interestingly, only three respondents reported having no difficulty with family members (either their own or partner’s) during caregiving or post-caregiving. These family members were supportive to the couple and accepting of the relationship.

Friends.

The major role of friends was to provide comfort and to just “listen” during caregiving and following the cessation of care. Some friends also assisted with hands-on care and with transportation to doctor’s appointments. Friends also helped clean and “get rid of things” after a partner had died or relocated. Friends also played a key role in helping respondents to re-engage in social activities following the cessation of care. As previously mentioned, some friends introduced or re-introduced respondents to the gay and lesbian community. Ted noted the importance of a support person who was not even a “person” at all, but rather “man’s best friend.” He asserted that his partner’s dog was a major support and comfort during his partner’s illness. Several respondents also noted that the best friends during caregiving and post-caregiving were former partners (of theirs or the care-receiver).

A few of the female respondents mentioned having a strong “family of friends” who supported them throughout caregiving and post-caregiving. Sally had a group of friends that she called a “lesbian collective.” This collective was made up of her partner’s sister and her partner (who lived on the other side of their duplex) as well as 6-8 other lesbian friends. The members of this collective helped with hands-on care as well as taking her partner to doctor’s appointments. Additionally, this group adjusted their diet to macrobiotics (to help her partner with her illness) and shopped, cooked, and ate dinner together. She said it was also like having their own support group. She says of this support, “Without them it would have been a devastating, isolating experience. To me it was sisterhood. I wouldn’t have survived without the love and support from my lesbian circle of friends.” Similarly, Anna recalls that several lesbian friends were always there by her side, helping her during caregiving. She says of the experience,

Our friends were in and out...I mean all the time. The lights were always on and the doors were never locked. I never had to call anybody, they were just there.

Let me tell ya, there is something about “family of choice.”

Maria and her partner also formed a “special group of support,” a group of friends (mostly lesbians) who provided emotional and physical support. Jim was the only male respondent who mentioned a group of friends who provided continual support and said, “Everybody had keys to everybody else’s house.” Some of these friends were also HIV positive.

A few respondents mentioned that some of their friends were not at all supportive in caregiving or post-caregiving. It was very upsetting for the respondents when some

friends “drifted away” during the course of their partner’s illness. Other friends had good intentions but were always too busy to help out. A few respondents reported that some friends abandoned them when their partner became ill. The respondents discovered that these were “superficial friends,” those who either could not deal with illness or who stopped calling because they knew the couple could no longer go to parties and clubs. As Jim exclaims, “We became very aware of the people who can walk with you and the people who cannot.”

Coworkers and employers.

As mentioned, many of the respondents were employed during caregiving and post-caregiving. During this time they were often juggling the demands of caregiving along with their responsibilities at work. Following the loss of a partner, respondents were also dealing with a tremendous loss while simultaneously trying to manage their workloads. As a result, their interactions with coworkers and employers also impacted the caregiving and post-caregiving situations.

The majority of the respondents were not “out” at work. It seems, however, that the coworkers who discovered the true nature of the relationship when the respondent’s partner became ill, offered emotional support. Supportive coworkers and employers also helped the respondents keep up with their workloads and were flexible when the respondents needed time off to care for their partners. In post-caregiving, they sent sympathy cards, attended partner’s funerals, and granted bereavement leave (even when formal policies did not account for partners). This was also the case for some caregivers who were not particularly “out” at work. Don, for example, admits that his boss and

coworkers gave him “a lot of leniency” as far as taking days off during caregiving and bereavement. And, he explains, “They didn’t say, ‘Oh, your gay partner died.’ They just knew I had to have bereavement leave.”

Several respondents described the reactions of coworkers when their partner died. These reactions were often discomfoting. A few respondents recalled that when their partner died, they did not receive the same empathy from coworkers as their heterosexual counterparts received when their spouses had died. As Barbara describes, “One person gave me flowers and two people gave me cards, but I think they had no concept. And, I did see that when one of their husbands died they got all sorts of things.” Edward recounts that when his partner died, his coworkers had to deal with, “A) That I’m gay, B) That my spouse has died, C) That he had AIDS...all at one time.” From this he learned that this was too much for them to deal with and in hindsight he is not surprised that they were of no support to him and did not fully recognize his loss.

A few respondents mentioned that because the bereavement policy at their workplace did not include same-sex partners, they were unable to take a leave after their partner had died. As mentioned, other respondents’ employers allowed them to take bereavement leave even though their policy did not account for partners. Still other respondents did not approach the subject with their employers and took vacation days or personal days during bereavement. Since the majority of respondents were not “out” in their workplaces, they often took vacation days or personal days during caregiving as well.

Formal Supports and Services

Formal supports include paid and volunteer personnel who work for an agency, church, hospital, clinic, etc. These supports also include persons employed in organizations outside of health and human services including funeral homes, cemeteries, newspapers, etc., with whom respondents had contact during caregiving and post-caregiving. Formal support services will also be discussed under this category. Most of the respondents reported having one or more negative experiences with formal support persons or services. Equally important is the fact that respondents also encountered incredibly supportive and understanding professionals in caregiving and post-caregiving. In general, there appeared to be no pattern to who was supportive and who was not supportive.

Before detailing their interactions with professionals, it may be of interest to reveal the types of services the respondents utilized in caregiving and post-caregiving (see Table 4.9). Twelve respondents mentioned receiving one or more mental health services. With regard to mental health and related services, nine respondents mentioned seeking support from formal support groups (mostly during bereavement) and nine respondents received individual or couples therapy from counselors, social workers, or psychiatrists. Four of these support groups were affiliated with gay, lesbian, or HIV/AIDS organizations. Twelve respondents reported using one or more in-home support service during caregiving. With regard to in-home services, seven respondents mentioned having home health services during caregiving, three respondents received hospice services, two respondents received meals on wheels, and one respondent received an aide from a

community organization. Four respondents were connected to HIV/AIDS or gay male health support services and one respondent received support from a lesbian health care organization. Six respondents reported affiliations and involvement in gay and lesbian spiritual, political, or social groups. Five respondents reported seeking support from gay and lesbian affiliated or “friendly” spiritual organizations and five respondents have been involved in gay and lesbian social or political groups. Three respondents were connected to organizations that specifically serve older gay men and lesbians in their area. Two respondents sought support through message boards or chat groups on websites intended for the gay and lesbian community. There was only one respondent who was not connected to any formal support services in caregiving or post-caregiving.

Table 4.9

Service Utilization of Respondents in Caregiving and Post-caregiving

Mental health services	In-home Services	G/L health care organizations	G/L spiritual, political or social groups	Older G/L services	Internet support
♀♀♀♀♀ ♂♂♂♂♂ ♂♂♂♂♂	♀♀♀♀♂ ♂♂♂♂♂ ♂♂♂♂♂	♀♂♂♂♂ ♂	♀♀♀♀♂ ♂♂♂♂	♀♀♂	♀♂

G/L- gay and/or lesbian

♀ - designates a female respondent who used one or more service from the categories above

♂ - designates a male respondents who used one or more service from the categories above

Negative experiences with professionals.

