THE CHALLENGES AND NEEDS IN USING TELEHOSPICE TO PROVIDE RURAL END-OF-LIFE CARE

by

Glenn Philip Townsend

A Master’s Report Submitted to the Faculty of the COLLEGE OF NURSING In Partial Fulfillment of the Requirements For the Degree of MASTER OF SCIENCE In the Graduate College THE UNIVERSITY OF ARIZONA

2010
STATEMENT BY AUTHOR

This master’s report has been submitted in partial fulfillment of requirements for an advanced degree at The University of Arizona and is deposited in the University Library to be made available to borrowers under rules of the Library.

Brief quotations from this master’s project are allowable without special permission, provided that accurate acknowledgment of source is made. Requests for permission for extended quotation from or reproduction of this manuscript in whole or in part may be granted by the head of the major department or the Dean of the Graduate College when in his or her judgment the proposed use of the material is in the interests of scholarship. In all other instances, however, permission must be obtained from the author.

SIGNED: Glenn Philip Townsend

APPROVAL BY MASTER’S REPORT DIRECTOR

This Master’s Report has been approved on the date shown below:

Pamela G. Reed, PhD, RN, FAAN  Date:
ACKNOWLEDGMENTS

I would like to thank my Mom, Glenda Townsend, for always being there, my Aunt, Judy Ponitz, for being my friend, Robert Olive, for always providing me with positive words of encouragement and my friend and colleague Janice Littlejohn, RN, BSN, MHA for providing support and encouragement during this endeavor and for believing in me even when I began to question myself.

In addition, I would like to thank the preceptors that gave up their valuable time to train and mentor a new nurse practitioner student. All my preceptors demonstrated a great knowledge based, enjoyed teaching and passing on their experiences. In order of rotation: Joyce Durham, MSN, FNP, ANP, David Briant, MSN, FNP, Keturah Volpe, MSN, FNP, Nicole Hanna, MSN, FNP and Dr. Francis Song, MD, MPH, MS. I wish acknowledge the guidance of Dr. Pamela Reed, RN, FAAN and Virginia LeBaron, MS, ACNP-BC, AOCN, ACHPN during this writing process.

Last, I thank my coworkers at St. Joseph’s Hospital and Medical Center for providing support, encouragement and a place to vent. My gratitude is extended to St. Joseph’s Hospital and Medical Center in Phoenix, Arizona, for continuing the tuition reimbursement program.
DEDICATION

I would like to dedicate my collegiate achievement to several people that are no longer here to see my accomplishments.

My father, the late Gordon Townsend, who showed me that no matter what challenges are presented: I control the outcome.

And to my grandparents, the late Glenn and Mildred Ponitz, who always believed in me and supported my decisions.

To my uncle, the late Steven Johnson, I thank him for being the first person to treat me like an adult. He once told me, if it is something you really want, then you will always have the power to make it happen.

And last, to my best friend, Donna Savage, MSN, MPM, RN, CNS, whom I met many years ago when I was a new graduate nurse on my first job. She instilled in me from the beginning to strive after my goals. It was her encouragement and support that provided me the support to begin this endeavor. Sadly, she lost her battle with Scleroderma and was unable to see me finish.

I would like to thank these very important people in my life. Without them, I would not be who and where I am today.
TABLE OF CONTENTS

LIST OF TABLES .................................................................................................................. 6
ABSTRACT ............................................................................................................................. 7

CHAPTER ONE: INTRODUCTION ....................................................................................... 8
Purpose ................................................................................................................................. 8
Background and Significance ............................................................................................. 8
Definition of Key Terms ..................................................................................................... 10
   Hospice ........................................................................................................................... 10
   Interdisciplinary Team .................................................................................................... 10
   Rural ............................................................................................................................... 10
   Telehealth ....................................................................................................................... 11
   Telehospice .................................................................................................................... 11
Summary ............................................................................................................................ 11

CHAPTER TWO: HOSPICE AND TELEHOSPICE ......................................................... 12
History of Hospice ............................................................................................................ 12
   Access to Hospice ........................................................................................................ 14
Overview of Telehealth ..................................................................................................... 15
   History .......................................................................................................................... 15
Summary ........................................................................................................................... 16

CHAPTER THREE: LITERATURE REVIEW ................................................................. 17
Telehospice Services ......................................................................................................... 17
   Starting with Telemedicine ......................................................................................... 17
Benefits of Telehospice ...................................................................................................... 18
Videophones ..................................................................................................................... 19
Patient and Healthcare Provider Perceptions of Telehospice .......................................... 21
Summary ........................................................................................................................... 26

CHAPTER FOUR: DISCUSSION ..................................................................................... 27
Conclusions from the Research on Telehospice ............................................................... 27
Recommendations ............................................................................................................. 29

