

Chapter One

INTRODUCTION

Caregiving for Persons with Chronic Illnesses

Case Scenario One: Herb and Jack

February 15, 2001

Herb (62) accompanies the ambulance that transports his partner of forty years, Jack (68), to the hospital. Herb called 911 when Jack became confused and dizzy and developed a severe headache earlier that morning. Two years ago Jack was diagnosed with congestive heart failure and high blood pressure. Since that time, Jack has adhered to his medication regime and the couple has restricted their diet to foods low in fat and salt. Although he has occasional shortness of breath, he has been able to carry out his normal, daily routine.

At the hospital, they discover that Jack has had a stroke and he is admitted immediately to the critical care unit. He requires life support during three of the ten days he spends in the hospital. When Jack's condition has stabilized, he is transferred to a nearby skilled nursing facility where he receives rehabilitation for the stroke.

After three weeks at the skilled nursing facility, he returns home and continues his rehabilitation with therapists from a home health agency. Because the stroke has left Jack with memory loss and paralysis on his right side, the level of care he requires has increased dramatically. As a result, Herb must now assist him with feeding, bathing, dressing and other personal needs. He must also assist him with transfers to and from

chairs, the bed, and his walker. Six months later, Jack suffers a severe stroke and dies before help can arrive.

Caregiving for a Loved One with a Chronic Illness

The above hypothetical scenario depicts a life challenge that many older couples, both heterosexual and homosexual, must face. As in the case of Herb and Jack, when one person becomes ill, the significant other often provides a variety of assistance, depending on the level of impairment. When a person accepts this responsibility, he/she is often called a “caregiver.”

Caregiving, although rarely defined in the literature, can be characterized as a role or activity in which a person provides care to a chronically ill or disabled relative or friend. Serving in this capacity can range from an hour per day to twenty-four hour care. Services provided in caregiving may include cooking, feeding, grocery shopping, budgeting and bill paying, running errands, housekeeping, providing transportation, changing medical dressings, managing and administering medication and injections, bathing, and toileting. Additionally, caregiving involves providing emotional support and supervision (Carter & Golant, 1994).

Many caregivers, such as Herb, provide care to loved ones that are chronically ill. In fact, a study conducted by the National Alliance for Caregiving (N=1,509) found that 70% of caregivers surveyed were caring for someone with a “long-term” or “chronic” illness (National Alliance for Caregiving and American Association of Retired Persons, 1997). Chronic physical illnesses include conditions that are long-term and irreversible,

including heart disease, diabetes, and cancer (Kart, Metress, & Metress, 1990). They also have continuous and often recurring effects on the health of an individual (The Robert Wood Johnson Foundation, 1996). Providing care to a loved one with a chronic illness, then, can become an enduring responsibility.

Special Issues for Herb and Jack

Although a hypothetical scenario, the caregiving crisis faced by Herb and Jack appears similar to those faced by many other couples in later life. Closer analysis of the situation, however, would reveal that Herb and Jack would be faced with special issues and challenges. Because of the nature of their relationship, they are affected by policies with which a heterosexual couple would not need to be concerned. Certain policies may also uniquely impact Herb's experiences in bereavement. These policies and the ways they may affect Herb and Jack are discussed below.

At the hospital and skilled nursing facility.

Because Jack has suffered a stroke, Herb may need to make decisions related to Jack's care in the hospital. Even if Herb has a health care power of attorney to make decisions for Jack, in many states a blood relative could overturn such an advanced directive. This may be especially problematic if the termination of life support becomes an issue. As Jack and Herb have been loving partners for four decades, Herb will likely want to stay at Jack's side at every possible moment in the hospital. Depending upon the policies of the hospital, visitation privileges in the critical care unit may be extended to "immediate

family” only, which, in some cases, means blood relatives or legal spouses (Ettlebrick, 1996).

Herb will also want to stay abreast of Jack’s condition while he is in critical care. Depending upon the policies of the hospital, information may only be provided to the “next of kin,” which, in some cases may not include a person who is not legally related to the patient. This “next of kin” rule may also exist within the skilled nursing facility. When Jack is in rehabilitation at the skilled nursing facility, conjugal visits (which are protected by law for spouses) will likely not extend to same-sex partners (Ettlebrick, 1996).