All but two respondents mentioned one or more negative encounters with formal support persons. These experiences with unsupportive professionals seemed to add a great deal of strain to an already difficult situation. As one respondent asserts, “It’s just another obstacle at a time when you don’t need more obstacles...every day and every hour in a situation like that (caregiving) is a challenge.” These negative encounters can be understood in terms of experiences related to the culture of health care organizations, staff attitudes towards same-sex couples, and additional discrimination based upon other characteristics of the care-receiver or caregiver (see Table 4.10 for experiences and reactions to this treatment).

Table 4.10

Experiences with and Responses to Unsupportive Professionals and Policies

Unsupportive actions of professionals	Unsupportive practices and policies	Respondents' responses to unsupportive actions and policies
Misdiagnosed serious conditions or provided insufficient or incorrect information	Refused to recognize partner as next of kin, primary contact or significant other	Ignored poor treatment
Failed to recognize patients as individuals and did not provide individualized care	Practiced insensitive and inappropriate intake procedures	Demanded respect from professionals and presented appropriate documents
Covertly expressed homophobic attitudes by being rude or hostile	Omitted the word "partner" from obituaries	Reported unsupportive staff to department heads
Overtly expressed homophobic attitudes by making slighting remarks and threats	Did not allow partners to share a mausoleum drawer	Used sarcasm in communicating with unsupportive staff
Discriminated against individuals on the basis of race, age, or HIV or mental health diagnosis		Paid additional fees to waive policies or ensure their wishes

Several respondents mentioned having negative experiences in caregiving with professionals in medical settings, including physician's offices, hospitals, clinics, and nursing homes. The respondents related these experiences to the culture of medical institutions and not necessarily the result of negative attitudes towards the couple because of their same-sex relationship. Many described the culture of medicine as profit-motivated as opposed to people-oriented. One respondent went as far to say that because of this motivation, the "medical people have developed little or no feeling towards patients." The negative experiences related to the culture of medicine most often involved either the misdiagnosis of a serious condition (such as cancer), not providing patients or their caregivers with sufficient or accurate information, or being too busy to focus on individual care. Many revealed their frustration and disillusionment with the practices in health care settings. As Jeffrey vents his frustration with physician care,

They don't really care to know the patient. You go to the kidney doctor and they only want to hear about kidney-related things and he is looking for symptoms A, G, and F so he can prescribe this, that and the other thing and you can come back in three months. They are so routine in their diagnosis and examinations and it seems so impersonal.

This lack of individual care also applied to social workers, as some were described as being too busy with discharge planning to be concerned with problems of the individuals or couple. Nurses were often described as being so rushed and overworked, that they had

little time to recognize patients as individuals. As Ted describes his experiences with nurses in the hospital,

I've tried to justify it because they are overworked but they just race in the room and they don't tell you what they are doing...(some) simply didn't want to communicate but just wanted to get the job done and get out because "I have other people to see after this."

Other negative experiences with professionals in caregiving and post-caregiving were attributed to staff biases and prejudices against gay men and lesbians. The nature of this treatment was often intangible but believed by the respondents to be rooted in prejudice. Although several respondents cannot say for certain that professionals were homophobic, they could sense from certain individuals that their relationship was not acceptable. Specifically, respondents described nurses who were not accepting of their relationship as "bitchy," "rude," "hostile," and "abrupt." They also said these nurses would "give us looks" and acted like they "didn't want anything to do with gay patients." They were also "not engaging" and "uneasy" in their interactions with the couple.

Mike and Sally were the only respondents to mention overtly homophobic gestures and comments made by professionals. The nursing assistants in the nursing home where Mike's partner was a patient asked his partner's mother if her son was the "husband or the wife" in his relationship with Mike. This was very upsetting to his partner's elderly mother because she was not completely comfortable with the same-sex relationship and did not wish to openly discuss it. He also shared that the nursing home staff made many other "slighting remarks" about the nature of their relationship. When Sally filed a

medical negligence lawsuit against her partner's physician, the physician's lawyers threatened to "out" them. She believes their thought was to persuade them to drop the lawsuit or settle out of court for a smaller sum. Other actions mentioned by respondents were not overtly homophobic but were thought by the respondents to be rooted in negative attitudes towards gay men and lesbians.

A few respondents mentioned negative encounters with professionals that were based upon other characteristics of the care-receiver or caregiver. As a result, these respondents experienced discrimination based upon race, age, and medical diagnosis. This discrimination may have compounded ill treatment based on sexual orientation. Four of the participants mentioned ill treatment based upon their partner's HIV/AIDS status. Ted explained that at the hospital, there were some nurses who did not want anything to do with them and he explains, "They didn't want anything to do with gay patients and certainly not somebody with AIDS." In contrast to this is the story that Mike told about his encounter with a staff member of a prominent gay and health lesbian organization. When he called to inquire about support groups for caregivers, he was told that the agency's support groups were only for persons with HIV/AIDS (the respondent's partner had colon cancer). He then asked the "counselor" if he could recommend other support groups and he said, "Look in the Yellow Pages."

Mike also mentioned a double-stigma, which involved his partner being gay and African American. He explained that the head nurse at the nursing home where his partner resided for a few weeks "really didn't like faggots" and "she made no bones about it." Plus, she did not like African Americans much either, as she made a comment

to his partner's mother that she was surprised that her son was so intelligent given his background. Interestingly, she was talking about a man with a Ph.D. from one of the most prestigious universities in the country. Mike also attributes his partner's misdiagnosed cancer to the fact that in the clinic, his partner "was just a number, and a Black number." Similarly, Jim recalls a time when his partner (who was African American) was in an accident and the ambulance, assuming he was poor, took him to the "no insurance" hospital.

Other respondents mentioned additional discrimination related to mental health status and age. Barbara's partner experienced discrimination based upon a mental health condition, as she suspects that nursing homes shuffled her around because they did not want to deal with her psychoses. Ursula and her partner faced discrimination based upon age. Ursula was very upset when her partner's cardiologist said, "You know, she is 78" when discussing her partner's condition and possible treatment. Her response to him was, "So what are you telling me...because she is 78 she is not worth while?"

Paul provided some very alarming examples of professionals who were unsupportive during caregiving. For example, he encountered an unsupportive hospice staff, professionals that completely neglected to recognize him as the significant other and also failed to offer any kind of counseling or bereavement services. This may sound surprising since the hospice field has had several years in which to experience and deal with the HIV/AIDS crisis (which has often included gay men as clients). Another surprising discovery was the fact that Paul did not experience any outreach or support

from the local Metropolitan Community Church (a predominantly “gay” church) in which he was a member.

