March 2006

Promotion of Hospice and Homecare Programs in Thailand: A Framework for the Assessment of Costs and Benefits

Batsirai Tafadzwa Mutetwa
Worcester Polytechnic Institute

Katherine A. Kelly
Worcester Polytechnic Institute

Lisa E. Novoson
Worcester Polytechnic Institute

Repository Citation

Mutetwa, B. T., Kelly, K. A., & Novoson, L. E. (2006). *Promotion of Hospice and Homecare Programs in Thailand: A Framework for the Assessment of Costs and Benefits*. Retrieved from https://digitalcommons.wpi.edu/iqp-all/244

PROJECT NUMBER: SZT C064

Promotion of Hospice and Homecare Programs in Thailand: A Framework for the Assessment of Costs and Benefits

An Interactive Qualifying Project Proposal Submitted to the faculty of the

Worcester Polytechnic Institute

in partial fulfillment of the requirements for the

Bachelor Degree of Science

By

Katherine Kelly
Batsirai Mutetwa
Lisa Novoson

In cooperation with The Mahavachiralongkorn Thanyaburi Cancer Center
Pathum Thani, Thailand.

Date: February 28, 2006

Professor Robert Krueger, Co-Advisor

Professor Seth Tuler, Co-Advisor

Abstract

Cancer is a leading cause of death in Thailand, yet the Mahavachiralongkorn Thanyaburi Cancer Center is the only facility utilizing hospice and homecare programs to address the needs of terminal cancer patients. Our project developed a Thai-specific patient quality of life survey to assess their program’s benefits. Coupled with protocols to record and compile patient data, our project provided the Cancer Center with a framework for proving the value of their services and promoting them to the Thai medical community.

Executive Summary

Introduction

In 2000, the World Health Organization reported that about 12% of deaths worldwide were caused by cancer and that about 80% of cancer cases in developing countries have already become terminal before diagnosis (WHO, 2005). For many patients and their loved ones, hospice and homecare offer an alternative approach to facing a terminal illness. Palliative care programs are geared towards ensuring that the final days of the patient are peaceful and dignified. However, in some developing countries, such as Thailand, palliative care programs such as hospice and homecare are not fully utilized.

The Mahavachiralongkorn Thanyaburi Cancer Center is the only hospital in Thailand with hospice and homecare services and seeks to be a pioneer in these areas. In order to achieve their goal they need two things; 1) an instrument for measuring the quality of life (QOL) their program produces, and 2) an information infrastructure to document and compile statistical data. With this information, the Cancer Center will be able to assess, analyze, and prove the value of the palliative care option to both other Thai cancer care facilities and the Thailand Ministry of Public Health.

Our research provided the Mahavachiralongkorn Thanyaburi Cancer Center with a framework to promote quality hospice and homecare to the medical community in Thailand. We developed a Thai-specific patient QOL survey to assess their program benefits. Coupled with our development of a protocol to record and compile important data, our project provided the Cancer Center the basic means for proving the value of their services.

Findings

In order to achieve our final goal of creating a framework for assessment of costs and benefits of terminal care services, we completed three objectives. These objectives were as follows:

1. Design a protocol for compilation of important patient demographic information,
2. Determine metrics to measure QOL in Thai terminally ill cancer patients for use in an evaluative survey, and
3. Examine hospice and homecare services and their associated costs.

In completing our objectives we made three key findings. The findings and their implications for our project are discussed below.

Finding #1: ***The palliative care programs at the Mahavachiralongkorn Thanyaburi Cancer Center are designed to reflect quality Western care practices.***

We identified four specific services offered by the Cancer Center that are designed to improve quality of life (QOL) and provide good palliative care. Although the design of these services implies an understanding of attributes of quality care, their effectiveness has not yet been assessed. However, their organization clearly illustrated the Mahavachiralongkorn Thanyaburi Cancer Center's intent to improve QOL by following practices that have been proven effective in Western settings.

The structure of time allocation in the hospice and homecare programs is aimed at improving patient QOL. We found that the services offered by the hospice and homecare teams were in line with the patient needs we identified through surveys and archival research. By exploring nurse time allocation we concluded that the homecare team is structuring their time to intentionally prioritize the improvement of QOL.

Individualized care and the building of trust are interrelated best care practices. The Mahavachiralongkorn Thanyaburi Cancer Center designs their programs so that the homecare and hospice nurses choose each patient's care program individually. Nurses are trained to become knowledgeable about each patient's personality, family, likes and dislikes and to respond accordingly. Evidence of personalization is seen when nurses note the individual fears of each patient and try to give care in a modified manner, or when nurses make sure to provide extra reading materials or writing notebooks to the patients they know have a personal interest in reading or writing. These types of actions allow for the development of close patient-caregiver relationships that build trust. This process is clearly aimed at positively affecting QOL.

The last service that reflects quality Western care practices is psycho-support therapy. These services are not a medical necessity except for the fact that they help maintain the patient's positive thinking. They give patient the impression that normal medical services are still useful, even though the nurse knows the patient is dying. Evidence of the use of this therapy can be found when the nurse takes blood pressure and temperature but does not record the data. More evidence is that the nurses always respect family wishes not to tell the patient the stage of their cancer. The structure of the program reflects quality palliative care services by being geared towards helping the patient remain positive.

Finding #2: ***The current information systems at the Mahavachiralongkorn Thanyaburi Cancer Center are not designed for cost-benefit analysis.***

This second major finding was based on our research on patient demographics and documentation of service costs. Patient demographic information is the basic information needed to start analysis studies. The statistics are also necessary to put cost-benefit analysis results in context. Additionally, the cost information itself needs to be compiled in a manner that facilitates analysis. This finding was developed from the examination of the organizations of both the demographic and cost documentation systems.

We noted that the existing demographic record system does compile information important to the context of a cost-benefit study. Some of the more relevant categories recoded are age, gender, type of cancer, medical needs, insurance information, payment type, caregiver, and length of stay. However, while all the necessary categories of patient demographics are being documented at the Cancer Center, records are spread throughout various information sheets and departments with out any method for compilation. Insurance information can be found for homecare patients but not always for ward ones. Additionally, ward patient records are stored in a separate area from hospice or homecare records. This infrastructure does not facilitate easy compilation.

In addition to demographics, service costs are also recorded for each patient. However, this data is documented for the sole purpose of billing patients after they have been discharged from the Cancer Center. Currently the record system only documents billable services and not associated costs. Included in these services are room costs, radiology treatment, prescription medication, blood work, oxygen, food, and anesthesia. Similarly to demographic data, none of this cost information is compiled for analysis. Within both documentation systems the important information is available and the capability for compilation exists. This central compilation is necessary before cost-benefit analysis can begin.

Finding #3: ***Assessment tools must be adapted to the Thai setting.***

Our last major finding was that adaptations to assessment tools are necessary in a Thai setting. When applying Western QOL assessment tools to a Thai terminally ill cancer patient, a few key differences must be accounted for. Specifically, these differences involve the content of QOL assessment tools and variables in surveying.

We found that in the Thai setting Western QOL influences need to be redefined. By redefining several categories and merging others, we found a way to culturally adapt Western QOL influences to a Thai setting and create our QOL survey. We found the best way to breakdown QOL is in the following five categories: physical, mental, spiritual, social, and economic. Evidence for these categories was obtained from nurses in focus groups and surveying. We found that the Western category of environment was viewed as a physical influence in the Thai setting. Also, the Western view of “disease acceptance” falls under spiritual rather than psychological. The Western category of self acceptance was also merged with mental influences. The purpose of these changes was to adapt a survey for assessing Thai QOL. More accurately defined categories lead to better and more valid results. The more valid the results, the more accurate benefit analysis will be in illustrating the worthiness of a program.

Another necessary adaptation of assessment tools to a Thai setting can be found in survey administration. We found that utilizing a well trained administrator eliminates cultural surveying variables. We identified three major variables that exist in the Thai setting that heavily influence results. These variables are patient education, language nuances, and administration bias.

Recommendations

Based on these findings we make the following recommendations:

Recommendation #1: ***Assess costs and benefits of hospice and homecare programs.***

We found that several steps still need to be taken in order for the Mahavachiralongkorn Thanyaburi Cancer Center to be assess the costs and benefits of their services. These steps will help them gather important demographic and service data, measure the QOL benefits, and assess program costs.

Step 1: *Continue to collect and centrally organize relevant data.*

By starting this now, the Cancer Center will be able to establish an extensive database of information from which valid conclusions can be drawn. The compilation of this information will facilitate future analysis of costs and benefits. Information sheets should be filled out for all patients that are treated by their palliative care programs and input into the programs we have designed.

Step 2: *Administer Patient QOL Survey with the help of a trained administrator.*

This step is necessary for minimizing surveying variables that affect the validity of collected data. Before surveying patients, it is crucial that administrators familiarize themselves with the material in our final deliverable to gain a thorough understanding of the survey.

Step 3: *Continue to research survey phrasing and language nuances.*

Improved phrasing of questions could greatly reduce miscommunications and interpretational inconsistencies. Precision in the phrasing of questions enhances the validity of results. With the help of a researcher who is fluent in both English and Thai, it would be easier to explore how language nuances and question phrasing affect patient responses.

Step 4: *Continue to research survey scoring systems.*

Once the QOL survey is administered, analysis of scores must be completed. The design of a scoring system can greatly affect the final QOL score. We recommend utilizing a scoring system that uses generalized weights. To establish accurate weights for such a scoring system more research needs to be done into Thai prioritization of QOL categories. Patients from a variety of palliative care programs should be surveyed.

Step 5: *Complete cost-benefit analysis.*

This type of analysis will be particularly useful for promoting services to other cancer care facilities in Thailand. Cost-benefits analysis is one powerful tool for assessing the cost and benefits of medical services. By completing such a study, both the costs and benefits of a program could be related to each other in monetary terms. Results from this type of analysis would create a strong argument for the implementation of these programs by clearly showing their financial feasibility and benefits.

Recommendation #2: *Promote hospice and homecare services.*

The second set of our recommendations include ways to promote hospice and homecare services.

Step 1: *Distribute our packet of materials and assessment tools to other care facilities.*

By distributing these packets, the Mahavachiralongkorn will be preparing others for a more in-depth discussion of the benefits of hospice and homecare programs. This packet clearly explains the hospice and homecare concepts and their benefits to patient QOL. It also includes our Patient QOL Survey to evaluate the effectiveness of various programs to improving patient QOL.

Step 2: *Compare services with those of other cancer care facilities.*

The results from these comparisons would illuminate the strengths of each hospital's services and possibly help prove the value of the Mahavachiralongkorn Thanyaburi Cancer Center's palliative care programs. It would be feasible to use our Patient QOL Survey in a comparative study between the six existing Thai cancer care facilities.

Step 3: *Conduct cost-effectiveness analysis.*

Cost-effectiveness shows how efficiently services use funds to achieve a desired health effect. By proving the effectiveness and efficiency of their hospice and homecare services to the Thai Ministry of Public Heath, they may be better able to petition for increased funding. Much of the necessary analysis information would have been previously compiled for cost-benefit analysis.

***Step 4:** Continue to individualize palliative care programs.*

This improvement on the quality of care will demonstrate best care practices for others to emulate and strengthen the Cancer Center's promotional campaign. It might be possible to work in conjunction with another hospital to identify which care programs work best in the Thai setting.

By following the recommendations discussed above, the Mahavachiralongkorn Thanyaburi Cancer Center will be able to promote hospice and homecare services. Implementation of these recommendations will also help the Mahavachiralongkorn Thanyaburi Cancer Center establish themselves as a leader in their field.

Acknowledgements

We would like to acknowledge the following people for their contributions to the success of our project work:

- Khun Ahn
- Joy Bhosai
- Professor Chrys Demetry
- Ruth Gerson
- Professor Rob Krueger
- Thitwan Lertpiya
- Lopburi Hospital Staff
- Mahavachiralongkorn Thanyaburi Cancer Center Staff
- Janet Mullen
- Khun Natchaa
- Dr. Patchai
- Professor Supawan
- Dr. Thanadej
- Professor Seth Tuler
- Professor Rick Vaz
- Khun Wannaa

Without their assistance, guidance and support we could not have completed our project as successfully. Thank you!

Table of Contents

Table of Tables

Background

Findings

1 Introduction

Cancer is a serious illness that affects millions of people worldwide. In 2000, the World Health Organization (WHO) reported about 12% of deaths worldwide were caused by cancer (WHO, 2005). The World Cancer Report released on April 3, 2003 predicted that by 2020 cancer rates could increase by 50% (2003). Although great strides have been made in treatments, in many cases it is still a terminal illness. The WHO reports that in developing countries about 80% of cancer cases have already become terminal before diagnosis.

For many patients, hospice and homecare offers an alternative approach to living with a terminal illness. Palliative care is used when patients decide to discontinue curative care. Palliative care programs are geared toward ensuring that the final days of the patient are peaceful and dignified. For terminally ill patients in the US approximately 90% of their time is spent in the home (HospiceNet, 2005). Therefore, homecare services are also a fundamental facet of palliative care programs. However, in some developing countries hospice and homecare are not fully utilized. Thailand, in particular, is an example of a developing country that is plagued by cancer yet only has a small handful of cancer care facilities and even fewer palliative care programs (WHO, 2000).

The Mahavachiralongkorn Thanyaburi Cancer Center is the only hospital in Thailand with hospice and homecare services and seeks to be a pioneer in these areas. Because their hospice system was adopted from a US model and was not developed in Thailand one of their main goals is to prove the value of the palliative care option to both other Thai cancer care facilities and the Thai Ministry of Public Health. There are many challenges to promoting this system in Thailand. First, in Thailand there is a strong stigma about cancer which deters patients from seeking medical attention. In a country such as Thailand, where cancer is one of the leading causes of death, this fear leaves many people deprived of the best medical relief available (Sriamporn et al., 2002). Second, for the Thais that actually choose to seek medical attention, American care practices may be physically relieving, but spiritually lacking. In America many programs provide patients with distraction from their illness, whereas Thai Buddhists try to use their remaining time to let go of the physical world. Finally, another deterrence is the lack of financial support from the Thai Ministry of Public Health.

The Mahavachiralongkorn Thanyaburi Cancer Center seeks to document the value of these services and promote their use more broadly in Thailand. Currently, no documentation exists of hospice and homecare services or their related costs. Most importantly, they have no Thai-specific instruments to evaluate hospital services or the quality of life (QOL) generated by these services. Without compilation of this basic information, the hospital cannot provide convincing proof about the effectiveness of their services to other hospitals or the Ministry of Public Health. Because hospice and homecare use for cancer in Thailand is still developing, clear evidence supporting this type of care is important.

Our research identified the aspects of quality end of life care from a Thai perspective and documented hospice and homecare services offered at the Mahavachiralongkorn Thanyaburi Cancer Center. We utilized a series of interviews and other methods to gather information in order to create a survey to measure quality end of life care specifically for the Thai context. We designed a protocol for the recording and compiling of important patient statistics. Finally, we used our background research and findings to create a comprehensive hospice and homecare packet of materials which includes descriptions of the benefits of these services to patient QOL and culturally adapted assessment tools. With this information, the Mahavachiralongkorn Thanyaburi Cancer Center has the basic means to promote quality hospice and homecare to the medical community in Thailand.

2 Background

The Mahavachiralongkorn Thanyaburi Cancer Center in central Thailand, 50km from Bangkok, is the first hospital to develop a cancer hospice (inpatient) in Thailand, as well as the first hospital to offer homecare services (outpatient). Originally, the Mahavachiralongkorn Thanyaburi Cancer Center was only a cancer clinic. In 2001, not only did they officially become a hospital, but they also founded their hospice program. Currently the Cancer Center specializes in head and neck cancers. Treatments offered at the Cancer Center include radiology, chemotherapy and surgery. The center even has its own on-site dentist who prepares patients before they have to undergo radiology treatment. The facility has a 200 bed capacity, but only 116 are open. The Cancer Center cares for patients in five provinces at a range of about 50 – 60km. If patients live further away from the Cancer Center or their treatment requires multiple steps daily, the patient can reside in one of the wards. Modeled after a US hospice, the Mahavachiralongkorn Thanyaburi Cancer Center Hospice has the most up-to-date technology.

The Mahavachiralongkorn Thanyaburi Cancer Center's goal is to become a leader in cancer care for other Thai hospitals to emulate. Specifically, they wish to promote the benefits of hospice and homecare services. Although they have the best facilities, they can not attain their goal until they establish an evaluative system that measures and shows the benefits of hospice and homecare services. There has been no compelling research done in the Thai setting to document the improvement experienced in quality of life (QOL) with the use of hospice and homecare services. Also, homecare services are not covered under any medical insurance plan in Thailand. The Thai Ministry of Public Health has yet to recognize homecare as beneficial medical services. Because of these reasons, other hospitals have little incentive to implement similar palliative care programs. Our research group will compile information about hospice and homecare costs and benefits into a comprehensive packet that supports the use of these programs.

This background chapter introduces information pertinent to the understanding of costs and benefits of hospice and homecare services in the Thai context. Hospice and homecare programs provide palliative care (rather than curative) and focus on a peaceful death. We will first explore the concept of hospice and homecare in Western and Thai societies and the important Thai cultural influences on hospice and homecare. Next, we examine ways to assess the benefits of hospice and homecare by measuring the different aspects that affect a terminal patient's QOL. Finally, we discuss some of the costs of hospice and homecare services and how to analyze them. With the knowledge presented in the following sections, we will be able to present the Mahavachiralongkorn Thanyaburi Cancer Center with concrete ideas on how to assess the benefits and costs of their palliative care programs.

2.1 Cancer in Thailand

The Mahavachiralongkorn Thanyaburi Cancer Center was founded in response to the growing need for cancer care in Thailand. Cancer is one of the leading causes of death in Thailand, claiming lives at a rate of 68 per every 100,000 people a year (WHO, 2000). In addition, hospital admission rates for cancer patients are approximately 78 people per 100,000, suggesting that almost 90% of diagnosed cancer patients die from the disease (WHO, 2000). The most prominent type of cancer appearing in Thailand is liver cancer, which affects both genders. Lung cancer is seen more frequently in males; cervical and breast cancers are emerging in females.

In Thailand, there is a strong stigma about cancer that deters many people from seeking early medical attention. This stigma is why so many cases of cancer have already become terminal before they are even diagnosed. Just the mention of being diagnosed with a cancer is like a death sentence to a Thai person. Many Thais do not realize that there are several methods of treating cancer and not all cases have to be terminal, especially with the aid of early detection. For example, a patient may have a growth and delay seeking medical treatment out of fear. By the time they do seek treatment, the illness has already progressed to a terminal phase.

Several measures have been taken by the Thailand Ministry of Public Health to address the cancer problem in Thailand. One step has been the creation of the National Cancer Control and Prevention Program (NCCP) (WHO, 2000). This program implements both standards for treatment of patients, and programs for cancer prevention. The goals of the NCCP according to the Cancer Registry and Cancer Control in Thailand (2004) are:

1. to make optimal use of limited resources to benefit the whole population;
2. to achieve high coverage with early detection and screening measures;
3. to ensure equality of access to cancer care; and
4. to improve control of symptoms.

The NCCP's four step system to achieve the aforementioned goals are prevention, early diagnosis, treatment, and then palliative care. Also, they have recently published reports on "Cancer in Thailand" that include the status and nature of the disease in Thailand (Sriamporn et al., 1993). Much of this information came from the Thailand National Cancer Registry, which gathers cancer information from over 50 hospitals for the use of research and analysis.

Though the Ministry of Public Health in Thailand is aware of the cancer problem and is working on the development of programs to combat it, more needs to be done. As of 2001, there were only six cancer prevention and control centers in the public sector of Thailand. Cancer incidents are on the rise, with a projected 120,000 new cases by 2010 (Cancer Control in Thailand, 2002). With a fatality rate of almost 90%, quality hospice and homecare programs are becoming an even greater necessity.

2.2 Terminal Care Programs

When diagnosed with a terminal illness, there are several options a patient may choose. Some decide to continue aggressive curative care despite their diagnosis. Others chose to receive only palliative care, which works to ensure that the final days alive are pain free and comfortable. Since the beginning of the international "death-awareness" campaign in the late 1960's several advances have been made in the actual caring for the dying person and their family (Mor et al., 1989). One key aid in the movement was the hospice/homecare approach to palliative care.

In this section, we review what makes hospice and homecare good palliative care programs for coming to terms with dying. First, we will describe in depth the concepts behind hospice and homecare and how these concepts are applied in Western and Thai societies. Second, we will discuss the specific responsibilities of the hospice and homecare team in ensuring that patients are comfortable. Finally, we will present some key characteristics of good hospice and homecare services. These sections provide the basic information about terminal care programs needed to begin to analyze their costs and benefits.

2.2.1 Variations in Palliative Care Programs

The goal of palliative care programs is to provide comfort for patients and families facing an incurable illness. There is an emphasis on quality of life and not necessarily quantity. A professional team works with the patient and family to ensure that the patient dies a dignified and comfortable death. Through palliative care programs, patients are not only treated for the physical ailments but also their psychological needs. As a result, palliative care programs have become an integral part of many terminally ill patients' final days. Palliative care programs typically consist of inpatient hospice services and/or outpatient homecare services. Although all palliative care programs have the same goal, they vary slightly in different medical communities. An understanding of these differences is crucial for trying to evaluate QOL in a palliative care program. Although little to nothing is written specifically about Thai palliative cancer care programs, the differences become clear upon observation. The following subsections explain the differences between the Western and Thai palliative care programs.

2.2.1.1 Western Palliative Care Programs- Hospice

In Western medical communities and texts, palliative care, hospice care and homecare are practically synonymous. This terminology overlap occurs because the majority of the care (about 90%) given to a terminally ill patient happens in their home (HospiceNet, 2005). Usually, hospice is thought of as a program through which a patient receives homecare services. Very few palliative care programs offer inpatient services. Patients discharged from a hospital who have decided to go the hospice route will become affiliated with a hospice where different professionals will aid the patient and their family as they go through their final days. Although many patients live longer, terminally ill technically means having a prognosis of 6 months or less to live (US Dept. of Health & Human Services, 2000). According to the Hospice Patient Alliance if at anytime the patient decides to resume curative care, the patient can discontinue with the hospice services.

Western hospice care encourages people to talk about what is going on: the patient is dying. Patients are fully informed of their medical condition and work with the palliative care team to come to acceptance. In Western cultures, this verbal communication is necessary for palliative care to be successful. Without communication, a patient may begin to feel increasingly disconnected from family and society (Moyer, 2000). In *The Hospice Handbook*, E. M. Kennedy states that “none (of us) should add to the loneliness of a dying person by refusing to acknowledge what is happening to him or her” (Hamilton & Reid, 1980 p.36). By addressing what is going on, there is a sense of connection within the family. Maintaining this connection allows the patient to pass away at peace.

2.2.1.2 Thai Palliative Care Programs-Hospice

The Thai hospice operates in a slightly modified manner. In the Western medical community, hospice and homecare services are basically the same, whereas in Thailand they are viewed as completely separate entities. In Thailand, hospices are not in charge of homecare services. Instead, they strictly provide inpatient services. In essence, Thai hospice is the same as Western inpatient hospice services.

At the Mahavachiralongkorn Thanyaburi Cancer Center Hospice, the only Thai cancer hospice in existence, the hospice ward of the facility is treated as any other cancer ward in the hospital. The ward has inpatients and nurses, and hosts patients in their last stages of illness. In accordance with the hospice concept, their goal is still to bring terminal patients towards acceptance and a dignified death. Because of cultural influences (to be discussed in section 2.3), patients know they have cancer but usually are unaware of the extent of their illness. Therefore, hospice care focuses on Buddhist teachings about life and death, rather than directly addressing the patient’s illness.

Another difference between Western hospices and the Thai cancer hospice is the length of stay of patients. The term “terminally ill” in Western views means a prognosis of six months or less to live. It is at that time that a patient would choose to go the hospice route. However, in the Thai cancer hospice the ward typically treats patients with approximately two weeks to live. Some families chose to bring the patient home for the very last days of life. Finally, it is important to note that at the Mahavachiralongkorn Thanyaburi Cancer Center Hospice beds are sometimes used to accommodate patients from other wards that are not terminally ill; these patients are not technically hospice patients even thought they may be residing at the hospice.

2.2.1.3 Thai Palliative Care Programs-Homecare

Thai palliative care programs also include homecare services. The ideas behind these services are essentially the same as the Western idea of hospice (which is almost exclusively homecare). Like hospice care in Thailand, homecare is also for terminally ill cancer patients, many of which also do not know about the degree of their illness. However, these terminally ill patients may receive treatment for weeks or sometimes months through the homecare program.

When patients have to decide between hospice and homecare, the Mahavachiralongkorn Thanyaburi Cancer Center strongly encourages homecare. This is not to discourage the use of their hospice, but instead, is recognition of the fact that homecare offers more comfort to a terminal patient than hospice services. This is why Western hospices generally offer only homecare services. Since the hospice program is relatively new in Thailand, it may see a shift towards homecare once it has become established.

2.2.1.4 Other Thai Palliative Care Programs- Lopburi Cancer Hospital

Although the Mahavachiralongkorn Thanyaburi Cancer Center is the only hospital in Thailand to use hospice and homecare services, other palliative care programs exist. One example is the palliative care program at the Lopburi Cancer Hospital. The goal of their palliative care program is the same as that of any other palliative care program in Thailand or the US, but their setup is slightly different. They mainly treat inpatients, who are spread throughout the various wards, rather than living together in one place. For their very final days, patients are moved to the “dying room” in the ICU ward. This unit offers privacy for the dying patient and their family, while also removing the patient from the view of others in the ward.

The Lopburi Cancer Hospital follows the model of holistic care established by the US’s National Cancer Institute (NCI). This includes addressing all the needs (spiritual, mental, bereavement counseling, etc.) of the patients and families. Their palliative care team includes a physician, a nurse, a counseling nurse and a social worker. Some therapy services include mediation, counseling from monks, beauty therapy, and arts-and-crafts.

There is no formal outpatient palliative care program. However, the Lopburi Cancer Hospital works in conjunction with other local hospitals and clinics by providing support for the patients that choose to remain in their homes. Nurses do not visit patients at home but are available via telephone for support and advice. Even though patients are encouraged to go home, the majority prefers to stay because pain management in the home is difficult, additionally many family members work and there may be no one available to take on the role of primary caregiver. Caregivers are given informational booklets (a Thai translation of US National Cancer Institute cancer care documents) about how to provide good care to a patient living at home.

2.2.2 The Palliative Care Team

The universal standard of palliative care is to minimize pain and discomfort during the term of illness (Panzer, 2005). To meet this standard in any country, there needs to be an informed, qualified professional care team in charge of care-giving. The slight variations in the specifics of palliative care programs in Western and Thai cultures are paralleled by the variations in their palliative care teams. Each member has a well defined role in patient care, and these individual roles come together to provide the patient with a full range of care.

In palliative care programs, an interdisciplinary team is designated to provide and supervise any care and services offered. This group is responsible for:

- establishing the plan of care for the patient;
- supervising the care as well as any other palliative services;
- reviewing and updating the care plan periodically; and
- determining the day-to-day palliative services and policies.

According to US federal health care standards the composition of the interdisciplinary team should include a medical doctor or doctor of osteopathy, a registered nurse, a social worker, and a counselor. If there are several interdisciplinary groups providing services to the patient there also needs to be a designated coordinator, which is usually a registered nurse who will give instructions of how the plan of care is to be implemented (US Dept. of Health and Human Services, 2000). Although the makeup and function of the Thai palliative care team is very similar, certain roles have been slightly adapted for Thai needs.

2.2.2.1 The Western Palliative Care Team

The physician plays “the most significant role in the determination and delivery of the patient’s medical care” (US Dept. of Health and Human Services, 2000). The role of the physician is to work with the patient and family to determine the most appropriate palliative care route. The doctor is a primary source of medical advice; he/she prescribes all the medication for pain relief and instructs the nurses on how to administer it.

Nurses are the next crucial part of the palliative care team. In hospice programs, nurses are the primary givers of every day care. Often, they are the ones that will spend the most time in contact with patients. Doctors visit as needed to address pain relief issues, but the nurses are available all day for the patients’ needs. For homecare services, the nurse who is assigned to the patient usually makes frequent visits to the patient’s home and assists where needed. The number of weekly visits is determined by the patient’s request as well as the stage of illness.

The role of the counselor is to provide care for the mental wellbeing of the patient. One aspect of this part of palliative care includes addressing the psycho-social needs of the patient. These needs may range from treating depression or anxiety to more extreme cases such as dementia (Open Society Institute, 2005). Another aspect of mental wellbeing that the counselor is responsible for is the spiritual state of the patient.

When spiritual counseling is needed or requested, the palliative care team will work with the patient to find the most appropriate spiritual guide according to the patient’s beliefs. In the US, this person might be the family’s priest. It is understood that “some patients have no desire to enter into explicit religious conversations or relationships” (Hamilton & Reid, p. xi). However, many of these patients still appreciate the comfort and company that a religious person can provide because of the sense of peace and understanding that they bring.

The hospice medical director is in charge of ensuring that the quality of care administered meets the needs of the patient. For US standards, this means that nursing services, physician services, and drugs must be routinely available on a 24-hour basis; this is the responsibility of the medical director (US Dept. of Health and Human Services, 2000). US federal regulations require that the medical director be a hospice employee who is a medical doctor or osteopathic doctor. He/she takes on the overall responsibility for any component of the patient care program at the hospice. According to the Hospice Patient Alliance, if there is any suspicion that there is poor quality care being provided by the hospice team, the medical director is required to intervene.

Technically, the family of the patient is not part of the hospice team, but they do have a very important role to play. As indicated by E.D. Kennedy in *The Hospice Handbook*, "the family understands needs that are beyond the knowledge of the health professionals" (Hamilton & Reid, 1980 p. vii). Family members can have valuable insight into patients' needs that those outside this relationship might not recognize. With the guidance of the family, the doctor and other professional staff can better recognize all of the patient's needs.

2.2.2.2 The Thai Palliative Care Team

In Thailand, the palliative care team addresses all the same patient needs but the responsibilities are distributed differently. Whether working directly with the patient in Western society or through the family in Thai society, the doctor still functions as the primary source of medical advice. However, the roles of nurses, family members and directors are noticeably different.

Nurses in Thailand take on much more than the basic every day care of terminally ill patients. The Thai palliative care team actually saves money because multiple professionals do not have to be hired. The first responsibility of a Thai nurse is to attend to the physical needs of the patients, but it is also their job to act as a social worker and counselor for their patients. The nurses serve as social workers because they work to discuss monetary issues patients are facing and how to minimize theses stresses. They also guide the patients towards helpful community resources. Thai nurses also work as counselors because they are very knowledgeable in the Buddhist teachings of life and death and usually are the patients' main source of guidance. Nurses take the time to work with the patients to help them accept their pain and move on from it. They reinforce the Buddhist values needed to help patients "let go." Often, when they come to understand that their pain only affects their body, not their soul, patients become less reliant on pain relieving drugs because of their nurse's advice. Similarly to Western hospices with internal clergy, many Thai hospices (cancer and non-cancer) have programs with local monasteries through which patients have contact with monks. These monks may not provide spiritual counseling but the mere interaction with them can be spiritually healing for many patients.

Also, nurses in Thailand are still in charge of homecare visits. Doctors work with the patients to come up with a homecare plan, but the nurses are the ones who implement it. In Thailand, these visits are typically very short, usually about half an hour. Because many families receiving homecare services are not well educated and may not administer pain relieving drugs correctly, homecare visits are also used as surprise checkups to make sure the family is providing the best care possible for the patient. It is the nurse's job to evaluate the situation and help the family remain on schedule with the recommended care plan.

Although the family is still not technically a part of the palliative care team, they have an even more important role in Thailand than in Western programs. Because of cultural influences in Thailand, it is the family rather than the patient that is informed about the degree of the illness. They are responsible for palliative care decisions, not just giving insight. This idea along with the cultural context will be discussed more in depth in Section 2.3.3.

Finally, because palliative care programs in Thailand are still developing, there are no legal standards from the Ministry of Public Health about the palliative care team. However, the same responsibilities are still addressed by various administrators in the hospital and hospice ward. The hospital director is still technically in charge of overall quality of care but may delegate control over every day matters to head nurses. Together, the standards the hospital director and staff strive to achieve are the same even though there are no laws enforcing them.

2.2.3 Characteristics of "Good" Palliative Care

Despite the structural differences between Thai and US palliative care programs, there is a general consensus of what constitutes "good" palliative care. Unlike the physical construction of a hospital building, where there are clearly defined standards to follow, the guidelines for creating a "good" palliative care program are more abstract. However, there is a recurring focus on the importance of individualized, humane care provided by a compassionate and involved staff. Sometimes, the more personal attention a patient receives in the palliative care program, the better they perceive their care to be. The nurses spend a large amount of time with the patient, and patients have been recorded as saying "I feel so safe when the nurse comes. It's as if I have a back-up team behind me; I don't have to be scared" (Hamilton & Reid, 1980 p.54). On the other hand, "bad quality" care has been stated as being routine and unrelated to patient needs (Journal of Advanced Nursing, 2001). A hospice that has a staff that is uninvolved and distant from patients has shown to be a significant factor in the lowered ranking of a hospice. The ideal level of personal attention may not be met in facilities that are lacking manpower. Clearly, the quality of individualized nurse care is an essential part of a good palliative care program.

With individualized care, the palliative care team is better able to meet the wide range of patient needs. These needs can vary from physical and emotional wellbeing to feelings of control and satisfaction. No two patients will have the exact same needs; where one might require more physical care, another might seek spiritual comfort. This creates the need for individual attention and patient specific plans of action. A good example of the possible breakdown of patient needs comes from a study that was done in 1999 as a report to the US Congress (MedPac, 1999). In this study, four sources were selected and compared. These comparisons were compiled in a table (Appendix A1).

There are differing views as to what aspects make up good palliative care programs. There have been large developments in the area of caring for the dying, but the biggest ambiguity has been that "there is not much understanding of the needs of dying people" (Hamilton & Reid, 1980 p.57). In *The Hospice Handbook*, it is especially emphasized that "the quality of care which dying patients receive, wherever they are can be significantly influenced by nurses" (Hamilton & Reid, 1980 p.47). HospiceNet and the Helpguide from the Center of Healthy Aging suggest a list of good questions for perspective patients and families to ask. Some important questions that might illuminate the quality of a hospital's services include:

1 whether they make a plan of care for each individual patient,
2 patient-to-caregiver ratios for each discipline,
3 average homecare visits,

4 response time and procedures followed for after-hours questions and concerns,
5 continuity of care i.e., having the same care providers as the illness progresses.

2.2.4 Summary

Palliative care programs have become an important approach to coping with a terminal illness. Even though the general concept of palliative care programs may be viewed differently from culture to culture, with a well informed team and good care practices, palliative care programs can greatly help relieve the pain of dying patients and their families. Although cost-benefit analyses of services can show their financial advantages, a service is not truly advantageous unless it also addresses the personal, cultural and spiritual needs of the patient.

2.3 Influence of Culture on Palliative Care

A person's culture often defines the way they view different situations. Many unspoken assumptions can be made between two people sharing cultural views. Because culture is passed through the generations and defines basic common sense of a society, its influence may be hard to see at times without an external perspective. In Thailand, culture and religion are such an important part of every day life that they need to be considered in practically everything. Thai culture has a particularly important influence in decision making during end of life care (Ian Anderson Continuing Education Program in End of Life Care, 2005).

In Thailand, cultural influences are essential factors to consider when designing, evaluating or studying palliative care programs. For example, different cultures have different explanations of illnesses. In western cultures, people tend to be more knowledgeable about diseases like AIDS; on the other hand, in some less developed countries, there are still strong stigmas associated with these illnesses (The Christian Science Monitor, 2003). According to the Ian Anderson Continuing Education Program in End of Life Care (2005), patients of two different cultures may have "discrepancies in perceptions of the problem, values and goals" during a period of illness; in other words, their culture affects their priorities. Similarly, under different cultures, the decisions during end of life care may be the responsibility of someone other than the patient.

Therefore, the palliative care team must use open and thorough communication to become aware of these values.

In this section, we will examine important aspects of Thai culture and their influence on palliative care programs. First, we discuss Buddhism and how it affects decision making and patient priorities. Next, we discuss the influence of family structure on terminal care in Thailand. Finally, we discuss how Thais deal with terminal disease, specifically cancer, and the cultural influences behind their actions. These ideas are not only important for understanding the daily activities in a Thai palliative care program; culture greatly affects patient priorities and must be used when developing ways to measure the benefits of these palliative care programs to patient quality of life.

2.3.1 Thai Spiritual Considerations- Buddhism

One very important cultural influence in Thailand is the prevailing practice of Buddhism. Many of the Thai specific considerations for good palliative care and programs to improve QOL that we will discuss stem from fundamental differences between their Buddhist society and the Western/Judeo-Christian society. First, we will describe the basic Buddhist values. Then, we show how the Buddhist beliefs in impermanence, change, merit, suffering and rebirth lead to a very different view of death than Westerners are familiar with (Ratanakul, 2004). Also, we discuss how some of these beliefs affect the types of physical treatment patients will undergo or forfeit. Finally, we describe how belief in karma, compassion, and personal sacrifice can greatly influence the type of care given by a Buddhist run facility (McGrath, 1998).