REFERENCES .................................................................................................................. 32
LIST OF TABLES

TABLE 1. Methods of Medicare Reimbursement .........................................................14
ABSTRACT

Rural residents often must seek out tertiary health care in the urban setting. This does not coincide with the philosophy of hospice: the right to chose one’s place to die. A large percentage of Americans, including those who live in rural areas, prefer to die in their own homes. However, hospices that accept rural patients find it difficult to meet the needs of hospice patients in a timely and effective manner. The purpose of this paper was to identify the challenges and needs of introducing telehospice to the rural hospice provider. To accomplish this, a literature review was done. Key findings of the literature review were that telehospice enhanced the end of life care for rural patients and caregivers but providers were resistant to its introduction. Recommendations based upon a synthesis of the findings and from this investigator’s clinical knowledge include conducting further research and gaining staff acceptance through education and training.
CHAPTER ONE: INTRODUCTION

The dying process is complicated; both physically and mentally. One of the many benefits patients receive from utilizing a hospice service is the holistic approach to meeting needs. Nursing and medical staff provide physical and emotional comfort. Non-nursing team members are available to provide spiritual, grief and financial information. In the event of a crisis, as perceived by the client, timely in person assistance may not be available to rural residents. The goal of hospice is to allow patients to die in a surrounding of their choice. Rural areas present a challenge in accomplishing this goal.

Purpose

The purpose of this descriptive report is to identify and summarize the advantages and challenges of introducing telehospice. A second purpose is to derive from this review a set of recommendations that can be used to support expansion of end of life services to residents in rural areas.

Background and Significance

Twenty percent of Americans live in a rural community (Wilson, Justice, Sheps, Thomas, Reid and Leibovici, 2006). One fourth of Medicare beneficiaries that die, live in rural areas (Casey et al., 2005). Rural residents are not as likely to use hospice services (Virnig, Ma, Hartman, Moscovice and Carlin, 2006).

Hospices that serve rural areas face several obstacles in being able to provide supportive care for terminally ill patients. Meeting patient’s needs in a timely manner can be a difficult.

Distance is the major obstacle for several reasons. Rural hospices are challenged with the ability to find staff willing to travel large geographical areas. Driving time from one residence to
another consumes the majority of the working day; decreasing the number of daily visits. An emergency or unscheduled visit becomes a time consuming venture for the hospice worker. The delivery of emergency medications and/or durable medical equipment (DME) may be delayed due to distance. Further, patients and their families are encouraged to participate in multidisciplinary care conferences; living in remote areas often makes a visit into the hospice office for a conference impractical.

Geography impacts the financial aspect of hospices. Currently, hospices’ largest payer source is Medicare (Casey, Moscovice, Virnig and Durham, 2005). Per diem fees are adjusted using a wage index (Casey, et al, 2005). Reimbursement rates for rural areas are routinely lower compared to urban hospices (Casey, et al., 2005). Rural hospices experience unique challenges compared to urban hospices; primarily distance. This is not considered when adjusting rural hospice reimbursement rates.

Rural residents generally drive to urban areas to receive tertiary care. End of life services need to be available in one’s home area (Wilson et al., 2006). Staying at home and remaining in one’s own community is typically desired by dying people (Wilson et al., 2006). Several elements factor in to rural coverage for end of life care. The low population of a large geographic area can create a challenge to providing home visits (Wilson et al., 2006). Medicare payments are not adjusted for the distance traveled. This creates a higher cost per patient visit. The use of telecommunications can address these challenges by decreasing the travel time and increasing availability of hospice staff.

Technology can provide a solution. “Telehospice has the potential to address barriers of quality end-of-life care by providing clinical and educational services directly to patients and
caregivers in their homes,” (Whitten, Doolittle and Hemlich, 2001, p. 5). Twenty percent of Americans live in a rural community (Wilson et al, 2006), and the use of telehospice could provide one fifth of the American population with end of life care services.

**Definition of Key Terms**

The following key terms related to end of life care will be defining in the following section. For this report, the following terms will be defined: Hospice, Interdisciplinary Team, Rural, and Telehospice.

**Hospice**

The American Academy of Hospice and Palliative Medicine (n.d.) describes hospice as a service that provides care to a person with a terminal diagnosis. The focus is no longer placed on a curative approach but rather on relieving and controlling symptoms. It is not a place, but a range of services (Kinsella, 2004).

**Interdisciplinary Team**

The interdisciplinary team is a group of professionals that gather together to discuss the delivery of care. The outcome is not based on the professionals’ values but rather focused on the patient’s goals (Oliver, Porock, Demiris and Courtney, 2005). In hospice care this team consists of nurses, physicians, social workers, volunteer coordinators, bereavement coordinators, nursing assistants and music therapists.

