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THE DEVELOPMENT AND TESTING OF THE LIFE SUSTAINING
TREATMENT ATTITUDE QUESTIONNAIRE (LSTAQ)

A DISSERTATION SUBMITTED TO THE GRADUATE DIVISION OF THE
UNIVERSITY OF HAWAII IN PARTIAL FULFILLMENT OF THE
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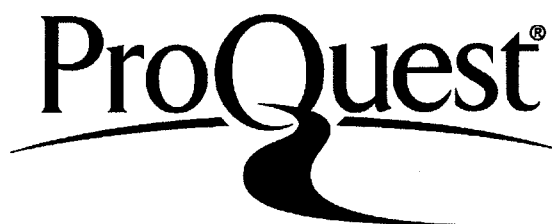
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DEDICATION

This work is dedicated to my late parents, Geminiano O. Caces and Sabina O.

Fontanilla and to my family, Ben, Kristine, Jonathan and Stephanie.

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I wish to acknowledge the special individuals in my committee, who are key to the completion of this dissertation: Dr. Joe Mobley, Dr. Kathryn Braun, Dr. John Casken, Dr. Francisco Conde and Dr. Bee Kooker. Thank you all for taking an unknown student and provided wisdom, support and encouragement in the completion of this dissertation. I am greatly indebted to you.

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ABSTRACT

Purpose: To develop and test the validity and reliability of the Life Sustaining Treatment Attitude Questionnaire (LSTAQ), a survey instrument to elicit family member decision-maker attitudes toward life sustaining treatments for the critically ill at end of life.

Background: Attitudes toward life sustaining treatments (LST) have been shown to influence decision-making at end of life (EOL). A reliable and valid tool to elicit attitudes specifically from family member decision-makers may help healthcare professionals facilitate decision-making during serious illness at end of life.

Methods: A 33-item LSTAQ instrument was tested in 170 adults. Construct validity was evaluated by exploratory factor analysis. Correlations established convergent and discriminant validity. Reliability testing for internal consistency was assessed by Cronbach's alpha and corrected split half reliability coefficients. All procedures were done with Statistical Package for Social Sciences (SPSS version 18) software (SPSS Inc., Chicago, Ill).

Results: A 30-item final LSTAQ tool was derived from this study. Principal components factor analysis extracted six factors explaining 62.7% of variance. Correlations with a similar tool supported convergence ($r = .72, p < .01$). Discriminant validity was confirmed by the absence of significant correlation with the dissimilar tool. LSTAQ internal consistency was good (Cronbach's alpha = .92). A preliminary exploration of differences in LSTAQ scores by ethnicity revealed a sampling size and distribution that was not optimally responsive to detection of ethnic differences.

Conclusion: The LSTAQ is a reliable and valid tool to elicit LST attitudes specifically from family member decision-makers. The knowledge gained may help healthcare professionals promote interventions that facilitate family decision-making on life support for the ill relative at end of life. This might help reduce decision difficulties that cause preventable discomfort, unnecessary treatment and prolonged suffering for the terminally ill patient, as well as avoidable distress among family members involved in decisions for the sick relative.

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CHAPTER 1. INTRODUCTION

While healthcare technology has achieved important gains in treating illness, it has also created complexities in dealing with care at the end of life. The variety of medical interventions has given healthcare a new ability to prolong life. Life sustaining treatments (LST) are intended to help the critically ill recover from acute illness. However, when recovery is no longer the goal of care, LST may interfere with the dying process.

In the absence of advance health care directives, healthcare professionals look to the family member for life support decisions when the patient is unable to communicate preferences for treatment. Current literature suggests that decision difficulties result in preventable discomfort, unnecessary treatment and prolonged suffering for the terminally ill patient, as well as avoidable distress among family members involved in decisions for the sick relative. The variety of treatment choices, preferences, cultural values and attitudes often make decision-making for the incapacitated adult at the end of life (EOL) a difficult task (Kwak & Haley, 2005).

In the United States, an estimated 20% of patients die while in the intensive care unit (ICU) or shortly thereafter (Angus, Barnato, Linde-Zwirble et al., 2004; Chapple, 1999). A majority of these patients are usually on LST, also called “life support”. This may include artificial airway, mechanical ventilation (respirator), cardiopulmonary resuscitation, hemodialysis and other invasive delivery systems for nutrition, hydration or medications for life threatening illness. Decisions to forgo or limit LST precede about 70% of deaths in the intensive care unit (Boyle, Miller & Forbes-Thompson, 2005;

Prendergast & Puntillo, 2002). Studies in North America indicate between 60%-80% family involvement in life support decision-making (Boyle, et al., 2005; Lang & Quill, 2004).

Attitudes have been shown to influence decision-making. Some studies indicate that a person's attitudes toward treatments at EOL may influence their personal decision on whether to use, withhold, withdraw or forgo life support (Angus et al., 2004). The abundant literature on EOL includes attitudes of patients, physicians, nurses and other healthcare providers. Little is known however, on family member decision-maker attitudes toward LST. Such attitudes may affect their decisions about the use of life support at EOL for the sick relative.

An attitudes questionnaire specific to this population may provide better information on family member decision-maker attitudes. Beliefs (perceived facts) and attitudes (perceived evaluations) are presumed to be results of multiple influences, and that preferences and decisions made generally imply what a person thinks or believes (Hodges, 1998).

Conceptual Background

This study is based on attitude and decision-making theories that link with culture and values. The attitude theory by Fishbein and Ajzen (1975) provides the framework that relates beliefs, attitudes, intentions and behavior toward a given object. Janis and Mann's (1977) theory of decisional conflict, extended by Balneaves and Long (1999) explains how personal factors such as values, preferences and goals of the decision-maker may play a major part in the course of action taken. Noone (2002) explains this as

a naturalistic decision-making process where the context is influenced by various personal and situational factors. Culture, as a major influence, directs human actions and decisions (Leininger & McFarland, 2006).

In trying to understand attitudes toward the use of life support in the ICU and EOL, Cook et al. (2006) suggest that such attitudes are grounded in values that are collective and community-based. This might imply that attitudes may differ by ethnicity or cultural group. The authors propose various research methods to get insights into such attitudes, such as decision support tools, qualitative studies, observational studies and surveys. Understanding these attitudes may offer valuable perspectives about strategies to help improve care for the dying, primarily in facilitating decision-making by the family member.

Statement of the Problem

While literature has a variety of research regarding life support at EOL, little is known about family decision-makers' attitudes toward LST and their influence on decisions made for a critically ill family member. There is also lack of data about attitudes toward LST among decision-makers of the many ethnicities and cultural groups that populate the United States today. Accurate data combined with research-based knowledge will help inform how healthcare providers deliver culturally appropriate care at the end of life. It starts with a valid and reliable instrument that measures the major components of decision-makers' attitudes toward LST for a critically ill relative at end of life.

Purpose of the Study

This study is the development and testing for validity and reliability of the Life Sustaining Treatment Attitude Questionnaire (LSTAQ), an instrument to survey the attitudes of family member decision-makers for critically ill adults towards LST at the end of life.

The specific aims of the study were:

- 1) To examine construct validity of the LSTAQ tool via exploratory factor analysis (EFA).
- 2) To assess convergence of the LSTAQ with a tool that measures a similar construct via correlations.
- 3) To evaluate divergence of the LSTAQ with an instrument that measures a dissimilar construct by correlations.
- 4) To assess items' performance and reliability via internal consistency calculation of Cronbach's alpha, Spearman-Brown split-half coefficient and inter-item correlations.
- 5) To explore the differences in LSTAQ scores by ethnicity via analysis of variance.

Hypotheses:

- 1) The LSTAQ is a construct valid instrument with at least three theorized dimensions of decision-maker attitudes toward LST for a sick family member.
- 2) A high correlation exists between the total scores of the LSTAQ and the Blackhall LST (Blackhall et al., 1999) attitude instrument.

- 3) No correlation exists between the total scores of the LSTAQ instrument and the Subjective Happiness Scale (Lyubomirsky & Lepper, 1999).
- 4) The LSTAQ is a reliable tool to elicit decision maker attitudes toward life support among potential family decision-makers.
- 5) There are significant differences in LSTAQ scores by ethnicity.

Significance

The LSTAQ will make an important contribution in obtaining knowledge of family decision-makers' attitudes toward life sustaining treatments for critically ill adults at EOL. For healthcare professionals, the recognition of family member LST attitudes will help improve communications to facilitate decision-making, minimize unnecessary suffering for the sick relative, reduce conflict among family and healthcare providers, and promote appropriate interventions in the delivery of quality end-of-life care.

Definition of Terms

This section provides definition of the terms used for this study.

Attitude. It is the term used to describe “learned predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object” (Fishbein & Ajzen, 1975, p. 15).

Culture. It is “the learned, shared and transmitted values beliefs, norms and lifeways of a particular culture that guides thinking, decisions, and actions in patterned ways and often intergenerationally” (Leininger & McFarland, 2006, p. 13).

Ethnicity. This term refers to a group that shares some attributes of a culture. It does not have firm boundaries with varying levels of acculturation and assimilation (Ward, 2003).

Decision-making. This refers to a cognitive process of reaching a decision, or a process by which one makes “choices, judgments and ultimately come to conclusions that guide behavior” (The International Encyclopedia of Communication, 2008).

Family member decision-maker. This describes a relative or next of kin, or a significant other who takes on the role as the surrogate for a patient who is unable to communicate for him/herself due to incapacity, sedation or severity of illness.

End of life (EOL). It is the period of time marked by disability or illness that increasingly worsens until death (DeSpelder & Strickland, 2005).

End-of-life care. This term refers to the support or medical care given during the time surrounding death, or the period where the person is recognized to be in a progressively declining condition. This period of time may be moments, days, weeks or months before death (National Institute of Aging, n.d.).

Life sustaining treatment. LST or “life support” is any treatment intended to prolong life. It may include artificial airway, mechanical ventilation, cardiopulmonary resuscitation (CPR), hemodialysis, and other invasive delivery systems for the provision of hydration, nutrition, medication and other treatments to sustain life. It is generally used in the setting of critical illness with the intention to reach a goal of recovery or cure.

Withdrawal of life support. It is a process where medical interventions are taken away from the patient, with the recognition that withdrawal of LST would likely result in the patient's death from the underlying medical condition (Counsell & Guin, 2002). It is

done after it is determined that medical options are exhausted and the prognosis is terminal (Prendergast & Puntillo, 2002).

Withholding life support. It refers to excluding, limiting or not initiating treatment under the same previously mentioned conditions. Consistent with current critical care practice and bioethics, this present study makes no distinctions between “withdrawing” and “withholding” LST. Both terms refer to removal or no further escalation of major life support modalities (Hall & Rucker, 2000). “Forgoing life support” is another term used for withdrawal or withholding LST.

Assumptions

It is assumed that LST decision-making for the terminally ill relative is a difficult process and that personal values and attitudes toward LST can affect decision-making for others. It is also assumed that eliciting knowledge of these attitudes can help ease the decision-making process by communication interventions and thus, improve EOL care for the terminally ill. An essential step to this process is to have a valid and reliable tool to measure attitudes, specific for the family decision-maker.

Summary

This chapter introduced the background to the development of the study, conceptual background, problem statement, purpose, hypotheses, significance, terminology and assumptions. Attitudes have been shown to influence decision-making in general. Not much is known, however about how family member decision-maker attitudes may influence LST decisions made for others. A valid and reliable survey

instrument to measure LST attitudes specifically among family decision-makers was not found in the review of literature. The purpose of this research is to develop and evaluate the reliability and validity of the LSTAQ for use among family decision-makers of the critically ill adult. A tool to examine attitudes from this particular group may help healthcare professionals facilitate decision making at end of life.

Chapter 2 will present a review of related literature and conceptual framework. Chapter 3 will present methodology. Chapter 4 will present the study results and Chapter 5 will discuss the findings and conclusion.

CHAPTER 2. LITERATURE REVIEW

The advancement of technology, with a variety of medical interventions, has given healthcare a new ability to prolong life. Life support or life sustaining treatments intended to help the critically ill recover from acute illness may also interfere with the end of life, when recovery is no longer the goal. Decision-making by a family member pertaining to life support for the critically ill and decisionally incapacitated adult at the end of life is often difficult, with the variety of treatment choices, preferences, cultural values and attitudes (Kwak & Haley, 2005; Matsumura, Bito, Liu et al., 2002). Despite abundant literature on end of life in general, there is limited knowledge of family member decision-makers and their attitudes toward life support treatments for the seriously ill relative.

Family member decision-making on life sustaining treatments at end of life

In the United States, with the current population nearly 305 million (U.S. Census Bureau, 2008), there are more than 2.4 million deaths annually. Eighty percent of deaths occur in hospitals and involve patients 65 years and older. Within 6 months before death, approximately 11% of Medicare recipients spend more than 7 days in the intensive care unit (Beckstrand & Kirchhoff, 2005). About 20% of intensive care unit (ICU) patients die while hospitalized (Angus et al., 2004; Chapple, 1999). Between 6.3% to 30% of all deaths in the United States occur in ICUs (Kirchhoff et al., 2002).

Throughout the United States, Canada and Europe, up to 70% of ICU deaths occur after forgoing life sustaining treatment (Boyle, 2005; Heyland et al., 2003;

Kirchhoff et al., 2002; Prendergast & Puntillo, 2002). Such decisions are often guided by the western view of patient autonomy which is promoted by the Patient Self Determination Act (PSDA), a federal law enacted in 1991. The PSDA intent was to uphold patient autonomy and self-determination. It requires Medicare or Medicaid funded healthcare organizations to inform patients of their right to complete advance directives and to document existing advance directives in patients' medical records (PSDA, 1995). Patient decision-making is supported by the use of advance healthcare planning and advance directives.

In the absence of such directives, the healthcare team looks to the family to make decisions. Studies in North America indicate that family members are involved 60% to 80% of the time with end-of-life decisions (Boyle et al., 2005; Lang & Quill, 2004). Tschann, Kaufman and Micco (2003) determined that family involvement, through the indirect measure of family presence at EOL, may reduce the use of technology as the patients die.

A European study of 78 ICUs found that family member desire to be involved in LST decision-making was 47%. Understanding and effectiveness of information received, anxiety and other psychological obstacles were factors in how much family members got involved (Azoulay et al., 2003).

Decision-making, as previously defined, implies a cognitive course of how one gets to a decision from a given set of options. This process may have inherent conflicts, making it difficult to choose the right alternative. Values and preferences of the decision-maker may play a major part in the course of action taken. This suggests a decision process based on the naturalistic decision making theory that “assumes a dynamic,

contextual environment and are influenced to varying degrees by different personal and situational factors” (Noone, 2002, p. 23).

Balneaves and Long (1999) extended the Janis and Mann (1977) theory of decisional conflict to explain this choice model. Noone (2002) summarized that decisional conflict occurs when “a choice of options is available and that decisions are influenced by personal variables, such as values, beliefs, goals and commitments as well as environmental variables, which are situation specific” (p. 23). In her review of health care related decision-making, a consistent finding was personal preferences.

Due to incapacity, critically ill patients are generally unable to actively participate in decision-making. Unless an advance directive was previously completed and disclosed, a proxy decision-maker, usually a family member is called upon to make LST decisions.

The two standards in surrogate decision-making are “substituted judgment” and the “best interest” principles. Under substituted judgment, the decision-maker makes a choice that genuinely represents the patient’s treatment wishes (Blatt, 1999). Decisions are based on the incapacitated patient’s known values and preferences (Buchanan & Brock, 1989). When the use of substituted judgment is not possible, the best interest principle is applied.

According to Beauchamp and Childress (2001), surrogates use the patient's best interest as the guiding principle for decision-making. It is based on an assessment of how best to protect and uphold the patient’s interest. After all known factors are weighed, the decision-maker chooses what resolution would be in the best interest of the patient. “Best interest” is promoted when the benefits of treatment outweigh the risks. For this literature review, distinctions between these two standards were not made.

The following section is a literature review of (1) family member LST decision-making experience, (2) decision-making, culture and LST attitudes, and (3) instruments to measure LST attitudes and decision-making.

Electronic databases were searched for relevant literature published between 1995 and 2009 such as the Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE/Ovid, PsycINFO and PubMed. This time frame was chosen to eliminate obsolete information given the rapidly evolving healthcare environment and changing demographics. The review time frame also allowed time for outcomes from the 1991 United States federal enactment of the Patient Self Determination Act (PSDA).

Initial broad topic search was on end-of life care in general. The objective was to explore the current state of EOL care and life support interventions in ICUs. Clarke et al. (2003) explored EOL care in acute care settings and identified patient and family-centered decision-making as one of the key domains in improving care at end of life.

Many studies that examined the views of patients and families regarding end-of-life topics were not specific to the family member's role as decision-maker. A narrower database search focusing on family decision-making regarding LST in the ICU was performed with the following search terms: "life support", "life support treatment", "life sustaining treatment", and "decision-making". These were used in various combinations with the terms "critical care", "intensive care", "end of life", "family", "family member", "surrogate", "withholding" "withdrawal".

Qualitative and quantitative research studies on the family decision-maker's role, process and experience in LST decision-making, research relating to adult critical care patients that entailed withdrawal/withholding LST and English version, full text articles

on studies published between 1995 and 2009 were included in the review. The following were excluded: (1) studies involving only clinician or healthcare professional decision-making, (2) pediatric and neonatal critical care patients, and (3) literature that focused solely on contentious issues of “euthanasia” and “physician assisted deaths” or advance directives. Dissertation abstracts and studies reported in abstract form were not included in this review.

Family member LST decision-making experience

The process of family member LST decision-making

The process of decision-making among family members regarding LST was described by Swigart et al. (1996). The concept of “letting go” or becoming willing to forgo life support involves complex phases of the family seeking out information, understanding about the illness and reviewing the patient’s past history while struggling to maintain family relationships and roles. “Letting go” involves

“these three processes in the context of critical illness: believing that they had done all they can and therefore now able to give up the goal of recovery and accept a peaceful death; having reviewed the patient’s life, found meaning and sense that given the condition, the patient would not want to continue life support, therefore moved toward closure; and finally bringing about the sense that they did the right thing and preserved family relationships” (p. 483).