2.3.1.1 Buddhist Values

Because Buddhism is so intertwined with Thai culture and everyday lifestyle, it is essential to understand its teachings as best we can. Despite some overlapping messages, there are clear basic differences between Judeo-Christian beliefs and Buddhism. Buddhism is a world religion but has no central creed that all are supposed to adhere to. In Sibley’s (2004) opinion, it is a “non-theistic” way of thinking; the existence or work of a creator is neither described in writings nor denied by them. Practice of Buddhism does not necessarily mean rejection of another belief system. Central and East Asian countries typically practice Mahayana Buddhism while those in Southeast Asia practice Theravada

Buddhism. The latter focuses strongly on the use of the Four Fold Truths (Battistini et al., 2003). The Four Fold Truths describe dissatisfaction or suffering *(dukkha)*, the origin of suffering, the cessation of suffering and the Eight Fold Path that leads away from suffering (*marga*). A reported 95% of the Thai population identify themselves as Theravada Buddhists (Coxhead et al., 2005).

Buddhists believe everything in the world is in a constant state of change. This idea of change is seen as the essence of life. Life is made up of five aggregates- the material form *(rupa)*, feeling *(vedana)*, perception *(sanna)*, disposition *(sankhara)* and consciousness *(vinnana)*, that are always undergoing some sort of change. Impermanence and insubstantiality are called *annica* and *anatta*. These ideas also play into the concept of the linkage of events. Every moment of life has been caused by a previous event and will cause a future event. In a sense, the present can be seen as both cause and effect (Ratanakul, 2004).

Personal liberation from this ongoing cycle of change is a core message and goal of Buddhism. With a great deal of meditation and practice, one can train the mind to think in a way that will better help oneself along the Eight Fold path and out of the cycle. This freedom is achieved through the accumulation of good merit (*punya*). This credit is carried over from life to life, helping the person to reach *nirvana*. Compassion and personal sacrifice are essential to the Buddhist when trying to earn good *punya* (Battistini et al., 2003). For example, this can be seen in practices of saving face and respect of elders. Any sacrifice that helps another reach *nirvana* will also help the person making the sacrifice as well.

2.3.1.2 Suffering, Death and Rebirth

Because all the patients in hospices are essentially dying, their views on suffering, death and rebirth play an important role in the way they want to be treated. For example, Buddhists have very different beliefs from Christians about these ideas. Therefore, to accurately assess QOL in hospice and homecare in Thailand, the Buddhist beliefs on these subjects must be taken into strong consideration.

For Buddhists, suffering is believed to come from one's attachment to the world. Desires caused by the human ego are a main source of suffering and evil. Any sort of dissatisfaction or unhappiness as well as physical pain can be classified as suffering in

Buddhism. In many Western hospices, activities are developed for long-term patients to give them a sense of normalcy, such as games or music. Many patients enjoy these programs and they are seen as beneficial to patient quality of life. Conversely, when the Mahavachiralongkorn Thanyaburi Cancer Center Hospice tried to use music therapy programs, they found that patients were reminded of old memories and spent most of the time crying. Instead of looking back happily on these memories, they became more attached to them; because of their Buddhist beliefs, the nurses viewed this program as only increasing the suffering of the patients and making it harder for them to accept their illness.

The Buddhist vision of suffering is very different from the Western idea that suffering has little or no value (Byock, 1996). In Buddhism, suffering is caused by self and an angry God or deity cannot be used as a scapegoat. Following the Eight Fold Path (*marga*) is the solution to suffering (Battistini et al., 2003). Buddhists do not have the belief that Judeo-Christians have in knowing that suffering will end in the next life with their reunion with their God; if poor *punya* has not been made up for, it will carry over in rebirth.

Originally a Hindu idea, the concept of rebirth was adopted and modified by Buddha. Because of their belief in the constant state of change in the aggregates of the world, the Buddhist view of rebirth is different than reincarnation. A doctor of the Mahavachiralongkorn Thanyaburi Cancer Center described rebirth by using an analogy of a car (the physical body) and driver (the soul). When a driver gets in an accident, sometimes the car cannot be used anymore, so the driver leaves the car and finds a new one; the car is different but the driver is the same. Dennis Sibley describes death in Buddhism as “a comma rather than a full stop, which means that the consequences of our actions do not necessarily come to an end when we die and can be carried forward into a future life – or series of lives” (2004). Because of this carry over effect, the state in which someone dies is critical to the outcome of their next existence.

Death is the natural outcome of life for Buddhists. It is the total dissolution of the five aggregates that make up a person, and it must be confronted for personal liberation from the cycle (Sibley, 2004). This is very different than the Western view of death as something to be avoided or put off for as long as possible. Westerners see death as a more definite end and many have a very difficult time accepting it. Also, Buddhists greatly value the sanctity of life. Killing, except for a few exceptions, is never acceptable. "Mercy killing" of patients and euthanasia is not permitted. On the other hand, "letting go," refusing treatments of disease that might postpone death, is accepted because it does not change the natural course of death (Ratanakul, 2004). This option to not pursue additional treatments is important for terminally ill Buddhists to have.

A "good" death in Buddhism is one where the mind is clear and open. The thoughts in a person's last living moments can have a profound impact on their rebirth experience. Clarity yields acceptance and without acceptance of death, the dying cannot move closer towards *nirvana*. For these reasons, many terminally ill patients actually refuse to take pain relieving drugs. They believe their suffering has great spiritual significance and is caused by their poor karma. This "karmic debt" will have to be paid eventually, in this life or the next, and drugs only postpone the acceptance and payment of this (Sibley, 2004). Refusal of drugs is only recommended after serious meditation and preparation to get the mind and body ready for the experience to come. Still, Thai Buddhists are humans and will react in many of the same way Westerners will to terminal illness. The Buddhist belief in tolerance may help staff handle these natural reactions and then guide the patient to acceptance (James, 1987).

One example of Buddhist beliefs being integrated into hospice care can be found in the Karuna Hospice Service in Brisbane, Australia. This facility was established in the early 1990's by a Buddhist visionary and already has a great reputation for unique and excellent care (McGrath, 1998). Typically patients there have less than six months to live. They are treated by a predominantly Buddhist staff. Here, it is easy to see how many of the teachings of Buddhism seem to compliment hospice care perfectly. Because of their strong belief in compassion, the staff is perceived as truly sincere in their care giving. It is not uncommon for nurses or doctors to ignore their schedule and stay all night with patients as needed; for them, this is an act of compassion through self denial and will help all involved in their spiritual paths. McGrath also noted that, because Buddhism is so tolerant of other religious paths, all patients felt extremely comfortable in asking for whatever type of spiritual help they needed. Overall, the beliefs of Buddhism practiced in the hospice greatly enhance the care environment.

2.3.2 Thai Family Structure

The care giving role during a terminal illness falls not only on the palliative care team but also on the patient's family and loved ones. Many patients choose to receive only homecare services; although a nurse comes to help on a regular basis, the family becomes the primary caregivers. Because our service examination and QOL analysis will include services that involve the family, it is important for us to explore the family structure in Thailand.

Traditionally, family ties in developing Asian countries are much stronger than those in America. Asian household structure varies greatly in comparison to American; it is much more common to find multiple generations living in one household (Sokolovsk, 2001). There is a particularly high rate of "skipped" generation households and in Thailand, more than 40% of grandparents live with grandchildren under the age of 18 (Lawson & Velkoff, 1998). Elderly parents in Asia are more likely to remain living with their children than in the US, though these numbers are falling.

Care for the sick is most often viewed as the responsibility of this close knit family. Women are typically the care giving gender, though male spouses also help out (Westley, 1998). However, in recent years more and more women have begun to work. In addition, life expectancy has increased 20+ years for men (and even more for women) since 1950, while birth rates have decreased. Therefore, the elderly population is growing and the available number of women to provide home care is shrinking. Moreover, David Clark and Jan Stjernswaerd (2003) found that in Thailand in 2002, there were only three organizations with hospice care for a population of about 60 million. Also, citizens only have about 10% coverage from pensions (Westley, 1998). It is easy to see that the provision of terminal care is going to be an increasingly serious problem in Thailand and other Asian countries experiencing the same changes. Another solution or addition to family care must be found.

Finally, palliative care provided solely by relatives can put strain on the family unit. Living with and caring for a terminally ill family member can be mentally exhausting. Similarly, the strains of physically caring for someone (e.g., lifting them, cleaning them) can be just as draining. John Knodel and Chanpen Saengtienchai (September 2002) reported the most common adverse health effects on care givers as anxiety, headaches, insomnia and fatigue. Also, Knodel and Saengtienchai (February 2002) found that usually care givers in less developed Asian countries will not complain because they view the task as less of a burden than Westerners might. Other strains may arise if some do not feel equal care contribution from all family members. Care giving takes a considerable amount of time; some may not be able to go to work to earn money, while others may be shunned by the community because of their absence from social events. Finally, the last act of care giving, the funeral, can be a long and tiring social event that lasts days. Although food and beverages are generally provided by the family, the guests are also expected to contribute. This greatly relieves some of the financial burdens on the family (Knodel & Saengtienchai, September 2002). The entire care giving experience may leave a family worn-out, and a better way of assisting them should be found.

2.3.3 Thai Management of Terminal Illnesses

Because of the strong influence of Buddhism and the family hierarchy in Thai culture, Thais have a very different way of addressing terminal illnesses than Westerners. Their culture, religion and social structure are so intertwined that they affect almost all aspects of everyday life and must be thoroughly considered. The strong belief in "saving face" even affects the medical world, where it is the responsibility of the family to decide whether or not to tell the patient about severity of their health conditions.

One governing social idea in Thailand is the need to save face. This can be seen in everyday situations such as people awkwardly smiling because they are uncomfortable or backing down from fights to avoid an argument. Most Thais feel it is not helpful to point out anything that is bad, so they do not do it. In the case of terminal illnesses, saving face often means that patients are unaware of the degree of their illness. They are aware that they are sick but not how sick they really are. It is understood that this information cannot be helpful to the patient and therefore, they should not be told by their doctor. Instead, the doctor defers to the family, who know the patient the best, to decide what exactly the patient should be told about the severity of their situation.

At the Mahavachiralongkorn Thanyaburi Cancer Center Hospice, Thai patients are not told directly by their doctors about their condition. In accordance with Thai culture, deference is given to family members of Buddhist patients for informing them about their illness. They also have several Islamic patients whose beliefs differ greatly from Buddhist patients'. Muslims have different traditions that require cremation immediately after death. Therefore, if a patient is known to be Muslim, they are told of their condition so that they can travel home to make appropriate arrangements. For these cultural reasons, it is essential for the staff to be aware of their patients' beliefs.

Because most patients are not aware of the degree of their illness, the term *hospice* in Thailand is used very sensitively. Although the hospice is actually in a separate building from the rest of the hospital, it is referred to as another ward, never a hospice. However, it still says "HOSPICE" in English on the entrance doors. We are told the Thai characters do not imply death the way the term "hospice" does in English, even though most patients there actually have about two weeks to live.

2.3.4 Summary

Internationally, the goals of palliative care programs are the same but cultural influences greatly affect how the goals are met. In Thailand, culture not only changes the content of the religious counseling offered but how patients will react to services (which they might refuse), how their disease is addressed, and who has the decision making power. The ideas for palliative care in Thailand are the same as those in Western culture, but the priorities for a Thai terminally ill patient are very different because of these cultural effects. It is critical to be aware of this influence on patient priorities before one can gain any understanding of the benefits of hospice and homecare, specifically what improves QOL for Thai terminally ill patients. This cultural understanding provides the context within which we must work to evaluate QOL validly.

2.4 Measuring Quality of Life

Quality of life has been defined as a "global evaluation of satisfaction with one's life" (Cooley 1998). It is also seen as one of the most important outcomes of effective end-of-life care. QOL measurements are necessary to ensure that patients receive the level of care they need. In addition, they can be used to generate the necessary data to prove or disprove the benefits of a care program. Valid assessments can only be conducted by utilizing an instrument that is sensitive to all aspects of the patient's life. The more suitable the survey is, the better the results.

The following sections will examine how to categorize and measure QOL. First we will investigate the elements that define QOL and how they can be grouped into different categories for Western cultures. We will discuss each of these categories in more depth and what they entail in the Western setting. Once the categories are explored, we will assess the strengths and weaknesses of some existing instruments for the measurement of QOL. Finally, we will discuss important considerations for adapting existing Western surveys to the Thai setting. Understanding these factors will be crucial to our development of a valid QOL measurement survey for Thai terminally ill cancer patients.

2.4.1 Categories of Quality of Life

To obtain a holistic picture of a patient's life, one must examine the myriad of factors that influence their life. This examination is no small task considering the wide range of influences experienced by a patient. However, it is made easier by grouping these influences into major categories. The categories that will be discussed are physical, mental, spiritual, and social (see Table 1). These domains were determined from the analysis of a variety of sources (Addington-Hall, 2001, Byock, 1996, MVQOLI, 2001, WHO, 2000, Woung-Ru Tang, 2004). To understand how to measure QOL it is necessary to explore all these categories in the context of how they will affect a patient's perception of their life.

The physical category is perhaps the easiest to define because most of the influences are tangible, concrete and measurable. The first set of these conditions involves the patient's physical body. Included in this set are pain management, symptom management, fatigue/energy, and nourishment. Pain management is one of the top priorities of palliative care. In this case quality care would be measured by the level of bodily suffering experienced by the patient. Closely related to this condition is symptom management. An example of this is respiratory support for patient who has trouble breathing. The levels of fatigue and nourishment can also be measured to determine the physical needs of a patient's body. The next set of physical conditions involves the body's response to its environment. These influences include climate, noise level, privacy, and ease of access to services. All of these factors are relevant to the comfort of the patients within their surroundings. To measure patient satisfaction with life, it is important to include how they feel about where they are spending their final days.

Table 1 Western QOL Category Breakdown

Adapted from: Addington-Hall (2001), Byock (1996), MVQOLI (2001), WHO (2000), and Woung-Ru Tang (2004).

Major Categories	Subcategories	Subcategory Sets
Physical	Physical Body	Pain management
		Symptom management
		Fatigue/energy
		Nourishment
	Body Response to Environment	Climate
		Noise Level
		Privacy
		Ease of access to services
Mental	Psychological	Positive Thinking
		Concentration
		Hope
		Acceptance of Death
		Letting go
	Self Acceptance	Self Esteem
		Dignity
		Appearance
	Independence	Patient Mobility
		Ability to perform daily tasks
Spiritual	Existential Wellbeing	Feelings about purpose in life
		Meaningfulness of their life
		Personal growth
		Standing in the world
	Religion	Influence on coming to terms with life
		Coming to terms with how they lived
		Preparedness to pass on
Social	Emotional Support	Caring
		Affection
		Trust shown from society
	Informational Support	
	Relationships with Friends and Family	Caring
		Affection
	Love and Trust	
Finances	Economic Pressure	

The next category includes the mental influences on a patient. These are not as concrete as physical conditions, but are just as important. The mental state can be further broken down into three sets: psychological, self acceptance, and independence. The psychological set includes such influences as positive thinking, concentration, hope, acceptance of death, and letting go. These factors play major roles in the mindset of a terminal patient, and thus affect the perception of QOL. The second set is self acceptance and includes aspects such as self esteem, dignity, and appearance. As with the first set, these dictate how happy the patient is with his or her life. The last set is level of independence. This subcategory considers the patients mobility, and ability to perform daily tasks such as eating, and bathing. When patients lose the ability to care for themselves, they often become frustrated with life or lose hope.

The third major category of QOL is the spiritual wellbeing of the patient. This category includes both the existential feelings of the patient and the patient's religious beliefs. Existential wellbeing consists of the patient's feelings about their purpose in life, the meaningfulness of their life, personal growth, and where they stand in the world. As one can imagine, these factors have a major impact on the patient's view of the quality of their life. If a patient feels they have lived life to its fullest, he or she will believe the quality of their life to be better. The patient's religious beliefs are equally as important, as they involve the patient's relationship with a greater power. Whether this higher power is Buddha, God, or nirvana or heaven, it influences the patient's ability to come to terms with their life, how they have lived, and their preparedness for passing on.

The last major category of QOL is social influences. This is an important category because it takes into account the effect society has on a patient's view of their life. Included in this category are emotional and informational support, relationships with friends and family, love and trust, and economic pressures. The support given by friends, nurses, and family can be a deciding factor in the happiness and QOL of a patient. This is comprised of the level of caring, affection, and trust shown from society. One last aspect that can alter the mindset of a terminal patient is financial worries. It is hard to worry about dying well when one is preoccupied with social pressures.

These four major categories encompass all the influences on QOL experienced by a patient. Some of the categories directly affect the comfort of the patient, but those that affect the patient's perception of life are considered as well. In order to gather a complete view of QOL, one must incorporate all of them into measurements.

2.4.2 Existing Quality of Life Measurement Instruments

There are several instruments in existence for the measurement of QOL that incorporate the categories of influences described above. There are surveys that focus on a single category, and there are also surveys that include all of them. There are even some holistic QOL surveys that take into account another factor by being adapted to specific illnesses, such as AIDS or cancer. Each model has strengths and weaknesses, and some are better for different purposes. Here we will examine all the types and their differences.

The first type focuses on a specific category of influence on QOL and provides a more in depth study of this category. One example of this kind is the Eastern Cooperative Oncology Group's ECOG-PSR, a rating system that focuses purely on the physical status of patients. Another is the American Pain Society's APS-POQ which is further specialized to patient pain. A tool to measure spiritual quality was developed by Paloutzian and Ellison (1982) and is used to rank the wellbeing of the patient. Finally, the Medical Outcomes Study Social Support Survey (1991) has developed to measure social QOL.

The primary advantage to this type of measurement tool is the level of detail and attention devoted to each specific category. Questions in these surveys can be more precise and explicit because more time can be devoted to the particulars of the category. These surveys need not be concerned with obtaining a holistic view of QOL. However, the advantages can be seen as disadvantages because the instrument does not illustrate the whole QOL of the patient. Although one aspect of a patient's life may be determined as having a high quality rating, they may be suffering low QOL in another category. The drawback of not considering these categories together is that a skewed measurement of patient QOL might be presented by the survey.

The next type of measurement tool is the general QOL survey, which incorporates all of the physical, mental, spiritual, and social influences into a quick, easy format. Some examples of these are the surveys were developed by Ferrans (1985), Spitzer (1981), and

McGill (1996). A more in-depth QOL survey is the Missoula-Vitas Quality of Life Index (MVQOLI) (2001). This survey links QOL ratings to patient priorities to give a weighted, more accurate score of QOL. For example, if a patient rated that his level of pain relief was of good quality, but also rated that physical components were less of a priority, the QOL would be lower than assumed on a regular QOL survey. The advantage of this strategy is that the personalization and adaptations make the collected data more valid. Another tested and well adapted survey is the WHO-QOL developed by the World Health Organization. There are two versions of this survey both short and long. The WHO is also developing modules of their WHO-QOL for specific diseases. This specification will allow the level of detail to be increased. It will also allow the attention to differences between diseases to be addressed.

The last type of QOL measurement instruments includes those that have already been adapted to specific diseases. Specifically, we examined those surveys pertaining to cancer patients. The first tool was developed in the mid 1970's and was a linear analog assessment. Since then there have been many steps to develop the best tool specific to cancer (see Appendix A2). One of the most recent steps has been the Hospice Quality of Life Index (McMillan, 1996), which is both cancer and hospice specific. This type of measurement tool is even more advantageous than the general QOL surveys. This is because the instruments are more finely tuned to the needs and categories of the patients.

2.4.3 Adapting Existing Surveys to Thai Culture

Each of the survey types mentioned above has their strengths and weaknesses. In this section we will discuss their specific disadvantages when applying them to a terminally ill patient in Thailand. We will also illustrate specific examples of when utilizing the existing surveys would be inappropriate and even harmful to patients.

The first major hurdle one must consider when adapting a survey to Thai culture is the Thai way of handling terminal illnesses. As discussed previously, Thai doctors and nurses do not inform the patient that they are terminal, or even at what stage of the illness they are in. The decision to share this information with the patient is left up to the family. This approach to managing diseases, such as cancer, means that Thai surveys cannot allude to the fact that patients are in their last stage of life. One can imagine the detrimental effects of a survey question such as "As the end of my life approaches, I am comfortable with the thought of my own death" on a Thai patient's psyche (MVQOLI, 2001). Another consideration one must look into is as simple as the introduction to the survey. By titling a survey "QOL in Hospice Patients" too much information has already been mistakenly given away.

Another drawback to using Western surveys in a Thai setting is the fundamental difference in religions. A crucial part of the Theravada Buddhism practiced in Thailand is that people will be reborn into their next life after death. The impact this idea has on a patient's mindset as they near the end of this life is profound. Thai patients do not see death as an absolute end of their life because they will be reborn. A question such as "How positive do you feel about the future" may produce skewed data in the Thai context (WHO, 1995). Some may draw the conclusion that Thai patients are generally more optimistic about their future then Western patients, when the case is simply that Thai patients are just looking forward to their next life. Correspondingly, Thai patients are taught by doctors and nurses to let go of the physical world in order for an easier passage into the next life. A Western survey statement such as "Life has become more precious to me; every day is a gift" would be looked at as a positive influence to QOL (MVQOL, 2001). In contrast, it would be the exact opposite in the case of a Thai terminally ill patient; any attachments to this life would be hampering their ability to easily pass on and thus decreasing their QOL.

In addition to the cultural differences needing consideration, the spiritual needs of a Thai patient must be addressed when adapting a survey. The influence of Buddhism in every day life in Thailand is much more visible than that of Catholicism, Protestantism, or Judaism in the Western world. In Thailand, a major influence on having meaning in life is the building of merit. The belief in karmic debt means that the Thai spend much of their time trying to do good deeds and help others. This category is generally overlooked by Western surveys, because it is irrelevant in its effects on QOL. The closest questions to this Thai spiritual belief are phrased similar to, "To what extent do you feel your life to be meaningful?" (WHO, 1995). These questions cannot but scrape the surface of this spiritual category for Thai patients. When adapting a Western survey to the Thai context, multiple questions need to be developed that can encompass all of the spiritual influences on QOL.

2.4.4 Summary

There are many purposes and tools for measuring quality of life. The statistics such measurements produce can be used to assess the effectiveness of services, to ensure the patient's needs are being met, or to do cost-benefit analysis. Whatever the purpose of the measurement, results are meaningless unless they are based on valid data. We have examined all the relevant categories of QOL and various evaluative instruments. We examined their strengths and weaknesses and also their disadvantages when used in a Thai setting.

One key trend in the successful surveys was personalization. The more tailored the questionnaire to the patient's specific situation, the higher the level of detail and relevant information. This translates to more valid data. One way to accomplish this personalization is to make the instrument both culture and disease-specific. In our case, the measurement tool would have to be catered to Thai Buddhist terminal cancer patients.

A well developed and personalized measurement instrument will produce data that can help to prove or disprove the benefits of services. This is half the information needed to complete cost benefit analysis. Once the benefits of a care program have been shown, it is crucial to also show the associated costs. In order to promote hospice and homecare, the Mahavachiralongkorn Thanyaburi Cancer Center will next need to document the cost of their services. This issue is discussed in the following sections.

2.5 Cost Analysis of Palliative Care Programs

Analysis of costs of hospice and homecare services can be used as a method of supporting the promotion of such programs in Thailand. By noting what services are provided, how much they cost to run and the associated benefits, the information supplied will serve as a tool to illustrate how improving QOL via these services is financially feasible. Documentation of the services, costs and benefits will give a holistic view of what monetary considerations should be taken into account when running hospice and homecare programs.

In this section we specifically examine the factors relevant to the economics of hospice and homecare programs. First, we discuss the need to document services in order to accurately calculate costs. Next, we discuss the different methods of costs analysis.

Finally, we discuss the cultural influences that are important to remember when interpreting cost analysis results.

2.5.1 Service Assessment and Costs Valuation

To complete cost analysis of palliative care programs, it is necessary to understand both the services offered and the proper metrics of measurement. Because the services offered differ between programs, it is necessary to incorporate the appropriate services in order to validly predict the cost of the whole program. Once services have been identified, they can be valuated by different methods in order to assign the appropriate units for use in analysis. In this section, we will discuss these beginning steps of cost analysis.

2.5.1.1 Types of Services and Expenses

The first step to cost analysis is identification of services and expenses. Programs at different hospitals will have a wide range of services to offer. Hospice and homecare services mainly focus on nursing and counseling (Sykes, 1998). As such, the services that need to be recorded for analysis are mostly performed by the nurses. In the 2004 annual US Congress report publication on Medicare Trends (2004), a list of billable hospice services was published (see Table 2). All of the main categories of palliative care programs were listed, including an open-ended category to allow for any other prescribed treatments. Although this is a fairly comprehensive list of services, costs can still be further broken down into more specifics.

Table 2 Medicare Billable Hospice Services

Adapted from: Medicare Trends (2004).

Billable Services	
Skilled Nurse Care	Therapy (Physical, Occupational, and Speech)
Medical Social Services	
Physician Services	Inpatient respite care (providing a limited period of relief for informal caregivers by placing the patient in an inpatient setting like a nursing home)
Patient Counseling (dietary, spiritual, and other)	
Short-term Inpatient Care	
Medical Appliance and Supplies	Any other items or services listed in a patient's care plan necessary for the palliation and management of the terminal illness
Drug and Biologicals for Pain Control and Symptom Management	
Home Health Aide Services	

One way to organize expenses is by categorizing them into common costs themes, rather than the types of costs. In a study done by Philip Jacobs (2001), participants were given a list of expenses associated with palliative care and asked to group them. They included costs whose burden could be carried either by the care facility, patient, family or society. Bridging values were determined to show the strength of the relationship between the grouped items; values varied between 0 and 1, 0 being the strongest relationship and 1 the weakest. These values were used categorize the expenses.

Costs were grouped into five clusters: travel and communication, financial costs, personal services, consumables and durables (Jacobs, 2001). Travel and communication costs included expenses such as taxi fares, airplane tickets and long distance telephone calls. They had the weakest relationships and many of these costs were viewed as optional costs. Financial costs included loss of patient job, family time off and insurance costs. Many of these costs were more related to the dying process rather than homecare or hospice specifically. Personal services included all of the palliative services addressed by Medicare's study (see Table 2) and more. Costs of these services were not necessarily paid for by the patient; for example, a friend might sacrifice time at work to help care for a patient. Finally, costs of supplies were grouped into consumables and durables. Consumable supplies are those that are quickly used up by a patient, such as food, oxygen or drugs. Durable supplies are those supplies that are needed to for care that can be used for long periods of time, such as wheelchairs, special beds and bed pans. For a complete list of the items examined and their bridging weights see Appendix A3.

2.5.1.2 Types of costs

Before one can place a value on a service, it is important to understand what types of services are generally used in economic analysis. These types of costs can be useful when trying to evaluate things such as the efficiency of a program, whether or not to add services or the average costs of patients. By understanding these costs, an executive can make the most appropriate decisions based on cost analysis results.

The first set of costs breakdown the major, tangible areas of direct costs to a hospital. Capital costs are the expenses needed to secure major assets, such as land, a building or permanent equipment. Operating costs are non-capital costs that can be easily assigned to different departments. These could include some salaries, equipment, or supplies. Overhead costs are used by several areas in a facility and the correct proportion of cost may be difficult to assign per department. For example, some overhead costs include electricity, laundry services, custodial services and administration. An example list of the direct costs discussed above can be found in Appendix A4. Direct costs can be fixed or variable. Fixed costs are not affected by the quantity of output (e.g. gained health units). Fixed costs can include rent, lease payments, and some salaries; no matter the outcome of services, these costs remain the same. Variable costs, such as food, supplies and quantity of services, vary in magnitude per patient and are affected by level of output units.

The second group of costs includes average and marginal costs. Average costs are the average cost per unit of output. For example, this might include the average cost of attaining a QOL level. Per Diem cost is the average cost of treatment per patient per day. Marginal costs are those extra costs needed per unit increase of outcome. For example, it might costs $100 to run a program for the fist participant, but each additional participant may only cost an additional $10. This marginal cost is very small in comparison to the startup cost for the initial participant and may suggest that more participants can be added without decreasing the efficiency of the program. More examples of these types of direct costs can also be found in Appendix A4.

Finally, non-market and opportunity costs must also be considered. Whenever a resource is used for one purpose, the opportunity for that resource to be used for another alternative purpose is forgone. This loss is also known as opportunity costs. Non-market costs are costs that do not have definite market values. For example, it is hard to place a value on family time, pain, or psychological costs. Another example list of indirect costs can be found in Appendix A5. The assignment of these indirect values as well as the assignment of more direct values will be discussed in the next section.

2.5.1.3 Valuation of services

Some services can be assigned purely monetary values, while for others this is not as easy. Consequently, an important challenge in assigning costs to services is determining the right metrics of measurement. An example of a monetary cost would be a cost of a prescription drug. These values are very straightforward and require simple tabulation rather than in-depth analysis. However, some services do not have specific monetary values. For these services, values that do not have clear costs need to be converted into financial terms by using appropriate metrics of measurement. An example of such a conversion would be assigning a pay rate to a nurse’s time spent caring for a patient or using fuel prices to assign costs to travel.

There are several methods for valuating services. First, some services and other expenses can be assigned values by using market prices (Hollander, 2001). This method can easily be used for supply items. Other expenses can be valuated by looking at the market prices of comparable items or services. Next, one can study a client’s willingness to pay for an item or service and the trade-offs that they are willing to make. Loss of productivity can be valuated with disability payments. Lastly, policy maker’s and professional’s views can be used to infer the value placed on different items. For example, the cost of a physical disfigurement can be valuated from the monetary judgments of a court hearing. Also, time lost by patients can be measure by indirect opportunity costs.

Finally, there are some services that have valuable benefits to patients and families that cannot easily be translated into monetary costs. Methods for valuating these less tangible costs are still debated and therefore, they are often omitted from cost analysis (NICHSR, 2004). For example, the increase in mental wellbeing of a patient cannot clearly be converted into monetary terms; therefore, metrics such as QOL, natural units (e.g., years of life) and adjusted health utility (e.g. Quality Adjusted Life Years) are used to assess the benefits of these services. This allows for analysis, even though it is not strictly financial.

One valuable example of a way to convert the intangible costs of services into billable items is the model used by Medicare (2004). Some of these services that Medicare examines are outpatient services, therapy and counseling, and homecare. There are three steps to breaking down a service into metrics that have monetary values (see Appendix A6). First, simple counts of services provided are recorded. For homecare services this might be the number of visits. Next, adjusted counts of the more specific service breakdowns are recorded. Continuing with the homecare example, services could then be categorized into who made the visit or what service was performed during the visit. Finally, economic analysis is used to assign a billing unit to each of these more specific services. Through this process, Medicare is able to convert abstract ideas into tangible costs. The results of this process are then used in cost analysis.

2.5.2 Methods of cost analysis

Cost analysis is used to compare cost units of measurement to units of outcome. The three types of cost analysis (summarized in Table 3) are cost-effectiveness, cost-benefit analysis and cost-of-illness. After services have been clearly identified and valuated, the most appropriate type of cost analysis for the purpose of the study can be chosen and completed.

Cost effectiveness analysis determines costs as they are related to natural units of standardized health effects (Brown & Smith, 2000). They focus on the amount of units gained, rather than how these units improve QOL. Cost-effectiveness analysis is often used to show the usefulness of under-funded programs; the value of such a program can easily be shown by analyzing marginal costs and outcomes of services. Three common subcategories of cost-effectiveness analysis are cost-minimalization, most-utility and cost-consequences.

Cost-benefit analysis assigns monetary weights to all outcomes of a program in order to complete strictly financial analysis. Cost-benefits analysis can be complete by either measuring net benefits or ratios (NICHSR, 2004). The ratio approach (÷ function) shows the amount of benefits that can be attained per unit of cost. Net benefits (- function) show the total monetary losses or gains of a service. Cost-benefit analysis is particularly useful for executives because it puts all expenses and outcomes in terms of monetary units.

Table 3 Types of Cost Analysis

Adapted from: Brown & Smith (2000) and NICHSR (August 2004).

		Cost-effectiveness				
	Cost-of-Illness	**Cost-effectiveness:**	***Cost-minimalization***	***Cost-utility***	***Cost-consequence***	**Cost-benefit**
Description:	Measure the economic effects of an illness	Determines the cost per unit of standardized health effect	Determines the least expensive service possible to achieve a pre-set outcome	Compares costs per time unit adjusted by utility weights	Compares costs with un-weighted categorized outcomes	Compares costs to benefits; both measured in monetary units
Cost unit of measurement:	$	$	$	$	$	$
Operator for comparison:	vs.	÷	vs.	÷	vs.	÷ or **-**
Outcome unit of measurement:	None	Natural units (e.g. Year of life gained)	Set as equal	Utility (e.g. QALY: Quality adjusted life year)	Natural units	Monetary ($)
Best for:	Measuring the burden of a disease on society.	Showing the usefulness of under funded programs.	Finding the most effective program alternatives.	Relating costs to one or more health effects	Comparisons of situations with multiple outcomes	Comparisons of potential benefits to costs
Other:		Measures the cost per natural unit gained, not the quality of unit gained.	By setting the outcome as good care one can compare continual care programs.	Biased against elderly who have shorter life spans. Benefits studied may not be common to all alternatives.		Benefits studied may not be common to all alternatives. Hard to assign Costs to value of human life.

One drawback of cost-benefit analysis is the difficulty of assigning value to human life. Large discrepancies can occur because of the basic demographics of the patient, such as age or gender (Hollander, 2001). For example, one study valued young males considerably higher than young females ($170,707 to $133,238 respectively) because men typically receive higher salaries. However, in later stages of life men (valued at $934) are considered to live “minimally productive lives” as opposed to women (valued at $5,705) who typically continue to do housework. Therefore, it is important to have the basic demographics of the population clearly defined in order to properly interpret results.

One final method of analysis is cost-of-illness analysis. This measure the economic burden caused by an illness. No outcome is studied in this analysis, simply the costs associated with the disease. Studies are typically done on a particular population, region or country.

2.5.3 Key Attributes of Cost Analysis

When using any of these methods of cost analysis, there are some key attributes (summarized in Table 4) that need to be considered. Because these attributes can vary between different studies, it is important for someone using cost analysis results to understand which attributes were used. Incorrect assumptions of these attributes can greatly alter analysis result interpretation.

Table 4 Key Attributes of Cost Analysis

Adapted from: Jacobs (2001) and NICHSR (August 2004).

Key Attributes	Idea	Examples
Comparator	What is the program being compared to?	Standard care Minimal care No care
Perspective	What point of view is the programs assessed from?	1st party: Patient, Family 2nd party: Hospital, Doctors, Community Programs 3rd party: Private Insurance, Government Insurance 4th party: Employer, Insurance Plan Sponsor Society as a whole
Direct Costs	What type of direct costs are being studied?	Healthcare related costs Non-healthcare related costs
Indirect Costs	What type of indirect costs are being studied?	"Productivity losses" Intangible costs
Average vs. Marginal Costs	Is the program effectively using resources?	Value of additional programs Cost per additional patient
Time Horizon	Are the effects of time on outcomes considered?	Magnitude of costs Outcome of improving health services
Discounting	Is the effect of time on monetary Values considered?	Inflation
Sensitivity Analysis	Are the effects of uncertainty in cost estimates considered, tested and proven to be minimal?	Variations in variable estimates Revelations that call for different recommendations
Resources Available	How does the patients monetary resources affect the costs spent?	High accessibility can yield high costs Low accessibility cannot yield high costs Needed costs vs. wanted costs
Nature of Payer	Is the payment plan of the payer considered?	Government insurance with small co-pays Private insurance with higher costs

The first set of attributes provides a basic context for the analysis being completed. This set includes comparator, perspective, direct costs, indirect costs, and marginal costs versus average costs (NICHSR, 2004). The comparator is the alternative that the service is being compared to. A service compared to minimal care standards might appear to have much higher benefits than a comparison with standard care. Perspective greatly influences how costs and benefits are valuated and prioritized. It might be very important to keep costs down from an insurance company's point of view, while the patient's family might be much more concerned with their loved one's QOL. Also, one must know which costs (indirect and direct) are being analyzed and which are being omitted. If an important cost is not analyzed, it is important to infer how it might have affected the outcome of cost analysis. Similarly, one must know if average costs or marginal costs are being measured. For example, average costs may show a program to be inefficient for a small patient population but extremely cost efficient when the marginal costs of increasing the treated population are considered.

The other set of attributes assess some of the validity issues within the analysis. The time horizon of a study can greatly affect the associated costs and outcomes of services (NICHSR, 2004). For example, as programs improve over time the positive output effects will increase. Also, as time passes costs of programs may increase as the value of monetary denotations change. This leads into the need to properly discount expenses that have been affected by inflation. For example, an item that costs $5 today might cost $5.50 two years from now; this item would need to be valued using one of these costs to make accurate comparison. Sensitivity analysis must also be done to determine the uncertainty caused by such estimates. Finally, attributes of the payer such as their accessibility to resources and payment plan, must be considered to account for the varying magnitude of costs (Jacobs, 2001).

