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# Health Care Professionals' Perspectives on Their Patients' Access to Hospice Care

Tammy Ferderer  
*St. Catherine University*

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# Health Care Professionals' Perspectives on Their Patients' Access to Hospice Care

By

Tammy Ferderer, B.S.W, LSW

MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
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Committee Members  
Jessica Toft, Ph.D. (chair)  
Beth Bouman, MSW, LGSW  
Sarah Clough, RN

The Clinical Research Project is a graduation requirement of MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's Thesis nor a dissertation.

### **Abstract**

Hospice is available to those who have been diagnosed with a terminal prognosis and have less than six months of life left. Although these benefits are available for much longer, most people are only utilizing hospice care during their very last days of life, less than 20 days. This short length of stay also does not allow the patient time to take full advantage of all the services that hospice has to offer. There seems to be barriers for individuals to receive a timely enrollment into hospice, whether it is the healthcare providers, the patients themselves, or their families. The purpose of this study was to take a look at ways doctors, nurses, and social workers promote or hinder access to hospice for their patients. If patients are eligible for hospice when they have less than six months to live, why are the majority waiting until the last few days or hours? The researcher utilized a mixed methods research design. An online survey through Qualtrics was available to doctors, nurses, and social workers. The final sample consisted of 14 doctors, nurses, and social workers. The researcher used computer software, Qualtrics, for descriptive data analysis. A qualitative content analysis was utilized to determine emerging patterns and themes gathered from the online survey. The findings indicated the same percentage of the respondents, agreed their professional education and training trained them to help patients understand their terminal diagnosis, yet they disagreed that their professional education and training prepared them to know when a hospice referral would be appropriate for those same patients. These findings also indicated that the majority of respondents still feel that the physician is responsible for making a referral to hospice. The social work profession needs to find a way to show the doctors and nurses that they are capable to assist with these patients and might even be a better choice to have these hard discussions with these patients and families as social workers are trained to work with these difficult issues.

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### Health Care Professionals' Perspectives on Their Patients' Access to Hospice Care

Death is a natural part of life. According to the National Hospice and Palliative Care Organization, 88% of individuals would prefer to die in their homes, free from pain and surrounded by those whom they love (2012). Hospice allows this to become a reality and offers services to individuals who have been diagnosed by their primary physician with a terminal illness and have less than six months to live. Hospice is an option that is covered by most insurance. Medicare also has a hospice benefit for coverage, for those who are eligible for Medicare benefits.

Dame Cicely Saunders is considered the founder of the hospice movement. She cared for individuals who were in their last stage of life and founded St. Christopher's Hospice, located in the United Kingdom. She chose the name, St Christopher, because he is the patron saint of travelers, which she wanted to represent as the hospice's mission to care for those traveling through their final stages of life (Silverman, 2009). She stated, "You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die" (Allina Health Hospice and Palliative Care, 2013). Hospice was first introduced into the United States in 1974 by Florence Wald, two pediatricians and a chaplain. Wald went to the United Kingdom to study hospice care under Dame Cicely Saunders. These individuals founded the first hospice in Bradford, Connecticut (National Hospice and Palliative Care Organization, 2013).

The individuals who choose to utilize hospice can be served in their homes, nursing homes, assisted living facilities, some hospitals, or at a stand-alone hospice facility (Hospice Association of American, 2010). The services that are provided by hospice are medical, emotional, and spiritual in nature. These services include: doctor services, nursing services,

medical equipment and supplies, drugs for symptom and pain control, home health aide, homemaking services, social work services, grief and loss counseling, spiritual care from the clergy through hospice or their own pastor, inpatient care, respite care, physical and occupational therapies, speech language therapies, dietary counseling, and bereavement services for their family for up to 13 months following their loved ones death (Hospice Association of America, 2010).

According to the US Census Bureau Statistical Abstract of the United States in the year 2012, there were 2,423,712 deaths in the US. In 2011 1,059,000 patients died under hospice care. That would equate to about 44.6% of all the people who died in the United States were using hospice when they passed away (National Hospice and Palliative Care Organization, 2012). The average length of service for hospice for those individuals who were enrolled in 2011 was 19.1 days (National Hospice and Palliative Care Organization, 2012). Hospice is available to those who have a terminal prognosis and have less than six months of life left (Hospice Association of America, 2010). This means that although the benefits of hospice are available for much longer, most people are only utilizing hospice care during their very last days of life, less than 20 days.

In fact according to the National Hospice and Palliative Care Organization (2012), the portion of the population that grew the most were those that only used hospice for seven days or less before they passed away. The percentage of this population was approximately 35.7%, which causes concern. This all too brief exposure to hospice does not allow patients and families time to take full advantage of the benefits of the program (Shin & Casarett, 2011).

The requirements to be eligible for hospice are a diagnosis of a life limiting illness and having less than six months to live. Having too short of a length of stay with hospice does not



give individuals who are dying adequate time to be able to accomplish important end of life activities such as closure, pain management, and time to grieve with their family (Waldrop & Rinfrette, 2009). The individual who is dying is not the only person who benefits from a longer length of stay with hospice; their loved ones benefit as well. They can get assistance with caring for their loved one. Helping a loved one die alone can be very scary, but having staff there to educate and support them through the stages of death can be comforting and normalizing. Short lengths of stay on hospice are also challenging for the hospice team. They do not have much time to do their assessments on how to best serve this individual and their family when the person is already in the last days of life (Waldrop & Rinfrette, 2009).

Patients' physicians have some control over when their patients sign up for hospice. Individuals need a physician's order to be eligible for the program. Since hospice has its primary focus on caring for the individual and no longer curing their disease, most doctors may see that as a failure to the practice of medicine (Shin & Casarett, 2011). Patients rely on their physicians to discuss their disease and their prognosis. One study reported half of the individuals who were diagnosed with metastatic lung cancer did not have the hospice discussion with their doctor within four to seven months after diagnosis (Huskamp, Keating, Malin, Zaslavsky, Weeks, Earle, Teno, Vernig, Kahn, He, and Ayanian, 2009). Early conversations however, about the end of life would likely be greatly valued as most individuals want the opportunity to prepare for the end of their life (Shin & Casarett, 2011).

There are some discrepancies with what is the appropriate timeline for individuals to be on hospice. It is extremely important to have the hospice discussion with patients at the right moment in their terminal disease process (Waldrop & Rinfrette, 2009). One study found that it was only after hospice had been called in to help during the final stage of life, that family

members really understood what hospice could offer. Most of these families, however, wished they would have been able to find out this information earlier (Casarett, Crowley, & Hirschman, 2004). Waldrop and Rinfrette (2009) state in the absence of clearly communicated diagnosis, patients and their families may not truly understand that the end is near. The doctor is typically the first person that is involved in bringing up the hospice option. Unfortunately, they often wait until late in the process to have the discussion.

This study will attempt to examine this gap of timely referrals to hospice to allow patients to be able to prepare for their last stage of life. If more patients and families were given the opportunity and information earlier, there might be a rise in the number of individuals who have a three month length of stay on hospice, rather than just an average of 19.1 days or as recent data indicates, seven days or less (National Hospice and Palliative Care Organization, 2012). The purpose of this study will be to take a look at what ways doctors, nurses, and social workers promote or hinder access to hospice for their patients. If patients are eligible for hospice when they have less than six months to live, why are the majority waiting until the last few days or hours?

## **Literature Review**

### **Understanding Hospice**

Hospice is a program that was started to provide quality and compassionate care to those individuals who are dying. The focus of hospice is on caring for the individual who is facing death within the next six months and no longer on curing their illness (National Hospice and Palliative Care Organization, 2013). Caring for those who are dying and their families is what hospice does best (Young Bushfield & DeFord, 2010). According to Dunn there are typically three goals for a person's medical care: a cure, stabilization of functioning, or preparing for a

comfortable and dignified death (2009). Most medical care today is focused on curing disease and illness. When there is no cure for the disease, the second goal of stabilization of function is usually sought. This functions to stop the disease from getting worse temporarily. When the other two goals are no longer valid, the third option is appropriately sought, that is preparing for having a comfortable and dignified death. This allows individuals to prepare for their death and allows closure for them and their loved ones (Dunn, 2009). When this third goal is important to individuals, then hospice can provide a great service of a good and appropriate death to those who are preparing to die. This good and appropriate death includes: to be pain free, to have optimal cognitive ability, to resolve residual conflicts, to satisfy possible last wishes, to give control to others they trust, to come to closure with one's life, and to accept the finality of life (Hobart, 2008).

The quality of the care that people receive while on hospice can mean many things to many different people, and a number of studies have been done to measure what those quality measures are. Hospice providers support people with information about a time in their life that most people are unfamiliar with, their death. Most people do not understand what their bodies go through when they are preparing to die. Hospice can help people to understand what this part of life looks like, so people do not have to be afraid with what is happening (Young-Bushfield & DeFord, 2010). They are also not just speaking to the individuals who are receiving services from hospice, they are also speaking to those that are the closest to them and sometimes those factors of quality are not always the same to each of these individuals.

