CLINICIAN ATTITUDES CONCERNING ETHICAL PRACTICE IN NUTRITION CARE:

A.S.P.E.N. MEMBER PRESPECTIVE

A thesis submitted in partial fulfillment of the requirements
For the degree of Master of Science in
Family & Consumer Sciences

by

Nader Nagy Armanios

May, 2015
The graduate thesis of Nader Armanios is approved:

________________________________________________________________________

Denise Baird Schwartz, MS, RD, CNSC, FADA, FAND, FASPN

________________________________________________________________________

Annette Besnilian, EdD., MPH, RDN, CLE, FAND

________________________________________________________________________

Elizabeth Sussman, PhD., RD

California State University, Northridge
ACKNOWLEDGMENT

I would never have been able to complete my Master’s and Thesis without the provision of my committee members, help from friends, and love and support from my family.

I wish to express my sincere gratitude to Dr. Annette Besnilian for giving me a second chance to pursue my passion while everyone else denied me this chance. I am forever grateful and indebted to her for giving me the opportunity to be part of the dietetic internship and later advocating on my behalf to complete this Master’s Thesis.

I am also grateful for meeting Denise Baird Schwartz along this wonderful journey that started with the dietetic internship. Denise has become a true inspiration to me and a treasured mentor whom I refer to for guidance, supervision, and wisdom. I grateful to have become part of her legacy and wish to continue on with her vision.

I would like to also express gratitude to Dr. Elizabeth Sussman who willfully agreed to head my graduate committee and provide me generously with all the help, support, and direction needed. I am thankful to have had such a great chair to my graduate committee.

Foremost, I would like to thank my family and friends: my parents Nagy Armanios and Mona Barsoum, my sisters Noha and Nada Armanios, and those close to my heart Carol Keriacoss, and John Abd-El-Malek for being there for me throughout this long journey. They have provided nothing but unconditional love and support, and have been there for me a backbone which kept me standing on my feet at times of failure before success. I am thankful every day to have such a tremendous support system to turn to any time.

I thank God every day for bringing all these people in my life to allow me to accomplish goals I never thought I can achieve in my lifetime. Thank you, God.

"Great success is built on failure, frustration, even catastrophe." ~ Sumner Redstone
# TABLE OF CONTENTS

Signature Page .......................................................................................................................... ii  
Acknowledgment ................................................................................................................... iii  
List of Tables .......................................................................................................................... vi 
List of Figures ....................................................................................................................... vii  
Abstract ................................................................................................................................ viii  

## CHAPTER 1: INTRODUCTION .......................................................................................... 1  
- Statement of the Problem ................................................................................................. 2  
- Purpose ............................................................................................................................... 2  
- Research Questions .......................................................................................................... 3  
- Hypotheses ......................................................................................................................... 3  
- Definitions .......................................................................................................................... 3  
- Assumptions ....................................................................................................................... 5  
- Limitations ........................................................................................................................ 5  

## CHAPTER 2: LITERATURE REVIEW ............................................................................. 6  
- History and Background of End-of-life Decision Making ............................................... 6  
- Current Practice and Beliefs of Decision Making ............................................................ 6  
- Current Approaches on End-of-Life Nutrition Support ................................................... 11  
- Summary .......................................................................................................................... 12  

## CHAPTER 3: METHODOLOGY ...................................................................................... 13  
- Survey Tool Assembly ...................................................................................................... 13  
- Assessment of Survey Tool Responses ........................................................................... 14  

## CHAPTER 4: RESULTS .................................................................................................. 16
Results from the Evaluation by Experts ................................................................. 16
Survey Results from A.S.P.E.N. Members ............................................................. 20
Pearson Chi-square and Fischer’s Exact Test ....................................................... 21

CHAPTER 5: DISCUSSION/CONCLUSION ......................................................... 28
Discussion ............................................................................................................. 28
Limitation ............................................................................................................. 30
Conclusion ........................................................................................................... 30

REFERENCES .................................................................................................... 32
APPENDIX A: International Clinical Ethics Section Core Advisers ..................... 37
APPENDIX B: Initial Survey Statements Evaluation ............................................. 40
APPENDIX C: A.S.P.E.N. Survey on Clinical Ethics ............................................ 41
LIST OF TABLES

Table 1. I.C. Ethics Advisers Initial Survey Evaluation .......................................................... 17

Table 2. Expert Panel Secondary Evaluation .............................................................................. 19

Table 3. Descriptive Characteristics ......................................................................................... 21

Table 4. Disciplines Rank Clinician Action Statement ............................................................. 26

Table 5. Disciplines Rank Healthcare Institution Action Statement .......................................... 27
LIST OF FIGURES

Figure 1. Steps to the Survey Development and Results Analysis ........................................ 17

Figure 2. Systemic process inquiry ......................................................................................... 23

Figure 3. Clinician action statements based on highest rank .................................................. 24

Figure 4. Healthcare institution action statements based on highest rank ......................... 25
ABSTRACT

CLINICIAN ATTITUDES CONCERNING ETHICAL PRACTICE IN NUTRITION CARE:

A.S.P.E.N MEMBER PERSPECTIVE

by

Nader Nagy Armanios

Master of Science in

Family Consumer Sciences

The purpose of this thesis was to develop a survey to identify current practice and attitudes of the American Society for Parenteral Enteral Nutrition (A.S.P.E.N.) members and assess needs for change and enhancement in dealing with ethical dilemmas in the healthcare setting. With the present day biomedical technological advancement, questions about clinician attitudes concerning ethical practice specifically with nutrition therapies arise. The controversy to initiate or continue nutrition support in some patients remains especially without a standardized systemic approach in place. The International Clinical Ethics Section (I.C. Ethics) of A.S.P.E.N. developed this survey to identify current practice and attitudes of A.S.P.E.N. members and assess education needs. Survey questions were assembled with input from 20 I.C. Ethics’ members, representing international clinicians from medicine, dietetics, pharmacy, and nursing with different levels of experience and two academic advisers. The A.S.P.E.N. office entered the survey into SurveyMonkey software to send to all A.S.P.E.N. members introduced in a newsletter. Results of the survey tool suggested that most clinicians are in agreement with what is imperative to minimize ethical dilemmas and improve end-of-life decision making. Overall, there was no significant difference between disciplines in how to improve clinical ethics application in nutrition care. Therefore, further research should investigate the possibility of
establishing standardized practice guidelines which will allow clinicians to incorporate evidence-based practice in bioethics and nutrition support.
CHAPTER I
INTRODUCTION

As the healthcare system advances and progresses in the modern day, questions about ethical dilemmas also arise, often involving nutrition. From media popular cases, such as Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo, and many other cases that go by without notice, the controversy to initiate or continue nutrition support remains a significant concern (Tanner, 2005). For a certain individual, best care may mean withholding nutrition support because the risks and burdens outweigh the benefits as observed by the cognizant patient, family, caregiver, or surrogate decision maker (Schwartz, & Pontes-Arruda, 2014).

End-of-life decisions remain influenced by various factors such as the troubling trichotomy which is identified as the “can” of life support technology, the “should” of bioethics, and the “must” of the law (Barrocas, 2006). Ethical dilemmas involving these factors may easily be prevented if healthcare institutions and clinicians follow a systematic approach to resolving such issues and impasses (Barrocas, 2006). Most institutions have a bioethics committee under which decisions on ethical dilemmas are made on case-by-case basis (Pearlman, 2013). Ethical dilemmas inevitably will arise in the healthcare setting; they existed prior to the development of the modern day evidence-based practice. Attending to evidence-based practice is an important component of the ethical decision-making process in medicine (Christiansen and Lou, 2001). Without scientific research, the care provider would simply be providing a theory compared to a verified fact. (Drazen, Solomon, Greene, 2013).

