Internship Report

Palliative Care at Pitt County Memorial Hospital

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Chapter 1

Introduction

Pitt County Memorial Hospital[1] is located on the western edge of Greenville. It is one of

the four academic medical centers in North Carolina. The hospital serves as a teaching hospital

for the Brody School of Medicine at East Carolina University (Vidant Health, 2012). Clinical

staff at Pitt County Memorial Hospital includes more than 500 physicians and 1,200 nurses.

Every year, acute, intermediate, rehabilitation and outpatient health services are provided to

more than 33,000 inpatients and 266,000 outpatients from all over the world (Vidant Health,

2012). Clinical education is emphasized by Pitt County Memorial Hospital as part of the

hospital's mission. Medical students, residents, nurses and other health professionals can get

practical training and education at Pitt County Memorial Hospital (Vidant Health, 2012).

Palliative care is designed to provide pain relief to patients through symptom management

and by addressing the spiritual, emotional, psychological and social burdens of life-threatening

diseases. At Pitt County Memorial Hospital, palliative care is focused on compassionate and

specialized care, with the goal of providing comfort and maintaining the highest possible

quality of life for patients and family members (Vidant Health, 2012). The palliative care team

includes physicians, nurse practitioners, nurses, social workers, chaplains, complementary

therapies and several trained volunteers. Services can be delivered in hospice house, nursing

home, home care, as well as in hospitals (Vidant Health, 2012).

For my graduate project, I engaged in an internship at the palliative care service of Pitt County Memorial Hospital in fall 2011, under the guidance of Ms. Susan Redding (MSN, FNP-C), a nurse practitioner in palliative care service department, and her team of palliative care givers. My goals for the internship were as following: (1) to observe how to conduct palliative care, and what kinds of services are provided in different settings, such as in hospital, at homes, or at nursing homes, (2) to understand the challenges in palliative care delivery and to learn how the service providers cope with them, (3) to consider whether the palliative care services can be adapted to care giving institutions in China. I conducted participant observations, including participation in meetings and doctor visitations, informal interviews and archival researches.

The purpose of this report is to explain what I did and learned during my internship. The report focuses on palliative care services, different care settings, the roles of different professionals in palliative care, and the influential factors in end-of-life decision making process. I will discuss the ethical dilemmas in end-of-life care delivery, including conflicts among physicians, patients and families, potential violations of patients' own willingness, and the lack of end-of-life care resources. Based on participant observation, literature review and my own evaluation, I will also discuss the potential adoption of palliative care in China.

Note:
    1. Pitt County Memorial Hospital was part of the University Health System in eastern

North Carolina. The University Health System changed the name to Vidant Health in January 2012. And Pitt County Memorial Hospital was renamed as Vidant Medical Center at the same time.

Chapter 2

Background: The Development of Palliative Care in the U.S. and in China

My internship at Pitt County Memorial Hospital was informed by scholarship in medical anthropology. Medical anthropology is a subfield of anthropology, and concentrations on health-related fields. It combines social, cultural, biological, and linguistic anthropological knowledge and methodology to illustrate the influential factors to health, illness experience and distribution, disease prevention and treatment, healing processes among different cultures, the social relations involved in therapy management, as well as pluralistic medical systems (Society for Medical Anthropology, 2009). Medical anthropology is an interdisciplinary science which draws upon anthropology, medicine, epidemiology, sociology, political science and environmental science to examine how human health is influences by culture, social construction, politics and globalization (Society for Medical Anthropology, 2009). My internship explored health and illness by examining the practice of palliative care within the framework of medical anthropological.

According to the World Health Organization (WHO), palliative care is "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems"(Davies, 2004: 14). Palliative care emphasizes on integral view of people, which takes a wide variety of needs into consideration, including physical, psychological, cultural, social, and material

needs (Davies, 2004:14).

Scholars have conducted many studies about palliative care services around the world (Sepulveda, 2002; Clavarino, 1999; Haley, 2002; Wang, 2004; Payne, 2005; Gjerberg, 2010; Kinzbrunner, 1995; Higginson, 2003). In the following part, I will discuss palliative care services development, patients' advance care planning and choices of sites of death, challenges in palliative care delivery, and palliative care within the context of Chinese culture.

A Brief Overview of Palliative Care Development

Life threatening illnesses affect hundreds of thousands of people worldwide, and cause great suffering and economic burden to patients and their families (Sepulveda, 2002:91). Palliative care is a low-cost and effective approach to care, which provides a feasible alternative to control the symptoms and improve the quality of life for patients (Sepulveda, 2002:91; Higginson, 2003: 164).

Over the past forty years, the definition of palliative care has been broadened several times by the WHO (Sepulveda, 2002:92). In the past, palliative care adopted a disease-specific approach and mainly concentrated on patients who were not responsive to curative therapy at the last stage of life. In contrast, now palliative care stresses the similarities and opportunities for collaboration among people who work with different diseases, and encourages the application of service as early as possible in the process of any chronic or life threatening illnesses (Sepulveda, 2002:92). In the past, a major emphasis of palliative care was pain relief;

now the palliative care approach has been extended to take all physical, emotional and spiritual needs of patients into account (Sepulveda, 2002:92). Palliative care also extends from merely taking care of patients to the considerations of the health and well-being of families, and providing support and counsel to those who are in bereavement (Sepulveda, 2002:92).

Palliative care was introduced to the United States more than 30 years ago (Connor, 2007: 89). Originally, palliative care in the United States began with the transplantation of the hospice care model practiced in the United Kingdom. In contrast to the United Kingdom, where hospice care was provided mainly in inpatient settings, palliative care in the United States put great emphasis on home care (Connor, 2007: 90). Connor (2007) states that this characteristic resulted from several U.S. factors, including a desire for independence, a distrust of medical institutions, and difficulties for non-profit end-of-life care operating outside the mainstream medicine. Another feature of the U.S. end-of-life care was the involvement of volunteers (Connor, 2007: 90). Today, approximately 400, 000 volunteers work in U.S. end-of-life care services. They play an important role and make significant contributions to the end-of-life care delivery (Connor, 2007: 90).

End-of-life care in the United States has developed significantly over the last 20 years. With the development of the Medicare Hospice Benefit, which is the reimbursement system for end-of-life care services, and the increased acceptance of end-of-life care in the U.S. health system, the number of palliative care and hospice sites has increased dramatically in both hospitals and the community (Connor, 2007: 93). In 2008, approximately 88% of the U.S. population had the access to end-of-life care within 30 minutes driving time from their homes,

and 98% have had the access to end-of-life care within 60 minutes driving time from their homes (Carlson, 2010: 1332-1333).

Palliative care is dealing with the quality of life rather than the quantity of days or months lived (Clavarino, 1999: 437). Evaluation of quality of life involves physiological process, as well as cultural factors (Clavarino, 1999: 439). Clavarino (1999) recruited 100 patients in to a longitudinal study of quality of life, and concluded that in the perspective of the patients, quality of life is a psychological construct of subjective well-being, which varies in individual experiences of health, happiness, satisfaction, disease and limitations of normal functions. It is important to get a more profound understanding of the care concentrations of service providers and the needs of terminal care patients, which would offer opportunities to improve communication between service providers and service users, and enhance the quality of services to reach better outcomes.

