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An Ethical Framework For Communication of Prognosis in Pediatric Critical Care Medicine

Amanda Mattone

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AN ETHICAL FRAMEWORK FOR COMMUNICATION OF PROGNOSIS IN
PEDIATRIC CRITICAL CARE MEDICINE

A Dissertation

Submitted to the Center for Healthcare Ethics

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Amanda L. Mattone

May 2018

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Amanda L. Mattone

2018

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PEDIATRIC CRITICAL CARE MEDICINE

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ABSTRACT

AN ETHICAL FRAMEWORK FOR COMMUNICATION OF PROGNOSIS IN PEDIATRIC CRITICAL CARE MEDICINE

By

Amanda L. Mattone

May 2018

Dissertation supervised by Dr. Gerard Magill

The focus of this dissertation is to create an ethical framework for communication of prognosis in the pediatric critical care setting. This dissertation argues that an ethical framework for communication of prognosis in the pediatric critical care setting is necessary because ethical communication transactions lead to better care for pediatric patients in critical care by enabling surrogate decision makers to make well-informed decisions. Moreover, a lack of effective communication skills can be detrimental to the patient. The need for such a framework is revealed by research indicating that physicians often lack the necessary education and skills for effective communication transactions to transpire.

This dissertation merges communication theory and bioethics to create a practical and ethical framework for communication of prognosis in the pediatric critical care setting. The first

chapter provides an introduction. Chapter two addresses communication theory for pediatric medicine. The third chapter introduces the notion of establishing rapport with the ethics of care. Chapter four uncovers how physicians can manage uncertainty in veracity for surrogate consent. The fifth chapter describes the importance of maintaining the physician-family relationship. Chapter six pulls together the literature from the previous chapters to create an ethical framework for communication of prognosis in pediatric critical medicine. Concluding remarks are noted in chapter seven. This dissertation reveals that an ethical framework for communication of prognosis in pediatric critical care medicine is not only necessary, but attainable and can be easily integrated into every day care.

DEDICATION

This dissertation is dedicated to the memory of my Aunt Elizabeth “Liz” Redano and my Great
Grandmother Tressa L. Thomson.

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TABLE OF CONTENTS

	Page
Abstract	iv
Dedication	vi
Acknowledgement	vii
Chapter One: Introduction	1
Thesis Statement	2
State of the Question	3
Chapter Two: Communication Theory for Pediatric Medicine	77
1. Communication Theory and Prognosis	78
a. Establishing Rapport with the Ethics of Care	82
i. Creating relationships through caring	83
ii. Taking responsibility of others through the voice of care	86
b. Managing the Uncertainty of Veracity	87
i. Responsibilities to communicate truthfully	88
ii. Dealing with communication ambiguity in pediatric medicine	92
c. Maintaining the Relationships between the Physician and Family	95
i. Instituting relationships; enhancing communication	95
ii. Family-centered care	97
2. Ethical Framework for Pediatric Communication	99
a. Ethics of Care	100
i. The virtue of caring	100
ii. Using virtues to communicate caring	101
b. Veracity for Surrogate Consent	103
i. Pediatric surrogate decision-making standards	104
ii. Ethical duty to communicate honestly	107
c. Physician-Family Relationship	109
i. Ethical considerations when building relationships	110
ii. Foundations of family-centered care in pediatrics	111
Chapter Three: Establishing Rapport with the Ethics of Care	122
1. Symbolic Communication Traditions	123
a. Semiotic Tradition	124
i. Identifying the semiotic tradition	124
ii. Semiotic tradition and establishing rapport	133

b.	Sociocultural Tradition	138
i.	Key elements of the sociocultural tradition	138
ii.	The sociocultural tradition and establishing rapport.....	141
2.	Ethics of Care.....	145
a.	Relational Autonomy	146
i.	Understanding relational autonomy	147
ii.	Relational autonomy and establishing rapport.....	150
b.	Meeting the Needs of Others	152
i.	Developing caring relationships	153
ii.	Addressing individual needs.....	156
Chapter Four: Managing Uncertainty in Veracity for Surrogate Consent.....		168
1.	Uncertainty Communication Theories.....	169
a.	Management/Reduction Theories	169
i.	Identifying management/reduction theories	170
ii.	Management/reduction theories and veracity for surrogate consent	174
b.	Framing Communication in Uncertainty	177
i.	Method of framing communication	178
ii.	Framing communication and surrogate decision-making.....	181
2.	Veracity for Surrogate Consent	183
a.	Surrogate Consent, Beneficence, and Best Interests.....	183
i.	Surrogate consent.....	184
ii.	Beneficence and best interests	187
b.	Disclosure and Impartiality.....	191
i.	Disclosing information to families and patient.....	191
ii.	The physician as a neutral party.....	195
Chapter Five: Maintaining the Physician-Family Relationship.....		205
1.	Relational Communication Theories	205
a.	Social Penetration Theory.....	207
i.	Characteristics of the social penetration theory	208
ii.	Social penetration theory and physician-family relationships	212
b.	The Sociopsychological Tradition	215
i.	Features of the sociopsychological tradition.....	215
ii.	The importance of family dynamics in pediatrics.....	218
2.	Physician-Family Relationship	221
a.	Paternalism & Partnership	222
i.	Avoiding paternalistic behavior	222
ii.	Creating a partnership	226
b.	Patient Autonomy as a Minor	229
i.	Deciding when to include children and adolescents in their	

care	230
ii. Including children in goal planning	232
Chapter Six: Ethical Framework for Communication of Prognosis in Pediatric Critical Care Medicine.....	245
1. Establishing Rapport with the Ethics of Care	245
a. Communication and the Ethics of Care	246
i. Symbolic Communication Tradition.....	246
ii. Communicating Through the Virtues of Caring	253
b. Moral Obligations of the Ethics of Care	255
i. Establishing Relational Autonomy	255
ii. Meeting the Needs of Patients and Families.....	257
2. Managing the Uncertainty in Veracity for Surrogate Consent	258
a. Communication and Managing Uncertainty in Veracity for Surrogate Consent	259
i. Uncertainty Communication Theories	260
ii. Recognizing Communication Biases	263
b. Ethical Accountability to Communicate Honestly Regarding Surrogate Consent	265
i. Understanding Surrogate Consent Standards.....	265
ii. Physician Neutrality.....	268
3. Maintaining the Physician-Family Relationship.....	269
a. Communication Strategies for Maintaining Physician-Family Relationships.....	269
i. Relational Communication Theories	270
ii. Family-Centered Care	272
b. Ethical Considerations of Physician-Family Relationships.....	274
i. Partnerships Over Paternalism.....	275
ii. Autonomy as a Minor	276
Chapter Seven: Conclusion.....	287
Bibliography	311

Chapter One: Introduction

“I don’t think it’s fair to family members. I think the family members need to know. If they say this kid’s not gonna make it, or whatever, they need to tell the family that. The family deserves to know that rather than being led on. It’s easier to prepare. We went for a long time thinking, it’s possible he’s gonna get better, until like a week prior to his passing. ... When did you realize my baby was gonna pass? Why didn’t you tell me then?” – Bereaved parent of a pediatric critical care patient.¹

Many physicians report similar feelings of anxiety when discussing an imminent death of a child with the child’s family members.² Physicians have also noted the painstaking difficulty in communicating with family members following a pediatric death.³ The focus on communication in the pediatric setting is uncommon, yet insurmountable as pediatric physicians often face additional stresses such as anxious or even hostile parents and patients.⁴ These reported apprehensions can have serious effects on the type of care pediatric patients and their families receive, especially at the end of life. An absence of honest, open, and truthful communication in pediatric medicine can lead to lackluster, uninformed, and unfair treatment. Children can appreciate fair and honest treatment as well as adults, and they have every right to receive such care.⁵ Research predominantly indicates that parents of critically ill children want physicians to provide honest and straightforward information regarding their child’s diagnosis and prognosis. Withholding such information can lead to feelings of false hope, betrayal, and distrust among parents. Effective communication is an indispensable tool when making decisions that are in the best interests of the pediatric patient.⁶ Pediatric critical care medicine was chosen as the focus of this framework due its unique nature. Pediatric

critical care medicine focuses on caring for infants, children, and adolescents with potential or existing life-threatening illnesses, diseases, or injuries. The goals of pediatric critical care medicine are to include the family to eliminate suffering and restore the patient's health while minimizing anxiety and complications. The importance of effective communication in pediatric critical care medicine is undeniable. Care in the pediatric critical care unit requires collaborative communication between members of the medical team, the patient, and the parents to make informative choices in the best interests of the patient.⁷ The pediatric intensive care unit is a place where effective communication is necessary, but can be difficult to achieve without the proper knowledge and tools. This unit is often a fast-paced environment where tensions are high between physicians, patients, and families, a place where life or death decisions must be made, and distractions to communication are prevalent.⁸ For simplicity, this dissertation uses pediatrics interchangeably with pediatric intensive care and pediatrician interchangeably with pediatric critical care physician.

Thesis Statement

The thesis is to present an ethical framework for communication of prognosis in the pediatric critical care setting. The main point is that ethical communication transactions are necessary insofar as they lead to better care for pediatric patients in critical care by enabling surrogate decision makers to make well-informed decisions. Communication techniques are essentially tools physicians have in addition to their typical medical devices. This dissertation calls for physicians to have a protocol to guide them when communicating with a vulnerable population such as pediatric critical care patients about prognosis.

The need for framework of interaction will be explained by exploring the notion of communication theory and how a lack of ethical communication can have a detrimental effect on all aspects of care in the pediatric critical care setting. Communication theory as it specifically relates to pediatric medicine will then be reviewed. Next, this analysis will explore how communication theory can be enlightened by related bioethics topics. How to establish rapport through the ethics of care, how to manage uncertainty in veracity for surrogate consent, and how to maintain the physician-family relationship will be discussed by integrating bioethics and communication theory. Lastly, the discussion will provide an ethical framework of communication of prognosis in the pediatric critical care setting. The framework will align communication theories and bioethics by creating a practical communication protocol.

State of the Question

The lack of an ethical communication framework in pediatric critical care medicine is problematic as pediatric physicians often experience difficulty in having authentic conversations regarding prognosis. When physicians find it difficult to honestly discuss the prognosis of their pediatric patients it makes truly informed consent nearly impossible for the surrogate decision maker. The lack of candid communication about prognosis can also give way to deceitfulness and false hope. This type of dishonest communication about prognosis in the pediatric critical care setting often leads to uninformed and unfair treatment for children and their families as it can leave them unprepared for what lies ahead. While physicians may not deliberately engage in dishonest communication strategies they are nonetheless problematic.

The relevance of this dissertation is manifest insofar as the literature identifies the communication problem without giving a truly solid recommendation to resolve the difficulty. This dissertation is also distinctive because it applies specifically to the discussion of prognosis in pediatric critical care medicine where there are often numerous ethical issues. Communication is a medical tool similar to the protocols and procedures surgeons are required to follow. Therefore, an ethical communication protocol is similarly needed.

Communication Theory for Pediatric Medicine

An exploration of relevant communication theories for discussing prognosis in the pediatric critical care setting and the ethical indications that resonate from those communication theories will be reviewed in this chapter. Specifically, communication theory and prognosis in pediatrics will be explored along with an ethical framework for communication in pediatric medicine.