Unsupportive policies and practices.

Respondents not only mentioned negative interactions with professionals, but they also cited problems with formal agency policies as well as informal policies and practices of professionals. These policies may have been formalized in writing or informal, including a professional’s interpretation or application of a formal policy or their own personal practices and operating procedures. These problems with policies occurred in caregiving and post-caregiving and were encountered in health care organizations as well as businesses in the community.

An overwhelming theme regarding the practices of professionals was that they often refused to acknowledge the respondents as “next of kin” and refused to give them information related to their partner’s condition. This practice was often backed up by a formal, written policy. As a result, getting needed information from hospital and nursing home staff was often a “struggle” for respondents. Even though respondents had legal documents in hand, treatment as the significant other was not guaranteed. For example, Mike, in his dealings with the nursing home staff said he had to “make them accept the fact that I was the primary contact.”

There were also other policies that enforced the belief that the respondents were not “next of kin.” These policies were as trivial as parking privileges. At a particular hospital, only “family members” could park for free while visiting their loved ones. Since Ted was not a blood relative, the hospital staff refused to let him park for free. He

explains that, “Maybe it’s a small issue, but it upset me...I had the will, the power of attorney... everything...but because I was not a blood relative, I couldn’t park.” It was not until his partner’s sister called and complained that the hospital “bent the rules” and allowed the respondent to park for free.

Respondents also cited the insensitivity of intake forms and practices of professionals as challenges they faced in caregiving. These forms and practices often pointed out the fact that the couples were not legal partners or kin. Jane notes that when she would take her partner to the emergency room, the physician would be looking around for a husband, mother, sister, or some other relative before discussing her partner’s care issues with her. Similarly, Ursula describes a typical intake procedure in the hospital involving her partner Susan,

Intake worker: Who is your next of kin?

Susan: Ursula Jones

Intake worker: (would ask about the relationship)

Susan: She’s my friend

Intake worker: Do you have any other relatives?

Susan: Yes, my stepbrother

Intake worker: What’s his name?

Susan: I would like Ursula’s name put down (as next of kin)

In bereavement, respondents faced challenges related to the policies and practices of community businesses. A few respondents mentioned having problems with the printing of their partner’s obituary in the local newspaper. In many of these cases, the obituary

was not printed the way in which the respondent had submitted it. Instead, the printed version omitted the word “partner,” “survivor,” or “longtime companion” when describing the deceased partner. A friend advised one respondent that this may happen, so he paid \$100 to have the obituary printed as he had written it (naming himself as the “survivor”). Of those respondents who were named the “survivor” in the printed obituary, a few mentioned receiving hateful phone calls or letters from unknown community residents.

Although a few respondents mentioned encountering insensitive policies with their local newspapers, one respondent also mentioned great difficulty with a cemetery. Ted, who had battled the hospital parking policy, in bereavement took on another discriminatory policy. Ted described how he and his partner had purchased a plot next to his parents in a mausoleum. They had purchased the plot together and had explained to the cemetery staff that they would be sharing a plot, as they were both going to be cremated. When his partner died, the cemetery refused to allow his urn to be placed in the plot. When the cemetery found out that it was going to be two men sharing the same plot, they said “nay-nay.” As a result, Ted had to keep his partner’s ashes at home for five months until he decided one Sunday to go over and threaten them with a lawsuit. In the face of this threat, the manager decided to allow the shared plot but stated that this would be the only time they would make this exception for two unrelated persons of the same gender. Of course, this would cost Ted an additional \$1,100.

Handling unsupportive professionals.

As detailed above, the respondents encountered insensitive and unsupportive professionals in a variety of health care and community settings. Respondents dealt with these persons in a variety of different ways, from ignoring the poor treatment to attacking the problem head-on. A few respondents noted that they asserted the fact that they were the significant other, had the proper legal documents, and demanded to be treated with respect. Some took less direct action and reported unfriendly staff members to department heads. Still others chose to use sarcasm, like asking the staff member if they were having a bad day. Lynn shares her view on handling unsupportive professionals and exclaims, “I think...and could be wrong...that people who get respect are the people that demand it.” She says she knows others who are treated poorly and when she asks them what they did about it they say, “Oh nothing, I just let them be assholes.”

Positive experiences with professionals.

The respondents did encounter professionals who were supportive during their time of need. And, as Jeffrey mentioned, it is important to point out family and professionals who are supportive of older gay and lesbian couples. To the respondents, supportive formal support persons were those with whom they felt “comfortable” and those who were understanding and respectful of the relationship. Additionally, supportive professionals were those who bent the rules and treated same-sex partners as “immediate family” as far as policies and decision-making were concerned (see Table 4.11 for positive experiences and ways to increase likelihood of positive experiences).

Table 4.11

Supportive Actions of Professionals and Ways to Increase the Likelihood of Having Positive Experiences

Supportive actions of professionals	<p>Made clients feel comfortable</p> <p>Were supportive and respectful of the relationship</p> <p>Bent the rules</p> <p>Treated partners as immediate family</p> <p>Hooked clients up with other supportive professionals and services</p>
Ways to increase the likelihood of having positive experiences	<p>Connect with HIV/AIDS or gay and lesbian specific agencies</p> <p>Network with other gay men and lesbians and refer each other to gay-friendly professionals</p> <p>Be upfront with professionals about the nature of the partner relationship</p> <p>Prepare and have on hand advanced directives and other legal documents</p> <p>Befriend supportive staff members</p> <p>Look “straight”</p>

Four of the male respondents mentioned having wonderful experiences with formal support persons. This may be due to the fact that most of the referrals made to these persons were made through HIV/AIDS service agencies. In Ted's situation, a case manager "hooked" him and his partner up with other supportive and understanding doctors, a support group, a hospice, a church, and even an agency that provided pet care specifically for couples dealing with HIV/AIDS. Even those respondents (both male and female) whose partners did not have HIV/AIDS had more positive interactions with staff who worked for agencies who served a high percentage of HIV/AIDS patients. This included home health agencies, hospices, and hospitals.

Respondents who participated in support groups in caregiving and post-caregiving had very positive experiences with group facilitators as well as other group members. There were no respondents who mentioned negative interactions with staff or members of support groups. Even members of support groups that were not gay, lesbian, or HIV/AIDS affiliated were welcoming and supportive of the respondents and their partners. For example, Paul reported having a wonderful experience with a "mixed" grief group. The group consisted of all women and he explained to them that his "lover" had died. He then told the group, "If there is anyone here who has a problem with that, all they have to do is tell me and I'll never come back." He attended the group for two years and socialized with members outside of their meetings.