Patient prognosis and patient wishes were significant factors in decision-making. To some of the study participants, these processes were laden with conflict, hope and grief, delayed decision-making and the prolongation of the end-of-life period.

Jacob (1998) utilized grounded theory to understand the experience of LST decision-making. This approach found that family members of patients in the ICU were willing and able to take responsibility for life support decisions for their critically ill relative. The author described the time of psychological resolution for the surrogate decision-maker as “looking back and going on” (p.33). The interactions and relationships between the family decision-maker and ICU clinicians played a major role in the acceptance of the experience and the decisions made.

Tilden et al. (1999) looked at the process of arriving at the decision to withdraw treatment. They found four phases experienced by family members to reach the decision. The “recognition of futility” of the relative’s condition and the realization of poor outcomes shifts to a second phase called “coming to terms”. The family member then assumes the surrogate role (called “taking on” the role) as a relative with relationships and responsibility. The final phase is called “facing the question” of whether to forgo life support. At 6 months after the decision, families still felt the need to confirm evidence that they had made the right decision, which the authors called “seeking a triangulation of certainty”.

Hayes (2003) found in a phenomenological study, that the decision-making experience of the surrogate decision-maker was multifactorial and iterative. It evoked two themes: “representation of the other”, which requires a process of reflection on substituted judgment as they represent the ill patient’s life, in order to make a sensible decision, and “memory manipulation”, with the time to recollect, establish and reconcile memories of the patient for a sound decision-making at the end of life and promote healthy grieving.

Meeker (2004), using grounded theory, determined family surrogate decision-making as a social process. Family decision-makers continuously integrated the values of caring for their sick family member and respecting the relative's autonomy. The process began with finding out the diagnosis, followed by surrogate activities called "standing with" and "acting for" the sick relative. The third phase involved dealing with the information and "working with family", that either facilitated or slowed down the decision-making the process. It ends with the consequences that the surrogate encounters as the decision-maker, called the "outcomes".

Vig et al. (2006) illustrated how surrogates plan to make decisions for their loved ones. The five bases for decision-making were (1) "conversations which gave knowledge of their relative's preferences, (2) relying on documents, which refer to advance directives, (3) shared lived experiences with the loved one, (4) the surrogates own values and preferences about life, and (5) the surrogates' networks or help from others" (p.1688). The authors concluded that the expectation of "substituted judgment" or "patient's best interest" standards may be vague. The data indicated that "many surrogates rely on other factors such as their own best interest or mutual interests of themselves and the patient, or intend to base substituted judgments on documents with which they have little familiarity" (p. 1688).

Limerick (2007) identified three domains in the decision-making process: the personal domain; ICU environment; and the decision domain. In the personal domain, the following themes were identified: gathering family support, "evaluating the patient's past and present condition, and viewing past and future quality of life". The ICU environment domain included "chasing doctors, developing relationships with the healthcare team, and

confirming probable medical outcomes”. The decision domain is comprised of getting to a new belief, “getting alone to make the decision, and communicating the decision” (p. 331).

Colclough and Young (2007) identified four dimensions in family understanding of the decision-making process at end of life. They are (1) “understanding the seriousness of the family members' condition, (2) “decision-making about life sustaining treatment”, (3) “readiness for the impending death”, and (4) “experience of the dying process” (p. 201).

Concepts related to family member LST decision-making

LST decision-making has been linked with conflict, stress, role strain, burden, guilt, regrets, communication and trust. Hiltunen et al. (1999) in the 1995 SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) study, identified “decisional conflict” in 24% of family members with sick relatives in the ICU. The findings implied that about one fourth of surrogate decision-makers did not know the life support preferences of their sick family member.

Abbott et al. (2001) recognized areas of conflict and psychosocial needs for families during decision-making on LST. Majority of the conflicts were between themselves and the medical staff. The burden of decision-making was lessened by knowing the patient’s end-of-life treatment preferences from past conversations.

In a qualitative, descriptive analysis, Norton et al. (2003) found that families experienced conflict and unmet communication needs during the often quick transition from aggressive curative treatments to palliative care. Badger (2005) confirmed this from

an ICU nurses' study that identified family discord, misunderstanding of the illness and the lack of clarity in the transition from cure to comfort care for the sick family member. This often led to conflicts and indecision. Winter and Parks (2008) showed that greater family discord was associated with stronger preferences for LST.

Hansen, Archbold and Stewart (2004) studied the concept of role strain and ease of decision-making for the family member. "Role strain" was described as the perceived difficulty in making the decision for an elderly relative. It was found to be a complex, dynamic and multifaceted phenomenon that spanned the time before, during and after the decision has been made about a family member's life support treatments. This study also introduced a new concept called "ease in decision-making", defined by the researchers as "the family caregiver's feelings of being without discomfort in making decisions to withdraw or withhold life support for an elderly relative and feelings of being content with the decisions that were made" (p. 383).

Although it was thought that the family decision-maker would experience ease from the outcome of the decision, none of the study participants stated that they felt satisfaction over their decision for the relative. Guilt from the specific decisions made was a factor in role strain.

Tilden et al. (2001) assessed the levels of stress associated with decisions to withdraw LST and looked at factors that affected stress. They compared families and clinicians on their reasoning about the decision. Stress level was high for family members immediately following the death of the family member, remained high six months later and then decreased over time. The highest stress factor was the absence of patient's advanced directives. To reach a decision, clinician and family collaborated in prioritizing

what the patient would want. In this process, however, the families were found to be more inclined than clinicians, to prefer “doing everything medically possible” to prolong the patient's life.

Trust and communication are also found to be factors affecting LST decision-making by the family member. Norton et al. (2003) recognized the family decision-maker's needs for competent and timely information, the need for honesty, clinician clarity, and the need for someone to listen. Skillful communication between and among clinicians and patients' families at the patients' end of life were essential for decision-making.

Russ and Kaufman (2005), from descriptive accounts of family member surrogates in decisions about withdrawal of LST, identified the burden of responsibility, regrets and inadequate communication. They found a lack of regard for the family member's perceptions, meanings and understanding in the midst of a crisis to make LST decision.

Tilden et al. (1999) noted that advance directives and honest communication from clinicians were two factors that most helped family members. The trajectory for communication covered the past, present and following the decision-making experience. Weigand (2006) found that mutual trust and interactions between family and healthcare provider were crucial in the LST decision-making process.

Other variables that may affect family member decision-making include the sick family member's functional role in the family, emotional dependence, family problem-solving style, ethnicity and religion (Blatt, 1999).

Summary of family member LST decision-maker experience

The experience of family members who make life support decisions for critically ill relatives had recurrent themes. Among them are the decision-maker's role, role strain, ease of decision-making, stress, conflict, guilt, regrets and burden. Stress factors included the inability to know exactly what the ill family member would have wanted in the situation, the ethics and morality of the decision being made, the reassurance of making the right choice, and bearing the burden of deciding to forgo LST. The need for information included knowing patient's wishes, the present patient condition and clinical information. Communication, reflection, coping and support were repeatedly noted as significant elements in the decision-making process. In a majority of the studies, elements of hope, personal beliefs and perceptions often came into play when decisions were made.

Although the studies were done in small samples and not representative of many cultural groups, the following commonalities confirm the core components of decision-making for the ill family member: (1) recognition of the situation, (2) understanding the information, (3) realization and taking on the decision-making role, (4) knowing or not knowing the sick relative's wants, and then (5) making the choice. The process is linked with tension, stress, conflict, burden and guilt felt by the decision-maker. According to Meeker and Jezewski (2005), the experience of decision-making at end of life may also include long-term physical and psychological effects from being decision-makers.

The course of decision-making in this context was illustrated from the time when the decision-maker recognizes the concept of "end of life" for the sick family member to the time of the "letting go" concept. The events and the processes connecting these two

concepts indicate the window where clinician interventions can play a key role in facilitating life support decision-making by family members.

Decision-making, culture and attitudes toward LST

Although dealing with the end of life is a universal phenomenon, in United States healthcare, decisions made on issues that surround it generally reflect the western tradition of individual control and patient autonomy. Other cultures and ethnic groups who are embedded in group-based values, such as those of Asian cultures, may encounter cultural conflicts when making end of life decisions.

According to Leininger and McFarland (2006), culture, a much broader concept than ethnicity is the “blueprint for guiding human actions and decisions” (p. 13).

Ethnicity refers to a group that shares some attributes of a culture. It does not have firm boundaries with varying levels of acculturation and assimilation (Ward, 2003).

On healthcare decision-making in general, McLaughlin and Braun (1998) explored Asian and Pacific Island cultures. They found potential divergence in choices between the predominant individualist values in United States healthcare and the collectivist values in Asian cultures. The authors suggested that these conflicts may possibly become barriers to quality end-of-life care.

On broad EOL issues, Braun and Nichols (1997) compared views among four Asian groups who live in Honolulu (Chinese, Japanese, Vietnamese, and Filipinos). They determined that sociocultural background, immigration history, philosophy and religion influence end-of-life practices. It included the “length of time in the United States, educational attainment, occupation, religious upbringing, ethnicity and culture of spouse,

exposure to other life events such as discrimination and war, and one's own personal experience with illness, with being the family caregiver, and experiences with death and dying" (p. 359). Blackhall et al. (1999) confirmed these findings, citing historical, philosophical, religious and cultural influences as some of the many factors affecting attitudes and values that influence decision-making.

Blackhall et al. (1999) studied 800 participants from four different ethnic groups. The authors determined ethnicity to be a primary influence in attitudes toward LST in terminal illness but the relationship is complex and sometimes contradictory. Korean Americans and Mexican Americans (compared to African Americans and Caucasians) less likely believed that the patient should make LST decisions, implying a collective or group decision-making process. They were found to have a more family-centered type of decision-making. Kwak and Haley (2005) reviewed EOL decision-making in general and found a variety of values and preferences among and within ethnically diverse groups, with Asians preferring group decision-making.

Nahm and Resnick (2001), in studying treatment preferences among older adults, found that African Americans, relative to Asian respondents, were more likely to ask for aggressive treatments. Although ethnicity in general was not found to be a factor, they found differences in treatment preferences between individuals of African American and Asian cultures.

Some studies, while not specific to LST decision-making, indicate that attitudes toward EOL may influence decisions on whether to use, withhold, withdraw or forgo LST (Blackhall et al., 1999; Matsumura et al., 2002; Nolan et al., 2003). Valente and

Haley (2007), while looking mainly at advance directives, found that ethnic groups had varied values and beliefs about specific life sustaining treatments.

Williams, Dunford, Knowles and Warner (2007) also cite ethnic and cultural differences in attitudes and LST decisions. In their study about British public attitudes to LST, white participants were less likely to prefer LST compared to Asian, Black and other respondents. Phipps, True and Harris (2003) found similar results in the United States.

In cross-cultural studies, acculturation has also been shown to influence attitudes toward end of life. Acculturation is described as the “process by which members of one cultural group assume the traits and behaviors of another cultural group” (Seidel, Ball, Dains & Benedict, 1999, p. 36). Matsumura et al. (2002) studied three Japanese groups with different levels of acculturation. All three groups preferred group decision-making about end of life. They all had negative feelings toward LST at EOL. Those more acculturated to Western values had a more positive attitude toward forgoing care.

Among the different ethnicities in the United States, there are some data on healthcare and EOL decision-making, but little data specific to family member LST decision-makers. Caucasians, African American and Mexican Americans were the most studied groups. Despite the fact that Asian Americans are one of the fastest growing populations (US Census Bureau, 2008), knowledge of LST decision-making among the different Asian groups in the United States is limited. Among the larger Asian populations, Japanese, Chinese and Korean Americans have some research literature. Filipinos, Vietnamese and other Southeast Asian groups are the least represented in US

research literature (Dela Cruz, McBride, Compas, Calixto & Van Derveer, 2002; Kwak & Haley, 2005).

On EOL decisions in general, commonalities and variations among groups exist (Yeo & Hikuyeda, 2000). Most Asians preferred family centered decision-making. Within group variations were associated to “cultural values, demographic characteristics, level of acculturation and knowledge of end of life treatment options” (Kwak & Haley 2005, p. 641).

Attitudes and decision-making

The attitude theory by Fishbein and Ajzen (1975) provides a framework that relates beliefs, attitudes, intentions and behavior toward a given object. Attitude, as previously defined, is “a learned predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object” (p. 15). It is the affect or a person’s feeling toward an object or an issue. Beliefs signify the cognition, knowledge, opinions or thoughts about the object. Intention is the probability factor that links the person to a behavior. This conceptual framework has a feedback loop at various stages of the process (Figure 1). It suggests that a specific behavior is determined by the person’s intention to perform that behavior. The “attitude toward performing a given behavior is related to his belief that performing the behavior will lead to certain consequences and the person’s evaluation of the consequences” (p. 17).

The behavioral intention described in this context is LST decision-making as influenced by beliefs and attitudes. The known direct consequences of the decision is uncertain survival or eventual demise of the critically ill family member (Figure 2).

Figure 1. Diagram of Fishbein & Ajzen Attitude-Behavior Theory (1975, p. 16)

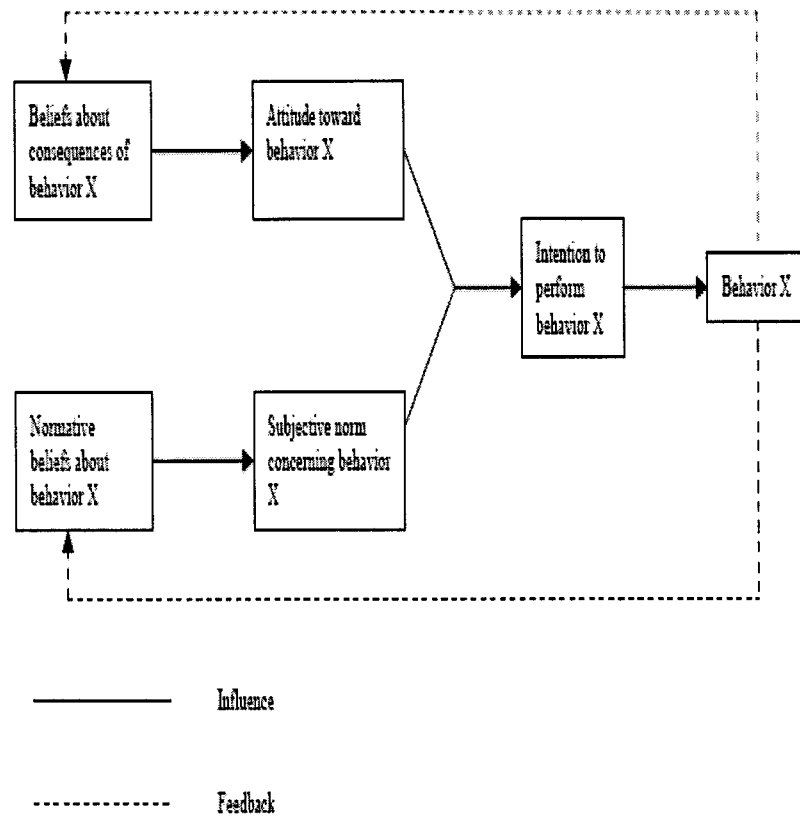
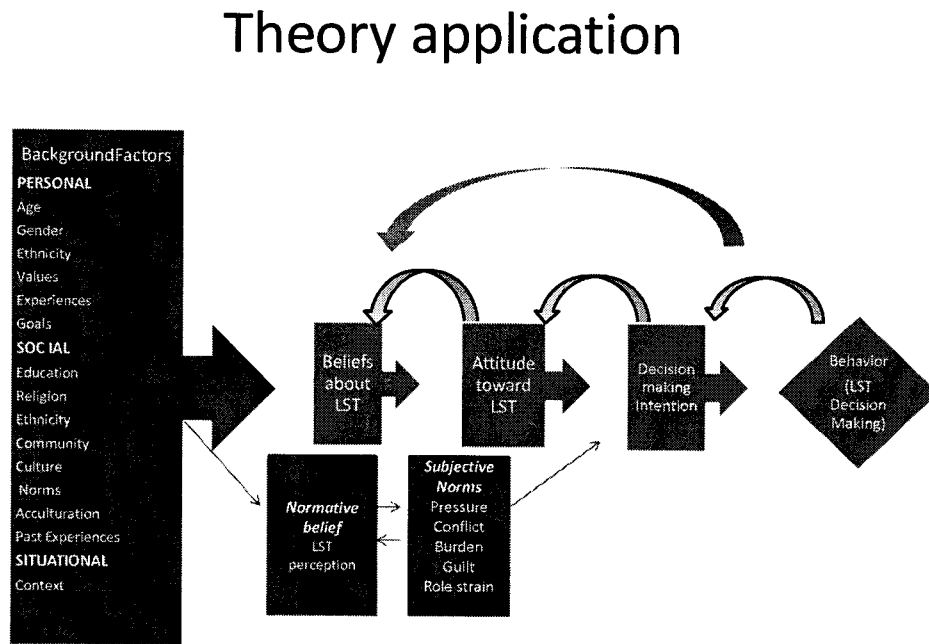


Figure 2. Theory Application



Conceptualization of LST attitude of family decision-maker

Cook et al. (2006) suggested that such attitudes are grounded in values that are collective and community-based. To try to get insights into attitudes toward life support, the authors proposed various research methods. Doing a survey is one of the methods recommended. Understanding these attitudes may offer valuable perspectives about strategies to help improve care for the dying, primarily in facilitating decision-making by the family member.

Measures of attitude toward LST decision-making

Given the little available information about attitudes of family member decision-makers toward LST and how attitudes influence decisions, a plan was made to study family member attitudes toward life support for the sick relative. A literature search was made for an attitude instrument specific to LST decision-makers for the sick family member. In addition to the databases previously searched in the first and second phases of literature review, the HaPI (Health and Psychosocial Instruments) database was accessed for published LST attitude instruments from 1995 to 2009. The following keywords were used: “life support”, “life sustaining treatment”, “attitude” and “decision-making”.

Inclusion criteria were: (1) Instruments that measured attitudes toward life support, (2) Study population involved patients, family members, lay people and healthcare professionals, (3) Questionnaire or scenario-based tools that used a quantitative measure, and (4) Full text articles that included information on validity and/or reliability testing of the tool.