1. Communication Theory and Prognosis

There is serious concern about the quality of communication and information transmitted from clinicians to parents in the pediatric setting.⁹ All too often children with fatal or potentially fatal diagnoses fail to receive proficient, empathetic, and reliable care.¹⁰ Pediatric physicians may experience more difficulty in having challenging conversations or communicating unfavorable prognoses with families. This difficulty may actually stem from a physician's compassionate disposition.¹¹ While a stringent definition of communication cannot necessarily be agreed upon, there are distinctive elements of communication that can be delineated. The first element being that communication is a transaction. Communication requires two or more people to

construct meaning together by taking each other into account and working together bestowing to a given set of rules. The second element of communication requires there is a creation of meaning. Words by themselves do not have meaning as people give meaning to words. Effective communication therefore requires people work together to create a shared meaning. Lastly, effective communication requires an exchange of symbols enabling people to create meaning. Symbols might take the form of nonverbal communication, verbal communication, or graphic communication.¹² Communication is essentially a procedure physicians use when consulting patients and families. A broad amount of research has shown that if physicians do not have good communication skills then care for the patient may be lacking.¹³ Data indicates that when physicians are proficient in communication then health outcomes for the patient tend to be better.¹⁴

a. Establishing rapport with the ethics of care

This section will review how physicians can establish rapport with patients and families through the ethics of care, how to create relationships through the notion of caring, and how to take responsibility for others through the voice of care will.

i. Creating relationships through caring.

The ethics of care is of utmost importance when establishing rapport in the health care setting. The ethics of care focuses on the relationship itself instead of individual preferences. A fundamental value of the ethics of care is to create lasting caring relations. A caring relationship shows mutual concern as one does not only learn how to care for someone, but also why they should care for someone. Caring for someone should bring people together and establish a relationship, such as that of a physician and a

patient.¹⁵ Relationships are, thus, created through the process of caring. Genuinely caring for someone creates the relationship, and the work it takes to care for someone is interpersonal.¹⁶ The ethics of care notes that when we take or assume responsibility for others we must attend to and meet the needs of those people. When rapport is established in pediatrics, physicians are able to care for their patients both medically emotionally. Truly caring for patients is not just tending to the work it takes to aid their medical condition, but also the relationship established and the motive that accompanies caring for that person. Trust also helps to establish relationships. This is an important factor when it comes to caring and establishing rapport.¹⁷

- ii. Taking responsibility of others through the voice of care.

Another central focus of the ethics of care is meeting the needs of those for whom we take responsibility and recognizing that sometimes those for whom we take responsibility are more vulnerable than others. Children are a vulnerable population, especially in the health care setting. Children are naturally dependent and require the care of others to ensure they develop and thrive. Children who are ill are even more dependent upon having others care for them.¹⁸ The ethics of care challenges the notion of universal care as each patient and each medical situation differ. Likewise, as care for each patient cannot be universalized, communication about care cannot be generalized either. How a physician communicates with one patient will be different from how they may communicate with other patients. Therefore, each patient deserves a communication transaction tailored to him or her. The communication should be uniquely tailored from one patient to the next.¹⁹ Carol Gilligan, a pioneer on care ethics research, notes that the ethics of care is an ethic grounded in communication. The ethics of care tends to the

importance of everyone having a voice and everyone being listened to and respected through paying attention, listening to others, and by responding to them helps to build solid relationships.²⁰

b. Managing the uncertainty of veracity

Managing the uncertainty of veracity is a daunting, yet important task for physicians to master when dealing with pediatric patients. The responsibilities physicians have to communicate in a truthful manner and how to deal with ambiguity when communicating will be examined in this section.

i. Responsibilities to communicate truthfully

Veracity in health care is essentially the transmission of information in an all-inclusive, impartial, and truthful manner. Veracity is built on the notion that there is a certain level of respect owed to others. When communication is initiated there is an embedded promise that what is spoken is truthful and not deceitful. In health care when doctor-patient relationships are established the patient is entering into an agreement that includes the right to truthful information regarding diagnosis, prognosis, procedures, etc. The physician also has the right to gather truthful information from the patient regarding their illness. Relationships in health care depend on trust and, therefore, veracity.²¹ Truthful communication in pediatrics can sometimes be difficult, but is undeniably important. Physicians who believe their intentions are good when they choose deceptive communication often overestimate the benefits and underestimate the harm of their decision. When physicians choose forms of deception over truthfulness they risk compromising the trust of the doctor-patient-family relationship. This also undermines

the surrogate decision maker's ability to make informed decisions. Physicians also have a responsibility to themselves to communicate truthfully as using deceptive communication tactics undermines their own credibility.²²

i. Dealing with communication ambiguity in pediatric medicine

Uncertainty in pediatric critical care medicine is always present, especially when discussing the state of an illness, treatment options, or prognosis. How uncertainty is managed can greatly affect the outcome of the communication transaction. Communication theories ascertain uncertainty by examining how individuals assess, manage, and cope in situations of veracity when a patient or family members are presented with a diagnosis of which little is known regarding the course of the disease.²³ Physicians are often leery about how much poor prognostic information to present to patients and their families because they fear patients will have emotional distress or give up completely.²⁴ Yet, when a child dies and proper communication has not taken place regarding the child's prognosis it can be damaging to the family. Family members may have memories of their child's unnecessary suffering and regrets about the uninformed decisions they made.²⁵ In an effort to maintain veracity, even in difficult situations, physicians should consider their communication options and think about the truthful means to fulfill their communication goals, as paternalistic deception is often never morally appropriate.²⁶

c. Maintaining the relationships between the physician and family

A key component of patient satisfaction is building a relationship between the involved parties. Enhancing communication and the notion of family centered care will

be reviewed in an effort to discover how solid relationships can enhance communication in pediatrics.

i. Instituting relationships and enhancing communication

Well-established relationships between the physician, patient, and family members can help reduce uncertainty and, thus, enhance physician-patient communication. Enhancing interpersonal relationships through effective communication is necessary in all aspects of medicine, and especially necessary in pediatric medicine. Some families may be apprehensive to discuss the imminent death of their child, or they may be hesitant to have necessary conversations about hospice care, life support, or other end of life matters if a solid relationship has not been established.²⁷ These conversations are imperative and require honest communication from all parties involved. Parents are often very dependent on medical information from clinicians; therefore, clinicians are ethically obligated to be aware of the way in which they address discernments about the child's diagnosis and prognosis.²⁸ Relationships and communication go hand-in-hand. Relationships are developed as a result of effective communication. Patients need their physicians to have technical expertise as well as good communication skills. When physicians have inadequate communication skills it can create avoidance and distance within the relationship.²⁹

ii. Family-centered care

Family centered care in pediatrics is an important and perhaps underutilized approach that can improve patient care, satisfaction, and communication. According to the American Academy of Pediatrics (AAP) a family centered approach to pediatric care

identifies that families should be the driving force of pediatric care and also recognizes that families deserve truthful, honest, and unbiased information regarding their child's condition.³⁰ A family centered approach to pediatric care acknowledges that emotional, social, and developmental support from families play a vital role in health care. Family centered approaches to health care have been shown to lead to improved health outcomes, more sensible distribution of resources, and greater overall patient and family satisfaction.^{31 32} Parents of critically ill children value information regarding their child being communicated in a timely manner as it reduces anxiety and progresses communication.³³ Research indicates that families should be included in physician rounds as it can increase parental satisfaction and open new lines of communication.³⁴ Family centered care is perhaps underutilized because some health care organizations fear including the family too much can be a hindrance to care as families may make unreasonable requests, easily misunderstand information presented during rounds, or ask too many questions which can be time consuming for the clinicians. Some physicians have a difficult time changing from "the way things have always been done, and patient centered care is not something that has always been done."³⁵ Although a more family-centered style of communication initially may take longer, it helps to avoid omissions by enhancing data collection from the physician and by providing a more satisfactory doctor-patient relationship.³⁶

2. Ethical Framework for Pediatric Communication

The ethical framework for pediatric communication will explore the notion of the ethics of care; more specifically the virtue of caring and what it means to use those virtues to communicate caring. Veracity for surrogate consent will also be explored in

terms of pediatric surrogate decision-making standards and the ethical duty that physicians have to communicate honestly with their patients and families. Lastly, the physician-patient relationship will be examined and the ethical considerations physicians must adhere to when building relationships with patients and families. The importance of foundations of family-centered care in pediatrics will be discussed.

a. Ethics of Care

The virtue of care will be reviewed to explore the significance of the ethics of care as part of the ethical framework for pediatric communication. Additionally, the use of virtues to communicate caring will also be addressed.

i. The virtue of caring

The virtue of caring is a cornerstone for health care as it serves to guide health care providers in relationships, practices, and actions beyond what they might find as their responsibilities in their professional code of ethics. The ethics of care is prominently known as a powerful form of virtue ethics as the ethics of care emphasizes the importance of personal relationships, sympathy, and compassion. The virtue of caring requires providers to not only be attentive to the patient and their wellbeing, but also attentive to the ethical principles guiding wellbeing.³⁷ This virtue is different from simply caring for patients as it refers to the willingness to care for people not only physically but also emotionally. Concern and caring for others goes beyond following a certain set of rules as it is more precisely a moral way of thinking. The ethics of care focuses on the actions of medical team members and how their actions either promote or demote positive relationships. The virtue of caring requires physicians to avoid

generalizations when caring for patients. Instead, they should tailor each medical encounter and communication transaction specifically for each patient. The virtue of caring also pays particular attention to relationships and emotions and how the two are interconnected. Being empathetic and engrossed in the patient's care is necessary for building moral relationships. Providing good care, therefore, requires physicians to not only care for the patient, but to address the needs of the patient and their family members based on individual circumstances.³⁸

ii. Using virtues to communicate caring

The relevance of the virtue of caring has been established. The theory also places emphasis on how one should communicate feelings of care to others, but beyond that special attention must also be paid to how one communicates that they care. There are five focal virtues health care providers can focus on to communicate caring. The virtue of compassion conveys an emotional awareness of the patient's anguish. In order for physicians to effectively communicate with patients, they must understand the patient's experience with their illness, the emotions they may have, and the role pain and suffering plays in the patient's life. The second virtue, discernment, focuses on how to communicate and help patients and surrogates reach decisions without being biased. Discernment is also how physicians respond to their patient's needs, such as whether a patient who has just received a poor prognosis needs comfort or time alone. Trustworthiness is another virtue essential for health care. Vulnerable patients and surrogates must feel comfortable and trusting of their health care professionals. In order to trust their health care professional's patients and surrogates must have confidence that their physician is acting morally and with the right motives. If physicians want to be

viewed as trustworthy to patients and family members then they must conduct themselves in such a way that patients and family members have confidence in their character. A fourth virtue, integrity, requires physicians be reliable and act within ethical norms. Physicians can communicate integrity by remaining sincere, not being deceptive, and not being hypocritical. Physicians can also communicate integrity by recognizing their own moral commitments and avoiding situations which may compromise their integrity. The final virtue, conscientiousness, focuses on the character trait of doing what is right because it is right. Some physicians may refuse to honor a patient's valid request because such a request goes against their conscientious beliefs. In situations such as these physicians should recognize and communicate their conscientious refusals so they avoid compromising patient's rights.³⁹ By recognizing and following these virtues physicians can communicate directly and indirectly to patients and their family members for whom they care.

b. Veracity for surrogate consent

Understanding the moral intricacies of the consent process in pediatric medicine is imperative when it comes to ethically communicating about treatment options. This section will outline the pediatric surrogate decision-making standards and the ethical duty physicians have to communicate in an honest manner.

i. Pediatric surrogate decision-making standards

Physicians and families have an imbedded responsibility to communicate openly and truthfully with each other to establish relationships with one another and help address the ambiguity that may arise in pediatric critical care medicine. Veracity is also of utmost

importance for family members who are surrogate decision makers for the patient. Children cannot be treated medically or ethically as “small adults.”⁴⁰ In pediatric medicine, children under the age of 18 are typically not considered to have the capacity to make their own medical decisions. Since pediatric patients are particularly vulnerable, the importance of protecting them is unyielding.⁴¹ Pediatric patients have a right to life, and they also have a right to mercy. Pediatric patients have a right to treatment that will result in a reasonable extension of their life. However, they also have a right to end of life care so as not to experience unnecessary suffering. Somewhere in between those two rights surrogate decision makers must make appropriate decisions for the patient.⁴² Typically, under common law, decisions regarding pediatric care are often left to parents or guardians.⁴³ It is generally accepted that parents want what is best for their children and, therefore, make the best surrogate decision makers for children who lack maturity, knowledge, and aptitude for judgment.⁴⁴ In pediatrics, surrogate decision makers typically use what is known as the best interests standard. The best interests standard requires that surrogate decision makers determine the highest net benefit among all available options in a way that promotes the wellbeing of the patient and the patient’s interests.⁴⁵ The best interests standard serves as a way to protect children and offers objective guidance by asking parents to make decisions based on maximum benefit and minimal harm for a particular patient, in a particular situation, and at a particular time.⁴⁶ The best interests standard is a key component to pediatric health care, yet it can only be truly operational when honest communication about the child’s diagnosis and prognosis occurs.

