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# The Systems in Critical Access Hospitals Which Support Individual Patient Care Decisions

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THE SYSTEMS IN CRITICAL ACCESS HOSPITALS WHICH SUPPORT  
INDIVIDUAL PATIENT CARE DECISIONS

by

Darlene Alanna Christiansen

Dissertation

Submitted to the Faculty of

Olivet Nazarene University

School of Graduate and Continuing Studies

in Partial Fulfillment of the Requirements for

the Degree of

Doctor of Education

in

Ethical Leadership

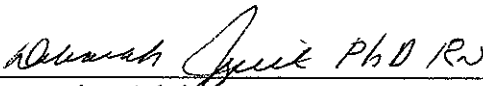

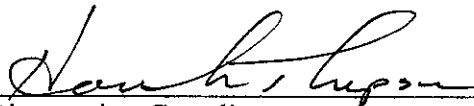

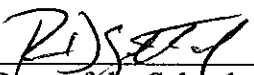

May 2010

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Dissertation

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## DEDICATION

This dissertation is dedicated to the critical access hospital organizations who participated in this study and to all critical access hospital markets that provide hospital care in generally rural America.

## ABSTRACT

by

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Health care in rural America has presented many challenges for health care organizations in ensuring patient autonomy in decision-making. Current literature has not reflected a distinction between the systems utilized in the general acute care hospital and the rural American critical access hospital to support the patient in the decision-making process. The purpose of this qualitative study was to identify the systems in place at a sample of critical access hospitals which support patient autonomy. Using a Grounded Theory method, data were collected and aggregated through an electronic survey tool and follow-up validation interviews. Recommendations include the development of staff educational programs to address methods for communicating clinical evidence and the development of staff competency programs to address patient needs.

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## CHAPTER I

### INTRODUCTION

The way patients make health care decisions is much more complicated than is often recognized (Kukla, 2007). Subsequently, the systems and processes to support the ability of the hospitalized patient to make individual health care decisions have continued to develop (Miller & Boulton, 2007). To add to this complexity, health care organizations have continued to be allowed to define the processes they use to support the individual decisions of a hospitalized patient (Bondeson, 2003; Miller & Boulton; Venneman, 2008). In addition, Medicare and Medicaid legislation, through the Balanced Budget Act of 1997, allowed health care organizations within the United States to diversify to ensure that health care needs were met in generally rural America (Centers for Medicare and Medicaid Services, Medicare Learning Network, 2007). The outgrowth of this diversification resulted in a newly licensed health care organization called the critical access hospital. Diversifying also allowed existing rural acute care general hospitals to seek re-licensure as critical access hospitals. At the end of 2007, there were 1292 licensed critical access hospitals in the United States. Consequently, this new category of health care organization began to apply for national accreditation.

As a nursing leader who is familiar with the rules and regulations of a national accrediting organization, this researcher identified which of these health care organizations were also dual-accredited. In 2001, the Centers for Medicare and Medicaid

Services also recognized the critical access hospital accreditation program that was developed by The Joint Commission. The Joint Commission website provides links to sources that address critical access hospital accreditation (Joint Commission, 2008). With this recognition from the Centers for Medicare and Medicaid Services, The Joint Commission was granted approval to complete the initial licensing reviews and ongoing evaluation reviews of critical access hospitals. At the end of 2007, The Joint Commission accredited 350 of the 1292 critical access hospitals. As a result of the new development of accredited critical access hospitals there is limited information regarding patient care decisions within these organizations.

A literature review completed to identify systems and processes in health care organizations which support the patient's ability to make individual care decisions did not reveal a distinction between the general acute care hospital and the critical access hospital. As a nursing veteran with over 40 years of experience, a nursing leader, and an ethicist, this researcher became knowledgeable regarding the challenges of these generally rural entities to address the provision of care while supporting the ability of the patient to make individual care decisions. Ensuring that the patient has relevant information to make an informed consent has been directly related to the quality of communication between health professionals and their patients (Earp, French, & Gilkey, 2008). Patient autonomy or the right of patients to have their care decisions honored has resulted in ethical dilemmas for healthcare organizations. The patient informed consent process must be ethically grounded, or absent of coerciveness, to support the patient's autonomy. One important factor in determining how a patient will make individual care decisions has historically been the physician-patient relationship. The importance of the



physician-patient relationship captured this researcher's interest to identify and collect specific information on dual-accredited and licensed critical access hospital's systems and processes used to support the patient's ability to make individual care decisions and to complete a comparison of the physician-patient treatment decision model identified by each of the rural health care organizations to theoretical models identified by Quill and Brody (1996).

### Statement of the Problem

The existence of licensed critical access hospitals has continued to increase on a regular basis. These organizations now serve approximately 21% of the United States population (American Hospital Association, 2007; Rural Assistance Center, 2008) but little is known regarding the mechanisms used by these hospitals to support the ability of the patient to make individual care decisions while ensuring an ethical process and maintaining patient autonomy.

The purpose of this study was to identify the systems and processes in place at dual-licensed and accredited critical access hospitals which support the ability of the patient to make individual care decisions. The process included identification of the physician-patient medical treatment decision model utilized by each of the rural health care organizations and a comparison of that model to three theoretical medical treatment decision models. The models used for comparison were the Paternalistic Model, Independent Choice Model, and the Enhanced Patient Autonomy Model identified by Quill and Brody (1996). The basis for the development of the models was the increasing shift in decision-making to the patient and the need to preserve autonomy in patient decision-making.

Quill and Brody (1996) cited the shift from paternalism to autonomy and noted that 25 years ago most major medical decisions were left exclusively in the hands of physicians. “They were usually made with beneficent intent but without open discussion much less the full participation of the patient” (p. 1). Furthermore, they indicated that:

The spirited exchange that characterizes joint decision-making by persons who care deeply about the patient’s outcome, described in the enhanced autonomy model, is a far cry from both the coerciveness of paternalism and the remoteness of the independent choice model. Final choices belong to patients, but these choices gain meaning, richness, and accuracy if they are the result of a process of mutual influence and understanding between physician and patient. (p. 4)

Quill and Brody’s (1996) models were supported by Charles, Gafni, and Whelan (1999) in their identification of three theoretical models or stages of decision-making. Their three decision models were identified as the Paternalistic Model, the Informed Model, and the Shared Model. Although many of the components of these sets of models mirror Quill and Brody’s models, Charles et al. further indicated that there are intermediate approaches. Their approaches denote that doctors in a clinical encounter may not use a pure model but rather a hybrid of elements of more than one model.

This research study was completed within a designated geographical area in the states of Illinois, Wisconsin, Indiana, and Iowa. This geographical area was selected as a convenience sample to accommodate follow-up validation interviews. The study identified the organization’s systems and processes to include the physician-patient medical treatment decision model, pure or hybrid, most often utilized by the hospitals.

This researcher also identified how health care organizations in mostly rural areas support the ability of the patient to make individual care decisions. Furthermore, comparisons between organizations within the designated geographical area can be made regarding the use of physician-patient decision-making models.

### Background

The support of ethical conduct in the treatment of patients was addressed by Earnest Codman, a United States physician in the early 1900s. Codman developed and maintained a patient medical outcomes management report (Brauer, 2001). He supported the public distribution of this report so that patients could be guided in their choices of physicians and hospitals (Brauer). Codman's attempts at informing patients were one of the initial documented strategies addressing collaboration with the patient. His actions fit into Quill and Brody's (1996) Independent Choice Model and into Charles et al.'s (1999) Informed Model.

As Quill and Brody (1996) referenced the shift from paternalism to autonomy they compared characteristics of two specific medical decision-making models to the paternalistic model. These two specific medical decision-making models are named independent choice model and enhanced autonomy model.

The original decision-making model was the paternalistic model (Quill & Brody, 1996). In the paternalistic model, information flow is generally one way from practitioner (physician) to patient. The original model was compared to the following two models, the independent choice and the enhanced patient autonomy models. The first model for comparison was the independent choice model. In the independent choice model, the physician's primary role in medical decision-making is to inform patients about their

options and the probability for success. In this model the patient makes the treatment decisions. The other model used for comparison was the enhanced patient autonomy model. In this model the patient and physician collaborate on the medical decision and have joint responsibility for the patient outcome (Quill & Brody).

Communication is the essential element for the success of these models. Epstein, Alper, and Quill (2004) further reviewed the importance of effectively communicating clinical information and evidence to patients to improve patient understanding and involvement in decisions. They stated:

Communicating evidence to patients has practical, relational, and ethical goals. Informed patients are more likely to participate actively in their care, make wiser decisions, come to a common understanding with their physicians, and adhere more fully to treatment. Communicating evidence can transform a physician dominated relationship into one that is relationship centered. (p. 2)

Referencing Quill and Brody's models, a physician-dominated relationship would mirror the paternalistic model and the relationship-centered model would mirror the enhanced patient autonomy model.

Kukla (2007) addressed the physician-patient relationship, patient autonomy in decision-making, and a patient's knowledge of health care. She noted that the way patients make health care decisions is much more complicated than is often recognized. The author stated "clinicians should respect and recognize their patients' capacity for autonomous inquiry and give these patients reasons to trust their expertise when appropriate rather than assuming their voices will be heard as unilateral and immediately authoritative" (p. 33).

Llewellyn-Thomas (1995) examined the scientific, clinical, political, and ethical reasons for studying patients' decisions about their health care. Patient choices may involve decisions about prevention, screening, clinical trials, urgent care, or palliative care. Llewellyn-Thomas stated the following.

Effects of patient consumerism on the physician-patient relationship, the development of clinical guidelines, and the current debate about the allocation of scarce health care dollars are generating intense interest in how patients make decisions. Overarching all of these, there is the ethical imperative to promote patient autonomy in appropriate ways in the elicitation of informed consent.  
(p. 101)

Miller and Boulton (2007) also addressed the concept of informed consent. They indicated that informed consent has been a concept that has attempted to capture and convey what is regarded as the appropriate relationship between physician and patient. They also indicated that the emphasis has traditionally been given to autonomy and the right to self-determination of the individual patient and that increased bureaucratic regulation and communication through information technology suggested opportunities to rethink and manage consent (Miller & Boulton).

Beauchamp and Childress (2009) addressed the meaning and elements of informed consent and specifically referenced the information and consent components.

Some commentators have attempted to define informed consent by specifying the elements of the concept and dividing the elements into an information component and a consent component. The information component refers to the disclosure of

information and the comprehension of what is disclosed. The consent component refers to both a voluntary decision and an authorization to proceed. (p. 120)

An element essential to any informed consent is a system of open communication.

rapport and open communication between the patient, health care provider, and health care organization lay the foundation for health care organizations to implement effective processes and systems to support the ability of the patient to make individual care decisions. Informed consent is one process utilized to involve the patients in their own care decisions. “Overall, informed and involved patients are empowered to make better health care decisions and choices, are more compliant with instructions, and are more satisfied with their care experiences” (Gottesman, 2008, p. 2).

#### Research Questions

The critical outcome for this research project was to identify those processes and systems, ethically grounded or absent of coerciveness, which support the ability of the patient to make informed care decisions in generally rural American health care organizations. The research was guided by the following four questions, all of which have measurability.

1. What are the current processes and systems which support the ability of the patient to make individual care decisions beginning at admission?
2. Which departments and individuals are involved in the current processes and systems?
3. Which physician-patient medical treatment decision model, pure or hybrid, is utilized in the organization?

4. What comparisons can be made regarding the physician-patient medical treatment decision model identified by each of the generally rural health care organizations?

#### Description of Terms

The following definitions provide clarity to the unique terms used in this research dissertation.

*Accreditation.* Accreditation is an independent objective evaluation of a health care organization and the services provided to ensure safe quality care and that applicable standards are met (Joint Commission, 2008).

*Autonomy.* Autonomy is the right to self-governance. The autonomous individual acts freely in accordance with a self-chosen plan with independence from controlling influences and capacity for intentional action (Beauchamp & Childress, 2009).

*Balanced Budget Act (BBA).* The Balanced Budget Act of 1997 was an omnibus legislative package enacted using the budget reconciliation process and designed to balance the federal budget by 2002. The Act contained major Medicare reforms and authorized states to establish State Medicare Rural Hospital Flexibility Programs (Centers for Medicare and Medicaid Services, Medicare Learning Network, 2007).

*Beneficence.* Beneficence refers to acting in the best interest of the patient. Principles of beneficence include preventing harm, removing harm, and promoting good (Beauchamp & Childress, 2009).

*Clinical ethics.* Clinical ethics is the application of moral values and judgments as they apply to medicine and the clinical care of patients (Rubin & Zoloth, 2004).

*Ethical conflict.* Ethical conflict occurs when moral values differ among individuals. Common medical moral values which could end up in conflict are beneficence, autonomy, and justice when this concerns the distribution of scarce health resources, and truthfulness and honesty as they relate to informed consent (Earp et al., 2008).

*Informed consent.* Informed consent is a legal, medical, and ethical concept that provides that a patient has a right to know the potential risks, benefits, and alternatives of proposed treatments. Informed consent is predicated on the duty of the physician to disclose to the patient information necessary to enable the patient to evaluate, decide, and authorize proposed treatments. (Beauchamp & Childress, 2009; Pozgar, 1999).

*Licensure.* Licensure is the process by which some competent authority grants permission to a qualified individual or entity to perform certain specified activities that would be illegal without a license (Pozgar, 1999).

*Paternalism.* Paternalism in medicine implies unquestioned acceptance by all parties that the physician's responsibility is to act on the patient's behalf, not at the patient's request (Flynn, 2000).

*Shared decision-making.* Shared decision-making is the result of an open collaborative relationship between physician and patient where knowledge and expertise are shared (Quill & Brody, 1996).

### Significance of the Study

The health care environment of rural America presents many challenges for health care organizations, individual practitioners, patients, and families. Health care



organizations and practitioners are challenged to meet legal and regulatory requirements while working to improve health care outcomes. Patients and families may face challenges navigating the health care system and making decisions due to knowledge deficits. They may also experience difficulty with decision-making due to value differences. Many of these challenges may be viewed as ethical conflicts and are traceable back to a lack of communication. Communication breakdowns between patients and their health-care team, between family members, or between members of the medical community, can all lead to disagreements and conflict. These breakdowns should be remedied and many apparently insurmountable “ethics” problems can be solved with open lines of communication (Earp et al., 2008).

This study examined communication strategies used within the physician-patient relationship and compared the physician-patient medical treatment decision model used within each organization to the models described by Quill and Brody (1996). The significance of this study is that, through qualitative research using an electronic survey tool and follow-up interviews, new information was gathered identifying specific systems and processes to include communication strategies in rural health care organizations which support the ability of patients to make informed decisions about their care. Current literature has not reflected a distinction between the general acute care hospital and the rural critical access hospital in the systems and processes utilized to support the patient’s ability to make individual care decisions.

The unique benefits of the study were the following.

1. The data aggregation of a research questionnaire tool which identified the rural organization’s structure and process to include communication strategies

and mechanisms to support patients in making informed decisions about their care while addressing the patients' ethnical and religious beliefs and language differences. The knowledge of organizational staff and the roles of other departmental staff were also assessed.

2. The ability of this research questionnaire tool to be utilized in other rural geographical areas.
3. A follow-up validation interview to a percentage of organizations participating in the original completion of the survey tool.
4. Collection of comparative data within a designated geographical area.
5. Distribution of aggregate and comparative data to all organizations that completed the questionnaire.
6. Inclusion of aggregate and comparative data into an educational program.

The conclusion of this study will lay the foundation for further research and education development opportunities. It will serve to increase the knowledge base of all consumers involved in this study and others who read it.

#### Process to Accomplish

The developmental evolution of clinical ethics has been addressed in many medical and clinical journals and ethics books. This dissertation builds upon the foundation of what has been researched and written while identifying specific systems and processes in place for a defined rural hospital population. Data were collected utilizing a survey instrument. The qualitative survey instrument answered the four research questions.

Following the approval of this research proposal by the Institutional Review Board at Olivet Nazarene University, data collection for each of the questions was completed through the implementation of an electronic data research questionnaire tool (Appendix A). Demographic data were collected as part of this data research electronic questionnaire tool (Appendix B). An invitation letter (Appendix C), intent to participate form (Appendix D), and informed consent form (Appendix E) were mailed to the total population of 90 dual-licensed and accredited critical access hospitals within the states of Illinois, Wisconsin, Indiana, and Iowa. Of the total population of 90 critical access hospitals, 24 hospitals were in Illinois, 34 hospitals were in Wisconsin, 22 hospitals were in Indiana, and 10 hospitals were in Iowa.

The consent form provided the organization the opportunity to agree to a follow-up validation interview if they consented to participate in the electronic survey process. Once the potential organization contacted this researcher by United States mail with the return of the intent to participate and informed consent forms, the electronic data survey tool was sent to the organization. The areas the research instrument addressed were the following.

1. Information regarding processes and systems utilized within the organization was collected.
2. Involved staff and departments within the organization were identified.
3. The physician-patient medical treatment decision model or hybrid was identified.
4. Data contributing to a comparative analysis between responses related to the physician-patient medical treatment decision model were gathered.

Data from the returned electronic data survey tools were coded (Appendix F) for comparison purposes. Data analysis began with the first returned survey tool and each returned tool was compared to the other returned tools to identify similarities and differences.

Follow-up validation interviews were completed with a percentage of organizations participating in the original completion of the electronic survey tool following the signing of appropriate consent forms. Questions used in the electronic tool were used in this site interview. Additional questions were developed based upon identified gaps in information received in the electronic survey (Appendix G). These site interviews were recorded pending approval of the site. If approval was not received from the site, hand-written notes were taken to record the discussion. Audiotapes and hand-written notes were transcribed verbatim using a transcription service. A summary report was developed for each site interview.

Coding of interview transcripts began with the initial interview. Data analysis began with the first interview and each interview was compared to the other interviews for the development of emerging themes and concepts. Demographic data were incorporated into the data analysis, coded, and used to identify the similarities or differences between the organizations' licensure status and levels of care. Every second interview was double coded. Double coding indicated that the second coder independently coded using the same coding schedule that the researcher used. The researcher and the double coder compared the coding of these interviews for consistency of categories. Double coding was done to mutual consensus. The summary report for each site interview conducted was compared with the site's submitted electronic

questionnaire. Aggregate reports for returned electronic survey process questionnaires and validation site interviews were then completed.

In this qualitative research, reliability and validity were concerns. Robson (2002) discussed the importance of establishing trustworthiness in flexible designs as well as fixed designs. Several methods were used to ensure trustworthiness of the data. First, this researcher maintained a journal to record observations and thought processes about the data. Second, triangulation was performed by validating the data with a data auditor, by checking data against other data, and by the utilization of subjects from multiple institutions. Finally, at the conclusion of the study, participants were mailed an aggregate summary of the results and an evaluation form (Appendix H) which allowed them to validate the completed process against original expectations.

## CHAPTER II

### REVIEW OF THE LITERATURE

#### Introduction

The purpose of this study was to identify the systems and processes in place at dual-licensed and accredited critical access hospitals, within a designated geographical area, which support the ability of the patient to make individual care decisions. The process included identifying the physician-patient medical treatment decision model and comparing that model to three existing medical treatment decision models.

Communication strategies which addressed the patient's ethnic and religious values and language differences were examined. The data gathered provided new information specific to the critical access hospital market and laid the foundation for further research and educational development opportunities. In Chapter 2, the literature which addressed the historical development of patient autonomy, patient autonomy and ethical conduct, ethical dilemmas and decision-making, ethical decision-making support mechanisms, communication and decision-making strategies, and physician-patient medical treatment decision models were reviewed.

#### Historical Development of Patient Autonomy

Patient autonomy has historical and philosophical roots in both Eastern and Western cultures. Although Western philosophy has the most significant impact on the current definition of autonomy, it was important to review Eastern philosophy. The

comparison of these foundational principles provided additional information on current bioethical philosophies.

In the history of Eastern philosophy, Confucius was considered one of the most influential thinkers of the time. Confucianism has been the dominant ideology in Chinese philosophy since the Han Dynasty which existed from 206 BC to 220 AD (Fu-Chang Tsai, 2001). Fu-Chang Tsai referenced that Confucianism directed social, political, educational, moral, and medical ethics principles and thoughts in Chinese society. He further stated “Confucius emphasized personal reflection in the pursuit of a reasonable social life and that physicians were expected to be virtuous to the point of achieving the moral standard of an ideal Confucian person, the superior man” (p. 45). Reason and morality, which are principles evident in the history of Eastern philosophy, were also evident in Western philosophy.

During the 1700s, Immanuel Kant was known as one of the most influential philosophers in the history of Western philosophy. His contributions to ethics and addressing the autonomous individual have continued to be referenced in current literature (Spriggs, 2005). Spriggs stated the following.

Kant does not allow determinism by things outside ourselves to count as autonomy. As rational beings Kant believed we are autonomous because we have freedom of the will and we are able to follow reason. Kant also believed this allowed the individual to act for reasons rather than being caused, and because of this, we are able to escape the determinism that is the fate of every non-rational being. (p. 9)

Kant linked autonomy, reason, and morality (Spriggs, 2005). Kant's writings reflected that it is through the individual's morality, the ability to rise above self-nature, and the individual's own self-interest that the individual reveals his or her dignity. Kant stated "autonomy is the expression of a free will that uses reason rather than instinct or desire" (Spriggs, p. 11). Through the next century, philosophers defined autonomy.

