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LOMA LINDA UNIVERSITY
School of Nursing
in conjunction with the
Faculty of Graduate Studies

Hospice Care in Malaysia: Knowledge, Attitude and Time of Discussion

by

Shanthi Ellen Solomon

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Nursing

June 2015

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

, Chairperson

Patricia Pothier, Associate Professor of Nursing

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Betty Winslow, Professor of Nursing

ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to Dr. Pothier who has been not only my committee chair, but also my supporter and cheerleader during my long doctoral journey. Patty I want to thank you, and hope that you can be proud of the researcher you have developed with your efforts.

I would like to thank my committee members for their advice and direction. I owe a debt of gratitude to Mark Haviland for his patience and genuine interest in my learning. Although I was encouraged by many well-wishers to continue with my higher education, Betty Winslow truly inspired me to do so. My gratitude knows no bounds for the many early morning conference calls during which we discussed what was important and what was not. Their support sustained me as I struggled through discovering that research uncovers things that were totally unexpected – I thank you for your time, support, and effort.

To Teddric Jon Mohr I owe a debt of gratitude for setting me on the path that led me to Loma Linda University. Thanks to my husband for staying by me through the long haul as I pursued my dream, showing love, patience and comfort and giving counsel when things seemed bleak. My hiking friends here at Loma Linda, your love and support through this long endeavor gave me hope and encouragement. The love and prayers of family and friends in Penang and India will always be treasured. And finally, I would like to thank God for providing me the undeserved opportunity to expand my world and ways of thinking.

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ABSTRACT OF THE DISSERTATION

Hospice Care in Malaysia: Knowledge, Attitude and Time of Discussion

by

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Doctor of Philosophy, Graduate Program in Nursing

Loma Linda University, June 2015

Dr. Patricia K.T Pothier, Chairperson

Despite available and adequate hospice care resources, fewer terminally ill patients in Malaysia use hospice care services than one might reasonably expect. It is reported that only around 10% of patients who die of terminal illness in Malaysia, die in hospice care (Devaraj, 2003). The projected number of individuals that should receive palliative care in Malaysia is 17 to 27% (Connor & Sepulveda Bermedo, 2014).

In order to study why hospice care is not accessed as expected, nurses and doctors in Penang and Sabah completed a survey measuring knowledge of current hospice practices, attitude toward caring for the dying, personal death anxiety and when they believe is the right time to discuss hospice care. No significant relationships were found between knowledge of hospice care, attitude towards caring for the dying and personal death anxiety and the decision of nurses and doctors to introduce the topic of hospice care with terminally ill or dying patients.

There being a lack of consensus on the interpretation of “terminal illness” and “dying patient”, the right time to discuss hospice could not be determined. Along with the identification of the gap in the process of terminally ill patients receiving end-of-life-care, this study has identified how a more relevant method of research for the Malaysian setting may improve the time and quantity of hospice referral.

CHAPTER ONE

INTRODUCTION

Background

Despite available and adequate hospice care resources in Malaysia, terminally ill patients often do not receive hospice care before death. They are either not referred to hospice, or not referred early enough (Devaraj, 2003). Not receiving hospice care, results in needless discomfort of mind and body to the families and the terminally ill patients (Loh, 2006). The reasons for this lack of referral to hospice in Malaysia are not known.

In the experience of the author, terminally ill patients are admitted to Intensive Care Units (ICU's) and acute care units by family members who do not know what else to do. The majority of such patients are unable to make treatment decisions. Therefore, families act as decision makers and grapple with the ethical battle of "giving up" versus "doing everything that can be done" (Borowske, 2012). When these patients have a respiratory or cardiac arrest while in the acute care unit, valiant battles are fought to preserve life. Often health professionals discover that these terminally ill patients were only on the acute care units because the families did not know about hospice care and that hospice care would have been more appropriate.

The Non Communicable Diseases (NCD) Country Profiles for 2014 indicate that 15% of the total of 146,000 deaths for that year in Malaysia was due to cancer (WHO, 2014). In Malaysia it is generally thought that only individuals dying of cancer require hospice care. Yet not all these individuals receive hospice care. More than 2.5 million people die each year in the United States. It is reported that at least 60% died in hospitals in the period between 1998 and 2011. An estimated half the number of those individuals

were cared for in ICUs at least 3 days before their deaths. Twenty percent of these patients died in the ICU after the decision to withhold life sustaining therapy (Lusardi et al., 2011). Based on this author's experience, there is a possibility that Malaysia has equivalent figures in terms of the percentage of patients who died in the ICU after the decision was made to stop therapy.

In comparison to the US where mortality records have been consistently maintained since 1900, Malaysia had no published reports of actual death rates for many years. Before 2002 the percentage of deaths that were medically certified remained around 30-40% (Karim, 1997). The World Health Organization's country profile of cancer in Malaysia indicated that 15% of the total 146,00 deaths were due to cancer (WHO, 2014). The National Cancer Registry of Malaysia published the 2007 cancer statistics in 2011 indicating an incidence rate of 10% (Omar & Tamin, 2011). According to the last documented census statistics, out of 48,841 deaths that were not medically certified but were reported, only 7% were due to cancer. Out of medically certified deaths, 10.3% were reported to be due to cancer (Department of Statistics, 2008). Information from the National Cancer Registry and the Census Department of the Ministry of Health, Malaysia, indicate that all reported deaths may not be medically certified. Sudden deaths and geriatric deaths which take place at home are generally reported by police without evaluation by medical personnel.

In considering the figures given, an inconsistency is clearly observed. Either the cancer rates are rising more rapidly than expected or the reports are not accurate. Such inconsistencies as well as a lack of research in hospice care make it difficult to determine the actual utilization rate of hospice care (Lim & Yahaya, 2003). Looi et al. (2004)

estimated the disease burden of cancer being 40,000 cases /year. The fact that only around 10% of patients who die of terminal illness in Malaysia, die in hospice care (Devaraj, 2003) when the projected number of individuals that should receive palliative care in Malaysia is 17 to 27% (Connor & Sepulveda Bermedo, 2014) is very inappropriate.

Since hospice care in Malaysia is largely utilized by individuals with cancer, and with an expected 40, 000 new cases of some form of cancer per year in a population of 27 million (Looi et al. 2004), a better understanding of hospice care is greatly needed.

This raises the questions: Why do patients end up in acute care, only to die? Were they referred to hospice care? Was hospice care discussed with them or their families? Who is responsible for the vital knowledge being given to terminally ill patients and their relatives about hospice care? When is the right time to provide information regarding hospice care to terminally ill patients? These and many other questions need answers, so that terminally ill patients and their families in Malaysia have the opportunity to deal with the normal, though painful, process of dying in a better way.

To begin with, there is a need to appreciate the final end of the spectrum of life, which is death. There is a need to understand the role of palliation, by all who deal with terminally ill patients and families. Finally, there is a need to understand what hospice care can do for patients and their families. With comprehension comes the ability to provide information.

The term “palliate” is a transitive verb, which means “to make the effects of (something, such as an illness) less painful, harmful, or harsh” (Meriam-Webster’s online dictionary, n.d). However to misinformed individuals, whether health professional or

not, the word appears to mean stopping medical care (Hanratty et al., 2006), whereas, palliative care is the active care of patients whose disease may not be responsive to curative treatment. Palliation of the symptoms of the disease along with psychosocial care for the whole person is what hospice care is about.

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2014 para 1). Along this line of thought, the National Hospice and Palliative Care Organization reports that hospice care may involve the provision of medical therapy to provide relief or decrease symptoms experienced by the patient, the supply of drugs medical care and equipment and the assistance with the emotional, spiritual and psychosocial aspects of dying (NHPCO, 2009).

The pictorial depiction in Figure 1 of hospice and palliative care was developed by Ferris (2002) for the Canadian Hospice Palliative Care Association (CHPCA). It involves care for the patient and family with the amount of hospice palliative care increasing as curative therapies decrease.

According to this model, the hospice palliative care approach during illness/bereavement aims to: (a) treat all active issues, (b) prevent new issues from occurring, (c) promote opportunities for meaningful and valuable experience, personal and spiritual growth, and self-actualization (Ferris et al., 2002, p. 115).

The CHPCA uses the combined term hospice palliative care to indicate seamless end of life care for those with life limiting illness. However it is agreed that the care

provided in the acute care setting is palliative care and similar care provided away from the acute care setting (at home or a specific hospice care facility), is considered hospice care (Ferris et al., 2002).

Canadian Hospice Palliative Care Association Model

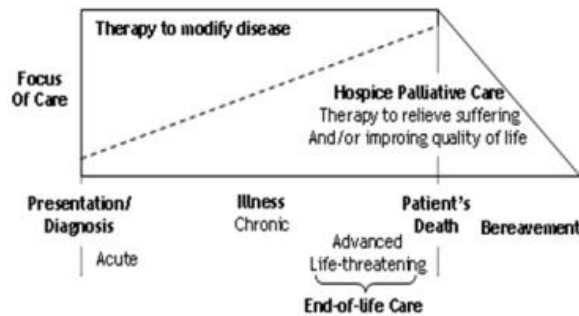


Figure 1 The Canadian Hospice and Palliative Care model

Malaysia as a Country

Malaysia has just recently risen onto the global economic scene. The United Nations Development Program ranked Malaysia 64th out of 186 countries on the Human Development Index (a composite statistic of life expectancy, education, and income indices) with a relatively well developed healthcare system that provides low cost to free health care for all Malaysian citizens (UNDP, 2013). Malaysia has a documented doctor patient ratio of 1:940 and a nurse patient ratio of 1:559. The World Health Organization recommends 1:600 and 1:200 respectively (Ministry of Health, 2006).

Although federally provided health care meets many specialty needs, hospice care which began in the 1990's is not a part of such care. Oncologists, in both the public and private sectors, recognized the need for palliative care in 1991, and hospice care as a natural progression of palliative care was started soon after (Leong, 2003). Hospice

care did not become a priority for the Malaysian Ministry of Health although palliative care did. Private hospice care services and associations were established to meet the lack of continuity of care provided in the palliative care units that were set up in government hospitals. The federal health care does not pay for hospice care, so the cost is the responsibility of families and is subsidized by funds raised by non-governmental organizations (NGOs). Satisfied families of the recipients of hospice care contribute to these funds as well. Twenty government hospitals have an established inpatient palliative care unit (PCU) with 6-12 beds each. A documented 90 organizations provide 110 hospice care services. Out of these, 22 non-governmental organizations (NGOs) account for 33 services, 20 of which are home care programs (Wright, Hamzah, Phungrassami, & Bausa-Claudio, 2008).

End of life care has been available for almost 20 years in Malaysia, but the main users of both hospice and palliative care are still individuals in advanced stages of cancer. Those with other terminal illnesses do not make use of palliative care or hospice care even towards the end of their lives. The anecdotal reporting of less than 10% of dying patients using hospice care (Devaraj, 2003) is supported by the findings of a study by Devi, Tang and Corbex in 2008. Seventy nine percent of individuals with cancer, treated at the Sarawak General hospital department of Radiotherapy, Oncology and Palliative Care, were diagnosed in the late stages. Many of them died before they could gain the full benefits of palliative and hospice care (Devi, Tang, & Corbex, 2008) .

Since the medical model for healthcare is primarily curative, death is frequently considered a failure of the efforts of health care professionals. For a clearer understanding of why terminally ill patients and families do not receive information or

referrals, it may be necessary to consider the resources for such information. How much do physicians and nurses know about hospice care? Do physicians and nurses know that certain principles of care, such as opiate drugs considered “dangerous” in regular medical care, may be appropriate for patients in hospice care? Are physicians and nurses equipped to address spiritual and psychosocial care? Answers to questions such as these may have implications for the use of hospice care.

Purpose and Aims of the Study

Based on the issues described, it may be assumed that fewer terminally ill patients in Malaysia use hospice care services than one might reasonably expect. Explanatory factors were expected to be an inadequate knowledge of hospice care practices, attitude towards caring for the dying and death anxiety.

The original purpose of this exploratory correlational study was to examine existing knowledge about hospice care, attitudes towards care of the dying, and death anxiety among nurses and physicians in Malaysia, in relation to the practice of providing hospice information to dying patients and families and referring them to hospice. During a preliminary analysis of data gathered, responses to the questions on dying patients and terminal illness seemed not to have been understood well. It became apparent that “terminal illness” was understood by participants to be cancer and “dying patient” was understood to be only those in the active dying phase. Therefore, the purpose was altered as follows;

The purpose of this exploratory correlational study was to examine existing knowledge about hospice care practices, attitudes towards care of the dying, and death anxiety among nurses and physicians in Malaysia and when they believe is the right time

to discuss hospice care. The specific aims were as follows:

Aim #1: Describe Malaysian nurses' and physicians' level of knowledge of hospice care practices; their attitude towards caring for the dying, their level of death anxiety and when they thought was the best time to discuss hospice care.

Aim #2: Examine the relationship between level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety.

Aim #3: Examine the association between selected demographic characteristics (e.g., years in practice, religion, specialty) and Malaysian nurses' and physicians' level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety.

A thorough examination of all factors that affect knowledge attitude and death anxiety was not within the scope of this study, and may be addressed through future research. Achieving suitable responses to the aims was expected to highlight probable perceptions and practices that may be conducive to or detrimental to the understanding of hospice care by Malaysian society. The findings were expected to provide insight into barriers as well as enablers to referrals and probable ideas as to how the prevalent knowledge and attitudes may be modified.

The terms "palliative care" and "hospice care" have not been clearly demarcated in many settings. In Malaysia, the terms "hospice" and "palliative care" have been used interchangeably. Since all hospice care is palliative care but not all palliative care is hospice care, one would expect a demarcation. Therefore, a better understanding of hospice care may provide an appreciation of the philosophy that underlies the practice. Although the focus of this study is hospice care, the implications of palliative care

research have been extrapolated. The reason is that the principles of care are the same, but more research is available on palliative care and they are closely related. The term “palliative care” will be used in reference to end-of life-care provided within a health care setting and the term “hospice care” will refer to care provided in the home or outside the acute care setting.

Definition of Major Constructs

For the purpose of this study, the following definitions will be used:

1. Palliative care – the treatment of the discomfort, symptoms, and related stresses (psychological and emotional) of serious illness including the relief from distressing symptoms which may be the side effects of treatments. Palliative care is provided in an acute healthcare facility.
2. Hospice care – the provision of medical therapy to provide relief or decrease symptoms experienced by the patient. It includes the supply of drugs, medical care, equipment, and assistance with the emotional, spiritual and psychosocial aspects of dying. Hospice care is most often provided in the patient’s own home.
3. Knowledge of hospice care practices – theoretic and experiential knowledge of how to deal with physical (symptom management) and psychosocial (emotional, spiritual and communication) aspects of caring for those who are terminally ill and dying.
4. Attitude
 - a. Death anxiety – An individual’s positive or negative evaluation of death, inclusive of personal death anxiety

- b. Attitude towards the care of the terminally ill – individual perceptions of what may be needed related to hospice care versus curative care for patients who are terminally ill or awaiting death.
5. Appropriate time to discuss hospice - the moment in the trajectory of a terminally ill and/or dying patient's life when hospice can be reasonably introduced.
 6. Subjective norms - an individual's perception about terminal illness and individual definition of dying itself. The perception may have a direct effect on the decision to provide hospice information. This in turn may be influenced by the perceived judgment of significant others e.g. other nurses/physicians, other health professionals, patients, patient's relatives. The term is taken from the Theory of Planned Behavior (Ajzen, 1991) and refers to the social norms of the professional group (i.e., nurses and physicians).
 7. Normative beliefs - an individual's perception of professional normative pressures, or relevant others' beliefs that he or she should or should not provide hospice information or refer to hospice. The term is taken from the Theory of Planned Behavior and refers to the social norms of the professional group (i.e., nurses and physicians).
 8. Theory - The specific constructs being studied, form a relationship that seems most suitable to explain how attitude, knowledge and behaviour are related. An interrelated set of constructs, which helps to provide structure and explain relationships among variables that make up the constructs, is considered a theory. The theory that seemed most suitable for this study was the Theory of Planned Behaviour (Ajzen, 1991). According to the Theory of Planned Behaviour, human

actions are guided by three types of considerations: (a) behavioural beliefs, (b) normative beliefs, and (c) control beliefs. Behavioural beliefs produce attitude toward behaviour, normative beliefs result in subjective norms and control beliefs give rise to the perception of behavioural control. The theory is further explained in the review of literature.

Significance of the Study

Since its inception in the UK and the US, the concept of hospice drew attention to a new sphere of patient care. It seemed initially more important to nurses than to physicians as physicians only referred patients whereas nurses provided the care (Miller, Miller, & Single, 1997). Studies indicate that primary care physicians as well as specialists have inadequate knowledge about the benefits of palliative care (Melvin & Oldham 2009) or consider hospice/palliative care as giving up (Brickner, Scannell, Marquet, & Ackerson, 2004). Similarly, studies among acute care nurses, specialized unit nurses and community nurses indicate that inadequate time to provide the psychosocial aspects of palliative care affected their choice of referral or recommendation. At other times apprehension about the psychosocial aspects of care prevented them from addressing hospice care (Lange, Thom, & Kline, 2007; Nebauer et al., 1996; Weigel, Parker, Fanning, Reyna, & Gasbarra, 2007). The present study was to have had implications for (a) patient care, (b) nurses, (c) hospice care in Malaysia and (d) for the Theory of Planned Behaviour applied in the Malaysian setting.

For Patient Care

Although hospice care services are meant for all terminal conditions, individuals with cancer remain the most common beneficiaries of hospice care in Malaysia (Devaraj,

2003). The Malaysian National Cancer Society (2006) reported a 14% cancer incidence rate out of which seventy percent present at advanced stages (Devaraj, 2003). By the time of diagnosis, curative treatment may not be effective, and hospice care referral right at the beginning of medical management would be most beneficial.

The World Health Organization has observed that the responsibility of the healthcare profession to ease the suffering will be fulfilled only when the provision of palliative/hospice care becomes a priority for public health and disease control. The World Health Organization expects hospice care to step in as part of seamless health care, stating that it is the responsibility of a country to its citizens to allow them to die well even when it cannot afford to provide them the best healthcare (WHO, 2014). Although the Malaysian government actively promoted the development of palliative care units in every general hospital, there are still doctors who do not know what practices are included in palliative care (Leong, 2003). There are nurses who do not know that the principles of pain management for terminally ill patients differ from that of pain management in other ill patients (Desai & Chaturvedi, 2003). The findings of this study were expected to influence the process of changing the existing lack of discussion/referral to hospice by documenting the need for end of life care to be provided by specifically trained nurses and doctors.

For Nurses

Nurses play a central role as caregivers and coordinators of care for patients who are terminally ill. Often nurses may be the only healthcare professionals to whom patients with cancer and their families can turn for more than just medical care (Weigel et al., 2007). Among their patients acute care nurses spend the most time with those who

are at the end of life, even though they may not be the ones who require the most time. This use of extra time with dying patients happens especially among nurses who are underprepared to provide end of life care. In attempting to balance the care of acutely ill patients along with the needs of the dying patient and family, acute care nurses are taxed beyond their ability, emotionally and physically. Knowing that such patients have a better resource than acute care hospitals may help relieve acute care nurses of compassion fatigue (Mitchell, Sakraida, Dysart-Gale, & Gadmer, 2006). They can help facilitate the receiving of appropriate care by the tactful provision of hospice information. A better understanding of hospice care practices would allow acute care nurses to realize that hospice care nurses are resources that other nurses could turn to, in situations where patients and families need such care.

Existing literature points out that most of the hospice care provided in Malaysia is rendered by nurses under the distant supervision of woefully inadequate numbers of physicians who understand palliative care and hospice management (Devi et al., 2008). The empowerment of nurses by allowing them to make decisions about medication and follow up care directly was shown to be an important determinant of a palliative hospice care programs efficiency (Devi et al., 2008). Nurses can then prepare family members to ask relevant questions when meeting with the healthcare giver to receive answers that guide their decision-making. Thus, the documentation of existing knowledge and attitudes of both physicians and nurses regarding hospice care would help in planning for necessary interventions according to areas of weakness. Such educational interventions may lead to a change in attitude towards hospice care which in turn may effect earlier discussion of hospice care by both nurses and doctors. Earlier discussion of hospice, in

turn, would allow hospital nurses who are not qualified to provide hospice care to use their time appropriately for patients who have acute care needs.

For Hospice Care in Malaysia

Pain and suffering may be considered to be one of the greatest tyrannies of mankind. In a country where health care is the right of every citizen, the treatment of pain is not a privilege only of those who can afford it, but a fundamental right of every living human being (WHO, 1996). That being said, health professions should be at the forefront of initiatives which help achieve such goals for all who suffer pain.

According to the World Health Organization declaration of 1990 (WHO, 2014) and the Barcelona declaration of 1996 (WHO, 1996), end-of-life care is to be included in every country's health services. The relief of suffering is to be made an ethical imperative such that every patient with an active, progressive, illness has a right to palliative care. It further calls for every doctor and nurse to bear the responsibility of employing the principles of palliative/hospice care in the care of these patients (Doyle & Woodruff, 2008).

In a country that has federal support for healthcare (Devi et al., 2008) but an unclear understanding of hospice care, Malaysia still has the potential for becoming a leader in hospice care in the region of South East Asia (Leong, 2003). Although a model for service delivery has been developed, it has not been being fully implemented. There is a great need for a clear definition of hospice care. The education of nurses and physicians could provide improved coordination among hospice and palliative care services – both nongovernmental and hospital-based (Leong, 2003). When there is a clear definition of hospice care, the provision of hospice information at the right time

may be better. Being able to define hospice clearly would in turn place healthcare professionals in Malaysia in total agreement with Dame Cicely Saunders promise to her patients “You must matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die” (Saunders, 2006, p. xxiii).

This study could provide the impetus for refining educational needs for health professionals and contribute towards the process of clearly defining the concept of hospice for the country, thereby arriving at the destination of promoting good end of life care as a human right.

For the Theory that Overarches the Study

Hospice care “is not just a new medical subspecialty but a way of thinking about medicine’s goals in a more penetrating way” (Callahan, 2000, p. 4). However when it has been acknowledged that hospice/palliative care has not been well conceptualized within the culture of a country, it becomes clear that providing hospice care information has not become a way of thinking for the health professionals who practice there. Choices and behaviors are said to be the outcomes of an interaction of factors in the human mind. Theories provide a framework for understanding patterns of thought, practice or situations. The Theory of Planned Behavior developed by Ajzen (1991) has been used to observe the influences on the choice of health professionals. The prediction of physician behavior has been the subject of some TPB studies (Bain, 2007; Grimshaw, Eccles, Walker, & Thomas, 2002; Millstein, 1996; Sanders & Satyvavolu, 2002). An examination of nurse behavior has also been considered in other studies using this theory (Dwyer, Williams, & Mummery, 2005). It would therefore be appropriate to use the

Theory of Planned Behavior to understand the discrepancies that lead to the inadequate use of hospice care services which are available to people in Malaysia.

The Theory of Planned Behavior is an evolving one, with continuing research adding to its application in understanding factors that influence or affect behavior. This study may further its application in understanding and predicting or influencing behavior of health professionals that would improve patient care for the terminally ill.

Summary

Based on what is understood from the Theory of Planned Behavior, the provision of hospice information to terminally ill patients at the right time may be improved by increasing knowledge of hospice care practices, a positive attitude towards care of the dying, lower death anxiety, and an increasing awareness of guidelines (normative beliefs) (Devi, Tang, & Corbex, 2006). In addition, support from colleagues provides evidence of utilization of hospice care services (subjective norms) (Friedman, Harwood, & Shields, 2002; Lorenz et al., 2008) and may decrease the sense of failure that comes from not having cured the patient. Integrating concepts of palliative care into continuing education sessions and routine assessment also have been effective (Bain, 2007; Grimshaw et al., 2002). The provision of hospice information at the right time may improve the quality of life for terminally ill and dying individuals. Research, reporting and dissemination of appropriate knowledge however, are necessary to begin such changes in Malaysia. This study considered the knowledge of nurses and physicians with regard to all aspects of hospice care. These aspects included their attitude to terminal illness, death anxiety and hospice care and when they thought discussion of hospice with their patients would be appropriate.

The knowledge of hospice and referral practices of physicians and nurses in Malaysia as well as their counterparts in other countries were considered. A critical review of literature to examine the conceptualization of end of life care, terminal illness, and personal attitude towards death in both groups was done. The knowledge, attitudes, and discussion/referral practice of nurses and physicians who are not specifically educated or trained in palliative care was considered by reviewing studies done selected countries. A conceptual model for the study was developed based on the Theory of Planned Behavior. An explanation of the research design and the philosophical assumptions supporting the design was formulated followed by a clearly stated problem statement, aims and an analysis plan.

This study used a questionnaire that reflected the objectives of the study with questions that focus on the individual variables. These variables are the knowledge of hospice care practices, attitudes towards care of the dying, death anxiety, and when nurses and physicians believe is the right time to provide hospice information. The relevant variables are discussed in the critical review of literature.

CHAPTER TWO

REVIEW OF LITERATURE

Introduction

This study attempted to examine existing knowledge about hospice care practices, attitudes towards care of the dying, death anxiety among nurses and physicians in Malaysia and when they believe is the right time to discuss hospice care.

To develop an understanding of what is already known about attitudes towards care of the dying, knowledge about hospice care and death anxiety, studies in countries that have similarities to Malaysia were also used in this review.

The knowledge and acceptance of hospice care by the general public is influenced by the attitudes of health care providers towards death and caring for the terminally ill as well as their knowledge of hospice care practices. In order to discover why existing hospice care services are not being used as much as expected, it was necessary to study the existing knowledge about hospice care by nurses and doctors. The Theory of Planned behavior demonstrates a close relationship between attitudes and knowledge with behavior; therefore both those factors were a part of this study. The existing knowledge of hospice care and the attitude of doctors and nurses other countries towards death and caring for the terminally ill, and the lack of published information regarding the same in Malaysia support the need for this study.

Palliative Care

Chronically ill individuals (irrespective of the length of time) can receive and benefit from palliative care. Palliative care is the total active care of patients whose disease may not be responsive to curative treatment but is not time restricted. According

to the World Health Organization (WHO), it is “an approach that improves the quality of life of patients and their families, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”(WHO, 2014 para. 1). Palliative care is treatment that pays attention to comfort and improves the quality of an individual’s life during a terminal illness. As per the National Hospice and Palliative Care Organization (NHPCO), activities included in palliative care are agreed upon by the individual, the physician(s), the primary caregiver, and the hospice team for relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life (NHPCO, 2013). This care provided away from an acute care setting (at home or a specific hospice care facility) is termed hospice care.

Hospice Care

In the US terminally ill patients, people who may no longer seek active treatment to cure them and who are not expected to live longer than six months, have the option to receive hospice care. In this system hospice is time restricted care unlike palliative care. Individuals may begin with palliative care provided in hospitals, and later move on to hospice provided at home. Hospice care includes practices of palliative care, but palliative care may not always include hospice care such as psychosocial preparation for death. Hospice care provides a team-oriented approach for expert medical care including pain management, as well as emotional and spiritual support as per the patient’s needs and wishes. Support is provided to the patient’s loved ones as well. The NHPCO states that “each of us has the right to die pain-free and with dignity, and that our families will

receive the necessary support to allow us to do so” (NHPCO, 2013 para 1). Therefore, the caring aspect of hospice care is made available in the patient’s home.

In Malaysia, palliative care services are provided (as inpatient, consultative or outpatient care) in public hospitals. Patients meeting the criteria set by the Ministry of Health receive care paid for by federal funding. On the other hand, all hospice care whether provided at home or in a freestanding facility is provided by non-governmental organizations. It may be paid for by the family, donations and by funds raised by non-governmental organizations (Lim, 2010)

It has been shown that hospice care programs differ from palliative care in terms of the care location, timing, payment, and eligibility for services. Hence, the literature review focuses on studies dealing with hospice care, but it also refers to principles and guidelines that direct palliative care with the intention of providing clarity of understanding.