Providing care at home.

Jack’s hospital and skilled nursing care are likely to be very costly. In addition, his in-home therapy and the countless number of medications and equipment he will require will also be of great expense. Although Medicare will pay for some of this expense (aside from the medications), it is possible that Jack may need to apply for Medicaid to cover the additional costs of care. His eligibility for Medicaid, of course, would depend on his income and assets. He may have to “spend down” his income and assets in order for Medicaid to pay for his care needs. In the case of spend-downs, policies exist that protect legal spouses from losing needed resources, including income and property. This protection is crucial when spouses require very costly, long-term care in nursing homes. Because they are not legal spouses, Herb would not be similarly protected (Cahill, South, & Spade, 2000).

Because Herb is 62, he may still be employed full or part-time. Since Jack will need care when he returns from the skilled nursing facility, Herb may need to take time off from work to care for him. Depending upon the policies of Herb's employer, he may not be able to take a paid leave since Jack may not be considered "family." At the federal level, the Family Medical Leave Act of 1993 does not account for same-sex couples. This policy allows for employees to take up to twelve weeks of unpaid leave time to care for a spouse or relative who is seriously ill (Cahill et al., 2000). Herb and Jack would not fall under the policy's definition of family, so an unpaid leave may also not be a realistic option in their case.

Furthermore, if it is discovered that Herb is caring for a same-sex partner, he may not have legal protection if his employer decides to terminate him because he is a homosexual. Currently, only eleven states and the District of Columbia have enacted laws that prohibit discrimination based on sexual orientation in private employment and only eighteen states and the District of Columbia have passed similar legislation related to public employment (van der Meide, 2000). Depending upon where they reside, Herb may have no legal recourse if he is terminated from his job.

Bereavement.

When Jack dies, Herb will not receive survivor benefits from Social Security. Survivor benefits are only awarded to legal spouses and children and these persons may receive a portion of the deceased Social Security income. Herb would also not be eligible for spousal benefits under the Social Security system. Spousal benefits allow a legal spouse, at retirement, to choose between the benefit they would receive based upon their

own work history or one-half of the amount paid to their spouse (Cahill et al., 2000). If Jack had made considerably more money than Herb over his lifetime, this issue would be significant. Herb would have no choice but to receive Social Security benefits based upon his own work history, even though he and Jack were life partners.

Retirement income, such as 401(k) plans and pensions, may also be an issue for Herb and Jack. If Herb wanted to “roll over” Jack’s retirement income to his individual retirement account (IRA), he would be subject to a twenty-percent federal withholding tax because they are not legally married. Because Herb and Jack are not considered legal spouses, they are also not protected under the Retirement Equity Act (REA) of 1984. As many pension plans have a joint and survivor annuity option (J & S option), all or a portion of the pension of a deceased spouse can be paid to the surviving spouse (Cahill et al., 2000). This would not be an option for Herb.

Jack may have prepared a will prior to his stroke. Even if he left his entire estate to Herb, the inheritance may be problematic. In many areas of the country, a blood relative could try to interfere with the wishes of the couple and may sue for inheritance of the estate. If no will was drafted, his inheritance would automatically be awarded to his legal survivors, namely a blood relative (Berger, 1982).

These are a few of the policy implications for the above scenario. Clearly, Herb and Jack would have special challenges to overcome in this series of crises. These challenges are largely related to the fact that their relationship is not legally recognized. At the present time, same-sex marriages are not recognized by law in the United States. In fact,

thirty states have adopted legislation that explicitly prevents “recognition and/or performance” of same-sex marriages (van der Meide, 2000).

Understanding the Diversity Among Caregivers

Based upon federal, state, and organization policies, one can guess that Herb’s experiences may be somewhat different from other caregivers. But, aside from speculation about policy, very little is known about the actual experiences of gay men and lesbians that provide care to their partners. Even less is known about the experiences of these caregiving partners in later life. In fact, much of what we know about caregiving among couples has been based primarily on the experiences of opposite sex spouses. The experiences of opposite sex spouses, along with those of adult daughters and daughters-in-law, have been the focus of much of the traditional caregiving literature.