To date, several different types of therapy techniques have been adopted in palliative care. Price (1995) examines the life review process along with palliative care and claims that life story narration, which is a verbal representation of life experiences and reflection, symbolizes the social and physical dependencies of people with life-threatening illness. Palliative care providers can effectively guide the life review process, and thus bridge the gaps between cultural systems and values led by materialism or individualism (Price, 1995: 467). In addition, art therapy interventions, which include drawing, museum education and other activities, have had far reaching positive results in mental health maintance, personal growth, self-expression and social interaction (Geue, 2010: 168). Music Therapy provides people with experience of

beauty, happiness, life meaning and inspiration, therefore, attributes to positive outcomes in both patients and care givers (Magill, 2009: 37). Palliative care adopts family focused grief therapy to assist family members and care givers to better get through the stage of bereavement, and improves social functioning (Kissane, 2006: 1215). With the development of therapy methods, more possibilities of terminal care will emerge and thrive.

However, there are still disparities in the palliative care development worldwide (Sepulveda, 2002: 91). The International Observatory on End of Life Care ranks all the countries in the world into four categories in references to the presence of palliative care services and the actual services they offer. The four categories are: no identified hospice-palliative activity; countries with the capacity of building hospice and palliative care services; countries with localized provision of hospice and palliative care; and countries where hospice and palliative care have been integrated widely into public health system (Wright, 2008: 470). 115 out of the total 234 countries of the world have palliative care services. Only 35 (15%) countries have the services integrated into the wider health care system and policy making (Wright, 2008: 471). Advocacy is needed worldwide for policy development and public health promotion of palliative care (Sepulveda, 2002: 91). There is a need to tailor palliative care services to the specific cultural and social contexts of the target populations in order to integrate into the existing medical systems (Sepulveda, 2002: 91).

Advance Care Planning

Advance care planning is a process of making decisions about future treatment before it is needed (Perkins, 2002:48). In 1990, the U.S. Supreme Court first stated that patients have the right of self determination and may accept or reject any proposed medical treatment, including life prolonging methods such as artificial delivery of food and water (Gillick, 2004: 7). The implications of the statement are far reaching. Patients should fully understand the benefits and burdens of treatment alternatives in order to exercise their autonomy effectively. Patients should also engage in advance care planning if they hope to maintain their autonomy (Gillick, 2004: 7). Advance directives are widely viewed as the most systematic attempt of advance care planning (Gillick, 2004: 7; Perkins, 2002: 48). Advance directives encompass living wills, which instruct what kind of care should be delivered at the end of life, and proxy designations, which state who should be the decision makers if the patient is not able to do so (Gillick, 2004: 7).

To date, legislations on advance directives have been passed in all 50 states and the District of Columbia in the United States. However, only 15% to 20% of the general population have a written directive (Gillick, 2004: 8; Tilden, 2004: 536). Sanders' (2008) study about death awareness and self-management shows that many patients are unprepared when facing the issues of terminal illness and the content of advance care planning materials play an important role in their decision making. Proper advance care planning materials can promote the open awareness and encourage people to think positively in life-threatening situations (Sanders, 2008: 990). Advance care planning materials should be framed according to specific cultural attitudes towards death and dying, in order to improve palliative care services (Sanders,

2008: 991).

Perkins (2002) argues that the decision to engage in advance care planning is strongly influenced by culture. This study shows that European Americans, Mexican Americans and African Americans all share the belief that dying patients have the rights to make their own treatment decisions, and advance care planning care help to guide the process (Perkins, 2002: 52). However, differences on the attitude towards advance care planning exist among ethnic groups. European Americans are more familiar with the concept of advance care planning. They believe the health care system serves patients' wishes and prefer to make decisions about terminal care as individuals (Perkins, 2002: 55). Mexican Americans and African Americans are less receptive to advance care planning (Perkins, 2002: 55). Mexican Americans believe the health care system controls the treatment and also serves patients well. They do not want futile life support. They rely heavily on their families on decision making, but they are reluctant to share their own wishes towards end-of-life care with anybody (Perkins, 2002, 53). African Americans tend to believe that the health care system controls the treatment and thus there is no use to communicate individual wishes with care givers. They value the family influence on terminal care, and they usually disclose their wishes to family members (Perkins, 2002: 55). It follows, that health professionals need to be informed about the differences of different ethnic groups, enhance their cultural sensitivity in advance care planning promotion process, and communicate with patients and families effectively (Perkins, 2002: 56).

Choices about Sites of Death

End-of-life experiences are strongly influenced by the choice for particular sites of death. Last Acts (2002) claim that facilitating a patient's death in his or her preferred location, such as hospital, nursing home or home, is an important indicator for quality of care. Though more than 70% of the American people express that they wish to die at home, most of them still die in an institutional settings (Last Acts, 2002: 13). Each year, about 50% of deaths occur in hospitals, about 24% occur in nursing homes, and about 24% occur at home (Gruneir, 2007:361).

The kind of end-of-life care patients receive depends on their access to medical care (Gruneir, 2007: 370). In the U.S., Medicare and Medicaid systems regulate the medical insurance coverage for many end-of-life services (Cartier, 2003: 2295). Medicare is the federal insurance for people who are 65 or older. As a government-sponsored social services benefit, Medicare covers billable medical services, which generally limits the end-of-life care in specialized nursing facilities and benefits to about 3 months (Cartier, 2003: 2290; Cartier, 2003: 2295). Medicaid is the federal health benefits for people who have no resources for daily life care, and its policy provisions vary widely by state (Cartier, 2003: 2295). Medicaid generally pays for basic physical and bodily care in long term institutional care settings, with the condition of personal bankruptcy of the patients (Cartier, 2003: 2295). Cartier (2003) argues that people who are eligible for Medicare sometimes are not poor enough to get Medicaid; thus, their medical insurance does not cover their long term care needs, which means they have to fund their own end-of-life care. The existence of Medicaid encourages the expansion of nursing home care, however, limits the options of end-of-life care for those who depend on

Medicaid systems (Cartier, 2003: 2295-2296). The level of state Medicaid payment rate has a strong positive correlation with nursing home deaths and a negative correlation with hospital deaths (Gruneir, 2007: 368). Policy gaps in the U.S. system of federal health insurance impacts many people's end-of-life experiences (Cartier, 2003: 2299).

Patients' anticipations for the service quality and individual characteristics are strong predictors of where people die (Cartier, 2003: 2297; Gruneir, 2007: 368). It is widely understood that hospital care provides better quality than nursing home care. Thus, people usually prefer hospital services and avoid nursing facilities (Cartier, 2003: 2297). When patients have the choice to request home care, they also tend to avoid nursing facilities, since their own home represents a safe and familiar place, where they can get support from families through difficult times (Cartier, 2003: 2297).

According to results from the National Home and Hospice Care Survey and the National Nursing Home Survey, home palliative care patients are more likely to be under 75 years old and married, while nursing home palliative care receivers are more likely to be 85 years old or older, and widowed (Han, 2008: 481). Nursing home palliative care patients are more likely to suffer from Alzheimer disease or heart disease than those that receive home care service (Han, 2008: 481). During their last months of life, nursing home palliative care patients are likely to receive more dietary or nutrition services, daily activity assistance, medication management, and physician services than home palliative patients (Han, 2008: 484). However, the quality of care in nursing homes is impacted by the institutional discomfort, lack of privacy of the physical environment, and lack of staffing and supervision (Kayser-Jones, 2003: 82).