In the 1800s John Stuart Mill, a philosopher and economist, identified the characteristics of autonomy as self-development, firmness, self-control, and the ability to choose a plan for life (Spriggs, 2005). Spriggs stated "from Mill we get the idea that autonomy is noninterference and because he refers to certain character traits that seem to define an autonomous person we also get the idea that autonomy is a psychological state" (p. 36). Having looked at the historical development of autonomy, Spriggs began to present the development of the contemporary idea of autonomy. Tauber (2005) was one of the philosophers who addressed the contemporary idea of autonomy.

Tauber (2005) defined three basic requirements of autonomy within a relational construct. The first requirement addressed that decision-making must be one's own and free of coercion. The second requirement identified that in order to fulfill the first requirement one must critically reflect on one's choices to ensure they are solely self-motivated. The final requirement described that one must assume responsibility for one's choices. Tauber further stated the following.

None of these measures precludes interdependence. Given the reality that few choices fulfill all of these requirements autonomy must be placed in a social context where supporting relationships enable individuals to achieve various degrees of autonomy and thereby act as freely as possible. (p. 121)



The most recent discussion of autonomy highlighted the concept as an essential ethical principle. Beauchamp and Childress (2009) defined “respect for autonomy” as the first principle of biomedical ethics and as the right to self-governance. They referenced that the autonomous individual acts freely in accordance with a self-chosen plan with independence from controlling influences and capacity for intentional action. Autonomy is a concept that is respected in health care today.

Achieving patient autonomy can be a challenge in critical access hospitals due to the potential lack of well defined processes which support the ability of the patient to make decisions about care. This lack of well defined processes may lead to poor patient centered communication behaviors. Poor communication may not support patient autonomy.

Earp, et al. (2008) identified examples of patient-centered communication behaviors and ethical conduct which support autonomy within the patient-provider relationship. Some of these include supportive, facilitative, responsive, informative, and participatory behaviors. Supportive behavior serves to address the fulfillment of basic medical responsibilities such as orienting the patient to the flow of the visit. Facilitative behavior addresses the patient’s goals and concerns and elicits discussion about psychological issues. Responsive behavior examines clues and probes about feelings and emotions and expresses support and empathy. Informative behavior provides biomedical information. Participatory behavior questions the patient’s expectations, encourages the patient’s questions, and provides opportunities for the patient to share in decision-making. These behaviors support ethical conduct in the treatment of patients. Educating physicians and other staff, in critical access hospitals, is essential to providing autonomy.

Developing and implementing defined processes lay the foundation for patient-centered communication which then supports the ability of the patient to make decisions about care. In addition to patient-centered communication behaviors, patient autonomy and ethical conduct are important.

### Patient Autonomy and Ethical Conduct

The importance of ethical conduct was documented as early as 2500 years ago. Hippocrates was a Greek physician born in 460 BC. He became known as the founder of medicine (Liebersohn, 2007). The Hippocratic Oath comprised the first set of precepts which formulated a voluntary, self-imposed, code of ethics for physicians (Faria, 1998). “The Oath provided for ethical conduct in treating the ill and vulnerable as well as protection of patient confidentiality” (p. 5). The Oath, in part, states “I will follow that method of treatment which, according to my ability and judgment, I consider for the benefit of my patients and abstain from whatever is deleterious and mischievous” (Faria, 1998, p. 4). The Hippocratic Oath, which defined ethical professional behavior, is a reflection of the Paternalistic Model.

Utilizing the paternalistic model, Quill and Brody (1996) identified that health care practitioners exhibit more control over treatment decisions which limits information sharing. In this model the physician decides what treatment to implement. As medical science evolved, the value of the patients’ involvement in their care decisions was increasingly recognized as an essential patient right in health care decision-making. This recognition supported health care organizational ethical conduct and eventually led to widespread changes in hospitals.

The focus of this widespread change in hospitals was to move toward a systems-oriented approach in assuring quality and safety of patient care. Patients, as a team member, would become partners in the healthcare system. Ernest Codman, a United States physician in the early 1900s, was an advocate of hospital reform and the frontrunner in treating patients as partners.

Codman was the acknowledged founder of what today is known as “outcomes management” in patient care (Brauer, 2001). Codman’s lifelong pursuit was to establish an end results system to track the outcomes of patient treatments. This was viewed as an opportunity to identify clinical errors or near misses and served as the foundation for improving the care of future patients (Brauer). Brauer stated the following about Codman.

In 1911, Codman opened a 20 bed proprietary hospital that was organized around the End Result Idea. He even offered a money-back warranty to patients, a radical proposition both then and today. For each patient, Codman maintained an end-result card which included presenting symptoms, initial diagnosis, treatment given, in-hospital complications, discharge diagnosis, and the result a year later. Codman gave the report to prospective patients. He also distributed it to notable hospitals around the country and encouraged them to follow his lead. (p. 17)

Codman’s actions fit into Quill and Brody’s (1996) Independent Choice Model and into Charles et al.’s (1999) Informed Model. Specific characteristics of the Independent Choice Model and Informed Model include the following. First, patients should be free to make choices unencumbered by the influence of the physician’s experience or other social forces. These models require that physicians withhold their

recommendations because they might bias the patient. Next, the physician should objectively answer questions but should avoid influencing the patient even if the physician has strong opinions or if the patient asks for advice. Finally, after the patient makes the decision, the physician's duty is to implement the medical aspects of that decision (Charles et al.; Quill & Brody). Although the movement to these models exhibited increased patient involvement in the decision-making process, collaborative decision-making between the physician and patient still had not been achieved. Health care organizations, including critical access hospitals, continued to struggle to define mechanisms to support increased patient autonomy.

Some areas where autonomous decision-making is especially difficult are during end of life and emergent care decisions. As remote rural healthcare organizations, critical access hospitals face these decision-making challenges on a daily basis. In the early 1990s advance directives were viewed as a reliable way to preserve patient autonomy and support healthcare ethical conduct when individual integrity was threatened. The passage of the Patient Self-Determination Act (PSDA) in 1991 was based upon widespread acceptance that everyone should have an advance directive. An advance directive preserves patient autonomy by having the patient define the type of health treatment and care he or she would like to receive in various health situations that may arise.

PSDA requires the health care organization to provide the patient certain information on admission (American Bar Association, 2008). The American Bar Association identified this patient information and stated the following.

The Patient Self-Determination Act (PSDA) requires health care organizations to give the patient, at the time of admission, a written summary of health care

decision-making rights and the facilities policies with respect to recognizing advance directives. The PSDA requires the health care organization to ask the patient if they have an advance directive and document that fact in the patient's medical record. It is up to the patient to insure receipt of the advance directive by the health care organization. The health care organization is required to educate their staff and community about advance directives and never discriminate against patients based on whether or not they have an advance directive. It is against the law to require that a patient have an advance directive. (p. 2)

Finally, the PSDA required the United States Department of Health to undertake a public education campaign. This included the development and approval of national educational materials and the assistance to individual states in the development of state documents. Effective education for the physician about the advance directive and full disclosure by the physician to the patient remained important in preserving patient autonomy and ensuring ethical conduct.

As health care organizations worked to seek ways to improve and support patient autonomy while maintaining ethical conduct, Pellegrino (2008) reminded health care providers about the importance of conscience. He stated that "conscience is a natural right that is fundamental and cannot be overridden by other pressing concerns" (p. 2). Pellegrino referenced autonomy as a reciprocal agreement where both patients and health care providers have autonomy based in their dignity as persons. Patients or health care organizations should not ask a health care provider to do something that violates their deepest professional beliefs. As patient involvement in the decision-making process has increased Pellegrino (2008) addressed the concern regarding the paradigm shift in the

physician-patient medical treatment decision process. He identified that the physician-patient relationship model has moved from “covenant to contract”. A covenant relationship is reflective of the paternalistic physician-patient medical treatment decision model whereas a contractual relationship is more reflective of the enhanced patient autonomy model identified by Quill and Brody (1996). Pellegrino stated the following.

Over the long history of medical ethics the relationship between patient and physician was something more than a civil contract for services. The patient relied on the physician’s expertise and personal integrity. With today’s autonomy movement the patient hires the doctor and he’s to do what you want him to do. There should be a balance. Everybody has values. Autonomy is itself a value.  
(p. 2)

Pellegrino (2008) indicated that the balance would be achieved through a practice where the physician would not impose any treatment on the patient that violates the patient’s deepest religious or personal beliefs and, conversely, a patient would not demand a particular treatment that violates the physician’s deepest religious or professional beliefs. When the physician and patient collaborate and do not make unreasonable demands, ethical conduct will be ensured. An example of such compromise is described in the following example.

Cheng (2007) identified the importance of ensuring ethical conduct in situations where compromise is needed. This compromise could result from differences between the physician’s professional beliefs and the family’s wishes. A grandmother, as the closest relative, became the decision-maker for her granddaughter who had deteriorated rapidly after a hospital admission. It was necessary for Cheng, the physician, to communicate

with the grandmother that there was no hope for improvement in the granddaughter's condition. The grandmother expected her granddaughter to survive and she requested that her granddaughter receive any treatment necessary to improve her medical condition. Cheng allowed the grandmother to express her feelings and then shared his medical expertise. The grandmother reconsidered and decided that current treatment should be stopped (Cheng). Luttrell (2001) and Boyd (2001) also addressed the role families play in treatment decisions for unconscious patients at or near the end of life. The authors identified that the family view regarding what is in the best interests of the patient is also relevant and should be taken into consideration. Patients in the role of directing their own care and treatment must accept responsibility for their decisions. It is important that the information provided in the physician-patient communication is free of physician bias.

Nessa and Malterud (1998) referenced that the practitioner's fundamental duty, to ensure ethical conduct, is to make it possible for the patients, with their different limitations, to obtain an adequate understanding of the basics of their diagnosis and proposed treatment. The physician should make the patient feel sufficiently secure to refuse the physician's suggestions. The physician or caregiver, when presenting information and choices to the patient, must provide this information without their own biases. This methodology again fits into Quill and Brody's (1996) Independent Choice Model and into Charles et al.'s (1999) Informed Model.

Respecting patient autonomy through establishing a patient-centered relationship is important in ensuring ethical conduct and developing a mutual understanding and respect between the health care provider and the patient. Fully embracing patient autonomy and maintaining ethical conduct requires attitudinal changes among health care

providers and patients. It is important to ensure patient autonomy and ethical conduct for all health care decisions in all health care environments. Attitudinal changes require recognition of the need for unbiased collaboration between the physician and the patient and the need for continuing education for physicians and all health care providers. The development of a collaborative model between the physician and the patient supports patient autonomy and achieves patient-centered care. Patient-centered care requires the health care provider to elicit the patient's point of view bringing to light personal values, care preferences, and patient psychological factors that impact health. Patient advocacy requires a relationship-centered approach to health care (Nessa & Malterud).

Patient advocacy, patient autonomy, and ethical conduct are particularly important in the critical access hospital setting where health care providers have numerous responsibilities and the assigned physician may not be initially available to evaluate the patient, collaborate with the patient to plan the care, and oversee clinical care. Engaging patients in the planning of care empowers patients to participate in care decisions. Without appropriate recognition of the challenges in achieving patient autonomy and attitudinal changes in these rural health care organizations, ethical dilemmas will result.

### Ethical Dilemmas and Decision-Making

Numerous situations that occur throughout the continuum of patient care can result in ethical dilemmas for both the patient and the provider of care. Ethical dilemmas involve care-planning situations or problems that have no clear cut or satisfactory solution. These ethical dilemmas may involve issues with patient autonomy and informed consent, patient advocacy, and professional roles and obligations.



## Discussion of Ethical Dilemmas

### *Autonomy and Informed Consent*

There are many distinct conceptions of individual autonomy in circulation and even more views of the value and importance of these various conceptions (O'Neill, 2003). In one survey of autonomy Dworkin (1988) noted the following.

Autonomy has been equated with liberty, dignity, integrity, individuality, independence, responsibility and self-knowledge, self assertion, critical reflection, freedom from obligation, absence of external causation, and knowledge of one's own interests. (p. 6)

O'Neill (2003) noted that "many accounts of informed consent in medical ethics suggest that it is valuable because it supports individual autonomy" (p. 4). The ethical importance of informed consent provides reasonable assurance that the patient has not been deceived or coerced. Informed consent cannot be provided by patients who are incompetent to consent. Informed consent has its place within relationships and between consenting adults. Informed consent would be questionable if the patient was mentally impaired, unconscious, demented, or under duress (O'Neill).

Kottow (2004) referenced that informed consent continues to be a desirable goal but there are circumstantial difficulties which emerge in respecting autonomy in clinical situations. He noted that the fully informed patient continues to be an exceedingly distant goal and that attempts to reach this status are subject to failure because sick people are emotionally unstable with impaired rational judgments. The issues that Kottow and other researchers have identified related to fully informing patients are not a new phenomenon.

Kirby (1983) reviewed this same issue through his identification that patients vary enormously both in their interest in and their capacity to absorb information about medical procedures. Another study explored reasons for the failure of patients to recall major portions of the information on consent forms (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Cassileth et al. in a study involving chemotherapeutic patients found that three factors were related to inadequate recall and lack of full disclosure. These factors were education, medical status, and the care with which patients thought they had read their consent forms before signing. The study reflected that only 40% had carefully read the consent form. Cassileth et al. stated “most patients believed that consent forms were meant to protect the physician’s rights” (p. 24).

In meeting the requirements of effective consent, Epstein (2006) discussed the conditions of validation of effective consent (p. 4). These conditions were identified as competence, adequate disclosure, and voluntariness and freedom from coercion. Legal competence to consent or refuse is established in different ways dependent on the situation. Relatively rigorous standards are normally applied only in cases where competence or incompetence is being challenged. Regarding adequate disclosure Epstein (2006) stated “contracts rarely contain all the relevant information however the contract presupposes that it does” (pp. 4-5). Important information, although potentially relevant, addressing risks and complications which could impact the success of follow-up care may be excluded. Exclusion of this information breaches the ability of the patient to reach an autonomous decision. Freedom from coercion and voluntariness should be considered inherent in effective consent. Freedom from coercion and voluntariness has been particularly challenging in psychiatric decision-making situations.

Wong, Poon, and Hui (2005) discussed the controversial practice of covertly administering medication. Wong et al. stated “ethical, legal, and clinical situations become more complex when the mental incapacity is temporary and when the medication actually serves to restore autonomy” (p. 1). In the case history discussed, a 25-year-old unemployed male, with a two-year history of paranoid schizophrenia, lived with his parents and a younger sister. This young adult had been refusing to take his antipsychotic medication and had become actively psychotic again. The mother requested that the physician provide her with the prescription for medication but never informed the physician that she was covertly administering this medication to her son. The medication was mixed in the young adult’s soup on a daily basis and served to reverse his psychotic mental condition.

The physician learned of the mother’s practice three months later which then presented a conflict between the principles of autonomy and beneficence. Autonomy addresses the patient’s right to self-governance with independence from controlling influences. Beneficence refers to acting in the best interest of the patient. Although the mother believed she was acting in the best interest of her son, his right to self-governance had been violated (Wong, Poon, & Hui). The physician addressed the issues of autonomy and beneficence by having this young adult agree to psychiatric follow-up and medication after further discussion about his financial assistance. Full disclosure, regarding the covert administration of medication, was not provided to this patient. Success of long-term program planning for this young adult may be jeopardized due to his past inability to commit to a long-term program and his current understanding that he had been able to cope without medications. Informed consent is not only important with

patients who have competency issues but equally important with patients who are fully competent.

The literature also reflected a number of examples of lack of informed consent and failure to support patient autonomy in non-psychiatric decision-making situations. Sheridan and Hatlie (2007) reviewed two cases where Sheridan's immediate family members experienced two medical errors with devastating effects. Failure to communicate and provide informed consent, timely medical support, and medical intervention resulted in permanent brain damage in Sheridan's newborn son and resulted in the death of Sheridan's husband. Pediatric cases, particularly older minors, may pose additional challenges.

Although laws such as the Patient Self-Determination Act encourage individuals to address their end of life treatment preferences, the rights of children and older minors have generally been ignored or overruled (Zinner, 2009). In studying the autonomy and decision-making ability of older minors, laws and courts have recognized that there are times when chronological age should not be the determining factor. Weir and Peters (1997) identified that advance directives, if used with sensitivity and care with older adolescents, could prove a valuable means of giving these pediatric patients a say in their care. The rights of children do not disappear merely because of a terminal illness. The moral obligation of health care providers and parents to listen to the children's wishes and end of life choices must not be ignored and may necessitate further exploration of a pediatric advance directive (Zinner). Implementing an effective informed consent process minimizes ethical dilemmas.

Informed consent needs to be practiced within a culture of openness. Walter (2008) stated “openness should entail patients not just receiving information from doctors but also having the right to see certain medical procedures” (p. 675). Walter viewed this as an opportunity to enhance and restore public trust in medical procedures.

In summary, ethical dilemmas can occur when there is a lack of effective mechanisms in place to ensure patient autonomy and patient advocacy. As previously discussed, the failure to inform the patient during the consent process can result in an ethical dilemma. This failure to support may be due to the absence of established organizational systems and processes. The current literature does not define systems and processes in place in critical access hospitals which support the ability of the admitted patient to make an autonomous decision regarding the provision of care. The lack of established effective mechanisms will result in failure to support patient autonomy and advocacy.

#### *Patient Advocacy*

The Institute of Medicine, Committee on Quality of Health Care in America (2001), has proclaimed that it is important to ensure that a hospital’s culture is based on collaboration and a belief in the efficacy of social support and personalization. When a hospital’s culture has this foundation, patients are more likely to receive safe and supportive care. As many proponents of patient-centered care have pointed out, hospital environments have traditionally been designed around the needs and schedules of the healthcare provider, rather than those of the patient (Berwick & Kotagal, 2004). Patient advocacy at the organizational level involves changing organizational culture to give

patients the tools they need to learn about their conditions and participate collaboratively with caregivers in their plans of care. A collaborative culture is also important in recognizing the important advocacy role all hospital staff can play in patient care. To provide additional support to health care organizations, including critical access hospitals, individual states have developed centers and coalitions addressing ethics and advocacy in health care. The states of Illinois, Indiana, Wisconsin, and Iowa provide the following resources.

The Center for Ethics and Advocacy in Healthcare in Illinois (2003) exists to ensure that individuals become part of their own healthcare decision-making. The Center's goal is to educate people to make wise decisions as they move through the Illinois healthcare institutions (Resources in Community Healthcare Ethics and Advocacy, 2008). In Indiana multiple organizations work closely with the State of Indiana to provide both patients and families with advocacy and support resources as well as educational programs. Several of these resources are provided through the Indiana University School of Medicine (Indiana University School of Medicine, 2002).

The Center for Patient Partnerships at the University of Wisconsin in Madison supports the empowerment of patients to make more informed medical decisions, negotiates insurance and financial issues, and finds local support for the patient (Center for Patient Partnerships, 2008). Finally, patient advocacy services in Iowa are supported by multiple organizations including the University of Iowa (University of Iowa, 2009). The University of Iowa leads efforts in Iowa to advance evidence-based medicine and stresses that evidence-based guidelines provide a framework for decision-making between the physician and patient rather than rules for which treatment options should be

used. These state-sponsored services also provide support to the critical access hospital in addressing the needs of a diverse patient population. Ethnic diversity and cultural diversity present their own set of challenges in the provision of care.

The United States is considered to be an ethnically diverse nation. Peterson-Iyer (2008) referenced that providing patients with health care that is sensitive to the values that emerge out of their particular ethnic or religious backgrounds can be referred to as “culturally competent care” (p. 1). It is important that health care providers challenge their own ethical assumptions to determine the appropriateness of the care being provided. Peterson-Iyer stated, “At times health care providers may even need to reconsider the belief systems and values that underlie Western clinical practices and perhaps rethink them in light of the patient’s beliefs and values” (p. 2). To ensure patient advocacy, care providers must also be sensitive to language and cultural issues.

Ethical dilemmas have continued to result when there is lack of patient advocacy due to language and cultural issues. Both language and culture have had a significant impact on delivering care when not addressed by health care organizations (Smedley, Stith, & Nelson, 2002). As the diversity of our nation continues to grow, critical access hospitals are encountering more patients with cultural and language barriers. These populations of Hmong, Hispanic, and Indian patients, who are indigenous to the states within this study, present unique communication challenges which may impact the ability of the health care organization to ensure patient autonomy and advocacy.

It is well recognized that communication is essential to quality care and patient safety. Direct communication can be inhibited by primary language barriers, hearing or vision impairment, literacy, culture, cognitive limitation, or disease. Effective

communication with people of different cultures is especially challenging. Cultures provide people with ways of thinking, seeing, hearing, and interpreting the world. When the languages are different and translation has to be used to communicate, the potential for misunderstandings increases. Individuals whose care is inhibited due to a communication barrier or a lack of sensitivity to a cultural belief may be at risk for poor outcomes (Flores et. al., 2003). In order to decrease health disparities, critical access hospitals need to take action to understand the needs of their patient populations and employ practices and processes that help address those needs.