- ii. Ethical duty to communicate honestly

Communicating has consequences and therefore also involves ethics. It may be easier to exaggerate or lie to patients regarding their prognosis, but it would be immoral.⁴⁷ When considering pediatric ethics, it is important to note that both the parent(s) of the child and the physician(s) have a fiduciary duty to the child who cannot legally make their own decisions. For parents to be able to make informed decisions for their child they need to be able to defer to the physician for evidence based clinical judgment; therefore, making the parents and the physician co-fiduciaries. Physicians, thus, have a moral obligation to communicate all medically reasonable alternatives to parents so they can make the best-informed decision for their child.⁴⁸ It is believed that physicians can contribute to surrogates making counterproductive medical decisions simply by the way they communicate the patient's prognosis.⁴⁹ It is not productive for physicians to communicate a sense of false hope to patients and their families.⁵⁰ However, in pediatric ethics, the physician also has a duty to protect the life of the patient when medical interventions exist that can be rationally expected to preserve the child's life given that the child would not have an overly impaired functional status or unnecessary pain and suffering. In these circumstances parents cannot ask pediatric physicians to act in ways that go against this ethical notion.⁵¹

The AAP advocates that in most circumstances there is a moral and ethical obligation to discuss the child's health and illness with the child.⁵² Although parents typically have the legal right to make decisions for their child this does not mean parents and physicians should omit children from discussions regarding their care. Not providing children with honest information and opportunities to discuss their fears and preferences can be morally problematic. It can segregate children and cause avoidable apprehension

for the child. Children and adolescents should be informed and involved in decision-making as long as their maturity level, medical condition, and cultural and family values allow for it.⁵³ Children's maturity, values, capacity to understand, and ability to participate in medical decisions also grows and evolves as they become adolescents. Adolescents bring an interesting dynamic to the decision-making process for pediatric patients as teenagers are no longer children, nor are they yet adults. While adolescents are not generally legally able to make their own health care decisions, they still may have strong opinions and preferences regarding their care. The opinions and preferences about medical care based on an adolescent's values cannot simply be ignored; they must be carefully considered by the parents and clinicians in a way that respects the patient's growing capacity to understand and also acts in their best interests.⁵⁴ Elements of the physician-family relationship will be discussed next.

c. Physician-family relationship

Establishing a concrete physician-family relationship is a cornerstone to ethical communication in pediatrics. The ethical complexities of building relationships with patients and families and the foundational elements necessary for family-centered care in pediatrics will be discussed.

i. Ethical considerations when building relationships

Contemporary bioethics, with its movement to autonomy and patient-centered care, generally supports and acknowledges the need to build relationships with not only patients, but also surrogate decision makers. Physicians have the ability to enhance the health care experience for the patient by acknowledging family members and their role in the patient's care. There are several moral implications physicians should consider when

building physician-family relationships. Effective communication and easy access to the physician provide the groundwork for building optimal relationships between the physician and family. One of the best relationship building techniques is for the physician to ensure that the patient and relevant family members have an accurate understanding of the patient's condition and prognosis.⁵⁵ The attitude and language used when communicating information about the patient's condition and prognosis have a direct effect on the type of relationship that will be built between the physician and family members. Effective communication can often eliminate feelings of distrust and disagreements between family members and the physician.⁵⁶ All interactions with the physician and family members should be patient-focused and conducted with respect for the patient's dignity, rights, and values. However, the physician should also validate the important role of the surrogate decision makers. Physicians should address concerns caretakers may have, and they should take into consideration the stress family members may be under. As a courtesy, and as a relationship building technique, physicians should refer family members to appropriate resources when they sense that they may need additional support. These ethical and professional considerations are meant to build, facilitate, and maintain physician-family relationships for optimal patient care.⁵⁷

ii. Foundations of family-centered care in pediatrics

There are several core principles considered essential when adopting a family-centered approach. A family-centered approach in pediatrics should focus on listening and respecting each patient and their family. Racial, ethnic, cultural, and socioeconomic backgrounds should be incorporated into care when it is deemed appropriate and necessary.⁵⁸ However, cultural and personal backgrounds should never compromise the

care received by the patient. Likewise, medical staff members should not be ethnocentric and disregard a family's views because they are different or uncommon.⁵⁹ Family-centered care should begin with the child's diagnosis and should extend beyond death when necessary. Indispensable supportive care and bereavement services should be offered to the family members in an effort to attend to the grief and emotions of the family.⁶⁰ Honest and unbiased communication with patients and families is also an integral piece of a family centered approach. Health literacy should be taken into account when communicating with families. Cultural and linguistic diversity should also be considered and respected. Families should be encouraged to attend rounds and should be included in rounds to encourage involvement in family decision-making.⁶¹ Clinical staff members should also provide necessary means of support for patients and families. If the clinical staff members cannot provide the specific support needed, they should consult another staff member who can provide the needed care. Lastly, clinicians should seek to empower patients and family members to make well-informed decisions regarding their child's care.⁶² There are four integral concepts all pediatric health care organizations should imbed into their family centered approach. The four concepts are: having respect for patient and family perspectives, sharing complete and accurate information with the patient and family members, encouraging participation from the family and patient when applicable, and collaborating with the family and patient in a way that excels medical care.⁶³

Establishing Rapport with the Ethics of Care

1. Symbolic communication traditions

All communication transactions are symbolic in nature and this symbolism plays an important role in communication within the health care setting. The symbols within any given message essentially give meaning to the communication transaction.

Understanding symbolism in the pediatric intensive care setting is ethically indispensable. The physician, patient, and parents may all attach different meanings to the same symbols. It is necessary for physicians to be able to recognize and address this in order to circumvent miscommunication.⁶⁴

a. Semiotic tradition

The semiotic tradition recognizes the importance of symbols in discourse. Semiotics helps one understand what goes into a message and how the message becomes meaningful. This section of the dissertation will identify the key components of the semiotic tradition and how those key components can be useful when physicians are trying to establish rapport with their patients and families.

i. Identifying the semiotic tradition

Symbols alone do not have meaning. A set of symbols gives meaning to the symbol itself. Meaning from symbols is derived from the symbol itself, the object, and the person. When communicating, the grammar used, the tone of voice, gestures, eye contact, and positioning will affect how the audience responds to the message.

Nonverbal communication is also symbolic in nature. Nonverbal communication occurs as groups of behaviors are used to express meaning. Nonverbal symbols are unique as many nonverbal codes elicit universal meaning despite cultural differences. Nonverbal cues, such as emotional displays, are often universal in nature. Nonverbal communication also allows the communicator to send multiple messages at once through

their facial expressions, body movements, voice, and other various signals.⁶⁵ Ninety percent of meaning in communication comes from non-verbal cues such as tone of voice, how one stands (or sits), and gestures during communication.⁶⁶ Nonverbal communication is an imperative piece to the entire communication process as nonverbal interaction is always present and leaves the biggest impact on the entire communication transaction. Nonverbal exchanges have the ability to continue even when verbal communication has halted.⁶⁷

ii. Semiotic tradition and establishing rapport

Establishing rapport is an essential part of the doctor-patient relationship, especially when critically ill children are involved. Parents and their children are often vulnerable in the health care setting as they are reliant on health care professionals to help them make important decisions regarding their child's health care.⁶⁸ In order to properly and effectively communicate physicians must be aware of the way in which their communication interactions affect the rapport. Even when physicians are not actively speaking they are still communicating.⁶⁹ It is imperative clinical workers understand that many factors can affect communication as well as how the message is received. For example, the context in which communication takes place can be a determining factor in how the message is perceived by the receiver.⁷⁰

Outside noise such as cell phones, beepers, and medical machines can also have an effect on communication and the physician-family relationship. Patient satisfaction, compliance, and trust is often dependent upon these types of nonverbal cues. It is important for physicians to be consciously aware that outside noise can affect rapport and the care the patient receives.⁷¹ How the physician positions himself while

communicating with the patient and family can also affect the relationship. Studies have shown that patients typically perceive physicians who sit down when they talk as more compassionate than those who stand. It has also been observed that physicians who sit down spend more time at the bed side.⁷² Patients and surrogates will likely base their first impressions about the relationship on the physician's non-verbal communication skills. Patients and surrogates may judge a physician's credibility, likeability, and dominance from the physician's nonverbal cues.⁷³

Emotions can also be communicated through nonverbal communication. Emotions can essentially shape the relationship between the physician, the patient, and the patient's family. While it is typically speculated that patients and their families show most of their emotion during conversations, this is not always the case. Physicians may also show their emotions regarding a given patient's situation. The emotions physicians show is often referred to as "the information behind the information." For example, a physician might say that there is hope for a patient's survival; however, their nonverbal emotions may indicate something different.⁷⁴ When verbal and nonverbal messages conflict, people are more likely to believe the nonverbal message.⁷⁵

Physicians can also increase trust and build rapport when dealing with pediatric patients by paying attention to the different signs a child may communicate when they have concerns or fears about their prognosis and condition. Pediatric patients may not communicate in a straight forward manner and it is up to the physician to recognize the different signs a child may have for concerns or fears. When physicians recognize these signs, they can initiate communication by asking the child if there is something they are worried about, what their expectations of the future are, or what the child is hoping for.⁷⁶

b. Sociocultural tradition

The sociocultural tradition focuses on the ways in which individuals together create realities. The key elements of the sociocultural tradition and how those elements are useful in establishing rapport will be reviewed.

i. Key elements of the sociocultural tradition

The sociocultural tradition is a variation of the sociopsychological tradition. This area of study looks at aspects of individuality such as individual effects, personalities, traits and the cause and effect of communication. The sociocultural tradition is symbolic in nature. It focuses on interactions between individuals and how those interactions build rapport. A key element of the sociocultural tradition is looking at how communication changes and maintains social interactions.⁷⁷ This tradition is important to health care communication because it recognizes the importance of the meaning of words and interactions within different social situations. Realities in this tradition are constructed through communication and, therefore, whatever is discovered through the communication transaction must be influenced by interaction patterns. The context the communication takes place in is considered critical to the meanings that occur. The sociocultural tradition also focuses on the role of identities within given social situations and how those identities are established and negotiated from one interaction to the next. This tradition also includes several variations such as social constructionism. Social constructionism identifies that knowledge is created through social interaction. The identity of any given object is constructed through how one talks about the object, the language used to describe the object, and the sharing of common experiences regarding a given object.⁷⁸

ii. The sociocultural tradition and establishing rapport

The sociocultural tradition is relevant to establishing rapport in the pediatric critical care setting, because physicians must learn to be mindful of their audience, the language they use, the perceived hierarchy, and the different cultural values families may have. Typically, physicians should use everyday language easily understood by those who may not understand medical terminology. Physicians should also make sure parents and patients have correctly understood the information in an effort to assess what needs to be repeated or requires further discussion. While it is necessary for physicians to respect the parent's need for hope in critical care situations, they should not be deceitful or ambiguous at any point during the conversation as it destabilizes trust and is unfair to the patient and family. Racial, ethnic, cultural, and socioeconomic backgrounds should be incorporated into care when deemed appropriate and necessary.⁷⁹ However, cultural and personal backgrounds should never compromise the care a patient receives.⁸⁰ The role the ethics of care plays in establishing rapport will be discussed next