Hospice services in the United States are considered excellent according to a survey done with individual's loved ones and their physicians (Hospice Management Advisor, 2011). These individual parties are in agreement that hospice can improve the lives of those who are dying and

are there to support their loved ones even after the person passes away (Ache, Shannon, Heckman, Diehl, & Willis, 2011). One measure of quality of care that a patient receives from hospice can be measured by the intent of the families to recommend hospice services to someone else. A study done by York, Jones and Churchman (2009) did just that. Out of 576 surveys, respondents reported at a rate of 97.6%, they would recommend hospice to someone else who was struggling with end of life issues. Most families and patients of hospice become very close with the staff who serves them during this time of need. Many interpersonal relationships are formed between the staff and the family during this time. Hospice will continue to follow the family with support for up to 13 months after the death of their loved one (National Hospice and Palliative Care Organization, 2012).

Hospice is a program that works toward providing quality care preceding the end of a person's life. They also address the needs of the family of the person who is dying (Csikai & Martain, 2010). "Hospice care is an interactive experience of tremendous intimacy that often has life-altering consequences for the patient, the family, and even the hospice team. Hospice teams aim to accomplish this experience by focusing on the whole family. In hospice, there is a belief that the family is the patient" (Young Bushfield & DeFord, 2010, p. 3).

Hospice is a service that is covered by Medicare, Medicaid and private health insurance companies. These benefits are available to all when one decides to choose care over curing their disease. For one to be eligible for hospice, a diagnosis of a life limiting disease is determined by their physician with less than six months to live, and an official order for hospice has to be written by the physician for hospice care (Hospice Association of American, 2010). This determination should assist health professionals, individuals with the life limiting disease, and their families to be able to understand that they are eligible for hospice care before the last week

of their life (Waldrop & Meeker, 2011). The diagnosis of the life limiting disease with less than six months to live has to be determined for hospice services to start and for these benefits to be covered by Medicare, Medicaid, and patient's private insurances.

In the United States the health care options are extensive. It is not an easy system to navigate if one does not already know or has already been involved with some of the options. People who have been diagnosed with a life limiting illness need to have people that are working to assist them in navigating this massive system. According to a study done by Csikai and Martin (2010), many people lacked an understanding of what hospice is and how they and their family could benefit from the service. This is unfortunate because families will be less likely to ask for hospice if they do not understand its merits. Therefore, education and communication of what hospice is and how one can benefit from the service is essential. The communication of this information to the patient and their family is important and directly relates to their satisfaction with the care that they receive. This information is important to receive before, during, and after hospice has started (York, Jones, & Churchman, 2009).

### **Timing the Transition to Hospice**

There is much debate among professionals of when the right time is to refer individuals to hospice care. As stated earlier, one of the requirements for admission to hospice is a signed order by a physician. The physician is typically the first person to have the hospice conversation with individuals who have been diagnosed with a life limiting disease. However, all parties including patients, their loved ones, and their physicians typically come to an understanding about what the life-limiting disease means at different times and each in their own way (Waldrop & Rinfrette, 2009). All three parties will need to shift their hope for a cure, to hoping for the best possible quality of life, which often times can be a difficult task. The individual's physician

is seen as being highly influential in how they and their loved ones understand their prognosis and the disease process. This can greatly influence the timing and length of hospice use (Waldrop & Rinfrette, 2009). In some studies, physicians have stated that they do not want to be perceived as giving up hope for a cure for their patient or seen as using hospice as a cost saving technique (Brickner, Scannel, Marquet, & Ackerson, 2004).

Doctors' worries about suggesting hospice, belies the fact that hospice is a program that generates a lot of discussion and controversy. This controversy centers on the issues of economics of healthcare and compassionate care for the patient with a terminal illness. Healthcare in the United States is expensive. Excessive testing, specialists, and care in the hospital can be costly to individuals and insurance companies (Stillman & Syrjala, 1999). Physicians worry that a suggestion of hospice will be seen by patients and their families as mainly a means to save health care dollars. This divergent perspective of hospice is seen as a large reason why physicians hesitate to refer patients to hospice (Csikai & Martin, 2010). However, having an open and honest discussion with patients about their illness and its progression could prompt patients to start hospice earlier, therefore resulting in a longer length of stay on hospice (Csikai & Martin, 2010).

**Reasons for Entering Hospice Earlier in the Disease Process.** Individuals who are diagnosed with a terminal illness with less than six months to live can benefit from an earlier admission to hospice. Currently, one-third of the individuals who are admitted into hospice die within one week and another one-third die within the first 30 days (Waldrop & Rinfrette, 2009). About 70% of patients who enter hospice do so experiencing unnecessary pain which could have been lessened by entering hospice earlier in their disease process. Of that 70%, 10% are experiencing uncontrollable pain (Becker, 2004). People who are preparing for their death do

not have to experience this level of pain when they choose hospice. Having a short length of stay on hospice is viewed by professionals as only having a minimal opportunity to accomplish end of life goals; such as closure, comfortable dying and effective grieving (Teno et al., 2007). This short length of stay does not allow the hospice provider enough time to get to know the patient, perform assessments, establish relationships and start effective interventions for the final days of the patient's life (Rickerson et al., 2005). This short length of stay also does not allow the patient time enough to take full advantage of all the services that hospice has to offer. These patients still value the ability to prepare and plan for the end of their life (Shin & Casarett, 2011). Late stage admissions to hospice are considered to be very chaotic by the family and the hospice team (Teno, Casarett, Spence, & Connor, 2012). According to Becker (2004), almost half of the caregivers surveyed felt their loved one was not referred to hospice with enough time to understand all of what hospice could offer to them. If individuals are not receiving the correct information in a timely fashion, there would seem to be a lack of understanding of how beneficial hospice can be for those who are facing a life limiting disease.

“People who are dying need the time to plan for the end of their life. They need time to put their affairs in order, time to speak with their loved ones, time to grieve, and it can also be time to celebrate and reminisce a lifetime” (Shin & Casarett, 2011). Short lengths of stays are not desirable for hospice care. The length of stays that are less than seven days do not allow for a quality end of life care that hospice can offer. These stays seem to be very stressful and upsetting to the family and their loved ones. Most of these types of stays do not allow for a peaceful death at home, which is most individual's wish. These types of stays tend to happen in a facility of some kind (Teno, Shu, Casarett, Spence, Rhodes, & Connor, 2007). These short length of stays and too late referrals have the families reporting they felt their loved ones had

unmet needs and showed a greater dissatisfaction with the end of life process (Teno et al., 2012). Studies have shown that experts believe that the appropriate referral to hospice is three months before death (Teno, Casarett, Spence, & Connor, 2012).

Having a hospice option in an advance care directive or living will would also benefit people in knowing that this would also be their wish if something were to happen and they were not able to speak for themselves. Advance care planning is a way for any individual to express to their physician and their loved ones about what they would like to see happen if they were not able to make health care decisions on their own. However, most advance care directives do not specifically talk about hospice care. Most advance care directives ask questions about mechanical ventilation, CPR/DNR, tube feedings, and intravenous fluid and medications (Hirschman et al., 2010). The good thing to note is that 70%, 114 respondents out of 165, individuals in the Hirschman et al study, did have an advance care directive or a living will filled out so their loved one would know how they felt about their wishes for this type of care. Having a healthcare directive is even more helpful for individuals who have no family, a caregiver, or are living alone. They do not have anyone that would know their wishes and this would help their medical professionals know what they would like to see happen to them (Miller, Kinzbrunner, Pettit, & Williams, 2004).

One gap that was recognized by participants, in a study done by Hobart, was a safe environment for people to discuss end of life issues when they are not in a moment of a health crisis. They also wanted more education on how to talk with and involve their family in the discussion to be able to decide about their death in their advance health care directive (2008). People do not always think all the way to the end of life when deciding about end of life issues. Education about a hospice option in an advance health care directive can be a key to getting this



conversation started. Educating people to discuss end of life options before the end of life is important (Hirsman et al., 2010).

### **Involvement of Healthcare Professionals**

There are different healthcare professionals who work in clinics, hospitals, and nursing homes that have contact with individuals diagnosed with a terminal illness and each has a potential role to play in discussing hospice. These healthcare professionals include doctors, nurses, and social workers, and each profession has its own perspective on which profession should start the hospice discussion. There have been considerations that each of these professions can collaborate with these patients to provide them with better care and service. When a person is dying from a terminal illness they have a variety of pressing needs. Having just one profession as an expert in all of these areas is truly an unrealistic goal. Therefore, utilizing an interdisciplinary team approach of doctors, nurses and social workers may be what is best to fully assist patients.

