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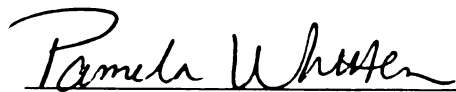
TELEHOSPICE: CHANGING HEALTH CARE POLICY TO ENHANCE SOCIAL  
SUPPORT FOR CAREGIVERS IN RURAL AREAS

presented by

Jennifer L. Gregg

has been accepted towards fulfillment  
of the requirements for

Ph.D. degree in Telecommunication

  
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**TELEHOSPICE: CHANGING HEALTH CARE POLICY TO ENHANCE SOCIAL  
SUPPORT FOR CAREGIVERS IN RURAL AREAS**

**By**

**Jennifer L. Gregg**

**A DISSERTATION**

**Submitted to  
Michigan State University  
In partial fulfillment of the requirements  
For the degree of**

**DOCTOR OF PHILOSOPHY**

**Department of Telecommunication/Mass Media**

**2002**



## **ABSTRACT**

### **TELEHOSPICE: CHANGING HEALTH CARE POLICY TO ENHANCE SOCIAL SUPPORT FOR CAREGIVERS IN RURAL AREAS**

**By**

**Jennifer L. Gregg**

Until the early 20<sup>th</sup> century death could occur at any age, usually from acute infectious disease or accident (Stillion, 1995). Death in childhood is rare today, however, because of antibiotics and immunizations. An adult child is much more likely to provide care for an elderly parent who is slowly dying from chronic illness. Accessing the services they need may prove to be a significant challenge for people living in rural areas (Buckingham, 1996; Buehler & Lee, 1992).

Hospice caregivers deal with a wide range of stresses every day, both physical and emotional. Not only is a hospice caregiver dealing with their own emotional adjustment to the death of a loved one, often a spouse, but also they are managing the physical symptoms of the illness for the patient. According to the 1997 National Caregiver Survey, more than 22 million U.S. households--nearly one-quarter of the population--contain someone caring for an older relative or friend (Caregiving & Persons, 1997). The value of family caregiving to society is estimated conservatively to represent nearly \$200 billion per year (Caregiving, 2002). Caring for a loved one at the end of life is difficult, to say the least. Caregivers often feel isolated and experience stress from the burden of caregiving itself and from balancing caregiving, work, and other family responsibilities (Caregiving, 2002).

Telemedicine, the use of telecommunication technologies to deliver health services over a distance, may be one means of potentially alleviating the stress on caregivers. The purpose of this dissertation was to examine the role of telehospice in providing support to caregivers of hospice patients. The researcher's goal was to evaluate the feasibility of using telehospice to meet the emotional needs of caregivers in the home setting and to examine the legislative context surrounding this added dimension of service to caregivers.

Using a framework of social support theory and both qualitative and quantitative methods, the researcher found that perceived social support was correlated with caregiver quality of life. Furthermore, caregivers in rural Michigan reported that although they have a social support network in place, very little respite care is available, and there is very little, if any, support from extended family. Although pilot projects with hospice patients have shown that patients and physicians feel telehospice is a beneficial service, caregivers are hesitant to use telecommunication technologies for their own support.

The researcher concludes that for telehospice to be successful in enhancing social support networks of caregivers in rural areas, a significant education component from hospice providers is necessary to illustrate benefits of the service for caregivers. Furthermore, policy needs to be enacted to provide for telehospice services to caregivers.

## ACKNOWLEDGMENTS

This project would not have happened without the help of several people. First, I'd like to thank my dissertation committee, Jacob Climo, Gary Doolittle, and Carrie Heeter. Your guidance and support has made it possible for me to pursue a line of research to which I am genuinely dedicated. I look forward to continuing our work together. A special thank-you to my dissertation advisor and mentor, Pam Whitten. I'm proud to be your first doctoral student, and I look forward to future projects together. Your training has been invaluable. Your friendship has been even more important. You've shown me how to be a scholar while proving it's also possible to be a mom.

Jeanne Parzuchowski, vice president of research at Hospice of Michigan, was an essential resource during this project. Thank you for your insight into the challenges and rewards of end-of-life care. I'd also like to thank Terri Rush at HOM for helping with subject recruitment and for answering all my questions without laughing.

I'd also like to thank the office staff of the telecom department at Michigan State, particularly Denise Mahoney and Vanessa Pollock, for putting up with me for all these years. I owe you much more than a dozen-or-so plastic forks.

Several people pitched in as babysitters so I could work nearly round-the-clock. Deb McKenzie and Lisa Meniketti juggled their own schedules so I could have more time to write. Hillary Morrison holds a special place in our family. Without your care of "the monsters," I never would have made it. We'll miss you.

Last, but definitely not least, I'd like to acknowledge the sacrifices made by my husband, Paul Sisler. You took on the role of both mommy and daddy so that I could

pursue my goals. This was not an easy journey and I sincerely appreciate your support through all of it.

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## CHAPTER 1

### INTRODUCTION

Life is a progression from birth to death, and until the early 20<sup>th</sup> century, death could occur at any age, usually from acute infectious disease or accident (Stillion, 1995). Death in childhood is rare today, however, because of antibiotics and immunizations. An adult child is much more likely to provide care for an elderly parent who is slowly dying from chronic illness. Due to advances in medical technology individuals today are living longer than ever, often living well beyond what some consider a positive quality of life.

Added to the stresses of advanced age is that of financial constraint and access to services. Patients and their families are faced with rising healthcare costs and insurance providers that reject claims as "not medically necessary" or "noncovered benefit" when in fact the person reviewing claims works for the insurance company, has never seen the patient and probably is not a healthcare practitioner (Vogin, 1999). Furthermore, for people living in rural areas just getting access to the services they need may prove to be a significant challenge (Buckingham, 1996; Buehler & Lee, 1992). In addition, the United States is facing a widespread critical nursing shortage. Projections estimate that by the year 2020 the number of registered nurses working in America will be 20% below the estimated need (Brownback, 2002). According to the American Hospital Association, hospitals around the country today have 126,000 nursing vacancies, or 12 percent of capacity (Janofsky, 2002). Health industry experts predict the number could triple over the next decade as baby boomers age.

Increased cost, difficulty accessing services, and the shortage of nurses and other providers mean that families and neighbors are taking on more of the responsibility for

providing care to patients near the end of life. While the role of caregiver has many benefits for both the patient and the care provider, it places considerable stress on the relationship and on the individual lives. Becoming a caregiver places the individual in a unique position on two spectra of social support: on the one hand, they are acting primarily as the donor of support to the person for whom they are caring, on the other, they are the recipient of support from members of their social network. The caregiver may be providing extensive personal care such as bathing and feeding the patient, or less personal care such as cleaning the patient's home, paying bills, or cooking meals. As a care recipient, they may be receiving financial assistance from other family members, receiving respite care from volunteers and friends, or receiving spiritual or emotional counseling from professionals. A person's ability to provide support may depend on the support they receive from their network, and vice versa, the support they receive from their network may depend on the care demanded by the patient (Pearlin, Aneshensel, Mullan, & Whitlatch, 1996).

Nearly 75 percent of caregivers are women. They devote an average of four-and-a-half years to caregiving, but often 10 or more (NAC & AARP, 1997). Fifteen percent of all caregivers, and more than 30 percent of those providing the highest levels of care report significant physical and emotional stress (NAC & AARP, 1997). Furthermore, those who report mental or emotional strain associated with the chronic stress of caregiving had a mortality risk more than 60 percent higher than individuals in noncaregiving roles (Schulz & Beach, 1999).

Telemedicine, the use of telecommunication technologies to deliver health services over a distance, may be one means of potentially alleviating the stress on

caregivers. The purpose of this dissertation is to examine the role of telehospice in providing support to caregivers of hospice patients. The researcher's goal is to evaluate the feasibility of using telehospice to meet the emotional needs of caregivers in the home setting. The remainder of this chapter will provide the reader with a brief history of hospice care in the United States, the background necessary for studying caregiving at the end of life, followed by a discussion of the purpose of this study.

### Hospice: A Concept of Caring

Hospice is care designed to provide comfort and support to patients and their families at the end of life, when a life-limiting illness no longer responds to cure-oriented treatments (HFA, 2002a). It represents a supportive philosophy of providing care to those whose life expectancy is measured in weeks or months. Hospice recognizes death as the final stage of a life journey, and enables patients and families to live their final days to the fullest in the comfort of home, surrounded by loved ones.

Hospice care is primarily provided in the home by a team of specially trained professionals, volunteers and family members, who address all symptoms of a disease. A family member typically serves as the primary caregiver and helps make decisions for the terminally ill patient (NHF, 2002b), though the primary caregiver could be a life partner, friend, or other relative. The goal of hospice care is to improve the quality of a patient's last days by offering comfort and dignity (HFA, 2002a); hospice neither prolongs life nor hastens death. The core interdisciplinary team of professionals and volunteers provides medical, psychological, and spiritual support to the terminally ill and their families (HAA, 2002a), with a special emphasis on controlling a patient's pain and discomfort. The team, which typically includes the patient's personal physician, hospice physician,

nurses, home health aides, social workers, clergy, volunteers, and speech, physical and occupational therapists as needed, coordinates an individualized plan of care for each patient and their family (Web, 2002). Hospice staff is on-call 24-hours a day, seven days a week, and there is no age limit for hospice care. Though approximately two-thirds of hospice patients are over the age of 65 (HFA, 2002b), both children and adults can receive the support of hospice during the final stages of life.

The majority of hospice patients have cancer, while others suffer from AIDS, Lou Gehrig's disease, heart or lung disease, and other fatal conditions (Web, 2002). About 63 percent of all hospice enrollees have at least one type of cancer as their primary diagnosis (Gage, 2000). The role of hospice remains the same, though, whatever the disease or condition--to provide professional medical care, to manage pain and other symptoms, and to meet social, emotional, and spiritual needs of the patient and their family.

#### Hospice services for patients and caregivers

Services available through hospice include: medical and nursing care; personal care; homemaker services; social work services; grief and counseling services; volunteer assistance; spiritual care; case management; and family training in patient care (Web, 2002). Because the nature of dying is unique for each person, the goal of the hospice team is to be sensitive and responsive to the patient's needs. A typical plan of care includes intermittent nursing care (often one visit each week) with 24-hour on-call nursing available for emergencies. A registered nurse specially trained in evaluating and caring for the terminally ill serves as case manager (HPA, 2002b). The case manager is the first and foremost contact the patient and family have with the hospice.

Physician's services, medical appliances and supplies related to the terminal illness, and outpatient drugs for symptom management and pain relief are also included in the plan of care (Web, 2002). Short-term acute inpatient care, including respite care, is also available to hospice patients and their families. The plan of care may also include home health aide and homemaker services. The hospice home health aide (sometimes called "CNA") provides basic bedside care for the patient (HPA, 2002a). The home health aide will often be the team member who actually spends the most time with the hospice patient and family because they are providing the basic care in the home and helping the patient with the routine activities of daily living (HPA, 2002a). The home health aide will make regular visits to the patient and family and provide help as needed for bathing, dressing, and eating, for example.

Hospice volunteers provide a wide range of services for patients and their families. The hospice industry started out as a service comprised primarily of volunteers, and volunteer services of a hospice are actually required by the Medicare federal standards of care (HPA, 2002c). Sometimes the help provided by volunteers make it possible for a patient to remain at home till the very end. Volunteers may sit with the patient, allowing the primary caregiver to go out. They may go shopping, run errands, prepare meals, read for the loved one and do many other tasks to help out (HPA, 2002c). Volunteers are a very important part of the hospice team

Non-denominational spiritual counseling is available to patients and their families upon request. Dietary counseling is available to patients and caregivers, and patients have access to physical therapy, occupational therapy and speech/language pathology

services if needed. Bereavement services and counseling are available to the patient's family for approximately one year after the patient's death (HospiceNet, 2002).

### Hospice history

Though the concept of hospice dates back to ancient times, it wasn't introduced in the United States until the 1970s. In 1974 the first hospice legislation was introduced to provide federal funds to support hospice programs, however, the legislation was not enacted (HAA, 2002b). Later that same year, the National Cancer Institute (NCI) provided funding for Connecticut Hospice, Inc., to begin providing in-home services (HAA, 2002a). In the late 1970s and early 1980s additional hospices received similar contracts from NCI (HAA, 2002b). In 1982, Congress provided a Medicare benefit (with a cap on overall per-patient expenses and inpatient hospital use) for hospice services (HAA, 2002b), and by the late 1980s the Medicare hospice population dramatically increased, primarily due to a Congressional mandate to increase reimbursement rates (HAA, 2002a). The Medicare Hospice Benefit was made permanent by Congress in 1986 (HAA, 2002b), and the reimbursement rate was increased by 10 percent. Today there are more than 3,100 hospice programs in the United States, caring for nearly 700,000 people each year (NHPCO, 2001). In 2000, the Department of Health and Human Services released "Medicare's Hospice Benefit: Use and Expenditures," confirming cost effectiveness of hospice in the last six months of life (HAA, 2002b).

While there has been growth in the number of hospices in the last twenty years, for many reasons only 15 percent of the dying in this country access this specialized service (Von Gunten, Neely, & Martinez, 1996). Furthermore, while the number of patients entering hospice continues to grow, the length of stay in hospice is getting

dramatically shorter (Klein, 2000). The average length of stay in 1998 was 59 days, down 20 percent from 1992 when the average length of stay was 74 days (Klein, 2000). Furthermore, 28 percent of hospice patients die within weeks or days of enrollment (Klein, 2000). According to a recent Gallop Poll, 90 percent of Americans would prefer to be cared for and die in their homes if faced with a terminal illness (Gordon, 2002a). Nursing homes are often the site of death for many elderly patients, yet nursing home residents have limited access to hospice care (Zerzan, Stearns, & Hanson, 2000).

### Challenges in rural areas

For rural populations, hospice expertise may not exist locally (Buehler & Lee, 1992). Buckingham, (1996) reports that hospice is more difficult to access in rural areas. Fifty-six million Americans live in nonmetropolitan areas. They make up one-fifth of the U.S. population but are spread out across four-fifths of the land area (ERS, 2002). There is a shortage of health providers in rural areas, and even though rural America has 33 percent of the population, only 12 percent of physicians and 18 percent of nurses choose to practice in rural areas (Buckingham, 1996). While the physician-to-population ratio has more than doubled since 1960, it has risen by less than 15% in the smallest rural communities, those of less than 10,000 population (Greene, 1999).

Also, geographically dispersed patients in rural areas are a challenge for hospice providers. Travel expenses and road conditions pose additional barriers. Because of these obstacles, many rural residents are forced to use inpatient or long-term care facilities for hospice services instead of having the choice of dying at home. Also, some patients experience their illness in isolation, without the support of family or friends serving in the caregiver role (Smith, 1994). For some, cost may prohibit access to



hospice professionals (Cher & Lenert, 1997). African Americans face additional barriers to accessing hospice services. For many, there is a lack of knowledge about hospice services and a lack of trust in the health care system as a whole (Reese, Ahern, Nair, O'Faire, & Warren, 1999) and fear about their own role in care.

Hospice care is often praised for its focus on emotional, psychological, spiritual, and social support. It also deals with the emotional impacts of the disease on the patient and the patient's family and friends, and offers a variety of bereavement and counseling services to families before and after a patient's death. Family members are integral participants in the process as they provide day-to-day care, often stepping into a caregiver role that is entirely foreign (Brown & Stetz, 1999). For this reason, the hospice team provides counseling and support to family members as well as patients.

Pain management is integral to excellence in the care of a hospice patient. This focus on pain as a symptom is due to its frequency; pain is the chief complaint of more than 70 percent of hospice patients (Cockburn, 1983; Perra & Schonwatley, 2001). Furthermore, the fear of pain is deeply interwoven into our society's fear of the dying process. Researchers have documented that a comprehensive pain assessment is the cornerstone for creating an effective hospice management plan (Forman & Sheehan, 1996; NCCN, 2000; Perra & Schonwatley, 2001). Pain must be controlled and contained before other symptoms can be handled effectively (Given, Given, Azzouz, Kozachik, & Stommel, 2001). Inadequate relief of pain has been shown to be related to depression, anger, isolation and even thoughts of suicide in a cancer population (Grossman, Sheidler, Swedeen, Mucenski, & Piantadosi, 1991).

Limited research exists regarding patient assessment of the quality of their care (Bredart et al., 1999). However, patients have told professionals that care at the end of life is less than optimal (Emanuel, Alpert, Baldwin Jr, & Emanuel, 2000). Satisfaction with hospice care appears to be more closely associated with quality of life than physical symptoms (Tierney, Horton, Hannan, & Tierney, 1998). Symptoms do, however, become important in later stages of hospice care. While pain and symptom management are the most significant factors to patients, other items also are consistently rated as important to quality at the end of life (Steinhauser et al., 2000). Steinhauser (2000) found that preparation for death, achieving a sense of completion, being involved in decisions about treatment preferences, and being treated as a "whole person" were also important to patients at the end of life. Patients also felt it important not to be a burden on others. In a recent report from the Robert Wood Johnson Foundation (RWJ, 2001), patients, family members and other caregivers rated having a nurse with whom one feels comfortable as one of the top five attributes important in end-of-life care. Other attributes important to respondents were: to be kept clean; to be able to name a decision-maker; to know what to expect about one's physical condition; and to have someone who will listen (RWJ, 2001).