Selection of Literature

A literature search was conducted using the databases – PubMed, CINAHL, MEDLINE, CANCERLIT, and PsycINFO. The terms “palliative care” and “hospice care” were used in a reiterative manner with “knowledge and attitude,” “physicians,” “doctors,” “nurses,” and “referral.” A total of 6,204 titles came up as relevant (based on the titles). All the articles that turned up repeatedly in each of the different searches were saved. A second set of searches were carried out with specific limiters, publication period 1993-2014, English language, full text, peer reviewed with the same key terms used earlier. Only full text research articles written in the English language, with an abstract, published between 1993 and 2014 were considered. The terms “palliative care”

and “hospice care” were used in a reiterative manner with “knowledge and attitude,” “physicians,” “doctors,” “nurses,” and “referral.” A third set of searches was carried out on the public domain using Google and Google Scholar. This search was carried out using the terms “palliative care” and “hospice care” in a reiterative manner with “knowledge and attitude,” “physicians,” “doctors,” “nurses,” and “Malaysia.” When the term “referral” was added in this search no titles showed up. Therefore, all articles and information found in the public domain pertaining to Malaysia and hospice were considered.

The selection of articles was determined first by relevance of the title, then the abstract. In the final selection, 265 peer reviewed research articles were considered potentially relevant and continued to abstract review. Of these, 198 articles were considered relevant to the topic of study as well as to information pertaining to hospice and palliative care. Eighty of these articles were considered specifically relevant to this study and underwent full review. A total of 30 articles related to knowledge, attitude and hospice discussion/referral were selected out of the 80 articles reviewed. These articles deal specifically with knowledge of hospice or palliative care, attitudes towards care of terminally ill or dying patients, perceptions of satisfaction or good care of the dying and use of hospice care. Therefore, these 30 articles were used to strengthen this literature review

In the search with the terms “palliative care” and “hospice care” with “knowledge and attitude,” “physicians,” “doctors,” “nurses,” and “Malaysia” without using limitations, a total of 25 articles was retrieved. From the retrieved search there were 6 research articles with some relevance to the topic although none addressed referral to

hospice care. Two of these articles make up part of the literature review with reference to Malaysia. The rest were opinion articles, news articles and information about hospice care. These results demonstrated a gap in the literature about the lack of use of hospice in Malaysia.

Additional sources included palliative care textbooks, important publications by authoritative organizations such as National Hospice and Palliative Care Organizations, the International Observatory on End of Life Care, the World Health Organization and Malaysian organizations, as well as works authored by key individuals in hospice care. Two systematic reviews and related articles referenced in the reviewed titles were used to double check the veracity of the literature review. An update through November 2014 yielded one additional study to the total number of articles used in this literature review.

This literature review provided an introduction to hospice care, inclusive of explanations for the similarities/differences in hospice care and palliative care. It clarified the reason for extrapolating from studies dealing with palliative care, although the focus of the study is hospice care. Following a brief descriptive review of the unique needs of the dying person and the acute care setting, selected articles of research conducted in different countries were reviewed for an understanding of the existing knowledge and attitudes of acute care nurses and physicians caring for dying patients. A major portion of the literature review touches on issues affecting the referral of terminally ill patients to hospice care. Perspectives of nurses and physicians regarding hospice care are also discussed. Finally, the review includes a discussion of the theoretical framework guiding the study and a brief explanation of the philosophical underpinnings of the study

The Unique Needs of the Dying

Dame Cicely Saunders, founder of the modern hospice system stated in 1967 that the needs of the dying person are “unique”. Elizabeth Kubler-Ross followed suit by identifying the intrinsic needs of the dying in her seminal work “On Death and Dying” (Kubler-Ross, 1997). These “unique needs” of the dying person were clarified in studies by various individuals. Two studies considered suitable to describe these unique needs were selected. The first of the selected studies reviewed was conducted by Steinhauser, Christakis, Clipp, McNeilly, McIntyre & Tulsky in 2000 and the second one published in 2004 by Osse Vernooij-Dassen, Schade, and Grol.

Steinhauser and colleagues (2000) conducted a study to determine what patients, families and health care practitioners considered as being important at the end of life. A national survey using a cross-sectional stratified random design was conducted of seriously ill patients (n = 340), recently bereaved family members (n = 332), and health care providers including physicians (n = 361), and others (n = 429). All the surveyed respondents (n = 1462) completed a questionnaire asking them to rate according to importance 44 attributes associated with end of life. Attributes listed included such things as being kept clean, maintaining dignity and having financial affairs in order. Respondents were also given a list of 9 items generated by focus groups and asked to rank them from most important (1) to least important (9) (Steinhauser et al., 2000).

All responses were examined and it was found that out of the 44 attributes rated in order of importance, 26 items were consistently rated as important by all four groups. These included items such as “pain and symptom management,” “decisions about treatment,” “achieving a sense of completion,” “preparation for death” and “being treated

as a whole person.” For the patients items rated very important (“preparation for death” and “being treated as a whole person”) were rated as significantly less important by physicians. Of the 9 attributes (generated by focus groups) that were to be ranked, some of the most important were “freedom from pain” “coming to peace with God” and “presence of family” and were ranked among the highest importance by all four groups. Dying at home was ranked the lowest by patients and family members (Steinhauser et al., 2000). It was something that was certain if they received hospice care.

The findings indicated that patients want to be able to plan for death. In order for such planning to happen, physician prognostication needs to be high on the list of priorities in caring for terminally ill and dying patients to give them time to prepare for death. The study demonstrated, however, that aspects of care critical for patients and family are not always considered critically important by physicians. Of the items ranked in order of importance, spirituality was found to be more important for patients in comparison to dying at home. This finding suggests that though physical care is crucial, it is only one component of end-of-life care (EOLC). Both, families and patients valued the psychosocial aspects of care more than the physical aspects of care. Hence, it would be important for physicians to recognize these other needs of patients and ensure the referral decision is made early enough to allow the patient to have the psychosocial needs of EOLC well met (Steinhauser et al., 2000).

The strengths of the study then include the design, the inclusion of all concerned groups, and a careful analysis of the findings including multinomial logistic regression. A limitation of this study is that the Veteran’s Affairs system had a very organized process in terms of end-of-life care which may not be found in other set-ups. By its very

nature, the clientele of the Veterans Administration (VA) comprises 78.2% male patients and 81.7% male physicians whereas bereaved family members were 79.7% female. Thus the sample does not reflect what one would find in a non-VA health care setting. The information however supports the proposed study because generalizations may be made in terms of perception as well as educational and socioeconomic background (Steinhauser et al., 2000).

The findings are indicative of a need for both education in psychosocial needs of the dying patient and willingness for early referral of the patient to hospice care. Malaysia is a strongly religious country and the need for spiritual preparation for death may be a very high priority for terminally ill patients. Being referred to hospice will help ensure that this need is met early in the course of the dying process.

All of the major religions strive for a peaceful experience at the end of life although each may have differing views regarding suffering itself. Although these religious traditions teach against deliberately hastening death, each allows efforts to relieve suffering at the end of life (Bauer-Wu, Barrett, & Yeager, 2007). Steinhauser and colleagues concluded that whether the respondents considered themselves religious or not, spirituality was clearly important as seen in the consensus related to the need for coming to peace before death. Whether social or interpersonal expressions of spirituality are expressed or not, the patients identified that issues of faith that are resolved within oneself is more important. This resolution occurs only when they are made aware of the time that is truly available to them. This awareness may occur more easily only when hospice care is discussed.

The second study by Osse Vernooij-Dassen, Schade, and Grol was conducted in 2007 to understand the self-reported needs of the dying patient. It was a non-randomized descriptive study conducted on a selectively sampled population to create an abridged questionnaire named “The Problems and Needs in Palliative Care Short Version” PNPC (sv) which would take less time to administer but would have a high correlation to the original questionnaire. The original questionnaire developed in 2004 is known as “The Problems and Needs in Palliative Care” (PNPC) questionnaire (Osse, Vernooij, Schadé, & Grol, 2004) and was used to gather data. Fifty nine general practitioners and 5 internists selected 112 patients (with metastasized cancer being cared for at home) using set criteria. The final sample consisted of 94 who completed the questionnaire. The participants were asked to identify the items as a problem or a need for which they required professional attention in discussion with their physicians (Osse, Vernooij-Dassen, Schade, & Grol, 2007).

Out of 90 items on the original questionnaire 33 items, related to activities of daily living, physical symptoms, autonomy, social issues, psychological issues, spiritual issues, financial issues and the need for information were used for a secondary analysis. These items made up the abridged version. The item responses and the dimension psychometrics were re-evaluated as if the patients had completed the short version.

The finding particularly relevant to this literature review is that psychological, spiritual and social issues in both versions were more closely related as a “need for care” than as a “problem.” The correlation was between 0.83 to 0.92 and Cronbach’s alpha was 0.80 and 0.86 respectively. This validity of the questionnaire is indicative of the importance placed on these unique needs of dying patients. Although the need for care of

physical symptoms was almost at the same level as psychological and social issues, it is seen once again that terminally ill patients perceived certain needs that may be different from individuals with non-terminal illnesses.

The limitations include the fact that the subjects only completed one questionnaire, but the analyses were done as though they had completed both. There is a chance that if the participants had completed both, there would have been differences in the responses. The authors admit that although the domains of the questionnaire in both forms are highly correlated, the PNPC (sv) does not provide as detailed a picture of the needs and problems of a dying individual. The population studied was a transient population, and based on various factors that affect individual perceptions, it may be difficult to generalize the findings from this particular sample. There was no comparison information provided by the caregiver who also undergoes some of the effects of terminal illness and dying. A comparison may have provided strength to the perception of an issue being a problem or a need for care.

The studies by Steinhauser and colleagues (2000) as well as the one by Osse et al. (2007), show that psychological and social issues are considered highly important in patients who are in the process of dying. It may also be said that health-care providers who do not have specialized training for hospice care may not be able to provide competent care for those needs. Being unable to address these unique needs is detrimental to the patient and family, but it may also leave the healthcare providers with a sense of incompleteness in the care provided. A greater injustice would be that the family would have a lack of closure. An ill person desires to have a sense of control of what is happening around him and to him, since he has no control over the

disease/condition itself. Therefore it would be justified if he wants to be in control of his psychosocial needs. Helping the patient achieve that sense of control is an important aspect of hospice care (Steinhauser et al., 2000).

The unique needs of a dying person are summed up by David Kessler, a thanatologist who worked closely with Elizabeth Kubler Ross, in his book *Needs of the Dying* (Kessler, 2000). The 16 unique needs described by Kessler based on his work experience are shown in Table 1 in comparison with the “Reasons for dissatisfaction with inpatient end-of-life care” identified by Shiozaki et al. (2005). These needs of the dying have been discussed in various ways by authors (Back et al., 2009; Csikai & Martin, 2010; Hawker et al., 2006; Shiozaki et al., 2005). The study by Shiozaki et al. had a greater number of the needs identified by Kessler. A systematic review of 21 qualitative studies (Dy, Shugarman, Lorenz, Mularski, & Lynn, 2008) summarizes that these needs together are said to make up a concept closely related to patient satisfaction. In order to have satisfaction with care, the needs described in the systematic review are a need for information, care giver experience, and psychosocial as well as physical needs.

Shiozaki and colleagues (2005) conducted a qualitative study to explore reasons given by bereaved families for dissatisfaction with inpatient palliative care services. The participants who made up the sample were selected out of the participants in a nationwide survey in Japan of family members who had lost a loved one to cancer. They were those who had received scores below 70 on the Care Evaluation Scale (which quantifies perception of the necessity for improvement in received care) a part of the questionnaire administered in a larger study.

Semi-structured face-to-face interviews were conducted by 5 graduate students and a retired palliative care nurse. Content analysis was completed by two psychologists who independently grouped themes according to similarities and differences. The presence or absence of each category in all the interview records was rated independently. The kappa coefficient that determined reliability was 0.63 which was within expectation.

The categorized reasons given by bereaved families for dissatisfaction with inpatient end of life care fell into 7 themes: (a) Lack of perceived support for maintaining hope; (b) lack of perceived respect of individuality, especially in attitudes toward death; (c) perceived poor quality of care, especially psychological care; (d) not being treated with dignity and inadequate explanation from physicians; (e) inadequacy of staffing, equipment, physician availability and timely administration of the same; (f) lack of accurate information about palliative care units; and (g) practical and economic burden of the family.

The study was limited to families who were dissatisfied. The majority of the participants of the main study were very satisfied. Although the number of people dissatisfied was small compared to those who were satisfied, the items identified are relevant to individuals and families experiencing terminal illness and death. Considering that agreement was secured for participation, selection bias may affect the strength of the findings. The study, conducted with a Japanese population where expectations may be higher because of the socioeconomic background of the country, may have limited relevance to Malaysia. However it is seen that that some of the identified needs fit under the categories of psychosocial needs and spiritual needs which may easily be overlooked

when care is provided in acute care settings.

A point relevant to this study is that the families identified negative images and inaccurate information about palliative care units in the general community. It has been reported that negative images of end of life care significantly correlated with late referrals (Casarett, Marenberg, & Karlawish, 2001). Late referrals lead to psychosocial needs not being met, and a sense of dissatisfaction arises in the minds of the survivors about palliative and hospice care.

The psychosocial needs discussed in the preceding studies may not be particularly perceived and addressed by physicians and nurses who do not have specific training to identify these needs. However, the needs exist and must be met in order for patient satisfaction with care provided by them. Understanding the unique needs of the dying person helps ensure that informed choices are made by the family and health care professionals early enough to have them met. The studies by Steinhäuser and colleagues (2000) as well as the one by Osse et al (2004) reveal a gap between what is desired by the patient and family and what is understood or provided by the health care personnel for the dying patient. The needs identified by Kessler further confirm that these felt needs are real to this population and must be met. Countries which have well organized hospice care programs accommodate the needs of the dying but still fall short. Table 1 compares the needs of the dying as identified by Kessler and reasons for dissatisfaction by bereaved families with end of life care by Shiozaki et al. (2005). The perceived dissatisfaction of the family members attests to the relevance of the items identified by Kessler.

Table 1

Comparison of Needs and Reasons for Dissatisfaction with EOL Care

No	Kessler(2000) Needs of the Dying	Shiozaki et al. (2005) Reasons for Dissatisfaction with Inpatient EOL Care by Family Members
1.	The need to be treated as a living human being	Lack of perceived respect of individuality, especially in attitudes toward death
2.	The need to maintain a sense of hopefulness, however changing its focus may be.	Lack of perceived support for maintaining hope
3.	The need to be cared for by those who can maintain a sense of hopefulness, however changing this may be.	Perceived poor quality of care, especially psychological care
4.	The need to express feelings and emotions about death in one's own way.	
5.	The need to participate in decisions concerning one's care.	Family's practical and economic burden
6.	The need to be cared for by compassionate, sensitive, knowledgeable people who will attempt to understand one's needs.	Not being treated with dignity and inadequate explanation from physicians
7.	The need to expect continuing medical care, even though the goals may change from cure to comfort goals.	Inadequacy of staffing, equipment, physician availability and timely administration of the same
8.	The need to have all questions answered honestly and fully.	Lack of accurate information about palliative care units
9.	The need to seek spirituality.	
10.	The need to be free of physical pain.	
11.	The need to express feelings and emotions about pain in one's own way.	
12.	The need of children to participate in death.	
13.	The need to understand the process of death.	
14.	The need to die in peace and dignity.	
15.	The need not to die alone.	
16.	The need to expect that the sanctity of the body will be respected after death.	

Summary

Unlike the countries where Shiozaki, Steinhauser and Osse and their colleagues have done their research, there is no documentation regarding needs of the dying patient in the Malaysian population. Considering that there is a universal apprehension about death, this author believed that similar findings would be elicited by studies carried out in Malaysia. Similar differences in perception/understanding of what the patient needs were, by physicians and nurses, could be reason for late referral of patients to hospice care. Healthcare professionals who are not trained specifically to deal with dying patients appear not to understand what constitutes true end-of-life care. True end-of-life care includes psychosocial and spiritual needs in addition to physical needs.

End of Life Care

End-of-life care is an evolving concept. Using Rodgers evolutionary method as a framework, Meghani (2004) did a concept analysis of palliative care tracing the history of its development as well as its changing definitions by different bodies across the United States of America. This concept analysis provides a clearer understanding of what is involved in end-of-life care. The author selected 491 articles of literature published over 38 years (1965-2003) to analyze the concept. Based on whether any part of the article helped to clarify the concept by delineating its evolution, contemporary meaning, scope, antecedents, attributes and consequences or not, eligibility for use was determined. Data gathered from a review of these articles was used to identify attributes, antecedents and consequences of palliative care. The author concluded that although palliative care is imperative at the end-of-life, the scope of palliative care is not limited to terminal care. Therefore “all terminal care qualifies as palliative care but not all palliative care is

terminal care” (Meghani, 2004, p. 158). This statement appears to imply the close relationship of palliative care and hospice care. It also is apparent that “hospice care” is considered as “terminal care.”

The author noted an interchangeability of the terms “palliative care” and “hospice care” (terminal care) by these bodies which has over the years, led to confusion regarding the scope of hospice care (which may be a factor in the underuse of both services). The actual scope of hospice care consisted of four attributes described as: (a) total, active and individualized patient care, which means “attending to patients” “total pain” and “suffering,” physical, emotional, social, spiritual and relational management and not just symptom management; (b) Support for the family or helping the family deal with the fear of losing a loved one, the fatigue of providing 24-hour care under distress, anxiety related to administering medications, providing intimate care that may be pain inducing, loss of wages and emotional burden. Receiving care for the patient offers the opportunity for the family to reconcile conflicts, heal relationships, and ensure professional support such as counseling, respite care, financial advice and bereavement support; (c) Interdisciplinary team approach which is the coordinated efforts of physicians, nurses, therapists, social workers, and clergy, and finally; (d) effective communication which would help the entire team inclusive of the family to anticipate and deal with situations even before they arise. Ensuring that all the four attributes become part of end-of-life care would require all concerned care providers, patients, and their families to engage in “open dialogue concerning advanced care planning, prognosis, and preferred treatment goals” (Meghani, 2004, p. 158).

Understanding that palliative care can provide holistic relief of suffering for patients diagnosed with actual or potential life-threatening illnesses, early in the course of a terminal illness has implications in the use of hospice care later on. By early initiation, patients, families, and providers get the time to work together in achieving the complex goals necessary for a good quality of life until actual death occurs. For those individuals who are unable to find a trajectory where treatment options offer a chance to lengthen life, hospice care must begin as early as possible to allow for time to benefit from it. When the outcome of good end-of-life care is understood, and the services used, “improved quality of life,” “relief of suffering,” and “enhancement of human dignity” are the natural results. Good “end-of-life care” can help patients discover new potential and meaning in life, heal relationships with self, others, and with spiritual entities; and find strength to deal with their illness. Such outcomes in turn would help them achieve appropriate closure with life. For the families of patients, receiving good end of life care resulted in “improved coping, decreased psychological distress, reduced feelings of guilt, and improved bereavement outcomes” (Meghani, 2004, p. 158).

The importance of hospice care may clearly be seen only when organized hospice care is provided at the right time, to ensure that the patient and the family transition through the illness and death in a manner that provides relief from suffering. Dr. Jennifer Temel of Harvard Medical School reported that patients who received end of life care earlier, had less aggressive care at the end of life but longer survival when compared to patients who received end of life care later (Temel et al., 2010). Longer survival indicates that quality of life is affected too, when patients receive end-of-life care earlier rather than later.

Summary

Now that the major portion of healthcare is provided outside of acute care facilities, end-of-life care as described in the concept analysis by Meghani (2004), equals hospice care provided at home by the family assisted by specifically qualified health professionals. With appropriately planned palliative care, even individuals who may not be termed “dying”, benefit from alleviation of suffering and improvement of quality of life by being given an opportunity to reconcile conflicts, heal relationships, and receive professional support such as counseling, respite care, financial advice and bereavement support. These aspects of care are relevant goals for the provision of well-planned hospice care for patients who are dying .

Hospice Care and Referral in Countries other than Malaysia

It has been suggested that although terminally ill patients, especially those with cancer, would like to spend their last days at home, existing resources may not be able to support this with the best outcomes (Bestall et al., 2004). Such outcomes are best achieved by the family and the patient upon being assisted by hospice care professionals. It was not always the case even in the United States. The description of the evolution of hospice in the US by Meghani (2004), shows that the process took more than 20 years for hospice care to become an integral part of healthcare although the concept of hospice care has been around long before the hospice of Turmanin in Syria provided care in AD 475 (Stoddard, 1978). However, through the efforts of Dame Cicely Saunders, an English nurse turned physician, the modern concept of hospice was introduced to England and the world.

At that time many hospices existed in England where care was given to the dying.

But Dame Cicely Saunders established St Christopher's Hospice in 1967 in London, because she believed there was more to hospice than was then available. She established St Christopher's to ensure a holistic approach by caring for a patient's physical, spiritual and psychological wellbeing at the end of life. The research and education carried out at St Christopher's has influenced hospice care around the world and led the way to establishing palliative care as a branch of medicine. In England, individuals needing hospice care receive it based on guidelines set by The National Institute for Health and Care Excellence (Doyle & Woodruff, 2013).

During a 1963 visit to Yale University, Cicely Saunders introduced the concept of holistic hospice care to medical students, nurses, social workers and chaplains. Using photographs of the patients and families cared for, she was able to demonstrate the dramatic differences in the lives of patients and families before and after hospice care (NHPCO, 2013).

In 1972 Elizabeth Kubler-Ross, a Swiss - American psychiatrist who specialized in near death studies, testified at the first national hearings in the US on the subject of death with dignity. In her testimony, Kubler-Ross stated with reference to the dying, that people should not be institutionalized. She recommended that families needed help with home care and visiting nurses to facilitate final care at home and allow the families and the patients to receive help in areas of spiritual, emotional, and financial needs (NHPCO, 2013).

In 1974 the federal government of the US introduced the first hospice legislation. Then in 1979 the Health Care Financing Administration (HCFA) initiated demonstration programs at 26 hospices across the country to assess the cost effectiveness of hospice

care and to help determine what a hospice is, and what it should provide. In 1986, Medicare Hospice Benefit was made available (NHPCO, 2009) to those who met criteria set by Medicare (Connor, 2007). A most important criterion is a certification of terminal illness with a prognosis of 6 months or less to live as determined by the physician. Referral to hospice may be initiated by any healthcare provider involved in the care of such patients although the actual referral must be signed by the primary physician or nurse practitioner.

The term “hospice” may be seen to describe 4 aspects of end-of-life care. In some countries it may only be a place of care for the dying, a unit within the hospital or nursing home or a dedicated facility. It may be an organization that provides care mainly in the patient’s own home. In other countries it may describe an approach to care in any setting and in the US it refers to the benefit available to Medicare beneficiaries (Emanuel, von Gunten, & Ferris, 1999). The National Hospice and Palliative Care Organization of the United States, and the International Association for Hospice and Palliative Care seem to combine the two terms. There is a resulting perception by health professionals and the public that the two types of care are interchangeable, to the detriment of the scope of palliative care services (Rodriguez, Barnato, & Arnold, 2007). Patients, families and often health care professionals are unwilling to initiate palliative care due to the assumption that it implies withdrawal of curative care (Back et al., 2009). The Canadian Hospice Palliative Care Association combines the terms “palliative care” and “hospice care” in order to ensure seamless care for individuals with life limiting diseases but accept that the terms differ only to determine the location of care. Hospice care is provided at home while palliative care is provided in a hospital.

Terminally ill patients and family first come into contact with physicians and nurses who may be expected to provide the first information regarding hospice. Most physicians and nurses are more likely to come in contact with only palliative care provided in acute care settings, than with hospice care. Therefore they may not really know about all of the practices in hospice care and the benefits to the patient and family when receiving hospice care. This may lead to terminally ill patients and family not receiving information pertaining to hospice care. A qualitative study by Bestall et al. (2004) demonstrates this possibility.

Bestall and colleagues conducted a study in the UK to explore the reasons for patients and families being referred to hospice care. A purposive sample of patients (in different stages of malignant and non-malignant illnesses), general practitioners, community nurses and other health care professionals involved in palliative care, was used to consider a wide range of perspectives about referral to palliative care. Data were gathered through semi structured interviews lasting 30-40 minutes using open ended questions. The questions were developed by secondary analysis of reports undertaken by researchers of the Academic Palliative Medicine Unit at the University of Sheffield (Bestall et al., 2004).

Rigor was maintained during the analysis by using independent researchers to identify quotes that were direct responses to the interview questions (negative and positive issues), grouping into themes, and coding to identify key issues and finally to reassess the transcripts of the interviews. The five key themes identified were: (a) reasons for referral to specialist palliative care, (b) reasons why patients are not referred, (c) timeliness of referrals, (d) continuity of care, and (e) use of referral criteria in

specialist palliative care.

The study received approval from the Trent Multi-Centre research ethics committee. Although the use of multiple individuals during the analysis is described, there are no descriptions of the individuals who carried out the interviews. Patients did not give reasons for non-referral or late referral, however professionals gave reasons for non-referral that they believed pertained to patients' feelings.

This study considered timeliness of referral as well as reasons for non-referral or late referral. The study identified that little is known about those patients that remained un-referred. The point of greater importance was that professionals inclusive of doctors felt that many patients were either referred too late or not at all and the reasons were not so much what the patients expected, but rather what the professionals thought the patients wanted. Table 2 was developed from the information found in the study to compare the reasons for referral and non-referral.

Patients did not fully understand all the reasons for being referred for palliative care. Modern hospice developed into what it is today in the UK. This study by Bestall and colleagues shows that despite a nationally organized system of health care delivery, palliative care is not equitable for all. The study also demonstrates that further education is an imperative for health care professionals to improve end of life care for dying patients in the UK. Both professionals and patient state that hospice referral was to manage symptoms. Table 1 shows reason for non-referral is based more on what the professionals think the patients want as well as their lack of knowledge. Among both groups there appears to be a lack of understanding of the true purpose of end of life care.

Physicians avoid discussion of hospice due to difficulty in accepting the “terminality” of the patient’s illnesses (Bestall et al., 2004).

Table 2

Reasons for Referral and Non-Referral

	Reasons for referral to Specialist Palliative Care	Reasons for non- Referral to Specialist Palliative Care
1	Both professionals and patients - to manage common symptoms and triggers for the symptoms, physical and psychological	Patient fails to access any form of help
2	Professionals thought - when patients had more than one symptom or problem and treatment was considered more complex	Lack of knowledge of GPs about specialist palliative care
3	Patients - admission needed for problems with side effects of medication:	Professional - patient unable to decide whether they wanted to be referred to specialist palliative care
4	Professionals - for social and practical problems	Professionals - patients have this image of the hospice as death row
5	When caregiver had reached a crisis point and was unable to provide all the support and care needed.	Professionals - lack of awareness about the types of services that were available

The juncture at which hospice care should fit in has been posited, but there is evidence from literature that a high percentage of patients receive hospice care very late or not at all (Bestall et al., 2004; Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005; Melvin, 2008). It was reported in the US, that of the 1.5 million individuals who died under hospice care in 2011, half of them received care for only 14 days (NHPCO, 2013f). Although there are various reasons given for this lack of referral or late referral to hospice, it appears to be primarily a lack of socialization to the idea of hospice care by health care workers as well as the patients and families,

In an exploratory study conducted by McNeilly and Hillary (1997) the social and contextual process of decision making to refer patients to hospice was examined. The

study sample included physicians (n = 46); home based patient family survivors (n = 61); non hospice patient family survivors (n = 20); hospice staff (n = 19) and home health care staff (n = 51). Additionally, a group of 20 hospice staff physicians, nurses, social workers and chaplains were interviewed as a group.

Knowing the benefits that hospice care confer on terminally ill patients and their families, this mixed methods study was conducted in the early 1990s to discover the optimal stage of entry into hospice care (McNeilly & Hillary, 1997). Each of the groups completed complementary questionnaires which had items derived from focus groups and consisted of objective and subjective information. With response rates from each group between 24-100 % a total of 197 subjects were part of this study. Physician response rate was 24%, home health care staff and home based hospice staff response rate was 100%, hospice family survivors response rate was 40% and home health family survivors response rate was 47%

The physicians responded to items related to number of terminally ill patients under their care, awareness of hospice, reasons for considering hospice, the time and manner of initiating and communicating hospice discussions, patients level of acceptance of terminal diagnosis, their intentions toward hospice and how they dealt with death. Staff responded to items related to the same questions as well as a few items on the Needs Satisfaction Scale used on the patients. Family survivors responded to items related to quality of relationships with caregiver, regrets, awareness of and reasons for considering hospice, initiation of hospice discussion, timing and communication of terminal diagnosis, patients' level of acceptance of diagnosis and the Needs Satisfaction Scale.