Instruments excluded were those that (1) solely measured healthcare professionals’ attitudes toward LST, (2) focused exclusively on attitudes towards advance directives, (3) measured only attitudes towards contentious death concepts such as euthanasia and physician assisted suicide, (4) were used for LST decision making for infants and children, and (5) published tools without information on instrument testing.

The literature search revealed some reliable and validated tools to measure patient and healthcare professionals’ attitudes toward LST at end of life. However, no

validated tool was found to specifically measure family member decision-maker attitudes toward LST for a sick family member at EOL.

There were 29 instruments found to measure patients', laypersons' and healthcare professionals' attitudes toward life support for oneself, combined with attitudes toward advance directives, care planning and attitudes toward death. Eight instruments that assessed attitudes toward LST included various methods of reliability or validity testing (Beland & Froman, 1995; Blackhall et al., 1999; Braun, Tanji & Heck, 2001; Catt et al., 2005; Gauthier & Froman, 2001; Heyland et al., 2002; Pearlman et al., 2000; Sulmasy et al., 2004). Few of the tools were used in more than one study. Some of the instruments used for patients were also used among health care providers. Proxy decision-makers were also included in comparison studies. A table of LST tools with published psychometric properties is provided in Appendix L.

The four tools that were used in family decision-maker studies measured other constructs, such as the quality and satisfaction with decision-making (Heyland et al., 2003) and the accuracy of surrogate LST decisions (Sulmasy et al., 2004; Pruchno et al., 2006; Zettel-Watson et al., 2008). Of these four tools, only Sulmasy et al. (2004) provided information on the instrument's internal consistency.

To date, there are reliable and validated tools to measure patient and healthcare professionals' attitudes toward LST at end of life. However, a validated tool to specifically measure LST attitudes of the family member decision-maker is lacking.

Because no appropriate scale was found to measure the construct to be studied, the literature and instrument search at this point, became the references for the LSTAQ instrument development.

Selected items from three instruments were modified into a decision-maker perspective and used in the pilot development of the original 47-question pool (Blackhall et al., 1999; Braun, Tanji & Heck, 2001; Catt et al., 2005).

The Blackhall instrument was used to measure attitudes about LST for oneself among older people aged 65 and over from four different ethnic groups. The two-part survey had 21 questions on beliefs and personal preferences about life prolonging technology. Thirteen general belief items were on a four-point Likert scale. The personal preference scale was composed of four situation-based items with two questions each, asking the respondent's personal preferences specific to the use of "breathing machine" and "cardiopulmonary resuscitation". Seven of the Blackhall general beliefs and preference items were drawn and modified for the development of the original 47-item pool. A more detailed description and the psychometric properties of the Blackhall instrument are included under the instrument section of this paper. The questionnaire is included in Appendix B (Blackhall et al., 1999).

The Life Support Preference Questionnaire (LSPQ) was devised by Beland and Froman (1995) to measure life support preferences in making decisions for oneself from the perspective of advanced planning. It focused on the consistency of life support attitudes over time. Subsequent development of this instrument by Gauthier and Froman (2001) produced a scale called Preferences for Care near the End of Life (PCEOL) to draw out attitudes from a healthcare-giver perspective. This scale was validated by Schirm et al. (2008) in a survey among nurses, social workers and nursing assistants. Because the LSTAQ study focus is the family member LST decision-maker, the items in the PCEOL were used solely for general reference for this present work.

Braun, Tanji and Heck (2001) explored ethnicity and attitudes toward planning for death in a four-section interview of five ethnic groups in Hawaii (50 each of Caucasian, Chinese, Filipino, Hawaiian and Japanese). Although the study focused on physician-assisted suicide, the third section of the project included items that were relevant to decision-making. Of the five factors extracted from factor analysis (“Discuss/Document”, “Trust”, “Fears”, “Religious Guidance” and “Fatalism”), “Fears”, as in “fear of a painful death” and “Trust”, as in “trusting MD” (physician) or “trusting family to make EOL decisions” appeared to have relevance to the LSTAQ construct. Thus, five items from the study were adapted to a decision-maker perspective and were included in the original 47-question pool.

Catt et al. (2005) developed an instrument called the attitudes to end-of-life instrument (AEOLI) to elicit the end-of-life attitudes of older people. The 27-item scale contained one decision-making attitude item for oneself, “I would prefer the doctors to make decisions about my care”. A second related item was a personal preference, “want to be kept alive at all costs”. Both items were revised into a decision maker viewpoint and added to the original 47-item pool.

The following section provides a summary of the pilot testing for reliability of the 47-item question pool developed from literature review. It is to assess decision-maker attitudes toward life sustaining treatments for a sick family member at the end of life. The tool is called the life sustaining treatment attitude questionnaire (LSTAQ).

LSTAQ pilot development

The purpose of the pilot study was to evaluate the reliability the student-researcher generated life sustaining treatment attitude scale. A 47-item questionnaire pool was designed to develop a life sustaining treatment (LST) attitude scale for future use among family member decision-makers for the sick relative at the end of life (Appendix O).

The generation of attitude items was based on reviews of conceptual studies, scientific literature, current practices at EOL specific to LST and the available published psychometrically tested scales for general attitudes, preferences and beliefs about life support decision-making at the end of life (Blackhall et al., 1999; Braun, Tanji & Heck, 2001; Catt et al., 2005; Hayes, 2003; Meeker & Jezewski, 2005; Norton et al., 2003; Wiegand, 2006).

After LST attitude items were identified, the 47-item pool was developed. Three subscales (general beliefs, personal wishes and LST decision-making attitudes for a sick family member) were theorized from literature review.

A four-point Likert scale format was utilized. Likert scaling is the most commonly used format in health care and attitude surveys (DeVellis, 2003). A scale with an even number of response options was chosen to be the most appropriate for drawing out a stance on the questions. There were four response options: *strongly agree (1)*, *agree (2)*, *disagree (3)*, *strongly disagree (4)*. Negatively worded items were reverse coded. A higher number indicated a decision-maker's more positive attitude toward LST for a sick family member at the end of life. A lower number indicated a less positive

attitude towards LST. Total scores were expected to range from 47 to 188 from the list of 47 items generated.

A self-report tool was chosen because of the sensitive nature of the construct being measured. It took into account the need for privacy and anonymity in answering the attitude questions.

The questionnaire included an introductory statement regarding life sustaining treatments in order to establish a standard baseline understanding among all respondents. Demographic information included gender, age, ethnicity, education level, religion, previous experience with a relative's admission to a hospital, an intensive care unit, involvement with LST decision-making for a family member, and experience with death and dying of a loved one.

Content and face validity were built into the development of the instrument by reliance on expert opinion. Five critical care nurses who work with patients typically on life support at EOL and an ethics committee member of a local 500-bed medical center were included in the expert review. Face validity was addressed by consultation with two adults who had a previous experience with EOL decision-making for a family member. There were no quantitative measures performed for face and content validity.

The item pool was tested on five adult volunteers who were asked to comment on wording and clarity. The wording on the 47-item pool was adjusted accordingly.

A convenience sample of 40 adults who live in Honolulu, Hawaii was recruited from work and social settings for pilot testing. Anyone over age 18, able to speak, write and read English at the 9th grade reading level, and who will be available to participate in a second session approximately 2 weeks later, was invited to participate. Consenting was

through verbal permission after approval (number 17015) was obtained from the University of Hawai'i Committee on Human Studies (UH-CHS) in May 2009.

After complete disclosure and verbal consent, the demographic questionnaire and LSTAQ tool were completed by the participant and collected by the researcher. It took approximately 8-12 minutes ($M=11$) to complete the survey. A follow up date for the second survey, approximately two weeks later, was set up with each participant. However, the second survey (retest) was completed between three to five weeks later due to difficulty in reaching the same respondents. All except one of the original respondents performed the retest, but three had not completely answered the retest questions. Data was collected over a 6-week period from June 4 to July 16, 2009.

The Statistical Package for Social Sciences (SPSS version 14.0) software (SPSS Inc, Chicago, Ill) was used for data entry and analysis. Descriptive and demographic data were summarized with frequency distributions.

The test-retest correlation, utilizing the individuals' total test 1 and 2 scores, assessed temporal stability of the scale. Reliability analysis included all 47 item responses obtained from test 1. Item analysis included item means, variances, centrality, and range of responses for each item. Items' performance was evaluated by item-total correlations (Pearson's r). Reliability testing for internal consistency was done by inter item correlation, Cronbach's alpha coefficient and Spearman-Brown split half measures.

Of the 40 English-speaking respondents, there were 14 male and 26 female participants of various ethnicities, with age ranging from 18 to over 75 years. Educational level ranged from beyond high school to post graduate level. Majority of the participants had past experiences with a relative in a hospital (77.5%) and in an intensive care unit

(55%). Eighty two percent stated prior experience with family member's death and dying and 47.5% had previous experience with LST decision-making for a loved one (Appendix P).

Total test scores indicated the tendency or attitude toward LST decision making for a family member. Scores were expected to range from 47 (least positive attitude) to 188 (most positive attitude toward LST). Of the 40 participants in the first survey, five did not completely answer all 47 questions, therefore, were not included in the test-retest analysis. Test 1 scores ranged from 52 to 113 ($M = 83$, $SD = 16$). One missing participant and three out of the 39 respondents in test 2 were not included in the test-retest assessment. Test 2 scores ranged from 56 to 108 ($M = 82$, $SD = 15$). Overall test 1 and test 2 correlation ($N = 33$) was Pearson's $r = .92$ ($p < .01$), indicating good temporal stability of the questionnaire (Appendix Q).

Item means, variances, centrality, range of responses for each item and item-item correlations did not considerably depart from norm. Item-total correlation of the 47-item tool ranged from Pearson's $r = -.21$ to $.70$ ($p < .05$). Six items with correlations less than $.3$ were deleted. Items 7, 14, 15, 41, 42, and 44 had the lowest correlations, with $r = .18$, $.27$, $.14$, $.14$, $-.21$ and $.16$ ($p < .05$), respectively.

Although redundancy may increase reliability, further reduction in the number of items was performed in order to decrease response burden in the future tool. Item-subscale correlations at $p < .05$ was performed. Three items (items 6, 12 and 16) with Pearson's $r < .4$ were removed from subscale 1. Two items (items 18 and 23) with the lowest item-subscale correlation ($r < .5$) were removed from subscale 2. From subscale 3,

three more items (items 32, 36 and 40) with the lowest item-subscale correlations ($r < .4$) were removed.

This pilot testing resulted in 14 items being removed from the scale. There were no major changes in internal consistency after the second series of item deletion. The revised tool's item-total scale correlations ranged from $r = .39$ to $.76$ ($p < .05$). Item-subscale correlations were between $r = .39$ to $.67$ in subscale 1, $r = .45$ to $.72$ in subscale 2, and $r = .38$ to $.76$ in subscale 3 ($p < .05$).

Both the original 47-item scale and revised 33-item scales' Cronbach's alpha coefficient was $.92$, indicating a high internal consistency and denoting a high average of inter item correlation. Original subscales 1, 2 and 3 Cronbach's alpha = $.82$, $.85$ and $.86$, respectively. Original total scale Spearman-Brown split half reliability coefficient was $.81$ and the three subscales' coefficients were $.82$, $.86$ and $.79$, respectively.

Revised subscales 1, 2 and 3 had Cronbach's alpha of $.82$, $.83$ and $.90$, respectively. Spearman-Brown split half reliability coefficient of total scale was $.74$. Subscales 1, 2 and 3 had coefficients of $.75$, $.86$ and $.85$, respectively (Appendix R).

Summary of Pilot Testing

Test-retest Pearson correlation was $r = .92$ ($p < .01$). Reliability testing for internal consistency was performed on the original test 1 results. The deletion of 14 items with poor correlations generated a revised 33-item LSTAQ. Item-total correlations ranged from $r = .33$ to 0.71 ($p < .05$). Cronbach's alpha coefficient of the 33-item scale was $.92$. The three hypothesized subscales, (1) general LST attitudes, (2) LST personal

preferences and (3) LST decision-making attitudes, had Cronbach's alpha = .81, .83 and .90, correspondingly.

The pilot study provided evidence of a reliable instrument to measure attitudes toward LST among decision-makers for a sick relative at the end of life. The tool requires validity testing and psychometric evaluation in a larger population of family member decision-makers for LST for the sick relative.

Summary of literature review

A large amount of literature describes the decision-making process regarding LST. There is some data about family member experience and process of LST decision-making for the ill relative, including some cultural influences on decision-making. Measures of LST attitudes for the family member decision-maker, however, were lacking. Although there are several LST attitude instruments used on laypersons, they were general in scope, addressing advance directives or care planning, common healthcare preferences and broad end of life issues such as spirituality and religion (Karel, Zir & Braun, 2003), comfort (Hall & Rucker, 2000) and preferences for place to die (Kagawa-Singer & Blackhall, 2001). Some published and tested instruments measured attitudes toward LST among patients and healthcare professionals, but none was found for specific use from the perspective of the family member decision-makers for life support for a sick relative.

A decision was therefore made to develop an attitude instrument to explore family member decision-maker attitudes toward LST, in addition to general beliefs and preferences. The literature review was then utilized for the pilot instrument development

and reliability testing. The pilot instrument development and reliability testing of a 47-item questionnaire pool resulted in 33-item LISTAQ that has good internal consistency and temporal stability.

CHAPTER 3. METHODOLOGY

The purpose of this research was to develop and evaluate the validity and reliability of a previously pilot tested life sustaining treatment attitude questionnaire for use among family member decision-makers for LST for the sick relative at the end of life. Validity was examined by factor analysis and correlations. Reliability was assessed by internal consistency measures, items' performance and inter item correlations. A secondary aim to explore differences of LST attitude scores by ethnicity was performed using univariate analysis of variance (ANOVA).

Sample

The rule of thumb for the minimum sample size in factor analysis is at least five participants per item (DeVellis, 2003). There were 33 items in the questionnaire, making 165 participants an adequate sample following this criteria. Another measure of sampling adequacy prior to factor analysis is the Kaiser-Meyer-Olkin (KMO) statistic. The KMO is defined as the “the ratio of the squared correlation between variables to the squared partial correlation between variables” (Field, 2005). Values (ranging from 0 to 1) closer to 1 indicate a pattern of relatively compact correlations. A value from .7 and above supports the use of factor analysis (Field, 2005; Munro, 2005).

This study surveyed a convenience sample of 170 adult volunteers with a self-declared potential to be life support decision-makers for sick family members. They were residents of Honolulu, Hawaii representing the major ethnicities of Caucasians, Chinese,

Filipinos, Japanese, Native or Part Hawaiian, Pacific Islander, other Asians and Blacks, Hispanic and other or mixed ethnicity.

Participants were recruited from the community including work, school or social settings. Inclusion criteria were: (1) anyone over age 18, (2) a self-declared potential to be a family member decision-maker for a sick relative, (3) able to speak, read and write English at the 7th grade Flesch-Kincaid reading level. Exclusion criteria were: (1) any unwilling adult, and (2) self-declared as unlikely to be a family member decision-maker.

A script was used as a recruitment tool, stating the purpose of the study, risk and benefit, and the time required to answer the survey (Appendix F). Participation was voluntary. A signed consent form was obtained from each participant (Appendix G).

Instruments

Four scales without identifiers were utilized: the 33-item Life Sustaining Treatment Attitude Questionnaire (LSTAQ), a 21-question Blackhall LST attitude survey, a four-item Subjective Happiness Survey and a 14-item demographic questionnaire.

Life Sustaining Treatment Attitude Questionnaire (LSTAQ)

Initial development and previous LSTAQ testing

The pilot testing of the original item pool for the LSTAQ was described in the preceding literature review section. The researcher-developed pool of 47 items was generated from reviews of conceptual studies, scientific literature, published and validated LST attitude instruments and current practices at end of life specific to LST.

Content and face validity were established by expert opinion of five critical care nurses, one hospital ethics committee member and two lay persons who had previous experience with EOL decision-making. Pilot testing for temporal stability and reliability in a sample of 40 adults guided the deletion of 14 items, resulting in a 33 item LSTAQ with a test-retest Pearson's $r = .92$ ($p < .01$). Revised 33-item LSTAQ Cronbach alpha coefficient is $.92$ ($p < .05$). Spearman-Brown split half coefficient is $.74$ ($p < .05$). The testing revealed good temporal stability at three to five weeks and a good internal consistency of the 33-item LSTAQ.

LSTAQ 33- item instrument

The LSTAQ 33-item instrument derived from the pilot reliability testing is the primary survey instrument for this present study. Likert scaling with a four-point response format for all items was retained from the pilot testing. A scale with an even numbered response options was chosen to be the most appropriate for eliciting a stance on the questions. The four response options are: (1) *strongly agree*, (2) *agree*, (3) *disagree*, and (4) *strongly disagree*. Negatively worded items were reverse coded. Wording of the instrument was established at the 7th grade reading level (Microsoft Flesch-Kincaid). Total scores were expected to range between 33 and 132, with higher numbers indicating a family member decision-maker's more favorable attitude toward LST for the sick relative at EOL (Appendix A).

Blackhall Life Sustaining Treatment Attitude Survey

The Blackhall LST survey tool was used to determine convergent validity with the LSTAQ (Appendix B). It is a 21-item scale used as one of the tools in a survey and

ethnographic interview of 800 participants to measure attitudes toward life support for oneself among four different ethnicities. The sample consisted of 200 each of European Americans, Mexican Americans, African Americans and Korean Americans. The Blackhall survey has two subscales: general attitudes toward life sustaining/prolonging technology and personal desire for life support. The first subscale is composed of 13 items with a four-point response scale ($4 = agree\ strongly$, $3 = agree\ somewhat$, $2 = disagree\ somewhat$ and $1 = disagree\ strongly$). After recoding negatively stated questions, individual items were summed to produce an overall attitude score. There was a response option of “don’t know”, for which the average score was imputed and the subscale total was recalculated. The subscale total score ranged from 13 to 52, where higher score implied a more positive attitude toward the use of LST (Blackhall et al., 1999).

The second subscale consisted of four items, with two questions per item, asking whether the participant wanted cardiopulmonary resuscitation (CPR) and mechanical ventilation, in specific settings, such as permanent vegetative state and terminal illness. The responses ranged from 1 = “want”, 0 = “don’t want” and 0.5 = “short time only”. These were added together to produce a summary personal desire score. There was a “not sure” response for which the average score was imputed and the total score was recalculated. The total personal desire score ranged from 0 to 8. Higher scores implied greater personal desire for LST (Blackhall et al., 1999).