2.5.4 Cost Influences

In the healthcare industry, money is an important factor that influences healthcare management, policy making and program development (Chirikos, 2002). In order to aid the promotion of hospice and homecare services in Thailand, it is important to understand all of the influences costs can have on these programs. The illustration of benefits of palliative care programs begins with examining the specific services and their associated costs. Other factors that influence the cost of a program are cultural setting, program structure, patient mix, payment and billing procedures, and external support. All of these aspects, which are summarized in Table 5, have to be considered when analyzing a program for its feasibility.

Cultural influences on the costs of a program arise from the variation in services from setting to setting. Different care trends are often exhibited when dealing with a variety of cultures and religions. For example, in a Western setting, it was noted that in the last year of life for a patient, “costs per week grew at an increasing rate” (Greer et al., 1989). However, in a different setting, the costs of care during the last year of life may decrease because the desire for curative care measures diminishes. It is this reason that makes conventional care much more costly than outpatient and Western-style hospice services.

Table 5 Cost Influences on Palliative Care Programs

Adapted from Chirikos (2002), Greer et al. (1989), McMillan (1996), and Sykes (1998).

Cost Influence Categories	Examples
Cultural Setting	Thai vs. American
Program Structure	Cost according to whole program vs. Cost according to individual services
Patient Mix	Cancer types, age, prognosis, etc.
Payment	Insurance programs
Billing Procedures	One bill after death vs. ongoing billing
External Support	Government and private organization support of programs

Also because programs are structured differently to include varied services, the cost of programs can differ greatly. When analyzing the cost of a whole program it is important to consider the combination of services. Each service has an associated cost that can range anywhere from extremely affordable to exorbitant. The costs can also be dependant on the local economy. The specific combination of these services the hospital chooses to use determines the overall cost of the program. Average cost per patient can also be determined by looking at the services received. For example, if a hospital typically treats patients that require more expensive services, the projected cost of the program to the hospital will be higher.

This suggests that another important influence on the cost of services is the mix of patients. Age, gender, and cancer diagnosis all play a role in which services the care system implements (Sykes, 1998). Different cancers can require different treatments, especially because of the ranges in pain felt by the patient. The time of admittance into hospice care, previous treatment and time needed for the disease to run its course are also part of the patient mix. The length of a patient's cancer from diagnosis to end of life has a major influence on cost because it determines the period over which the patient will need treatment. Cancer Centers that focus on short term cancers may experience a reduction in care costs per patient because no long term services are necessary (Greer et al., 1989). This might be reflected in the costs of the Mahavachiralongkorn Thanyaburi Cancer Center Hospice because the average patient's length of stay is considerably shorter than in a traditional Western hospice.

Another influence on the cost of palliative care is patient payment procedures. Payment procedures are the ways patients pay for their services and whether or not they receive financial support from the government, insurance agencies or other sources. This is important to consider because each method places a different financial burden on the hospital, thus influencing the cost of a program. By considering all the different payment plans, a palliative care program can better estimate service costs. This information is also useful for patients so they are able to see all the details of payment rates when choosing a terminal care program to pursue.

Also influencing the rates of these services are the methods in which patients are billed. Some patients are billed per hour, per visit, or per service received. Depending on which method is used by the hospital, costs may rise or fall. For example, a study by the Hospice Association of America found that paying per visit is more expensive than paying per hour if a patient only requires a service for a short period of time (see Appendix A7). For patients who require constant monitoring it is more advantageous to pay per visit. There are also some programs that choose to pay the professionals according to specific services provided. These methods are important to note because it is up to the hospital to choose the appropriated medical service. For example, if the hospital provides a doctor to a patient when a nurse would suffice, it is more likely that a patient without financial aid will not be able to pay for the service and the hospital will have to bear a bigger financial burden.

One other factor that can influence the cost of a program is the level of external financial support. This plays a major role in a hospital's willingness to develop a program not covered by insurance. If assistance is not offered to alleviate the cost of programs, there is little incentive for their initiation. In the US this led to the Tax Equity and Fiscal Responsibility Act, which states that hospices participating in the National Hospice Organization are eligible for reimbursement. The National Hospice Society is another organization that has been known to fund approximately 40% of palliative care costs for hospices (Sykes, 1998). No comparable programs exist for Thai terminal care facilities, thus decreasing the incentive to even use those types of services. These types of systems encourage growth and financial stability. Therefore, they could be very helpful when developing homecare and hospice programs.

2.5.5 Cost Summary

By analyzing the benefits and costs of programs, one can gain insight into why a program is important to add. Although the benefits of programs are important, cost analysis of services is necessary when proving the financial feasibility of implementing new programs. The various services offered in a program must be observed, recorded and converted into monetary values with the appropriate metrics. Also, it is important to recognize the different influences on cost that may vary according to the situation. When all of this information is combined with non-monetary benefits of programs, one may then begin cost-benefit analysis. This type of documentation provides concrete evidence that might be the factor in the decision making of a healthcare executive.

2.6 Background Summary

With our research into palliative care programs, we have identified what many organizations feel is the standard for good palliative care. To determine these best practices, we first had to develop an understanding of what actually goes on in palliative care and who performs what work. This information provided us the background knowledge of palliative care needed in order to study QOL in hospice and homecare facilities in Thailand. Also, it helped us know what data to collect so that the hospital can complete cost and benefit analysis of different services.

3 Methodology

Our research into hospice and homecare practices and Thai culture gave us the background knowledge necessary for us to work on the development of a framework for assessing program costs and benefits in terminal cancer facilities. In order to accomplish our goal we completed the following objectives:

1. Design a protocol for compilation of important patient demographic information,
2. Determine metrics to measure quality of life in Thai terminally ill cancer patients for use in an evaluative survey, and
3. Examine hospice and homecare services and their associated costs.

The research objectives and data collection and analysis procedures we utilized to accomplish these objectives are discussed in the following sections.

3.1 Design a Protocol for Compilation of Important Patient Demographic Information

For the Mahavachiralongkorn Thanyaburi Cancer Center to assess their services, they must first have statistics about basic patient demographics such as age, gender and type of cancer. Our first part of this objective was to explore the records system and how it works in order to determine the types of information currently being recorded. Secondly, we identified other categories of information necessary for statistical research. Next, we worked in conjunction with a Fulbright scholar who was also doing research on patient demographics, to provide the Mahavachiralongkorn Thanyaburi Cancer Center with an instrument to compile their patient data in the hospice and homecare sectors. Finally, we were able to test the instrument. We began compilation of information and determined demographics of the patients currently receiving hospice and homecare services. By completing these objectives, we provided the Mahavachiralongkorn Thanyaburi Cancer Center with a way to continue compilation of important information necessary for promoting hospice and homecare.

Our group examined both how the existing systems work and also the specific data being documented. We needed to know what type of system it is, how it is organized, and who is involved in recording of data. This information became important later when we worked together with the Fulbright scholar to suggest a method of compiling valuable statistical information. We helped design patient information sheets that could be used for both our research purposes and hers (see Appendix D). With respect to the data itself, we wanted to see how detailed the documentation is. We looked for categories such as, patient age, gender, type of cancer, length of stay, religion, and degree of knowledge of illness. All of these variables gave us a better understanding of what information is currently available at the Mahavachiralongkorn Thanyaburi Cancer Center.

After examining the current system at the Mahavachiralongkorn Thanyaburi Cancer Center, we determined what information in the records was important for the hospice and homecare services also for their statistical analysis. These data could be used for keeping a compiled record of what types of patients go through hospice and homecare routes. In our other objectives and future research this information could also be used to stratify samples for data collection.

To obtain information about the records system a combination of observation and archival research was conducted. First we took an informal tour of how the existing system works in the hospice and homecare departments. With the help of some medical staff, we were able to look at patient record forms from the hospital and hospice. Second, archival research was conducted by using the physical records themselves. We looked at the hospital records and observed the type of data being recorded. To understand who obtains the data as well as how they go about recording the information, we observed the system at work in one of the wards at the Cancer Center. During our homecare visits, the head nurse explained what information they record for homecare patients. With this knowledge, we were able to identify if gaps existed in their records system that might be important for research.

The culmination of our research resulted in the design of a protocol to compile important information. We created a simple database using Microsoft Excel to store the information that we identified as important. It also included basic instructions on how to enter this information. The final compiled data could be easily accessed to view important homecare and hospice patient statistics. To start the Mahavachiralongkorn Thanyaburi Cancer Center off on compiling these statistics, we worked with the Fulbright scholar and gathered and entered information about the patients currently receiving care in the hospice and through homecare. The nurses filled out a basic informational sheet (see Appendix D2 and D4) about each patient. These data were entered into our program to generate statistics about the current patient population.

In order for the Mahavachiralongkorn Thanyaburi Cancer Center to achieve their goal of proving the value of homecare and hospice services, they need patient demographics as a source of basic but essential information. We were able to provide them a way of compiling and analyzing useful data. These statistics may be useful not only for their long term goal, but could also provide insight for other administrative decisions. Moreover, these demographics could be useful in the future for cost benefit analyses of services; in order to find average treatment costs, the demographics of an "average" patient must first be determined. Lastly, these demographics are essential in defining the population treated by the hospice and homecare services for future research.

3.2 Create a Tool to Assess the Quality of Life in Terminally Ill Thai Cancer Patients

Our second research objective was to create a survey to be used specifically in Thailand to evaluate the quality of life (QOL) of terminal cancer patients. To complete our objective we first sought to determine metrics to measure the quality of life of Thai terminally ill cancer patients. Second, we sought to create an evaluative survey using these metrics. Unlike the US QOL survey the hospital uses now, our survey was designed with the Thai beliefs specifically in mind.

With a clear way of measuring the benefits of hospice and homecare on improving quality of life, the Mahavachiralongkorn Thanyaburi Cancer Center would be able to better promote their services and encourage other hospitals to add similar ones. This in turn could raise the bar for cancer care all over Thailand and hopefully encourage more patients to seek treatment. The main goal of palliative care programs is to provide the best QOL possible in a patient's last days. Without a tool for evaluating QOL, the Mahavachiralongkorn Thanyaburi Cancer Center cannot show that they are achieving their goal as a palliative care program.

3.2.1 Generating Categories for Evaluating Quality of Life

Our first step was to generate categories that influence a patient's QOL. Some factors that we already identified through our background research (see section 2.2.3 and Appendix F1) were physical, psychological, ability to do daily activities, social, spiritual, environmental, self-acceptance and economic. These ideas came mainly from Western studies but were also comparable, if not almost identical, to ideas presented in international and Thai specific QOL studies (see section 2.4.2). We theorized that the factors that affect QOL for a Thai patient would be similar to those that affect a Western patient, but that the importance of the factors could be prioritized differently in Thailand. In fact, an influence viewed as positive in one culture may be valued negatively (and vice versa) in the other. By researching how these factors are prioritized by Thai patients, we were able to refine and organize them into five general categories with which we designed our survey.

Our main challenge in determining these categories of influences was the cultural differences between Thailand and the US. Some services that improve QOL for US patients might be detrimental to patients in Thailand. It was important for us to focus on this and remember that we were evaluating QOL in respect to their culture, not ours. To do this, we relied mainly on our background research to guide us on whether or not these ideas on QOL applied to our project's context. We also utilized semi-structured focus groups conducted with a few of the Cancer Center's medical staff (see Appendix B. Semi-structured focus groups are useful when key ideas have already been developed (Singleton & Straits, 2005). We chose this approach because we were already aware of the gaps in our background knowledge that needed to be filled. We learned that staff agreed that in theory some of the factors were the same, but the reasoning and importance were different.

We also used the aforementioned focus group to obtain more information about the staff's opinions on what is important to patient QOL. During this meeting, we asked open ended questions about the influence on Buddhism and Thai culture on end of life care. The staff spoke mostly about the real importance of Buddhism in a Thai patient's life and how it affects their priorities (see Appendix B). With this information, we gathered important medical opinions to support the inferences we would make from our

QOL patient priorities surveys. The staff also helped give us a better understanding of some of the intricacies that occur everyday in the hospital.

After our focus group meeting, we created a survey to determine the Thai prioritization of the factors we identified. This survey asked about the importance of various factors regarding QOL from the Thai point of view. In this survey, we listed several different QOL influences (see Appendix F1). In order to obtain the Thai perspective of these issues, we asked 34 staff members (doctors and nurses) to order the importance of each of these factors on a scale of 1-9, where 1 was the most important. The initial survey was translated into Thai but still had several problems that needed to be worked out. Several staff members tied various conditions and were asked to adjust their answers so that each number was only used once. We also included an “Other” category to rank in our survey to see if there were any major factors that are important to measuring QOL that we overlooked. We chose most of the survey population to be nurses because they have more daily contact with patients and might have better insight into patient thoughts.

Next, our survey was revised and administered. Another group meeting was held with some medical staff and a translator to adjust the wording and format of the survey so that it could be better understood by the staff. Because the majority of the staff can read English, we decided not to retranslate our survey into Thai after changing the format; it remained in English and a doctor accompanied us to clarify any problems staff members might have. Surveying was spread out over two days in order to get a bigger survey population.

The data from the survey were compiled for analysis in spreadsheets and with graphical representations of the rankings. We obtained statistical data such as averages, ranges, and standard deviations. As suggested by Singleton and Straits (2005), we then used these data to establish central tendencies and data scattering. These statistics were presented in tables and pie charts, both of which provide an easily comprehensible way of assessing responses with merely a quick glance and were particularly helpful in conquering the language barrier we encountered. Responses from the “Other” option were recorded and organized into different categories. By considering these data, we were able to identify any recurring ideas that should have been taken into consideration.

The findings from our survey helped us determine how to group these influences into categories for our QOL survey.

We were able to obtain even better insight into the Thai perspective by analyzing the numerical responses together with the information learned through our focus groups. This method was much more effective than using simple surveys or archival research alone. In comparing the two sets of results, we looked for continuity in our data. We observed whether or not our understanding of Thai priorities determined from the survey matched up with the priorities of the staff in focus groups. We were also able to understand the reasoning behind Thai prioritization of the factors we examined. For example, many Western patients value their independence (ability to do daily activities, being self reliant, etc.) because they do not want to burden their family. Many Thai patients value this because without it, they loose their ability to help others and build good merit.

3.2.2 Creating a Patient Quality of Life Survey for Pre-testing

With the insight gained from the findings of our staff surveys, focus groups and existing surveys, we created our first draft of the QOL survey for terminally ill patients. This survey was the first step towards our final patient survey format. Our survey allowed us to continue to build our understanding of the Thai view of QOL while also illuminating any pitfalls we needed to address in our surveying techniques. Because of the difficulties we experienced in translating our staff survey, we decided it would be worthwhile to “pre-test” our survey. The purpose of a pre-test is not to gather statistical information but rather to test formatting issues (Singleton & Straits, 2005). We used our pretest to work out any major problems, knowing that minor problems would become more evident during our pilot survey feedback. This pre-test also aided us in our goal of developing an accurate instrument.

Our pre-test survey was composed of questions that evaluated the patient’s current QOL (see Appendix F4 and F5). Questions were designed using the findings from our staff survey and our knowledge of the Thai views on terminal illness. Particular attention was paid to the wording of the questions. We needed to make sure that the instrument did not imply that the patient was dying. We also needed to phrase questions so that saving face would not be necessary and patient would not be deterred from answering truthfully. Because many of the patients were in last stages of illness, surveys were also designed for easy use. The survey could be either administered via nurse or taken directly by the patient. Originally, we wanted to use a ranking system of Agree-Neutral-Disagree. However, after we learned that Thai people do not usually use the term "neutral," we decided to define our scale using a Never-Sometimes-Always scale.

Our pretest involved surveying both nurses and patients. Many of the metrics we were trying to evaluate were difficult to measure. Even with the use of the best translators available, there was still room for error in the translation process. We sought the aid of the staff in giving us their opinion of the survey we created. We made sure our intent was clear, that our questions were appropriate and that we were getting the feedback we wanted for each question. We also double checked for clarity issues by administering our pretest to 5 patients in Ward 6 at the Mahavachiralongkorn Thanyaburi Cancer Center. Nurses were asked to indicate on the actual survey if the patient experienced any confusion with any of the questions. This allowed us to ensure the ease of use of the survey to be piloted.

3.2.3 Creating and Piloting a Final Patient Quality of Life Survey

By pre-testing the survey, we tried to work out in advance any problems concerning clarity and wording. Several questions were reworded and directions were adjusted to be as clear and concise as possible. We then moved to designing our pilot and final survey. This survey used a similar format to the survey we pre-tested. In addition to the information included in the pre-test, it included a section for the patient to prioritize the major QOL categories (see Appendix F6 and F7).

We administered this survey to 10 patients at the Mahavachiralongkorn Thanyaburi Cancer Center. At the time, there were about 8 patients in the hospice and 8 in homecare. We only surveyed about half of the hospice patients knowing that we would need to use them again as a survey population for our final survey. We then proceeded to survey 5 more patients at Ward 6 in the hospital. Although the patients we surveyed in Ward 6 were not technically terminally ill, we felt they still provided valuable insight given that many of the patients in the hospice also do not think that they are terminal.

In addition to administering the pilot at the Cancer Center, we also piloted it at a Cancer Center in Lopburi. This step had two advantages. First, it allowed us to obtain as much feedback as possible and second, it tested the instrument's validity in another terminal care setting. In order to make useful improvements for our final survey, we needed to get as much feedback as possible. At Lopburi, the survey was administered with the help of a doctor from the Cancer Center and other staff from the Lopburi hospital. This iteration of our survey allowed us to analyze more feedback and also to see if any problems arose in an alternate setting.

With the feedback and findings from our pre-test and pilot, we were able to finalize question phrasing. The format was modified to facilitate easy scoring and analysis. Basic but clear directions were included on how to administer the survey. Finally, we actually used our official survey on 6 patients in the Mahavachiralongkorn Thanyaburi Cancer Center Hospice. This information was compiled and later scored in order to create a sample of what statistics might look like after compilation. Our next challenge was to develop our scoring system.

3.2.4 Creating a System for Analysis

We then focused on our scoring methods. Our research taught us that although QOL can be broken into many categories, those categories do not all have equal influences. Our goal was to create a scoring system that was reflective of these priorities. With the comparison of three possible systems, we were able to choose a scoring system that we feel produced valid scores.

Our method for creating a possible scoring system took several steps. First, we assigned values to patient Never-Sometimes-Always responses with a functional coding system. A functional coding system can be used to make data computer-readable (Singleton & Straits, 2005). Then, we comparatively analyzed several possible systems to score these values. The first system involved analyzing QOL scores with respect to each individual's prioritization of influences. The next scoring system used generalized weights for each category. The last system involved assigning all the categories an equal weight. Formats for three possible scoring systems can be found in Appendix F8-10.

The methods for developing our first and third possible scoring systems were easier to design but the second required that we suggest our own weights. To do this, we needed to survey patients about their priorities. First, we created a simple survey that asked patients to rank our major QOL influences 1-5. This survey was administered to 27 patients at the Mahavachiralongkorn Thanyaburi Cancer Center. Patient responses were statistically analyzed in the same manner that we used with the staff surveys. We also used information gathered from our patient survey pilot and administration. In the last section of this survey, patients indicated how important each category was to their QOL. This survey was administered to 6 patients at the Mahavachiralongkorn Thanyaburi Cancer Center and piloted with 15 patients at the Cancer Center in Lopburi. These patient responses were also compiled and analyzed. From critical analysis these two patient priority data sets and our understanding of Thai culture, we created weights for our second scoring system.

Finally, we compared the scores obtained from our three possible weighting systems. Patient responses were scored using all three systems. These scores were compiled into a chart that clearly showed the variation in scores between each system (see Appendix F13). We computed mean, mode, median and standard deviations to help with analysis. We then looked for trends to identify which of these systems produced the most valid data in order for us to suggest its use with our final survey format.

3.3 Examine Hospice and Homecare Services and Their Associated Costs

Our third research objective was to examine hospice and homecare services and their associated costs. This objective helped us to enhance the capabilities of the Cancer Center to analyze the cost of their services. This research was aimed at determining their level of preparation for future cost benefit analysis. A complete in-depth cost-benefit analysis was beyond the scope of our project, but we still identified information that would be useful in the Mahavachiralongkorn Thanyaburi Cancer Center's greater goal to help them at a later time. To complete our objective we first examined the offered hospice and homecare services and then explored the record system utilized to document service costs.

Our first step was to examine the services offered by the hospice and homecare programs. The purpose of first identifying the services was to become knowledgeable on all the areas of potential cost. This then proved useful when exploring the documentation of service costs because it enabled us to critically look at which services were being assigned costs.

In identifying the services offered by the hospice and homecare programs we utilized a combination of interviews and observation to obtain results. We accompanied the homecare nurse on several home visits. While on those trips we made note of many different aspects of services. Some of these aspects were commuter time, counseling sessions, and physical care. For hospice services we interviewed the head nurse and were able to determine services specific to hospice. We explored such aspects as the amount of time spent on nurse care, frequency of meals, and family visits. In addition to the services offered by the nurses, we also looked at the services of the facility, e.g. air conditioned rooms or a TV.

Once the knowledge of basic offered services had been established, we were able to critically examine the cost record system. A combination of informal interviews and archival research were the utilized methods for obtaining data. We spoke to the financial officer and obtained the billable information for the thirty most recent hospice and homecare patients. These records allowed us to see which hospice and homecare services were being documented and the values of associated costs. We compiled this information in Microsoft Excel and computed average patient costs and standard deviations (see Appendix E2). This is the type of information needed to begin cost analysis. The records also enabled us to identify other categories of recorded information that would be pertinent to future cost-benefit analysis. Along with the physical records, we examined the system itself. We explored at how the obtained data was stored and what efforts were being taken for central compilation. This type of compilation would be necessary for organizing studies on program effectiveness.

3.4 Create a Final Deliverable

The goal of our methodology was to produce to the Mahavachiralongkorn Thanyaburi Cancer Center a means to assess and document costs and benefits of hospice and homecare services with the intention of promoting alternative terminal cancer care in Thailand. In the previous sections we discussed our methods for documentation and measuring the QOL benefits of their services. Our final deliverable given to the director of the Cancer Center was a comprehensive packet detailing the costs and benefits of hospice and homecare services.

This packet included everything needed for a director of a medical facility to easily understand all the components of hospice and homecare. The sections in the packet covered the ideas behind palliative care programs, the importance of documenting patient demographics, how to measure QOL, and the finances of specific services. Also included are all the measurement instruments and analysis tools discussed in the methodology chapter. The final QOL survey and the patient demographics sheet are both accompanied by explanations and instructions for administration and analysis. This compilation of information allows for a quick and easy understanding of all the aspects important to hospice and homecare. It was our intention to have this packet used to spread knowledge while at the same time promoting the use of palliative care programs.

3.5 Overcome Challenges to Validity

Several problems with the validity of the data we collected challenged us in our project. First, many of the people we wanted to gather information from were in a very sensitive state of mind. We needed to plan our surveys well so that we were not asking the same people an overwhelming amount of questions. Our first step was to approach the staff about the most sensitive way to gather these data. We realized that many patients and families may not have had the time, emotional strength or desire to answer questions. One step we took to understand this problem was visiting a US hospice in Massachusetts to discuss possible ways to gather this type of information. However, we also realized that Thai views on death are drastically different than American views and the information we gathered may not have been applicable.

Next, we learned that an important point to recognize when conducting surveys was patient and interviewer bias. Often during interviews and focus groups, the interviewer may exhibit bias or lead the person being interviewed toward a specific answer, therefore compromising the validity of the data. As interviewers it was necessary to be as objective as possible. Another possible problem for interviews was the language barrier. Because we are not fluent in Thai and the Mahavachiralongkorn Thanyaburi Cancer Center staff are not entirely fluent in English, miscommunications were frequent. It was important to be aware of this and reconfirm our interpretations of what we were being told.

Finally, it is contrary to Thai culture to point out things that are bad or in need of improvement. Saying these negative comments is viewed as unhelpful and Thais feel strongly about the idea of “If you don’t have anything nice to say, don’t say anything at all.” Therefore, surveys and interviews might have presented conditions as being better than the Thais actually feel they are because of their natural tendency to save face. This compromises validity of results because it is sometimes difficult to decipher true answers.

On the other hand, in terms of population samples, we feel that our data had potential to be very accurate. In many cases, we could consider almost all patients and nurses of the homecare and hospice systems due to their small population sizes. Based on these numbers, our group hopes that any surveying or archival research done on a sample population was accurately representative of the whole.

3.6 Methodology Summary

With the knowledge gained by our research objectives, we were able to achieve our goal of providing Mahavachiralongkorn Thanyaburi Cancer Center with the means to promote hospice care in Thailand. By knowing about the people being treated, what they are being treated for, and what services they receive, we could fully understand the needs of those involved. By combining our preliminary research into quality hospice care, Thai lifestyle and the impact of culture on end of life decisions with the information gathered through our research objectives, we were able to create a system to evaluate QOL in Thailand. We were also able to develop protocols for documenting demographic and cost information relevant to the future use of cost benefit analysis. In completing our project, we not only provided the hospital with important information about current conditions of hospice and homecare patients, but also the means to conduct future analysis and service promotion.

4.0 Findings and Discussion

In completing our objectives and analyzing our data, we made many findings about palliative care in Thailand. Some of these were directly applicable to our objectives while others aided us by broadening our understanding of our project. All of these findings were useful in our project goal of creating a comprehensive hospice and homecare packet for assessing terminal care. Through our research, three made major findings emerged. First that the palliative care programs at the Mahavachiralongkorn Thanyaburi Cancer Center are designed to reflect quality Western care practices. Second, their current information systems are not conducive to demonstrating the costs and benefits of palliative care. Third, adaptations to assessment tools are necessary in a Thai setting. The following sections explore each finding in depth and present our supportive evidence and sub-findings from which we made our major findings.

4.1 Finding #1: Service Design Reflects Quality Western Care Practices

The palliative care programs at the Mahavachiralongkorn Thanyaburi Cancer Center are designed to reflect quality Western care practices. Through observation and interviews we identified four specific services offered by the Cancer Center that are aimed at providing good palliative care (see section 2.2.3):

1. Service time allocation,
2. Individualized care,
3. Building trust, and
4. Psycho-supportive therapy.

Though not yet assessed for their actual quality of life (QOL) benefits, each one of these services implies an understanding of the necessary attributes of quality care as modeled in Western care practices. This section discusses these services, their designs, and their implications for the goals of the Cancer Center's palliative care programs.

4.1.1 Service Time Allocation

Our first sub-finding suggests that hospice and homecare nurses allocate their time according to a structure that they think will improve patient QOL. In all of the cases we visited, we noted that the main focus of the visit was to check the physical wellbeing of the patient. Physical wellbeing was not always addressed immediately, depending on the appropriateness of the situation, but it was clearly prioritized over other considerations. An example of this is that the nurses take care to administer medicines before spiritually counseling a patient.

After the quality of the patients physical well being had been thoroughly addressed, we observed that the homecare nurses were free to focus on other services such as counseling and social work. For a specific breakdown of the services we observed being offered during visits see Table 6.

Table 6 Summary of Homecare Services

Observed on February 1, 2006
See Appendix C for more detail.

	Case 1	Case 2	Case 3	Case 4	Case 5
MEDICAL					
Basic physical exam	X	X	X	X	X
Check medical equipment		X		X	
Check medication supply	X			X	
Make care suggestions		X	X		
Provided supplies/medicine	X				X
Wound care					X
COUNSELING					
Discussion of fears	X	X			X
Provide company	X	X	X	X	X
Psycho therapy	X	X	X		
SOCIAL WORK					
Discussed finance	X	X			

We observed that the priority of services offered by the homecare team to be in line with the priorities we identified from our staff survey. Therefore, we concluded that the homecare team is structuring their time in a manner that they believe is the most conducive to improving patients' QOL. This design implies that the Mahavachiralongkorn Thanyaburi Cancer Center intentionally organizes their time allocation to prioritize improving QOL.

4.1.2 Individualized Care

Our second finding was that the Cancer Center's palliative care programs are designed to facilitate the development of individualized care. As stated in our background chapter, the personalization of care is one of the most important features of good palliative care. This feature is addressed by the Mahavachiralongkorn Thanyaburi Cancer Center because their homecare and hospice nurses choose each patient's care program individually. Part of their care programs is to also become knowledgeable about each patient's personality, family, likes and dislikes. For example, a homecare nurse will take note of a specific patient's fear, and provide counseling or support as necessary (see Appendix C for more examples). Another example of individualization is when hospice nurses provide extra reading materials or writing notebooks to patients they know to have a personal interest in reading or writing. The intent of these actions is to personalize care according to individual patient needs, and in turn positively affect the QOL of patients.

4.1.3 Building Trust

One of the ways in which personalized care can positively affect the QOL of patients is through building trust. Trust is an important influence on the QOL of a patient. In Western care practices, the close relationships between patient and caregiver formed by individualization of care facilitate this trust building. The organization of the Mahavachiralongkorn Thanyaburi Cancer Center's palliative care programs, with respect to the building trust, reflects Western best care practices

The Mahavachiralongkorn Thanyaburi Cancer Center has organized its programs in such a way that they reflect the methods used to build trust in a Western setting. For example, the patients in the homecare program are visited once a week, and the same individual caters to all their medical, psychological and spiritual needs. Similarly, with only five hospice nurses, the hospice program is structured to increase patient and caregiver familiarity. One of the responsibilities of the hospice nurses is to sit and talk with patients even when there is no medical need for their presence. The intimate atmosphere allows for close knit personal bonds and trusting relationships to develop.

4.1.4 Psycho-Supportive Care

The last service we identified that supports our major finding was that the Mahavachiralongkorn Thanyaburi Cancer Center utilizes psycho-support therapy. The goal of psycho-support therapy is to help maintain the patient's positive thinking. Positive thinking is an extremely important influence on QOL because it allows the patient to better enjoy their final days of life and avoid feelings of despair. Employing this type of therapy is a sign of the Cancer Center's efforts to reflect quality Western practices.

In the Cancer Center's hospice and homecare programs, we observed that psycho-support was often used in cases where the patient, in accordance with the family's wishes, was unaware of the degree of their illness. Nurses performed services that were not medically useful but helped maintain the patient's positive attitude. For example, psycho-support therapy was given in some cases by taking the temperature and the blood pressure for the terminal patient, even though this information was of no medical importance and was not even recorded. The nurses give the impression that normal medical services are still useful, even though they know their patient is dying. This program structure is geared towards helping the patient remain positive, and thus improving their QOL

.

4.1.5 Section Summary

The organization of the specific hospice and homecare services illustrates the Mahavachiralongkorn Thanyaburi Cancer Center's intent to improve QOL through their programs. The existing programs reflect attributes of quality Western practices that have been proven to improve QOL. However, even though all of the services reflect a design that is aimed at providing quality palliative care, it is important to note that effectiveness cannot be proved until assessments are done.

4.2 Finding #2: Information Systems Are Not Designed for Cost Analysis

Cost-benefit analysis is a convincing tool when proving the value of services and promoting programs. While completing our first objective, we made two sub-findings from which we drew this bigger finding. The first sub-finding was that the patient demographic information necessary for defining, completing and interpreting cost-benefit analysis is systematically recorded but not centrally organized. The second parallels the first in that service costs are also systematically recorded but not compiled for analysis. The following section will examine both findings in detail and their relationship to the bigger finding.

4.2.1 Records System for Patient Demographics

We found through our research that demographic information about patients at the Mahavachiralongkorn Thanyaburi Cancer Center is systematically recorded, but it is not compiled in a manner that allows for easy analysis. Patient demographics are vital to defining, completing and interpreting cost-benefit analysis. Information about the patient base give context to the study boundaries, numerical QOL scores and analysis results. These demographics are also a valuable management tool in decision making. If a program is cost effective for one type of cancer patient but a hospital never treats that specific illness, the benefits are irrelevant.

In our first objective we had identified important patient demographics that we felt needed to be available if cost-benefit analysis were to be carried out. From our observations of the records system and physical patient records, we observed that the hospital was taking down all of the important information, but that it was not being centrally organized. See Appendix D1 for a list of information recorded in patient records. Records were spread throughout various information sheets and departments with out any method for compilation. An example of this is that patient insurance information and payment types are recorded for homecare, but not for the general admitted patient. Another example is the lack of standardization of the homecare records. Without recording these data in an organized manner, one does not have the basic information needed to start any type of analysis.

We also recognized that the current patient base at the Mahavachiralongkorn Thanyaburi Cancer Center is too small for immediate statistical analysis. With only eight patients currently in homecare and six in the hospice ward, trends cannot be seen and conclusions cannot be drawn from the patient demographics even if they were properly compiled. Any trends that could be identified might be coincidental and are unrepresentative of a larger population. With a records system in place, it may take a few years for enough data to be compiled from new patients to produce valid statistical data. This also serves as supportive evidence that the Cancer Center's system is not currently conducive to cost-benefit analysis.

4.2.2 Records System for Service Costs

Similar to our findings concerning patient demographics, we found that the Mahavachiralongkorn Thanyaburi Cancer Center currently does not have the means for statistical analysis of service costs. The evidence supporting this finding came from our meeting with the financial department and our own observation. We found that they record but do not centrally compile cost for homecare and hospice services, and that they have no means for recording the non-monetary benefits of their services. The following subsections discuss each of these facts in support of our finding.

4.2.2.1 Records System for the Financial Department

Also similar to the manner in which patient demographics are handled at the Mahavachiralongkorn Thanyaburi Cancer Center, cost data are systematically recorded but not centrally compiled for use in statistical analysis. Through our data obtained from the accounting department we know that specific categories of cost are recorded. Examples of these billable services range from room costs, radiology treatment, and prescription medication (see Appendix E1 for full list). These types of services are recorded for each patient, but for the sole purpose of billing them after they have been discharged from the center. None of this information is compiled for analysis, but the capability exists. The records document enough information to compute values such as average cost of service per patient, or average amount paid for medication. These are the types of values necessary for the preparation of cost-benefit analysis.

4.2.2.2 Measuring Service Benefits

While examining the accounting records from the Mahavachiralongkorn Thanyaburi Cancer Center, we also found that with the exception of the financial costs of services, no other service benefits are documented. These service benefits are primarily organized in non-monetary categories. The following section examines how the lack of measurement instruments for QOL benefits undermines the ability to analyze costs and benefits.

In particular, we found that the Mahavachiralongkorn Thanyaburi Cancer Center does not have an evaluative department or instruments to record QOL benefits. Although it is hard to allocate specific monetary costs to some palliative care services, it is essential to recognize their non-monetary value. These services can be measured in terms of the positive effects they have on a patient's life rather than the monetary costs to a hospital or family. We found that the Cancer Center's only source of evaluation was an un-adapted American QOL survey translated into Thai. This type of tool cannot properly detect the Thai-specific benefits. The Mahavachiralongkorn Thanyaburi Cancer Center has homecare and palliative care programs that are designed to provide good quality of life for Thai terminally ill patients. In order to prove the effectiveness of the programs, these benefits need to be measured by a QOL survey or other evaluative tool specific to Thai terminal cancer treatment.

4.3 Finding #3: Tool Adaptations are Necessary in a Thai Setting

Our last major finding was that adaptations to assessment tools are necessary in a Thai setting. Our research exposed us to the Western ideology for breaking down QOL categories, and also many Western measurement tools. When applying these to a Thai terminally ill cancer patient, a few key differences must be accounted for. Our supportive evidence comes in the form of two findings. First, QOL categories are best broken into physical, mental, spiritual, social and economic. Second, we found that there are many variables in surveying. In the following sections each piece of evidence will be discussed in depth and related to our major finding.

4.3.1 QOL Categories

We found that in the Thai setting, Western QOL influences are best reorganized into five major categories. These categories are:

1. Physical,
2. Mental,
3. Spiritual,
4. Social, and
5. Economic.

The reason for redefining the categories is supported by our research, focus groups, and the analysis of data gained through our preliminary medical staff survey. This section will further explore and discuss this necessary adaptation.

Through administering our preliminary staff survey, we realized that Western QOL categories were not entirely applicable in a Thai setting (see section 2.4.1). We learned that some of the Western categories overlapped each other causing confusion when distinguishing their influences on QOL. There are many ways in which to divide QOL influences. Our survey used a list of eight categories and asked the medical staff at the Mahavachiralongkorn Thanyaburi Cancer Center to prioritize them based on their importance to a Thai terminally ill cancer patient. The results are compiled in Table 7.

Table 7 Patient Priority Results

Category	**Overall Ranking**	**Mean**	**Times ranked #1**
Physical	1	2.8	10
Psychological	2	3.1	6
Spiritual	3	3.7	5
Social	4	4.0	4
Self- Acceptance	5	4.1	2
Ability to do daily activities	6	5.2	1
Environment	7	6.5	0
Economics	8	6.7	0
Other	9	8.3	0

The four categories of psychological, spiritual, social, and self acceptance were ranked very close together, suggesting that there may have been overlap in some of the ideas presented. In these cases, the mean or the number of times the category was ranked most important were very similar. Psychological, spiritual, and social were ranked first in importance 6, 5, and 4 times respectively. Additionally, the averages between spiritual, social, and self acceptance were very close in values of 3.7, 4.0, and 4.1 respectively.

