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Sons Providing Care at End-of-Life : Common Threads and nuances

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SONS PROVIDING CARE AT END-OF-LIFE:

COMMON THREADS AND NUANCES

by

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DISSERTATION APPROVAL

The abstract and dissertation of Patricia Ebert for the Doctor of Philosophy in Social Work and Social Research were presented September 28, 2006, and accepted by the dissertation committee and the doctoral program.

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ABSTRACT

An abstract for the dissertation of Patricia Ebert for the Doctor of Philosophy in Social Work and Social Research presented September 28, 2006.

Title: Sons Providing Care at End-of-Life: Common Threads and Nuances

Family care is common in the majority of families in the United States, the primary care providers for older adult family members most often are wives, daughters or daughters-in-law. As the proportion of the oldest old continues to expand so too will the need for family careproviders. Recent demographic changes have served to deplete the pool of available caregivers. Caregiving research has naturally evolved into investigations into the experiences of women with little attention paid to the care contributions men make.

This investigation examined the perceptions of sons who served as primary caregivers for their dying elderly parents. It was an initial attempt to learn about the contributions they provided and the challenges they faced, in order to better understand their world view of caregiving separate from their female counterparts.

A secondary analysis of data from a study entitled, "Family Perceptions of Community-Based Dying" conducted at the Oregon Health & Science University's (OHSU) Center for Ethics in Health Care and School of Nursing in Portland, Oregon was used to investigate the experiences of thirty sons providing care to elderly parents.

A qualitative approach was utilized to analyze the responses to three open ended questions from these caregivers.

The implications from this analysis suggest these thirty sons became actively engaged in the care provided and the decisions made in relation to their parents at end-of-life. Unlike other caregiver groups studied to date these men identified dementia, nutrition-related issues and respiratory problems as the symptoms their parents endured at end-of-life which they found most distressing.

Research on supportive services for male caregivers has been limited. Additional efforts are needed to gain a greater understanding into the needs of these son caregivers so that gender relevant programs can be created in order to support the caregiving roles they are engaging in. Based on the need to engender all family care providers at end of life, given the dwindling number of available family members and the increasing need for family care for this older adult population at the end of their lives, additional study is needed.

Dedication

I would like to extend my heartfelt appreciation to the over 400 caregivers I interviewed as part of their participation in the Family Perceptions in Community-based Dying study at Oregon Health & Science University from 2000 to 2002, with a special mention to the thirty son caregivers who served as the focus of this study. The hours spent during those telephone interviews afforded me the privilege of learning more about their experiences while caring for dying family members. I am wholly indebted to each of you.

While I was undertaking a more thorough examination of the information shared by the thirty adult sons in this study, I was moved by the accounts they shared. The openness exhibited and the courage summoned in order to share painful details just a few short months after the death of a family member, will remain with me forever. With few studies that focus on men engaging in care for their family members and fewer still on sons, I have attempted to illuminate the contributions made with the hope that others will follow suite in the future.

My personal experience with the deaths of two family members just preceding this study have also had an indelible impact on my views about dying and death. My sister, Mary Ebert succumbed to breast cancer after a multiple-year battle and was the first person I ever had the privilege of being with when death arrived. My Mom, Dorothy Ebert, was the second. She died a little more than a year later, being robbed of many quality years of life because of Alzheimer's disease. The death experiences I shared with these two family members following long, physically and emotionally draining illnesses helped to set the stage for the experiences I was fortunate to have had while conducting these interviews.

Acknowledgements

I would like to express my deepest appreciation to Pam Miller, my dissertation chair for her support, patience and guidance throughout a very long process while she was going through some difficult times herself. I would also like to acknowledge my other committee members: Joan Shireman who has remained an incredible supporter over many years; Susan Hickman who I had the good fortune to meet early on during my tenure as a research assistant; Vicki Cotrell who I had the good fortune to meet after she graciously agreed to serve on my committee; and Leslie McBride who I first got to know as a graduate student and whose support and expertise I could not have done without.

I would also like to acknowledge my colleagues on the Family Perceptions study including: Susan Tolle, the co principal investigator, who served as my 'fairy godmother' early on during this project; Linda Drach, the project director whose friendship I continue to value and Virginia Tilden, the other co- principal investigator who also served as a very important person in my process.

My most abiding appreciation goes to my family members: my daughters Chloe and Erin for their patience, love and understanding and to my sister Suzy whose support I could not have done without. Last but certainly not least I would like to acknowledge my many wonderful friends and colleagues (and colleagues who have become friends) that I have had the good fortune to collect over the past five years. It did indeed take a village....

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Introduction

Family Caregiving at End-of-Life

Providing care for family members at the end of life has been a part of our culture in the United States since Colonial times. Many changes occurred altering the landscape for our family members at the end of life as we moved from being an agrarian society to an industrial one and then into a technological one. The greatest of these changes has been the host of advances in modern medicine, which over time began to extend our lives. Who most often dies, the length of time it takes to die, and the settings in which people prefer to die but most often do not, are a few of the many components at end of life that have undergone profound change as the result of these medical advances in the last one hundred years.

Who Dies & How They Die

For the first time in the history of our country, over 75% of all deaths occur among our older adult population (DeSpelder & Strickland, 1999). The circumstance in which this segment of the population dies has also helped to alter our perceptions of death. While the majority of those who die today are older adults, they frequently have experienced many years of chronic illness before dying. They have reached an advanced age because they were fortunate enough to live in a time in which modern medical advances have eliminated many of the illnesses that would have led to death a century ago. Unfortunately however, the projected increases in the number of elderly have also raised concern about the costs of the care they might need as the end of life approaches. In 1900, those over the age of sixty-five comprised only 4% of the population. With the current median age at death of 76 years, adults age 65 and over now comprise 13% of the U.S. population. By the year 2011, the generation referred to as "Baby Boomers" (i.e., born between 1947 and 1974), will begin to turn 65 years of age. It has been projected that by the year 2030, those who are 65 or older will then account for one out of every five Americans, effectively doubling the size of the older adult population that exists today (Federal Interagency Forum on Aging-Related Statistics, August, 2000). This segment of the population routinely encounters an increased burden of chronic medical conditions as they age, conditions that often have an uncertain prognosis. This leads them to be the consumers of over 35% of the total personal healthcare dollars spent in the United States (Glasgow, 2000).

Changes in the Trajectory to Death in the Twentieth Century

In the twentieth century, medicine entered the modern age when illness and many diseases could be prevented and often completely cured. Medical advances led to an increase in life expectancy from 47 years in 1900 to 76 years today (Federal Interagency Forum on Aging-Related Statistics, August, 2000). The first kidney machine was developed at the end of WWI and was followed by dialysis machines in the 1960s, providing long term therapy and extending the lives of countless people with end stage renal disease (Hoefler, 1994). Breakthroughs in innovative surgeries and medical hardware such as pacemakers & defibrillation equipment were joined by innovations made in the transplantation of lungs, liver, kidneys, pancreas and bone marrow (Webb, 1997).

However, while we are living longer the attending consequence often comes in the need to live with chronic conditions (Bern-Klug, 2004). Author Aaron Wildavsky suggests that these advances have created a population of 'would have dieds' (Wildavsky, 1977, 107). Five out of the six most common causes of death for older Americans are chronic diseases and include heart disease, cancer, stroke, chronic obstructive pulmonary disease and Alzheimer's disease. Heart disease was responsible for 40% of all deaths for those considered to be the oldest old (i.e., age 85 and older), (Federal Interagency Forum on Aging-Related Statistics, August, 2000). These and other chronic degenerative diseases, which are often age-related, now take a slower more progressive pace toward death. An example of this comes from research on a population of adults who live with chronic heart conditions and was undertaken as part of the long term Framingham study that began in 1948. The study found that while patients are now surviving their once fatal heart attacks by having bypass surgery and living with the help of new medications, they are also living in a more impaired and far more seriously ill condition (O'Rourke, 1993). The difficulties this medical situation poses for families becomes apparent as they attempt to provide care for critically ill family members without ever knowing how long they will have to do it or how long they will be able to do it (Webb, 1997).

Realities /Desires for Place of Death

Dying at home surrounded by family was commonplace one hundred years ago. As medicine has advanced, people began to routinely seek medical care in hospitals throughout their lifetime, more often than not dying in them as well. In the last several decades, our ability to provide medical care to both the chronically and terminally ill has become the norm but has come with a trade off (Glick, 1992). While the sickest of our citizens continue to receive advanced medical care, the need for long term care, not traditionally provided by hospitals, has increased the older adult population's need for informal care (Kaye, 1988). There has been a growing national trend for this care to be provided in community based settings which includes homes, nursing facilities, assisted living facilities or adult foster care homes (Last Acts, November, 2002). With wide variations from state to state, death occurs outside of a hospital setting (i.e., community based setting) for 50 to 90% of Medicare-aged older adults (Wennburg & Cooper, 1999). This broad range suggests there is great variability across the county in terms of where older adults are likely to die. Data also suggests that between 20 to 25% of the older adult population die in nursing facilities, a number which is expected to grow (Glasgow, 2000). Although 70% of Americans report they would like to die in their own home, only about 24% have the opportunity to do so (Last Acts, November 2002). In contrast to these national statistics, the communities in the state of Oregon have some of the highest rates of out of hospital deaths among Medicare eligible older adults, with a range of 84 to 88% (Wennburg and Cooper, 1999). Oregon also ranks as a state with the second highest rate of deaths, at 35.1% of all deaths, occurring at home nationwide (Last Acts, November 2002).

Family Members as Providers of Care at End of Life

While family care is common in the majority of families in the United States, the primary care providers are predominantly women. For older adult family members this most often means wives, daughters or daughters-in-law. These female family members are now providing an estimated 70 to 80% of all caregiving support to this segment of the population (Brody, 2004). As the proportion of the oldest old, age 85 and older continues to expand, so too will the need for family care providers. Demographic changes have occurred however, which have had an effect on the pool of family members available to provide this care. A considerable decline in birth rates from the mid 1950s to the present has served to decrease the number of younger family members (National Center for Health Statistics, 2005). Additionally the availability of female family members has also been altered as more women have entered the paid workforce in the last two decades (Neal, Ingersoll-Dayton & Starrels, 1997).

The dominant 'caretaking' roles traditionally taken on by women have been tremendous. The many aspects of caregiving including those that are often physically, financially and emotionally burdensome have been the subject of numerous investigations over the last twenty years (Brody, 1981; Brody, 1985; Horowitz, 1985; Montgomery & Kamo, 1989; Neal, et al. 1997; Stone, Cafferata & Sangl, 1987; Zarit, Stephens, Townsend & Greene, 1998).

In the last decade, research has begun to demonstrate that men are providing care to a host of family members over the life span (Chang & White-Means, 1991; Harris, 1993; Ingersoll-Dayton, Starrels & Dowler, 1996). Although our sociological picture has most often portrayed caregiving as a women's issue, it is gradually changing as we become more aware of the diverse and expanding contributions men are making in the area of caregiving (Morano, 1998; Neal, et al. 1997; Thompson, 2002). As the breadth of their caregiving roles continues to evolve and expand, public perception needs to keep pace with these men who are committed to take on the challenges of family caregiving (Femiano & Coonerty-Femiano, 2002). The research undertaken to date on male care provision has primarily focused on spouses caring for wives with cognitive impairment and gay men caring for their partners with HIV/AIDS (Kaye & Applegate, 1990; Kramer, 2002). Many of these studies however have come in the form of comparisons to women providing this same type of care (Allen, 1994; Horowitz, 1985; Ingersoll-Dayton, et al. 1996; Morris, Woods, Davies, & Morris, 1991). Beyond these two groups, little research has investigated caregiving males. This has been due in part to the amount or type of care provided. Researchers have frequently concluded that men did not provide as much care as women (Allen, 1994; Almberg, Jansson, Grafstrom, & Winblad, 1998; Neal, et al 1997) were providing lower level or less hands on types of care (Collins & Jones, 1997; Dwyer & Coward, 1991; Miller & Cafasso, 1992) or were reporting lower levels of burden as a result of the care they were providing (Collins & Jones, 1997; Faison, Faria & Frank, 1999; Gold, Cohen, Shulman, Zucchero, Andres & Etezadi, 1995; Yee & Schulz, 2000). From this vantage point the care men were providing may have been viewed to be of less significance and most often not burdensome enough to warrant investigation. Kaye and Applegate, researchers who have studied men and caregiving, have suggested the 'feminine lens' applied to much of the caregiving research to date has not always permitted investigations into the contributions men make in the area of caregiving in a very objective manner (Kaye & Applegate, 1990). With so many more women engaged in caregiving, the research naturally evolved into investigations that focused on their experiences in an effort to better understand them.

This investigation undertook the task of examining the contributions men make to family members at the end of life. It afforded a unique opportunity to utilize data from a larger study of family caregivers in which a surprising number of sons served as primary caregivers for their dying parents. It is believed that by looking at the contributions they provided and the challenges they faced, we can begin to come to a greater understanding of their worldview of caregiving separate from the contributions of their female counterparts. Based on the need to engender all family care providers at end of life, given the dwindling number of available family members and the increasing need for family care for this older adult population, the results of this investigation will prove to be an important contribution to the body of social work research.

Social workers routinely take the lead in providing emotional and social services to the dying and their family members. Their knowledge and skills place them in a unique position, allowing them to serve as moderators and collaborators in the dying process with family members and other healthcare providers. The findings from this study suggest these sons were highly involved in the end-of-life issues and professional care provided to their dying mothers and fathers. The end-of-life symptoms identified as being most difficult for them further suggests their level of engagement. A greater understanding of the ways in which an increasing number of sons are choosing to be involved in providing care is important for social workers who engage with family members at end of life. This knowledge will provide them with tools to not only support and encourage the care these men are providing, but also to help create an environment that readily accepts men and the care contributions they make to their dying elderly parents.

Literature Review

Older Adults: The Importance of Care by Family Members

Almost seventy years ago social scientists predicted the growth of urbanization and industrialization in the United States would lead to the weakening of the support structure and ties previously provided by family, friends and neighbors (Wirth, 1938). It was based on the belief that rural societies enjoyed family relationships and close personal ties, while urban societies were characterized by weaker personal relationships and secondary group relationships outside of the family structure. It was further believed that the migration to urban areas that accompanied industrialization would reduce contact with and support from kin (Wirth, 1938). It was during this time that intergenerational households were commonplace. Older adults were often residing with younger family members, particularly if their health was failing or if they were widowed (Hareven, 1996; Uhlenberg, 1993). The practice of co-residency began to gradually decline, with the greatest period of change occurring from 1960 to 1998. Census data indicate that the largest contributing factor for this decline was an increase in the number of older women living alone (Brody, 2004).