Traditional Caregiving

The general or “traditional” caregiving literature has been accumulating since the late 1970s. Much of this literature has focused on family caregiving for older adults. In this attention, studies have shown caregiving to be a very challenging role, as numerous studies have pointed to the often aversive effects caregiving can have on a caregiver (Brody, 1981; Cantor, 1983; Poulshock & Deimling, 1984; Robinson, 1983; Zarit, Todd, & Zarit, 1986). Despite these effects, research has also shown that persons provide care out of a commitment to their loved ones and to avoid institutionalization (Carter & Golant, 1994). Moreover, many caregivers take pride in their care and ability to keep

loved ones in the home environment (Farran, Keane-Hagerty, Sallowat, Kupferer, & Wilken, 1991).

The traditional caregiving literature has contributed greatly to the understanding of the caregiving experience and its often-aversive effects. This literature, however, exhibits several methodological and conceptual problems and biases as well. The representativeness of samples utilized is questionable, as the majority of studies have drawn samples from more formal sources, including support groups and community agencies, thus presenting a bias towards those caregivers likely to patron such groups and agencies (Barer & Johnson, 1990). Additionally, caregiving studies tend to include primarily those who are white, middle class, and (presumably) heterosexual, while also studying caregivers who are either (heterosexual) spouses, daughters, and daughters-in-law. Caregiving models, then, may reflect the biases of these populations.

Challenges to Traditional Caregiving

Only recently have attempts been made to study diverse populations of caregivers. As a result, the experiences of cultural minority caregivers, including Hispanics and African Americans, have become more visible and better understood (Delagado & Tennstedt, 1997; Fredman, Daly, & Lazur, 1995; Hinrichsen & Ramirez, 1992; Mui, 1992; Wood & Parham, 1990). Some studies have also looked at the experiences of other minority caregivers, including gay men and lesbians who provide care to partners, family members, and friends. The majority of these studies have focused on caregiving for

persons with HIV/AIDS, while fewer studies have examined caregiving in the broader gay and lesbian community.

In response to the epidemic that began in the 1980s, research has given some attention to the special caregiving experiences of those caring for persons with HIV/AIDS (Folkman, Chesney, & Christopher-Richards, 1994; Turner & Catania, 1997; Turner, Catania, & Gagnon, 1994). Many of these studies have focused on the experiences of gay men who provide care to their partners. These studies have found caregivers for this population to have similar strains related to caregiving as those in the traditional caregiving literature, including physical, emotional and financial strains. Differences were apparent, however, in the make-up of their support systems and concerns related to their own HIV status.

Although challenging the image of the heterosexual spouse or adult daughter as the caregiver and adding to our increased understanding of caregiving among same-sex couples, the HIV/AIDS caregiving literature also presents several limitations. To begin, this is a caregiving experience that is somewhat specific to gay male partners. One of the major limitations for comparison is the fact that the majority of HIV/AIDS caregivers (in studies) have been under the age of forty. Additionally, the HIV/AIDS caregiving literature often leaves out an important group, the group comprised of lesbians. Additionally, the body of HIV/AIDS literature does not provide for the experiences of gay men and lesbians who provide care for partners with chronic diseases other than HIV/AIDS.

A few studies have tackled the topic of caregiving in the broader gay and lesbian community (Frederikson, 1999; Tully, 1989). These studies primarily establish the involvement of gay men and lesbians in family caregiving and detail their opinions about services they would prefer should they need care themselves. As with the HIV/AIDS caregiving literature, these studies do not adequately represent the experiences of those over the age of 50. For example, under 10% of the respondents in Frederikson's study were over the age of 50 and only 8% were caring for someone over the age of 65. As an added bias, over 90% of those Tully (1989) surveyed had described their health as "excellent" or "good" and were not currently candidates for hands-on care.