When analyzing our results for response trends, we found that our categories were not culturally adapted. The overlap we observed in staff responses suggested that some confusion existed in the way we defined our categories. In order to properly measure QOL for the use in benefit analysis the tools must be well adapted. These facts indicated that we needed a further evaluation of each survey category. Thus, we used the information gained from a focus group to reanalyze each of the four categories.

In analyzing them, we identified several instances where overlap was indeed occurring. One example of overlap was found through our focus group when a nurse asked why “letting go and accepting your illness” both fell under the psychological category instead of spiritual in the Thai context. In talking to more people we determined that for Thais these aspects are really considered spiritual influences. Another example was that through our discussions with the head dentist we also realized that hope can be categorized as a mental influence and not spiritual in the Thai setting.

Another way to adapt these categories the Thai setting, is to remove confusion and overlap by completely merging some Western groups of influences together. In our research, focus groups and surveying, we noticed that some groups overlapped so much that we could consider them as one bigger category. An example of this are the categories of self acceptance and psychological. In the category of self acceptance we placed comfort with appearance and dignity, both of which change a patient's level of self acceptance, but also highly influence the psychological state. Another example of this is the environmental and physical categories. All of the environmental factors such as, noise level, privacy, and living conditions can all be categorized as the patient's physical influence from surroundings.

By redefining several categories and merging others, we found a way to culturally adapt Western QOL influences to a Thai setting. This was vital to the creation of our QOL survey. With a well adapted survey for measuring QOL, better and more valid results can be obtained. The more valid the results, the more accurate benefit analysis will be in illustrating the worthiness of a program.

4.3.2 Variables in Surveying

Another necessary adaptation of assessment tools to the Thai setting can be found in survey administration. We found that utilizing a well trained administrator eliminates cultural surveying variables. As we began designing, translating, and administering our surveys, our iterations illuminated the following variables:

1. Influence of patient education,
2. Language related complications, and
3. Survey administration techniques.

These variables were important to analyze because they not only affected how we designed our survey but also how we administered, analyzed and scored it. In this section we first discuss the variables that exist in a Thai setting. We also explain their influences on survey results and data validity.

4.3.2.1 Influence of Patient Education

The first of the Thai specific variables we found was how the varying levels of patients' education affected the successful completion of our surveys. In Western countries, people are continuously exposed to different types of surveys, evaluation forms and tests throughout their education and everyday life. Certain survey formats are very commonly used and are easy to administer on this type of "trained" population. However, in Thailand survey administration is not as common. Although some of the patients in the Cancer Center had completed higher levels of education, many had not. At times, our surveys were confusing for these patients.

For the less educated patients it was hard to obtain valid data even from a "simple" survey format such as the one used in our patient priority survey. For those patients, often the format was too confusing. For example, when we asked one uneducated patient to rank our QOL categories according to their importance from 1-5, he did not understand how to rank categories that did not directly affect him at the time. Also, from observing the administration of several of these surveys, it was clear that some miscommunication was occurring from the excessive length of time it took to explain our "simple" instructions. In the US, a survey such as our Patient Priorities Survey (see Appendix F2 and F3) might take 1-2 minutes to administer, but in a ward at the Mahavachiralongkorn Thanyaburi Cancer Center we observed that it took some patients over 5 minutes for the survey to be explained, re-explained and administered.

At first, we thought some of these problems could be treated as statistical outliers, but as more unexpected results came back, we realized something was wrong with the data we were receiving. For example, about 25% of patients surveyed in the wards answered that their financial status was more important to them than their level of pain. This was the exact opposite of what we expected based on our staff surveys, interviews and understanding of Thai culture. Although these results were possible, they were highly improbable. Some patients might have ranked our QOL categories according to how concerned they currently were about these categories, not how important they feel each is to their QOL.

Finally, we found that the level of education also needed to be considered in the word choice of our survey. Again, categories such as “physical” and “psychological” were very clear for many of the younger, more educated patients. However, some of the older patients from the rural areas asked for clarification on some of the words. It was necessary to change how certain questions were phrased to allow for all patients to clearly understand what we were asking without changing the meaning of our survey questions. For example, psychological was changed to mental because the vocabulary was too formal for some patients with lower education levels to clearly understand.

4.3.2.2 Language Related Complications

The next variable we identified was that there are several problems one encounters while trying to overcome the English-Thai language barrier. Unlike English, Thai is a very contextual language. A question such “Krapaw yuu thii nay” could be translated into “Where is the purse,” or “Where is the conductor,” with any combination of verb tenses. Because they do not use verb tenses and many words (even those with the same spelling and tones) have multiple connotations, it may be very difficult to understand a sentence in Thai out of context. Therefore, it is possible that our directions about the importance of our categories to a patient’s quality of life might be misinterpreted. For example, the verb tense might make it unclear if we are asking about factors that affect a patient now, in the past or in the future. Therefore, it was necessary to change our survey format for the Patient Priorities Survey to eliminate this problem as best we could.

Because of the sensitivity of subjects being evaluated, it is essential that each patient understands exactly what is being asked for in a question. Basic nuances in each language may translate similarly but not have the same connotation. For example, it is very different for a patient to be hopeful about their recovery than to be wishful. Although they translate similarly, being hopeful implies that there might be a chance of recovery and wishful implies that there probably is not a significant chance.

The last factor we encountered while translating documents into the Thai language was that English can sometimes be clearer than Thai. For example, some staff members did not understand the meaning behind some of our questions in our Thai survey we used for pre-testing, but when presented with the English version, they understood our intent better. For example, the English phrase “level of energy” when translated into Thai can have multiple connotations and meanings. If the English is used to accompany the question, the administrator can better understand the context and intent of the question. Many staff members can read English because it is the language that their medical records are kept in. What this means is that even though a Thai person will be administering our survey, the original English format is still necessary for clarification.

4.3.2.3 Variables in Survey Administration

Finally, we found that the administration of our surveys greatly affected the validity of our data. Administration factors such as level of knowledge, continuity of methods, and understanding of language nuances might completely alter how survey directions or questions are interpreted. Because our survey needs to function with either self-administration or external administration, these factors needed to be considered in the design, instructions, piloting and analysis of our survey. Although several of these factors are universal to surveying in any setting, in Thailand they are compounded by the complexity of the language.

We found it to be very important that surveys were administered in the same way to each patient. Taking this step ensures continuity and consistency within the surveying process and helps protect the validity of the data. If a question is understood or interpreted differently from one patient to another, the results will not be comparable. For example, when conducting our patient QOL priority survey, different trends emerged from different wards. Each of these samples had a different administrator that might have explained the survey differently. It is probable that this difference in survey administration affected the results of our survey.

We found that in order to accurately assess QOL, it is important to have honest, uninfluenced patient responses. We observed several types of patient bias in the surveying process. First, bias was created by the Thai practice of saving face. Some patients were reluctant to divulge their true feelings about their QOL. In one case, a nurse reported several responses that were contradictory to her personal understanding of her patient’s situation. Next, patient bias was created by the presence of family members. In several cases, family members remained close by while the survey was being administered. With a whole section devoted to relationships with loved ones in our

Patient QOL Survey, uninfluenced results could not always be obtained because of their presence. Similarly, bias also existed in the section of our survey that referred to the patient's level trust in their caregivers. It is unlikely that patients will be completely truthful while responding to these questions if their personal caregiver is administering their survey. Through our research and the observation of our survey being administered, we feel we have gained valuable knowledge about how to culturally adapt surveying techniques to obtain valid statistical data in a Thai setting.

4.4 Findings Summary

The three major findings encompass all the areas we identified through our research that we felt pertained to the Mahavachiralongkorn Thanyaburi Cancer Center's ultimate goal of promoting hospice and homecare services. We found that they provide programs that reflect best care practices and also have information systems that can be adapted to document demographic and cost information. We made findings that helped us develop and properly adapt measurement tools for valid data collection. In our next chapter we will discuss the next steps needed to be taken by the Mahavachiralongkorn Thanyaburi Cancer Center to utilize our tools and address their opportunities for hospice and homecare promotion.

5.0 Recommendations and Summary

Based on our background research and the findings we identified through our surveying, observation and interviews, we developed several recommendations for the Mahavachiralongkorn Thanyaburi Cancer Center. These recommendations will help them achieve their goals of becoming a leader in their field and promoting hospice and homecare services in Thailand. The first set of recommendations will help the Cancer Center assess the costs and benefits of their hospice and homecare programs. The second set of recommendations will the help them promote theses services. The following sections discuss in detail each of these major recommendations and the smaller steps needed to complete them.

5.1 Recommendation #1: Assess the Costs and Benefits of Hospice and Homecare Programs

We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center assess the costs and benefits of their hospice and homecare programs. By completing this recommendation the Cancer Center will be able to measure the effectiveness of their care programs. With a clear presentation of theses data, executive decision makers will have easily interpreted information. Described below are five necessary steps for program assessment.

5.1.1 Step #1: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center continues to collect and centrally organize important data.*

By starting this now, the Cancer Center will be able to establish an extensive database of information from which valid conclusions can be drawn. This database should include patient demographics, costs of services and measured quality of life (QOL). The compilation of this information will both facilitate future analysis studies and give context to results.

With these data, the Mahavachiralongkorn Thanyaburi Cancer Center will be able to speak more clearly about services they offer, the people they treat and their patients' QOL. They may for example be able to show how different services benefit different types of patients. This could be strongly influential when trying to convince other hospitals to adopt similar service programs. Finally, the compilation of this information may be helpful in illuminating other trends in patient demographics, services, and costs that the hospital is unaware of.

To collect and organize this information, we strongly recommend that the Cancer Center uses the recommended sheets found in Appendix D2-5. We have already started compilation of these data using these sheets, but the population sizes we have are very small. Sample compilations of patient demographics we collected can be found in Appendix D6. A sample of patient QOL scores can be found in Appendix F13. A summary of costs of the 30 most recent hospice and homecare patients can be found in Appendix E2. It is necessary to continue the compilation of this data in order for valid conclusions to be drawn during future analysis. The first step of this compilation is to make sure that these sheets are filled out for all patients that are treated by their palliative care programs. Demographic information should be input into the Microsoft Excel programs we have designed (see attached CD). This database could be used to reveal data such as demographic trends or averages costs.

5.1.2 Step #2: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center conducts our Patient QOL Survey with the help of a trained administrator.*

To validly measure patient quality of life, the administration of our survey should be overseen by a knowledgeable, informed and involved staff member. This step is key in minimizing the discrepancies caused by the surveying variables we identified (see section 4.3.2). The better trained the administrator, the more valid the data obtained will be.

By taking the appropriate amount of time to familiarize themselves with the survey content, the administrator should be well prepared to address problems caused by varying levels of education, surveying techniques and language nuances. Before surveying patients, it is crucial that an administrator be completely aware of the intricacies of our survey and the meaning of each question. In our final deliverable packet, we included a section that describes in more detail the intent of each question (see Appendix H). An administrator needs to be sensitive to the level of education of each patient so that they can give appropriate explanations. They must pay careful attention to how they explain questions in order to prevent patient bias or discontinuity in results. Also, an administrator needs to be aware of connotations in the medical world to make sure he/she is not unknowingly influencing the patient. Also, we recommend that the administrator not be the patient's personal caregiver in order to eliminate bias. Finally, it is important to administer the survey without the presence of the family, who can affect the truthfulness of a patient's responses.

5.1.3 Step #3: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center continues to research survey phrasing and language nuances.*

Because our Patient QOL Survey could be an extremely valuable tool in assessing the benefits of palliative care programs in Thailand, it is important keep striving to perfect it. Continuous refinement of the measurement instrument is necessary to ensure data validity. This step will also further aid the survey administrator by improving the phrasing of questions, thus reducing miscommunications and interpretational inconsistencies. Best phrased questions may yield more valid, comparable results.

With the help of a researcher who is fluent in both English and Thai, it would be easier to explore how language nuances and question phrasing affect patient responses. In our short time working at the hospital, we completed several iterations testing our survey phrasing and made wording changes based on the feedback from staff, our pretest and our pilot test. However, because we cannot speak or read Thai, we were not able to fully understand these language nuances. For example, we observed difficulties in understanding and translating phrases such as "level of energy" and "loved ones." Further research and surveying could be done to see which specific phrases change the way a patient scores each aspect of their QOL; questions aimed at the same intent could be phrased slightly differently and the responses of the patient compared for analysis. For example, a topic such as the emotional state of the patient could be addressed by asking *Do you experience feelings of sadness, dejection or anxiety?* or by asking *Do you experience feelings of happiness and joy?*. Although these both are aimed at the same idea, the presentation of this question might affect a patient's response. Without proper phrasing, accuracy of the data collected cannot be guaranteed; imprecise questions leave room for misinterpretation and data error.

Two possible contacts for doing such research are Kitikorn Meesapya of the Thai Ministry of Public Health and Sucheera Phattharayuttawat, PhD. of the Mahidol University. The WHO designs QOL surveys that are intended for universal use. Kitikorn

Meesapya was their principle investigator for the development of the Thai WHO QOL Survey. By contacting him it may be possible to gain further insight into how they developed their Thai specific survey. Another possibility would be to contact Sucheera Phattharayuttawat, PhD., who helped develop a Thai specific patient QOL survey using pictures. Both of these would be good options because they have studied important cultural differences in designing a Thai specific survey. For more information about these two possible contacts, see Appendix G1.

Even with thorough testing of these language factors, it would still be very difficult to create a survey that could be reliably self-administered by patients. This again supports the need for an informed survey administrator (see section 5.1.2). However, any further improvements on phrasing that can be made to our Patient QOL Survey would make the job of the administrator easier by eliminating possible sources of confusion.

5.1.4 Step #4: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center continues to research scoring systems.*

Although we have developed a good scoring system for the Patient QOL Survey we designed, we highly recommend that the Cancer Center continues to research other ways to score patient responses. Our recommended scoring system (see Appendix F8) determines patient QOL scores based on how they prioritize the five QOL categories. We chose this scoring system after comparing it with two other alternatives (see Appendix F9 and F10). As noted in our findings, some patients had difficulties with certain surveying techniques; this type of analysis leaves some room for misinterpretation of the prioritization questions (see Appendix F6; questions 19-23). A scoring system with accurate generalized weights (such as in Appendix F9) would eliminate the need for this last section of questions. This would also eliminate both the potential problems caused by these questions and reduce the time and effort needed for a patient to complete the survey. Also, this type of generalized weighting system would simplify the scoring process.

To establish accurate weights for a scoring system, more research should be conducted about Thai prioritization of QOL categories. In our research we tried to establish this system with our patient priority survey. However, because of the small size of our sample population and unexpected problems with survey format, we were unable to draw definite results. Further surveying would need to be completed identify trends in patient priorities. Furthermore, because our Patient QOL Survey is designed for universal use in all palliative care facilities, it will be important to study patient priorities in a variety of palliative care programs. However, it is possible that further research would show that clear trends cannot be established.

It is important to note that other scoring options that we did not explore may also exist. If such a system was identified and adapted for use with our Patient QOL Survey, new results could be compared with results from the other scoring alternatives. These comparisons could be presented in a table similar to that which we used to determine which scoring system was best (see Appendix F13). All possibilities should continue to be researched, analyzed and compared in order to find the best combination of simplicity and accuracy.

Finally, we recommend the use of computer programs to complete survey scoring in a consistent manner. Although many Thais prefer to use paper evaluation sheets over computer input programs, these programs eliminate human error in the mathematical steps. One possible program has been formatted into an excel sheet that we have enclosed in our final deliverable (see attached CD). This program requires only the input of patient responses to determine a patient's QOL score.

5.1.5 Step #5: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center completes cost-benefit analysis.*

This type of analysis will be particularly useful for promoting their services to other cancer care facilities in Thailand. Cost-benefits analysis is one powerful tool for assessing the cost and benefits of medical services. By completing such a study, both costs and benefits of a program could be related to each other in monetary terms. Results from this type of analysis would create a strong argument for the implementation of these programs by clearly showing their financial feasibility and benefits.

In completing cost-benefit analysis there are several important factors and questions we recommend that the Cancer Center considers. These considerations will be helpful to the setup of their cost-benefit analysis study, the interpretation of results and the validation of analysis techniques. By being knowledgeable about these ideas beforehand, the Mahavachiralongkorn Thanyaburi Cancer Center will be better prepared to recognize and address validity concerns during the cost-benefits analysis study.

There are many important considerations that can be used to critique and evaluate cost analysis. We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center studies and defines the key attributes (Table 4, section 2.5.3) of their study. By identifying and bounding these variables, they will be able to clearly define the context of their study and eliminate sources of error. One way to consider these attributes would be to use the questions that are posed by Marcus Hollander in his 2001 study of cost-analysis (see Appendix G2). These questions evaluate economic analysis studies by examining the following:

1. Definition and boundaries of the study,
2. Chosen alternatives,
3. Effectiveness of evidence,
4. Accuracy and credibility of cost and outcome measurements,
5. Consideration of time effects,
6. Use of sensitivity analysis, and
7. Applicability of results to user needs.

These ideas touch upon all of the key attributes we defined. Although they were designed to be used to evaluate an economic study after completion, the Mahavachiralongkorn Thanyaburi Cancer Center will be able to identify problems as they arise by familiarizing themselves with these ideas.

5.2 Recommendation #2: Promote Hospice and Homecare Services

We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center promote their hospice and homecare programs. By completing this recommendation the Cancer Center will have taken the first steps in promoting these services to the Thai medical community and the Ministry of Public Health. Described below are four necessary steps for program promotion.

5.2.1 Step #1: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center begins to initiate discussion of the benefits of hospice and homecare services by distributing our final deliverable packet (see Appendix H) to influential members of the Thai medical community.*

Although many medical professionals are probably aware of the use of these programs in US facilities, they may not be aware of the exact ways they are used in the Mahavachiralongkorn Thanyaburi Cancer Center. Even with future QOL studies and in-depth cost-benefit analysis, if the other Thai hospitals are unaware of the hospice and homecare alternatives to palliative care, the Mahavachiralongkorn Thanyaburi Cancer Center will not be able to effectively promote their services. Our packet includes information about:

- What are hospice and homecare?
- Quality of life
- QOL surveys
- QOL Survey question explanations
- Patient QOL Survey
- QOL survey analysis score sheets
- Patient demographics
- Patient information sheet
- Services and associated costs
- Cost analysis

By distributing these packets, the Mahavachiralongkorn will be preparing others for a more in-depth discussion of the benefits of hospice and homecare programs. This packet clearly explains the hospice and homecare concepts and their benefits to patient QOL. It also includes our Patient QOL Survey to evaluate the effectiveness of various programs to improving patient QOL. This packet is not the only useful tool for the promotion of hospice and homecare, but it can be used to start the process.

5.2.2 Step #2: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center compares services with other cancer facilities.*

The results from these comparisons would illuminate the strengths of each hospital's services and possibly help prove the value of the Mahavachiralongkorn Thanyaburi Cancer Center's palliative care programs. Results from these critical comparisons would also be used to help better establish themselves as the leader in their field. Currently, we do not know where the Mahavachiralongkorn Thanyaburi Cancer

Center ranks amongst the few other cancer hospitals in Thailand. Because they want to be a pioneer, leading the way for other hospices in Thailand to follow, it is essential that they fist clearly demonstrate the strengths of their palliative care programs.

To show the benefits of their programs, the Mahavachiralongkorn Thanyaburi Cancer Center should study the quality of life at the various hospitals. Because only six cancer hospitals exist in Thailand, it would be very feasible to have a comparative study between the various hospitals. One possible tool to utilize would be our Patient QOL Survey. The responses could be analyzed using the scoring sheet we designed. This would allow for clear comparisons to be made because the same measurement tool would be used in every hospital. Scores of patients receiving different services could be compared. High scores would pinpoint best care practices for improving patient QOL. These practices could then be integrated into existing Thai palliative care programs.

5.2.3 Step #3: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center completes cost-effectiveness analysis.*

This type of analysis will be particularly useful for promoting their services to the Thai Ministry of Public Health. Although cost-benefit analysis is good for showing the value of services, cost-effectiveness shows how efficiently services use funds to achieve a desired health effect. By proving the efficiency of their hospice and homecare services to the Thai Ministry of Public Heath, they may be better able to petition for increased funding. Completion of such analysis would also require a professional economist. However, if this was done after the completion of cost-benefit analysis, it would be probable that much of the necessary information would already have been gathered.

5.2.4 Step #4: *We recommend that the Mahavachiralongkorn Thanyaburi Cancer Center continues to improve their services through the individualization of their palliative care programs.*

Because the individualization of programs for each patient improves patient QOL, the individualized their programs become, the better they will be. Service improvements will help build upon their argument for expanding palliative care programs by demonstrating best care practices for others to emulate. They are currently the only hospice and homecare model in Thailand and therefore it is their job to set the standard of care as high as possible. This perseverance will also help them establish themselves as a leader in their field.

We recommend that more options be researched on how to continually improve these programs for each patient. We have already seen many instances where care has been highly individualized in the hospice and homecare programs. The level of nurse attention and personal patient knowledge is consistently high. Still other options for individualizations may exist. For example, programs like laughter therapy and massage therapy are used in many US hospices. At the Lopburi Cancer Hospital they are currently researching aromatherapy, message therapy and relaxation techniques. It might be possible to work in conjunction with another hospital to identify which of these programs work best in the Thai setting. By researching the possible benefits of the addition of such programs, the Mahavachiralongkorn Thanyaburi Cancer Center will be able to produce a higher QOL.

5.3 Recommendations Summary

Cancer is a leading cause of death in Thailand, yet the Mahavachiralongkorn Thanyaburi Cancer Center is the only facility utilizing hospice and homecare programs to address the needs of terminal cancer patients. By following the recommendations discussed above, the Mahavachiralongkorn Thanyaburi Cancer Center will be able to assess and promote these services. The spread of such knowledge would not only help achieve their goal of becoming a leader in their field, but also work towards their ultimate goal of improving cancer care in Thailand.

6 References

Aaronson, L. S., Forbes, S.A., & Woung-Ru, T. (2004). Quality of Life in Hospice Patients with Terminal Illness. *Western Journal of Nursing Research*, 26(1), 113-128.

Addington-Hall, J. and Kalra, L. (2001). Measuring quality of life: Who should measure quality of life? *British Medical Journal*, 322,1417-1420.

Asia Looks to Thailand's AIDS Success Story. (2003). *The Christian Science Monitor*. Retrieved December 3, 2005 from http://www.csmonitor.com/2003/1120/p08s01-woap.html

Battistini, T., Palma, M., Roberts, A. & Vigneau, C. (2003). *Recommendations to Improve Quality of Life at the Pakkred Home* (Report No. 03D005I). Bangkok, THA: Pakkred Home.

Brown, G.C., & Smith, A. F. (2000). *Understand Cost Effectiveness: A Detailed Review*. Retrieved February 16, 2006 from http://bjo.bmjjournals.com/cgi/reprint/84/7/794

Byock, I. B. (December 2001). *Missoula-Vitas Quality of Life Index (MVQOLI)*. Retrieved January 23, 2006 from http://www.dyingwell.com /MVQOLI%20V25.htm

Byock, I. B. (May 1996). The Nature of Suffering and the Nature of Opportunity at the End of life. *Clinics in Geriatric Medicine*, 12(2), 237-252.

Cancer Registry and Cancer Control in Thailand, (2004). *NCCP, Ministry of Public Health*. Retrieved November, 21 from http://home.att.ne.jp/grape/jacr/iacrmeeting/a3.pdf

Chindavijak, K., Ferley, J., Martin, N., Parkin, D.M., Sriamporn, S., Sriplung, H., Sontipong, S., Vatanasapt, W. and et al. (1993). Cancer in Thailand 1988-1991. *IARC Technical report*, (16), 164.

Chirikos, T. N. (January/February, 2002). Cancer Economics: On variations in the cost of treating cancer. *Cancer Control*, 9(1). 59-66.

Clark, D., & Stjernswaerd, J. (2003). *Palliative Medicine- a Global Perspective.* Doyle, Derek, Hanks, Geoffrey, Cherny, Nathan I. & Calman Kenneth (Eds.), *Oxford Textbook of Palliative Medicine.*

Cohen, S.R., Hassan, S.A., Lapoint, B.J., & Mount, B.M. (1996). Quality of life in HIV disease as measured by the McGill Quality of Life Questionnaire. *AIDS*, 10, 1421-7.

Cooley, M. E. (1998). Quality of life in persons with non-small cell lung cancer: A concept analysis. *Cancer Nursing*, 21, 151-161.

Coxhead, I., Rooney, D. F., Stott, P. A., & Wyatt, D. K. (2005). Thailand: Religion. *MSN Encarta*. Retrieved February 24, 2006 from http://encarta.msn.com/encyclopedia_761561385_3/Thailand.html

Culture in End of Life Care. (2005). *Ian Anderson Continuing Education Program in End of Life Care.* Retrieved November 19, 2005 from http://www.cme.utoronto.ca/endoflife/Modules.htm

Ferrans, C.E., & Powers, M. (1985). Quality of Life Index: Development and Psychometric Properties. *Advances in Nursing Science*, 8(1):15-24.

Gage, B., Miller, S. C., Coppola, K., Harvell, J., Laliberte, L., Mor, V., & Teno, J. (March 2000). US Department of Health and Human Services. *Important Questions for Hospice in the Next Century.* Retrieved February 16, 2006 from http://aspe.hhs.gov/daltcp/reports/impques.htm

Global Cancer Rates could Increase by 50% to 15 Million by 2020 (2005). *World Health Organization*. Retrieved November 21, 2005 from http://www.who.int/mediacentre/news/releases/2003/pr27/en/

Hamilton, M. & Reid, H. (1980). *A Hospice Handbook: A New Way to Care or the Dying.* Grand Rapids, MI: William B. Eerdmans Publishing Company.

HelpGuide: Hospice Care. Retrieved November 21, 2005, from http://www.helpguide.org/elder/hospice_care.htm

Hollander, M. J. (April 2001). *Final Report of the Study on the Comparative Cost Analysis of Homecare and Residential Care Services*. Retrieved February 16, 2006 from http://www.homecarestudy.com/reports/full-text/substudy-01-final_report.pdf

Hospice Association of America (2002). *Hospice fact and statistics.* Retrieved on January 23, 2006 from http://www.nahc.org/Consumer/hpcstats.html

HospiceNet: *For patients and families facing life-threatening illness*. Retrieved October 30, 2005, from http://www.hospicenet.org/html/concept.html

Jacobs, P. (April 2001). *Costs of Acute Care and Home Care Services*. Retrieved

February 16, 2006 from http://www.homecarestudy.com/reports/full-text/substudy-09-final_report.pdf

James, J. (1987). *The Many Faces of Death*. Penang, Malaysia: Inward Publishing.

Journal of Advanced Nursing (January, 2001). *Patients' and relatives' experiences and perspectives of 'Good' and 'Not so Good' quality care*: Retrieved November 21, 2005, from http://www.blackwell-synergy.com/links/doi/10.1046/j.1365-2648.2001.01689.x

Knodel, J., & Saengtienchai, C. (February, 2002). AIDS and Older Persons: The View from Thailand. *PSC Research Report* (Report No. 02-497). University of Michigan: Population Studies Center.

Knodel, J., & Saengtienchai, C. (September, 2002). Health Impacts of Co-residence with and Caregiving to Persons with HIV/AIDS on Older Parents in Thailand. *PSC Research Report* (Report No. 02-527). University of Michigan: Population Studies Center.

Lawson, V. A. and Velkoff, V. A. (1998). Caregiving. *International Brief: Gender and Aging*, 98.

MedlinePlus (January, 2006). *Drug Instructions*. Retrieved February 6, 2006, from http://www.nlm.nih.gov/medlineplus/druginfo/medmaster/a682788.html

McGrath, P. (1998). Buddhist spirituality--a compassionate perspective on hospice care. *Mortality, 3(3).*

McMillan, S.C. (1996). *Quality-of-Life Assessment in Palliative Care:* Retrieved January 23, 2006 from http://www.moffitt.usf.edu/pubs/ccj/v3n3/article4.html

McMillan, S.C. (1996). The quality of life of patients with cancer receiving hospice care. *Oncology Nurse Forum*, 23(8): 1221-1228.

MedPac (1999): *Report to the Congress: Selected Medicare Issues*: Retrieved November 21, 2005, from http://www.medpac.gov/publications/congressional_reports/Jun99%20Ch7.pdf

MedPac (2004): *Report to Congress: New Approaches in Medicare:* Retrieved January 23, 2006 from http://www.medpac.gov/publications/congressional_reports/June04_Entire_Report.pdf#search='congress%20report%20medicare%20trends%202004%20Hospice%20care%20in%20Medicare%3A'

Mor, V., Greer, D.S., & Kastenbaum, R. (1989). *The Hospice Experience.* London: The John Hopkins Press.

Moyers, B. (Reporter). (2000). *On Our Own Terms: Moyer on Dying* [Part II of Television series]. *A Different kind of Care.* Princeton, NJ: A Production of Public Affairs Television, Inc.

National Information Center on Health Services Research and Health Care Technology (August 2004). HTA 101: IV. COST ANALYSIS METHODS. Retrieved February 16, 2006 from http://www.nlm.nih.gov/nichsr/hta101/ta10106.html

Paloutzian, R., & Ellison, C. (1982). Loneliness, spiritual well-being, and the quality of life. In Peplau, L. A., & Perlman, D. (Eds.), *Loneliness: A sourcebook of current theory, research and therapy*. New York: Wiley.

Panzer, R. (2005). Hospice Patient Alliance. Retrieved November 10, 2005, from http://www.hospicepatients.org

Project on Death in America (2005). *Open Society Institute*. Retrieved November 19, 2005, from http://www.soros.org/initiatives/pdia/articles_publications/publications/memo/whatis

Ratanakul, P. (July 2004). The Buddhist Concept of Life, Suffering and Death, and Related Bioethical Issues. *Eubios Journal of Asian and International Bioethics*, 14(4), 1-23.

The Robert Wood Johnson Foundation: *Accounting for the Costs of Caring Through the End of Life*. Retrieved January 17, 2006 from http://www.promotingexcellence.org/cost_accounting

Sen, P. (2003). Thailand Offers Tourists 'the Aids Attraction'. Retrieved November 10, 2005 from http://greatreporter.com/mambo/index2.php?option=com_content&do_pdf=1&id

Sherbourne, C. D. & Stewart, A. (1991). The Medical Outcomes Study (MOS) Social Support Survey. *Social Science Medicine*, 32 (6), 705-714.

Sibley, D. (June 22, 2004). *Buddhist Perspective on Death and Dying.* Presented at the workshop for Culture and Faith in Hospices and Palliative Care in the United Kingdom.

Singleton, R.A., & Straits, B.C. (2005). *Approaches to Social Research*. New York: Oxford University Press.

Sokolovsk, J. (2001). *Living Arrangements of Older Persons and Family Support in Less Developed Countries*.

Spitzer, W.O., Dobson, A.J., Hall. J., et al. (1981). Measuring quality of life of cancer patients: A concise QL- Index for use by physicians. *Journal of Chronic Diseases*, 34585-597.

Sriamporn, S., Vatanasapt, P., Vatanasapt, V. (2002). Cancer Control in Thailand. *Japanese Journal of Clinical Oncology*. Retrieved November 10, 2005 from http://jjco.oxfordjournals.org/cgi/content/abstract/32/suppl_1/S82

Sykes, N. (1998). "The Costs and Benefits of Hospice Care". *Catholic Medical Quarterly*. Retrieved November, 19 from http://www.catholicdoctors.org.uk/CMQ/May_1998/hospice_care.htm

Thailand Health Profile 1999-2000. *World Health Organization*. Retrieved November 19, from http://w3.whosea.org/EN/Section313/Section1525_6902.htm

Unknown Author. (2003). *Heaven or Hell: A Glimpse of Wat Prabaht Nam Phu. The Indochina Media Memorial Foundation*. Retrieved November 10, 2005 from http://www.immf.or.th/AIDS_04/Heaven_or_Hell.aspx

US Department of Health & Human Services. (2000). *Health Care Financing Administration, Department of Health and Human Services: Hospice Care*. Retrieved November 11, 2005, from http://www.access.gpo.gov/nara/cfr/waisidx_00/42cfr418_00.html

Westley, S. B. (April, 1998). Asia's Next Challenge: Caring for the Elderly. *Asia-Pacific Population and Policy*, 45, 1-4.

World Health Organization. (February, 1995). WHOQOL-100 Fried Trial. Retrieved January 23, 2006 from http://www.who.int/evidence/assessment-instruments/qol/documents/WHOQOL-100.pdf

7 Appendices

Appendix A: Background information

A1: Comparison of conceptions of the domains of quality care at the end of life

	Singer et al. 1999	Emanuel and Emanuel 1998	Institute of Medicine 1997	American Geriatric Society 1997
Overall			Overall quality of life	Global quality of life
Physical	Receiving adequate pain and symptom management	Physical Symptoms	Physical well-being and functioning	Support of function and autonomy
Emotional		Psychological and cognitive symptoms	Psychological well-being and functioning	Physical and emotional symptoms
Social	Strengthening relationships	Social relationships and support	Psychosocial well-being and functioning	
Spiritual		Spiritual; and existential needs	Spiritual well-being	
Control	Achieving a sense of control: avoiding inappropriate prolonging of dying			Advance care planning aggressive care near death
Satisfaction			Patient perception of care family perception and well-being	Patient and family satisfaction
Family	Relieving burden	Economic demands and care giving needs	Family perception and well-being	Family burden bereavement
Other		Hope and expectations		Provider continuity and skill; survival time

(from http://www.medpac.gov/publications/congressional_reports/Jun99%20Ch7.pdf)

A2: Quality of Life Tools Chart

Quality-of-life Tool for Cancer Populations

Instrument	Palliative Care Tool	Year Published	Dimensions	Self Report	Length	Validity Data	Reliability Data
Quality-of-Life Index (Spitzer et al)	Yes	1981	Activity, living, health, support, outlook on life	No	Interview focusing on five areas	Yes	Yes
Hospice Quality-of-Life Index	Yes	1996	Physical/function, psychological, social/spiritual, financial	Yes	25 numeric rating scale items	Yes	Yes
Linear Analog Self-Assessment	Unclear	1976	Physical, social, psychological effects of disease, personal relationships	Yes	25 visual analog scale items	Limited	No
Functional Living Index -Cancer	For use in clinical trials	1984	Physical well-being, psychological state, family interaction, social ability, somatic sensation	Yes	22 Likert-like items	Yes	No
Quality-of-Life Index (Padilla et al)	For cancer patients	1990	Symptom control, physical well-being, psychological well-being	Yes	14 visual analog scale items	Yes	Yes
Quality-of-Life Index – Cancer Version	For cancer patients	1990	Satisfaction and importance of health/functioning, socioeconomic well-being, psychological/spiritual well-being, family	Yes	70 (35 satisfaction items weighted by 35 important items on a 6-point rating scale)	Yes	Yes
Cancer Rehabilitation Evaluation System-Short Form	For cancer patients	1991	Physical, psychological, medical interaction, medical interaction, marital and sexual problems	Yes	59 Likert-like items	Yes	Yes
Functional Assessment of Cancer Therapy General	For cancer patients	1993	Physical, functional, social, emotional, relationship and doctor	Yes	28 Likert-like items	Yes	Yes
Quality-of-Life Questionnaire-Cancer	For use in clinical trials	1993	Functional (physical, role, socials, cognitive, emotional), financial symptoms	Yes	30 items on a 0-to-100 scale	Yes	Yes

(http://www.moffitt.usf.edu/pubs/ccj/v3n3/article4.html)

A3: Clusters of Palliative Care Expenses

Table 1: Cluster Items and Bridge Values for Clusters of

Item Number Cost	Bridge Value
Cluster #1 – Travel and Communication	**0.48***
29. special transportation (DATS)	0.29
30. chauffeur/driver	0.30
1. air ambulance	0.33
22. automobile parking	0.33
26. taxi fare	0.33
24. travel accommodation	0.34
27. automobile expenses	0.35
25. airplane tickets	0.38
28. travel meals	0.41
65. ambulance	0.44
9. telephone long distance	0.79
83. cell phone / pager	0.95
31. car: special equipment	1.00
Cluster #2 – Financial Losses Expenses	**0.34**
5. loss of job	0.28
6. lost working time for caregiver	0.29
51. time off work for helpers	0.29
2. financial support from others	0.31
37. quick sale assets	0.32
82. insurance	0.37
8. moving costs	0.49
Cluster #3 – Personal Services	**0.41**
14. cooking assistance	0.18
16. shopping assistance	0.18
18. additional residential help	0.18
54. child care	0.20
11. housekeeping assistance	0.23
15. respite care	0.23
23. accounting services	0.26
46. legal services	0.26
94. social worker	0.26
21. counseling costs	0.28
4. funeral costs	0.30
62. physician documentation	0.35
91. dental care	0.35
10. pastoral services	0.38
7. barber/hair stylist	0.47
13. yard maintenance	0.49
93. hearing care	0.58
92. eye care	0.59
34. alternative therapies	0.61
41. medical insurance	0.79
20. medical literature	0.87
12. nurse visits	0.89

Cluster #4 – Supplies / Consumable	**0.27**
57. urine bags	0.11
58. catheters	0.12
3. masks	0.14
38. rubber gloves	0.14
40. tubes	0.14
47. diapers	0.20
59. bowel supplies	0.20
50. dressings	0.21
17. oxygen	0.23
32. lotions	0.30
35. medications	0.43
33. prescription drugs	0.44
63. nutritional supplements	0.46
36. special cosmetics	0.69
Cluster #5 – Supplies / Durable	**0.06**
69. foam wedges	0.00
42. toilet lifts	0.00
87. over-bed table	0.00
19. canes	0.01
61. commode(s)	0.01
88. railings	0.01
89. toilet arms	0.01
72. transfer poles	0.01
60. bed railings	0.01
86. bath seats	0.01
74. furniture blocks	0.01
39. bed pan(s)	0.02
45. bathtub railings	0.02
70. wheelchair cushions	0.02
75. pressure relief devices for limbs	0.02
85. hair wash trays	0.02
76. smoking devices	0.03
66. limb slings	0.03
68. collars	0.03
48. walker	0.03
49. special bed	0.04
84. stair lifts	0.04
64. ramp(s)	0.04
67. splints	0.05
77. show horns	0.05
44. I.V. pumps	0.06
56. spenco pad	0.07
43. intravenous bottle stands	0.08
52. dosette	0.08
81. Sitz baths	0.10
55. side stream (oxygen delivery)	0.11
79. adaptive clothing	0.11
80. special footwear	0.11
73. intercom (monitor)	0.12
53. wheel chair	0.12
90. voice box	0.19
78. reachers	0.23
71. transfer belts	0.30

(from http://www.homecarestudy.com/reports/full-text/substudy-09-final_report.pdf)

A4: Examples of Direct Costs

Understanding Cost Effectiveness

Table 1: Some major examples of direct and direct non-medical costs*

Direct medical costs	***Direct non-medical costs***
Inpatient hospital Care	Care provided by friends and family
Specialized hospital, terminal, or hospital care	Housekeeping
	Modifications to home for patient
Nursing homes	Social services
Institutional or home health care	Retraining
Emergency rooms	Repair to property (i.e., alcoholism, etc)
Physician services	Program monitoring and evaluation
Primary care physicians	
Medical specialists	Law enforcement costs
Other ancillary staff	Data analysis
Psychologists	
Social workers	
Physical and occupational therapies	
Nutritionists	
Volunteers	
Ambulance workers	
Medication use	
Treating side effects	
Preparation of drugs	
Training in new procedures	
Dispensing and administration	
Monitoring	
Overhead allocated to technology	
Fixed cost of utilities	
Space	
Storage	
Support services	
Capital costs (depreciated over time)	
Construction costs fro facilities	
Relocation costs	
Device and equipment costs	
Variable cost of utilities	
Medication costs	
Prescription and non-prescription costs	
Drug costs	
Monitoring costs	
Research and development costs	
Diagnostic test costs	
Treatment costs	
Prevention costs	
Rehabilitation costs	
Training and education costs	

*Adapted from *A practical guide to prevention effectiveness: decision and economic analysis*. Atlanta, GA: Center for Disease Control, 1993: 103.