Patients' preferences for home care at the end of life propose challenges for both medical professionals and family care givers (Exley, 2007: 2317). Exley (2007) argues that, being cared for at home does not necessarily mean at the physical space of "home", but rather being at a private and comfortable setting, accompanied by loved ones. Home care requires more than visiting hours, but rather a redistributing care in a home environment, which needs to be accomplished under the guidance of health professionals (Exley, 2007: 2325). Family members may not have adequate knowledge or experience to identify physical symptoms or other problems for the patients. Therefore, health professionals should be cautious when they use the information given by the families as references (Resnisky, 2007: 454). Family care givers often suffer from both psychological stress and financial burden of end-of-life care (Tilden, 2004: 538). Primary family care givers provide the most physical care, when coping with the emotional difficulty caused by witnessing their loved one's impending death (Tilden, 2004: 238). Medical expenditures are paid by the families if the patients do not have proper insurances, especially for the medications. And the existence of financial burdens sometimes leads to the reluctant decision to limit the patients' life-sustaining treatment (Tilden, 2004: 238).

Challenges in Palliative Care

Death is a difficult, universal human experience (Perkins, 2002: 52). Palliative care delivery frequently encounters various challenges caused by the limitation of health policies,

conflicts among physicians, family members and patients in the decision making process, lack

of resources and care givers and so forth (Gjerberg, 2010: 679; Connor, 2007: 94).

Kinzbrunner (1995) states that most of the ethical dilemmas faced by U.S. end-of-life care

professionals emerge in reference to alignment with Medicare Hospice Benefit. Medicare

Hospice Benefit requires that patients must have a prognosis of 6 months or less left before

death, and the inpatient care is restricted to pain and symptom management which cannot be

accomplished in other settings. When these criteria are fulfilled, the end-of-life care can be

reimbursed on a per diem basis (Kinzbrunner, 1995: 29). Thus, when physicians refer patients

to end-of-life care, they face ethical dilemmas regarding the proper treatment decisions and

courses. For example, it is difficult for physicians to predict a patient's prognosis is 6 months or

less; physicians need to decide to what extent they should provide patients with full

information of their illness as the prerequisite of the Medicare Hospice Benefit. In addition

physicians are consistently concerned about the use of morphine, artificial nutritional support

and parental hydration for terminally ill patients (Kinzbrunner, 1995: 30-33).

Although end-of-life care tends to focus on individuals, family members are involved in

many aspects of end-of-life decision making and care (Haley, 2002: 284). Studies show that

families actively participate in chronic illness care giving, advance care planning, and decision

making during terminal illness and imminent death (Haley, 2002: 285-290). When a patient

does not have explicit terminal care preference or planning, family members are often asked by

physicians to propose a decision based on what they believe the patient would have wanted

(Haley, 2002: 290). However, family members' decisions may conflict with the patients'

willingness, and violate the patients' autonomy and integrity (Haley, 2002: 291; Gjerberg, 2010: 680). How to communicate with families and deal with the conflicts among different opinions towards end-of-life care remain to be dilemmas for health professionals (Gjerberg, 2010: 681).

Another challenge for palliative care development is related to work force issues (Connor, 2007: 96). Russ (2005) claims that in hospice settings, there are frequent exchanges and distributions of valued resources, which include money, care, touch, stories and love. Care givers are usually motivated by two different economies. One is characterized by ethics, which involves pure sacrifice and charity. The other is characterized by standards of efficiency and discipline, which involves cost containment and profit making (Russ, 2005: 129). The rapid growth of palliative care in the U.S. demands a substantial increase in actual care givers (Russ, 2005: 131). Connor (2007) states that new specialty in the education of physicians, nurses, social workers, and spiritual and religious service personnel regarding palliative care should be encouraged.

In cope with the workforce demand, over the past years, medical teachings about the care for people who are dying have been steadily increasing around the world. Scholars discuss what palliative care education should include and how the education should be delivered (MacLeod, 2007; Kolb, 1984; Hawkins, 1993; McNamara, 1993). MacLeod (2007) argues that the concept of care requires a commitment on a holistic level instead of merely attending to physical symptoms. More attention should be paid to the education of health professionals about care motivations and preparations for facing a patient who is dying. Kolb (1984) suggests that the acquisition of knowledge about palliative care for health professionals could be

accomplished by a combination of the following approaches to patient needs with the help of a mentor: concrete observation, reflective observation, abstract conceptualization and active experimentation. Hawkins (1993) claims that reading autobiographies and biographies that describe experiences of illness will give care providers rich examples and a deeper understanding of the needs and life world of terminal-ill patients. In cross-cultural settings, palliative care professionals also need to acknowledge the presence of different languages, specific cultural concepts, religious and spiritual beliefs, as well as the influence of social relationships (McNamara, 1997: 363).

Palliative Care and Chinese Culture

The aging population in China has grown rapidly in size in recent years (Flaherty, 2007: 1295). According to the United Nations, an aging society is defined as having at least 7% of its population aged 65 or older (Flaherty, 2007: 1295). China reached 7.6% in 2005, and is expected to have more than 25% of aging population members in 2050 (Gao, 2007: 211). As a result of one child policy, which was published in 1980s, the typical Chinese family structure in the near future will be four grandparents, two adult children and one grandchild (Flaherty, 2007: 1295). The grandparents may not have enough children or grandchildren to take care of them. Lack of care givers and lack of care giving facilities will lead to serious problems about long term care and end-of-life care, which Chinese people have not yet addressed (Flaherty, 2007: 1296; Gao, 2007: 211).

Scholars have studied Chinese perspectives on health care and end-of-life decisions (Payne, 2005; Chen, 2001; Bowman, 2001). Chinese values towards health and end of life are influenced by Chinese philosophies and religions, such as Confucianism, Buddhism and Daoism (Payne, 2005: 112; Chen, 2001: 271). Due to the Confucian ideal of filial piety in China, living arrangements for the elderly pose special significances for many Chinese people. Usually, elderly people would like to co-reside with one or more married children, and receive emotional, instrumental, and financial support from them (Sereny, 2011: 197). Older people who face the end-of-life situation usually rely on their children, especially the male ones, to negotiate with health professionals (Payne, 2005: 112; Chan, 2005: 30). Buddhism encourages people to do good deeds to receive good reciprocation, therefore, many people to believe that being morally good and being peaceful will benefit their health (Payne, 2005: 112). Daoism teaches people to be in harmony with nature. Under the influence of Daoism, Chinese tend to perceive death as a natural extension of life (Chen, 2001: 271).

The research of Bowman (2001) shows that when making end-of-life decisions, Chinese people tend to take a series of issues into consideration. These issues include the maintenance of hope and emotional harmony, the suffering and the burden for the patients and family members caused by the life-threatening illnesses, the expect for the future when entering a new life cycle after death, the respect for the opinions of doctors and family members. Some Chinese people think that a good death is when a person has completed his contribution to society and family, for instance, the work obligations are successfully fulfilled, and children are married and self-sufficient (Bowman, 2001: 461). End-of-life decisions are likely to be

made based on collective discussion among all members of an extended family (Payne, 2005: 112).