Legal factors about end-of-life care are important to consider (Meisel et al., 2000). Patients/families, and care providers often find themselves considering clinical actions they may see as appropriate, but may raise legal concerns. Myths and misconceptions persist about what is ethically and legally acceptable (Meisel et al., 2000). Among the most common legal myths
regarding end-of-life care is withholding/withdrawing of artificial nutrition and hydration (ANH) in the critically ill patients (Meisel et al., 2000).

**Statement of the Problem**

Due to the increased sensitivity of the discussion on end-of-life, clinician and institutions have not been able to set a standard care practice (Barrocas, 2006). Advance directives (AD) and Physician Orders for Life-Sustaining Treatment (POLST) have helped over the years to improve the process which surrounds ethical dilemmas and end of life. Yet, only between 18% and 30% of Americans have completed an AD. Patients of all backgrounds tend to develop mistaken beliefs toward ADs and POLSTs such as fear of early withdrawal of care, and neglect manifested in poor care management (Maller, 2013).

Existing research in artificial nutrition and bioethics face many limitations; such as (a) lack of scientific data, (b) narrowed position on the topic that may or may not be generalized to standard practice, (c) absence of measurable outcomes for improving quality of life at the end-of-life stage (Christiansen and Lou, 2001; Barrocas, 2006; and Tamburini, 2003).

**Purpose**

The purpose of this research is to determine if members of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) have already developed a proactive, integrative, systemic process that addresses nutrition support and clinical ethics in their current practice. This research also aims to survey members of A.S.P.E.N. to identify what they feel is most important to include as part of standard care process involving clinical ethics. It is also the intent of this research to determine if there are differences between and among disciplines (physicians, dietitians, pharmacists, and nurses). This research will provide a knowledge base to add to the current literature and will help direct future studies to important areas of interest. This survey,
potentially, could be the corner stone for developing standardized end-of-life care, dealing with nutrition support.

**Research Questions**

Q1: Is there a significant difference between respondents’ primary role in nutrition support to ranking clinician actions as most important to integrate clinical ethics into nutrition support practice?

Q2: Is there a significant difference between respondents’ primary role in nutrition support to ranking healthcare institution actions as most important to integrate clinical ethics into nutrition support practice?

**Hypotheses**

Based on the review of literature in Chapter 2, the following research hypotheses were developed.

1. There will be significant differences among disciplines in ranking clinician actions as most important.

2. There will be significant differences among disciplines in ranking healthcare institution actions as most important.

**Definitions**

1. **Advance Directive.** A written instruction, such as a living will or Durable Power of Attorney for Health Care (DPAHC), recognized under state law, relating to the facilitation of healthcare when individual is incapacitated. (National Hospice and Palliative Care Organization, 2013).

2. **American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.).** Interdisciplinary organization founded in 1976 made up of ~6000 members including dietitians, physicians, pharmacists, and nurses which aims to advance the science and practice of
clinical nutrition. Most members are involved with overlooking clinical nutrition therapy in their practice and specifically parenteral and enteral nutrition (A.S.P.E.N., 2015).

3. **End of life.** Individuals with advance incurable illnesses (acute and/or long-term) who are expected to die within the next twelve months (Shuker, & Newman, 2014).

4. **Physician Orders for Life-Sustaining Treatment (POLST).** A form that gives critically ill patients the choice in regards to their end-of-life care (e.g. medical treatment, life-sustaining measures, such as mechanical ventilation, feeding tubes, and cardiopulmonary resuscitation) (California POLST, 2015).

5. **Clinician Action Statements.** As defined by the survey in question one: a) prevent ethical dilemmas with early communication with patient, family, and/or surrogate decision maker about patient wishes for life-sustaining treatments for short and long-term, b) incorporate evidence-based medicine on benefits versus risk/burdens of nutrition support, c) include ethical decision making for nutrition support into clinical practice d) achieve early communication with clinicians, patients, and family through family care meetings, e) utilize shared decision making and health literacy in nutrition support education (Appendix C).

6. **Healthcare Institutions Action Statements.** As defined by the survey in question two: a) establish a process to obtain advance directives, Physician Orders for Life-Sustaining Treatment (POLST) and/or begin early discussion of healthcare wishes, b) meet individuals’ needs with informed healthcare decision makers and consistent healthcare team approach, c) develop a proactive, integrated systematic process, including policies and procedures for ethical decision making for nutrition support, d) consult or involve
palliative care teams early for the critically ill patient or individuals near end of life, e) promote interprofessional roles in clinical ethics and communication (Appendix C).

Assumptions

This thesis was created based upon certain assumptions.

- All participants are A.S.P.E.N. members.
- Participants will fill out the survey without pressure from others.
- Participants will be able to read and write in English, the language of the survey.
- Participants will be able to comprehend the survey questions.
- Participants will complete the survey truthfully as they believe without any pressure.
- Participants will complete all survey questions.
- All data was entered and analyzed correctly.

Limitations

This survey will help add a new perspective to current literature as it will help identify present practices and recognize needs for change. However, certain limitations remain.

- The survey tool used was constructed by the investigators with the help of an expert panel and has not been validated.
- The survey was only given to A.S.P.E.N. members; other clinicians who are not members with A.S.P.E.N. were not included in the survey.
- Questions were ranking only, not open-ended which did not allow for other thoughts and input from respondents.
- The survey was limited to healthcare professionals working in a clinical setting, and may not be generalizable.
CHAPTER II
REVIEW OF LITERATURE

History and Background of End-of-life Decision Making

At the turn of the 19th century, life expectancy was approximately 41 years (Cutler, Deaton, & Lleras-Muney, 2006). Compassionate care was once a physician’s only tool available to treat his/her patients, at the end of life. (Barry & Edgman-Levitan, 2012). During this time, physicians were trained to practice within the capacity of resources they had at hand; they were encouraged to engage patients in the conversation about their options and likelihood of survival (Jones, McCullough, & Richman, 2008). It was the attention to the patient’s needs and their symptoms manifested in their illness that marked the special relationship between the patient and their doctor (Kaba & Sooriakumaran, 2007).

Current Practice and Beliefs of Decision Making

Today, Americans are living longer (Brugger et al., 2013). By 2030, more than 20% of the United States population are expected to be 65 years of age and older, compared with 13% in 2010 and 9.8% in 1970 (US Census Bureau, 2014). As the population ages, the issue of end-of-life care becomes a more familiar topic of discussion (American Psychological Association, 2015). This literature review includes published research and theories on the topic of bioethics and providing life-sustaining treatment, specifically, nutrition support. It focuses on the history of bioethics and end-of-life care, which includes decision-making regarding the continuation or cessation of artificial nutrition and hydration (ANH).