Blackhall total scale’s Cronbach’s alpha was .82. Items’ Cronbach’s alpha ranged from .41 to .92. The test- retest correlation (Pearson’s r) was .92 ($p < .0001$) (Blackhall et al., 1999).

Construct validity information was not available. Consent to utilize the tool was obtained from the publisher, Elsevier (Appendix H) and from Dr. Leslie Blackhall, the primary author of the study (Appendix I).

Subjective Happiness Scale

The Subjective Happiness Scale (SHS) is a published four-item instrument to measure global subjective happiness. Lyubomirsky and Lepper (1999) developed this short instrument with one item asking the respondents to rate themselves on a seven-point scale of 0 = “a not very happy person” to 7 = “a very happy person”, and a second item asking to rate themselves relative to their peers. Two other items provide descriptions of happy and unhappy people, and then ask the respondents the extent to which the descriptions portray themselves. Total score range was 4 to 28, after recoding of the fourth item, which was negatively stated. A higher number indicated a subjectively happier person (Appendix C).

The psychometric properties of the SHS tool are as follows: Cronbach’s alpha ranged from .79 to .94 ($M = .86$) in 14 studies with a total of 2,732 participants from college and high school campuses and from older adults in the United States and Russia. Temporal stability at three weeks to one year ranged from Pearson’s $r = .55$ to $.90$ ($M = .72$). Convergent validity with five other happiness survey scales ranged from $r = .52$ to $.72$ ($M = .62$). Discriminant validity for the SHS was assessed by correlations with student grade point average and scholastic aptitude test scores. According to the author, the low correlations confirmed discriminant validity (Lyubomirsky & Lepper, 1999).

The Subjective Happiness Scale measures a concept dissimilar to the LSTAQ; therefore, it was used to determine discriminant validity. Permission to use the tool was

obtained from the publisher Rightslink (Appendix J) and the primary author, Dr. Sonja Lyubomirsky (Appendix K).

Demographic Questionnaire

The demographic questionnaire has 14 items. It is prefaced by a question of whether the participant is a potential decision-maker for a relative in poor health, as mentioned in the study inclusion criteria.

The questions included gender, age, ethnicity, country of nativity, number of years in the United States, primary language spoken at home, marital status, education level, religion, personal experience of serious illness, personal experiences of having a family member or loved one in a hospital, in an intensive care unit, LST decision-making for a family member, and experience with death and dying of a relative or loved one. In addition to ethnicity, these items are some of the assumed influences of LST attitudes, based on review of literature (Blackhall et al., 1999; Blatt, 1999; Braun & Nichols, 1997; Kwak & Haley, 2005; Matsumura et al., 2002; Valente & Haley, 2007; Yeo & Hikuyeda, 2000) (Appendix D).

Protection of Human Subjects

Human subjects protection was addressed via the Institutional Review Board (IRB) of the University of Hawai'i Committee on Human Studies (UH-CHS). Approval was obtained on April 27, 2010, prior to data collection. IRB requirements for disclosure, consenting, confidentiality, and data storage and aggregation were adhered to. All survey participants were asked for a written consent after complete disclosure. All data were

aggregated and kept confidential. No personal information was used for data collection, research analysis or publication (Appendix E).

Hard copies of completed survey instruments were kept in a locked file. The separate signed consents were stored in a separate locked file. The study database is stored in a password protected computer and storage drive by the principal investigator. All survey materials were destroyed by shredding upon study completion.

Data Collection

After disclosure and signed consent, the four survey tools were given to each volunteer to complete and then collected by the researcher. It took approximately 20-30 minutes ($M = 27$) to complete the process. A \$10 incentive was provided for each volunteer participation. Of the 180 surveys distributed, five volunteers were not able to complete all four instruments and five withdrew for other reasons. Data was collected over an eight-week period from May 15, 2010 to July 15, 2010.

Data Analysis

The Statistical Package for Social Sciences (SPSS version 18.0) software (SPSS Inc, Chicago, Ill) was used for data entry and analysis. Descriptive and demographic data were examined and summarized with frequency distributions. Analysis included all 33-item responses. Substitution of the item mean was used for missing data (Field, 2005; Munro, 2005; Tabachnick & Fidell, 2007). Reanalysis was performed after item deletion and final factor analysis.

Factor analysis

Initial construct validation by exploratory factor analysis was performed with principal component analysis, using both orthogonal (varimax) and oblique (direct oblimin) rotations. Factor analysis is a statistical method to analyze relationships among large numbers of variables, resulting in the clustering of a variable around one or more dimensions, which describe many of the variables under study (Munro, 2005). The author describes factor analysis as a statistical tool to reduce a data set, and that in research literature of nursing and other healthcare professions, factor analysis is often used in the instrument development process. It is a method of organizing the items in factors during the development of a new measurement tool. A combination of the test items that are believed to belong together as part of the construct is called a factor.

According to Tabachnick and Fidell (2007), factor analysis determines which variables in a set make logical subsets. The specific goals of factor analysis and principal component analysis are:

“to summarize patterns of correlations among observed variables, to reduce a large number of variables to a smaller number of factors, to provide an operational definition for an underlying process by using observed variables or to test a theory about the nature of underlying processes” (p. 608).

This type of analysis helps identify the factors that define the construct (DeVon et al., 2007). In this study, the construct is the decision-maker's attitude toward LST for the sick family member. To explore interpretability of the results, several factor extraction methods were performed, including the eigenvalue cut off criteria of greater than 1 with a scree plot and a forced factor extraction with three, four, five and six

components. Tabachnick and Fidell (2007) state that “decisions about the number of factors and rotational scheme are based on pragmatic rather than theoretical criteria” (p. 611).

Final analysis to test for construct validity was done with principal component analysis with oblique (direct oblimin) rotation and eigenvalue extraction method. Although orthogonal rotation is the usual technique used for instrument development, this method assumes no correlation among the factors (Field, 2005; Munro, 2005). The alternative oblique rotation assumes that the factors are not completely unrelated to each other, thus implying correlations among the factors. Field (2005) recommends the oblique rotation for factors that maybe correlated, such as naturalistic data involving people, as is the case in this study.

Reliability testing

After factor analysis, scale testing was performed to determine internal consistency of the factors extracted. Testing was performed for the total scale and each of the identified components. Item analysis included item means, variances, centrality, and range of responses for each item. Item-total correlations (Pearson's r) assessed items' performance. Reliability testing for internal consistency was done by inter item correlation, Cronbach's alpha coefficient and corrected Spearman-Brown split half reliability measures.

Cronbach's alpha reliability coefficient indicates internal consistency or the proportion of the variability in a scale that is due to the true score and not due to error (DeVellis, 2003). Split half measures using the Spearman-Brown method confirm

internal consistency. Split half reliability randomly divides all items into two sets from results of a tool. The total or corrected score for each half is calculated using the Spearman-Brown formula, producing the split-half reliability estimate or the correlation between these two total scores (Carmines & Zeller, 1979).

Convergent and Discriminant Validity testing

These two tests for validity were completed after the final scale was determined. Convergent and discriminant validity testing were performed on the new LSTAQ total score and its subscales' total scores, using correlations with the similar and dissimilar tools. Convergence was assessed with the Blackhall life support attitude survey (Blackhall et al., 1999). Convergent validity is demonstrated by significant correlation between tools that measure related theories or constructs (DeVellis, 2003).

Discriminant validity was determined by correlating the LSTAQ scores with the scores in the Subjective Happiness Scale (Lyubomirsky & Lepper, 1999), an instrument that measures subjective global happiness. Discriminant or divergent validity is tested with a scale that measures a dissimilar construct (Cohen & Swerdlik, 2005). According to DeVellis (2003), there should be no significant correlations between scores in tools that measure unrelated constructs.

Analysis of variance

The secondary aim was to explore the differences in LSTAQ scores by ethnicity. It was performed with univariate analysis of variance (ANOVA). ANOVA is a parametric statistical test that measures differences between two or more groups by

comparing between and within group variance (Munro, 2005). This analysis assumes that the scores must be normally distributed and there is evidence of homogeneity of variance across groups.

Summary

This methodology was to provide evidence of validity and reliability of the LSTAQ, a tool designed to elicit LST attitudes from family member decision-makers for the seriously ill adult. In a convenience sample of 170, the testing method for construct validity was exploratory factor analysis with oblique rotation. Correlations techniques were employed to test for convergent and discriminant validity. Reliability (internal consistency) was evaluated by Cronbach's alpha and the corrected split half Spearman-Brown coefficients. Univariate analysis of variance (ANOVA) was performed to explore differences in mean LSTAQ scores by ethnicity.

CHAPTER 4. RESULTS

This section provides a summary of the study's demographic data, the results of statistical analyses for the validation and reliability testing in the final stage of LSTAQ instrument development. A brief exploration of differences in LST attitudes by ethnicity is included.

Participant Characteristics

One hundred eighty packets were distributed to prospective participants who live in Honolulu, Hawaii. One hundred seventy (94%) packets with all four completed questionnaires were returned. The convenience sample consisted of 95 (56%) females and 75 (44%) males, ranging in age from 18 to 84 years old ($M = 39.5$). Self-reported ethnicity included Black, Caucasian, Chinese, Filipino, Hispanic, Japanese, Native/Part Hawaiian, Pacific Islander, Other Asians and Mixed ethnicity. Nativity indicated that 130 (77%) were born in the United States and 40 (23%) were born outside the United States. Residency in the United States ranged from three to 78 years ($M = 33.8$). Education level ranged from high school to post graduate education. Marital status indicated 43% single and 46% married respondents. Forty eight percent were Catholics and 25% designated their religion as "Other Christian". Eighty nine percent did not have past experience with serious illness but 63% had experienced having a relative in a hospital and 54% had experienced having a sick relative in an ICU. Sixty nine percent of the participants indicated that they had experienced death and dying of a family member. Those who had experienced LST decision-making for a sick family member comprised 24% (Table 1).

Table 1. Participant Characteristics

<i>Characteristics</i>		<i>N (%)</i>
Gender	Male	75 (44)
	Female	95 (56)
Age ($M = 39.5$, $SD = 16.8$)	18-84 yrs	170 (100)
Country of Birth	USA	130 (77)
	Other	40 (23)
Years lived in USA ($M = 33.8$, $SD = 16.1$)	3-79 yrs	169 (100)
Ethnicity	Black	7 (4)
	Caucasian	33 (19)
	Chinese	10 (6)
	Filipino	60 (35)
	Hispanic	4 (2)
	Japanese	15 (9)
	Native/Part Hawaiian	15 (9)
	Pacific Islander	10 (6)
	Other Asian	10 (6)
	Mixed/Other	6 (3)
	Primary language spoken at home	English
Other		32 (19)
Marital Status	Single	73 (43)
	Married	79 (46)
	Separated/ Divorced	13 (8)
	Widowed	5 (3)
Education level	Some High School	6 (4)
	High School Graduate	17 (10)
	Some College	77 (45)
	Bachelor's Degree	41 (24)
	Post graduate	29 (17)
Religion	Catholic	81 (48)
	Protestant	18 (11)
	Other Christian	43 (25)
	Buddhist	8 (4)
	Other	20 (12)
Experienced Serious illness	No	151 (89)
	Yes	19 (11)
Experienced Relative in a Hospital	No	63 (37)
	Yes	107 (63)
Experienced Relative in ICU	No	79 (46)
	Yes	91 (54)
Experience with Relative Death/Dying	No	52 (31)
	Yes	118 (69)
Experience with LST DM	No	129 (76)
	Yes	41 (24)

Data Analysis

The items for the LSTAQ were screened for univariate outliers. No significantly out of range values were found. Ten missing LSTAQ item values (.07%) were identified and coded as missing data. Item 12 had three missing values, item 28 had two blank responses and items 3, 5, 23, 24, and 33 each had one missing response. Substitution of mean was done for missing item responses (Field, 2005; Munro, 2005; Tabachnick & Fidell, 2007). The minimum sample size for factor analysis was satisfied with the final sample size of 170, at 5.2 cases per item (DeVellis, 2003).

Construct Validity

Factor analysis

All 33 items of the LSTAQ were screened for factorability using the correlations criteria between .30 and .90. For moderate correlations, Munro (2005) suggests a criterion of r matrix range between .30 and .70 for inclusion. Field (2005) advocated a range of r between .50 to .90, suggesting that the items should correlate “fairly well but not perfectly” (p. 648).

Each item correlated at a minimum of $r = .30$ with at least one other item. The communalities for all items were above .30 (range .46 to .79), indicating a common variance of each item with the other items. These statistics supported each item’s inclusion in the factor analysis. Anti image correlation matrix (diagonals) met criteria of correlation over .50. They ranged from .59 to .95. All 33 items were included.

Exploratory factor analysis was performed with principal component analysis with oblique (direct oblimin) rotation. The number of factors was initially determined by

eigenvalues of greater than 1 with a scree plot, factor correlation matrix and pattern loadings over .35 and the explainable percentage of variance (Field, 2005; Munro, 2005).

The Kaiser-Meyer-Olkin measure of sampling adequacy was .883, exceeding the minimum value of .7 (Munro, 2005). Bartlett's test for sphericity was statistically significant ($\chi^2(528) = 2964.93, p = .000$), indicating a non-identical matrix. The Bartlett's test for sphericity examines whether the variance-covariance matrix is proportional to an identity matrix. A significant test confirms that the correlations matrix is not an identity matrix, therefore, there are some relationships between variables that measure similar things and that they can be placed in clusters (Field, 2005).

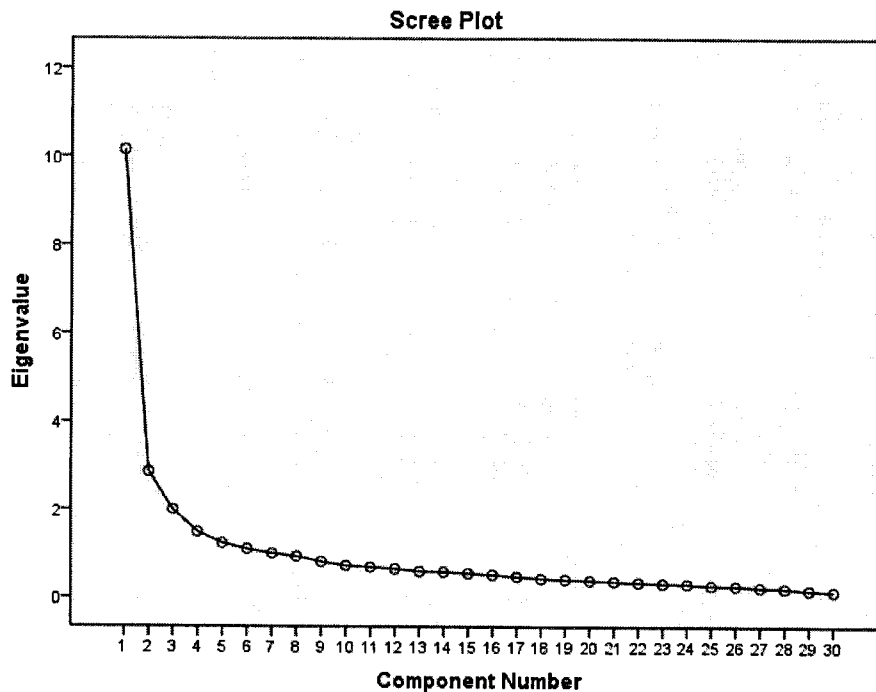
Using the eigenvalue criteria of greater than 1, seven components were extracted at .35 loading, explaining 63.6% of total variance. The first factor explained 33.6% of the variance, the second factor 8.8%, and the third factor, 6.1% of variance. Factors 4, 5, 6 and 7 explained 4.8%, 3.7%, 3.5% and 3.1% of the variance, respectively.

An exploration of solutions with 3, 4, 5, 6 and 7 components using both orthogonal (varimax) and oblique rotations revealed no major differences in values and factoring. Scale testing of the seven extracted components revealed component 5 (items 10 and 17) with a low alpha (.159), leading to deletion of the component. This original seven factor solution was followed by a forced extraction of six components criteria of .30 to determine clustering of the lower loading items. A criteria of .30 is the minimum acceptable factor loading (Munro, 2005).

The oblique (direct oblimin) rotation was chosen for final solution following the scree plot "leveling off" and for ease of interpretation and previous theory support. Factor 1 had eigenvalue of 10.14 and factor 2 had 2.86. Factors 3, 4, 5 and 6 had

eigenvalues of 1.99, 1.49, 1.22 and 1.1, respectively. All the other factors were below eigenvalue of 1, representing the “rubble” in the scree plot (Figure 3).

Figure 3. Eigenvalues and Scree plot (30 item LSTAQ)



There were four items that were problematic during interpretation. Items 22 and 25 did not load into the pattern matrix, therefore were removed. Item 7, from the deleted component 5 in the seven-factor extraction, cross loaded into the new six-factor (component 4), therefore it was retained. Item 10 was removed because it did not cross load at .30 on second extraction.

The resulting 30-item LSTAQ, with the deletion of items 10, 22 and 25 produced a six factor LSTAQ scale explaining 62.7% variance. Factor 1 had a variance of 33.42 and factor 2 had 9.55. Variances for factors 3, 4, 5 and 6 were 6.65, 4.9, 4.09 and 3.65,

respectively. These factors became the LSTAQ subscales. Naming of the factors or subscales were based on the meanings of the variables with the highest item loadings (Munro, 2005). The six subscales were named: (1) “Honoring Other’s Wishes” for items 20, 16, 9, 13, 21, 12, 24 and 2, (2) “Family Consensus/Conflict Avoidance” for items 31, 32 and 33, (3) “Personal Value-Based Decision-making” for items 27, 28 and 30, (4) “General Beliefs” for items 7, 1, 17, 8, 11, 23 and 19, (5) “Personal Wishes for items 6, 15, 18, 14, 5 and 3, and (6) “Reliance on Medical Expert” for items 26, 29 and 4. The final factor loading matrix (.30 to .78) and communalities (.44 to .78) for the final 30-item six-factor solution are presented in Table 2.