Studies reveal many barriers in end-of-life care services among Chinese people. First of all, open discussions about terminal illness and end-of-life issues are considered inappropriate in Chinese culture (Payne, 2005: 113; Bowman, 2001: 461; Chan, 2005: 30). Talking about death is perceived to be discouraging and harmful to the patients, and may potentially bring bad luck and hasten the death (Payne, 2005: 113; Chan, 2005: 31). Scholars have conducted studies about the perspectives of end-of-life experiences of Chinese elderly in the U.S. and in the UK. They found that end-of-life care is not viewed as a positive choice by most people, and a do not resuscitate order may be viewed disrespectful to life (Chan, 2005: 31; Seymour, 2007: 880). Many people remain in full code status and reject end-of-life care even when they are terminally ill, to maintain a sense of hope (Chan, 2005: 31; Seymour, 2007: 880).

Secondly, although Chinese culture values the decision of families, the proxy decision-making feature of the advance care planning documents is generally unaccepted (Bowman, 2001: 461). The reason is that the identification of proxy or proxies potentially limits the opinions of families who are not named, and impact the family collective decision making (Bowman, 2001: 461). Bowman (2001) suggests that it can be beneficial if the entire family is involved in advance care planning after a clear diagnosis of illness.

Third, unrealistic family expectations, family conflicts, and the physicians' ethical dilemmas towards end-of-life treatment also contribute to the barriers of palliative care

provision in Chinese culture (Wang, 2004: 129). Because of the influence of Confucian ethics implication on family values and family roles in medical decision making, a physician is supposed to enhance interconnection among family members and the family harmony (Payne, 2005: 113). Medical service providers report that when caring for dying patients, they feel more competent in controlling pain or other physical symptoms than performing effective communications with families and patients, and managing depressions and other psychological afflictions (Wang, 2004: 127). More specific training in palliative care and research on the social and cultural context of end-of-life decision making processes is expected to help improve terminal care for Chinese elderly people and other patients with life-threatening illness (Wang, 2004: 129).

Forth, palliative care development in China is challenged by the current structure of Chinese health care system (Flaherty, 2007: 1299). In China, health care is primarily based on fee for service, and not everybody has health insurance (Flaherty, 2007: 1295). It is hard to afford long term medications and hospitalizations, especially for people in rural areas or in lower- and middle- class (Flaherty, 2007: 1295, 1297). Though the aging population increased rapidly, health insurance coverage in elderly population has decreased. In 1993, 87.1% of men were covered, but 76.7% in 2003 (Gao, 2007: 112). And only 55.4% of the women were covered in 2003 (Gao, 2007: 112). The phenomena impacted the hospitalization rates among aging people, and some of them refused to have medical services due to financial difficulties (Gao, 2007: 214). Moreover, the health care facilities for elderly and end-of-life care are far from enough. For example, at the end of 2005 in China, there were 1.5 million beds in elderly

care institutions at the nursing home level, including social welfare institutions for the aged, elderly people's homes, senior citizens' lodging house and nursing homes, which could accommodate only 0.8% of Chinese total aging population (Flaherty, 2007: 1298). In response, China proposed a plan to incorporate services for seniors in to community development (Flaherty, 2007: 1298).

Another problem is the lack of education about end-of-life care for the elderly. In China, there are no formal geriatric fellowships or national board certifications in hospitals or universities (Flaherty, 2007: 1298). Symptom control and palliative care have not yet been adopted as a practice specialty (Wang, 2004: 125). More education is needed in the areas of aging and care for physicians, nurses and other health professionals. There is still a long way to go before the general population will accept the concept of end-of-life care (Flaherty, 2007: 1299).

Chapter 3

Methodology

I adopted participant observation as the main method of data collection during my internship. There are three different roles that a fieldworker can take on during field work: complete participant, complete observer and participant observer (Bernard, 2006: 347). Being a complete participant involves becoming a member of the group without letting people around

notice the ongoing research. Being a complete observer involves following people around and recording their activities with little interaction. In contrast, participant observation involves gaining a close and intimate familiarity with a specific culture, becoming a member of a group, following people and collecting information, then removing oneself in order to record and analyze what one has learned intellectually (Bernard, 2006: 347). A participant observer can be either an observing participant or a participating observer. Observing participants are insiders who observe and record some aspects of life around them, while participating observers are outsiders who participate in some aspects of life around them and record as they can (Bernard, 2006: 347).

Participant observation makes it possible to collect many different kinds of data. Qualitative data can be collected during participant observation by writing field notes, taking photographs, audio recording, informal interviews, unstructured interviews, and semi-structured interviews; meanwhile, quantitative data can be collected based on direct observation and structured interviews (Bernard, 2006: 344). In addition, the qualitative data can be quantified during analysis and vice versa (Bernard, 2006: 451). I found participant observation to be a useful and efficient method during my internship.

Participant observation provided me the opportunity to work closely with end-of-life care providers, to gather information about the care system and to gain intuitive understanding of end of care services in Pitt County Memorial Hospital.

As a participant observer, I followed doctors and nurses in the rounds in inpatient hospice

house and nursing home; I shadowed nurses, social workers, volunteers and chaplain in the palliative care unit and other units around the hospital; I visited patients' homes with a nurse, a social worker and a chaplain for home hospice and bereavement services. In addition I observed weekly palliative care service team meetings, advanced care planning meeting held for members of the community in a community center outside the hospital and other meetings of the palliative care personnel with various hospital related administrative units.

During my participant observation, I jotted down field notes concentrating on several issues: physical settings of different places; interactions among providers, families and patients; the roles of providers; and the cooperation among different department within hospital system about end-of-life care. I wrote descriptive notes based on my daily jottings of observations at the end of each day of my internship.

To organize the data I had gathered as a participant observer of patient visits and meetings with end-of-life care givers, I created a database. In this database I organized the dates, places, patients' demographic information, and issues that occurred in provider-patient communications. I analyzed the data by using SPSS software, and I identified issues which needed more discussions and more explorations.

I also conducted informal interviews with end-of-life care providers, including two doctors, two nurse practitioners, one nurse, two social workers and two chaplains, to get more knowledge about the services, related health policy, difficulties in care delivery, as well as other supporting systems. In addition, I conducted four separate semi-structured interviews.

This series of interviews included a social worker who is assigned to Medical Intermediate Unit (MIU), a case manager of the rehabilitation department, a family therapist associated with the palliative care service and the language services manager of the university health system. My goal was to study their range of cooperation with the palliative care services and their professional experiences and job responsibilities. After completion of the informal and semi-structured interviews, I scanned my jottings for patterns and related themes, such as collaboration among different medical departments and the comparisons of service scopes. More information can be found in the findings section.

Chapter 4

Findings: What I Learned during the Internship

In this section, I will discuss what I learned during my internship. Issues include the different roles of health professionals, the features of different care settings, the cooperation between palliative care services and other medical departments, the characteristics of the

patients, and the problems and dilemmas in palliative care delivery.

Roles of Service Providers

End-of-life care involves a multi-disciplinary service approach to meet the physical, psychological, social, cultural, and spiritual needs of patients with life-threatening illnesses and their families. An end-of-life care team includes doctors, nurses, pharmacists, nursing aides, nurse practitioners, social workers, chaplains, volunteers and other medical professionals. Each of these service professionals undertakes specific roles in end-of-life care and cooperates with other service personnel to achieve better outcomes for patients.