The findings showed that although 71% of physicians reported bringing up hospice care with their patients only 2.2% of these patients used hospice services. However, 26% of the physicians had not initiated hospice discussion with their terminally ill patients. Twenty eight percent were aware of hospice services but only 26% understood the hospice concept. Twenty three percent had become aware of hospice services because of their terminally ill patients having received hospice care. A majority of the physicians reported being comfortable dealing with discussions of terminality, but 11% negatively characterized the discussions as being euphemisms about death. Twenty eight percent of physicians considered it inappropriate to discuss hospice until all avenues of cure had been tried, while 23% considered it appropriate once the illness had been diagnosed as terminal. Almost half (43%) considered only patients who had accepted their terminal diagnosis and desired to die at home as being suitable for hospice referral. Analysis showed that physicians with a greater number of terminally ill patients considered it their responsibility to discuss terminality with their patients and also felt that their patients accepted the terminality. These physicians were also more open to resources (printed material) that would help their patients accept their diagnosis and the prognosis.

The analysis of family survivor information indicated that the older the survivor, and higher the education, the greater their acceptance of early information regarding hospice. The decision for hospice placement made by the survivor (family) was higher among Caucasians (75%) if they were more closely related to the patient. These were generally spouses (67%), and they received hospice information prior to family member illness from a relative or friend (36%) and received further information from the

physician (60.7%), after diagnosis of the illness. Among the home health survivors, 40% had not heard of hospice, and 55% received information from physicians during the illness of the family members. They would have welcomed hospice information at the time of diagnosis as compared to hospice survivors who would have welcomed such information only after confirmation of terminality. According to information provided by the survivors, almost 25% of hospice patients made the final decision for hospice themselves following the provision of information.

The subjective and objective data provided by staff identified the barriers and facilitators to hospice referral. Staff of home healthcare believed that both patients and families did not fully understand the services provided by hospice whereas hospice staff believed that patients and families did not choose hospice as they had difficulty discussing it and accepting the terminality of the disease. The staff of both agencies cited four barriers to patient referral to hospice: (a) insufficient knowledge/education of the physicians about palliative care, (b) non provision of education about pain control and death education in medical school, (c) inadequate awareness of hospice, its benefits and personal discomfort with hospice concept by physicians; and (d) physicians lack of comfort with death. The three structural barriers identified at physician level for referral included: (a) Difficulties with hospice admission criteria, (b) DEA drug restriction, and (c) fear of losing control of their patients. Staff perceived four barriers for accepting hospice discussion referral by patients and family which were (a) Hospice information not being given at time of diagnosis for older terminally ill patients, (b) cultural and societal barriers, (c) misperceptions of hospice and (d) inadequate community and cultural education/knowledge on death and dying.

This study demonstrates that knowledge of hospice care practices, comfortable attitudes towards the phenomenon of death and the early provision of hospice information are necessary for ensuring that dying patients and families get the full benefits of hospice care. Reports from the families indicate that optimum time for hospice information would have been at determination of terminal diagnosis. The study indicates that a positive attitude towards hospice care and good knowledge of hospice care practices are essential facilitators of hospice referral by physicians. The response to the question - When is the right time to provide information regarding hospice care to terminally ill patients? Is it right at the beginning when terminality is determined.

Referral to hospice care may be the last gift given to a patient by healthcare professionals who have established a professional relationship with him or her. There is anecdotal evidence for hospice referral being the kindest thing for a patient on every level although it may be difficult for the doctor who is trained according to the curative model. It allows for the emotional and psychological upheaval that begins at diagnosis, to be dealt with as the family begins the preparation for bereavement with dignity. It allows time for optimal quality of life to be experienced in the final phase of human life and relieves the sense of desperation and fear of loss that the patient and family experience.

Although hospice has been around for more than 30 years in the UK and the US there are still barriers to referral for hospice care or even introducing the topic of hospice care. Since referral can occur only if information is provided regarding hospice three studies that deal with barriers to hospice care show evidence of such barriers. The first study conducted by Brickner, Scannell, Marquet & Ackerson (2004) is based on the premise that obstacles to hospice utilization were perceived differently by patients and

physicians. The second study by Friedman, Harwood and Shields (2002) was a qualitative study to consider the perceptions of professionals regarding barriers to referral. The third study reported by Johnson and Slaninka (1999) looked at barriers to early access of hospice as perceived by 4 groups of individuals involved in caregiving.

Brickner and colleagues (2004) conducted a study to determine the value placed on hospice service benefits by physicians based on professional experience with hospice and knowledge about hospice referral. Using an anonymous survey, the authors intended to determine perceived barriers to hospice referral based on the physicians' perceptions of hospice and their own referral pattern along with their perceived and actual knowledge of appropriate hospice diagnosis. In the cross-sectional descriptive study, a convenience sample of 111 salaried physicians was taken from 2 hospitals under the Kaiser Permanente health care system. The survey questionnaire developed by the authors has no psychometric information provided in the article. Knowledge was measured by the ability to identify eight appropriate candidate diagnoses for hospice referral.

The study refers to the doctors own insight regarding allegations of financial loss that may keep doctors from referring patients to hospice and attempted to address it. An analysis of the responses showed that 78% of the physicians considered themselves as having adequate knowledge to discuss hospice referral but only 18% correctly identified the diagnosis appropriate for hospice referral. Seventy two percent did not believe that lack of knowledge hindered hospice referral but of these only 12% knew about the actual guidelines provided by the National Hospice and Palliative Care Organization (NHPCO) for appropriate candidate diagnosis. In terms of the value of hospice services 18% of the physicians believed that hospice provided better pain control and 42% agreed that

hospice provided better guidance in the process of death. With regard to barriers to referral nearly 11% thought that referring to hospice may indicate loss of hope for patients and 28% of physicians were concerned the family members of the patient might perceive referral as a loss of personal income. The most common barrier to hospice referral was difficulty in accurately predicting death within 6 months. (Brickner et al., 2004).

Although the physicians in the study claimed to refer patients to hospice there were no actual numbers to support the claim. The authors did not ask how many patients had been referred to hospice by the participating physicians in a given period of time. This study did not consider the hospice concepts or practices of hospice care as being part of the required knowledge. The personal attitude towards death and feeling of relinquishing the curer's role was not considered. Evidence of personal attitude regarding the relinquishing of the role would have been significant as it has been mentioned earlier that personal attitude did affect knowledge. In general the findings of this study suggest that educational effort is needed to help physicians remain informed about the advances in palliative care and hospice practices.

A significant finding was that the physicians seemed to have internalized the professed public attitude of doctors being concerned with only financial interest (Brickner et al., 2004). The aspect of public attitude regarding doctors being concerned with only financial self-interest is a concern in Malaysia where the doctor is not a salaried professional. Referring the patient to a palliative care physician would result in a loss of income to the primary doctor. A qualitative study may address that concern, but it is a

delicate issue asking a physician whether he thinks that referral would mean a loss of income.

The second study by Friedman, Harwood and Shields published in 2002 focused on physician referrals and factors that affected referrals. Thirty experts in hospice care (from across the US) were taken from a list put together by the Robert J Woods foundation based on prior collaborations and underwent in-depth telephone interviews. The sample included representatives of national and state hospice associations, renowned leaders of hospice care, some physicians who are strong supporters of hospice, hospice advocates from managed care and insurance companies, and hospital discharge planners. Semi structured telephone interviews and site visits to four hospices provided validated data. Although the researchers developed the interview guide themselves, no psychometrics were included in the published article. Rigor was maintained by the use of multiple analyzers for major themes identified (Friedman et al., 2002).

The enablers and barriers to hospice referral were grouped into three categories: (a) physicians and other healthcare professionals, (b) patients/families and (c) the hospice system. According to the findings, physicians who valued a collaborative and interdisciplinary approach to medicine, had a better understanding of palliative care (by continuing medical education), and had good prior experience with hospice, and were the most likely to refer patients to hospice.

Enablers related to patients and families included education of consumers about hospice by various media as well as personal contact and early outreach to terminally ill patients. Enablers related to the hospice system were changes in rules governing hospice admissions and Insurance and Medicare reimbursement policies. Enablers related to

physicians were: (a) physicians who appreciated a collaborative interdisciplinary approach, (b) a better understanding of palliative care practices, (c) the provision of pre-referral information and ongoing information after patient has been referred and (d) good relationships with physicians by discharge planners.

There were eight barriers to hospice referral on the part of physicians were (a) physician discomfort with discussing end of life issues, (b) difficulty in confronting the death of their patients, (c) socialization to the curative model leading to aggressive cure oriented care to the very last stages of the disease,(d) perception of personal failure if patient does not get a cure, (e) physicians fear of death, (f) physician discomfort with quantity of opioids used in hospice care, (g) lack of knowledge about hospice care, and (h) perception that referral is not in their best financial interest (Friedman et al., 2002).

Barriers to accepting hospice referral by patients and families included: (a) discomfort with confronting end of life issues, (b) association of hospice care with “giving up” and (c) lack of information regarding hospice. There was also the difficulty that patients face is transitioning to hospice care because of the sense of attachment to the care provider or the health care setting that had become a part of life itself.

Barriers to referral related to the hospice system include: (a) eligibility requirement of “6 months to live”, (b) lack of standardization of managed care directives and (c) the inordinate time required by physicians to help sort out all the paperwork for financial issues.

This study by Friedman and colleagues (2002) is a first step in understanding difference between the number of those who needed hospice, and those who actually received hospice services. One of the limitations of this study includes the fact that

although the findings were about referrals, the actual experience of patients who were referred was not taken into account. Secondly, this well-organized study failed to include doctors who did not refer patients to hospice. They may have been able to provide additional information that may not have been considered by those had referred. It was also interesting to note that the physician barriers to referral numbered more than referral enablers.

The discomfort with discussing end of life issues and confronting the death of patients are findings that are relevant to the current study. This relevance is because Asian religions and cultures may have a perspective of death which is different from the western Christian culture and religion (Bauer-Wu, Barrett & Yeager, 2007).

Eastern religions tend to consider death as a consequence of one's choices and actions and therefore may perceive dying as a penance. Western concept of life and death although influenced by Christianity allows an acceptance of pain relief and comfort in the process of dying. For the Hindu, death is release from the cycle of life, in Judaism death is punishment and for the Muslim death is penance (Bauer-Wu, Barrett & Yeager, 2007). In research conducted on medical students in the U.S, it was determined that fear of death or inadequate exposure to death during their education had an effect on their perception of palliative and hospice care and referrals (Fischer, Gozansky, Kutner, Chomiak, & Kramer, 2003; Gibbins, McCoubrie, & Forbes, 2011; Hallenbeck & Bergen, 1999). Therefore, exploring the discomfort by looking at attitudes towards care of the dying and to death itself may help shed light on changes that will be needed.

Johnson and Slaninka (1999) conducted a retrospective, exploratory descriptive study to address the issue of persisting, late, crises-oriented access to hospice care more

than 20 years after hospice care was established in the US. One part of the stratified sample consisted of primary caregivers of patients who had died (within 5 to 190 days after accessing care) chosen from one hospice agency (n = 11). Another set of participants included interdisciplinary hospice staff (n = 20), a third set were hospice volunteers (n = 22) and the last set consisted of referring physicians (n = 30). Data were gathered using a semi structured interviews for primary caregivers and a self-administered questionnaire for the physicians, staff and volunteers. There were four barriers ranked according to highest rate of perception (a) Inaccurate perceptions about hospice by caregivers, (b) refusal or failure to acknowledge terminality of the condition, (c) perception of hospice as having given up on the patient and loss of hope, and (d) inability to decide on ideal timing to access hospice.

The limitations of the study included the small caregiver sample, not using physicians who did not refer patients to hospice and failure to have the physicians identify their role related to late access to hospice. The data collection instrument was developed for the study based on results of similar studies that were conducted between 1983 and 1993. Content validity was established by 5 experts. It was interesting to note that all the hospice staff (100%) and most of the volunteers (86%) perceived that physician reluctance to shift from curative to comfort care was a major barrier to referral to hospice care. Caregivers stated that older physician, knowledge deficit by physicians and denial of referral created hospice access barriers. Physicians consistently disagreed with statements on the questionnaire regarding physician related barriers to hospice (Johnson & Slaninka, 1999).

There are other physicians who believe that the treatment expectation of the medical community being cure oriented is a barrier to hospice referral. They also believed that starting palliative care was perceived as a failure on the part of the physician (McGorty & Bornstein, 2003). In similar studies major reasons for non-referral included lack of physician experience and awareness of hospice practices (McNeilly & Hillary, 1997), lack of knowledge about available hospice programs (McGorty & Bornstein, 2003) and very limited personal experience working with hospice (McNeilly & Hillary, 1997).

Summary

All of the studies reviewed point to the inadequacy of education and training that leads to negative attitudes and poor knowledge with regard to end of life care and hospice referral. This translates into inefficiency of physicians in dealing with dying patients and their families thereby denying the dying patients and their families the basic right to good quality of life and an opportunity to have the specific psychosocial needs met.

The studies also show a failure to refer to hospice at the right time or not at all. Barriers to referral for hospice and palliative care as per the researchers include (a) lack of knowledge, training and education among health professionals about palliative or end-of-life care b) inability to deal with issues related to death and dying, (b) lack of standardized criteria to guide the referral process, (c) patients being either older people or those from minority ethnic groups, and (d) having to deal with people who have non-malignant terminal/chronic conditions or those who felt socially excluded.

It is reported in Malaysia that 23% of patients referred to hospice died within 10 days (Devaraj, 2003), and an unreported number died on the day they were referred (Loh,

2006). Thus, there is a need to identify and measure the causes of late access and address the concern in order to ensure that all those who are terminally ill have an opportunity to benefit from alleviation of suffering and have an improvement of quality of life until death. These studies had considered attitude towards care of terminally ill and knowledge of hospice care as both these components of healthcare personnel contribute to information being provided to patients about hospice care. The present study also considered these factors as it appeared to affect the provision of information about hospice care to terminally ill and dying patients.

Hospice Care in Malaysia

In Malaysia, the term hospice is not used in the same manner as in the US. It does not indicate remunerative benefits in the state sponsored medical care available to citizens. Hospice care in Malaysia is not covered by the federal health scheme. Here the distinction between hospice care and palliative care lies in who provides the care. As stated earlier, hospice care is provided by non-governmental bodies whereas palliative care (whether at home or in an acute care setting) is provided by mainly public medical institutions.

In an article published in *The International Observatory on End of Life Care News*, the authors state that there is a need for research in hospice care to document the difference hospice care makes for patients and families (Payne, Preston, Turner, & Rolls, 2013). However in Malaysia, research is necessary to first document the lack of use of hospice in order to determine the reasons for such lack of use. It is only such reasons are determined, will research on the differences between those who receive hospice care and those who do not, have relevance. The present study attempted to understand the existing

knowledge and practices in order to determine what changes needed to be made. A knowledge of hospice care practices, attitude towards caring for the dying and the personal death anxiety of health care professionals has been examined along with when the right time for hospice referral would be.

In the literature search for comprehensive information on palliative care and hospice in Malaysia, a total of 6 articles described the concept of hospice and palliative care as it is understood in this country. Three of the documents were reports of research on end of life care. Richard Leong, the National Advisor for Palliative Medicine Service, clarifies that palliative care first began in Malaysia in 1991, with a growing interest in the field and reported development both through the government and nongovernmental organizations.

Although palliative care was initially considered a Western concept, interested health officials took on the challenge of improving the quality of life of cancer patients (Leong, 2003). The Director General of the Ministry of Health, Malaysia, impressed by a small palliative care unit set up in East Malaysia in 1994, encouraged the setting up of palliative care units throughout the country. These palliative care units opened in state hospitals were unable to ensure seamless transition to home care as hospice care was not a part of the system of care. Home hospice care began to be provided by nongovernmental organizations to make up for this identified deficiency. To date, there are 18 palliative care associations in the country and three well known NGO hospice care facilities in operation. The paradox however, is that the rapid growth in number of palliative care units has resulted in many of the services being run by insufficiently prepared doctors and nurses. Therefore specialists do not refer patients to the palliative

care units. Many years after the setting up of inpatient palliative care units, there are still those who believe that palliative care is simply nursing care of the dying. Most of those who receive hospice care in Malaysia are individuals with cancer.

A document developed by the Ministry of Health, Malaysia in 2010 outlines how the palliative care units are to be run. Titled an Operational Policy, it outlines a simplistic approach to the development of palliative care as a subspecialty of medicine. The criteria for admission as well as recommendations for follow up are subjective and dependent on further development in health professional training and education and availability of specialists. It is recommended that patients be referred to palliative care specialists at diagnosis based on a model developed by Robert Twycross in 2002 (Lim, 2010). Other recommendations include 1:1 nurse patient ratio, admission of non-cancer patients with incurable chronic medical illnesses which are progressively fatal with no further options for active medical management, or who request to withhold all further active management which will inevitably result in deterioration and death; and patients who have acute medical or surgical conditions which are not reversible and will inevitably deteriorate rapidly in an acute ward or ICU and require terminal care (Lim, 2010).

Most palliative and hospice care efforts in Malaysia focus on management of pain and physical symptoms only. A study by Loh (2006) explored the perception of terminally ill patients and their families about the adequacy of psychosocial care provided in inpatient palliative care. The cross sectional descriptive study was conducted over a period of six months. The study used a convenience sample of patients with cancer stage 3 or 4 from one palliative care ward in Malaysia (n=30) and one family member for each patient (n=30). Data were collected by a single researcher using a structured interview

guide and related to physical care, social care, psychological care and spiritual care. The patients and family members were interviewed separately to minimize bias. Assessments of physical care included the management of pain, hydration, nutrition, hygienic care and other physical symptoms. Social care included assessment and advice related to home environment, financial issues, and family support. Psychological care referred to assessment and care of anxiety, depression, fear and related emotions. Spiritual care dealt with assessment and care of spiritual distress (Loh, 2006).

A greater number of the patients were male (60%) and a greater number of caregivers were female (73.3%). A larger number of the participants were Malay (40%) compared to Chinese (33.3%) and Indian (26.7%). The reported perception of the four areas of care has been gathered from the study and depicted in Table 3.

Table 3

Perceptions of Care Being Met

Components of Care		Patients (%)	Family (%)
Physical	Adequate	86.7	73.3
	Inadequate	13.3	20.0
Social	Adequate	40.0	33.3
	Inadequate	60.0	66.7%
Psychological	Adequate	26.7	16.7
	Inadequate	73.3	83.3
Spiritual	Adequate	0.0	0.0
	Inadequate	100	100

The author posits that psychological needs are not dealt with because such needs are less obvious than physical needs. The real fact is that the nurses working in the palliative care wards are not specifically trained in palliative care, and may not be able to identify or deal with psychological needs. Similarly spiritual care is a neglected area of care because the health care professional and the patients are usually of different religions and not talking about spiritual matters is a way to be respectful of one another's beliefs. Secondly, government hospitals do not give importance to the provision of spiritual care. Social care (caring for financial needs) is slightly better addressed than psychological and spiritual care. This attention to social care may be due to the well-known practice of patients who are too poor to pay for medical care being given free treatment if a letter of proof can be produced from a community leader (Loh, 2006).

The majority of patients (86.7%) and family members (73.3%) felt that physical care was adequate. This perception of adequacy of physical care may be explained by the fact that pain and other symptoms can be handled in a hospital setting by regular nurses and doctors (Loh, 2006).

The use of palliative care services differs from the hospice care use in the study by Hong and colleagues (2011) in the neighboring country of Singapore where racial and religious mix of the population is similar to Malaysia. Hong and colleagues (2011) published an analysis of data from the Cancer Registry pertaining to how the place of death for cancer patients related to other determinants. Prior studies had reported that 12.4% of cancer deaths had been in hospice while 35.8% had been at home. This study examined place of death for patients with cancer and the relationship with demographic characteristics as well as disease related factors with death at home or hospice. A cross

sectional analysis of all patients in the registry who had died during the study period of 10 years was conducted (n = 52120). The places of death were homes, in patient hospices, hospitals and others (Hong et al., 2011).

Results from this analysis determined that 52.9% of the patients died in the hospital and 30% died at home. Only 10.7 % died in a hospice. Regression analysis demonstrated that the older a patient was, the more likely he would die at home. More females (32.6%) died at home than males (28.5%); more Malay patients died at home (47%) compared to Chinese (28.7%) and Indians (27.3%). More Chinese patients died in hospice (11.6%) compared to Indians (8.0%) and Malays (3.5%). Patients who died in hospice were in more advanced stages of cancer (14.3%), and only 1.1% of patients who died in hospice had diagnoses other than neoplasms (Hong et al., 2011).

The inferences made regarding the effect of Islamic tenets on the Malays is a point of interest. Islamic teachings perceive that suffering is a way of atoning for sin and this may help the patient and family develop coping skills when dealing with terminal illness and this teaching may explain why Malays prefer dying at home and their limited use of hospice. For this reason the religious background of the participants in the present study is an important factor. A majority of the nurses are Malay and there is a probability of their religious perception affecting their decision to provide hospice care information.

Although the population composition is not equivalent with that of Malaysia, the racial and religious backgrounds are similar. The findings are therefore pertinent to the Malaysian setting because the number of individuals who died in hospice in Singapore is similar to the figures given for use of hospice in Malaysia (around 10%).

Summary

It may be seen that sociocultural differences exist that may need to be considered in looking at how knowledge of hospice care, attitude towards caring for the terminally ill and death anxiety affect the practices of providing hospice information. The recommendations and expectations for hospice care are based on the general knowledge of hospice care. However the differences and similarities of religion and culture of the nurses and doctors and their patients may have a bearing on the provision of hospice care information.

Hospice Referral in Malaysia

Although the need for palliative care is enormous, late referrals are the norm, (Khoo, 2003). Of the individuals enrolled in hospice in one city, 80% died at home (Devaraj, 2003), but there is no documentation about how those who were not enrolled died. More than 10 years after the Malaysian government actively promoted the development of palliative care units in every general hospital, there are still doctors who do not know what practices are included in palliative care (Leong, 2003). There is no documentation of the why terminally ill individuals or their families do not seek out hospice care. Neither is there any information regarding awareness of hospice and palliative care availability among the general public.

One of the reasons for late referrals may be attributed to the lack of understanding of hospice care practices by nurses and doctors. The fact that 23% of referred cases died within 10 days (Devaraj, 2003), and others died on the day they were referred (Loh, 2006) may be due to factors other than the knowledge of hospice care practices by nurses and doctors. The choice or acceptance of family and patients to use hospice is unknown.

Of the 6 articles published on end-of- life care, the only one dealing with referrals was published in 2006 by Devi and colleagues. It is a description of the results of an exploratory study conducted in Sarawak, Malaysia on the setting up of home based palliative care (PC). Sarawak is a part of Malaysia where half the population lives in villages that are difficult to access.

Sarawak, located on the island of Borneo is less developed than the mainland of the country of Malaysia. Out of the 21 government hospitals serving a population of 2.25 million there are two referral centers, one cancer center and 3 PC units. Although there are 119 health centers and 97 rural clinics most of them are manned mainly by nurses with a diploma level education. With an age standardized incidence of 146/100, 000, cancer is considered to be of great concern and in 1994 an “early cancer surveillance” program led to estimations that more than 90 % of adult cancer patients were seen at the regional hospital. Of these, 79% of the patients were diagnosed at late stages. The home based PC program initiated in 1994 with nurses, pharmacists and doctors who had participated in a training program covering the basics of PC, provided pain management, wound care, pressure sores care, physiotherapy, nutrition, aromatherapy and counseling.

Due to the high turnover of doctors, nurses were empowered to be the actual liaisons with the state hospital overseeing the home-based PC program instead of physicians. A simplified system was set up to allow referral to the regional hospital. The oncologist in charge saw each of the patients and planned the care with the PC trained staff of the area the patients came from. Availability of pain medication was made a priority. Morphine was supplied for up to 3 months based on accessibility to the city or nearest pharmacy. Professionals who staffed the program were trained annually

and equipment needed by the patients at home was funded by finances set aside for this program. Public awareness was an integral part of this effort (Devi et al., 2008).

The authors report that in the 8 year period, the number of patients who benefited from the home based end of life care increased by 61%. During the study period there were no reports of illegal use of morphine, leading the authors to be confident that the percentage of patients benefiting from the palliative care was close to a 100 percent, although the number of late diagnosed patients did not change much, going down from 79% to 71%. The main barriers to efficient home care in this study were the beliefs of the patient/family in alternative therapy and fears of addiction to morphine. In comparison with small programs in communities in other parts of the world, the author reports that this model of PC is sustainable in a country such as Malaysia due to the greater support it received from the government (Devi et al., 2008).

Due to the topography (a large part of Sarawak relies on water transportation, which can be severely interrupted during the rainy season) as well as the fact that most of the population relied on one oncologist and one oncology/radiotherapy department, it was relatively simple to run the program. The most positive aspect of this report is that the referral process was simplified, and appears to have been carried out well although most of the referrals turned out to be late because of late diagnosis of cancer.

This study is not generalizable to the rest of Malaysia for a few reasons. The peninsular part of Malaysia is more developed than East Malaysia, serviced by private and public hospitals with many more specialists who have the authority to refer or not to refer. Nurses are not empowered to perform any kind of referral in the other states of Malaysia. Since there is greater access to healthcare facilities, there is less need for

nurses to go house to house. However, based on the recommendations of the operational policy published by the Ministry of Health, and the varying availability or access to specialized care, this report gives a good picture of changes needed for a better method of referral to hospice care.

A pertinent point in the study by Devi and colleagues was the absence of reference to psychosocial care. The study only addressed the management of physical symptoms. The study by Loh (2006) clearly showed a need for psychosocial issues to be addressed in terminally ill patients in Malaysia. The management of psychosocial issues can best happen only if information about hospice is given early enough and referrals to hospice occur with enough time for the patient and family to benefit from hospice care.

The International Observatory on End of Life Care (IOELC) based at Lancaster University in the UK, studies the progress of end of life care around the world. The then director of the IOELC stated in 2007 that “one element in the struggle is the production of better information about what already exists, how provision varies from place to place, as well as a careful analysis of some of the factors that promote or impede successful development” (Clark, 2003 p.41). Country to country there have been developments that have increased the use of hospice care - such as legislation in Kerala, India (De Lima, 2009), and national plans for the development of palliative care as in the United States. Volunteers and nonprofessionals with very basic training are providing timely assistance for those who need the elements of palliative care in many underdeveloped countries (Clark, 2003). However, as seen through the concept analysis of palliative care by Meghani (2004), the ultimate success of end of life care rests on the commitment of

health professionals to recognize and integrate the changing needs of end of life care into everyday practice.

Summary

Multiple studies demonstrate a lack of understanding among doctors and nurses regarding what hospice care does and what palliative care really is studies similar to the ones reviewed repeatedly refer to the barriers of hospice referral (Back et al., 2009; Cherlin et al., 2007; Cramer, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2003; DeVader & Jeanmonod, 2012; Fischer et al., 2003; Frommelt, 1991; Hanratty et al., 2006; Rodriguez et al., 2007). Lack of understanding among the public and the healthcare professions prevent the early provision of hospice information. Literature and other information pertaining to referral are not easily available for Malaysia. This lack of documented information brings into question the extent of awareness about hospice care practices and how it affects the patients as well as the families in terms of the provision of right information and referral to hospice. Can doctors who do not have a good understanding of hospice care practices provide the best information to patients who may need such information? Can nurses who are not aware of hospice care practices and not empowered to refer, be expected to provide hospice information at the right time? The studies considered in this section clearly show that the answer to both questions is an emphatic “no.”

Knowledge and Attitude toward End of Life Care

Although provision of care to dying patients is part of a collaborative effort, there is a need to understand the whys and the hows of the decisions made for patient care. Twelve articles which were the results of well-designed studies on attitudes, knowledge

and discussion/referral behavior of physicians and nurses, conducted over the last twenty years were selected out of thirty studies considered. Some of these studies show that the inability of acute care nurses to provide care and initiate discussions for hospice is related to lack of knowledge of narcotics (Desai & Chaturvedi, 2003; Edwards, 2001; Xue, Schulman-Green, Czaplinski, Harris, & McCorkle, 2007). Similarly an inadequate understanding of the pharmacological management of pain is given as a reason for nurses and physicians not providing adequate pain relief (Fineberg, Wenger, & Brown-Saltzman, 2006; McCaffery, Ferrell, O'Neil-Page, Lester, & Ferrell, 1990; Visina, Chen, Gerthoffer, Biggs, & Ting, 2003). A good number of physicians and nurses are unable to rightly assess psychosocial needs of the dying patient without the right assessment questions and adequate training (Osse et al., 2007). It is an accepted fact that nurses spend the most amount of time with patients as compared to doctors (Fakhoury, 1998). Nursing education places considerable emphasis on psychosocial care due to the whole person approach. However it does not mean that all nurses are competent in end of life care as it relates to the management of symptoms in a dying patient (Ferrell, 2005), and providing support and communication to families of dying patients (Kirchhoff et al., 2000; Norton & Talerico, 2000).