Today with increased life spans, more than half of the older adult population is married and living with a spouse or partner in an independent household (Climo, 1992; Sauer & Coward, 1985). With 75% of the population aged 65 and older now residing in urban areas in the United States, it appears these earlier predictions of weakened family ties have not held up over time. Several studies have provided evidence that this phenomenon never materialized, revealing that urban older residents were more likely to have family living nearby and see them more frequently than their rural counterparts (Bultena, 1969; Stoller, 1983; Stone, et al. 1987). Recent estimates suggest that for 46% of adults aged 65 and over, their adult children live within 20 minutes or less of their home and only 18% of this older adult population have children living more than an hour's drive away (U.S. Dept of Labor, Women's Bureau, 1998).

Many families enjoy a reciprocal relationship over a lifespan. Older adults frequently provide support to their adult children and their grandchildren, enjoying support and care in return when they are facing chronic illness and disability. It has been estimated that 80% of all care provided to adults over the age of 75 who are chronically ill receive this care from family members (Stone, et al. 1987).

As has been suggested earlier, the population of older adults has continued to expand in the last century. Dramatic changes in mortality and fertility rates have contributed to the dramatic increases in not only the number but the proportion of the older adult population. The age group of 65 and over is expected to expand from 31 million in 1990 to 79 million by the year 2050 (Day, 1992). A two hundred and forty percent increase is expected in the growth of the oldest old (age 85 and older) by the year 2040, a segment of the population most likely in need of medical care and informal care due to chronic illness and/or disability (Kramer, 2002).

Along with these demographic changes we have also experienced economic changes that have had a major impact on this segment of the population. In the last two decades health care costs have skyrocketed and reforms to contain these costs have placed a tremendous burden on families attempting to provide assistance with informal care. One of these reforms has been a diagnosis-related prospective reimbursement system (Diagnosis Related Groupings/DRGs) that limits length of stays in hospitals but in effect increases the likelihood that frail elderly patients will be discharged from the hospital "quicker and sicker" (Kaye & Applegate, 1990). Changes in the reimbursement of costs for nursing facility stays and home care have also been put into place to counteract rising costs for care reimbursed by Medicare. Due in large part to the financial implications of providing care in institutional settings, a gradual shift to care provided in community settings has occurred. The result has been shortened hospital stays and the release of critically ill patients, most often older adults, into the community, ostensibly to be cared for by family members as they recuperate (Kaye, 1988).

Caregiving Defined

Prior to examining the concept of caregiving, it is important to define the way in which it will be used here and explore who the providers of this care tend to be. Additionally an explanation into some of the ways in which it has been examined in the literature will be provided. Defined in this context, caregiving will refer to informal or unpaid voluntary care provided to family members. Caregiving has been examined in terms of the relationship to the care receiver, the type of care provided, the living arrangements, as well as the amount and duration of care provided (Barer & Johnson, 1990). The definition used has helped to determine the number of caregivers;

the extent of the difficulty of their tasks; and the impact caregiving has had from an individual perspective to a societal one (Stone, 1991).

Who Does It: The 'Carers'

An older adult's informal caregivers often include a range of family members including a spouse, adult children, other family members, neighbors and friends. The care provided most often consists of informational, emotional and/or instrumental support (Coward, et al. 1993; Spitze & Logan, 1990; Zarit, Reever & Bach-Peterson, 1980). The results of studies vary but women generally provide 72% to 80% of the care provided to chronically ill older adults (Stone, et al. 1987; Brody, 2004). Recent data suggests that almost 29% of primary and secondary caregivers are daughters, 24% are wives and 20% are female nonrelatives (Stone, et al. 1987). Studies that have focused on family care provision by men often report comparisons between the care provided by men and women (Horowitz, 1985; Dwyer & Coward, 1991; Montgomery & Kamo, 1989). Findings suggest that women engage in care that is often hands on or personal in nature and are better equipped than men to do so because of their nurturing qualities and abilities to provide emotional care to recipients (Gillian, 1982; Sommers, 1985). Alternatively some of these same studies have suggested the care provided to family members by men is less personal in nature, allowing them a greater emotional distance while focusing on concrete, instrumental tasks (Dwyer & Coward, 1991; Horowitz, 1985; Lutsky & Knight, 1994; Miller & Cafasso, 1992).

Implications of Providing Care

It has only been within the last thirty years that research into the aspects of caregiving for older adults has come into being. In that time the health and wellbeing of caregivers has been studied with increasing intensity with the majority of investigations focusing on the negative aspects of care provision (Brody, 1981; Gallagher, Rose, Rivera, Lovett & Thompson, 1989; George & Gwyther, 1986; Zarit, et al.1980). These studies have given rise to scales and measures that provide tools to assess caregiver burden and caregiver stress, terms which have since become commonplace in the literature. In part because of the enormity of the caregiving tasks for both younger and older family members undertaken primarily by women, Elaine Brody referred to this group as women in the middle in the 1980s (Brody, 1981). This phrase has continued to help provide a somewhat visual representation of the care responsibilities bestowed upon many women, who have caregiving responsibilities for older as well as younger members of their families (Brody, 2004). Although many aspects of caregiving have been studied, three areas that have frequently served as general topical areas for caregiving research include the physical, emotional and financial stress associated with providing this kind of care to an older adult family member.

Physical Stress

Assistance with transportation, shopping, cleaning, or cooking are frequently the types of care initially provided by family members. However as older adult family members become more chronically ill, the need for assistance often increases. The care scenario often leads to assistance with personal care such as bathing, feeding, or dressing (Faison, et al. 1999). The types of family care provided to older adults is most often determined by their functioning level and the gender of the caregiver, with personal care most often provided by wives and daughters (Cantor, 1991; Stoller, 1983). In a study of employed women who were providing care for an elderly family member, participants reported providing an average of eight different tasks, ranging from household responsibilities to personal care (Anastas, Gibeau & Larson, 1990). Certain types of tasks are often found to be more burdensome for caregivers than others. Montgomery, Gonyea & Hooyman (1985) found that two types of tasks, those involving personal care and assistance with transportation and errands, were most often reported by female care providers as burdensome. They were not seen as burdensome because of the hours of service they entailed but because they created conflicts for these employed women as they attempted to meet the other demands in their lives (Montgomery, et al. 1985)

Emotional Stress

Perhaps the greatest focus has been placed on studies that have investigated the various forms of emotional burden endured as the result of family care provision to an older adult. Studies that have looked at the kinds of care provided by women to older adult family members concur that the assistance is more labor intensive and time-consuming care than that provided by men. Women also report greater health-related consequences as a result. They report more mental health problems, often in the form of depression and greater social isolation as well (DeVries, Hamilton, Lovett &

Gallagher-Thompson, 1997). Men in caregiving roles often report less stress but greater satisfaction as a care provider (Matthews, 1998). Women who are employed and find themselves juggling care for a frail elderly family member also report increasing emotional stress as they attempt to combine these two roles (Neal, et al. 1997; Scharlach, Sobel & Roberts 1991; Stone & Short, 1990). However, studies have also demonstrated that having a greater amount of family support, including family visits, tended to help reduce stress and burden among employed female caregivers (Montgomery, et al. 1985; Zarit, et al.1980).

Family care provision frequently involves not only providing care but also finding others to provide various services and then managing those services. Research has suggested that providing personal care for older adults could be even more stressful than finding and managing the assistance provided by others (Archbold, 1983). Additional research however suggests that caregivers undertaking the tasks of finding and managing this kind of help were reporting more stress than those carers without paid help (Orodenker, 1990). Employed caregivers who had more social support demonstrated a reduced amount of interference between their roles as caregiver and employees (Scharlach, et al.1991). Two thirds of these employed caregivers also reported having to rearrange their work schedules, decreasing their hours or having to take an unpaid leave in order to meet their family member's needs which leads to additional stress for them (DHHS, June 1998).

Financial Strain

Beyond the emotional and physical strain carried by family members providing care, there are financial burdens as well. The enormity of the 'work' that caregiving entails has also been captured in terms of the equivalent costs that would have to be borne if families were not willing to provide this informal care. It has been estimated that 26 million Americans provide an average of 18 to 20 hours weekly caring for an older adult family member (Levande, Herrick and Sung, 2000). Calculating this care by an average hourly wage resulted in a total cost estimated between $197 and $200 billion a year (DHHS, 1998; Levande, et al. 2000). The importance of this care provision can be seen when considering that 10% of older adults who are living independently would have to resort to institutional care if it were not for their family members (Glasgow, 2000).

The financial burdens which families often face can include not only the obvious direct costs associated with the hands on care needed by their elderly family member or the need to hire help but can include indirect costs as well. These can include lost income or missed employment opportunities such as promotions. Women frequently report taking leaves of absences from their jobs and many eventually face making an even bigger decision which results in quitting their jobs completely when the demands of caregiving become too great (Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993; Neal & Wagner, 2001). This interrupted employment can have long range implications that can result in fewer retirement benefits as well (Metropolitan Life Insurance Company, 1997; Stone, et al.1987).

Men as Caregivers: An Overview

Although research on caregivers has spanned three decades, the preponderance of studies has not provided much insight into the role men play. This situation has occurred largely because more women traditionally took on caregiving roles for ill family members. Studies on caregiving have provided comparisons between the contributions women and men make, focusing on the gender differences in the amounts of caregiving and the types of caregiving provided (Fromme, Drach, Tolle, Ebert, Miller & Perrin, 2005). Studies that began in the 1980s placed the focus on women as primary caregivers to older adults (Brody, 1981; George & Gwyther, 1986; Horowitz, 1985; Stoller, 1983). Many of these investigations demonstrated that men were engaged in less care overall and were often not providing as much personal care to family members as their female counterparts. The results of these studies helped to marginalize the contributions made by men (Kramer, 2002) making their contributions seem less significant. Overtime the focus on women, wives, mothers, daughters, daughter-in-laws, sisters and sisters-in-law has helped to perpetuate the 'feminine lens' through which care provision is largely viewed today.

The gradual increase in studies of male caregivers in the last decade has helped to provide a preliminary glimpse into the importance of focusing on yet another potential source of family caregivers. While the majority of these studies have been small and have found their focus in the disease-specific nature of the ill family member, they have moved caregiving research into yet another dimension.

Male Caregiving and Alzheimer's disease

While it has been estimated that 28% of all caregivers to older adults are men, a majority of these men were found to be husbands (Stone, et al. 1987). As spouses of Alzheimer's patients, husbands have been the focus for the vast majority of the examinations into male caregiving to date (Chang & White-Means, 1991; Fitting, Rabins, Lucas & Eastham, 1986; Harris, 1993; Harris & Bichler, 1997; Kaye & Applegate, 1990). These men were found to have provided care because their female spouses and the usual caregivers for others were no longer able to care for themselves. Due to the burdens involved in this type of care, the caregiving aspects for family members were found to continually increase over time. The amounts and levels of care which were being provided by these husbands were viewed as unprecedented in terms of the care men had previously provided thus peaking the interest of caregiving investigators (Kaye & Applegate, 1990; Zarit, Todd & Zarit, 1986)

Findings from the limited studies on husbands has often focused on issues relating to their commitment, control and mental health issues as they provide care for their cognitively impaired wives (Fitting, et al. 1986; Horowitz, 1985; Stone, et al. 1987; Zarit, et al.1986). Yet many of the findings are inconsistent or contradictory in terms of their use of social support (Motenko, 1988; Stone, et al. 1987; Zarit, et al. 1986), the effects their caregiving had on their relationships with their wives (Fitting, et al.1986; George & Gwyther, 1986; Motenko, 1988), their coping strategies (Miller, 1987; Zarit, Zarit & Reever, 1982) and their sense of emotional attachment and commitment (Gilligan, 1982; Miller, 1987; Motenko, 1988).

Male Caregiving and HIV/AIDS

The second most common disease-specific focus for investigation into male caregiving is HIV/AIDS. It has been estimated that 41 to 53% of all primary caregivers for individuals with HIV/AIDS in the United States are male and most often a gay male, making them a unique group of caregivers ((Turner, Catania & Gagnon, 1994). Their caregiving roles have often evolved because of relationship commitments and/or because ties to their 'traditional' extended family network have been severed (Mullan, 1998). Not only do these caregivers face the stressors that caregivers in general encounter, but they are often impacted by stressors uniquely associated with this disease (Turner & Catania, 1997). They can include: (1) the stigma associated with HIV/AIDS which stems from the fear of contagion and homophobia (Herek & Glunt, 1988); (2) their relatively young age as a caregiver (LeBlanc & Wright, 2000); (3) multiple experiences with previous AIDS deaths (Martin, Dean, Garcia, & Hall, 1989); and (4) the uncertain trajectory of this illness (Folkman, Chesney, Cooke, Boccellari & Collette, 1994). If the caregivers were also infected with HIV their stress may be magnified knowing they may be witnessing an end-of-life situation that is likely to be their own (Wright, 2000).

Male Caregiving and Cancer

Although cancer is currently ranked as one of the leading causes of death in the United States, investigations into the provision of cancer care by males is somewhat limited. The studies that have been carried out have largely focused on spouses providing care for wives with breast cancer. With estimates that one in eight women will develop this form of cancer sometime in her lifetime and with young as well as older women suffering the effects of a cancer diagnosis, it should be a particularly important focus of male caregiving research (American Cancer Society, 2003). Although treatment advances have increased survivorship to 63% fifteen years after diagnosis, the demands on family care providers can increase over time (ACS, 2003).

Much of the research on breast cancer and family caregiving has been drawn from the patient's perspective (Ciambrone & Allen, 2002). Studies which focused on relationship issues found that couples who had perceived their relationships as emotionally close seemed to fare better through the course of breast cancer treatment than those whose relationships were not as close (Dorval, Maunsell, Taylor-Brown & Kilpatrick, 1999; Lichtman, Taylor & Wood, 1987; Neuling & Winfield, 1988; O'Mahoney & Carroll, 1997; Rose, 1990). The strength of the pre-surgical relationship not only helped couples through the often-difficult adjustments following mastectomy (Wellisch, Jamison & Pasnau, 1978) but also helped to predict a husband's physical and emotional adjustment (Hoskins, Baker, Budin, Ekstrom, Maislin, Sherman, Steelman-Bohlander, Bookbinder & Knauer, 1996). Longitudinal studies with larger sample sizes which focus on men's caregiving activities and experiences with regard to breast cancer would provide a better assessment of the challenges these male caregivers face and aid in the development of strategies to strengthen the assistance they are attempting to provide their partners (Hoskins, et al.1996).