Several respondents did not expect to encounter supportive professionals. There were several comments made during the interviews that highlighted this expectation. Ted said that he felt "fortunate" to have found supportive professionals. Jane noted that it is the

“exception” when you encounter, for example, a physician who would want to discuss care issues with a same-sex partner. In talking about her future plans, she also felt she would be “lucky” if she ran across accepting medical professionals. Additionally, Paul was surprised when he received support and acceptance from members of the grief group in which he participated. Several respondents stated they had friends who have had totally opposite and very negative experiences with professionals. Not only did respondents feel “lucky” to have run across supportive professionals, but several also noted an underlying fear of being treated badly because of their same-sex relationship. Maria describes this best when she shares, “Even though I was not treated badly, I always had that fear that I could be treated badly...there is always a threat that you carry around in your heart that they can be bad to you.”

While sharing their experiences with supportive professionals, respondents also shared their views on how to increase the likelihood that an older gay man or lesbian can have positive encounters with formal support persons. Clearly, being connected with an HIV/AIDS service or agency specific to gay and lesbians can increase the chances of being served by supportive and understanding professionals. Being connected with other gay men and lesbians can also increase the likelihood of supportive treatment. For example, Marjorie and her group of friends all go to the same physician (who is heterosexual and very accepting). She believes that this type of networking is important and says, “If you find a supportive MD, tell others to go to that person too.” Many also cited positive experiences as the result of having a gay or lesbian friend or contact in an organization, such as a mortician, funeral director, social worker, therapist, etc.

Several respondents stated that how one is treated depends somewhat on the actions of the individual or couple. Some suggested that a way to increase the likelihood of supportive treatment was to be upfront with professionals about being the significant other. Being upfront, some believe, can head off misunderstandings. Lynn, who advocates directness with professionals, describes how she approached professionals,

I went in there with my head up and my heart open and my honesty right there in the middle of my hand and said this is who I am and this is the way it's gonna be...like it or lump it. From day one they knew where I stood on this issue. They knew that I was the most important person in her life. Being up front from the beginning.

For some, part of being up front with professionals was having powers of attorney and similar documents. Many believed the presence of these documents facilitated better treatment by professionals. These documents and their use will be discussed in greater detail under the section "Long-term planning and decision-making." Some also believed that befriending supportive staff members also facilitated better treatment, particularly in a hospital setting. These staff members could "look out" for the interests of the couple and ward off those who were less than compassionate. Additionally, one respondent mentioned that "the way you look" could effect the way one is treated by professionals. He explained that he and his partner both looked straight but said that "if you are an effeminate man, you won't get treated the same."

Attitudes regarding professionals and formal support services.

In addition to sharing their specific experiences with professionals and support services, respondents also offered their general feelings about formal support persons and services. Most evident were the respondents' attitudes toward mental health services, support groups, and in-home services. A few respondents mentioned their apprehension about seeking counseling for bereavement issues. Mike explained that he did not have much regard for psychiatrists or psychologists but would "rather have an understanding friend" with whom he could talk. He goes on to say that, "The problem is between my ears, so I'm the one who has to deal with it." Although she was very apprehensive about seeking services, Jane did point out that mental health today is a lot different than it was "years ago." This may be a generational attitude or may also be a result of the psychiatric profession's past categorization of homosexuality as a mental illness.

Respondents were also leery about joining support groups. These were support groups that did not exclusively serve gay men and/or lesbians. Much of this apprehension was credited to a fear that the other members would not accept them. Several respondents also mentioned that it was important for them to be with others who understood what they were going through. Members of regular support groups, many feared, could not understand what they were going through in caregiving for or losing a same-sex partner. Mike said he did not want to go to a "straight" support group because "maybe they would be supportive and maybe not." Paul said when he learned that a support group consisted of mostly women that "I just didn't fit in with what they were dealing with" and "I could hardly bare my soul to them." Even the respondents who had positive experiences with

support groups admitted that they were initially very apprehensive about attending the group.

A few respondents mentioned their discomfort with in-home support services. This included home health, visiting aide, and hospice services. Jane was very apprehensive about having home health coming into their home. Her partner received home health services a few times during caregiving. It bothered her greatly to have others coming into their home and she worried about what they would think about the relationship. Carie would also be uneasy about professionals coming into their home because “it does look like a lesbian museum.” She was particularly concerned about others coming into their home because she and her partner were once evicted from an apartment for being lesbians.

Disclosure of the Relationship

Respondents were often faced with disclosure issues related to their same-sex relationships and had to deal with disclosure to family, coworkers, and professionals. For some, “coming out” to these persons had been done prior to the onset of their partner’s illness. For others, disclosure became necessary or desired during caregiving and post-caregiving. Disclosure to these persons ranged from direct verbalization to the “don’t ask, don’t tell” approach. The respondents also shared their opinions regarding disclosure of the relationship.

Disclosure to family.

Eleven of the respondents mentioned that they or their partners had directly verbalized the nature of their relationship to one or more family members prior to or during caregiving. A few respondents did not disclose the true nature of the relationship until after their partner had died. Disclosure to family members was often done to protect the rights of the caregiver or widowed partner as the primary decision-maker or benefactor. Other times it was done out of respect to the family members, to include them in this very personal aspect of their lives.

Several respondents were verbally open about the nature of their relationship to one or more family members. This disclosure occurred before, during, or after caregiving. Some respondents and their partners had been “out” to family members long before caregiving began. Ted’s family referred to his partner as his “partner” and Ted’s cousin even included Ted’s partner in a family history document. Ted’s parents also purchased a mausoleum plot with him and his partner. For others, like Brian, the partner’s illness or death precipitated the need for disclosure to family members. Brian’s partner did not come out to his family until he was dying from HIV/AIDS. Brian says, “there were lots of tears” during this time and his partner’s family was very hurt that they did not tell them prior to this time. On his partner’s side, he feared being rejected if they knew he was gay and had HIV/AIDS.

Some of the respondents preferred not to directly disclose the nature of the partner relationship to family members. Although she had one sister who was aware that she was a lesbian, Jane said that her relationships with women were an “untouchable subject” in

her family. Similarly, Ursula explains, “You just don’t talk about it...it’s like being in the army with my family.” Although some of the respondents did not have open communication with family members about the nature of the partner relationship, this did not mean the couple was not accepted or was ostracized. In Ursula’s case, the word “lesbian” was never uttered in her family nor was the true nature of the relationship disclosed, but her partner was also included in family functions and their relationship was accepted.

Several respondents mentioned that even though they did not disclose to their families, that the family members knew “on some level” without being verbally informed. As Marjorie asserts, “Gay people always think that everybody is stupid except for them...and the family always knows.” Paul explains that his mother never approached him about the nature of the relationship, but he said, “I know a mother knows what the hell is going on.” Anna came out to her mother after her partner died. She said her mother “didn’t bat an eye” and ended up being an active member of their local PFLAG (Parents and Friends of Gays and Lesbians) chapter. Prior to her discussion with her mother, she describes how her mother interpreted the relationship,

She had it all neatly figured out...so many young men had gone off and died in WWII and there were not enough men to go around and that it was cheaper for two women to share a home than it was for each of them to own a home individually. She had it all neatly figured out in her mind...all of which would have been logical except that we were lesbians.