In a study conducted in Midwestern United States acute care nurses were found to have negative attitudes when caring for terminally ill patients, because of the emotional strain that is created in moving back and forth between enhancing life in most of their patients and then preparing for death with the occasional hospice patient (Weigel et al., 2007). In this descriptive study using a convenience sample of 151 nurses, apprehension in the provision of end of life care was examined. The sample of nurses represented

seven hospital units. Data was collected using a trimmed down version of the Physician End-of-Life Attitude Scale (PEAS) which was adapted with questions framed to suit nurses. The original PEAS was validated against the Communication Apprehension dying scale which was the measure of a laypersons communication apprehension (Levetown, Hayslip, & Peel, 1999). With a Cronbach's alpha of 0.89 and a Pearson's r equal to 0.7 (construct validity), the PEAS is considered a very reputable measure of apprehension. The adapted scale referred to as the Professional End-of-life Care Attitude Scale measured three aspects: (a) communication apprehension, (b) professional impact (anxiety about giving unpleasant information, being objective and controlling emotions during caregiving) and (c) personal impact (level of discomfort when interfacing with dying individuals) of caring for dying persons.

In the analysis it was noted that there was no difference between nurses who had personal experience with death, clinical experience with death during nursing school and specific education regarding terminal illness and those that did not have any of these when it came to communication apprehension. The authors suggest that acute care nurses mask fears about interacting with dying patients. Men had greater apprehension during caring for the dying than women. Although there may have been inflation or minimizing of responses due to the method of self-report, probable lack of understanding and small sample size with few men, the findings speak to the need of ensuring that dying patients and families need better prepared nurses to address this unique need (Weigel et al., 2007).

Although it measures attitude well, the Professional End-of-life Care Attitude Scale contains a number of questions pertaining to advanced directives which is not being considered. The scale was not a good fit for the study conducted in Malaysia as the

questions demonstrate a greater autonomy for nurses than may be seen in Malaysia. However, this study clearly demonstrates the need for better prepared nurses to provide end of life care (Weigel et al., 2007).

Nurses and clinicians working in the acute care areas are not aware of the specific practices of palliative/end of life care (Franks et al., 2000). Misconceptions exist especially in the use of narcotics (Edwards, 2001). In the belief that they manage pain well for their patients along with the misconception that addiction to narcotics is a possibility even in terminally patients, nurses and physicians fail to include patients in the discussion regarding further pain management (Visina, Chen, Gerthoffer, Biggs, & Ting, 2003).

Often physicians do not know about hospice services, practices and policies that may make referral and transition of care easier (Ogle, Mavis, & Wang, 2003). The information provided in such articles and studies answers the question – Can doctors and nurses who do not have a good understanding of hospice care practices provide the best information to patients who may need such information? No they cannot.

To further explore the inadequacy of underprepared health professionals providing care for the dying, another well-designed study conducted in 2003 that demonstrates the knowledge and attitudes of nurses as related to hospice care has been reviewed. This cross sectional study by Cramer and colleagues (2003) surveyed nurses employed in 6 randomly selected hospitals in a state in the New England region of the United States. Using a two staged strategy 30 nurses were first randomly selected from each of the hospitals according to set criteria. After completing a hand delivered study questionnaire only those that had completed responses were used for the analysis (n =

174). The components measured in the survey were: (a) proportion of terminally ill patients that the nurse discussed hospice with, out of the total number of terminally ill patients cared for in the previous 3 months; and (b) the proportion of families of terminally ill patients the nurse had discussed hospice with, out of the total number of terminally ill patients care for in the previous 3 months. Knowledge of hospice (objective measurement and self-report) and attitudes were measured using an instrument developed and tested by some of the authors and had previously demonstrated good test retest validity as well as construct validity (Bradley et al., 2001; Bradley et al., 2000).

The analysis of data gathered showed that the respondents were predominantly female (94.8%), white (94.2%) and religious (67.2%) and more than half (58%) had a baccalaureate degree or higher (Cramer et al., 2003). A total of 145 nurses had cared for terminally ill patients in the prior 3 months with an average of 7 patients cared for by each nurse. Although 69% of respondents indicated satisfaction with their interaction with hospice caregivers, only 30% felt that they were trained enough to care for terminally ill patients. More than half (52%) of those who cared for terminally ill patients did not discuss hospice with the patients and more than one third (35%) did not discuss hospice with the family of the terminally patients (Cramer et al., 2003).

The characteristics most closely associated with initiation of hospice discussion included greater self-rated knowledge, hospice training, greater comfort with initiating such discussions and greater perceived physician responsibility for ensuring that patients were provided with information regarding available support services for end of life care. Here we see the response to the question - Are there any other factors besides knowledge

that has an implication on information provision and/or referral to hospice? It is the attitude of the nurse towards the knowledge of hospice care practices.

Paradoxically, less education was more closely associated with initiation of hospice discussion than attitude. However, religiosity and a satisfying personal experience with death or hospice care were also related to initiation of hospice discussion. The authors conclude that both attitudes and knowledge are important factors related to discussion of hospice with patients. The authors posit that higher educated nurses are more curative oriented causing them to avoid hospice discussion (Cramer et al., 2003).

The limitations of the study include an almost exclusively white small sample and self-report, but similar findings were found in three other studies (Frommelt, 1991; Schreiner, Hara, Terakado, & Ikegami, 2004; Vejlgard & Addington-Hall, 2005). These studies also reported that nurses who had been specifically prepared to work with the terminally ill demonstrated a more positive attitude in the care of the dying than those who had no specific preparation. It may be seen that a better understanding of how to care for the dying has an effect on attitude towards caring for the terminally ill.

Physicians who feel obliged to provide end of life care, face the challenge of finding balance between “withdrawal of care” (Prendergast & Puntillo, 2002) “giving up” (Bestall et al., 2004), and ensuring “supportive care.” Unfortunately clinicians more often rely on specialty consultation (Salahuddin et al., 2008) because of newer cancer therapies that are constantly being developed and tried. This reliance on specialty consults for newer therapies not only delays hospice referral (Mintzer & Zagrabbe, 2007) until almost the last week of life, it may also keep physicians from really paying attention

to what is being learned about the need for hospice care. They remain unaware of current practices in palliative and hospice care (Hanratty et al., 2006) and how to begin discussions for hospice care (The SUPPORT, 1995).

The lack of awareness of hospice care practices has been reported in multiple studies. It is said to begin during the initial education period. As per literature, existing medical curricula fails to prepare doctors for their role in caring for dying patients by omitting meaningful discourse about dying patients during their academic years and much needed meaningful contact with this population (Gibbins et al., 2011; Hanratty et al., 2006; Lloyd-Williams & MacLeod, 2004; MacLeod, 2000). In an effort to address this inadequacy, studies have been conducted among medical students. One key study conducted over a period of 5 years among medical students, demonstrated that those who had personal or professional experience with death that was meaningful, had more positive attitudes and higher knowledge of end-of-life care (Anderson, Williams, Bost, & Barnard, 2008). In this descriptive prospective study by Anderson and colleagues, surveys were completed physicians who graduated between 2001 and 2006 from the University of Pittsburgh Medical School at graduation (n = 380). Half of these physicians had completed a similar survey earlier during medical school (n = 190). The information gathered included personal experience with death, exposure to death and dying patients during medical school and self-rated knowledge about end-of-life care (symptom management, ethics, treatment appropriateness and hospice care). It was found that over 70% of the students reported personal experience with death and caring for dying patients or witnessing a death. As students, they had cared for an average of 3 dying patients. Almost all students reported a positive attitude towards physician

responsibility and ability to care for the dying, but a significant percent reported negative emotional reaction to end-of-life care (Anderson et al., 2008).

Comparisons between the students who had the survey twice and those who did it only at graduation found that those who did it once scored less on the knowledge test than those who did it twice. This occurrence demonstrates that awareness had developed by taking the test. There was statistical significance in the analysis of those who cared for a higher average of dying patients scoring higher on the knowledge test. In the paired analysis it was observed that those who came in with positive attitudes towards death and caring for the dying retained it through medical school, and those who came in with negative attitudes developed more positive attitudes over the course of time. Students who had personal or professional experience with death showed more positive attitudes towards physician responsibility and an ability to care for the dying patient and family. These students were less likely to report negative emotional reactions towards end-of-life care. A dose effect between exposure to dying patients and attitudes and knowledge was observed. Among students who cared for an average of 3 dying patients, 94% reported that physicians have a responsibility to provide bereavement care to the family members of the dying patient, whereas of those who did not provide care for dying patients during their student days only 67% agreed to this responsibility.

This lack of experience during student days may account for later failure to refer dying patients to hospice as practicing physicians. Those who did not help care for any dying patients over the course of medical school ($n = 52$) scored a mean of 76% correct ($SD = 14$) on the knowledge test, while those who helped cared for 1–4 patients ($n = 231$) scored 79% ($SD = 12$), and those who helped care for 5 or more patients ($n = 91$) scored

82% ($SD = 12$). The more positive attitudes and higher knowledge in graduates who had personal and professional experience with death provided support for curriculum change at the university. Once again it is seen that other factors besides knowledge have implications on provision of information about hospice. It is the attitude that was developed towards death and caring for the dying (Anderson et al., 2008).

Although the study is limited by a below average response rate (47%), paired testing being done only on the last cohort of students, and self-report on death exposure as well as the use of an non-validated questionnaire, the findings are statistically significant, $p = 0.04$. The study demonstrates that attitude is affected by early and satisfying experience in dealing with dying individuals.

While the findings are pertinent to the study being conducted in Malaysia, the questionnaire and the method used are not relevant to the culture and the population. The study does demonstrate that preparation to provide end of life care needs to begin early in professional training. It also supports the premise that knowledge about end of life care engenders a feeling of responsibility for the dying patient to have the best care (hospice care).

Research by Hallenbeck and Bergen (1999) provides support for the interpretation of the study by Anderson et al. Soon after the American Board of Internal Medicine and American Medical Association called for better training of physicians in end of life care, Hallenbeck and Bergen conducted an non-randomized experimental, retrospective before and after design study. They intended to evaluate intern experience in end-of-life care and self-assessed changes in attitudes and knowledge following a mandatory rotation in inpatient hospice and in a nursing home

A convenience sample of interns was used in this mixed methods study and no information is provided about human subjects protection or consent (n = 27). The interns participated in a mandatory 4 week rotation on an 11 bed, inpatient hospice ward and a nursing home. They were provided training in palliative care during this time and spent 50% of their time looking after hospice and nursing home patients. At the end of this period they completed a questionnaire that examined prior experience with death, and changes in knowledge, skills and attitude. The questionnaire used a retrospective before rotation and after rotation design.

Findings pertaining to prior experience with death showed only 2 of the subjects reported death of a first degree relative. All reported caring for at least 1 dying patient and 55% had cared for dying patients only in acute care. Fifty nine percent had little experience with caring for a dying patient receiving standard comfort care (not using an IV). Most interns (70%) had rarely visited a hospice or nursing home. The study dealt clearly with training, experience and attitude and the effect such training had on their behavior.

Regarding training in caring for the dying and nursing home patients, 85% reported having received training in medical school on death and dying, 33% received medical school training in hospice care, and 26% in nursing homes. However clinical exposure was minimal. Eleven percent reported having visited home hospice for half a day and just 1 intern had received training in symptom management for the dying.

Modeling of critical encounters with dying patients showed that 22% had never witnessed an attending have an advanced directives discussion with patients. Nineteen percent of interns had never witnessed the sharing of bad news (poor prognosis or death

of the patient). Forty four percent of participants reported never having seen an attending convey news of death to the family. In considering attitudes after rotation, most interns increased their scores of sense of preparation from 2.2 to 4.3 indicating a significant improvement in their sense of preparation to deal with end-of-life care.

The responses for self-assessed knowledge and major knowledge deficiencies were identified before rotation but there was significant increase in post rotation scores for pain management, symptom management, addressing psychosocial changes in dying and grieving. Responses to the open ended questions revealed themes relating to appreciation for the importance of end-of-life care and personal impact of the special rotation.

The participants indicated that there were significant changes in knowledge, attitude and perception of ability to care for dying patients and their families. It speaks to the point that inadequate training in dealing with death and dying may be the root cause for the avoidance of referral of patients to hospice care (Hallenbeck & Bergen, 1999). The fact that these students did not have a modeling of advanced directives, conversations about end of life care and the giving of bad news gives a better picture of how ill prepared doctors are to deal with patients who are terminally ill and dying. Although there is no evidence of such ill-preparedness among physicians in published literature for Malaysia, the methods used in educational preparation of doctors allows for extrapolation of the same issues among physicians there as well.

In response to the question “Who is responsible for the vital knowledge being given to terminally ill patients and their relatives about hospice care?” A qualitative study by Hanratty and colleagues (2006) exploring the understanding of palliative care by

doctors was reviewed. Although both palliative care and hospice care have been in existence for over 40 years in the UK, this study conducted by Hanratty et al (2006), demonstrated the poor grasp of the role of palliative care on the part of physicians. A cross section of doctors practicing in one region of the National Health System in the UK formed the study population. Seven focus groups were conducted among groups of general practitioners (GPs) (n = 5), academic GPs (n = 5), cardiologists (n = 5), geriatricians (n = 6), palliative care physicians (n = 6) and internal medicine physicians (n = 4) who provided care for patients with heart failure. A total of 36 physicians out of which only 10 were female made up the sample.

Each focus group was done with people of the same specialty in order to prevent disruptive power relations and status perceptions that could affect honest expression. Data regarding doctors understanding of palliative care was derived from the opening question “Can you tell me what you understand by palliative care?” The discussion that followed covered theoretical and practical aspects of palliative care.

Care was taken to ensure rigor and the identified themes were discussed by a multidisciplinary group of eight authors. The data elicited from those with education and experience in palliative care was used to compare and contrast with the viewpoints of the non-specialist groups (Hanratty et al., 2006).

Although it was unanimously agreed that palliative care was much more than a medical service, the physicians were unable to decide the right time to begin palliative care. Palliative care was seen as a straightforward medical practice but there was a parallel perception that palliative care was not necessarily the “province of the doctor.” It was felt that palliative care was “not very medical” and was basically a “nursing based”

care for the terminally ill. This reasoning may account for the non-involvement of doctors in palliative care as well as the tendency to delay handing over the patient to palliative/hospice care as physicians could not give over their patients to the nurses who provided the end-of-life care. The GPs and geriatricians expressed the view that although there was a lot of “specialism” in palliative care, they were equally capable of handling the dying patient since “mortality of life is 100%.” The cardiologists admitted to disliking failure which was how the death of the patient was seen. They along with others felt that handing over to palliative care was failure on their own part. This study supports the premise that physicians really do not know when the right time is, to provide information regarding hospice care to terminally ill patients (Hanratty et al., 2006).

In this study conformation to group norms due to the homogeneity of the groups may be considered a limitation. However the researchers attempted to overcome this limitation by combining responses to direct questions with direct or implied references throughout the discussion of particular themes.

The attitudes that prevent doctors from either ensuring the provision of good palliative care or referring patients to hospice has been seen in three other studies (Block & Sullivan, 1998; Ogle, Mavis, & Wang, 2003; Ogle, Mavis, & Wyatt, 2002). The researchers attributed this perception to the fact that physicians are historically socialized into believing that their knowledge of medical science equips them to have the best opinion regarding the care of the ill and the dying. These same attitudes may be a reason for delayed referral or non-referral of terminally ill patients to hospice care. Therefore it may be seen that physicians have the greatest responsibility for vital knowledge being given to terminally ill patients and their relatives about hospice care. Although the study

was conducted in the US, it may be extrapolated to the situation in Malaysia for two reasons. Physicians are trained to make independent choices. The socialization into believing that their knowledge of medical science equips them to have the best opinion for their patients is common to doctors around the world. In countries where nurses are considered to be real team members, doctors may receive recommendations more easily from them. In Malaysia nurses do not have the degree of autonomy in practice as may be experienced in the US. Since they are expected to only do as the doctor says, the belief that doctors have the best opinion has an even greater negative impact on the possibility of nurses recommending hospice care.

Summary

All these studies demonstrate an inadequacy of educational preparation among nurses and physicians for providing end-of-life care, which may translate into non positive attitudes towards hospice referral. This inadequacy translates into inefficiency of physicians in dealing with dying patients and their families. Dying patients and their families are thus denied the basic right to good quality of life and an opportunity to have their specific psychosocial needs met. Indirectly it affects nurses in such a way as to prevent them from even thinking of introducing the topic of hospice care.

The PEAS scale would not be suitable for use in Malaysia due to questions on advance directives and certain medications used. As it is the first of its kind in Malaysia the author perceives a need to keep the questions relevant to the culture. However, like Weigel et al. (2007) this author decided that no incentives would be given for the study when conducted in Malaysia.

Similarly not all the questions on the scale used in the study by Cramer et al (2003) were considered completely relevant to the Malaysian context; however the findings of the study clearly demonstrate the gap in the lack of utilization of hospice services due to the attitude of the nurses. Nurses in Malaysia cannot independently initiate conversations pertaining to end-of-life care and/or hospice. They may only do so after the physician has informed the patient about the outcome and prognosis related to the patient's condition. The onus of referral lies on the physician.

Education on End-of-Life Care

Eric Cassel in his classic work titled "The Nature of Suffering and the Goals of Medicine" discussed the lack of theoretical instruction on the relief of suffering in medical education (Cassel, 1982). In 1999 The Education for Physicians on End of life care project was launched. The following year the End-of-Life Nursing Education Consortium (ELNEC) project was begun, both with the intention of improving care for patients at the end of life. Studies conducted by Harvard University, Dartmouth Medical School and others have documented evidence indicating that educational programs are essential in addressing the unmet needs of professionals working with patients who are the end of life (EOL).

The End-of-Life Nursing Education Consortium (ELNEC), is a national initiative in the US, and has done much to improve palliative care by training nurses to meet the unique needs of the dying patient (Sherman, Matzo, Panke, Grant, & Rhome, 2003). It is hoped that change in the basic education curriculum may result in decreasing apprehension among nurses. Acute care nurses who practice in environments focused on the curative model, may not be able to discuss hospice care with patients and families due

to lack of knowledge (Cramer et al., 2003). Fear or apprehension to communicate such information may be another reason (Weigel et al., 2007). With changing nurse patient ratios and the increased acuity of the patients, quality communication time is a near impossibility. Lack of exposure to additional knowledge and training in end-of-life issues does make a difference in how nurses attitudes impact the initiation of hospice discussion (Cramer et al., 2003). The physicians attitude towards hospice referral as well their hesitancy to “give up hope” and patient/family unwillingness to accept prognosis (Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005) remain obstacles.

In a landmark study by Katherine Frommelt (1991), the attitudes of nurses caring for terminally ill patients and families demonstrates the need for death education. Studies conducted in the 80’s showed that nurses had a negative attitude towards patients who were terminally ill. Frommelt sought to determine if death education could have a change on nurses’ attitudes when caring for terminally ill patients.

Using a quasi-experimental design on a convenience sample of nurses (n = 34), Frommelt used a questionnaire she designed in 1988 for a pre and post intervention assessment of attitude. This questionnaire called the Frommelt Attitudes Toward Care of the Dying Scale (FATCOD) had been used and tested for validity and reliability and demonstrated an interrater agreement of 0.98 and Pearson’s Coefficient of 0.90 for test-retest reliability. It consists of a 30 item scale scored on a 5 point Likert scale. The educational intervention consisted of a case study, a role play and group discussions based on annotated bibliography that was provided (Frommelt, 1991).

The demographics of the participants demonstrated the national average in terms of education at that time. Over 50% had a diploma level education, 20.6% had a BSN and 2.9% had a master's degree in nursing. Another 5.9% of the participants had a master's degree in a field other than nursing. Out of the study participants 75.6% of nurses reported being inadequately prepared to provide care for the terminally ill when filling out the pretest questionnaire. An unexpected finding was that one group were hospice nurses who had experience in caring for the terminally ill, and this resulted in a significant effect on the attitude scores. However, even these nurses had a significant difference in their post intervention scores for attitude

Table 4 shows the results of all the nurses together. Nurses with different levels of education when combined had changes in their attitudes which were statistically significant. This finding indicates that a combination of death education plus experience reflected a more positive attitude toward caring for the terminally ill (Frommelt, 1991).

Table 4

Pre-education attitude compared to post-education attitudes. Paired t-test results

Nurses' attitudes	<i>N</i>	<i>Mean</i>	<i>SD</i>	<i>SE</i>	<i>t</i>	<i>DF</i>	<i>2-Tail</i>
Pre-education	34	4.3049	0.310	0.056	2.97	33	0.006
Post education		4.4157	0.326	0.053			

*p = <.01

The findings of this study demonstrate that additional training is required for nurses to have changes in their attitude toward terminally ill patients. It indicates that what is learned about death and dying in the basic nursing education is not adequate enough to provide good end-of-life care. This change in attitude may reflect in the

provision of information regarding hospice care which may lead to a greater use of the facilities and resources available.

The FATCOD described in this study was shortened, modified and validated in a later study conducted by the author (Frommelt, 2003). The repeated use and validation of the shortened version of the FATCOD in multiple studies demonstrated that it would be a good fit in the present study. The FATCOD was not used in its entirety for the study conducted in Malaysia because there were questions that were similar to questions in the Revised Death Anxiety Scale which was also used.

Prior to the implementation of educational programs in end of life care in medical schools in the US, a study led by Sullivan, Lakoma and Block (2003) of Harvard University was conducted involving 62 randomly selected medical schools. A national probability sample of 1,455 fourth year medical students, 296 third year residents (randomly selected from stratified specialties) and 287 faculties (stratified by specialty) provided data for this study. The faculty and residents provided validation for the study that looked at attitudes, quantity and quality of education and preparedness to provide end-of-life care as well as the perception of the value of care for dying patients. Aspects of clinical experience and the “hidden curriculum” referred to by Dr. Charles von Gunten (von Gunten, 2007) were also addressed. IRB exemption was granted by the Dana Farber Cancer Institute.

The hidden curriculum identified as a major and modifiable contributor to inadequacies in physician education is characterized by the following:

- A paucity of teaching about end-of-life care.

- Lack of exposure to care of dying patients at home and to models of care for the dying such as hospice.
- Perceived communications by teachers that end-of-life care is less important than other aspects of care.
- Tolerance of lack of preparation for clinically ubiquitous psychosocial and communication tasks related to end-of-life care, and
- Perceived mixed messages about end-of-life care

(Sullivan, Lakoma, & Block, 2003, p. 693)

The hidden curriculum is what is seen demonstrated by the role models/ teachers during professional education. Becoming a professional involves education, development of skills and socialization into the role of a professional. The researchers observed the impact of the hidden curriculum in this study along with individual experience.

The survey questionnaire based on information provided through resident focus groups, curricula from existing model programs for EOLC and recommendations from the National Consensus Conference for Medical Education in EOL care, dealt with specific dimensions in EOLC. These dimensions included what is considered by palliative care experts as being core competencies – pain management, non-pain symptom assessment and management, communication with patient and family, discussion of hospice and referral, psychosocial support, spiritual care and self-awareness. The content validity of the questionnaire was ascertained through extensive review by experts. The three main domains considered were: (a) attitude towards end-of-

life care, (b) perception of preparation to teach about end-of-life care, and (c) perception of the end-of-life care culture in the hospitals.

The analysis of data evidenced that 99% of participants believed that physicians have a responsibility to help patients at the end-of-life to prepare for death, but more than half the student participants did not perceive the importance from their teachers. Forty four percent of the subjects thought it was depressing to care for dying patients and 27% dreaded dealing with the distress of the families (Sullivan et al., 2003).

Regarding preparation, between 9%-18% of the students had some end-of-life care course or clerkship in the area and about 17% of the faculty reported teaching about any aspect of end-of-life care. Between 70-80% of the faculty felt they were moderately or very well prepared to teach about pain management, discussing patient's end of life care and fears about dying as well as providing bereavement care.

Regarding the quality of EOL preparation 84% of students perceived the quality of end-of-life teaching to be much lower than the general quality of teaching in the institutions. More than half the residents felt unprepared to teach students or junior residents how to manage their feelings about patient's death or help families during bereavement. However when asked about changes being needed in end-of-life care education 98% of faculty and 99% students believed changes were necessary.

Fewer than half of the students and residents perceived that meeting psychosocial needs of the patients was a core clinical competency. More than 50% of the faculty and residents reported that care for the dying was only a little rewarding or not at all. Thirty seven percent of the residents reported not posting students to dying patients in order to

protect the family (61%), because it was complicated (44%), or to protect the student (15%) from an upsetting experience (Sullivan et al., 2003).

The limitations to the study include self-report which could lead to overestimation of knowledge and skills, non-validation of the questionnaire used and low response rate of the faculty. Despite these limitations, the findings of this study clearly demonstrate that doctors are not socialized into the culture of identifying and providing for the psychosocial needs of the dying patient. Although they appreciate the value of physical care, psychosocial and spiritual needs are not considered important enough to be learned about. Individual attitudes towards death and dying as well as providing care for terminally ill patients are not being systematically addressed. It needs to be understood that “the goals of protecting the patients and students would be better served by providing students and residents adequate training in how to interact with and adequately care for dying patients and their families...” (Sullivan et al., 2003, p. 692). Only then would referral for specialized care of the dying individual be considered the norm by physicians.

Summary

Norms are what guide behavior. In a profession, education and knowledge provides norms for behavior for professional practice. If provision of hospice information or referral is a desired norm within the profession then there is a need for the knowledge to become a part of what guides behavior. Education on end-of-life care therefore, requires that health professionals have knowledge of not only the physiological and pharmacological needs of dying patients, but also psychosocial needs. This education needs to begin early so that the earliest experiences with death and dying are

dealt in a knowledgeable way that prepares for future practice. Although nurses in Malaysia are introduced to the idea of psychosocial needs, the study of social sciences is not a strong feature in the nursing curriculum. It would mean that Malaysian nurses do not have the knowledge needed to provide end-of-life care without additional education and training.

The unique needs of dying individuals and their families include physical, psychosocial and spiritual components. The current concerns with practices of hospice discussion or referral to hospice include a lack of knowledge, professional preparedness and personal attitudes towards death and caring for the dying. More often than not the focus on providing curative care and maintaining objectivity may prevent unprepared physicians and nurses in acute care from using opportunities to communicate with families about hospice. There is an unnamed gap between what is needed by terminally ill or dying patients and families and what they receive in terms of medical care. There are factors as yet unidentified that affect the gap between what is provided for the patients and what is not.

Theoretical Framework

Although the need for “research and critical evaluation alongside the delivery of care” was recognized by the pioneers of hospice care, evidence shows a hampering in the development of a research culture in the organizations that provide the care (Richards, Corner, & Clark, 1998, p. 399). This may be due to the fact that most hospices are either separate from academic institutions or funded by nongovernmental organizations or governmental insurance with the result that research funding in hospice matters has been scarce. Never the less there is some available literature on various aspects of hospice

care and related concepts. Certain aspects of hospice are discovered every now and then as gaps. Sometimes the gaps pertain to a region or culture and at other times to an aspect for an individual discipline. Empirical evidence gained by researching such gaps contributes not only to knowledge but also to improvement in processes and outcomes.

The Application of the Theory of Planned Behavior

The Theory of Planned Behavior (TPB) (Ajzen, 1991), guided the design of this research, as a major predictor of behavior is intention. Intention may be seen as the cognitive representation of a person's readiness to perform a behavior, and may be considered to precede the behavior itself (Perkins et al., 2007). Intention is determined by attitude toward the specific behavior, subjective norms and the perceived behavioral control in the individual performing the behavior. Attitude is defined as a feeling or way of thinking that affects a person's behavior (*Meriam Webster Dictionary, 2015*). Attitude may be affected by The Theory of Planned Behavior proposed by Ajzen in 1985, implies that only specific attitudes toward the behavior in question may be expected to predict that particular behavior. In addition to measuring attitudes toward the behavior, people's subjective norms (beliefs about how people they care about view the behavior in question) also need to be measured. To predict intentions, knowing the beliefs regarding the behavior is as important as knowing the person's attitudes towards that particular behavior. Perceived behavioral control influences intentions to perform a behavior. Perceived behavioral control refers to people's perceptions of their ability to perform a given behavior. Such predictors lead to intention and as a rule, the theory holds that the more favorable the attitude and the subjective norms, the greater the perceived control an

individual feels. This makes a person's intention stronger to perform the behavior in question.