Table 2. Factor loadings and communalities based on PCA with direct oblimin rotation of 30- item LSTAQ (N = 170)

<i>Item</i>	<i>F1</i>	<i>F2</i>	<i>F3</i>	<i>F4</i>	<i>F5</i>	<i>F6</i>	<i>Communality</i>
Q20: I will not stop life support for my family member, no matter what	.70						.71
Q16: Even if there is no hope for cure, I want to have life support machines until I die	.67				.34		.78
Q9: Life support machines should be used to prolong life at all costs	.66		.30				.65
Q13: Life support in a dying person should never be taken away, even if it is only delaying death	.64						.68
Q21: I will ignore my relative's refusal of life support	.62						.44
Q12: A good death must use all life support available	.61		-.31				.69
Q24: If life support is available, I will request its use for my relative who had earlier refused	.44				.37		.62
Q2: I will feel uneasy if life support is removed from a dying person.	.38		-.34				.46
Q33: I will use life support for my sick relative if there is family conflict		.72					.55
Q32: I will say “no” to life support for my sick relative <u>only</u> if there is family agreement.		.67					.57
Q31: I will refuse life support for my sick relative <u>only</u> if I have his/her written instruction.		.61					.54
Q27: If I do not know my sick relative's wishes, I will request all kinds of life support.			-.78				.74
Q30: I will use life support for my dying relative who has not stated his/her wishes.			-.72				.76
Q28: If my relative did not express his/her wishes, I will request comfort care only.			-.70			.45	.71

Q7: A dying person's request to forgo life support should be honored at all costs.				.86			.68
Q1: A person dying of a terminal illness should be allowed to refuse life support.				.65			.54
Q17: My wish to forgo life support should be honored at all costs.		.37		.59			.55
Q8: Removing life support according to the wishes of a dying patient is a human way to die.				.48		.34	.55
Q11: A person dying of terminal illness should be allowed to die naturally, with no life support attached.				.43			.54
Q23: I will withhold life support for my sick relative who does not want life support.				.43			.56
Q19: I will honor my dying relative's wish to skip life support at all costs.				.40			.60
Q6: Life support should not be used if it will cause more pain or suffering for a dying person.					.79		.60
Q15: If there is no hope for cure, I want to spend my last days naturally without artificial means.					.65		.62
Q18: If I am dying of terminal illness, I want a peaceful death with no machines attached to me					.59	.35	.67
Q14: I do not want machines to prolong my life if I am dying of terminal illness.					.55		.65
Q5: It is not kind to use life support machines in a terminally ill dying patient.			.50		.50		.66
Q3: I will honor my dying relative's wish to skip life support at all costs.			.40		.49		.70
Q29: I will depend on the doctor's judgment to stop life support for a relative who did not express his/her wishes.						.73	.67
Q26: I will follow doctor's opinion to stop life support for my dying relative.						.68	.61
Q4: A person who is dying of terminal illness should be kept alive with life support.						.38	.57

Note. Factor loadings < .30 are suppressed

Reliability

The scale statistics indicated item means of 2.12 and a variance of .15 for the 30 items. The total scale statistics are as follows: $M = 63.61$, $SD = 12.96$, variance = 168. A normal distribution was assumed, based on the skewness (- .008) and kurtosis (.884) that were within acceptable range. Higher scores indicated more positive attitude towards LST. The scale item statistics are presented in Table 3.

Item total correlations were within acceptable range ($r = .35$ to $.72$, $p < .05$)

except for three items below range. Calculation of Cronbach's alpha and Spearman-Brown split half measure indicated good internal consistency of the LSTAQ. Total scale Cronbach's alpha is .92 and Spearman-Brown split half coefficient is .89.

Composite scores were created for each of the six subscales, based on the mean of the items that had their primary loadings on each factor. Subscale 1, with eight items, had Cronbach's alpha of .88. Cronbach's alpha for subscales 2, 3, 4, 5 and 6 were .65, .78, .82, .84, and .64 respectively. Spearman Brown coefficients for factors 1, 2, 3, 4, 5, and 6 were .90, .63, .65, .80, .76, and .72 respectively. Overall, the subscales' coefficients were minimal to good for a new scale (Munro, 2005). Reliability statistics are summarized in Table 4.

Table 3. Summary Item Statistics

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	2.12	1.494	2.953	1.459	1.976	.158	30
Item Variances	.617	.462	.854	.392	1.847	.010	30
Inter-Item Correlations	.281	-.243	.773	1.017	-3.178	.032	30

Table 4. Summary Reliability Statistics for the six LSTAQ Subscales (N = 170)

Sub-scales	No. of items	Cronbach's alpha	Split Half - Spearman Brown Coefficient
Factor 1	8	.88	.90
Factor 2	3	.65	.63
Factor 3	3	.78	.65
Factor 4	7	.82	.80
Factor 5	6	.84	.76
Factor 6	3	.62	.72
Total Scale	30	.92	.89

Convergent validity

Convergent validity of the 30-item LSTAQ was assessed using Pearson Product-Moment Correlation Coefficient (r). As expected, there was a positive correlation between total LSTAQ score and the total Blackhall LST score at $r = .72$ ($p < .01$). The two Blackhall subscales (Personal Beliefs and Personal Preferences) correlated with the total LSTAQ at $r = .79$ and $.64$ ($p < .01$) respectively. There were statistically significant correlations between the subscales of LSTAQ and two subscales of the Blackhall tool, except for LSTAQ subscale 2, which did not show significant correlations with both Blackhall subscales and LSTAQ subscales 4, 5 and 6. Table 5 presents the summary of correlations between the LSTAQ and Blackhall subscales.

Table 5. Correlation Coefficients (r) of LSTAQ and Blackhall Subscales

LSTAQ Subscales	Blackhall General Belief	Blackhall Personal Preferences
1. Honoring Others' Wishes	.77 ($p < .01$)	.61 ($p < .01$)
2. Family Consensus/Conflict Avoidance	.10 ($p > .05$)	.70 ($p > .05$)
3. Personal Value-Based Decision for Others	.63 ($p < .01$)	.54 ($p < .01$)
4. General Beliefs	.57 ($p < .01$)	.45 ($p < .01$)
5. Personal Wishes	.63 ($p < .01$)	.53 ($p < .01$)
6. Decision Reliance on Medical Expert	.43 ($p < .01$)	.33 ($p < .01$)

Discriminant validity

Discriminant validity was examined by correlations using Pearson's r between the LSTAQ and the SHS tool. As anticipated, there was no statistically significant correlation between the total scores of the two instruments ($r = -.14, p > .05$). Because the two measures assessed different constructs and there was no correlation, discriminant validity was met.

LSTAQ Scores and Ethnicity

An exploration of differences of LST attitude scores by ethnicity was performed. Univariate analysis of variance (ANOVA) indicated that although there was a difference in LSTAQ attitude scores among different ethnicities, it was not statistically significant at $F(9, 165) = .982, p = .457$ (Appendix M). All the 10 ethnicities were included in this preliminary analysis (Appendix M). A graph of the results is presented in Appendix N. No further analysis was performed at this time.

CHAPTER 5. DISCUSSION

In this study, the 33-item scale was tested to quantify potential decision-maker's attitudes toward LST for a seriously ill family member. A new 30-item LSTAQ was derived from factor analysis, following deletion of three items not loading in the pattern matrix at the minimum criteria of .30 (Munro, 2005). Principal components analysis (PCA) was used because the primary purpose was to identify and compute LSTAQ scores for the factors underlying the construct of decision-makers' attitudes toward LST for the sick family member.

Oblique (direct oblimin) PCA yielded 6 factors: (1) "Honoring Other's Wishes", (2) "Family Consensus/Conflict Avoidance", (3) "Personal Value-Based Decision-making", (4) "General Beliefs", (5) "Personal Wishes, and (6) " Decision Reliance on Medical Expert". All these factors represent the different clusters of beliefs and values related LST decision-making.

It was hypothesized (hypothesis 1) that the scale will have at least three components in the construct (general beliefs, personal wishes and general LST decision-making attitudes). The extraction of six factors included the two general LST beliefs and wishes for oneself, as theorized, and four other factors (compared to one hypothesized) in the construct of family member decision-maker LST attitudes.

Two of the factors (Factor 4, "General Beliefs" and Factor 5, "Personal Wishes") correlated highly, as expected, with Blackhall's LST attitude survey's two subscales ("General Beliefs" and "Personal Preferences") because some of the LSTAQ items in these subscales were derived from the Blackhall subscale 1. These 2 factors in the

LSTAQ and Blackhall scale are based solely on one's attitude towards life support for oneself, for any layperson or health professional. Personal beliefs or values have been noted to affect decision-making. Noone (2002) suggested that personal beliefs and preferences are a consistent finding in health care related decision-making.

The four other factors that emerged added the dimension of decision-making for another person, specifically the decision-maker attitudes toward LST for the incapacitated family member at end of life. Factor 1, "Honoring Other's Wishes," suggests the decision-maker's thoughts on whether or not to honor the other person's wishes based on how strongly the decision-maker believes in LST. The items that comprise these factors, however, did not differentiate the proxy decision-making concepts of "substituted judgment" versus "the best interest" principle.

Factor 2, "Family Consensus/Conflict Avoidance" reflects the dependence of the decision-maker on family concordance and avoiding family conflict (Badger, 2005; Norton et al., 2003; Winter & Parks, 2008). Swigart et al. (1996) suggest that consensus with family and conflict avoidance are distinct areas in LST decision-making for a relative. There were only three items in this factor and had a non-significant relationship with the other five factors. This may suggest a bigger domain in the family member decision-making process that was not adequately explored in the item development.

Factor 3, "Personal Value-Based Decision-making," denotes decisions made for another based on the decision-maker's own personal values when the sick person's wishes are not known. Vig and Taylor (2006) noted that one basis used by family members for decision-making for a loved one was "the surrogate's own values and

preferences”. As in factor 1, the items were not explicit in the differentiation between the principles of substituted judgment and the patient’s best interest.

Factor 6, “ Decision Reliance on Medical Expert,” implies decision-making based on dependence on the medical expert to confirm their thoughts on LST for their sick family member (Limerick, 2007; Norton et al., 2003; Tilden et al., 1999; Weigand, 2006). There were only three items in this component, which might not have adequately addressed all dimensions of decision reliance on the expert. Another observation could be that reliance on the expert suggests a belief in a paternalistic type of decision-making. This is another concept that could be explored in relation to LST decision making.

The four factors specific to LST decision-maker attitudes (“Honoring Other’s Wishes”, “Family Consensus and Conflict Avoidance”, “Personal Value-Based Decision-making” and “Reliance on Medical Expert”) indicate domains that all relate to attitudes toward LST decision-making for the sick relative. The items in these factors represent distinct sets of beliefs that pertain to the specific construct on how a family member decides for a sick relative. Because the LSTAQ was developed for LST family member decision-makers, the addition of these four subscales gives a clearer insight that is specific to this population. These four subscales provide a basis for understanding what the family decision-maker is likely to be going through when faced with LST decisions for the sick relative. These subscales therefore give strong support to use the LSTAQ to draw out attitudes from family member LST decision-makers. The LSTAQ is a construct valid instrument with six components of decision-maker attitudes toward LST for a sick family member (hypothesis 1).

The positive correlation between the total scores of the LSTAQ and the Blackhall LST attitude instrument verified convergent validity (hypothesis 2). It explains that these two convergent tools measure the similar construct of LST attitudes. However, they are not completely identical because the Blackhall scale measures LST attitudes for oneself, while the LSTAQ measures LST attitudes of the family decision-maker for the sick family member at EOL. At the same time, the LSTAQ incorporates LST attitudes for oneself as a factor affecting decision-making for others, as found in literature review (Vig & Taylor, 2008).

The lack of significance in the correlation pattern of one of the resulting subscales (Subscale 2: “Family Consensus/Conflict Avoidance”), as previously discussed under the factors section, raises an issue of a possible increase in measurement error due to the factor being comprised of only three items. It may also be due a potentially larger, dimension in family member attitudes to LST decision-making for a relative that is yet to be explored.

Divergent validity was confirmed by the absence of correlation between the LSTAQ and the SHS (hypothesis 3). Divergence adds to construct validation by verifying that the construct being measured by the LSTAQ (decision-maker attitude towards LST for a family member) is dissimilar from the construct measured by a divergent tool. In this study, the divergent tool (Subjective Happiness Scale) measures the unrelated construct of subjective global happiness.

Reliability indicates the consistency of the tool across the scale items. The results of internal consistency measures supports hypothesis 4. The LSTAQ is a reliable tool for use among LST family member decision makers.

The exploration of differences in LSTAQ scores by ethnicity in this sample did not support hypothesis 5. Analysis of variance indicated that there was a difference in LSTAQ attitude scores among the different ethnicities, but it was not statistically significant. Because the study was primarily done to develop and test for reliability and validity of a new instrument, the sampling approach was not ideally designed for analysis of variance by ethnicity.

Although the study met ANOVA assumptions of normally distributed LST scores and had evidence of homogeneity of variance (Appendix M), the unequal ethnicity group sizes limited this analysis. The statistical question addressed by ANOVA is based on the assumption that all groups are equal (Munro, 2005). Adequate power to accurately explore the ethnicity hypothesis was also not addressed a priori.

The study participants composed a heterogeneous sample of the different ethnicities in Hawaii, but the convenience sample distribution was not necessarily representative. Over one third (35%) were of Filipino ethnicity. There were 19% Caucasians, nine percent Native Hawaiians, nine percent Japanese and six percent each of Chinese, Pacific Islander and other Asians. The remaining nine percent of participants were comprised of Black, Hispanic and other mixed ethnicities.

Ethnicity distribution in Honolulu county in 2008 is as follows: 15.9% Caucasians, 8.3% Chinese, 16.2% Filipinos, 22.9% Hawaiian, 25.3% Japanese and 11.4% other ethnicity (Hawaii State Department of Health, 2008).

A comparison of study participant ethnicity and Hawaii Department of Health ethnicity distribution is presented in Table 6.

Table 6. Comparison of Participant ethnicity and Hawaii Department of Health Data

Ethnicity	<i>N</i> (%)	Hawaii DOH Data (2008) Honolulu County
Black	7 (4)	-
Caucasian	33 (19)	15.9%
Chinese	10 (6)	8.3%
Filipino	60 (35)	16.2%
Hispanic	4 (2)	-
Japanese	15 (9)	25.3%
Native/Part Hawaiian	15 (9)	22.9%
Pacific Islander	10 (6)	-
Other Asian	10 (6)	-
Mixed/Other	6 (3)	11.4

In comparing the study sample to other studies that found ethnicity to be an influence on LST attitudes, the sampling methods were different. Quota sampling by Blackhall et al. (1999) surveyed an equal number of 200 from each of four different ethnicities. Braun, Tanji and Heck (2001) also used quota sampling of 50 each from five different ethnicities.

Majority of the LSTAQ study participants were younger with a mean age of 39.5 years, while the Blackhall et al. (1999) and Matsumura et al. (2002) study participants were recruited from senior and retirement centers, indicating an older age group of respondents.

In this study, 86% of the respondents had some college level education and higher. Most of the participants had experiences with a relative's being in a hospital (63%), in an intensive care unit (54%) and with a relative's death and dying (69%). Twenty four percent had previous experience with LST decision-making for a family member. These characteristics may have influenced scale item responses.

Limitations

The convenience sampling is one methodological limitation in this study. As previously mentioned, this sampling method was designed primarily for instrument development, but was not optimally set up to test for ethnicity differences in LSTAQ scores, a secondary aim in the study. There were 10 ethnic groups of different sampling sizes. The variability in sampling distribution by ethnicity limited the power for analysis.

Additionally, convenience sampling results would be biased toward those who were willing to participate, therefore limiting generalizability.

The responses in a self report tool could reflect socially acceptable answers instead of true participant opinions. The Likert four-point scale may have limited the participants' response choices, inducing answers that may not have reflected the true opinion.

Although the LST tool response scale format was easy to follow, the item questions involved a moderate response burden from participants. This burden is a limitation partly attributable to the nature and sensitivity of the subject matter. Ethical and moral values may hamper responses in this historically contentious topic which is often confused with euthanasia. A more careful phrasing of the item questions may be necessary to differentiate the construct from controversial topics. Wording of the item questions may have influenced the answers in this multidimensional construct, most likely increasing measurement error.

The study sample consisted of prospective LST decision-makers, with 24% stating previous experience with LST decision making. Data were collected from participants whose potential decision-making processes were at different stages, from a

remote to immediate probability of LST decision-making for a family member. Future testing might include family members who are in the immediate course of LST decision-making.

The results are based on a sample size that minimally meets criteria for factor analysis. Future testing of the LSTAQ for tool validation would benefit from a larger and more homogeneous population.

Discussion Summary

Initial reliability and validity testing of the LSTAQ produced acceptable test-retest reliability (from pilot testing), internal consistency reliability, and construct, convergent and divergent validity based on established criteria (Carmines & Zeller, 1979; DeVellis, 2003; Field, 2005; Munro, 2005; Tabachnick & Fidell, 2007). The LSTAQ scale, composed of these six factors, provides a basis for understanding the LST attitudes of a decision-maker for the sick relative. As suggested in the literature, the attitudes affecting this type of decision-making for others, and even for oneself, are complex and often affected by conflict. Such attitudes have been shown to influence use of LST and in some cases, resulting in prolonged patient suffering (Swigart et al., 1996; Tilden et al., 2001; Vig & Taylor, 2006; Winter & Parks, 2008).

Recommendations for future research

One recommendation for future research is to further test the psychometric properties of the LSTAQ in a more homogeneous group, such as participants who are at

the same stage in the decision-making process, or those who belong in similar demographic grouping, such as cultural group or ethnicity.

For future surveys, the LSTAQ may be used in comparable groups with quota sampling to readdress the ethnicity hypothesis by analysis of variance.

Subsequent LSTAQ studies might include validated measures of acculturation in homogeneous ethnicity groups. Future cultural and language adaptations of the tool for use in ethnically diverse groups will enable cross-cultural comparisons and enhance culturally competent care at end of life. In addition, exploring the impact of paternalistic influences on LST decision-making may provide further insights into this phenomenon.