A. Ethics of care

The ethics of care is a key component in establishing rapport with patients and their families. More specifically, relational autonomy and what it means to meet the needs of others through the ethics of care will be explored.

a. Relational autonomy

Relational autonomy highlights the social framework within which patients and their surrogates exist, and it acknowledges the emotional aspect of decision-making in health

care. This section will offer an overview of relational autonomy and its importance when establishing rapport with patients and families.

i. Understanding relational autonomy

When dealing with pediatric patients the physician's role is tremendously important in relational autonomy. Physicians have a responsibility to not only offer factual guidance in decision-making, but also to take into account the exceedingly emotional experience of parents making decisions for their critically ill child.⁸¹ The relational methodology to autonomy transpires within relationships because of that particular bond of connection. Relational autonomy goes a step further than the traditional notion of autonomy by requiring health care professionals to not only consider a patient's capacity to make decisions, but by also respecting their self-identity. Physicians should attend to their patient's notion of self-identity which may include bodily characteristics (such as age, abilities, and inabilities), how the patient networks with others (how trusting is the patient, how does the patient solve problems, and how does the patient communicate effectively), and social factors (such as culture and religion, familial and marital status, work status, etc.). Addressing self-identity as part of autonomy in health care allows one to see how and why patients and their surrogates may make decisions. Relational autonomy encourages a dyadic relationship (or triangular in pediatrics) by encouraging patients and their surrogates to participate in the decision-making process, voice their feelings regarding care, ask questions, and take responsibility in their health care.⁸²

ii. Relational autonomy and establishing rapport

Attention to relational autonomy in pediatric medicine is important as it requires a partnership be established for the physicians to understand and be responsive to their patient's self-identities and needs. When physicians respect a patient's autonomy by supporting their self-identity they provide emotional support for the patient and their family, they seek to balance the power in the relationship, and they address any inequalities the patient may face which may affect their healthcare outcomes. Thus, they are able to institute rapport with patients and their surrogates. Relational autonomy also helps to build rapport as it supports family-centered care in pediatrics. In family-centered care physicians seek a partnership with the patient and their surrogate. Similarly, the approach for relational autonomy also focuses on individualizing care for the patient and their surrogates. These factors nurture an environment where rapport can be established as the physician is concerned with the patient's values and interests beyond the scope of their physical and mental health.⁸³ Relational autonomy goes a step further in pediatrics and acknowledges the need to not only build rapport with surrogate decision makers but also with the patient. Relational autonomy recognizes the need to authenticate the emotional experiences of children and adolescents. It also recognizes the need to allow adolescent patients to express their autonomous desires regarding their care based on who they are and who they want to be. While there are limits to adolescent autonomy it is still important to include adolescents in conversations regarding their care.⁸⁴

b. Meeting the needs of others

Meeting the needs of others is a pivotal aspect of the ethics of care. It addresses ways in which physicians can develop caring relationships with their patients and

families, and how to recognize and meet the individual needs of patients and families.

This will be further explored in this section.

i. Developing caring relationships

The fundamental focus of the ethics of care is meeting the needs of those who we take responsibility for, especially those who are dependent such as children. In an effort to meet the needs of those who are dependent, the ethics of care focuses on the relatedness of those who need to be cared for and those who are doing the caring. When caring for someone else the person doing the caring must be cognitively aware of the needs, desires, and thoughts of the person being cared for. Providing good care for patients requires fundamental ethics education so providers can understand the deeper importance of nurturing as a caring approach.⁸⁵ It is important the person doing the caring also tends to themselves and their own needs. If the needs of the care giver are neglected, they will not be able to provide support for others as efficiently. Developing caring relations with others is ethically significant in health care because it expresses the ways in which others matter to each other. This emerges as an interpersonal connection. Developing caring relations in health care is both a practice and a value. Developing caring relations as a practice builds trust between the patient and the caregivers by showing mutual concern and the interconnectedness of the relationship. Trust is relational and cannot be achieved in isolation. Developing caring relations allows the caregivers, the patient, and the family members to develop a relationship where they can trust each other enough to respect each other's rights.⁸⁶

ii. Addressing individual needs

Physicians must not only be able care for their patients on a general level, but they must also strive to meet their patient's individual needs. Pediatric patients often range in age, growth, and maturity and, therefore, meeting their individual needs can be somewhat of a unique challenge. Furthermore, there are cultural values that must also be taken into consideration when meeting the needs of pediatric patients and their families.

Addressing and meeting these individual needs can help build rapport and a triadic relationship between the physician, parents, and patients. Physicians should remain open to different cultures and value systems and adapt to those differences when possible.

Physicians should also consider variability within different cultures and seek to be culturally proficient when possible.⁸⁷ Many critically ill patients not only need their emotional and physical needs met, but also their communication needs. Communication in intensive care settings can often be difficult as there are many medical hindrances to communication such as intubation, sedation, or the use narcotics. In order to build rapport and meet the patient's needs, physicians should use skilled communication tactics. For example, a physician should consider their patient's developmental stage, their wakefulness, and their overall ability to process information before communicating with them. When a patient is unable to verbally communicate, physicians should pay careful attention to their nonverbal cues and should be able to recognize purposeful and non-purposeful movement. Some patients may need additional communication help such as the assistance of a specialized keyboard, a booklet of pictures to point to what they need, or even the use of a lip reader to interpret their needs.⁸⁸

Managing Uncertainty in Veracity for Surrogate Consent

1. Uncertainty Communication Theories

Reducing uncertainty is key to managing veracity in pediatrics as people tend to find greater communication satisfaction when uncertainty is minimal.⁸⁹ Uncertainty management/reduction theories will be reviewed in addition to the notion of framing communication and how framing can hinder the reduction of uncertainty.

a. Management/reduction theories

Uncertainty management and uncertainty reduction communication theories will be reviewed in this section. Additionally, how uncertainty communication theories can help physician's aide surrogate decision makers in their decision-making process will be explored.

i. Identifying management/reduction theories

Uncertainty in pediatric critical care medicine is always present especially when discussing the state of an illness, treatment options, or prognosis. How that uncertainty is managed can greatly affect the outcome of the communication and healthcare transaction. Uncertainty theories seek to describe how individuals assess, manage, and cope with ambiguous situations.⁹⁰ The Uncertainty Reduction Theory (URT) explores how we gain knowledge about other people. In communication within the health care setting the doctor, the patient, and the family may all wish to learn more about each other in order to establish a grounded relationship, reduce uncertainty, and increase trust. A person's nonverbal behavior may help to reduce uncertainty when communicating. Self-disclosure is one tactic typically used to reduce uncertainty. When one person discloses something about themselves, the other involved parties typically reveal something about themselves in return.⁹¹ URT is a prognostic model in pediatric critical care medicine. It

shows how to reduce uncertainty through verbal and nonverbal communication and social interaction. Essentially, if the physician provides relevant information (name, position, what to expect, etc.) early in the encounter then patient anxiety should decrease and communication should increase.⁹² A similar theory is the Uncertainty Management Theory (UMT) which claims patients and their families may remain uncertain regardless of the amount of information they have received to reduce that uncertainty. Patients or their family members may attempt to avoid medical information if they are uncertain about whether or not they will be able to accurately understand the given information, if they feel the physician has all the authority in the communication transaction, or if they do not believe the given information will help them manage their medical situation. UMT recognizes the importance of revisiting goals of care when patients or their family members may wish to seek more information in an effort to reevaluate what they consent to.⁹³

ii. Management/reduction theories and veracity for surrogate consent

Pediatric physicians have an obligation not only to their patients, but also to the surrogate decision makers.⁹⁴ Physicians are typically uncertain about how much poor prognostic information to present patients and their families because they fear patients will have emotional distress or give up completely.⁹⁵ However, family members need accurate and honest information in order to make informed surrogate decisions regarding their child. Despite the angst difficult conversations create, data does not show that honest discussions about prognosis are harmful for either adult patients or for children and parents.⁹⁶ Even in the age of informed consent pediatricians often disagree and struggle with the appropriateness of disclosing distressing information to parents and

children. Another struggle with open and honest communication in pediatrics is deciding how much information to give parents and children about medical conditions when the prognosis is uncertain.⁹⁷ While it is challenging to predict the medical future for a patient, physicians sometimes respond to this uncertainty by evading the conversation all together, giving an ambiguous prognosis, or focusing the conversation on treatment rather than outcomes.⁹⁸ In an effort to aid surrogates in their decision-making process physicians should focus the conversation on outcomes that are possible. In order to understand what outcomes parents and children are hoping for clinicians should be trained to actively listen to parents and patients in an effort to create a compass for decision-making based on a shared vision for the patient's future as the illness unravels.⁹⁹ When it comes to pediatrics, honest and open communication about a child's prognosis can actually relieve stress, support hope, and help reduce uncertainty even if the prognosis is uninviting.¹⁰⁰

b. Framing communication in uncertainty

Framing is a communication method often used in health care to manipulate an interaction, yet its use is characteristically unethical as it hinders the ability for truly informed consent to occur. This section will describe the method of framing communication and how framing can negatively affect surrogate decision-making.

i. Method of framing communication

Framing in communication occurs when one presents logically equal information in divergent ways to achieve varying effects. In health care, framing typically functions to manipulate the perception of the risks or benefits of a given treatment. The way

physicians communicate risks or benefits and how the patient or the patient's family interprets them can vary depending on the language chosen by the physician. Interpretations of risks and benefits can differ depending on whether physicians use words such as rarely, sometimes, or often in comparison to the use of numerical data to describe the risks or benefits of a given treatment. How numerical information is presented can also sway the treatment choices that surrogates consent to. For instance, one could say there is a 70 percent chance of survival with a given treatment, or a 30 percent chance of death with a given treatment.¹⁰¹ How the risk information is formatted by the physician can influence parental views on treatment benefit.¹⁰² Framing can also be negative or positive, or used for loss or gain. For example, if a physician does not want a patient to take a particular course of action they might highlight the side effects of the treatment. On the other hand, if they want a surrogate to choose a certain treatment option they might modulate the side effects and overemphasize the effects. Physicians might also stress the disadvantages of not adhering to a certain treatment option instead of presenting the advantages of alternate treatment options.¹⁰³

ii. Framing communication and surrogate decision-making

Framing communication techniques hinder a surrogate decision maker's ability to make truly cognizant decisions. The way information is presented has different motivational effects and can heavily influence which treatment options are chosen and adhered to. However, manipulating information in such a way is morally problematic and can have severe implications on patient care. Clinicians should be conscious of their biases and their ability to frame information. Physicians should present information in a reasonably fair and balanced manner. They should also be able to discern factors

affecting how they should deliver information such as the surrogate's literacy level, or their preference for numerical data versus descriptive data.¹⁰⁴ Communicating risks and benefits of treatment options is meant to help surrogates make informed decisions; however, it can have the opposite effect if framing is used by clinicians.¹⁰⁵ One of the most important benefits of communicating honestly about prognosis is that the information exchanged allows families and patients to make informed decisions even at the end of life. It has been found that adult patients who have unrealistic expectations about their prognosis tend to choose more aggressive and life-pro longing therapies. In comparison, patients who recognize their poor prognosis tend to prefer palliative care. Less aggressive care is subsequently associated with a better quality of life near death. However, the most important factor is that patients who have honest conversations with their physician about their prognosis are more likely to receive the care that they want, whether that be life prolonging care or palliative care. This research suggests patients who are more aware of their prognosis are thus more prepared to make autonomous decisions as communication about prognosis supports patients' autonomy. While much of the research focuses on adult patients, evidence suggests surrogates face the same issues when making decisions for pediatric patients.¹⁰⁶