**Rural**

The United States Census Bureau [USCB] (2000) definition for rural will be used: an area not classified as “urban.” The USCB (2000) classifies urbanized areas of having a general population density of 1000 people or more per square mile and together have a minimum
population of at least 50,000 people. Urban is defined as places of more than 2500 persons outside of the urbanized areas.

**Telehealth**

Telehealth is the use of telemedicine to remove distance and time barriers in providing health care services (Schlachta-Fairchild, Varghese, Deickman and Castelli, 2010).

**Telehospice**

Telehospice involves the use of technology by hospice professionals to provide routine hospice care via remote communications to end of life patients (Kinsella, 2004). This includes the use of the telephone or videophone (Kinsella, 2003). With the increase of home computer technology, using a webcam may be the next available form of telehospice.

**Summary**

Challenges are presented to hospices providing care to rural area residents that are not present in the urban setting. The main obstacle is distance. This obstacle not only makes routine visits difficult, but can affect the provision of emergent crisis intervention. The rural population is less likely to be able to access hospice services. Hospices that deal with a high rural census may encounter financial difficulties due to Medicare reimbursement issues. Staffing becomes a challenge when having to provide 24 hours coverage to a large geographical area. Taking advantage of the electronic communication world may be the answer.
CHAPTER TWO: HOSPICE AND TELEHOSPICE

History of Hospice

Hospices were used for weary travelers to obtain rest (Connor, 2007). This continued on for hundreds of years (Enck, 2010). The earliest documented hospices where run by religious groups providing care for travelers that fell ill during their journeys (von Gunten and Ryndes, 2005). Select locations were established to provide end of life care in France, Ireland, England and Scotland (vonGunten and Ryndes, 2005). Hospice emerged as its own entity from the works of Dr. Cicely Saunders. St. Christopher’s Hospice was founded in 1967, by Dr. Saunders, in a suburb of London, England (von Gunten and Ryndes, 2005).

According to Connor (2007), Dr. Saunders’ hospice philosophy focused on three components: research, education and care focusing on physical, emotional, spiritual and social. The hospice movement continued to spread internationally and was introduced in the United States when Dr. Cicely Saunders paid a visit to Florence Wald, then Dean at Yale’s School of Nursing (Hoffman, 2005). The first United States’ hospice was established in New Haven, Connecticut in 1974 (Hospice Foundation of America, 2010).

Variations exist between English and American hospice philosophies. American hospices focus care on the patient at home (Connor, 2007). Another variation was the significant role of volunteers in the United States’ hospice programs (Connor, 2007). Professional care is provided by interdisciplinary teams that consisted of nurses, chaplains, psychosocial services and physicians (Connor, 2007).

Dr. von Gunten and T. Ryndes (2005) state that the word hospice has four definitions: patient and family health care pursued in the home; a place to provide care at end of life; a facility
developed for end of life care; and another term for the Medicare Hospice Benefit (MHB) that pays for the majority of hospice patients.

Overall, hospice refers to a philosophy of care at the end of life that addresses the patient and family holistically, focusing on the physical, emotional, social, and spiritual needs of the patient and the psychosocial and spiritual needs of the family during end-of-life care and in bereavement. The emphasis is on providing relief from physical pain and emotional suffering and facilitating development and well-being during this last phase of life. Typically, this means choosing palliative care rather than aggressive treatment during the last six months to one year of life.

The Medicare Hospice Benefit, through Social Security Act amendments, was passed in 1982 (Hoffman, 2005; Connor, 2007). The benefit was made permanent in 1985 after three years of information was presented to congress. Hospice benefits are paid at a fixed rate consisting of four levels of care (see Table 1).
TABLE 1. Methods of Medicare Reimbursement

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Routine Home Care</td>
</tr>
<tr>
<td>2</td>
<td>Continuous Home Care (for crisis, avoid hospitalization)</td>
</tr>
<tr>
<td>3</td>
<td>General Inpatient Care</td>
</tr>
<tr>
<td>4</td>
<td>Inpatient Respite (for up to 5 days)</td>
</tr>
</tbody>
</table>

The rates are fixed daily and the hospice will take a loss if the patient’s care exceeds the daily rate. Hospices are allowed to keep any excess income if the patients’ daily cost is under the allocated per diem fee. If it costs $78.00 to care for a home patient and the MHB daily reimbursement rate is $100.00; the hospice has a profit of $22.00 that day. But if the daily cost of care is $122.00 and the reimbursement is $100.00; the hospice lost $22.00 on that patient. This per diem payment system causes the hospices to focus on cost effective treatment.