**Doctors.** The primary healthcare professional who is involved with an individual choosing hospice is their physician. The physician is typically the first person to start the conversation with patients; 60% are reported to be involved in the decision to enroll in hospice (Hirschman, Corcoran, Straton, & Kapo, 2010). The American Medical Association (AMA) does have policies that are considered best practices for physicians when working with patients at the end of life. These policies are a set of normative statements that the association developed on healthcare issues and the healthcare system. According to the AMA (2012), in Opinion E-2.037 Medical Futility in End of Life Care, physicians have an obligation to shift the intent of their care to comfort care and closure when an intervention to prolong their patient's life becomes futile. The AMA policy on end of life care continues to discuss withholding or

withdrawing life sustaining treatment in Opinion E-2.20. This policy states that the commitment of the physician is to sustain life and to relieve suffering. However, it also states that when the treatment to sustain life conflicts with the relieving of suffering the preference of the patient in treatment should prevail (American Medical Association, 2012).

Within the moments of physician's obligations to life sustaining treatments and their obligation to shift their care to comfort and closure when treatments become futile, options regarding end of life can be utilized. This timing can be difficult for physicians to gauge. There are some perceived barriers to initiating the end of life conversation with patients who have been diagnosed with a terminal prognosis. These barriers can include: ability to have the end of life discussion, inadequate communication, providing curative measures, and accurate prediction of the disease track. One of the barriers in initiating hospice sometimes lies in the hands of the individual's doctors and their ability to have the end of life discussion with their patients (Bonebrake, Culver, Call, & Ward-Smith, 2010). Having this discussion with terminally ill patients can be difficult. Doctors are trained in the curative model. It may be difficult to talk with a patient that they have been working towards a cure about their death which may be eminent. Having the conversation about end of life may be mistaken by some as giving up hope for a cure for their patients (Bonebrake, Culver, Call, & Ward-Smith, 2010). Inadequate communication between doctors and their patients about end of life has been seen as a barrier for individuals and their families to understand all the options that are available to them (Shin & Casarett, 2011).

Accurately predicting some ones disease track can be difficult. It is not easy for doctors to accurately predict when someone is going to die within the six month window that hospice requires. Everyone's disease process is different. People with the same diagnosis do not always

follow the same path as others. This accurate prediction can be a barrier for doctors to give a referral for hospice, 37% of physicians that were surveyed cited this accurate prediction as a barrier to offer hospice as an option (Brickner et al., 2004). However, the doctor should be able to give accurate information about the disease process and its projected trajectory. This should allow doctors to be able to speak to their patients about the disease and speak to them about the process (Csikai & Martin, 2010).

It has been speculated that physicians are the ones that are not speaking to the patients about hospice in enough time for these individuals to take full advantage of the program. Brickner et al. (2004) surveyed physicians regarding their knowledge and attitudes about hospice. The results showed that 78% of physicians believed that hospice was an underutilized program. The results also showed that 84% of these physicians were not able to correctly identify what an appropriate hospice diagnosis would be. Of these physicians still 85% believed that they were making hospice referrals when they were appropriate. These results point to a contradiction; they believed they were making appropriate hospice referrals, even though they could not correctly identify appropriate times to transition to hospice. Another study found that physicians who were 50 years of age and older were less likely to understand and offer hospice as an option than their younger counterparts. This study also found that most physicians saw the patients and families as a barrier to offering hospice care rather than themselves. They stated that these patients and families were not ready to discuss end of life options (Ogle, Mavis, & Wyatt, 2002).

Other healthcare professionals that individuals who are diagnosed with a life limiting illness come in contact with include social workers and nurses. Nurses and social workers have been found to be underutilized by doctors for their assistance with these patients (Csikai &

Martin, 2010). In a study done by Hirschman, Corcoran, Straton, and Kapo (2010) only 25% of doctors' utilized social workers in hospice discussions and only 20% involved their nurse. These professionals having training to assist their patients in making informed decisions. Csikai and Martin (2010) argue that these professionals can use each other's expertise in their different roles in patient care to be able to discuss care options in depth. They suggest that doctors and nurses could discuss medical care, the disease process, and care options while social workers could discuss the psychosocial aspects of the end of life process with the individual and their family (Csikai & Martin, 2010).

**Nurses.** Nurses provide excellent care to their patients. They are working alongside of the doctors and have more time with patients providing care than the physicians have. Nurses have great knowledge of patient care and the disease process. Nurses would be a good resource for doctors to discuss end of life options with their patients (Bonebrake, Culver, Call, & Ward-Smith, 2010). Nurses, however should not talk about end of life options with their patients without the doctor's knowledge as this could provide conflicting information between the medical professionals and their patients. However, because of nurse's unique role with patients, their involvement in the hospice discussion may make sense. Patients in one study discussed that the nursing staff offer valuable skills like kindness, compassion, and being genuine when they work with patients who were dying (Knapp, Madden, Wang, Kassing, Curtis, Sloyer, & Shenkman, 2011).

Nurses who work in a nursing home setting have a crucial role in referring their patients to hospice. These nurses, however, have been shown to not be supportive of hospice. More often hospice in a nursing home is seen as getting in the way of the care these patients, as they are already receiving care from the nursing staff at the nursing home (Knapp et al., 2011). Also

access to hospice care in nursing home is influenced by the facility and staff who care for these individuals (Zerzan, Sterns, and Hanson, 2000). Zerzan, Stearns, and Hanson, (2000), found that only one percent of the nursing home population was enrolled in hospice care. This study also discussed that approximately the same number of individuals die in their home as compared to nursing homes. However, those who die in a nursing home are less likely to receive supplemental care from a hospice agency. Clearly, setting plays a role in nurse's perspectives about hospice care.

**Social Workers.** Social workers have an opportunity to be of great assistance to doctors when working with patients who are faced with end of life decisions. Unfortunately, most doctors only refer to social workers after the decision has been made by the individual and this is typically only to get them connected with a hospice program (Csikai & Martin, 2010). Social workers typically only see patients in these health care settings on an as needed basis (Reese & Raymer, 2004). Social workers have a skill set and orientation that nurses and doctors are not taught in their training. Social workers are educated to advocate for their clients self-determination and what works best for their client. Social workers are also trained to assess the whole person, their environment, and also systems that might be affecting their decisions towards the end of their life (Reese & Raymer, 2004). Social workers empower their clients to help in the decision making process, and they offer them a safe place to be able to talk about their life and death. Social workers can also help the patient be able to talk with their family members about the end of their life (Hobart, 2008). They could therefore play a pivotal role in presenting hospice not as giving up on life, but as preparing for a good death, something which doctors may resist.

Social workers are typically underutilized in healthcare settings as professionals who are trained and educated to assist their clients and families deal with end of life issues. Social workers can be seen as having less medical knowledge as they are not trained within the curative medical model. Social workers roles are typically only as liaisons between family and other healthcare professionals and as professionals who facilitate needed referrals for services (Csikai & Martin, 2010). Social workers also have limited access to patients if they are not referred to them by the physician. The social worker may not even know that the patient is having difficulty with an end of life decision as they do not have consistent contact with patients in a clinic or hospital as the doctor or nurses do (Reese & Raymer, 2004).

Individuals' physicians may not have the availability or desire to discuss end of life options such as hospice to their patients who are facing a terminal diagnosis (Csikai & Martin, 2010). That is when physicians may need to turn to other healthcare professionals, such as nurses and social workers, to assist them in an interdisciplinary team approach when discussing end of life options.

### **Research Question**

Getting adequate and timely information about hospice seems to be the key that is missing for people to understand how beneficial hospice could be for those who are dying from a life limiting illness and their family members. The research shows physicians may have limited knowledge as to what services hospice can offer, when to refer to hospice, and may not be ready to accept defeat of an illness they could not cure. Evidence suggests that families and patients do not understand all that hospice offers until in hospice; but it is arguable that people need this information sooner to make an informed decision about when to start hospice, as well as to be able to plan more fully for the end of their life. By providing this information at an earlier stage

in the course of treatment, healthcare providers may be able to have a more informed and ultimately a timelier referral to hospice (Casarett, Crowley, & Hirschman, 2004).

The literature that was reviewed showed that there are many barriers for individuals to receive a timely enrollment into hospice, whether it is the healthcare providers, the patients themselves, or their families. Individuals tend to only use hospice during their very last stages of life, although they could benefit greatly from earlier involvement. This research study will ask the question, in what ways do doctors, nurses, and social workers promote and hinder access to hospice when patients are diagnosed with a terminal illness.