Doctors diagnose diseases, make medical decisions, inform patients and families about the patients' conditions and treatment options, and make medical referrals. Nurses attend the patients every day, record patients' conditions, conduct pain control and other related medical procedures. Nurses also report the patients' and families' needs to doctors, and explain the doctors' medical recommendation to patients and families, serving as a bridge. In home end-of-life care, nurses check the patients' medical supply during every visitation. Pharmacists often provide helpful information on the effects of the drugs that patients are taking. Nurse aides assist the patients in daily activities, such as cleaning their bodies and changing clothes.

Nurse practitioners, on the other hand, only provide advice and consultations for patients and families with end-of-life care needs. They don't dispense medical care directly. Nurse practitioners try to give patients and families as much information about the patients' care

options as possible. They coordinate the discussions about end-of-life issues among patients, families, physicians and nurses, with the aim of figuring out what is the best for the patients. Nurse practitioners also participate in the end-of-life care system development and implementation.

Social workers usually deal with the patients' various documents such as advance care planning and medical insurance. They coordinate the information needs among different groups, such as families, nurses, doctors, insurance companies, health care institutions, and community churches, providing counseling, referral, advocacy services to help patients and families. Their task is to solve practical problems.

Chaplains provide guidance for spiritual concerns and act as an active part in bereavement support. In addition, specially-trained volunteers can provide emotional and practical support, including respite, to patients and their families, and also engage in different stages of bereavement support. Other medical professionals, such as occupational therapists and music therapists, work together with the end-of-life care team, and help patients cope with the end-of-life process according to their expertise.

Places for End-of-life Care

Palliative care service at Pitt County Memorial Hospital is designed to give relief to terminally ill patients through symptom management. The ultimate goal of palliative care in Pitt County Memorial Hospital is to provide comfort and maintain the highest quality of life

during the last phase of life (Vidant Health, 2012).

Whenever doctors think their patients can benefit from palliative care services, they request the palliative care service team to visit the patient for an initial consultation about their services. The palliative care consultation involves discussing the patient's condition with the patient and his or her family members, providing information about possible medical procedures and potential results, exploring the patient's own opinions towards end-of-life care, figuring out the needed end-of-life decision documents and the way that the patient's will can be valued most. At Pitt County Memorial Hospital, three palliative care nursing practitioners provide palliative care consolation across the hospital system, organize family meetings, and assist in care arrangements.

When end-of-life care decision is made, the patient is then referred to one of the following five locations that provide palliative care: the inpatient hospice house, the nursing home, the palliative care unit, the home hospice or other facilities within the local hospital system. Some patients stay in the same unit and get visitation and follow-up care by nurse practitioners and volunteers.

The decisions about where to get end-of-life care can be influenced by the patient's requests and physical condition, the doctors' recommendations, the families' opinions, the availability of care givers, and the patient's advanced care planning and insurance status. End-of-life care in inpatient hospice house, palliative care unit and other units within the hospital meets the needs of patients whose symptoms should be closely observed and

efficiently controlled under the doctors' guidance. Home hospice is usually assigned to patients whose symptoms can be controlled at home, and who have family care givers or personal care givers. A patient can also be placed in nursing home if it is proper for his or her situation. Bereavement support is provided by chaplains, volunteers, and support groups after the patient's death. The goal of this service is to help the family members cope with sorrow and grief.

The following part is a description of inpatient hospice house, palliative care unit, home hospice and nursing home, as well as the related services.

Inpatient Hospice House

Located at 920 Wellness Drive, Greenville, the Service League of Greenville Inpatient Hospice House provides inpatient hospice care to patients, who have symptoms that are difficult to manage at home. The inpatient hospice services aim at bringing comfort, dignity and peace to patients and their families (Vidant Health, 2012). Patients are admitted to the inpatient hospice house under in reference to doctors' referrals. Before admission, patients must have already received hospice care and have a Do Not Attempt Resuscitate order. Although the Service League of Greenville Inpatient Hospice House operates under Vidant Home Health and Hospice System, patients from other referring hospice agencies could also be admitted (Vidant Health, 2012).

The inpatient hospice facility includes eight private rooms, family living room and dining room, fully functional kitchen and garden area. Facilities in each of the patient rooms include

an advanced medical bed, a sofa, a table, a shelf, a refrigerator, chairs, closets, a patio door towards garden area and so forth. Patients are welcomed to bring personal items for their own comfort, such as pillows, carpets, clothes, and they can also bring photos, postcards, books which can be put on the shelf and serve as a reminding of good times. Sometimes, family members can spend the night in patient's room, and there is no limitation on the number of family members who would like to visit.

The care station in the inpatient hospice house serves as an office area for doctors, nurses and social workers. Doctors, nurses, and social workers often have discussion about patients' situation, exchange opinions, and keep patients' records on charts in care station.

Nursing Home

The Golden Living Center located at 2910 MacGregor Downs Road, Greenville, provides nursing home services for the elderly. The nursing home facility includes 152 beds in private rooms or shared rooms, dining rooms, living rooms, lounges, rehabilitation center and so forth. The facilities in patient room include beds, bathroom, TV sets, closets and sofa. Patients are welcomed to bring their own furniture in consideration of their room size.

Usually, there are about 140 patients living in the center. Several doctors were in charge of the patients in turn, and each of them was responsible for about 85 patients. The patients' rooms are separated by four hall ways, and a nurse and several nursing aids are in charge of patients in each hall way.

The establishment of a hospice facility at Golden Living Center is a result of the center's

collaboration with other local, licensed hospice agencies (Golden Living Center, 2010). The hospice care team includes nurses, social workers, chaplains, volunteers, and bereavement managers, aiming at providing medical, emotional, practical, and spiritual support to the residents with terminal illnesses and their families (Golden Living Center, 2010).

Palliative Care Unit

In the Palliative Care Unit at Pitt County Memorial Hospital, twelve acute care beds are designated to meet the short-term needs of patients and families who are in need of palliative care at the end of life. Services ranged from symptom control while treating disease, to care of symptoms during the dying process. Patients and families referred to palliative care get visitation or respite services by nursing practitioners and specially trained volunteers.

Bereavement support is also provided when needed. Family members of all adults who die at the hospital receive a sympathy card, a letter of condolence, and suggestions about dealing with grief from the palliative care service (Vidant Health, 2012).

Home Hospice

Home hospice in Pitt County Memorial Hospital is part of Vidant Home Health and Hospice System. Their services cover patients and families in 17 eastern North Carolina counties, and in most cases, patients remain in the comfort of their homes and receive expert, compassionate care (Vidant Health, 2012). Similar to the missions of other palliative care providers, the main goal of home hospice care is to help patients live their final days with dignity and as free of pain as possible, comfort fear, anxiety and loneliness, and address

concerns about family and friends (Vidant Health, 2012).

Each hospice patient is assigned to a special care team, including physicians, chaplains, social workers, nurses, nursing aids and so forth. Each patient gets a nursing visitation at least every other week, and some patients can be visited several times a week based on their needs. In addition, a social worker visits patients once a month. Sometimes, a home hospice patient can be referred to the inpatient hospice house and spend several days there, during which time the doctors will adjust the medication and control the symptoms.

If a patient requests for home hospice services, the typical service period is 90 days. After 90 days, the patient can have another 90 days on hospice. After that, the patient is not on hospice any more, for hospice cannot keep patients for that services if they are getting better, but the patient will get a doctor visitation every two months afterwards. Bereavement support lasts 13 months or more after death. Home hospice team is on call 24 hours a day, seven days a week.