Trust and understanding between a patient and physician can only emerge through communication. In their research with Hispanic patients, Fiscella, Franks, Doescher, and Savor (2002) found that patients who primarily spoke Spanish had fewer physician visits, received less preventative care, and were more dissatisfied with their care compared with their bilingual peers. Fadiman (1997) explored the cultural clash between a small county hospital and a refugee family from Laos over the care of a Hmong child diagnosed with severe epilepsy. The failure to communicate resulted in lack of appropriate medical care for this child with devastating results. Szasz and Hollender (1997) referenced that when people leave the culture in which they were born and raised and migrate to another; they usually experience the new culture as threatening. Szasz and Hollender stated, “It also happens that people exposed to cross cultural experiences turn their attention to the very customs which formed the social matrix of their lives in the past” (p. 585). These cross-cultural challenges create difficulty in critical access hospitals in establishing effective relationships which are non-threatening with health care providers and ensuring patient



autonomy and advocacy. Patient autonomy and advocacy can be supported through establishing ethics consultation services within critical access hospitals.

The purpose of these ethics consultation services is the provision of assistance for patients, families, surrogates, and health care providers in addressing uncertainty or conflict regarding ethical issues that emerge in health care. Reiter-Theil (2000) stated that “one of the reasons for increasing ethical awareness in the health sector is the plurality of values” (p. 199). These include different religious values, contrasting political ideologies, different lifestyles, and personal preferences. Medical interventions and economic constraints are other reasons for the need for ethical competence.

Establishing effective patient advocacy programs in critical access hospitals requires the development of a collaborative organizational culture. Patient advocacy programs are important to ensure patient autonomy and ethical conduct. Mechanisms such as state sponsored advocacy services and organization ethics consultation services further support the critical access hospital’s diverse patient population.

It is also important to consider the professional roles and obligations of staff that provide care to the critical access hospital’s patient population. Society, as well as the health care institution, has identified behaviors that are expected of professionals. The critical access hospital must ensure these behaviors support patient autonomy and advocacy.

#### *Professional Roles and Obligations*

The American Nursing Association and the American Medical Association, as professional associations, address nursing and medical roles and expected ethical conduct in professional practice. Both professional organizations have ethical codes of conduct

which provide standards of ethical behavior. Nurses and physicians have an obligation to act in ways that will merit the trust, confidence, and respect of patients and other health care professionals.

The American Nursing Association (2003) referenced that the role of nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations. Nursing professionals have the responsibility to support patient autonomy and ensure patient advocacy through respecting the rights of patients.

The American Medical Association Principles of Medical Ethics preamble identified certain principles as a standard of conduct which defines the essentials of honorable behavior for the physician (American Medical Association, 2001). These principles include that the physician will be dedicated to providing competent medical care with compassion and respect for human dignity and rights, the physician will respect the rights of patients and safeguard patient confidences and privacy within the constraints of the law, and that the physician will regard responsibility to the patient as paramount. Nurses and physicians typically work under organizational policies and procedures.

Job descriptions or organizational policies mandate that nurses and physicians perform certain duties. Professional role obligation may lead to conflicting loyalty. Ethical dilemmas in nursing have been related to lack of resources such as staff, time, and conflicts of interest involving professional hierarchies (Kalvemmark, Hoglund, Hansson, Westerholm, & Ametz, 2004). This lack of resources particularly impacts the registered nurse in critical access hospitals as registered nurses may find themselves to be the only

health care professional on duty. Ethical dilemmas may also result when nurses have moral objections to providing specific services. As health care providers, nurses have an obligation to minimize disruption in the delivery of care and minimize burdens on other providers by alerting their colleagues and supervisors to these objections. Organizational conscientious objection policies may specify that a professional who has invoked the right to refuse to provide a service must not interfere with the patient's ability to obtain it elsewhere or by another provider (Berlinger, n.d.). Physicians may have unique dilemmas in critical access hospitals due to their rural location and organizational structure.

Physicians face ethical dilemmas in determining care strategies for their patients. The rural critical access hospital environments pose additional challenges for physicians. A critical access hospital must have at least one physician to provide oversight of care but he or she is not required to be on-site. Mid-level practitioners, identified as physician assistants, nurse practitioners, or clinical nurse specialists, are allowed to be an active independent part of the critical access hospital medical staff and provide direct service to patients (Rural Assistance Center, 2008). In certain, very limited, circumstances the coverage could be provided temporarily by a registered nurse. As of October 1, 2007, the Centers for Medicare and Medicaid Services required that any hospital, including a critical access hospital, that does not have a physician on-site 24 hours per day, seven days per week, provide a notice to all patients upon admission. The notice must address how emergency services are provided when a physician is not on-site (Emergency Services Provision, 2007). This is seen as an ethical dilemma as the attending physician is not present and mid-level practitioners or the registered nurse may not have the expertise to provide needed care.

Building the bridge while serving as a patient advocate is reflected in Quill and Brody's (1996) enhanced patient autonomy medical treatment decision model. In this model, care providers engage the patient in open dialogue, inform the patient about therapeutic possibilities and their probability for success, explore both the patient's values and the physician's values, and then offer recommendations that consider both sets of values and experiences. Characteristics of this patient-centered model include active listening, honest sharing of perspectives, suspension of judgment, and genuine concern about the patient's best interests (Quill & Brody).

### *Conclusion*

To minimize the occurrence of health care ethical dilemmas, maximize support for the ability of each patient to make individual care decisions, and build a strong health care network for the future, partnerships between health care organizations, health care practitioners, patients, and the community need to be developed. This is particularly important for the rural critical access hospital as it may be the sole health care provider in a geographical area.

All stakeholders including the patients and professional caregivers must take responsibilities for successful outcomes. For patients, responsibilities could include the development of healthy lifestyles and the adherence to agreed upon treatment plans. Professional responsibility and accountability could be achieved through building in assessments of the quality and outcomes of patient care into system-wide, integrated, performance monitoring mechanisms. Taken together, Levine et al. (2007) referenced the obligations from an ethical framework that ensures that the patient is seen as part of the

health care team and that developed systems and processes support patient advocacy, patient autonomy, and the ability of the patient to make individual care decisions.

Developed systems and processes include ethical decision-making support mechanisms which become part of the health care organization's general operations. Staff must work to safeguard and foster the rights and interests of patients and develop an effective partnership. The research completed did not identify specific support mechanisms in critical access hospitals.

### Ethical Decision-Making Support Mechanisms

Organizations need to build a foundation to support patient advocacy, patient autonomy, and the development of ethical decision-making processes. These processes include some practices or mechanisms which are official processes or which are part of an organization's general operations and culture. The role of leadership is inherent to these types of activities. Leadership support is required to recognize, prioritize, and ethically drive efforts that establish policies and procedures to improve care to better meet the needs of diverse populations. A commitment to patient advocacy and autonomy can be reflected at the highest level by incorporating these ideals into an organization's guiding principles, organizational planning, and health care organization-wide policies, procedures, and operating mechanisms.

Specific organization-wide policies guide physician and staff behavior. Consensus building processes which can include hospital leadership, physicians, nurses, and community members lead to hospital-wide policies which provide consistency in patient care processes. This consistency builds the framework to support patient autonomy. Consensus building respects the autonomy of all parties involved and better ensures

quality, fairness, and an efficient decision-making process (Spriggs, 2005). Health care organization policies and procedures to support decision-making processes often include specific mechanisms to support staff in resolving ethical conflicts. These may include both staff and information mechanisms.

### *Staff Mechanisms*

Staff mechanisms, for ethical decision-making support, may include the use of an interdisciplinary care-planning team, social services, clergy support, an ethics consultation service, and patient and family advisory councils. The interdisciplinary care-planning team provides staff with the opportunity to understand the continuum of care as it is related to the care-giving processes and the opportunity to thread in discussion of ethical concerns. Many health care organizations also include the patient, family, social services, and clergy representation in this process. Social service and clergy staff, in addition to participation in the care-planning processes, may provide additional support to the patient through advocacy programs. These advocacy programs may include ethical decision support in assistance with advance directives, lending a supportive ear, coordination of an ethics consultation meeting to resolve ethical concerns of the patient or family, and the provision of spiritual support (Healthcare at West Virginia University, 2008).

Ethics consultation services can be provided both formally and informally. In a formal structure the service may have designated personnel or outside consultants to provide health care staff support during ethical dilemmas. In an informal structure both internal and external volunteers may be assigned to meet, when called, to address the identified ethical issues or the organization may rely on state universities or a larger

health care system to provide these services (Healthcare at West Virginia University). Beauchamp and Childress (2009) identified that institutional ethics committees through open discussion and debate, help to resolve disagreements, generate reasoned options, and foster better thinking and clearer decisions. These outcomes support the continued development of partnerships between patients, families, and health care organizations.

In a patient-centered and family-centered health care system a partnership is established between the patient, family, and organization (Grant, 2006). Patients and families are integrated into the organization's care-delivery system through involvement in planning care, decision-making, and improvement processes (Ponte et al., 2003). Earp et al. (2008) referenced that former patients and families may serve on advisory councils that address care related issues, quality improvement initiatives, existing and new program evaluations, facility design, and staff education. The benefits of adopting a culture of family-centered care, defined by Earp et al., are the following.

Family-centered care is increasingly linked to improved health outcomes, lower health care costs, more effective allocation of resources, reduced medical errors and litigation, greater patient, family, and professional satisfaction, increased patient and family self-efficacy and advocacy, and improved medical health education. Family-centered care, with its reliance on having providers and care systems work respectfully with families, can help build trust with traditionally marginalized populations, making it a promising approach for helping to reduce health disparities between minority and majority populations. (p. 66)

To be truly effective in enhancing quality and safety, patient-centered and family-centered care must be comprehensively integrated into the organizational culture. In

addition to staff mechanisms, information mechanisms support staff in resolving ethical conflicts.

### *Information Mechanisms*

Information mechanisms, which support staff in resolving ethical conflicts, may include the use of a number of internal and external forms and established organizational processes and systems. An advance directive, health care proxy, medical power of attorney, and living will are information mechanisms which could be completed prior to the need for a hospitalization and brought with the patient upon admission. The origin of directives can be traced back to 1976.

Living wills were given official legal status in 1976 when the Natural Death Act was passed in California (Blondeau, Valois, Keyserlingk, Hebert, & Lavoie, 1998). On June 11, 2000, an update to this law went into effect that made several changes to the Living Will and Medical Power of Attorney forms. First, this updated law required only one physician to decide whether the patient is able to make his or her own health care decisions (West Virginia Center, 2005). Previously, two physicians were required to make this determination. Secondly, the updated forms have also been written in clearer language. No legal intervention, such as involvement of an attorney, is needed to complete either of these advance directives.

One form of an advance directive, sometimes known as a living will, can be considered a vehicle which would allow for continuation of negotiations between health care providers and the patient after the patient has been rendered temporarily or permanently incompetent (Flynn, 2000). Advance directives are generally drafted by an individual in order to limit care should they become incompetent with a poor prognosis



(Pozgar, 1999). An advance directive could be used to state an individual's wishes to have maximum treatment rendered for as long as possible. In addition to a living will, another form of advance directive is a health care proxy. A health care proxy is also known as a Durable Power of Attorney (DPA).

A health care proxy or DPA allows an individual to appoint a health care agent to make treatment decisions in the event he or she becomes incapacitated and unable to make decisions for himself or herself. Pozgar (1999) referenced that the appointed agent should know about and interpret the expressed wishes of the patient and then make decisions about the medical care and treatment to be administered or refused.

Wrigley (2007) identified that the proxy should be seen as an advisor to the professional medical team in helping make best-interests judgments rather than substituted judgments. In the best-interests principle of surrogate decision making the proxy makes an assessment of the patient's best interests and makes a decision based on that assessment. When substituted judgment is used the proxy uses their special knowledge of the patient's preferences to make the decision that the competent patient would have made. Wrigley defined the critical difference between best interests and substituted judgment as follows.

In the best-interests role, although the proxy may use their knowledge of the patient's preferences, their decision should be, not a direct reflection or second-guessing of the patient's wishes, but only what the proxy would consider best for the patient in a particular set of circumstances. (p. 527)

An individual can also plan for the time when he or she may no longer be competent through the use of a medical power of attorney document. A medical power of

attorney is a legal document, signed by a competent adult, designating a person that the competent adult trusts to make health care decisions on the competent adult's behalf when this individual is no longer competent. The competent adult is known as the principal and the designated person to act on his or her behalf is known as the agent (Texas Medical Association, 1999). An agent is generally an individual who is well known and trusted by the principal. The agent should be familiar with an individual's values and preferences and is ordinarily a family member or close friend (Flynn, 2000). A principal may choose to write his or her agent a letter stating personal values and wishes, feelings about life and death and any specific instructions, and to attach a copy of this letter to his or her medical power of attorney (West Virginia Center, 2005). The consent or refusal of the medical power of attorney's identified agent is as meaningful and valid as the principal's consent or refusal.

In summary, information mechanisms which assist the patient in planning for his or her future care also assist health care organization staff in preventing ethical conflicts. As a result of worldwide demographic change, health care providers will increasingly care for patients from different cultural backgrounds. Differences in beliefs, values, and health care practices have created care challenges between health care providers and patients (Crawley, Marshall, Lo, & Koenig, 2002). When considering ethical decision-making support mechanisms, health care providers must remain sensitive to specific beliefs and practices of the populations they serve.

### *Conclusion*

Organizational ethical decision-making support mechanisms assist staff in advocating for the patient, supporting patient autonomy, and achieving patient-centered

care. Patient-centered care requires health care providers to elicit the patient's point of view bringing to light personal values, care preferences, and psychosocial factors that impact health (Earp et al.). Patient advocacy requires a relationship-centered approach to health care (Tresolini, 1994). The philosophical premise of this approach is that the relationships among the health care provider, the patient, the health care organization, and the community are the primary drivers of health. This mutually constructed understanding between the health care provider and the patient then informs decision-making and patient-appropriate autonomy (Earp et al.). Within this relationship-centered model, patient and family knowledge, values, beliefs, and cultural backgrounds have been incorporated into the development, planning, and delivery of care (Conway et al., 2006).

The implementation of these ethical decision-making support mechanisms would have even greater benefit in the critical access hospital organization. With limited physician and professional nursing staff it will be difficult to achieve patient-centered care and patient advocacy without additional support. The current research does not distinguish between the mechanisms used in critical access hospitals from acute care hospitals. This research study gathered this information for critical access hospitals.

#### Health Communication and Decision-Making Strategies

Health communication includes the study and use of communication strategies to inform and influence individual patient and community decisions that enhance health. It links the domains of communication and health and is increasingly recognized as a necessary element of efforts to improve personal and public health (National Cancer Institute, 2008). For patients and health care providers, effective health communication

can raise awareness of health risks and viable solutions to provide the motivation and skills needed to reduce these risks, help patients find support from others in similar situations, and effect or reinforce attitudes (Padmanabhan, 2008). Health communication can also increase the demand for appropriate health services and decrease the demand for inappropriate health services. Workman (2007) referenced that early effective communication about goals, prognosis, and options would improve patient care at or near the end of life by enhancing choice and facilitating palliative care.

An effective communication system includes several important elements. These elements address that communication must be understandable and adopt an audience centered approach (Lund, 2006). These considerations are particularly relevant for racial and ethnic populations who may have different languages and sources of information. Interventions that account for the cultural practices and needs of specific populations have shown success. An intervention that used the novella, a popular form of Latino mass media, to reach young people and their parents, sought to improve parent-youth communication in Hispanic families and to influence the attitudes of adolescents about alcohol (Lalonde, Rabinowitz, Shefsky, & Washienko, 1997). This intervention was determined to have a positive impact on Hispanic youth.

Even with access to information and services, disparities may still exist because many individuals lack health literacy. Health literacy is increasingly vital to help patients navigate a complex health system and better manage their own health. Differences in ability to read and understand materials related to personal health as well as to navigate the health system appear to contribute to health disparity issues (Earp et al.). The lack of health literacy within the rural critical access hospital creates disparities due to the

cultural diversity and ethnicity of the patient population. In addition to the farming community residents, Hispanic, Hmong, Mexican, and Indian are the patient populations typically served in this study. Interpreters, in these rural areas, may not be readily accessible, limiting effective communication. Current research has not defined disparity rates specific to the critical access hospitals within the states that were researched.

### *Health Literacy*

Lund (2006) addressed the importance of health literacy. Health literacy can be defined as the patient's ability to obtain, process, and understand basic health information and services in order to make appropriate health decisions. Low health literacy is associated with poor understanding of written or spoken medical advice and adverse health outcomes (North Carolina School of Medicine, 2009). Patients with low health literacy are less likely to comply with treatment protocols because they do not understand the instructions. Literacy problems are particularly prevalent among racial and ethnic minorities, older adults, people with less education or with cognitive impairments, and low income individuals (Kutner, Greenberg, Jin, & Paulsen, 2003). In one study, the North Carolina Institute of Medicine literacy task force examined strategies for improving health communications (North Carolina Institute of Medicine). The task force identified universal strategies to improve health literacy awareness among health care professionals and literacy professionals and developed recommendations to incorporate health literacy strategies into adult literacy and adult basic education (North Carolina Institute of Medicine). The Institute of Medicine report acknowledged that a major impediment to appropriate communication about health is the limitation on provider time that is often required by health maintenance organizations and provider plans.

Most of the current efforts to improve health outcomes and reduce health care costs depend on an informed health care consumer. Patients cannot make informed health care decisions if they do not understand the health information they receive (North Carolina Institute of Medicine, 2007). An effective communication system will lead to the ability to make informed decisions. Prior to meeting the treatment needs of patients, effective communication with the health care provider must be established. The physician-patient medical treatment communication and decision process is critical to understand what the health issues are and to develop a collaborative health care plan to address the identified health issues.

*Physician-Patient Medical Treatment Communication Decision Process*

Information and patients' rights to self-determination have been central aspects of the debate on decision-making in medicine for several decades. The emphasis on individual preferences and the demand for respect for the rights of citizens regarding decisions about treatments have led to the ideal of informed decision-making. Patients should be empowered by information about their diagnosis, treatment options, and prognosis to make treatment decisions that correspond to their preferences and values (Giacomini, 2000).

This approach to decision-making stands in contrast to the traditional, paternalistic model of decision-making, according to which physicians made treatment decisions based on their knowledge and views with respect to the best medical treatment for a patient (Schildmann, Grunke, Kalden, & Vollmann, 2008). In the past two decades, the model of informed decision-making has been increasingly criticized. It has been argued that the model of the informed decision reduces the role of physician to

technician, who, according to this model, should use their knowledge and skills to implement patients' wishes (Charles, Gafni, & Whelan, 1997; Emanuel & Emanuel, 1992). This criticism suggests that values of the medical profession no longer form part of the physician-patient medical treatment decision process.

### Specific Models

Various authors have proposed decision-making models, pure or hybrids, taking into account the possible roles of physician and patient (Brody, 1980; Charles et al., 1997; Emanuel & Emanuel, 1992; Llewellyn-Thomas, 1995; Quill, & Brody, 1996; Siegler, 1985; Szasz & Hollender, 1956). Szasz and Hollender proposed three models of the physician-patient relationship. These were identified as the activity-passivity model, the guidance-cooperation model, and the mutual participation model (Szasz & Hollender). The activity-passivity model simulated the parent-infant model of communication, the guidance-cooperation model simulated the parent-child model of communication, and the mutual participation model simulated the adult-adult model of communication. The consumer movement of the 60s and 70s promoted the mutual participation relationship with its emphasis on respecting the wishes of patients (Fu-Chang Tsai, 2001).

Characteristics of four other models have been described by Emanuel and Emanuel (1992). These four models are identified as paternalistic, deliberative, interpretative, and informed. In the paternalistic model the physician is in control. The physician's role is seen as guardian and supporter of the patient's well-being. In the deliberative model the patient is in control. The physician's role is seen as friend and teacher. The physician's task is the persuasion of the patient with respect to health-related

values as well as informant to the patient and implementer of the patient's selected intervention. The interpretative model also identifies that the patient is in control. The physician's role is that of advisor and interpreter. Following discussion with the patient the physician gains an understanding of the patient's values, shares his expertise with the patient, and then implements the patient's selected intervention. Finally, the informed model also identifies that the patient is in control. The physician's role is one of technical expert and his task is the provision of relevant factual information and implementation of the patient's selected treatment.

The deliberative and interpretative models reflect that information flows back and forth between the physician and the patient (Emanuel & Emanuel). The flow of information in both the paternalistic model and informed model travels from physician to patient. The deliberative and interpretative models are important models for the critical access hospital. Due to the populations served, the back and forth information flow supports patient-centered communication and the development of a partnership between the physician and patient. As models are reviewed communication is seen as an important component of the physician-patient relationship. Current literature does not distinguish critical access hospitals from the total population of acute care hospitals. There is no specific information for these rural health care organizations regarding decision-making models and communication effectiveness.

### Communication

Effective communication improves patient satisfaction and health outcomes whereas poor communication and unprofessional behavior are linked to patient complaints and potential malpractice complaints (Epstein & Hundert, 2002; Institute of



Medicine Report, 2003; Levinson, Roter, Mullooly, Dull, & Frankel, 1997; Papadakis, Osborn, Cooke, & Healy, 1999). Programs to build communication skills and professionalism must be integrated throughout medical education as recognized by the Accreditation Council for Graduate Medical Education (2005).

The Accreditation Council for Graduate Medical Education Outcomes Project (2005) requires that residency training programs assess six core competencies. These core competencies include interpersonal and communication skills that result in effective information exchange and learning with patients, their families, and other health care professionals (Accreditation Council for Graduate Medical Education).