Sons and Caregiving

While the majority of investigations into men as caregivers have focused on husbands of Alzheimer's patients, partners with HIV/AIDS and spouses with breast cancer patients, two studies have suggested that sons actually comprise 10 to 12% of all primary and 52% of all secondary caregivers (Tennestedt, McKinley & Sullivan, 1989; Stone, et al. 1987). The majority of studies on sons as caregivers however are in keeping with the gender comparisons (i.e., sisters vs. brothers) that are prevalent throughout the caregiving literature (Horowitz, 1985; Lee, Dwyer & Coward, 1993; Matthews, 2002; Montgomery & Kamo, 1989).

In a study conducted by Harris (2002) a different sort of comparison involving sons was undertaken, that of adult sons and elderly husbands. This author used a qualitative research approach to not only gather some insights into the daily concerns and issues faced by these two groups of male caregivers but to also help illuminate the commonalities and differences that may have existed. Like much of the previous research on male caregiving, this study's focus was on care providers of Alzheimer's disease patients. Each of these men (n=60) had a spouse or mother for whom they served as a primary caregiver.

Several themes emerged for these sons and husbands in this study which included: (1) a comfort level in taking control of their caregiving experiences believing it was a natural extension of being male; (2) a belief that their problem-solving skills were the strengths they brought to their roles as caregivers, feeling it was a result of their experience in the "world of work" (p.222); (3) a sense of being ill-prepared to take on the roles of a nurturer or caregiver; (4) an overriding sense of commitment toward their ill family member; and (5) their deep sense of loss based on their respective relationships with either their wife or their mother. The differences that were evident were largely based on their relationship to the care receiver (i.e., husband or son) or to generational issues due to age differences (Harris, 2002).

While many studies of caregivers have been undertaken and much has been learned, fewer studies have focused on men as caregivers and fewer still on sons (Matthews & Heidorn, 1998). Comparative studies of sons as caregivers with female siblings or with husband caregivers have highlighted the differences that exist between these groups. Few studies to date have focused solely on sons in an effort to gain a more in-depth understanding of their unique caregiving experiences and needs. These insights will be critical in tailoring supportive services and interventions specifically focused on their caregiving scenarios. It is for these reasons this study of sons as caregivers was undertaken.

Caregiving at End of Life

Care provision by family members at end-of life, defined by Teno and Coppola (1999) as those who are considered to be actively dying and for whom death is expected in a matter of weeks, has also undergone a considerable amount of study. One of the biggest dilemmas facing investigators who are desirous of conducting this type of research is capturing families and patients for study. Because the health care setting is often used to define who is dying, a significant number of studies have been undertaken in terminal care settings where patients could be found receiving hospice or palliative care or as patients in an intensive care unit of a hospital (Covinsky, Goldman, Cook, Oye, Desbiens, Reding, Fulkerson, Connors, Lynn, & Phillips, 1994; George, 2002). Given that an average of 50% of all deaths nationwide still occur in a hospital (Wennburg & Cooper, 1999), this has become the most frequently used setting in which to investigate aspects of patient care and family caregiving at end-of-life.

The largest hospital-based study of its kind was conducted from 1989 to 1994. This national study entitled SUPPORT (The Study to Understand Prognoses for Outcomes and Risks of Treatment) followed the cases of over nine thousand people who entered five major medical centers throughout the country. These patients and their families were followed from the time they entered the hospital until death or until a six month period of time had passed. Some of the study's major findings that relate to family impact suggested that:

(1) over one third of the patients were so impaired that a considerable amount of caregiving assistance was routinely needed from another family member;

(2) 20% of family members had to quit their jobs or make a major life change as a consequence of the care needed;

(3) for 17% of patients the cost of care precipitated a major change in family plans including a move to another home, altering educational plans or effecting another family member's medical care;

(4) for almost 30% a major source of income was lost or family savings were spent; and

(5) for 12% the caregiving tasks became compounded when another family member became ill or was in some way unable to function because of the physical or emotion strain of caregiving (SUPPORT Principal Investigators, 1995).

The SUPPORT researchers also learned from following these study participants how very difficult it was to determine time from critical illness to death for those followed during the study period.

An example of this difficulty came from those suffering from congestive heart failure, the most common heart-related cause of death in America. Researchers often found these patients living for one to two years in a severely impaired state prior to the end stages of their illnesses. These heart patients often just became weaker over time and yet continued to live because medical technology had advanced to the point that their symptoms could be managed by way of treatments and medications. "Heart failure just begets heart failure", is a sad reality shared by Sherwin Nuland in "How We Die" for these patients, their families and health care providers (Nuland, 1993, p.28).

For many end of life studies, generalizability has been an issue. Studies conducted in single healthcare settings such as a hospital (SUPPORT, 1995; Tilden, Tolle, Garland & Nelson, 1995) or hospice care (Redinbaugh, Baum, Tarbell and Arnold, 2003), utilizing specific populations like the elderly (Hanson, Danis & Garrett, 1997); or disease specific illnesses like cancer or heart disease (Seigal, Raveis, Houts & Mor, 1991; Stanley & Frantz, 1988) have placed limits on their ability to be reflective of the broad spectrum of experiences of the dying and their families. Fewer studies have been undertaken utilizing population-based sampling which includes a range of settings, ages and illnesses in order to more fully achieve representation. One of the first studies of its kind was undertaken in Oregon from 1996 to 1997 (Tolle, Tilden, Rosenfeld & Hickman, 2000). This study's purpose was to identify barriers to care at end of life utilizing a population-based sample addressing the previously limiting factors of setting, focus and sampling. The investigators called on families to provide their perspectives about the final month of life for their family member, subscribing to Hanson, et al's belief that families are "uniquely qualified to define priorities to improve terminal care" (Hanson, et al. 1997, p. 1339).

In an effort to build on the previous study's finding and owing to Oregon's high rates of out of hospital deaths in comparison to national averages (Wennburg & Cooper, 1999; Tolle, Rosenfeld, Tilden & Park, 1999), a second study was carried out from 2000 to 2002. Data from this study entitled, "Family Perceptions of Community-Based Dying" will be used to further investigate the experiences of the sample of male caregivers who identified themselves as sons of the study's decedents (Tilden, Tolle & Drach: RO1 NR 03526)

> *"I'm glad that you're doing this (study). It may not help my dad. We don't deal with the terminally ill very well. In my dad's case he went quickly. His quality of life in the last 5 months was poor but then he went quickly in the last few days".*

Methodology

A secondary analysis of data from the study entitled, "Family Perceptions of Community-Based Dying" was used to investigate the experiences of adult sons providing care to elderly parents who died in a community-based setting. All study participants were interviewed by this researcher, yielding both quantitative and qualitative data. The purpose of this study was to investigate the research question, "How do sons manage (provide) care to elderly parents at end-of-life?" The qualitative data was extracted and qualitative methods were used to uncover the nature of sons providing care to elderly parents at the end of life in order to facilitate the development of a thick description of their perceptions and experiences. This immersion in all aspects of the larger study allowed this researcher to fully experience each aspect of this investigation from case finding through data analysis.

The "Family Perceptions" study utilized a telephone survey design and was conducted at the Oregon Health & Science University's (OHSU) Center for Ethics in Health Care and School of Nursing in Portland, Oregon. The purpose of the original study was to examine the end-of-life experiences of decedents and their family caregivers who died outside of a hospital in a state in which a large percentage of deaths occur in community settings.

Prior to data gathering, human subject approval was garnered from the Institutional Review Boards at OHSU and the Public Health Division for the State of Oregon. Oregon death certificates were then selected using a computer-generated random sampling approach. This allowed for a large sampling frame and helped to avoid the selection bias of convenience sampling. Sampling in this manner also allowed for the inclusion of decedents who may have received little or no formal health care services.

Locating family members to serve as informants was facilitated by the use of death certificates (Tilden, Drach, Tolle, Rosenfeld and Hickman, 2002). Because death certificates issued in the state of Oregon merely list the name of an "informant", or individual who provides personal data and demographic information, additional case-finding strategies were required to locate suitable informants. These included the use of obituaries, electronic telephone directories, digital directories and databases, property ownership information garnered via local public assessment and taxation offices or contact information available through the state's Department of Motor Vehicles.

A random sample of 8% of the 29,130 non-Hispanic Caucasian deaths (n=2,269), were selected on a monthly basis for 21 months between June 2000 and March 2002. Due to Oregon's small minority population and because previous research suggested that ethnic minorities are more likely than whites to die in a hospital, 100% of eligible minority deaths (n=779) were also selected in the same time period. Decedent eligibility included being age 18 or over and dying due to natural causes in a community setting (i.e., home, nursing facility, foster care, assisted living facility or in-patient hospice) in the state of Oregon. Deaths due to suicide, homicide, accident or those undergoing medical examiner review were excluded due to the lack of care by family members. Seventy three percent of decedent's family members were located and of those 88% were determined to be eligible for participation in this study.

During the initial phone call the study was explained and preliminary questions were asked to determine eligibility. If the contact qualified as a study participant (i.e., being age 18 or older and relating they were 'somewhat' to 'very involved' in the decedent's care and decision-making in the last month of life), they were invited to set a future interview date. A 'family member' was defined as an individual having a significant relationship to the decedent by blood, marriage or other close affiliation. Potential respondents were also made aware that printed materials would be mailed to their homes with the option of completing a return postcard if they decided to decline participation prior to their interview date. Telephone interviews were completed for 71% of those who were located and confirmed to be eligible (n=1189) two to five months after their family member's death. Only one respondent per decedent family was interviewed. The median interview was 35 minutes with a range of 10 to 125 minutes. At the conclusion of the interview, the respondents who exhibited grief responses were offered referrals to bereavement services in their communities. All data were entered and verified by staff research assistants.

Study data included information from death certificates and information from family informants. Death certificates yielded data relating to the decedent's age, gender, race, ethnicity and informant's name as well as cause, date and location of death. The study questionnaire contained 69 items with single indicators and embedded scales which were used to index advance directives, use of life sustaining treatments, hospice enrollment, decedent symptom experience and perceived distress, family financial hardship, out-of pocket expenses and caregiver strain (e.g., sleep disturbance, physical/emotional drain, and confinement). The questionnaire's demographic questions included: relationship to decedent, age, gender, racial heritage, religious affiliation and importance of religion. This telephone survey drew its items and scales from a variety of sources that have been fully detailed in an earlier publication (Tilden, et al. 2004). Quantitative data were analyzed using SPSS version 11.0.

The telephone questionnaire also contained three open-ended questions that will be the focus of this analysis. The first was a preliminary question which stated, "Before I begin asking the next questions, would you briefly tell me about < >'s last few days and what happened leading up to his/her death? I don't know anything about the circumstances of his/her death." The second question, asked at the conclusion of the interview stated, "Is there anything else you want to add about < > that we haven't talked about or anything you want to ask me?" The third question followed a series of inquiries into their family members' specific symptoms in the last week of life and asked, "Of all his/her symptoms, which was most distressing to you?"

Analysis of Son Caregiver Data

Utilizing a qualitative approach for the analysis of this data is particularly appropriate for this study. It is in keeping with the assumption that all of the concepts pertaining to this phenomenon have not been identified in a particular population or that the relationships between concepts are poorly understood or conceptually underdeveloped. An assumption of this nature is in keeping with the research that has been carried out to date on the perceptions and experiences of sons providing care to elderly parents at the end of life.

In selecting a qualitative analytical framework for this study, several factors were taken into consideration. This data on sons providing care to their parents at end-of-life offered an opportunity to examine the personal experiences of these men in the context of a large representative study and to undertake a study of male caregivers which has not been attempted before on a scale of this size. Engaging in telephone interviews afforded these male study participants the opportunity to share their experiences about caring for their dying parents in a non-clinical setting, in the comfort of their own home, with the added benefit of anonymity. This interview method yielded very rich data and offered a unique opportunity to begin the process of gaining a greater understanding of their caregiving perspectives without the overlay of the usual feminist lens of caregiving. The need for a framework which utilized as much text from these interviews as possible was important, as was the need to enter into the analysis without the development of preconceived constructs.

Miles and Huberman (1994) have developed a well defined framework for analyzing qualitative data. Their approach advocates for the use of tight conceptual frameworks underscoring the importance of achieving reliability and validity. This framework includes data reduction and the displaying of text via matrices and tables in order to achieve valid and reliable research. They have further suggested this approach is particularly useful for studies which are attempting to gain greater insights into “better understood phenomenon” where the use of tighter constructs is advantageous (Miles & Huberman , p.17). The paucity of research which has been undertaken on this population of caregivers, clearly demonstrates that the phenonmenon of sons in a caregiving role has been an understudied group. Applying the Miles and Huberman approach to the analysis of this data would have been incongruent with the goals of this study which strove to uncover the caregiving constructs important to these men. Although perhaps useful tools to employ in subsequent studies of sons providing care, these techniques were not felt to be conducive for this initial study of son caregivers.

The general analytical framework of grounded theory, originally developed by Glaser and Strauss (1967), provided the best approach to capture as much of the data from the open-ended questions as possible. Within this framework text can be systematically analyzed in a methodological fashion using a series of coding and categorizations and seemed best suited to more fully explore the caregiving experiences of these men. A further testament to the appropriateness of this approach comes in the form of the original monographs developed by Glaser & Strauss, which had a focus on the study of dying (Glaser & Strauss, 1965; Glaser & Strauss, 1968). Expanding into the rigors of a true grounded theory study that required continuous data collection was not possible given the design constraints of the larger study. This initial study of caregiving sons was also constrained in its ability to fully comply with the protocols of this framework that would have lead to the development of theory. This limitation was given careful consideration. However by applying the well defined methodology provided by grounded theory, the data from these interviews was reduced and organized, producing themes and descriptions, thus illuminating the essence of the caregiving experiences of these sons. The result was a solid exploratory study of the perceptions of these caregiving sons' experiences that will serve as a foundation upon which to construct future investigations and a theoretical framework. This initial examination also successfully captured qualitative data that might have gone unexplored as part of the larger quantitative study and served as an additional benefit.