Disclosure to coworkers and employers.

The respondents also had to deal with disclosure issues in the workplace, as they may have had to miss work to care for their partners. Not surprisingly, the respondents were the least “out” in their workplaces as compared to other areas of their lives. All but two of the respondents did not discuss their partner status to their coworkers or employers. As a result, many had to lie about why they would need to take time off to care for their partner. Jane said she ended up “burning a lot of vacation time” to care for her partner and said she learned to “build excuses.” Some of the excuses she “built” were, “My best friend is going to surgery and her mother needs someone to sit with her” and “I have personal business to take care of.” She says this was necessary because she was the “breadwinner” of the house and could not risk her job. Similarly, Ben explained to his employer that he “had a sick parent at home.” Other respondents recalled that their coworkers and employers knew that they were taking care of someone at home but may not have known it was a same-sex partner. Interestingly, Edward’s workplace had supportive policies for caregivers (regardless of the nature of the relationship) but he did not take advantage of these policies at the time and did not want to disclose the details of his caregiving situation.

The respondents that confided in a coworker received support from those persons. Paul shared that when he disclosed to a coworker, she told him that she had figured the relationship was more than a friendship and she offered her support. Others mentioned that they confided little by little to coworkers as their partner’s condition progressed. In some cases, this was because the stress of the situation increased and it became more

difficult to hide their need to care for their partner. Ursula's partner never verbally disclosed the nature of their relationship to her employer or coworkers but Ursula was always invited to company functions and they offered her an attorney to help with any problems she had in bereavement.

Disclosure of the relationship in the workplace was noted by a few respondents as being a learning experience for those with whom they worked. Coworkers were able to see the deep commitment and emotional attachments of these same-sex couples. Some were also able to see that these relationships were as valid as any legal marriage. Even the respondents who did not receive an outpouring of support from coworkers, admitted that their coworkers were able to see the significance of the partner relationship. Barbara finally broke down during caregiving and disclosed the true nature of her relationship with her partner to her coworkers. Although they were minimally supportive, it was not until an incident that occurred after her partner had died that they truly understood the meaning of the partner relationship. She shares this experience,

About six months later (after her partner had died) our facility got merged with a large chain. I was in a meeting and started to read the policy manual and started to cry. They stopped the meeting and asked, "Why are you crying?" I explained that the new company defined (a worker's) family as "anyone you deem family to be." They didn't understand and I said, "You know, we were more married than most couples and yet we didn't have legal recognition and I couldn't get bereavement (leave)." I think they had this great moment of "oh."

Disclosure to professionals.

The respondents were also faced with the issue of the disclosure of the relationship to professionals. Twelve of the respondents mentioned that they were verbally “out” as a couple to one or more professionals during caregiving and/or post-caregiving. This disclosure was mentioned mostly in terms of disclosure to professionals during the caregiving experience. During caregiving, the respondents were faced with disclosure to professionals in institutional settings like hospitals and nursing homes, to staff from in-home services like hospice and home health, and to staff in private physician offices.

As previously mentioned, some respondents advocated for direct verbalization of the nature of their relationship to the professionals they encountered in caregiving. They felt that this left little room for misunderstanding as to who was the significant other and caregiver. For some, verbal disclosure was done at the first meeting with professionals. For others, disclosure did not occur until the need to clarify the relationship arose. Maria had to clarify the nature of their relationship with her partner’s surgeon. The surgeon assumed that she and her partner were just friends. She explained to him, “No, this is not friendship, this is beyond friendship...we are a couple.” She believes a prejudice often exists, as professionals do not see older persons as sexual and especially not as homosexual. For some professionals, then, their interactions with these couples were a learning experience.

Others mentioned that although they were not verbally “out” with professionals, they assumed that the professionals understood the nature of the relationship. A few respondents noted that it was evident in the way they touched or physically took care of

their partner and/or how they spoke to him/her. It may have also been evident in that the respondent always accompanied his/her partner to the doctor or was always at the hospital at his/her bedside. They may have also known that the two lived in the same house and were not related by blood. As Marjorie explains,

I always give people the benefit of the doubt of not being stupid. There were conversations between her and me that you would really have to be stupid not to pick up on it. I didn't say, "Hey, you know we are lovers," but I handled things as if we were a couple.

Similarly, Lenny says that their advanced directives defined "how I was connected with him." Others also shared that advanced directives helped clarify the nature of their relationship and enforce their rights as a couple. Still others would drop hints to professionals, like saying "she lives with me" or "I'm her best friend."

Opinions regarding disclosure.

The respondents also voiced their opinions about disclosure to persons outside of the partner relationship and their circle of friends. Some do not understand the need to be "out" to persons outside of the relationship. These respondents chose not to be verbally "out" to family, coworkers, professionals, or much of the outside world. As Lenny contends, "My own personal bias is that heterosexuals don't talk about the kind of sex they have. I don't quite understand why I have to wear a badge that says 'I like other guys'." Others mentioned that they are just not comfortable being verbally "out" with others. In contrast, other respondents felt that "being in the closet is not necessary" and

that hiding who you are only adds stress to the individual's or couple's lives. As Jim explains,

As long as you are secretive and as long as you tiptoe around, it remains your problem. Put it out on the table and be direct and up front...and it then becomes their problem. They can either deal with it or they can't. They can make the choice.

Long-term Planning and Decision-making

Additional issues that emerged in this study were those related to planning and decision-making. These issues included plans regarding the couple and long-term plans of the respondent. These plans may have been made prior to the onset of care or during caregiving or post-caregiving. The reasons for these decisions will also be discussed.

Decisions Regarding the Couple

Decisions regarding the couple included health care advanced directives, division of property and finances, and future plans together. All but four of the respondents reported that they had set up advanced directives for their partner prior to or during caregiving. These advanced directives included living wills, powers of attorney, and "do not resuscitate" orders. Of those who set up these directives, the respondents were noted as the primary decision-maker on the documents. In addition, the majority of the respondents served as the executors of their partners' wills and were willed most of their partners' estates. The main reasons that respondents mentioned for acquiring powers of

attorney and specifying wills were so that the partner's family of origin or adult children could not challenge their decisions and that health care providers would understand the wishes of the couple. In addition, several respondents noted the desire to make their wishes very clear to all of those involved in the partner's care and in the couple's life.