Hospice benefits were chosen by 40% of Medicare beneficiaries in 2006 (Enck, 2009). One third of these patients were referred within the last week of their lives. Most are referred because of a cancer-related illness.

Access to Hospice

Connor (2007) writes that the original hospice patient population consisted of white suburban cancer patients. In 2007, Connor wrote that 60% of all patients who died from cancer received hospice services. Currently, there is a significant increase in non-cancer patient admissions. The most common non-cancer diagnoses are dementia, congestive heart failure, stroke, and Chronic Obstructive Pulmonary Disease.

Geography is an obstacle that has not been addressed by hospice providers. Whereas 49% of Arizona deaths were covered by hospice services, only 11% of Alaskan deaths received
hospice care (Connor, 2007). Homecare is provided to 80% of all hospice patients (von Gunten and Ryndes, 2005). Thus, the problem is not the lack of hospices or the funds to support hospice care, but rather the lack of access to those hospices by people who live in rural areas.

Providing care to rural residents is not a challenge because of a lack of hospice organizations but rather because of lack of access to the available hospice organizations. According to Enck (2009), there were 59 hospices in 1978, 440 in 1980 and grew to 4200 currently. The difficulty arises when one patient is located 100 miles from another.

**Overview of Telehealth**

One must understand the concept of telemedicine in order to grasp the full meaning and value of telehospice. The terms telemedicine, telehealth and telenursing are used interchangeably. For the purpose of this report, the term telehealth will encompass these three terms.

**History**

Telenursing, which is nursing care provided via telemedicine, has been in existence for 35 years (Schlachta-Fairchild, Varghese, Deickmand and Castelli, 2010). Use of telehealth eliminates the distance and time obstacles. In the American Recovery and Reinvestment Act of 2009, the use of telehealth has been used as a core strategy by the Obama administration (Schlachta-Fairchild et al., 2010).

Methods of delivering telehealth services include, but not limited to, the use of telephones, videophones, computers, fax machine and wearable sensors (Schlachta-Fairchild et al, 2010; Kinsella, 2005). A key issue to making the use of electronics a success is the providers' ability to remain connected with the patient. This can be accomplished with the use of two
strategies: listening and communication (Schlachta-Fairchild et al., 2010). Methods to reinforce one is understanding and caring is the use of the reflection technique (Schlachta-Fairchild, 2010). The receiver “reflects” the message back to the sender with some additional feedback.

**Summary**

Hospices began as a place for travelers to get rest. The rest place transformed over the years into a place for individuals to receive end of life care with support of health care professionals. Dr. Cicely Saunders was known for establishing the first hospice that provided inpatient care to terminally ill individuals. Dean Wald invited Dr. Saunders to the United States. This merger of information led to the first United States hospice being established in 1974. The United States’ hospice concept focuses on home care versus England’s inpatient theme. Medicare is the largest source of funding for hospice care. Even though payment is available, a large difference of terminally ill patients electing hospice benefits is based on geography. Using telehealth could assist in meeting the needs of the remotely located patient.
Telehospice Services

Telehospice services that are provided with telemedicine are called telehospice. The majority of hospices utilize some form of telehospice. This is accomplished with the use of telephones in providing advice, comfort and support. Telephones allow hospice professionals to provide support when they are not available for in home visits (Wilkes, Mohan, White and Smith, 2004). The telephone system is also utilized by hospice services at night to assist patients and caregivers during crisis situations (Wilkes et al., 2004). Telephone visits often involve a nurse calling the patient to ensure the use of the treatment plan, answer any questions and provide early symptom control (Riegel, Carlson, Kopp, LePetri, Glaser and Unger, 2002). The use of the telephone can be enhanced by adding a video system.

The rural hospice access gap could be reduced by the use of telehospice (Kinsella, 2004). Telehospice would allow patients and their caregivers to establish a quick visual connection with a hospice professional. Nursing staff make up the majority of hospice employees. One social worker may cover many patients spread out over a large area. It is not always an option for a social worker, chaplain, or bereavement professional, working in a rural setting, to be available for immediate personal home visits when a crisis occurs.

Starting with Telemedicine

Limited research is available on the use of telehospice. The home health industry was an initial site for telehealth research. Hopp, Woodbridge, Subramanian, Copeland, Smith and Lowery (2006) conducted a study on the outcomes of telehealth interventions with 37 home care patients. The intervention group had contact with the health care staff via home visits, telephone
and a video unit. Results indicated that the mental health satisfaction increased within the intervention group. In addition, the overall satisfaction of equipment use was high. There were no statistically significant differences between the intervention and control groups in regard to changes in physical health, inpatient admissions, emergency room visits or general satisfactions on home care (Hopp et al., 2006).