#### Physician Values and Impact on Physician-Patient Communication

The physician's job is to evaluate the patient and to determine meaning and significance to the chaos of data presented to him to formulate a response. The physician's tools for making sense of clinical data include a highly developed intellect (Martin, 1978). As with any other evaluating subject, the physician has value orientations to support and inform him in his work. Martin stated these value orientations include the following.

The physician has idiosyncratic interests and his personal likes, desires, and objects of affection help to provide him with an image of an ideal self. By generalization, the physician thinks of the kind of person his patient ought to be. The physician ascribes meaning and significance to his patient's situation according to his own criteria and goals. (p. 204)

The physician's professional code of ethics demands that, above all personal interest, he devote himself to the welfare of his patient, the general good of society, the

scientific advance of medicine, and the integrity of his profession (American Medical Association Judicial Council, 2001). The responsible decision and appropriate action for the physician requires applying his special skills and values to contribute meaning and significance to the clinical data so that he may understand the objective reality of the patient and interact effectively with the patient. The physician needs to realize that the patient's values and life orientations may be different from his own. These differences may influence which physician-patient medical treatment decision model, pure or hybrid, is used. It is important to note that current research does not distinguish between the acute care hospital and the critical access hospital.

A qualitative study on physician views about the importance of shared values in HIV positive patient care was conducted by Lawlor and Braunack-Mayer (2004). This paper explored the application of the value sharing model for a designated patient population. The perception of shared values is important to group membership processes and the development of social and group identities (Marques, 1998; Mullin, 1999). The results were presented as a comparison between the views of physicians who were identified as homosexual and those who were heterosexual. Lawlor and Braunack-Mayer commented this analytical approach was used because each physician explicitly identified his sexual preference to the interviewer without being asked to do so.

It was also clear that the doctors made their sexual preference clear to their patients. The decision on the part of the doctors to make their sexual preference clear implies an investment of significance in the perceived relationship between the care of HIV positive patients and the sexual identification of the provider of care (Lawlor & Braunack-Mayer). The respondents made it clear that sexual identification mattered.

Value sharing, for the homosexual physicians, was found to be an avenue to identify with their patients that allowed them to create the trusting and safe relationship described as desirable and, at the same time, diminish the patient's fear of rejection. Value sharing, for the heterosexual physicians, was found to be a useful tool in developing the clinical relationship, however its absence did not preclude the development of an appropriate and therapeutic relationship.

The physician-patient medical treatment communication and decision process has continued to have its challenges. In September, 2008, The New York Times began a web column entitled "Doctor and Patient". Its first column, "Healing the Doctor-Patient Divide," was written by a surgeon who suggested the problem is the loss of the ability to communicate thoughtfully with one another (Chen, P., 2008). The author referenced that more and more Americans feel disconnected from their doctors especially compared to a generation ago and certainly have less confidence in the profession as a whole. This New York Times web site has been open to public comment and feedback since the posting of the first column. In the first six days, 439 comments were posted on the blog. A critic of this web site identified that the column does not allow for conversation or discussion but serves as a repository of stories with minimal healing potential and underscored that it widens the communication divide between physician and patient (Snyder, 2008).

The physician-patient relationship has traditionally been structured around the clinical model (Kushner, 1981). Patients seek a relational model which is focused on the quality of the process of physician-patient interaction. To find the balance between physician power and patient choice, Quill and Brody (1996) identified that physicians must work on the development of communication skills, negotiation skills, and power

sharing skills with training in medical interviewing, self-awareness, and clinical reasoning. The key to successful physician-patient relationships is based on the recognition that patients are partners in the decision-making process.

Effective health communications require partnering with the patient, teamwork, and developing of continuous quality improvement strategies to ensure organization systems and processes do not fail to support patient autonomy (Lutz, 2008). Lutz identified the two important elements of a successful customer strategy as leadership engagement and ownership of the customer experience. Health care leaders are expected to demonstrate measurable outcomes and the attainment of certain competencies (Stefl, 2008). The competencies were identified through the work of the Competency Task Force that was convened by the Healthcare Leadership Alliance. The Healthcare Leadership Alliance is a consortium of major professional associations in the health care field which include the American College of Healthcare Executives, the American College of Physician Executives, the American Organization of Nurse Executives, the Healthcare Financial Management Association, the Healthcare Information and Management Systems Society, and the Medical Group Management Association and its educational affiliate, the American College of Medical Practice Executives (Stefl). The competency domains include communication and relationship management, leadership, professionalism, knowledge of the health care environment, and business skills and knowledge. Although all domains can be viewed as interdependent, two of the domains specifically address patient and community relationships.

The first of these domains is communication and relationship management. Stefl (2008) stated the Healthcare Leadership Alliance Competency Task Force identified that

“communication and relationship management is the ability to communicate clearly and concisely with internal and external customers, to establish and maintain relationships, and to facilitate constructive interactions with individuals and groups” (p. 364). The second of these domains is professionalism. Garman, Evans, Krause, and Anfossi (2006) stated the Healthcare Leadership Alliance Competency Task Force identified that “professionalism is the ability to align personal and organizational conduct with ethical and professional standards that include a responsibility to the patient and community, a service orientation, and a commitment to lifelong learning and improvement” (p. 1).

### *Conclusion*

The establishment and maintenance of patient and community relationships is important to the achievement of patient-centered care. As a result of the re-focus on patient safety and quality of care, hospitals have needed to evaluate practices, policies, and attitudes within their organizations. The Joint Commission (2008) referenced that patients have the greatest stake in their own care thus should be respected as equal partners. The literature has also reflected that patients do not always act alone but often rely on family or others to whom they are emotionally tied (Levinson, Kao, Kuby, & Thisted, 2005; Sheridan & Hatlie, 2007; White, Braddock, Bereknvei, & Curtis, 2007). Family and significant others must then be considered in the health care partnership.

The engagement of patients and families in the planning of care empowers patients to participate in care decisions, provide self-care, and protect themselves from potential harm. The Joint Commission’s National Patient Safety Goal 13 specifically requires health care organization staff to encourage patients’ active involvement in their care as a patient safety strategy (Joint Commission, 2009b). The rationale for this goal is

that communication with the patient and family about aspects of care, treatment, and services is an important characteristic of a culture of safety.

Instilling patient-centered care is not just about changing practices and policies but must also address the need to change organizational culture. For care providers to be empathetic to patients the hospital must also have an empathetic culture for care providers. Care providers need to be supported through systems that protect them from harm and from doing harm. To achieve a culture that is patient-centered and supportive of the ability of the patient to make individual care decisions, hospital leadership and all care providers must share common beliefs and values. This focus on patient autonomy, patient advocacy, and patient-centered care will support the continued development and implementation of effective health communication and decision-making strategies.

#### Summary of the Literature Review

There are a variety of factors that have been identified as possible influencers on the development of organizational systems and processes to support the ability of the patient to make individual care decisions. Although patient autonomy, patient advocacy, and the physician-patient medical treatment decision processes have continued to evolve throughout history, it is clear from the literature review that health care has not fully achieved shared decision-making or a relationship-centered physician-patient partnership. Spring (2008) identified that health decision-making is both the lynchpin and the least developed aspect of evidence-based practice. Spring stated “the literature is largely silent about how to accomplish integrative, shared decision-making” (p. 866). In addition, the range of available, well-validated algorithmic decision-support tools remains limited (Bates, Kuperman, & Wang, 2003). For care to be collaborative it matters as well that

patients genuinely participate throughout the decision-making process. Street (2007) and Epstein and Street (2007) noted that collaborative care requires the preconditions of communication, comprehension, and trust. Good communication will not, in and of itself, guarantee good decision-making and the challenge of integrating evidence, patient preferences, and resources still remains (Spring).

In addition to the remote locations of critical access hospitals, another factor that may impact patient autonomy and patient advocacy is the physician-patient medical treatment decision model utilized in these generally rural health care organizations. There may be limited medical professional availability in these remote locations facilitating the usage of mid-level physician extenders such as physician assistants or nurse practitioners (Rural Assistance Center, 2008). This limitation may further reduce the ability of the patient to exercise autonomy or make an informed decision as it places another layer between the attending physician and the patient. To further complicate this staffing issue, there is growing national concern over shortages of physicians. By 2020, the United States may be short 85,000 physicians (Accreditation Council for Graduate Medical Education, 2005).

In addition to physician shortages, the critical access hospital may experience other staffing shortages. Critical access hospital staff may have multiple responsibilities and thus may be inadequately trained in all responsibilities to provide full support to the patient in making individual care decisions. Pervasive staffing problems challenge the ability of the hospital to perform its most fundamental functions.

As patients' needs and health care delivery become more complex it is difficult for clinicians to keep pace. Hospitalized patients have higher acuity and are more likely

to have co-morbidities while hospital stays have shortened. Hospitals, particularly critical access hospitals in rural America, may need to accomplish more with fewer health care professionals. To address patient care issues, team-based care may need to be initiated to accomplish more with less. Teamwork has also been noted to have a significantly positive impact on the safety of health care (Baker, Salas, & King, 2005). Studies have also reflected that well functioning teams make fewer mistakes than do individuals (Baker et al.).

Having all caregivers working toward the same end goal will build team skills and encourage effective team work. The cultural diversity, ethnicity, and increasing prevalence of chronic illness among patients of all ages should compel health care organizations to pursue models of care and support mechanisms that would best meet the needs of all patients (Joint Commission, 2008).

The mechanisms used to support the ability of the patient to make individual care decisions in rural America need to be investigated further. Currently research does not address the critical access hospital market. Thus, this study was developed to identify, describe, and compare the systems and processes in place at dual-licensed and accredited critical access hospitals, within a designated geographical area, which support the ability of the patient to make individual care decisions. This research will add specific information, related to critical access hospitals, to the literature as well as lay the foundation for further research and education development opportunities.



## CHAPTER III

### METHODOLOGY

#### Introduction

The developmental evolution of clinical ethics supporting patient autonomy in decision-making has been addressed in many medical, clinical, and ethics journals and books. This dissertation built upon the foundation of what has been researched and written while identifying specific systems and processes in place for a defined rural hospital population called critical access hospitals. Current literature has not reflected a distinction between the general acute care hospital and the rural critical access hospital in identifying the systems and processes utilized to support the patient's ability to make individual care decisions.

The purpose of this qualitative study was to identify and collect information on the systems and processes in place at dual-licensed and accredited critical access hospitals which support the ability of the patient to make individual care decisions. The researcher also gathered data on the physician-patient medical treatment decision model utilized by each of the rural health care organizations so that a comparison could be made to three existing medical treatment decision models. The models used for comparison were the Paternalistic Model, the Independent Choice Model, and the Enhanced Patient Autonomy Model identified by Quill and Brody (1996). The basis for the development of the models was the increasing shift in decision-making from the physician to the patient

and the need to build a collaborative relationship between the physician and the patient and preserve autonomy in patient decision-making. The research was guided by the following four questions.

1. What are the current processes and systems which support the ability of the patient to make individual care decisions beginning at admission?
2. Which departments and individuals are involved in the current processes and systems?
3. Which physician-patient medical treatment decision model, pure or hybrid, is utilized in the organization?
4. What comparisons can be made regarding the physician-patient medical treatment decision model identified by each of the generally rural health care organizations?

### Research Design

Data were collected for each participating critical access hospital utilizing Zoomerang, an electronic survey instrument. Follow-up interviews were conducted at seven of these same organizations through conference calls for the purpose of validation of information. This researcher worked directly through the participating organization's Chief Nursing Executive who completed the electronic survey instrument and served as the content professional if the organization was selected for a follow-up validation call. The Chief Nursing Executive was selected based on his or her multiplicity of roles and responsibility for the coordination of patient care.

The qualitative electronic survey instrument answered the four research questions. The specific areas the survey instrument identified were the organization's processes and

systems to support the patient's autonomy, the involved staff and departments within the organization, and the organization's physician-patient medical treatment decision model. Comparative analysis data between organizational responses, related to the physician-patient medical treatment decision model, were also gathered.

The electronic survey instrument, via Zoomerang, was completed using components of a questionnaire developed as part of the California Endowment-funded project titled *Hospitals, Language, and Culture: A Snapshot of the Nation*. The project was conducted under the auspices of The Joint Commission, a national and international healthcare accrediting body (Joint Commission, 2007). The author received approval to use these components from The Joint Commission leadership in November, 2008 (Appendix I). Quill and Brody's article introduced concepts that were used for comparative purposes in the development of components related to the physician-patient medical treatment decision models. The rural healthcare organizations participating in this research study identified the components through the electronic survey instrument.

Overall the electronic survey instrument identified the rural organization's structure and process to include communication strategies and mechanisms to support patients in making informed decisions about their care while addressing the patients ethical and religious beliefs and language differences. The knowledge of organizational staff and the roles of other departmental staff were also assessed. Finally, the electronic survey instrument allowed for the collection of comparative data within a designated geographical area.

A percentage of organizations who had participated in the original completion of the electronic survey tool also participated in the follow-up validation interviews. The

organization had completed the required consent forms prior to the interview. Questions used in the electronic tool were used in the organization interview. Additional questions were developed based upon the identified gaps in the information received in the electronic tool survey. The electronic data collection survey instrument and follow-up validation organizational interview questions were developed using the grounded theory qualitative study method as a reference (Jezuit, 2001; Joint Commission, 2007).

This research study used the method of constant comparison, grounded theory. Jezuit (2001) stated that grounded theory is based upon the fact that not only is the researcher familiar with the study, but the study subjects are selected based upon the premise that they can contribute information about the problem. Robson (2002) further referenced the grounded theory method. This type of study seeks to generate a theory, or hypothesis, which relates to the focus of the study. This theory, or hypothesis, is grounded in data obtained during the study. The research study questions were designed to elicit new information regarding the identification of the systems and processes in place at dual-licensed and accredited critical access hospitals.

## Population

### *Characteristics*

Critical access hospitals, serving rural America, are a new licensing category of health care organizations which emerged through the Medicare and Medicaid legislation within the Balanced Budget Act of 1997. This legislation allowed health care organizations within the United States to diversify to ensure that health care needs were met in generally rural America (Centers for Medicare and Medicaid Services, Medicare Learning Network, 2007). Critical access hospitals may have a maximum of 25 beds and

are required to be located more than a 35-mile drive or, in the case of mountainous terrain or in areas with only secondary roads available, a 15-mile drive from an acute care hospital or another critical access hospital.

The Centers for Medicare and Medicaid Services require an annual average length of stay of no more than 96 hours per patient for acute inpatient care. Critical access hospitals must also comply with all applicable Conditions of Participation, including the requirement to make available 24-hour emergency care services seven days per week. The intent of critical access hospitals, who have met these criteria, is to keep hospital-level services in rural communities. Therefore, critical access hospitals are required to satisfy designated criteria to assure that they are located in rural areas and that there are no other acute care hospitals or critical access hospitals close by (Centers for Medicare and Medicaid Services, Medicare Learning Network, 2007).

In addition to licensure by the state agencies representing The Centers for Medicare and Medicaid Services, critical access hospitals can choose to be accredited. Accreditation criterion require that they meet The Joint Commission additional standards to ensure effective leadership and safe quality care. Critical access hospitals seek accreditation, which is optional, because it strengthens community confidence in the quality and safety of care, treatment, and services and improves risk management and risk reduction.

### *Demographics*

Sixteen of 90, or 17.8%, of the dual-licensed and accredited critical access hospitals within the states of Illinois, Wisconsin, Indiana, and Iowa participated in this study. This researcher worked directly through the participating organization's chief

nursing executive who completed the electronic survey instrument and served as the content professional if the organization was selected for a follow-up validation call. The chief nursing executive was selected based on his or her multiplicity of roles and responsibility for the coordination of patient care.

All 16 chief nursing executives were female with an average tenure in nursing of 33.3 years. These nursing executives' average years in their present position totaled 7.6 years with one nursing executive having less than one year experience. When queried regarding attending previous ethics courses or in-services, their responses were varied. Twelve (75%) of the nurses had attended a formal ethics course or program whereas 15 (94%) had attended some type of an ethics in-service. One nursing executive from organization 8 responded that she had not attended either an ethics course or an ethics in-service. It was clear from the completed survey that this organization had formal written policies and procedures which support the ability of the patients to make informed individual decisions regarding the provision of their care. A validation call was not conducted due to this researcher's inability to make follow-up contact with this organization.

The first 12 questions on the electronic survey instrument addressed the organization identification data. Organization identification and demographic data are important as this information identifies the level of services which are provided to the geographical area in which the critical access hospital is located.

The organizational identification data were incorporated into the data analysis, coded, and used to identify the similarities and differences between the organization's licensure status and additional services provided. Figures 1 and 2 depict this information.

Additional services are often provided by the critical access hospital market in order to meet the needs of the communities they serve. With these health care organizations being the sole provider of health care and located in generally rural America it is important for these organizations to diversify. Each of the chief nursing executives identified that their organization provided general outpatient services to include outpatient surgery. Twelve (75%) provided space for physician offices and 10 (63%) provided homecare services. The other services described included ambulance services, hospice care, outpatient mental health programs, outpatient geriatric-psychiatric programs, and inpatient and outpatient dialysis programs.

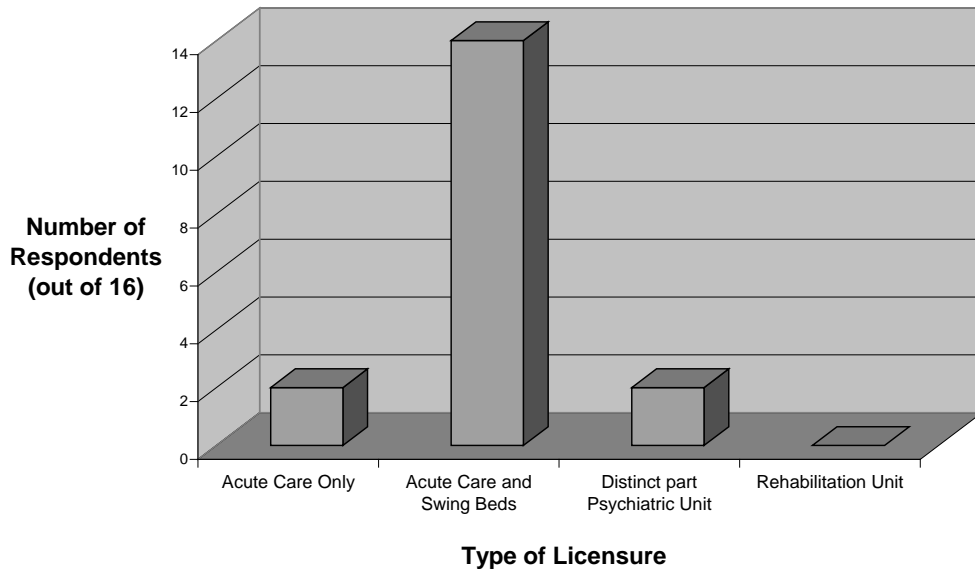


Figure 1. Demographic data identifying the organization’s licensure types.

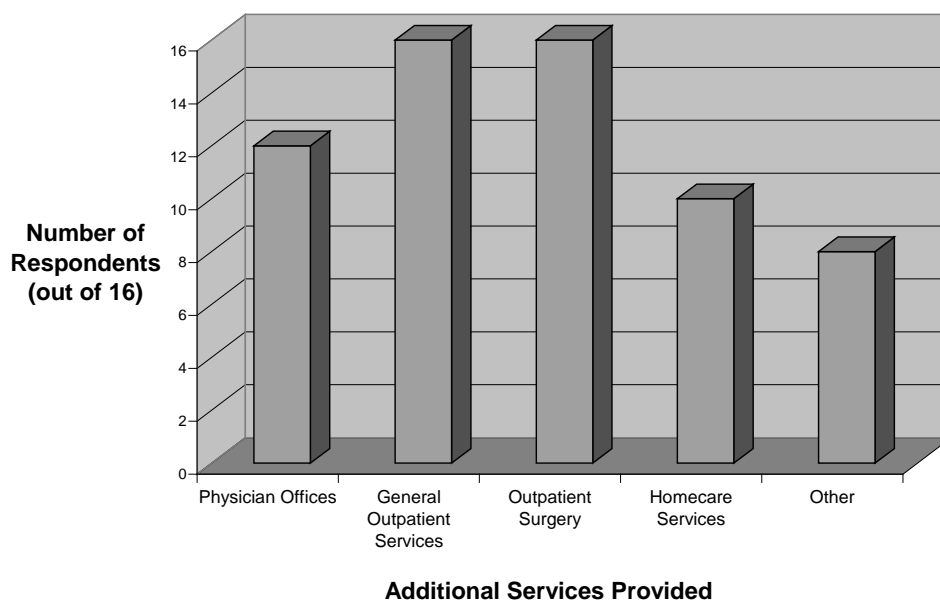


Figure 2. Demographic data identifying types of additional services provided.

### *Inclusion Criteria*

The population for this research study was limited to dual-licensed and accredited critical access hospitals. The author selected a defined population as a convenience sample to accommodate follow-up validation organization interviews and included the states of Illinois, Wisconsin, Indiana, and Iowa. Of the total population of 90 dual-licensed and accredited critical access hospitals, 24 hospitals were in Illinois, 34 hospitals were in Wisconsin, 22 hospitals were in Indiana, and 10 hospitals were in Iowa. Each dual-licensed and accredited critical access hospital in these four states was invited to participate in this research study.