### **Conceptual Framework**

#### **Curative Model**

All physicians are educated in their training within the curative medical model. This medical model as defined in the Mosby's Dictionary of Medicine, Nursing and Health Professionals (2009) is: "the physician focuses on the defect or dysfunction within the patient, using a problem solving approach. The medical history, physical examination, and diagnostic test provide the basis for the identification and treatment of a specific illness. The medical model is thus focused on the physical and biologic aspects of specific diseases and conditions". Also in the word curative as defined within Webster's Dictionary (2013), "is serving to cure or heal: pertaining to curing or remedial treatment." No actual definition has ever been widely accepted by the medical profession for the curative model (Fox, 1997). Fox (1997), defined the curative model as "the approach to clinical medicine that narrowly focuses on the goal of a cure, the eradication of the cause of an illness or disease" (p. 761). Within the medical educational system, future physicians spend the vast majority of their training within acute care hospitals where the curative model is predominant. However, only 13% of all physicians to patient

contact actually occur in this setting. That means that over 85% of contact between physicians and patients occur in other settings such as clinics, long term care, hospice, and home care (Fox, 1997).

The curative model can assist in explaining why physicians may have difficulty in having end of life discussions with patients who are terminally ill and who could benefit from an earlier referral to hospice. The curative model/medical model is a science based model. If the goal of medicine is a cure, then death from that illness would be considered a failure (Fox, 1997). This notion is in conflict with being able to have a good death. No one in their career wants to be seen as a failure. Most doctors would probably state they got into medicine to help people who are suffering from disease, and ultimately they wanted to help people. With the vast amount of training and education that doctors receive, at times equates to a certain hierarchy within the healthcare profession. Those who have the most knowledge typically command the most authority within its profession. This is where crossing professional boundaries and accepting assistance from other healthcare professions, like nursing and social services, could be very beneficial for doctors to best serve their patients who are facing an end of life decision. These other two healthcare professions have different training than physicians and could be of great service in working with these types of patients.

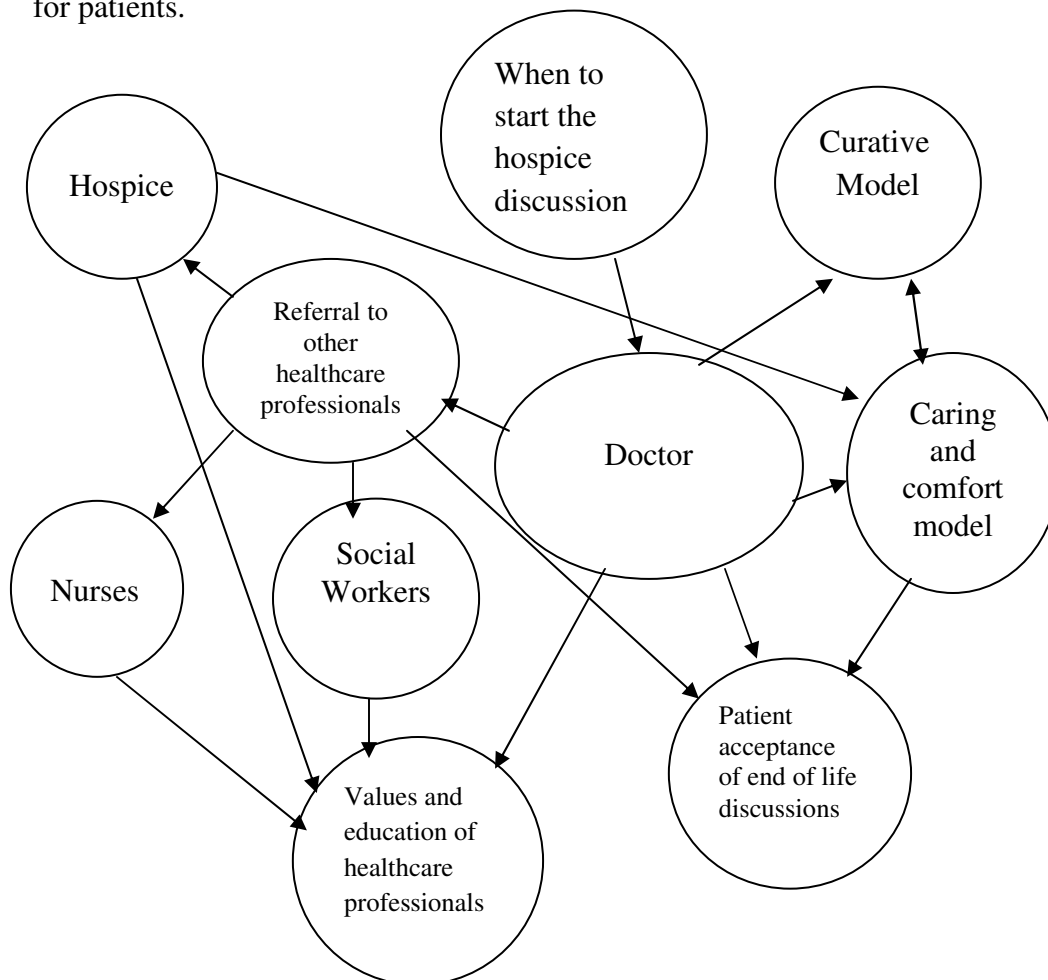
### **Ecological Perspective**

The ecological perspective can assist healthcare professionals in understanding how problems in the environment may be affecting the care that they are providing. When a patient is diagnosed with a terminal illness and is facing end of life decisions, there are different aspects within their environment that can affect these difficult decisions, including the healthcare professionals that are explaining to them all of their options for care.



The main tenant of the ecological perspective is that all organisms that exist are interdependent on one another and that all humans have and follow a life cycle (Forte, 2007). Self action and interaction are also integral parts of the ecological model (Forte, 2007). Self action refers to individuals choosing to act in the most rewarding way for them, regardless of surrounding environment. Interaction, on the other hand, refers to individuals choosing to act or make decisions that take the environment around them into consideration. Healthcare professionals, i.e.: doctors, nurses, and social workers, need to understand all elements that are affecting patients who have been diagnosed with a terminal illness when trying to decide when to start discussing options about end of life. The following eco-map will illustrate factors which can influence healthcare professionals when considering discussing end of life options with their patients who are faced with a life limiting diagnosis.

Figure 1: Factors that affect healthcare professionals considering discussing end of life options for patients.



All of these different systems may have a different effect on when healthcare professionals discuss end of life options with their patients who have been diagnosed with a terminal prognosis and death is likely within six months. If the healthcare professionals are utilizing an interdisciplinary team approach for their care, they can truly relay the same information to their patients and assist the individual to make a more informed decision. They can also assist each other within the strengths these different professions were trained in. Working together as a team to provide the best possible care for their patients who are facing death.

## **Method**

### **Research Design**

The researcher utilized a mixed methods research design. An online survey was conducted which consisted of open and closed ended questions. This design worked well for this study as the researcher was able to be more exploratory in nature to what healthcare professionals believe are ways that they promote or hinder timely access to hospice for their terminally ill patients.

### **Sample**

The final sample consisted of 14 healthcare professionals i.e.: doctors, nurses, and social workers who are licensed in Minnesota and have the availability to refer terminally ill patients with less than six months to live to hospice. These individuals were given an opportunity to go online and fill out a questionnaire regarding how they promote or hinder their patients' access to hospice. The sampling method for this research that was utilized was the snowball method. A snowball method is one in which participants may suggest someone else who might be willing to participate in the study (Berg & Lune, 2012). These healthcare professionals were practitioners

in hospitals, clinics, nursing homes, assisted livings, community service agencies, and hospice organizations. These individuals were asked to pass along information regarding this survey to other healthcare professionals that they knew and who would be interested in participating in the online survey. The researcher sent the initial participants an information sheet with the link to the on-line survey requesting their participation. These initial participants were also asked to forward the survey request through email to other potential participants.

### **Protection of Human Subjects**

#### **Recruitment**

The researcher sent out six initial emails to doctors, nurses, and social workers who are licensed to practice in Minnesota and have the availability to refer someone to hospice. These initial participants are licensed doctors, nurses and social workers who are known to the researcher through professional contacts. These initial participants do not directly supervise or work with the researcher. The researcher asked that these six initial participants forward the email containing information about the research to other potential participants asking them to participate in the on-line survey.

#### **Confidentiality**

The survey that was offered was available online through Qualtrics. There is no way of identifying any participant with their responses as there was no identifying information gathered. The researcher was also not aware of the responses of the initial participants as there was no way to identify their responses. Therefore, all human subjects remained anonymous and their responses protected. The use of Qualtrics assisted the researcher in keeping the participants responses confidential and anonymous.

**Letter of Informed Consent**

As the participants went online to complete the questionnaire, they completed a consent form before the questionnaire started. This consent form addressed what the researcher is studying, the purpose, the process for completing the interview, the risks/benefits of participating in the study, confidentiality, voluntary nature of the study and the contact information for the researcher and the research chair (see appendix A for the informed consent form). Participants electronically agreed with the consent form before the online questionnaire started. If the participants did not agree and click no, the participants were directed to the end of the survey and no information was gathered. Participation in this study was voluntary and participants were able exit out of the questionnaire at any given time and the survey was terminated.

This project was approved by the University of St. Thomas Institutional Review Board prior to conducting the research. This ensured that the researcher had approval to conduct the research. This research was conducted under the supervision of Jessica Toft, Professor at the University of St. Thomas.