2. Veracity for Surrogate Consent

This section of the chapter will explore how surrogate consent in pediatrics can be made more accurate and genuine by helping surrogates understand their role as the decision maker, and by helping physicians understand their role as an impartial party responsible for full disclosure.

a. Surrogate consent, beneficence, and best interests

A detailed summary of what it means to be a surrogate decision-maker and what it takes to give authentic surrogate consent in pediatrics will be offered in this section of the chapter. How beneficence and best interests pertain to pediatric surrogate consent will also be discussed.

i. Surrogate consent

Physicians and surrogate decision makers have a deeply rooted responsibility to act in the best interests of pediatric patients. Surrogate decision makers for pediatric patients have an expansive (but not boundless) right to make decisions for their child. In order to make well-informed decisions in the best interest of their child, surrogate decision makers also have the right to receive support from the medical team regarding their decisions. They also have the right to have all relevant information regarding their child's diagnosis and prognosis explained to them so they can provide parental informed consent for the treatment of their child.¹⁰⁷ However, this is not always easily done as physicians must manage their uncertainty and own biases in order to provide the most accurate and truthful information to surrogate decision makers. Patients and family members may report that physicians are coming off as cold hearted or insensitive when they are delivering bad news; the truth is most physicians are just uncomfortable and undereducated when it comes to this type of communication.¹⁰⁸ A 2000 study on the impact of treatment goals and palliative care with pediatric cancer patients found that parents recognized that their child had no chance for cure on average of 150 days before the child died. Physicians, on the other hand, recognized the patient had no chance for a cure on average 330 days before their death. The study concluded that early recognition and communication by physicians to parents can create the opportunity for surrogate

decision makers to reevaluate the treatment plans and goals of care for the patient.¹⁰⁹

Discussing a child's prognosis openly and honestly not only allows patients and parents to reassess their goals of care, but it also gives parents and clinicians the opportunity to discuss thoughts about the child's future and create a compass for future decision-making. The benefits of these discussions are two-fold as pediatric patients benefit from well-informed parental decision-making, and parents benefit emotionally by knowing what is ahead.¹¹⁰ If physicians are able to better communicate prognoses honestly and deal with their uncertainty, they can help patients and their families at the end of life stage make well-informed decisions, thus avoiding unnecessary care.¹¹¹

ii. Beneficence and best interests

Beneficence and best interests essentially go hand in hand, especially when discussing veracity for surrogate consent. Being honest in communication is typically always beneficent and in the patient's best interests. Beneficence is the idea that we should not harm or cause harm to others, we should defend the rights of others, we should help those people who have disabilities or who may be in danger, and we should contribute to the well-being of others while treating them in an autonomous manner.¹¹²

The best interests standard requires surrogate decision makers to determine the highest net benefit among available options. The best interests standard is meant to protect the well-being of incompetent persons by requiring their surrogate decision makers to attend to a methodology evaluating the risks and benefits of a given treatment to its alternatives. Best interest standards are meant to benefit the patient and, therefore, the focus of best interest judgments must be on the value of life for the patient, not on the value that person's life has for others.¹¹³ If surrogate decision makers are to consent to treatment

they believe to be in the best interest of their child, then physicians must divulge information about the patient, their diagnosis, and their prognosis in a truthful and beneficent manner.

b. Disclosure and impartiality

Who to disclose information to and how much information to disclose is one of the biggest questions health care providers must ask themselves when they are interacting with pediatric patients. How physicians should disclose information to patients and families while maintaining a neutral party status will be discussed.

i. Disclosing information to families and patients

Uncertainty in what lies ahead often creates anxiety for physicians, especially when families and patients are knowingly hoping to hear a good prognosis. Physicians are often so distressed by the idea of discussing a poor prognosis or impending death that they are hesitant to even discuss the poor prognosis and possible treatment options. For example, patients with cancer are often misled to believe that their palliative care has curative potential, thus giving patients and surrogates a sense of false hope.¹¹⁴ A 2001 study found that physicians might deliberately withhold information from pediatric cancer patients in an effort to provide misleading and overly optimistic life expectancy assessments. The study also noted that the younger the patient was the more likely a physician would be to provide an overly optimistic life expectancy assessment, rather than an honest and more reasonable assessment.¹¹⁵

Parents of children with cancer report that they want to know their child's most accurate prognosis because it helps them make better informed decisions. It is also

reported that honest prognostic disclosure in the pediatric cancer setting has not been associated with higher rates of parental distress.¹¹⁶ Parents need information regarding their child to be properly disclosed, because it supports informed decision-making. Physicians have an ethical obligation to truthfully disclose information to family members and pediatric patients (when appropriate). Research suggests surrogates and patients who are aware of their prognosis are more likely to make well-informed decisions, especially for patients who are facing a life-threatening diagnosis where their goals of care should align with what is clinically possible. Surrogates and patients who have received proper disclosure about a poor prognosis are more likely to receive the care that they want. Whether the care is life prolonging or palliative, properly disclosing prognostic information, even in the pediatric setting, supports patient autonomy and patient values.¹¹⁷ Research indicates that the majority of parents want straightforward information regarding their child's diagnosis. Parents who find the diagnosis to be extremely upsetting often request additional information. While unfavorable diagnostic information may be difficult to communicate, it does not lessen a parent's desire for such information.¹¹⁸

ii. The physician as a neutral party.

When discussing diagnostic and prognostic information physicians should do their best to remain impartial. Physicians should recognize their biases and avoid any type of framing communication.¹¹⁹ Physicians who lack objectivity can fall into the trap of being deceptive. For example, doctors may occasionally use anecdotal evidence to make the prognosis appear better than it may be. It is not unlikely for physicians to sometimes recall and describe one or some of their similar patients who recovered from

comparable circumstances. However, in medicine it is rare that any two cases or any two patients are exactly alike. Therefore, relying on anecdotal evidence from previous patients is often misleading and provides a sense of false hope for the patient and family.¹²⁰

In some cases, physicians can be deceitful by failing to offer alternatives to continuing treatments when a patient's disease is diagnosed as incurable. A 2002 study of conversations between 118 terminal cancer patients and their physicians found patients were generally informed that their disease was incurable and about the goals of anti-cancer treatment. However, alternatives to anti-cancer treatments were not typically communicated to them.¹²¹ While it is necessary for physicians to respect the parent's need for hope, they should not be deceitful or ambiguous at any point during the conversation because it destabilizes trust and is unfair to the patient and family.¹²² When physicians lack impartiality while discussing prognostic information they hinder the surrogate's and patient's ability to make truly cognizant decisions in the best interests of the patient.

Maintaining the Physician-Family Relationship

In order to discuss how physicians can maintain the physician-family relationship several relational communication theories will be examined. The physician-family relationship will also be explored in depth by looking at the differences between paternalism and partnerships and how to maintain patient autonomy including for minors.

1. Relational Communication Theories

It is ethically imperative providers know how to properly communicate in order to build and maintain relationships with patients and families. Conversations that occur are

seldom ever isolated. They are typically connected over time and create communication contexts. Relationships are dynamic as they are encompassed of communication patterns and receptive behaviors.¹²³ Pediatrics relationships are even more complex as the triangular provider-patient-family relationship can greatly affect health care outcomes. Therefore, relationships must not only be established, but also maintained. According to the AAP, a family centered approach to pediatric care identifies that families should be the driving force of pediatric care while recognizing that families deserve truthful, honest, and unbiased information regarding their child's condition.¹²⁴ This segment of the dissertation will discuss the social penetration communication theory and the sociopsychological tradition.

a. Social penetration theory

The social penetration theory is a communication theory proposing that relationships continually develop over time through the process of self-disclosure, and that self-disclosure increases after satisfactory interaction occurs. This section of the chapter will give an in-depth overview of the social penetration theory and how this theory can be applied to the maintenance of physician-family relationships.

i. Characteristics of the social penetration theory.

The social penetration theory is a communication theory describing how relationships develop through communication with each other as relationship building is not a one-sided endeavor.¹²⁵ The social penetration theory also proposes that relationships continually develop over time through the process of self-disclosure, and that self-disclosure increases after satisfactory interaction occurs. The social penetration theory suggests four stages of occurring relational development. The first stage is known as the

orientation stage where general information such as height, weight, and age might be shared. The second stage is the exploratory stage in which fairly general and pertinent information is shared such as your first name, where you live, and where you work. The third stage is an intermediate stage in which information is only occasionally shared and not concealed. The final stage is where private information might be disclosed such as one's core values or beliefs. As more information is shared in the relationship the breadth and depth of the relationship grows. The breadth of the relationship includes the different kinds of things you might learn about another person, and the depth of the relationship includes the detailed information you might learn about someone.¹²⁶

ii. Social penetration theory and physician-family relationships

Typically, when the social penetration theory is not applied to health care transactions, it is still applicable in the health care setting. Providers should be aware of their need to reduce patient and family member uncertainty and the effects a good doctor-patient relationship can have on patient care. Providers should also be aware that patients and family members may be hesitant to share pertinent personal information if a grounded relationship is not established between all parties involved. Within the social penetration theory there is often reciprocity. Yet, in health care communication there is typically a lack of reciprocity as the patient and family members are divulging personal information, but the physician is not interchanging such information.¹²⁷ Many physician-family relationships last for a decent amount of time, especially in the critical care setting. The social penetration theory is valuable to physicians because it helps in the understanding what happens to a relationship once it is already developed. If the relationship begins to weaken then depenetration may occur. This happens when

communication begins to occur in less depth than previously, which can be detrimental to the well-being of the patient. People involved in any relationship, especially a health care relationship, have certain ethical obligations they must strive to fulfill. There is the obligation of empathy, where all involved parties should strive to understand the other's point of view and how they might be feeling in a particular situation. There is also an ethical duty to communicate honestly and arrive at decisions by discussing them and not forcing them. It is ethically imperative all parties in the relationship manage their interactions appropriately so everyone is comfortable with the communication. Lastly, there is an ethical duty to maintain a support system within the relationship.¹²⁸

b. Sociopsychological tradition

The sociopsychological tradition asserts that behavior, personality traits, and attitudes can all effect communication transactions. This section of the chapter will review the key features of the sociopsychological tradition and how this tradition can lead to an understanding of the importance of family dynamics in pediatric medicine.

i. Features of the sociopsychological tradition

The sociopsychological tradition is a dominant communication theory addressing situations where individual personality traits are important, how judgments can be biased by beliefs, and how individuals have apparent influence over one another.¹²⁹ The sociopsychological tradition is the study of the individual social being and how individuals are bound together by social collaboration. Communicator tendencies are also important to the sociopsychological tradition as they can predict how others will react and interact with the communicator. This tradition also focuses on relational

schemas. Schemas are the memories used when interacting with others. Since every person's experiences are different their schemas will also be different. Schemas also create scripts, or an idea of how an event should play out based on past experiences.¹³⁰ Relational schemas consist of knowledge about oneself, others, and the relationships one has with others. Beyond the relational schemas are the schemas that exist within a given family. Family schemas will guide what one knows about relationships in general, what one knows about family relationships in general, and what one knows about their specific relationships with their own family members. Understanding the different types of family schemas and family communication patterns is key in pediatric medicine as much of the communication that occurs is family based.¹³¹

Family communication is typically not random. Scholars have identified four different family types. The first family type is the consensual family. Consensual families are high in conversation and conformity meaning they like to communicate and engage in discussion. In this type of interaction, the parent is typically the decision maker. These families tend to value open communication, but they also value parental authority. A second family type is a pluralistic family. A pluralistic family also likes to engage in communication but are low in conformity. Parents value their children's opinions and do not feel the need to control their children's decisions. The third family type is the protective family. A protective family is often low in conversation meaning they do not engage in communication often and expect conformity. In a protective family there is little communication and parents are typically the authoritative figures. Parents in these types of family do not feel the need to explain their decisions to their children. The final type of family is laissez-faire. Laissez-faire families are low in

conversation and conformity meaning they are particularly uninvolved with each other and decision-making. They do not often care what other family members do.¹³² Family dynamics in pediatrics can be very diverse as more and more children are living in “non-traditional” family structures such as single parent homes. Understanding the different family communication patterns and dynamics can help physicians gauge how to build relationships based on family structures. Even when parents do live together, they may not always agree on the same things or have the same health care goals in mind for their child.¹³³

ii. The importance of family dynamics in pediatrics

Understanding that every family operates and copes with bad news differently can help health care providers properly communicate with each family on an individual level. Incorrect assumptions about a parent’s understanding of their child’s condition can create confusion and misunderstandings. Some parents and families may not initially accept or even understand that their child’s prognosis is poor. Some parents may resent suggestions of palliative care because they feel as though they are giving up on their child. Yet other parents may have a strong inclination to protect their child from pain and suffering. Many families will seek outside information such as information from the internet regarding their child’s condition. It is because of this reason that it is imperative physicians ask each family what they understand about their child’s condition. Physicians should continue to work with each family to understand their child’s medical condition and prognosis, to review their goals of care, and to create a care plan that is medically possible while respecting family concerns.¹³⁴

2. Physician-Family Relationship

Building a relationship and maintaining that relationship through communication is imperative to maintaining the quality of the physician-family relationship.¹³⁵ The differences between a paternalistic relationship and a partnership in healthcare will be reviewed. What it means to have patient autonomy as a minor will also be explored.

a. Paternalism and partnership

This section introduces key ideas for maintaining the physician-family relationship in pediatrics such as how physicians can best avoid paternalistic behavior and how to create a partnership with patients and families. It will also be explored how minors can be included in making autonomous decisions.

i. Avoiding paternalistic behavior.