While hospice care may be available, some physicians fail to refer patients or provide referrals very late in the course of dying (Johnson & Slaninka, 1999). In fact, a report by the Robert Wood Johnson Foundation found that physicians often ignore the last wishes of terminally ill patients, even when patients filed advanced directives (Gordon, 2002b). Mor, Hendershot, and Cryon (1989) found that use of hospice services is limited by lack of referrals and general unawareness of available services by the public. Furthermore, Christakis and Escarce (1996) found that older adults, the very individuals

most likely to need the services, are even less likely to be aware of hospice care.

Prigerson (1991) found that patient acknowledgement and physician disclosure of terminality were major determinants to access. The role of hope for caregivers also plays an important part in accessing hospice services. Some caregivers may perceive that hospice means giving up hope for their loved one (Herth, 1993; Johnson & Slaninka, 1999).

### Purpose of This Study

As noted earlier, most patients at the end of life prefer to die at home in the care of loved ones. Furthermore, due to increases in healthcare costs and shortages in skilled nursing care, families are looking for alternatives for providing end-of-life care at home. However, healthcare policy has not kept up with changing medical needs in this country. Current reimbursement structures for end-of-life care do not allow for alternatives such as telemedicine. Also, issues of privacy and liability place limits on the utilization of technology in healthcare.

In order to fully understand the role that telemedicine might play in the lives of hospice caregivers, the current research will take a two-pronged approach. First, it is crucial to speak directly with hospice caregivers to determine their needs. At the same time, it is vital to examine the current policy structure for hospice in the United States to understand the potential for shifting delivery systems. In an effort to rigorously study this context, an appropriate method of inquiry is the case study. According to Yin (1989), "a case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (p.

23). This case study employed multiple methods to study social support within the context of caregiving. It combined the analysis of quantitative data, policy analysis, and individual interviews. These methods resulted in an in-depth understanding of the challenges of being a caregiver and how telemedicine might provide support to individuals in this role.

This dissertation is composed of five chapters. The first chapter introduced the concept of hospice care and provided the rationale for the basic issue to be examined. The second chapter outlines existing research relevant to this study. Chapter three outlines the methods employed in this study. The fourth chapter presents the results of the investigation. Finally, chapter five discusses the implications of the findings and provides recommendations for future study.

## CHAPTER 2

### LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Americans are social creatures. For the most part we live in communities, we attend public schools, we go to birthday parties, and we have friends with whom we enjoy spending time. These social relationships are believed to enhance our feelings of self-worth and self-esteem (Antonucci, 1990), and are the very relationships we rely on in times of need. Social support is the instrumental, emotional and informational assistance provided to us by others (Miller et al., 2001). It is prevalent in our daily lives and plays an especially vital role in times of stress. Although social support can be seen in many ordinary exchanges of daily life, it is by no means universal. Not everyone has access to supportive relationships. Those with supportive relationships do not benefit from them equally. In fact, some supportive relationships are actually problematic. As noted earlier, the purpose of this study is to determine what role, if any, telemedicine might play in enhancing social support relationships of hospice caregivers. It is important to determine what roles are particularly important to hospice caregivers, and how to enhance access to these relationships.

This chapter will begin by providing the context for studying the role of caregivers and the challenges of those faced with caring for the dying. The next section will discuss social support and its role in the lives of caregivers. Social support has been studied extensively for more than 20 years, though conclusively defining it is still elusive. A brief historical perspective and review of the social support literature will provide the theoretical framework for the current project. Finally, this chapter will provide a brief

history of telemedicine and its role in providing hospice services, concluding with a discussion of its potential for addressing challenges of hospice caregivers.

### The Burden of Caregiving

Hospice caregivers deal with a wide range of stresses every day, both physical and emotional. Not only are hospice caregivers dealing with their own emotional adjustment to the death of a loved one, often a spouse, but also they are managing the physical symptoms of the illness for the patient. The caregiver may be making financial decisions with which they are uncomfortable or unfamiliar, making emotional decisions regarding care of their loved one, and may in fact be dealing with deterioration of their own physical well-being.

According to the 1997 National Caregiver Survey, more than 22 million U.S. households--nearly one-quarter of the population--contain someone caring for an older relative or friend (Caregiving & Persons, 1997). The majority of caregivers are women with an average age of 45 (Wagner, 1997), who report higher levels of depression and social isolation than male caregivers (Cossette, Levesque, & Laurin, 1995). More than half of female caregivers are employed full-time (Group, 1997). The value of family caregiving to society is estimated conservatively to represent nearly \$200 billion per year (Caregiving, 2002).

Research has shown that families provide the overwhelming majority of care at home for ill people (Given & Given, 1991), although neighbors, friends or other volunteers may take part in caregiving. Caring for a loved one at the end of life is difficult, to say the least. Caregiving begins at diagnosis or when the patient first becomes ill, and continues several months after the patient dies (Brown & Stetz, 1999). It

includes physical care, economic strain, stress, helplessness and depression (Boucher & Jackson, 1996), and can be either formal or informal. Caregivers often feel isolated and experience stress from the burden of caregiving itself and from balancing caregiving, work, and other family responsibilities (Caregiving, 2002). A major reason for admission of hospice patients to the hospital is exhaustion of the primary caregiver (Bramwell, MacKenzie, Laschinger, & Cameron, 1995).

Brown and Stetz (1999) proposed a theoretical model for people taking care of friends or family with terminal illness. Four phases of the model of caregiving include: (1) becoming a caregiver, (2) taking care, (3) midwifing the death, and (4) taking the next step. These phases include managing family issues, dealing with the health care system and preparing for death.

*Becoming a caregiver* has a profound effect on the lives of caregivers, and often requires significant changes (Brown & Stetz, 1999). For many, significant work occurs at the onset, and may include gathering information about the disease for themselves and the ill person. Hospice caregivers deal with a range of emotional responses. They may face emotional shock and disbelief at the patient's diagnosis, and may become a caregiver as a natural or expected role because of the nature of their relationship with the patient. *Taking care* of the patient includes guiding, giving and doing for the patient to meet his or her needs (Stetz & Brown, 1997). This may include managing family issues, dealing with the health care system, and preparing for death. Stommel et al. (1995) found that caregivers face a wide variety of tasks when caring for a loved one.

As the caregiving role progresses, caregivers take a central role in managing events and interactions during the final days and hours of the patient's death. *Midwifing*

*the death* involves providing comfort and coordinating resources during the dying process. Caregiving at this time can be traumatic, as many caregivers have never witnessed a death before while also providing care. The final step in Brown and Stetz's model is that of *taking the next step*. After death occurs, caregivers must work to bring closure to their caregiving roles. Activities of closure take place during the days and weeks after the patient's death and require adjustments by the caregiver (Brown & Stetz, 1999).

For some, death brings relief and freedom from intensive caregiving. For others, the intensity of grief might outweigh the caregiver's sense of relief. Bouton (1996) found that formalized bereavement services assist in this final step (see also Reimer Penner, 1996; Siebold, 1992). Delivery of effective bereavement care is often impeded, however, because it occurs in isolation from other hospice services (Bouton, 1996). Staff and volunteers who provide bereavement care do so without the active involvement of the team that provided hospice services to the patient, even though caregiver bereavement services are an integral part of the continuum of hospice care.

Literature in this field documents the importance of the overall health and well being for caregivers. Effective services are crucial to minimize the damaging impacts of caregiver burden. For example, research has shown that increased overall mental health is associated with a better quality of life for caregivers (Weitzner, Jacobsen, Wagner Jr, Friedland, & Cox, 1999), while more emotional distress and worsening patient performance status are associated with poorer caregiver quality of life. For families living in rural areas, Buehler and Lee (1992) found that the greater the decline of the ill person and the longer the dying process, the more families saw their role as difficult and



perceived resources to be inadequate. Given et al. (1993) found that patient symptom severity and patient immobility predicted caregiver burden and depression. As patients' symptoms and functioning improved, caregivers' negative reactions to caring declined. Chentsova-Dutton et al. (2000) found that caregivers reported experiencing high levels of depression, anxiety, and anger. Hospice caregiving was associated with deterioration in physical health and in social and occupational functioning. However, awareness of distress symptoms among hospice caregivers could lead to timely proactive clinical intervention that may prevent bereavement complications (Given et al., 2001).

Chang et al. (2001) found that arranging help from confidants and friends was relatively easy for caregivers, while arranging paid and unpaid help in the home was more difficult. Difficulty in arranging help was significantly correlated with caregiver burden and depression, and negatively correlated with satisfaction (Chang, Brecht, & Carter, 2001). Chang et al. (2001) also found that younger caregivers reported greater amounts of burden. The burden of caring for terminal patients often has a negative effect on a caregiver's quality of life (Smeenk et al., 1998), and accumulates over time (Duijnste, 1994).

### Support for caregivers

Caregivers are both psychologically and physically impacted by the caregiving process (Baumgarten et al., 1994; Given, Collins, & Given, 1988; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Schulz, Visintainer, & Williamson, 1990; Schulz & Williamson, 1991). However, support for caregivers provided by hospice care (McMillan, 1996a) and good terminal patient care appear to ameliorate these negative effects. Hull (1991) found that 24-hour phone access to hospice nurses was a vital aspect

of hospice care. Caregivers who keep busy, think positively, and learn more about the patients' illness have better coping strategies (Steele & Ritch, 1996). Hull (1992) found that caregivers who compared themselves to others in similar situations were encouraged in their own circumstance and had increased self-confidence. Furthermore, Hull (1992) found that creating time away from caregiving responsibilities allowed caregivers to rest and recuperate by participating in other activities and focusing on personal goals. Caregivers were better able to cope with impending death by shifting their focus to more controllable activities such as preparing the patient's favorite food. Caregivers who felt uncertain and out of control were helped by focusing on the present and by taking one day at a time.

Langner (1993) found that establishing a routine also increased a sense of control for caregivers. Talking through problems with friends and family was also an effective coping strategy. Caregivers need encouragement to maintain hope and a positive attitude so that they can continue caregiving. Ricard (1991) found that caregivers supported by a neighbor experienced a decrease in emotional distress. Social, volunteer, and professional supports all demonstrate a positive impact on caregivers (Steele & Ritch, 1996), and those with more frequent positive contacts with family and friends report lower levels of burden than those with less frequent or more negative contact (Li, Seltzer, & Greenberg, 1997).

Often, responsibilities associated with the caregiving role continue into the bereavement period. For example, managing health care bills may continue to be time-consuming as well as challenging. Moving ahead may be facilitated by supportive services for caregivers. Perhaps caregivers who receive positive feedback from others

about their caregiving contribution will reaffirm their own role in the dying process. However, obtaining bereavement services in rural settings is an additional challenge because of the smaller population (Wilker & Lowell, 1996).

To further understand the responsibilities associated with caregiving it is important to understand the social network in which a caregiver lives. Although social support and social network are distinctly different concepts, they are inextricably linked because all of a person's support is located within the web of their surrounding relationships (Wellman & Wortley, 1990). As noted in chapter one, the hospice caregiver is working with a team of providers from the hospice organization. They may also be receiving support from family members, neighbors, and member of their religious community. It is vital that researchers be aware of the caregiver's support network, not just their individual role as spouse, sibling, child or friend.

### The Role of Social Support in Caregiving

Social support is a multifaceted concept that has a long history in both sociology and psychology. In fact, Durkheim (1951) highlighted the importance of social ties in his classic work on suicide. Freudian theorists often point to problems with attachment and social relationships in early childhood as leading to psychological problems later in life. Social support involves a multitude of activities and relationships. Vaux (1988), in fact, states that "no single and simple definition of social support will prove adequate because social support is a metaconstruct: a higher-order theoretical construct comprised of several legitimate and distinguishable theoretical constructs" (p. 28).

Cassel (1974) laid much of the groundwork for the study of social support in health outcomes, focusing on social support and its role in stress-related disorders.

Cassel viewed support as being provided by primary groups (family and close friends) and serving in a protective function, protecting the individual from stressful experiences (Vaux, 1988). Caplan (1974) extended the study of social support to include groups other than family and close friends, particularly neighborhood-based groups, community caregivers such as clergy, and formal caregivers. Caplan emphasized the importance of support systems for individuals facing everyday demands (Vaux, 1988). Finally, Cobb (1976) provided an early conceptual definition of social support in which he proposed that social support be viewed as information leading a person to believe he or she is cared for and loved, is valued and esteemed, and belongs to a network of communication and mutual obligation (Vaux, 1988). Cobb's major emphasis was social support as a buffer for stress, and concluded that adequate social support can protect people in crisis (Cobb, 1976).

Two general models of social support have come out of years of research: stress-buffer model and direct effects model. In the stress-buffering model, social support protects individuals from the effects of stressful conditions. According to Cohen (1985), a buffering effect is dependent on the level of stress. A direct effect of social support, on the other hand, occurs no matter what the level of stress (Cohen & Wills, 1985); it is independent from the stress process (Vaux, 1988). Many previous studies of social support have found that a direct effect consistently occurs regardless of the severity of stress while a buffering effect occurs inconsistently or weakly (Hashimoto, Kurita, Haratani, Fujii, & Ishibashi, 1999). Pearlin et al. (1996) found, however, that in addition to direct moderating effects on depression, social support also exerts important indirect effects by moderating the stressors leading to depression. However, these moderating

effects were only found with instrumental supports, not with emotional supports (Pearlin et al., 1996). Methodological and conceptual problems cause a great variety of findings for these models.

Studies of social support primarily center on three issues: the range of social ties that are relevant to support, the relative importance of social relationships and behaviors versus the individual's perception of these, and the forms that support might take (Vaux, 1988). Although the forms and types of support caregivers receive from their network varies greatly, most forms of support can be categorized as either instrumental or expressive support (Pearlin et al., 1996). Instrumental support refers to services and resources to help with caregiving demands. Expressive support is the actions, gestures and words that engage the caregiver's thoughts, feelings, and perceptions (Cohen & Wills, 1985). Both types of support can be divided into formal or informal support.

Research has demonstrated that the adequacy of social support is directly related to the reported severity of psychological and physical symptoms (Zimet, Dahlem, Zimet, & Farley, 1988). Greater amounts of support reduce caregiver burden and increase well-being (Given, Stommel, Collins, King, & Given, 1990; Stommel, Given, & Given, 1990). Pearlman et al. (1996) found that more than 60 percent of caregivers report that there is "no one who regularly helps to look after the impaired relative" (pp. 285). Clipp (1990) found that caregivers who continued to maintain their social network through telephone calls, visits with friends and family, and club attendance reported high instrumental support. Conversely, caregivers who report low social networks through these variables also reported low instrumental support. Furthermore, research has shown that the type of support has an effect on caregiver burden. For example, Dwyer and Miller (1990) found

that informal networks such as family and friends generally reduce the amount of burden. Barusch and Spaid (1989) found that formal sources such as paid providers do not necessarily reduce burden, however, this has been contradicted in later studies by McMillan (1996) and Given (2001).

Occasionally, social support is unhelpful. It may not be the result of willful hurting of one person by another, but in fact may occur because of unsuccessful attempts at support (Pearlin et al., 1996). For example, a neighbor may provide misguided advice or have inappropriate timing for offering support. Support is usually given when one perceives the presence of need for support. Pearlin et al. (1986) found that caregivers often mask their problems from others. This is especially common among spousal caregivers who want to shield their adult children from knowing the extent of their own hardships or the extent of the patient's illness (Pearlin et al., 1996).

Caregivers who have difficulty arranging respite care or feel their social support network is not helpful may be at increased risk for distress. George & Gwyther (1986) and George (1987) found an inverse relationship between caregiver burden and satisfaction with support received. Social support may increase caregivers' health outcomes, but also may cause stress for the caregiver if there is conflict within the support network (Vrabec, 1997). Other studies have shown that greater conflict in the caregiver network increases burden and depression (Kiecolt-Glaser, Dyer, & Shuttleworth, 1988).

#### Caregiver isolation

Chang et al. (2001) found that caregivers who were married had less difficulty arranging support, while caregivers who were handling more roles such as employment

and caring for other dependents had more difficulty arranging help. Female caregivers and married caregivers reported more frequent contact with members of their social support network (Chang et al., 2001). Isolation, however, is a common problem for caregivers. Pearlin et al. (1996) reported that about 60 percent of caregivers reported seeing friends once a month or less. Among caregivers with relatives in the area, about one-third reported seeing relatives once a month or less (Pearlin et al., 1996).