The Theory of Reasoned Action (TRA), (also developed in part by Ajzen) was the precursor to the theory of planned behavior (TPB) and has been successfully used to predict a variety of health related behaviors. It explains behaviors that are under full volitional control. However, for behaviors that require skills, opportunities and are not fully under ones volitional control, perceived behavioral control is considered (Millstein, 1996). A study reported in 1996 describes the use of both TRA and TPB for prospective prediction of physician behavior. The behavior concerned was education of adolescent patients on the transmission HIV and sexually transmitted diseases. As earlier studies comparing the two models have shown that there was a very slight difference in the predictability of highly controllable behavior, the study by Millstein used both models. The final sample consisted of 765 actively practicing primary care physicians of 5 different specialties. 36% percent were female. A stratified random sample of 2, 087 were contacted by mail using the AMA listing of practicing physicians in the US. Data were collected twice 6 months apart. Although there was an initial 60% response the second survey resulted in a 65% response of those who participated in providing data the first time. Due to excluding participants with missing data, the final sample consisted of 765 individuals.

The items on the survey instrument were derived from open ended interviews conducted with 20 physicians. These interviews were conducted to identify salient beliefs concerning positive and negative consequences of preventive services and most important individuals, groups and institutional referents that may influence them to

provide the service. Ten consequences of educating adolescents on HIV and sexually transmitted diseases were identified on which survey participants could agree or disagree to six varying degrees. Each of these 10 consequences was assigned two judgments on which survey participants could decide on acceptability or not on a 6 point Likert scale. The scores were used to determine attitude.

To determine norms that may influence their behavior four salient referents were identified in the interviews and study participants were asked to assess their familiarity with these referents and their motivation to adhere to these referents. Perceived behavioral control was determined by a direct question asking the physicians to rate their control on a six point scale on educating the adolescents. To determine behavioral intention physicians were asked to determine the percentage of adolescents they intended to educate over the next 6 months. Behavior was assessed by asking for the percentage of adolescents they believed that had been educated by them in the previous 6 months.

The analysis revealed that the predictability of TPB model was significantly greater for behavioral intention, but both models posit only indirect effects for attitude and social norms. There was a significant direct effect for perceived behavioral control even for subsequent behavior. Significant relationships were determined between behavioral control, behavior and behavioral intention with p values of less than 0.0001 (Millstein, 1996).

Summary

As the study by Millstein (1996) evidenced superiority in the ability of the TPB model in predictive power on physician behavior, it was the theory of choice used to design the present study looking at the behavior of physicians with regard to provision of

hospice information at the right time. The perceived behavioral control may be the expectation of the Ministry of Health, Malaysia, The World Health Organization and the hospice associations to provide the best care for dying patients. Social norms would consist of the knowledge received through education and societal expectation of physicians. Although attitude did not demonstrate direct effects, in the study, it has a part in the model. It may be said that the results of attitude may be different in different settings due to the other factors that affect attitude.

CHAPTER THREE

RESEARCH DESIGN

Review of available literature reveals a lack of understanding of factors that affect the beliefs of nurses and physicians regarding discussion of hospice with terminally ill patients. Similarly in Malaysia this lack of understanding appears to exist. This lack of understanding may underlie non-referral or late referral of possibly deserving terminally ill patients. Malaysian nurses and doctors have the greatest responsibility for the care of terminally ill patients, and thus, they compose the study group.

Purpose of the Study

Empirical studies conducted in many countries showed that management of end of life care is inadequate (Casarett, Van Ness, O’Leary, & Fried, 2006; Lorenz, Asch, Rosenfeld, Liu, & Ettner, 2004; Melvin, 2008; Ogle et al., 2002). The psychosocial needs of terminally ill patients are often not acknowledged by either physicians or nurses and remain under addressed aspects of care.

In Malaysia, communication between clinicians and patients regarding alternative treatment options is limited. Communication between physicians and patients is affected by multiple factors. One of the barriers to patient-physician communication was a lack of understanding between the physician and the patient regarding the needs of a dying individual (Khan, Hassali, & Al-Haddad, 2011). The authors point out that the inability to communicate satisfactorily combined with lack of preparation to deal with psychosocial needs of a person who is dying, demonstrated a need for hospice referral. Although, hospice care personal are specifically prepared to identify and care for psychosocial needs as well as physical/medical needs of patients, the channel to hospice

care is through clinicians and nurses who provide acute care and who may be the least equipped to take on this responsibility.

It has been suggested that fundamental shifts in the attitudes towards terminal illness are needed among clinicians for them to make the needed changes, which will ensure that terminally ill patients receive the kind of care they need (Bradley et al., 2000; The SUPPORT Principal Investigators, 1995). Measures for change can be addressed only after current knowledge, attitude and practices of health professionals are assessed with regard to palliative and hospice care.

Because the medical model for healthcare primarily embraces the curative aspect, death is often considered a failure of the efforts of healthcare professionals (McGorty & Bornstein, 2003). Therefore, a clearer understanding of why terminally ill patients and families do not receive information or referrals is needed. How much the physicians and nurses know about hospice care needs to be considered along with their perception about the right time to introduce the topic of hospice care.

Based on the issues concerning the lack of use of hospice, it was assumed that fewer terminally ill patients in Malaysia use hospice care services than expected. Explanatory factors were assumed to be inadequate knowledge of hospice care practices, a less positive attitude toward caring for the dying, and a greater death anxiety among the nurses and physicians in Malaysia. It is understood that many factors have an influence on these study variables as well. Some of these could be demographic factors, therefore demographic factors that would be analyzed included age, gender, specialty, experience, and religion. Other factors are outside the scope of this paper.

Specific Aims of the Study

The purpose of this exploratory correlational study was to examine existing knowledge about hospice care practices, attitudes towards care of the dying, and death anxiety among nurses and physicians in Malaysia and when they believed was the right time to discuss hospice care. The specific aims towards achieving the purpose would be described by answering specific questions following analysis of the data:

Aim #1: Describe Malaysian nurses' and physicians' level of knowledge of hospice care practices; attitude towards caring for the dying, level of death anxiety, and when they thought was the best time to discuss hospice care.

Question #1: What are the levels of knowledge of nurses and physicians about hospice care practices as measured by the Palliative Care Knowledge Test?

Analysis: Means, standard deviations, and minimum and maximum values were described for physician and nurse groups for level of knowledge of hospice care practices as measured by the Palliative Care Knowledge Test (PCKT).

Question #2: What are the attitudes of nurses and physicians toward caring for the dying?

Analysis: Means, standard deviations, and minimum and maximum values were described for physician and nurse groups for attitude towards caring for the dying as measured by the Frommelt Attitudes toward Care Of the Dying Scale (FATCOD).

Question #3: What are the levels of death anxiety of nurses and physicians?

Analysis: Means, standard deviations, and minimum and maximum values were described for physician and nurse groups for level of death anxiety as measured by the Revised Death Anxiety Scale (RDAS).

Question #4: When do participants believe is the right time to discuss hospice care as measured by short answer questions, “What is your main reason for not discussing hospice care hospice?” and “What are the conditions under which you will feel it appropriate to discuss hospice care with your patients?”

Analysis: Tabulation of specific comments used to describe reasons for not discussing hospice care and to describe the right time to discuss hospice care.

Question#5: What are the differences between nurses and physicians in level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety?

Analysis: Differences between nurses and physicians level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety means were determined by use of independent sample t-tests.

Aim #2. Examine the relationship among levels of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety.

Question #6. What is the inter-correlation among levels of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety, of the physician and the nurse samples?

Analysis: The relationship between level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety were analyzed with Pearson’s r correlation for the physician and nurse subgroups.

Aim #3: Examine the association between selected demographic characteristics (e.g., years in practice, religion, specialty) and Malaysian nurses’ and physicians’ level of

knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety.

Question #7: What is the association between selected demographic characteristics (e.g., years in practice, religion, specialty) and Malaysian nurses' and physicians' and attitude towards dying and anxiety?

Analysis: Continuous measures of demographic characteristics (e.g. years in practice, were analyzed with the Pearson's r statistic. Binary demographic characteristics (e.g. gender) were analyzed using the independent sample t test statistic. For demographic characteristics that are multi-category variables (religion and specialty) groups were collapsed in order to have meaningful results and analyzed using t tests. Analysis of association was conducted for the physician and nurse subgroups. As the subgroups of the data involving religion and specialties were too small, they were collapsed in order to achieve meaningful results.

Theoretical Framework

To understand why terminally ill patients and families do not receive information or referrals, the study considered how much the physicians and nurses knew about hospice care and the practices involved. The meaning of death to an individual can be a personal perception based on prior experience with death or the beliefs related to death and influenced by the religious upbringing. According to research on the relationship between attitudes and behaviors, the more favorable an individual's attitude and subjective norms related to an expected behavior, the stronger would be an individual's intention to perform the behavior (Ajzen, 1991). Therefore it was surmised that the

personal attitude towards caring for the dying and towards death may affect the decision to provide information about hospice.

The premise of the Theory of Planned Behavior, on which this study is based, is that knowledge and attitude affects behavior. Therefore the questions that were to be answered included “Does the knowledge of hospice practices affect the behavior of nurses and doctors in providing information to terminally ill patients about hospice?” or “Does knowledge of Hospice practices in Malaysia as well as attitude towards death and dying patients affect the practice of providing hospice information to the patients by nurses and physicians?” The responses as well as the demographic information together were expected to provide an insight into possible changes that may be needed, to either change practice or enhance current practice.

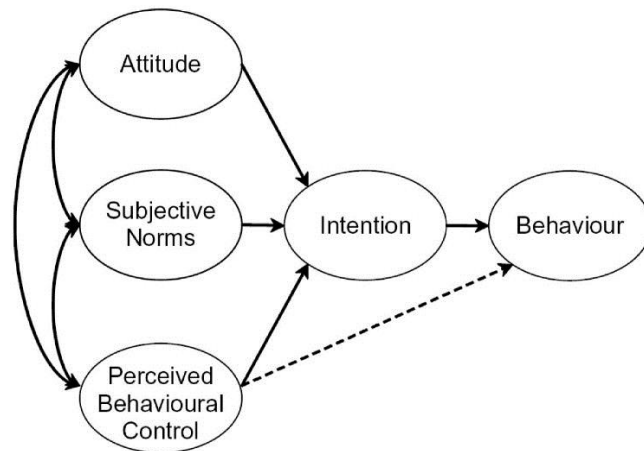


Figure 2 - Model for Theory of Planned Behavior Sourced from Ajzen (1991) pg. 182.

In the Theory of planned behavior (Figure 2) attitude to the behavior, subjective norms (knowledge and expectations related to the behaviors) and perceived behavioral control are depicted as having an effect on the intention to perform a behavior. Attitude, subjective norms and perceived behavioral controls may be described as follows:

1. Attitude - a feeling or way of thinking that affects a person's behavior. It may be affected by age, gender, religion, culture and upbringing.
2. Subjective norms - knowledge of hospice care practices and exposure to hospice care
3. Perceived behavioral controls - professional body expectation, legislation or prior positive experiences with hospice

Intention to perform the behavior could be measured by directly asking if participants would choose to discuss hospice care. Based on the identified concern of the behavior of discussing hospice care not being performed as much as expected, it was more important to identify and study the first three components of the model and assume that intention would be affected without measuring the degree of intention. For this study, intention to perform the behavior was not measured, however based on the TPB model, it was assumed that behavior would be affected by knowledge of hospice care practices, attitudes towards caring for the dying and personal death anxiety. The existing social and legal expectation or perceived behavioral controls is also assumed to affected knowledge and attitude.

The theoretical framework developed for this study (Figure 3) depicts the relationship between knowledge of hospice care practices and attitudes toward death and the care of the dying on the behavior of providing information about hospice by nurses and doctors. It does not deal with the behavioral intention due to the assumption that intention is directly affected by knowledge and attitude. It may be seen that prior positive experience adds to both knowledge and attitude which appears to have an effect on the expected behavior which was to have been the discussion of hospice or hospice referral.

As the study progressed it was observed that it would not be possible to consider all of the factors contributing to the decision to provide information to the patients. Prior positive experience and attitude towards use of hospice was not included in the questions. It was also observed that key factors such as religion and culture which were not included in the model may have had a strong role in the decision to provide hospice information.

Factors that Influence Decision to Discuss Hospice

The theoretical model that was developed for this study was based on the following factors which were expected to be true:

1. Acknowledgement of psychosocial needs in the terminally ill impacts the attitude towards the unique needs of the dying person. This in turn was expected to have a direct effect on intention to provide information about hospice to the patient and family.
2. Knowledge of hospice care practices was expected to affect the attitude towards specialized hospice care to meet the needs of the dying person. Such a change in attitude based on knowledge was expected to influence the provision of information regarding hospice care.
3. Prior positive experience with death/terminal illness/hospice as a student, or later was expected to affect existing personal attitude towards death and dying. This was expected to have a direct effect on the decision to discuss hospice care.

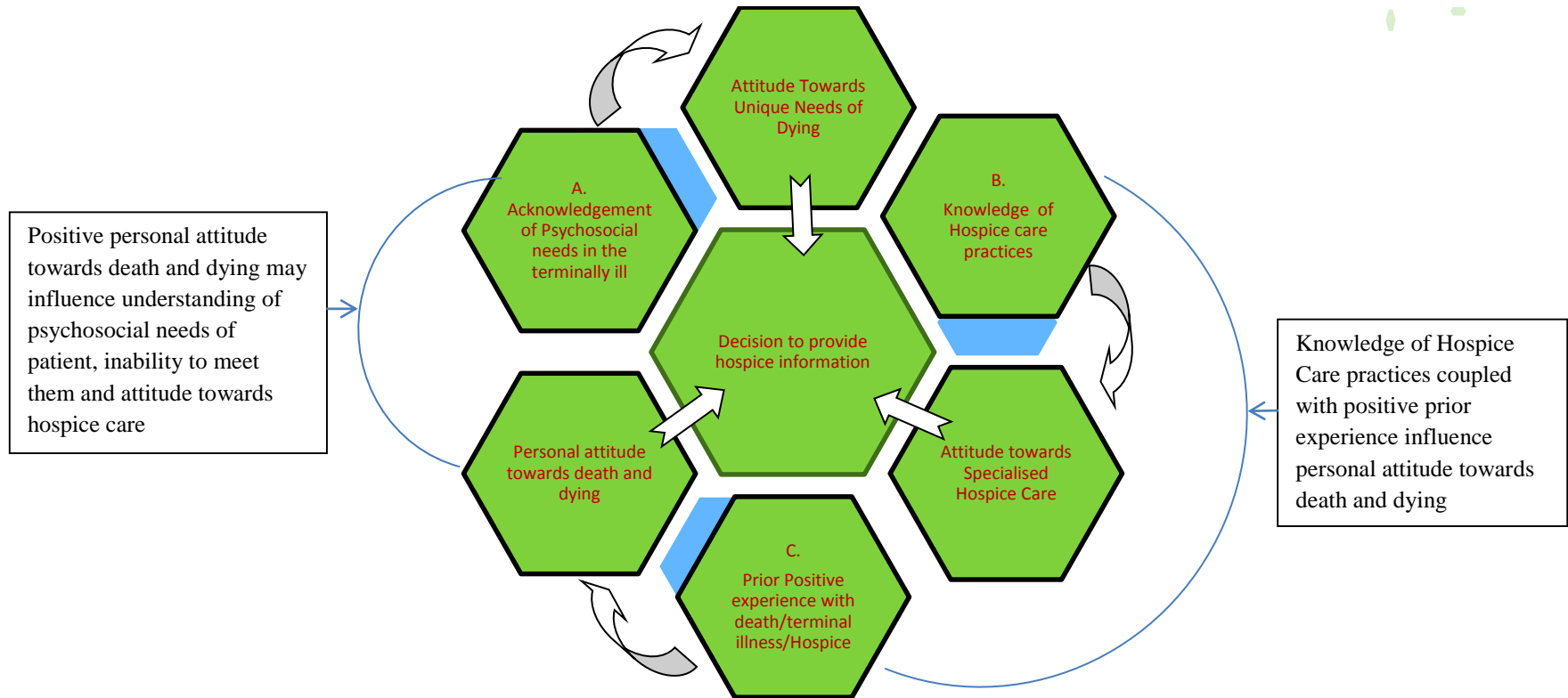


Figure 3 Factors that Influence Decision to Discuss Hospice

The findings of the study were expected to shed light on what factors actually affected the practice of hospice information provision as seen in the model. A desired outcome was that personal acknowledgement of a lack of knowledge and ability to provide the aspects of care needed by the patients would have an effect on the nurses and doctors accepting the need for hospice care in their patients. Perceived behavioral controls were not being specifically looked at in this study, since the provision of hospice information and the referral of patients to hospice is not a mandated or legislated expectation. As the data collection progressed, it was observed that measuring the quantity of the practice of hospice discussion or referral would not be feasible. The responses to the question on practice of hospice discussion and referral showed that there was a high probability of the terms used having been misunderstood.

Study Sample

The sample for this study was drawn from health care professionals practicing in Sabah in East Malaysia and Penang in West Malaysia. Doctors who were members of the Sabah and Penang Branches of the Malaysian Medical Association were sent an email invitation to participate in the survey. Those members who did not have an email on record and all RNs were given hard copies of the survey.

There were a total of 9 independent bio-demographic variables. Practice specialties were further broken down into 6 (certain specialties were collapsed into one variable for analysis). Religion broke the sample into at least four groups. This made a total of 20 variables. There were 3 variables that described the knowledge and attitudes with regard to hospice care and 1 independent variable. In order to ensure accuracy in the analysis of groups, the target sample size was set at 120 after discussion with an

experienced researcher and statistician. To ensure adequate statistical power, minimize probability of statistical errors, improve the accuracy of the population estimates, and allow for greater generalizability of results larger samples are desirable (Osborne & Costello, 2004). The sample for this study would not be considered a large sample, but adequate based on the “rule of thumb.” The desired number of subjects, 120, also was based on the ratio of number of subjects and independent variable for regression analysis (“rule of thumb” 5 to 10 per independent variable). (Regression analyses were not run, however, given the results detailed in Chapter IV). Therefore a total of 5 subjects for 24 variables would require an N of 120.

Studies have shown that response rates for web surveys is around 44% (Lin & Van Ryzin, 2012) and among nurses and physicians, under 60% if no incentives are offered (VanGeest, Johnson, & Welch, 2007; VanGeest & Johnson, 2011). The questionnaire for this study (Appendix C) was administered both electronically and in paper and pencil format with no incentives offered. This was done to meet the needs of those members of the professional associations who had and did not have an email on record. To achieve a sample size of 120 with an expected response rate of less than 50% 300 invitations were sent out. However, many of the responses turned out to be incomplete. The period of data collection was extended from 6 months to eleven months, and at the final count a total of 550 individuals had been contacted in different ways.

Doctors who were on the email address list of their professional organization, were sent the invitation to participate by the medical association offices in Sabah and Sarawak. Those who were not on the mailing list were sent hard copies of the invitation and the survey. As the professional association for nurses did not respond to the

permission request, nurses from two hospitals in Penang were given hard copies of the invitation and the survey by the directors of nursing. Some nurses who participated in the survey then invited nurses that they knew working in Sabah, to participate in the survey by using the electronic survey link.

Data Collection Procedure

Demographic Data

The demographic data collected included the year of completion of professional training, discipline (RN or MD and respective specialty), gender, age, and years in practice, religion and prior exposure to hospice or palliative care. Benner (1984) found that it takes approximately 3 years for a novice to become an expert performer, therefore, it is expected that doctors and nurses who have been in practice for at least three years, may be considered expert enough to realize when terminally ill patients may need more care than they can provide (Benner,1984). Thus, the respondents had a minimum of three years of practice.

The items under demographic data gathered are explained as follows:

1. Year of graduation determined number of years as a professional – the assumption being that the individual has been in active practice since graduation as is common in Malaysia.
2. Age, gender, religion, and any training regarding palliative care or knowledge of palliative care is needed for analysis within groups and between groups.
3. Specific specialty information was collected to consider the differences in knowledge or practice among the various specialties. At the same time, nurses and doctors involved in the care of children and obstetric patients and who are not

expected to come across terminally ill patients would be grouped together and excluded from the analysis. However, their views could be compared with that of those doctors who did provide care for terminally ill and dying patients for the short answer questions. Palliative care was included so that any difference that existed between them and other specialties could be compared.

To be able to use the same questionnaire for both RNs and physicians, it was assumed that nurses who work with patients of the different specialties or in specific areas would choose that particular specialty.

4. Individual religious beliefs may have an effect on the behavior or attitude pertaining to hospice care, therefore religion information was gathered.

In Malaysia, it is accepted that anyone who is of the Islamic faith is Malay.

Similarly, Hindus are Indian and Buddhists are Chinese. A small percentage of Chinese are Christian, and an even smaller number of Indians are Christian. The distribution of races is Malay = 59%, Chinese 25%, Indian = 8% and others = 6%, (Bureau of East Asian Affairs, 2007). As per census data regarding the mainstream religions, 60.4% of the total population is Muslim, 19.2% are Buddhists, 9.1% are Christians, and 6.3% are Hindus. The rest claim to be free thinkers or are uncommitted to any religious persuasion. Therefore, information gathered included religion, but not ethnicity, because religion and ethnicity are considered to be directly related in Malaysia.

5. To differentiate between the knowledge of those who have an understanding of hospice care practices and those who did not, two questions regarding prior use of hospice or any training about hospice or palliative care were included.

Data Collection Tool

The independent variables of knowledge of hospice care practices and attitude toward death, and caring for the dying, were considered precursors of the behavior of providing information or referring to hospice. They were measured using an adaptation of scales that have been developed and tested multiple times. The questions assess attitude toward the care of the dying patient, health professionals' personal death anxiety, and knowledge of existing practice in palliative/ hospice care. The assessment also included knowledge of current practices of hospice information provision and/or referral to hospice.

The analysis of data gathered by this questionnaire was expected to support the statement that knowledge of current hospice practices, personal attitude towards death, and personal attitude towards caring for the dying had a direct relationship to the beliefs of nurses and doctors regarding the right time to discuss with terminally ill patients (or their families) in Malaysia. The questionnaire (Appendix C) consisted of modified versions of the scales described:

Palliative Care Knowledge Test

The Palliative Care Knowledge Test (Nakazawa et al., 2009) was selected for use in this study, as it is the latest one developed and is inclusive of wider range of current practices in hospice care (such as the use of anticholinergics and morphine in higher titrations for respiratory issues). Its reliability and validity has been tested on two samples of a population of healthcare professionals in Japan. The items were generated based on literature review and discussion among a panel of 9 experts. This test measures the level of knowledge of the individuals about symptom management as well as

psychosocial care given to terminally ill patients. It deals with specific issues faced by the patient and also the topics at the end of life that may be “delicate,” such as teaching the family to allow the patient to verbalize his/her feelings about death. The questions on symptom management, such as metoclopramide and haloperidol being used to manage ileus in the dying patient deal with best practices developed following extensive research. Although nurses and doctors may know the problems faced by the dying patient, they may not know what can be done about it. The questions, although not exhaustive, cover key aspects in all areas of patient care. In the primary article publishing the psychometrics of the PCKT, the authors have requested that credit be given for the scale each time it is used. Thirty-eight of the original 40 items from the Palliative Care Knowledge Test were included in the questionnaire. A question regarding disclosure does not have a right or wrong answer based on the regulations in Malaysia. Therefore, the response to that question was analyzed separately. A question pertaining to the use of pentazocine was dropped, as pentazocine is not commonly used for pain management in hospice care in Malaysia. Unlike the true or false responses expected by Nakazawa et al. (2009), the expected response in this study was just Yes and No to the statements to maintain consistency in the method of administration of all the scales in the survey. The validity and reliability for the original scale are found in Table 5.

The Frommelt Attitudes towards Care of the Dying Scale

Designed and named after the author Katherine H M Frommelt, this scale has been used, modified, and validated in studies conducted across 8 countries. Because death touches all people and yet the greater part of it is unknown, there is a certain amount of fear associated with it. The inability of society to come to terms with death

has socialized many to avoid facing the inevitability of death and all that goes with it. This test assesses individual perceptions of the nurses and doctors about the terminally ill patient and family and how they should or should not deal with terminal illness and death. It is currently used in 63 colleges, universities and health care programs across the United States (Frommelt, 1991, 2003) to help individuals deal with personal issues to provide the best care for the dying. The scale is available on line with a request for credit to be given upon use of the scale. The scale consists of 30 Likert-type items scored on a five-point scale. There are an equal number of positively and negatively worded items.

In the original scale, positive items were scored from one for strongly disagree to five for strongly agree. Negative worded items were scored in the opposite direction with higher scores reflecting more positive attitudes. However, for a first time study in Malaysia this author believed it was more important to determine the presence or absence of a positive attitude rather than to measure the degree of the attitude, therefore the items were scored as “yes” and “no” instead of using the 5 point Likert scale. This decision, in retrospect appears to have had a detrimental impact on the study. The responses were re-coded during preparation of the data for analysis to depict more positive attitude or less positive attitude towards caring for the terminally ill and dying. Higher scores indicated more positive attitude, whereas lower scores indicated a less positive attitude. Questions about anxiety related to death were not used in this study, to keep the data collection questionnaire shorter and to avoid repetition of the questions in the death anxiety scale, reducing the actual questions to 19 instead of the original 30. The validity and reliability for the original scale are shown in Table 5.

The Revised Death Anxiety Scale

A 19-item Death Anxiety scale was designed to assess health care professionals' attitudes towards death (Templer, 1970). It subsequently has been used and modified (Black, 2007; Merrill & Lorimor, 1998; Templer, 1970), but the revisions did not show any greater validity and reliability than the original scale. The questions from the original scale have been integrated into other questionnaires and repeatedly tested for validity and reliability. A coefficient alpha of 0.76 was achieved in a group of college students; test-retest reliability was acceptable too. The same scale was tested on psychiatric patients and demonstrated similar findings. The questions elicit responses about deep-seated feelings towards death that cross religious and cultural beliefs. The Revised Death Anxiety Scale (RDAS) used and tested by Thorson, based on the Death Anxiety scale not only covers perceptions about the act of dying, but also the finality of death, burial and the beyond (Thorson & Powell, 1992).

The revised scale RDAS was used for this study to examine the desire of physicians and nurses to provide their patients with a choice of hospice care based on their personal feelings toward death. The author has provided written permission online to use it. The RDAS is a scale with 25 statements, 17 phrased positively and eight negatively. Responses are on a 5 point Likert format. Items are scored with the value 0 given for least anxiety and 4 for the highest death anxiety; responses to negatively phrased items are reversed in the scoring process. The possible range of an individual respondent's total score is from 0 to 100. Scoring of 4 for strongly agree, 3 for agree, 2 for neutral, and 1 for disagree with strongly disagree scoring 0 for the following items – 1,2,3,5,6,7,8,9,12,14,16,18,19,20, 22 and 24. Scoring for items 4, 10, 11,13, 17, 21, 23

and 25 are 0 for strongly agree, 1 for agree, 2 for neutral, 3 for disagree, and 4 for strongly disagree. Items left blank get a score of 2 for neutral. The scores can be added up for the respondents' total score. Based on a pilot study, which showed a need to shorten the data gathering tool, items 21-25 were removed leaving a total of 19 questions. Again to maintain consistency in the method of administering the whole questionnaire in the present study, items were scored as "yes" and "no" instead of using the 5 point Likert scale. Therefore, the score is only 1 for a positive response and 0 for a negative response with the possibility of a total score being equal to 19. The changes in scoring as well as the dropping of the questions have impacted reliability and validity of the findings of the study. The validity and reliability for the scale are found in Table 5.