In order to create and maintain a positive physician-family relationship, physicians must work to evade paternalistic behavior and respect patient autonomy by working with patients and families in a partnership. Paternalism often enters the healthcare transaction as physicians typically have more knowledge, training, and insight regarding a patient's condition. Therefore, they may have strong opinions on what they believe to be in the patient's best interest. When a physician is acting in a paternalistic way they may use forms of framing such as nondisclosure of information, coercion, manipulating information, or even refusing to acknowledge or carry out surrogate wishes. Physicians may also unknowingly act in a paternalistic way by not disclosing information they think may cause harm to the patient or their family members. This type of information is often desired and not harmful to patients or family members.¹³⁶

In pediatrics there are limitations to the types of decisions surrogates can make. In such cases paternalism may be necessary. If surrogate decision makers wish to make

decisions that are potentially dangerous, irreversible, unlikely to work, or may cause major harm, then a physician may intervene and limit the surrogate's decision-making capabilities. Likewise, physicians may sometimes deny treatment requested by surrogate decision makers if it is deemed to be medically ineffective. Physicians can circumvent paternalistic behavior by making sure patients and family members are fully informed and that their decisions are voluntary. Physicians should explain the risks and benefits of treatments and medical interventions in a fair and unbiased way for surrogates to make morally appropriate decisions for their child. Physicians should also be mindful that the perception of risks and benefits will differ from family to family and understand that decisions contrary to what the physician might choose are not poor decisions so long as they do not pose a potential danger or major harm to the patient.¹³⁷

ii. Creating a partnership.

In an effort to build and maintain a relationship between the patient, the family, and the physician a partnership between all involved parties should be established. Establishing a partnership over paternalism is imperative to sustaining honest communication practices. Physicians should seek a viewpoint from the patient and families' perspective in order to understand how families might react to certain information and as well as to the choices they might make regarding their child's health. The idea of establishing a partnership is a new phenomenon in medicine. Paternalism was previously the dominant way of conducting medicine. In a partnership patients and families take more responsibility for their health care. they can make choices within reason based on their own value and belief systems. When a partnership is established it distinguishes the ideology that although physicians may know what choice may be most

medically appropriate, they can never know what is best for their patients based on the science of medicine alone. When the physician views the patient as a partner they recognize that it is the patient's values and beliefs that must govern the health care transaction, not their own. When a partnership is established physicians and patients can work together to decide what is in the patient's best interests based on their overall well-being, not just their immediate medical well-being.¹³⁸

b. Patient autonomy as a minor

Though patients who are considered minors may not legally be able to make fully independent decisions regarding their care, they can still exercise their autonomy. This section will explore how and when to include pediatric patients in their care and how to include them in goal planning for future care.

i. Deciding when to include children and adolescents in their care

It used to be common practice to try to protect children from learning about their diagnosis or prognosis. There has, though, been a shift in medicine that supports including and informing children of their medical conditions in a consistent manner with their intellectual and emotional maturity, personal preferences, and family values. Surrogate decision makers still typically get to choose how much information to share with their child, but physicians can encourage parents to include their child and they can help parents prepare for such discussions while being mindful of cultural barriers deeming communication about death with a child as inappropriate.¹³⁹ Surrogates and physicians should also consider the ethical principle of autonomy. While autonomy is more concise when dealing with adult patients, it still applies to children as well. When

children are involved in their medical decisions it improves communication between the triad and therefore satisfaction with the care received tends to also increase.¹⁴⁰

Physicians should take the opportunity to help families understand that clinical research suggests neglect of the opportunity to speak with their child to discuss the child's concerns and fears can often lead the pediatric patient to experience feelings of isolation, guilt, and anxiety about their own care. Parents may also feel lasting blame for eluding the conversation. Once it has been decided to include the child in conversations regarding their care, it is important to recognize that communication techniques and styles will vary from child to child. The child's cognitive ability must be assessed in order to evaluate what they can understand regarding their illness and possible death. The physician and family members must also consider how long the child has been dealing with their illness as well as the child's past experiences with illness. Parents and physicians should appropriately respond to questions raised by the patient, they should not attempt to circumvent questions, or provide too little information to the child. Some children may not wish to immediately have any further discussion regarding their prognosis. Family members and physicians should pay special attention to the nonverbal communication a child may engage in such as their drawings, expressions, or emotions. Stuffed animals or other comforting toys may also be useful in soothing the child during these discussions.¹⁴¹ In some cases, children may not want to know or may not be ready to know about their diagnosis. In addition, they may wish to forgo a certain treatment. In these situations, the parent still has the decision-making authority; however, in certain situations the wishes of the patient may be respected until there is a better understanding of their fears and concerns.¹⁴²

ii. Including children in goal planning

Goal planning is another way to include children in their care and develop relationships between the family and the physicians. It is important for children to remain informed regarding their medical condition as long as it is deemed appropriate. It is also important for children to be involved in discussions regarding goals of care and even end of life care.¹⁴³ Physicians should bear in mind that communication techniques will differ depending on the patient's age and capacity to understand. Doctors should also be mindful of different cultural, religious, and family values. Physicians can work with parents on how to include the patient in goal planning, bearing in mind that not including the child can prevent parents and physicians from appreciating the child's values, goals, and their experiences regarding their disease and prognosis. Physicians should consider what the child truly understands regarding their medical condition when creating a care plan that includes the patient. They should address the child's hopes and fears for both the present and the future. Doctors should also make certain the child understands that they will be cared for regardless of the outcome. Physicians should determine whether the child needs more information regarding their diagnosis, prognosis, and/or treatment options, and they should examine how the parent's goals and the child's goal converge or diverge.¹⁴⁴ Managing goals and care in the pediatric realm is undeniably complex. It is rare that there will there be one correct decision. The correct decision is one encompassing the family, patient, and physician, and evolves over time to suit the needs of the family and patient. Collaborative goal planning and decision-making seeks to reevaluate goals as the illness progresses. This type of collaboration

facilitates open communication and care plans that are acceptable to all parties involved.¹⁴⁵

Ethical Framework for Communication of Prognosis in Pediatric Critical Care Medicine

The sole purpose of this dissertation is to provide an ethical framework for communication of prognosis specifically in pediatric critical care medicine. The impact communication has on healthcare and the overall health of patients is insurmountable, yet healthcare organizations rarely have procedures for communication transactions in place. Evidence continues to support the notion that an organized approach to communication demonstrably improves healthcare delivery.¹⁴⁶ Research also shows that physicians typically have little to no formal communication training in medical school. Most physicians garner their communication skills from their preceptors with no guidelines for the use of communication in the clinical setting.¹⁴⁷ Many preceptors have had no formal communication training and they are typically hesitant to depart from a stringent medical model.¹⁴⁸ Despite the impact communication of diagnosis has on patient satisfaction, compliance, and quality of life, there is little data available on how physicians deliver bad news. Furthermore, there is no conclusive method available to physicians on how to deliver bad news.¹⁴⁹ The ethical framework for communication will be generated by reviewing how rapport can be established through the ethics of care, how to manage uncertainty in veracity for surrogate consent, and how to maintain the physician-family relationship once it is recognized.

1. Establishing Rapport with the Ethics of Care

One of the most central elements of effective communication in any health care transaction is creating a relationship between the physician, the patient, and the family

members. A fundamental way to create rapport is through voicing the ethics of care.

This section will review communication components of the ethics of care and the moral obligations imbedded within the ethics of care.

a. Communication and the ethics of care

Communication is imperative to the ethics of care. For physicians to have the ability to establish rapport through the ethics of care they must first understand the key components of communication that are pertinent to the ethics of care. This section will explore necessary information regarding symbolic communication traditions and how physicians can put symbolic communication traditions to work by communication through the virtues of caring.

i. Symbolic communication traditions.

Physicians must have a basic understanding of symbolic communication traditions in order to be able to adhere to this ethical framework for communication in pediatric critical care. Since all communication transactions are symbolic to an extent, physicians must understand how symbolic communication works. Miscommunication often occurs when symbols do not align within the communication transaction. Any miscommunication, especially in pediatric critical care, can be devastating.¹⁵⁰

The semiotic communication tradition is a key component of the ethical framework for communication as it recognizes the role symbols play in communicating. How a doctor communicates has the ability to affect the rapport. When physicians are communicating with their patients and families the grammar they use, their tone of voice, the gestures they use, the amount of eye contact they make, and even how they position

themselves when they speak will all affect how their patients and the families of their patients respond to their message.¹⁵¹ When physicians are given the opportunity to learn about symbolic communication traditions they can better understand the role nonverbal communication plays in their communication transactions. By being seated during a communication transaction physicians are likely to spend more time with the patient, they are also more likely to be observed as compassionate by the patient and family than if they had chosen to stand.¹⁵² An integral piece to the communication framework is understanding that even when communication is not taking place verbally, it is still occurring nonverbally as 90 percent of meaning in the conversation will come from nonverbal cues.¹⁵³ Physicians and patients alike will judge each other's nonverbal cues. Research has suggested that patients perceive physicians who are more nonverbal and emotionally expressive more positively.¹⁵⁴ In pediatrics, it is ethically necessary for physicians to pay attention to the symbols pediatric patients may try to communicate. It is likely that many pediatric patients will not communicate in a straight-forward verbal manner. Many pediatric patients may show signs that they have concerns or fears; however, they may not verbally communicate this. When physicians are aware of these symbolic interactions they can be better prepared to recognize these signs and initiate communication with the patient to discuss their fears and concerns.¹⁵⁵ The sociocultural communication tradition is also pertinent to this communication framework as it focuses on the interactions between people, and how those interactions have the ability to build or breakdown rapport. This tradition focuses on the roles and identities of those involved in the communication transaction. In an effort to build rapport and have positive communication outcomes physicians should be aware of their audience, the

language that they use, how their hierarchy will affect the communication transaction, and the different cultural values each party has. Physicians should strive to include different backgrounds and beliefs so long as care to the patient is not hindered.¹⁵⁶ When physicians can understand the traditions and theories guiding communication about caring, they can better accomplish the first step of the communication framework and consequently build rapport with patients and families.