**Data Collection**

The researcher conducted research by the participants completing an online survey through the use of Qualtrics. A semi-structured online survey regarding healthcare professionals experience in working with referring individuals, who have a terminal illness with less than six months to live to hospice, was administered to these professionals. The on-line survey consisted of closed ended questions that refer to some demographic information such as profession, how long they have been in practice, age, and gender. The online survey also had open ended questions that allowed the researcher to explore more in depth what the healthcare professionals

see as ways they can promote or hinder their patients' access to hospice (see Appendix B for a complete list of survey questions).

### **Data Analysis**

Upon completion of the online survey, the researcher used computer software, Qualtrics, for descriptive data analysis. A qualitative content analysis was utilized to determine emerging patterns and themes gathered from the online survey, "content analysis is a careful, detailed, systematic examination and interpretations of material in an effort to identify patterns, themes, biases and meanings" (Berg & Lune, 2012). These themes were sorted into categories and the researcher looked for patterns, commonalities, and even discrepancies within these themes (Berg & Lune, 2012).

### **Findings**

The objective of this research study was to survey doctors, nurses, and social workers about ways in which they promote or hinder their terminally ill patient's access to hospice.

### **Demographics**

The respondents' ages ranged from 26 to 51 and above. The largest percentage of the sample at 43% was the age range of 20-30. The next largest age group of the sample was 41-50 with 29%. The age group of 51 and above had 21% of the respondents and the smallest age group represented in the in the sample was 31-40 with only 7%. This group of respondents was a fairly young group. The vast majority of the respondents were female. The sample consisted of 2 (14%) male and 12 (86%) female respondents.

The respondents were asked to classify in what health care profession they are licensed in the state of Minnesota. The following Table 1 shows the distribution of those results.

Table 1 Profession Frequency Distribution

<b>Profession</b>	<b>Response</b>	<b>Percent</b>
<b>Physician</b>	3	21%
<b>Nurse</b>	5	36%
<b>Social Worker</b>	6	43%
<b>Total</b>	<b>14</b>	<b>100%</b>

The final sample consisted of 14 doctors, nurses, and social workers who work with terminally ill patients in Minnesota, who have an opportunity to refer someone to hospice. The social work profession had the highest percentage represented in the sample at 43%, followed by the nursing profession at 36%. The physician had the lowest percentage represented in the sample at 21%.

Respondents were also asked to state where they primarily practice their profession. The data showed the majority of respondents primarily practiced their profession in a skilled nursing facility at 36% (n=5). The 'other' category was listed as the next highest at 21% (n=3). This other category showed two respondents practicing at an adult day program and one at a community service agency. Practicing at a hospital and an assisted living facility were equal at 14% (n=2) each. Also equal were a primary care clinic and a specialty clinic at 7% (n=1). Surprisingly, there were no respondents who practiced within a hospice setting. Table 2 shows the breakdown of this distribution.

Table 2 Practice Location Frequency Distribution

<b>Practice Location</b>	<b>Response</b>	<b>Percent</b>
<b>Hospital</b>	2	14%
<b>Primary Care Clinic</b>	1	7%
<b>Specialty Clinic</b>	1	7%
<b>Assisted Living Facility</b>	2	14%
<b>Skilled Nursing Facility</b>	5	36%
<b>Hospice</b>	0	0%
<b>Other (Please Specify)</b>	3	21%

### **Professional Education and Training**

The respondents were asked a series of three questions regarding their experience with referring terminally ill patients to hospice and if they felt they were prepared to do this given their professional education and training. The choices for their responses were: strongly disagree, disagree, neither disagree or agree, agree, and strongly agree. The first question asked all three professions when they reflected back on their professional education and training how much did they agree that they were prepared to help patients understand their terminal diagnosis? All three of the physicians answered that they agreed that they felt prepared to help patients understand their terminal diagnosis. In the nurse category, one nurse strongly disagreed that they were prepared within their professional education and training to help patient understand their terminal diagnosis. However, four other nurses agreed that they felt trained to help patients understand their terminal diagnosis. Social workers had an even split with this question. Three of them disagreed and three of them agreed that they felt that their professional education and training prepared them to help patients understand their terminal diagnosis. Table 3 shows these results.

Table 3 Education and Training to Understand Diagnosis

<b>When you reflect back on your professional education and training, how much do you agree you were prepared to help patients understand their terminal diagnosis?</b>					
<b>Profession</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>Physician</b>	0	0	0	3	0
<b>Nurse</b>	1	0	0	4	0
<b>Social Worker</b>	0	3	0	3	0
<b>Percentage</b>	7%	21%	0%	71%	0%

In this sample, doctors were most likely to report feeling prepared to discuss their patients' terminal illness with them. Overall this data showed that 71% of the respondents agreed their professional education and training prepared them to help patients understand their terminal diagnosis.

The respondents were asked to reflect back on their professional education and training, and consider how much they agreed that they were prepared to determine when a hospice referral was appropriate for terminally ill patients. Table 4 shows these results.

Table 4 Education and Training to Determine Hospice Referral

<b>When you reflect back on your professional education and training, how much do you agree you were prepared to determine when a hospice referral is appropriate for terminally ill patients with less than six months to live?</b>					
<b>Profession</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neither Agree nor Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>Physician</b>	0	3	0	0	0
<b>Nurse</b>	1	2	1	1	0
<b>Social Worker</b>	1	3	1	1	0
<b>Percentage</b>	14%	57%	14%	14%	0%

Interestingly, with this question, not one physician agreed that they were prepared to determine when a hospice referral was appropriate for their terminally ill patients. Only one nurse and one social worker agreed that they felt their education and training helped prepare them to determine



when a hospice referral was appropriate with terminally ill patients. Surprisingly 71% of the physicians, nurses, and social workers either strongly disagreed or disagreed that their professional education and training prepared them to know when a hospice referral is appropriate for terminally ill patients. One social worker who neither agreed or disagreed they were prepared commented on this question stating,

*Our education included what hospice was and the programming but learning when a hospice referral is appropriate came with job experience and working with our team of professionals which includes doctors, nurses, and social workers.*

Another social worker who reported they agreed with knowing when to refer to hospice stated,

*I believe I was trained on how to identify when hospice is appropriate for patients and when they might benefit from signing on to hospice. I was also trained to work with medical professionals on identifying this.*

It is curious that the same percentage of the respondents, 71%, agreed their professional education and training trained them to help patients understand their terminal diagnosis, yet they disagreed that their professional education and training prepared them to know when a hospice referral would be appropriate for those same patients.

When these same professionals were asked how confident they felt they were in discussing hospice with patients not one of them chose the not confident category. The following table shows these results.

Table 5 Confidence Level

<b>How confident are you in discussing hospice with patients?</b>				
<b>Profession</b>	<b>Not Confident</b>	<b>Somewhat Confident</b>	<b>Confident</b>	<b>Very Confident</b>
<b>Physician</b>	0	2	0	1
<b>Nurse</b>	0	3	2	0
<b>Social Worker</b>	0	2	2	2
<b>Percentage</b>	0%	50%	29%	21%

However, these results also show that 50% of the respondents only felt somewhat confident with their skills in discussing hospice with patients who have a terminal diagnosis. The physician's responses showed two thirds of the respondents felt only somewhat confident in discussing hospice with terminally ill patients and only one physician felt very confident in discussing hospice. The social work respondents seem to be the most confident out of these health care professionals in discussing hospice with patients. The social work respondents had two respondents feeling somewhat confident, two respondents felt confident, and two social work respondents felt very confident in their skills with discussing hospice with terminally ill patients. These results did show that none of the respondents felt not confident in their skills to discuss hospice with patients.

### **Determining Factors for Hospice**

The respondents were asked to describe what their determining factors were when they referred someone to hospice. Some overarching themes from all three professions that came out of this question were: patient's preference, readiness of the patient, family acceptance, type of prognosis, worsening of the patient's condition, and education about the patient's prognosis/diagnosis and about hospice. However, certain professions emphasized particular themes.

**Physicians.** The three physician respondents described the actual prognosis of the patient being the most important determining factor when referring a terminally ill patient. Another determining factor the physician group described as being important is the patient's acceptance of the diagnosis and prognosis and being ready to accept a referral to hospice from their physician. One physician stated,

*The type of prognosis is very important when deciding to refer a terminally ill patient to hospice, as well as the patient's acceptance of that prognosis.*

Another physician stated,

*Prognosis of the patient is the most important and if I believe they may be ready to accept the hospice referral.*

Another theme presented by the physician respondents was the patient's wishes for the direction of their medical care. One physician stated,

*The patient's preference to avoid future hospitalization.*

The physicians who described what their determining factors for hospice were seemed to focus their responses solely on medical reasoning for these terminally ill patients. They place a lot of emphasis on the prognosis and whether the patient was ready to accept the prognosis and the hospice referral.