Isolation is the deprivation of social contact and content. It implies barriers to interaction. Voluntary isolation occurs when an individual disengages himself from society (Bennett, 1980). For the hospice caregiver, voluntary isolation may be the result of refusing to allow others to care for a loved one. Involuntary isolation is the result of physical deterioration coupled with the death of a spouse and/or other peers (Bennett, 1980). A caregiver may be involuntary isolated because she does not have readily available respite care for the hospice patient and is therefore unable to maintain her social network. For the hospice caregiver, isolation may begin during the caregiving process and may continue even after the death of the caregiver's loved one. Studies have shown that isolation and lack of connectedness to others are predictors of morbidity and mortality (LaVeist, Sellers, Elliott Brown, & Nickerson, 1997; Rowe & Kahn, 1997). Isolation, coupled with other stresses associated with caregiving, could pose a serious health risk for caregivers.

While isolation and loneliness are not the same thing, isolation often leads to feelings of loneliness. Isolation, as noted earlier, is often defined as having few contacts with family and friends, while loneliness is an unwelcome feeling of lack or loss of companionship (Townsend, 1973). Weiss (1973) even referred to loneliness as emotional

isolation. The effects of isolation and loneliness may be reversible through resocialization and communication (Rathbone-McCuan & Hashimi, 1982).

Clipp and George (1990) found that female caregivers also were most often in situations of high support and male and older caregivers were most often in low support. Furthermore, they found low-income caregivers had low support and caregivers with low life satisfaction also had low support. Interestingly, however, they found that spouse caregivers providing care at home were likely to have low support, while adult child caregivers noted an increase over time (Clipp & George, 1990). This suggests that those in most need of support, older adults, caregivers providing in-home care and those with low income and low life satisfaction, are also the ones receiving the least support. Rapp et al. (1998) found that older adult caregivers who were able to create and be a part of helpful social relationships reported better perceived health, less depression, more perceived benefits of caregiving, and a better quality of life.

Race plays a role in determining social support of caregivers. Miller and Guo (2000) found that white men and women caregivers reported adult children and friends/neighbors as their largest source of support. African American women also mentioned adult children and other relatives as the largest source of support, while African American men were more likely to rely on friends and neighbors. White caregivers reported larger support networks than African Americans, and were more likely to use formal resources (Miller & Guo, 2000).

#### Role of technology in social support

Research has begun to explain how new technologies may support or hinder social networks. In the much-publicized "Internet Paradox" study, Kraut et al., (1998)



found that the Internet actually decreased the size of the individual's social circle and increased the individual's depression and loneliness. This study has been widely criticized, however, and Larose, Eastin, & Gregg (2001) in fact found Internet communication with friends can alleviate depression. In a replication of the "Internet Paradox" study, Wastlund, Norlander, & Archer (2001) found that no variables used to measure psychological well-being were correlated with any variable measuring Internet usage. Communication, including contact with neighbors, friends, and family, and participation in social groups improves social support and well-being (Cohen & Wills, 1985; Diener, Suh, Lucas, & Smith, 1999). If communication is a user's major reason for using the Internet, it follows then that the Internet should have positive social effects on the user's life. In a follow up to the "Internet Paradox" study, (Kraut et al., 2002) found that any negative effects of using the Internet had dissipated. In fact, the researchers found that participants experienced positive effects on communication, social involvement, and well-being from using the Internet. Using the Internet did, however, have better outcomes for extraverts and those with more social support but worse outcomes for introverts and those with less support.

Researchers at the University of Washington found that Internet newsgroups and chat rooms function like offline public places in which people meet and form friendships (Parks & Roberts, 1998). Friendships formed online were no less valuable than face-to-face ones, and a significant number of them moved from virtual to physical acquaintance. Studies have shown, however, that heavy e-mail users have weaker social relationships than those who do not (Riphagen & Kanfer, 1997), and heavy Internet users spend less time communicating with family members (Cole, 2000). Other studies, however, have

found that heavy Internet users report *more* social support and more in-person visits with family and friends than those who use it less (Project, 2000). Walther and Boyd (2002) found that online social support has a number of attractions to users, including availability at any time and anonymity to others.

Social support has been shown to have a positive effect on health or illness outcomes (Rowland, 1989), and has been linked with compliance with medical treatment (Levy, 1983). The benefits of improved mental and physical health from modified social support suggest that social support is an area that may be easy, effective, and economical in which to intervene (Rowland, 1989). Interventions to increase social support for caregivers do not take place in a vacuum, however. Researchers and clinicians attempting to provide innovative ways to increase social support must deal with economic and political system surrounding health care in this country.

#### Health Care Policy and End-of-Life Care

Health care policy can either support or impede options for providing innovative care to patients at the end of life and their families. According to the National Hospice Work Group (2002), policy makers must address issues regarding patient enrollment in hospice, hospice enrollment review process, a rural hospice waiver, and financing of pain medications. As for telemedicine, the technology behind the service is advancing faster than the laws that apply to its use. Three broad issues regarding regulation of telemedicine are quality of care, access to services, and cost (Volker, 2000; Whitten, 2001).

## Telemedicine policy

Regulation of the *quality of care* of telemedicine involves licensure, and medical malpractice, among others. Licensure is a state-based patient protection system (Volker, 2000; Whitten, 2001). Because telemedicine has the potential to involve service across state lines, state cooperation or federal regulation must be considered. The Federation of State Medical Boards of the United States, Inc., proposes a limited license for physicians who "regularly or frequently" practice telemedicine (Whitten, 2001). The American Medical Association, on the other hand, proposes that states require a full license for all physicians practicing telemedicine within a state (Whitten, 2001). Professional medical organizations have other recommendations for physician licensing standards. Nurse licensing must also be addressed for widespread use of telemedicine.

The threat of malpractice action is another issue which impacts the widespread use of telemedicine. Malpractice liability is a potential concern for practitioners already dealing with complicated issues due to technology. Telemedicine may in fact affect a patient's quality of care, and the use of technology itself could lead to malpractice liability suits. There is no evidence so far, however, that malpractice claims have increased as a result of telemedicine (Volker, 2000). In fact, telemedicine may reduce the incidence of malpractice by bringing care to a patient who might not otherwise have healthcare. Volker (2000) suggests that informed consent may be a more feasible approach to regulating telemedicine. A patient needs to be advised of possible alternatives and enough information provided that would enable the patient to make an informed decision.

*Access* is another issue which must be considered from both a state and federal viewpoint. At the federal level, the 1996 Telecommunications Act requires the FCC to ensure that rural health care providers have access to essential telecommunications systems to deliver services at rates comparable to those offered in urban areas (Volker, 2000). Each state shares the responsibility for implementing the Act. Regulating software and hardware is another potential deterrent to the diffusion of telemedicine. Currently the FDA is responsible for regulating telemedicine devices. While the FDA has taken a proactive approach in this area, the guidelines they rely on are vague and ambiguous (Volker, 2000). Finally, patient privacy and confidentiality must be protected during telemedical exchanges. The use of telemedicine often increases privacy concerns because of the transmission and storage of personal information. During a telemedicine consult, for example, the patient's records and medical history will be shared with consulting physicians and staffs supporting the telemedicine system (Volker, 2000). Without privacy protections, telemedicine will not be considered a viable treatment alternative. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) required the Department of Health and Human Services to develop regulations relating to privacy standards (Whitten, 2001). Entities related to the provision of health care must comply with HIPAA by April 2003. The Bush Administration, however, has proposed to repeal the privacy provisions of HIPAA (Pear, 2002).

*Regulating cost* is another primary concern for the successful widespread implementation of telemedicine. The issue of paying for telemedicine is a complex issue. The search for cost containment solutions to rising health care costs signal a strong future for telemedicine (Volker, 2000). As the population ages and medical science continues

to prolong life and cure disease, there will be more chronic conditions needing treatment. Telemedicine has the potential to address these needs. Medicare has traditionally covered telemedicine services that do not involve face-to-face interaction with patients (Whitten, 2001). Medicare now covers consults in professional shortage areas. Home health visits also pose a unique challenge for reimbursement. Medicare authorizes home health care agencies to use telemedicine as part of their services, however, telemedicine consults are not considered visits for purposes of payment (Whitten, 2001). Medicaid regulation is determined on a state-by-state basis. Telemedicine is covered under Medicaid in about 20 states (Whitten, 2001).

#### Hospice policy

The high cost of medical care for the dying raises concerns for families facing the death of a loved one. Families and care providers are seeking innovative ways to provide the highest caliber care to patients while containing costs. This is especially important for families in rural areas. Many people in rural areas are self-employed or work for small, privately owned business, and may have limited, if any, health insurance (Vrabec, 1995). People in rural areas often rely on informal networks of family and friends for assistance with health care needs (Vrabec, 1995). According to Vrabec (1995), older adults in rural areas use fewer formal services because of several barriers: 1. Inadequate financing of rural health centers; 2. Lack of awareness of existing services; 3. Decreased availability of health care providers and 4. Geographic distance from services.

Providers who attempt to provide comprehensive care for patients facing fatal illness must work through complex reimbursement structures (Fowler & Lynn, 2000). Approximately 75 percent of deaths occur while the patient is in the Medicare system,

and reimbursement rules differ for acute settings from long-term care facilities to home health to physician visits to hospice (Fowler & Lynn, 2000). Consequently, providers may not know how to bill for appropriate care when a patient is expected to die. Hospice care, however, is seen as a cost-effective alternative to the high costs of hospitals and traditional institutional care (HAA, 2002a). Much of the savings is realized because families provide general services such as meals and personal care. Forty-five states also offer hospice care as an option under Medicaid, and hospice is covered under most private insurance plans, HMOs, and other managed care organizations (HAA, 2002a). Hospice agencies also rely heavily on grant and community money to support unreimbursed care for patients with no insurance (HAA, 2002a).

Hospice users tend to be older than the general Medicare population (Gage, 2000). Approximately five percent of hospice users in 1996 were younger than 65, compared to 12 percent of all beneficiaries (Gage, 2000). Nearly 40 percent were between 75 and 84 years old, and more than 25 percent were at least 85 years old, compared to only 10 percent of the total Medicare population. It is estimated that nearly half of Medicare expenditures are used for care of eventually fatal illnesses (Fowler & Lynn, 2000). The Medicare Hospice Benefit was implemented in 1983 and is primarily based on a *per diem* rate—the home care hospice rate multiplied by the number of days on service (Fowler & Lynn, 2000). In the late 1980's the Medicare hospice population dramatically increased, due in part to Congressional mandate to increase reimbursement rates by 20 percent (HAA, 2002a). In 1996, hospice expenditures from Medicare totaled \$2 billion, up from \$8 million in 1984 (Gage, 2000). The number of hospices

participating in Medicare increased from 31 in 1984 to nearly 3,000 in 2000 (HAA, 2002a).

Hospice reimbursement under Medicare is quite comprehensive, often including most prescription drug costs, but is limited to people with a prognosis of less than six months to live and avoiding hospitalizations and high-tech interventions (Fowler & Lynn, 2000). Under the Medicare Hospice Benefit, patients elect to receive non-curative treatment and services by waiving the standard Medicare benefits for treatment of a terminal illness (NHF, 2002a). While receiving hospice services, Medicare will continue to pay for treatment of health problems not related to the terminal illness (NHF, 2002a). Patients are eligible for hospice benefits under Medicare for two 90-day periods, followed by unlimited 60-day periods. The patient must be certified as terminally ill at the beginning of each period (HospiceNet, 2002). A recent report from the Institute of Medicine calls on policymakers, providers and the public to embark on a variety of measures to improve end-of-life care (Medicine, 1997), including developing "better tools and strategies for improving the quality of care" (p. 8). Furthermore, recent recommendations to the Medicare Payment Advisory Commission (MedPAC) include revisiting the definition of prognosis for hospice referrals (Von Gunten, Ferris, D'Antuono, & Emanuel, 2002).

Currently only limited benefits for caregivers are specifically designated by the Hospice Medicare Benefit: respite care, chaplain services, and bereavement counseling. "Respite care may be provided in a Medicare-approved facility such as a freestanding hospice facility, a hospital, a nursing home or other long-term care facility, which is covered by Medicare for up to five days at a time" (NHF, 2002a). To facilitate caregiver

well being and quality of life, it is important to consider additional services for them. For caregivers in rural areas, however, accessing support networks may be difficult.

Communication technologies could play an important role in providing access to friends, family, and other supportive individuals.

### Communication Technologies

Studies of the introduction of the telephone suggest that it solidified and deepened social relationships (Fischer, 1992). What the telephone did in the 1920s, new communication technologies can do in the new millennium. Advances in technology in recent years have expanded the options for using new communication technologies for providing home healthcare. As noted earlier, telemedicine, the use of telecommunication technologies to deliver health services over a distance, may be one means of potentially alleviating the stress on caregivers.

### History of Telemedicine

As early as the 1950s, innovative applications of telemedicine were being tested. Wittson and colleagues used telemedicine in 1959 when they set up telepsychiatry consultations via microwave technology between the Nebraska Psychiatric Institute in Omaha and the state mental hospital 112 miles away (Jones & Colenda, 1997; Wittson , Affleck & Johnson, 1961; Whitten & Gregg, 2001). Groundbreaking teleradiology work was attempted that same year in Montreal, Quebec, by Jutra (1959).

The 1970s included a flurry of telemedicine activity as several major projects developed in North America and Australia (Whitten & Gregg, 2001). Although none of these projects survived after external funding was withdrawn, program evaluations suggest that the equipment was reasonably effective at transmitting the information



needed for most clinical uses and that users were for the most part satisfied (Dongier, Tempier, Lalinec-Michaud & Meunier, 1986; Conrath, Puckingham, Dunn & Swanson, 1975; Fuchs, 1974; Murphy & Bird, 1974).

A series of telemedicine pilot projects were demonstrated in the 1960s, 1970s, and 1980s (Whitten & Gregg, 2001). The 1990s, however, exhibited incredible growth in telemedicine. In 1990, there were four active telemedicine programs. By 1997, there were almost 90 such programs (Grigsby & Allen, 1997). Many of these programs were created because of clinical need (Whitten & Gregg, 2001). For example, the program at the University of Kansas was originally proposed by rural practitioners who required access to certain medical subspecialties (Allen, Cox, & Thomas, 1992).

In the early 1990s, new and fairly inexpensive digital technologies became available that enabled video, audio and other imaging information to be digitized and compressed (Whitten & Gregg, 2001). This facilitated the transmission of information over land lines with relatively narrow bandwidths, instead of through the more expensive satellite or relatively unavailable private cable or fiber optic lines. Technological enhancements in recent years have further expanded the telemedicine paradigm. Telemedicine providers have a wide range of choices for the equipment and delivery structures they can develop for provision of care.

#### Technical specifications

Traditionally telemedicine analysts have looked at telemedicine services in relation to the level of interactivity inherent in the service (Whitten & Gregg, 2001). In the past, this has often meant the amount of bandwidth available. A traditional analog telephone line can transmit audio signals at a rate of 64 kilobits per second (kbps). This

is quite adequate for audio transmission, but when one wishes to send additional information such as video signals, additional bandwidth is needed to make the transmission smoother (Whitten & Gregg, 2001). Recent developments in telecommunications, however, are reshaping the way bandwidth is viewed. For example, the availability of new transmission services such as cable modems, ISDN, and DSL are reshaping the amount of bandwidth available for telemedicine applications (Whitten & Gregg, 2001).

Telemedicine services are typically delivered in three formats: store and forward, Internet, and synchronous interactive video (Whitten & Gregg, 2001). During a store-and-forward application, a piece of health data is collected and transmitted to a medical provider who retrieves the information, analyzes it and responds at his or her convenience (Whitten & Gregg, 2001). Common store-and-forward applications include teleradiology, teledermatology, and telepathology. Store and forward telemedical services are the least interactive of the three modalities.

Internet medicine is now one of the fastest growing segments of health care (Whitten & Gregg, 2001). It can be interactive, such as chat rooms where multiple participants are on-line discussing an issue, or simply an information service from which users download information. Medical services provided over the internet include medical equipment and supplies, clinical services, health insurance, medication, alternative medicine, and health information and continuing education (Steinfeld, Whitten and Kingsley, 1999).

Interactive video (ITV) telemedicine services are fully interactive (Whitten & Gregg, 2001). In these cases, medical care and education are conducted between two or

more parties that are both physically present in front of some form of ITV equipment. They can see and hear each other in real time and even share documents from which they are working. Videoconferencing can occur on room-based systems running at very high transmission speeds or can occur from a desktop personal computer at lower speeds. There are even videoconferencing technologies that can run through traditional analog phone lines. Within this category are traditional notions of telemedicine: a physician in a city treating a senior citizen located hundreds of miles away where he or she would not have access to this type of physician (Whitten & Gregg, 2001).

#### Potential for enhancing social support

On-line networks have the potential to minimize isolation and loneliness and provide opportunities to meet people with similar interests (White, McConnell, Clipp, & Bynum, 1999). New technologies have been used successfully to provide support to a variety of users. Whitten, Collins et al., (1998) found that telehealth equipment could be installed and used to see patients in their homes. Patients perceived the system as a valuable resource felt that the technology lived up to their expectations. The CHES project at the University of Wisconsin, Madison, is a computer-based system designed to help individuals cope with a health crisis or medical concern (CHES, 2000a). CHES, or Comprehensive Health Enhancement Support System, combines various services and resources into one system so patients can easily access information and other support services as needed. Research has shown that CHES improves the quality of life for patients, improves emotional well being, and improves the relationship between patient and physician (CHES, 2000b).