Significance to Nursing

The foundation of good research is the psychometric soundness of the instrument used. To obtain accurate data about attitudes of family member decision-makers towards life support for a sick relative, it is essential to have a reliable and valid instrument. Accurate data collected with a psychometrically tested scale, such as the LSTAQ, can provide valuable insight for healthcare providers in improving communication and adapting interventions to make the LST decision-making process easier for the family member, with the eventual goal of improving end of life care.

The LSTAQ may benefit healthcare professionals in three specific ways. First, as a data gathering tool, the use of the validated LSTAQ can provide precise information on family decision-maker attitudes toward LST for the sick relative. This would assist the healthcare professional in planning personalized interventions to facilitate the decision process, both in the remote and immediate phases of LST decision-making.

Second, in the immediate setting of an intensive care unit, the LSTAQ may be used as an assessment tool to determine where the family decision-maker for LST is situated in the decision-making process. The review of literature identified the trajectory of family member decision-making for the incapacitated adult at end of life whose wishes might not be known. It is from the time of the decision-maker's recognition of end of life for the sick relative to the concept of "letting go". For the ICU clinician, this is the window where individualized communication interventions can play key role in facilitating life support decision-making by family members.

Azoulay et al. (2003) noted that the family's understanding and the effectiveness of information received, anxiety and other psychological obstacles were factors in family involvement in decision-making. The current state of EOL care and life support interventions in ICUs identifies patient and family centered decision-making as one of the key domains in improving care at end of life (Clarke et al., 2003). This provides the healthcare professional the opportunity to adapt personalized approaches in communication, such as information sharing, appropriate guidance and other nursing strategies to facilitate family member decision-making. It is however recognized that the stressful state of having a relative in critical condition maybe a barrier to the use of LSTAQ.

Third, in more proactive settings, the LSTAQ can be used as a staging tool to determine LST decision-making attitude level and to formulate timely interventions that are tailored according to the different feedback loops illustrated by the Fishbein and Azjen attitude-behavior framework. This approach can be utilized in the different settings in the health care continuum, such as in family decision-making in ambulatory care,

urgent care, critical care, chronic care and palliative care settings. However, this process may also involve extensive individualized attention to the family decision-maker.

Overall, the knowledge gained from the LSTAQ about family member LST decision-making attitudes for a sick relative may give the clinician a broader understanding when communicating with family. The awareness and understanding achieved through use of the LSTAQ can help address decision-maker needs and challenges when making LST decisions for a loved one.

Conclusion

The purpose of this research was to develop and evaluate the LSTAQ instrument validity and reliability. The methods employed, namely construct validation by exploratory factor analysis, convergent and discriminant validity testing and scale reliability testing provided evidence that the LSTAQ is a reliable and valid tool to measure decision-makers' attitudes toward LST for a sick family member at end of life. Sampling limitations for analysis of variance did not allow for exploration of differences in LSTAQ scores by ethnicity.

In summary, the knowledge to be gained from the use of the valid and reliable LSTAQ scale might help promote appropriate clinician interventions and nursing approaches to deliver quality end of life care. This is achieved by individualized communication strategies that facilitate LST decision-making by the family member and consequently, reducing decision difficulties that can cause preventable discomfort, unnecessary treatment, and prolonged suffering for the terminally ill patient, as well as avoidable distress among family members involved in LST decisions for the sick relative.

Appendix A. LSTAQ 33- item Survey

Introduction

Life sustaining treatments, also called “life support” are treatments or machines used to maintain life or to treat conditions that endanger life. They may be one of the following:

- *Artificial breathing tube*
- *Breathing machine (ventilator)*
- *Dialysis (machine that works like the kidney)*
- *Artificial tube to deliver food, water or medicine*
- *CPR (CardioPulmonary Resuscitation: pressing the chest up and down and giving electric shocks to restart a heart that stopped)*
- *Intravenous medications (medicine given through the vein such as antibiotics or medicine to help the heart or blood pressure)*

Pain medicines are **not considered life support, but are called **comfort measures**.*

“Comfort measures only” means a request to relieve pain and discomfort only. It is not life support.

Instruction: *Please check box that most closely represents your own thoughts toward each statement*

		Strongly Agree	Agree	Disagree	Strongly Disagree
1	A person dying of a terminal illness should be allowed to refuse life support.				
2*	I will feel uneasy if life support is removed from a dying person.				
3	If someone is dying of terminal disease, life support should not be used to prolong his/her life.				
4*	A person who is dying of terminal illness should be kept alive with life support.				
5	It is not kind to use life support machines in a terminally ill dying patient.				
6	Life support should not be used if it will cause more pain or suffering for a dying person.				
7	A dying person’s request forgo life support should be honored at all costs.				
8	Removing life support according to the wishes of a dying patient is a humane way to die.				
9*	Life support machines should be used to prolong life at all costs.				
10	It is all right to remove life support from a terminally ill person who is close to death.				
11	A person dying of terminal illness should be allowed to die naturally, with no life support attached.				
12*	A good death must use all the life support available.				
13*	Life support in a dying patient should never be taken away, even if it is only delaying death.				

14	I do not want machines to prolong my life if I am dying of terminal illness.				
15	If there is no hope for cure, I want to spend my last days without suffering.				
16*	Even if there is no hope for a cure, I want to have life support machines until I die.				
17	My wish to forgo life support should be honored at all costs.				
18	If I am dying of terminal illness, I want a peaceful death with no machines attached to me.				

Instruction 2: If you are deciding for a terminally ill family member with no hope for survival, please mark what most closely agrees with your thoughts:

		Strongly Agree	Agree	Disagree	Strongly Disagree
19	I will honor my dying relative's wish to skip life support at all costs.				
20*	I will not stop life support for my family member, no matter what.				
21*	I will ignore my relative's refusal of life support.				
22	I will ask to remove life support that has already been started, if my relative did not want it.				
23	I will withhold life support for my sick relative who does not want life support.				
24*	If life support is available, I will request its use for my relative who earlier had refused.				
25	I will refuse life support measures for my relative who wants comfort care only.				
26	I will follow doctor's opinion to stop life support for my dying relative.				
27*	If I do not know my sick relative's wishes, I will request all kinds of life support.				
28	If my relative did not express his/her wishes, I will request comfort care only.				
29	I will depend on the doctor's judgment to stop life support if a relative did not express his/her wishes.				
30*	I will use life support for my dying relative who has not stated his/her wishes.				
31*	I will refuse life support for my sick relative <i>only</i> if I have his/her written instruction.				
32*	I will say "no" to life support for my sick relative <i>only</i> if there is family agreement.				
33*	I will use life support for my sick relative if there is family conflict.				

For office use only: Legend: * reverse coding

Appendix B. Blackhall Life Sustaining Treatment (LST) Survey

A. General attitude toward life sustaining/prolonging technology

Please check the box that indicates your opinion	Strongly Agree 4	Agree Somewhat 3	Disagree Somewhat 2	Disagree Strongly 1	Don't Know
1. If life-prolonging technology exists, it should always be used.					
2. Doctors should generally try to keep their patients alive on machines for as long as possible, no matter how uncomfortable the machines are.					
3. If a patient is dying, it is best not to prolong their lives by medical means.					
4. Life sustaining machines should never be stopped even if the patient appears to be dying because there is always the chance of a miracle.					
5. It is a doctor's duty to stop life prolonging treatments of patients if the patient does not want them anymore.					
6. Even if I were terminally ill, I would want everything done to keep me alive as long as possible.					
7. Life sustaining machines are often painful.					
8. When a person is permanently unconscious (in a coma), with no hope of waking up, medical treatments usually should not be used to keep them alive.					
9. Even if my condition is hopeless, I would want my life prolonged as much as possible.					
10. I would not want machines used to keep me alive.					
11. Present day medical care frequently prolongs dying without providing any real benefit to the patient.					
12. If a patient is unable to breathe without a breathing machine, it would be wrong to take them off the machine (even if the condition is hopeless) because that would be killing the patient.					
13. The use of life sustaining machines can be humiliating to the patient.					

B. Personal desire for life support - please check or circle the box that indicates your choice.

1. If you were in a coma or in a persistent vegetative state (permanently unconscious) and you might live a long time but in the opinion of your physician had no hope of regaining awareness no matter what was done, would you want:

<i>(a) CPR (a technique to try to start the heart and lungs if they have stopped, using artificial breathing, pumping up and down on the chest and electrical shock or drugs)</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	
<i>(b) Mechanical ventilation? (artificial breathing machine)</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	<i>For short time only</i>

2. If you were in a coma and your physicians felt that there was a small but uncertain chance of regaining full awareness and function but a greater chance of surviving with severe mental disabilities, would you want:

<i>(a) CPR?</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	
<i>(a) Mechanical ventilation?</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	<i>For short time only</i>

3. If you had brain damage or brain disease which although you were awake made you unable to recognize people, or to speak meaningfully to people, or to live independently, but ***had no terminal illness***, and the following treatments could prolong your life but not reverse the brain damage, would you want:

<i>(b) CPR?</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	
<i>(b) Mechanical ventilation?</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	<i>For short time only</i>

4. If you had brain damage or brain disease which although you were awake made you unable to recognize people, or to speak meaningfully to people, or to live independently, but ***had a terminal illness***, and the following treatments could prolong your life but not reverse the brain damage, would you want:

<i>(c) CPR?</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	
<i>(c) Mechanical ventilation?</i>	<i>Want</i>	<i>Don't want</i>	<i>Not sure</i>	<i>For short time only</i>

Blackhall LST tool scoring instructions***A: “General Attitudes toward LST”***

1. Scoring: 4= agree strongly, 3= agree somewhat, 2= disagree somewhat, 1= strongly disagree
2. Reverse coded (negatively worded 7 items) : A3, A5, A7, A8, A10, A11, A13
3. Sum individual items together to create overall attitude score.
4. Average attitude score is imputed for any response of “don’t know”, then total attitude score is recalculated.
5. Score range 13-52 (Higher score indicates mote positive attitude toward use of LST)

B. “Personal desire for life support”

1. CPR questions: 1=want, 2= don’t want, 3= not sure
2. Mechanical ventilation: 1=want, 2= don’t want, 3= not sure, 4= for a short time only
3. Individual items recoded as 1= want, 0= don’t want and for mechanical ventilation, 0.5= for short time only
4. Responses (not including ‘not sure’ responses) are summed together to create overall personal desire score.
5. The average personal desire score is imputed for any response of ‘not sure’, then total personal desire score is recalculated.
6. Personal desire score range is 0-8. Higher score implies greater personal desire for LST

Appendix C. Subjective Happiness Scale (SHS by Dr. Sonja Lyubomirsky)

Subjective Happiness Scale

Instructions to participants: For each of the following statements and/or questions, please circle the point on the scale that you feel is most appropriate in describing you.

1. In general, I consider myself:

1	2	3	4	5	6	7
not						a very
a very						happy
happy						person
person						

2. Compared to most of my peers, I consider myself:

1	2	3	4	5	6	7
less						more
happy						happy

3. Some people are generally very happy. They enjoy life regardless of what is going on, getting the most out of everything. To what extent does this characterization describe you?

1	2	3	4	5	6	7
not at						a great
all						deal

4. Some people are generally not very happy. Although they are not depressed, they never seem as happy as they might be. To what extent does this characterization describe you?

1	2	3	4	5	6	7
not at						a great
all						deal

*Item 4 Reverse Scored

Appendix E. Institutional Review Board Approval Letter


UNIVERSITY OF HAWAII

Committee on Human Studies

MEMORANDUM

April 27, 2010

TO: Jane C. Misola, RN
Principal Investigator
School of Nursing

FROM: Nancy R. King 
Director

SUBJECT: CHS #18094- "Development and Testing of the Life Sustaining Treatment Attitude Questionnaire (LSTAQ)"

Your project identified above was reviewed and has been determined to be exempt from Department of Health and Human Services (DHHS) regulations, 45 CFR Part 46. Specifically, the authority for this exemption is section 46.101(b)(2). Your certificate of exemption (Optional Form 310) is enclosed. This certificate is your record of CHS review of this study and will be effective as of the date shown on the certificate.

An exempt status signifies that you will not be required to submit renewal applications for full Committee review as long as that portion of your project involving human subjects remains unchanged. If, during the course of your project, you intend to make changes which may significantly affect the human subjects involved, you should contact this office for guidance prior to implementing these changes.

Any unanticipated problems related to your use of human subjects in this project must be promptly reported to the CHS through this office. This is required so that the CHS can institute or update protective measures for human subjects as may be necessary. In addition, under the University's Assurance with the U.S. Department of Health and Human Services, the University must report certain situations to the federal government. Examples of these reportable situations include deaths, injuries, adverse reactions or unforeseen risks to human subjects. These reports must be made regardless of the source funding or exempt status of your project.

University policy requires you to maintain as an essential part of your project records, any documents pertaining to the use of humans as subjects in your research. This includes any information or materials conveyed to, and received from, the subjects, as well as any executed consent forms, data and analysis results. These records must be maintained for at least three years after project completion or termination. If this is a funded project, you should be aware that these records are subject to inspection and review by authorized representatives of the University, State and Federal governments.

Please notify this office when your project is completed. We may ask that you provide information regarding your experiences with human subjects and with the CHS review process. Upon notification, we will close our files pertaining to your project. Any subsequent reactivation of the project will require a new CHS application. Please be aware that unless we are notified otherwise, this will automatically expire 5 years from the approval date.

Please do not hesitate to contact me if you have any questions or require assistance. I will be happy to assist you in any way I can.

Thank you for your cooperation and efforts throughout this review process. I wish you success in this endeavor.

Enclosure

1960 East-West Road, Biomedical B104, Honolulu, Hawaii 96822-2303
Telephone: (808) 956-5007, Facsimile: (808) 956-8683, Website: www.hawaii.edu/irb

An Equal Opportunity/Affirmative Action Institution

Appendix F. Recruitment Script

RECRUITMENT SCRIPT (IRB Attachment)

Hello, my name is Jane Misola, a student at the University of Hawaii of School of Nursing. I am doing a project to test a survey questionnaire about life support attitudes. I am looking for any adult who may possibly be a decision maker on life support treatments for a sick relative in the future.

It is an anonymous survey, identified only by numbers. There will be 4 survey forms. It will take approximately 20-30 minutes to complete. Participation is voluntary and will require a separate signed consent. You will get a copy of the consent and you will be given an incentive of \$10 for the time you spend participating in the survey.

Would you like to participate?

Appendix G. Written Consent Form

AGREEMENT TO PARTICIPATE

Reliability and Validity Testing of a Life Sustaining Treatment Attitudes Questionnaire (LSTAQ)

Principal Investigator: Jane C. Misola, RN, MS, CCRN

University of Hawaii School of Nursing

Purpose

The purpose of this survey is to test a questionnaire to examine attitudes toward "life support" among adults who are potential decision makers for sick relatives at the end of life. It will also look at other factors that may affect beliefs and feelings toward life support.

Benefits

Although I may not directly benefit, the results of this project may increase knowledge about attitudes toward life support. It may benefit persons who, in the future, will have to deal with life support decisions for the sick relative. It may help improve care for the terminally ill who are on life support.

Project description

This research project has been explained to me. Participation is voluntary. If I agree to participate, I will sign a consent form and fill out four (4) survey forms during this meeting. It will take approximately 20-30 minutes to complete all the forms. I understand that I will receive \$10.00 for the time spent in participating in the survey.

The completion date of the research project is December 2010.

Risks

I understand that participating in this research project may possibly involve psychological discomfort, loss of privacy and time spent. I will be completing the questionnaires in a private area to provide me with time alone. The researcher will be available for assistance and to answer any questions I have. I understand that the questionnaires will have no identifying information. It will be marked by number rather than by name, to protect my privacy. I further understand that the results of the survey may be used for research purposes and the results will be reported as a group. Confidentiality will be maintained to the extent allowed by law. All information will be destroyed when the study is completed.

Voluntary right to withdraw

I understand that my participation is voluntary. Choosing not to participate or withdrawal from the project at anytime will not affect my relations with the University of Hawaii School of Nursing and its staff.

If I have questions, I can contact the study investigator, Jane Misola, RN, MS at 671-6770 or misola@hawaii.edu. If I cannot obtain satisfactory answers to my questions about my involvement in this project, I may contact the Committee on Human Studies, University of Hawaii, 1960 East-West Rd. Bioethics Bldg. B-104, Honolulu, HI 96822 at 956-5007 or uhirb@hawaii.edu.

I have read and understand the information, and I give my consent to participate in this survey. I have received a copy of this consent form.

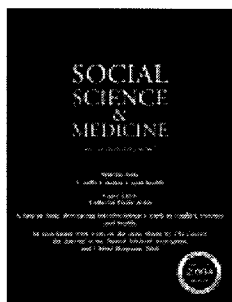
Print Name _____

Signature _____

Date _____

Appendix H. Copyright Permission from Elsevier: Blackhall LST Survey

“Reprinted from Publication title, Vol /edition number, Author(s), Title of article / title of chapter, Pages No., Copyright (Year), with permission from Elsevier [OR APPLICABLE SOCIETY COPYRIGHT OWNER].”



Title: Ethnicity and attitudes towards life sustaining technology

Author: Leslie J. Blackhall, Gelya Frank, Sheila T. Murphy, Vicki Michel, Joycelynne M. Palmer, Stanley P. Azen

Publication: Social Science & Medicine

Publisher: Elsevier

Date: June 1999

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Logged in as:
Jane Misola

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Issue number	12
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Appendix I. Author Permission to Use Blackhall LST Survey

Subject RE: Request Permission: LST survey tool
 From "Blackhall, Leslie *HS" <LB9X@hscmail.mcc.virginia.edu>
 Date Thursday, March 25, 2010 8:59 am
 To Jane Caces Misola <misola@hawaii.edu>

Sure, I'll have to send you a hard copy. Do you have a snail mail address?
 Leslie

From: Jane Caces Misola [misola@hawaii.edu]
 Sent: Wednesday, March 24, 2010 7:41 PM
 To: lb9x@virginia.edu
 Subject: Request Permission: LST survey tool

Hello Dr. Blackhall,

My name is Jane Misola, a critical care nurse and a doctoral student at the University of Hawaii School of Nursing in Honolulu, Hawaii. My dissertation focus is on life sustaining treatment attitudes among family member decision-makers of the critically ill at end-of-life. I am trying to develop survey instrument to examine LST decision-maker attitudes in the Hawaii setting.