A similar study was conducted by Johnston, Wheeler, Deuser and Sousa (2000). The intervention group was given video access to nurses in addition to the use of home and telephone visits. The results indicated that no changes in disease knowledge, ability to care for oneself, medication compliance or patient satisfaction occurred (Johnston et al, 2000). However, 90% of the participants in the intervention group indicated that they were appreciative of the video visits, confident in the assessment received and comfortable discussing their personal problems (Johnston et al., 2000).

**Benefits of Telehospice**

When delivering end of life care, it is considered the gold standard to provide 24 hours access to a health care professional (Phillips, Davidson, Newton and DiGiacomo, 2008). Australia supports a system of universal health care coverage and has a mandate to provide equitable service delivery. However, Australians in rural and urban areas do not receive the same level of service (Phillips et al., 2008). Based on the gold standard, a local after-hours support system by telephone was established in regional Australia. Patients and/or caregivers could call in with concerns and questions. Support was provided by generalist nurses. The nurses were provided with telephonic support education and were able to obtain real time patient information while on the telephone. Phillips et al. (2008) initiated a study of this process among the 357
patients registered in the rural palliative care program. The study began on March 31, 2005 and ended November 15, 2006.

A review of the data shows that only 10% of the patients or their caregivers accessed the telephone support system. The most common reasons for utilizing telephonic support was issues regarding medication usage, symptom management and anxiety (Phillips et al., 2008). According to Phillips et al. (2008), most issues experienced by the callers could be resolved over the telephone. The authors concluded that the caregivers overwhelmingly were complimentary to the use of the telephone support they received.

The cost effectiveness of such a program proved beneficial. There was a savings by patients not utilizing emergency services and not having to send a professional to the home. Also, it was concluded that by having generalist nurses, this service could be expanded to other conditions, particularly cancer services (Phillips et al., 2008).

**Videophones**

Videophones provided additional benefits to telehospice. These phones can be connected using a standard house land line. This would allow the patient to see the end of life care professional as well as allows for the patient to be seen. There have only been a few studies conducted on the use of videophones in regards to end of life care. It is even more limited when one includes the rural area aspect. The following literature provides information on the use of videophones in providing telehospice.

Whitten, Doolittle and Mackert (2004) collected data from 187 patients who received telehospice services, via videophone, in their homes between 2000 and 2002. The data reviewed by Whitten et al. (2004) was obtained from a study conducted in urban and rural Michigan.
Patients from four hospices within Michigan were invited to participate. Stipulations were that the patients must reside in a personal home with current landline phone service available at the time of enrollment (Whitten et al., 2004). Videophones were placed in the homes using the pre-existing phone lines. Enrollment began in February 2000 and data collection was completed in October 2002 (Whitten et al., 2004). Data were gathered on the patient’s perception on the use of telehospice services. During this time period, 749 telehospice visits were conducted. Forty-percent of the patients in the study were living in a rural area. However, 59% of the telehospice visits were conducted on the rural patients (Whitten et al., 2004). In terms of the type of visits being conducted during this study, routine visits were the main use of telehospice services, consisting of almost 70% of all visits, 29% of the visits were unscheduled, and less than 1% of the visits were for emergencies. The overall conclusion indicated patient and professional satisfaction (Whitten et al., 2004).

Whitten et al., (2004) also provided an example of emergency use. At 3:00 AM, a caregiver called in to the service to report the patient was having extreme abdominal pain. The nurse asked the caregiver to scan the entire length of the patient with the videophone. The nurse was able to see that the catheter was kinked. The nurse explained to the caregiver on how to rectify this problem. The use of this system saved the nurse from having to drive 120 miles round trip and saved the hospice the cost of hourly wages to make such a visit. In addition, the patient’s discomfort was relieved instantly versus having to wait until a nurse arrived.

Another potential benefit of telehospice including videophones is patient access to the team and the family unit. Hospice caregivers consider the patient and family as a single unit of care (Oliver, Demiris, Wittenberg-Lyles and Porock, 2009). In developing a plan of care, it is
highly encouraged to have the input of all team members and the patient/caregiver. Family members and/or patients are not always able to attend interdisciplinary team (IDT) meetings for a variety of reasons. One of these reasons is geography. Oliver et al. (2009) studied the use of the videophone in IDT meetings. Use of the videophone would allow the patients and/or caregivers to participate in the IDT meetings. Oliver et al. (2009) proposed that the inclusion of families and patients in biweekly IDT meetings would improve satisfaction, care coordination and communication and access to specialists. They concluded that the use of the videophone offers a potential solution to overcome geographical challenges (Oliver et al., 2009).