Ben and Carrie were the most concerned about the intrusion of others into the plans made by the couple. Ben was one of only a few respondents to mention the interference of family members. Ben made sure that his partner signed advanced directives and they also got joint ownership of their house. He took these actions because he worried that his partner's family would "take over and tell me to take a walk." He says that his partner's family challenged him on the advanced directives during caregiving and even tried to take him to court over ownership of the house and its contents after the death of his partner. Ben explains, "I had to hire a lawyer and prove everything that I had (in the house)." Carie, who currently provides care for her partner, reports that they have spent a few thousand dollars for a special level power of attorney and that they have done extensive financial planning that includes having their money tied up in a trust fund so that if one dies, the other is sure to receive the money in the trust. She says of this comprehensive planning, "We have been very, very clear because, basically, we want to be married and we bought as much of a marriage package that we can." They worry that a judge could overturn their advanced directives. Carie and her partner are also fearful that her partner will need nursing home care in the future and that their needs as a couple will not be validated. She doubts that they would have conjugal visit rights or that they would be treated as a couple.

A few respondents did not set up advanced directives for their partners during caregiving. These respondents offered reasons for not setting up advanced directives, including not wanting to discuss such matters or deal with the situation or not needing these type of documents during that particular time. Some also mentioned that they, instead, made it verbally clear to everyone involved that the respondent would be taking care of the partner. Sally states that she did not know why they did not set up advanced directives during caregiving, especially since she was in law school at the time.

There appeared to be great variety in the arrangements of finances and property held by the respondents and their partners. Six of the respondents reported that they had joint finances and property ownership with the care-receiver at the time of caregiving. Six respondents and their respective care-receivers had completely separate finances and property ownership. Others had a mixture of joint and separate accounts and property. These arrangements did not appear to be dependent on the duration of the relationship.

The respondents provided their rationales for separate finances and property ownership. Jane, who had been with her former partner for over twenty years, explains that she never wanted joint property ownership because she is “just too independent” and “didn’t want any legal hassles.” Jeffrey states that he and his partner had separate finances and property because it was easier for accounting purposes and that tax-wise it worked out to their advantage. He says of the arrangement, “Everything belonged to ‘us.’ There was no ‘this is yours and this is mine’, not ever. On paper it was separate, but everything was collective.” Others mentioned that they had separate finances because their partner was not as careful with money or had credit problems. Although

the couple may not have initially had joint finances and property ownership, as the partner became increasingly ill, some of the couples began “signing” items over to the caregiver. Some sought joint property ownership or acquired a deed to assure that the couple’s home would go to the caregiver when the care-receiver died.

Eight respondents mentioned that they had made retirement plans with their partner prior to or during caregiving. Many of these plans involved buying retirement property and/or making plans to relocate. Some of these plans were specific and were being put into action while others were the “dreams” of the couple. A few of these respondents and/or their partners were already retired at the time of caregiving. The destruction of these future plans was upsetting and stressful for the respondents. As Anna recounts,

We had worked all of our lives, we didn’t owe anybody and our home was paid for. I was retired and she was old enough to retire. And damn you woman, you went off and left me. Of course, it (dying) is the ultimate form of abandonment.

Long-term Plans of the Caregiver

Plans of the caregiver include their own retirement plans, advanced directives, and plans for future care. It is important to note that there is a wide range of ages of the respondents, with some being currently retired and others ten years or more away from retirement. Overall, the respondents who were not currently retired did not seem to have extensive plans for retirement. Some reasons for not actively planning for retirement included not wanting to think about retirement right now or not having enough income in a retirement fund. Others are determined to keep working and some have just begun new

careers or educational programs. Interestingly, for those who were not currently retired, the existence of retirement plans was not dependent on the age of the individual. For some, retirement plans also involve the plans and desires of their current partner.

Because specialized retirement communities are beginning to develop in the U.S., respondents were specifically asked about whether or not they had heard about retirement communities for gay and lesbian seniors. They were also asked to share their thoughts on that type of housing for the future. Most thought specialized communities were a good idea and an option for gay and lesbian seniors. Both Jane and Ted commented on how these communities would provide a non-homophobic and accepting atmosphere. Ted asserts that gay men and lesbians have always been “second class citizens” and have had to lead “double lives.” To him, a specialized retirement community would offer a place where “we could do say what we want to...where we don’t have to lead double lives.” Similarly, Jane states that, “We’ve been mixing all of our lives in the heterosexual world, so why not have special freedoms in the later years?...why go back to a closeted-style of living? In the last few years of life, you should live it.” Brian exclaims, “I would like to be around those with similar intellect...those who like opera, good food and gardening...all the clichés!” Many commented on how it would be a sense of community. Despite its appeal, some worried about the affordability of specialized housing. Maria had a different opinion on specialized housing and says, “I would rather see policy change (to have equal rights) than to have to segregate myself.” Although not necessarily planning to retire in a gay and lesbian retirement community, a few

respondents mentioned that they are currently or plan to relocate to a “progressive” area, where there are sexual orientation legislation and gay-friendly health and human services.

It does seem that many of the respondents have documents that clearly state their wishes, including advanced directives and wills. As mentioned, some of the respondents are currently in partner relationships and some have set up advanced directives with their new partners. Many, however, deny the possibility of needing care in the future. This was a common theme among respondents and several of them openly admitted it.

Despite this denial, many of the respondents are very concerned about becoming ill and needing to rely on someone else for care. As Jeffrey states, “I can go out and get hit by a bus, but please don’t let me get sick.”

Some of the respondents voiced fear and concern about who would be there for them if they were to need care. An overwhelming theme was that the respondents did not want to be cared for in a long-term care facility. This appeared to be partly related to their desire to remain in their own homes and partly due to their fear of how they would be treated (as a homosexual) in a facility setting. Some feared that they would be ridiculed by nursing home staff and would not be able to be safely out as a gay man or lesbian in a facility. Many also added that long-term care insurance is too expensive for them at this time.

Respondents commented on the availability of friends or family members to take care of them if needed. A few respondents felt that they could rely on their circle of friends if they needed assistance. Having friends that could provide a great deal of care seemed to be the exception among these respondents. Marjorie is currently involved in a

community, mostly made up of older lesbians, who provide assistance to other members of the housing community. She says they have a “system” where if someone is ill, they will type up a notice and post it on the bulletin board. Community members then sign up to perform certain tasks for the individual such as preparing meals or transporting to the doctor. She believes she can rely on this network if she should become ill and actually did receive assistance when she had her hip replaced. A few of the respondents worry that they would become dependent upon their adult children for care. Lenny, for example, does not want to have to move in with his daughter and “become a piece of furniture in her house.”

Suggestions for Changes to Health and Human Services

The positive and negative encounters the respondents had with formal support persons and services have been described. The actions they took to combat ill treatment have also been discussed. Likewise, their attitudes about formal services and suggestions for how to increase the likelihood of finding supportive professionals have also been detailed. In addition, respondents offered suggestions for changes that could be made to health and human services. These changes would help the professionals and agencies better meet the needs of older, same-sex couples (see Table 4.12 for suggested changes). The respondents’ suggestions related to professionals’ treatment of consumers, education and training, changes to larger systems, and the responsibility of consumers. This particular interview question received the most “charged” responses from the respondents than any other aspect of the interview.