Similarly, teleconferencing has been used to support isolated rural women undergoing treatment for breast cancer (Curran & Church, 1998). This study found that patients were satisfied with the teleconferencing technology and that the technology itself was not a deterrent or inhibiting factor for the self-help support group. Furthermore, respondents favorably compared the teleconferencing support group to face-to-face support groups in terms of group cohesion, formation of strong emotional and personal bonds among participants, and development of positive self-image. The authors concluded that teleconferencing could help satisfy the needs of isolated rural breast cancer survivors.

Patients of Kaiser Permanente Medical Center liked using a home video system, found it simple to use, and stated that it felt very reassuring (Johnston, Wheeler, Deuser, & Sousa, 2000). Furthermore, staff satisfaction using the system was very high. In Germany, elderly people were connected via a broadband video communication system to a telecare center. The system, known as the TeleCommunity, was designed to allow elderly and mobility-impaired people to live independently while reducing the demand on social service resources (Erkert, 1997). Patients reported positive satisfaction with the system and considered it an “irreplaceable enrichment to their lives.” For many of the elderly clients, the system gave them a feeling of security and involvement. They reported it was important for them to know daily contact was available to them if needed.

In Japan, videophones using full-color motion pictures and sound have been used to assess at-home rehabilitation programs of the disabled elderly. Use of the videophone increased the communication abilities of older persons, stimulated the patients’ attention, and improved their comprehension and expression. While these results are physical and

cognitive, rather than emotional, the videophone improved patients' self-esteem and sense of belonging to society (Takano, Nakamura, & Akao, 1995).

Seniors in isolated areas have used communication networks to communicate with people their own age through electronic mail, computer bulletin boards and computer forums, on a wide variety of topics (Elmer-Dewitt, 1990). Use of the Internet and e-mail has also been shown to have positive effects on seniors in nursing homes (McConatha, McConatha, Deaner, & Dermigny, 1995; McConatha, McConatha, & Dermigny, 1994). On-line networks can provide an opportunity to communicate on emotional and social issues that are particularly relevant to older adults (Furlong, 1989).

Telecommunication technologies have the potential to address barriers to accessing support services for hospice caregivers. To date, however, telemedicine has been used to support the care of patients. This dissertation addresses the feasibility of groundbreaking care for families and other caregivers. Hospice care has been successfully delivered directly into a patient's home via telehealth (telehospice) for clients in underserved rural locations and for those with limited caregiver support (Doolittle, Yaezel, Otto, & Clemens, 1998; Doolittle, 2000). Whitten, Cook, and Doolittle (1998) found that caregivers perceived that telehealth might improve access and conceivably decrease costs for hospice patients. Furthermore, users were generally satisfied with the telehospice system, and nurses and social workers acclimated to the video calls (Doolittle et al., 1998). Telehospice allowed the nurses to visit and treat patients without leaving their home/offices (Doolittle et al., 1998), reinforcing the advantages of not having to drive long distances in rural settings. Doolittle et al. also

examined the cost concerns of telehospice, and for traditional hospice services the cost was approximately \$135 per visit while the telehospice visit was \$29 (Doolittle, 2000).

A telehospice pilot program on West Prince Edward Island, Canada, is evaluating the effectiveness of home-based technology in the provision of palliative care to patients in rural and isolated communities (OHIH, 2001). Though the hospice infrastructure is less formalized in Canada than in the US, data from this project suggest telehospice is a useful tool to supplement volunteer services.

Finally, a bi-state Kansas and Michigan telehospice project addresses the issues of cost, access implications, and delivery of telehospice service in both rural and urban settings. Hospice providers are highly satisfaction with the telehospice equipment, specifically in terms of increasing access to patients, delivery of hospice care, and overall enjoyment of the telehospice visits, and felt a high comfort level while using the telehospice equipment (Whitten & Doolittle, 2002; Whitten, Doolittle, Hellmich, & Cook, 2000). Hospice patients reported that telehospice increased their access to their provider, especially during the night hours or in case of an emergency. Further, caregivers reported that an increased level of comfort was associated with the equipment due to the video component of the service, suggesting that the equipment could be used to enhance social support to caregivers.

### Summary

In summary, social support plays in important role in the lives of caregivers of hospice patients. However, for caregivers in rural areas, accessing those most important to them may be difficult or even impossible. The use of communication technologies could prove to be an innovative way to address issues of caregiver health and well-being.

This study posits that to fully understand the role that communication technologies could have in the lives of caregivers in rural areas, one must understand the importance of social support to caregivers and the political and economic context in which caregiving at the end-of-life takes place. Therefore, the primary objectives of this research are (1) to understand the needs of hospice caregivers in rural areas and (2) to make healthcare policy recommendations for using technology to enhance support to hospice caregivers. These objectives will be met through a series of specific research questions designed to address the issues at hand.

- **RQ1: What do hospice caregivers perceive as their sources of social support?**
- **RQ2: What is the relationship between perceived social support and the caregiver's quality of life?**
- **RQ3: What is the potential for telehospice to address caregiver needs?**
- **RQ4: What legislative and regulatory mandates are in place that affect delivery of mediated social support? What changes will be necessary to facilitate use of communication technologies to support hospice caregivers?**

## CHAPTER 3

### METHODOLOGY

Choosing the appropriate research strategy for collecting and analyzing empirical evidence is crucial to completing any research project. Each strategy, an experiment, a survey, a case study, etc., has its own advantages and disadvantages. One strategy is not inherently better than another, although one particular strategy may be more appropriate in a given situation. Choosing the most suitable strategy can be based on 1) the type of research question being asked; 2) the extent of control an investigator has over actual behavioral events; and 3) the degree of focus on contemporary as opposed to historical events (Yin, 1989, 1994). When a study focuses on exploratory "what" questions, as this one does, the goal is to develop pertinent hypotheses and propositions for further study. The current research is a case study which uses social support theory as a guide to investigating the help that caregivers of hospice patients receive from their support network. Furthermore, this case uses policy analysis techniques to prescribe legislative and regulatory changes necessary to make telemedicine successful in providing support to hospice caregivers. According to Yin (1989), "a case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (p. 23).

After choosing the appropriate strategy it is necessary to determine a plan, or research design, for the study. The research design, in effect, is a plan for getting from *here* to *there*, where *here* is the set of questions to be answered, and *there* is some set of conclusions (Yin, 1994). The main purpose of the design is to address what questions to



study, what data are relevant, what data to collect, and how to analyze the results (Yin, 1994).

For the case study on rural caregivers, this investigation centers on each participant's experiences as a hospice caregiver. The purpose is to get at the main significance of the experience to individuals when they discuss their social support network and the effect being a caregiver has had on their quality of life. To achieve this goal, a topic-centered narrative was gathered to enable the researcher to identify major themes, concerns and experiences that relate directly to the individual's adjustment to becoming a caregiver. Data for part I of this project were gathered through semi-structured interviews with hospice caregivers. The use of open-ended questions enabled the participant to describe individual experiences in a coherent manner (Agar, 1980; Agar & Hobbs, 1985), a "key-informants" approach for collecting data (Pelto & Pelto, 1979). Key-informants are selected because they are knowledgeable about the topics being researched. They are also able and willing to communicate their knowledge (Kumar, Stern, & Anderson, 1993). According to Borg and Gall (1989), using the key-informant approach has many advantages. Key-informants can "provide insights that no amount of observation would reveal. They can also provide insights into processes, sensitize the researcher to value dilemmas, and help the researcher see the implications of specific findings" (p. 399).

For the policy analysis section of this research project, data were gathered through analysis of documents and interviews with pertinent people involved in hospice governance. The National Hospice Work Group provided archival data related to hospice regulation and proposed changes to the Medicare Hospice Benefit. Law articles and

research reports related to telemedicine were also used as archival data. Gloria Dana, governmental affairs director for Hospice of Michigan, provided information directly related to hospice care in the state of Michigan, Ken Drees, technical assistance director for the National Hospice and Palliative Care Organization provided background information regarding Medicare and Medicaid funding for hospice, as did Ted Feaster of the Chicago Regional office of the Center for Medicare and Medicaid (CMS). Finally, Sally Newman of the Family Caregiver Alliance provided information about grassroots efforts to expand services to caregivers nationwide.

### Subjects and sampling

#### Hospice caregiver case study

To carry out this study, a purposive sampling technique was used. The population for part I of this project was English-speaking caregivers of cancer patients living in rural Michigan who were enrolled in Hospice of Michigan in the last six months. As noted earlier, cancer is the dominant diagnosis in the hospice population. Because of such prevalence of cancer among hospice patients, the current project is limited to caregivers of cancer patients. As part of the requirements of the University Committee on Research Involving Human Subjects (UCRIHS), one hundred letters to potential participants were mailed from Hospice of Michigan two weeks prior to telephone interviews. However, due to the nature of hospice care, one-third of the potential participants had died within the two weeks before telephone calls could be started. Therefore, fifty-one subjects were successfully recruited through the research and regional offices of Hospice of Michigan. Telephone interviews took place over a three-week period in May 2002.

Hospice of Michigan (HOM) is one of the largest nonprofit hospice programs in the United States, serving more than 7,000 patients a year in 45 Michigan counties (HOM, 2002a). HOM is licensed by the State of Michigan and is certified by Medicare, and offers a full range of medical and support services (HOM, 2002a). Services include physical support such as pain management and symptom control; emotional and spiritual support; grief support for families and friends after the loved one's death; volunteer services for respite care, household chores, listening; and financial assistance regardless of the patient's ability to pay (HOM, 2002b). HOM provides 85 percent of care in the patient's or family's home, at one-third the cost of traditional care (HOM, 2002b). Research shows that nearly 90 percent of HOM patients experience a decrease in the pain level within 36 hours of admission (HOM, 2002b).

Hospice of Michigan was originally founded in 1980 as Hospice of Southeastern Michigan until its merger in 1994 with nine other hospices (HOM, 2002b). It is the oldest and largest hospice program in Michigan, and serves a wider geographic area than any other nonprofit hospice in the country (HOM, 2002b). It provides 25 percent of all hospice care in Michigan, and has more than 500 full- and part-time employees, and 900 volunteers (HOM, 2002b). HOM is one of only a few hospices in the world with a dedicated pediatric team, and was the first hospice in Michigan to care for patients with AIDS (HOM, 2002b).

### Policy analysis

Data regarding cost and reimbursement of telehospice was primarily obtained from Federal documents related to the Medicare Hospice Benefit and from interviews

with relevant experts. Experts also provided information regarding licensure and liability.

### Data Gathering Procedures

#### Hospice caregiver case study

Approval from the University Committee on Research Involving Human Subjects (UCRIHS) was obtained prior to interviewing. Before data collection, participants were assigned a code number, and were sent a letter briefly describing the project. At the start of each interview the caregiver gave verbal consent to continue the interview. Furthermore, they were reminded of their right to refuse to participate at any time during the interview. No names or identifiers that could single out a caregiver were used. Participants were assured confidentiality. Each interview took approximately ten to twenty minutes, and was conducted from the researcher's office at Michigan State and from the researcher's home, primarily because they occasionally took place in the evening and on weekends.

Because participants were asked open-ended questions about their experience as a hospice caregiver, and due to typically low response rates of mail surveys, telephone interviews were used as the primary data collection method when working with caregivers. Previous research has shown that there are few consistent differences in data quality between in-person and telephone interviews (Lavrakas, 1998). There are several advantages to using telephone interviewing. For example, the equipment is readily available and relatively inexpensive; there are no travel costs associated with the method, and the minimal long-distance charges are much less expensive than travel costs. Finally, the interviews were conducted at the convenience of the caregivers, based on the

availability. There are a few risks when conducting telephone interviews that must be addressed. For example, there could be unexpected and unexplained disconnections. Telephones may strengthen confidentiality, but also limits the interview's knowledge about the participant's affect. Finally, the length of the interview is necessarily shorter than face-to-face interviews because most people do not want to spend long periods of time on the telephone. Despite the lack of indications of affect, the telephone interviews did communicate the personal and sensitive aspects of the caregivers' perspectives more clearly than using only numerical data from standardized instruments.

Caregivers were asked to describe what they perceive to be their sources of support through a series of open- and closed-ended questions. The open-ended questions allowed the caregiver to volunteer information he or she thought appropriate and was not led or biased by the interviewer. One problematic area with open-ended questions is getting the respondent to give full detailed responses (Seidman, 1998). To address this concern, probes were developed to encourage caregivers to continue, amplify or clarify an answer. An interview guide was developed to assist in collecting the data from the interviews. The interview guide was divided into the following four sections:

1. Caregiver Quality of Life Index (CQLI). The CQLI (McMillan, 1996b) was designed for use specifically with hospice caregivers and consists of four items that assess emotional, social, financial and physical quality of life. Each item is rated from 0 (lowest quality) to 100 (highest quality), though a modified 10-point scale was used to facilitate telephone interviewing. Empirical data have supported both the validity and reliability of the scale (Salek, 1998). Internal consistency of the index ranges from .76 to .88. See Appendix A for items of the CQLI.

2. **Multidimensional Scale of Perceived Social Support (MSPSS).** It is undisputed that those providing informal care to an ill or disabled older adult are vulnerable to burden and psychological distress. However, perceived social support can reduce the detrimental effects of stress on psychological or emotional well being (Atienza, Collins, & King, 2001). Research suggests that perceived social support is far more related to predicted outcomes than the actual support received (Huff, 2001). The MSPSS (Zimet et al., 1988) was designed to assess perceptions of social support from family, friends, and significant others. It consists of 12 items measured on a 7-point rating scale ranging from *very strongly disagree* (1) to *very strongly agree* (7). Reliability for the scale is .88, and the test-retest reliability for the scale is .85, demonstrating good internal reliability and adequate stability over time. See Appendix B for items of the MSPSS.

3. **Open-ended questions.** Open-ended questions were used to give participants an opportunity to elaborate about the challenges of being a caregiver, details of their social support network, and the effect caregiving has on their physical and emotional health. See Appendix C for open-ended questions asked during telephone interviews.

4. **Sociodemographics.** Sociodemographics were used for comparison between caregivers of similar and different backgrounds. See Appendix D for sociodemographic questions asked during telephone interviews.

Each participant received a letter giving a brief description of the study two weeks prior to the telephone interview. Subjects were then called and verbal consent for the interview was obtained. The researcher conducted the telephone interviews during May 2002, using the guide to focus the data-collection process. Flexibility was retained to

probe into each participant's statements and replies and to pursue additional issues related to the focus of the study that were not included in the interview guide. Extensive notes were taken during each interview. The interviews lasted from 5 to 15 minutes, with an overall average of 10 minutes.

Through telephone interviews, extensive data were collected in order to produce an in-depth understanding of the current status of caregiver quality of life and access to support services in rural Michigan. The data provided by the participants consisted of words in the form of rich verbal descriptions (qualitative data) as well as quantitative data. The use of quantitative data allows for comparison of this data with previous studies of social support, and comparison between measures.

### **Policy Analysis**

Part II of this project is the policy analysis of current regulations as they pertain to providing social support services to hospice caregivers, and making recommendations for providing enhanced services to caregivers. Policy analysis is a social, as well as political, activity that is more art than science (Bardach, 2000). It involves personal decision-making that draws on intuition as much as method. It goes well beyond taking intellectual responsibility for the quality of the work, however. The subject matter of a policy analysis concerns the lives and well-being of a large number of people (Bardach, 2000). Also, the process and results of the analysis involve other professionals and interested parties. These parties contribute to a quality product. Bardach (2000) provides an eight-step framework for successfully conducting a policy analysis. The first two steps, defining the problem and assembling the evidence, pertain directly to this section of Chapter 3, data gathering procedures. They will be addressed in Chapter 4, Results. The

final six steps, described below as part of data analysis, will be addressed in Chapter 5 as they pertain to implications of the project and recommendations for policymakers.

- **Definition of the problem--**Defining the problem is a crucial step in a policy analysis. It gives the researcher a reason for doing the work and a sense of direction for gathering evidence. It is a deceptively simple step subject to two dangerous pitfalls (Bardach, 2000). The first hazard is implying a solution when defining the problem. "Projected solutions must be evaluated empirically and not legitimated merely by definition" (Bardach, 2000) (p. 5). For example, to say "Federal regulations prohibit access to services for caregivers in rural areas" implies that the solution to access for caregivers is to change federal regulations. This cannot be determined until the problem has been empirically studied.

The second concern when defining the problem is causal claims implied in diagnostic problem definitions. Causes of problems must be real, not simply assumed to be real. The causal chain that is alleged to cause the problem must be evaluated in order to determine if in fact the problem is actually a problem. For example, to say "Lack of social support causes a decrease in quality of life" implies that lack of social support is a problem. The situation must be evaluated to determine if there is a lack of social support in the lives of caregivers, and if it is in fact causing a decrease in their quality of life. In the current research, the problem is that caregivers of hospice patients are under considerable stress.