### *Recruitment*

The sample that was contacted was 100% of dual-licensed and accredited critical access hospitals within the states of Illinois, Wisconsin, Indiana, and Iowa. Dual-licensed



and accredited critical access hospitals were identified from The Joint Commission public website and its associated links (Joint Commission, 2008). Initial recruitment of these 90 critical access hospitals occurred in February, 2009, through the United States mail. Each mailing included an invitation letter, intent to participate form, informed consent form, and a stamped self-addressed envelope for return of the signed intent to participate form and informed consent form to the researcher. The initial mailing was sent to the organization's chief nursing executive listing the generic title and not a specific name. A second mailing and reminder (Appendix J) was sent three weeks after distribution of the initial mailing in March, 2009, to 85 of 90 critical access hospitals who had not responded to the initial mailing. This second mailing listed the specific name of the chief nursing executive for 40 of the 85 critical access hospitals. For the remaining 45 of the 85 critical access hospitals, positions were either not filled or names could not be obtained through either public web access or a direct call to the organization. A third and final mailing was sent in April, 2009, to 77 of 85 critical access hospitals who had not responded to the second mailing.

Seventeen of 90 (18.9%) of the critical access hospitals within the states of Illinois, Wisconsin, Indiana, and Iowa agreed to participate in this research study. Each of these organizations returned the intent to participate form and informed consent form in the provided self-addressed stamped envelope to this researcher. This method of recruitment was selected to maximize participation in the study.

Sixteen of 17 of the initial critical access hospitals remained in the study which resulted in a 17.8% participation representation of the critical access hospitals within the designated four states. The one organization which opted out of the study failed to

complete the electronic survey tool. Of the total sample population of 16 dual-licensed and accredited critical access hospitals, 3 hospitals were in Illinois, 6 hospitals were in Wisconsin, 3 hospitals were in Indiana, and 4 hospitals were in Iowa. The researcher did not send out additional mailings to re-invite other dual-licensed and accredited critical access hospitals outside of the initial acceptance pool of critical access hospitals.

#### Data Collection

Following approval of this research proposal by the Institutional Review Board at Olivet Nazarene University, 100% of dual-licensed and accredited critical access hospitals within the identified four states were mailed the invitation letter, the Intent to Participate Form, and the Informed Consent Form. This initial mailing to 90 dual-licensed and accredited critical access hospitals occurred in February, 2009. In March, 2009, a second mailing was sent to dual-licensed and accredited critical access hospitals who had not responded to the first mailing. A third mailing was completed in April, 2009. A total of 17 of 90 (18.9%) dual-licensed and accredited critical access hospitals initially agreed to participate in this research study.

The author then sent the electronic survey instrument, via Zoomerang, to the Chief Nursing Executive in each of the 17 critical access hospitals upon return receipt of the signed intent to participate and the informed consent forms. This distribution began in April, 2009, and continued through June, 2009. A reminder e-mail was sent to each Chief Nursing Executive not returning the electronic survey instrument two weeks after the initial distribution. Follow-up reminder e-mails were also sent on a monthly basis. 16 of 17 critical access hospitals completed and submitted the electronic survey instrument which resulted in a 17.8% participation representation.

Follow-up validation conference call interviews were conducted from August through early November, 2009. Organization selection for the follow-up validation call was based on identified information gaps from the responses received in the organization's completion of the electronic survey instrument. These identified information gaps included the following.

1. The lack of written policies to support the ability of the patient to make informed individual decisions regarding the provision of their care. The electronic survey instrument identified 2 of 16 organizations where the chief nursing executive had responded there were no written policies.
2. The chief nursing executive's formal educational level. In review of the data, 2 of 16 Chief Nursing Executives identified that their highest level of education was a Bachelor in Science of Nursing. The Joint Commission requires that the nurse executive possess a postgraduate degree in nursing or a related field, the knowledge and skills associated with an advanced degree, or a written plan to obtain these qualifications (Joint Commission, 2009a).
3. The physician-patient medical treatment decision model (pure or hybrid).
4. The lack of defined communication mechanisms for executive and board leadership regarding patient ethical issues.

Self-selected, purposive, convenience samples of seven organizations were contacted for follow-up validation calls. In purposive sampling the population of subjects is selected for the information that they can specifically add to the context of the study.

Within grounded theory this type of purposive sampling is referred to as theoretical sampling (Robson, 2002). Theoretical sampling is where the persons or

organizations studied are chosen to assist the researcher to formulate the theory. Although the sample size is proposed, not exact, the data collection continued until saturation occurred, meaning that no new information was produced. Gay, Mills, and Airasian (2006) referenced that this point is generally known as data saturation. Scheduled follow-up validation conference call interviews were audio taped after approval was received from each of the selected organizations. If approval was not received from the organization hand-written notes were taken to record the discussion. Audiotapes were transcribed through a transcription service and a summary report developed.

As stated in Chapter 1, reliability and validity were concerns in this research study. Robson (2002) discussed the importance of establishing trustworthiness in flexible designs as well as fixed designs. Several methods were used to ensure trustworthiness of the data. First, the researcher maintained a journal to record observations and thought processes about the data. Second, triangulation was performed by validating the validation interview data with a data auditor, by checking data against other data, and by the utilization of subjects from multiple institutions. At the conclusion of the study, participants were mailed an aggregate summary of the results and an evaluation form which allowed them to validate the completed process against original expectations.

#### Analytical Methods

The first 12 questions of the electronic survey instrument addressed key demographic and organizational identification data. The demographic schedule contained questions that related to organizational licensure status and types of services and the chief nursing executive's overall responsibilities, years in nursing practice, level of education,

and exposure to ethics. These data were incorporated into the data analysis, coded, and used to identify the similarities or differences between the organizations and demographics. Figures were developed to reflect the similarities and the differences related to licensure status and services provided.

Questions 13-42 in the electronic survey instrument gathered essential information which addressed the four research questions. This information included the current processes and systems which supported the ability of the patient to make individual care decisions beginning at admission, the physician-patient medical treatment decision model, pure or hybrid, utilized in the organization, and the departments and individuals involved in the current processes and systems. The data gathered also supported a comparative analysis of the physician-patient medical treatment decision models. The further utilization of figures depicted this information. To respond to research questions 1, 2, and 3, the constant comparison method of qualitative data analysis was used.

Constant comparison is the repeated comparison of information from data collection and emerging theory (Robson, 2002). Data analysis began with the first interview. Each follow-up validation interview was compared to the other interviews and analyzed for coding categories and common themes that may begin to generate a theory. Categories were initially developed intuitively by the researcher, based upon professional knowledge, using names and relationships and may have included functions, means-ends relationships, attributes, or a sequence of events. A preliminary coding schedule was developed before the first interview based upon this researcher's knowledge. The initial coding categories were provisional which allowed change, if needed, as the data were

analyzed and compared (Robson). As the data were analyzed and compared no changes were made to the preliminary coding schedule. This method began the process of concept formation through review of the properties in the categories.

Interview transcripts were coded and each interview was coded and analyzed prior to the occurrence of the next interview. A masters prepared nurse with experience in critical access hospitals and qualitative data double coded every second interview which ensured accuracy of the coding categories and subsequent developing theory. Double coding means that the second coder independently coded every second interview using the same coding schedule that the researcher used. The researcher and the double coder then compared the coding of these interviews for consistency of categories and themes. Double coding was done to mutual consensus.

Constant comparison and concept development stimulated thinking about the data. Journaling about the concepts allowed for adjustments to the interview process. Journaling also allowed for further exploration of different data to conceptualize theory development and reveal the history of category development. The journal was reviewed for concept development by the second coder. The developed theory was based on the data collected (Leedy & Ormrod, 2005). To maintain confidentiality all data were reported as aggregate data.

Throughout the study confidentiality was maintained utilizing several mechanisms. Codes were used for all audiotapes, transcribed data, and demographic forms. Names and actual addresses of each of the critical access hospital organizations were removed from the transcribed data and replaced by the name of the state in which the organization was located. Audiotapes were locked in a cabinet separate from the

transcribed data and were destroyed at the study's conclusion. The transcriber utilized for data processing was informed about the confidential nature of the information on the audiotapes and requested not to disseminate or discuss the information with anyone but the researcher or dissertation committee. At the conclusion of the study, organization checks were conducted through mailing a summary of the study results and an evaluation form to the chief nursing executive of the organization. Each mailing included a stamped, self-addressed, envelope for the return of the evaluation form.

### Limitations

Several limitations may have jeopardized this study. First, the semi-structured interviews produced a large amount of data that needed to be analyzed. Second, this grounded theory study cannot be replicated as a result of the unique characteristics associated with the research. In this study these characteristics included a limited geographical region, a self-selected, purposive convenience sampling chosen for the validation follow-up conference calls, and the unique characteristics of each interviewed organization. Third, the researcher, as an instrument, had the potential to jeopardize the neutrality of the study through the introduction of personal bias. Fourth, multiple interpretations of the data could have limited the development of the theory. Leedy and Ormrod (2005) also referenced that due to the prescribed set of guidelines that the researcher must follow for analyzing data and constructing a theory that the structure itself may have limited the researcher's flexibility and predisposed the researcher to identify categories prematurely. As described within the analytical methods section these limitations should have been minimized by the methods implemented to increase the validity of the data.

### *Summary*

In summary, grounded theory is the research method that was implemented to identify the systems and processes utilized to support the patient's ability to make individual care decisions within dual-licensed and accredited critical access hospitals. Data were collected using an electronic survey instrument, Zoomerang, and follow-up, semi-structured, audio taped interviews. The collected data were then analyzed to reveal any developing concepts or theories. Actions were implemented to increase the validity of the data and protect the confidentiality of the collected information.



## CHAPTER IV

### FINDINGS and CONCLUSIONS

#### Introduction

The purpose of this chapter is to describe the systems and processes in place within dual-licensed and accredited critical access hospitals which support the patient's ability to make individual care decisions. This research study was completed within a designated geographical area within the states of Illinois, Wisconsin, Indiana, and Iowa. The geographical area was selected as a convenience sample to accommodate follow-up validation interviews. Data collected through the electronic survey instrument, via Zoomerang, and the follow-up validation interviews were analyzed and the findings reported for each of the four research questions. Conclusions, based on the research data, were provided with implications and recommendations given.

Literature which addressed the historical development of patient autonomy, patient autonomy and ethical conduct, ethical dilemmas and decision making, ethical decision-making support mechanisms, communication and decision-making strategies, and physician-patient medical treatment decision models was also reviewed. In the data collected, the research was guided by the following four questions.

1. What are the current processes and systems which support the ability of the patient to make individual care decisions beginning at admission?

2. Which departments and individuals are involved in the current processes and systems?
3. Which physician-patient medical treatment decision model, pure or hybrid, is utilized in the organization?
4. What comparisons can be made regarding the physician-patient medical treatment decision model identified by each of the generally rural health care organizations?

Data analysis, using the grounded theory methodology, was completed which specifically identified the organization's processes and systems to support the patient's autonomy, the involved staff and departments within the organization, and the organization's physician-patient medical treatment decision model. Data were collected for the analysis from the use of the electronic survey instrument and follow-up validation interviews. The electronic survey instrument identified the rural organization's structure and process to include communication strategies and mechanisms to support patients in making informed decisions about their care while addressing the patients' ethical and religious beliefs and language differences. The knowledge of organizational staff and the roles of other departmental staff were also assessed. Finally, the electronic survey instrument allowed for the collection of comparative data within a designated geographical area. Seven organizations who had participated in the original completion of the electronic survey tool also participated in the follow-up validation interviews.

At the time of this study, literature had not reflected a distinction between the general acute care hospital and the rural critical access hospital in the systems and processes utilized to support the patient's ability to make individual care decisions. This

chapter will summarize new information gathered regarding the systems and processes in place at dual-licensed and accredited critical access hospitals.

## Findings

### *Research Question 1*

*Current processes and systems.* The first research question was designed to identify the organization's current information mechanisms which support the ability of the patient to make individual care decisions and to define where the process is initiated. This was accomplished through questions within the electronic survey instrument and follow-up validation interviews. The results of the survey and validation interviews identified the following.

*Policies and procedures.* Written policies are usually based upon accepted, well-defined, standards of practice and clinical guidelines. Standards of care are needed to establish consistency as well as expectations and patterns for practice. Written policies also articulate what is done, who is served, as well as what clinical services and resources are needed. Written procedures delineate the processes and activities necessary to implement policies; in other words, the day-to-day operations. Procedures are usually based on professional guidelines when they are available. Procedures can cover processes such as care planning and steps to be taken to support the ability of the patient to make informed decisions.

In 15 of the 16 organizations the chief nursing executives identified established written policies to support the ability of the patient to make informed individual decisions regarding the provision of their care. In 12 of the 16 organizations formal written procedures were also in place. Written policies allowed for the identification and

assessment of an ethical issue, a resolution process to include a collaborative discussion with the patient, and an implementation and evaluation processes. The implementation and evaluation processes included the evaluation of the documentation of a case consultation and an interview with the patient and family post consultation. The themes of patient autonomy and ethical conduct and communication and decision-making strategies were identified and verified during the survey and validation interview processes. Organization 4 which had identified in the electronic survey instrument that they had no formal policies and procedures was scheduled for a follow-up validation interview.

Organization 4 stated in the electronic survey instrument, “If we have a patient that has need of informed decision, we have the social worker talk to the patient and family”. As a nursing leader, this researcher identified that this non-written process does not define the role of the provider in eliciting the patient’s concerns. In the review of the literature, Earp et al. (2008) addressed examples of patient-centered communication behaviors and ethical conduct which support autonomy within the patient-provider relationship. These authors identified the importance of well-defined processes and participatory behavior by the provider which questions the patient’s expectations, encourages the patient’s questions, and provides opportunity for the patient to share in decision-making.

In speaking with Organization 4 during the follow-up validation interview, the chief nursing executive was asked if the absence of a written policy or procedure created any patient care issues within the organization. This organization was part of a Catholic

corporation. The strength of the church's leadership and oversight was evident in her reply.

It doesn't seem to be. There is a committee, but it only meets ad hoc, you know, when they need to. And so, there hasn't been a need since I've been here. So, I haven't seen it at work at all. You know, we are a Catholic organization and we rely on our leadership to direct us. (Interview 1, organization 4, lines 85-90)

This chief nursing executive acknowledged that the church corporate leadership had written policies that directed decisions for the organizations within their system. These corporate written policies also addressed the presence of ethics consultation support services which support patients in making informed decisions regarding the provision of their care. This chief nursing executive further referenced that the membership on the corporate ethics consultation support service represented each of the organizations.

*Ethics consultation services.* Ethics consultation services provide ethical decision-making support to organization staff, patients, and families. This may include lending a supportive ear, coordination of an ethics consultation meeting to address the ethical concerns of the patient or family, and the provision of spiritual support. Although seven of the organizations responded that they did not have an ethics consultation service each of these organizations listed staff members or departments and other resources involved in established processes to support the ability of the patient to make informed decisions. All of the organizations responded that their internal processes include, at a minimum, one source of documentation in the clinical medical record to identify the process of support provided to the patient to make informed individual decisions. The clinical

medical record nursing notes and the clinical record physician progress notes were the most frequently cited as the sources of this documentation.

All of the organizations responded that they have multiple tools, staff, and other mechanisms in place to support the ability of the patient to make individual care decisions and ensure that information about language interpretation needs, religious beliefs, and cultural background is available to both patients and staff. Each of the respondents had advance directives, living wills, and informed consent information available for their patients. The themes of ethical decision-making support mechanisms and decision-making strategies were identified and verified during the survey and validation interviews. The inclusion of these mechanisms and strategies in an organizational formal plan is important to ensure leadership oversight.

*Organizational formal plans.* The development of formal plans reflects a commitment by the organization governance and leadership to support the ability of the patient to make individual care decisions. Thirteen of the Chief Nursing Executives identified in the survey that the organizational leadership developed formal plans. The existence of formal plans was also addressed during the validation interviews. The chief nursing executive of Organization 4 stated her critical access hospital was part of a larger religious system and responded that plans are made there to support the patient. Organization leadership then follows the system's formal plans. Giving one example of an ethical issue she stated the following.

We weren't sure that the surgery could be done here, a GYN sterilization procedure, and there were some ethical issues for the patient with that. But

mainly, we just went to the system's leadership for discussion and direction. In this case we were given approval for the procedure due to the patient's coexisting medical diagnosis. (Interview 1, organization 4, lines 95-100)

Organizational formal plans which support patient's autonomous decisions can be written into strategic, business, and budget plans. Organization 3 identified that their formal plan was also written into a policy format. Seven of the chief nursing executives identified that their organizations integrated formal plans to support the ability of the patient to make decisions into multiple areas addressing a combination of strategic, business, and budget plans. Strategic formal plans were most often identified by organizations. To ensure consistent implementation of these formal plans, orientation and on-going education of staff, leadership, and governance regarding internal processes are important.

*Orientation and on-going education.* Each of the participating organizations provided orientation and on-going education regarding internal ethical processes to support patients' decisions. The chief nursing executive in Organization 4 had not responded in the electronic survey instrument that the organization oriented and educated staff regarding internal processes which support the ability of the patient to make decisions about the provision of their care. Her validation interview confirmed that the organization had oriented and educated staff. She stated, "I just re-educated everyone because that was one of our joint commission tags. Everyone had a little posttest" (Interview 1, organization 4, lines 495,496,507).

The importance of orientation and on-going education was acknowledged by all participating critical access hospitals. However, the surveys and validation interviews

identified that success in implementing consistent processes to ensure ethical decision-making support mechanisms and decision-making strategies is often determined by leadership involvement. Assigning executive and managerial staff accountability for assuring that individual care decisions made by the patient have been followed has supported success in the outcomes of patient care.

*Executive and managerial staff accountability.* Fifteen of the chief nursing executives identified that their critical access hospitals had executive or managerial staff with assigned responsibility. This assigned responsibility ensured that individual care decisions made by the patient are followed. Monitoring and oversight were accomplished through medical record review and reports by staff. Executive or managerial staff with assigned responsibility included the chief executive officer, the medical director, the nursing director, nursing staff, social services, members of the ethics consultation service, and clergy. Four chief nursing executives had initially responded that there was no responsibility assigned to the executive or managerial level. In the validation interviews this researcher conducted with three of the four organizations the following information was gathered.

The chief nursing executives for Organizations 3, 4, and 5 referenced that the assigned responsibility was not documented but formally given to nursing services. Because nursing is consistently with the patient all addressed that if it had anything to do with the hospital support of the patient that they would have knowledge of it. As chief nursing executives they referenced that they would work with nursing staff to provide the patient the needed support. The chief nursing executives referenced that they did not respond to the question because assigned responsibility was not formally documented.



The chief nursing executive in Organization 3 provided an example of an ethical issue in which she was first involved but then needed to involve other executives and managers within her organization. She stated the following.

A patient had fallen and the nurse that happened to be caring for the patient had a drug diversion issue that we didn't find out until after the fact. The lawyers had found out that this nurse was released, and knew that the same nurse had cared for the family member, and so they were trying to tie those two together. It really brought up a lot of ethical questions about putting patients at risk. (Interview 5, organization 3, lines 236-249)

The support of ethical conduct, by leadership, in the treatment of patients is important. Leaders, through their assigned accountability, must accept the responsibility for ensuring that individual care decisions made by the patient have been followed. In order to make informed responsible decisions organizational leadership, including the governing body, must be supported by systems which support effective communication and informational processes.

*Governing body informational processes.* Fifteen of the Chief Nursing Executives identified mechanisms used with their governing body to inform them of patient ethical issues. These mechanisms included having a governing body member sit on the organization's ethics committee or quality council and discussion of ethical issues at board level meetings.

Prior to the validation interviews 1 of the 15 organizations, Organization 3, had not identified any mechanisms for the governing body to be kept informed regarding patient ethical issues. Several mechanisms were listed under this question with an

opportunity for the organization to specify other unlisted mechanisms. Organization 3 stated “none of the above” in the other, please specify, space. During the validation interview with Organization 3 the chief nursing executive did reference that discussion did occur at the board meetings relative to patient ethical issues. She referenced there was some confusion on her part, that the mechanisms listed in the survey did not specifically address committee reports, and stated the following.

Well, we all receive an annual ethics and compliance educational module that it also goes to our Board. As far as updates, if it were an admission issue, it would come through our quality review, you know, if it affected patient care. We have a Physician Quality Review Committee. It would also come through our customer relations department if it had to do with something other than a physician issue. But, I would be the one to bring that type of thing up, because I do an annual report for the Board. So, anything that we would have addressed that way would come through that report. (Interview 5, organization 3, lines 541-558)

One chief nursing executive representing Organization 8 provided no informational response to this question nor was a follow-up validation call conducted due to this researcher’s inability to make follow-up contact with this organization.

*Initiation of process.* Informed decision-making provides that a patient has a right to know the potential risks, benefits, and alternatives of the proposed treatments. Informed decision-making is predicated on the duty of the physician to disclose to the patient information necessary to enable the patient to evaluate, decide, and authorize proposed treatments (Beauchamp & Childress, 2009). The process should be initiated at the point of entry into a health care organization.

Question 16 identified where the process to support the ability of the patient to make informed individual decisions was initiated. Eleven of the Chief Nursing Executives responded that the process began on admission to the organization. Three responses provided specific information identifying the Emergency Department, following transfer to an assigned clinical unit, and that this process would begin wherever the point of care was initiated. In the one response which addressed that the process would begin following transfer to an assigned clinical unit, it was noted in the validation interview with Organization 5 that this nursing executive did not have leadership accountability over the Emergency Department. When this was specifically addressed during the validation interview she stated the following.