(from http://bjo.bmjjournals.com/cgi/reprint/84/7/794)

A5: Examples of Indirect Costs

Table 2: Some major examples of indirect costs*

Indirect costs (quantifiable in monetary terms)	*Indirect or intangible costs (not quantifiable in monetary terms)*
Change in productivity due to:	Psychological costs
Change in health status	Apprehension grief, impending death
Change in morbidity	Disfigurement
Change in mortality	Disability
Job absenteeism	Loss of employment
Lost income of family members	Loss of opportunities from future job
Forgone leisure time	Pain
Time lost seeking medical services	Changes in social functioning daily living
Time spent attending patient (e.g. hospital visits)	Value placed on patient's health and wellbeing

*Adapted from *A practical guide to prevention effectiveness: decision and economic analysis*. Atlanta, GA: Center for Disease Control, 1993: 103.

(from http://bjo.bmjjournals.com/cgi/reprint/84/7/794)

A6: Service Counts and Billing Units Chart

Construct Service Unit Grid

“Filling-In” the data on the Service Unit Grid should start with program intervention resources, including days/hours of administrator time, training time, transportation services and other program inputs. Generalizing intervention resources can result in loss of important service units. Grid construction should start with internal identification or accounting of all services for the program under consideration.

The illustrative service grid is broken into parts and starts with Inpatient Hospital (item 1) and goes through Community Services (item 13).

Health Care Service	**Simple Counts**	**Adjusted Counts**	**Billing Units**
1. Inpatient Hospital[1] *Hospitalization is the most clear-cut of medical services. Note that hospitalizations also include a physician component.*	▪ Hospital admission ▪ Hospital days *Medicare 2001 payments for “typical” end-of-life hospitalizations averaged $6,829 for 5.9 days, or $1,154 per day.* *Medicare payments are about half to two-thirds as much as commercial payments.* *With cost-to-charge ratios for hospitals averaging 50%, Medicare* *Payment may proxy institutional cost as well as payer cost. Payments are made for initial hospital care.* *99222 $114.01 (mid-level of intensity) Subsequent hospital care* *99232 $56.24 and Hospital discharge day* *99238 $67.72. Thus a three-day admission would cost, at least $238.*	▪ Hospitalization by diagnosis and/or major service ▪ ICU/CCU/Room day + length of stay *Levinsky et al. provide resource use (% using) for ICU, Catheterization Dialysis, Ventilator, Pulmonary artery monitor -but not cost of each (payments are by DRG)* *Use of ICU and procedures all add to physician cost. Many diagnoses (especially surgical diagnosis) have implied physician services.*	▪ Hospitalization (all days – adjusted for diagnosis = DRG) + length of stay ▪ ICU/CCU/Room day + length of stay ▪ Rehabilitation Unit + length of stay ▪ ICD-9 procedures *Adjustments for DRGs – Diagnosis Related Groups) common to end-of-life care in one study given on the hospital worksheet.* *Note that payment amounts are total, and include the patient-paid portion, the deductible, which is $792 (Per Benefit Period) in 2001.*

Health Care Service	**Simple Counts**	**Adjusted Counts**	**Billing Units**
2. Outpatient "Outpatient" covers many services – some similar to physician office visits, some like hospitalizations.	▪ Visits + services ▪ Pharmacy ▪ Injectibles ▪ Chemo ▪ Home infusion ▪ Imaging For outpatient visits common to the average of those observed in one study, $250 for the facility component and $175 for the physician component total $425. All services received during a visit need to be considered costs.	▪ Visits by type of service received + services Examples: radiation single area (300) = $99.48, radiation 3 or more areas (302) = $412.47.	▪ Visits by ambulatory visit groups AVG / ambulatory patient classification APC + services APCs (Average Per Capita Costs) include a National Payment Rate (local area wage adjusted) and a Coinsurance rate (averaging 20%). For APCs, the 2001 minimum is $0 and maximum is $14,250.
3. Emergency Room Emergency room visits, like outpatient care, cover a variety of services.	▪ Visits The distribution of ER visits may differ for palliative and end-of-life care, but the overall average is for mid-level visits, for which the total Medicare payment is $168.75.	▪ Visits by type of service Including additional procedures lends greater clarity on resource use.	▪ Visits by relative value units -- RBRVs/ RVUs (physician) and/or APC (facility) RVUs: Medicare/Average 99282 M=27.93 A=66 99283 M=62.74 A=138 99284 M=97.94 A=215 APCs: 610 Low Level $67.32 611 Mid Level $106.01 612 High Level $160.27 + additional services, procedures

Health Care Service	**Simple Counts**	**Adjusted Counts**	**Billing Units**
4. Physician2 Physician services are paid by fee schedules by most payers. There is no clear concept of “cost” for physicians, since fees are income. Radiology, anesthesiology and pathology in-hospital are included in the DRG payment. Some primary care physicians are capitated to care for patients within their panel; therefore, they do not bill for component services or visits of those patients.	Visit to physician Routine Office Visit are generally paid by duration of visit Level 1 <15, $21 Level 2 15-29, $37.49 Level 3 30-44, $52.41 Level 4 46-60, $82.64 Level 5 60+, $120.90 The majority of visits (1 hospice study) are level 3. Among Medicare and fee surveys, $50 is common.	Visits to primary care physicians (evaluation and management) Visits to specialists (by specialty) Visits to clinics Telephonic consultations Visits associated with procedures vary substantially in cost.	Visits by CPT-4 or service codes Note that payment amounts are total, and include the patient-paid portion, the deductible, which is $100 (Per Year)for Medicare in 2001 and coinsurance, which is 20%. Primary care physician fees are similar among Medicare and private insurance. Private insurance fees for specialist procedures average double Medicare rates. Medicaid averages65% of Medicare rates.

5. Laboratory Tests Most individual lab tests are not very expensive, \$10-\$30, but often times many tests are ordered.	Number of tests Counting the number of tests can be difficult, as institutional “shorthand” is often used. One unpublished hospice study used \$25 as an average cost/test.	Number of tests by type and location	Tests by CPT-4 (physician) and/or APC (outpatient) Included for inpatient care

Health Care Service	**Simple Counts**	**Adjusted Counts**	**Billing Units**
6. Drugs[3] *Medications may be delivered in hospital (included in most prices), provided to patients on an outpatient basis or provided to patients during treatment (IV).*	▪ Number of prescriptions (separate from Cancer chemotherapy and other services) *For medications provided during treatment, there may also be a provider payment.*	▪ Number of prescriptions by type / medication / dose / time	▪ Drugs by uniform code
7. Therapy and Counseling	▪ Counseling visits	▪ Visits by provider type (social worker, chaplain, volunteer, physician, physical therapist, occupational therapist, dietitian, other therapist) ▪ Caregiver after-hour call ▪ Volunteer hours	▪ Visits and length (hours, minutes) by provider type and CPT-4 (if applicable)

8. Nursing Home[4]	▪ Admission and length of stay *For SNF (skilled nursing facility) care, Medicare average rates for 2001:* *Urban: $295/day* *Rural: $304/day*	▪ Admission and length of stay by diagnosis and facility type (SNF, nursing home, etc.)	Admission and length of stay by diagnosis and facility type (SNF, nursing home, etc.) ▪ Days –adjusted for resource utilization groups (RUGs) or activities of daily living (ADLs) *Adjustments for RUGs given on the SNF worksheet.*

Health Care Service	**Simple Counts**	**Adjusted Counts**	**Billing Units**
9. Home Care[5]	▪ Number of visits *Total average per visit $43.54, which may include many services.*	▪ Visits by provider type (skilled nurse, occupational therapist, respiratory therapist, etc.) ▪ And service *Nurse Practitioner Visits* *E&M visits receive 85% of the physician fee.* *Nurses get paid Prospective Payments System (PPS) rates.*	▪ Visits by provider type ▪ Days for respite and continuous and inpatient care and professional care
10. Hospice[6]	▪ Admission ▪ Number of visits	▪ Number of visits (duration of course of care) by type (home visit, spiritual visit, bereavement visit, volunteer visit, and hospice days)	▪ Visits by provider, treatment and time per visit
11. Medical Equipment	▪ Durable medical equipment (DME) by product class (respiratory, physical therapy, etc.)	▪ DME by product type ▪ Consumables	▪ DME by HCPCS Code ▪ Consumables

12. Paid/Unpaid Caregiving[7]	▪ Days of care	▪ Hours/day, days/week by provider type ▪ For family/friends, days/hours work lost; loss of job; loss of job benefits	▪ Days of paid care, by provider type ▪ For family/friends, days/hours work lost; loss of job; loss of job benefits
13. Community Services	▪ Number of services	▪ Services by type (counseling, day care, financial, legal, meal assistance, pastoral and transportation)	▪ n/a

(from http://www.promotingexcellence.org/cost_accounting/monograph/downloads/als_appendix_b.pdf)

A7: Hourly Pay Rates Chart

Average Hourly and Per Visit Compensation of Selected Hospice Caregivers, October 2002

	Per-Hour Rate Range				Per-Visit Rate Range		
	Average Minimum ($)	**Average ($)**	**Average Maximum ($)**		**Average Minimum ($)**	**Average ($)**	**Average Maximum ($)**
Registered Nurse (RN)	17.47	21.05	24.63		31.39	36.72	42.04
Practical Nurse (LPN)	12.22	14.79	17.36		20.06	23.95	27.84
Physical Therapist	21.29	25.90	30.51		39.44	44.59	49.73
Social Worker (MSW)	15.82	19.11	22.40		38.12	42.84	47.57
Dir. of Volunteer Svcs.	14.01	17.07	20.13		n/a	n/a	n/a

Source: *Hospice Salary & Benefits Report 2002-2003*, Hospital & Healthcare Compensation Service in cooperation with Hospice Association of America, 2002
Notes: The average rate is based on the reported weighted average of workers with the same job title in an agency. Similarly, the minimum and maximum averages are weighted by agency. **Physical Therapist** organizes and conducts medically prescribed therapy programs involving exercise and other treatments. **Social Worker** identifies and analyzes the social and emotional factors underlying client illness, Master's of Social Work degree required. **Director of Volunteer Services** organizes and directs a program for recruiting and training volunteer workers. **Practical Nurse** is a licensed Practical Nurse.

(from http://www.nahc.org/Consumer/hpcstats.html)

Appendix B: Hospice Information Focus Group - January 19, 2006

Time: 12:30pm-1:25pm
Interviewers: Katherine Kelly, Batsirai Mutetwa and Lisa Novoson
Interviewee: Dr. Patchai, Dr. Salind and Khun Ahn
Translators: Dr. Patchai, Joy Bhosai
Place: The Mahavachiralongkorn Thanyaburi Cancer Center
Notes: Activities they have tried in the hospice

- Aromatherapy failed:
  - Some patients cannot smell
  - Can’t please all patients with one smell
- Music therapy:
  - Jazz failed because patients did not like it
  - Thai music also failed
    - Most patients began to cry instead of becoming happier
    - Reminded of good memories
    - Missed these memories and became sad
    - Harder to get patients to let go of these memories
- Reading programs:
  - Most patients prefer to read or be read to
  - Want to hear about Buddhist teachings
  - Also like to share stories about their own lives where applicable
- Finals days of patients in hospice
  - Most patients sleep- maybe only awake 4-5 hours a day
  - Want a quiet, peaceful environment
  - Patients are “in their own world”
    - Starting to detach themselves from the physical
    - Notice that family is there but do not always seem to have interest
    - Create their own environment
    - May not respond when nurses talk to them about their emotions
- Buddhism and spirituality
  - Peaceful and happy thoughts will help their rebirth
  - Nurses try to reinforce Buddhist teachings to patients to help them pass on
    - Patients need to understand themselves
    - Teach them how to put mind over matter
      - Their pain affects their spirit, not their soul
      - Recognize that pain comes from their past merit
      - The pain will pass
        - Not used to pain at first- scared, overwhelmed
      - Patients begin to train themselves
        - Use the call button less
    - Some patients begin to use fewer drugs
      - They are in pain but can almost zone it out
      - Positive thinking distracts them from the pain
    - Patients who do not accept the pain continue on with intensive drug treatments
    - Drug does will always be increased when needed depending on the progression of the disease
        - Does not mean patients are not accepting of the pain
        - Natural progression of disease often calls for increased meds
    - Homecare patients usually need fewer drugs
- Customization of services to patients
  - Family knows patient is terminal- their decision to tell patient or not
  - Patient and family are asked about patient likes and dislikes
    - “Sunpatan”- basket offerings to monks
    - Making alms to gain merit
  - Monks come to visit on Thursdays

Appendix C: Homecare Visits

C1: Compilation of Homecare Demographics and Services

Observed on February 1, 2006

	Case 1	Case 2	Case 3	Case 4	Case 5
Age	44	53	56	74	48
Gender	male	female	female	male	female
Type of Cancer	appendix	cervical	cervical	lung	breast
Caregiver	sister	daughter	self	daughter in law	son
Number of Previous Visits	4	6	6	10	78
Duration of Visit (min)	30	40	25	40	35
Payment Method	30 BHT	30 BHT	Government Official	30 BHT	30 BHT

	Case 1	Case 2	Case 3	Case 4	Case 5
MEDICAL					
Check medication supply	**X**			**X**	
Provided supplies/medicine	**X**				**X**
Check medical equipment		**X**		**X**	
Basic physical exam	**X**	**X**	**X**	**X**	**X**
Wound care					**X**
Make care suggestions		**X**	**X**		
COUNSELING					
Psycho therapy	**X**	**X**	**X**		
Discuss fears	**X**	**X**			**X**
Provide company	**X**	**X**	**X**	**X**	**X**
SOCIAL WORK					
Discussed finance	**X**	**X**			

C2: Homecare Cases Recording Sheets

Observed on February 1, 2006

CASE 1	**Age:** 44 years
Cancer Type: Cancer of the appendix	**Caregiver:** His sister
Number of previous visits: 4	**Insurance:** 30 Baht Scheme
Time of visit: 9:50 am	**Duration of visit:** 30 minutes

Patient Family Info:

Caregiver Info: She is uneducated and knows her brother is terminal. She has not told him because she refuses to acknowledge and has hope for his recovery.

Other: Very little money, therefore sometimes cannot afford some medical supplies, for instance gauze to dress the patient's abdominal wound.

Patient Condition:

Medical Complications:
Alertness during visit: Alert but lethargic
Medication: Morphine Tablets, other weaker painkillers, and multivitamins
Nutrition: Only eats soft foods, and mainly fluids
Prognosis: ?
Other: Little movement so urinates through tube into bag

Nurse Actions:

Medical: Made sure there was enough medication, and also supplied more pain killers. Ensured they were keeping to medication regiment and had enough supplies to dress an abdominal wound. Nurse-aid took blood pressure and temperature.

Counseling: Talked to patient and caregiver and hearing anxieties about cancer and family history with the disease. Someone in the family had recently died from the disease. Nurse-aid checks blood pressure and temperature just for psych-support; the information is not really necessary. It is a technique of maintaining the patient's good mental state; placebo effect.

Social Work: Talking about finances with family.

Other Findings:

CASE 2	**Age:** 53 years
Cancer Type: Cervical	**Caregiver:** Her daughter
Number of previous visits: 6	**Insurance:** 30 Baht Scheme
Time of visit: 11:30 am	**Duration of visit:** 40 minutes

Patient Family Info:

Caregiver Info: Has a small home-run laundry service business. She knows her mother is terminal but has not told her, and maintains hope for recovery.

Other: Worried about her business; going to the Cancer Center with her mother for treatment. So she was a little hesitant when nurse suggested going to the Cancer Center for IV Fluids.

Patient Condition:

Medical Complications: Cancer metastasized to brain and now she forgets information about time. Symptoms show the cancer may have metastasized to the lungs.
Her breathing is twice the normal rate and has difficulty. She therefore requires oxygen to help her breath. She is also bedridden so has tube hooked to urine bag.

Alertness during visit: Awake, but lethargic

Medication: None because she is not in pain

Nutrition: Only liquids, orally.

Prognosis: 4 weeks

Other: Own a small oxygen tank that is filled near the home but only lasts 4 hours. So every 3 hours the tank has to be refilled because they have no way of getting the bigger tank filled.

Nurse Actions:

Medical: No medication given because she is not in pain. Gave patient a lower body physical to check for pressure wounds around the legs. Also instructed patient's daughter to check for bedsores and other such pressure wounds. Before leaving, she moved patient onto side, as daughter should do. Blood pressure and temperature were taken.

Counseling: Listened as patient talked about her anxiety about the cancer. Makes sure patient is comfortable and has lots of physical contact e.g. holds her hand. Nurse-aid took her blood pressure and temperature for psycho-support.

Social Work: Counseled daughter about monetary problems, especially with getting her mother to the Cancer Center for minor treatment.

Other Findings:

CASE 3 **Age:** 56 years

Cancer Type: Cervical **Caregiver:** Self

Number of previous visits: 6 **Insurance:** Gov. Official Plan

Time of visit: 12:20pm **Duration of visit:** 25 minutes

Patient Family Info:

Caregiver Info: -
Other: Her husband is a Thai Government official, so she is covered under his insurance plan.

Patient Condition:

Medical Complications: Her right leg is bigger then her left because of the cancer metastasizing and sometimes the swollen leg does not respond. The fluid in the leg needs to be drained occasionally. Uses a walker sometimes
Alertness during visit: Very alert and chatting with the nurse
Medication: Goes to a doctor once a month to get more
Nutrition: Eats anything
Prognosis: 6 months
Other: Starting to show more distinct terminal symptoms e.g. chronic pain

Nurse Actions:

Medical: Nurse showed her some exercises to do with her upper body. Nurse-aid took patient's blood pressure.
Counseling: The nurse just talked to her about everyday things. The patient just seemed happy to have someone to talk to.
Social Work:

Other Findings:

CASE 4

Cancer Type: Lung Cancer

Number of previous visits: 10

Time of visit: 1:45pm

Age: 74

Caregiver: Daughter-in-law

Insurance: 30 Baht Scheme

Duration of visit: 40 minutes

Patient Family Info:

Caregiver Info: -
Other: -

Patient Condition:

Medical Complications: Cancer spread from right to left lung. The cancer metastasized to the bone. The left arm is swollen and painful.
Alertness during visit: Alert, but very tired. He had trouble staying seated up, and he was also very concerned about the arm swelling.
Medication: Uses alternative medication e.g. Tramol is an opiate.
Nutrition: Can eat solid foods
Prognosis: 1 month
Other: -

Nurse Actions:

Medical: Checked the medication they had. Examined patient's swollen arm, and feet; inspected oxygen tank.
Counseling: Talked to both the caregiver and patient and answered questions.
Social Work:

Other Findings:

CASE 5

Age: 48 years

Cancer Type: Breast

Caregiver: Her son

Number of previous visits: 78

Insurance: 30 Baht

Time of visit:

Duration of visit: 35 minutes

Patient Family Info:

Caregiver Info: Lives in a house with several family members. Her son stayed with her all day, and her husband dresses her wound.

Other: -

Patient Condition:

Medical Complications: Had a breast removal operation, but the cancer had metastasized to the bone and lungs. Because of the bone cancer, her left arm is fractured and her right arm is swollen. In a lot of pain, and can not move either arm. She also has a wound that covers the top quarter of the right chest, due to the cancer. There are also symptoms of other cancerous organs.

Alertness during visit: Very alert and chatting to nurse.

Medication: Takes morphine and other strong pain medication

Nutrition: Can eat solid foods

Prognosis: 6 months

Other: Started in the homecare program because of bone metastasis, after breast removal operation.

Nurse Actions:

Medical: Gave her a morphine injection after cleaning out her chest wound.

Counseling: The patient complained about pain and nurse counseled her for her anxiety.

Social Work:

Other Findings:

Breast cancer has a long prognosis that is why she has been a homecare patient for so long.

Appendix D: Patient Demographics

D1: Mahavachiralongkorn Cancer Center Recorded Information

Admitted Patients Recorded Information

Patient Personal Information

- Patient Name
- Sex
- Marital Status
- Ethnic Group
- Reason for admittance
- Who lives with the patient
- Religion
- Occupation
- Emergency person to be notified
- Date of Birth
- Age
-

Hospital Information

- Admission Number
- ID number
- Hospital Number
- Department admitted into
- Ward admitted into
- Information on who gave the patient's medical history
- Does patient accept treatment
- Way patient arrived in ward (e.g. walking, wheelchair, bedridden)
- Dates if admission and Discharge
- Length of stay in hospital
- Discharge status (e.g. complete recovery, death, improvement)
- Type of discharge (e.g. with approval, by escape, death)
- Attending Physician's signature
-

Medical History

- Principal diagnosis
- Complications
- Other diagnosis
- Patient responsiveness (e.g. alert, restless, confused, coma)
- Does the patient have any prosthetics?
- Disease History i.e. past and prevalent illnesses
- Mental state (e.g. confusion, mania)
- Suicide attempts history
- Has the patient lost weight in the last 6 months
- Bowel movement history
- Surgeries
  - Dates
  - Reasons
- Non-surgical procedures
- Vital Signs (e.g. Blood pressure, weight)
- Is patient in need of life-support equipment
- Drugs in use
- Food allergies
- Psychological state (e.g. anxiety, depression)
- Level of counseling care (e.g. high, low,)
- Sleep history
- Nutrition history

D2: Hospice Patient Statistics Survey: English Version

Patient Survey

Section 1 : General Background Information

1. Level of Education
   ☐ None ☐ Elementary School ☐ High School
   ☐ College Prep ☐ Bachelors Degree ☐Graduate Degree

2. Salary
   ☐Below 10,000 BHT ☐ 10,000-19,999 BHT ☐ 20,000-29,000 BHT
   ☐30,000-49,000 BHT ☐ 50,000 BHT or above

3. Who do you live with?
   ☐ Mom/ Dad ☐ Spouse ☐ daughter/son ☐ other relatives ☐friends

4. Where are you originally from?
   ☐ Bangkok ☐ Near Bangkok ☐Central Thailand ☐North
   ☐Isaan ☐ South

5. Approximately how far is your house from a health clinic?
   ☐1 km or less ☐ 1-5 km ☐ 5-10 km ☐ 11-15km
   ☐ 16-20 km ☐ 20km or over

6. Approximately how long does it take you to get to a health clinic?
   ☐Not more than 10 minutes ☐10-30 min ☐30min-1 hour
   ☐1-2 hours ☐ more than 2 hours

Section 2: Patient Information

1. How do you think that you got your illness?
   ☐ Infection ☐ Genetic Lineage ☐ Bad Merit ☐ from someone else
   ☐abnormal cell growth ☐ diet ☐other

2. What were your first signs and symptoms?
   ☐ Pain ☐ Bleeding/ Discharge
   ☐Mass growth ☐ Chronic Illness/ Infection
   ☐Loss of weight/Appetite ☐ Fever ☐Other

3. What did you first do when you first started experiencing symptoms?

☐ See a Doctor ☐ Bought own Prescriptions ☐ Nothing
☐ Herbal Treatment ☐ Other

4. When did you first see a doctor after you began experiencing your symptoms?
   ☐ Right Away ☐ Less than 2 weeks ☐ 2 Weeks to 1 month
   ☐1-2 Months ☐ 2-3 Months ☐3-6 Months
   ☐ 6 months-1 year ☐ Over 1 year

5. From question 4, if you waited, what were reasons for why you waited? Please rank 1-6, if possible.
   ☐Scared
   ☐ Thought that the problem would go away on its own
   ☐ Transportation
   ☐ Money
   ☐No One to Take/Escort to the Hospital
   ☐ Sought other treatments
   ☐ Didn’t want to bother family
   ☐ Thought that is was unable to be treated
   ☐ Other___________

6. When did you begin treatment after you found out about your condition?
   ☐ Right Away ☐ Within 2 weeks ☐ 2 weeks – 1 month
   ☐1-2 Months ☐ 2-3 Months ☐ 3-6 Months
   ☐ 6 Months – 1 year ☐ over 1 year

7. How curable do you think your condition is?
   ☐ Curable ☐50/50 ☐Not Curable ☐Not Sure Either Way

8. How curable do you think cancer is in general?
   ☐ Curable ☐50/50 ☐Not Curable ☐Not Sure Either Way

9. Please rank the categories

		High Chance	Low Chance	Same Chance
Education	High			
	Low			
Financial Situation	Good			
	Bad			

D3: Outpatient Statistics Survey: English Version

Nurse Outpatient Questionnaire

Section 1: General Background Information

1. Patient Hospital No.___________________Date Survey was completed_________
2. Sex ☐ Male ☐ Female
3. Age ☐ 20-30 years old ☐ 31-45 years old ☐ 46-60 y.o. ☐ Over 61
4. Marital Status ☐Single ☐Married ☐ Divorced/Separated
5. Healthcare Provider
   ☐ 30 BHT program ☐ Employer ☐Government ☐ Private Pay
   ☐ Private Insurance

Section 2: Patient Medical Information

1. Diagnosis____
2. Stage of Cancer

	Stage 0	Stage 1	Stage 2	Stage 3	Stage 4
Stage when patient first found out					
Stage when the patient first sought treatment					

3. Treatment action
   ☐ Radiation ______________Fraction
   ☐ Chemotherapy_________Cause
   ☐ Surgery
   ☐Palliative Treatment

4. How long has the patient stayed here?
   What is the estimated amount of time that the patient will remain in the hospice?

D4: Hospice Patient Statistics Survey: Thai version

µµ µ s

F O S e F O s t✓ O O
☐ F µ OS S
s

t HN µ S µµ µ s

µS S O
☐ s µS S ☐ s S
☐ s ts S ☐ tµ
☐ ☐ OS

t OF µF
☐ tS µ ☐ ,000- , µ
☐ ,000- ,000 µ ☐ ,000- ,999 µ
☐ s SS ,000 µ

µ FF t t µ t S µ t µ s SS
☐ p s ☐ s t ☐ µ ☐ p O☐ p

S p p s
☐ S O p ☐ se ☐ FS O ☐ F
☐ F S tO ☐ F

t O Sµ O pt µ S
☐ s S Ss ☐ - Ss ☐ - Ss ☐ - Ss
☐ - Ss ☐ s SS Ss

S S O
☐ s S ☐ - ☐ – s
☐ - s ☐s SS s

s S t S µF s µ t

s ss S F O S F S S
☐

□ S sp
□ S s S
□ s S
□ S µ O S
□ µ s S O
□ O s
□

S s S OS µ t F O
□ µ □ s OF O Ss S S S
□s S O S □s O F s S O O
□ S µ □s □

S t O s ss S F O S
□ pµ p t □ t µ O □ s
□ s p □

t pµ p t O S ss S F O S
□ pµ p t □ s S
□ - □ - □ -
□ - □ – □ s SS

S s pµ p t p
µ s SS tO s µ - : s S- t
□ S
□F s µ t O s S O
□ S O s S
□ s OS O
□ s s F p
□ S s S t
□F s s S

S t µS S O Spµ p t F O
□ □ s S □ -
□ - □ - □ - □
– □ s SS

F sF O SS S

□ t □ □ s t □ s

t F S S Fs O t O
□ t □ □ s t □ s

F t S Fs Os Ss S t OS t O

t		s S S s S	s S S t	S
S S	0			
ß S O				
	s			

D5: Outpatient Statistics Survey: Thai Version

µµ µ s

F O S e F O s t✓ O O
☐ F µ OS S

s

t
HN µ S µµ µ s

p ☐ t ☐ O

t ☐ - ☐ - ☐ - ☐s SS

p☐ ☐ s ☐ s t t

F t S S F O
☐ S p ☐ S OFs☐ OS ☐ O ☐ S

s S t S µF s µ t

S t F

t O F	O t	t	t	t	t
- s pµF O S					
- s µS S S p t p OF O S					

S S S p t µ s SS
☐ Radiation Fraction
☐ Chemotherapy Cause
☐ Surgery ☐ Palliative Treatment

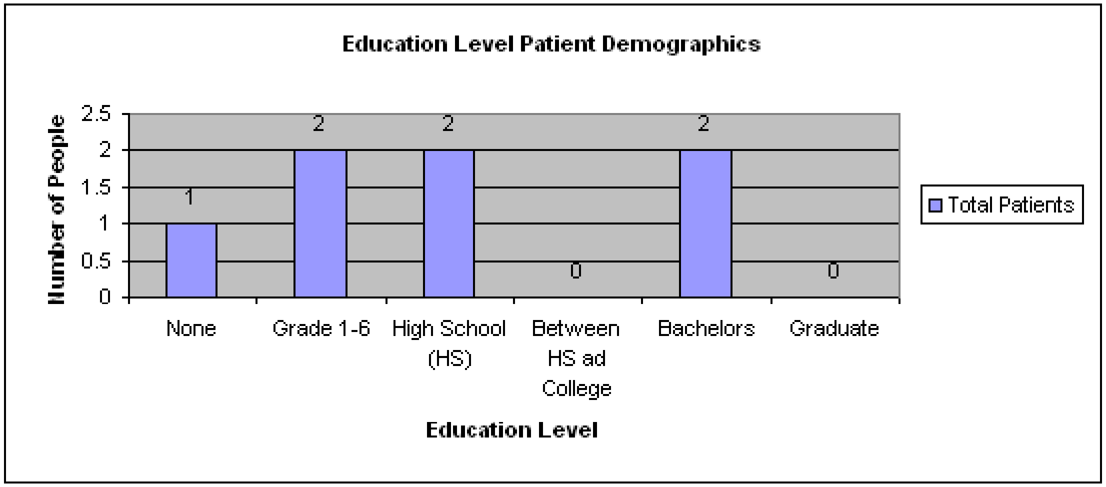
D6: Patient Statistics Compilation

Patient Demographics

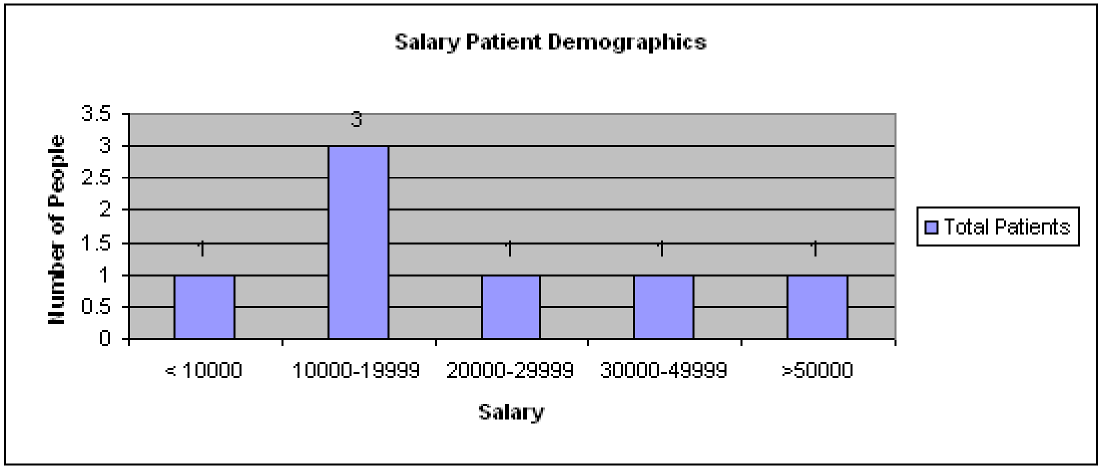
Part 1 Patient Survey

	Question Number					
	1	2	3	4	5	6
Patient Number	**Education**	**Salary**	**Who lives with you**	**Originally from**	**Distance traveled**	**Time taken to get to clinic**
24701247	None	< 10000	Kids and Spouse	No Response	No response	No Response
24803106	Grade 1-6	20000-29999	Kids and Spouse	Near Bangkok	11-15 km	10-30 min
24802590	Bachelors	>50000	Kids and Spouse	Middle of Thailand	>20 km	30min-1hr
24802926	Grade 1-6	10000-19999	Kids and Spouse	Middle of Thailand	>20 km	>2 hr
2482779	High School	30000-49999	Kids and Spouse	Southern Thailand	1-5 km	<10 min
248056	High School	10000-19999	Kids Only	Middle of Thailand	>20 km	1-2 hr
24802978	Bachelors	10000-19999	Spouse Only	ISAAN (poor area)	>20 km	1-2 hr

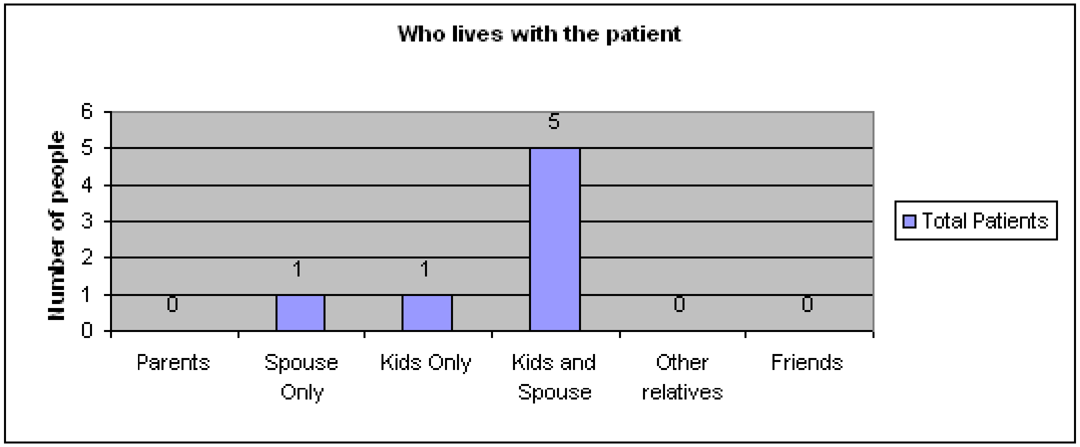
Education	**Totals**
None	1
Grade 1-6	2
High School (HS)	2
Between HS ad College	0
Bachelors	2
Graduate	0