- **Assemble the evidence--**Gathering data that can be turned into evidence is one of the most time consuming tasks of a policy analysis (Bardach, 2000). Gathering data includes reading documents, hunting in libraries, poring over studies and statistics,



interviewing people, and so on. Unlike most social science research, part I of this dissertation for example, most policy research is derivative rather than original. Analysis is conducted on data and ideas already developed by others. The policy analyst is primarily charged with discovering, synthesizing and interpreting existing data.

Original data for the current project will be collected from interviews with legislative counsel at Hospice of Michigan and with national hospice experts. Existing data that will play a prominent role in the analysis include state and national government documents and current research pertaining to telemedicine, among others.

### Data Analysis

#### Hospice caregiver case study

Data from open-ended questions were then content analyzed, allowing the researcher to analyze the narratives according to established protocols for the project. Content analysis is a research technique for systematically examining the content of communications—in this instance, the interview data. Participants' responses to interview guide questions and related issues that arose during the interview process were read and filed according to the topic or issue addressed. The topic-centered narrative enabled the researcher to identify major themes, concerns and experiences that relate directly to the participant's role as a hospice caregiver. Namely, the information was sorted into categories. Responses were analyzed thematically with emergent themes ranked by how frequent they were mentioned and subsequently categorized.

Descriptive statistics from the closed-ended questions were analyzed using SPSS.

## **Policy analysis**

Using the Bardach (2000) framework, the final six steps for successfully completing a policy analysis are described below. These will be addressed in detail in Chapter 5, Discussion and Implications.

- **Construct the alternatives--**Alternatives are policy options or alternative courses of action to solve or mitigate the problem. In the early stages of analysis it is important to consider a variety of alternatives. Alternatives might be ideas of political actors, proposals of relevant institutions, political ideologies relative to the subject being studied, or interventions in the system that holds the problem in place or keeps it going. One alternative to be considered during analysis is the status quo, or the outcome if current conditions continue undisturbed. In later stages of the analysis, however, alternatives will be limited to three or four principal options. Bardach (2000) suggests creating a model of the problem in order to identify alternative solutions.

- **Select the criteria--**Criteria are evaluative standards used to judge the goodness of the projected policy outcomes associated with each of the alternatives. In other words, the criteria are the researchers value judgments and subjective standards applied to the projected outcomes. Selecting criteria requires the researcher to make judgments as to whether and why an outcome is desirable. Possible criteria include: (1) efficiency, an important evaluative consideration in cost-effectiveness and cost-benefit studies; (2) equality, equity, fairness and "justice"; (3) freedom and community. Some criteria are practical in nature and have to do with what happens to an alternative as it moves through the policy adoption process. These are generally categorized as legality, political acceptability, robustness under conditions of administrative implementation, and

improvability (Bardach, 2000). For example, a feasible policy must not violate constitutional or statutory law.

- **Project the outcomes--**Projecting outcomes is the hardest step in a policy analysis, and is often omitted altogether. This is the heart of the current case: projecting outcomes that might reasonably apply to providing support services to hospice caregivers.

- **Confront the trade-offs--**This requires clarifying trade-offs between possible outcomes associate with different policy options for providing support services to hospice caregivers. According to Bardach (2000), the most common trade-off is between money and service. In this case, the trade-off may be between cost and social benefit.

- **Decide--**This step involves making a decision based on the completed policy analysis. If the decision is difficult at this point, it may be an indication that further analysis is necessary.

- **Tell the story--**After completing the above steps, policy recommendations will be made so as to provide social support services to hospice caregivers.

## CHAPTER 4

### RESULTS

This study was descriptive in nature. The primary focus was to understand the social support networks of caregivers of cancer patients living in rural Michigan and the effect these support networks have on the caregivers' quality of life. This study then sought to understand how telecommunication policy impedes or encourages the role of new communication technologies in enhancing social support among caregivers.

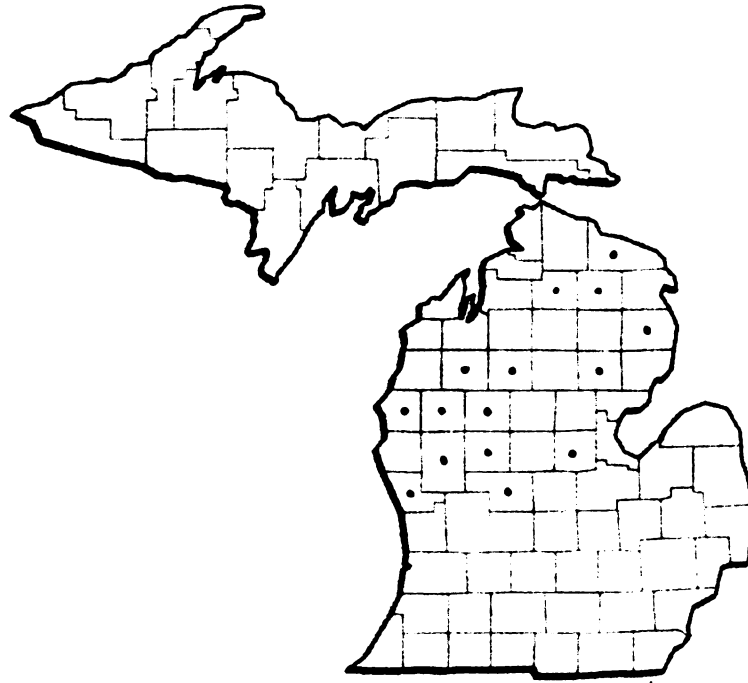
The purpose of this chapter is to report findings based on interviews with hospice caregivers and hospice policy experts, which provide rich and detailed information for the case study. Furthermore, reported here are findings from in-depth analysis of a variety of documents related to hospice and healthcare policy. The chapter begins with a discussion of the context in which the research took place. The remaining sections address the specific research questions which sought to understand the support networks of rural caregivers, the effect caregiving has on their quality of life, and what governmental policies are in place that impact the efforts of new technologies to mediate and enhance current caregiver networks. A discussion of the results follows in the final chapter.

#### Frame of Reference

The purpose of this dissertation is to examine the potential role of telehospice in providing support to caregivers of hospice patients. Medical care in the United States is at a crossroads. Providers are seeking ways to provide better service while containing cost. As noted earlier, Whitten and Hellmich (2000) and Whitten and Doolittle (2002) found that hospice providers were highly satisfaction with a telehospice pilot project,

specifically in terms of increasing access to patients, delivery of hospice care, and overall enjoyment of the telehospice visits. Providers were highly comfortable while using the telehospice equipment (Whitten & Doolittle, 2002; Whitten, Doolittle & Hellmich, 2001; Whitten et al., 2000). Furthermore, the hospice patients reported that telehospice increased their access to their provider, especially during the night hours or in case of an emergency. Telehospice has proven to be an innovative way to provide services to patients, and needs to be tested as a revolutionary means for supporting caregivers of patients at the end-of-life. Services for caregivers are languishing in a model ineffective at supporting healthcare in rural areas. In particular, telehospice may be a means of providing services to caregivers in rural areas, those who may not have access to services in any other way.

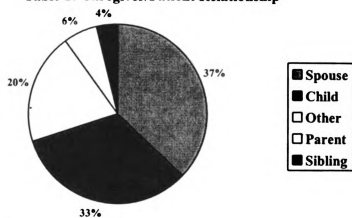
In order to better understand the current case, it is necessary to understand the context in which the research took place. The sample of participants was drawn from all primary caregivers who were English speaking and caring for a hospice patient with a cancer diagnosis in rural Michigan. Letters were sent to 98 potential participants from Hospice of Michigan two weeks prior to telephone interviews. Fifty-one subjects (52 percent of the original sample) were successfully recruited through the research and regional offices of Hospice of Michigan. Caregivers in this study received services through the Alpena, Big Rapids, Cadillac, Freemont, Gaylord, and Ludington offices of Hospice of Michigan. In all, caregivers were in 15 counties in Michigan; one caregiver was located in another state. See Figure 1.



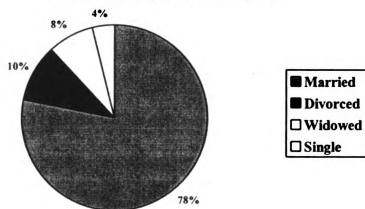
**Figure 1: Map of Michigan detailing rural counties participating in the study.**

Eighty percent of the caregivers were family members; nearly 40 percent of the caregivers were spouses, while slightly more than a third of the caregivers were the patient's adult children. Nearly 80 percent of the caregivers were women, slightly higher than the national average at 73 percent (NAC & AARP, 1997). The average age of caregivers in this study was between 51 and 60 years old. The youngest caregiver was in her 20s while the oldest caregiver happily reported she would be 91 in two weeks. Nearly 80 percent of the caregivers were married, more than 95% were Caucasian, and the large majority (70 percent) had a high school education. Tables 1-5 demonstrate the demographic breakdown of the hospice caregivers.

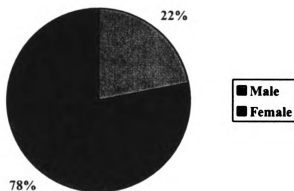
**Table 1: Caregiver/Patient Relationship**



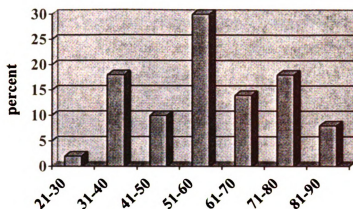
**Table 2: Caregiver Marital Status**



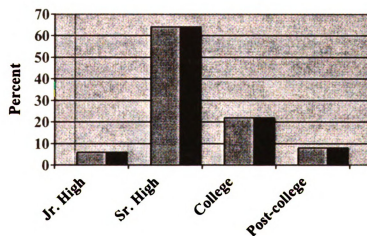
**Table 3: Caregiver Gender**



**Table 4: Caregiver age**



**Table 5: Caregiver Education**

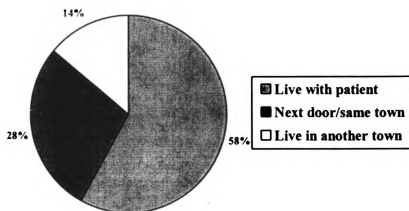


Caregivers in Michigan spend an average of 14 hours each day with their hospice patient. More than a third, however, (36 percent) report spending 24 hours per day with the patient. Caregivers report an average of slightly more than two hours per day for their own activities, away from caregiving, work and other family roles. Thirty percent of caregivers, however, report having less than an hour to themselves each day, while ten percent report six or more hours per day for their own activities. The majority of

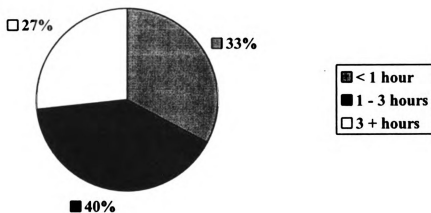


caregivers, 58 percent, live with the hospice patient, while an additional 28 percent live either next door to the patient or in the same town.

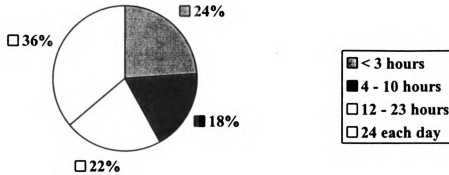
**Table 6: Caregiver/patient Living Arrangements**



**Table 7: Caregiver Personal Time per Day**



**Table 8: Caregiver Time with Patient Per Day**



Twenty-two percent of the patients being cared for by participants in this study were diagnosed with lung cancer. This follows national data suggesting lung cancer is the most common of all cancers. Cancer is the second leading cause of death in the U.S. (NCHS, 2002), and about 63 percent of all hospice enrollees have at least one type of cancer as their primary diagnosis (Gage, 2000). The total number having some type of cancer is even greater. Cancer accounts for six of the top ten primary diagnoses in the hospice population, with lung cancer being the most common (Gage, 2000). Ninety-eight percent of hospice patients with cancer die during hospice enrollment (Gage, 2000). Ten percent of the patients in the current study had colon cancer, and eight percent of the patients had either prostate or breast cancer. Remaining patient diagnoses included leukemia, kidney, ovarian, pancreatic, and lymphoma, among others.

In order to address the purpose of this research, namely to understand the role of social support in the lives of caregivers, its effect on quality of life, and the potential for enhancing support to caregivers through mediated communication, the specific research

questions will be addressed in order. The caregiver case study will be discussed in detail followed by the policy analysis.

### Research Questions

#### Caregiver Sample

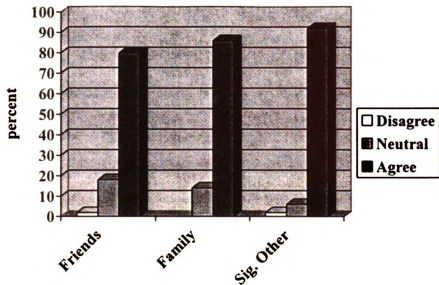
#### **RQ1: What do hospice caregivers perceive as their sources of social support?**

Two primary methods were used to answer this research question. First, perceived social support was measured in part by the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988). As noted earlier, this 12-item instrument measures three factors of perceived support from family, friends, and significant other. Second, interview data from open-ended questions were content analyzed to determine participants' perceptions of social support.

#### Quantitative measurement

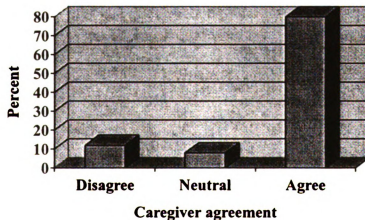
The majority of caregivers of hospice cancer patients in Michigan have a support network of friends, family, and significant others that they feel they can rely on if necessary. As measured by three factors of the MSPSS, 80 percent of caregivers agreed that they have a friend whom they could call on for help; 86 percent of caregivers can rely on family for help, and 92 percent of caregivers reported that there is a special person in their life whom they could count on for support. The seven-point measurement scale of the MSPSS was collapsed into three points for ease of reporting. See table 9.

**Table 9: Caregiver Sources of Perceived Social Support**

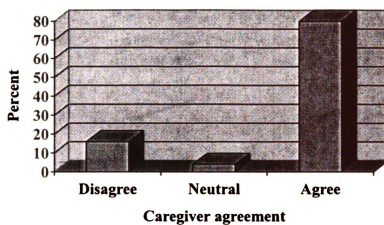


The friendship support factor was measured by degree of agreement/disagreement on four items: "friends really try to help me;" "count on friends when things go wrong;" "friends with whom to share joys and sorrows;" and "talk about problems with friends." See Tables 10 - 13 for details on these items.

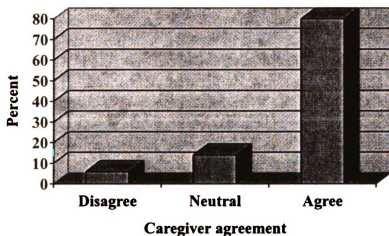
**Table 10: "My friends really try to help me"**



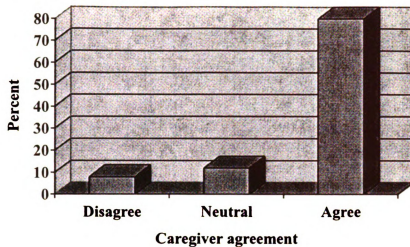
**Table 11: "I have friends with whom to share my joys and sorrows"**



**Table 12: "I can count on friends when things go wrong"**

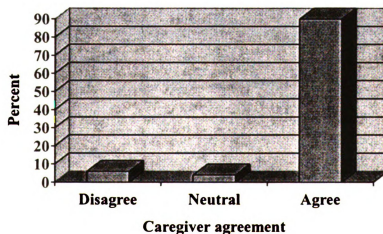


**Table 13: "I can talk about my problems with my friends"**

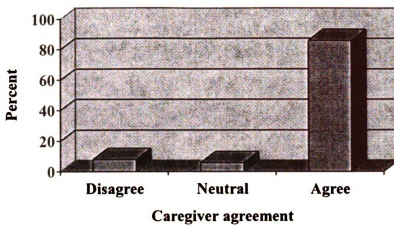


The family support factor was measured by degree of agreement/disagreement on four items: "family really tries to help;" "emotional help and support from family;" "talk about problems with family;" and "family is willing to help make decisions." See Tables 14 - 17 for details on these items.