**Patient and Healthcare Provider Perceptions of Telehospice**

The purpose of Whitten, Doolittle and Macker’s (2004) study was to identify the patients’ perception of telehospice. Thirty-five patients were interviewed during this study. Sixty percent of the patients stated the best thing about telehospice was the access to immediate care. When asked about making changes to the telehospice service, 70% of the patients responded that no changes were needed. Mixed reviews were received when patients were asked about differences in care provided by telehospice versus in person visits. Seventy-seven percent reported some difference. However, one stated that it was due to a lack of physical closeness and another stated that it was because you can see a provider whenever you want via video (Whitten et al., 2004). Twenty-five percent stated that some change in the equipment was needed. The most frequent suggestion was to have a bigger phone. The conclusion was that 60% of the patients believed that telehospice provided a positive experience to their dying process. One patient reported that just having it available was a “peace of mind” (Whitten et al., 2004).
It is not only the patients’ perceptions that will influence the use of telehospice availability. Providers must become familiar with the use of visiting a patient without physical contact. Whitten, Doolittle and Mackert (2005) used the same data from their study in 2004 to gather information to determine telehospice acceptance among providers.

They began this study with the awareness that more rural offices utilized telehospice services than providers that practice in the urban setting (Whitten et al., 2005). Fifty-five percent of the total visits were with rural patients.

Five focus groups were conducted to gather data. Three questions were posed to the providers participating. These questions ranged from pre-use perceptions, did perceptions change during use and impact of perception on use of system. The data showed that providers’ perceptions of telehospice did not change during the study period. Whitten et al., (2005) stated, “Evaluators believe that providers approached this telemedicine project with specific perceptions regarding comfort, ease of use, and value.” Two significant items were identified: 1) conducting more than 11 visits provided a better comfort level with use of the equipment and 2) the more experienced providers felt stronger about the positive use of telehospice.

Providers expressed understanding of the benefits of telehospice but still preferred in person visits. Some nurses stated that they were afraid of losing their mileage reimbursement, a significant portion of their incomes (Whitten et al., 2005). Greater than 60% of the nurses were concerned of the changes that may occur in the nature of their work. They viewed the services as a potential threat to autonomy they have as a home health nurse.

A small study was conducted in New South Wales, Australia pertaining to the professionals’ viewpoints on the use of a telephonic support system (Wilkes, Mohan, White and
Smith, 2004). The sample consisted of 48 health professionals and 21 nurses who worked with palliative care patients received questionnaires. The nurses who answered the calls were asked if they would participate in an interview. The respondents were low in number. A total of 22 questionnaires were received from professionals, while 15 nurses returned their questionnaires. Four telephone interviews were conducted with nurses.

Both quantitative and qualitative data were collected. Information was gathered from log books, journals, interviews and questionnaires. The information was gathered eight weeks after the start of the study. It was established that 12 calls were received in that time period. Issues addressed pertained to specific care concerns. The overall response by all health care providers was positive (Wilkes et al., 2004). According to Wilkes et al. (2004) one important finding was a concern about sense of security felt by the patients and caregivers that the service was available. Another issue that arose was the need for publicizing the available service since the service will not be used if no one is aware of its presence (Wilkes et al., 2004).

Once a hospice acquires videophones, the challenge is to get staff participation. Day, Demiris, Oliver, Courtney and Hensel (2007) address the underutilization of videophones. The authors state the literature supports patient and caregiver satisfaction with the introduction and use of telehospice in end of life care. However, literature does not support provider acceptance. Day et al. (2007) state that literature demonstrates that providers have positive perceptions of technology in providing care and yet do not utilize the equipment once it is acquired. Providers hold the key to whether or not patients are introduced to telehospice services.

Day et al. (2007) conducted a study on two United States midwestern hospices. One was in rural Missouri and one in urban Missouri. In both facilities, the videophones were introduced
as tools to be used in addition to in person visits. Contact with patients would include routine follow-up, emotional crisis intervention and emergency assessments (Day et al., 2007). The study involved 17 participants from two separate United States midwestern hospices. One interview question pertained to the staff members’ initial response to the introduction of videophones in their hospice.

The results indicated that 12 staff members were initially positive to the use of the technology and five members were skeptical about its use. Nurses were generally more positive towards the videophone use than the social workers (Day et al., 2007). Perceived benefits of the use of videophones included enhanced communication, decreased caregiver anxiety and the ability to conduct patient assessments. Additionally, staff that has never seen the patients, such as medical directors and on-call nurses, would be able to interact with the patients (Day et al., 2007). Twelve staff members also included the use of the videophones in team meeting and connecting with distant family members.