Medical Advances

With the emergence of the bio-medical model of illness at the turn of the 20th century, medicine has become more advanced with a plethora of available therapies, such as vaccines, drugs, and intricate procedures (Cutler, Deaton, Lleras-Muney, 2006; Kaba & Sooriakumaran,
The patient-physician relationship began to transform from physicians treating patients to physicians treating diseases. The new bio-medical model of illness suggested that symptoms were no longer the disease; rather, symptoms suggested the possibility of the presence of an underlying issue. Physicians were forced to expand and develop their clinical expertise and anatomical understanding to correctly diagnose and treat patients (Kaba & Sooriakumaran, 2007). The outcome was a disease-centered approach to care, where physicians were trained to view patients merely as complex cases requiring special assessment (Green, Carrillo & Betancourt, 2002). Today in the 21st century with the significant advancement in biomedical technology, the healthcare system is moving beyond the bio-medical model of illness and incorporating the biological, psychological and social aspects of the patient’s illness. The patient and their family are now being reinserted as part of the decision-making process (Gabriel & Normand, 2012; Anjum, 2014). As an example of patient-inclusive decision making, Stewart et al., conducted an observational study which revealed that patient-centered care and good communication between the patient and physician predisposed patient’s health through positive perception. Positive perception was associated with improved outcome, and enhanced patients’ emotional state (Stewart et. al., 2000). Another study, considering stroke patients and the ethical issues regarding transparent communication between the healthcare team and the family in the post-stroke rehabilitation phase, revealed that communication, availability, and attitudes of the interdisciplinary team was key to better management (Rochette et. al., 2014). Yet, only one third of primary care physicians, as of 2006, have adopted patient-centered approach in their primary care setting (Audet, Davis, & Schoenbaum, 2006). There is more work to be done to reach an altogether patient-centered care health system where quality of life is the center of care.
Quality vs Quantity

With all these advances, perhaps the next question is what is more important: quantity of life or quality of life? Modern medicine has helped add more years to the life expectancy of people. During the olden days, a heart attack or stroke simply indicated end of life, however today stents, bypasses, and many other treatment can add significantly to an individual’s life expectancy (Quality vs Quantity, 2013). The medical school curriculum is merely focused on the success of clinical interventions and the measure of benefits (Schapira, 1999). These benefits are usually defined as the number of years added to life (Lankarani, 2013), however it may not be accurate to define success only by years of life. Quality of life is a fluid-like concept which is defined differently between one individual and another. It marks the differences in social, psychological, demographic, and other cultural upbringings (Tamburini, 2003). Notably, quantity of life is simpler to measure versus quality of life, which is more complex and multifaceted to pinpoint. Despite the contest, the utilization of the many ‘quality of life’ instruments and measures available in current literature is key to improving the clinical practice. This will serve as common ground to improved individual care. (Tamburini, 2003). It can be suggested that quality of life may yield an increase in quantity (defined as years) but quantity does not necessarily equate to quality.

Bioethical Considerations

Bioethics, a fairly new area of medicine, began to evolve in the late 1960s to early 1970s with the Catholic moral tradition becoming the founding body addressing ethical dilemmas in the clinical care setting (Brody, et al., 2011). During the early beginning of bioethics development, mechanical ventilation was not a common medical intervention among healthcare institutions; as a result the Catholic founders of bioethics referred to artificial nutrition mostly as the ultimate
burdensome measure for prolonging life (Betowski, 1960). In an address to an International Congress of Anesthesiologists in 1957, Pope Pius XII presented the Catholic stance and emphasized the importance of alleviating pain while allowing patients to peacefully pass away (Pope Pius XII, 1957). The common belief among Catholics was that man is indebted to maintain his life through ordinary means, only; however, not obliged to partake in extraordinary measures (Betowski, 1950). Today the Catholics have not changed much. Pope Francis’ most recent address to the Pontifical Academy for Life speaks to the importance of palliative care for the elderly to alleviate suffering in the final phase of life to ensure quality of life (Pope Francis, 2015).

Bioethics then progressed to ascertain patient-centered care, focusing on patient rights and autonomy (Brody, et al., 2011). Patients with the ability to voice their wishes are ethically the ultimate decision makers, and when capacity for decision making is lacking, the authority of care is transferred over to a surrogate decision maker under which they are able to refuse, forgo, and/or withhold any type of intervention they may see or feel is unnecessarily prolonging life. The decision is no longer up to the physician’s discretion (Pellegrino, 2000). During the early years of bioethics, little data was available regarding artificial nutrition and hydration (ANH) – it was unknown if it was categorized under life-sustaining treatments or not (Hoffman, 1986). Here began the debate. Is ANH a life-prolonging therapy under which a patient or a decision maker may refuse? Or is it a basic need, not a treatment, which must be provided regardless of wishes? (Protection of Human Subjects, 1983).

Two core arguments came about ANH: 1) Medical nutrition (nutrients delivered through a tube or intravenously) is always indicated as a necessary mean of comfort and dignity to the patient; a mere focus on the extra-ordinary measure of providing artificial nutrition. 2) Medical
nutrition and non-medical nutrition (food and fluids consumed orally) serve the same purpose and convey care and compassion…starvation does not provide care and compassion; a contrast view that all nutrition is an ordinary basic need for life (Hoffman, 1986). Those who supported the compulsory use of ANH argued that acting otherwise threatened the relationship between the physician and the patient (Siegler & Weisbard, 1985). On the contrary, bioethicists supporting the right of patient to refuse ANH argued that withholding feeding and hydration during the end of life does not necessarily equate to the common felt hunger and thirst (Cohen, 1988).

Regardless of which argument one supports, any medical treatment nearing the ‘dying phase’ should merely be focused on the comfort and wishes of the patient (Raijmakers et. al., 2010).

**The Law**

Decisions on providing ANH and/or withholding requires a consideration of not just bioethics but also legal values. It is a legal obligation to obtain patient/surrogate decision maker’s consent to start or withdraw ANH. Not respecting the individual’s wishes may hold the clinician liable to legal action (National Collaborating Centre for Acute Care, 2006). The competent adult, with capacity, has the total right to make any decision regarding their care or their loved one’s care even if refusal will result in potential death of the patient (National Collaborating Centre for Acute Care, 2006). An individual is deemed competent to make informed choices if they are able to form rational thoughts and make voluntary decisions (Maillet, Schwartz, Posthauer, 2013). If there is any doubt with regards to an individual’s capacity to make informed decisions, legal advice should be warranted and if need be, the decision can be made by the Court of Law (National Collaborating Centre for Acute Care, 2006).
Current Approaches on End-of-Life Nutrition Support

A.S.P.E.N & Academy of Nutrition & Dietetics (AND) Position

In 2010, A.S.P.E.N. provided guidelines on end-of-life nutrition support for clinicians caring for patients and families involved with ethical concerns on ANH (Barrocas, et. al., 2010). Decisions taken with regards to ANH require the incorporation of evidence-based medicine (EBM), the ability to assess risks versus benefit and use clinical judgment, and effective communication with patients, families, and/or surrogate decision makers (Barrocas, et. al., 2010).

Further, the position of the Academy of Nutrition and Dietetics (AND) states that patient, families, and surrogate decision makers have the right to request or refuse ANH as a medical intervention (Maillet, Schwartz, Posthauer, 2013). As members of the interdisciplinary medical team who are directly involved in the nutrition care planning of patients, registered dietitians (RDs) shall have adequate knowledge in clinical nutrition, ethical decision making, and communicative skills. Dietetic practitioners directly involved with nutrition support assume responsibility to continue to improve their knowledge and skill set when to maintain reliability within the interprofessional team (Schwartz, 2015). RDs can become the bridge that connects the communication between patients and decision makers, and the medical team, concerning ANH (Maillet, Schwartz, Posthauer, 2013; Schwartz, 2015).

Advance Directives (AD) and Physician Orders for Life-Sustaining Treatment (POLST)

As an additional measure of communication among the aforementioned parties, ADs and POLSTs can be utilized to further express patients’ wishes for end-of-life care and minimize ethical dilemmas. The efficacy of ADs and POLSTs in the critically ill patients has been thoroughly researched. Through a cross-section design of 58,000 individuals who passed away from 2010-2011, approximately 18,000 had a completed POLST. Results suggest that those with a completed POLST always receive the treatment they wished for, whether comfort measures
only, limited intervention, or full treatment (Fromme, et. al., 2012). The study revealed that 6.4% of patients who chose comfort measures only died in a hospital, compared with 22.4% and 44.2% of patients who chose limited intervention and full treatment, respectively. Furthermore, about 34.2% of patients who did not complete a POLST died in a hospital (Fromme, et. al., 2012). In a different study which focused on outcomes of the medical decision-making process by AD status, they found that the presence of an AD in the patient’s chart during their hospitalization received the necessary treatment as explained in their written will (AD) versus those without an AD in their medical chart (Shapiro, 2015).