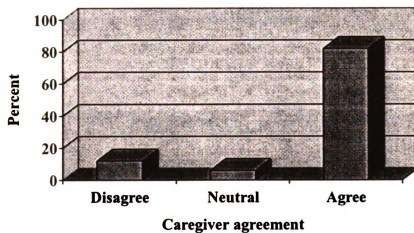
**Table 14: "My family really tries to help me"**



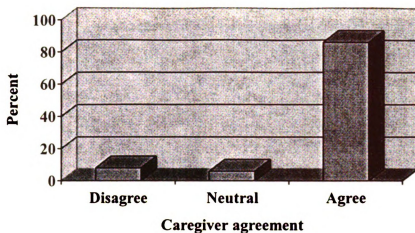
**Table 15: "I get the emotional help and support from my family"**



**Table 16: "I can talk about my problems with my family"**

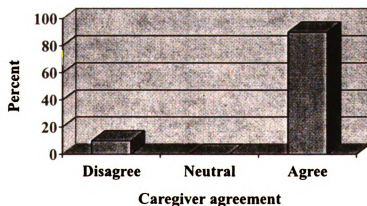


**Table 17: "My family is willing to help me make decisions"**



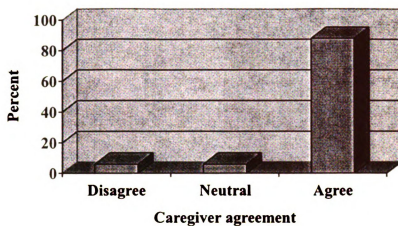
The "significant other" factor was measured by degree of agreement/disagreement on four items: "special person around when I am in need;" "special person to share joys and sorrows;" "special person is a real source of comfort;" and "special person cares about my feelings." See tables 18 - 21 for details on these items.

**Table 18: "There is a special person who is around when I am in need"**

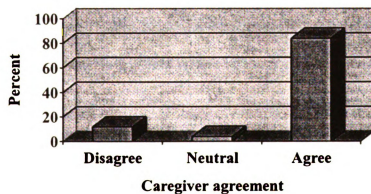




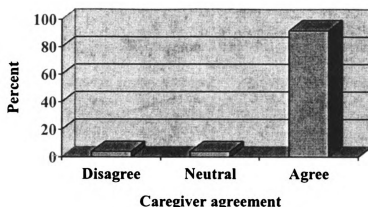
**Table 19: "There is a special person with whom to share my joys and sorrows"**



**Table 20: "There is a special person who is a source of comfort to me"**



**Table 21: "There is a special person who cares about my feelings"**



Interestingly, none of the factors, family, friends, significant other, was significantly correlated with gender, marital status or education. Education, however, was significantly correlated ( $r = -.369$ ,  $p = .001$ ) with support from a significant other. This mirrors existing research, as well as simple logic.

#### Qualitative measurement

Caregivers were asked to discuss who helps them in their caregiving role. Half of the caregivers interviewed reported that other family members help in the caregiving role. "My brother and sister-in-law come over to visit, help with the grocery shopping, take [the patient] out to dinner. I'm very satisfied with the help I get." "My stepdaughter comes on weekends to mow the lawn and give me a break." "My dad is good for a reality check. He helps keep things in perspective." About a third of the caregivers reported that they received help from friends and neighbors. "My friends, family and neighbors have been very supportive. They make meals for me, come over so I can get out. I have one friend, I call her my 'honorary grandma,' she's my steel spine. She goes with me to

doctor visits and helps explain medical terms." "I have a very special friend, who's been a friend for many years. We've been through tough times together." Caregivers rely on a variety of friends for emotional support. "I talk with my hairdresser a lot because she's also lost someone to cancer. She can understand what I'm going through." "I have a friend who lives out of town, but she's very busy. Often she's not available. But she's been there forever. I can talk to her about my fears, my hurt, my anger, my sadness." One caregiver pointed out an important aspect of being a hospice caregiver. "My family tries to provide help. My sister is far away, but I have aunts who are available. Even with help, though, the load lands on one or two people."

Caregivers also received help from professional caregivers such as hospice providers, and from members of the spiritual community. As one caregiver noted, "My sisters have helped in the past, but mostly I rely on my Christian friends. They provide emotional support, watch my kids, provide food, whatever I need." Another caregiver commented that her immediate family tries to help, but her extended family does not. "The only help has been from hospice and my immediate family, my husband and kids. My brothers and sisters would call but not come over to help. My extended family hasn't provided any help. I would've died without hospice." Several caregivers commented that their family helps when it can, but that they have responsibilities of their own. "My daughter helps when she can. Both of my parents live here, so she'll come over and clean my house when she has time. But she has a family of her own to take care of." One caregiver noted she was satisfied with the help she currently received, but expressed concern about help in the future. "My husband is doing well right now. I get enough support from my friends and my church. But what about later, when he gets bad? Will

people be around to help then?" Another caregiver seemed to echo her concern. "I had help at the beginning but now no one helps. People back away. No one wants to be around now."

Several caregivers reported that the only help they receive is from hospice. Many commented that family members are too far away or physically unable to help, so they must rely on professional support. "My sisters would help if they were here, but they live in California, so the only help I get is from hospice." "My brother helps as much as he can. He comes to visit about once a month. My mother's friends can't help...she's 93 and they're as old as she is." Another caregiver commented that even with family at home she feels she is the only one in the caregiving role. "My husband travels so much that he isn't around to help. I need more help. I can't get my father-in-law to eat lunch if I'm not there to fix it. I work and when I'm not home he won't eat."

For most caregivers, Hospice of Michigan is an important resource. "My husband helps some, but hospice is a blessing. I couldn't do without them." One caregiver commented, "I live out of state. My sister-in-law helps when she can, but we couldn't do it without Hospice. The nurse, social worker, and minister have been such a help." Another caregiver commented on the difficulty of asking for help. "They're my kids but I can't dump on them. They want to help but I just can't [accept help from them]. I've been in their situation and you don't know what to do, so at least they're trying. It's not easy."

Caregivers are not always satisfied with the help they receive, however. Some caregivers feel they shouldn't always have to ask for help, and wish their support network would offer assistance more often.

In summary, caregivers relied most heavily on immediate family for support but also considered friends an important source of assistance. While some caregivers commented that they receive help from their extended family, many caregivers reported that their families are too far away, or unwilling to provide instrumental assistance. Several caregivers received emotional assistance from distant family and friends through frequent telephone calls. One caregiver mentioned that she used e-mail to keep in touch with friends and family in another state. However, the majority of care comes from family members in the immediate area, from neighbors, and from professional sources such as Hospice of Michigan and the local Area Agency on Aging. Even when caregivers had a network of support, the primary caregiver reported being just that, the one involved in the majority of care. The next section of this chapter explores the relationship of support and caregiver quality of life.

**RQ2: What is the relationship between perceived social support and the caregiver's quality of life?**

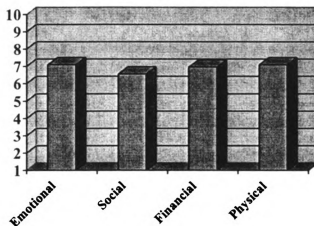
Two primary methods were used to answer this research question. First, the Caregiver Quality of Life Index (McMillan, 1996b) measured caregiver quality of life on four factors: emotional, social, financial, physical. Second, interview data from open-ended questions were content analyzed to determine participants' perceptions of their quality of life.

**Quantitative measurement**

Hospice caregivers in Michigan generally report a positive quality of life on the four dimensions reported here. The Caregiver Quality of Life Index CQLI was originally designed as a 100-point scale to be administered in person. Means on the CQLI in

national samples range from 54.1 to 88.3 (McMillan, 1996b). To facilitate telephone interviews, participants were asked to rate their quality of life on a scale of one to ten. Means ranged from 6.57 to 7.10. See Appendix x for the four items of the CQLI. Table 22, below, shows the mean score for quality of life on each of the factors.

**Table 22: Caregiver Quality of Life Index**



A correlation was conducted to test the relationship between quality of life and perceived social support. Support from friends and significant others were significantly correlated with the caregiver quality of life index ( $r=.488$ ,  $r=.394$ ,  $p=.01$ ), however, family support was not significantly correlated ( $r=.257$ ).

**Table 23: Correlation Matrix, CQOL and MSPSS**

	Caregiver QOL Index	Support from friends	Support from family	Support from significant others
Caregiver QOL Index	$r=1.000$			
Support from friends	$r=.488^{**}$	$r=1.000$		
Support from family	$r=.257$	$r=.586^{**}$	$r=1.000$	
Support from significant others	$r=.392^{**}$	$r=.675^{**}$	$r=.542^{**}$	$r=1.000$

**\*\*** $p=.01$

Several of the individual items from the two measurements were significantly correlated. Support from friends was significantly correlated with emotional quality of life ( $r=.407$ ,  $p=.01$ ); social quality of life ( $r=.344$ ,  $p=.05$ ); and physical quality of life ( $r=.560$ ,  $p=.01$ ). Support from a significant other was also correlated with emotional quality of life ( $r=.298$ ,  $p=.05$ ); social quality of life ( $r=.466$ ,  $p=.01$ ); and physical quality of life ( $r=.453$ ,  $p=.01$ ). Interestingly, however, support from family, was only correlated with physical quality of life ( $r=.349$ ,  $p=.05$ ), suggesting family members take on the role of providing instrumental support but emotional support comes from friends and significant others. This logically follows that a caregiver would rely on a friend or confidant for emotional support before an extended family member.

The caregiver's quality of life was significantly correlated with living arrangements ( $r=.279$ ,  $p=.05$ ). People *not* living with the patient have a more positive quality of life. This makes sense in that caregivers who are able to go home to a different location have more respite from their caregiving role. Interestingly, marital status was not correlated with caregiver quality of life, nor was time spent with patient or time for personal activities.

### Qualitative measurement

When asked how being a caregiver has affected the participants' physical health, many caregivers reported being "tired", "worn out", and "drained." When asked about their emotional health, caregivers reported that the experience had made them anxious and depressed. "This has been rotten. It's really affected me. I got so depressed I had to go on medication." "I'm tired all the time. I work full time then come home to caring. It's emotionally draining too. I don't let my worries out. I didn't want to put him in a

nursing home, but I just couldn't take care of everything." For participants with their own health concerns, the role of caregiver takes an additional toll on their lives. "This is really stressful for me. It causes my fibromyalgia to flare up. When the stress level is high, I have to try harder or else I get overwhelmed." Caregivers also report increased blood pressure, weight gain, difficulty sleeping, and exhaustion. "I don't sleep too well. If he coughs I wake up. I'm always worried."

Several caregivers reported that they work to keep themselves physically and emotionally healthy. "I've learned to take care of myself. I keep laughter in the house and don't allow pity parties. I've learned the benefits of staying active and I exercise on a regular bases." Many participants also commented on the ups and downs, "the rollercoaster" of caregiving. "I'm generally a positive person. I have a good cry, then I feel better." "I had a deep depression but when that happens I talk myself out of it."

In summary, friends and confidants play an important role in hospice caregivers' quality of life. As with social support, extended family have a limited impact on quality of life. Caregivers report that their role is exhausting and emotionally taxing, emphasizing the need for respite care. This is echoed by the fact that caregivers who do not live with the patient, who are able to go home to other responsibilities, have a more positive quality of life.

### **RQ3: What is the potential for telehospice to address caregiver needs?**

From a caregiver perspective, research question three was measured by asking caregivers if they would be interested in using new communication technologies, specifically videophone equipment, in their caregiving role. Caregivers were told that the videophone would connect to another party via standard telephone lines, and that they





could use the system to connect with hospice nurses, social workers, spiritual care workers, financial counselors, members of their church or religious community, and family members in other towns or states. Seventy percent of caregivers said they would not be interested in using telehospice equipment. Caregivers commented "The hospice staff is so responsive that I don't need anything else," and "The phone works just fine. I can page the hospice staff if I need them." Caregivers also commented that the patient wouldn't want any other technology in the home. "We tried to get him to use a lifeline but he refused. He wouldn't want this around." Other caregivers thought telehospice might be useful for emergencies, but did not envision it for other circumstances.

It is interesting that hospice caregivers did not envision telehospice equipment as a resource for themselves, but only as a resource for the patient. Caregivers repeatedly mentioned that the patient would not want the equipment in the home, or that when there was a concern for the patient the caregiver could call the hospice nursing staff. Even when prompted, most caregivers could not conceive of a situation in which they would want to use videoconferencing equipment, reinforcing the traditional paradigm that hospice services are for patients, not caregivers.

Also interesting is that caregivers in rural areas did not refer to limited hospice resources or cost of providing care. Caregivers commented that if they needed services for the patient they would page the nurse, not mentioning the travel time it might take the nurse to reach them. Caregivers did not mention any difficulties with reimbursement, instead commenting that "the hospice office takes care of all that." A few caregivers expressed frustration when a bill was inadvertently sent to the home instead of the hospice office, reinforcing the idea that they're not responsible for costs of care.

Caregivers did not exhibit much insight into actual costs associated with end-of-life care. It is important to recognize that the majority of patients being cared for by caregivers in this study were receiving hospice services through Medicare. Because of the nature of Medicare reimbursement, the patient and caregiver are shielded from costs associated with care, as all bills are taken care of directly by the hospice provider. None of the caregivers discussed difficulties in receiving care, although a few caregivers mentioned having several different nurses. This could be related to nursing shortages in rural areas.

Services that the caregiver needed for themselves included respite care, a break from caregiving to sleep, the opportunity for personal care such as haircuts and massage treatments, a chance to visit grandchildren in other states, someone to run errands or help with housework, time for exercise on a regular basis. In situations where the patient was living in a residential facility, professional staff frequently comments they needed better staffing at the facility. They also commented they would like a break room away from families because it was sometimes difficult maintaining composure in front of visitors. Family members of patients in residential facilities commented they would like the ability to see the patient at any time. Some of these family members had a significant commute to reach the facility.

While telehospice cannot address all the needs of caregivers, it has the potential to address some of them. For example, family members who live some distance from the patient could use videoconferencing to keep in touch with the patient. Caregivers could use the equipment to keep in touch with other family members in distant locations, such as seeing grandchildren in another state when they are not able to leave the patient for

any length of time. It has the potential to provide respite in certain situations depending on the patient's health at the time.

### Policy Sample

As noted in Chapter 3, part two of this project is the policy analysis of current regulations as they pertain to providing social support services to hospice caregivers. Using the framework provided by Bardach (2000), the first two steps in the policy analysis are described below, as they pertain directly to the results chapter of the dissertation. The remaining six steps in the framework will be addressed in the following chapter, as they pertain to discussion and recommendations for providing enhanced services to caregivers.

*Defining the problem* is a crucial step in Bardach's framework for a successful policy analysis. It gives the researcher a reason for doing the work and a sense of direction for gathering evidence. The problem as defined for the current research is: caregivers of hospice patients are under considerable stress. The *evidence* used to address the problem is described within the research questions below.

### **RQ3: What is the potential for telehospice to address caregiver needs?**

From a policy perspective, research question three was addressed through analysis of current research about telemedicine, archival data, and interviews with policy experts from state and federal organizations.

In testimony before the U. S. House of Representatives, Robert Berenson, Director of the Center for Health Plans and Providers, Health Care Financing Administration, said,

Telemedicine, with its ability to provide medical services via telecommunications systems, holds great promise for extending

access to care in rural and other medically underserved areas. We understand that rural beneficiaries face unique challenges in accessing the medical care they need, particularly access to specialists. Helping them is a high priority for us (Testimony of Robert A. Berenson, M.D., Director, Center for Health Plans & Providers, Health Care Financing Administration, 2000).

As noted earlier, providing hospice care in rural areas poses unique challenges. Hospice is more difficult to access in rural areas Buckingham, (1996). Travel expenses and road conditions pose physical barriers, while a shortage of health providers poses access barriers. Even though rural America has 33 percent of the population, only 12 percent of physicians and 18 percent of nurses choose to practice in rural areas (Buckingham, 1996). Medical specialists, including physicians with hospice expertise, may not exist locally (Buehler & Lee, 1992).

In addition to access issues, many people in rural areas are self-employed or work for small, privately owned business, and may have limited, if any, health insurance (Vrabec, 1995). While people in rural areas have lower overall incomes and less education, cost of providing services is actually more expensive. Furthermore, the majority of caregivers in the current study were older than 50. Rural older Americans have characteristics and needs that differ from their urban counterparts. They are often more isolated, have lower incomes, and have greater challenges actually accessing health services due to transportation needs. Rural residents are more likely to stop care as a result of cost (Blazer, Landerman, Fillenbaum & Horner, 1995). Rural residents are also less likely to obtain health care at a hospital. Even though the older population is almost universally covered by Medicare and Medicaid in the US, substantial differences in out-

of-pocket expenses such as transportation mean that health care is not equally accessible to all.

The majority of caregivers in the current study were women, mirroring previous caregiver data. In addition to geography impacting economic variables, there are also gender-based disadvantages to rural caregivers. For example, elderly women in the US outnumber elderly men three to two (Whitten & Gregg, 2001). As the death of a husband often leads to acute economic changes for the surviving wife, health analysts need to consider changing needs due to economic constraints. Services available through telemedicine have the potential to impact access to health care for such economically challenged older Americans.

In a recent report to the Governor, the Michigan Commission on End of Life Care emphasized the importance of the needs of caregivers while they are caring for the dying, and for the grief and bereavement that accompanies and follows the death of a loved one (Commission, 2001). Support for caregivers must include attending to the emotional, physical and financial demands on families caring for a loved one at home. The commission recommends incorporating caregiver services directly into the patient's plan of care. Furthermore, the commission recommends improving reimbursement streams to fill the need for skilled respite care (p. 36).