Three disadvantages were perceived: 1) Equipment issues; 2) Patient and family issues; and 3) Staff issues. Ten respondents perceived equipment as being the major barrier to use of the system. The most frequently used word was unreliable (Day et al., 2007). The best description of this concern was that the equipment needed to work the first time and every time. Respondents were critical of the video quality and some were concerned over the audio abilities. Three people had never seen the picture, but had heard it was of poor quality. Four people said the video and audio were of a good quality. A call was never placed by the majority of the respondents.

When asked about the appropriateness of the patient for a videophone referral, the answers were conflicting. Some said the patient should be bedridden versus those who responded
the patient should be mobile (Day et al., 2007). The final responses from staff summed up the mixed perceptions. One stated that it would be good to use more technology while one stated that there was no need for it (Day et al., 2007).

Oliver, Demiris, Day, Courtney and Porock (2006) interviewed two hospice caregivers regarding the use of a videophone to improve provider communication. The authors’ goal was to establish if the use of technology was effective for managing a clinical intervention. Two participants were recruited from a small rural midwestern hospice. A videophone was installed using a regular household telephone line. The participants consisted of two male caregivers. The first participant was a 77 year old retired gentleman. He utilized the technology for 100 days until his health declined. This participant was receptive to the installation and his first reaction to the use of the phone was to “laugh out loud at seeing an image on the videophone,” (Oliver et al., 2006). A week later, the research assistant contacted the participant via a standard telephone and the participant expressed disappointment that he was not contacted by videophone.

The second participant was a 75 year old gentleman. He utilized the videophone while his wife was receiving hospice services. The videophone was used for 30 days prior to the death of his wife. This participant was interested in the videophone and asked for the user’s manual in order to utilize other features of the machine. This participant and his wife offered to develop a one page instruction sheet. Other family members became interested in the videophone and the participant’s daughter inquired as to where she could obtain one. As the patient’s condition deteriorated, the participant became less interested in the study and moved the videophone out of the way.
During this study, the hospice staff was reluctant to refer participants. They became frustrated with the installation process. Instead of using the staff for data collection, a graduate research assistant (GRA) was brought in for the study. The staff became more receptive after viewing the interactions. During an IDT meeting, one nurse reported how much the first participant enjoyed the videophone. The majority of the calls remained generated by the GRA and not by the staff.

The final article reviewed addressed reasons for the slow adaptation of telehospice. Whitten, Holtz, Meyer and Nazione (2009) conducted interviews and focus groups with 25 hospice employees. All the employees had received videophone training prior to the study. However, 39% of the respondents reported no training (Whitten et al., 2009). It was discovered that leaders of the hospice did not endorse the use of videophones. The respondents reported that they believed the equipment was easy to use. The majority of the nurses that responded stated that they were not anxious about the use of the machine but there was a lack of incentive to implement use (Whitten et al., 2009). The authors conclude that the findings of this study “suggest that rewards for videophone usage or punitive action for non-usage are matters that warrant further investigation,” (Whitten et al., 2009).

Summary

Rural hospices have limited funds and yet must provide care to patients in a large geographical area. The use of videophones has been explored in the use of providing end of life care. The initial response to technology appears to be accepted more by the patients and their caregivers than by the professional hospice community. Even after a trial period, some providers remained skeptical of the use of technology in hospice care.
CHAPTER FOUR: DISCUSSION

Conclusions from the Research on Telehospice

Eleven articles were reviewed for the purpose of this paper. The research covered the areas of initial use of telehealth in home care, the use of telehospice via videophone and the perceptions of patients and hospice staff. Journals such as *Journal of Hospice and Palliative Nursing*, *Journal of Palliative Medicine*, *American Journal of Hospice and Palliative Medicine* and *The Journal of Rural Health* provided the majority of articles.

The use of videophones may allow rural patients that are facing end of life issues to obtain previously unavailable care. Videophones can be utilized to conduct routine visits, as well as provide emergency support (Whitten et al., 2004). Research on the use technology in reaching out to rural hospice patients is limited.

When deciding to conduct research using telehospice, the tools chosen can influence the acceptance of telehospice. Without careful assessment and implementation, the tool can lead to user dissatisfaction with the telehospice system. According to Kinsella (2001), the challenge in tool selection is two-fold:

1. First selection of the tools must occur by developing a tool to provide information on the research topic.

2. Matching the appropriate patient with the correct tool by selecting patients that will be able to use the chosen tool.

The tool used should be able to provide the researcher with needed data from the participants. Selection of participants must match with the chosen tool. The tool needs to be user
friendly as this is already a stressful time and the participants should not be expected to devoted limited time to completing a data collection device.