I've never heard of any issues. ER doesn't report to me. But, you know, I think I would still hear from the Medical Director as he also sits on the Executive Team. So, we meet weekly, and I think I would have heard if there were any issues by now. (Interview 3, organization 5, lines 449-455)

Through their weekly meeting this chief nursing executive expressed confidence that she would be advised of any issues although no formal process had been developed. Following the discussion with this researcher, she intended to discuss further strategies with the medical director of the emergency department.

Two nursing executives representing Organizations 4 and 8 provided no response to this question. In the validation interview with the chief nursing executive of Organization 4, she referenced that the process began wherever the point of care was initiated. This chief nursing executive was not sure as to why she had not responded to

the survey question. As discussed previously a validation call was not completed with Organization 8.

*Communication barriers.* Although literacy was not a direct question asked within the electronic survey instrument, the chief nursing executive in Organization 9 identified literacy in general as an issue during the validation interview. She referenced that she has always emphasized with her staff that effective communication is key to ensuring positive patient outcomes yet she learned a valuable lesson within her own organization. She shared a story regarding a patient who could not read and the failure of her and her staff to identify this communication deficit.

A couple of years ago we had a dialysis patient. The nurse that was caring for this patient was very sensitive and very in tune with that and made some beautiful charts for medication. We'd come back and find that things hadn't necessarily been followed. We did not realize until the dialysis patient needed to go to a facility approximately 45 miles from here, and the nurse had a map. The daughter happened to be with them and happened to say to the nurse, "Well, my dad can't read." We had never picked up on that previously to know that he would not have understood the medication directions. We assumed that he understood what it was that we were telling him and could follow them. (Interview 4, organization 9, lines 1097-1120)

This chief nursing executive identified that the organization learned from this experience and focused on patient instructions and education really trying to gear materials to a fourth grade level, especially with pre-op teaching and post-op discharge instructions. In-house educational sessions for all staff and managers were completed

which focused on very simple exercises. Emphasis was also placed on thoroughly assessing the patient's educational needs based upon a thorough assessment of their literacy. Tools and printed materials were developed to use in patient education.

This same chief nursing executive from Organization 9 further related a story of a patient who had been resuscitated which violated the patient's advanced directives. Hand-off communication processes and systems had not been utilized when the patient was transported to radiology. In reviewing the data no other chief nursing executive addressed these communication issues.

*Summary.* Information related to the specific aims (appendix K) of research question 1 was gathered through different questions within the electronic survey instrument and the follow-up validation interviews. The organizations' current information mechanisms which support the ability of the patient to make individual care decisions were defined. Finally, the point of care where the process was initiated was identified. The themes of patient autonomy and ethical conduct, ethical dilemmas and decision-making, ethical decision-making support mechanisms, and communication and decision-making strategies were identified and verified through the surveys and the validation interviews.

#### *Research Question 2*

*Staff and departmental participation.* The second research question was designed to identify involved staff and departments in the current processes who support the ability of the patient to make individual care decisions. This section will provide a general overview of staff participation.

All agencies identified more than one staff member and department as being involved in the current process to support the ability of the patient to make individual care decisions. Sixteen of the critical access hospitals involved the attending physician whereas five of the organizations also involved non-attending physicians. Roles of the non-attending physicians included a physician member of the ethics committee and other members of the medical staff who were available to provide support in decision-making.

Initially, Organization 4 cited no physician involvement however it was evident in the validation interview, when discussing the physician-patient medical treatment decision models, that the attending physician was involved in varying degrees in the process. This nursing executive stated that the physician's involvement was dependent on his or her relationship with the patient. When questioning the discrepancy in response between the survey and the validation interview the chief nursing executive of Organization 4 identified she was thinking of staff who were generally assigned to the patient and had not actually considered the physician's role.

When an organization has an established process to support the ability of the patient to make informed individual decisions regarding the provision of their care and has identified the departments and staff involved they may identify lead staff. Lead staffs are accountable for coordinating the process and may include staff from one department or multiple departments. Results from this study identifying lead staff will be addressed in the next section.

*Lead departments and staff.* Ten of the chief nursing executives identified that one department or staff member does take the lead in coordination of this process in providing support to the patient in making informed care decisions. The departments

and staff members included social services, nursing services, affiliated religious sisters, a staff registered nurse who had additional education in ethics and is a member of the system ethics committee, and the vice-president of quality improvement. In the six organizations where no lead was identified nursing services was recognized as the lead. All chief nursing executives recorded that nursing services, including the staff and supervisory nurse, are also responsible for ensuring that all information in the medical record which support the ability of the patient to make informed decisions is kept up to date. In addition, this same question identifies that nursing services are supported in the maintenance of updated information in eight of the organizations by the attending physician. In 10 of the organizations the maintenance of updated information was also completed by social services.

It is evident from the data that nursing services carries the greatest accountability. Nursing services, within the critical access hospital systems, are often the only hospital employees consistently with the patient and the family throughout the 24-hour period. The bedside nurse cares for the patient, communicates with the patient and family, coordinates the care-planning processes with the patient, family, physician, and other care providers, and ensures that appropriate mechanisms are utilized to resolve ethical conflict.

*Ethical conflict resolution.* Ethical conflict occurs when moral values differ among individuals. Each of the critical access hospitals had staff mechanisms in place to resolve ethical conflicts. All of the organizations used a combination of staff from different areas; however lead staffs, accountable for coordinating the process, were identified by 10 of the chief nursing executives. Lead staff included the attending

physician, nursing director, ethics physician chair, ethics consultation service member, and social services.

Staff from different departments utilized to support the resolution of ethical conflicts included social services, clergy support staff, and the hospital's interdisciplinary care-planning teams. Ten of the organizations also utilized an internal or external ethics consultation service. Patient advocacy programs such as organization ethics consultation services are important to ensure patient autonomy and ethical conduct. The themes of patient autonomy and ethical conduct, ethical dilemmas and decision-making, ethical decision-making support mechanisms, and communication and decision-making strategies were again identified. In consideration of ethical decision-making strategies and ensuring patient autonomy it was also important to consider the patient's religious values and cultural background.

*Recognition of religious beliefs and cultural background.* All of the critical access hospitals have established mechanisms to ensure that information about religious beliefs and cultural backgrounds accompany the patient throughout the continuum of care. These mechanisms include documentation in the medical record, coded bracelet or other form of identification, and data confirmed by case management. Twelve of the of the chief nursing executives also identified specific staff who are responsible for ensuring this information is kept up to date. Specific staff included nursing, physician, admissions staff, and case management staff.

A specific example of meeting the religious needs of patients was given by Organization 3 during the validation interview. The chief nursing executive discussed a patient who had been admitted from a mosque. The patient had been required to have a



priest with him. The priest's responsibility was to pray over and bless everything that was brought into the room, prior to touching the patient. This included nourishment, treatments, supplies, and medications. She stated, "So, it was actually very time consuming, but we were able to meet the needs of the patient from that perspective. We would do that for anybody that was admitted" (Interview 5, organization 3, lines 516-521). Organization 3 had identified the themes of patient autonomy and ethical conduct and communication and decision-making strategies.

In the establishment of effective patient advocacy programs it was also important to consider interpreter services. Due to the critical access hospital's remote location and diverse patient population the inclusion of interpreter services has ensured effective communication while supporting patient autonomy and ethical decision-making processes.

*Interpreter services.* All of the critical access hospitals had mechanisms for the provision of interpreter services to support the ability of the patient to make decisions about the provision of care. Fifteen of the organizations utilized a telephone interpreter service. The one organization not utilizing a telephone interpreter service contracted with a trained interpreter. Eleven of the organizations used multiple mechanisms to meet the needs of the patient. Multiple mechanisms included trained bi-lingual staff and trained staff interpreters. Nursing services were identified by 12 organizations as being responsible to ensure that available interpreter services were secured when needed by the patient, whereas three organizations identified social services as being responsible. The remaining organization used its trained contracted Spanish interpreter to secure other

services as needed. This question further addressed the themes of ethical conduct and communication and decision-making strategies.

*Summary.* In summary, each chief nursing executive identified the staff and departments involved in the organization's current processes and systems which support the ability of the patient to make individual care decisions. Information related to the specific aims (Appendix K) of research question 2 was gathered through different questions within the electronic survey instrument and the follow-up validation interviews. The themes of patient autonomy and ethical conduct, ethical dilemmas and decision making, ethical decision-making support mechanisms, and communication and decision-making strategies were again identified.

### *Research Question 3*

*Physician-patient communication models.* The third research question was designed to identify the physician-patient medical treatment decision model, pure or hybrid, utilized in each of the critical access hospitals. Three theoretical medical treatment decision models identified by Quill and Brody in 1996 were used for comparison. These were the Paternalistic Model, the Independent Choice Model, and the Enhanced Patient Autonomy Model. The basis for the development of the models was the increasing shift in decision-making to the patient and the need to preserve autonomy in patient decision-making.

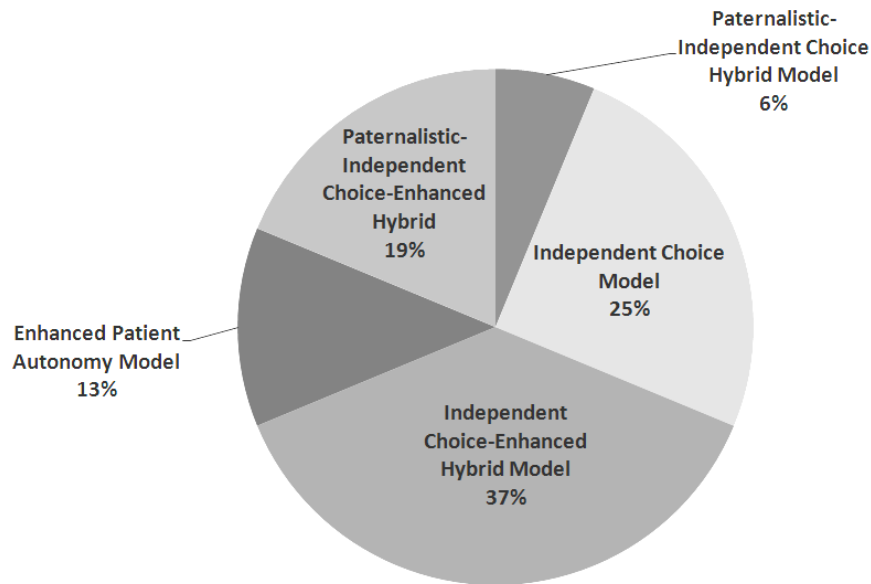
In the Paternalistic Model, information flow is generally one way from physician to patient. There is limited information sharing between the physician and the patient and the physician has more control over treatment decisions. In the Independent Choice Model, the physician's primary role in medical decision-making is to inform patients

about their options and the probability for success. The physician withholds his or her recommendations to avoid biasing the patient and the patient makes the treatment decisions. In the Enhanced Patient Autonomy Model the physician and patient share their knowledge and expertise. They then collaborate on the medical decision and have joint responsibility for the outcome of patient care. The medical treatment decision model utilized in a clinical encounter may also include a hybrid of elements of more than one model dependent on the physician-patient relationship and the ability of the patient to participate in decision-making.

Question 20 listed 13 components and directed the respondent to select the components which best fit into the organization's current physician-patient medical treatment decision model. No limit was placed on the number of components which could be selected nor were the components identified with any specific model. The results of the electronic survey instrument and validation interviews identified the following.

All of the chief nursing executives provided information on what model was most often used. Thirteen of the 16 organizations selected multiple components to identify the physician-patient medical treatment decision model in place within their organization. Three of the 16 selected only one component. Initial findings, pre-validation, are identified in Figure 3 and were based only on the survey findings. Figure 3 also identifies whether the physician-patient medical treatment decision model utilized in each of the critical access hospitals, was pure or hybrid. Commonalities among all organizations reflected that the hybrid physician-patient communication models are most often used. Of the three hybrids reflected in Figure 3, it is evident that the independent choice-enhanced patient autonomy hybrid model is used more frequently in organizations. In this hybrid

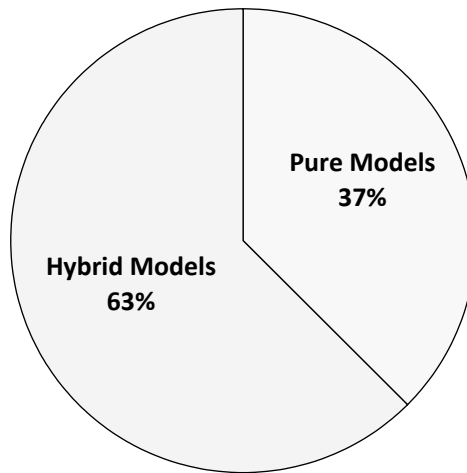
model the patient has more control over treatment decisions while, at times, the physician and the patient collaborate on the medical decision. This outcome supported the literature reviewed which cited the shift from paternalism to autonomy.



*Figure 3. Physician-Patient Relationship Models: Pre-Validation.*

Figure 4 provides a summary of Figure 3 and identifies the initial, pre-validation, aggregate percentage split between organizations that use a pure model as compared to organizations with a hybrid model. This figure reflected that the pre-validation critical access hospital organization processes most often mirrored a blend of the three models.

The hybrid models included in Figure 4 were the Paternalistic-Independent Choice-Enhanced Patient Autonomy model, the Paternalistic-Independent Choice model, and the Independent Choice-Enhanced Patient Autonomy model. The pure models included the Enhanced Patient Autonomy model and the Independent Choice model.



*Figure 4. Physician-Patient Relationship Models (Pure versus Hybrid): Pre-Validation.*

*Validation Interview Comparison.* Information from the seven validation interviews conducted, which reference the physician-patient medical treatment decision model, was compared to the pre-validation information. Three of the 16 organizations that selected the pure model were also selected for a validation interview. They were Organizations 3, 9, and 16. In each of the three validation interviews, following discussion between this researcher and the chief nursing executive, consensus was reached regarding the model which best reflected the physician-patient communication processes.

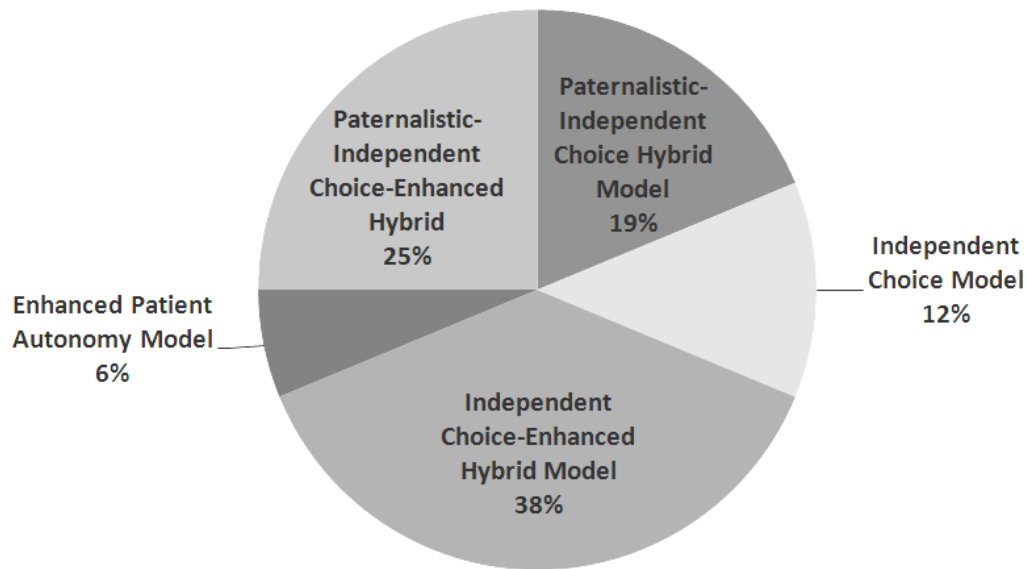
Although the question in the survey addressed the physician-patient communication relationship and the participant was asked to select all applicable components, these three chief nursing executives selected one component and referenced they were seeking the best response. When detail of the three models was provided during the interview process each of the three chief nursing executives was able to

address actual physician-patient communication processes within their organization. The results of the survey reflected that all other chief nursing executives selected multiple components.

The model of Organization 3 was initially identified as an independent choice pure model. The chief nursing executive selected one component of independent choice. During the validation interview she identified a paternalistic-independent choice model and stated, “I think the physician is still in the decision-making mode, more so than incorporating the patient and the family into that. We’re working on that but it is something that they’re aware of” (Interview 5, organization 3, lines 438-446).

The model of Organization 9 was also initially identified as an independent choice pure model. The chief nursing executive completing the question again selected one component of independent choice. During the validation interview a paternalistic-independent choice model was identified. She referenced that there is a high level of trust in the physician by the patients and that the patients tend to allow physicians to make the medical decisions.

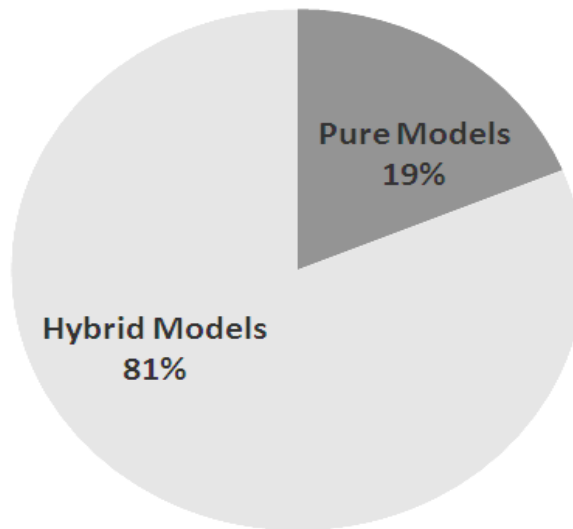
Organization 16’s model was initially identified as an enhanced patient autonomy pure model. The chief nursing executive selected one component of the enhanced autonomy choice. During the validation interview a paternalistic-independent choice-enhanced patient autonomy model was identified. The chief nursing executive strongly felt, after discussion, that the decision model was a mix of all three models. Figure 5 reflects changes in these three organization’s communication models after the validation interviews were conducted.



*Figure 5. Physician-Patient Relationship Models: Post-Validation.*

The post-validation aggregate percentage split between organizations that use a pure model as compared to organizations with a hybrid model is identified in Figure 6. The critical access hospital organization processes continue to generally mirror a blend of the three models. The use of hybrid models increased from 63% to 81%. This was due to the validation interviews conducted with Organizations 3, 9, and 16. The pure models originally selected by the organizations were changed to hybrid models which increased the percentage of hybrids but decreased the percentage of selected pure models. Of the hybrid models it is evident in Figure 5 that the independent choice-enhanced patient autonomy hybrid model remained the model most often utilized.

Selected pure models decreased from 37% to 19%. The 19% represents three organizations that were not selected for validation interviews. This decision was made based on the review of the survey and that the chief nursing executives in each of these three organizations had selected more than one component within the grid.



*Figure 6. Physician-Patient Relationship Models (Pure versus Hybrid): Post Validation.*

*Summary.* In summary, each chief nursing executive described the physician-patient medical treatment decision model utilized in their organization. Information related to the specific aim (Appendix K) of research question 3 was gathered through question 20 within the electronic survey instrument and the follow-up validation interviews. The themes of patient autonomy and communication and decision-making strategies were identified and verified during the survey and validation interviews.

*Research Question 4*

*Physician-patient communication model comparison.* The fourth research question was designed to identify the comparisons between the organizations' models and the comparisons between each of the four states. This was accomplished through comparison of the survey responses for question 20 which addressed the components of the physician-patient medical treatment decision models. The results of the data summarized in Table 1 identify these comparisons.



Table 1

## Organization and State Specific Physician-Patient Decision Model Comparison

Organization Number	Physician-Patient Treatment Decision Model	State
Organization 1	Independent Choice-Enhanced Patient Autonomy Hybrid	Wisconsin
Organization 2	Independent Choice-Enhanced Patient Autonomy Hybrid	Wisconsin
Organization 3	Paternalistic-Independent Choice Hybrid	Illinois
Organization 4	Paternalistic-Independent Choice Hybrid	Illinois
Organization 5	Paternalistic-Independent Choice-Enhanced Patient Autonomy Hybrid	Iowa
Organization 6	Independent Choice-Enhanced Patient Autonomy Hybrid	Illinois
Organization 7	Independent Choice-Enhanced Patient Autonomy Hybrid	Wisconsin
Organization 8	Paternalistic-Independent Choice-Enhanced Patient Autonomy Hybrid	Indiana
Organization 9	Paternalistic-Independent Choice Hybrid	Iowa
Organization 10	Independent Choice-Enhanced Patient Autonomy Hybrid	Iowa
Organization 11	Enhanced Patient Autonomy Pure Model	Wisconsin
Organization 12	Independent Choice Pure Model	Wisconsin
Organization 13	Independent Choice-Enhanced Patient Autonomy Hybrid	Iowa
Organization 14	Paternalistic-Independent Choice-Enhanced Patient Autonomy Hybrid	Wisconsin
Organization 15	Independent Choice Pure Model	Indiana
Organization 16	Paternalistic-Independent Choice-Enhanced Patient Autonomy Hybrid	Indiana

The researcher also sought to identify the physician-patient medical treatment decision models utilized in each of the four states. These four states were Wisconsin, Illinois, Iowa, and Indiana. Although each of the four states used hybrid communication models, Wisconsin and Indiana organizations also identified the use of pure models.