**Summary**

Bioethics is a short-lived area of science yet very impactful to the lives of many individuals (Brody, et al., 2011). It has yet to be more developed and further understood by the healthcare professionals who are directly dealing with ethical cases. With cultural differences and diversified societies the current debate will remain an active issue. Training young healthcare professionals is essential to establishing the foundation of knowledge and communication while understanding the law. It is imperative to further utilize POLSTs and ADs to minimize ethical dilemmas in the clinical care setting (Maller, 2013; Brugger, et al., 2013).
CHAPTER III
METHODOLOGY
In this chapter, the research method and design for this survey is illustrated. The purpose of this survey tool is to identify current practice of A.S.P.E.N. members in bioethics, and determine needs for change. The location and methods for selecting the subjects are explained in this chapter. This study involved a survey design, and quantitative analysis of the responses as further explained below.

Survey Tool Assembly

Expert Selection Procedure for evaluating the tool

The survey was created as part of the International Clinical Ethics Section (I.C. Ethics) of A.S.P.E.N., using a literature review of the past five years identifying suggested actions by hospitals and clinicians to optimize clinical ethics in nutrition care. Twenty members of the I.C. Ethics section, and two advisers from California State University, Northridge (CSUN) contributed as core advisers in the construction of the survey, and two researchers, the chair of the I.C. Ethics Section, and a CSUN student member of I.C. Ethics Section (Appendix A). All advisers were carefully chosen based on their involvement, experience, and expert knowledge in bioethics. The expert panel represented an interprofessional international clinicians from medicine, dietetics, pharmacy, nursing, and academia with different levels of experience. None of the members received any compensation or reimbursement for evaluating the survey tool.

Expert Survey Tool Evaluation Process

The twenty-two expert panel members participated in a two-step process to evaluate the survey. The first step consisted of general feedback and content review of the overall survey from the twenty I.C. Ethics members. They evaluated 10 statements (Appendix B) about Clinical Ethics from the A.S.P.E.N. Core Curriculum 2012, the past 5 years of literature on the topic, and
the Institute of Healthcare Improvement (IHI) Conversation Ready Health Care Community for organizations committed to working to develop reliable care processes based on specific core principles. Each adviser from the I.C. Ethics section was electronically mailed a chart with the 10 items and asked to rank each item in order of importance. Feedback was considered by the investigators and necessary changes were applied. The strongest selected statements were incorporated into the survey tool in addition to general demographic questions. The investigators then used the format of the general A.S.P.E.N. Membership Survey (required 15 minutes to complete) given to A.S.P.E.N. members in April 2014 with content modification/reduction to allow the survey to be completed in approximately 5-10 minutes. The expert panelists were then consulted once more on the second step of the evaluation process. The second step included 17 experts from the I.C. Ethics section and the 2 academic advisers. Each expert was asked to complete the finalized survey tool based on three defined components: a) timeliness of completion, b) conciseness of content, and c) clearly defined purpose of the survey. They were asked to give a score from 1-5 to each of the above components. The scores were added and divided by the maximum points available, separately for each component. It was decided by the investigators consensually that a score of 70% and above was considered acceptable; any score below 70% required a modification.

Assessment of Survey Tool Responses

The completed survey (Appendix C) was announced through a weekly electronic newsletter available only to A.S.P.E.N. members. A three week return period was specified to maintain reliability that respondents were nutrition support clinicians. The participants were all clinicians from multiple disciplines who were directly involved in nutrition support practice. Since the study was not conducted on human trials, and was a survey, it was exempt from an institution review board (IRB) approval as noted by the California State University, Northridge
IRB. The survey ensured privacy and confidentiality by using an independent software, SurveyMonkey. SurveyMonkey is an online survey software which uses secure sockets layer (SSL) to protect sensitive information and ensure anonymity, and offer Health Insurance Portability and Accountability Act (HIPPA) compliant features.

**Survey collection and analysis**

After a 3-week return period the survey was made unavailable by being removed from SurveyMonkey. Qualitative, descriptive analysis was performed by the A.S.P.E.N. office using the SurveyMonkey option for analyzing surveys on the completed 154 surveys. Further statistical analysis was conducted using SPSS 22.0 software (IBM, Armonk, NY). Chi-square test and Fischer’s exact test were applied to analyze differences among disciplines and additional data on ranking of clinician and healthcare institution action statements; p<0.05 was considered significant. It is important to note that statistical analysis was only performed on questions that addressed the investigator’s research questions. Researchers only looked at the highest ranked action statement by clinicians. The reason only the highest ranked statement was considered is that investigators wanted to research if there are any differences in how disciplines, and the population they are directly involved with in their practice affected which statement the respondents thought was most important.
CHAPTER IV

RESULTS

The purpose of this research was to determine if members of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) have developed a proactive, integrative, systemic process that addresses nutrition support and clinical ethics in their current practice. This research also aimed to survey members of A.S.P.E.N. to identify what they feel is most important to include as part of standard care process involving clinical ethics. It was also the intent of this research to determine if there are differences between and among disciplines (physicians, dietitians, pharmacists, and nurses). In order to appropriately determine what clinicians felt is more important to include as part of standard practice, a survey tool was created. This chapter will discuss: (1) the results from the construction of the survey tool with input from the expert panel chosen by the researchers, (2) the results from the statistical analysis of the pilot run of the survey tool validation through the online software SurveyMonkey.

Result from the Evaluation by Experts

During the development of the survey (figure 1), 10 statements (Appendix B) were submitted to 20 I.C. Ethics members for content review and legitimacy. The experts scored each proposed statement giving it a score of (1-5); the total maximum points for each statement was 100. All statements received at least 87% or above agreement from the core advisers as seen in Table 1 making all statements appropriate for inclusion in the survey.

During the second step of the evaluation and construction of the survey, the responses of the academic advisers were added to the twenty I.C. Ethics member experts and were asked to take the full survey and give the following defined components a score from (1-5): 1) timeliness of completion, 2) conciseness of content, 3) clearly defined purpose of the survey. Seventeen I.C. Ethics advisers and two academic advisers completed the second step of the evaluation making
the maximum number of points 100 for all three categories (table 2). The highest scored was item 1 (timeliness of completion), receiving 84%, followed by item 2 (conciseness of content) receiving 83%. Item three (clearly defined purpose) received a score of 78%.

Figure 1. Steps to the Survey Development and Results Analysis

Table 1

I.C. Ethics Advisers Initial Survey Evaluation

Ranking of initial 10 statements (Appendix B) for inclusion in survey

<table>
<thead>
<tr>
<th>Name</th>
<th>#1</th>
<th>#2</th>
<th>#3</th>
<th>#4</th>
<th>#5</th>
<th>#6</th>
<th>#7</th>
<th>#8</th>
<th>#9</th>
<th>#10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diego Arenas Mayo, MD</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Humberto Arenas Márquez, MD</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>David A. August, MD</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Albert Barrocas, MD, FACS, FASPEN</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Kelly Green Corkins, MS, RD, LDN, CNSC</td>
<td>3</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Yimin Chen, MS, RD, CNSC</td>
<td>5</td>
<td>3</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Eric H. Frankel, MSE, PharmD, BCNSP</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Five year literature review. Clinician + Healthcare Institutions action

Action statements submitted for review by the 20 I.C. Ethics Section members.

Approved statements were integrated in the overall survey.

Overall survey tool submitted for evaluation by 22 expert panel members (including academic advisers).

Final survey tool completed & submitted to A.S.P.E.N. to include in the next newsletter to all members.