Table 4.12

Respondents' Suggestions for Changes to Health and Human Services

Change agent	Action
Professionals	<p data-bbox="659 611 1094 642">View all consumers as individuals</p> <p data-bbox="659 722 1279 789">Spend more time getting to know the patient and explain the procedures that are being performed</p> <p data-bbox="659 869 956 900">Have more compassion</p> <p data-bbox="659 980 1349 1012">Not judge consumers and accept diversity in lifestyles</p> <p data-bbox="659 1092 1349 1159">Accept a same-sex partner as the significant person in the care-receiver's life</p>
Organizations	<p data-bbox="659 1268 1317 1335">Be sure that the language used on agency forms are sensitive to a variety of human relationships</p> <p data-bbox="659 1415 1370 1482">Recognize same-sex partners as couples and grant them the same privileges as legal spouses and relatives</p> <p data-bbox="659 1562 1276 1593">Provide a supportive and accepting environment</p> <p data-bbox="659 1673 1357 1776">Provide sensitivity training (which includes health and human services agencies as well as educational programs)</p>

Change agent	Action
Larger systems and society	Become more accepting of same-sex couples
	Enact laws that establish equal rights for gay men and lesbians
	Establish federal benefits for same-sex partners
Gay men and lesbians	Gay and lesbian staff members can become more visible to consumers and can advocate for sensitive policies and procedures
	Older gay men and lesbians can give professionals the opportunity to be supportive
	Older gay men and lesbians can be more clear in their communications with professionals
	Older gay men and lesbians can become more informed, inquisitive and assertive with professionals
	Older and younger members of the gay community can provide more support to caregiving couples

Treatment of Consumers

Several suggestions were made that apply to the treatment of all consumers, heterosexual as well as homosexual. These suggestions applied mostly to hospital personnel and settings. Respondents believe that professionals should view all consumers as individuals, which is not often the case because they are so rushed when providing services. This also involves having a little more compassion and as Ben suggests, “Think about being in their place and then take care of them.” This necessitates explaining the procedures they are performing and spending more time getting to know the special needs of each patient.

Respondents also had suggestions for how professionals should view and treat gay men and lesbians and same-sex couples. One suggestion is that professionals should not judge patients and consumers and should accept diversity in lifestyles. As Jim asserts, “If you are trained to be a doctor, then be a good doctor and don’t be a judge of human nature.” Professionals should also accept the same-sex partner as the significant person in the care-receiver’s life. This may mean accepting him/her as the “partner” or “friend,” with whichever term the client is comfortable. The language used on agency forms should also be more sensitive to a variety of human relationships. As Marjorie explains, “This nonsense of taking for granted that everybody has a spouse...it’s offsetting.” Professionals should also recognize these persons as “couples” and grant them the same privileges as legal spouses and relatives. Several respondents also mentioned that if professionals provide a supportive environment, one where they are accepted as “family,” then partners will not have to “lie” about how they are related to the care-receiver or

worry about what to say to be able to be respected as the person who “is the most dear” to him/her.

Education and Training

Many respondents believe that acceptance of same-sex relationships among professionals can be facilitated through sensitivity training. Professionals in hospitals, nursing homes, and clinics should be required to have training related to gay and lesbian consumers. Edward, who is tired of being asked if he is “married” when he goes into a new health care clinic, believes that professionals “should be taught gender neutral language and how to engage patients in a very open way and be prepared to be sensitive to any life circumstance.” Sally believes this training should begin in higher education. This education should occur in medical schools, nursing programs, schools of social work, etc. Students in these programs should be taught “the honor of same-sex relationships.”

Changes to Larger Systems

A few respondents went one step further and suggested that changes be made to a much larger system. A few respondents assert that societal attitudes towards same-sex couples need to change. Jane claims that we need “to establish another term in our society like ‘significant other’. OK, so this is the person who looks after you, takes care of you and your affairs. That’s all that needs to be said.” Maria believes that equal rights must exist before professionals’ behaviors can change. She believes that “once we get larger

things (policies) in place, like marital rights, same-sex couples will be treated like family in hospitals and other settings.” If policy is in place, she says, “They won’t have the power to act out.” She compares this fight to the civil rights and women’s rights movements, where policies mandate fair treatment. For Maria, equal rights will mean,

Equal rights in the hospital...in insurances...health benefits...and I want to be able to hold her hand in public like husbands and wives do and people who love each other do. I think we have to continue to work towards that.

One respondent advocates for a very specific policy change at the federal level. Carie, who is currently providing care for her partner (a veteran), would like to see a move towards veteran’s benefits for same-sex partners. She claims that there are “thousands upon thousands” of partners of veterans who should be able to receive care in the VA clinics and receive additional income. She says part of the problem is that the VA does not want to pay for these extra benefits and she says of their policies, “Isn’t it interesting, don’t ask, don’t tell, then don’t pay...that’s exactly what is behind all of that.”

Responsibility of Consumers

A few respondents also mentioned the equal responsibility of consumers and professionals for ensuring supportive health care and human service environments. Marjorie suggests that gay and lesbian staff members can become more visible to older gay men and lesbians in health care settings. This can be done by an individual wearing a pink triangle or rainbow pin on a jacket and can let a person know that he/she is in a welcoming atmosphere. Staff members can also push organizations to remove insensitive

terminology on forms and to ensure that policies and procedures are supportive of gay men and lesbians. Older gay men and lesbians themselves can also allow professionals the chance to be supportive. As Marjorie explains,

I think sometimes we are our own undoing and that people are more receptive than we think they are and we have to give them a shot. We really have to give them a chance to support us, to accept us. We shouldn't walk around taking it for granted that they disapprove because they don't always disapprove.

A few respondents also advise that older gay men and lesbians must be very clear in their communications with professionals that they are the "partner." As Ursula points out, "If I keep using the word 'friend...friend...friend', hey, ya know...what is that? 'Partner' tells you more about me and our relationship." In general, all caregivers and care-receivers need to be more informed, inquisitive, and assertive with medical professionals. Other gay men and lesbians also need to rally around the couple and help and support post-caregivers to prevent loneliness and depression. It is important for older gay men and lesbians to have someone with whom to talk and someone who knows what they are going through. There should also be more intergenerational interaction and support, although a few respondents stated that younger gay men and lesbians often have little contact with older gay men and lesbians.