Because of the nursing shortage, Gloria Dana, government affairs director for Hospice of Michigan, reports that Hospice of Michigan is looking for alternatives that are less dependent on nursing staff. "We're trying to figure out the model that's less nurse-dependent. Telehospice might provide support where there are no nurses" (Dana, 2002).

Telehospice could be one means for providing one-on-one grief and bereavement counseling in areas of the state where limited nursing staff exists.

Furthermore, Dana reports that the average reimbursement for HOM is \$116 per day. The reimbursement rate is actually less in rural areas, even though providing services may in fact cost more. Furthermore, the reimbursement rate is constant between adult and pediatric patients, while the cost for providing services for pediatric patients is much higher. Dana reports that the reimbursement rate has not kept up with inflation as HOM's average cost for service is \$155 (Dana, 2002).

The Rural Policy Research Institute (RUPRI) Center for Rural Health Policy Analysis recommends changes to the Medicare program to *obtain* and then *maintain* equality for benefits and costs for beneficiaries, regardless of where they live (Panel, 2001). Furthermore, the Center recommends that any changes to Medicare should ensure that beneficiaries have comparable choices available to them and have access to all medical services.

As noted earlier, hospice care has been successfully delivered into patients' homes via telehealth. Telehospice allowed nurses to visit and treat patients without leaving their home/offices (Doolittle et al., 1998), reinforcing the advantages of not having to drive long distances in rural settings. Hospice providers are highly satisfaction with telehospice equipment, specifically in terms of increasing access to patients, delivery of hospice care, and overall enjoyment of the telehospice visits (Whitten et al., 2000). Hospice patients reported that telehospice increased their access to their provider, especially during the night hours or in case of an emergency. Further, caregivers reported that an increased level of comfort was associated with the equipment due to the video

component of the service, suggesting that the equipment could be used to enhance social support to caregivers.

**RQ4: What legislative and regulatory mandates are in place that affect delivery of mediated social support?**

Providing mediated social support takes place within a larger context of hospice policy and telecommunications policy. For purposes of clarity, these two perspectives will be addressed separately.

**Hospice policy**

Since creation of the Medicare Hospice Benefit in 1982, hospice has demonstrated its capacity for expert and compassionate care of the dying. However, according to the National Hospice and Palliative Care Organization (NHPCO), along with the growth of hospice has come increased governmental oversight which creates barriers to access (Swiger, 2002). Despite hospice's growth, the Medicare Hospice Benefit is one of Medicare's smallest programs, accounting for approximately two percent of Medicare's total outlays (Mahoney, 1998). Historically, care in the last year of life is the most costly in the healthcare timeline (Swiger, 2002). In a report to Congress, the Medicare Payment Advisory commission (MedPAC) stated that end-of-life care accounted for approximately 25 percent of Medicare spending between 1994 and 1998 (MedPAC, 1999). Medicare payments in the final year of life averaged \$26,000 in 1997, six times what Medicare spent on other beneficiaries. According to Swiger, because physicians view death as a failure, every medical and technological advancement is used to fight the inevitable, making dying the most expensive health-related episode (Swiger, 2002). As noted earlier, even though hospice referrals have increased, time spent in



hospice has decreased. Because of increased cost during the first and last days of hospice, a recent study funded by the Robert Wood Johnson Foundation recommending re-basing the reimbursement rate to account for inflation, and to pay a higher rate for the first and last days of hospice care (Huskamp, Beeuwkes Buntin, Wang, & Newhouse, 2001).

According to the U. S. General Accounting Office (GAO), while the number of Medicare recipients enrolled in hospice more than doubled between 1992 and 1998, only one in five Medicare beneficiaries used the hospice benefit (GAO, 2000). The growth of hospice has increased scrutiny from government regulators (Swiger, 2002). According to Swiger, this has had the unintended consequence of creating administrative and regulatory barriers to the deliver of optimal end-of-life care by hospice programs in the U. S. The MedPac report (MedPAC, 1999) states that due to audits by the Office of the Inspector General (OIG), physicians are reluctant to make six-month prognoses in all but the clearest cases to avoid any perception of fraud. As noted earlier, recent recommendations to MedPAC include revisiting the definition of prognosis for hospice referrals (Von Gunten et al., 2002).

Other barriers to increasing hospice services for caregivers come from inconsistency of interpretations of the Centers for Medicaid and Medicare (CMS) Conditions of Participation. In some CMS regions, the entire interdisciplinary care team is required to approve all changes in a patient's plan of care, even if the change could easily be identified by on-site professionals (Swiger, 2002). CMS has also modified the role of hospice medical directors, requiring them to participate in and agree to all new changes and revisions to the patient's plan of care. This requirement duplicates the

review of the attending physician since the attending physician often provides the orders for most changes to the plan of care, without any adjustment to the *per diem* reimbursement.

Ken Drees, technical assistance director for the NHPCO, states that a key issue for caregivers in the home is the need for additional services such as respite care. According to Drees, Medicaid provides for a personal aide service in the home, allowing family caregivers respite of up to four hours a day. However, once a patient is referred to a hospice program and covered by the Medicare Hospice Benefit, the personal aide service is considered a duplication of services, eliminating the respite benefit for caregivers (Drees, 2002).

According to Gloria Dana, government affairs director for Hospice of Michigan, grief support is required of hospice providers in Michigan. However, it is not a reimbursable benefit under the Medicare Hospice Benefit (Dana, 2002). Furthermore, grief support is not limited to patients and families. Counseling can take the form of children's bereavement camps, school programs for coping with loss or crisis intervention, or work release and substance abuse programs with county jails. In 2000, Hospice of Michigan served 5000 people through support groups and one-on-one counseling (Dana, 2002). The majority of this counseling and support is not a reimbursable benefit. In addition to the nursing shortage, a shortage of Master's prepared social workers adds to hospice's struggle to provide quality care (Swiger, 2002).

#### Telecommunications Policy

Berenson (2000) testified that telemedicine usage prior to September 2000, was limited. Although the Balanced Budget Act of 1997 expanded coverage options, it also

precluded the use of telemedicine under conditions where it is commonly used outside of Medicare. Berenson expressed concern regarding this limit to the use of telemedicine within Medicare, but also about the broader implementation of telemedicine.

There is very little published, peer-reviewed scientific data available on when telemedicine use is medically appropriate. It is difficult to project potential cost implications. And there are potential program integrity issues that should be addressed proactively (Testimony of Robert A. Berenson, M.D., Director, Center for Health Plans & Providers, Health Care Financing Administration, 2000).

Among the restrictions of the Balanced Budget Act (BBA) of 1997 were:

- Telemedicine services could only be provided to a beneficiary in a rural health professional shortage area
- Services were limited to "consultations," defined as a "face-to-face" physician and patient encounter in which the patient is present at the time of the encounter. This eliminates reimbursement for store-and-forward technologies.
- Registered nurses and other medical professionals not recognized in the Medicare statute cannot receive payment for a teleconsultation. This is a severe limitation for rural areas where there is already a shortage of physicians. Also, health care providers such as clinical psychologists, who may be able to receive Medicare payment in limited circumstances but who are not recognized in the statute, cannot receive payment for teleconsultation.
- Consulting and referring practitioners must share payments and line charges or facility fees are not reimbursable.

As of September 30, 2000, after almost two years of telemedicine reimbursement under the BBA, Medicare had reimbursed a total of \$20,000 for 301 teleconsultation claims (Kumekawa, 2001). At the end of December 2000, Congress passed a benefits improvement and protection act which addressed many of the limitations of the telehealth requirement of the BBA:

- The improvement act eliminated the fee-sharing requirement. Under the new law the originating site will receive a facility fee of \$20 and the specialist will receive the full physician payment.

- The improvement act eliminated the requirement that a physician or eligible practitioner must present the patient at the originating site, enable nurses and other medical care specialists to use telemedicine.
- Expansion of the eligible geographic areas and expansion of the number of eligible services to be reimbursed (Kumekawa, 2001).

The improvement and protection act made significant improvements toward providing mediated social support for caregivers, however, as yet telemedicine is not covered under the Medicare Hospice Benefit. Furthermore, only limited benefits are specifically spelled out by Medicare for caregivers, as noted above.

In summary, caregiver in rural Michigan perceive they have a support network to help them when necessary. When discussing help, caregivers most often point to their need for instrumental resources such as mowing the lawn, cleaning the house, or going to the grocery store. However, when asked about their health, caregivers describe in detail the effect caregiving has had on their emotional health. Although there was mention of the effect on their physical health, many caregivers reported that caregiving has made them depressed, anxious and worried. The relationship between perceived support and quality of life is a subtle one. Caregivers have a support network, but the possibility exists that the type of support they need is not necessarily the type of support they have.

Furthermore, when asked about additional support, many caregivers said they have everything they need and would get through the caregiving role in their own way. This points to a lack of understanding of the role communication technology in caregiving.

The caregivers also displayed a lack of understanding about the difficulties of providing hospice care in rural areas. The great majority of caregivers sincerely appreciated the role of Hospice of Michigan. They commented that they "could not have survived" without hospice. They did not, however, give any indication about how

difficult it is for hospice to provide quality service, or how technology might facilitate caregiver services in the future. Finally, because of the difficulty of maintaining a quality workforce in rural Michigan, HOM is looking for innovative ways to provide services. Although this might be facilitated by technology, several policy issues need to be addressed, including reimbursement, liability, licensure, and privacy concerns.

## CHAPTER 5

### DISCUSSION

At its premise, this study adopted the assumption that social support networks are important to hospice caregivers in rural areas. This study sought to document this phenomenon by identifying the context in which the participants provide care. This dissertation attempted to determine how hospice caregivers experienced their world by collecting their accounts of who provides support for them in their caregiving roles, what type of support they receive, and how caregiving affects their quality of life. A second assumption made by the researcher is that caregiving exists within a framework provided by public policy, and is directly affected by rules governing hospice care for patients. This study sought to document the healthcare policies that affect caregivers in their caregiving role by synthesizing information from policy experts, archival data, and relevant research reports.

The purpose of this final chapter is to offer the researcher's account of the relationship between a hospice caregiver's social support network and his or her quality of life. Furthermore, it underscores the significance healthcare policy would play in enhancing support services through the use of telecommunication technologies. A discussion of the implications of this study and future directions for research precedes an acknowledgment of the strengths and limitations of this project.

#### Caregiving in Rural Michigan

This case reiterated some existing beliefs about hospice caregiving while illuminating new effects of this important role. The participants in the sample mirrored larger population studies of caregivers. The great majority of caregivers were female

family members between the ages of 51 and 60. Many caregivers reported spending 24 hours each day with the hospice patient, leaving little or no time for their own activities.

The interpretation below is based on themes illuminated by the results in Chapter 4.

#### Redefining support

When asked about the type of support they received, many caregivers commented that others help them "mow the lawn" or "do the dishes." Help was often described in terms of instrumental support, "doing" something. When caregivers were asked about the effects of caregiving on their health, however, they most often commented that it made them anxious, depressed and lonely. This provides an almost dichotomous definition of help: caregivers think of support as instrumental but what they may need more of is emotional support. Telemedicine has the opportunity to reposition support in terms of the benefits of emotional support. Caregivers could use technology to access emotional support from friends, family, and professionals. A few caregivers noted that caregiving had taken such a toll on their emotional health that they were being treated for depression. Telemedicine could provide access to their physician or professional counselor as a necessary component of the support network.

A few caregivers reported that they work very hard to keep themselves emotionally and physically healthy. This may become difficult as the caregiving role progresses. Others commented that they used to exercise on a regular basis but caregiving now kept them at home. Telemedicine could provide opportunities for caregivers to join support groups at distant locations, or even exercise classes in a neighboring community center.

### **Support from immediate versus distant friends and family**

Through discussions with caregivers in Michigan, we have learned that the majority perceives they have a support network of friends, family and significant others which they can rely on if necessary. Nearly all of the caregivers (92 percent) reported they could rely on a significant other for support. Though slightly less, the overwhelming majority of caregivers felt they could rely on family (86 percent) and friends (80 percent) for support.

Caregivers with extended families in the immediate area seemed to rely heavily on family members for support. However, many caregivers reported that they receive little or no support from distant family. Throughout the U. S., rural areas generally have a higher proportion of older persons in their total population than urban areas. Furthermore, women constitute a larger share of the older population, especially in the older age groups (ERS, 2002). Rural areas are aging rapidly as a result of aging-in-place, out-migration of young adults, and in-migration of older persons from metro areas, straining community resources to provide needed services. What effect will these trends have on this sense of social support from family? Furthermore, some caregivers, particularly those whose children were not yet adults, reported they don't want to rely on their kids for support. Telehospice has the potential to connect distant family members into the caregiver's support network. This would provide the caregiver with an avenue of emotional support while not feeling she is burdening her children. In addition to supporting the caregiver, telehospice would give distant family members the opportunity to interact with the hospice patient directly.



A few caregivers mentioned that members of their support network used to be available to help, but as the patient's disease progressed they either didn't know how to help, or felt uncomfortable with the patient's condition. When implementing technology, specialists typically try to find the technology that is the least invasive, or the least likely to look like a machine. In this shift of thought, however, would the telemedicine technology itself provide enough of a barrier that those who are uncomfortable being in the immediate vicinity of the patient feel more comfortable providing emotional support? Gregg (2001) found that homebound elderly felt comfortable using technology to interact with groups they were not comfortable interacting with in person. For members of the support network who don't know how to help, telemedicine provides the opportunity to facilitate a quick conversation with the caregiver, a "how are you today." This might address concerns that members of the support network have about wearing out the patient by spending too much time in the home, or about concerns for their own time constraints.

#### Challenges to professional healthcare providers

As noted earlier, healthcare organizations throughout the U. S. are facing a critical nursing shortage. Hospice care by its very nature relies heavily on nurses experienced in end-of-life care. The caregivers interviewed in this project, however, did not seem to have a sense or understanding of the challenges the organization faces in providing quality care in rural areas. A few caregivers mentioned that they had had care provided by several different nurses, but did not seem to conclude that this was a result of staffing shortages. Jeanne Parzuchowski, vice president of research for the Maggie Allessee Center for Quality of Life at Hospice of Michigan, noted the challenges HOM faces in finding and keeping nurses experienced in end-of-life care, particularly in its rural

offices. Furthermore, she noted that her organization is searching for innovative care options that are less nurse-intensive. "Hospice of Michigan strives to be a leader in quality of care. We're trying to provide the model that could lead the nation to the next level of care for patients and families at the end of life" (Parzuchowski, 2002).

Caregivers seemed to believe that immediate access to professional care providers was an inherent right of being enrolled in hospice. Americans have long held the belief that immediate access to care is part of our national freedom. Does the nursing shortage change this right to immediate care, shifting the focus to alternatives to face-to-face interaction? Telemedicine could help provide immediate access to remote medical care when face-to-face care is not possible.

#### A new paradigm of care

As noted earlier, caregivers repeatedly mentioned the need for respite care. Limited respite for caregivers at home is available from hospice volunteers. Caregivers can have extended respite--up to five days--by admitting the patient to an approved care facility. However, most caregivers and patients are unwilling to use this option. What is the potential for telehospice as a means of respite? If the hospice patient is in relatively good health, telemedical technologies could be used to connect the patient to a distant family member or a professional care provider at another location, allowing the caregiver the opportunity for personal time. If the patient is near death, however, telehospice would not be a viable care alternative because the respite provider at a distance would not be able to provide immediate or emergency assistance to the patient if necessary.

Caregivers interviewed for this project consistently referred to hospice services available to the patient. When probed, they often responded that they knew they could

talk with the social worker, but the patient's care was priority. Few of the caregivers were able to focus on their own physical and emotional health, however. What if hospice was able to provide additional services to caregivers? Caregivers play a vital role in caring for patients at the end of life, but often suffer because of it. Using telehospice, hospice organizations could enhance the services for caregivers of the dying.

Most caregivers from this project could not conceive of a situation where they would want to use telehospice equipment. This points to a lack of understanding of the possibilities created by new technology and the need for educating caregivers about their options. Several caregivers did mention that it would be nice to talk with distant family members on a more regular basis, or again, thinking of the patient, that it would be nice for the patient to see distant relatives one more time before dying. Empowering caregivers to take care of their own needs, even subconscious ones, shows that they are valued in society. In the U. S. we applaud parents for raising children. We should applaud caregivers for helping people die.

#### Quality of mediated support

Daft and Lengel (1984) proposed that communication media have varying capacities for resolving ambiguity, bringing multiple interpretations together, and facilitating understanding (Trevino, Daft, & Lengel, 1990). Communication media, then, can be characterized as "rich" or "lean" based on their ability to facilitate shared meaning. Rich media have the greatest capacity to facilitate shared meaning while lean media have the least capacity.