Results from the survey were analyzed using SPSS software.
<table>
<thead>
<tr>
<th>Name</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trisha Fuhrman MS, RDN, LD, FAND</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Carol Ireton-Jones, PhD, RDN, LD, CNSC,</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>FACN, FASPEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mitchell Kaminski, MD</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Lucinda K. Lysen, RD, LD, RN, BSN</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Laura Matarese, PhD, RD, LDN, CNSC,</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>FADA, FASPEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carol McGinnis, MS, RN, CNSN</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Laura Matarese, PhD, RD, LDN, CNSC,</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>FADA, FASPEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lucinda K. Lysen, RD, LD, RN, BSN</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Laura Matarese, PhD, RD, LDN, CNSC,</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>FADA, FASPEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carol McGinnis, MS, RN, CNSN</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Cheryl Monturo, PhD, MBE, ACNP-BC</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>1*</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Debbie Motley RD MPH CNSC</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Alessandro Pontes-Arruda, MD, MSc, PhD,</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>FCCM</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Martine Sealy, BSc</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>5</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Kirsten Shell, PharmD, BCPS</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Christina Valentine, MD, MS, RD</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>John R. Wesley, MD, FACS, FAAP,</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>FASPEN</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>93</td>
<td>88</td>
<td>91</td>
<td>88</td>
<td>95</td>
<td>87</td>
<td>91</td>
<td>92</td>
<td>91</td>
<td>90</td>
</tr>
</tbody>
</table>
### Table 2

*Expert Panel Secondary Evaluation. Score 1-5*

<table>
<thead>
<tr>
<th>Name</th>
<th>#1</th>
<th>#2</th>
<th>#3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diego Arenas Mayo, MD</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Humberto Arenas Márquez, MD</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>David A. August, MD</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Albert Barrocas, MD, FACS, FASPEN</td>
<td>4</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td><strong>Annette Besnilian, EdD, MPH, RD, FAND</strong></td>
<td>4</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Kelly Green Corkins, MS, RD, LDN, CNSC</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Yimin Chen, MS, RD, CNSC</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Eric H. Frankel, MSE, PharmD, BCNSP</td>
<td>5</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Trisha Fuhrman MS, RDN, LD, FAND</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Carol Ireton-Jones, PhD, RDN, LD, CNSC, FACN,FASPEN</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Mitchell Kaminski, MD, FASPEN</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Lucinda K. Lysen, RD, LD, RN, BSN</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Laura Matarese, PhD, RD, LDN, CNSC, FADA, FASPEN</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Carol McGinnis, MS, RN, CNSN</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Cheryl Monturo, PhD, MBE, ACNP-BC</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Debbie Motley RD MPH CNSC</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Alessandro Pontes-Arruda, MD, MSc, PhD, FCCM</td>
<td>4</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Martine Sealy, BSc</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Elizabeth Sussman, PhD, RD</strong></td>
<td>5</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Kirsten Shell, PharmD, BCPS</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>
Note. Survey Evaluation Tool. ** Academic Advisers

<table>
<thead>
<tr>
<th></th>
<th>5</th>
<th>5</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christina Valentine, MD, MS, RD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>John R. Wesley, MD, FACS, FAAP, FASPEN</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL % to achieve “strongly agree” for statement</td>
<td>84/100 (84%)</td>
<td>83/100 (83%)</td>
<td>78/100 (78%)</td>
</tr>
<tr>
<td></td>
<td>n=19</td>
<td>n=19</td>
<td>n=19</td>
</tr>
</tbody>
</table>

1) Can be completed in a short period of time (84% total average). 2) Concise and easily understood (83% total average). 3) Goals are clearly defined from the beginning (78% total average).

**Survey Results from A.S.P.E.N. Members**

Of the 167 respondents, 154 completed the survey. Only completed surveys were analyzed; 88% of respondents practiced in the USA, and 12% worked outside the USA as shown in Table 1. Dietitians represented the largest group at 70%, pharmacists (14%), physicians (8%), nurses and nurse practitioners (4%), and the remaining respondents were researchers, educators, and students. Although the total number of respondents was small, the even distribution of regions within the USA indicated in Table 1 also added diversity of input. The hospital was identified as the primary practice setting by 88% of the respondents. Forty percent of the respondents were involved in nutrition support for over 25 years, 10% were involved in the field for five years or less. As seen in Figure 2, 48% of respondents stated that their current clinical practice has developed a proactive, integrated, systemic process, including policies and procedures for nutrition support which concludes that more than half of the clinicians who responded to this survey have yet to develop a systemic approach to prevent ethical dilemmas in the healthcare setting.
Pearson Chi-square and Fischer’s Exact Test

Pearson chi-square was conducted to examine the correlation between the two categorical variables defined in disciplines and their highest ranked action statements from questions 1 and 2 of the survey (Appendix C). Fischer’s exact test was applied given some of the cells contained less than 5 observations.

Pearson Chi-square and Fisher’s Exact Correlations

Table 4 depicts the ranking of clinician action statements that could integrate clinical ethics into nutrition support practice. Table 5 represents the ranked healthcare institution (i.e. hospitals, long-term care facilities, home health) action statements that could integrate clinical ethics into nutrition support practice. No statistical differences between and among disciplines were seen in neither clinician action statements nor healthcare institutions action statements. Clinicians, regardless of their discipline, exhibited no statistical significant difference in what they indicated as most important to include as part of standard care process involving clinical ethics neither from clinician nor healthcare institution perspective.

Table 3

*Descriptive Characteristics*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n-value</th>
<th>Response Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discipline</td>
<td>(n = 154)</td>
<td></td>
</tr>
<tr>
<td>Dietitian 107</td>
<td>107</td>
<td>69.5%</td>
</tr>
<tr>
<td>Educator 3</td>
<td>3</td>
<td>1.9%</td>
</tr>
<tr>
<td>Nurse 3</td>
<td>3</td>
<td>1.9%</td>
</tr>
<tr>
<td>Nurse Practitioner 3</td>
<td>3</td>
<td>1.9%</td>
</tr>
<tr>
<td>Pharmacist 21</td>
<td>21</td>
<td>13.6%</td>
</tr>
<tr>
<td>Physician 12</td>
<td>12</td>
<td>7.8%</td>
</tr>
<tr>
<td>Physician Assistant 1</td>
<td>1</td>
<td>0.6%</td>
</tr>
<tr>
<td>Researcher 6</td>
<td>6</td>
<td>3.9%</td>
</tr>
<tr>
<td>Student 1</td>
<td>1</td>
<td>0.6%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>5</td>
<td>3.2%</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---</td>
<td>------</td>
</tr>
<tr>
<td>Years of Experience</td>
<td>(n = 154)</td>
<td></td>
</tr>
<tr>
<td>&lt;2 years</td>
<td>3</td>
<td>1.9%</td>
</tr>
<tr>
<td>2 - 5 years</td>
<td>12</td>
<td>7.8%</td>
</tr>
<tr>
<td>6 - 15 years</td>
<td>41</td>
<td>26.6%</td>
</tr>
<tr>
<td>16 - 25 years</td>
<td>37</td>
<td>24.0%</td>
</tr>
<tr>
<td>&gt;25 years</td>
<td>61</td>
<td>39.6%</td>
</tr>
<tr>
<td>Practice Setting</td>
<td>(n = 154)</td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>135</td>
<td>87.6%</td>
</tr>
<tr>
<td>Long-term care facility</td>
<td>1</td>
<td>0.7%</td>
</tr>
<tr>
<td>Home care</td>
<td>6</td>
<td>3.9%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>12</td>
<td>7.8%</td>
</tr>
<tr>
<td>Country of Practice</td>
<td>(n = 154)</td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>136</td>
<td>88.3%</td>
</tr>
<tr>
<td>Outside USA</td>
<td>18</td>
<td>11.7%</td>
</tr>
<tr>
<td>Region</td>
<td>(n = 135)</td>
<td></td>
</tr>
<tr>
<td>West</td>
<td>37</td>
<td>27.4%</td>
</tr>
<tr>
<td>Midwest</td>
<td>38</td>
<td>28.1%</td>
</tr>
<tr>
<td>South</td>
<td>34</td>
<td>25.2%</td>
</tr>
<tr>
<td>Northeast</td>
<td>26</td>
<td>19.3%</td>
</tr>
</tbody>
</table>
Figure 2. Systemic process inquiry. Has your clinical practice setting developed a proactive, integrated, systematic process, including policies and procedures for nutrition support?