Numerous studies have focused on the life experiences of gay men and lesbians over the age of 50 (Berger, 1996; Kehoe, 1986b; Kelly, 1977; Kimmel, 1978; Kimmel & Sang, 1995; Kooden, 1997; Sang, Warshow, & Smith, 1991). Despite this growing attention in the literature, studies have primarily focused on the adjustment of older gay men and lesbians to old age and developmental issues of gay men and lesbians in midlife. In effect, literature that centers around gay men and lesbians 50+ does not account for their involvement as caregivers. In addition, literature that focuses on gay and lesbian caregivers excludes the experiences of persons over the age of 50. As a result, very little is known about the experiences of midlife and older gay men and lesbians who provide care to chronically ill partners.

Caregiving and Chronic Illness in the United States: A Growing Challenge

The Present and Future of Chronic Disease

Although little is known about the diversity among caregivers, a great deal is known about the extent of chronic disease in this country. Chronic health conditions, such as congestive heart failure and high blood pressure, are currently the “leading causes of illness, disability, and death in the United States” (The Robert Wood Johnson Foundation, 1996, p.13). In fact, in 1998, chronic diseases such as heart disease, diabetes, and chronic liver and pulmonary diseases ranked as top causes of death for persons over forty-five (National Center for Health Statistics, 2000). It was estimated that the year 2000 would see 105 million persons with chronic health conditions. This number is estimated to rise to 150 million by the year 2030 and 42 million of those “will be limited in their ability to go to school, work, or to live independently” (The Robert Wood Johnson Foundation, 1996, p.8).

As medical care for those with chronic illness can be quite costly, these costs are expected to rise dramatically in the upcoming years. The medical costs related to care for persons with chronic conditions is expected to rise from \$470 billion (in 1995) to \$906 billion by the year 2050. These costs may include formal support services, such as inpatient and outpatient medical care, home health care, in-home personal care, skilled nursing care (nursing home), rehabilitation, services related to home modification and assistive technologies, and adult day care (The Robert Wood Johnson Foundation, 1996).

Informal care to persons with chronic illnesses can also be very costly. As caregiving can require many hours of intense hands-on care, the cost of care to caregivers can be

quite high. The National Alliance for Caregiving (1997) found 41% of the caregivers they surveyed who reported that they knew how much out-of-pocket experiences they incurred in caregiving, the average amount for these caregivers was \$171 per month. Similarly, the care provided by informal caregivers of family and friends is estimated to value \$196 billion dollars a year. This amount far exceeds the amounts spent on formal caregiving services provided in nursing homes or through home health services (National Academy on an Aging Society, 2000).

Although they are the foremost causes of death and disability, people are and will continue to live longer with chronic health conditions. In addition, as persons age, chronic conditions increase in “number and in their severity” (The Robert Wood Johnson Foundation, 1996). In effect, caring for persons with chronic conditions will become an immense challenge as we witness the future boom in the older adult population.

An Aging Society and the Growing Need for Care

As Peterson (1999) states, “Unlike global warming, there can be little debate over whether and when global aging will manifest itself” (p. 42). Global aging is a term used to describe the tremendous worldwide growth that is expected to occur in the older adult population. With this growth, the world will witness an unprecedented phenomenon: one in which societies will be older than ever before; where the number of the “old-old” (those 85+) will largely outnumber the “young-old” (those 65-84); and a never before seen “economic burden” of older persons on those who are of working age (Peterson).

Although the growth in the aging population will have worldwide implications, projections have been made about the future of the aging population in the United States. Peterson (1999) proposes that we will see the “Floridization” of the United States by the year 2021. By that time, this country’s population will resemble that of the state of Florida, that currently has a striking nineteen-percent of its population over the age of 65. Population projections estimate that by 2050, one in five persons in the U.S. may be 65+ (U. S. Census Bureau, 1995). Life expectancy will jump from 72 years for men to 86 years by 2050. For women, the current life expectancy of 79 years will increase to 92 years. With the increasing life expectancy, the percentage of those 65+ is expected to soar in the upcoming years. Moreover, the population of those 85+ is considered to be the fastest growing segment of the population. The total growth of the 85+ population is expected to increase to over 400% from 1995 to 2050 (Siegal, 1996).