Table 5

Validity and reliability information of the original measures before modification

	Name of Scale	No of items	Scoring	Internal consistency	Reliability	Validity
1	Palliative Care knowledge Quiz (Nakazawa)	40 Across 5 domains	Right wrong and unsure	KR (20) =0.81	0.88	Based on experts opinion of content validity
2	Frommelt Attitude Toward Care of the Dying (FATCOD)	30 items	5 point Likert scale		Pearson Product-Moment Correlation Coefficient = 94 and 90	content validity index (CVI) = 1.00 interrater agreement of 0.98
3	Revised Death Anxiety Scale	25	5 point Likert Positive items score 4 for strongly agree and negative items score 0 for strongly agree	KR (20) = 0.76	Cronbach's Alpha 0.85 Pearson Product-Moment Correlation Coefficient = 0.83	

The Most Recent Experience with Death

The questions pertaining to the most recent experience with death are a modification of the questions used in the Program in Palliative Care Education and Practice inventory (Block & Sullivan, 1998; Cherlin et al., 2007) conducted at Harvard University. Used in multiple cohorts over 4 years, their questions have demonstrated good reliability and validity (the scale is available online with a request from the authors to ensure that they are given credit for the scale). In a pilot test of this instrument at a private hospital in Penang, Malaysia, the questions (as they were presented from the questionnaire used in the Program in Palliative Care Education and Practice inventory conducted at Harvard University), did not elicit responses that were suitable for the Malaysian setting. Therefore, the questions were modified to more directly reflect referral practice as well as discussion of hospice. Physicians were asked about the number of terminally ill patients cared for in the last six months; the number of patients that hospice was discussed with and the number of patients referred to hospice. They were also asked for their reasons for not referring patients to hospice.

To maintain consistency in the method of administering the whole questionnaire, the question regarding referral was rephrased for nurses to just deal with hospice discussion after responding to a question regarding recent experience with dying patients. Both physicians and nurses were also asked for their reason for discussing or not discussing hospice care with patients.

Ethics Approval

Approval was granted by Loma Linda University Institutional Review Board (Appendix B) and the Adventist Clinical Research Center in Penang (Appendix J) prior to

beginning the study. A brief proposal of the study (Appendix F), the letter of invitation inclusive of consent information (Appendix D) and the questionnaire as well as a detailed description of the data collection process were submitted to the Loma Linda University IRB. The proposal outlined the identified lack of information provided to patients about hospice in the Malaysian setting. The letter of invitation provided information as to why the study was being conducted and why nurses and doctors were the subject of the study. It also included consent information therefore consent was considered implicit, if the questionnaire was completed.

Data Collection Process

The data was collected using the six page self-reported questionnaire (Appendix C) that included demographic data as well as the modified scales described. The participants that completed the paper pencil survey received an invitation to participate which also provided information for consent along with the survey. Participants that received the electronic invitation could only access the electronic link to the survey after reading the consent information

The data collection was coordinated by the Adventist Clinical Research Center (ACRC) in Penang to ensure anonymity. The Malaysian Medical Association Branch offices for the states of Penang and Sabah were approached by the researcher for access to their registries by the ACRC (Appendices G& H). The invitation to participate was sent to the members by email or hardcopy as determined by the association secretariat. Copies of the documents as well as self-addressed envelopes provided by the ACRC were mailed by the secretariat to those members who did not have email addresses on record. The participants were reminded that no identifying data was to be submitted. They were

also informed that participation in this study was voluntary and that there would be no remuneration. For those who receive the email, an electronic link led to the questionnaire on Qualtrics (the survey system used by Loma Linda University). The research assistant at the ACRC entered the data from the completed paper surveys received from the members of the medical association branches, into the electronic survey database. Two reminders were sent by the respective association secretariat to improve participation.

As the professional nursing associations were not able to be brought on board, the CEO's of two private hospitals granted permission for collection of data and the respective directors of nursing had the surveys distributed to nurses working in the facility. All responses were received by the researcher without any personal identifying information. The names of those who received the questionnaire are not known to the primary investigator.

The inclusion criteria were (1) full time employees (2) licensed nurses and physicians (3) working in acute care settings. The participants ranged in age from 21 to 65.

Data Protection

Some of the data was gathered electronically using the qualtrics system used by Loma Linda University. The data gathered using paper surveys was entered into the qualtrics system and the paper surveys shredded and discarded by the author. No data was transported in the form of hard copy. The data was stored electronically in a portable hard drive with password protection, in a secure location in a locked cabinet. It was transported from Malaysia personally by the author when needed. At the end of the research period the data was stored at Loma Linda University according to university

regulations. All data on the portable hard drive will be purged three years after the completion of the study. During this period of time the hard drive will be kept in a locked cabinet.

CHAPTER FOUR

DATA ANALYSES

Clinical observation and anecdotal reports consistently have shown that fewer terminally ill patients in Malaysia use hospice care services than one might reasonably expect. Moreover, it appears that nurses and physicians may not have an adequate depth of knowledge of hospice care practices. Among other explanatory factors are attitudes toward caring for the dying and personal anxieties around death, in general.

In the present chapter, available data were analyzed with the aim of addressing both the broad issues of hospice service underuse as well as the research questions described in the previous chapter. As noted, chapter 4 follows the order of the aims of the study.

This chapter comprises the analyses of the data; interpretations of these findings will be detailed in chapter 5. The analysis of data was carried out in two phases. The first part, which is based on the results of the questionnaire, deals with a quantitative analysis of data. The second, is based on the results of the responses to two open questions, and an interpretation of the reasons for not discussing hospice and when would be a good time to provide hospice information.

Data Cleaning and Preparation

There were a total of 179 responses from the 550 surveys that were distributed (an initial return rate of 33%). Evaluation of the responses to arrive at a final sample was done in a three-step process.

1. Forty-eight of the 179 responses contained only demographic data or only assigned ID numbers; therefore, they were removed, leaving 131 subjects.

2. One hundred and thirty-one subjects had completed most of the questions.

The scoring of the items in the scales was recoded as per the directions given by the original authors to rectify reverse coded items. The frequencies of each variable were checked to ensure that the data were within range. The average scores were computed for each item, and then the total score for each scale was calculated as new variables that would be used in the analyses. After the average score for each of the items in the scales was computed, three subjects were dropped due to the volume of missing data. The sample size became 128.

3. The responses were grouped by cohorts based on discipline (i.e., physicians

and nurses) for comparison of the scores of the Palliative Care Knowledge Test (PCKT), the Frommelt Attitude Towards Caring for the Dying (FATCOD), and the Revised Death Anxiety Scale (RDAS). Some data are presented for all participants (combined nurses and physicians), also.

Following the preliminary descriptive analysis, four more subjects were dropped because there was no indication of discipline (nurse or physician). A total of 124 subjects made up the final sample (final response rate: 23%).

Once the data set was complete, a new variable, years of experience was computed from the existing variable, year of graduation. An examination of frequencies in the demographic data was done to check for missing data in order to ensure that responses were complete enough to be meaningful and to correct or delete out of range values.

General Descriptive Analyses

The demographic data are described separately for nurses and physicians in

Tables 6 and 7.

Table 6

Sample Description, Continuous Variables (N = 124)

Variable	Nurses (n = 72)				Physicians (n = 52)			
	n ^a	M	SD	Min - Max	n ^a	M	SD	Min - Max
Age	67	35.37	10.74	25-65	51	44.71	10.86	24-65
Years of Exp	71	11.83	9.68	1-40	50	19.56	10.56	4-39

Note. n^a may not total 124 for individual variables due to missing data.

Table 7

Sample Description, Categorical Variables (N = 124)

Variables	Nurses (n = 72)		Physicians (n = 52)	
	n	%	n	%
<u>Gender (n = 124)</u>				
Male	5	6.9	34	65.4
Female	66	91.7	17	32.7
Missing	1	1.9	1	1.9
<u>Religion (n = 124)</u>				
Islam	3	4.2	5	9.6
Hindus	7	9.7	3	5.8
Buddhist	23	31.9	9	17.3
Christian	33	45.8	33	63.5
Other	6	8.3	2	3.8
<u>Specialty (n = 124)</u>				
Med-Surg/GP	21	29.2	23	44.2
Internal Med	1	1.4	4	7.7
Oncology	7	9.7	1	1.9
Surgery	7	9.7	2	3.8
Pediatrics	2	2.8	3	5.8
Obstetrics	1	1.4	2	3.8
Other	31	43.1	16	30.8
Missing	2	2.8	1	1.9

Of the total sample, 66.9% were female, whereas 31.5% were male. The greater proportion of physician respondents were male (65.4%), whereas 32.7% were female; 1.9% did not indicate gender. The greater proportion of nurse respondents were female (91.7%), whereas 6.9% were male; 1.4% did not indicate gender. An independent samples *t* test conducted to compare the ages of physicians and nurses showed that there was a significant age difference (physicians were considerably older). Physicians ($M = 44.71$ years, $SD = 10.86$) and Nurses ($M = 35.37$ years, $SD = 10.74$) $t(107.16) = 4.64$, $p = 0.000$. Correspondingly, nurses on average were less experienced ($M = 11.83$ years, $SD = 9.68$) than physicians ($M = 19.56$, $SD = 10.56$).

Preliminary descriptive analysis showed that group comparisons (i.e., statistical tests) would be invalid due to small numbers in some categories of the religion variable. To address this, data from this variable was collapsed into new groups with Christians making up one group and all other religions and “other” making up the second group. The religious mix of the total sample before collapsing was 53.2% Christian, 25.8% Buddhist, 8.1% Hindu, 6.5% Islam and 6.5% others.

Having nurses choose a specialty was a challenge as very few nurses actually had specialized qualification. No specific instructions were given to the nurses on how best to mark this question. Nurses self-selected from a list of choices to represent their work area. There were 29.2% nurses who selected general practice areas, 1.4% internal medicine, 9.7% general surgery, 2.8% pediatrics, 1.4% obstetrics, and 9.7% oncology. Forty-three percent of the respondents selected other specialties without specifying areas, and 2.8% had missing data.

The greatest proportion of the physician respondents was general practitioners (44.2%), whereas 44.2% practiced in other specialty areas, many of which were not specified. Among the named specialties, 7.7% were in internal medicine, 3.8% were general surgeons, 5.8% were in pediatrics, 3.8% were in obstetrics, and 1.9% were in oncology; 1.9% had missing data.

The specialty group categories also had small numbers in some categories (e.g. surgery = two physicians), so they were collapsed into 2 groups. Group 1 consisted of those in general practice and Group 2, all other specialties.

After collapsing the categories of religion and specialty, there appears to be a roughly equal distribution of nurses by religion (Christian = 33 and Other = 39) and of physicians by specialty (General Practice = 23 and specialties =28) as shown in Table 8.

Table 8

Sample Description of Collapsed Categorical Variables (N = 124)

Variables	Nurses (n = 72)		Physicians (n = 52)	
	n	%	n	%
<u>Religion (n = 124)</u>				
Christian	33	45.8	33	63.5
Other	39	54.2	19	36.5
<u>Specialty (n = 124)</u>				
General Practice	21	29.2	23	44.2
Specialties	49	68.1	28	53.8
Missing	2	2.8	1	1.9

Analyses by Aims of the Study

Aim #1

To describe Malaysian nurses’ and physicians’ level of knowledge of hospice care practices, attitude towards caring for the dying, level of death anxiety, why they did

not discuss hospice care, and when they believed was the right time to discuss hospice.

Table 9 describes the scores of the Palliative Care Knowledge Test (PCKT) used to measure knowledge of hospice care practices, Frommelt Attitude Toward Care of the Dying (FATCOD), and the Revised Death Anxiety Scale (RDAS) used to measure death anxiety.

Table 9

Description of Scores for the Study Scales PCKT, FATCOD and RDAS

Scales	Nurses (n = 72)				Physicians (n = 52)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
PCKT	72	22.72	3.92	15-31	52	25.07	3.76	16-33
FATCOD	72	15.14	2.26	11-19	52	15.91	2.55	10-19
RDAS	72	8.58	4.26	1-18	52	7.66	3.74	2-19

There was a significant difference in the PCKT scores for Nurses ($M = 22.72$, $SD = 3.92$) and physicians ($M = 25.08$, $SD = 3.7$); $t(112.7) = 3.38$, $p = 0.001$. This suggests that physicians had a better knowledge of hospice care practices than nurses.

An independent samples t -test conducted to compare the scores of physicians and nurses for the attitude towards caring for the dying (FATCOD scores) indicate that there was no significant difference: nurses ($M = 15.14$, $SD = 2.26$) and physicians ($M = 15.91$, $SD = 2.55$); $t(101.7) = 1.74$, $p = 0.083$. Similarly, there was no significant difference in the scores for the Revised Death Anxiety Scale (RDAS) scores: nurses ($M = 8.58$, $SD = 4.3$) and physicians ($M = 7.6$, $SD = 3.7$); $t(117.4) = -1.3$, $p = 0.208$.

Figure 4 is a histogram showing the range of scores for the entire sample before considering the range of scores separately for nurses and physicians. Corresponding numbers are shown in Table 20 (Appendix A). Scores were transformed to percent

correct for these graphs, which is why the numbers differ from those presented in the tables.

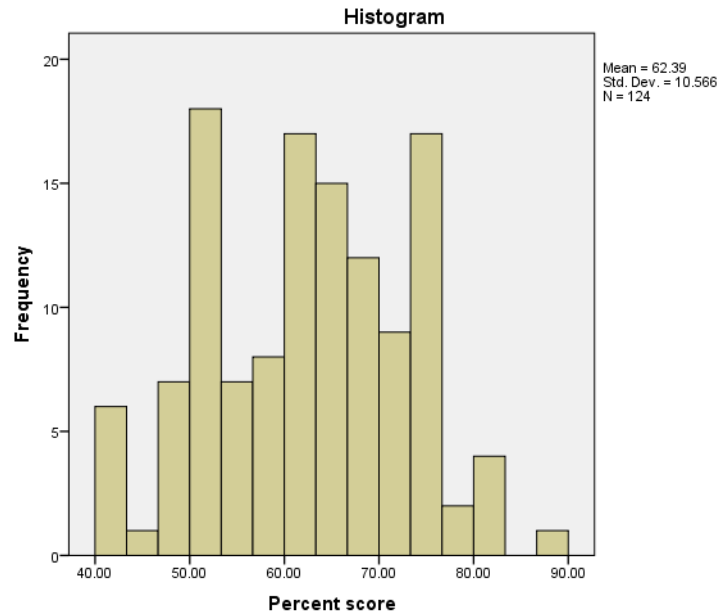


Figure 4 PCKT Scores Range for the Whole Sample, Nurses and Physicians Combined

The scores ranged from 41% to 87% correct for the Palliative Care Knowledge Test and appears to fall into a pattern that approximates a normal curve. However, when the range of scores was evaluated separately for physicians and nurses, there was a difference (Figures 5 and 6).

The scores for the Palliative Care Knowledge Test for Nurses seen in Figure 5 is skewed; this reflects lower scores among many nurses (more than physicians) on questions of knowledge of palliative care practices.

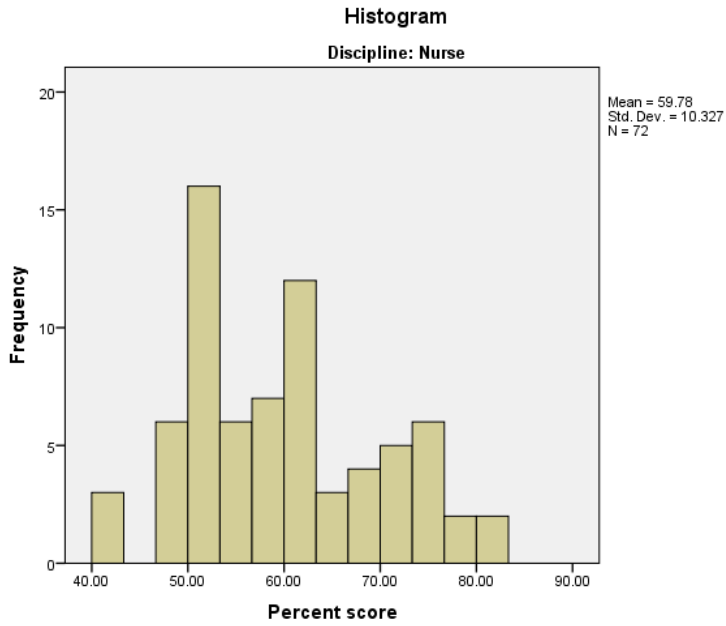


Figure 5 PCKT Scores Range for Nurses

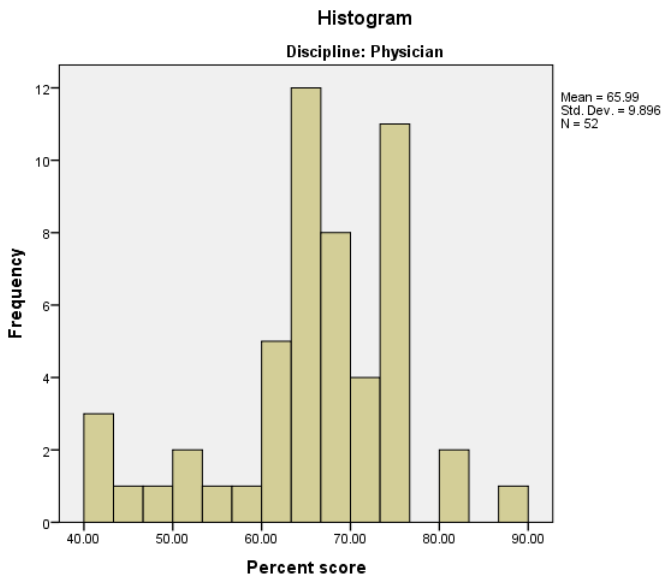


Figure 6 PCKT Scores Range for Physicians

The scores for the Palliative Care Knowledge Test for physicians are slightly “less normal.” Scores are shifted to the right, which corresponds to their higher mean score (i.e., when compares to nurses). The actual scores as seen in Table 33 (Appendix B)

An inductive content analysis of the responses to the questions “*What is your main reason for not discussing hospice care*” and “*What are the conditions under which you will feel it appropriate to discuss hospice care with your patients?*” was done. The author printed out the responses and highlighted words and phrases used repeatedly by the participants that depicted their understanding of the questions. These phrases were categorized to demonstrate the reasons for not discussing hospice care and conditions under which it was appropriate to discuss hospice care with terminally ill individuals and their families. Table 10 lists the categories of reasons for not discussing hospice with the phrases used.

Table 10

Phrases Used for Categories of Reasons for Not Discussing Hospice

Categories	Phrases used
Lack of Readiness	Unable to accept diagnosis, family reject idea of hospice, patient not interested, family refuse hospice discussion, family not open,
Family Support Available	Family wants home care, family support, only care by family wanted, family wants patient to die at home,
No Hospice Services	No hospice available, no known hospice
Not Enough knowledge	Do not know about hospice, no knowledge
Discussed Hospice	Discuss when needed, always discuss, I support hospice care, patients are informed about hospice
No Contact with Dying Patients	No contact, not encountered dying patents, no such patients, not take care of patient, work in areas that do not have dying patients, see patients only for short time, only critical care patients
Other Responses	Patients pass away in ICU, prognosis is good, language barrier, patient dies in ICU

Table 11 lists the phrases used to describe the reasons for not discussing hospice.

Table 11

Phrases used for Categories of Right Time for Hospice Discussion

Categories	Words used
End Stage Cancer	Terminal stage cancer, confirmed Malignancy with secondaries, Cancer relapse, palliative care needed, advanced cancer, advanced stage, Terminally ill cancer patient
Patient and Family Readiness	Depressed about dying, willing to accept, family accepts diagnosis, patients ready to die, when patient allows discussion, when family is helpless, family agree, patient is mentally positive, newly diagnosed, depressed patients
Dying Patients	Dying soon (<6 months), given up by doctors to die, prognosis is certain for death, suffering in final stage, when patient want to die at home,
Terminal Illness	Incurable disease, terminally ill, end stage diseases (other than cancer), Diagnosis with limited lifespan, Chronic illness - poor response to treatment
No more Treatment Possible	Nothing we do matters anymore, prognosis is poor, no longer receives curative care, no knowledge of disease outcome, No further treatment. comatose patients
Other Responses	(Diseases other than cancer), financial problem, no family support, elderly patients with multiple morbidities, when I feel PC is safe, when patient asks, when sure of quality home care, when they cannot understand doctor, caregiver cannot cope, family need respite, other family commitment, no caregiver, patient not happy at home, family struggle to care, need medical equipment, need training, need home nursing
Hospice not known	Family don't know about hospice

Seventy four participants responded, including 12 nurses and 8 doctors who reported no contact with dying patients was used. Of these 23 gave reasons for not discussing hospice care that were related to their perception of family and patient concerns listed under the categories of Lack of Readiness and Family Support Available, as shown in Table 12. Nine acknowledged that they did not know enough about hospice, and 4 claimed there were no hospice services available. See Table 12

Table 12

Reasons for Not Discussing Hospice Care

Responses	Nurses (n = 48)		Physicians (n = 26)	
	n	%	n	%
Lack of Readiness	8	16.6	1	3.8
Family Support Available	15	31.3	10	38.5
No Hospice Services	1	2.1	3	11.5
Not Enough knowledge	7	14.6	2	7.7
Discussed Hospice	4	8.3	2	7.7
No Contact with Dying Patients	12	25.0	8	30.8
Other Responses	1	2.1	0	0

Nineteen individuals used “terminal illness” and 6 used the words “dying patient” with reference to the question “*What are the conditions under which you will feel it appropriate to discuss hospice care*” (See Table 13). However, a greater number (21) gave reasons that were not directly related to the illness itself. They came under the category Other Responses which included financial problem, no family support, caregiver cannot cope, family need respite, other family commitment, no caregiver, patient not happy at home, family struggle to care, as some of the times when hospice discussion would be appropriate. It seemed that when family inabilities to provide care arose, it was considered appropriate to discuss hospice care. Table 13 describes the responses.

Table 13

Right Time to Discuss Hospice Care

Responses	Nurses (n = 60)		Physicians (n = 41)	
	n	%	n	%
End Stage Cancers	5	8.3	9	22.0
Patient & Family Readiness	18	30.0	9	22.0
Dying Patients	3	5.0	3	7.3
Terminal Illness	9	15.0	10	24.4
Other Responses	21	35.0	7	17.1
No More Treatment Possible	4	6.6	2	4.9
Hospice not known	0	0	1	2.4

Whereas 18 nurses wanted to wait for patient and family readiness, only 9 physicians considered perceived patient and family readiness to be an important factor to discuss hospice care. Six of the total respondents wanted to wait until all treatments were exhausted before discussing hospice. Nurses gave more variable reasons under the category of other reasons than doctors did for why hospice was not discussed. Most of those reasons had to do with availability of a caregiver or difficulties faced by family with caring for the patient at home.

Aim #2

The second aim was to examine the interrelationships among level of knowledge of hospice care practices (PCKT), attitude towards caring for the dying (FATCOD), and level of death anxiety (RDA). Table 14 and Table 15 show the correlations between the scores of the three measures.

Table 14

Correlations for Knowledge, Attitude, Death Anxiety and Years of Experience for Nurses

Variables	Score for <i>PCKT</i>	Score for <i>FATCOD</i>	Score for <i>RDAS</i>	<i>Yrs of Exp</i>
<u>Total Score for PCKT</u>	1			
Pearson Correlation				
Sig. (2-tailed)				
N	72			
<u>Total Score for FATCOD</u>				
Pearson Correlation	0.12	1		
Sig. (2-tailed)	0.31			
N	72	72		
<u>Total Score for RDAS</u>				
Pearson Correlation	0.002	-.140	1	
Sig. (2-tailed)	0.98	0.24		
N	72	72	72	
<u>Years of Experience</u>				
Pearson Correlation	0.16	0.13	-0.22	1
Sig. (2-tailed)	0.19	.241	0.28	
N	71	72	71	71

There were no significant correlations among the scores of the three measures and years of experience for nurses.

There was a statistically significant positive correlation between attitude towards caring for the dying (*FATCOD*) and the measure for knowledge of palliative care (*PCKT*) among the physicians. There was also significant negative correlation between the death anxiety (*RDAS*) scores and attitude towards caring for the dying (*FATCOD*) among the physicians; however, there were no significant correlations for years of experience and any of the measures.

Table 15

Correlations for PCKT, FATCOD, RDAS and years of experience for Physicians

Variables	Score for <i>PCKT</i>	Score for <i>FATCOD</i>	Score for <i>RDAS</i>	Years of Exp
<u>Total Score for PCKT</u>	1			
Pearson Correlation				
Sig. (2-tailed)				
N	52			
<u>Total Score for FATCOD</u>		1		
Pearson Correlation	0.473**			
Sig. (2-tailed)	0.00			
N	52	52		
<u>Total Score for RDAS</u>			1	
Pearson Correlation	-0.173	-0.297*		
Sig. (2-tailed)	.22	.032		
N	52	52	52	
<u>Years of Experience</u>				1
Pearson Correlation	-0.034	0.008	0.029	
Sig. (2-tailed)	0.81	0.953	0.840	
N	50	50	50	50

Aim # 3

To examine the association between selected demographic characteristics (e.g., years in practice, religion, specialty) and Malaysian nurses' and physicians' level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety.

Tables 16 and 17 describe scores for males and females in the nurse sample and the physicians' sample.

Table 16

Knowledge (PCKT Score), Attitude (FATCOD Score), and Death Anxiety (RDAS Score) for Nurses by Gender

Variables	Male (n = 5)				Female (n =66)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
PCKT	5	18.87	2.47	15-22	66	23.08	3.85	15-31
FATCOD	5	14.80	0.44	14-15	66	15.15	2.36	11-19
RDAS	5	8.09	2.29	5-11	66	8.64	4.41	5-11

Table 17

Knowledge (PCKT Score) Attitude (FATCOD Score) and Death Anxiety (RDAS Score) for Physicians by Gender

Variables	Male (n = 34)				Female (n =17)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
PCKT	34	24.56	4.03	16-31	17	26.15	3.10	16-31
FATCOD	34	16.02	2.49	10-19	17	15.93	2.63	10-19
RDAS	34	7.22	3.64	2-19	17	8.67	3.93	4-18

There was statistical significance for the PCKT score differences for male nurses ($M = 18.67$, $SD = 2.47$) and female nurses ($M = 23.08$, $SD = 3.85$); $t(5.59) = -3.66$, $p = 0.01$. The number of male nurses, however, was small (5) compared to nurses (66). Thus, one cannot have confidence in the stability of the findings. For example, low statistical power may have disallowed judging the almost four-point difference in knowledge scores (females higher) to be judged significant.

Tests for statistical significance were run for scores of the measures by gender.

There was no statistically significant difference between PCKT scores for male physicians ($M = 24.56, SD = 4.03$) versus female physicians ($M = 26.15, SD = 3.10$); $t(40.42) = -1.55, p = 0.12$. There was no statistical significance between FATCOD scores for male nurses ($M = 14.80, SD = 0.44$) versus female nurses ($M = 15.15, SD = 2.36$); $t(69) = -0.33, p = 0.74$. There was no statistical significance between FATCOD scores for male physicians ($M = 16.02, SD = 2.49$) versus female physicians ($M = 15.93, SD = 2.64$); $t(49) = 0.12, p = 0.90$. There was no statistical significance between RDAS scores for male nurses ($M = 8.09, SD = 2.30$) and female nurses ($M = 8.64, SD = 4.41$); $t(6.51) = -0.47, p = 0.65$. There was no statistical significance between RDAS scores for male physicians ($M = 7.22, SD = 3.64$) versus female physicians ($M = 8.67, SD = 3.93$); $t(30) = -1.27, p = 0.21$

Table 18 describes the PCKT scores for the nurses and physicians by religion.

The two largest groups were Buddhists and Christians. In Table, 16 the groups have been collapsed into Christian and All Other Religions.

Table 18

Knowledge (PCKT Score) by Religion

Variables	Nurses ($n = 72$)				Physicians ($n = 52$)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
Islam	3	21.33	4.93	18-27	5	22.17	5.13	16-28
Hinduism	7	23.11	4.04	19-30	3	27.40	1.21	26-28
Buddhism	23	22.95	3.14	18-29	9	25.95	2.00	23-29
Christian	33	22.49	4.41	15-31	33	25.20	3.77	16-33
Other	6	23.30	4.32	18-29	2	23.00	7.07	18-28

Table 19 shows the breakdowns for the collapsed religion groups. A *t* test for independent samples was done to check for association between religion and the PCKT scores using the collapsed religion variable.

Table 19

Knowledge (PCKT Score) by Collapsed Religion Groups

Variables	Nurses (<i>n</i> = 72)				Physicians (<i>n</i> = 52)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
Christian	33	22.49	4.42	15-31	33	25.20	3.78	16-33
All Other	39	22.91	3.50	18-30	19	24.87	3.83	16-29

There was no statistically significant difference between PCKT scores for Christian nurses (*M* = 22.49, *SD* = 4.42) versus nurses from all other religions (*M* = 22.91, *SD* = 3.50); *t* (70) = -0.447, *p* = 0.65. Similarly, there was no statistically significant difference in the PCKT scores for Christian physicians (*M* = 25.20, *SD* = 3.78) versus physicians from all other religions (*M* = 24.87, *SD* = 3.83); *t* (50) = 0.297, *p* = 0.76.