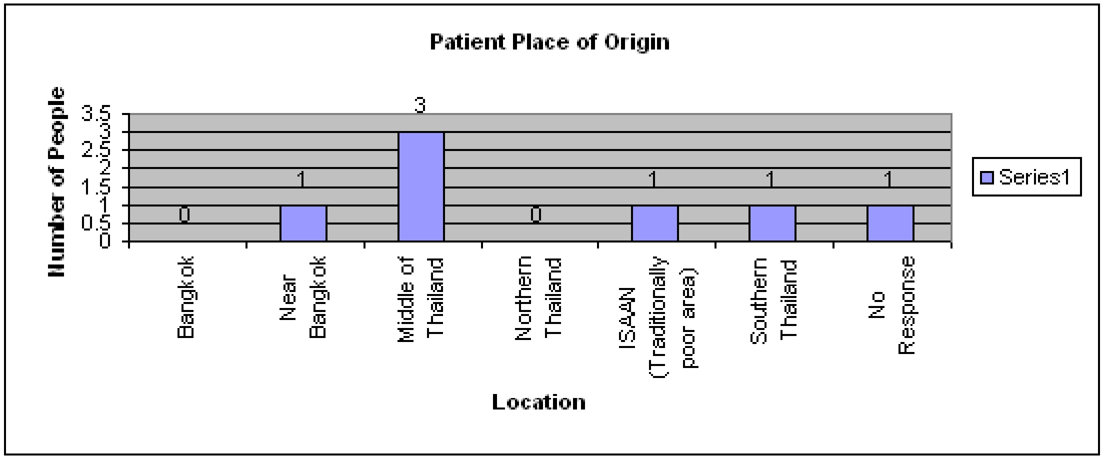
Salary	**Totals**
< 10000	1
10000-19999	3
20000-29999	1
30000-49999	1
>50000	1



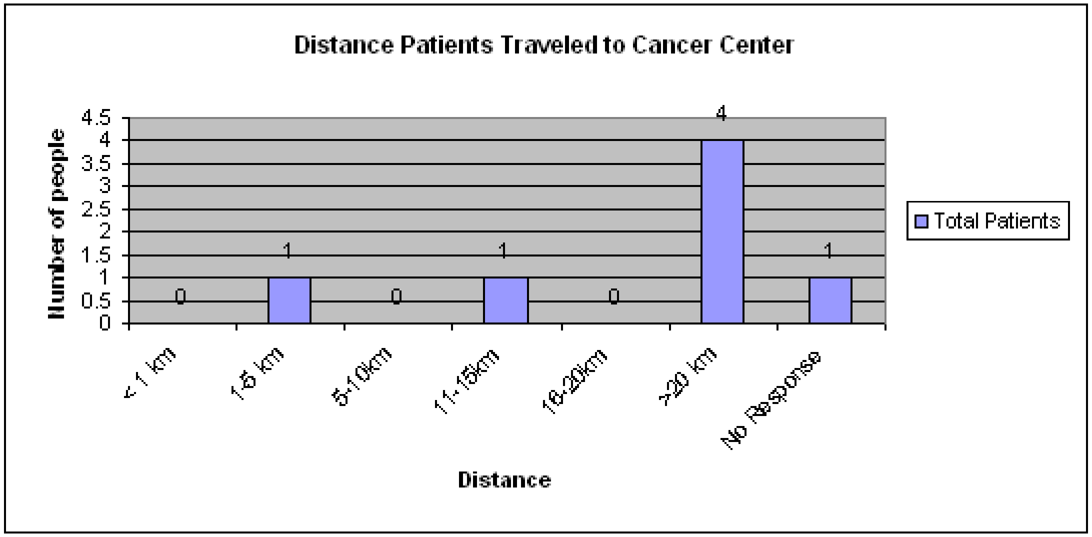
Who lives with the patient	**Totals**
Parents	0
Spouse Only	1
Kids Only	1
Kids and Spouse	5
Other relatives	0
Friends	0



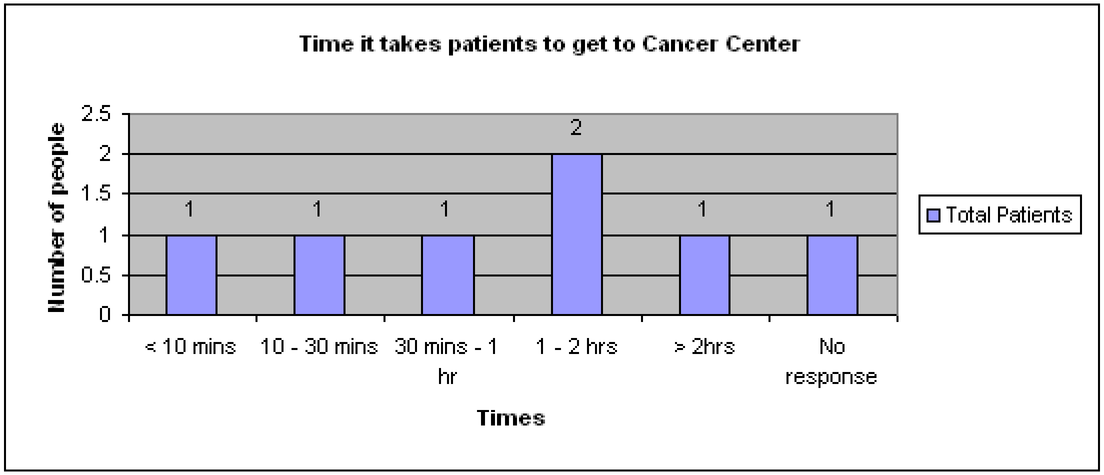
Place of origin	**Totals**
Bangkok	0
Near Bangkok	1
Middle of Thailand	3
Northern Thailand	0
ISAAN (Traditionally poor area)	1
Southern Thailand	1
No Response	1



Distance Traveled	**Totals**
< 1 km	0
1-5 km	1
5-10km	0
11-15km	1
16-20km	0
>20 km	4
No Response	1



Time Taken	**Totals**
< 10 mins	1
10 - 30 mins	1
30 mins - 1 hr	1
1 - 2 hrs	2
> 2hrs	1
No response	1



Patient Demographics

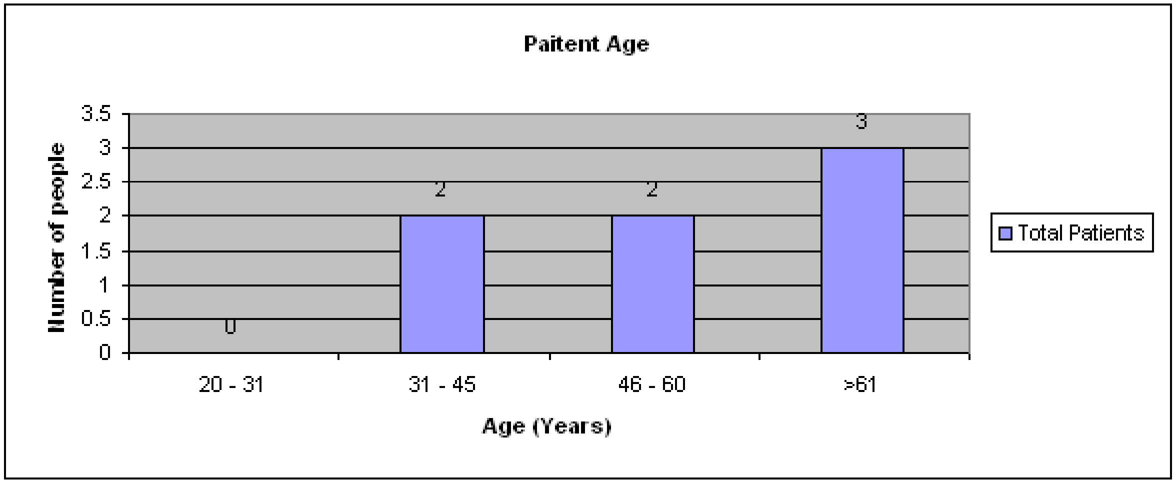
Part 1 Nurse Survey

Patient Number	Gender	Age	Marital Status	Insurance
24701247	Male	>61	Married	30 Baht
24803106	Male	>61	Married	Government
24802590	Male	>61	Married	Out-of-pocket payer
24802926	Male	31 - 45	Married	30 Baht
2482779	Female	31 - 45	Married	Government
248056	Female	46 - 60	Divorced/Separated	30 Baht
24802978	Female	46 - 60	Married	Government

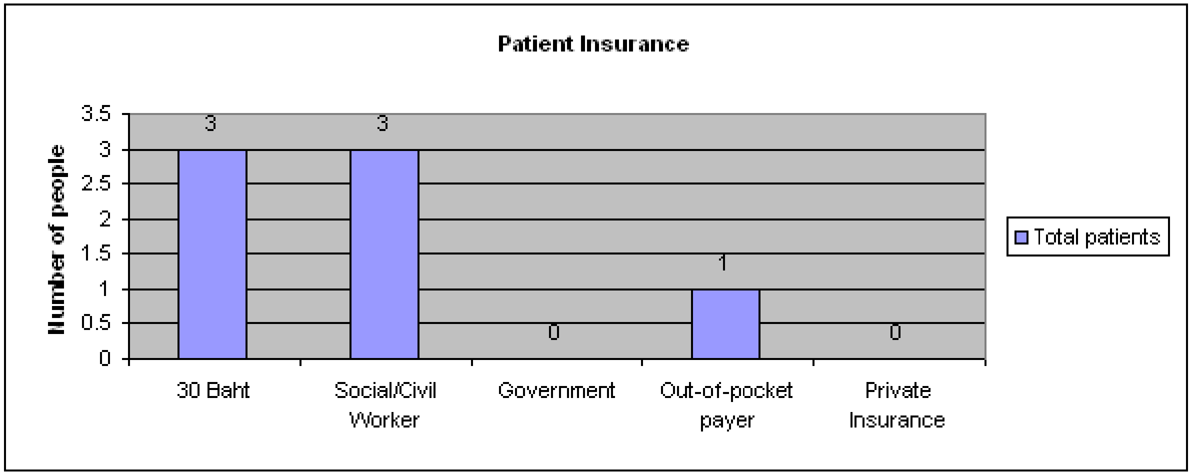
Patient Gender	**Totals**
Female	3
Male	4

Patient marital status	**Totals**
Single	0
Married	6
Divorced/Separated	1

Patient Age	**Totals**
20 - 31	0
31 - 45	2
46 - 60	2
>61	3



Insurance	**Totals**
30 Baht	3
Social/Civil Worker	3
Government	0
Out-of-pocket payer	1
Private Insurance	0



Appendix E: Costs

E1: Cost Documentation Template

Hospice and Homecare Services Cost Sheets

Patient No.

Cost Sheet								
Room								
Food								
Medication								
X-ray								
Radiotherapy								
Anesthesia								
Surgery								
Blood work								
Oxygen								
Cost of Services								
Other								
Total								
How are health services paid?								
How much does the government								
contributes to the cost?								

E2: Hospice ad Homecare Cost Statistics

Hospice Costs

	Average	Standard Dev.
Room	8848.33	10607.24
Food	4656.36	4490.17
Medication	16962.46	21112.15
X-ray	1016.26	2401.25
Radiotherapy	8370.53	9426.33
Anesthesia	0.00	
Surgery	0.00	
Blood work	1361.11	1432.61
Oxygen	6810.00	7937.89
Cost of Services	14410.19	13916.03
Other	2361.63	2254.58
Total	47515.60	41490.50

Homecare Costs

	Average	Standard Dev.
Room	13356.90	26531.47
Food	7353.85	8798.59
Medication	39373.20	88118.79
X-ray	2151.46	5234.33
Radiotherapy	10283.33	8695.96
Anesthesia	0.00	
Surgery	5146.67	6262.31
Blood work	3618.33	6578.89
Oxygen	8077.27	6677.92
Cost of Services	14443.41	17039.98
Other	2355.54	2769.20
Total	81373.16	122332.85

Appendix F: Quality of Life

F1: Staff Quality of Life Survey

Quality of Life of Terminally Ill Patients Survey

We are students from Massachusetts, USA doing research on the cost and benefits of homecare and hospice services for terminally ill patients. This survey includes questions to help us better understand what a Thai patient would value most during their final days. Please take a few minutes to answer this survey.

This is a list of conditions of a patient that can affect quality of life. In this survey we would like you to rank how important you think these conditions are to a terminally ill patient's quality of life. Please rank these conditions in order of importance from 1- 9, (1 being the most important and 9 the least important). Please use each number once. If you feel there are any other important conditions, please write them in and rank them.

How important are these conditions to a terminally ill patient's quality of life?
(1 = most important, 9 = least important)

_____ Physical conditions (pain, discomfort)
_____ Psychological conditions (positive thinking, hope)
_____ Ability to do daily activities by themselves
_____ Social – good relationship (family, friends, others)
_____Environmental conditions (noise, clean, temperature)
_____ Spiritual (purpose in life, beliefs, merit)
_____ Self –acceptance of patient (feel good about yourself)
_____ Economic situation (money)
_____ Other: ___________________________________

I am a : Doctor ☐ Nurse ☐ Other _________________

Thank you for your help. If you have any comments, please write them below.

Comments:

F2: Patient Priorities Survey: English Version

Patient Quality of Life

We are students from Massachusetts, USA doing research on the homecare and hospice services. Please take a few minutes to answer this survey. This is a list of factors that affect quality of life. In this survey we would like you to rank how important you think these factors are. Please rank these factors in order of importance from 1- 5, (1 being the most important and 5 the least important). Thank you for your help.

___ Physical Factors
___ Mental Health Factors
___ Spiritual Factors
___ Social Factors
___ Financial Factors

F3: Patient Priorities Survey: Thai Version

——

—

— /

— / /

——

F4: Patient Pretest Survey: English Version

Patient Quality of Life

We are students from Massachusetts, USA doing research on patient quality of life. This survey includes questions on different factors that we have found to influence a patient's quality of life. Please take a few minutes to respond to the best of your ability.

Instructions: Please mark a check ( ) in the column that best indicates your feelings on the topic.
There are 5 sections. Please answer all questions.

Physical

		Never	Hardly Ever	Occasionally	Often	Always
1	Are you satisfied are you with the management of your pain and discomfort?					
2	Are you satisfied are you with your level of energy?					
3	Are you satisfied are you with your ability to do daily activities?					
4	Are you comfortable with your living conditions?					

Mental Health

		Never	Hardly Ever	Occasionally	Often	Always
1	Do you feel positive about your future?					
2	Do you experience feelings of sadness, dejection or anxiety?					
3	When you look in the mirror, do you feel comfortable with your body?					
4	When you are with others, are you self-conscious because of the effects of your illness?					

Spiritual

		Never	Hardly Ever	Occasionally	Often	Always
1	Do your beliefs give you enough support to face your disease?					
2	Do your attachments to loved ones, possessions, and memories make you sad?					
3	Do you feel at peace with yourself?					
4	Are you satisfied with the spiritual merit (punya?) you've earned in this life?					

Social

		Never	Hardly Ever	Occasionally	Often	Always
1	Are you satisfied with the state of your relationships with your loved ones?					
2	Can you rely on your loved ones to help you during your illness?					
3	Do you receive enough love and affection from those around you?					
4	Do you feel safe and secure with the caregivers in your life?					

Financial

		Never	Hardly Ever	Occasionally	Often	Always
1	Do you worry about paying for your medical services?					
2	Do you worry about how your disease affects your family's financial situation?					

F5: Patient Pretest Survey: Thai Version

Patient Quality of Life (

5

1						
2						
3						
4						

5						
6						
7						
8						

9						
10						
11						
12						

13						
14						
15						
16						

17						
18						

F6: Patient Pilot/Final Survey: English version

Patient Quality of Life

We are students from Massachusetts, USA doing research on patient quality of life. This survey includes questions on different factors that we have found to influence a patient's quality of life. Please take a few minutes to respond to the best of your ability.

Instructions: Please mark a check ( ) in the column that best indicates your feelings on the topic.
There are 5 sections. Please answer all questions.

1. Physical

		Never	Hardly Ever	Occasionally	Often	Always
1	Are you satisfied are you with the management of your pain and discomfort?					
2	Are you satisfied are you with your level of energy?					
3	Are you satisfied are you with your ability to do daily activities?					
4	Are you comfortable with your living conditions?					

2. Mental Health

		Never	Hardly Ever	Occasionally	Often	Always
5	Do you feel positive about your future?					
6	Do you experience feelings of sadness, dejection or anxiety?					
7	When you look in the mirror, do you feel comfortable with your body?					
8	When you are with others, are you self-conscious because of the effects of your illness?					

3. Spiritual

		Never	Hardly Ever	Occasionally	Often	Always
9	Do your beliefs give you enough support to face your disease?					
10	Do your attachments to loved ones, possessions, and memories make you sad?					
11	Do you feel at peace with yourself?					
12	Are you satisfied with the spiritual merit (punya) you've earned in this life?					

4. Social

		Never	Hardly Ever	Occasionally	Often	Always
13	Are you satisfied with the state of your relationships with your loved ones?					
14	Can you rely on your loved ones to help you during your illness?					
15	Do you receive enough love and affection from those around you?					
16	Do you feel safe and secure with the caregivers in your life?					

5. Financial

		Never	Hardly Ever	Occasionally	Often	Always
17	Do you worry about paying for your medical services?					
18	Do you worry about how your disease affects your family's financial situation?					

6. Overall

		Very Unimportant	Unimportant	Neutral	Important	Very Important
19	How important are physical factors to your quality of life?					
20	How important are mental health factors to your quality of life?					
21	How important are spiritual factors to your quality of life?					
22	How important are social factors to your quality of life?					
23	How important are financial factors to your quality of life?					

F7: Patient Pilot/Final Survey: Thai version

Patient Quality of Life (

6

1

1						
2						
3						
4						

2

5						
6						
7						
8						

3

9						
10						
11						
12						

4

13						
14						
15						
16						

5

17						
18						

6

19	?					
20	?					
21	?					
22	?					
23	?					

F8: Analysis Type 1

Analysis Type 1

This sheet assesses patient quality of life. You will need the patient's response form filled out, and if you are doing this from on paper, you may need a calculator. There are 6 parts to this analysis sheet and each part needs to be completed in order to determine the patient's quality of life.

Part 1

This part has 5 subsections, each corresponding to the 6 sections on the patient quality of life survey. For each response given to questions in the survey, there is an associated value (ranging from 1-5). You will need the patient response survey to complete this section. At the end of each subsection, you will need to add up the scores for later use.

1. Physical Factors

Question #	Score						
							Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
1	1	2	3	4	5	➡	
2	1	2	3	4	5	➡	
3	1	2	3	4	5	➡	
4	1	2	3	4	5	➡	

+ ________________

Total 1 = **(** **)**

2. Mental Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
5	1	2	3	4	5	➡	
6	5	4	3	2	1	➡	
7	1	2	3	4	5	➡	
8	5	4	3	2	1	➡	

+

Total 2 = ( )

3. Spiritual Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
9	1	2	3	4	5	➡	
10	5	4	3	2	1	➡	
11	1	2	3	4	5	➡	
12	1	2	3	4	5	➡	

+

Total 3 = ( )

4. Social Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
13	1	2	3	4	5	➡	
14	1	2	3	4	5	➡	
15	1	2	3	4	5	➡	
16	1	2	3	4	5	➡	

+

Total 4 = ( )

5. Financial Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
17	10	8	6	4	2	➡	
18	10	8	6	4	2	➡	

+

Total 5 = ( )

Part 2

To complete this section, you will need the patient response form. Please indicate which response the patient chose, and note the score in the provided space.

6. Overall

Question #	Score							
	Very Unimportant	Unimportant	Neutral	Important	Very Important			
19	1	2	3	4	5	➡	____________	= Weight 1
20	1	2	3	4	5	➡	____________	= Weight 2
21	1	2	3	4	5	➡	____________	= Weight 3
22	1	2	3	4	5	➡	____________	= Weight 4
23	1	2	3	4	5	➡	____________	= Weight 5

Part 3

Please use the values obtained from Parts 1 and 2. If you are filling this sheet on paper, you may need a calculator.

(________) **X** (________) = **(** ______________ **)**
Total 1 **X** **Weight 1** **Score 1**

(________) **X** (________) = **(** ______________ **)**
Total 2 **X** **Weight 2** **Score 2**

(________) **X** (________) = **(** ______________ **)**
Total 3 **X** **Weight 3** **Score 3**

(________) **X** (________) = **(** ______________ **)**
Total 4 **X** **Weight 4** **Score 4**

(________) **X** (________) = **(** ______________ **)**
Total 5 **X** **Weight 5** **Score 5**

Part 4

Using the score values obtained in Part 3, please take the total. This is subtotal A.

(__________) + (__________) + (__________) + (__________) + (__________) = **(____________)**

Score 1 Score 2 Score 3 Score 4 Score 5 Subtotal A

Using the score values from Part 2, please multiply each value by 20, and then take the total. This is subtotal B.

(Weight 1 X 20) + (Weight 2 X 20) + (Weight 3 X 20) + (Weight 4 X 20) + (Weight 5 X 20) = Subtotal B

(_____ X 20) + (_____ X 20) + (_____ X 20) + (_____ X 20) + (_____ X 20) = **(____________)**

Subtotal B

Part 5

Using the values obtained in Part 4, divide Subtotal A by Subtotal B.

Subtotal A / Subtotal B = Subtotal C

(__________) / (__________) = **(________________)**

Subtotal C

Part 6

To determine the percentage Quality of Life, use Subtotal C from Part 5, and multiply it by 100.

Subtotal C **X 100 =** **QOL Score**

(__________ **)** X 100 = ______________

F9: Analysis Type 2

Analysis Type 2

This sheet assesses patient quality of life according to predetermined weights. You will need the patient's response form filled out, and if you are doing this form on paper, you may need a calculator. There are 5 parts to this analysis sheet and each part needs to be completed in order to determine the patient's quality of life.

Part 1

This part has 5 subsections, each corresponding to the 5 sections on the patient quality of life survey. For each response given to questions in the survey, there is an associated value (ranging from 1-5). You will need the patient response survey to complete this section. At the end of each subsection, you will need to add up the scores for later use.

1. Physical Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
1	1	2	3	4	5	➡	
2	1	2	3	4	5	➡	
3	1	2	3	4	5	➡	
4	1	2	3	4	5	➡	

\+ ____________

Total 1 = **(** **)**

2. Mental Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
5	1	2	3	4	5	➡	
6	5	4	3	2	1	➡	
7	1	2	3	4	5	➡	
8	5	4	3	2	1	➡	

+

Total 2 = **(** **)**

3. Spiritual Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
9	1	2	3	4	5	➡	
10	5	4	3	2	1	➡	
11	1	2	3	4	5	➡	
12	1	2	3	4	5	➡	

+

Total 3 = (   )

4. Social Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
13	1	2	3	4	5	➡	
14	1	2	3	4	5	➡	
15	1	2	3	4	5	➡	
16	1	2	3	4	5	➡	

+

Total 4 = (   )

5. Financial Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
17	10	8	6	4	2	➡	
18	10	8	6	4	2	➡	

+

Total 5 = (   )

Part 2

Please use the values obtained from Part 1. If you are filling this sheet on paper, you may need a calculator.

(____________) X 3.9 = (____________)
Total 1 X 3.9 = Score 1

(____________) X 3.4 = (____________)
Total 2 X 3.4 = Score 2

(____________) X 4.0 = (____________)
Total 3 X 4 = Score 3

(____________) X 3.2 = (____________)
Total 4 X 3.2 = Score 4

(____________) X 3.0 = (____________)
Total 5 X 3 = Score 5

Part 3

Using the score values obtained in Part 2, please take the total. This is subtotal A.

(________) +(________) + (________) + (________) + (________) = **(____________)**
Score 1 Score 2 Score 3 Score 4 Score 5 Subtotal A

Part 4

Use the value obtained in part 3 (subtotal A) and divide it by 320.

(_______________ **) / 350 =** **(** _______________ **)**
Subtotal A Subtotal B

Part 5

Uses the value of obtained in Part 4 (subtotal B) and multiply it by 100. This is your QOL Score.

(_______________ **) * 100 =** **(** _______________ **)**
Subtotal B QOL Score

F10: Analysis Type 3

Analysis Type 3

Using this Quality of Life assessment, each question is weighted the same. You will need the patient's response form filled out, and if you are doing this from on paper, you may need a calculator. There are 3 parts to this analysis sheet and each part needs to be completed in order to determine the patient's quality of life.

Part 1

This part has 5 subsections, each corresponding to the 6 sections on the patient quality of life survey. For each response given to questions in the survey, there is an associated value (ranging from 1-5). You will need the patient response survey to complete this section. At the end of each subsection, you will need to add up the scores for later use.

1. Physical Factors

Question #						
	Score					Question Score
	Never	Hardly Ever	Occasionally	Often	Always	
1	1	2	3	4	5	➡
2	1	2	3	4	5	➡
3	1	2	3	4	5	➡
4	1	2	3	4	5	➡

+ ______________

Total 1 = **(** **)**

2. Mental Factors

Question #	Score					Question Score
	Never	Hardly Ever	Occasionally	Often	Always	
5	1	2	3	4	5	➡
6	5	4	3	2	1	➡
7	1	2	3	4	5	➡
8	5	4	3	2	1	➡

+

Total 2 = (   )

3. Spiritual Factors

Question #	Score					Question Score
	Never	Hardly Ever	Occasionally	Often	Always	
9	1	2	3	4	5	➡
10	5	4	3	2	1	➡
11	1	2	3	4	5	➡
12	1	2	3	4	5	➡

+

Total 3 = (   )

4. Social Factors

Question #	Score					Question Score
	Never	Hardly Ever	Occasionally	Often	Always	
13	1	2	3	4	5	➡
14	1	2	3	4	5	➡
15	1	2	3	4	5	➡
16	1	2	3	4	5	➡

+

Total 4 = **(** **)**

5. Financial Factors

Question #	Score					Question Score
	Never	Hardly Ever	Occasionally	Often	Always	
17	5	4	3	2	1	➡
18	5	4	3	2	1	➡

+

Total 5 = **(** **)**

Part 2

Using the total score values obtained in Part 1, add up the 5 totals to obtain Subtotal A

(__________) + (__________) + (__________) + (__________) + (__________) = **( )**
Total 1 Total 2 Total 3 Total 4 Total 5 Subtotal A

Part 3

Using the Subtotal A value obtained in Part 2, multiply by 90/100 to obtain the Quality of Life percentage.

(__________) X 90/100 = **( )**
Subtotal A X 90/100 = QOL %

F11: Nurse Priority Survey Results

Sample size: 28 nurses

Department	**Nurses surveyed**
Dentistry	1
Hospice	1
ICU	4
Outpatient	3
Pharmacy	4
Radiology	5
Ward 6	10

Overall Ranking of Important Factors to Terminal Cancer Patient's

Rated from 1 to 9; 1 being the most important and 9 being the least important.

Physical	1
Psychological	2
Spiritual	3
Social	4
Self-Acceptance	5
Ability to do daily activities	6
Environment	7
Economics	8
Other	9

This conclusion was reached by considering the individual categories, as shown below. According to the number of nurses who answered the survey, the mead, mode and standard deviation of different factors was also used in considering the above overall ranking.

Mean, Mode and Standard Deviation

Mean:
The average taken by dividing the number rank given by the total number of nurses who responded to the survey.

Mode:
This is the most reoccurring number in the group

Standard Deviation:
Measures the average numerical distance each value is in relation to the overall average.

Note: All the values below were determined using Microsoft Excel.

Factor	**Mean**	**Mode**	**Standard Deviation**
Physical	3.0	1	2.08
Psychological	3.1	1	1.86
Daily activity ability	5.0	5	1.83
Social-good relationship	3.9	4	1.95
Environment	6.4	7	1.75
Spiritual	3.7	3	2.07
Self-acceptance	4.2	3	2.06
Economic	6.6	8	1.89
Other	8.5	9	n/a

F12: Patient Priority Results

Hospice Results

Physical	Mental	Spiritual	Social	Economic
2.0	1.0	3.0	4.0	5.0
3.0	2.0	1.0	4.0	5.0
2.0	3.0	5.0	1.0	4.0
4.0	1.0	3.0	2.0	5.0
3.0	2.0	5.0	4.0	1.0
4.0	2.0	3.0	1.0	5.0
3.0	2.0	1.0	4.0	5.0
3.0	1.9	3.0	2.9	4.3

Ward 6 Results

Physical	Mental	Spiritual	Social	Economic
3.0	1.0	4.0	5.0	2.0
2.0	3.0	4.0	5.0	1.0
3.0	1.0	5.0	4.0	2.0
4.0	5.0	1.0	3.0	2.0
5.0	2.0	3.0	1.0	4.0
5.0	4.0	1.0	3.0	2.0
1.0	5.0	4.0	2.0	3.0
1.0	2.0	5.0	4.0	3.0
4.0	3.0	5.0	2.0	1.0
1.0	2.0	3.0	5.0	4.0
5.0	4.0	3.0	2.0	1.0
1.0	2.0	5.0	3.0	4.0
1.0	2.0	5.0	4.0	3.0
4.0	1.0	3.0	2.0	5.0
1.0	3.0	4.0	2.0	5.0
4.0	1.0	2.0	3.0	5.0
4.0	3.0	5.0	2.0	1.0
3.0	4.0	5.0	2.0	1.0
2.0	3.0	5.0	4.0	1.0
3.0	2.0	4.0	5.0	1.0
2.9	2.7	3.8	3.2	2.6

Radiology Results

Physical	Mental	Spiritual	Social	Economic
5.0	4.0	3.0	1.0	2.0
5.0	4.0	3.0	2.0	1.0
2.0	1.0	3.0	4.0	5.0
4.0	3.0	3.0	2.3	2.7

Overall Averages

Physical	Mental	Spiritual	Social	Economic
3.0	2.5	3.5	3.0	3.0

F13: Comparisons of QOL Scores

Score tabulated from 21 patients at the Lopburi and Mahavachiralongkorn Thanyaburi Cancer Centers.

Patient #	**Type 1**	**Type 2**	**Type 3**
1	92.00	90.60	98.90
2	71.70	73.30	78.90
3	81.20	83.70	91.10
4	76.00	74.80	85.60
5	84.80	81.40	91.10
6	51.00	51.70	56.60
7	46.70	41.40	51.10
8	88.30	82.30	90.00
9	80.50	78.90	88.80
10	88.60	88.20	97.80
11	85.20	84.80	94.40
12	68.90	72.30	80.00
13	53.70	47.90	57.80
14	53.50	55.80	61.10
15	58.60	57.40	68.90
16	51.30	49.80	56.70
17	62.00	64.70	68.90
18	67.20	65.10	75.60
19	66.30	60.00	70.00
20	62.50	56.30	71.10
21	62.00	61.50	70.00

Mean	69.14	67.71	76.40
Median	67.20	65.10	75.60
Mode	62.00	N/A	91.10
Standard Deviation	14.15	14.62	14.81

Appendix G: Recommendations

G1: Contact Information

Kitikorn Meesapya
Bureau of Mental Health, Technical Development Department of Mental Health
Ministry of Public Health
Tivanon Road
Nonthaburi 11000, Thailand
Phone: 66 2 9511300-40 Ext. 8205
E-mail: kitikorn@health.moph.go.th

Sucheera Phattharayuttawat, PhD.
Department of Psychiatry, Faculty of Medicine, Siriraj Hospital
Bangkok 10700, Thailand
Phone: 0-2419-7000 ext. 4277
Fax: 0-2411-343

G2: Considerations for Economic Evaluations

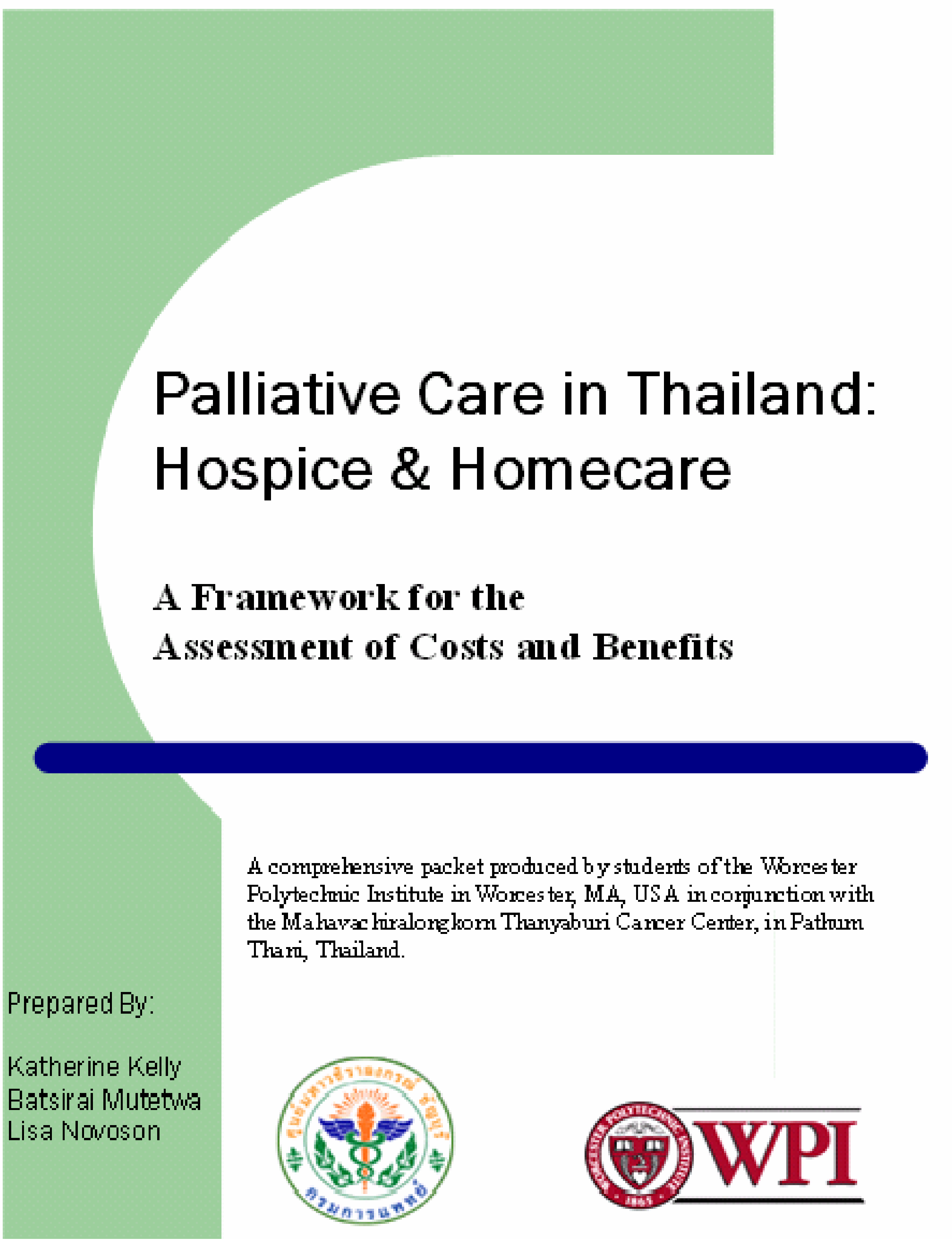
Ten questions to ask of any published economic evaluation

1. Was a well defined question posted in answerable form?
    a. Did the study examine both costs and effects of the service(s)?
    b. Did this study involve a comparison of alternatives?
    c. Was a viewpoint for the analysis stated or was the study placed in particular decision-making context.
2. Was a comprehensive description of the competing alternative given (that is can you tell who did what to whom, where and how often)?
    a. Were any important alternatives omitted?
    b. Was/should a do nothing alternative have been considered?
3. Was there evidence that the program's effectiveness has been established? Was this done through a randomized controlled clinical trial? If not, how strong was the evidence of effectiveness?
4. Were all important costs and consequences for each alternative identified?
    a. Was the range wide enough for the research question at hand?
    b. Did it cover all relevant viewpoints (for example those of the community of society, patients and third party payers)?
    c. Were capital costs as well as operating costs considered?
5. Were costs and consequences measure accurately in appropriate physical units (for example, hours of nursing given, number of physician visits, days lost from work, years of live gained) prior to valuation?
    a. Were any identified items omitted from the measurement? If so, does this mean that they carried no weight in the subsequent analysis?
    b. Were there any special circumstances (for example use of resources) that made measurement difficult? Were these circumstances handled appropriately?
6. Were costs and consequences valued credibly?
    a. Were the sources of all values (for example market values, patient or client preferences or views, policy maker's views and healthcare professional's judgments) clearly identified?
    b. Were market values used for changes in involving resources gained?
    c. When market values were absent (for examples when volunteers were used), or did not reflect actual values (for example clinic space was donated at a reduced rate) were adjustments made to approximate market values?
    d. Was the valuation of consequences appropriate for the questions posted (that is, was appropriate type or types of analysis chosen- cost-effectiveness, cost-benefit or cost-utility- selected?
7. Were costs and consequences adjusted for different timing?
    a. Were costs and consequences that occurred in the future discounted to their present values?
    b. Was any justification given for the discount rate used?

8. Was an incremental analysis of costs and consequences of alternatives studied? Were the additional costs generated by the use of one alternative over another compared with the additional effects, benefits or utilities?
9. Was a sensitivity analysis performed?
    a. Was justification provided for the range of variables (for key parameters) in the sensitivity analysis?
    b. Were the study results sensitive to changes in the values (within the assumed range)?
10. Did the presentation and discussion of the results of the study include all issues of concern to the user?
    a. Were the conclusions of the analysis based on some overall index or ration of costs to consequences, for example cost-effectiveness ratio?
    b. Were the results compared with those of other studies that had investigated the same questions?
    c. Did the study discuss the generalizability of the results to other settings and patient/client groups?
    d. Did the study allude to or take into account other important factors in the choice or decision under consideration (for example distribution of costs and consequences of other relevant ethical issues)?
    e. Did the study discuss issues of implementation such as the feasibility of adopting the preferred program given existing financial or other constraints and whether any freed resources could be used for other worthwhile programs?