**Nurses.** When responding to the question, "What are your determining factors when referring someone to hospice," nurses were more descriptive than the physicians. They listed specific medical diagnoses the terminally ill patient would have for them to refer them to hospice. These diagnoses included: end stage Alzheimer's disease, failure to thrive, end stage cancer, and medical conditions such as, significant decline in the patient's health, declining weight, loss of appetite. One nurse commented,

*If the patient is experiencing symptoms of failure to thrive, declining weight, appetite, end stage Alzheimer's disease or has a significant drop in overall health.*

They also described what the patient's goals about their prognosis would be towards the end of life to determine whether a referral to hospice is appropriate or not. One nurse stated,

*What the patient's goals are for end of life, if they want palliative or are they looking to treat.*

Patients as well as their family's willingness to accept the prognosis was also mentioned as a determining factor. Another nurse stated,

*Patient's willingness to accept the prognosis, their beliefs and their family.*

Also, nurses commented on the degree to which the patient was educated about their diagnosis and prognosis affected their knowledge about how hospice could benefit them. One nurse stated,

*Readiness of the client to accept hospice, also to determine if they have been given enough information about their diagnosis as well as education regarding hospice.*

Nurses did speak to some of the medical parts of determining factors when referring someone to hospice, but they also went in a different direction than their medical counterparts, the physicians. These nurses also discussed education about hospice as well as including the patient's beliefs towards the end of life as well as their families. This may show that nurses do focus their care not only on the medical part but also on the more humane parts at the end of life.

**Social Worker.** Social workers also agreed with the nursing participants that weight loss and decline in overall health are some medical conditions that assist them in determining when to refer someone to hospice. They also described changes in the patient's activities in daily living (ADL's), participation with life, and an exacerbation of the patient's diagnosis. One social worker commented,

*Some determining factors I utilize are weight loss, decline in participation, ADL changes, and exacerbation of diagnoses.*

The social work group did go beyond medical conditions and describe areas such as, when the patient chooses a comfort focus for their care over aggressive treatment is a good determining

factor of when to refer someone to a hospice program and asking the patient what their treatment goals are for their diagnosis. One social worker commented,

*If they have six months or less to live, if they and their family are at a stage in which they are prepared for hospice and how hospice might benefit this patient at the end of life. I also consult with the medical team to make sure it is medically appropriate as a doctors order is needed for the referral as well.*

This group also described educating the patients on what hospice can offer them. One social worker stated,

*The option of hospice should be talked about when the patient is diagnosed with the terminal illness. This should be one of the options that is discussed when the healthcare professional is talking about their options right away.*

Another social worker stated,

*I provide education to clients and families about hospice then advise them to speak to their physicians.*

Social workers tend to look at the entire person and how this diagnosis is affecting them. Social workers are taught to look at the person and their environment and provide the person with information and options that work best for them.

### **Benefits of Hospice**

Respondents were asked to list benefits they saw for patients who have a terminal illness to be referred to hospice. All participants responded to the question. Some of the responses were very similar to what was found in the research. They saw patients getting better care with symptom and pain management. They reported hospice was better able to assist patients with pain control and comfort when their terminal illness progressed. One physician stated,

*Some benefits for hospice are pain management and extra support from more professionals.*

Another physician responded,

*Hospice provides incremental access to on-call nursing and physician services and expertise in symptom monitoring and treatment.*

They stated hospice was able to offer patients time with closure and a better quality of life when they were in the last stage of life. One social worker responded with,

*Benefits include pain management (so that emotional and spiritual aspects can be addressed), quality of life, family counseling, comfort care, and life review.*

One nurse stated,

*Hospice offers time for closure, better quality of remaining time because of pain control, education, and psychosocial support.*

A social worker in a skilled nursing facility stated,

*A benefit of hospice is an extra set of hands/eyes to the team to work alongside of our team at the skilled nursing facility. This program brings comfort to our residents and their family to help carry out the wishes of our residents during end of life care.*

Hospice not only provided support and care of the patient but they also provided support for their family. One social work participant stated,

*Increased services overall including services to benefit the quality of life for the patient as well as the family. These benefits include: massage, music therapy, pet therapy, spiritual care, social work, and medical care. This increase of services can help the patient remain in their home when they are at the end of their life and can assist their family members. This will allow them more quality time to spend time together.*

Another benefit that was listed by the respondents was that hospice staff was able to provide education to the patient as well as their family on the dying process. They are able to let them know the changes the human body will experience as it starts to shut down. Respondents stated that hospice staff can make this time less scary and more normalizing for both the patient as well as their family. One nurse stated,

*A benefit of hospice is clinical support and guidance for caregivers and the recipient, dignity in the dying process, comfort from pain/health change and guidance in their decline from experts.*

The participants were also asked to describe any benefits they saw for their patients to have an early referral to hospice as opposed to a week before death. The major themes that came from this question showed: longer time with comfort, better pain control, supplies, extra staff support, time for closure of the patient and family, better symptom management, and education about the dying process. These responses were not much different than what the participants saw as just benefits of hospice for terminally ill patients. One response that spoke directly about an early referral for hospice:

*Hospice is really intended to be used before the person is actively dying to assist in quality of life for whatever the patient has left even though it can be beneficial to have it a week before death as well. The patient and family will get so much more out of the services as far as assisting the patient with quality of life if they are referred and signed on earlier in the end of life process.*

The respondents described many benefits that terminally ill patients are able to receive when they sign up for hospice. These professionals see hospice as a beneficial program for those

who have been diagnosed with a terminal illness and believe that the earlier patients sign up the more benefits they will be able to receive from the program.

### **Barriers to Hospice**

The participants were asked to describe some barriers they saw for terminally ill patients to receive a referral to hospice. The data describes fear as being a big barrier for patients and for providers. That fear can manifest itself in multiple ways. Fear of death by the patient, family and also the health care provider. Some physicians fear that offering a hospice option shows the patient they are giving up hope for a cure. Lack of understanding of what hospice is, is seen as another barrier to a timely referral to hospice. It was stated by multiple respondents that the patient and family themselves are seen as a barrier to a timely hospice referral. They may not be ready to accept a hospice referral. One social worker stated,

*Most of the time patients and family are hesitant because they have not yet processed the terminal diagnosis or believe that hospice is a death sentence. Many patients and families believe that if they sign on to hospice their loved one will die shortly after and do not see that people can still live for quite some time while receiving hospice benefits. I also see that doctors are not proactive about discussing end of life with patients and if the discussion is not had about the terminal illness or end of life in the first place, then it is hard to approach the discussion of hospice as well.*

Another physician respondent stated,

*Providers fear that hospice is too much associated with immediate death with reluctance to raise the issue before that it would hasten death. Variation in interpretation of eligibility between hospices. Statements by hospice providers that enrollment in hospice precludes future hospital care or efforts to maintain function.*



It is an interesting point that this physician participant who works with patients who are dying makes. One barrier to hospice could be that the patient is discouraged to go to the hospital when they are in hospice and any interventions to assist in maintaining function. This information about hospice itself could be discouraging a lot of people to sign up. Because when people have been in distress before they called 911 and go the hospital. When they are on hospice they are encouraged to call their hospice provider and a nurse will come out and they are discouraged to go the hospital.

All of these professionals have their opinions about what they see as barriers to a timely referral to hospice care by terminally ill patients. The most common barriers that were discussed in this section were: patient readiness, family denial, delayed referral by the physician, fears, myths, and lack of understanding of what hospice is and how it can benefit terminally ill patients.

### **Team Approach**

In the survey the participants were asked to respond to the question of how often they utilize other health care professionals to assist them in referring terminally patients to hospice.

Table 6 shows the results of this question.

Table 6 Other Professional Assistance with Referral

<b>Answer</b>	<b>Frequency</b>	<b>Percent</b>
<b>Never</b>	0	0%
<b>Rarely</b>	0	0%
<b>Sometimes</b>	5	36%
<b>Often</b>	7	50%
<b>All of the Time</b>	2	14%

It is refreshing to see that 100% of the respondents utilized other health care professionals at least some of the time to assist them in speaking to their terminally ill patients about hospice. At least 50% use other health care professionals often.

The survey further asked the participants what other health care professionals have assisted them when speaking to patients about hospice. The health care professionals that were listed were: physicians, nurses, nurse practitioners, social workers, hospice workers. What was unique about these responses was that all the social workers listed more of a team approach such as the doctor, nurse, and social worker. All of the nurses and physicians did not list social workers at all in their list of health care professionals that assisted them in speaking to patient about hospice. The physician and nurse respondents all choose the physician as being responsible for making a referral to hospice. One physician respondent stated,

*I mostly refer patients to hospice so they can explain to the patients what hospice can specifically offer them. I notice that it is typically a hospice social worker that comes out for this purpose.*

The participants were asked which health care professional's responsibility it was to make a referral for a terminally ill patient to hospice. Table 7 shows the results of this question.