In Wisconsin, three of the six participating organizations used the independent choice-enhanced patient autonomy hybrid model. The remaining three organizations each used a different model. Organization 11 used the enhanced patient autonomy pure model with the chief nursing executive selecting three of the four components listed in question 20. Organization 12 used the independent choice pure model selecting two of the five components. Organization 14 used communication methods reflecting a hybrid of all three models, paternalistic, independent choice, and enhanced patient autonomy.

In Illinois, two of the three participating organizations used the paternalistic-independent choice hybrid model. In the original pre-validation information in question 20, one of these two organizations, Organization 3, identified their physician-patient communication process as an independent choice pure model. Through the validation interview process it was determined with the chief nursing executive that the paternalistic-independent choice hybrid model more accurately reflected the communication processes utilized between the physician and patient. Organization 6 used the independent choice-enhanced patient autonomy hybrid model.

In Iowa, two of the four participating organizations used the independent choice-enhanced patient autonomy hybrid model. Organization 9 used the hybrid model that reflected the paternalistic-independent choice and Organization 5 used communication methods reflecting a hybrid of all three models.

In Indiana, two of the three participating organizations used a hybrid of all three models, paternalistic, independent choice, and enhanced patient autonomy. In the original pre-validation information in question 20 one of these two organizations, Organization 16 identified its physician-patient communication process as an enhanced patient autonomy pure model. Through the validation interview process it was determined with the chief nursing executive that the paternalistic-independent choice-enhanced patient autonomy hybrid model more accurately reflected the communication processes utilized between the physician and patient. The remaining organization used the independent choice pure model with the chief nursing executive selecting three of the five components.

*Communication model comparison summary.* Information related to the specific aim (Appendix K) of research question 4 was gathered within the electronic survey instrument and the follow-up validation interviews. Comparisons were made between each organization and between the four states of Wisconsin, Illinois, Iowa, and Indiana.

#### *Summary of Findings of Research Questions*

In summary, the findings reflect that the data collected both in the electronic survey instruments and the validation interviews verified that the four research questions have been answered. Information related to the specific aim of each research question was gathered. In addition, the depicted figures and table support the gathered information and the findings. The themes of patient autonomy and ethical conduct, ethical dilemmas and decision-making, ethical decision-making support mechanisms, and communication and decision-making strategies were validated. Conclusions will be identified in the next section addressing each of the four research questions

## Conclusions

The first research question addressed the need to identify the organization's current information processes and systems which support the ability of the patient to make individual care decisions at admission. Questions within the electronic survey instrument queried the chief nursing executive on the existence of information processes and systems.

In building a foundation to support the patient in making informed decisions, strong information processes and systems, to include written policies and procedures, are needed to elevate the priority of these issues within the organization, drive efforts, and draw staff support. This systems approach will work toward meeting the needs of a diverse patient population. The chief nursing executive in Organization 9 spoke to the importance of this and the critical role of leadership during the validation interview process and stated the following.

We have done something differently since I would have answered that survey and that is we have implemented or have a policy now called chain of command that gives a little more direction to staff, whether they're being direct caregivers or not, as to how that process should be. We've had it in place, but it hasn't been formalized to the point of being a written policy. We now have a policy that gives staff very specific directions as you go through the shift change; you go through your nurse manager. They would contact me if it's one of the clinical areas that report to nursing. And you also involve the physician, department head, or the chief of staff if unable to reach the physician chair. Well, you know, it was a policy that we kind of had kicked around and thought that we needed to have it in

writing and more formalized. So, we have done that in just the last couple of months, have been working on it and have gotten Board approval on it since we are a county owned hospital. Being a county-owned hospital everything's pretty much transparent and public that goes on here as far as operations and other decisions. (Interview 4, organization 9, lines 414-440)

Additional information support mechanisms included organizational strategic, business, and budget plans. Twelve (75 %) of the chief nursing executives responded in question 35 that their leadership develops these formal plans and all of these executives responded in question 36 that their efforts to support the ability of the patient to make decisions about their care are driven, to some extent, by law and regulation. Through the seven validation interviews it was noted that several of the organizations are county owned and receive tax levies through their county assessments. The county constituents, for these organizations, appoint the governing board members and the board meetings are public. As described previously in Organization 9's statement, there is a higher level of transparency and accountability to the public.

The organizations' current information systems which support the ability of the patient to make individual care decisions were defined. Recurring themes addressing patient autonomy and ethical conduct, ethical dilemmas and decision-making, ethical decision-making support mechanisms, and communication and decision-making strategies were identified. In conclusion, it is the leadership's commitment to establish a strong foundation which will determine the success of the organization in supporting patient autonomy. Committed action to include organizational planning, development of

strategic, business, and budget plans, and organization-wide systems to support improved patient care processes are necessary to build this strong foundation.

The second research question addressed the identification of involved staff and departments to support the ability of the patient to make individual care decisions. Questions within the electronic survey instrument specifically queried the chief nursing executive on which staff members were involved in the process and whether one staff member or department takes the lead role in ensuring that the patient is supported. It was evident from the responses from each chief nursing executive that more than one staff member and department are involved in the current processes. The chief nursing executive in Organization 16 identified the multiple needs of her organization's patient population due to cultural ethnic diversity within her town.

The organizations' staff and departments which support the ability of the patient to make individual care decisions were defined. The themes of patient autonomy and ethical conduct, ethical dilemmas and decision-making, ethical decision-making support mechanisms, and communication and decision-making strategies were again identified and verified during the validation interviews. In summary, the validation interviews provided evidence that to explore the issues, staff must work together by evaluating current practices, discussing barriers, and identifying gaps.

The third research question allowed for identification of the physician-patient medical treatment decision model, pure or hybrid, which was utilized in each organization. The electronic survey instrument and the follow-up validation interviews were used to identify the specific model used in each of the critical access hospitals. The model components used for comparison were taken from the Paternalistic Model, the

Independent Choice Model, and the Enhanced Patient Autonomy Model identified by Quill and Brody (1996). Data in the Findings section of this chapter reflects both pre-validation and post-validation findings. In review of this post-validation data it is evident 81% use hybrid models and 19% use a pure model. The most frequently used hybrid model, in six of the organizations, is the Independent Choice-Enhanced Patient Autonomy Model. However, it is important to note that in 7 of the 10 remaining organizations, the physician-patient medical treatment decision hybrid models also use components of the paternalistic model. Four of the seven organizations use the Paternalistic-Independent Choice-Enhanced Patient Autonomy hybrid model and three of the seven organizations use the Paternalistic-Independent Choice hybrid model.

In review of the information collected during the validation calls and in consideration that the critical access hospital is generally located in a remote rural area, the following conclusions were reached for this population. Physician-patient medical treatment hybrid models are used more frequently than pure models. This conclusion is based on the facts that staff and patients living in the same geographical area have developed personal, spiritual, and working relationships when they present to the critical access hospital for care. These relationships are generally based on trust and belief that the physician will do no harm. Beneficence, as defined in Chapter 1, refers to acting in the best interest of the patient. Principles of beneficence include preventing harm, removing harm, and promoting good. Thus, paternalistic behaviors by the physician could be perceived by the patient as a source of comfort and not as a loss of autonomy. The themes of patient autonomy and ethical conduct and communication and decision-making strategies were again identified.

The fourth research question addressed comparisons regarding the physician-patient medical treatment decision model used in each participating organization and between and within each of the four states. Although additional information regarding the physician-patient communication processes was collected in the participating states, it is not possible to draw conclusions from this limited comparison data.

### Implications and Recommendations

Current literature has not reflected a distinction between the general acute care hospital and the rural critical access hospital in identifying the processes and systems utilized to support the patient's ability to make individual care decisions. This qualitative study identified and gathered new information related to specific information, staff, and physician systems and processes in place for a defined rural hospital population. It will serve as a reference point and foundation for further studies.

As a result of this study, it is evident that additional internal and external educational programs need to be developed and implemented. Internal educational program needs should be identified focusing on the multiple needs of the staff to include effective staff-patient communication strategies. These effective communication strategies need to address methods for communicating clinical evidence to patients to improve the care recipient's understanding of the proposed care processes and ensure involvement in decisions. Communicating evidence to patients on a level in which they can understand has practical and ethical implications. This process may transform a paternalistic relationship between the physician and allied staff members and patient into one that is more collaborative and relationship-centered. This transformation and transparency supports patients in their ability to make informed decisions.



Specific skills to be taught or reinforced are the ability to communicate complex information using non-technical language, facilitative skills to encourage patient involvement, and negotiation methodologies. Communication strategies must also give consideration to the patient's language literacy and health literacy. Through the acquisition of these skills, staff within the critical access hospital can assess their current practices and take action to treat each patient as a unique individual.

One of the challenges within the critical access hospital market in ensuring that the patient's needs are met is limited staff resources. This can be the result of the physical location of the organization and is often financially driven. In these situations, competency of staff based on the complexity of the organization must be addressed. Staffs often need to be cross-trained in multiple areas which may include pediatric medicine, adult medical-surgical medicine, psychiatric medicine, and rehabilitation. In consideration of future research projects, several new questions arise which might prove interesting. These questions would address competency assessment of the new provider of care, orientation processes to the organization, and systems in place to ensure continued competence.

Gathering the data without direct contact with the organization resulted in a process limitation in this study. In addition, because follow-up validation interviews were only completed for a percentage of participating organizations, based on a self-selected, purposive, convenience sample, it is unknown if new information might have been collected if each organization had participated in a validation interview. If this study, using a survey instrument and follow-up validation interviews were to be replicated, suggestion for future action would be to conduct two visits to each participating

organization. The goal of the first visit would be completion of the survey instrument during a face to face interview. This would provide the immediate opportunity for further clarification of the initial survey questions increasing the reliability and validity of the study. Following the review of the collected data against other data from the initial interviews, a second visit would be conducted. The goal of the second visit would be to validate any identified gaps of information gathered from the first visit. Although this two-step process might lengthen the time needed to conduct this study, it would result in an improved methodology to ensure trustworthiness.

This research study was conducted within four states, in a limited geographical area. Additional, broader, research is needed to identify the processes and systems in place to support the patient's ability to make individual care decisions in dual-licensed and accredited critical access hospitals. With this additional research further comparisons will be able to be made regarding care provided in rural America.

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Appendix A

Electronic Data Research Questionnaire Tool



Electronic Data Research Questionnaire Tool

1. Organization  
Name \_\_\_\_\_
2. Organization Mailing  
Address \_\_\_\_\_  
\_\_\_\_\_
3. Critical Access Hospital Licensure Status: Please check all that apply.  
 Acute Care Only  
 Acute Care and Swing Beds  
 Distinct part Psychiatric Unit  
 Rehabilitation Unit
4. Additional types of services provided at this Critical Access Hospital Site: Please check all that apply.  
 Physician Offices  
 General Outpatient Services  
 Outpatient Surgery  
 Homecare Services  
 Other: Please specify \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
5. Title of professional completing questionnaire: Please specify. \_\_\_\_\_
6. Please provide a brief description of responsibilities. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
7. Have you held other positions in your organization?  
 Yes  
 No  
If yes please identify the positions. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
8. Highest level of education: Please check appropriate box.  
 Associate Degree  
 Diploma  
 BSN

- MSN
- PhD/DNSc/EdD
- Other: Please specify \_\_\_\_\_

9. Total years of nursing or healthcare experience: \_\_\_\_\_

10. Years in present position with this organization: \_\_\_\_\_

11. Have you completed an ethics course or program?

- Yes
- No

12. Have you attended an ethics inservice presentation?

- Yes
- No

13. Does the organization have an established policy to systematically support the ability of the patient to make informed individual decisions regarding the provision of their care? This written policy would allow for identifying and assessing any ethical issue, demonstrating a resolution process to include a collaborative discussion with the patient, and demonstrating an implementation and evaluation process.

- Written Policy
  - Yes
  - No

14. Does the organization have an established written procedure to systematically support the ability of the patient to make informed individual decisions regarding the provision of their care? This written procedure would allow for identifying and assessing any ethical issue, demonstrating a resolution process to include a collaborative discussion with the patient, and demonstrating an implementation and evaluation process.

- Written Procedure
  - Yes
  - No

15. Does the organization have an established non-written process to systematically support the ability of the patient to make informed individual decisions regarding the provision of their care? This non-written process would allow for identifying and assessing any ethical issue, demonstrating a resolution process to include a collaborative discussion with the patient, and demonstrating an implementation and evaluation process.

- Non-written Process
  - Yes
  - No

Please forward a copy of your written process, via e-mail, to [dchristi@olivet.edu](mailto:dchristi@olivet.edu).  
(This e-mail address belongs to the researcher for this study, Darlene Christiansen.)

16. If the organization has an established process to systematically support the ability of the patient to make informed individual decisions regarding the provision of care when is this process initiated?

- a. Physician Offices
- b. Admission to the Organization
- c. Emergency Department
- d. Outpatient Department
- e. Following transfer to assigned clinical unit
- f. Other: (please specify)\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

17. Does your organization have an ethics consultation service?

- a. Yes
- b. No

If yes please describe the composition of this service and the role of its members. \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

18. If the organization has an established process to systematically support the ability of the patient to make informed individual decisions regarding the provision of their care which staff members or departments are involved in this process? Please check all that apply.

- a. Attending Physician
- b. Non-attending Physician-please specify\_\_\_\_\_

c. Nursing Services \_\_\_\_\_

- d. Social Services
  - e. Clergy Support Staff
  - f. Ethics Consultation Services
  - g. Community members
  - h. Other organization staff members-please specify\_\_\_\_\_
- 
- 

19. Does one staff member or department take the lead in coordination of this process?

- a. Yes
- b. No

If yes please specify the lead staff member or department.\_\_\_\_\_

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20. While considering the importance of the physician-patient relationship please review the medical treatment decision model components identified in the list below. In your organization which components best identify the components of this relationship. Please select all applicable components.

- Information flow one way from physician to patient
- Physician has more control over treatment decisions
- Limited information sharing between physician and patient
- Physician determines treatment decision
- Physician's role is to inform patients about care options and probability for success
- Physician withholds recommendations to minimize biasing of the patient
- Physician objectively answers questions avoiding influential statements
- Patient has more control over treatment decisions and makes final decision
- Physician's responsibility is to implement the medical aspects of the patient's decision
- Physician and patient share knowledge and expertise
- Physician and patient collaborate and develop a relationship of mutual exchange and open dialogue

- Physician explores both the patient and their own values and offers recommendations that consider both sets of values and experiences
- Physician and patient collaborate on the medical decision and have joint responsibility for the patient outcome

21. If the organization systematically documents the process of supporting the ability of the patient to make informed individual decisions which includes identifying and assessing ethical issues, demonstrating a resolution process to include a collaborative discussion with the patient, and demonstrating an implementation and evaluation process please check all sources of documentation.

- a. Clinical medical record/nursing notes
- b. Clinical medical record/physician history and physical
- c. Clinical medical record/physician progress notes
- d. Interdisciplinary Care Planning document
- e. Separate file maintained on the clinical unit
- f. Separate file maintained by specific department/unit – please specify \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
- g. Other source – please describe \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

22. If the organization has tools, staff, or processes in place which support the ability of the patient to make decisions about care please check all that apply.

- a. Clinical Guidelines
- b. Admission Packet Information
- c. Initial Assessment Information
- d. Interdisciplinary Care Planning Process
- e. Advance Directive Information
- f. Informed Consent Process
- g. Process for Withholding Resuscitative Services
- h. Process for Withholding of Life Sustaining Services
- i. Ethics Consultation Services
- j. Clergy Support
- k. Process for decision making in emergency situations
- l. Mechanism for documentation of verbal discussion
- m. Other-please describe \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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23. If the organization has mechanisms in place that accompany the patient throughout the continuum of care to inform caregivers of decisions the patient has made please check those that apply.

- Documented in the patient record
- Documented in other files not in the medical record
- Always flagged in the same section of the medical record
- Coded bracelet or other form of identification
- Communicated by the attending physician
- Communicated by other assigned specific individual
- Communicated by specific department/unit
- Please identify other assigned specific individual or specific department/unit\_\_\_\_\_

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24. If the organization has mechanisms in place that accompany the patient throughout the continuum of care to inform caregivers of decisions the patient has made who is responsible for ensuring this information is up to date?

- Attending Physician
- Nursing Services
- Social Services
- Clergy Support Staff
- Interdisciplinary Care Planning Team
- Ethics Consultation Services
- Other organization staff members-please specify\_\_\_\_\_

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25. If the organization has information mechanisms in place to resolve ethical conflicts please check all that apply.

Information Mechanisms

- Advance Directive
- Health Care Proxy

- Medical Power of Attorney
- Living Will
- Informed Consent Process
- Withholding resuscitative services process
- Withdrawing of life sustaining services process
- Decision making in the emergency situations
- Documenting Verbal Discussions
- Other: \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

26. If the organization has staff mechanisms in place to resolve ethical conflicts please check all that apply.

Staff Mechanisms

- Interdisciplinary Care Planning Team
- Social Services
- Clergy Support Staff
- Ethics Consultation Services
- Other \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

27. If the organization has staff in place to resolve ethical conflicts (as identified above) does the organization identify a lead person to coordinate the process?

- Yes
- No

28. If you answered yes to the above question, please identify this lead person.

- Attending Physician
- Consulting Physician
- Nursing Director
- Staff Nurses
- Ethics Consultation Services Member
- Interdisciplinary Care Plan Team member-please specify \_\_\_\_\_

29. Does the organization's lead person identified to coordinate the process have other responsibilities?

- Yes
- No

If yes please identify these other responsibilities. \_\_\_\_\_

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30. Does the organization have mechanisms to ensure that information about religious beliefs and cultural background accompany the patient throughout the continuum of care to support the ability of the patient to make decisions about care? If yes please check all that apply.

- Documented in the patient record
- Communicated by specific department/unit
- Communicated by other assigned specific individual
- Coded bracelet or other form of identification
- Please identify any other mechanism not listed. Please also identify the role of the other assigned individual and the specific department or unit if those are checked in the list above.

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31. If the organization has mechanisms in place that accompany the patient throughout the continuum of care to inform caregivers about religious beliefs and cultural background which staff is responsible for ensuring this information is up to date? Please specify.

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32. Does the organization have established informational processes which support the ability of the patient to make decisions about care? If yes please check all that apply.

- Illness related educational material
- Wellness related educational materials



- Patient Rights information
- Informed Consent documents
- Refusal of Care process
- Discharge Instructions
- Advance Directive information
- Withholding resuscitative services process
- Withholding of life sustaining services process
- Other-please describe\_\_\_\_\_

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33. Does the organization have mechanisms for the provision of interpreter services to support the ability of the patient to make decisions about care? If yes please check all that apply.

- Trained staff interpreter
- Trained contracted interpreter
- Trained volunteer
- Untrained volunteer
- Trained bi-lingual staff
- Untrained bi-lingual staff
- Family members or friends of patients
- Telephone interpreter service
- Other\_\_\_\_\_

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34. If the organization has mechanisms for the provision of interpreter services to support the ability of the patient to make decisions about care which staff is responsible for ensuring that available mechanisms are secured. Please specify.

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35. If the organization develops formal plans to support the ability of the patient to make decisions about the provision of care please check all plans that apply.

- Strategic
- Business
- Budget

- Other \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

36. To what degree are your efforts to support the ability of the patient to make decisions about the provision of care driven by law and regulation?

- Very Strongly
- Strongly
- Somewhat
- Very Little
- Not At All

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

37. Does the organization have executive/managerial level staff with assigned responsibility for assuring that individual care decisions made by the patient are followed?

- Yes
- No

38. If you responded yes to question 25 please identify which departments/offices are represented by the executive/managerial staff? Please check all that apply.

- a. CEO executive office
- b. COO executive office
- c. Medical Director
- d. Medical Staff department
- e. Nursing Director
- f. Nursing department
- g. Social Services
- h. Ethics Consultation Services
- i. Clergy
- j. Other (please describe): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

39. What mechanisms does your governing body utilize to be informed regarding patient ethical issues? Please check all that apply.

- Organization Ethics Committee Representative
- Specific Patient Discussion at Board Meeting Level
- General Discussion regarding patient ethical issues at Board Level
- State System Agency Representative (ie: State Ethics Board)
- Other (please describe): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

40. Does the organization orient and educate staff regarding internal processes which support the ability of the patient to make decisions about the provision of care?

- Yes
- No

41. If the organization orients and educates staff regarding internal processes which support the ability of the patient to make decisions about the provision of care, which hospital staff are oriented/educated? Please check all that apply.

- a. Governing body
- b. Senior management
- c. Physician staff
- d. Other licensed independent practitioner staff
- e. Nursing staff
- f. Respiratory Staff
- g. Cardiology Staff
- h. Administrative Staff
- i. Ancillary Departmental Staff
- j. Please identify other licensed independent practitioner staff and ancillary departmental staff if these categories were checked above and any other staff/departments not listed.