Utilizing this approach provided the opportunity to explore the phenomenon of adult sons providing care to their parents at the end of life. Following the tenets of Glaser & Strauss the goals of this study attempted to master the central criteria defined by its authors that address fit, understanding, generality and control. The goals included the development of conclusions which: (1) 'fit' into the substantive area of caregiving research, (2) are comprehensible to both caregiving sons and practitioners who will be addressing their unmet needs, (3) are abstract enough and include sufficient variation that it would be applicable to a variety of caregiving contexts and (4) are able to provide control with regard to the actions needed to be undertaken by practitioners toward the development of appropriate services for adult sons in order to encourage and support the valuable role they are playing as they provide care to their parents at end-of-life.

The trustworthiness of this design was addressed in a variety of ways. Adequacy as defined by Glaser and Strauss (1967) was assured through the use of an initial set of responses from a subset of sixty-three caregiving son respondents. All respondents were interviewed by this researcher and considered for the initial analysis in this study. Consistency was assured through the use of coding techniques outlined by Glaser (1978) who provided a definition of coding on two levels, substantive and theoretical which was utilized in this investigation. Substantive or open coding was initially undertaken to fracture or 'open' the data. Strauss (1987) believed in the importance of looking at the minutia and open coding became an important tool in this process. During this initial phase a codebook was developed which contains the labels of codes, definitions for codes (e.g., concerns relating to changes in residence, sources of emotional strain, perceptions on death event), or other data explaining the coding category. A series of theoretical codes were then utilized and provided a process for linking the data back together again.

An audit trail was established and includes evidence of how the data were reduced, synthesized, and includes process notes. Utilizing the software program NVivo applied considerable rigor to the data analysis process. This program provided the medium to maintain records of all research processes, and procedures as nodes (codes) were developed into node sets (sets of codes) and further developed into hierarchical trees. An additional feature permitted the responses from the three questions to be assigned an individual color, allowing data to be combined and separated as needed.

Overall these caregiver sons as individuals were not seen as discrete units of analysis, per se. This investigation in the tradition of qualitative research, focused on the content of their responses, analyzing all responses phrase by phrase into discrete units. In this way a concerted effort was made to fully capture the caregiving topics most important to them. It also allowed for individual or similar topics occurring more than once in the responses of an individual participant to be accounted for and thus more fully highlighting its importance.

Discriminate Sample

For the purposes of this study only 447 of these interviews were considered for inclusion in this investigation. This subset represents the data from interviews conducted by this researcher. A total of 112 male respondents were interviewed, representing 25% of the total number of caregivers interviewed. This subset included 32 husbands, 63 sons/steps sons, 3 sons-in-law, 7 brothers or brothers-in-law, 1 father and 6 considered to have other non-immediate family relationships.

The subset of 63 respondents identifying themselves as sons to the decedent, were all initially considered as possible subjects for further study. In order to further reduce this subset, the caregiver's level of involvement in care for their parent was used as a measure for their inclusion in the final subset of respondents for study. This qualifying question was asked at the beginning of each interview and stated, "First I would like to ask how involved you were in < >'s care and decision making during the last month of his/her life?" All sixty-three respondents were asked to choose from three levels of involvement ranging from "somewhat involved"; " very involved (I) shared in the care and decision making with others"; or "very involved (I was) the main person who cared or made decisions for him/her". Of these 63 interviews conducted, 49% (n=31) categorized themselves as very involved and the main caregiver of the decedent, 44% (n=28) reported being very involved but sharing the care with others and 6% (n=4) reported being somewhat involved in the care of the decedent. This cohort of caregivers was largely Caucasian, with only four identifying themselves as Native American, one African American and one Asian Pacific Islander. For nearly two thirds of this group (n=42), their mother was the decedent for whom they provided care. The interviews for 16% of these respondents were under 25 minutes in length, for 75%, 30 to 55 minutes and for 8% an hour or more.

Table 1.

Discriminate Sample

Level of caregiving	%	N
Somewhat involved	6%	4
Very Involved/Shared in care	44%	28
Very Involved/Main caregiver	49%	31

Parent cared for	N
Mother	42
Father	21

Interview length	%
Under 25 minutes	16%
30 to 55 minutes	75%
60 minutes or more	8%

The tenets of theoretical sampling as defined by Strauss and Corbin (1990) suggest that sampling should be tied to the theoretical relevance of certain concepts and the ability to recognize them as relevant indicators. With the goal of learning as much as possible about the caregiving experiences of these sons, the level of care in which they were engaged was the primary criteria used in selecting respondents for further study. Hence the responses from those identifying themselves as being the primary caregiver for their dying parents (i.e., those responding, 'very involved, I was the main person who cared or made decisions' to the qualifying question) were selected for further investigation. The rationale for this approach was founded in the belief that these individuals may have had the greatest range and depth of caregiving based on the amount of caregiving responsibility they undertook.

Caregiver Profile

A total of 30 son caregivers who identified themselves as having undertaken this level of care were selected for study after eliminating one respondent due to conflicting demographic information (i.e., gender recorded as female). Using selected descriptive data for this sample of caregivers revealed the majority (73%) provided care for their mothers (n=22) at the end of life, with the remaining 27% (n=8) caring for their fathers. Death occurred in a nursing facility for 40% of these families (n=12) and in the decedent's home for 27% (n=8). For 33% (n=10) the place of death was categorized as 'other', which included foster care homes, assisted living facilities or in-patient hospice. The median age of this largely Caucasian group of men was 55.5 years, with a considerable range of 32 to 74 years of age. On average the length of these telephone interviews were a little over 45 minutes, with over half of these sons (n=16) engaging in interviews at or above this level. By comparison the average interview length for a largely female (70.8%) subset of Family Perception study respondents who cared for a family member aged 65 or over was 35 minutes (Tilden, et al. 2004).

Table 2.

Son Caregiver Profile

Age	N	
30s	2	
40s	7	
50s	9	
60s	10	
70s	2	
Parent cared for	**N**	**%**
Mother	22	73%
Father	8	27%
Place of death	**N**	**%**
Nursing facility	12	40%
Decedent's home	8	27%
Other	10	33%

Substantive Coding

The software program, NVivo, version 2.0 (QSR International) was chosen to analyze the qualitative data for this study. This program was selected because of its data linking mechanisms and coding capabilities.

During the initial phases of open coding, 5 cases were chosen to facilitate the development of a codebook in which to categorize responses. The selection of these cases was based on the length of the interviews conducted, which ranged from 25 minutes to 85 minutes, with a median of approximately 45 minutes. Five interviews were 55 minutes in length and were chosen to serve as the initial sample in which to code. The transcripts of the responses to these three questions (i.e., "would you briefly tell me about < >'s last few days and what happened leading up to his/her death"; "is there anything else you want to add about < > that we haven't talked about or anything you want to ask me"; and "of all his/her symptoms, which was most distressing to you") were read line by line with each meaningful segment assigned to a descriptively worded category (code). The initial coding process of responses to questions regarding the decedent's last few days and the concluding question asking if there were any additional comments, yielded a total of 73 codes. These codes were then reapplied to each new segment of data with additional codes developed as necessary. The process of developing further coding for the responses to these same questions for the remaining 25 cases yielded an additional 89 codes, for a total of 162 codes.

The responses to a question inquiring about the decedent's symptom, which the respondent found most difficult, were also coded. Although five out of thirty son caregivers included in this analysis had no response to this question, there were 34 discrete responses to this question given by the remaining twenty-five caregivers. The responses were grouped into fourteen categories and then prioritized from the greatest to the least number of responses in each category.

Theoretical Coding

Responses to the initial and final survey questions were analyzed to reveal common themes and subsequently reduced to twenty-six node sets or categories. The largest eight sets will be reported on in detail here and include 177 passages. The number of passages in each of these eight categories ranges from 44 to 13. The remaining 148 passages were categorized into 18 additional sets, ranging from 10 to 3 passages each, will be reported on as well in a less detailed fashion. While these remaining sets of passages were of equal in importance in terms of the data collectively, many of these comments were either very brief or general in nature (e.g., costs of care, care-related decisions, changes in residence), or were related to the expected end-of-life condition of the decedent (e.g., general slowing down, activities in the last few days, awareness level). All are certainly worthy of a more concentrated examination in future studies of caregiving at end-of-life.

Findings

Responses to Initial and Final Questions

As previously stated the content from two open-ended questions was used as the main source of data for this study. The first question was asked at the beginning of the interview and stated, "would you briefly tell me about < >'s last few days and what happened leading up to his/her death?" Responses from an additional question asked at the conclusion of the interview and stated, "Is there anything else you want to add about < > that we haven't talked about or anything you want to ask me?" was also included in this analysis. Additionally the responses to a question which asked, "Of all his/her symptoms, which was most distressing to you?" were included in this analysis. While all thirty men provided responses to the initial question, four did not offer any comment when asked if they wanted to add any additional information at the conclusion of the interview.

Primary Nodes

The category containing the greatest number of passages (n=44) referenced the care provided to the decedent by healthcare professionals, with an equal number occurring in both the responses to the initial question and the concluding one. The majority of the passages referred to the respondent's dissatisfaction with the care provided in which references to unavailable physicians, poorly trained facility staff, and a general lack of much need communication by staff & physicians had been encountered.

> *"I do wish the doctor that did the surgery on her had thought a little more before he talked to me. I told him my mom had never revealed to me that she was in pain before all of this. He made me feel like I wasn't telling him the truth."*

The passages that referenced positive experiences (n=10) cited the care provided by foster providers most often. Five separate caregivers suggested the care provided to their parent at end of life was in this type of setting, and three specifically shared positive comments about the care their parents received in a foster care setting.

> *"I decided to move her into a foster care place. She (care provider) treated her like she was her own (family)"*

The next largest category of passages contained comments (n=36) that largely referenced specific physical and mental health conditions of the decedent. Not surprisingly the vast majority (n=33) occurred as the respondents were asked to recount their parents' last few days. A large number (n=13) of these caregiving sons chose to go back further than the time just preceding death to share a considerable amount of information regarding physical health symptoms and conditions, prior health issues, as well as mental health issues and behaviors.

The third largest category (n=25) contained a variety of end-of-life related comments. These included thoughts about the need for families to communicate their wishes including the importance of and consequences of not knowing a family members wishes about care, the need for greater awareness and societal improvement in dealing with end-of life, their opinions about physician aid in dying and the use of life sustaining treatments, their personal reflections about their caregiving experiences, advice for other caregivers, and the importance of making a home death possible for their family members.

"Knowing what they want is very helpful.
It was for both my Mom & Dad"

The next category of comments in priority order related to hospice care (n=22). The majority merely commented that their family member had hospice care. Six caregivers provided positive comments suggesting that both the decedent and respondent were relieved that hospice care was provided and others remarked about the quality of care provided by the hospice nurses. Two also suggested their family member had previously had hospice care. Two caregivers recounted a less than positive experience and another was unhappy when they were unable to engage hospice services for help with bathing and household chores.

Table 3.

Hospice Care

Hospice care in last 6 months	N	
No	9	
Yes	21	
Hospice care in days	Median	Range
	33 days	1 to 180 days

"Hospice was one of the greatest things. We had a fellow from (name of hospital). He was excellent in working with her. He had been with her the first time she had hospice, too."

In priority order, the next category contained comments (n=18) that related to specific treatments, hospital stays, tests run, or medication given to their parents. All of these passages were derived from responses to the initial question about their family member's end-of-life scenario in the last few days of life.

A fairly large number of passages (n=17) were found in the responses to both questions that referred to dementia or a dementia-related disorder experienced by their parent. Nine individual son caregivers shared information that recounted long or short-term dementias, relating the devastating effects of dementia on their parents and their frustrations in trying to secure care services for them.

> *"I found that the health care system for those that have Alzheimer's make it difficult. It was difficult to take my mom for appointments, she would get agitated and they were always late."*

The next sets of passages (n=15), with one exception, were all found in the responses to the concluding question. These comments were largely retrospective in nature and included some of the activities these caregivers engaged in following their parent's death. Most of the retrospective comments related to the positive aspects of this experience, including their pride in having been involved in caregiving, the knowledge gained and lessons from it, and the activities they have engaged in as a follow up to their parents' deaths. Two respondents also expressed appreciation for having been involved in the study.

> *"My solution to my (grief) about his death, I worked on the family photo albums. In my mind, I remember my father 12 to 15 years ago."*

The last set of responses (n=13) which will be detailed here related to involvement by other family and non-family members in the care of the dying parent and were found in response to both the initial and concluding questions. These passages related to one family's tradition of helping, to support received from a spouse and siblings, and to the assistance provided and visits from non-family members, friends and a clergyman.

"I had a lot of support with my wife. She was still working and I could retire early."

Table 4.

Primary Nodes

Node description	N
Care provided by professionals/in facilities	44
Physical/mental health conditions	36
Thoughts, opinions, personal reflections	25
Hospice care noted	22
Treatment, hospital stays, surgeries or medications	18
Dementia-related issues/dementia symptoms	17
Activities following/ in response to loss	15
Care/support provided by other family	13

Table 4 continued.

Primary Nodes

Secondary Nodes

The remaining 148 passages were categorized into eighteen sets which included: general comments about the decedent or family's difficulty at the end-of-life (12 passages); comments noting the decedent was generally slowing down (10 passages); thoughts/reminiscence of the decedent (10 passages); very general comments relating to cost of care (10 passages); the decedent's activity in the last few days/moments of life (10 passages); changes in residence due to care needs (10 passages); changes in the decedent's awareness level or increases in sleep in the last few days (9 passages); incidences in which the time reported was expanded beyond the last few days (8 passages); pain issues noted (8 passages); living arrangements mentioned (8 passages); decedent's participation in after death event activities (6 passages); issues relating to healthcare issues for other family members (6 passages); general comments about care provided/decisions made by respondent (6 passages); time estimates given/ not given by providers regarding their parents' trajectory to end of life (5 passages); nutrition/hydration issues (4 passages); respondent suggestions regarding being a medical professional (4 passages); general comments about the decedent/respondent relationship (3 passages); and suggestions the decedent was active given their advanced age (3 passages). All of these categories of comments were certainly important areas of concern for these son caregivers, even if their ranking failed to place them among those most often mentioned by the majority of caregivers.

Table 5.

Secondary nodes

Node description	N
General decedent/family difficulty	12
Reminiscence of decedent	10
General re: cost of care	10
General re: decedent activity last few days	10
General re: residence change/care needs	10

Table 5 continued.