I have been following your impressive work and articles about end-of-life care and am particularly interested in the tool that you used in the 1999 article in the Social Science & Medicine journal "Ethnicity and attitudes towards life sustaining technology".

May I request your personal permission to use your survey tool to confirm concurrent validity of my tool, which I will be using for my dissertation research? Permission from Elsevier Science, Ltd is pending. A hard copy of this permission request is mailed to your UVA hospital address at:

Univ. of Virginia Hospital/Black Ce
 1224 W Main St # 201
 Charlottesville, VA 22903

Thank you and I look forward to hearing from you.

Very Respectfully,
 Jane C. Misola
 Student -University of Hawaii School of Nursing (OPN1)
misola@hawaii.edu

Appendix J. Copyright Permission from Rightslink: Subjective Happiness Scale

RIGHTSLINK
Copyright Clearance Center



Thank You For Your Order!

Dear Jane,

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Appendix K. Correspondence and Personal Permission to Use Subjective Happiness Scale from author, Dr. S. Lyubomirsky

Re: request permission to use SHS

▶ [Sonja Lyubomirsky <sonja.lyubomirsky@ucr.edu>](mailto:sonja.lyubomirsky@ucr.edu)

Wednesday, April 7, 2010 5:54 am

[Jane Caces Misola <misola@hawaii.edu>](mailto:misola@hawaii.edu)

[Lyubomirsky & Lepper, 1999.pdf](#)

You don't actually need my permission, but you are welcome to use it. Just be sure to cite the scale validation paper (attached). My book (see below) also has information about the scale. Good luck,
--Sonja

Sonja Lyubomirsky, Ph.D.
Professor and Graduate Advisor
Department of Psychology
University of California
Riverside, CA 92521
My academic web site: www.faculty.ucr.edu/~sonja/

The How of Happiness: A Scientific Approach to Getting the Life You Want (Penguin Press, 2008) Book web site: www.thehowofhappiness.com
My blog at Psychology Today:
blogs.psychologytoday.com/blog/the-how-happiness

On 4/7/10 4:55 AM, "Jane Caces Misola" <misola@hawaii.edu> wrote:

> Hello Dr Lyubomirsky,
>
> I am a doctoral student at the University of Hawaii- Manoa School of
> Nursing. I am inquiring about your Subjective Happiness Scale published in
> 1999
>
> I am interested in using it as part of my dissertation research, which is
> the development of a decision making attitude instrument.
>
> I would like to get your personal permission to use your SHS Scale on
> approximately 165 individuals of different ethnicities in Hawaii. I have
> already obtained electronic permission to use from the publisher (Rightslink).
>
> I will mail an official hard copy of this request after instructions from
> you.
>
> Hope to hear from you soon.
> Thank you,
> Jane Misola, RN, MS
> misola@hawaii.edu
> (808) 671-6770

Appendix L. Table of Psychometrically Tested LST Attitude tools

Legend: **DM**: Decision Making; **FA**: Factor Analysis; **EOL**: End of Life; **HC**: Health Care; **Int**: Interview; **LST**: Life Sustaining Treatment; **PA**: Path Analysis; **PCA**: Principal Components Analysis; **Q**: Questionnaire; **See**: Scenario

Author/Title/Journal	Year	Tool	Sample	Reliability	Validity	Remarks
Beland & Froman. Preliminary validation of a measure of life support preferences. Image Journal of Nursing Scholarship.	1995	Q	116 adults + varied	Cr α 0.94 2 wk stability: 0.85, 0.73	Face & Content FA .38-.62 item loading	Life Support Preference Questionnaire used by Libbo & Russel (1995); Proxy Accuracy DM; Froman & Owen (2003); Cantalejo (2009) validation
Blackhall, Frank, Murphy et al. Ethnicity and attitudes towards life sustaining technology. Social Science Medicine.	1999	Q & Int	800: 4 groups Euro Am Mex Am Afri Am Kor Am	Cr α 0.41-0.92 Scale α 0.82 Test Retest: r = .92, p<.0001	Content Construct validity not described	Questionnaire Survey with ethnographic interview Adapted by Lee (2003) Hongkong study
Braun, Tanji & Heck. Exploring the Impact of Ethnicity and Attitudes Toward Planning for Death. The Gerontologist.	2001	Int	5 ethnic grps: Caucasian Chinese, Filipino, Native Hawaiian, Japanese	Cr α done No data	FA: quantify attitudes PA: influence of ethnicity, attitude factors	"Advocacy to Discuss Wishes", "Trust in Family & Physician to Make Decision", "Reliance on Religious Guidance", "Fears & Anxiety About Life's End", "Fatalism About Death's Timing" Fil/Haw less support for PAS
Catt, Blanchard, Addington-Hall et al. The development of a questionnaire to assess the attitudes of older people to end-of-life issues (AEOLI). Palliative Medicine.	2005	Q	Pilot 50; 129 older adults	Pilot reliability Retest Cohen's k >0.04 Cr α 0.52-0.68	Pilot: face validity	AEOLI
Gauthier & Froman.	2001	Q	198	Cr α 0.68 -	Content	PCEOL 77 item

Preference for care near the end of life: scale development and validation. Research in Nursing and Health.			adults	0.91 Test Retest 0.80-0.94	(expert) 0.96 CVI EFA, PCA	Likert Validated by Schirm (2004) Autonomy DM ; HC DM, family, spirituality
Heyland & Tranmer. Measuring family satisfaction with care in the intensive care unit: Development of a questionnaire and preliminary data. Critical Care Medicine.	2003	Q	Pilot testing	"yes" (no info)	Content & Face validity (no info)	Scale 5-pt DM satisfaction, quality
Pearlman, Cain, Starks et al. Preferences for life-sustaining treatments in advance care planning and surrogate decision making. Journal of Palliative Medicine.	2000	Int	Surrogate	Cr α 0.83 (0.77 - 0.86)	—	Preference in LST and Advance Care Planning
Sulmasy, Terry, Weisman et al. The accuracy of substituted judgments in patients with terminal diagnoses. Annals of Internal Medicine.	2004	Int	50 Pt & Surrogate	K-R 0.93-0.97	Yes (no data)	Structured paired interview Compare treatment preferences: 66% accuracy

Appendix M. ANOVA: Ethnicity and LSTAQ Score

Descriptives

new LSTAQ Scale Total

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
					Black	7		
Caucasian	33	61.9027	12.85991	2.23862	57.3428	66.4626	36.00	99.00
Chinese	10	64.4000	13.06565	4.13172	55.0534	73.7466	39.00	88.00
Filipino	60	66.4082	12.57387	1.62328	63.1600	69.6564	36.00	111.00
Hispanic	4	65.0000	8.52447	4.26224	51.4357	78.5643	53.00	73.00
Japanese	15	63.2000	11.85146	3.06003	56.6369	69.7631	45.00	81.00
Native/Part Hawaiian	15	59.1333	16.64274	4.29714	49.9169	68.3498	33.00	87.00
Pacific Islander	10	59.7000	15.67057	4.95547	48.4900	70.9100	30.00	81.00
Other Asian	10	58.4000	12.52730	3.96148	49.4385	67.3615	36.00	73.00
Other/Unknown/Mixed	6	64.6667	7.78888	3.17980	56.4927	72.8406	58.00	79.00
Total	170	63.6195	12.96530	.99439	61.6565	65.5825	30.00	111.00

Test of Homogeneity of Variances

new LSTAQ Scale Total

Levene Statistic	df1	df2	Sig.
.648	9	160	.754

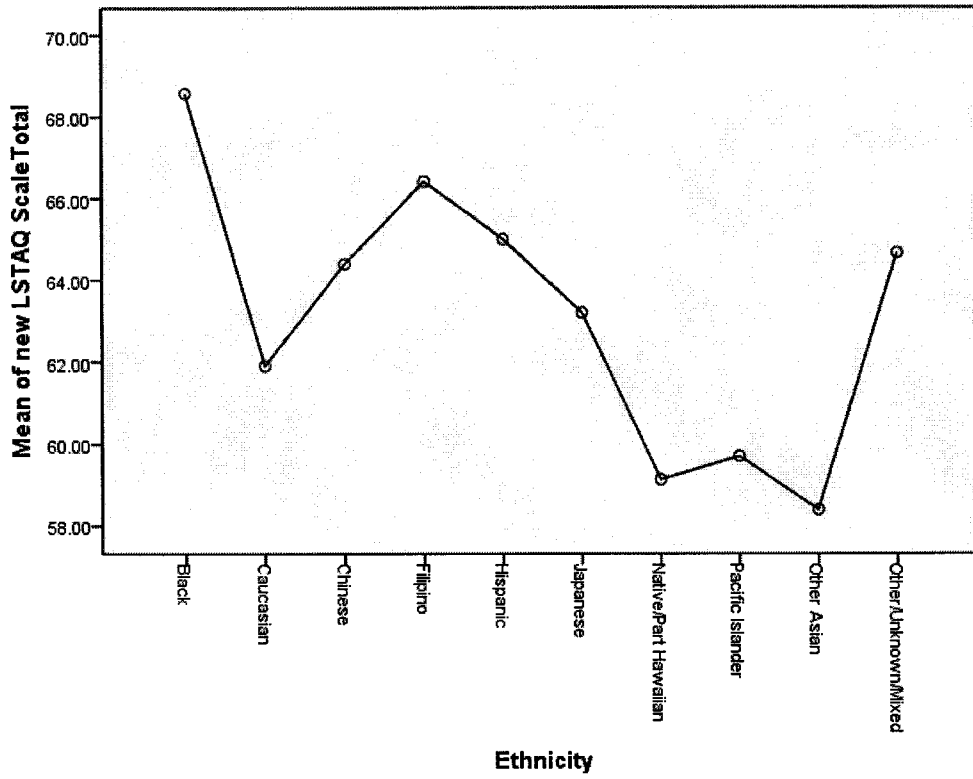
ANOVA

New LSTAQ Scale Total

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	1486.751	9	165.195	.982	.457
Within Groups	26921.964	160	168.262		
Total	28408.715	169			

Appendix N. ANOVA: Ethnicity and LSTAQ Scores Graph

Graph of ethnicity and LSTAQ Scores



Appendix O. Pilot Development Original 47-item Question Pool

<i>ITEM POOL QUESTIONS</i>	
1.	A person dying of a terminal illness should be allowed to refuse life-support treatments.
2.	I feel uncomfortable with anyone who removes life support from a terminally ill dying patient.
3.	If someone with terminal disease is dying, life support should not be used to prolong his/her life.
4.	A person who is dying of terminal illness should be kept alive with life support as long as possible.
5.	It is not compassionate to use life support machines in a terminally ill dying patient.
6.	Medical technology should be used to prolong life under all circumstances.
7.	Life support treatments that have been started should be removed if it serves no purpose except to delay death.
8.	Life support treatments should not be used if it will cause more pain or suffering than the hope of cure.
9.	Life support should not be used for a terminally ill patient who has requested "comfort measures only"
10.	Removing life support based on the wishes of a terminally ill patient at the end of life is a compassionate way to die.
11.	Terminally ill patients should be made comfortable at end of life by not using life support machines.
12.	It is acceptable to refuse life support for a terminally ill person who is close to death.
13.	The practice of letting a terminally ill person to die naturally, without life support, should be allowed.
14.	In general, life support treatments are painful and uncomfortable
15.	A good death must use all the heroic measures and life support available.
16.	Life support in a dying patient should never be taken away, even if its only purpose is to delay death
17.	If I am dying of a terminal disease, I should be allowed to die naturally without life support equipment.
18.	My request for "comfort measures only" should honor my refusal of life support at end of life.
19.	If I am dying of terminal illness with no hope for recovery, I do not want machines to prolong my life.
20.	If I am dying of terminal illness with no hope for recovery, I want all kinds of life support available, in order to live as long as I can.
21.	If there is no hope for cure or meaningful recovery, I want to spend my last days without suffering.
22.	For me, to "die without suffering" means no life support machines attached to my body at the end of life.
23.	Even if there is no hope for a cure or meaningful recovery, I want to have life support machines until I die.

24. If there is no hope for a cure or meaningful recovery, I will request to have “comfort measures only” at the end of life.
25. My refusal of life support should be honored at all costs.
26. If I am terminally ill at the end of life, I want a peaceful death without life support objects attached to me.
27. I want all kinds of life support to keep me alive as long as possible.
28. I will honor my family member’s wish to refuse life support even if it is not my own preference.
29. I am not willing to stop life support for my family member, no matter what.
30. I will not honor my family member’s refusal of life support because it is not my own preference.
31. If my relative did not want life support, I will respect his/her request by allowing the removal of life support that has already been started.
32. If life support has already been started, I will not allow its removal under any circumstances.
33. Life support should not be used if my sick relative had earlier stated that he/she did not want treatments to prolong life.
34. If my sick relative does not want life support, I will not allow it to be used at the end of life.
35. I will not honor my sick relative’s decision to refuse life support, if it means saying “no” to a treatment that is available.
36. I would follow his/her decision to refuse life support treatment, under all situations.
37. I will follow my family member’s request for “comfort measures only” by not allowing the use life support.
38. “Comfort measures only” allows my terminally ill family member a compassionate way to die.
39. I would disregard my sick relative’s refusal of life support because I do not agree with it.
40. If my family member did not express his/her wishes for end of life care, I will request all available life support.
41. If my relative did not express his/her wishes, I will request “comfort care only” and say “no” to life support at end of life.
42. If my dying family member did not express his/her wishes, I will depend on the doctor’s judgment to stop life support.
43. I will maintain life support for my dying, sick relative who does not have a written document to refuse treatments.
44. I will follow the medical expert’s decision to stop life support for my sick dying relative.
45. I will refuse life support for my sick relative <u>only</u> if I have a written instruction from him/her.
46. I will say “no” to life support for my terminally ill relative, <u>only</u> if I have agreement from other family members
47. I will insist on life support for my relative if there is <u>no</u> agreement among my family members.

Appendix P. Pilot testing Participant Characteristics

Characteristics		<i>N</i>	%
Gender	male	14	35.0
	female	26	65.0
Age	18-25 yrs	11	27.5
	26-35 yrs	6	15.0
	36-45 yrs	5	12.5
	46-55 yrs	10	25.0
	56- 65 yrs	6	15.0
	66-75 yrs	1	2.5
	76 yrs and above	1	2.5
Ethnicity	Caucasian	7	17.5
	Hispanic	1	2.5
	Japanese	4	10.0
	Native Hawaiian	1	2.5
	Chinese	6	15.0
	Filipino	18	45.0
	Other Asian	3	7.5
Marital Status	other	1	2.5
	single	18	45.0
	married	20	50.0
	divorced	1	2.5
Education level	High School Graduate	2	5.0
	Some College	19	47.5
	Bachelor's Degree	13	32.5
	Post graduate	6	15.0
Religion	Unknown/undocumented	2	5.0
	Catholic	20	50.0
	Protestant	4	10.0
	Other Christian	7	17.5
	Buddhist	5	12.5
	Other religion	2	5.0
Experience in a hospital	yes	31	77.5
Experience in ICU	yes	22	55.0
Experience with Death/Dying	yes	33	82.5
Experience with LST DM	yes	19	47.5

Appendix Q. Pilot testing test-retest table

Participant #	Test 1	Test 2
1	73	70
2	72	66
3	96	87
4	56	56
5	101	97
6	*	-
7	*	105
8	105	100
9	105	107
10	60	58
11	52	57
12	58	58
13	81	93
14	75	73
15	60	56
16	84	90
17	81	81
18	*	81
19	86	78
20	71	69
21	89	76
22	79	*
23	107	96
24	68	73

25	81	84
26	79	84
27	97	98
28	107	108
29	*	*
30	104	97
31	92	88
32	78	82
33	70	85
34	89	91
35	76	80
36	100	100
37	113	*
38	.*	86
39	77	78
40	89	81
Grand Total	2911	2969
Mean	83	82
N	35	36
SD	16	15

*Incomplete items

Appendix R. Pilot testing Statistics

Summary of Reliability Statistics - Original scale

Sub-scales	# of items	Cronbach's alpha	Split Half- Spearman Brown Coefficient
LST General Attitude (items 1-17)	17	.82	.82
LST Personal Preferences (items 18-27)	10	.85	.86
LST Decision Making for family member (items 28-47)	20	.86	.79
Total Scale	47	.92	.81

Summary of Reliability Statistics (Revised Scale)

Sub-scales	# of items	Cronbach's alpha	Split Half- Spearman Brown Coefficient
LST General Attitude (items 1-17)	11	.81	.75
LST Personal Preferences (items 18-27)	8	.83	.86
LST Decision Making for family member (items 28-47)	14	.90	.85
Total Scale	33	.92	.74

Appendix S. Final LSTAQ Scale (30-item)

Introduction

Life sustaining treatments, also called “life support” are treatments or machines used to maintain life or to treat conditions that endanger life. They may be one of the following:

- *Artificial breathing tube*
 - *Breathing machine (ventilator)*
 - *Dialysis (machine that works like the kidney)*
 - *Artificial tube to deliver food, water or medicine*
 - *CPR (CardioPulmonary Resuscitation: pressing the chest up and down and giving electric shocks to restart a heart that stopped)*
 - *Intravenous medications (medicine given through the vein such as antibiotics or medicine to help the heart or blood pressure)*
- *Pain medicines are **not** considered life support, but are called **comfort measures**.*

“Comfort measures only” means a request to relieve pain and discomfort only. It is not life support.

Instruction: Please check box that most closely represents your own thoughts toward each statement

		Strongly Agree	Agree	Disagree	Strongly Disagree
1	A person dying of a terminal illness should be allowed to refuse life support.				
2*	I will feel uneasy if life support is removed from a dying person.				
3	If someone is dying of terminal disease, life support should not be used to prolong his/her life.				
4*	A person who is dying of terminal illness should be kept alive with life support.				
5	It is not kind to use life support machines in a terminally ill dying patient.				
6	Life support should not be used if it will cause more pain or suffering for a dying person.				
7	A dying person’s request forgo life support should be honored at all costs.				
8	Removing life support according to the wishes of a dying patient is a humane way to die.				
9*	Life support machines should be used to prolong life at all costs.				
11	A person dying of terminal illness should be allowed to die naturally, with no life support attached.				
12*	A good death must use all the life support available.				
13*	Life support in a dying patient should never be taken away, even if it is only delaying death.				
14	I do not want machines to prolong my life if I am dying of terminal illness.				
15	If there is no hope for cure, I want to spend my last days without suffering.				