With the increasing population of those 65+, and especially those 85+, there will likely be a growing number of individuals afflicted with chronic illnesses and physical impairments. Many of these individuals will require some kind of care. The need to provide care for this segment of the population, then, will also grow significantly in the years to come (Siegal, 1996).

There is a growing concern that the future pool of available caregivers may be insufficient to meet the needs of older persons who are chronically ill. This concern is based upon household statuses and the elder dependency ratio. In the upcoming years there will be an increase in “vulnerable groups” of older persons, including the old-old who live alone and unmarried persons with no living children or siblings. It is expected

that 45% of those 65+ will live alone by the year 2020. Additionally, the “elderly dependency ratio” (which is the number of persons 65+ for every 100 persons ages 18-64) will also grow significantly in the upcoming decades. This ratio is expected to jump from 21.2 in 2010 to 36.5 by 2040 (Siegal, 1996).

Rationale for the Present Study

The future will likely witness a rise in the number of persons with chronic health conditions as well as a rise in the cost to care for these persons. Hopefully, there will also be growing number of individuals who will accept the challenge of providing care to their significant others and loved ones. Currently, professionals and services are not well equipped to understand or to meet the special caregiving needs of midlife and older gay men and lesbians. The lack of attention specifically to midlife and older gay and lesbian caregivers can possibly be attributed to a belief that what is known from the traditional caregiving literature will apply to all populations of adults and their caregivers. This lack of attention to the diversity among caregivers can prove to be detrimental to the way professionals provide medical and social services.

Social workers, in particular, can expect to encounter caregivers in need and in crisis in a variety of settings, including home health and hospice, hospital, mental health, and local departments of social services. Social workers employed in these types of settings, who base their practice with caregivers on what is known from the traditional caregiving literature, are not likely to be sensitive to the special needs and experiences of midlife and

older same-sex partners. Counseling and resource planning that takes place in such situations could be inappropriate, less effective, and potentially harmful.

Not only does the lack of attention to the caregiving experiences of midlife and older gay men and lesbians have the potential to impact social work practice, but it is also likely to adversely affect social and health care policy and programming. First, it is well documented that the majority of caregivers for older adults provide care in the home to avoid nursing home placement (Chenoweth & Spencer, 1986; Colerick & George, 1986). Additionally, home care has been shown to reduce overall health care expenditures, protecting against an average yearly nursing home cost of \$47,000 (AARP, 1999). Caregivers, then, are clearly the best defense against the rising costs of institutional care and the strain those costs place upon the Medicare and Medicaid systems. It is therefore in the best interest of the government and social and health service agencies to understand the problems faced by caregivers and to provide supportive programs. Understanding the diversity of caregiving experiences is imperative in providing effective and supportive programs for caregivers.

Steven Zarit, a forerunner in caregiving research, asked the question in a 1989 editorial, "Do we need another stress and caregiving study?" (Zarit, 1989). This researcher believes the answer is "yes." In addition to the wealth of information regarding caregivers for older adults, future studies need to continue to shed light on caregiving in social minority populations. In particular, the caregiving literature needs to be expanded to include the experiences of midlife and older gay and lesbian caregivers that provide care

for same-sex partners. An exploratory study examining the unique experiences of this caregiving population is long overdue and certainly warranted.

Purpose of the Present Study

In response to this need for exploration and expansion, a qualitative study was designed and conducted. The purpose of this study was to understand the experiences of midlife and older gay men and lesbians who provide care for chronically ill, same-sex partners. It was also apparent that the existing caregiving literature has not given adequate attention to the lives and experiences of caregivers after care has ended. To add to this concern, Martin and Doka (2000) have noted that gay and lesbian grieving has been “understudied.” In response to the lack of knowledge in this area, the present study also sought to understand the respondents’ experiences following the cessation of care. Given this understanding, it is then possible to develop and share implications for supportive policies and effective health care and human service practice with this special population of caregivers.

Given this purpose, Chapter Two details the literature relevant to this topic, illuminating the lack of knowledge about the experiences of midlife and older gay and lesbian caregivers and pointing to the importance of expansion in this area. Chapter Three describes the methods used in the study. Chapter Four presents the findings from the present study and Chapter Five offers implications of the study findings as well as suggestions for future research in this area.