N-value = 153, Yes = 63 (41.2%), No = 73 (47.7%), N/A = 17 (11.1%)
Figure 3. Clinician action statements based on highest rank. Clinician action statements that could integrate clinical ethics into nutrition support practice based on highest rank given by respondents. A) Prevent ethical dilemmas with early communication with patient, family, and/or surrogate decision maker about patient wishes for life-sustaining treatments for short and long-term. B) Incorporate evidence-based medicine on benefits versus risk/burdens of nutrition support. C) Include ethical decision making for nutrition support into clinical practice. D) Achieve early communication with clinicians, patients, and family through family care meetings. E) Utilize shared decision making and health literacy in nutrition support education.
Figure 4. Healthcare institution action statements based on highest rank. Healthcare institution action statements that could integrate clinical ethics into nutrition support practice based on highest rank given by respondents. A) Establish a process to obtain advance directives, Physician Orders for Life-Sustaining Treatment (POLST) and/or begin early discussion of healthcare wishes. B) Meet individuals’ needs with informed healthcare decision makers and consistent healthcare team approach. C) Develop a proactive, integrated systematic process, including policies and procedures for ethical decision making for nutrition support. D) Consult or involve palliative care teams early for the critically ill patient or individuals near end of life. E) Promote interprofessional roles in clinical ethics and communication.
Table 4

Chi-square and Fischer’s Exact Test Highest Ranked Clinician Action Statements and Disciplines

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Clinician Action Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
</tr>
<tr>
<td>Dietitian</td>
<td>22 (19.8)</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>7 (33.3)</td>
</tr>
<tr>
<td>Physician</td>
<td>6 (46.2)</td>
</tr>
<tr>
<td>Nurse</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>Researcher</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

Note. $\chi^2 (2, N = 154) = 13.80, p > .05$; Fischer’s: $p > 0.5$

n = the number of times each statement received a ranking of 1. (%) = percent within disciplines.

A) Include ethical decision making for nutrition support into clinical practice decision maker about patient wishes for life-sustaining treatments for short and long-term. B) Incorporate evidence-based medicine on benefits versus risk/burdens of nutrition support. C) Prevent ethical dilemmas with early communication with patient, family, and/or surrogate. D) Achieve early communication with clinicians, patients, and family through family care meetings. E) Utilize shared decision making and health literacy in nutrition support education.
Table 5

*Chi-square and Fischer’s Exact Test Highest Ranked Healthcare Institution Action Statements and Disciplines*

<table>
<thead>
<tr>
<th>Disciplines</th>
<th>Clinician Action Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A n (%)</td>
</tr>
<tr>
<td>Dietitian</td>
<td>26 (23.4)</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>4 (19.0)</td>
</tr>
<tr>
<td>Physician</td>
<td>5 (38.5)</td>
</tr>
<tr>
<td>Nurse</td>
<td>1 (16.7)</td>
</tr>
<tr>
<td>Researcher</td>
<td>1 (33.3)</td>
</tr>
</tbody>
</table>

*Note.* $X^2(2, N = 154) = 12.78, p > .05;$ Fischer’s: $p > .05$

n = the number of times each statement received a ranking of 1. (%) = percent within disciplines.

A) Meet individuals’ needs with informed healthcare decision makers and consistent healthcare team approach. B) Promote interprofessional roles in clinical ethics and communication. C) Establish a process to obtain advance directives, Physician Orders for Life-Sustaining Treatment (POLST) and/or begin early discussion of healthcare wishes. D) Develop a proactive, integrated systematic process, including policies and procedures for ethical decision making for nutrition support. E) Consult or involve palliative care teams early for the critically ill patient or individuals near end of life.
CHAPTER V
DISCUSSION/CONCLUSION

Discussion

This research tried to investigate multiple areas that involve nutrition support clinicians and clinical ethics. The survey tool was created to match the purpose of this research. Initially, the investigators wanted to determine how A.S.P.E.N. members integrate clinical ethics into their own practice in nutrition support. Given the survey was available to only A.S.P.E.N. members, it was assumed that the majority of respondent are current practitioners in a healthcare setting; confirmed in Table 3. More than half of the clinicians who responded to this survey stated in Figure 2 that they do not have any set guidelines or policies for nutrition support at the end-of-life phase. This proposes a validation to the problem statement under which this research was based on; clinicians and institutions have not been able to set a standard care practice (Barrocas, 2006). The healthcare institutions that employs more than half of the participants lack a standard protocol to prevent and alleviate ethical dilemmas in nutrition support. It is implied that these healthcare institutions could have an increased number of bioethical cases, compared to facilities that have a standard protocol in place.

The study further aimed to survey members of A.S.P.E.N. to identify what they feel is most important to include as part of standard care process involving clinical ethics in nutrition support while determining if there are differences between and among disciplines (physicians, dietitians, pharmacists, and nurses). Figures 3 and 4 give a clear representation to how respondents felt is most important based on the percentage distribution of each action statement. The clinician action statement with the highest frequency was: to prevent ethical dilemmas with early communication with patient, family, and/or surrogate decision maker about patient wishes for life-sustaining treatments for short and long term. This is an important finding as the reader
now has a better understanding on what clinicians themselves feel with regards to important 
clinician actions. All disciplines regardless of specific profession can establish early 
communication with the aforementioned parties to coincide with patient’s wishes. It is simply 
not exclusive to only one discipline but to the whole multidisciplinary team involved in each 
patient’s care. Training young healthcare professionals is essential to establishing the foundation 
of knowledge and communication. Undergraduate education can be the first utilized area to 
 exposes students to end-of-life care issues which they can build on throughout their academic 
experience. Good communication skills underline patient-inclusive decision making and will 
reflect improved and positive outcomes (Stewart et al., 2000). On the other hand, clinicians felt 
that it is of utmost importance for healthcare institutions to establish a process to obtain advance 
directives, POLSTs and/or to begin early discussion of healthcare wishes (Figure 2). With an 
advance directive or a POLST, clinicians are able to practice and perform their duties knowing 
that the treatment measures they are offering mirror patient wishes. As already proven, those 
with a completed advance directive or POLST will always receive the treatment they wished for, 
whether comfort measures only, limited intervention, or full treatment (Fromme, et al., 2012). 
The challenge will be how to establish this process to obtain advance directives and/or POLSTs 
as a cohesive healthcare team who will allow patients and families to feel comfortable with 
indicating their wishes. It is, after all, the attitudes of the interdisciplinary team that is key to 
better care management (Rochette et. al., 2014). Overall, not seeing statistical significance 
among disciplines in both clinician and institutional action statements suggest that most 
clinicians are standing on common grounds, and have likely achieved the multidisciplinary 
cohesiveness to improve upon healthcare practices and end-of-life decision making. This in itself
proposes strength in the results achieved, although further research is needed to strengthen current findings.