ii. Communicating through the virtues of caring

Once physicians have mastered the symbolic communication traditions and theories they can better understand and communicate through the virtues of caring. Caring for patients goes beyond just physically caring for them as the emotional aspect of care is also relative. The actions of physicians will either promote or discourage positive doctor-patient-family relationships. The virtues of caring call for physicians to avoid generalizing medicine and to instead tailor each encounter specifically to the patient and their needs. Physicians can then use the pertinent symbolic communication traditions and communicate with patients through the virtues of caring. The virtues of caring include understanding the patients experience from their perspective and the role the illness plays in their life. Physicians can also learn to be cognizant of how and when to respond to their patient's needs. They may look for nonverbal clues that suggest the patient needs comforting or time alone. Physicians can build better rapport with patients and families when they prove they are trustworthy through verbal and nonverbal communication methods. Physicians must also communicate that they have integrity and that they are a reliable source of information. If a physician's verbal and nonverbal messages are contradicting, then the physician's integrity may be compromised. Lastly, physicians

should be assiduous and communicate in an ethical manner because it is the right thing to do.¹⁵⁷

b. Moral obligations of the ethics of care

The ethical framework for communication of prognosis in pediatric critical care medicine also requires physicians to understand their moral obligations as they pertain to the ethics of care. In order to properly follow this communication framework, physicians should be able to understand the importance of establishing relational autonomy and how to meet the needs of patients and their families.

i. Establishing relational autonomy

The ability to understand and establish relational autonomy is an integral piece in the ethical framework for communication of prognosis in pediatric critical care medicine. Relational autonomy calls for rapport to be established so pediatric physicians can not only understand, but can also respond to their patients' and surrogates' needs based on their self-identity. Relational autonomy allows physicians to understand how and why patients and surrogates make the medical decisions they make. Relational autonomy calls for physicians to understand their patient's notion of self-identity through characteristics such as age, abilities, inabilities, communication capabilities, culture, religion, and work status. Relational autonomy supports the triadic relationship in pediatrics by asking patients and their surrogates to participate in the decision-making process, voice their feelings regarding the care they are receiving, and take responsibility in their health care.¹⁵⁸ Relational autonomy is also indispensable in pediatrics as it recognizes the need for adolescent patients to express their desires regarding medical care

and decisions based on their self-identity. While there may be legal limitations to autonomy in pediatrics, a positive rapport can be built by conveying information appropriately to patients in their conversations regarding their care. Furthermore, establishing relational autonomy is of utmost importance as physicians not only have the moral duty to offer their patients and surrogates factual guidance in decision-making, but also to take into account the emotional experience of the patient and surrogate.¹⁵⁹ Establishing relational autonomy is a precursor to effectively meeting the needs of patients and their families. This will be described next.

ii. Meeting the needs of patients and families

A cornerstone to the ethics of care revolves around meeting the needs of others, especially those for whom we take responsibility for and for those who are dependent such as children. When physicians care for patients and their families they must be aware of the needs, desires, and thoughts of those they are caring for. Trust and rapport is built when doctors meet the needs of those they have taken responsibility for.¹⁶⁰ Physicians must be able to meet the individual and unique needs of patients based on their age and abilities. They should remain open to different cultures, values, and communication needs. Patients may require additional communication needs based on their age, intellectual ability, or medical hindrances such as intubation or sedation. Physicians may need to use skilled communication tactics to connect with their patients in these situations.¹⁶¹ Establishing rapport with patients and families is necessary when discussing prognosis in pediatric critical care medicine. In order to establish rapport physicians must strive to meet the needs of their patients and families. Those needs can be met when physicians are aware of communication tactics through the ethics of care.

The next step in the communication framework is managing the uncertainty in veracity for surrogate consent. It will be discussed next.

2. Managing the uncertainty in veracity for surrogate consent

Once rapport is established within the triadic doctor-patient-family relationship, physicians will need to understand how to maintain that relationship in an ethical manner. Recognizing and managing their own uncertainties when communicating about surrogate consent can achieve this. This section of the communication framework will explore the role communication plays in managing uncertainty in veracity for surrogate consent, and how physicians are held ethically accountable to communicate honestly regarding issues of surrogate consent.

a. Communication and managing uncertainty in veracity for surrogate consent

Physicians must be aware of their uncertainties when communicating about the prognosis of pediatric patients, how those uncertainties effect the authenticity of surrogate consent, and how to ethically manage any uncertainties they may have. This section will explore what physicians should know about uncertainty communication theories and how they can recognize their communication biases.

i. Uncertainty communication theories

Physicians should have a basic understanding of uncertainty communication theories in an effort for physicians to better manage their reservations when communicating with patients and surrogate decision makers. It is important for pediatric physicians to have an understanding of uncertainty communication theories because they have an ethical obligation to communicate truthfully with both the patient and the

surrogate decision maker.¹⁶² The Uncertainty Reduction Theory (URT) must be understood to help physicians in getting to know their patients and family members on a more personal level. The physician will likely want to get to know the patient and their family on a more private level. Likewise, the patient and family will want to get to know the physician. In order to reduce uncertainty self-disclosure will typically occur. When self-disclosure occurs one person typically discloses something about themselves and the other involved parties typically follow.¹⁶³ When uncertainty is reduced it allows for greater communication satisfaction to occur. When uncertainty is not reduced people tend to avoid communication and situations that make them uncomfortable. Patients and family members may avoid receiving medical information if they are uncertain about their relationship with the physician, or their ability to understand the medical information.¹⁶⁴ When physicians are not trained to communicate in situations that may make them feel uncertain, such as when a patient's prognosis is poor, they may attempt to elude the conversation all together or provide the family with indefinite information to spare patients and families from emotional distress.¹⁶⁵ This type of ambiguous communication is morally problematic. Physicians must be trained to understand how to reduce uncertainty through proper communication as authentic communication can actually help relieve stress and support optimism even in situations where the prognosis is disconsolate.¹⁶⁶

ii. Recognizing communication biases

In order to communicate in a truthful manner, physicians must also be able to recognize their own communication predispositions. Moreover, they must not use those preconceptions to influence surrogate decision makers. When uncertainty remains within

the triadic relationship physicians may sometimes knowingly, or unknowingly, employ a method of communication known as framing communication. Framing communication is morally problematic as it presents rationally equal information in ways to manipulate the function of the treatment being discussed. The language chosen by the physician can influence the surrogate's interpretation of the risks and benefits of a treatment depending on the words used and how the information is presented.¹⁶⁷ Physicians must be taught to be aware of their biases and how their ability to frame can influence patients and surrogates. Physicians should know the importance of presenting information in an impartial and balanced way. Presenting information in a fair way allows for surrogate decision makers to make objectively informed decisions.¹⁶⁸ When uncertainty reduction techniques are employed physicians have a chance to create a relationship with the patient and family, and to reduce their inclination to frame information.

b. Ethical accountability to communicate honestly regarding surrogate consent

It is ethically necessary for physicians to hold themselves accountable to provide patients and family members with authentic and truthful information regarding prognosis and treatment options. In order to provide surrogates with genuine information, physicians must understand their responsibility to the patient and surrogate decision maker as well as how to remain a supportive yet impartial party.

i. Understanding surrogate consent standards

Surrogate consent is often more complicated in pediatrics than in adult medicine. This is because patients typically cannot provide consent for themselves and, therefore, physicians and surrogates are responsible to act in the best interests of the pediatric

patient. Surrogate decision makers have the legal right to have all relevant information regarding their child's diagnosis and prognosis explained to them in a suitable manner so they can make cognizant decisions and provide consent for the treatment of their child.¹⁶⁹ Both the physician and the surrogate must act in the best interests of the patient. Ethics requires the physician to provide the surrogate with reasonably accurate information regarding their diagnosis and prognosis.¹⁷⁰ The ethical framework for communication of prognosis in pediatric critical medicine helps physicians understand the importance of surrogate consent standards and how to ethically adhere to those standards. Physicians must avoid providing ambiguous information by managing uncertainty. Providing ambiguous information is morally problematic and is a serious disservice to the patient and the surrogate because it hinders any ability to make well-informed decisions.¹⁷¹

ii. Physician neutrality

A final way to help manage the uncertainty in veracity for surrogate consent is for physicians to remain a neutral party. Physicians should be aware that while they may possess certain religious or moral values they should not attempt to push their views onto their patients or surrogates.¹⁷² When physicians lack objectivity in their communication techniques they can end up being deceptive in the way they communicate about the patient's diagnosis and prognosis. Physicians should be aware of ways to help them maintain neutrality. They should always offer alternatives to treatments. When a patient's prognosis is deemed incurable they should allow the family to make cognizant decisions by offering alternatives to continue treatment and to discontinue treatment. Physicians should never rely on or provide false hope through anecdotal evidence.¹⁷³ An ethical framework for communication of prognosis in pediatric critical medicine notes the

importance of physician neutrality because patients and surrogates have the right to information relevantly related to the decisions they need to make. When patients and surrogates do not receive this information in a neutral manner it becomes unethical on the physician's part as it interferes with autonomy.¹⁷⁴

3. Maintaining the Physician-Family Relationship

How to establish rapport through the use of the ethics of care and how physicians should manage their uncertainty in veracity for surrogate consent have been explored as part of the ethical framework for communication of prognosis in pediatric critical care medicine. This section will describe how to maintain the physician-family relationship through the means of communication tactics by reviewing the ethical implications of physician-family relationships.

a. Communication strategies for maintaining physician-family relationships

It becomes important for physicians to maintain the physician-family relationship once it has been established. Physicians can better understand how to maintain the triadic relationship through means of relational communication theories and the notion of communication-based family-centered care.

i. Relational communication theories

It is imperative for physicians to understand several relational communication theories as they relate to the ethical framework for communication of prognosis in pediatric critical care medicine. Conversations physicians have with their patients and surrogates are rarely ever remote events. Each conversation tends to build upon the last.

Social penetration is the first theory physicians must be aware of to adhere to this framework. The social penetration theory describes how relationships continue to dynamically evolve over a period of time and involve self-disclosure. Each time physicians have a satisfactory interaction with patients and their surrogates the breadth and depth of the relationship will grow through different stages. Physicians should understand these different junctures and how to proceed to the subsequent stage. Establishing a grounded triadic relationship and maintaining it is pivotal to the ethical communication framework, because reciprocity in communication is not likely to occur if a relationship is not established and sustained.¹⁷⁵

The sociopsychological tradition focuses on relational schemas. It is also an important relational communication theory relevant to the framework. Relational schemas are particularly important in pediatric critical care medicine as all families communicate differently based upon their family type. Physicians should understand the different family types and how to communicate with each.¹⁷⁶ Physicians should be able to tailor their communication to each individual family and assess the families need for further clarification. Physicians should understand that conversations may need to be revisited as patients and parents grapple with their prognosis and continue to learn about their condition.¹⁷⁷

ii. Family-centered care.