Table 20

Knowledge (PCKT Score) by Specialty

Variables	Nurses (<i>n</i> = 70)				Physicians (<i>n</i> = 51)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
Gen Prac	21	21.54	3.56	15-28	23	24.36	3.96	16-33
Int Med	1	24.00		24-24	3	26.50	2.38	24-29
Oncology	7	26.64	2.42	22-30	1	29.00		29-29
Gen Surg	7	19.85	1.78	18-23	2	29.50	2.21	28-31
Peds	2	21.00	2.82	19-23	3	25.09	0.86	24-26
OB-Gyn	1	25.00		25-26	2	25.16	0.72	25-26
Other	31	23.00	4.17	15-31	16	25.13	4.23	16-29

Analysis of PCKT consisted of a *t* test for independent samples for general practice versus the collapsed specialties as shown in Table 19. There was no statistically

significant difference between PCKT scores for nurses who identified with general practice ($M = 21.54$, $SD = 3.56$ versus nurses from specialty areas ($M = 23.05$, $SD = 3.98$); $t(42) = -1.56$, $p = 0.12$. Similarly, there was no statistically significant difference in the PCKT scores for general practice physicians ($M = 24.36$, $SD = 3.96$) versus physicians from specialty areas ($M = 25.78$, $SD = 3.55$); $t(44) = -1.32$, $p = 0.91$.

Table 21

Knowledge (PCKT Score) by Collapsed Specialty

Variables	Nurses ($n = 70$)				Physicians ($n = 51$)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
General Practice	21	21.54	3.56	15-28	23	24.36	3.96	16-33
Specialties	49	23.05	3.98	15-31	28	25.78	3.55	16-31

Table 22

Knowledge (PCKT Score) Among Those With and Without Prior Training in Palliative Care/Hospice.

Variable	Nurses ($n = 72$)				Physicians ($n = 52$)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
With Training	23	23.28	4.34	18-31	22	25.44	4.35	16-33
Without Training	48	22.31	3.65	15-31	30	24.82	3.31	16-31
Missing	1	0	0	0	0	0	0	0

The t test for independent samples shows no statistically significant difference in the PCKT scores for nurses with prior training in palliative/hospice training ($M = 23.28$, $SD = 4.34$) versus nurses without prior palliative/hospice training ($M = 22.31$, $SD = 3.65$); $t(37) = 0.93$, $p = 0.36$. Similarly, there was no statistically significant difference between the PCKT scores of physicians with prior training in palliative/hospice training ($M = 25.44$, $SD = 4.35$) versus physicians without prior training in palliative/hospice training ($M = 24.82$, $SD = 3.31$); $t(38) = 0.56$, $p = 0.58$ as seen in Table 22.

Table 23 shows the FATCOD scores distributed by religion, and Table 24 shows the scores of Christians versus all other religions grouped together.

Table 23

Attitude (FATCOD Score) by Religion

Variables	Nurses (<i>n</i> =72)				Physicians (<i>n</i> = 52)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
Islam	3	14.00	1.73	13-16	5	15.57	1.12	14-17
Hinduism	7	15.27	2.27	12-18	3	15.26	1.55	14-17
Buddhism	23	14.98	2.30	11-18	9	16.78	2.48	12-19
Christian	33	15.32	2.34	11-19	33	15.91	2.64	10-19
Other	6	15.17	2.31	11-18	2	14.00	5.65	10-18

Table 24

Attitude (FATCOD Score) by Collapsed Religion Groups

Variable	Nurses (<i>n</i> =72)				Physicians (<i>n</i> = 52)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
Christian	33	15.32	2.35	11-19	33	15.91	2.65	10-19
All other Rel.	39	14.98	2.20	11-18	19	15.93	2.44	10-19

The *t* test for independent samples shows no statistically significant difference in the FATCOD scores for Christian nurses ($M = 15.32$, $SD = 2.35$) versus nurses from all other religions ($M = 14.98$, $SD = 2.20$); $t(70) = 0.637$, $p = 0.526$. Similarly, there was no statistically significant difference for the FATCOD scores of Christian physicians ($M = 15.91$, $SD = 2.65$) versus physicians from all other religions ($M = 15.93$, $SD = 2.44$); $t(50) = -0.026$, $p = 0.98$. Refer Table 24

When proceeding to analyze FATCOD scores, it was clear that small numbers in some groups precluded running a one way ANOVA (See Table 25). Therefore all the specialists were collapsed into one group and the general practitioners remained a separate group. The new groups could support valid statistical testing.

Table 25

Attitude (FATCOD Score) by Specialty

Variables	Nurses (n =70)				Physicians (n = 51)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
Gen Prac	21	15.29	2.3	11-19	23	15.69	2.61	10-19
Int Med	1	16.00		16-16	4	15.75	3.59	11-19
Oncology	7	14.29	2.62	11-17	1	16.00		16-16
Gen Surg	7	15.70	1.96	12-18	2	19.00	0.00	19-19
Paeds	2	17.00	0.00	17-17	3	14.67	3.78	12-19
OB-Gyn	1	13.72		14-14	2	17.00	2.82	15-19
Other	31	15.08	2.33	11-19	16	15.86	2.22	10-19

Table 26

Attitude (FATCOD Score) by Collapsed Specialty Areas

Variables	Nurses (n =70)				Physicians (n = 51)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
General Practice	21	15.29	2.30	11-19	23	15.69	2.62	10-19
Specialties	49	15.12	2.26	11-19	28	16.03	2.55	10-19

The *t* test for independent samples shows no statistically significant difference in FATCOD scores (as shown in Table 26) for nurses who identified as being in general practice ($M = 15.29$, $SD = 2.30$) versus nurses working in specialty areas ($M = 15.12$, $SD = 2.26$); $t(37) = 0.27$, $p = 0.79$. Similarly, there was no statistically significant difference for the FATCOD scores of general practice physicians ($M = 15.69$, $SD = 2.62$) versus physicians from the collapsed specialty groups ($M = 15.69$, $SD = 2.62$); $t(46) = -0.47$, $p = 0.64$.

Table 27

Attitude (FATCOD Score) Among Those With and Without Prior Training

Variables	Nurses (<i>n</i> = 71)				Physicians (<i>n</i> = 52)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
With Training	23	15.39	2.35	11-19	22	16.27	2.68	10-19
Without Training	48	15.08	2.21	11-19	30	15.65	2.47	10-19

The *t* test for independent samples of FATCOD scores among participants with and without prior training (shown in Table 27) shows no statistically significant difference in the FATCOD scores for nurses with prior training in palliative/hospice training ($M = 15.39, SD = 2.35$) versus nurses without prior palliative/hospice training ($M = 15.08, SD = 2.21$); $t(41) = 0.53$ $p = 0.60$. Similarly, there was no statistically significant difference for the FATCOD scores of physicians with prior training in palliative/hospice training ($M = 16.27, SD = 2.68$) versus physicians without prior training in palliative/hospice training ($M = 15.65, SD = 2.47$); $t(38) = 0.53, p = 0.60$.

Death Anxiety scores could not be compared meaningfully among groups divided by religion due to varying size of the groups (Refer to Table 28). Therefore the smaller groups were collapsed to form a group titled “All Other” and were compared against “Christians” (Refer to Table 29).

Table 28

Death Anxiety (RDAS Score) by Religion

Variable	Nurses (<i>n</i> = 72)				Physicians (<i>n</i> = 52)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
Islam	3	10.00	5.00	5-15	5	7.20	2.38	4-10
Hinduism	7	7.29	5.90	1-18	3	6.81	1.71	5-8
Buddhism	23	8.98	5.02	1-17	9	8.14	2.07	6-12
Christian	33	8.30	3.32	4-17	33	7.43	4.08	2-19
Other	6	9.45	4.29	5-16	2	11.95	8.41	6-18

Table 29

Death Anxiety (RDAS Score) by Collapsed Religion groups

Variable	Nurses (n =72)				Physicians (n = 52)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
Christian	33	8.30	3.33	4-17	33	7.43	4.09	2-19
All Other	39	8.83	4.95	1-18	19	8.08	3.10	4-18

The *t* test for independent samples shows no statistically significant difference in the RDAS scores for Christian nurses ($M = 8.30$, $SD = 3.33$) versus nurses from all other religions ($M = 8.83$, $SD = 4.95$); $t(66.78) = -0.541$ $p = 0.59$. Similarly, there was no statistically significant difference for the RDAS scores of Christian physicians ($M = 7.43$, $SD = 4.09$) versus physicians from all other religions ($M = 8.08$, $SD = 3.10$); $t(50) = -0.604$, $p = 0.548$.

Death Anxiety scores could not be compared meaningfully among groups divided by specialty due to varying size of the groups (See Table 30). Therefore the smaller groups of internal medicine, general surgery and other unspecified specialties were collapsed to form a group titled “Specialties” and were compared against “General Practice” (See Table 31).

Table 30

Death Anxiety (RDAS Score) by Specialty

Variables	Nurses (n =70)				Physicians (n = 51)			
	n	M	SD	Min - Max	n	M	SD	Min - Max
Gen Prac	21	8.45	3.50	3-17	23	7.53	3.34	2-18
Int Med	1	2.00		2-2	3	8.75	6.94	4-19
Oncology	7	8.71	4.34	1-13	1	7.27		7-7
Gen Surg	7	9.86	4.74	5-17	2	5.00	0.00	5-5
Paeds	2	12.00	7.07	7-17	3	8.00	2.00	6-10
OB-Gyn	1	7.00		7-7	2	9.00	4.24	6-12
Other	31	8.47	4.69	1-18	16	7.58	4.21	3-18

Table 31

Death Anxiety (RDAS Score) by Collapsed Specialty

Variables	Nurses ($n = 70$)				Physicians ($n = 51$)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
General Practice	21	8.45	3.51	3-17	23	7.53	3.35	2-18
Specialties	49	8.68	4.65	1-18	28	7.70	4.13	3-19

The *t* test for independent samples shows no statistically significant difference in the RDAS scores for nurses in general practice ($M = 8.45$, $SD = 3.51$) versus nurses from specialty areas ($M = 8.68$, $SD = 4.65$); $t(50) = -0.229$, $p = 0.83$. Similarly, there was no statistically significant difference for the RDAS scores of general practice physicians ($M = 7.53$, $SD = 3.35$) versus physicians from collapsed specialty areas ($M = 7.70$, $SD = 4.13$); $t(49) = -0.163$, $p = 0.87$.

The last set of tests was to compare Death Anxiety scores among groups that had prior training and those that did not have prior training (See Table 32).

Table 32

Death Anxiety (RDAS Score) Among Those with and Without Prior Training

Variables	Nurses ($n = 71$)				Physicians ($n = 51$)			
	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max	<i>n</i>	<i>M</i>	<i>SD</i>	Min - Max
With Training	23	9.48	4.78	1-17	22	7.33	4.09	3-18
Without Training	48	8.17	4.02	1-18	30	7.92	3.51	2-19

The *t* test for independent samples shows no statistically significant difference in the RDAS scores for nurses with prior training in palliative/hospice training ($M = 9.48$, $SD = 4.78$) versus nurses without prior palliative/hospice training ($M = 8.17$, $SD = 4.02$); $t(37) = 1.14$, $p = 0.26$. Similarly, there was no statistically significant difference for the RDAS scores of physicians with prior training in palliative/hospice training ($M = 7.33$,

$SD = 4.09$) and physicians without prior training in palliative/hospice training ($M = 7.92$, $SD = 3.51$); $t(41) = -0.55$, $p = 0.59$.

Summary

The findings of the statistical analysis were unexpected. The small groups as well as the apparent misunderstanding of some of the terms used in the questionnaire precluded predictive analysis that was expected to provide support for the premise of the Theory of Planned Behavior. An assumption going into the study was that knowledge of hospice practices as well as positive attitudes to caring for the dying and lower death anxiety would have resulted in decisions to provide hospice information to terminally ill patients and their families. This assumption was not supported by the study, and possible reasons are discussed in chapter 5.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Although hospice care is available in Malaysia, it is underused, and the reasons for this are unclear. In the present study, explanatory factors were anticipated to be an inadequate knowledge of hospice care practices, attitude towards caring for the dying, and personal death anxiety. Because nurses and physicians are the the main source of information for terminally ill patients and families regarding hospice care, this exploratory correlational study sought to examine existing knowledge about hospice care practices, attitudes towards care of the dying, death anxiety and when they believed is the right time to discuss hospice care.

Summary and Discussion of Findings

Knowledge of Hospice Care Practices

A not unexpected finding was that physicians had a better knowledge level of palliative care (as measured by the PCKT) than nurses (Table 9). This may be explained by the fact that pre requisite qualification for nursing school in Malaysia is equivalent to a grade 10 education, whereas qualification for medical school is grade 12. Diploma nursing takes three years to complete and a medical degree takes four years of college with two years of housemanship (similar to internship in the US). The shorter period of education that nurses undergo would not allow adequate time for a greater depth of study. Neither could the shorter nursing curriculum include an in-depth understanding of palliative care. Therefore the higher scores for doctors are expected.

The distribution of scores for nurses' vs physicians shows that a greater percentage of nurses had relatively poor knowledge of palliative care. Conversely a larger number of physicians had higher scores when compared to nurses knowledge ($p =$

0.001). These higher scores by physicians may be explained by the statement by Dr. Ednan Hamzah of Hospice Malaysia, cited in the country report by the International Observatory on End of Life Care, that Palliative Care has been added to the medical school curriculum in Malaysia (Wright, Wood, Lynch, & Clark, 2006). There is no published information regarding the addition of palliative care knowledge into the nursing curriculum. That being the case, it was inappropriate to administer a test for nurses in terms of the content as they may not have been exposed to the rationale for the hospice care practices at any time in their course of work and study.

In retrospect only about 60% of the PCKT questions (Appendix C) apply just to the care of dying patients. It may be said that the PCKT questions applied more to the care of any chronic illness rather than just terminally ill and dying patients hence, the scores may not have been a true reflection of the level of knowledge of palliative care. There is a possibility that using only the 20 questions that were psychometrically validated may have resulted in answers specific to palliative care.

The fact that the nurses had lower scores for the PCKT implies that they had a poorer understanding of the care of patients with chronic illness. In considering the scores range for physicians (Figure 6), it may be said that their knowledge for care of the chronically ill was also not as high as it should be based on the PCKT. These implications are worth being considered in a more detailed study at a later date.

Lastly the questions may not have been clearly understood by the nurses due to the lack of fluency in English. Although nursing education is provided in English, the basic education of nurses is mainly in Chinese, Malay or Tamil. The results of the study

provide strong support for the use of data gathering tools in the language of the subjects to ensure comprehension and accuracy.

Attitudes Toward Death and Care of the Dying

There was no significant difference between the mean scores for nurses and physicians in terms of attitude towards caring for the dying (FATCOD Scores) and personal death anxiety (RDAS scores) as may be seen in Table 9. Having changed the expected response from a Likert scale to a yes/no answer, the degree of negative or positive attitude towards the responses for the FATCOD and RDAS were not truly assessed. Besides this change, the FATCOD scale had questions pertaining to anxiety removed, thereby decreasing the validity of the measure and lowering the chances of accurate measurement of the particular domain of attitude.

The second aim of the study was to examine the relationship between level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety. There was a statistically significant correlation between PCKT and FATCOD scores for physicians. Doctors who had higher scores in the Palliative Care Knowledge Test also had higher scores in the Frommelt Attitudes Toward Care of The Dying scale. Similarly, there was a statistically significant negative correlation between death anxiety (RDAS scores) and the scores for FATCOD. It is reasonable that those with less personal death anxiety would find it easier to care for the dying. It could also be expected that such individuals would find it easier to discuss hospice.

No relationship was found between the PCKT and FATCOD with the nurses. Because many of the questions on the PCKT did not specifically address purely palliative care, the responses of the nurses stood a greater chance of being guessed rather than

being informed choices. Therefore, it is difficult to interpret the relationship between the PCKT and the other two measures accurately.

Reasons for Not Discussing Hospice and Right Time to Discuss Hospice Care

The participants were asked why hospice care was not discussed and when would be the right time to introduce palliative care discussion. Fifty of the 124 participants did not respond to the first question. The reasons given for not discussing hospice care were tabulated by specific terms used repeatedly by the subjects. Of the 74 who responded, the reasons given were similar to reasons given in studies done in other countries. Eight nurses gave “Lack of readiness of the family or patient” as a reason for not discussing hospice while only 1 physician did so. Other reasons given were “not enough knowledge to discuss hospice care” (7 nurses and 2 physicians), and family support available (15 nurses and 10 physicians) See Table 12 . This indicates a lack of understanding of what hospice care really is.

It was of interest to note that there were 12 nurses and 8 physicians who claimed they did not care for dying patients, but still gave reasons to determine when it would be good to introduce hospice care to dying patients. Their opinion of a good time to introduce hospice, along with the way the words “terminal illness” and “dying patient” were used, indicated a disconnect with their claim of not caring for dying patients. Hence the reason given by 1 nurse and 3 physicians of no hospice services being around was a surprise after the efforts by the public health sector to improve awareness regarding hospice care.

It is also surprising that there are individuals who do not know of the existence of hospice care in both Penang and Sabah, where palliative care and hospice have been well

established for over 25 years. This lack of knowledge of hospice existence may be considered one of the most important reasons for the lack of referrals to hospice. The purpose of providing end-of-life care regardless of what causes end of life, is to help patients live well until they die. What these participants think as being suitable reasons for not discussing hospice care differs greatly from the actual purpose of end-of-life care. Hospice care would provide for relief of psychological and spiritual needs and help teach the family how best to care for the dying patient.

The statements that the family wanted the patient to die at home or family unable to accept diagnosis are important reasons related to the lack of use of hospice by dying patients in Malaysia. It may be said to indicate an inadequate awareness of what hospice care is about by the participants. Their lack of knowledge of what hospice care is may prevent them from disabusing the patient or family of misperceptions of when hospice should be considered.

The lack of consensus on the right time for discussion of hospice affects patient care adversely. For example, it has been reported that in Malaysia, 70% of patients with cancer present at the hospital at stage three (Devaraj, 2003). If these patients have nurses and doctors who want to wait until they and their families have accepted the diagnosis or the fact that no curative measures are available before discussing hospice, they (the patient and family) will not have a chance of benefiting from hospice care.

An aspect of delay in discussing hospice which was not considered in this study was the known tendency of the family to protect the terminally ill/dying patient from the knowledge of impending death. This tendency prevents everyone from reaching the point of readiness to accept the diagnosis, let alone death before it actually happens. The act

or desire of hiding the actual diagnosis or prognosis from the patient is referred to as “collusion” and is said to be a universal phenomenon (Chaturvedi, Loiselle, & Chandra, 2009) and may be manifested as family members holding back bad news from the patient or by various health professionals hiding prognosis from the patient or families. In Malaysia, as in many other cultures the decisions are made by dominant family members who by virtue of their position as husband, father or grandfather practice collusion due to the misguided notion of being protective (Chaturvedi, Loiselle, & Chandra, 2009; Khoo, 2006).

Taking into consideration the psychological effects of discovering a malignancy and the cultural tendency of collusion, there is a need for doctors and nurses to provide clear and tactful information regarding hospice soon after diagnosis. Waiting to do so based on the reasons given by the participants does not allow enough time for the family or the patient to prepare for death.

The third aim of the study was to examine the association between selected demographic characteristics (e.g., years in practice, religion, specialty) and level of knowledge of hospice care practices, attitude towards caring for the dying, and level of death anxiety. In considering the scores for the measures in relation to the demographic variable gender, the scores on the PCKT showed a statistically significant difference between female and male nurses. The male nurses had a mean score of 18.87 whereas the female nurses had a mean score of 23.08. However, the small number of male nurses ($n = 5$) makes it difficult to have confidence in these findings. The demographic variable “years of experience” did not seem have an effect on the scores of all three measures.

Unlike other studies, greater experience did not seem to improve knowledge, attitude towards care of the dying or reduce death anxiety.

As stated in the previous chapter the grouping of subjects by religion and specialty would not provide meaningful results for analyses due to small group numbers, therefore the groups were collapsed and tests run. The groups for religion included Christian, Islam, Buddhism Hinduism and others. All religions other than Christian were collapsed into a new group named “other.” The areas of practice of the participants included general practice, internal medicine, general surgery, oncology, pediatrics, obstetrics and gynecology and others. When collapsing the areas of practice, general practice made up the first group and all the other areas formed the group “specialties.”

The *t* tests run for the collapsed groups (religion and specialty) in relation to the scores of the three measures yielded no statically significant results. As detailed in the literature review, studies done elsewhere showed significant relationships among the measures and specialty, religion and experience. These relationships led to the conclusion that knowledge of hospice care, a positive attitude towards caring for the dying and low death anxiety resulted in a capability to discuss hospice with terminally ill and dying patients (Cramer et al., 2003). However, this was not found with the Malaysian sample. Therefore, no predictive tests could be run that could lead to conclusions and recommendations for improvement. The reasons for this inability are discussed as limitations.

The assumption that fewer terminally ill patients in Malaysia use hospice care services than expected because of inadequate knowledge of hospice care, a poor attitude towards caring for the dying and greater death anxiety, cannot be supported. Although it

is seen that nurses and doctors have a limited understanding of the right time for provision of hospice information, the data gathered is not sufficient to determine why it is so. Only 4 nurses and 2 doctors (out of the 74 who responded to the question), discussed hospice with their patients (Table 12). Since a large number of patients are diagnosed at a later stage the fact that 18 nurses and 9 physicians believe they should wait for family and patient readiness to accept poor prognosis indicate the chances of very few patients benefiting from hospice care.

It was the intention of the author to use the conceptual model to predict cause effect by regression analysis, regarding the impact of knowledge and attitude on the practice of discussing hospice. However, that was not possible due to (a) the statistical non-significance of data due to the validity and reliability changes effected by the modification of scales, (b) the high non response rate to the questions pertaining to discussion of hospice, and (c) the likelihood that the questions were not fully understood by a sample that had a low fluency in English.

Strengths of the Study

It was the first study of its kind done in Malaysia to measure the knowledge level of hospice care practices. The study had the support of key individuals involved in hospice care, thereby ensuring support among the professional association for physicians. Using professional association databases and having an uninvolved individual send out the invitations removed bias. Using an electronic survey method with the physicians decreased chances of corrupting the data by manual data entry. Theoretically, the survey method used for data collection was good but may be strengthened through the offering of incentives.

The unmodified scales used to measure death anxiety and attitude towards caring for the dying have good reliability and have been well tested in different cultural situations. Our results suggest that they be used without the modifications done in the present study for greater validity.

Limitations of the Study

The surveys were sent to a population that had a low fluency in English. Primary and secondary education in Malaysia is mainly in languages other than English. Because nursing education is carried out mostly in English, the assumption was made that the survey could be administered in English, anticipating their ability to understand the questions. However as data collection took place, it became apparent that the expected fluency to comprehend the questions was not present. This issue was not observed during the pilot study as those who participated in the pilot study were specifically selected to help identify concerns with the questionnaire. There was bias in the choice of participants and therefore a possibility that the pilot sample had higher English fluency.

Although the professional association for doctors was brought on board to support the study, the professional associations for nursing did not do so. As a result the wider population of nurses was not reached using the electronic method of administering the survey. Instead the majority of nurses completed a paper pencil survey in two hospitals in Penang. Relying on two private hospitals and the passing along of the survey website by participants may decrease the generalizability of the study.

Physicians and nurses seem to have misinterpreted the questions pertaining to care of the dying patients. It became apparent that their perceptions of terminally ill referred to the active dying process and not to the terminality of the disease condition itself.

Similarly the term “dying person” appears to have been interpreted as only those in the active dying process.

The Palliative Care Knowledge Test was chosen over the Palliative Care Knowledge Quiz because it appeared to cover the different facets of palliative care without including advance directives and too many questions with medications not used in Malaysia. However, early in the data gathering phase, it could be seen that the PCKT was not a suitable questionnaire to use for this study. The Palliative Care Knowledge Test is not specific enough to determine level of palliative care knowledge as the questions are too broad and may cover the care of many chronic illnesses.

The FATCOD has been used in multiple studies with a Likert type response. Having adjusted it to a yes/no response and removing the anxiety questions appears to have diminished the impact of the responses as well as its reliability. In order to adjust it to a more culturally relevant format, the changes could have just included simpler language without removing the questions on anxiety or translated into the Malay. It appears to have impacted the relationship between attitudes toward caring for the dying and death anxiety.

All of the scales were modified to elicit yes/no responses instead of using the original Likert type responses. These choices made to modify the PCKT, FATCOD and RDAS and not use them in their entirety following the pilot study, probably seriously affected validity and reliability of the scales. Reliability may have been sacrificed for the convenience of the participants.

Implications of the Study

Implications for Practice

The apparent misinterpretation of the terms “dying person” and “terminal illness” as well as the lack of knowledge of hospice care practices indicates a need for creating greater awareness among both nurses and doctors regarding the terminology and practices used universally in hospice care. Although the facilities are available for hospice care, until doctors and nurses are able to know with certainty what the terms describe or what is involved in end of life care, deserving patients may not receive information regarding hospice.

The mistaken ideas identified in the study by Hanratty et al (2006) were that that palliative care was “not very medical” and was basically a “nursing based” care for the terminally ill. The physicians felt that they were equally capable of handling the dying patient as the palliative care specialist. These ideas appear to be reflected in the reasons given doctors in this study for not introducing the topic of hospice care. Doctors who do not understand the facets of palliative care, attempt to provide care for which they are not prepared. The average score, based on the mean scores for the PCKT was 59% among nurses, and 66% among physicians. Based on these scores both doctors and nurses do not appear to have the level of knowledge needed according to the PCKT. More importantly they may not have an understanding of the rationale for palliative care practices, which may have an impact on the decision to discuss hospice care with patients even when it appears they are not ready. The remedy is certainly to provide focused knowledge which is better begun during the educational days for both professions (Anderson et al, 2008).

Implications for Policy

It was observed by Devi et al (2008) that empowering nurses to make referrals provided a wider coverage of patients in palliative care. Although nurses may be the most important determinants in the success of the hospice program, the findings from this study indicate a need for further testing of nurse empowerment before implementation. Since palliative care is not a part of the nursing curriculum, Malaysian nurses may not have an in-depth understanding of pharmacology and pathophysiology as nurses in countries do where they have greater autonomy. It would therefore be beneficial to have focused in depth hospice care education before empowering nurses to make referrals to ensure that patients get clear and solid information. Similar to what ELNEC has done in the United States, nurses in Malaysia would benefit from a unified program where a deeper understanding of the pharmaceuticals used in hospice care as well as a more in-depth knowledge of the physiology of dying is gained. However, empowering nurses to bring up the topic of hospice care may provide a resource for terminally ill patients and families to learn about hospice care.

Since hospice care is not regulated by legislation and is paid for by NGO funding, referring the patient to a palliative care physician results in a loss of income to the primary doctor in Malaysia. A centralized cancer program such as what is practiced in Sarawak appears to have promise in the other states of Malaysia. With better knowledge among doctors and nurses loss of income may become a lower priority than ensuring that patients receive the best care.

Implications for Future Research

It is important to keep in mind language barriers of communities where English is a second language. When surveys are sent out in English, it would be better to qualify or define the terms used “terminally ill” and “dying patient” with a specific example including timeframe. It would be even better to have the survey translated by experts to get more accurate responses. Because the scales used in the study have not been used in Malaysia before, it would be benefit from psychometric analysis when it is used in research with a sample that clearly understands the questions and provides appropriate responses.

In addition, using separate sets of questions on palliative care for doctors and nurses may get more specific levels of knowledge assessment. This would make up for the difference in level of education between nurses and doctors as well as the lack of exposure of nurses to palliative care in the educational curriculum. It may be best to have the measures used translated into Malay, in order to get greater accuracy in responses. Future research to validate the findings about the lower knowledge of nurses would need a sample with nurses from more areas of practice and with longer experience to provide a better representation of the population being studied.

Hospice is a very specialized area of patient care. The best resources are those individuals who have wide experience in the field. If the interest of such individuals can be gained at the outset, the research may be made more effective through the connections they provide. Research in the area of hospice is important in order raise awareness among health care providers as well as the public. Awareness of the facets and benefits of hospice will help make the expectations of the World Health Organization a reality

It may make the research well-rounded to have a specific qualitative portion to the research plan. Involving some patients and/or family members of terminally ill and dying patients would strengthen the findings and support the recommendations. Similar to the studies by McNeilly and Hillary (1997); Steinhauser et al (2000); Shiozaki et al (2005) and Osse, Vernooji-Dassen, Schade & Grol (2007), involving patients, data gathered from the doctors and nurses would be validated and the research findings more generalizable.