**Limitations**

The limitations of this study can be summarized into one main limitation, generalizability. The survey was only offered to members of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) who are directly involved with nutrition support and so it cannot be generalized to all clinicians. Also, the survey tool used in this study has not been validated yet. Perhaps, the next step can be validating the survey tool to augment the validity and reliability of the results obtained.

**Conclusion**

Bioethics, end-of-life care, decision making, life-sustaining treatments, nutrition support all powerful keywords in the lives of the critically ill patients who are in the dying phase. This research is just one step of many needed to standardize care in bioethics. The results achieved establish an important junction in the discussion about end-of-life care practices involving nutrition support. It is not surprising that when endeavoring to answer the main research questions the results revealed no statistical significance between disciplines in respect to clinician or healthcare institution action statements in Figures 3 and 4 and Tables 4 and 5. These results are not unexpected given all respondent were A.S.P.E.N. members who are directly involved with nutrition support. Yet given the variety of disciplines and backgrounds of the respondents that participated in this research, they all came to agree on the same focus without major differences.

This survey has started a foundation for healthcare changes especially in a setting where clinicians mostly agree without significant differences. The results suggest that there are no
statistical significant differences among and between disciplines in how they rank clinician and healthcare institution action statements. The results further suggest that approximately half of the respondents practice in a facility that does not have a standardized systemic approach to prevent ethical dilemmas. Finally, the results propose the following action statements as a possible foundation for future research to build and expand on to strengthen current practices and ultimately achieve a standard care process for integrating nutrition support into bioethics 1) clinicians shall prevent ethical dilemmas with early communication with patient/family and incorporate evidence-based medicine on benefits versus risk/burdens of nutrition support; 2) healthcare institutions shall establish a process to obtain advance directives and/or begin early discussion on healthcare wishes and consistent healthcare team approach. These two action statements may serve as the cornerstones for starting a new era of bioethical practice to alleviate burdens on clinicians, patients/families, and surrogate decision makers during a time when it is difficult to make life-altering decisions.
REFERENCES


https://www.nutritioncare.org/

http://go.galegroup.com.libproxy.csun.edu/ps/i.do?id=GALE%7CA373005654&v=2.1&u=csunorthridge&it=r&p=HRCA&sw=w&authCount=1


Rochette, A., Racine, E., Lefebvre, H., Lacombe, J., Bastien, J., & Tellier, M. (2014). Ethical issues relating to the inclusion of relatives as clients in the post-stroke rehabilitation process as perceived by patients, relatives and health professionals. *Patient Educ Couns*,


doi:10.1215/03616878-2888424


doi: http://dx.doi.org/10.1016/j.jand.2015.01.002


APPENDIX A

International Clinical Ethics Section Core Advisers and Investigators

CORE ADVISERS

Diego Arenas Mayo, MD
Director of Clinical Nutrition Unit
Sanvite
Guadalajara, Mexico

Humberto Arenas Márquez, MD
Intestinal Failure Unit, Sanvite
Zapopan, Mexico

David A. August, MD
Professor of Surgery
Chief, Division of Surgical Oncology
Rutgers Cancer Institute of New Jersey
Rutgers Robert Wood Johnson Medical School
New Brunswick, New Jersey, USA

Albert Barrocas, MD, FACS, FASPEN
Chief Medical Officer
Atlanta Medical Center
Atlanta, Georgia, USA

Annette Besnilian, EdD, MPH, RDN, CLE, FAND
Executive Director
Marilyn Magaram Center
Department of Family and Consumer Sciences
California State University Northridge
Northridge, California, USA

Kelly Green Corkins, MS, RD, LDN, CNSC
Clinical Pediatric Dietitian
LeBonheur Children’s Hospital
Memphis, Tennessee, USA

Yimin Chen, MS, RD, CNSC
Neonatal Dietitian
RUSH University Medical Center,
Chicago, Illinois, USA
Eric H. Frankel, MSE, PharmD, BCNSP  
Metabolic Support Service & Neonatal Clinical Lead Pharmacist  
Truman Medical Center, Kansas City, Missouri  
West Texas Clinical Pharmacy Associates, Inc.  
Lubbock, Texas, USA

Trisha Fuhrman MS, RDN, LD, FAND  
Nutrition Support Consultant  
Ballwin, Missouri, USA

Carol Ireton-Jones, PhD, RDN, LD, CNSC, FACN, FASPEN  
Private Practice Dietitian/Nutrition Therapy Specialist  
Carrollton, Texas, USA

Mitchell Kaminski, MD  
President/Medical Director  
Paradigm Shift Wound Care  
Northbrook, Illinois, USA

Lucinda K. Lysen, RD, LD, RN, BSN  
Nutrition Support Consultant  
Chicago, Illinois, USA

Laura Matarese, PhD, RD, LDN, CNSC, FADA, FASPEN  
Associate Professor  
Department of Internal Medicine  
Division of Gastroenterology, Hepatology and Nutrition  
Brody School of Medicine  
East Carolina University  
Greenville, North Carolina, USA

Carol McGinnis, MS, RN, CNSN  
Sanford USD Medical Center  
Sioux Falls, South Dakota, USA

Cheryl Monturo, PhD, MBE, ACNP-BC  
Assistant Chair & Associate Professor of Nursing  
John A. Hartford Claire M. Fagin Fellow  
College of Health Sciences  
West Chester University of Pennsylvania  
West Chester, Pennsylvania, USA

Debbie Motley RD MPH CNSC  
Mission Hospital  
Mission Viejo, California, USA
Alessandro Pontes-Arruda, MD, MSc, PhD, FCCM  
Professor of Medicine – Christus College/School of Medicine  
Fortaleza, Ceara, Brazil  
Medical Affairs Director, Medication Delivery Asia-Pacific Baxter Healthcare  
Singapore

Martine Sealy, BSc  
Hanze University of Applied Sciences  
Groningen, Netherlands

Kirsten Shell, PharmD, BCPS  
South Fulton Medical Center  
Atlanta, Georgia, USA

Elizabeth J. Sussman, PhD, RD  
Assistant Professor  
Director, Didactic Program in Dietetics  
Department of Family and Consumer Sciences  
California State University, Northridge  
Northridge, California, USA

Christina Valentine, MD, MS, RD  
Cincinnati Children's Hospital Medical Center  
Assistant Professor/Neonatologist  
Cincinnati, Ohio, USA

John R. Wesley, MD, FACS, FAAP, FASPEN  
Adjunct Professor of Surgery Feinberg School of Medicine  
Division of Pediatric Surgery Ann & Robert H. Lurie Children’s Hospital  
Chicago, Illinois, USA

INVESTIGATORS

Nader Armanios, RD  
Clinical Dietitian  
Masters of Science Candidate  
Olive View-UCLA Medical Center  
California State University, Northridge  
Sylmar and Northridge, California, USA

Denise Baird Schwartz, MS, RD, CNSC, FADA, FAND, FASPEN  
Nutrition Support Coordinator  
Providence Saint Joseph Medical Center  
Burbank, California, USA
APPENDIX B

Initial Survey Statements Evaluation

1. Integrate ethical decision-making for artificial nutrition and hydration into clinical practice.

2. Develop a proactive, integrated, systematic institution process, including institution policies and procedures for ethical decision-making for artificial nutrition.

3. Meet individuals’ needs in the hospital with a focus on patient-centered care, use of advance directives, informed healthcare decision-makers, and consistent healthcare team approach.

4. Incorporate evidence-based medicine, clinical data on benefits versus risk/burdens of nutrition support therapies.

5. Achieve early whole patient-centered care with professionals/disciplines communicating together and with the patient and family through family care meetings.

6. Use of palliative care teams early for the critically ill patient or individuals at near end-of-life.

7. Utilize demonstration of clinical ethics, including patient-centered care, shared decision-making, and health literacy in ethics education involving nutrition support.