A few respondents voiced concerns that these changes are not easily implemented and the remedies are not easily taken. Ted thinks that this tolerance and acceptance of diversity is not easily learned for some as "they are a product of their upbringing and their family's value system and that (prejudice) is something that takes generations to

wipe out.” Similarly, Maria believes that even if oppression is removed, that prejudice will still remain because personal feelings are extremely difficult to change. Others mentioned that many older gay men and lesbians will find it difficult to be upfront with professionals and will be resistant to disclosure. One respondent noted that some have been closeted for a very long time and “have been very successful in the closet.” He adds that when a partner becomes ill, disclosure becomes “inescapable” and this may be the first time they have ever had to disclose the nature of their relationship. Further, another respondent stated that although visibility is desperately needed to change the current conditions, many older gay men and lesbians are afraid to come out and be visible.

Suggestions for Sampling and Other Methodology Issues

Due to the difficult nature of sampling this “hidden population,” I solicited feedback from the respondents about how best to recruit older gay and lesbian caregivers for this study. Other issues, such as the difficulty of recruiting current caregivers, the comfort level of potential participants in responding to a study ad, and self-disclosure on the part of the researcher were also discussed.

To uncover effective sampling strategies, it seemed logical to “go straight to the source” and ask members of the population instead of strictly relying upon the writings and experiences of other researchers. Most of the suggested resources and avenues for recruitment were ones already explored, including Metropolitan Community churches, HIV/AIDS services, and gay and lesbian newsletters. A few novel sampling strategies were uncovered in this process. One respondent suggested advertising in the general

media, as she says, “They have come a long way and have proven that they can now spell homosexual.” We agreed, however, that this approach may attract “hate people.” I decided not to place ads in the general media (such as newspapers and magazines) as my home phone number was used as the contact number for the study. Ads were, however, placed on general caregiving message boards on the Internet. Inquiries were not received through advertising on these sites.

Another respondent suggested “Gay AA” (special gay Alcoholic Anonymous groups) as a lot of people in Gay AA have HIV/AIDS and are attending meetings because alcohol counteracts the effects of many of their HIV/AIDS medications. Ads were sent to several of these groups, but I did not receive inquiries through these groups. Another novel suggestion was to send flyers to services in cities that have a high percentage of gay and lesbian retirees, including Palm Springs, CA and Fort Lauderdale, FL. Although it is an excellent suggestion, the mention of sampling in popular gay and lesbian retirement areas did not come until the conclusion of the study.

Several respondents knew of other persons (mostly gay or lesbian friends) who were currently or had previously cared for a partner. I asked the respondents to pass along information on the study and contact information to these persons. Unfortunately, additional respondents were not recruited through this strategy. This does, however, point to the potential for successful snowball sampling with this population. Many respondents also suggested health care and gay and lesbian organizations in their own communities that may be good contacts for recruiting additional study participants.

A few respondents also had opinions about the style and context of an ad for the study. One respondent suggested that a large ad, with a thick border, placed in a gay and lesbian newspaper would really “grab” a reader’s attention. I had placed ads in several gay and lesbian newspapers, although limited finances restricted the size and style of the ads. A short newsletter article was also written early on in this study and a call for additional study respondents was included at the end of the article. One of the respondents commented that often “it is not just putting an ad in the paper” that gets responses. After reading the newsletter article of the initial findings, his interest was sparked in the study and from the article, he states, “I could see that you were a serious researcher and that you knew what you were talking about and were doing something important.” Other respondents also noted that they were impressed with the topic and felt that was important. Interestingly, one respondent mentioned that ads posted on the web might be perceived as being more “suspicious” and less credible.

I also discussed a variety of sampling issues with the participants. One of these issues was the difficulty of recruiting persons who are currently providing care. Most of the respondents noted that current caregivers are likely to be too busy to participate. Brian said that he was so busy during caregiving that if he would have been asked to participate in this study at that time he would have responded, “Yeah, when?” Paul also added, “It is a very difficult time and even though you know what’s going to happen, you really don’t want to be confronted with that situation.” Ted echoed this thought and said that when the caregiving ended, he really did not want to talk about the experience for almost a year.

In addition to current caregivers, the respondents noted other segments of this population who are difficult to reach. It was suggested that older lesbians (in their 70s+) are more difficult to reach because they are more in the closet. Similarly, it was mentioned that older gay men and lesbians of color, those involved in gay spiritual organizations, and those in the Southern region of the country may also be more in the closet. To highlight the difficulty of reaching persons who are “in the closet” Ben explains, “When people are in their closets, they throw away the bloody key.”

Another issue that was discussed in the interviews was the comfort of a potential participant in responding to an ad for the study. It was mentioned that some people may be afraid to be “outed” by responding to an ad for this type of study. Related to this issue, a few of the initial respondents specifically asked me either prior to or during the interview if I was a lesbian. After I confided my sexual orientation with one participant, he then mentioned the fact that he was a teacher and did not want to be “outed” in his workplace. Because the sexual orientation of the researcher seemed to matter to a few of the early respondents, I changed the flyer and advertisements to include a statement that the researcher was “involved in the gay community.”

Following the experience of these early interviews, I began asking respondents whether it mattered to them if a researcher conducting this kind of research was gay or lesbian himself/herself. All of the respondents who were asked this question claimed that the sexual orientation of the researcher did not matter to them. As Lynn states, “The way I look at it, if you’re brave enough to ask, I’m brave enough to tell.” Don said he is more interested in the focus on the study and what it is seeking and says, “The fact that you are

(a lesbian) is marvelous.” He also claims, “There are a lot of people who think if you are not (gay/lesbian) you couldn’t understand and I am not so sure that is true.”

At times, the disclosure of sexual orientation complicated the research process. For example, in some instances it was clear that respondents assumed that because I was a lesbian, that I understood a particular term they used or situation they described. Some, then, seemed surprised when I probed for further explanation. One respondent attributed a particular lack of understanding as a generational difference and said that “polyamory” (a committed relationship among more than two people) was a “thing of the 60s” that was somewhat common in the gay community. The respondent graciously pointed me to literature on the topic and mentioned that she knew of a polyamorous caregiving relationship among three older gay men.

From the beginning, it was very clear that several of the respondents had a vested interest in the study and its findings. Several commented on the importance of this type of study and one respondent mentioned that she had been “waiting” for someone to research this topic area. In addition to their belief in the importance of the study, a few respondents also wanted to have access to and input into the presentation of the study findings. This was apparent in their interest in seeing the findings. One respondent, who has participated in other gay and lesbian aging studies, commented that study respondents should have “editorial say” in the write-up of the results because some studies that she knew of were “horrendous” in how they represented the experiences of the study participants. Others were also interested in where the results would be disseminated. A few respondents specifically asked about “where” the results “would go.” Many hoped

that the results would be available to health and human service professionals, in order to effect changes in current practices and increase knowledge of and empathy for this population of caregivers. Others also hoped that the findings would be available to other gay men and lesbians who are going through the same experience. As Ben explains, “It is important for people to share their stories and for other people to hear their stories. It’s important for people to know that they are not alone.”