42. What processes does the organization utilize to orient/educate? Please check all that apply.

- New employee orientation
- Ongoing training
- Departmental training
- Competency assessment/evaluation

- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Appendix B  
Demographic Schedule

## Demographic Schedule

1. Organization Name \_\_\_\_\_
2. Organization Mailing Address \_\_\_\_\_  
\_\_\_\_\_
3. Critical Access Hospital Licensure Status: Please check all that apply.
  - Acute Care Only
  - Acute Care and Swing Beds
  - Distinct part Psychiatric Unit
  - Rehabilitation Unit
4. Additional types of services provided at this Critical Access Hospital Site: Please check all that apply.
  - Physician Offices
  - General Outpatient Services
  - Outpatient Surgery
  - Homecare Services
  - Other: Please specify \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
5. Title of professional completing questionnaire: Please specify. \_\_\_\_\_
6. Please provide a brief description of responsibilities. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
7. Have you held other positions in your organization?
  - Yes
  - No

If yes please identify the positions. \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8. Highest level of education: Please check appropriate box.

Associate Degree

Diploma

BSN

MSN

PhD/DNSc/EdD

Other: Please specify \_\_\_\_\_

9. Total years of nursing or healthcare experience: \_\_\_\_\_

10. Years in present position with this organization: \_\_\_\_\_

11. Have you completed an ethics course or program?

Yes

No

12. Have you attended an ethics inservice presentation?

Yes

No

Appendix C  
Invitation Letter



## Invitation Letter

Dear Chief Nurse Executive,

The healthcare environment of rural America presents many challenges for critical access hospitals, individual practitioners, patients, and families. Safe quality healthcare is every patient's right. The way patients make healthcare decisions is dependent on appropriate communication and understanding between the healthcare provider and the patient. As the nation's critical access hospitals increasingly provide care to diverse populations these hospitals need to insure they have appropriate systems and processes to support the patient's ability to make individual care decisions. The patient informed consent process must be ethically grounded to support patient autonomy.

My name is Darlene Christiansen and I am a Doctorate of Education in Ethical Leadership candidate at Olivet Nazarene University and a practicing nursing leader in the healthcare field. The purpose of this electronic questionnaire is to identify the systems and processes in place at dual licensed and accredited critical access hospitals which support the ability of the patient to make individual care decisions. This research study will be completed within the states of Illinois, Wisconsin, Indiana, and Iowa.

Your organization is dual licensed and accredited. Your participation would involve 30 minutes for completion of an electronic data research questionnaire tool with a possible 90 minute follow-up interview to be completed via conference call or on-site visit to your organization. This electronic data research questionnaire tool is being sent to the chief nurse executive within the critical access hospital for completion.

The follow-up interview would be conducted to clarify statements or themes from the electronic data research questionnaire tool and would be arranged at your convenience. Finally, you will be able to review and evaluate the findings of the study results when it is completed. Your assistance with this study is greatly appreciated and will serve to increase the knowledge base of all consumers involved in this study and lay the foundation for further research and educational developmental opportunities.

Please review the enclosed consent form for additional information about the procedure and safeguards for the study.

If you would be willing to participate in this study please complete the intent to participate form and informed consent form and return them by mail in the enclosed, self-addressed, stamped envelope. I will answer any questions about the research and can be reached at 630-968-2783.

I look forward to your participation.

Sincerely,  
Darlene Christiansen, MBA, RN, Ed.D (candidate)

Appendix D  
Intent to Participate Form

Intent to Participate Response

Identification of Systems within Critical Access Hospitals Which Support The Patient To Make Individual Care Decisions Study

Yes, I am willing to participate in the completion of the electronic research data questionnaire tool for this study on the identification of systems within critical access hospitals which support the patient to make individual care decisions.

Name: (please print)\_\_\_\_\_

Signature\_\_\_\_\_

Name of Critical Access Hospital\_\_\_\_\_

Address\_\_\_\_\_

Phone Number\_\_\_\_\_

E-mail Address\_\_\_\_\_

The best time and method (e-mail, phone) to reach me is:

◆Time of Day\_\_\_\_\_

◆Communication Method\_\_\_\_\_

I agree to a follow-up validation interview. The date and time of this interview would be arranged at your convenience within the time schedule required for the study and would be conducted by this researcher at the location of your organization or via conference call. There would be no expense to the organization for the researcher's time, travel, or maintenance.

0 YES

0 NO

Please return this intent to participate response with the informed consent form in the enclosed, self-addressed, stamped envelope.

Appendix E  
Informed Consent Form

## Informed Consent Form

Name of Principal Investigator: Darlene A. Christiansen

Telephone number: (630) 968-2783

Title: Ed.D (C)

### INTRODUCTION

You are being invited to take part in a research study being sponsored by Olivet Nazarene University. You are being invited to participate in this study because your healthcare organization is dual-licensed and accredited as a critical access hospital.

### PURPOSE OF THE STUDY

This study involves research. The purpose of this research is to identify the systems and processes in place at dual-licensed and accredited critical access hospitals which support the ability of the patient to make individual care decisions.

### RESPONSIBILITIES, EXPECTATIONS, AND PROCEDURES

Following receipt of the intent to participate and this informed consent form the Chief Nurse Executive within the dual-licensed and accredited critical access hospital will be requested to complete and submit an electronic data research questionnaire tool. The electronic tool completion time is anticipated to be 30 minutes. Following receipt and coding of this electronic data collection tool the Chief Nurse Executive may be asked to participate in a 90 minute follow-up interview session to clarify responses. The Chief Nurse Executive will also be asked to complete an evaluation form to validate the completed process against original expectations at the conclusion of the study.

### POTENTIAL RISKS

There are no known or potential risks to the subject or to the organization in which they work. This study will not involve patient interaction or the use of protected patient information. Data collection will be reported in an aggregate summary and confidentiality will be maintained through defined processes.

### POSSIBLE BENEFITS

There are multiple potential benefits to this study as identified below.

1. Aggregate comparative data will be collected which will identify the systems and processes in place at dual-licensed and accredited critical access hospitals which support the ability of the patient to make individual care decisions.
2. Aggregate and comparative data will be distributed to all organizations that completed the questionnaire.
3. Aggregate and comparative data will be incorporated into an educational program.
4. The conclusion of this study will lay the foundation for further research and educational development opportunities.

### COST AND COMPENSATION

Costs to the subject will include only their time for completion of the electronic data research questionnaire tool and possible follow-up validation interview. Subjects will not be paid or offered other compensation for participation in the study.

### VOLUNTARY PARTICIPATION

All participation is voluntary. There is no penalty to anyone who decides not to participate. Participants will not be penalized if the decision is made to stop participation at any time during the research project.

CONFIDENTIALITY

Records of participation in this research project will be maintained and kept confidential according to systems and processes identified by the Olivet Nazarene University Institutional Review Board. Identification codes will be used on all transcribed data and audiotapes.

Locations and names of individuals will be removed from the typed transcripts. Audiotapes will be stored in a locked cabinet, separate from the transcribed data, and will be destroyed according to systems and processes identified by the Olivet Nazarene University Institutional Review Board. Computer access to the transcribed data will be available by a code known only to the researcher. All data will be reported only in aggregate form. Audiotapes and transcribed data will be available only to the researcher, transcriber, double coder, and dissertation committee. Olivet Nazarene University IRB will have access to your files as they pertain to this research study. In the case of any report or publication from this study, the identity of participants will not be disclosed.

QUESTIONS

Questions are encouraged. Please contact Darlene Christiansen with any questions about this research study via phone at (630) 968-2783 or via e-mail at dchristi@olivet.edu.

By signing below, you are consenting to participation in this research study.

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Print Name of Participant

Date

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Signature of Participant

Date

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Signature of Principal Investigator

Date

Appendix F  
Coding Schedule



## Coding Schedule

### ETHICAL PRINCIPLES/VARIABLES

- E1• Autonomy: the patient directs the care and makes the decision
- E2• Do the “right thing”: perform correct actions
- E3• Care: relationships involving concern and interest in another person’s well-being
- E4• Withholding resuscitative services process: a process and order not to resuscitate the patient
- E5• Withholding life sustaining services process: a process and order to withhold nutritional and pharmaceutical life sustaining mechanisms
- E6• Ethical Conflict: when moral values differ among individuals.
- E7• Informed Consent: provides that a patient has a right to know the potential risks, benefits, and alternatives of proposed treatments
- E8• Paternalism: implies unquestioned acceptance by all parties that the physician’s responsibility is to act on the patient’s behalf, not at the patient’s request
- E9• Enhanced Patient Autonomy Physician-Patient Medical Decision-Making Model: The result of an open collaborative relationship between physician and patient where knowledge and expertise are shared. Physician and patient have joint responsibility for medical treatment decision and patient outcome.
- E10• Paternalistic Physician-Patient Medical Decision-Making Model: Unilateral medical decision model which is the result of one-way information flow from physician to patient where physicians have control over treatment decisions with limited information sharing. The physician makes the treatment decisions.
- E11• Independent Choice Physician-Patient Medical Decision-Making Model: In this model the physician’s primary role in medical decision making is to inform patients about their options and the probability for success. Patients are free to make choices unencumbered by the influence of

the physician's experience. The patient makes the treatment decisions and the physician implements the medical aspects of that decision.

E12• Advocacy: to facilitate the patient's concerns or decisions to others

E13• Disclosure: provide all information to insure an informed decision

E14• Truthtelling: be truthful and honest in providing information

E15• Written Policy: Formal written guidelines or instructions which typically have both operational and technical components and enable organization staff to act in a coordinated fashion across disciplines.

E16• Written Procedure: A written procedure is a step-by-step guide to direct organization staff through a task.

E17• Non-written Process: An informal, non-written, guideline which directs the care provided to a patient.

E18• Ethics Consultation Service: A resource providing staff and/or written resources to support the hospitalized patient in resolving ethical conflicts when making individualized health care decisions.

E19• Organization Internal Processes: Processes, specific to the organization, which support the ability of the hospitalized patient in making individualized health care decisions.

E20• Organization Mechanisms: Tools, staff, or processes, specific to the organization, which support the ability of the hospitalized patient in making individualized health care decisions.

- a) Communication/documentation
- b) Lead professional coordination
- c) Resolution of Ethical Conflicts
- d) Religious Beliefs/Cultural Background

## TASK VARIABLES

T1• Options: possible alternatives for action

T2• Treatment option: available options for care and treatment

T3• Support mechanism: persons or methods utilized to provide support to a person

T4• Support person: someone who offers guidance and assistance to the patient

## PROFESSIONAL VARIABLES

P1• Experience: previous involvement with the situation or a similar situation

P2• Communication: express thoughts, feelings, and information by verbal, non-verbal, or written methods

P3• Conflict: a state of opposing ideas or values

P4• Support: information and staff mechanisms to resolve ethical conflicts

## ENVIRONMENTAL VARIABLES

EN1• Organization: A critical access hospital providing different levels of services to acute and chronically ill patients

EN2• Role: duties and responsibilities as a result of a person's professional position or positions

Appendix G  
Interview Guide

## Interview Guide

1. Have you worked in other critical access hospitals prior to your position in your current organization?
  - a. If yes, what positions did you hold and what were your responsibilities in these positions?
  - b. If no, please provide a brief overview of your past work history and job responsibilities.
2. Have you been involved in ethical patient care issues during your tenure as a CNE in this organization?
3. Please describe the issue and situation.
  - a. When did it occur?
  - b. Who were the persons involved?
  - c. Who was the decision maker?
  - d. Were additional resource staff brought into the decision-making process?
  - e. Who were these staff and what type of support did they provide?
  - f. How was the patient supported in their ability to make informed decisions?
  - g. Whose values were the most important during this situation?
  - h. Was this a sudden event or did you expect it to occur?
4. Did the situation have any impact on your values or other staff values?
  - a. Personal (e.g. go against religious practices)?
  - b. Professional (e.g. lying to a patient)?
  - c. If yes to a and/or b how did you address this impact?
  - d. Were you supported, within the organization, as you addressed the impact?
  - e. Were there any changes made to the organization's processes or practices?
5. What was your role during this situation?
  - a. Was the role acceptable to you?
  - b. Was your involvement what you expected it to be?
6. Did your current policy, procedure, provide appropriate direction in this situation?
7. If the organization does not have a written policy and/or procedure how was the direction that was taken determined?
  - a. Who was the decision-maker in determining the direction taken?
  - b. Was this direction acceptable to you?
  - c. Would you have made a different decision in determining the direction taken?
  - d. Was the patient supported in their ability to make informed decisions?
8. If the organization has an established process to systematically support the ability of the patient to make informed individual decisions regarding the provision of care when is this process initiated?
9. While considering the importance of the physician-patient relationship and the medical treatment decision process how is the patient supported in their ability to make informed decisions?

- a. Is there a physician (MD or DO) in-house 24 hours a day, 7 days per week?
  - b. What types of allied health professionals are utilized when a physician is not available (e.g. physician assistant, nurse practitioner)?
  - c. When the physician is not immediately available what is the organization process and is the physician always involved in the final decision-making process? Please provide an example of an actual occurrence.
  - d. Does the physician use other support staff (team approach) when discussing options with the patient or does the physician work independently with the patient?
  - e. If the physician works with other support staff when discussing options for care with the patient please identify these support staff (e.g. nursing, clergy, social services, other physicians).
  - f. Who has more control over treatment decisions (physician or patient)?
  - g. What systems and processes are in place to insure that the patient is supported in their ability to make informed decisions?
10. Overall, in actual practice, which of the following physician-patient medical treatment decision models is most often utilized in your organization?
- a. Paternalistic Model (e.g. information flow is from physician to patient, physician has more control over decision and determines treatment decision, limited information sharing between physician and patient)
  - b. Independent Choice Model (e.g. physician informs patient about care options and probability for success, physician withholds recommendations to minimize biasing of patient, physician objectively answers questions avoiding influential statements, patient has more control over treatment decisions and makes final decision)
  - c. Enhanced Patient Autonomy Model (e.g. physician's responsibility is to implement the medical aspects of the patient's decision, physician and patient share knowledge and expertise, physician and patient collaborate and develop a relationship of mutual exchange and open dialogue, physician explores both the patient and their own values and offers recommendations that consider both sets of values and experiences, physician and patient collaborate on the medical decision and have joint responsibility for the patient outcome)
11. Does the organization have mechanisms in place to inform caregivers about religious beliefs and cultural background?
- a. What processes are in place to insure that religious beliefs and aspects of cultural background are supported?
  - b. Have you had a need to implement these processes within the past year (if yes, please describe)?
  - c. How are staffs educated in these processes?
12. How are staff educated and oriented regarding internal processes which support the ability of the patient to make decisions about the provision of care?

13. How is the executive and managerial level staff informed regarding patient ethical issues?
14. How is the governing body informed regarding patient ethical issues?
15. What type of education occurs at the governing body level regarding potential and actual patient ethical issues and how the organization's systems and processes support the patient in their ability to make informed decisions?

Appendix H  
Participant Evaluation Form



## Participant Evaluation Form

Dear Chief Nursing Executive,

I wish to thank you again for agreeing to participate in the research study "The systems in critical access hospitals (CAH's) which support individual patient care decisions". The questionnaire and follow-up validation interviews enabled me to capture important new information identifying specific systems and processes which support the ability of the patient to make informed decisions about their care within a designated geographical area. This information included the identification of physician-patient communication processes in the rural health care organizations participating in this study.

The final step in a grounded theory method is validating the participant's agreement that the completed process met your original expectations. Attached is a questionnaire which asks questions related to specific areas of the data collection. I have enclosed a copy of the original questionnaire tool for you reference as I understand it has been a period of time since you completed it. Please know that the tool components cannot be used for other research purposes without approval of this researcher.

Following completion of the questionnaire, please return it to me in the enclosed stamped, self-addressed, envelope by February 19, 2010.

Included in this packet is an aggregate summary of the results of the research study. If you have questions about the questionnaire or the aggregate summary of the results, you may contact me by phone at 630-487-0646, or e-mail at [dchristi@olivet.edu](mailto:dchristi@olivet.edu).

Once again, thank you for your participation.

Sincerely,

Darlene A. Christiansen R.N., L.N.H.A., M.B.A., Ed.D. (candidate)

**Participant Evaluation Form**

**Please answer the following questions and return this form, via United States mail, in the enclosed self-addressed, stamped envelope. Thank you for your participation in this research study.**

1. Did the questions in the electronic (Zoomerang) survey tool identify all systems and processes in place in your organization which support the ability of the patient to make informed decisions about their care?

YES

NO

2. If the questions in the electronic (Zoomerang) survey tool did not identify all systems and processes in place in your organization which support the ability of the patient to make informed decisions about their care please identify your organization's additional systems and processes.

Additional Systems &  
Processes: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. Did the questions in the electronic (Zoomerang) survey tool identify all departments and individuals involved in the current processes and systems within your organization?

YES

NO

4. If the questions in the electronic (Zoomerang) survey tool did not identify all departments and individuals involved in the current processes and systems within your organization please identify departments and individuals not addressed.

Additional departments and  
Individuals: \_\_\_\_\_

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5. Did the electronic (Zoomerang) survey tool provide enough information (question 20) to identify the components of the physician-patient medical treatment decision model, pure or hybrid, utilized in your organization?

YES

NO

6. If the electronic (Zoomerang) survey tool did not provide enough information to identify the components of the physician-patient medical treatment decision model, pure or hybrid, utilized in your organization what additional information would have been helpful to you?

Additional Information  
Needed: \_\_\_\_\_

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7. Overall, did the electronic (Zoomerang) survey tool identify the systems and processes in place at your critical access hospital which support the ability of the patient to make individual care decisions?

YES

NO

8. Did the process of using the electronic (Zoomerang) survey tool provide an effective mechanism to complete the questionnaire?

YES

NO

9. If the process of using the electronic (Zoomerang) survey tool did not provide you an effective mechanism to complete the questionnaire please identify alternative mechanisms for completion which would have simplified the process for you (ie: paper process, telephone interview, etc.).

Alternative Mechanisms/Processes:

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10. Did the process of completing the electronic (Zoomerang) survey tool meet your original expectations of how information would be gathered for this research study?

YES

NO

11. If you responded no to question 10 please identify the additional steps which should have been added to the process to meet your original expectations of how information would be gathered for this research study?

Additional Process

Steps: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**12.** If you did participate in a follow-up validation interview did the process of participating in this interview add value to your overall participation in this research study?

YES

NO

**13.** If you answered yes to question 12 please describe what made your involvement in the validation interview more valuable to your overall participation.

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**14.** Please identify any other mechanisms of data gathering which you believe would add validity and value to future critical access hospital research studies.

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Appendix I

Authorization Letter from The Joint Commission

Authorization Letter from The Joint Commission

November 19, 2008

To: Darlene A. Christiansen, Ed.D candidate, Olivet Nazarene University

Darlene,

I am writing to confirm that we have authorized you to use in your dissertation study -- currently titled "Identification of Systems and Processes Within Critical Access Hospitals Which Support the Ability of the Patient to Make Individual Care Decisions" -- components of the questionnaire developed as part of the California Endowment-funded project *Hospitals, Language, and Culture: A Snapshot of the Nation*, which was conducted under the auspices of The Joint Commission by Amy Wilson-Stronks, Erica Galvez, et al.

Paul

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The information transmitted is intended only for the person or entity to which it is addressed and may contain confidential and/or privileged material. Any review, retransmission, dissemination or other use of this information by persons or entities other than the intended recipient is prohibited. If you received this in error, please immediately contact the sender and delete the material from any computer.

Appendix J

Follow-up Reminder to Invitation Letter



## Follow-up Reminder to Invitation Letter

Dear Chief Nurse Executive,

Three weeks ago you were mailed an invitation to participate in a research study to identify the systems and processes in place at dual licensed and accredited critical access hospitals which support the ability of the patient to make individual care decisions. This mailing also included the following two forms.

- 1) intent to participate form
- 2) informed consent form

If you have mailed the intent to participate and informed consent forms back to me, thank you. If you have not, please reconsider participation in this research study. Your participation would involve 30 minutes for completion of an electronic data research questionnaire tool with a possible 90 minute follow-up interview to be completed via conference call or on-site visit to your organization. I have also enclosed copies of the intent to participate and informed consent forms.

There are multiple anticipated benefits to organizations who participate in this study as identified below.

1. New information will be gathered. Current literature has not reflected a distinction between the general acute care hospital and the rural critical access hospital in the systems and processes utilized to support the patient's ability to make individual care decisions.
2. Aggregate comparative data will be collected which will identify the systems and processes in place at dual-licensed and accredited critical access hospitals which support the ability of the patient to make individual care decisions.
3. Aggregate and comparative data will be distributed to all organizations that completed the questionnaire.
4. Aggregate and comparative data will be incorporated into an educational program.
5. The conclusion of this study will lay the foundation for further research and educational development opportunities.

Please be assured that all records of participation in this research study will be kept confidential according to systems and processes identified by the Olivet Nazarene University Institutional Review Board.

I will answer any questions about the research and can be reached at 630-968-2783. I look forward to your participation.

Sincerely,  
Darlene Christiansen, MBA, RN, Ed.D (candidate)

## Appendix K

### Specific Aims-for Dissertation Questions

### Specific Aims-Dissertation Questions

- 1) Describe information mechanisms regarding processes and systems utilized within the organization which support the ability of the patient to make individual care decisions beginning at admission.
- 2) Define where the process is actually initiated to systematically support the ability of the patient to make informed individual decisions regarding the provision of care.
- 3) Identify involved staff and departments involved in the current processes and systems.
- 4) Describe the physician-patient medical treatment decision model utilized in the organization.

### Related Electronic Tool Questions

- 1) 13, 14, 17, 21, 22, 23, 25, 30, 32, 33, 35, 36, 39, 40,42
- 2) 16
- 3) 18, 19, 22, 24, 26, 27, 28, 29, 31,34,37, 38, 41
- 4) 20