As noted by Day et al. (2007), the introduction of telehospice services may be met with preconceived notions on the part of the staff. Hospice teams expressed a fear that a loss of personal contact will develop with the use of technology. Along with that, nurses fear a change in job roles and lost income.

Overall, hospice staff may express some reluctance with the use of technology in order to provide patient care. It was mentioned in one study that the administrative staff did not endorse the use of telehospice and this influenced the staff’s perception. However, with proper staff education and involvement, the use of telehospice was greeted with less pessimistic views. This was demonstrated by Demiris et al. (2004) as they identified the study ended with hospice staff having a positive attitude towards telehospice.

The studies reviewed generally reflected an overall satisfaction by patients. The case study concerning two caregivers (Oliver et al., 2006) demonstrated that caregivers were receptive to the use of telehospice because it not only may have improved communications but, as in the case of the second participant, may also have increased family support. Unfortunately, the study was very limited with only two participants. One area of limitation in this case study was that information was not gathered on the benefits of using the videophones for symptom management and caregiver support.

Whitten et al. (2004) concluded that patients expressed a sense of satisfaction with the use of telehospice. Patients reported that telehospice had enhanced their end of life experience.
Patients expressed enjoying the immediate access to providers. However, one must consider if this same outcome could be accomplished with a regular telephone.

The inclusion of patients and caregivers in the development of a plan of care is a key element of hospice. The use of videophones would allow patients and their caregivers to participate in IDT meetings. This would allow patients to see who is talking and to be able to meet all members of their care team.

All of the studies had one element in common: a small sample size, with most under 50 participants, and one with 200 participants. This limits generalizability of the findings as the samples are not reflective of all hospice staff, patients or caregivers. The length of the studies was limited. Oliver et al. (2006) collected data over 100 days. The study by Whitten et al. (2004) was conducted over two years and involved 187 participants. As this was the largest of the studies, it still does not provide a large sampling to be reflective of overall hospice recipients.

**Recommendations**

As a result of this literature review and synthesis, several recommendations were identified. The recommendations are diverse, as this area of focus is relatively new to practice, research, and policy.

The first recommendation focuses on continued research efforts. There is a distinct need for research on distance technology for end of life care to rural residents. Further research needs to incorporate larger samples, examining the influences of technology over time. As technology is always changing, new research needs to include evaluation of the use of newer technology such as computer video conferencing, as it emerges in other health care settings.
As with anything new, there is a period of growth. The buy in by hospice staff is needed in order for telehospice to be successful. Thus, a second recommendation is to design education and provide for practice experiences using the new technology, to enhance the comfort level and acceptance among staff.

Third, a more practical recommendation concerns the use a nurse practitioner in conducting the telehospice visits. This would benefit both the hospice and the patient. These nurse practitioner visits could be utilized as both nursing and provider visits. Thus, it would eliminate one step in the care process of having the nurse act as a middleman between the provider and the patient.

Fourth, recommendations concerning policies for financial management of telehospice are important if this technology is to be a sustainable approach for end of life patient care. Rural hospices typically receive less reimbursement than urban hospices. The use of technology to reduce costs may be a significant innovation to increase the services to over 25% of the United States population. Thus, one recommendation is that there be a change in financial reimbursement of the rural hospice system by which the payment system accounts for the distance between patients and driving time. In addition, grants may be used to help cover the start-up costs of implementing and evaluating new technology such as videoconferencing. These monies can help defray the purchase cost and the hospice would then have to absorb only the training expenses.

Last, guidelines should be established by each hospice regarding the number and type of visits that can occur with a patient. The use of telehospice may include basic guidelines that apply across patients, but should also include judgment on an individual level. The use of
telehospice may be used as a supplement rather than as a primary mode of care at the end of life. Dying is a very personal experience and the need for in person visits remains the central concept. Thus, guidelines need to be developed to determine which and when patients are appropriate for the use of telehospice. Nurses, based upon their scientific and clinical knowledge, develop keen insights into the kind of care needed by patients and families facing end of life.

The case manager nurse needs to be the deciding factor on what patient is appropriate to use telehospice, as well as, when it is appropriate to introduce telehospice to the patient and caregiver. Further, these care decisions depend upon the autonomy and unique role of the hospice nurse, contrary to the concerns about diminished autonomy voiced by some nurses in the research reported here.

Research and clinical experience provide beginning evidence that the use of telehospice benefits rural patients’ end of life experience. Telehospice can reach out to and make a difference for those who otherwise would be excluded from expert nursing and non-nursing care because of geography. Maintaining low costs and providing quality health care access to patients at end of life requires particularly creative interventions. Bringing together research, practice, and financial recommendations are important for the future design of nursing interventions that can enhance the end of life experiences for individuals and their families who reside in rural areas of the nation.
REFERENCES