Source adapted from Drummond and Stoddart (1985), P. 365

Appendix H: Final Deliverable



Palliative Care in Thailand: Hospice & Homecare

A Framework for the Assessment of Costs and Benefits

A comprehensive packet produced by students of the Worcester Polytechnic Institute in Worcester, MA, USA in conjunction with the Mahavachiralongkorn Thanyaburi Cancer Center, in Pathum Thani, Thailand.

Prepared By:

Katherine Kelly
Batsirai Mutetwa
Lisa Novoson

Forward

In 2000, the World Health Organization reported about 12% of deaths worldwide were caused by cancer and that about 80% of cancer cases in developing countries have already become terminal before diagnosis (WHO, 2005). In Thailand specifically, cancer is one of the leading causes of death, claiming lives at a rate of 88 per every 100,000 people a year. In addition, hospital admission rates for cancer patients are approximately 78 people per 100,000, suggesting that almost 90% of diagnosed cancer patients die from the disease (WHO, 2000). For many patients and their loved ones, hospice and homecare offer an alternative approach to facing a terminal illness. Palliative care is used when patients decide to discontinue curative care. Palliative care programs are geared towards ensuring that the final days of the patient are peaceful and dignified. However, in some developing countries, such as Thailand, hospice and homecare are not fully utilized.

This is a comprehensive packet detailing an approach for assessing costs and benefits hospice and homecare systems. Specifically discussed is how to evaluate the effectiveness of a program and how to prepare services for cost-benefit analysis. The intention of such an assessment is the promotion of these alternatives to terminal care programs. Included are explanations of hospice and homecare, a quality of life survey and instructions for administration and analysis, a patient demographics sheet and instructions for compilation, and a breakdown of services and associated costs.

Inside this Packet:

Additional information, documents and programs can be found on the attached CD.

What are Hospice and Homecare?

Hospice and homecare are both alternative terminal care programs that give strictly non-curative care. As such, they are considered palliative care programs. The goal of a palliative care program is to ensure that the final days of a patient are pain free and comfortable. They also provide support for families whose loved ones are facing an incurable illness. Improving the quality of life (QOL) of a patient is the desired result of all palliative care programs. A professional team works with the patient and family to make sure that the patient dies a dignified and comfortable death. Through palliative care programs, patients are not only treated for the physical ailments but also their psychological needs.

Palliative programs aim to provide holistic care to their patients. In order to accomplish that task, the programs must offer services that cover all the areas of patient needs. These areas and a list of commonly found hospice and homecare services are listed below. To meet these needs, palliative care programs utilize a combination of medicines, therapies, counseling sessions, and clinics. The goal of each service is to provide support for the patient. This support ranges anywhere from management of pain, to management of financial documents, to bereavement sessions for grieving family members. By offering many services, a palliative care program has the opportunity to improve the quality of all aspects of a patient's life.

> *"To cure sometimes, to relieve often, to comfort always"*
>
> - I. Jon Russell

Examples of Palliative Care Services

Physical
- Pain management through medication
- Symptom management through external support
- Physical therapy
- Nutrition planning
- Exercise programs
- Beauty therapy
- Massage therapy

Social
- Care clinics for relatives/caregivers
- Support groups
- Illness education seminars
- Bereavement counseling

Financial
- Social work

Spiritual
- Meditation classes
- Positive thinking
- Readings of Buddhist teachings

Psychological
- Relaxation techniques
- Emotional support groups
- Music therapy

Hospice and Homecare in Thailand

Palliative care programs typically consist of inpatient hospice services and/or outpatient homecare services. In Western medical communities, palliative care, hospice, and homecare are practically synonymous because the majority of the care (about 80%) given to terminally ill patients happens in the home (HospiceNet, 2005). Contrary to the Western model, Thai hospice operates in a slightly modified manner. In Thailand, hospice and homecare services are completely separate entities. At the only Thai cancer hospice, in the Mahavachiralongkorn Cancer Center, all of the services are inpatient.

Quality of Life

What is Quality of Life?

QOL has been defined as a "global evaluation of satisfaction with one's life" (Cooley 1998). It is also seen as one of the most important outcomes of effective end-of-life care. A good QOL means that the patient is comfortable with the management of his/her illness.

Measuring Quality of Life

QOL assessments are necessary to help a hospital ensure that their patient's needs are being met. In addition, measuring QOL can generate the necessary data to prove or disprove the benefits of a care program. Those same data can also be a powerful tool to prove both the effectiveness and success of a care program. Valid assessments can only be conducted by utilizing an instrument that is sensitive to all aspects of the patient's life. To obtain a holistic view of the life of a patient, one must examine the myriad of factors that influence their life. This examination is no small task considering the wide range of influences experienced by a patient. However, it is made easier by grouping these influences into major categories. The categories are physical, mental, spiritual, social, and finance. To understand how to measure QOL it is necessary to explore all these categories in the context of how they will affect a patient's perception of their life.

QOL Categories

Physical
- Physical Body
    - Symptom management
    - Pain management
    - Fatigue/energy
    - Nourishment
    - Climate
- Body Response to Environment
    - Noise Level
    - Privacy

Social
- Emotional Support
- Informational Support
- Caring relationships
- Affection and Love
- Trust

Financial
- Economic Pressure
    - Familial burden
    - Monetary restrictions

Spiritual
- Self Acceptance
    - Self Esteem
    - Dignity
    - Appearance
    - Meaningfulness of their life
    - Personal growth
- Existential Wellbeing
    - Standing in the world
    - Influence on coming to terms with life
    - Coming to terms with how they lived
- Religion
    - Preparedness to pass on

Mental
- Psychological
    - Hope
    - Positive Thinking
    - Concentration
- Independence

The following pages contain a survey that has been adapted and tested with Thai terminally ill cancer patients. Instructions and survey question explanations are provided, as well as a system for scoring results.

Page 5

QOL Surveys

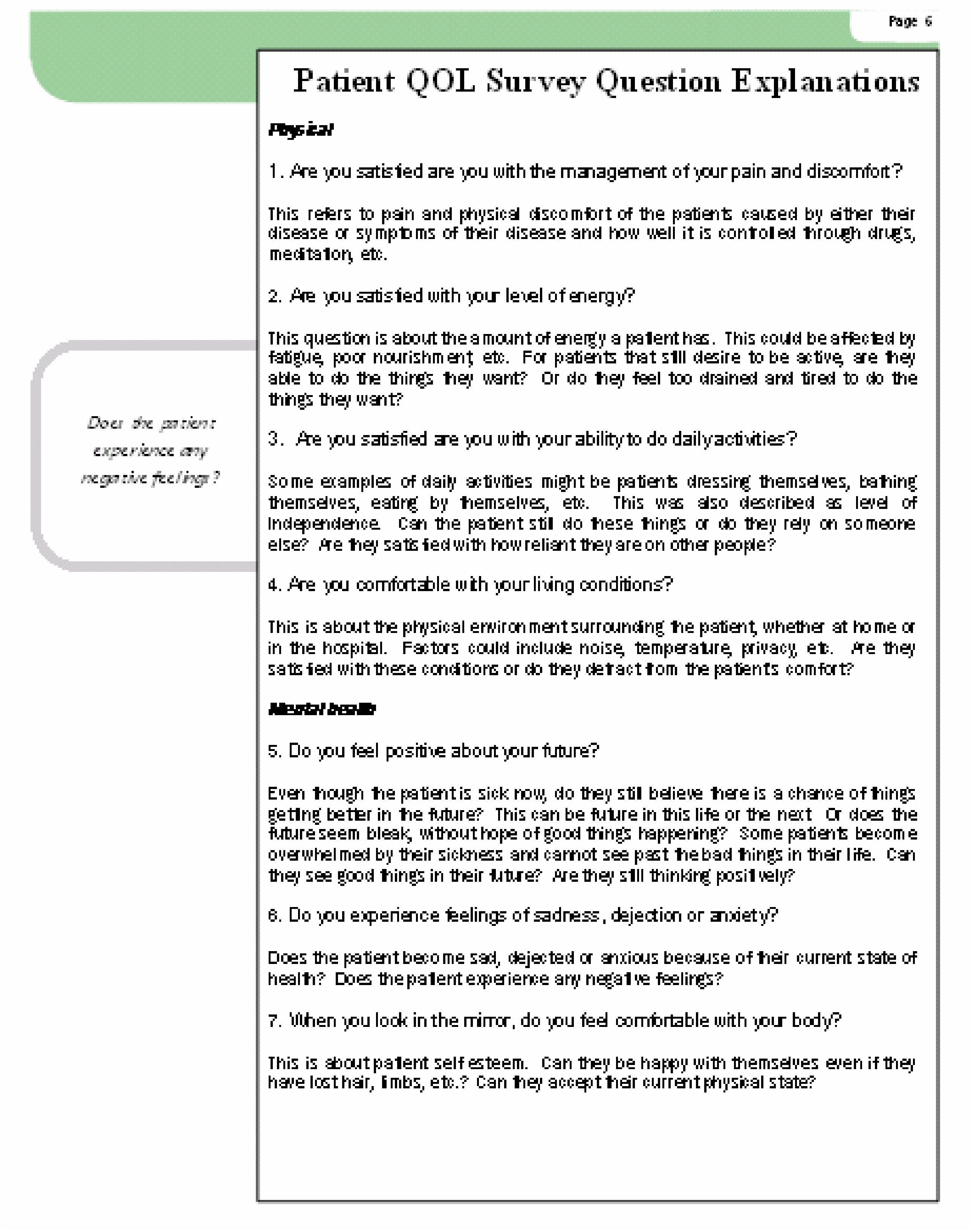
Instructions for QOL Survey Administration

The administration of this survey should be overseen by a knowledgeable, informed and involved staff member. This is key to eliminating the discrepancies caused by the survey variables. An administrator needs to be fully aware of the purpose of the survey and the meaning of each question. They must pay careful attention to how they clarify any questions in order to prevent patient bias or discontinuity in the results. They need to be sensitive to the level of education of each patient so that they can give appropriate explanations. Also, an administrator needs to be aware of language nuances and connotations in the medical world to make sure he/she is not unknowingly influencing a patient.

Before surveying patients, it is crucial that an administrator be completely aware of the intricacies of our survey. For this reason, the pages 6-8 describe in more detail the intent of each question. By taking the appropriate amount of time to familiarize themselves with this material, the administrator should be well prepared to accurately administer this survey. The English version of our survey can be found on pages 9&10; the Thai version can be found on the CD provided.

Instructions for QOL Survey Analysis

Once the QOL patient survey has been administered, compilation and analysis are needed to make use of the data obtained. A hardcopy of the scoring sheet can be found on pages 11-13; this can also be found on the CD, as well as an excel program for computing these scores. This scoring method weights the QOL scores according to each individual patient's priorities and has been cross analyzed with two other processes to check validity.



Patient QOL Survey Question Explanations

Physical

1. Are you satisfied are you with the management of your pain and discomfort?

This refers to pain and physical discomfort of the patients caused by either their disease or symptoms of their disease and how well it is controlled through drugs, meditation, etc.

2. Are you satisfied with your level of energy?

This question is about the amount of energy a patient has. This could be affected by fatigue, poor nourishment, etc. For patients that still desire to be active, are they able to do the things they want? Or do they feel too drained and tired to do the things they want?

3. Are you satisfied are you with your ability to do daily activities?

Some examples of daily activities might be patients dressing themselves, bathing themselves, eating by themselves, etc. This was also described as level of independence. Can the patient still do these things or do they rely on someone else? Are they satisfied with how reliant they are on other people?

Does the patient experience any negative feelings?

4. Are you comfortable with your living conditions?

This is about the physical environment surrounding the patient, whether at home or in the hospital. Factors could include noise, temperature, privacy, etc. Are they satisfied with these conditions or do they detract from the patient's comfort?

Mental health

5. Do you feel positive about your future?

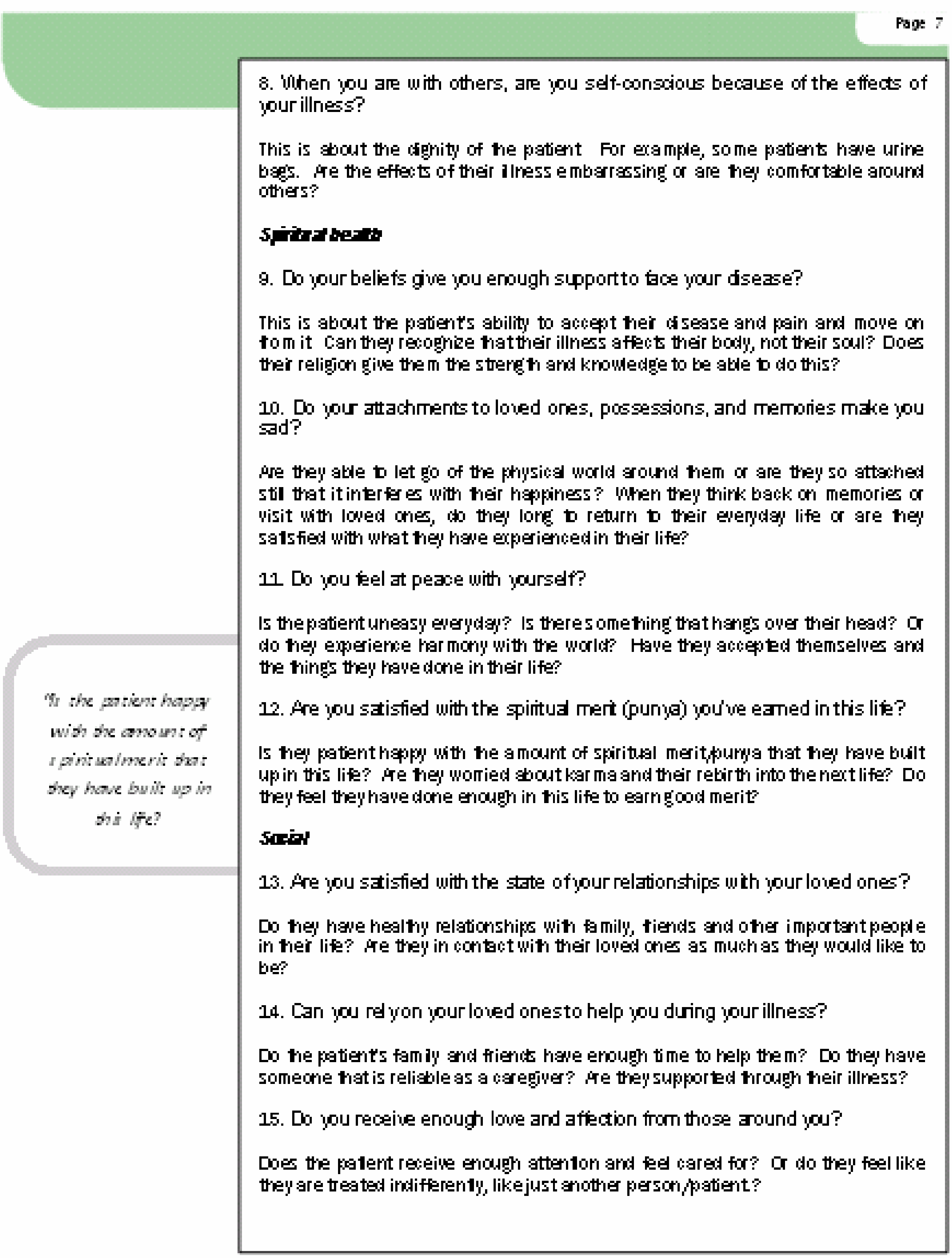
Even though the patient is sick now, do they still believe there is a chance of things getting better in the future? This can be future in this life or the next. Or does the future seem bleak, without hope of good things happening? Some patients become overwhelmed by their sickness and cannot see past the bad things in their life. Can they see good things in their future? Are they still thinking positively?

6. Do you experience feelings of sadness, dejection or anxiety?

Does the patient become sad, dejected or anxious because of their current state of health? Does the patient experience any negative feelings?

7. When you look in the mirror, do you feel comfortable with your body?

This is about patient self esteem. Can they be happy with themselves even if they have lost hair, limbs, etc.? Can they accept their current physical state?



Page 7

8. When you are with others, are you self-conscious because of the effects of your illness?

This is about the dignity of the patient. For example, some patients have urine bags. Are the effects of their illness embarrassing or are they comfortable around others?

Spiritual health

9. Do your beliefs give you enough support to face your disease?

This is about the patient's ability to accept their disease and pain and move on from it. Can they recognize that their illness affects their body, not their soul? Does their religion give them the strength and knowledge to be able to do this?

10. Do your attachments to loved ones, possessions, and memories make you sad?

Are they able to let go of the physical world around them or are they so attached still that it interferes with their happiness? When they think back on memories or visit with loved ones, do they long to return to their everyday life or are they satisfied with what they have experienced in their life?

11. Do you feel at peace with yourself?

Is the patient uneasy everyday? Is there something that hangs over their head? Or do they experience harmony with the world? Have they accepted themselves and the things they have done in their life?

12. Are you satisfied with the spiritual merit (punya) you've earned in this life?

Is they patient happy with the amount of spiritual merit/punya that they have built up in this life? Are they worried about karma and their rebirth into the next life? Do they feel they have done enough in this life to earn good merit?

"Is the patient happy with the amount of spiritual merit that they have built up in this life?

Social

13. Are you satisfied with the state of your relationships with your loved ones?

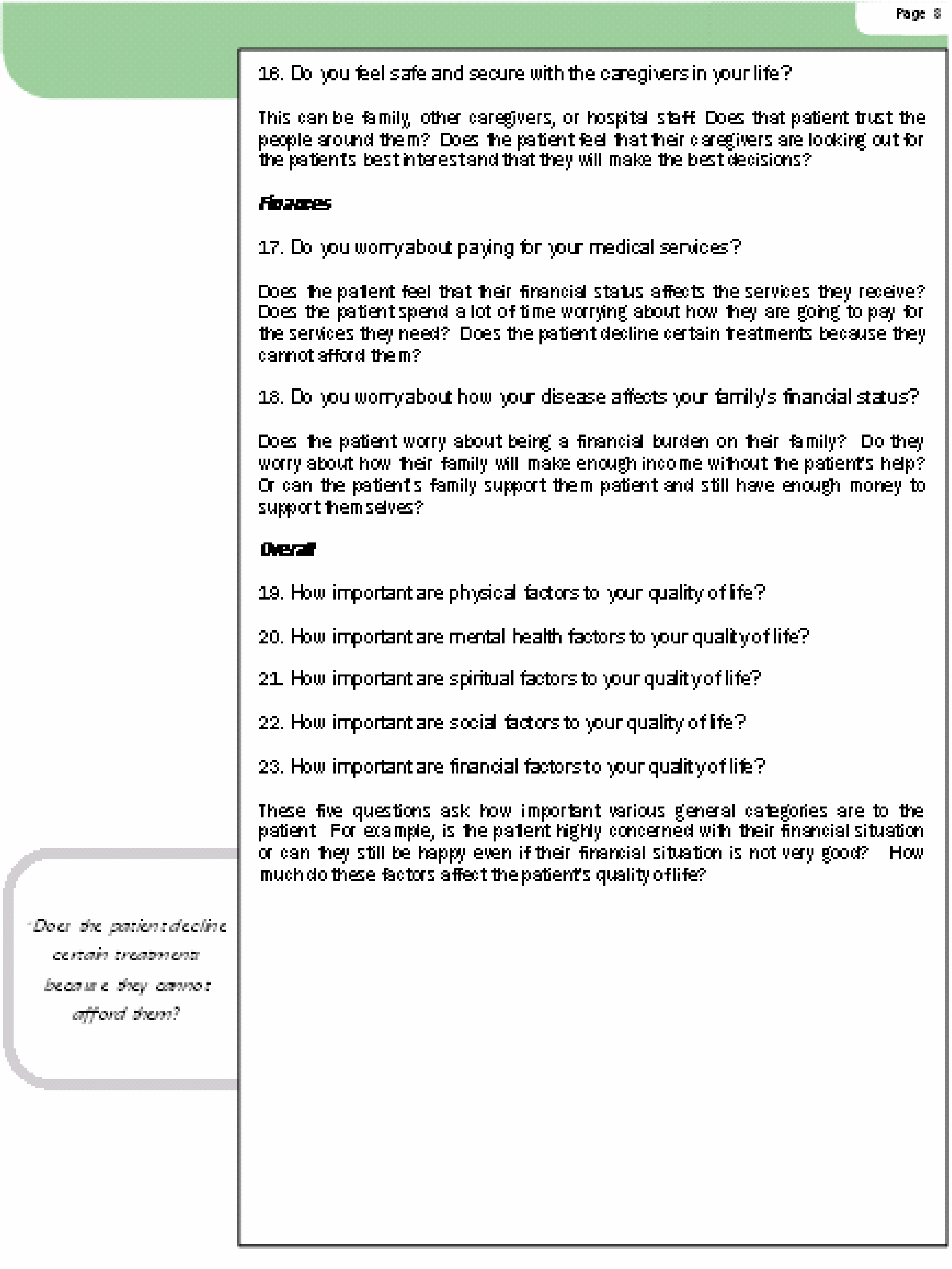
Do they have healthy relationships with family, friends and other important people in their life? Are they in contact with their loved ones as much as they would like to be?

14. Can you rely on your loved ones to help you during your illness?

Do the patient's family and friends have enough time to help them? Do they have someone that is reliable as a caregiver? Are they supported through their illness?

15. Do you receive enough love and affection from those around you?

Does the patient receive enough attention and feel cared for? Or do they feel like they are treated indifferently, like just another person/patient?



Page 8

16. Do you feel safe and secure with the caregivers in your life?

This can be family, other caregivers, or hospital staff. Does that patient trust the people around them? Does the patient feel that their caregivers are looking out for the patients best interest and that they will make the best decisions?

Finances

17. Do you worry about paying for your medical services?

Does the patient feel that their financial status affects the services they receive? Does the patient spend a lot of time worrying about how they are going to pay for the services they need? Does the patient decline certain treatments because they cannot afford them?

18. Do you worry about how your disease affects your family's financial status?

Does the patient worry about being a financial burden on their family? Do they worry about how their family will make enough income without the patient's help? Or can the patient's family support them patient and still have enough money to support themselves?

Overall

19. How important are physical factors to your quality of life?

20. How important are mental health factors to your quality of life?

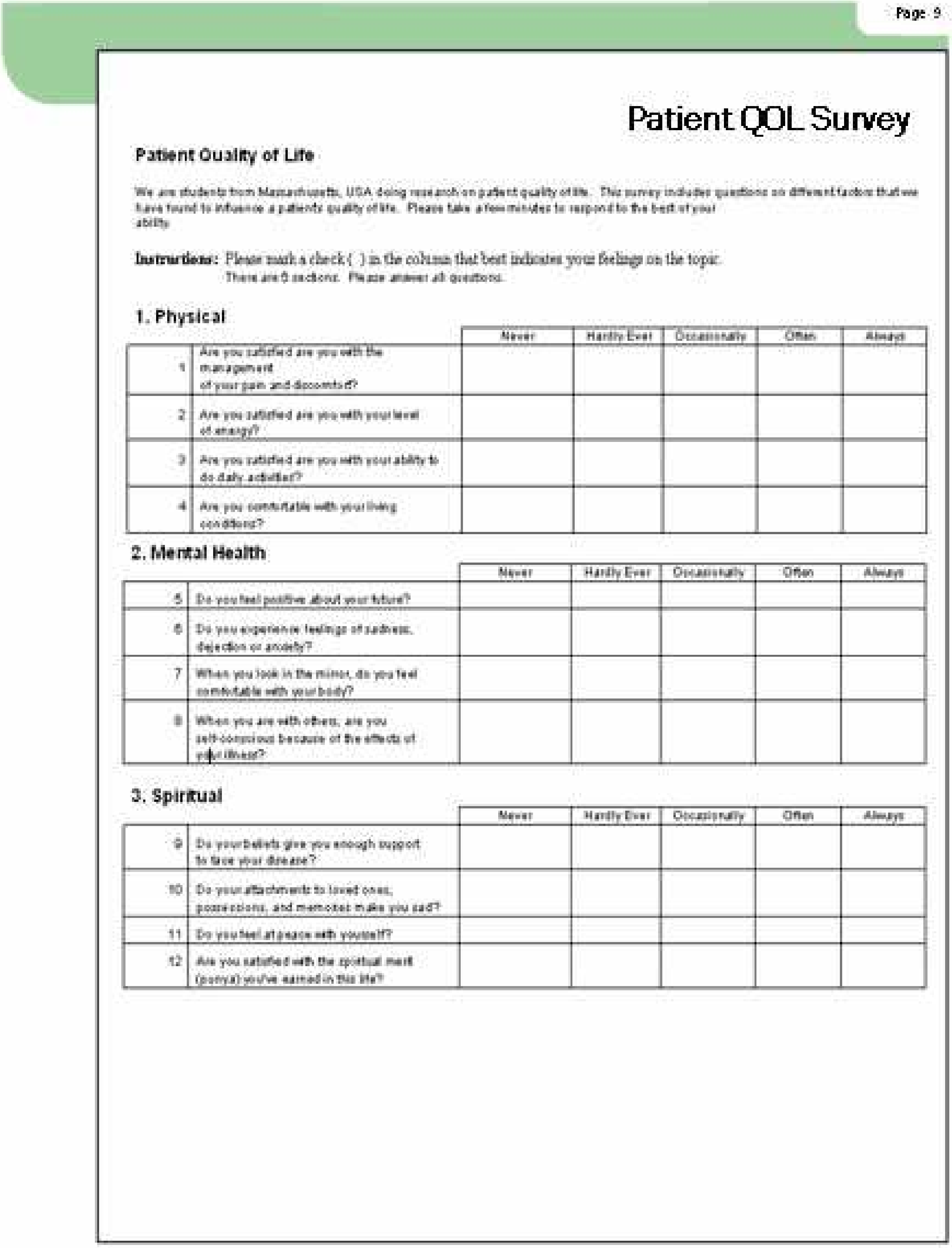
21. How important are spiritual factors to your quality of life?

22. How important are social factors to your quality of life?

23. How important are financial factors to your quality of life?

These five questions ask how important various general categories are to the patient. For example, is the patient highly concerned with their financial situation or can they still be happy even if their financial situation is not very good? How much do these factors affect the patient's quality of life?

"Does the patient decline certain treatments because they cannot afford them?



Page 9

Patient QOL Survey

Patient Quality of Life

We are students from Massachusetts, USA doing research on patient quality of life. This survey includes questions on different factors that we have found to influence a patients quality of life. Please take a few minutes to respond to the best of your ability.

Instructions: Please mark a check ( ) in the column that best indicates your feelings on the topic.
There are 5 sections. Please answer all questions.

1. Physical

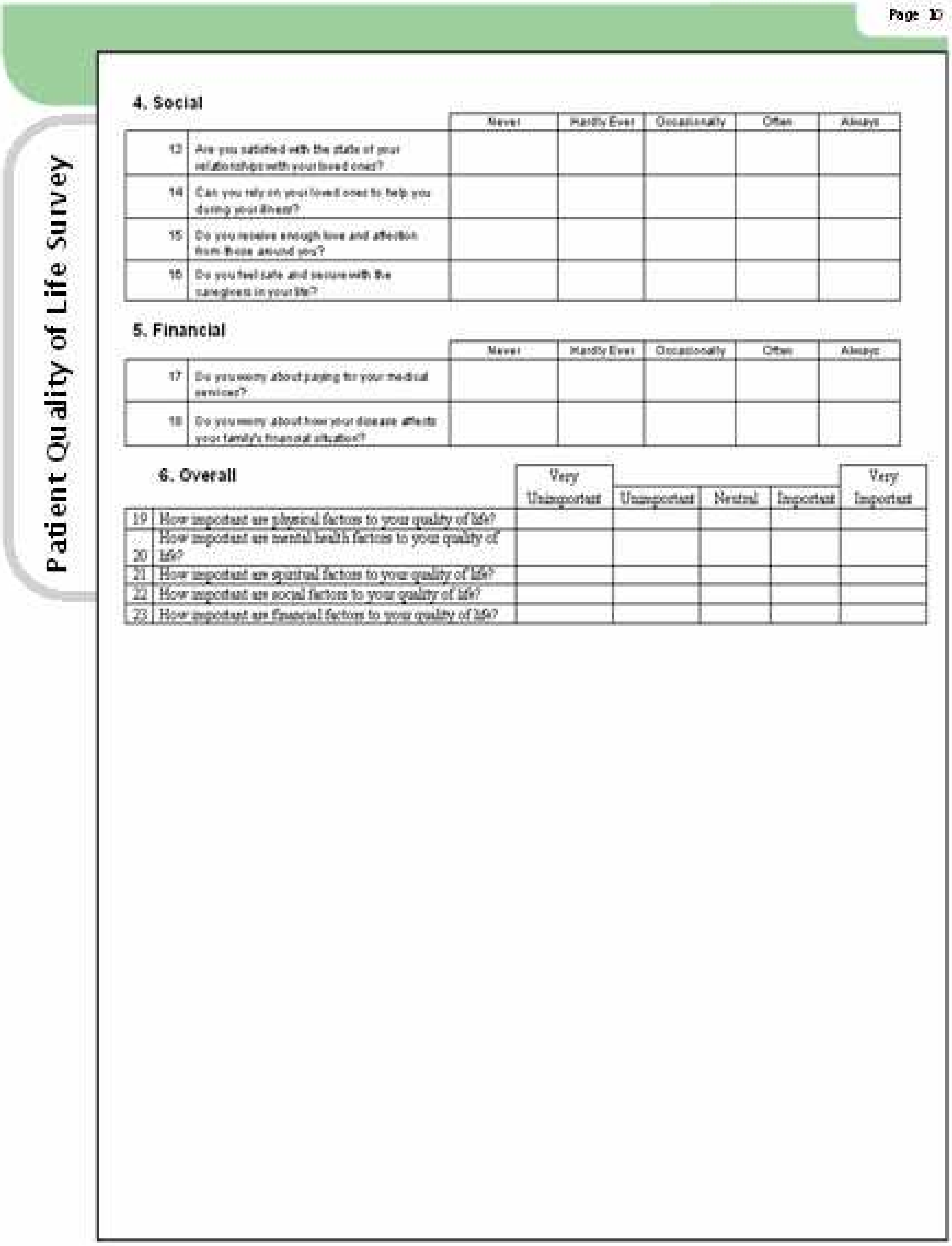
		Never	Hardly Ever	Occasionally	Often	Always
1	Are you satisfied are you with the management of your pain and discomfort?					
2	Are you satisfied are you with your level of energy?					
3	Are you satisfied are you with your ability to do daily activities?					
4	Are you comfortable with your living conditions?					

2. Mental Health

		Never	Hardly Ever	Occasionally	Often	Always
5	Do you feel positive about your future?					
6	Do you experience feelings of sadness, dejection or anxiety?					
7	When you look in the mirror, do you feel comfortable with your body?					
8	When you are with others, are you self-conscious because of the effects of your illness?					

3. Spiritual

		Never	Hardly Ever	Occasionally	Often	Always
9	Do your beliefs give you enough support to face your disease?					
10	Do your attachments to loved ones, possessions, and memories make you sad?					
11	Do you feel at peace with yourself?					
12	Are you satisfied with the spiritual merit (punya) you've earned in this life?					



Page 10

Patient Quality of Life Survey

4. Social

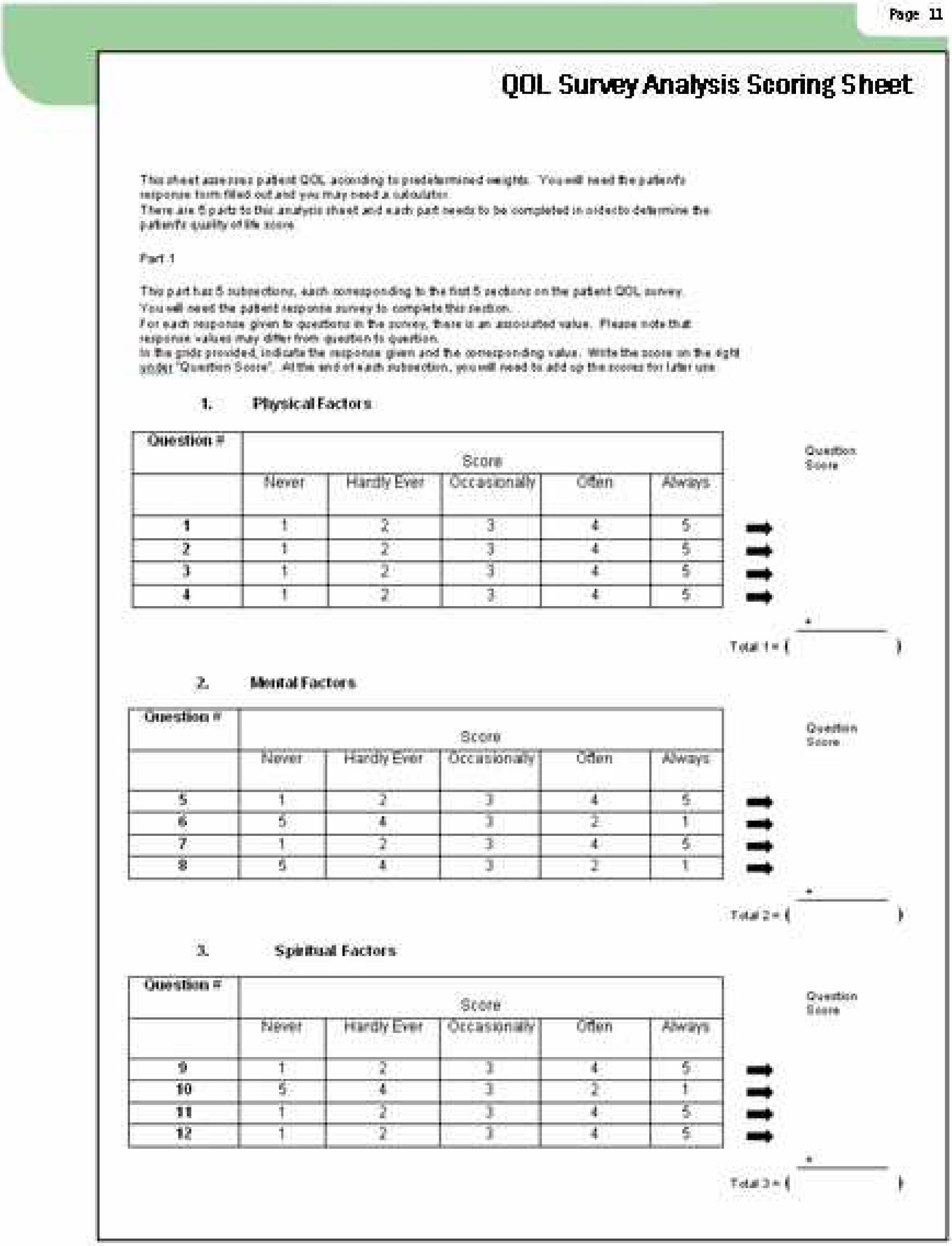
		Never	Hardly Ever	Occasionally	Often	Always
13	Are you satisfied with the state of your relationships with your loved ones?					
14	Can you rely on your loved ones to help you during your illness?					
15	Do you receive enough love and affection from those around you?					
16	Do you feel safe and secure with the caregivers in your life?					

5. Financial

		Never	Hardly Ever	Occasionally	Often	Always
17	Do you worry about paying for your medical services?					
18	Do you worry about how your disease affects your family's financial situation?					

6. Overall

		Very Unimportant	Unimportant	Neutral	Important	Very Important
19	How important are physical factors to your quality of life?					
20	How important are mental health factors to your quality of life?					
21	How important are spiritual factors to your quality of life?					
22	How important are social factors to your quality of life?					
23	How important are financial factors to your quality of life?					



Page 11

QOL Survey Analysis Scoring Sheet

This sheet assesses patient QOL according to predetermined weights. You will need the patient's response form filled out and you may need a calculator.
There are 5 parts to this analysis sheet and each part needs to be completed in order to determine the patient's quality of life score.

Part 1

This part has 5 subsections, each corresponding to the first 5 sections on the patient QOL survey.
You will need the patient response survey to complete this section.
For each response given to questions in the survey, there is an associated value. Please note that response values may differ from question to question.
In the grids provided, indicate the response given and the corresponding value. Write the score on the right under "Question Score". At the end of each subsection, you will need to add up the scores for later use.