Secondary nodes

Node description	N
Decedent awareness level	9
Time reported greater than last few days	8
Living arrangements mentioned	8
Decedent participation in death event	6
Health care issues for other family members	6
General re: care decisions	6
Time estimates re: end-of-life trajectory	5
General nutrition/hydration	4
Respondent comments re: being medical professional	4
Decedent active given age	3
General decedent/respondent relationship	3

Worst Symptom

The data collected from the responses to the question that asked these caregivers to identify the symptom that most bothered them helps to underscore the particular importance placed on some of these issues. Five of these son caregivers however did not choose to identify a symptom or set of symptoms that bothered them. The responses from the remaining son caregivers constituted 34 individual symptoms that were placed into 14 symptom categories. The most frequently mentioned category of symptoms (n=9) related to their family member's dementia or dementia-type behaviors as the most distressing symptom for them. The passages in this category also included their parent's inability to communicate/interact as well.

> *"When he got distressed, it was over his business. With the dementia, it pulled the controlling blanket away."*

Nutrition-related comments (n=6) followed as the category in which there was also a great concern. Comments in this category included their family member's inability to eat, lack of appetite, refusal to eat, being weak and losing weight.

> *"The refusal to eat, because I knew the net result of that."*

The category with the next greatest number of passages (n=4) contained respiratory-related comments suggesting the decedents' struggle to breathe. The remaining worst symptom passages (n=15) were sorted into eleven categories with only one to two in each category. They included: not knowing what to do for the decedent; a diminished quality of life; diarrhea; Parkinson's disease; the decedent's lack of control over their environment; vomiting; an inability to keep the decedent company; and the respondent's anticipation of loss.

Table 6

Worst Symptoms- Primary

Node description	N
Dementia/Dementia-type behavior	9
Nutrition /results of nutrition deficiency	6
Respiratory symptoms	4

> *"I couldn't take seeing her fight for breath. Her lack of appetite was also hard because I couldn't find something she would eat."*

Discussion

This study used a qualitative research approach to gain insights into the perceptions of adult sons who provided care to their elderly parents at end of life. While men constituted 29% of the total number of caregivers in the larger study from which this investigation was drawn, the caregivers who were sons comprised 15%, making them the largest group of male caregivers in the "Family Perceptions in Community-based Dying" study. The investigation of this subset of thirty son caregivers utilized the responses from three open-ended questions to more fully explore their experiences and served to highlight some key findings that will aid in the development of an enhanced set of supportive services for this group of caregivers.

Well over 93% of the son caregivers interviewed by this researcher identified themselves as either (a) the main family member who cared or made decisions or (b) a caregiver sharing these responsibilities with other family members. Focusing on those thirty sons who identified themselves as the main caregiver provided the opportunity to more fully examine the perceptions of a group of son caregivers who chose to engage in a high level of involvement in the care provision for their dying parents.

Initial and Concluding Questions

The most frequent response category for this group of men suggests the level of connectedness they had to their parents' end of life experience. These passages most often referred to the care provided by healthcare professionals and nursing facilities, with accounts of unavailable physicians, poorly trained facility staff and a lack of communication on the part of some providers. These findings are in keeping with those found in an earlier study conducted at OHSU in which families reported communication problems with providers and uncaring behavior and attitudes of physicians (Tolle, Tilden, Rosenfeld & Hickman, 2000). This category also contained positive comments, which were most often directed toward foster care providers. Five caregiver sons reported having positive care experiences in this setting. A study conducted by Hanson and colleagues which included both community and hospital-based deaths, asked family informants to report on the negative and positive aspects of end-of-life care for their family member. This study concluded there was a greater need for improved communication by physicians, more time spent with their ill family member's physician, as well as more discussion of expected treatment outcomes and life expectancy. This same study also found 58% of respondents to be generally satisfied with physician services and 69% positive about hospital care, with the lowest amount of positive comment directed at nursing facility care (Hanson, et al, 1997).

Sharing aspects relating to the physical and mental health symptoms/conditions their parents were experiencing served as the second largest response category. Although some of this data was found in the concluding remarks, the majority came in response to the initial question and reasonable given the fact that it was provided before the interview questions were posed. Close to one half of all respondents chose to recount information about their parent's long-term health issues as well. This information was clearly outside the 'last few days' time frame suggested in the study question. The level of detail and the extended time frame used to recount their parents' health scenarios was remarkable. This kind of information could only have been provided by family members with considerable knowledge of and a long standing connection to the decedent's healthcare issues, and serves as an indicator of the role these sons took on as caregivers.

The third largest category that contained a host of end-of-life related passages, revealed an array of comments and evidence of the impact these caregiving experiences had on these respondents. They included the need for greater communication among family members about end-of-life care wishes, their opinions about life sustaining treatments, physician aid in dying and personal reflections about their unique experiences. In a state other than Oregon, the prominence of comments such as these might seem surprising. However since 1994 with the advent of a statewide media campaign just prior to the passage of the Death with Dignity Act, through the affirmation of this legislation again in 1997, Oregonians likely have a heightened sensibility about these issues. Fromme and colleagues have further chronicled how these local and national events relating to end-of-life may have had an impact on an array of end-of-life issues (Fromme, et al., 2004).

In contrast to the disappointing encounters with some healthcare providers, passages that related positive hospice care experiences fell into one of the top four largest categories of responses. The numbers of Oregonians utilizing hospice services while dying have nearly doubled since 1996 (Fromme, Tilden, Drach & Tolle, 2004) and the high rates of enrollment in Oregon in comparison to other states has also been documented (Tolle, 1998; Last Acts, 2002). Seventy percent of this group of caregivers had family members enrolled in hospice. This is slightly greater than the 60% participation rate of a Family Perceptions study which focused on caregivers of patients 65 years and old and an overall 25% hospice enrollment at end-of-life nationally (Tilden et al, 2004). It is gratifying that a positive hospice experience ranked as one of the largest response categories for this group of son caregivers given the overall high use of hospice service in Oregon.

The next largest category of responses for these son caregivers contained comments that were related to the specific treatments, hospital stays, surgeries or medications. These types of responses, while similar to the physical/mental health condition remarks reported on earlier, were placed in a separate category because they were treatment-focused. The comments in this category were detailed as well and serve as yet another indicator of the level of involvement these son caregivers chose to take on.

Dementia or dementia-related symptoms comprised the next largest category of responses. Seven son caregivers included references such as these, with six out of seven responses occurring in the introductory phase of the interview when asked to recount their parent's last few days. With an estimated 4.5 million adults suffering the debilitating effects of dementia or dementia-type syndromes in the United States, it is not surprising these son caregivers cited it with such frequency during these interviews. The onerous dementia-related caregiving issues faced by family members include an increasingly diminished decision-making capacity and the need to prepare for progressive declines, which can last two to twenty years (Volicer & Hurley, 1998).

The difficulties of care options are compounded by the limitations placed on the Medicare reimbursement for hospice services. With criteria for hospice care that includes only those with a life expectancy of six months or less, it precludes those with dementia and somewhat unpredictable trajectory to death from easily qualifying for care (Volicer, 1997).

Another large category of comments related passages in which these sons shared the positive aspects of their caregiving experience, including knowledge gained, lessons learned and activities undertaken as a follow up to their parents' deaths. Considering the number of positively focused responses shared by these sons as they look back retrospectively on to their experiences, while likely still experiencing the painful residual feelings of loss over the death of their parent is heartening.

This category was followed by one in which they recounted the various family and non-family members who also took part in the care provided to their parents. The sharing of these incidences of assistance by other family members seemed to suggest a grateful acknowledgement on the part of these adult sons. Singularly perhaps these categories of comments may not seem significant. Embraced in total however a different picture begins to emerge, one in which these son caregivers revealed the strength of their connection to the end-of- life experiences of their elderly parents.

Most Distressing Symptom

The responses to the question in which they were asked to identify the end-of-life symptom that was most difficult for them was revealing as well. Their parents' dementia or dementia-type symptoms were the most often-mentioned distressing symptom for them. The difficulties these caregivers experienced as the result of these types of symptoms were further magnified by the fact that dementia or dementia-related disorders also appeared with great frequency in the passages found in the responses to the open-ended questions. Overall one third (n=10) of these caregivers reported their parents' dementia or dementia type symptoms as being the most distressing symptom. While older adults with dementia are most often found within nursing facility settings, only half of these sons had parents in this setting, the other half were in the decedent's home or in 'other' settings (i.e., foster care, assisted living, in-patient hospice). Having some understanding about the care and treatment issues for those with dementia is especially important for family members who undertake the role of caregiver. Resistance to physical care, eating-related disorders and weight loss are common and can pose major dilemmas for caregivers (Singer & Luxenberg, 2003). Those with dementia often have an inability to report pain that can not only impact the quality of their lives but have other consequences that can include agitation, aggressive behavior or wandering (Volicer, 2005). Dementia is a risk factor for falls, increases the risk for delirium from acute illness and some medications and makes communication more challenging (Singer & Luxenberg, 2003). Prior to the progression of dementia family caregivers need to be aware that decisions relating to treatment at end of life should be made so they can be carried out according to previously expressed preferences (Volicer, 2005).

Nutrition related concerns including an inability /refusal to eat, losing weight or becoming weak were also distressing symptoms for this group. There were seven sons who cited these types of concerns when asked about the worst symptom for them. Interestingly however, even though the loss of the ability to chew and swallow in advanced stages is common in most types of dementias, the sons who cited nutrition difficulties were a distinctly different group from those who mentioned dementia or dementia-related symptoms. In a society such as ours there is a great deal of symbolism around eating and drinking with the act of feeding often being equated to acts of caring, compassion and nurturance (ANA Position Statement, 1992). However there is evidence that the provision of nutrition and/or hydration may actually hinder the body's natural progression toward death making the dying process more difficult. A study conducted by McCann, Hall and Groth-Juncker found that administration of food and fluids to terminally ill cancer patients played a minimal role in providing comfort, with few reports of hunger and complaints of thirst readily relieved with mouth care or minimal sips of liquids (McCann, Hall & Groth-Junker, 1994). Family caregivers need to gain a greater awareness that a loss of appetitive is a common occurrence for dying patients and the lack of nutrition and hydration will not contribute to their suffering (Blasi, Hurley & Volicer, 2002).

Respiratory-related symptoms were the last major set of responses these sons related as particularly difficult for them. Most frequently they related these difficulties in terms of watching their parents struggle to get enough oxygen at end-of-life. These types of symptoms have been difficult for other caregivers as well and were reported most broadly in the multi-site SUPPORT study. The caregivers in this study reported a slightly different set of overall symptoms that disturbed them and in order of concern were pain, fatigue and shortness of breath (SUPPORT Principal Investigators, 1995). This suggests that only one symptom, shortness of breath, shares a commonality with this sample of son caregivers. Future research into the possible reasons for these discrepancies would be warranted.

Sons Care: Similarities and Differences

One of the implications from this data suggests these thirty caregiving sons did not remain on the periphery as concerned family members but became actively engaged in the care provided and the decisions made in relation to their parents at end-of-life. They recounted their experiences in considerable detail, providing a small glimpse into the weeks and months leading up to and sometimes beyond the death of their parents.

"This was the best thing that ever happened to me."

In terms of their engagement, they are probably not unlike the legions of daughters who have provided care to their dying parents. They were distressed by the ravages of the illnesses and symptoms their parents endured, were engaged in the care provided to their parents by healthcare professionals, and were moved to share their thoughts about the variety of end-of-life issues all families face, including their personal reflections on their participation in their parents' deaths. These are the common threads they share as members in the group of family caregivers.

However, as son caregivers they also exhibit nuances. They remain a small minority whose importance and numbers will need to grow in order to help shoulder the burden of care for our ever-expanding aging population. Research on supportive services for male caregivers to date has been limited and efforts are needed to gain a greater understanding into the types of support that would be most beneficial to them. Given the thirty year old lens with which caregiving has been viewed, gender relevant interventions will be needed in order to engage more men in the type of care provided by these son caregivers.

> *"I believe my mother went peacefully. I don't feel like I did enough. I made her two promises. She didn't want to be in a nursing home and wasn't. She asked that I take her back to (name of state of birth) and I'm doing that".*

Implications for Social Work Practice

Finding ways to support sons who are choosing to take on the role of caregiver to their parents at end-of-life is important now and into the future, as changing demographics begin to shift the dynamics of family caregiving. Small shifts in the equation may have already begun. In an examination of a subset of Family Perception study participants who provided care for adults aged 65 and older, the percentage of wives caring for their husbands (18.2%) was almost equal to the number of sons (17.6%) who were caregivers to their parents (Tilden, Tolle, Drach & Perrin, 2004).

Caregivers like the sons in this study are providing end-of-life care for their dying loved ones in a variety of settings. A limited amount of research has been conducted on interventions for informal caregivers providing this type of care and none have focused specifically on sons who were providing care (McMillan, 2005). In her comparative study of husbands and sons serving in caregiving roles, Harris found that while husbands desired skill training sons most often preferred information which could help to supplement their roles as caregivers (Harris, 2002).

Studies have been undertaken which demonstrated the importance of including education as a component of programs for family members providing care at end-of-life. In the course of creating a conceptual model of quality end-of-life care that was patient-focused and family-centered, Teno and colleagues convened focus groups of bereaved family members. Part of the their feedback included the importance of educating family members so they in turn could feel confident enough to provide care at home to their dying loved ones (Teno, Casey, Welch & Edgman-Levitan, 2001). A meta analysis conducted by Sorenson et al. (2002) of seventy eight caregiver interventions revealed those interventions that included an educational component had a considerable effect on caregiver outcome variables including caregiver subjective well being and patient symptoms (Sorenson, Pinquart & Duberstein, 2002). Additionally, special care units found within some larger healthcare institutions like the Veterans Administration Hospital in Massachusetts which utilize a hospice approach, stress the importance of offering education programs for the family members of their residents (Panke and Volicer, 2002).

Caregiver Education: Informal Programs

The findings from this study of son caregivers suggested that hospice services were not only welcomed but thought to be positive experiences as well. Oregon currently has one of the highest rates of hospice care use in the nation and with 70% of the elderly parents in this study receiving hospice care these end-of-life services could serve as a conduit for expanded service delivery. Allowing hospice providers to offer additional information and educational services as a billable service, which does not currently exist within the current schedule of allowable services for reimbursement, would greatly enhance the care provided by these son caregivers. A few new programs in other parts of the country are now attempting to work within the limitations of the Medicare reimbursement system by offering expanded services and coverage. One such program in Massachusetts utilizes volunteers to offer pre-hospice services and in the state of Florida patients can now be referred for hospice services with a terminal prognosis of twelve months rather than the usual six (Walker, 2005). Within the last two years, Aetna Insurance Company has also responded with a program entitled Compassionate Care that allows for a twelve-month hospice benefit for terminally ill patients and an enhanced network of information on end-of-life issues for families (http://www.aetna.com/news).