16*	Even if there is no hope for a cure, I want to have life support machines until I die.				
17	My wish to forgo life support should be honored at all costs.				
18	If I am dying of terminal illness, I want a peaceful death with no machines attached to me.				

Instruction 2: If you are deciding for a terminally ill family member with no hope for survival, please mark what most closely agrees with your thoughts:

		Strongly Agree	Agree	Disagree	Strongly Disagree
19	I will honor my dying relative's wish to skip life support at all costs.				
20*	I will not stop life support for my family member, no matter what.				
21*	I will ignore my relative's refusal of life support.				
23	I will withhold life support for my sick relative who does not want life support.				
24*	If life support is available, I will request its use for my relative who earlier had refused.				
26	I will follow doctor's opinion to stop life support for my dying relative.				
27*	If I do not know my sick relative's wishes, I will request all kinds of life support.				
28	If my relative did not express his/her wishes, I will request comfort care only.				
29	I will depend on the doctor's judgment to stop life support if a relative did not express his/her wishes.				
30*	I will use life support for my dying relative who has not stated his/her wishes.				
31*	I will refuse life support for my sick relative <i>only</i> if I have his/her written instruction.				
32*	I will say "no" to life support for my sick relative <i>only</i> if there is family agreement.				
33*	I will use life support for my sick relative if there is family conflict.				

For office use only: Legend: * reverse coding

REFERENCES

- Abbott, K., Sago, J., Breen, C., Abernethy, A., & Tulskey, J. (2001). Families looking back: one year after discussion of withdrawal or withholding of life-sustaining support. *Critical Care Medicine*, 29, 197-201.
- Angus, D., Barnato, A., Linde-Zwirble, W., Weissfeld, L., Watson, R., Rickert, T., et al. (2004). Use of intensive care at the end of life in the United States: An epidemiologic study. *Critical Care Medicine*, 32, 638-643.
- Azoulay, E., Pochard, F., Chevret, S., Adrie, C., Annane, D., Bleichner, G., et al. (2004). Half the family members of intensive care unit patients do not want to share in the decision-making process: a study in 78 French intensive care units. *Critical Care Medicine*, 32(9), 1832-1838.
- Badger, M. (2005). Factors That Enable or Complicate End-of-Life Transitions in Critical Care. *American Journal of Critical Care*, 14, 513-521.
- Balneaves, L.G., & Long, B. (1999). An embedded decisional model of stress and coping: implications for exploring treatment decision making by women with breast cancer. *Journal of Advance Nursing*, 6, 1321-1331.
- Beauchamp, T.L., & Childress, J.F. (2001). *Principles of Biomedical Ethics*. 5th ed. New York, NY: Oxford University Press.
- Beckstrand, R.L., & Kirchhoff, K. (2005). Providing End-of-Life Care to Patients: Critical Care Nurses' Perceived Obstacles and Supportive Behaviors. *American Journal of Critical Care*, 20(14), 395-403.
- Beland, D.K., & Froman, R.D. (1995). Preliminary validation of a measure of life support preferences. *Journal of Nursing Scholarship*, 27, 307-10.

- Blackhall, L., Frank, G., Murphy, S., Michel, V., Palmer, J., & Azen, S. (1999). Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine*, 48(12), 1779-1789.
- Blatt, L. (1999). Working with Families in Reaching End of Life Decisions. *Clinical Nurse Specialist*, 13(5), 219-223.
- Boyle, D., Miller, P., & Forbes-Thompson, S. (2005). Communication and End-of-Life Care in the Intensive Care Unit: Patient, Family, and Clinician Outcomes. *Critical Care Nursing Quarterly*, 28(4), 302-316.
- Braun, K. L., & Nichols, R. (1997). Death and dying in four Asian American cultures: a descriptive study. *Death Studies*, 21, 327-359.
- Braun, K. L., Onaka, A.T., & Horiuchi, B.Y. (2001). Advance directive completion rates and end of life preferences in Hawaii. *Journal of American Geriatrics Society*, 49, 1708-1713.
- Braun, K. L., Tanji, V., & Heck, R. (2001). Support for physician-assisted suicide: Exploring the impact of ethnicity and attitudes toward planning for death. *The Gerontologist*, 41, 51-60.
- Buchanan, A.E., & Brock, D.W. (1989). *Deciding for Others: The Ethics of Surrogate Decision Making*. New York, NY: Cambridge University Press.
- Carmines, E.G., & Zeller, R.A. (1979). *Reliability and validity assessment*. Thousand Oaks, CA: Sage Publications.
- Catt, S., Blanchard, M., Addington-Hall, J., Zis, M., Blizard, R., & King, M. (2005). Older adults' attitudes to death, palliative treatment and hospice care. *Palliative Medicine*, 19(5), 402-410.

- Chapple, H. (1999). Changing the game in the intensive care unit: letting nature take its course. *Critical Care Nurse*, 19(3). Retrieved from <http://80-gateway.ut.ovid.com.prx.hml.org/gw1/ovidweb.cgi>
- Clarke, E., Curtis, J., Luce, J., Levy, M., Danis, M., Nelson, J., & Solomon M. (2003). Quality indicators for end-of-life care in the intensive care unit. *Critical Care Medicine*, 31(9). Retrieved from <http://80-gateway.ut.ovid.com.prx.hml.org/gw1/ovidweb.cgi>
- Cohen, R., & Swerdlik, M. (2005). *Psychological Testing and Assessment*. New York, NY: McGraw Hill.
- Colclough, Y., & Young, H. (2007). Decision making at end of life among Japanese American families. *Journal of Family Nursing*, 13(2), 201-25.
- Cook, D., Rucker, G., Giacomini, M., Sinuff, T., & Heyland, D. (2006). Understanding and changing attitudes toward withdrawal and withholding of life support in the intensive care unit. *Critical Care Medicine*, 34(11S), S317-S323.
- Counsell, C., & Guin, P. (2002). Exploring family needs during withdrawal of life support in critically ill patients. *Critical Care Nursing Clinics North Am*, 14(2), 187-91.
- Dela Cruz, F.A., McBride, M., Compas, L., Calixto, P., & Van Derveer, C. (2002): White Paper on the Health Status of Filipino Americans and Recommendations for Research. *Nursing Outlook*, 50, 7-15.
- DeSpelder, L.A., & Strickland, A.L. (2005). *The Last Dance: Encountering Death and Dying* (7th ed.). New York, N.Y: McGraw Hill.

- DeVellis, R. F. (2003). *Scale development: Theory and applications* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- DeVon, H., Block, M., Moyle-Wright, P., Ernst, D., Hayden, S., Lazzara, D., et al. (2007). A Psychometric Toolbox for Testing Validity and Reliability. *Journal of Nursing Scholarship*, 39(2), 155-164.
- Field, A. (2005). *Discovering Statistics using SPSS* (2nd ed.). Thousand Oaks, CA: Sage.
- Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention, and behavior: An introduction to theory and research*. Reading, MA: Addison-Wesley.
- Gauthier, D.M., & Froman, R.D. (2001). Preference for care near the end of life: scale development and validation. *Research in Nursing and Health*, (24) 298-306.
- Hall, R., & Rocker, G. (2000). End-of-life care in the ICU: treatments provided when life support was or was not withdrawn. *Chest*, 118(5). Retrieved from <http://80-gateway.ut.ovid.com.prx.html.org/gw1/ovidweb.cgi>
- Hansen, L., Archbold, P., & Stewart, B. (2004). Role strain and ease in decision-making to withdraw or withhold life support for elderly relatives. *Journal of Nursing Scholarship*, 36(3), 233-238.
- Hansen, L., Archbold, P.G., Stewart, B., Westfall, U.B., & Ganzini, L. (2005). Family caregivers making life-sustaining treatment decisions: Factors associated with role strain and ease. *Journal of Gerontological Nursing*, 31(11), 28-35.
- Hawaii State Department of Health, Honolulu. Hawaii Health Survey 2008. Retrieved from http://hawaii.gov/health/statistics/hhs/hhs_08/hhs08t11.pdf
- Hayes, C. (2003). Surrogate Decision-making to End Life-sustaining Treatments for Incapacitated Adults. *Journal of Hospice & Palliative Nursing*, 5(2), 91-102.

- Heyland, D., Rucker, G., O'Callaghan, C., Dodek, P., & Cook, D. (2003). Dying in the ICU: perspectives of family members. *Chest*, 124, 392-398.
- Heyland, D.K., & Tranmer, J.E. (2002). Measuring family satisfaction with care in the intensive care unit: Development of a questionnaire and preliminary data. *Critical Care Medicine*, 16, 142-149.
- Hiltunen, E.F., Medich, C., Chase, S., Peterson, L., & Forrow, L. (1999). Family decision making for end-of-life treatment: The SUPPORT nurse narratives. *Journal of Clinical Ethics*, 10, 126-134.
- Hodges, S. (1998). The Construction of Attitudes and Beliefs. Retrieved from <http://www.uoregon.edu/~sdhodges/attbel.htm>
- Jacob, D.A. (1998). Family members' experiences with decision making for incompetent patients in the ICU: A qualitative study. *American Journal of Critical Care*, 7(1), 30-36.
- Janis, I. L., & Mann, L. (1977). *Decision making: A Psychological Analysis of Conflict, Choice and Commitment*. New York, NY: Free Press.
- Kagawa-Singer, M., & Blackhall, L. (2001). Negotiating cross-cultural issues at the end of life: "you got to go where he lives". *Journal of American Medical Association*, 28, 2993-3001.
- Karel, H., Zir, A., & Braun, K. (2003). Knowledge, Practice, and Attitudes toward End of Life issues among Adults in Hawaii. *California Journal of Health Promotion* (1S), 125-130.

- Kirchhoff, K., Walker L., Hutton, A., Spuhler, V., Cole, B., & Clemmer, T. (2002). The vortex: families' experiences with death in the intensive care unit. *American Journal of Critical Care*, 11, 200-209.
- Kwak, J., & Haley, W. (2005). Current research findings on end of life decision making among racially or ethnically diverse groups. *The Gerontologist*, 45, 634-641.
- Lang, F., & Quill, T. (2004). Making Decisions with Families at the End of Life. *American Academy of Family Physicians*, 7, 719-723, 725-726.
- Leininger, M.M., & McFarland, M.R. (2006). *Culture Care Diversity and Universality: A Worldwide Nursing Theory* (2nd ed.). Sudbury, MA: Jones & Bartlett.
- Limerick, M. H. (2007.) The process used by surrogate decision makers to withhold and withdraw life-sustaining measures in an intensive care environment. *Oncology Nursing Forum*, 34(2), 331-339.
- Lyubomirsky, S., & Lepper, H. S. (1999). A measure of subjective happiness: Preliminary reliability and construct validation. *Social Indicators Research*, 46, 137-155.
- Matsumura, S., Bitto, S., Liu, H., Kahn, K., Fukuhara, S., Kagawa-Singer, M., et al. (2002). Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. *Journal of General Internal Medicine*, 17(7), 531-539.
- McLaughlin, L. & Braun, K. (1998). Asian and Pacific Islander cultural values: considerations for health care decision making. *Health & Social Work*, 23(2), 116-126.

- Meeker, M.A. (2004). Family surrogate decision making at the end of life: seeing them through with care and respect. *Qualitative Health Research*, 14(2), 204-225.
- Meeker, M. & Jezewski, M. (2005). Family decision making at end of life. *Palliative & Supportive Care*, 3(2), 131-142.
- Munro, B. (2005). *Statistical Methods for Health Care Research* (5th ed.). Philadelphia, PA: Lippincott, Williams & Wilkins.
- Nahm, E.S., & Resnick, B. (2001). End-of life treatment preferences among older adults. *Nursing Ethics*, 8(6), 533-543.
- National Institute of Aging (n.d.). End of Life: Helping with Comfort and Care. Retrieved from <http://www.nia.nih.gov/HealthInformation/Publications/endoflife/>
- National Institutes of Health. (2004). National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care. Retrieved from <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>
- Nolan T., & Bruder, M. (1997). Patients' attitudes toward advanced directives and end-of-life treatment decisions. *Nursing Outlook*, 45, 204-208.
- Noone, J. (2002). Concept Analysis of Decision Making. *Nursing Forum*, 37(3), 21-32.
- Norton, S., Tilden, V., Tolle, S., Nelson, C., & Eggman, S. (2003). Life support withdrawal: communication and conflict. *American Journal of Critical Care*, 12, 548-554.
- Patient Self-Determination Act. (1995). Final Revisions: Vol. 60. No. 123, page 33294
Retrieved from <http://www.cobar.org/docs/psda.pdf?ID=181>

- Pearlman, R., Cain, K., Starks, H., Cole, W., Uhlmann, R., & Patrick, D. (2000). Preferences for Life Sustaining Treatments in Advance Care Planning and Surrogate Decision Making. *Journal of Palliative Medicine*, 3, 37-48.
- Phipps, E., True, G., & Harris, D. (2003). Approaching the end of life: attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *Journal of Clinical Oncology*, 21, 549-554.
- Prendergast, T., & Puntillo, K. (2002). Perspectives on care at the close of life - Withdrawal of life support: intensive caring at the end of life. *Journal of the American Medical Association*, 288(21).
- Pruchno, R. A., Lemay, E. P., Field, L., & Levinsky, N. G. (2006). Predictors of patient treatment preferences and spouse substituted judgments: The case of dialysis continuation. *Medical Decision Making*, 26, 112-121.
- Russ, A., & Kaufman, S.R. (2005). Family Perceptions of Prognosis, Silence, and the “Suddenness” of Death. *Culture, Medicine & Psychiatry*, 25(1) 103-123.
- Schirm, V., Sheehan, D., & Zeller, R. (2008). Preferences for Care Near the End of Life: Instrument Validation for Clinical Practice. *Critical Care Nursing Quarterly*, 31 (1), 24-32.
- Seidel, H.M., Ball, J.W., Dains, J.E., & Benedict, G.W. (1999). Cultural awareness. In: *Mosby's Guide to Physical Examination* (4th ed.). St Louis, Mo: Mosby.
- Sparks, L. (2008). Family decision-making. In W. Donsbach (Ed.), *The International Encyclopedia of Communication*. Oxford, UK and Malden, MA: Wiley-Blackwell.
- Statistical Package for Social Sciences, version 14.0 software (SPSS Inc, Chicago, Ill).

Statistical Package for Social Sciences, version 18.0 software (SPSS Inc, Chicago, Ill).

Sulmasy, D. P., Terry, P. B., Weisman, C. S., Miller, D. J., Stallings, R. Y., Vettese, M. A., et al. (1998). The accuracy of substituted judgments in patients with terminal diagnoses. *Annals of Internal Medicine*, 128, 621-629.

Swigart, V., Lidz, C., Butterworth, V., & Arnold R. (1996). Letting go: family willingness to forgo life support. *Heart & Lung: The Journal of Acute and Critical Care*, 25(6). Retrieved from <http://80-gateway.ut.ovid.com.prx.hml.org/gw1/ovidweb.cgi>

Tabachnick, B., & Fidell, L. (2007). *Using Multivariate Statistics* (5th ed.). Boston, MA: Allyn and Bacon.

The International Encyclopedia of Communication. (2008). W. Donsbach (Ed.). Oxford, UK and Malden, MA: Wiley-Blackwell.

Tilden, V., Tolle, S., Nelson, C., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research*, 50(2), 105–115.

Tilden, V., Tolle, S., Nelson, C., Thompson, M., & Eggman, S.C. (1999). Family decision making in foregoing life-extending treatments. *Journal of Family Nursing*, 5(4), 426-442.

Tschann, J.M., Kaufman, S.R., & Micco, G.P. (2003). Family involvement in end-of-life hospital care. *Journal of the American Geriatrics Society*, 51(6). Retrieved from <http://80-gateway.ut.ovid.com.prx.hml.org/gw1/ovidweb.cgi>

US Census Bureau. (2004). Profile of General Demographic Characteristics: 2000 Data Set: Retrieved from

http://factfinder.census.gov/servlet/QTable?_bm=n&_lang=en&_qr_name=DEC_2000_SF1_U_DP1&ds_name=DEC_2000_SF1_U&geo_id=04000US15

U.S. Census Bureau. (2008). 2008 Population Estimates. Retrieved from

http://factfinder.census.gov/servlet/SAFFPopulation?_submenuId=population_0&_sse=on

Valente, S., & Haley, B. (2007). *Culturally diverse communities and end-of life care.*

American Psychological Association, Washington, DC. Retrieved from

<http://www.apa.org/pi/eol/fsculturallydiverse.pdf>

Vig, E.K., Taylor, J.S., Starks, H., Hopley, E.K., & Fryer-Edwards, K. (2006). Beyond substituted judgment: how surrogates navigate end-of-life decision-making.

Journal of the American Geriatrics Society, 54(11), 1688-1693.

Ward, L. (2003). Race as a Variable in Cross Cultural Research. *Nursing Outlook*, 51, 120-125.

Wiegand, D. (2006). Families and withdrawal of life-sustaining therapy: state of the science. *Journal of Family Nursing*, 12(2).

Williams, N., Dunford, C., Knowles, A., & Warner, J. (2007). Public attitudes to life-sustaining treatments and euthanasia in dementia. *International Journal of Geriatric Psychiatry*, 22(12), 1229-1234.

Winter, L., & Parks, S. (2008). Family Discord and Proxy Decision Makers' End of Life Treatment Decisions. *Journal of Palliative Medicine*, 11, 1109-1112.

Yeo, G. & Hikuyeda, N. (2000). Cultural issues in end-of-life decision making among Asians and Pacific Islanders in the United States. In K. Braun, J.H. Pietsch, P.L.

Blanchette (Eds.), *Cultural Issues in End-of-Life Decision Making*. Thousand Oaks, CA: Sage Publishers.

Zettel-Watson, L., Ditto, P., Danks, J., & Smucker, W. (2008). Actual and Perceived Gender Differences in the Accuracy of Surrogate Decisions about Life Sustaining Medical Treatments among Older Spouses. *Death Studies*, (32), 273-290.