Table 7 Health Care Professional Responsibility

<b>Answer</b>	<b>Response</b>	<b>Percent</b>
<b>Physician</b>	8	62%
<b>Nurse</b>	0	0%
<b>Social Worker</b>	1	8%
<b>All of the above</b>	5	38%

When looking into the results of this question the physician received the highest percentage with 62% of the responses. A few of the individuals commented on why they chose the physicians as being responsible due the fact the physician is needed to write a medical order for hospice. No one - not even the nurses - selected a nurse as being responsible for referring a patient to hospice. Thirty-eight percent of the respondents chose all of the above; however all of these responses came from social workers. A social work respondent stated,

*All three of these professions can utilize each other's strengths to assist the patient and their family in understanding how a hospice referral can benefit all of them.*

One nurse respondent stated,

*Nurses cannot refer with clout, but MD's order this and nurses can direct to discuss with the MD.*

A physician respondent stated,

*The MD is needed for the actual order, but all disciplines can assist with offering information and education regarding hospice.*

It would seem that doctors may be a bit more open minded about involving nurses and social workers in offering information and education about hospice. These nurse respondents seem to be somewhat closed to the idea of any profession other than the doctor when it comes for the professionals to refer their patients to hospice. Social workers seem to be the profession that is completely open to assisting these professionals when talking to patients about an end of life option like hospice. It was interesting how one physician explained that all these healthcare disciplines can assist with offering information and education regarding a hospice referral yet only thought the physician is responsible for making the referral.

### **Timing**

The respondents were asked what they felt was an optimal length of time for someone to receive the maximum benefits from being on hospice. The responses ranged from at the most six months to the lowest of at least one month. All participants agreed that the longer the time the more benefits the patients would be able to receive from hospice as well as their family. A social work respondent stated,

*This is hard to put a time frame on as it really depends on the patient's life expectancy, severity of their illness, other available supports, and where they are at in processing their illness. However that being said, I would say if possible, for the average person three to six months would be most ideal.*

One nurse respondent stated,

*One month or greater, to establish a connection with hospice staff, to accept and understand educational/information about the dying process, allow enough time for decisions to be made regarding pain control and end of life choices.*

These health care professionals believe that the longer length of time that a patient is able to be on hospice, the greater the benefit they will be able to receive from hospice.

### **Discussion**

This research attempted to explore how health care professionals, doctors, nurses, and social workers, promote or hinder their terminally ill patient's access to hospice. It looked at ways in which these professionals thought their professional education and training prepared them to work with terminally ill patients: first, to understand their diagnosis and second, how to know when to refer their patient to hospice. This research also looked at what types of benefits these professionals thought hospice would provide to these patients as well as what are the barriers for terminally ill patients to receive a timely referral to a hospice program. This study also looked to these health care professionals to see what they thought was an appropriate length of time for a terminally ill patient to be on hospice before they pass away as well as any benefits they saw for patients to have an early referral to hospice as opposed to a week before death. Lastly this study looked to what health care professional they thought was responsible for

making a referral to hospice for patients who have been diagnosed with a terminal illness and have less than six months to live.

### **Education and Training**

The respondents' professional education and training seemed to get mixed reviews by these professionals on how well it prepared them to talk with terminally ill patients about their diagnosis and determining when to refer these individuals to hospice as an option. It may be that professionals' educational theoretical orientations affected how they perceived hospice. The doctors and the nurses are trained in their formal school education in the medical model. Social workers, in contrast, are trained to look at the whole person and their environment as well as the patients self determination. This study found that 71% of all the participants felt that their professional education and training prepared them to help patients understand their terminal diagnosis. However the same percentage of respondents, 71%, disagreed that their professional education and training prepared them to determine *when* a hospice referral was appropriate for those same terminally ill patients.

These findings support the research done by Brickner et al. in 2004 whose results showed that 84% of physicians were not able to correctly identify when it was appropriate to refer someone to hospice. However this study also showed that despite professionals believing they were not trained when to refer to hospice, 85% of them believed they were making hospice referrals when they were appropriate.

This may indicate that most health care professionals know about hospice but may not know when the appropriate time to refer someone to hospice (even though they believe they do). This lack of understanding may indeed be a barrier for terminally ill patients to receive a timely referral to hospice. The findings may show that physicians are still influenced by the medical

curative model, even when considering hospice. This model may also explain why it may be difficult for physicians to be able to talk to a terminally ill patient about hospice as an option. They do not want to be seen as giving up hope for a cure for their patient. Fox (1997) describes this as an approach to medicine that focuses on a cure or the eradication of the disease. Fox asserted that if the goal of medicine is to cure, then death from that illness would be considered a failure.

### **Benefits of Hospice**

The findings show the participants understand that hospice is a beneficial program for terminally ill patients with less than six months to live. The participants' responses to questions about what they saw as benefits of hospice for terminally ill patients did coincide with what was found in the research. These professionals stated that the benefits of hospice they noted are: time for closure, better pain control, family counseling, more supportive services, being able to die with dignity, education, and better quality of life at the during the end of life process. These findings were similar to what Young-Bushfield and DeFord (2010) who found that hospice can help people understand what death looks like so people do not have to be afraid of what is happening. Becker (2004) also found that hospice allows the dying patient to have better pain control, and educate people who are dying that they do not have to experience unnecessary pain. Shin and Casarett (2011) also found that people who are dying need time to put their life in order and being on hospice helps them to be able to do this

An area that was a bit of a surprise was, a social work respondent noted that if the dying individual signed on to hospice while in a skilled nursing facility they would be able to get extra one-to-one care while in a skilled nursing facility. This possibility of more care is not commonly known and it may be that it is not widely advertised, especially by nurses in a long-term

facilities. Knapp et al (2011), found that nurses are often not supportive of hospice within a nursing home facility. More often hospice in a nursing home is seen as getting in the way of the care these patients, as they are already receiving care from the nursing staff at the long term care facility (Knapp et al., 2011). However, this respondent was a social worker and not a nurse in a long term care facility. This may indicate that social workers in long term care facilities are assisting more in making referrals to hospice for the patients that live there and have a terminal diagnosis with less than six months to live. At minimum it shows others what benefits hospice would have for the patients as well as lighten the load of staff.

### **Barriers to Hospice**

The findings showed some barriers for patients with a diagnosis of a terminal illness in receiving a timely referral to hospice. This study found that the physicians listed lack of understanding of the benefits of hospice by the patients and fear of death as the most prominent barriers. The nurse respondents listed: the physician not discussing hospice as an option, lack of education of what hospice is, and fear of dying by the patient and the family as barriers for patients in receiving a hospice referral. The social work respondents listed: lack of education about prognosis, physician inexperience with discussing dying with the patient, patient/family not accepting the diagnosis, and fear that hospice will bring about death faster are barriers for patients receiving a referral to hospice. The most common barriers that were listed in this study pointed to the patient and family not ready to accept hospice and lack of education given about hospice. The nurse and the social work respondents both point to the barrier of the doctors' lack of communication to the patient about hospice as an option.

These findings are supported by the research that was found while doing this project. Bonebrake, Culver, Call, and Ward-Smith (2010) found that a barrier to hospice sometimes lies

in the hands of the patient's doctor and their ability to have an end of life discussion with their patient. The doctor was listed many times by these professionals as not providing or making the recommendation to hospice when they are with their patients, as well as not engaging in adequate communication with their patient and the doctor. Most of the research seems to point to the physician being the health care professional that typically is not providing the information about hospice.

Interestingly, the research reviewed was unsupportive of the notion that the patient nor the family is not ready to discuss or hear about the option of hospice when discussing end of life options for terminally ill patients. This study, however, found these health care professionals felt the patient and family are seen as being resistive to hearing about end of life options such as hospice. Respondents indicated that the mention of hospice was like a death sentence and led to a strong emotional reaction. In the present research, physicians were universally seen as the integral health care professional who does make the hospice referral most of the time. Given this, the research would indicate that the physicians' lack of communication with their terminally ill patient would be seen as a large barrier for patients to receive a timely referral to hospice.

### **Timeliness of the Hospice Referral**

Hospice is a program for those who have been diagnosed with a terminal illness with less than six months to live. The respondents of this research were asked what they felt was the optimal length of time for someone to receive the maximum benefit of being on hospice before they passed away. While the responses represented a variety of length of time, from a month to six months, it is worth noting that the least amount was a month. This is supportive of previous research that has been done on this topic. According to the National Hospice and Palliative Care Organization (2012) 44.6% of people in the United States passed away utilizing a hospice



program of some kind. That is less than 50% of those that died. What is even more shocking is that 35.7% of that population utilized hospice for less than seven days before they passed away and this proportion of the population is growing. This brief exposure to hospice does not allow patients and families time to take full advantage of the benefits of the program (Shin & Casarett, 2011). If hospice has been shown to be helpful not only for the terminally ill patients but their family as well, why is the proportion of those utilizing hospice for seven days or less so large and growing?