Home hospice is trying to get family members involved as much as possible. Nurses teach the family members about the patient's medication, and encourage them to take care of the patient. If a patient does not have a family care giver but still wants to have home hospice, he or she might end up with a personal care giver or finding a place in nursing home under the coordination of the social worker.

Cooperation with Other Departments

Palliative care services at Pitt County Memorial Hospital involve wide collaborations from various departments across the hospital system, which benefit patients, families, and the development of end-of-life care service system. During my internship, I learned about some of these collaborations by participating in several meetings with Ms. Susan Redding (MSN, FNP-C), and conducting semi-structured interviews. I interviewed a social worker who is assigned to the Medical Intermediate Unit (MIU), a case manager of the rehabilitation department, a family therapist associated with the palliative care service and the language services manager of the Vident Health System.

According to Ms. Susan Redding (MSN, FNP-C), three major meetings are held once a month: steering committee meeting, ethics committee meeting and community meeting. The participants of each meeting work in from different departments of the hospital or volunteer in the community organization. The steering committee meeting discusses general policies, procedures, and related matters affecting the palliative care services as a whole. During the period of my internship, the committee discussed issues related to newly published laws such as the Palliative Care Information Act, proposals for collecting palliative care stories to serve as educational resources, and proposals for seeking support from a larger number of health care providers. The ethics committee meeting mainly focuses on issues related to end-of-life ethics, such as the procedures for getting permission for palliative care and comparisons between Advanced Directives and resuscitation status of patients in different departments. The community committee meeting concentrates on promotion, education and advocacy about end-of-life care within the community. For example, the meetings discussed issues related to

regular advance care planning clinics, health fairs, films and art exhibitions about end of life, reporting events on local newspapers, as well as donations from community members.

Palliative care service providers cooperate closely with other units at Pitt County Memorial Hospital. The cooperation between palliative care services and MIU, and the collaboration between palliative care services and the rehabilitation center can serve as illustrative examples. Palliative care team members provide consults for patients in both MIU and the rehabilitation center, about coping with end-of-life issues and possible care options. Services in MIU and rehabilitation center have different scopes from those in palliative care department. In MIU, the patient is under close observation and the medical plan for a patient may be still changing, while in palliative care unit, the patients are usually stabilized and the medical directions are very clear. The rehabilitation center aims at helping patients regain better physical or psychological functions, while palliative care services help patients to stay comfortable. Patients in other units in the hospital get similar end-of-life consults when they need them. And all the collaborations among palliative care services and other units aim at providing the most proper services for each patient.

The family therapy within end-of-life care services aims at providing a safe space for the patients to express their concerns about end-of-life issues and share their stories in their life span. The family therapist I interviewed helps the patients to reframe the information in their minds and lead the patients to be more calm and peaceful. The family therapist also collaborates with the palliative care team to evaluate patients' mental status and propose for further care options. Moreover, the family therapist works with volunteers on the bereavement

groups every week, providing guidance about the group conversation and helping people cope with their loss.

The collaboration between language services and palliative care services focuses on end-of-life care documents translation and interpretation for non-English-speaking services users. According to the language service manager of the university health system, over 90% of the translations and interpretations in eastern North Carolina health care are between Spanish and English. At Pitt County Memorial Hospital, the advanced directives were translated to Spanish in 2009. Members of the palliative care team helped the translators to understand the end-of-life concepts and ideas, so that the translation could be more appropriate adapted to cultural concepts of native Spanish speakers. When face to face interpretations are needed in end-of-life care settings, the language service manager will coordinate the interpreters and make arrangements to serve patients. Upon requests, materials such as music or movies in a foreign language can also be provided by language services to end-of-life care users.

Palliative care service team meets with other departments around the hospital is continuously interested to create more opportunities for cooperation. It will be beneficial for the system of palliative care services at Pitt County Memorial Hospital, if the meaning of palliative care is understood by more health professionals, and there is more communication among various departments.

Characteristics of Patients

During my internship, I shadowed doctors, nurses, volunteers, social workers and chaplains and talked to them about end-of-life care services in the inpatient hospice house, home hospice, nurses home, advanced care planning clinic, palliative care unit and other units across the hospital. I observed 45 patients in total. Among the 45 patients, 17 of them were male (38%) and 28 of them were female (62%). According to the information provided by palliative care service providers, the patients comprise three ethnicities: 26 of the patients were European-American (58%), 16 of them were African-American (35%) and 3 of them were Latino American (7%).

Based on my observation, in end-of-life care services, there was no significant difference in gender distribution among the three ethnicities. Among the 26 European-American patients, 10 were male and 16 were female. Among the 16 African-American patients, 6 of them were male and 10 of them were female. Among the 3 Latino American patients, 1 of them was male, and 2 of them were female. However, as a whole, there were more female patients participating in end-of-life care than male patients. Reasons for the greater proportion of female patients need to be explored.

The ages of patients in my observation range from 33 to 94. There were only two patients under 50, who were in their thirties, one sought for palliative care and the other sought for bereavement support. 30% of the patients were over 80. The average age of the patients I observed was 70 (SD 15.60), which holds for both male and female patients. The average age of European-American patients was 74 (SD 13.52). The average age of African-American patients was 62 (SD 16.60). The average age of Latino American was 83 (SD 8.08). The

African-American patients were relatively younger than the other two ethnic groups of patients, while Latinos were relatively older. Number of Latino Americans and all others may be too small to make a prediction or statement. More research is needed in order to explore whether Latinos are few in number to search for palliative care and whether they have palliative care needs only when they get older than average people.

Among all the patients I visited, 29 out of the 45 were older than 65 years old. That is the benchmark for elderly, as defined by the WHO (World Health Organization, 2012). Among the patients who were older than 65 years old, 11 of them were male (38%), and 18 of them were female (62%). Among the patients who were younger than 65 years old, 6 of them were male and 10 of them were female. Thus, there was no significant difference in gender distribution of the age categories.

Meanwhile, there are differences in ethnic distribution by age. Among the patients who were older than 65 years, 21 of them were European-American (72.4%), 5 of them were African-American, and all three Latino American patients belonged to that group. In contrast, among the patients who were younger than 65 years old, 5 of them were European-American (31%), 11 of them were African-American (69%) and none of them were Latino American.

Age differences can be observed in different service places. In my observation, the average age of the seventeen patients in other units across the hospital was 65 (SD 17.14), the average age of the seven patients in inpatient hospice house was 67 (SD 17.68), the average age of the four patients in advanced care planning clinic was also 67 (SD 2.22), the average age of

the seven patients in home hospice was 71 (SD 14.55), the average age of the four patient in nursing home was 76 (SD10.60), and the average age of the six patients in palliative care unit was 85 (SD 8.61). Basically, patients in palliative care unit and nursing home were older than patients in other end-of-life care service places. This age distribution may be due to the patients' physical conditions, needs for specific kinds of care, their insurance status and availability of care givers. No particular patterns were observed regarding the ethnic distribution in different services places, due to the small sample size.

Among all the patients I observed, 64.4% of them were accompanied by their families during the visitations. However, only 25% of patients in both inpatient hospice house and nursing home were with family. In contrast, all the seven patients in home hospice were accompanied by their families. The availability of family care givers may have influences on the choices of service places.