Social workers who practice in hospice and/or palliative care settings would be uniquely qualified to provide these expanded educational services on an as needed basis for these son caregivers. The need for enhanced communication between caregivers and health care providers, which was highlighted in the comments made during these interviews, is another important area in which social workers can play an important role. By working with providers and their families, social workers can encourage and mediate much needed discussion in order to ensure the best possible care for the dying family member. Recent research has clearly demonstrated that social work involvement greatly enhances hospice outcomes (Reese and Raymer, 2004).

Given the amount of informal care provided by family members and the increased need for a greater investment in this type of care for our ever-expanding older adult population in the future, it is incumbent on our policy makers to find creative ways to support family caregivers as well. Suggested opportunities for overall reform in end-of-life care have included increases in allocations for the support of local caregiving activities though the Older Americans Act (Shugarman, Lorenz and Lynn, 2005) and these activities could include educational programs as well. Reimbursement for these programs could be offered through programs that already offer services to caregivers including hospital palliative care programs and hospice providers.

Caregiver Education: Formal Programs

Findings from this investigation suggest that educational forms of support for this group of sons would be most effective if offered early in the caregiving scenario. Their roles as caregivers often began long before the last month of their parents' lives, as evidenced by the accounts many provided when asked to report on 'the last few days'. Areas of concern highlighted by this group of son caregivers suggest that interventions that focus on education would be beneficial for them. Informational workshops on topics relating to disease specific illness, symptomatology and care issues would be most beneficial for these caregivers. The prominence of dementia and nutrition/hydration issues in the responses of these sons would make them especially important topics to offer. Issues relating to the navigation of the health services system (e.g., techniques for communicating with health care providers; available services) or end-of-life related topics (e.g., advance care planning, life-sustaining treatment, etc.) would all be suitable short-term seminar topics.

Pilot programs, in which lunchtime brown bag educational sessions have been held for caregivers in workplace settings, have proven to be a successful format and a convenient non-threatening way to provide information to caregivers who are also employed (Neal, et al. 1993). Although all employers are not able to provide formal supportive services for their employees who are also caregivers, a growing number have been doing so for many years. In a recent study of employees at three Fortune

500 companies who also provide care to an older adult family member, men were found to be engaging in this kind of care at an increasing rate and feeling overwhelmed as they struggled to juggle their competing roles (Metropolitan Life Insurance Company, 2003).

However, merely offering educational opportunities for men may not be sufficient to ensure their participation. Kaye (2002) and Barusch (2000) have both underscored the importance of specifically targeting these services, making them 'male friendly'. They suggest offering services in a location comfortable for men; and having men serve as leaders and participants, providing opportunities for men to contribute, serve as experts, take control, and participate in decision making. Additionally they suggest that the focus of these services remain on information provision with opportunities for goal attainment and include only a moderate amount of relationship building skills (Kaye, 2002).

Social workers can play an integral role in securing the information needed by caregiving sons. As professionals trained to work with diverse groups, they possess the skills to look beyond the feminine lens of caregiving in order to foster and support the contributions being made by emerging groups of caregivers like these sons. By working with elderly parents and their son caregivers, social workers can help to ascertain the information needed thereby facilitating their understanding of treatment options and prognoses.

While the majority of these son caregivers were likely still employed, their age range (i.e., 32 to 74 yrs) suggests that others may no longer be in the workplace.

Services offered outside the workplace would also be important and may represent an opportunity for private practitioners to offer a range of supportive services on a fee-for–service basis. The services of independent geriatric care managers are available with increasing frequency and could serve as a neutral source of information and assistance for this group of sons who may no longer be in the workforce.

Conclusion

Strengths and Limitations

One of the strengths of this study of son caregivers was its ability to draw from the Family Perceptions study data that achieved a large sampling frame due to its use of state of Oregon death certificates. The strength of random sampling was also carried to this smaller study thus avoiding selection bias and permitting the inclusion of decedents and caregivers who had received little formal healthcare services. However like the larger study, this investigation was limited by possible recall bias due to the two to five month lapse in time from death to data collection. It was limited as well by the inability to interview family members who could not be located, did not have a telephone or had communication difficulties. Considerable strength was gained by drawing data from interviews that were all conducted by this researcher.

The research design that was deliberately imposed served as an additional strength of this study. A greater reliance was placed upon utilizing the qualitative data from three open-ended questions as the foundation for this investigation into the sons' perceptions and experiences, rather than relying on the abundant available quantitative data. This analysis specifically drew from these questions in an effort to use data unencumbered by the traditional caregiving research paradigm. This design choice is in keeping with the belief that if caregiving research methods have been developed under the rubric of a 'feminine lens' then utilizing the qualitative data provided by these male subjects, through open ended questions, may more accurately reveal their perceptions and caregiving experiences.

Conversely the design limitation was the small number of open-ended questions that were included in this instrument. Additional questions relating more specifically to these son caregivers' experiences, including their suggestions for needed support or information may have enhanced the investigation into the perceptions and experiences of this population of sons providing care to their elderly parents. The greatest and most obvious limitation continues to be that the data utilized for this investigation was drawn from the "Family Perceptions of Community-based Dying" which was not developed with the intent of examining the experiences of son caregivers.

Suggestions for Future Research

As a preliminary investigation and one that relied on the analysis of existing data, the evidence clearly points to the need for further study. Future investigations which focus on the individual son caregiver's experience, rather than on the decedent's, will provide the opportunity to gain a richer understanding of the role these men played in the end of their parents' lives. In an effort to address the 'feminine lens of caregiving', future intervention studies are needed which are specifically designed for son caregivers in order to test protocols for this population of caregivers, determine differences between primary and secondary caregivers, and gain a greater understanding into the types of formal services or social supports that are most needed and desired. While this study tended to take a rather homogenous view of these sons due to a lack of detail about them, future studies should also attempt to gather more demographic information (e.g., ethnicity, religious affiliations, employment status, etc.) in order to capture the differences among this population of caregivers as well.

The secondary nodes into which many responses fell but were not fully explored, is an area which needs further illumination. While many of the references made (e.g., costs of care, change in residence/care needs, living arrangements, healthcare issues for other family members, and parents' participation in death event) were general in nature, they all are worthy of further exploration into the possible meanings and effects they had on these sons' caregiving experiences. Investigations into the opinions some of these sons shared as they relate to life-sustaining treatments and the consequences of not knowing about their own parents' wishes also merits further study. An examination into the kinds of caregiving tasks undertaken by these sons might also help in order to determine the kind of support/information these sons might find useful in their roles as caregivers.

Although it was not the focus of this research, future endeavors could also explore what these caregivers found distressing about the 'worst symptom" they identified in order to determine if it interfered with the caregiver dyad. Additionally an examination could investigate the possible impact the caregiving relationship (i.e., father/son, mother/son) may have had on the son caregivers' perceptions and responses.

Studies that investigate the benefits of extending the usual hospice benefits to one year prior to death and /or offering services as part of a pre-hospice program are necessary. Findings could help underscore the need for these benefits to terminal patients and their families. If cost savings could also be documented it may serve to expand the time frame for hospice benefits nationally and the much needed end-of-life education for families. Additionally an investigation into programs currently designed for family members provided by national organizations like the Alzheimer's Disease Association, could provide a solid foundation upon which to build programs which seek to address the needs of emerging groups of caregiving sons.

"I hadn't thought about this and you've asked questions that have made me think about things. I don't know what my mom learned over her lifetime to make her be so strong."

Next Steps

While utilizing the data from the Family Perceptions in Community-based Dying study made this initial investigation into the caregiving experiences of these adult sons possible, the results fully highlight the need for a more thorough investigation. Posing questions that focus more specifically on these sons' caregiving experiences rather than on the death event of their parents will be part of the important next steps. Piloting informal educational services via hospice providers and/or palliative care programs and designing workplace lunch time seminars on those topics identified as being most critical which include an evaluative component, would also serve as prudent next steps in this investigation of sons as caregivers.

This preliminary investigation into sons providing care at end-of-life served as an important first step. As more men and sons in particular engage in caregiving roles for their parents, the challenge to find ways to support their efforts needs to be recognized and addressed. An adjustment in the 'feminine lens' of caregiving will naturally occur as more research on this population of caregivers is conducted. Broadening that lens will also be necessary when building a network of gender sensitive community services which Kaye (2002) suggests will become increasingly important if we expect men to survive and thrive in the caregiving roles they will attempt to undertake in the future. It is hoped that the illumination of the caregiving experiences of this group of sons will be embraced, nurtured and expanded through further study in an attempt to encourage more sons to participate in caregiving, which will in turn help to counter balance the diminishing pool of available caregivers for dying elderly family members.

> *"It is a final gift you can give somebody (to have them die at home). You have to make some sacrifices, the time is short and you don't get to do this again."*

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Appendix A

Family Perceptions Survey Instrument

DEMOGRAPHIC QUESTIONS

1. First, I'd like to ask how involved you were in < >'s care and decision making during the last month of his/her life? Would you say that you were:

0 Not involved at all
1 A little involved
2 Somewhat involved
3 Very involved; you shared in the care or decision making with others
4 Very involved; you were the main person who cared or made decisions for him/her

7 Not applicable
8 Don't know/no opinion
9 Refusal

IF NOT INVOLVED AT ALL (0), A LITTLE INVOLVED (1), OR 7, 8, OR 9, THEN DO NOT CONTINUE INTERVIEW AND ASK IF THERE IS SOMEONE WHO WAS MORE INVOLVED WHOM YOU MIGHT CONTACT. THANK PARTICIPANT FOR THEIR TIME.

We have some information about him/her from his/her death certificate, but we don't know anything about you. I'd like to begin by asking some questions so we can know a little bit more about you and < >.

2. What was your relationship to < >? (RESPONDENT WAS DECEDENT'S __________)

1 Husband
2 Wife
3 (Unmarried) Partner
4 Daughter or Step-daughter
5 Son or Step-son
6 Daughter-in-law
7 Son-in-law
8 Sister
9 Brother
10 Sister-in-law
11 Brother-in-law
12 Mother
13 Father
14 Other Relative
15 Friend
16 Attorney
17 Health Care Provider
18 Other______________________

(Shall I refer to him/her as your (relationship) or by his/her first name? _______________Thanks.)

3. What is your age? _________years old

4. Your gender is: (DO NOT ASK UNLESS AMBIGUOUS)

1 Male
2 Female

5. How would you describe your racial heritage?

1 African American
2 Asian American
3 Bi-Racial or Multi-Racial____________________
4 Caucasian/European American
5 Hispanic American
6 Native American
7 Other___________

6. What, if any, is your religious affiliation?

0 None
1 Catholic
2 Jewish
3 Muslim
4 Protestant
5 Other ______________

9 Refusal

7. How important is religion in your life?

0 Not at all important
1 A little bit important
2 Somewhat important
3 Very important

8 Don't know/no opinion
9 Refusal

8. What, if any, was < >'s religious affiliation?

0 None
1 Catholic
2 Jewish
3 Muslim
4 Protestant
5 Other______________

9 Refusal

9. How important was religion in his/her life?

0 Not at all important
1 A little bit important
2 Somewhat important
3 Very important

8 Don't know/no opinion
9 Refusal

---

10. Before I begin asking the next questions, would you briefly tell me about < >'s last few days and what happened leading up to his/her death? I don't know anything about the circumstances of his/her death.

Thank you. That helps me better understand what happened as I ask the rest of the questions. There are 2 kinds of questions in this survey. Some are yes-no questions, and for some, I will read you a list of choices and you tell me which best fits.

DECISION MAKING: ADVANCE DIRECTIVES

This section is about life-sustaining treatments. Life-sustaining treatments are medical treatments designed to prolong life, such as CPR or a ventilator (breathing machine).

12. Did you or other family members know < >'s wishes about the use of life-sustaining treatments?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

13A. Did < > have any type of written document about his/her wishes for life-sustaining treatments (e.g., living will, advance directives, Power of Attorney for health care, personal note)?

0 No (IF NO, ASK B)
1 Yes (IF YES, ASK C AND D)

7 Not applicable
8 Don't know/no opinion (ASK B)
9 Refusal

→→ IF NO:

B. Did < > ever talk about whether or not he/she wanted life-sustaining treatments?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

→→ IF YES:

C. What was this document called?

____

D. Approximately how long before < >'s death was it written and signed? (most recent version)

1 Days before death
2 1 to 2 weeks before death
3 Less than 6 months before death
4 6 months to 1 year before death
5 More than 1 year before death

7 Not applicable
8 Don't know/no opinion
9 Refusal

DECISION MAKING: TREATMENTS

Now I would like to ask you some questions about decisions regarding < >'s medical treatment at the end of his/her life. Did < > receive any of the following life-sustaining treatments in THE LAST MONTH of his/her life to help keep him/her alive?

14. CPR (Cardiopulmonary resuscitation)?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

15. Ventilator/breathing machine?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

16. Tube feedings?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

17. IV fluids?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

18. Did he/she receive any other treatments to keep him/her alive?

0 No
1 Yes ⇨ (IF YES) **Please describe:**______________________________

7 Not applicable
8 Don't know/no opinion
9 Refusal

19A. Were any decisions made NOT TO START life-sustaining treatments for < >?

0 No (IF NO, SKIP TO #20)
1 Yes (IF YES, ASK B AND C)

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. Can you remember when there first was talk about NOT STARTING life-sustaining treatment? (INCLUDING LIVING WILL DISCUSSIONS)

1 Days before death
2 1 to 2 weeks before death
3 Less than 6 months before death
4 6 months to 1 year before death
5 More than 1 year before death

7 Not applicable
8 Don't know/no opinion
9 Refusal

C. Who would you say *primarily* made decisions NOT TO START life-sustaining treatments?

1 Patient/decedent
2 One family member
3 Family members as a team
4 Healthcare providers
5 Other ____________

7 Not applicable
8 Don't know/no opinion
9 Refusal

20A. Were there any disagreements about NOT STARTING life-sustaining treatment?

0 No disagreement (IF NO, SKIP TO #21)
1 A little bit of disagreement (ASK B)
2 Some disagreement (ASK B)
3 A lot of disagreement (ASK B)

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. Can you tell me a little bit about this disagreement regarding NOT STARTING life-sustaining treatments?