1. Physical Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
1	1	2	3	4	5	➡	
2	1	2	3	4	5	➡	
3	1	2	3	4	5	➡	
4	1	2	3	4	5	➡	

+

Total 1 = ( )

2. Mental Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
5	1	2	3	4	5	➡	
6	5	4	3	2	1	➡	
7	1	2	3	4	5	➡	
8	5	4	3	2	1	➡	

+

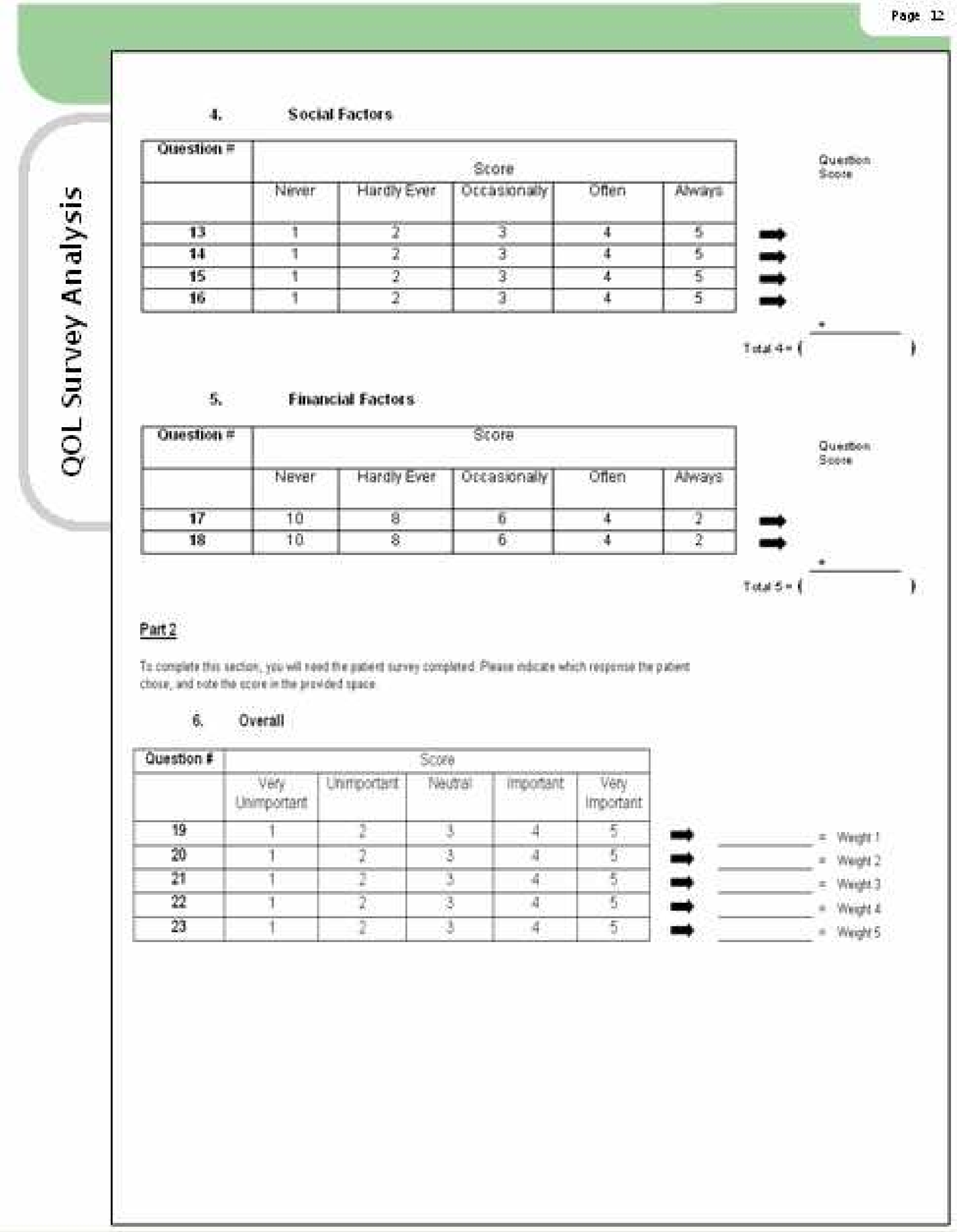
Total 2 = ( )

3. Spiritual Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
9	1	2	3	4	5	➡	
10	5	4	3	2	1	➡	
11	1	2	3	4	5	➡	
12	1	2	3	4	5	➡	

+

Total 3 = ( )



4. Social Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
13	1	2	3	4	5	➡	
14	1	2	3	4	5	➡	
15	1	2	3	4	5	➡	
16	1	2	3	4	5	➡	

Total 4 = (* ______)

5. Financial Factors

Question #	Score						Question Score
	Never	Hardly Ever	Occasionally	Often	Always		
17	10	8	6	4	2	➡	
18	10	8	6	4	2	➡	

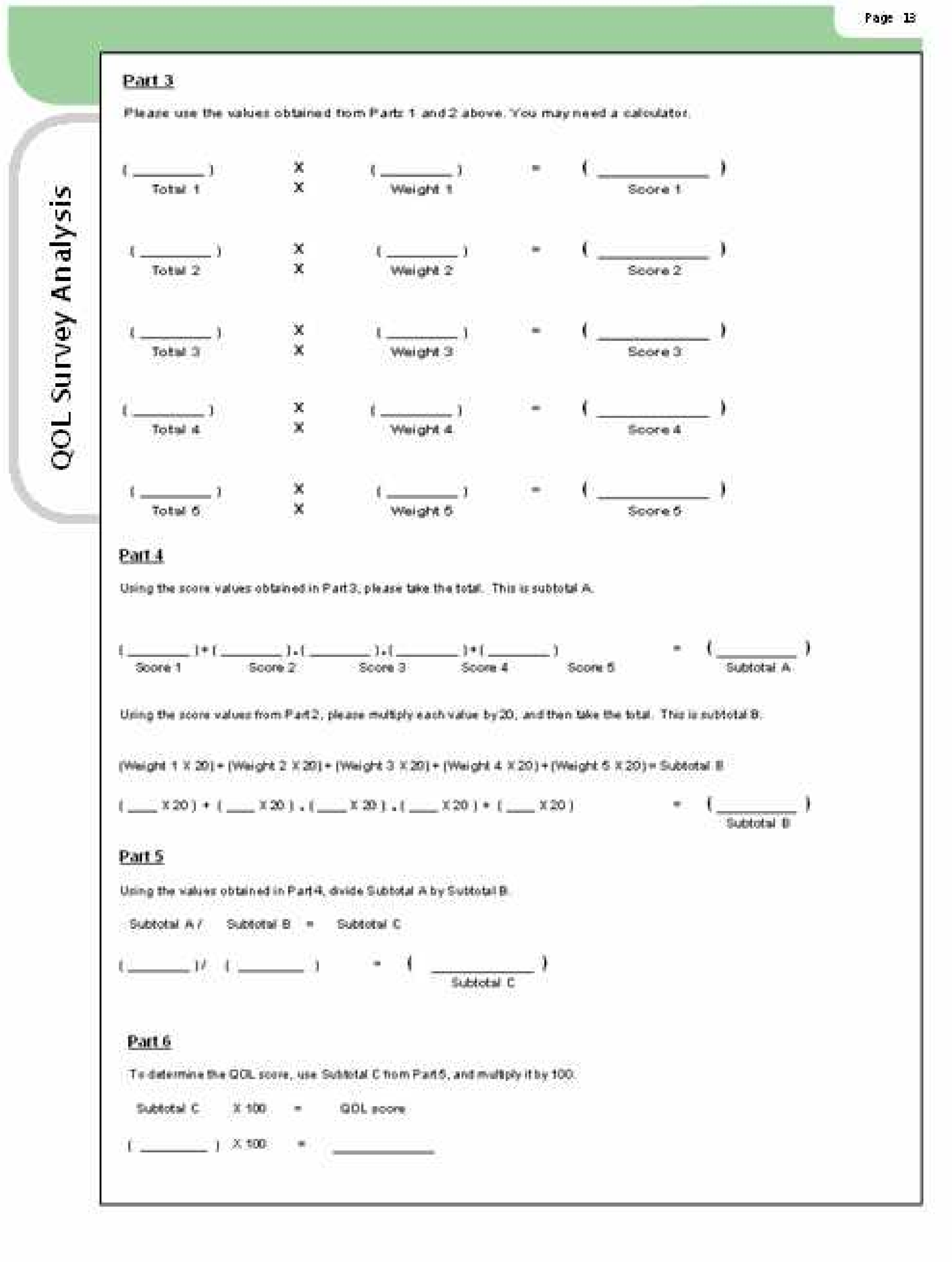
Total 5 = (* ______)

Part 2

To complete this section, you will need the patient survey completed. Please indicate which response the patient chose, and note the score in the provided space.

6. Overall

Question #	Score						
	Very Unimportant	Unimportant	Neutral	Important	Very Important		
19	1	2	3	4	5	➡	______ = Weight 1
20	1	2	3	4	5	➡	______ = Weight 2
21	1	2	3	4	5	➡	______ = Weight 3
22	1	2	3	4	5	➡	______ = Weight 4
23	1	2	3	4	5	➡	______ = Weight 5



Page 13

QOL Survey Analysis

Part 3

Please use the values obtained from Parts 1 and 2 above. You may need a calculator.

(________) X (________) = (____________)
Total 1 X Weight 1 Score 1

(________) X (________) = (____________)
Total 2 X Weight 2 Score 2

(________) X (________) = (____________)
Total 3 X Weight 3 Score 3

(________) X (________) = (____________)
Total 4 X Weight 4 Score 4

(________) X (________) = (____________)
Total 5 X Weight 5 Score 5

Part 4

Using the score values obtained in Part 3, please take the total. This is subtotal A.

(_______) + (_______) + (_______) + (_______) + (_______) = (_________)
Score 1 Score 2 Score 3 Score 4 Score 5 Subtotal A

Using the score values from Part 2, please multiply each value by 20, and then take the total. This is subtotal B.

(Weight 1 X 20) + (Weight 2 X 20) + (Weight 3 X 20) + (Weight 4 X 20) + (Weight 5 X 20) = Subtotal B

(____ X 20) + (____ X 20) + (____ X 20) + (____ X 20) + (____ X 20) = (_________)
Subtotal B

Part 5

Using the values obtained in Part 4, divide Subtotal A by Subtotal B.

Subtotal A / Subtotal B = Subtotal C

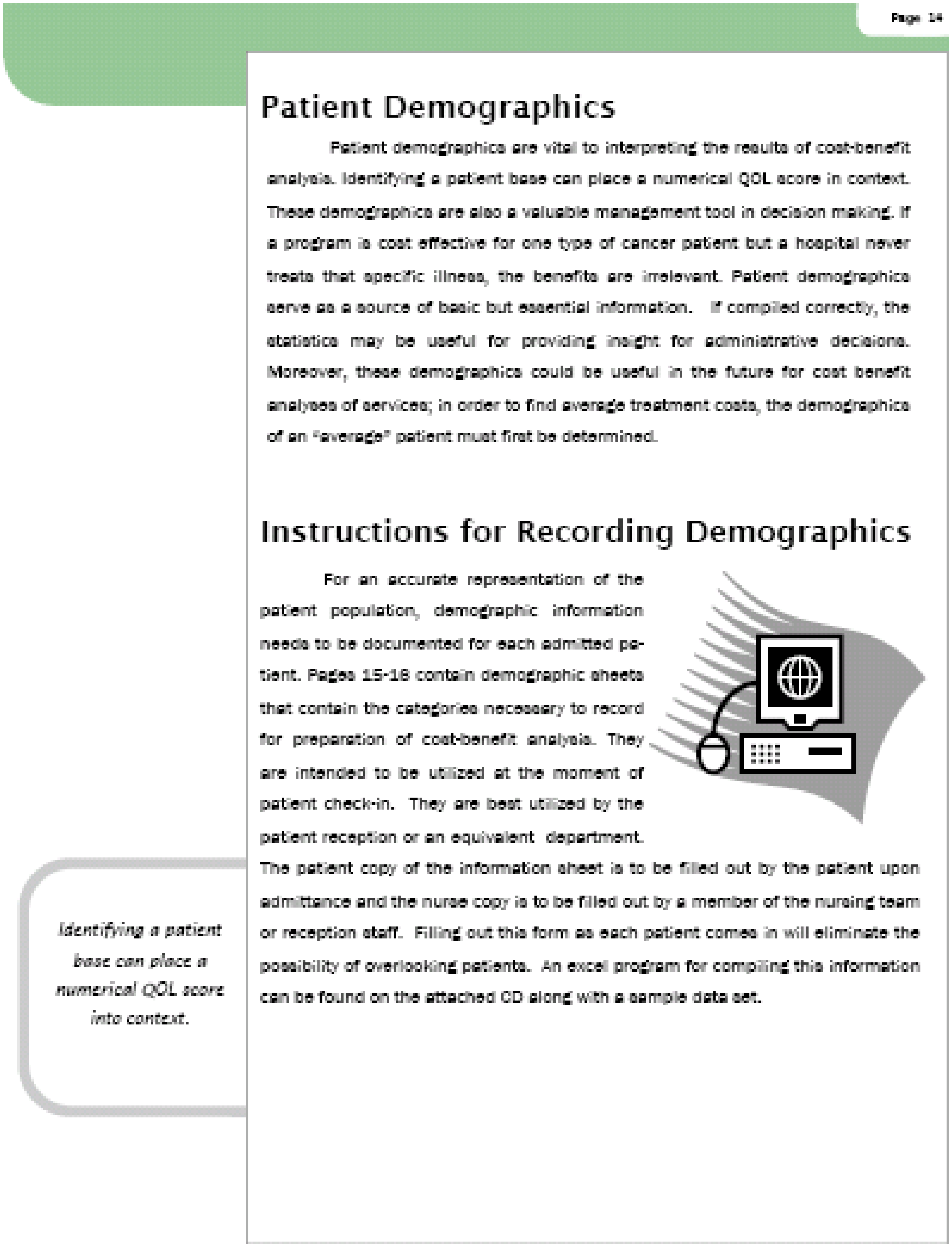
(_______) / (_______) = (___________)
Subtotal C

Part 6

To determine the QOL score, use Subtotal C from Part 5, and multiply it by 100.

Subtotal C X 100 = QOL score

(________) X 100 = ___________



Page 14

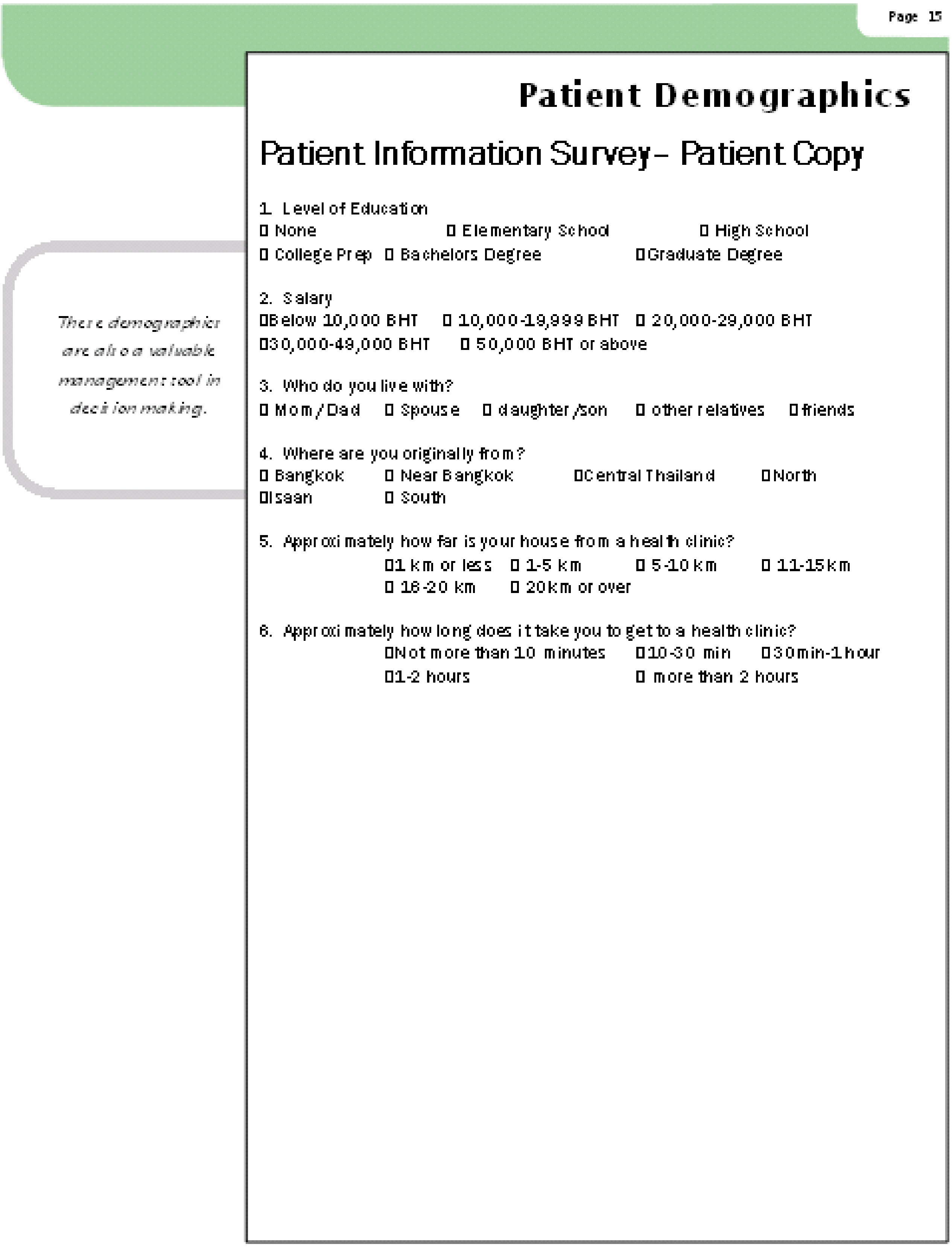
Patient Demographics

Patient demographics are vital to interpreting the results of cost-benefit analysis. Identifying a patient base can place a numerical QOL score in context. These demographics are also a valuable management tool in decision making. If a program is cost effective for one type of cancer patient but a hospital never treats that specific illness, the benefits are irrelevant. Patient demographics serve as a source of basic but essential information. If compiled correctly, the statistics may be useful for providing insight for administrative decisions. Moreover, these demographics could be useful in the future for cost benefit analyses of services; in order to find average treatment costs, the demographics of an "average" patient must first be determined.

Instructions for Recording Demographics

For an accurate representation of the patient population, demographic information needs to be documented for each admitted patient. Pages 15-18 contain demographic sheets that contain the categories necessary to record for preparation of cost-benefit analysis. They are intended to be utilized at the moment of patient check-in. They are best utilized by the patient reception or an equivalent department. The patient copy of the information sheet is to be filled out by the patient upon admittance and the nurse copy is to be filled out by a member of the nursing team or reception staff. Filling out this form as each patient comes in will eliminate the possibility of overlooking patients. An excel program for compiling this information can be found on the attached CD along with a sample data set.

Identifying a patient base can place a numerical QOL score into context.



Page 15

Patient Demographics

Patient Information Survey – Patient Copy

These demographics are also a valuable management tool in decision making.

1. Level of Education
☐ None ☐ Elementary School ☐ High School
☐ College Prep ☐ Bachelors Degree ☐ Graduate Degree

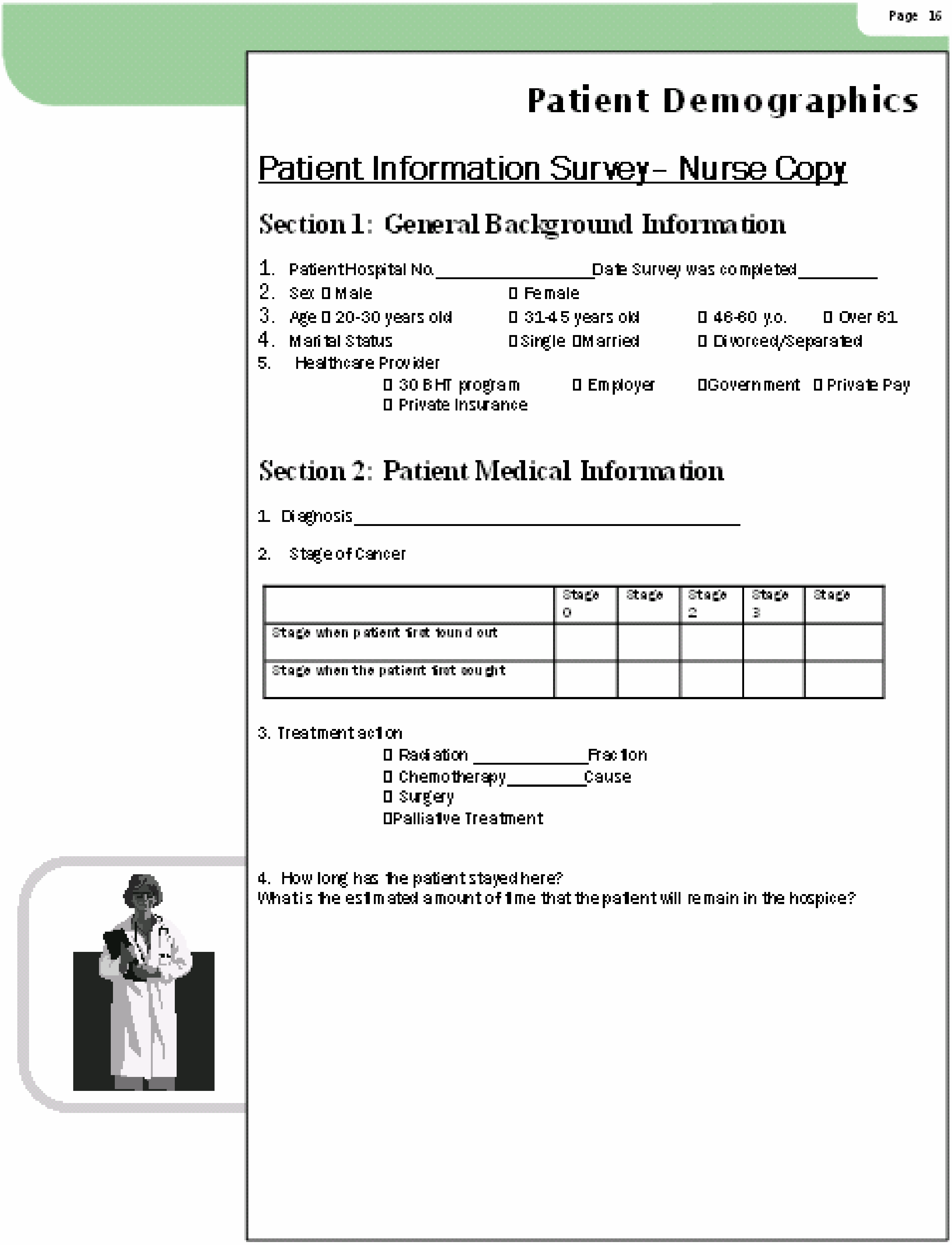
2. Salary
☐ Below 10,000 BHT ☐ 10,000-19,999 BHT ☐ 20,000-29,000 BHT
☐ 30,000-49,000 BHT ☐ 50,000 BHT or above

3. Who do you live with?
☐ Mom/Dad ☐ Spouse ☐ daughter/son ☐ other relatives ☐ friends

4. Where are you originally from?
☐ Bangkok ☐ Near Bangkok ☐ Central Thailand ☐ North
☐ Isaan ☐ South

5. Approximately how far is your house from a health clinic?
☐ 1 km or less ☐ 1-5 km ☐ 5-10 km ☐ 11-15 km
☐ 16-20 km ☐ 20 km or over

6. Approximately how long does it take you to get to a health clinic?
☐ Not more than 10 minutes ☐ 10-30 min ☐ 30 min-1 hour
☐ 1-2 hours ☐ more than 2 hours



Page 16

Patient Demographics

Patient Information Survey – Nurse Copy

Section 1: General Background Information

1. Patient Hospital No.________________ Date Survey was completed________
2. Sex ☐ Male ☐ Female
3. Age ☐ 20-30 years old ☐ 31-45 years old ☐ 46-60 y.o. ☐ Over 61
4. Marital Status ☐ Single ☐ Married ☐ Divorced/Separated
5. Healthcare Provider
   ☐ 30 BHT program ☐ Employer ☐ Government ☐ Private Pay
   ☐ Private Insurance

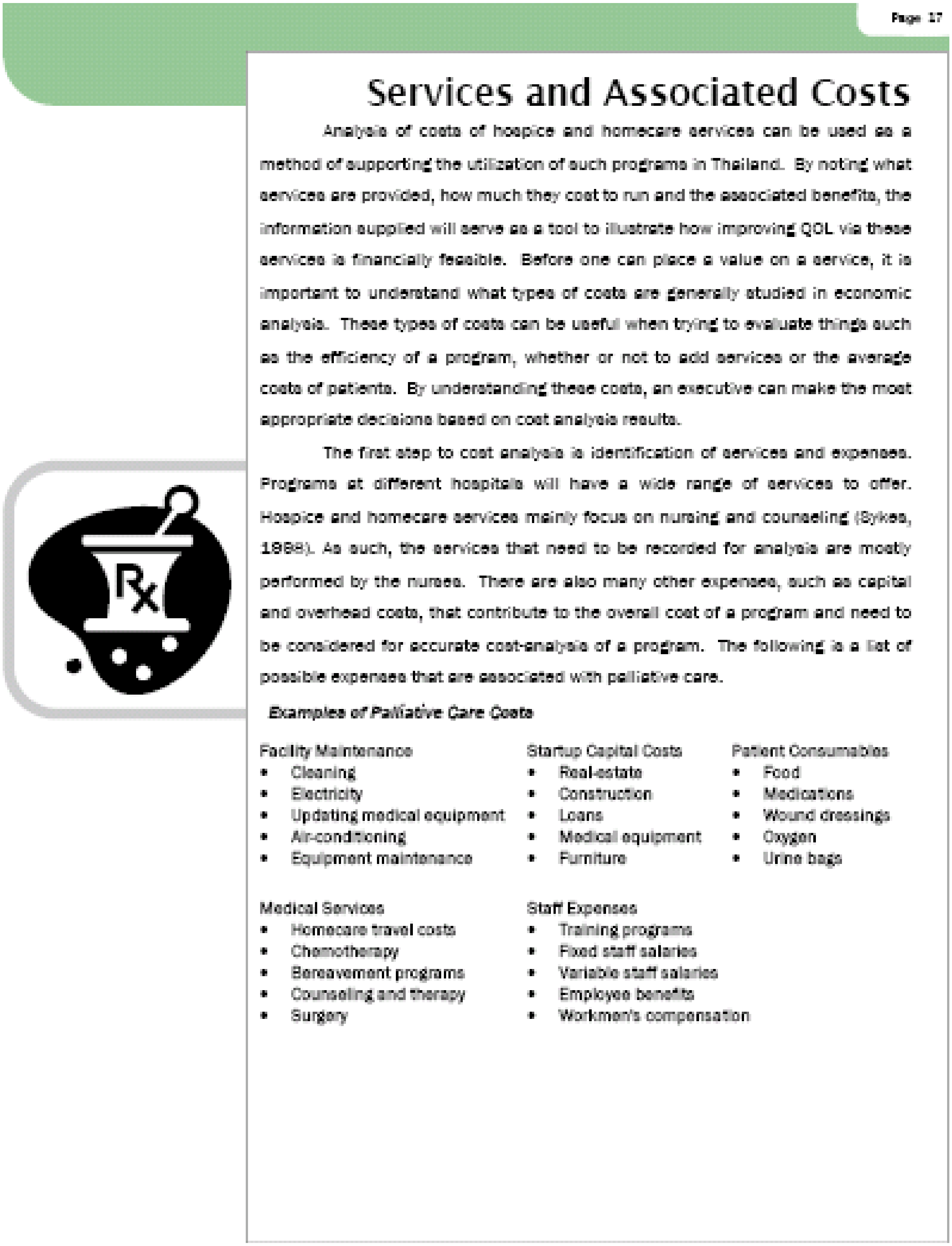
Section 2: Patient Medical Information

1. Diagnosis____
2. Stage of Cancer

	Stage 0	Stage	Stage 2	Stage 3	Stage
Stage when patient first found out					
Stage when the patient first sought					

3. Treatment action
   ☐ Radiation ____________ Fraction
   ☐ Chemotherapy________ Cause
   ☐ Surgery
   ☐ Palliative Treatment

4. How long has the patient stayed here?
What is the estimated amount of time that the patient will remain in the hospice?



Services and Associated Costs

Analysis of costs of hospice and homecare services can be used as a method of supporting the utilization of such programs in Thailand. By noting what services are provided, how much they cost to run and the associated benefits, the information supplied will serve as a tool to illustrate how improving QOL via these services is financially feasible. Before one can place a value on a service, it is important to understand what types of costs are generally studied in economic analysis. These types of costs can be useful when trying to evaluate things such as the efficiency of a program, whether or not to add services or the average costs of patients. By understanding these costs, an executive can make the most appropriate decisions based on cost analysis results.

The first step to cost analysis is identification of services and expenses. Programs at different hospitals will have a wide range of services to offer. Hospice and homecare services mainly focus on nursing and counseling (Sykes, 1988). As such, the services that need to be recorded for analysis are mostly performed by the nurses. There are also many other expenses, such as capital and overhead costs, that contribute to the overall cost of a program and need to be considered for accurate cost-analysis of a program. The following is a list of possible expenses that are associated with palliative care.

Examples of Palliative Care Costs

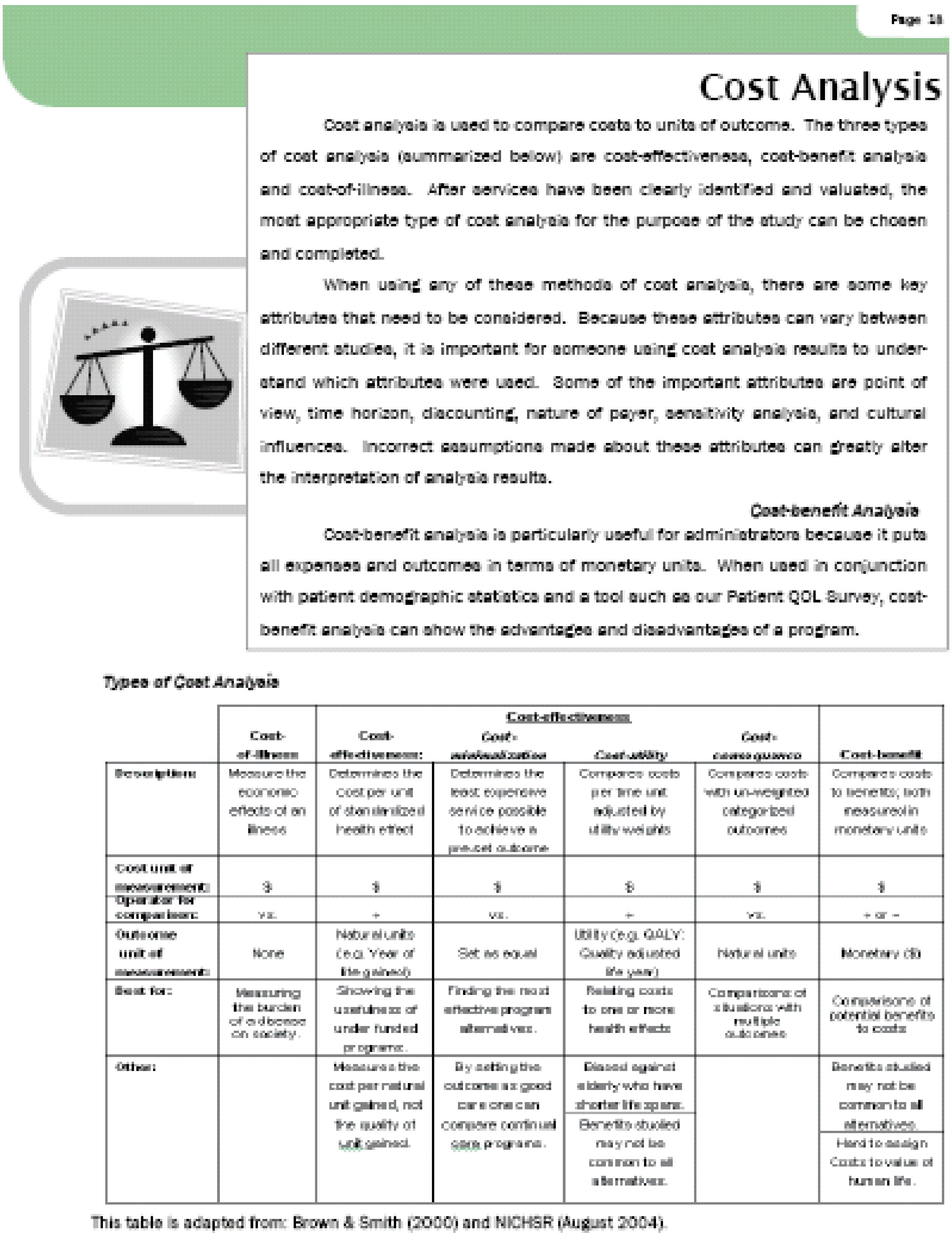
Facility Maintenance
- Cleaning
- Electricity
- Updating medical equipment
- Air-conditioning
- Equipment maintenance

Startup Capital Costs
- Real-estate
- Construction
- Loans
- Medical equipment
- Furniture

Patient Consumables
- Food
- Medications
- Wound dressings
- Oxygen
- Urine bags

Medical Services
- Homecare travel costs
- Chemotherapy
- Bereavement programs
- Counseling and therapy
- Surgery

Staff Expenses
- Training programs
- Fixed staff salaries
- Variable staff salaries
- Employee benefits
- Workmen's compensation



Cost Analysis

Cost analysis is used to compare costs to units of outcome. The three types of cost analysis (summarized below) are cost-effectiveness, cost-benefit analysis and cost-of-illness. After services have been clearly identified and valuated, the most appropriate type of cost analysis for the purpose of the study can be chosen and completed.

When using any of these methods of cost analysis, there are some key attributes that need to be considered. Because these attributes can vary between different studies, it is important for someone using cost analysis results to understand which attributes were used. Some of the important attributes are point of view, time horizon, discounting, nature of payer, sensitivity analysis, and cultural influences. Incorrect assumptions made about these attributes can greatly alter the interpretation of analysis results.

Cost-benefit Analysis

Cost-benefit analysis is particularly useful for administrators because it puts all expenses and outcomes in terms of monetary units. When used in conjunction with patient demographic statistics and a tool such as our Patient QOL Survey, cost-benefit analysis can show the advantages and disadvantages of a program.

Types of Cost Analysis

		Cost-effectiveness				
	Cost-of-illness	**Cost-effectiveness:**	***Cost-minimalization***	***Cost-utility***	***Cost-consequence***	**Cost-benefit**
Descriptions:	Measure the economic effects of an illness	Determines the cost per unit of standardized health effect	Determines the least expensive service possible to achieve a pre-set outcome	Compares costs per time unit adjusted by utility weights	Compares costs with un-weighted categorized outcomes	Compares costs to benefits; both measured in monetary units
Cost unit of measurement:	$	$	$	$	$	$
Operator for comparison:	vs.	÷	vs.	÷	vs.	÷ or −
Outcome unit of measurement:	None	Natural units (e.g. Year of life gained)	Set as equal	Utility (e.g. QALY: Quality adjusted life year)	Natural units	Monetary ($)
Best for:	Measuring the burden of a disease on society.	Showing the usefulness of under funded programs.	Finding the most effective program alternatives.	Relating costs to one or more health effects	Comparisons of situations with multiple outcomes	Comparisons of potential benefits to costs
Other:		Measures the cost per natural unit gained, not the quality of unit gained.	By setting the outcome as good care one can compare continual care programs.	Biased against elderly who have shorter life spans. Benefits studied may not be common to all alternatives.		Benefits studied may not be common to all alternatives. Hard to assign Costs to value of human life.

This table is adapted from: Brown & Smith (2000) and NICHSR (August 2004).

Works Cited

Brown, G.C. & Smith, A. F. (2000). Understand Cost Effectiveness: A Detailed Review. Retrieved on February 18, 2006 from http://bjo.bmjjournals.com/cgi/reprint/84/7/784

Cooley, M. E. (1998). Quality of life in persons with non-small cell lung cancer: A concept analysis. *Cancer Nursing*, 21, 151-161.

HospiceNet: *For patients and families facing life-threatening illness*. Retrieved on October 30, 2005, from http://www.hospicenet.org/html/concept.html

National Information Center on Health Services Research and Health Care Technology (August 2004). HTA 101: IV. COST ANALYSIS METHODS. Retrieved February 18, 2006 from http://www.nlm.nih.gov/nichsr/hta101/ta10106.html

Russel, J.(2000). To comfort always. *Journal of Musculoskeletal Pain*, 8(3).

Acknowledgements

We would like to acknowledge the following people for their contributions to the success of our project work. Without their assistance, guidance, and support we could not have completed our project as successfully. Thank you!

- Khun Ahn
- Joy Bhosai
- Professor Chrys Demetry
- Professor Rob Krueger
- Thitwan Lertpiya
- Lopburi Hospital Staff
- Mahavachiralongkorn Thanyaburi Cancer Center Staff

Janet Mullen
Khun Natchea
Dr. Patchai
Professor Supawan
Dr. Thanadej
Professor Seth Tuler
Professor Rick Vaz

Further Reading

For more information on the content of this packet, please see our full research report included on the CD. This report include background research information, methodology, findings and recommendations. The research detailed in the full report provided the means to create this packet.