Ethical Dilemmas in Providing Palliative Care

During the process of end-of-life care delivery, palliative care providers at Pitt County Memorial Hospital are faced with various ethical challenges. During the period of my observations, the most frequently encountered dilemmas included conflicts between physicians, patients and their family members, potential violations of patients' autonomy and integrity, and the lack of end-of-life care resources. In this section, I will discuss each of the three dilemmas and how palliative care providers cope with these challenges and the solutions they devise to

handle them.

Ethical Dilemmas

The first category of ethical dilemma in my observations was the conflicts between physicians, patients, and patients' family members, which were frequently experienced by palliative care providers. Many factors contributed to this phenomenon. Different departments of the hospital process different goals for patient care. For example, the Intensive Care Unit and the Oncology Department usually aim at sparing no efforts to save patients' life with modern medical tools, while palliative care and hospice services aim to keep patients as comfortable as possible. When a patient is transferred between different units within the hospital system, different opinions and lack of communication among medical personnel from different departments may result in conflicts over the proper treatments for patients.

Based on my observations family members often wanted a more active or aggressive medical treatment than the patient or the medical staff regardless of the limited ability of medical treatment designed to prolong life. However, end-of-life care concentrates on helping people to deal with death more peacefully and without the involvement of invasive and expensive technology other than pain relief medicine.

In addition, different family members held different expectations with the patient for the outcome. It seemed more difficult for the younger family members to accept the concept and meaning of end of care, due to the fear of losing beloved parents or grandparents. A case about care options for a patient in her eighties I encountered in my internship can serve as an

illustrative example. The patient had dementia and found it difficult to swallow. A nurse practitioner working for palliative care services organized a family meeting between the patient's daughter, son-in-law, and two grandchildren to discuss the patient's situation and end-of-life care options. Since the patient was stabilized at that time, her discharge from the hospital was about to begin. The four members debated with each other whether the patient should get a feeding tube and whether the patient should go to a hospice house. The patient's daughter and son-in-law thought they should avoid risks regarding contracting germs and getting discomfort which would be caused by the feeding tube and keep the patient as comfortable as possible. However, the grandchildren argued that if they discontinued nutrition for their grandmother, they would starve her. The word "starve" made the patient's daughter very sad and she cried at the meeting. The family members reached no solution that could be acceptable to all of them, and the nurse practitioner had to suggest they take more time to think things through and communicate with each other. Conflicts within the family often lead to ethical dilemmas which are very difficult to solve, and many patients suffer during their last stage of life if an explicit decision towards their therapy or end-of-life care is not reached.

The second category of ethical dilemma in my observations was potential violations of patients' autonomy and integrity. The first potential violation of the patients' willingness was related to information release. Medical personnel sometimes tried to provide the patients as much information as possible, regarding his or her illness, stage of life, and options of medical care, because concealing such messages held back the discussion of appropriate treatment courses. However, it was possible that a patient would rather not have this kind of information

due to his or her cultural background or life experiences.

This kind of ethical dilemma was also closely associated with the question of termination of life-prolonging treatment, especially when the patient was unconscious or in the status of dementia. It was difficult to identify whether the patient truly wanted to continue life-prolonging medical procedure, such as artificial feeding, antibiotics treatment and blood transfusion. Moreover, some patients got hospitalizations under the pressure of their family members, which was against the patients' wishes and the health care providers' recommendations. This phenomenon often occurred when the patients did not have proper advanced care planning documents, such as the "Do Not Attempt Resuscitation (DNAR)" form. For instance, when I shadowed palliative care service volunteers, I observed a patient in his eighties for several times. He had bladder cancer and other diseases and was in his last stage of life. He was very weak and unconscious most of the time. Palliative care should be beneficial for him regarding his physical and psychological situation. However, he had not drafted advance directives and his sons preferred an active treatment. Due to his lack of a proper advance care planning document and his incapability to develop one at that time, he had to stay in the hospital and receive various aggressive therapies and life prolonging treatments, which did not make any improvement to his health status, and he suffered a lot. I encountered similar sad stories several times during my internship. Palliative care providers have to deal with the dilemmas, and they try their best to coordinate with the patients' family members and other departments of the hospital to provide comfort for patients who are referred to the palliative care service by their primary physicians.

Another category of ethical dilemma is related to the lack of end-of-life care resources. Lack of end-of-life care resources encompasses many aspects, including shortage of medical staff, inadequate knowledge of cultural competence, limitation of care places and care givers, and limitation of medical insurance. This kind of dilemma often leads to unsatisfactory care outcomes at the end of life.

The palliative care department at Pitt County Memorial Hospital has only three nurse practitioners, who provide over one hundred consults across the hospital system every month. Although the palliative care team members managed to conduct consults and follow-ups for each referred patients, the shortage of palliative care service personnel has the potential to impact the quality of care.

Patients of palliative care services come from various cultural backgrounds. Different cultures have different perspectives towards end of life. Sometimes, during my internship, I observed that it was difficult for care providers to understand the expectations of patients and family members from another culture. Also, most of the reading materials provided for patients and family members were written in English, which led to communication barriers for non-English speaking service users. Thus, cultural competence, proper translations and interpretations during palliative care process were often in high demand.

Patients sometimes preferred to have home care or stay in a certain place while receiving end-of-life care. However, the limitation of services, facilities and technology in different health care institutions contributed to various obstacles to fulfill their wishes. And some

patients may not have available family care givers, which made it very difficult to provide home care of high quality.

One of the most striking problems, which led to this kind of dilemma, was the limitations to care caused by the rules and regulations developed by patients' medical insurance providers. For example, Medicare and Medicaid are available to certain groups of patients at different medical services coverage packages. When a patient needed an end-of-life care treatment which was not covered by his or her insurance policy, the patient and family members experienced an economic burden when they wanted to facilitate palliative care or had to choose against this care option. For instance, I observed a female patient in the palliative care unit with a nurse practitioner. The patient was in her nineties and had dementia. Her health had deteriorated such that she needed a feeding tube and stayed in the hospital receiving palliative care for several months. However, her medical insurance did not cover inpatient palliative care services. To be covered by her insurance, she had to be transferred into a nursing home, where the personnel might not be able to pay close attention to her and take care of her feeding tube issues. Under the coordination of a social worker, the palliative care team found the patient a swing bed in a community hospital, which was designed to offer medical rehabilitation to patients who no longer need acute care but require additional inpatient care. If the patient accepted medical services there, she could get medical care of hospital standard and be covered by the insurance. The palliative care team members, especially the social workers, deal with this kind of dilemma with great efforts. The limitations of care options caused by the patients' medical insurance coverage affect the quality of palliative care.

Solutions Devised by Palliative Care Providers

Ethical dilemmas propose great challenges to the quality of palliative care services, and impact the experiences of patients and family members. To cope with these ethical challenges, palliative care providers at Pitt County Memorial Hospital adopt various strategies.

First, palliative care involves a multi-disciplinary approach to meet the needs of patients with life-threatening illnesses and their family. An end-of-life care team includes various medical professionals. Each of the professionals undertakes specific role in the delivery of end-of-life care, and cooperates with other professionals in the team.