8. Prevent ethical dilemmas with early communication between clinicians and patient/family/surrogate decision-maker about patient wishes for life-sustaining treatments for short and long-term use.

9. Develop a proactive, systematic process in each facility to obtain advance directives, Physician Orders for Life-Sustaining Treatment (POLST) and/or begin discussion of the topic of healthcare wishes.

10. Promote interprofessional roles in clinical ethics and communication dealing with nutrition support therapies.
APPENDIX C
A.S.P.E.N. Survey on Clinical Ethics

Please complete the following short survey about clinical ethics and nutrition support practice. A member of the International Clinical Ethics Section (ICES) has pledged $1 to the Jonathan Rhoads Research Foundation for every survey completed.

The goals of the survey are to:
1. Rank clinician and healthcare institution actions to integrate clinical ethics into nutrition support practice.
2. Prioritize measurable goals that could indicate opportunities for improvement in communication and patient-centered care to enhance clinical ethics practice.
3. Identify current clinical ethics practice of A.S.P.E.N. members.
4. Select education methods for engaging nutrition support clinicians in clinical ethics.

1) **Please rank in order of importance these clinician action statements that could integrate clinical ethics into nutrition support practice.**

<table>
<thead>
<tr>
<th>Clinician Action Statements</th>
<th>1 = most important</th>
<th>5 = least important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Include ethical decision-making for nutrition support into clinical practice.</td>
<td></td>
<td>( )</td>
</tr>
<tr>
<td>Incorporate evidence-based medicine on benefits versus risk/burdens of nutrition support.</td>
<td></td>
<td>( )</td>
</tr>
<tr>
<td>Prevent ethical dilemmas with early communication with patient, family, and/or surrogate decision-maker about patient wishes for life-sustaining treatments for short and long-term.</td>
<td></td>
<td>( )</td>
</tr>
<tr>
<td>Achieve early communication with clinicians, patients, and family through family care meetings.</td>
<td></td>
<td>( )</td>
</tr>
</tbody>
</table>
Utilize shared decision-making and health literacy in nutrition support education. ( )

2) Please rank in order of importance these healthcare institution (i.e. hospitals, long-term care facilities, home health) action statements that could integrate clinical ethics into nutrition support practice.

| Healthcare Institution Action Statements | 1 = most important  
<table>
<thead>
<tr>
<th></th>
<th>5 = least important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet individuals’ needs with informed healthcare decision-makers and consistent healthcare team approach.</td>
<td>( )</td>
</tr>
<tr>
<td>Promote interprofessional roles in clinical ethics and communication.</td>
<td>( )</td>
</tr>
<tr>
<td>Establish a process to obtain advance directives, Physician Orders for Life-Sustaining Treatment (POLST) and/or begin early discussion of healthcare wishes.</td>
<td>( )</td>
</tr>
<tr>
<td>Develop a proactive, integrated, systematic process, including policies and procedures for ethical decision-making for nutrition support.</td>
<td>( )</td>
</tr>
<tr>
<td>Consult or involve palliative care teams early for the critically ill patient or individuals near end-of-life.</td>
<td>( )</td>
</tr>
</tbody>
</table>
3) The Institute for Healthcare Improvement (IHI) is developing processes to educate bedside care staff to become more “conversation ready” to address end-of-life issues with their patients. Please rank in order of importance these action statements for clinicians and healthcare institutions, developed IHI?

<table>
<thead>
<tr>
<th>Clinician and Healthcare Institution Action Statements</th>
<th>1 = most important</th>
<th>5 = least important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engage with our patients and families to understand what matters most to them at the end-of-life.</td>
<td></td>
<td>()</td>
</tr>
<tr>
<td>Steward this information as reliably as we do allergy information.</td>
<td></td>
<td>()</td>
</tr>
<tr>
<td>Respect patient’s wishes for care at the end-of-life by partnering to develop shared goals of care.</td>
<td>()</td>
<td></td>
</tr>
<tr>
<td>Exemplify this work in our own lives so that we understand the benefits and challenges.</td>
<td>()</td>
<td></td>
</tr>
<tr>
<td>Connect in a manner that is culturally and individually respectful of each patient.</td>
<td>()</td>
<td></td>
</tr>
</tbody>
</table>

4) Please rank in order of importance these measurable goals that could indicate opportunities for improvement in communication and patient-centered care to enhance clinical ethics practice.

<table>
<thead>
<tr>
<th>Measurable Goals</th>
<th>1 = most important</th>
<th>5 = least important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase in number of patients on nutrition support with an advance directive on chart.</td>
<td>()</td>
<td></td>
</tr>
<tr>
<td>Decrease in number of patients with designated decision-makers.</td>
<td>( )</td>
<td></td>
</tr>
<tr>
<td>Increase in number of patients in intensive care unit with family care conferences.</td>
<td>( )</td>
<td></td>
</tr>
<tr>
<td>Increase in number of critically ill patients with palliative care consults.</td>
<td>( )</td>
<td></td>
</tr>
<tr>
<td>Reduction in number of gastrostomy tube placements in patients with advanced dementia, based on defined criteria.</td>
<td>( )</td>
<td></td>
</tr>
</tbody>
</table>
5) In your current clinical practice which of the following occurs? Select all that apply

( ) Include ethical decision-making for nutrition support, while discussing options for therapies, based on patient’s quality of life goals.
( ) Incorporate evidence-based medicine on benefits versus risk/burdens of nutrition support therapies.
( ) Practice early communication with patient, family, and/or surrogate decision maker about patient wishes for life-sustaining treatments, nutrition support, for short and long-term.
( ) Participate in early communication with interprofessional clinicians, patients, and family through family care meetings.
( ) Utilize shared decision-making and health literacy in nutrition support education.
( ) Review patient’s medical record for advance directives and/or Physician Orders for Life-Sustaining Treatment (POLST), as part of your initial patient assessment.

6) Has your clinical practice setting developed a proactive, integrated, systematic process, including policies and procedures for nutrition support?

( ) Yes ( ) No ( ) N/A

7) Are you currently or have previously been a member of a biomedical ethics committee?

Yes ( ) No ( )

8) Have you completed your own advance directive and discussed content with your designated decision-maker?

Yes ( ) No ( )

9) Which of these would be the most helpful to engage and educate nutrition support clinicians in clinical ethics? Select up to three choices

( ) Abstracts at Clinical Nutrition Week, or other healthcare organization meetings
( ) Articles in Nutrition in Clinical Practice and Journal of Parenteral and Enteral Nutrition, or other nutrition related journals
( ) ASPEN Connect Resources in International Clinical Ethics Section and Food for Thought
( ) Case Study Presentations
Didactic Lectures

Ethics Toolkits online on A.S.P.E.N. website

Role Play Demonstration at A.S.P.E.N. Sessions

**10) Which of the following describes your primary role in nutrition support?**

- Dietitian
- Educator
- Nurse
- Nurse practitioner
- Pharmacist
- Physician
- Physician assistant
- Researcher
- Student
- Other: ____________________________________________________________

**11) How many years have you been involved in nutrition support?**

- < 2 years
- 2-5 years
- 6-15 years
- 16-25 years
- > 25 years

**12) What is your primary practice setting?**

- Hospital
- Long-term care facility
- Home care
- Other: ____________________________________________________________
13) What area of practice do you spend the majority of your time working in as it relates to nutrition support practice? Select all that apply
   ( ) Adult
   ( ) Pediatric
   ( ) Neonatal

14) In what country are you located?
   United States (listed first)

15) In what state are you located?

16) Are there other areas of clinical ethics involving nutrition support that were not addressed in this survey?
   Yes ( )   No ( )
   If yes, indicate here: ______________________________________________________
   ______________________________________________________________________