Conclusion

The overarching purpose of the present study was to examine existing knowledge about hospice care practices, attitudes towards care of the dying, and death anxiety among nurses and physicians in Malaysia and when they believed is the right time to discuss hospice care. The responses to the survey, which included questions related to each of the identified variables, showed that in this study there was no statistically significant relationship between knowledge of hospice and attitude towards caring for the dying. This finding differed from what was expected based on the theoretical framework used. Secondly, the responses to items regarding the right time to discuss hospice revealed a lack of consensus on the meaning of the words “terminally ill” and dying patient. The responses given for not discussing hospice shows that in spite of efforts put into developing the palliative and hospice care systems, there are still nurses and doctors who do not know about hospice care or truly understand the benefits of hospice care for patients.

Although there are many limitations to this study, it is evident that the study has revealed a need for a greater familiarization of nurses and doctors with the concepts of hospice care. There is an even greater need for detailed studies with more relevant tools

among the health care provider population in Malaysia to clearly document their actual knowledge and attitude towards hospice care. Such documentation may provide support for legislation or policies to improve or increase the number of terminally ill patients and families having the hospice care discussion early enough to truly benefit from hospice care.

The study evidences a need for more than just knowledge of hospice care practices but a deeper understanding of the concepts of hospice care by both nurses and doctors. It provides support for considering all factors that affect attitudes toward caring for the dying and individual death anxiety such as cultural and religious factors. It demonstrates the need for the use of specific and relevant measures that are developed for the specific setting or suitable adapted.

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APPENDIX A

PERCENT SCORES OF PCKT

Table 33

Percent Score of PCKT for Whole Sample

	<i>Frequency</i>	<i>Percent</i>	<i>Cumulative Percent</i>
40.54	2	1.6	1.6
42.11	3	2.4	4.0
43.24	1	.8	4.8
45.95	1	.8	5.6
47.22	1	.8	6.5
47.37	6	4.8	11.3
50.00	10	8.1	19.4
52.63	8	6.5	25.8
55.26	6	4.8	30.6
55.88	1	.8	31.5
56.76	1	.8	32.3
57.89	6	4.8	37.1
58.06	1	.8	37.9
60.00	1	.8	38.7
60.53	6	4.8	43.5
63.16	10	8.1	51.6
63.89	1	.8	52.4
64.71	1	.8	53.2
64.86	4	3.2	56.5
65.79	9	7.3	63.7
67.57	1	.8	64.5
68.42	11	8.9	73.4
71.05	7	5.6	79.0
72.97	2	1.6	80.6
73.68	10	8.1	88.7
74.19	1	.8	89.5
75.68	1	.8	90.3
76.32	5	4.0	94.4

78.38	1	.8	95.2
78.95	1	.8	96.0
81.58	4	3.2	99.2
86.84	1	.8	100.0
<i>Total</i>	124	100.0	

Table 34

Percent Score for PCKT among Nurses

		Frequency	Percent	Cumulative Percent
Valid	40.54	2	2.8	2.8
	42.11	1	1.4	4.2
	47.22	1	1.4	5.6
	47.37	5	6.9	12.5
	50.00	9	12.5	25.0
	52.63	7	9.7	34.7
	55.26	5	6.9	41.7
	55.88	1	1.4	43.1
	56.76	1	1.4	44.4
	57.89	5	6.9	51.4
	58.06	1	1.4	52.8
	60.00	1	1.4	54.2
	60.53	4	5.6	59.7
	63.16	7	9.7	69.4
	64.86	1	1.4	70.8
	65.79	2	2.8	73.6
	68.42	4	5.6	79.2
	71.05	4	5.6	84.7
	72.97	1	1.4	86.1
	73.68	3	4.2	90.3
	76.32	3	4.2	94.4
	78.38	1	1.4	95.8
	78.95	1	1.4	97.2
	81.58	2	2.8	100.0
Total		72	100.0	100.0

Table 35

Percent Score of PCKT for Physicians

		Frequency	Percent	Cumulative Percent
Valid	42.11	2	3.8	3.8
	43.24	1	1.9	5.8
	45.95	1	1.9	7.7
	47.37	1	1.9	9.6
	50.00	1	1.9	11.5
	52.63	1	1.9	13.5
	55.26	1	1.9	15.4
	57.89	1	1.9	17.3
	60.53	2	3.8	21.2
	63.16	3	5.8	26.9
	63.89	1	1.9	28.8
	64.71	1	1.9	30.8
	64.86	3	5.8	36.5
	65.79	7	13.5	50.0
	67.57	1	1.9	51.9
	68.42	7	13.5	65.4
	71.05	3	5.8	71.2
	72.97	1	1.9	73.1
	73.68	7	13.5	86.5
	74.19	1	1.9	88.5
	75.68	1	1.9	90.4
	76.32	2	3.8	94.2
	81.58	2	3.8	98.1
	86.84	1	1.9	100.0
Total		52	100.0	

a. Discipline = Physician

APPENDIX B

IRB EXEMPT NOTICE



LOMA LINDA UNIVERSITY
ADVENTIST HEALTH
SCIENCES CENTER

INSTITUTIONAL REVIEW BOARD

RESEARCH PROTECTION PROGRAMS
24887 Taylor Street • Suite 202 • Loma Linda, CA 92350
(909) 558-4531 (voice) • (909) 558-0131 (fax)

Exempt Notice

IRB# 5130122

To: Pothier, Patricia K
Department: School of Nursing
Protocol: Relationship of existing practices of discussion/referral for hospice care among nurses and physicians in Malaysia with self rated knowledge and attitude towards hospice care

Your application for the research protocol indicated above was reviewed administratively on behalf of the IRB. This protocol is determined to be exempt from IRB approval as outlined in federal regulations for protection of human subjects, 45 CFR Part 46.101(b) (2).

Stipulations of approval:

Please note the PI's name and the IRB number assigned to this IRB protocol (as indicated above) on any future communications with the IRB. Direct all communications to the IRB c/o Research Protection Programs.

Although this protocol is exempt from further IRB review as submitted, it is understood that all research conducted under the auspices of Loma Linda University will be guided by the highest standards of ethical conduct.

Signature of IRB Chair/Designee: R L Rigsby Date: 5/13/13

Loma Linda University Adventist Health Sciences Center holds Federalwide Assurance (FWA) No. 00006447 with the U.S. Office for Human Research Protections, and the IRB registration no. is IORG0000226. This Assurance applies to the following institutions: Loma Linda University, Loma Linda University Medical Center (including Loma Linda University Children's Hospital, LLU Community Medical Center), Loma Linda University Behavioral Medicine, and affiliated medical practices groups.

IRB Chair:
Rhodes L. Rigsby, M.D.
Department of Medicine
(909) 558-2341, rrigsby@llu.edu

IRB Administrator:
Linda G. Halstead, M.A., Director
Research Protection Programs
Ext 43570, Fax 80131, lhalstead@llu.edu

IRB Specialist:
Mark Testerman
Research Protection Programs
Ext 43042, Fax 80131, mtesterman@llu.edu

APPENDIX C
QUESTIONNAIRE

Assessment of Knowledge, Attitude and Practice
Regarding Hospice Care

DEMOGRAPHIC DATA

Please circle or fill in the response / statement that is closest to what best describes you / your response.

1. **Education:** What year did you graduate as a health professional? _____
2. **Discipline:**
 - a. Physician
 - b. Nurse
3. **Gender:**
 - a. Male
 - b. Female
4. **Age:** _____
5. **Specialty:**
 - a. General practice
 - b. Internal medicine
 - c. Oncology
 - d. General Surgery
 - e. Pediatrics
 - f. Obstetrics
 - g. Palliative care
 - h. Other (please specify) _____
6. **Years in practice:**
 - a. Less than 3 years
 - b. More than 3 years
7. **Religion:**
 - a. Islam
 - b. Hinduism
 - c. Buddhism
 - d. Christian
 - e. other
8. **Experience with Hospice (volunteer service or use by relatives or friends) :**
YES NO
9. **Received some training in palliative/hospice care (e.g. conferences, workshops etc.)**
YES NO

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Institutional Review Board
Approved 5/13/2013
5130122 Chair R. L. Rios, MD

This section of the questionnaire contains questions about care provided by hospice

Please circle your response.

- | | | |
|---|------------|-----------|
| 10. Hospice care should only be provided for patients who have no curative treatments available | Yes | No |
| 11. Hospice care should not be provided along with anti-cancer treatments | Yes | No |
| 12. What is important for quality of life varies among individuals. | Yes | No |
| 13. The patient provided hospice care must accept death. | Yes | No |
| 14. When a patient with cancer has pain, opioids should be started first. | Yes | No |
| 15. One of the goals of pain management is to get a good night's sleep. | Yes | No |
| 16. When cancer pain is mild, non-opioids should be used more often than opioids. | Yes | No |
| 17. When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used. | Yes | No |
| 18. Regular use of an analgesic drug is effective for management of cancer pain. | Yes | No |
| 19. Some antidepressant and anticonvulsant medications help relieve cancer pain. | Yes | No |
| 20. Even if breakthrough pain occurs when opioids are taken on a regular basis, the next dose should not be given earlier than scheduled. | Yes | No |
| 21. Long-term use of opioids can often induce addiction. | Yes | No |
| 22. Use of laxatives is effective for preventing opioid-induced constipation. | Yes | No |
| 23. Increase in opioid dosage should be limited because respiratory depression can occur as a side effect. | Yes | No |
| 24. Use of opioids does not influence survival time. | Yes | No |
| 25. Morphine should be used to relieve dyspnea in cancer patients. | Yes | No |
| 26. When opioids are taken on a regular basis, respiratory depression will be common. | Yes | No |
| 27. Oxygen saturation levels are correlated with dyspnea. | Yes | No |
| 28. Evaluation of dyspnea should be based on subjective report of patients. | Yes | No |
| 29. Anti-cholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients. | Yes | No |
| 30. The only effective way to alleviate bronchial secretions in dying patients is by suctioning. | Yes | No |
| 31. During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient discomfort. | Yes | No |
| 32. Benzodiazepines should be effective for controlling delirium. | Yes | No |
| 33. Some dying patients will require continuous sedation to alleviate suffering | Yes | No |

34. Morphine is often a cause of delirium in terminally ill cancer patients.	Yes	No
35. Delirium occurs frequently in patients who are prone to mental symptoms.	Yes	No
36. A gastric tube must be inserted to relieve symptoms caused by digestive tract obstruction.	Yes	No
37. At terminal stages of cancer, higher caloric intake is needed compared to early stages.	Yes	No
38. A decrease in oral intake associated with cancer can only be treated with infusion.	Yes	No
39. Even if oral intake is not possible because of digestive tract obstruction, total parenteral nutrition often improves quality of life if performance status is good.	Yes	No
40. There is no route except central venous for patients unable to maintain a peripheral intravenous route.	Yes	No
41. When patients receive an infusion of 1000 mL or more per day, pleural effusion and ascites tend to worsen.	Yes	No
42. Steroids should improve appetite among patients with advanced cancer.	Yes	No
43. When patients with ileus use metoclopramide, stomach ache and vomiting may worsen.	Yes	No
44. Intravenous infusion will not be effective for alleviating dry mouth in dying patients.	Yes	No
45. Most Malaysians want full disclosure of bad news including estimated prognosis.	Yes	No
46. Communication skills can be learned.	Yes	No
47. Information that patients and families request and the degree to which patients and families take part in decision making may change according to the course of the illness and the condition.	Yes	No
48. Uncertain information should not be given to patient or family because it may cause additional anxiety.	Yes	No

This section of the questionnaire contains statements about caring for the dying

49. Families need emotional support to accept the behavior changes of the dying person.	Yes	No
50. As a patient nears death, the nonfamily caregivers should withdraw from his/her involvement with the patient.	Yes	No
51. Families should be concerned about helping their dying member make the best of his/her remaining life.	Yes	No
52. The dying person should not be allowed to make decisions about his/her physical care.	Yes	No
53. It is beneficial for the dying person to verbalize his/her feeling	Yes	No
54. Families should maintain as normal an environment as possible for their dying member.	Yes	No

55. Care should be extended to the family of the dying person.	Yes	No
56. Caregivers should permit dying persons to have flexible visiting schedules.	Yes	No
57. The dying person and his/her family should be the decision makers.	Yes	No
58. Addiction to pain relieving medication should not be a concern when dealing with a dying person.	Yes	No
59. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	Yes	No
60. Dying persons should be given honest answers about their condition.	Yes	No
61. Educating families about death and dying is not a non-family caregiver responsibility.	Yes	No
62. Family members who stay close to a dying person often interfere with the professional's job with the patient.	Yes	No
63. It is frustrating to have to continue talking with relatives of patients who are not going to get better.	Yes	No
64. When patients begin to discuss death I feel uncomfortable	Yes	No
65. Dying patients make me feel uneasy.	Yes	No
66. I feel pretty helpless when I have terminally ill patients in my care.	Yes	No
67. It makes me uncomfortable when a dying patient wants to say goodbye to me.	Yes	No

The next section of the questionnaire contains statements about feelings towards death in general.

68. I fear dying a painful death	Yes	No
69. Not knowing what the next world is like troubles me	Yes	No
70. The idea of never thinking again after I die frightens me.	Yes	No
71. I am not at all anxious about what happens to the body after burial.	Yes	No
72. Coffins make me anxious.	Yes	No
73. I hate to think about losing control over my affairs after I am gone.	Yes	No
74. Being totally immobile after death bothers me	Yes	No
75. I dread to think about having an operation.	Yes	No
76. The subject of life after death troubles me greatly	Yes	No
77. I do not mind the idea of being shut into a coffin when I die.	Yes	No
78. I am not afraid of a long, slow, dying.	Yes	No
79. I hate the idea that I will be helpless after I die.	Yes	No
80. I am not at all concerned over whether or not there is an afterlife	Yes	No
81. The thought of never feeling anything again after I die upsets me.	Yes	No
82. The pain involved in dying frightens me.	Yes	No
83. I am looking forward to new life after I die.	Yes	No
84. I am not worried about ever being helpless	Yes	No

85. I am troubled by the thought that my body will decompose in the grave Yes No
- 86. The feeling that I will be missing out on so much after I die disturbs me.** Yes No
87. I am worried about what happens to me after I die. Yes No

Most Recent experience with death

The next questions ask about experience with patients' deaths.

88. Approximately how many dying patients have you provided care for, in the last 6 months? _____

These items to be completed by doctors only

89. Of these patients how many of them did you discuss hospice with? _____
90. Of the number of dying patients cared for, how many did you refer to hospice care?

91. What is your main reason for not discussing hospice care or referring to hospice?

These items to be completed by nurses only

92. Out of the number of dying patient you have cared for, with how many did you discuss hospice care? _____
93. What is your main reason for not discussing hospice care hospice?

This question is to be completed by all respondents.

94. What are the conditions under which you will feel it appropriate to discuss hospice care with your patients?
- a. _____
- b. _____
- c. _____
- d. _____

APPENDIX D

INFORMED CONSENT

Invitation to Participate in a Research Study

Researcher: Shanthi E Solomon, MS RN (PhD Student – Loma Linda University, Loma Linda, California) ssolomon@llu.edu

What is the research about and why is it being done?

This research is being conducted to obtain information on the existing knowledge and attitudes toward care of the dying, attitude towards death and current practice of recommendation or referral for Hospice Care by doctors and nurses.

Why am I being invited to participate in this research?

As a physician / nurse, you hold a position in society that impacts the health and happiness of the people you serve. It has been determined by existing records and other studies that, despite available and adequate hospice care resources in Malaysia, terminally ill patients who would benefit from hospice, are not being referred or not referred early enough. This results in the patient and the family suffering needless pain and psychological trauma.

We do not know how knowledge and attitude towards hospice care relates to information sharing about hospice care with patients and families by doctors and nurses in Malaysia. This study will use the information you provide to help determine how knowledge about, and attitudes toward hospice care, relate to ensuring that terminally ill patients and their families get the best care available.

What do have to do if I agree to be in the study?

If you agree to participate in the study, click on this link ([_____](#)) and complete the survey. This study consists of a number of statements that have been developed and tested to measure attitudes and knowledge about hospice care, death and caring for the dying. You are requested to participate in this study to begin the process of bringing about changes relating to this problem that has been identified. The survey will take 30-45 minutes to complete. The time you spend will be invaluable to the health and benefit of the people you serve in Malaysia.. The completion of every item will be greatly appreciated.

How will this study benefit me?

The information obtained from this study may not help you directly. However, the information gained may improve your perceptions of end of life care, leading to better usage of hospice care by terminally ill patients. This may lead to a better preparation for death by the relatives of such patients

Are there any risks involved with being in the study?

There are no anticipated risks or harms to you as a result of your participation in the study. Although, answering some of the questions on care of the dying patient or attitude towards may bring on feelings of sadness or anxiety.

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5/20/22 Chair R.L. Ripplino*

What steps have been taken to minimize participant risk?

An ID number will be assigned to your responses. Your actual identification will be unknown to the researcher and to anyone else. You are requested not to place your name, location of practice or any information that can identify you. This survey is anonymous.

What else do I need to know?

Around 300 doctors and nurses in Malaysia will be participating in this study. Your decision to participate is completely voluntary. You have the right to stop answering questions if it makes you very uncomfortable. The final date to provide your input towards this important study is -----

Whom can I contact with any questions or concerns?

If you have any questions pertaining to the study or the questionnaire, you may contact Shanthi Solomon at ssolomon@llu.edu. If you wish to contact an impartial third party not associated with this study regarding any question or complaint you may have about this study, you may contact the Adventist Clinical Research Centre at Penang Adventist Hospital at (604) 222-7737.

Loma Linda University
Adventist Health Sciences Center
Institutional Review Board
Approved 5/13/2013
5130122 Chair *R. J. Riquelme*

APPENDIX E
COVER LETTER

Shanthi Ellen Solomon
Loma Linda University School of Nursing
West Hall, Loma Linda
CA 92354

Date

Dear

As a physician / nurse, you hold a position in society that impacts the health and happiness of the people you serve. It has been determined by existing records and other studies that, despite available and adequate hospice care resources in Malaysia, terminally ill patients who would benefit from hospice, are not being referred or not referred early enough. This results in the patient and the family suffering needless pain and psychological trauma.

We do not know how knowledge and attitude towards hospice care relate to information sharing about hospice care with patients and families.

This study will use the information you provide to help determine how knowledge about, and attitudes toward hospice care, relate to ensuring that terminally ill patients and their families get the best care available.

This study consists of a number of questions that have been developed and tested to measure attitudes and knowledge about hospice care, death and caring for the dying. I would like to request your assistance by participating in this study to begin the process of bringing about changes relating to this problem that has been identified. The questionnaire will take 30-45 minutes to complete. The time you spend will be invaluable to the health and benefit of the people you serve in Malaysia.

You are free to choose not to participate, but I would greatly appreciate your completing every item on the survey. The attached consent information answers questions you may have.

This particular study may increase your interest and understanding of hospice care. More importantly this study may help guide education and policy regarding hospice care.

The final date to provide your input towards this important study is -----.

Thank you for your invaluable contribution.

Regards,

Shanthi Ellen Solomon, PhD(c), RN

APPENDIX F
BRIEF PROPOSAL

Despite available and adequate hospice care resources in Malaysia, terminally ill patients who would benefit from hospice care are either not being referred early enough or not at all. The reasons for not referring to hospice are unknown.

Purpose

The purpose of this descriptive correlational study is to examine current nurse and physician knowledge about hospice care, existing attitudes towards care of the dying, death anxiety and hospice discussion or referral practices with potential hospice patients/families in Malaysia.

The specific aims for the study are:

1. To assess the knowledge of Malaysian nurses and physicians regarding hospice care practices,

This will be accomplished using the Palliative Knowledge Care Test as the practices for hospice and palliative care are similar.

2. To assess the attitudes of Malaysian nurses and physicians towards care of the dying

This will be accomplished using the Frommelt Attitudes Toward Care of the Dying questionnaire

3. To assess individual attitudes of Malaysian nurses and physicians towards death and dying

This will be accomplished using the Death Anxiety questionnaire

4. To document current practice of hospice discussion with patients/families by nurses in Malaysia.

This will be accomplished by having nurses' respond to questions on discussion about hospice with patients over the last 6 months.

5. To document current hospice referral practice by doctors in Malaysia

This will be accomplished by having doctors respond to questions about their hospice referral practices over the last 6 months

6. To determine whether a relationship exists between referral behaviors and knowledge about hospice practices and attitudes towards care of the dying,; death anxiety, and selected biographic/demographic variables

This will be accomplished descriptive statistics and bi- and multi-variate statistical analysis. Univariate analyses will describe sample separately for nurses and physicians. Across group (nurse and physician) comparisons will be made for the three tests as well.

Bivariate analyses will describe the relationships between biographic/demographics, knowledge, attitudes and death anxiety with the dependent variable of discussion about/ referral to hospice. One way analysis of variance and t-tests will be used.

Multivariate tests will include ordinary least square regression with percentage referrals as the dependent variable, and biographics-demographics and test scores as the independent variables.

APPENDIX G

LETTER TO SABAH MEDICAL ASSOCIATION

March 28, 2013

Dr. Heric Corray,
Medical Director, Queen Elizabeth Hospital 1,
Kota Kinabalu
Sabah, Malaysia

Dear Dr. Corray,

Approval letter from Sabah Medical Association for access to membership list

Dr. Oomen has informed me about your goodwill towards the research study pertaining to the current knowledge of hospice practices among the physicians. Thank you for the willingness to allow access to the membership of the Sabah Medical Association.

I am an employee of Penang Adventist Hospital working on a PhD at Loma Linda University in Southern California and currently in the US; therefore I am really grateful for this opportunity. As I would like to assess and document the knowledge and attitudes of doctors and nurses who are not directly involved with hospice and palliative care, the target groups are the nurses and non-palliative care physicians in Penang and Sabah. I would like to study these two groups because historically these two states played important roles in the hospice and palliative care movement in Malaysia.

In order to ensure that research conducted by students here abides by ethical principles, IRB approval will only be given upon receipt of approval letters from responsible individuals in the country where the research will be conducted. I would greatly appreciate some form of an approval letter from you even via email that I can turn in to the IRB.

To maintain anonymity I have requested the Adventist Clinical Research Center at Penang Adventist Hospital, to send out an invitation with a link to the survey. However, I understand that you would like the link to be given to the secretariat of SMA. Thank you for that form of assistance. I need at least 30-40 responses if possible from Sabah. More would be better. I will be allowed to collect data only after IRB approval. Therefore I can only send the link and the consent form as soon as my University approves the study. Right now they are waiting for the approval letters that are required from Malaysia.

Looking forward to a statement/letter of approval directed to me.

Sincerely

Shanthi Ellen Solomon, RN PhD (c)
Loma Linda University, School of Nursing

APPENDIX H

LETTER TO MALAYSIAN MEDICAL ASSOCIATION

March 28, 2013

Dato' Seri Dr T. Devaraj
Vice Chairman, Penang Hospice Society
Rumah Hospice
250A Jalan Air Itam 10460 Penang

Dear Dato',

Approval from Malaysian Medical Association, Penang for access to membership list

Thank you for your courtesy in allowing me to experience the work of Penang Hospice society some years ago. After a long break I have returned to the US to complete my doctorate. As I had previously informed you, I have focused on hospice care.

Following an extensive literature search, it appears that despite available resources only about 10% of terminally ill patients in Malaysia receive hospice care early enough to receive relief physical symptoms and psychosocial preparation for death. I am interested in seeing if there is a relationship between knowledge and attitudes towards hospice care and care of the dying with discussion about or referral for hospice care.

I would like to assess and document the current knowledge and attitudes of doctors and nurses who are not directly involved with hospice and palliative care, the target groups are the nurses and non-palliative care physicians in Penang and Sabah. I would like to study these two groups because historically these two states played important roles in the hospice and palliative care movement in Malaysia.

In order to ensure that research conducted by students here abides by ethical principles, IRB approval will only be given upon receipt of approval letters from responsible individuals in the country where the research will be conducted. I would greatly appreciate your assistance in securing an approval letter from the Penang Branch of the Malaysian Medical Association even via email that I can turn in to the IRB.

To maintain complete anonymity I have requested the Adventist Clinical Research Center at Penang Adventist Hospital, to send out an invitation with a link to the survey. I need at least 75 - 80 responses if possible from doctors in Penang. More would be better in order to ensure that I have solid data and good power for the study.

I will be allowed to collect data only after IRB approval. Therefore I can only send the link and the consent form as soon as my University approves the study. Right now I am waiting for the approval letters that are required from Malaysia.

I would greatly appreciate your validation for the study so that an approval can be granted by the President of the Penang Branch of MMA to access their membership list. If there are any questions that need to be answered, I am willing to do so.

Sincerely
Shanthi Ellen Solomon, RN PhD (c)
Loma Linda University, School of Nursing

APPENDIX I

LETTER TO SABAH STATE MEDICAL DIRECTOR

October 10, 2013
De Christina Rundi,
Pengarah Kesihatan Negeri Sabah,

Dear Dr. Rundi,

Approval letter from Pengarah Kesihatan Negeri Sabah for enlisting nursing members of Malaysian Nurses Association, Sabah Branch

I am seeking approval for a research study of nurses and doctor's attitudes and knowledge of hospice care that I would like to conduct in Sabah and Penang. I am an employee of Penang Adventist Hospital working on a PhD at Loma Linda University in Southern California.

My university wants to ensure that research conducted by students here abide by ethical principles. Therefore approval will be granted by them only upon receipt of approval letters from responsible individuals in the country where the research will be conducted. I would greatly appreciate your help, in granting me an approval letter as Pengarah Kesihatan Negeri Sabah, to enlist nursing members of the Malaysian Nurses Association, Sabah Branch to participate in the survey.

Following an extensive literature search, it appears that despite available resources only about 20% of terminally ill patients in Malaysia receive hospice care early enough to receive relief physical symptoms and psychosocial preparation for death. I am interested in seeing if there is a relationship between knowledge and attitudes towards hospice care and care of the dying with discussion about or recommendation for hospice care.

Therefore it is important that the knowledge and attitudes of doctors and nurses who are not directly involved with hospice and palliative care be looked at. Hence, the target groups are the nurses and non-palliative care physicians in Penang and Sabah. I would like to study these two groups because historically these two states played important roles in the hospice and palliative care movement in Malaysia.

The invitation will be sent by mail to the members by the Adventist Clinical Research Center at Penang Adventist Hospital. The information conveyed will remain totally anonymous. I would like the invitation sent out to the whole membership to give me a chance of a good response rate. Hence I need your approval for members on Malaysian Nursing Council, Sabah Branch to be involved in this research. The Penang Adventist Hospital's Adventist Clinical Research Centre is where the invitations will be sent out from. I will have no knowledge of who receives the invitations.

Attached is a brief write up about the research that will be part of the information sent to the invited participants.

Please let me know if there are any questions that require answers and I will respond promptly.

Thank you for your assistance.

Sincerely

Shanthi Ellen Solomon, RN PhD (c)
Loma Linda University, School of Nursing

APPENDIX J

LETTER FOR STUDY CO-ORDINATION

**Shanthi Ellen Solomon
26269 Picton Avenue
Loma Linda University
California 92354**

June 4, 2012

Dear Shanthi

Having considered the brief proposal submitted, the Adventist Clinical Research Centre (ACRC) is willing to allow the pilot testing of the questionnaire in Penang Adventist Hospital, subject to approval by the Institutional Review Board of Loma Linda University.

It may be beneficial to the patients of Penang Adventist Hospital to have you study the relationship between knowledge of current end of life care delivered by hospice, personal attitude towards death, and attitude towards caring for the dying, and the practice of referral decisions made by doctors and nurses for terminally ill patients. I believe that the findings of the research may make a valuable contribution to the care of patients and families in Penang.

Please ensure that the ACRC is kept apprised of any situation related to any part of the study during the period you will be collecting information.

Regards,

Edward Nathan
Adventist Clinical Research Centre

APPENDIX K

PERMISSION TO USE THE REVISED DEATH ANXIETY SCALE



RightsLink®



Title: A revised death anxiety scale
Author: James A. Thorson, F. C. Powell
Publication: Death Studies
Publisher: Taylor & Francis
Date: Nov 1, 1992
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