Second, the palliative care team actively seeks cooperation with other departments within the hospital system. Steering committee meeting, ethics committee meeting and community meeting are held once a month. The participants of these meetings, who work in different departments of the hospital or volunteer in different community organizations, discuss issues regarding palliative care services, which include health policies, ethics, language services, education, promotion and donation.

Third, whenever making medical recommendations, the palliative care providers try their best to communicate with the patients and families, to understand the needs and expectations from the patients' and families' perspectives. The palliative care team provides consults services across the hospital, organizes family meetings, coordinates among doctors, nurses, health care institutes in order to achieve better service outcomes.

Furthermore, the palliative care service department at Pitt County Memorial Hospital

organizes regular community activities in various community centers in eastern North Carolina. Some of these activities include clinics, movies, and reading theaters. Their goal is to educate people about advanced care planning, and encourage conversations on topics about end of life.

In sum, end-of-life care providers, patients and families have to deal with various ethical challenges when they face life-threatening illnesses. Some of these issues include conflicts between physicians, patients and families over the appropriate course of treatment; potential violations of patient autonomy and integrity; and the dilemmas caused by a lack of end-of-life care resources. These challenges may negatively affect the quality of care. Most of the ethical dilemmas are difficult to overcome. The improvement of palliative care services call for wide coordination of policy making, information and education, reaching daily health care delivery. It is important to encourage discussions and conversations about end-of-life issues, to help all involved people cope with ethical dilemmas.

Chapter 5

Discussion

My internship with palliative care services at Pitt County Memorial Hospital informed me about how palliative care is carried out in different settings, the different roles of health professionals, the cooperation between palliative care service department and other units of the hospital, the general characteristics of service users and the challenges faced by palliative care providers during the care delivery process. In this section, I will discuss the implications of my findings and explore the possibility that Chinese people will adopt palliative care services.

Implications of the Findings

Differences in the distribution of age, gender and ethnicity of patients in different care settings emerged as one of the main observations during my internship. Older female

European-Americans disproportionally use palliative care more than other ethnic groups and age groups. This observation can be related to the overall distribution of age, gender and ethnicity in the general population. However, different perspectives towards end-of-life care among different groups may also contribute to this phenomenon. Most of the palliative care service users belong to the elderly; in addition, patients in the palliative care unit and in nursing homes were generally older than those in the inpatient hospice house, the advance care planning clinic and other units across the hospital. The choice of service settings can be influenced by the patients' physical status, physicians' evaluations and recommendations, their own wishes, availabilities of family care givers and the patients' medical insurance coverage.

Palliative care providers at Pitt County Memorial Hospital help patients and family members cope with end-of-life issues, and try to help the patients maintain the highest quality of life possible given their medical prognosis. Quality of life is influenced by both physical status and the psychological construct of subjective well-being (Clavarino, 1999: 451-452). It is important for palliative care providers to understand what the patient's own perspective about good quality of life is and how he or she wants to accomplish it. People from different cultures and religions have different beliefs regarding dying, death and bereavement. Improvement of cultural competence can help the palliative care professionals better understand the patients' expectations, and better communicate with patients and family members about the diagnosis, prognosis and care options.

Some of the difficulties in palliative care delivery resulted from lack of communication among different departments within the hospital. If more education programs about end-of-life

issues can be incorporated with medical professional educations, more understanding and recognition of the importance of palliative care can be obtained by health professions, which will contribute to the improvement of end-of-life care services. Promotion of palliative care education programs to general population can help more people understand the concepts of palliative care, and will possibly reduce the conflicts among physicians, patients and family members when discussing end-of-life issues.

Palliative care services are also challenged by the limitations of medical insurance and lack of resources. Wide collaboration is called for to solve these problems, from policy making, health care investments, facility constructions, and workforce preparations. More attention is needed from the other units of the health care system to facilitate the development of palliative care, to achieve a better outcome for end-of-life care.

The Likelihood of Adoption of Palliative Care Services in China

As the aging Chinese population continues to grow rapidly, China will face serious challenges in long term care and end-of-life care for the elderly. However, in my opinion, China may not be ready yet to adopt the palliative care service model of Pitt County Memorial Hospital. My reasons are as follows.

I think the biggest obstacle for end-of-life care promotion in China is people's attitudes towards end-of-life issues. Most people are very conservative about the topic of end of life. They would not like to talk about dying or death openly, for they think it is very negative and

discouraging. Although Buddhism encourages people to view death as a part of life cycle, and Daoism encourages people to view death as a natural extension of life (Chen, 2001: 271), many people still think the longer they can live, the better. Thus, many patients and family members choose aggressive therapies, regardless of the results and the quality of life. Besides, Chinese people value their families' opinion very much, if the family members insist the patient to have an aggressive therapy, it is unlike that the patient will refuse it. The concepts of palliative care and hospice have been known to many people in China yet. Thus, more education about end-of-life issues is needed before Chinese people accept this service specialty.

Lack of palliative care medical health professionals proposes barriers for the adoption of palliative care in China. At Pitt County Memorial Hospital, palliative care services benefit from the multi-disciplinary approach. Physicians, nurses, nurse practitioners, nursing aides, social works, chaplains and volunteers perform different roles in end-of-life care services, and help both patients and family members from every aspect at the end of life, including care options, facilities, payments, daily care, psychological and spiritual issues. In contrast, there are few specialists on end-of-life issues. The care providers themselves may not be familiar with palliative care. And there are even less services in the end-of-life psychological or spiritual area. As in the U.S., the development of palliative care will be benefited, if more education about end-of-life care is incorporated with the education process of medical professionals.

The adoption of palliative care in China will also be challenged by the medical payment system and the lack of care givers. The coverage of medical insurance and social welfare

among Chinese population are relatively low, and many people cannot afford long term or end-of-life medical care services, especially people in rural areas or in lower- and middle- class (Flaherty, 2007: 1295). Palliative care, thus, even as a low cost medical service, may cause financial burdens to patients and family members. Moreover, at current situation, the number of professional care givers and family care givers may be not enough, which will impact the quality of end-of-life care.

In my opinion, other than reforms of the medical education and the health care system, there are two additional ways start the promotion of palliative care in China. The first one is to organize more end-of-life care volunteer organizations in younger generations, which encourage younger people to understand and become involved in end-of-life care services, and prepare ordinary people to deal with end-of-life issues. The volunteers can also help to solve some problems regarding lack of care givers and spiritual services, since they can visit the patients and families regularly, providing some basic care and help people cope with psychological stress caused by the end of life. The second one is to form a family experience department in hospitals. The department should be responsible for the follow-ups after the patients' deaths or after their discharge from the hospital. Feedbacks from the patients and families will help health care providers to recognize where the improvements are needed in their medical services.

Conclusion

In conclusion, the multi-disciplinary approach of palliative care at Pitt County Memorial Hospital addresses the spiritual, emotional, psychological and social burdens of life-threatening diseases, and helps the patients and family members to obtain a better quality of life. More improvement of cultural competence and the communication among different departments will benefit the services. The development of palliative care calls for all inclusive coordination from policy making, health care investments, facility constructions, and workforce preparations. The rapid growth of aging population in China poses big challenges for long term care and end-of-life care. However, there may still be a long way to go before China adopts a palliative care system. Reforms in health care system and social welfare system are needed. Education about end-of-life issues for both medical professionals and general population is also needed to facilitate a change of attitudes along with the rapidly occurring changes in cultural practices in China.

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