The richness of a medium is based on four criteria: 1) availability of instant feedback to quickly understand the message; 2) capacity to transmit multiple cues to

convey interpretations; 3) use of natural language; 4) personal focus of the medium (Trevino et al., 1990). According to this hierarchy, face-to-face communication is considered the richest communication medium and impersonal written documents such as reports and bulletins are the leanest media. Is telehospice equipment a rich enough medium to facilitate shared meaning between caregivers and their support network? A videophone is less rich than face-to-face communication but more rich than a telephone. Both the telephone and videophone allow for instant feedback and use natural language. The videophone, however, provides the opportunity to transmit multiple cues, both verbal and nonverbal. Furthermore, the video signal has an added dimension of personal focus that the telephone does not provide. The video component adds an emotional sense of security that is not available with standard telephone service. Caregivers report that they are satisfied with telephone access to hospice professionals and distant friends and family. Could the added dimension provided by the video be a positive force toward improving the caregiver's quality of life? Additional research needs to critically analyze the differences between video and audio support.

Furthermore, communication exhibits a "sense of being with another" known as social presence (Biocca, Harms, & Burgoon, Submitted). For example, individuals having a conversation while sharing breakfast would have a high sense of social presence. Mediated social presence, on the other hand, occurs when individuals are interacting in a mediated environment, such as over the telephone or videophone. Low levels of social presence are represented by a peripheral sense of being with another, while higher levels of social presence are characterized by a deeper psychological involvement or connection (Biocca, Harms, & Gregg, 2001). In a mediated environment,

there are varying degrees of a "sense of being with another." Using this framework, a high level of social presence should increase communication satisfaction. Telehospice equipment could enhance the communication between caregivers and distant family members by enhancing social presence.

### Policy Implications

Continuing with the Bardach (2000) framework used in Chapter 4, policy implications of the current research are described in detail below. The final steps for successfully completing the analysis regarding policy implications include: (1) constructing possible alternatives to mitigate the problem; and (2) selecting the criteria with which to judge the projected outcomes. Those steps regarding policy recommendations include: (3) projecting outcomes; (4) confronting trade-offs between possible outcomes; (5) deciding which outcomes to recommend; and (6) telling the story. This analysis reinforces the role that policymakers play in providing health services in the country. Furthermore, as organizations seek innovative ways to provide quality care while minimizing cost, they are guided and constrained by existing legislative and regulatory policy. Issues of importance that came out of this investigation are detailed below, followed by recommendations for policy makers.

### Constructing alternatives to mitigate the problem

#### *Barriers to access*

Previous research has documented the need for hospice services in rural areas. For the most part, however, the caregivers in this study felt they had access to healthcare providers when they needed it. Caregivers felt they could call Hospice of Michigan and have a nurse sent to the patient's home if necessary. They did mention that on occasion

they have had to wait a considerable time for the nurse to travel to their location. While this was not perceived specifically as a barrier to access by the caregiver, it was perceived as an inconvenience (reinforcing the idea discussed earlier, that immediate access to healthcare providers is a right).

Caregivers also mentioned the need for respite care and the lack of support from distant family members. The Medicare Hospice Benefit is one barrier to using telemedicine as a barrier to respite care. Respite for caregivers currently must be provided by a hospice volunteer at the patient's home or by checking the hospice patient into a Medicare-approved inpatient facility. One alternative, using the Bardach framework, is to update the Medicare Hospice Benefit to allow for respite care reimbursement when care is provided by hospice staff at a remote location. As noted earlier, respite care provided by telemedicine would need to be examined in greater detail, and possible constraints implemented to account for the patient's health.

Another alternative for respite care would be to have services reimbursed directly for the caregiver. This would require that the caregiver's insurance provider, or Medicare or Medicaid if appropriate, would see this as a service necessary for the caregivers health. Emotional health is a very real part of life, and the caregiver needs respite care for their own well-being. Traditional or telemedical respite could be a service reimbursed through the caregiver's insurance rather than the patient's. As noted earlier the burden of caring for terminal patients often has a negative effect on a caregiver's quality of life (Smeenk et al., 1998), and accumulates over time (Duijnste, 1994). Several of the caregivers in this study reported they were being treated by a physician for depression as a result of their caregiver role. It is also important to remember that the value of family caregiving to

society is estimated conservatively to represent nearly \$200 billion per year (Caregiving, 2002), and that a major reason for admission of hospice patients to the hospital is exhaustion of the primary caregiver (Bramwell et al., 1995). The economic cost of *not* providing services to caregivers could far outweigh the cost to society of providing them.

*Limits to telemedicine within hospice policy*

Currently, hospice services are reimbursed as a per diem service. At this time the Medicare Hospice Benefit does not specifically address whether services for the patient are provided in person or via telemedicine technologies. To make sure caregiver services can be delivered via telehospice, and services for the patient for that matter, this legislation should to be amended to specifically address that services are reimbursable no matter what the delivery modality. One alternative for providing reimbursement through the Medicare Hospice Benefit is to consider the revisions to the Balanced Budget Act described earlier. When Congress passed the Benefits Improvement and Protection Act they laid the groundwork for using telemedicine in hospice care. Technology currently in use has limited costs associated with it because it runs on standard telephone lines, therefore there is no need to address line charges. If a caregiver wants to talk with family in another state they will incur long-distance phone charges, but with most service providers these charges would be limited. The Benefits Act also addresses physician charges on the originating and receiving ends of the telemedical call. Because the services to caregiver would be between family and friends there would be no charge. If there were a consultation with a physician, it would be directly into the caregiver's home so there would be no receiving physician. The Benefits Act cleared up the requirement

regarding who is eligible to provide services, paving the way for nurses and social workers to provide care to caregivers in their homes.

### *Mandated counseling*

As discussed by Gloria Dana, governmental affairs director for Hospice of Michigan (Dana, 2002), hospice programs are mandated to provide counseling to families during the time the patient is receiving end-of-life care and after the patient's death. This is an important service that Hospice of Michigan strives to provide. Prior to the patient's death the service is covered under the umbrella of the *per diem* payment to hospice. However, after the patient has died, the service is no longer reimbursable but is mandated as part of legislation guiding hospice care in the U. S. Telemedicine provides one option for making one-on-one care available to family members while maintaining cost outlays for hospice. Another alternative for providing counseling after the patient's death would be to have services reimbursed directly for the caregiver. This would require that the caregiver's insurance provider, or Medicare or Medicaid if appropriate, would see this as a service necessary for the caregiver's health. While death is a very real part of life, this may be the first time many hospice caregivers have been actively involved in the death of someone so close to them. The caregiver may need counseling to deal with their emotional response to the death of a loved one. Telemedical counseling services could be a service reimbursed through the caregiver's insurance rather than the patient's.

### *Opportunities to provide other types of counseling*

While not directly within the scope of this project, it is important to acknowledge the other types of counseling support provided by hospice programs. Within Michigan, HOM provides crisis counseling in schools, counseling to inmates in county jails, and



support groups for residents dealing with other health-related challenges. Telehospice provides an opportunity to expand the scope of this care. Telecommunication technologies have been used successfully in schools and jails to provide other types of medical care. Providing mediated support groups or counseling is simply an extension of this model.

#### *Facilitate timely care*

While not specifically a services for caregivers, timely patient care does have an effect on a caregiver's quality of life. If a patient is uncomfortable, the caregiver is most likely emotionally anxious and concerned. As noted earlier, the Centers for Medicaid and Medicare (CMS) enacted policy requiring that hospice medical directors review all changes to a patient's plan of care. For some hospices this has created a considerable delay in their ability to provide timely care. By using telehospice equipment, medical directors would have the ability to review changes at the same time as the attending professional provider in the patient's home. For example, if the attending nurse determines that palliative chemotherapy is necessary, the medical director could review and approve the plan of care while the nurse is still at the patient's residence, providing immediate feedback and the ability to quickly address patient's needs.

#### Policy Recommendations

Support networks are important to hospice caregivers. Support, however, is often defined by caregivers as instrumental, such as provision of services. By reflecting on how caregiving affects their lives, however, it becomes apparent that caregivers may need increased emotional support. Telehospice provides an opportunity for redefining support for caregivers. Furthermore, it provides and opportunity to access emotional support

from friends and family members in other communities and states. By accessing distant members of their support networks, caregivers can feel they are relying on more people for help, rather than burdening a few who are nearby. This in turn reduces the burden for professional support networks such as hospice services and Area Agencies on Aging.

While providing mediated services to caregivers defines a new paradigm for care, hospice agencies have always considered the support of caregivers as part of their mandate. It is apparent from this project that it is the caregivers themselves who do not see caregivers support services as the realm of hospice care.

#### Selecting criteria for judgement and projecting outcomes

As noted earlier, Bardach (2000) reinforces that projecting outcomes is the most difficult step in the policy analysis, and is often left out altogether. Using the Bardach framework, the criteria that were selected for judging the alternatives described above were: (1) increased cost verses social good; (2) implications for privacy; and (3) implications for liability). The following outcomes and their trade-offs should be considered in regards to providing mediated social support for hospice caregivers.

1. Hospice providers need to embark on an education program for caregivers, detailing the services available to them as caregivers, and the benefits to caregiver health from using these services. This education program will require creative solutions such as videotaped scenarios for describing potential uses of telehospice. The inability of participants in this study to envision uses of telehospice creates the need for an innovative educational program. The *trade-off* to hospice is that an education program will use human and monetary resources in an industry already facing shortages.

2. The Centers for Medicare and Medicaid need to approve caregiver services for reimbursement over and above the *per diem* rate provided for patient care. The *trade-off* is that reimbursement for caregiver services will further deplete the resources of Medicare and Medicaid. On the other hand, as noted earlier, one of the most common reasons for admission of a hospice patient into the hospital is because of caregiver exhaustion. Enhanced support services to caregivers could alleviate this aspect of patient care.
3. The Centers for Medicare and Medicaid need to approve telemedical services as reimbursable through the Medicare Hospice Benefit to facilitate timely care for patients and to facilitate caregiver well being. Again, the *trade-off* is further reduction of Medicare and Medicaid budgets. Providing telemedical services, however, has significant benefits to society. Telemedicine facilitates care to people in rural areas who may not otherwise have access to this important aspect of healthcare.
4. While it is important and necessary to have legislation guiding the provision of healthcare in this country, the day-to-day decisions for care are left to the physician supervising care. For telehospice to be a valuable resource for patients and caregivers, the decision to use it must be available to the hospice team. Legislation needs to be enacted that leaves delivery decisions to provider, allowing them to use telehospice when it would be beneficial. The *trade-off* is that use of telehospice could be abused by not continuing in-person patient care. Hospice programs will need to have reviews to guarantee they are providing quality hospice care.

5. Coverage of mental health services has been limited for some people in this country. Insurance companies, as well as Medicare and Medicaid, need to provide for coverage of mental health visits, including those delivered by telemedical technologies. As noted earlier, mental health is an important aspect of an individual's quality of life, and if not attended to, can become very costly to society. The *trade-off* is possible fraudulent use of technology.

#### Implications and Future Directions

Because of the descriptive nature of this study, specific implications for future telemedicine research became evident. Results from this study illustrate the potential role of telemedicine in providing social support to hospice caregivers. This indicates a shift in the hospice paradigm, however, at least from the caregiver perspective. Caregivers in this study constantly referred to services for the patient, but did not envision services for themselves. Changes in policy such as those recommended here could have a significant positive impact caregivers. Hospice caregivers are providing an invaluable resource to society and legislation needs to be in place to assist them in this important role. Caregivers in Michigan felt they had a support network but some members of that support network were not easily accessible. Technology is in place to facilitate support, now the policy needs to be in place to facilitate technology.

#### Strengths and Limitations

The purpose of this study was to examine the potential role of using telemedicine to provide support services to hospice caregivers. Specifically, it looked at the current network of social support of caregivers and the healthcare policy context for providing telehealth services.

Previous research on caregivers has looked at the effect social support has on caregivers' lives. This study makes a unique contribution in its' examination of the policy structure surrounding provision of additional services to caregivers. Through policy analysis, this research used archival data and communication with policy experts to establish a framework for providing mediated social support. Furthermore, the discussions with caregivers highlighted their perceptions of the role of hospice as a provider of services to them as well as the patients, and of their lack of insight into the difficulties of providing care in rural areas.

This study is not without limitations, however. First, some see a single case as a limitation. While caregivers were spread throughout 15 rural counties in Michigan, their perceptions could be quite different from caregivers in other states. Nearly 100 percent of the caregivers in this study were white. To gain a more complete understanding of the role of telemedicine for providing support to caregivers, a more diverse population should be sampled.

Because this researcher was interested in speaking with caregivers who are still active in their caregiving role, and to better control the project, interviews were conducted with caregivers of cancer patients who are still receiving hospice care. However, one might get very useful data from participants who are done being caregivers. They might have important insight after being away from the caregiving role for some period of time. Another weakness of the study was the inability of participants to envision a video technology. The researcher did not envision the difficulty participants would have in discussing potential uses of telehospice, and therefore did not have important interview probes in place to explain the system in greater detail.

In addition, there were important voices omitted from this study: those providing support to the caregiver. Receiving support is one-half of the equation. To gain a complete perspective on the role of telemedicine in providing support, the perspective of the support provider needs to be addressed. Would distant family members play a more active role in providing emotional support if they were able to see as well as talk with the caregiver? Would distant family members be able to provide respite for caregivers? Would distant family members play a more active role in providing care, such as working directly with professional service providers?

This dissertation provides a strong foundation for the next step of research and action in this area. It is the beginning of a research and policy development agenda which the researcher intends to continue. The next important step is to securing funding to test the impact of telehospice equipment on social and emotional well being of caregivers. Another important action is to talk with the support providers of caregivers and find out how they would like to use technology to aid in providing support. Finally, it is important to further develop and implement the policy recommendations which were the result of this research. Without governmental support, the impact of telemedicine for caregivers could be severely limited.

In summary, this project makes a unique contribution to the study of hospice caregivers by integrating the role of technology in the context of care. In addition, the dual methodology of the study, a case study approach with caregivers and policy analysis, provides additional insight into the potential of telemedicine for enhancing support. However, this project is limited by its focus on Caucasian caregivers in

Michigan, the limited number of caregiver interviews, and the exclusion of support providers from the study.

APPENDIX A

CAREGIVER QUALITY OF LIFE INDEX

1. On a scale of 1 to 10, please rate your **emotional** quality of life, where *lowest* quality applies to someone who is depressed, anxious, insecure, alienated, and lonely, and *highest* quality of life applies to someone who is emotionally comfortable with self, others, and environment.
2. On a scale of 1 to 10, please rate your **social** quality of life, where *lowest* quality applies to someone whose social relationships are unsatisfactory, of poor quality, few; and help from family and friends is not even available now and then. *Highest* quality applies to someone whose social relationships are very satisfactory and extensive; at least one person would assist him or her indefinitely.
3. On a scale of 1 to 10, please rate your **financial** quality of life, where *lowest* quality applies to someone who is constantly worried about medical costs and present and future living expenses. *Highest* quality of life describes someone who feels confident of his or her financial status now and in the future.
4. On a scale of 1 to 10, please rate your **physical** quality of life, where *lowest* quality applies to someone who has no energy or is physically ill and feels unable to maintain normal activities. *Highest* quality describes someone who is energetic, in good physical health, and is able to maintain normal activity levels.



## **APPENDIX B**

### **MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT**

1. There is a special person who is around when I am in need.
2. There is a special person with whom I can share my joys and sorrows.
3. My family really tries to help me.
4. I get the emotional help and support I need from my family.
5. I have a special person who is a real source of comfort to me.
6. My friends really try to help me.
7. I can count on my friends when things go wrong.
8. I can talk about my problems with my family.
9. I have friends with whom I can share my joys and sorrows.
10. There is a special person in my life who cares about my feelings.
11. My family is willing to help me make decisions.
12. I can talk about my problems with my friends.

**APPENDIX C**  
**OPEN-ENDED QUESTIONS**

1. Do you have others who help you? If so, whom and how?
2. Have you been satisfied with the help others have given you? Why or why not?
3. Do you have someone you can talk to when you are feeling run down or blue? If so, who and what do you talk about?
4. What would make your life as a caregiver easier?
5. If you had someone to do something special for you while you were a caregiver, what would you ask for?
6. Does anyone ever provide assistance that is unhelpful? Whom? How?
7. Have family members or others criticized you about your caregiving role?
8. What has been the effect of caregiving on your physical health? On your emotional health?
9. Have you needed services that you couldn't get? What services? Why weren't they available?
10. Have you had difficulty submitting services to insurance/Medicare? Explain.
11. If you could use technology such as a video phone call, would you use it to talk with:  
your nurse; your social worker; a spiritual care worker from hospice; a financial counselor; someone from your church, family members living in other towns/states; other?

**APPENDIX D**  
**SOCIODEMOGRAPHICS**

1. Age
2. Gender
3. Education
4. Marital status
5. Ethnicity
6. Relationship to patient
7. Amount of time spent w/ patient
8. Amount of time for self
9. Living arrangements

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