I'm going to ask you those questions again -- but this time about decisions TO STOP life-sustaining treatments once they had already been started.

21A. Were any decisions made TO STOP life-sustaining treatments for < >?

0 No (IF NO, SKIP TO #22)
1 Yes (IF YES, ASK B AND C)

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. Can you remember when there first was talk about STOPPING life-sustaining treatments?

1 Days before death
2 1 to 2 weeks before death
3 Less than 6 months before death
4 6 months to 1 year before death
5 More than 1 year before death

7 Not applicable
8 Don't know/no opinion
9 Refusal

C. Who would you say *primarily* made decisions TO STOP life-sustaining treatments?

1 < > (Patient/decedent)
2 One family member
3 Family members as a team
4 Healthcare providers
5 Other ____________

7 Not applicable
8 Don't know/no opinion
9 Refusal

22A. Were there any disagreements about STOPPING life-sustaining treatment?

0 No disagreement (IF NO, SKIP TO #23)
1 A little bit of disagreement (ASK B)
2 Some disagreement (ASK B)
3 A lot of disagreement (ASK B)

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. Can you tell me a little bit about this disagreement regarding STOPPING life-sustaining treatments?

6

FAMILY IMPACT

I'd like to know more about what it was like for you in the LAST SIX MONTHS OF < >'S LIFE.

PROBLEM	A. ASK "In caring for < >, ...?" IF "No" THEN SCORE B AS 7 AND SKIP TO NEXT ITEM NUMBER. IF "Yes," ASK B. B. "How much did that distress or bother you?"					IF "N/A" (not applicable), "D/K" (don't know) or "Refusal," SKIP TO NEXT ITEM NUMBER.		
23. A. Was your sleep disturbed?	0 No (SCORE B AS 7, SKIP TO #24)				1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How much did that distress or bother you?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 A great deal	7 N/A	8 D/K	9 Refusal
24. A. Was it physically draining for you?	0 No (SCORE B AS 7, SKIP TO #25)				1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How much did that distress or bother you?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 A great deal	7 N/A	8 D/K	9 Refusal
25. A. Was it emotionally draining for you?	0 No (SCORE B AS 7, SKIP TO #26)				1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How much did that distress or bother you?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 A great deal	7 N/A	8 D/K	9 Refusal
26. A. Was it confining? (E.g., less time for self)	0 No (SCORE B AS 7, SKIP TO #27)				1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How much did that distress or bother you?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 A great deal	7 N/A	8 D/K	9 Refusal
27. A. Did you have to adjust your work schedule?	0 No (SCORE B AS 7, SKIP TO #28)				1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How much did that distress or bother you?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 A great deal	7 N/A	8 D/K	9 Refusal
28. A. Was it financially straining for you?	0 No (SCORE B AS 7, SKIP TO #29)				1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How much did that distress or bother you?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 A great deal	7 N/A	8 D/K	9 Refusal

29A. Was < > enrolled in hospice at any time during the last 6 month's of his/her life?

0 No (IF NO, SKIP TO #30)
1 Yes (IF YES, ASK B)

B. How long did < > receive hospice care? (# days, weeks, months) ______________
(Specify unit of time)

30A. What type of health care coverage, if any, did < > have? (CIRCLE ALL THAT APPLY)

0 None (IF NO, SKIP TO #31)
1 Medicare (ASK B)
2 Medicaid or Oregon Health Plan (ASK B)
3 Private Insurance (ASK B)
4 Other ______________________(ASK B)

8 Don't know/no opinion
9 Refusal

B. Were prescription drugs covered (either partially or in full)?

0 No (SKIP TO #31)
1 Yes (ASK C)
8 Don't Know/No opinion
9 Refusal

C. How much did < > pay for prescription drugs?

0 None of the cost
1 Some of the cost (1%-49%)
2 Half of the cost (50%)
3 Most of the cost (51%-99%)
4 Other ____________________

8 Don't Know/No Opinion
9 Refusal

31. Who had *primary* responsibility for the financial costs associated with < >'s care at the end of his/her life?

1 < > (decedent) (including insurance payments, co-pays, trusts, etc.)
2 You (respondent)
3 Other family members
4 Other ______________________

8 Don't know/no opinion
9 Refusal

32. Which range best describes the annual household income of (FINANCIALLY RESPONSIBLE PERSON(S)):

1 less than $15,000/yr
2 more than $15,000, but less than $30,000/yr
3 more than $30,000, but less than $60,000/yr
4 more than $60,000, but less than $100,000/yr
5 over $100,000/yr

8 Don't know/no opinion
9 Refusal

33A. Were anyone's finances affected by the costs associated with < >'s care at the end of his/her life?

0 No (IF NO, SKIP TO #34)
1 Yes (IF YES, ASK B)

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. Whose finances were affected? (CIRCLE ALL THAT APPLY)

1 < >'s finances
2 Your (respondent's) finances
3 Other family members' finances
4 Other ___________________________

7 Not applicable
8 Don't know/no opinion
9 Refusal

34. Did his/her illness result in the loss of a major source of income for <FINANCIALLY RESPONSIBLE PERSON(S)>**?**

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

35A. Did anyone in the family have to quit their job or reduce the number of hours worked in order to care for < >?

0 No (SKIP TO #36)
1 Yes (ASK B)

B. How much of a financial impact did that have?

0 None
1 Mild
2 Moderate
3 Severe

8 Don't Know/No opinion
9 Refusal

36. Did anyone in the family have to INCREASE hours of work or get a second job because of the costs of < >'s illness?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

37. Did the costs of < >'s illness mean having to use most or all of <FINANCIALLY RESPONSIBLE PERSON(S)>**'s savings?**

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

38. Did the costs of care for < >'s illness mean that <FINANCIALLY RESPONSIBLE PERSON(S)> **needed to get a 2nd mortgage or take out a loan?**

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

39A. Did the costs of care for < >'s illness require him/her to make significant changes in his/her living arrangements?

0 No (SKIP TO #40)
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. What change in living arrangements did < > have to make? Did he/she: (CIRCLE ALL THAT APPLY)

1 Move into the home of family or friends
2 Move to a facility where he/she could receive care
3 Have someone move in with him/her (to provide care, share expenses)
4 Other ____________________

40A. Did the costs of care for < >'s illness require anyone else in the family to make significant changes in their living arrangements?

0 No (SKIP TO #41)
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. What change in living arrangements did <AFFECTED FAMILY MEMBER(S)> have to make? Did he/she: (CIRCLE ALL THAT APPLY)

1 Move in with < >
2 Move closer to < >
3 Move to a less expensive place to live
4 Other ____________

A lot of people tell us that they have "out of pocket" costs that are not covered by insurance or Medicare. I'm going to read you a list of possible expenses and you can tell me whether they came up in caring for < >. Please do NOT include money that was later repaid to you by insurance.

OUT OF POCKET EXPENSES	A. ASK **"Were there any out of pocket costs for__?"** IF "No," SCORE B AS 7 AND SKIP TO NEXT ITEM NUMBER. IF "yes," ASK B. B. IF SO, ASK **"How much of a financial hardship was that for <FINANCIALLY RESPONSIBLE PERSON(S)>?"**					IF **"N/A"** (not applicable), "D/K" (Don't Know), OR **"Refusal,"** SKIP TO NEXT ITEM NUMBER.		
41. A. Paid help (at home or in NH/AFH)?	0 No (SCORE B AS 7, SKIP TO #42)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much a hardship?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
42. A. Nursing home or adult foster care?	0 No (SCORE B AS 7, SKIP TO #43)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much a hardship?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
43. A. Transportation?	0 No (SCORE B AS 7, SKIP TO #44)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much a hardship?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
44. A. Medications?	0 No (SCORE B AS 7, SKIP TO #45)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much a hardship?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
45. A. Special equipment and supplies?	0 No (SCORE B AS 7, SKIP TO #46)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much a hardship?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal

46. Were there any other out-of-pocket expenses we missed? If yes, please describe.

PAIN AND OTHER DISTRESSING SYMPTOMS

Now I want to ask you about < >'s pain and other distressing symptoms during the LAST WEEK of his/her life.

47. Which word best describes the level of comfort of < > in the week before his/her death? Would you say that he/she was: (CODE FOR HIGHEST LEVEL OF PAIN OR DISTRESS)

1 Comfortable
2 In mild pain or distress
3 In moderate pain or distress
4 In severe pain or distress
5 Other ______________________

7 Not applicable
8 Don't know/no opinion
9 Refusal

48. Overall, which word best describes his/her level of confusion (during the last week of life)?

0 None
1 Mild
2 Moderate
3 Severe

7 Not applicable
8 Don't know/no opinion
9 Refusal

49. Overall, which word best describes the level of physical pain he/she was feeling (during the last week of life)?

0 None
1 Mild
2 Moderate
3 Severe

7 Not applicable
8 Don't know/no opinion
9 Refusal

Now I am going to ask you about specific symptoms < > may have had in the last week of his/her life.

50. Was < > responsive (conscious/awake) in the last week of life?
IF RESPONSIVE FOR ANY PART OF LAST WEEK, CODE YES

0 No (SKIP TO #63)
1 Yes

SYMPTOM	A. ASK **"Did he/she seem to _____ in the last week of his/her life?"** IF "No," SCORE A, B, AND C AS 7 AND SKIP TO NEXT ITEM NUMBER. B. IF "Yes" THEN ASK **"How often did he/she _____?"** C. THEN ASK **"How much did that distress or bother him/her?"**	IF "N/A" (not applicable), "D/K"(don't know), OR "Refusal," SKIP TO NEXT ITEM NUMBER.		
51. A. Did he/she seem to feel sad?	0 No (SCORE B AS 7, SKIP TO #52) 1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How often?	0 Never 1 Rarely 2 Occasionally 3 Frequently 4 Almost constantly	7 N/A	8 D/K	9 Refusal
C. How much did that distress him/her?	0 Not at all 1 A little bit 2 Somewhat 3 Quite a bit 4 Very much	7 N/A	8 D/K	9 Refusal
52. A. Did he/she seem to worry?	0 No (SCORE B AS 7, SKIP TO #53) 1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How often?	0 Never 1 Rarely 2 Occasionally 3 Frequently 4 Almost constantly	7 N/A	8 D/K	9 Refusal
C. How much did that distress him/her?	0 Not at all 1 A little bit 2 Somewhat 3 Quite a bit 4 Very much	7 N/A	8 D/K	9 Refusal
53. A. Did he/she seem to feel irritable ?	0 No (SCORE B AS 7, SKIP TO #54) 1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How often?	0 Never 1 Rarely 2 Occasionally 3 Frequently 4 Almost constantly	7 N/A	8 D/K	9 Refusal
C. How much did that distress him/her?	0 Not at all 1 A little bit 2 Somewhat 3 Quite a bit 4 Very much	7 N/A	8 D/K	9 Refusal
54. A. Did he/she seem to feel nervous?	0 No (SCORE B AS 7, SKIP TO #55) 1 Yes (ASK B)	7 N/A	8 D/K	9 Refusal
B. How often?	0 Never 1 Rarely 2 Occasionally 3 Frequently 4 Almost constantly	7 N/A	8 D/K	9 Refusal
C. How much did that distress him/her?	0 Not at all 1 A little bit 2 Somewhat 3 Quite a bit 4 Very much	7 N/A	8 D/K	9 Refusal

SYMPTOM	A. Ask "Did < > seem to (have) _______ in the last week of his/her life?" IF NO, SKIP TO NEXT ITEM NUMBER. B. IF YES, THEN ASK "How much did that distress or bother him/her?"					IF "N/A" (not applicable), "D/K"(don't know), OR "Refusal," SKIP TO NEXT ITEM NUMBER.		
55. A. Lack of appetite?	0 No (SCORE B AS 7, SKIP TO #56)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much did that distress him/her?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
56. A. Lack of energy?	0 No (SCORE B AS 7, SKIP TO #57)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much did that distress him/her?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
57. A. Feel drowsy?	0 No (SCORE B AS 7, SKIP TO #58)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much did that distress him/her?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
58. A. Constipation?	0 No (SCORE B AS 7 SKIP TO #59)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much did that distress him/her?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
59. A. Dry mouth?	0 No (SCORE B AS 7, SKIP TO #60)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much did that distress him/her?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
60. A. Difficulty breathing?	0 No (SCORE B AS 7, SKIP TO #61)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much did that distress him/her?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal
61. A. Pain?	0 No (SCORE B AS 7, SKIP TO #62)			1 Yes (ASK B)		7 N/A	8 D/K	9 Refusal
B. How much did that distress him/her?	0 Not at all	1 A little bit	2 Somewhat	3 Quite a bit	4 Very much	7 N/A	8 D/K	9 Refusal

62. Of all his/her symptoms, which was most distressing to <u>you</u>?

PHYSICIAN-ASSISTED SUICIDE

Now we'll move to the last topic.

Oregon is a unique state because it is the only state where physician-assisted suicide is legal under certain conditions. We are trying to learn more about what citizens in Oregon think about this and whether families are discussing it.

63. First, what is your general overall opinion about the idea of physician-assisted suicide?

1 Opposed
2 Neutral
3 In favor

7 Not applicable
8 Don't know/no opinion
9 Refusal

64. What was < >'s general overall opinion about physician-assisted suicide?

1 Opposed
2 Neutral
3 In favor

7 Not applicable
8 Don't know/no opinion
9 Refusal

65. Were there conversations between < > and anyone in the family about the topic of physician-assisted suicide?

0 No
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

66. Do you think < > ever considered it as an option for himself/herself during his/her illness?

0 No **(IF NO, SKIP TO #68)**
1 Yes

7 Not applicable
8 Don't know/no opinion
9 Refusal

67A. Did < > ever make a request for physician-assisted suicide?

0 No (IF NO, SKIP TO #68)
1 Yes (IF YES, ASK B)

7 Not applicable
8 Don't know/no opinion
9 Refusal

B. How would you describe the request? Would you say it was:

1 Informal (e.g., talking with family or friends) (IF INFORMAL, SKIP TO #68)
2 Formal (made request to physician) (IF FORMAL, ASK C)
3 Both informal and formal (IF BOTH, ASK C)

7 Not applicable
8 Don't know/no opinion
9 Refusal

C. Could you tell me a little bit about the formal request?

68. Is there anything else about the topic of physician-assisted suicide that you want to mention?

CLOSURE

69. That is the end of our questions. Is there anything you want to add about < > that we haven't talked about or anything you want to ask me?