There seems to be a disconnect between the agreed upon value of hospice and the timeliness of receiving information and education about hospice for terminally ill patients. People need to be educated that a hospice option does not cause immediate death. With hospice assisting them, they may be able to prolong their life due to the excellent care they are receiving. This also means they have controlled pain and allows for more time for closure with their life and their loved ones.

### **Identifying Responsibility for Referral to Hospice among Professionals**

This study asked its participants which health care professional they thought was responsible for referring terminally ill patients to hospice. This study showed that the majority, 62%, chose the physician as the health care professional who is responsible for referring a terminally ill patient to hospice.

The research that was found for this study was supportive of these findings. Hirschman, Corcoran, Straton, and Kapo (2010) found that 60% of physicians reported that they are the first health care professional to discuss hospice as an end of life option. However, a few studies pointed out that doctors could refer to nurses and social workers to allow for a more unified team effort in talking with terminally ill patients about hospice during end of life discussions.

Bonebrake, Culver, Call, and Ward-Smith (2010) discussed how nurses would be a good resource for doctors to discuss end of life options with patients as nurses typically have more access to patients than doctors. Hobart (2008) discusses that social workers can assist as they are trained to be able to talk to the patients and their family about end of life issues. In support of this notion, Csikai and Martin (2010) argue that doctors may not have the availability or desire to talk about end of life options with patients. This then would be a great time for these doctors to start including these other health care professionals that they have access to.

### **Implications for Social Work Practice/Policy**

Social workers are highly educated and licensed professionals. They work in many different areas and with a wide variety of patients within the health care industry. This research has shown that most of the social workers surveyed believe that they have the skills necessary to assist other health care professionals when making a referral to hospice for patients who have been diagnosed with a terminal illness with less than six months to live. The doctor is still responsible for writing the order for hospice; however nurses and social workers can and should play a role in assisting the doctor in the referral for these terminally ill patients. The social work profession needs to find a way to show the doctors and nurses that they are more than capable to assist with these patients and might even be a better choice to have these hard discussions with these patients and families as social workers are trained to work with these difficult issues. Alternative practices should be investigated for best practices when it comes to discussing end of life issues with terminally ill patients. These alternatives practices could include utilizing an interdisciplinary team (IDT) approach with terminally ill patients and better training for health care professionals with end of life options for terminally ill patients.

### **Implications for Policy**

Talking with patients about the end of life seems to be a difficult conversation to have. Maybe this type of conversation should not be mostly one medical professions responsibility, the doctors. This responsibility could be shared with other medical professionals such as social workers and nurses. The doctor is still needed by policy to write the order for the person to be eligible for hospice and this could be the reason most professionals believe that it the responsibility of the medical doctors to have the hospice conversation. This could be an opportunity to add to the policy that nurses and social workers in these medical settings are mandated to be involved in these conversations about end of life issues with terminally ill patients. There are policies out there that mandate that there needs to be an interdisciplinary team to discuss how the patient is doing as well as future planning and options for care. Why is it not mandatory that there needs to be an interdisciplinary team approach when discussing end of life options for terminally ill patients. This could be added to scope of practice for licensing requirements. Having a Death with Dignity Act enacted could significantly improve the end of life for terminally ill patients.

### **Strengths and Limitations**

There were strengths in this research design. This survey was on-line therefore; the survey had built in anonymity for the respondents. Participants are generally more honest with on-line surveys when their responses are completely anonymous. With this survey being only on-line, there was no interviewer effect. The researcher had no access to the respondents; therefore, there was no way to influence the respondents' answers in any way (Monette, Sullivan, & DeJong, 2011). On-line surveys have the availability to reach many different respondents as opposed to face to face interviews where one would only have access to those that

are within a certain vicinity of them. On-line surveys can be a strength with professionals who are short on time. An on-line survey does typically take less of the respondent's time than a face to face interview.

One limitation to the research that was conducted was that of the sample size utilized. A larger sample of healthcare professionals could be beneficial for them to understand that they are part of the barriers that the individuals face when signing up for hospice. Another limitation could be the way the respondents are recruited. The researcher had no control who was asked to take the survey. The respondents themselves asked their colleagues to go on-line to complete the survey. There are some limitations to doing an on-line survey as opposed to doing a face to face interview. The researcher lost the face to face contact with the participants. People communicate more than with their words, they also communicate with their body language. The researcher was also not able pay attention to the respondent's tone of voice or visual cues with use of an on-line survey.

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## **Appendix A**

### Consent Form

#### Study of Health Care Professionals Perspectives on Their Patients' Access to Hospice Care

I am conducting a study on healthcare professionals assist their patients in accessing hospice care when they have been diagnosed with a terminal illness. Hospice services are available to individuals who have been diagnosed with a terminal illness and have less than six months to live. You were selected as a possible participant because you are a healthcare professional who have the potential for working with patients who could be referred to hospice. Please read this before and agree to its content before proceeding on to the survey.

Tammy Ferderer, Social Work student at the University of St. Thomas, is conducting this study under the supervision of Jessica Toft who is a Professor at the University of St. Thomas.

#### **Background Information:**

The purpose of this study will be to take a look at in what ways doctors, nurses, and social works provide or hinder access to hospice for their patients.

#### **Procedures:**

If you agree to participate in this study, you agree to proceed on to participate in the online survey that could take up to 20 minutes.

#### **Risks and Benefits of Participating in the Online Survey:**

A benefit to completing this online survey is that it will allow for the researcher to learn more about how healthcare professionals promote or hinder their patient's access to hospice care.

#### **Confidentiality:**

Confidentiality is built into the nature of the online survey. There is no request for personal information and no way for the researcher to connect individual responses to the participants.

#### **Voluntary Nature of the Study:**

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of St. Thomas. If you decide to participate, you are free to withdraw at any time. You can simply exit the online survey at any time and your responses will not be recorded. You are also free to skip any of the questions on the survey.

**Statement of Consent:**

I have read the above information. I consent to participate in the online survey.  
(Online there will be a box that will be checked to be able to continue on with the survey)

**Appendix B**

## Survey Questions

- 1) What is your profession?
  - a) Doctor
  - b) Nurse
  - c) Social Worker
  
- 2) What is your age?
  - a) 20-30
  - b) 31-40
  - c) 41-50
  - d) 51 +
  
- 3) What is your gender?
  - a) Female
  - b) Male
  
- 4) Where do you primarily practice your profession?
  - a) Hospital
  - b) Clinic
  - c) Hospice
  - d) Long Term Care Facility
  - e) Other
  
- 5) What is your race?
  - a) Caucasian
  - b) African American
  - c) Asian
  - d) Native American
  - e) Hispanic
  - f) Other
  
- 6) Do you feel within your training you were taught when a hospice referral is appropriate for terminally ill patients with less than six months to live?
  - a) Yes
  - b) No
  
- 7) How much training have you had with regards to helping patients/clients understand their terminal diagnosis?

- 8) How much training have you had with regards to discussing end of life options for patients who have been diagnosed with a terminal illness?
- 9) What are the requirements for a patient to be eligible for hospice?
- 10) Do you feel that hospice is a program that is beneficial to individuals who have a terminal prognosis with less than six months to live?
  - a) Yes
  - b) No
- 11) What are some of the benefits that you see for patients/clients who have a terminal prognosis with less than six months to live to have a referral to a hospice program?
- 12) Do you refer your patients/clients who have been diagnosed with a terminal illness to hospice?
  - a) Yes
  - b) No
- 13) What factors influence your decision to refer your terminally ill patients who have less than six months to live to hospice?
- 14) How often do you refer patients/clients who have a terminal diagnosis with less than six months to live to a hospice program?
- 15) Do you ever utilize other healthcare professionals to assist you in referring patients to hospice?
  - a) Yes
  - b) No
- 16) If you answered yes to the previous question, what healthcare professionals have assisted you in talking to your patients about hospice before they have signed on with hospice?
- 17) If you answered No to the previous question, have you ever considered utilizing nurses and or social workers to assist you in speaking to your patients about hospice services?
- 18) Do you see any benefits/risks to working with nurses or social workers when speaking to your patients who are terminally ill about hospice? If so what would they be?
- 19) When do you feel is the appropriate time to refer a terminally ill patient who has less than six months to live?

- 20) Approximately 35% of the population who utilized hospice before they passed away did so within how many days of death?
- a) 20 days
  - b) 90 days
  - c) 7 days
  - d) 45 days
- 21) Do you know what the benefits are for your patients to have an early referral to hospice as opposed to a week before death?
- 22) What barriers do you see that patients/clients who have been diagnosed with a terminal prognosis with less than six months to live have with receiving an early enough referral to hospice?
- 23) What do you feel is an appropriate length of time for someone to receive the full benefit of being on hospice before they die?
- 24) What healthcare professionals responsibility is it to make a referral for terminally ill patients with less than six months left to live to hospice?