Appendix B

NVivo/Main Study Nodes

Main study node count

```
:;GCV1|1
:;GCA1|2|NVivo, Project: Most Involved, User: Administrator
:;GCZ163
1= All Tree Nodes
:;GCM1|1|Memo for node All Tree Nodes
All Tree Nodes
:;GCE
:;GCR1|1|1
2= /change in residence due to care need
3= /progressive cancer death
4= /specific treatments~medications
5= /physical health~symptoms
6= /emotional health~symptoms
7= /~D~ behavior
8= /decrease in ADLs
9= /extended time reported on
:;GCM1|9|Memo for node (8) extended time reported on
respondent reported events prior to the last few days
:;GCE
:;GCR1|9|9
10= /healthcare system comment
11= /bedridden
12= /physical symptom w~declining health
13= /not in pain
14= /pain med not needed much
15= /prior health issues
16= /~R~ special relationship w~D
17= /other family helping w~care
18= /prior medical histories recounted
19= /other family who couldn't help w~car
20= /family accommodates to help
21= /family tradition of helping
22= /advice for other caregivers
23= /falls
24= /hospice involved
25= /dissatisfaction w~care facility
26= /dissatisfaction w~care providers
27= /satisfaction w~care providers
28= /positve~pleased with hospice experie
29= /other family illnesses
30= /~R~ personal health issues
31= /hospitalization
32= /energy loss
33= /negative ~poor~ test results
34= /~D~ non-responsiveness
35= /sleeping habits
36= /unsuccessful w~food
37= /tests run non-specific
38= /~D~awareness level
39= /unwanted medical treatments
40= /reminiscence
:;GCM1|40|Memo for node (39) reminiscence
comments made +/- by respondent in form of reminiscence
:;GCE
:;GCR1|40|40
41= /~D~ inability to communicate
42= /~D~ living arrangement
43= /~R~worked xtra for income
44= /+ agency assistance
45= /estimate given till EOL
46= /~D~ rec'd$$public assistance
```

Main study node count

```
47= /~R~ turned prof provider
48= /~R~ mental health issues
49= /Dementia present
50= /~R~ was a med professional
:;GCM1|50|Memo for node (49) ~R~ was a med professional
physician; EMT
:;GCE
:;GCR1|50|50
51= /~R~ was a prof in training
52= /description of death
53= /care issues of other family affected
54= /difficulty w~care professionals
55= /no estimate till EOL
56= /~D~ participation in death event
57= /~D~ lived alone
58= /not knowing how soon death would occ
59= /w~knowledge would have changed care
60= /~R~ positive aspect of death event
61= /~D~ [positive affect @EOL
62= /~D~ vists w~family & friends
63= /~R~ personal satisfaction w~involvem
64= /prior hospice experience
65= /unable to treat due to AD
66= /family chose to have treatment despi
67= /repeat hospice care
68= /D in foster care
69= /change in care facilty due to bad ex
70= /~D~ estrranged from all but ~R~
71= /~R~ helped get services in place
72= /negative relationship ~experience w~
73= /providers help to get hospice in pla
74= /~D~ pleased w~hospice care
75= /advocating  use of ADs
76= /Need for families to talk about EOL
77= /consequences of not discussing EOL i
78= /type of cancer noted
79= /appreciation for study
80= /thoughts re~not doing 'terminal' wel
81= /Quick EOL
82= /date of death noted
83= /lost will to live
84= /~D~ in pain
85= /~D~ stopped eating~drinking
86= /died before expected
87= /knowing decedent's preferences impor
88= /unable to eat~no appetite
89= /~D~ prayed to die
90= /~D~ unwilling to bathe
91= /unable to engage hospice
92= /health providers unsympathetic
93= /PAS comment
94= /difficulty finding a care facility
95= /unable to get help with care transit
96= /services difficult for those w~Alzhe
97= /physical symptoms w~approaching deat
98= /~D~conversations w~deceased family
99= /~D~ last few words
100= /~R~ retrospective on changes they'd
101= /~R~ unexpected  EOL experience
102= /cancer treatment
103= /D ~wouldn't let go~
```

```
                    Main study node count
104= /~R~ donated ~D~ 's personal belongin
105= /Study's queries made ~R~ think
106= /positive attribute of D
107= /D's desire to die earlier
108= /positive death event
109= /D's positive experience in foster ca
110= /R  felt had unususal personal situat
111= /R personal faith issues
112= /~R~ difficult ending
113= /D wanted to be @ home
114= /negative hospice experience
115= /D in asst living facility
116= /D unhappy in care facility
117= /R made daily visits
118= /D's prior health fair given age
119= /D decline w~advanced age
120= /D active given age
121= /R feels society should do more than
122= /R plans future advocacy activities
123= /R w~D @ death
124= /description of death activity
125= /prof caregivers helped w~pain meds~c
126= /effects of dementia
127= /~R~ dissatisfaction w~doctor
128= /overall difficulty for ~D~
129= /~D~ lifetime accomplishments
130= /~R~ grief solution
131= /~D~ had surgery
132= /~R~ disillusionment w~medical scienc
133= /other ~non-family helping w~care
134= /sattisfaction w~care facility
135= /~R~ visited facility after death
136= /dementia w~increased age
137= /~R~ personal refelctions on old age
138= /~R~ personal care for ~D~ @ EOL
139= /~R~ felt didn't do enough
140= /~R~ promises made to ~D~
141= /~D~ said not afraid to die
142= /Death easier on ~D~ than family
143= /~R~ had support from other family me
144= /~D~doing well for advanced age
145= /care was expensive
146= /positive foster care experience
147= /$$ issues w~care
148= /another family death occurred @ same
149= /brought home due dissatisfaction w~c
150= /visit w~priest
151= /~R~ happy to be @ home to die
152= /R's thoughts ablout having death @ h
153= /LST not appropriate w~advanced age
154= /general failing health
155= /general~nursing facilities
156= /~D~ in high cost~quality facility
157= /~R~awareness that all could not affo
158= /Long term dementia
159= /~D~ in VA facility
160= /~D~ chose facility because of costs
161= /caregivers did best to make D comfor
162= /Hard for R to see dad like that
163= /EOL experience would have bothered D
1 > +2 +3 +4 +5 +6 +7 +8 +9 +10 +11 +12 +13 +14 +15 +16 +17 +18 +19
```

```
                    Main study node count
+20 +21 +22 +23 +24 +25 +26 +27 +28 +29 +30 +31 +32 +33 +34 +35 +36
+37 +38 +39 +40 +41 +42 +43 +44 +45 +46 +47 +48 +49 +50 +51 +52 +53
+54 +55 +56 +57 +58 +59 +60 +61 +62 +63 +64 +65 +66 +67 +68 +69 +70
+71 +72 +73 +74 +75 +76 +77 +78 +79 +80 +81 +82 +83 +84 +85 +86 +87
+88 +89 +90 +91 +92 +93 +94 +95 +96 +97 +98 +99 +100 +101 +102 +103
+104 +105 +106 +107 +108 +109 +110 +111 +112 +113 +114 +115 +116 +117
+118 +119 +120 +121 +122 +123 +124 +125 +126 +127 +128 +129 +130 +131
+132 +133 +134 +135 +136 +137 +138 +139 +140 +141 +142 +143 +144 +145
+146 +147 +148 +149 +150 +151 +152 +153 +154 +155 +156 +157 +158 +159
+160 +161 +162 +163
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Appendix C

Stage Four Coding/Nodes Sets

Stage #4 Coding
N=26 node sets prioritized # of passages /set
(Updated 1/16/06 two sets combined into 1- reducing over # sets from 27 to 26)

PROVIDER /FACILITY COMMENTS/DIFF FINDING CARE:
1)Respondent or Decedent Dissatisfaction w/ care, doctor, facility
#s 24; 25; 53; 68; 71; 91; 115; 126; 131; 148
passage count total=29

2)Positive comment re: caregiver/facility
#s 26; 72; 108; 124; 133; 145; 160
passage count total=10

40)Negative Comments Re: Healthcare System
#s 9
passage count total=3

48)Needed Help w/Living Arrangement Transition
#s 93; 94
passage count total=2

Total passages= 44

PHYSICAL/ MENTAL HEALTH ISSUES
6)Physical health symptoms noted
#s 4; 11
passage count total=16

7)Prior health issues noted
#s 14; 17
passage count total=11

31)Presumed Cause of Death
#s 51
passage count total=3

22)Decedent Mental Health Issues
#s 5; 6
passage count total=6

Total passages=36

ADVOCACY/ADVICE/EOL RELATED SUGGESTIONS

9)Advocacy/advice/EOL related suggestion or comment
#s 21;74;75; 76; 79;86;92;112; 120; 121;136;150; 151; 152; 154
passage count total=25

Total passages=25

HOSPICE MENTIONED

4)Hospice mentioned
#s 23 (neutral); 27 (+); 66 (neutral); 73 (positive);
90 (negative); 113 (negative)
passage count total= 22

Total passages=22

TESTS RUN/SPECFIC TREATMENTS NOTED

3)Tests run/specific treatments/medicines
#s 3; 30; 32; 36; 101; 130
passage count total=16

46)Treatments Not in Keeping w/ Decedent's Wishes
#s 38; 65 (family initiated)
passage count total=2

Total passages=18

ISSUES RELATED TO DEMENTIA

10)Issues Related to Dementia/Dementia Mentioned
#s 48; 64; 95; 125; 135; 157
passage count total=17

Total passages=17

(CREATED 1/16/06)RETROSPECTIVE/FOLLOW UP TO DEATH EVENT POSITIVE IN HELPING @ EOL/APPRECIATE STUDY

14)Respondent Personal Positives in Helping @ EOL
#s 59; 62
passage count total=6

17)Appreciative of being in study
#s 78; 104

passage count total=2

RESPONDENT FOLLOW UP TO DEATH/LESSONS LEARNED
8)Respondent activities/follow up to death event
#s 103; 129; 134; 139
passage count total=4
36)Retrospective/ Lessons Learned from EOL Experience
#s 99; 138
passage count total=3

Total passages=15

OTHER FAMILY/NON FAMILY HELPING
13)Other family/non-family help
#s 16; 18; 19; 20; 132; 142
passage count total=10
39)Visitors
#s 61; 149
passage count total=3

Total passages=13

GENERAL COMMENTS;DECEDENT & FAMILY DIFFICULTY @ EOL
42)Comments Re: Diff for Decedent @ EOL/Desire to Die/Lost Will
#s 82; 88; 102; 106; 111; 127; 162
passage count total=8

45)Death Hard for Respondent/ Family Members
#s 141; 161
passage count total=2

35)Unexpected EOL Experience
#s 100
passage count total=2

Total passages=12

REMINISCENCE
27)Reminiscence of Decedent
#s 39; 105; 128
passage count total=10

Total passages=10

GENERAL/DECEDENT SLOWING DOWN

43)Decedent- General Slowing Down/Doing Less
#s 7; 10; 22; 31; 89; 118; 153; 80
passage count total=10

Total passages=10

COSTS OF CARE
5)Related to costs of care
#s 42; 43; 45; 144; 146; 155; 156; 159
passage count total=10

Total passages=10

DECEDENT LAST FEW DAYS ACTIVITIES
32)Decedent Activities @ EOL; Last Few Days or Moments
#s 60; 96; 97; 98; 123; 140
passage count total=10

Total passages=10

CHANGE IN RESIDENCE DUE TO CARE NEEDS
20)Changed Residence Due to Care Needs
#s 1
passage count total=10

Total passages=10

AWARENESS LEVEL/SLEEPING
25)Decedent Awareness Level/Sleeping
#s 37; 33; 34; 40
passage count total=9

Total passages=9

TIME REPORTED EXPANDED
30)Time reported beyond Last Few Days
#s 8
passage count total=8

Total passages=8

PAIN ISSUES NOTED
11)Respondent in Pain
#s 83
passage count total=4

12)Respondent Not in Pain/Pain Meds Not used Much
#s 12; 13
passage count total=4

Total passages=8

LIVING ARRANGEMENTS
29)Living Arrangements Noted
#s 41; 56; 67; 114; 158
passage count total=8

Total passages=8

POSITIVE DEATH EVENT/ACTIVITIES
15)Decedent's Participation in Death Event
#s 55
passage count total=4
16)Noted Positive Death Event
#s 107
passage count total=2

Total passages=6

RESPONDENT/OTHER FAMILY HEATHCARE ISSUES
18)Other Family Health or Care Issues
#s 28; 52; 147
passage count total=4
23)Respondent Health Issues (All)
#s 47 (MH); 29 (physical)
passage count total=2

Total passages=6

CARE GIVEN/CARE DECISIONS; W/DECEDENT @ DEATH
33)Respondent w/Decedent @ EOL
#s 122
passage count total=2

38)Personal Care/ Care Decisions Provided by Respondent @ EOL
#s 70; 116; 137
passage count total=4

Total passages=6

TIME ESTIMATE GIVEN/NOT GIVEN
28)Comments Given Relating to Time Estimate/No Time Estimate re: EOL
#s 44; 54; 57; 58; 80
passage count total=5

Total passages=5

NUTRITIION/HYDRATION
19)Nutrition/Hydration Issues

#s 35; 84; 87

Total passages=4

RESPONDENT IN MEDICAL PROFESSION
26)Respondent Medical Prof/ Semi Prof/Prof in Training
#s 46; 49; 50
passage count total=4

Total passages=4

RERSPONDENT DECEDENT RELATIONSHIP
21)Respondent-Decedent Interpersonal Relation
#s 15; 69
passage count total=3

Total passages=3

Moved this into set named Adv/Adv/EOL related suggestions
DECEDENT/RESPONDENT DESIRE TO BE @ HOME
37)Decedent/Respondent= Desire To Be @ Home
#s 112; 150; 154
passage count total=3

Total passages=3

1/9/06 Changed total set count to 27 (previously 28)

ACTIVE GIVEN AGE
44)Was Active Given Age
#s 117; 119; 143
passage count total=3

Total passages=3

24)Quick Death (ELIMINATED THIS ONE)
80 PUT IN GENERAL SLOWING
#85 PUT IN TIME ESTIMATE GIVEN/NOT GIVEN
#s 80; 85
passage count total=2

CONSIDER NOT USING
34)Respondent's Faith Issues
#s 109; 110
passage count total=3

41)Death from CA

#s 2; 77
passage count total=4

47)Date of Death Noted
#s 81
passage count total=1