In order for the ethical framework for communication of prognosis in pediatric critical care medicine to be effective physicians must understand the importance of family-centered care and how to provide such care. In a family-centered approach to care the physician is essentially treating the entire family. The emotional, social, and

developmental support families offer the patient will play a role in the patient's overall health. Enabling families to make well-informed decisions for patients by providing them with reasonably rational and unbiased information is a cornerstone to family-centered care. A family-centered approach to care helps to maintain the triadic relationship by providing care for the patient and family from diagnosis through death when applicable. Providing proper supportive care for the patient and family is essential for the maintenance of the relationship. This method of care also engages the patient and family by including them in physician rounds and encouraging communication and participation.¹⁷⁸

a. Ethical considerations of physician-family relationships

Building and maintaining relationships in healthcare have a moral dynamic which physicians must also consider. This section will review the importance of maintaining relationships in an ethical manner through creating partnerships, avoiding paternalism, and recognizing minor patients as autonomous individuals.

i. Partnerships over paternalism

If physicians are to maintain the triadic relationship in an ethical framework for communication of prognosis in pediatric critical care medicine than they must learn how to establish a partnership with the patient and family instead of a paternalistic relationship. Paternalism may occur innocently as most physicians typically have more knowledge, training, and insight regarding the patient's diagnosis. Paternalism is not compatible with this framework because paternalistic physicians often attempt to frame or hide information so the surrogate will act in what the physician believes is the patient's

best interests.¹⁷⁹ It is morally indispensable for physicians to know how to build partnerships with their patients and families. A partnership embraces the notion that while physicians may sometimes know what choice is most medically appropriate they can never understand what is best for their patients based solely on the science of medicine. A triadic partnership requires empathy and it requires the patient and family to take more responsibility in the patient's health care. A partnership is essential to maintaining relationships within the ethical framework for communication as it encourages physicians, patients, and families to work together as a team to decide what is in the best interests of the patient's overall physical, mental, emotional, and medical well-being.¹⁸⁰

ii. Autonomy as a minor

Although many pediatric patients are considered minors, including the patient and informing them about their diagnosis is a strong way to help build and maintain the physician-family relationship. The ethical framework for communication of prognosis in pediatric medicine would guide physicians to include patients when appropriate. Including pediatric patients in their care and decision-making not only improves communication and outcomes among the triad, but it gives patients the opportunity to discuss their fears regarding their diagnosis and prognosis. The communication framework would assist physicians in having ethical and meaningful conversations with patients and their families, even in end of life situations. Physicians should know how to work with surrogates to properly include the patient in goal planning. Not including the patient can be morally problematic as it restricts physicians and surrogates from understanding the child's goals and values.¹⁸¹

The ethical framework for communication of prognosis in pediatric critical care medicine strives to give physicians the knowledge, confidence, and support they need to have some of the most challenging conversations they may ever face. The framework advocates for patients and families as it morally obligates physicians to focus their communication on a more individual level so families can make the best decisions possible.

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Chapter Two: Communication Theory for Pediatric Medicine

“Words are the most powerful tool a doctor possesses, but words, like a two-edged sword, can maim as well as heal.”¹

Communication is so common and tangled up in everyday life that the importance of the act of communicating can often be lost as something that just naturally occurs. Yet, communication is much more intricate than that.² Communication is always present and always occurring both deliberately and inadvertently. It is a dynamic which is unending. Communication is how one shares meaning and how people transfer information to one another. It is the core of everyday life. While communication may be something every person does every single day, it is extremely multifaceted as well as necessary for functioning well in society. There must be senders and receivers and there are different channels through which messages can be sent and received. Different situations and experiences will affect communication transactions.³ For physicians to be effective communicators they must be able to understand the theoretical nature of communication as well as the important research done in the field. Physicians must also understand what makes communication effective and what makes communication ineffective. Doctors who communicate effectively can make a substantial difference in their patient’s overall wellness. There is a plethora of research showing the insufficiencies in communication training in medical school. Yet, communication theory and communication skills can be easily taught and learned.⁴

The skill of communicating effectively is important in health care, but understanding the theory behind different communication transactions is also important. Understanding the theoretical nature of communication allows physicians to see beyond the monotonous routine of communicating and to help them transform their communication style into an exchange

adjustable to each patient and family.⁵ Although the word theory may be difficult to define, it is broadly described as the way one understands something, in a theoretical sense. Communication theories emerge from the process and realities of communicating. Health communication is one of the most necessary human understandings. Health communication is significant as the patient's disease and prognosis often shapes the interaction. Health communication also attempts to distinguish what the disease means to the patient. There is a lot of uncertainty in health communication. How this uncertainty is communicated about is imperative to how patients will cope with their disease and prognosis. Understanding communication theories aids physicians in their ability to apply their communication knowledge to their practice.⁶

Researchers Edwards and Hugman recognized six issues physicians should reflect upon when planning to communicate with patients. They are deciding what the purpose of the message is; considering the state of the mind the patient or their surrogate may be in, including their intellectual abilities and emotional state; the climate which the message will be received in; the channel used to communicate the message; how the physician will obtain feedback to make sure the message was received; and evaluating the effectiveness of the message.⁷ Relevant communication theories and the ethical indications that could be used by physicians to aid in the discussion of prognosis in pediatric critical care medicine will be explored. This will help in understanding how communication theory can be used and applied to pediatric medicine. Specifically, communication theory, prognosis, and the ethical framework for pediatric communication will be discussed.

1. Communication Theory and Prognosis

When a physician gives a patient a prognosis they are essentially using medical-based science to assess the likelihood of an outcome (both short term and long term) due to a patient's

medical ailment. Prognosis is an imperative element to medicine and clinical decision-making, especially in pediatric critical care. The starting point for care of a patient is when a prognosis has been identified. The given prognosis will map the way for the consideration of risks and benefits of treatments and what type of care the patient will qualify for, either hospice, palliative care, etc. The prognosis is fundamentally the threshold upon which clinical decisions are made.⁸ Evolving and communicating accurate prognoses is a vital clinical skill. Yet, it is typically not well done by physicians. Many physicians lack training in the proper development and communication of prognoses and, therefore, seek to avoid such conversations about prognosis.⁹ A lack of training in communicating about prognosis may stem from the concept that physicians used to be taught to decide whether or not to tell the patient of their prognosis. In more recent times there has been a shift towards transparent communication about prognosis and including the patient and/or their family in decision-making. Nevertheless, there is a lack of guidance on how to properly achieve transparent communication regarding prognosis. Due to the lack of guidance, physicians often remain in limbo with how much prognostic information they should reveal to the patient. They must decide whether to include statistics about survival rates and life expectancy, whether they should speak of hope, and how to balance communicating prognosis while complying with the legal requirements to provide patients with all necessary information to make informed decisions. Studies have shown that even when prognosis is discussed the communication transaction is typically not done well as there is often a lack of lucidity at the end of the conversation. While physicians are often taught strategies for communicating bad news, there are no specific guidelines for discussing prognosis with patients.¹⁰ The lack of communication training and communication skills makes it difficult for physicians to meet the fundamental obligations for fully informed consent. However, studies show that when

physicians are taught to apply communication principles to discussing poor prognosis they create strategies for communication and become more confident in the communication transaction.¹¹

When prognosis is being discussed there is an exchange of information that must be done correctly for effective communication to take place. During the exchange physicians need to gather all necessary information from patients to establish the proper diagnosis and treatment regimen. How physicians gather this information will ultimately affect the outcome of the healthcare transaction. Research shows that physicians tend to interrupt patients during this phase of the consultation and, therefore, patients typically do not get to share all the information they intended to share. During the exchange patients need to know about their diagnosis and understand their treatment options. To correctly facilitate this exchange of information all involved parties must participate in information giving and information seeking. Research shows that physicians often communicate less than 50 percent of medical information available to patients regarding their diagnosis and treatment. This is because they believe patients do not want access to all of the information. However, many times patients and families want as much information as possible regarding their diagnosis and treatment options.¹²

Some physicians find the emotional burden of communicating poor prognoses to be too much and will sidestep the conversation until it is no longer avoidable. This typically occurs at the very end of a patient's life. A lack of communication about prognosis is a disservice to the patient and their family as they lose treasured time with their families by spending more time in the hospital. In addition, they lose the ability to make truly informed decisions.¹³ Physicians often report that dialogue about poor prognosis is taxing and uncomfortable, especially when patients react in an emotional manner. Physicians can be taught to use emotional reactions to provide an empathetic response to the patient and their emotions. The physician can show the

patient they are aware how stressful the prognosis is on them and when the patient is ready they can continue to communicate about goals of care and treatment options. Along with a patient's emotional reaction, physicians also worry about destroying any hope the patient may have.¹⁴ Some physicians may avoid truthful communication about prognosis to instill hope in the patient. They may believe there are health benefits to holding onto hope whereas a grim diagnosis could destroy that hope.¹⁵ Compassion and the yearning to preserve hope among patients and families will sometimes drive physicians to withhold prognostic information. Yet, studies have shown that transparent prognostic disclosure and open communication give parents and patients hope even when the prognosis is grim.¹⁶ Though communicating about a child's poor prognosis is often trying for parents hear, many parents report that is essential in helping them make sure they do the best they can for their child given the diagnosis. Parents even report finding hope in honesty when the physician is straightforward about the prognosis.¹⁷ Physicians should not avoid communication about prognosis to preserve hope. Studies have found that hope can go beyond a favorable diagnosis. Although many parents hope their child could be cured, they may also be hopeful that if cure is not a reality then their child will have a fulfilling end of life experience.¹⁸ Evidence shows that physicians may dim some patients' hope when they withhold information from the patient or try to downplay the seriousness of the prognosis, thereby ruining the credibility of the physician and the doctor-patient relationship.¹⁹ Not fully disclosing information to patients and surrogate decision makers also undermines patient rights as patients have the right to full disclosure. Some researchers argue that even if telling a patient about their prognosis may cause them emotional harm or depression there is greater harm in denying them their rights by not divulging such information.²⁰ Physicians must always remember that not communicating news about a patient's prognosis does not correlate to good news for patients and

families. In fact, it often makes them fearful for what is to come.²¹ Establishing doctor-patient relationships with the ethics of care will be discussed next.

a. Establishing Rapport with the Ethics of Care

Establishing a solid doctor-patient relationship is a cornerstone to any healthcare transaction. The importance of the physician-patient relationship has been described since the time of the Greeks, yet there has been a steady deterioration of communication as a fundamental focus in medicine as much of the focus is on the scientific nature of medicine.²² The doctor-patient relationship is a multifaceted interpersonal relationship. It is a relationship involving two or more people who are often reluctantly creating a relationship that is unequal in status and requires communication about issues that are often emotionally loaded as the patient's life may very well depend on these conversations. The doctor-patient relationship requires cooperation from all involved parties.²³ The physician must take time to get to know the patient and their medical needs. When the doctor and patient can relate to each other they form mutual respect and rapport progresses. Rapport is an essential component to cultivating strong relationships. A physician's interpersonal communication skills are necessary mechanisms to building rapport. Likewise, the feat of doctor-patient communication transactions depends not only on the physician's communication skills, but also on the rapport between the doctor and the patient.²⁴ Research continues to point to the notion that communication makes a large impact on the doctor-patient relationship. Physician-patient relationships are emotional bonds and physicians must pay special attention to the interpersonal needs of their patients.²⁵

The ethics of care is a moral theory focusing on meeting the needs of others, particularly those we are accountable for such as those who are dependent. Throughout life there are cycles of dependence and independence as all people will need care at some point in their lives.

Children are especially dependent. The ethics of care deems interpersonal relationships as vital to morality and places a high amount of value on people's emotions. In the ethics of care caring for others and the collective experience of caring are highly valued.²⁶ A substantial way to build rapport is by communicating through the ethics of care and thus creating relationships through caring and taking responsibility of others through the voice of care.

- i. Creating relationships through caring

Creating rapport and caring for someone requires a certain degree of interpersonal communication to take place. The better the rapport, the easier and more operative communication will become. Patients continually point to the notion of caring and how it effects the doctor-patient relationship. When a patient believes a physician cares about them it makes communication much more genuine. A strong foundation between the physician and the patient is necessary for subsequent clinical encounters.²⁷ Currently, communication in pediatrics is often less than ideal. Studies show that residents often feel they receive insufficient education when it comes to communicating bad news in pediatrics as much of the focus is often in adult medicine.²⁸ The pediatric physician's ability to communicate caring with compassion is an obligatory clinical necessity. This is especially the case when dealing with children who have life threatening illnesses. However, this vital link to pediatric care is often missing.²⁹

Physicians can build rapport and create relationships with their patients and foster an environment of excellent clinical communication through showing their patients they care by use of the ethics of care. Caring for someone is both emotional-based and action-based. The ethics of care seeks to build relationships by focusing on the individual. The theory begs the question how can we care for this individual? Tronto, a contributor to *The Ethics of Care*, notes that there are four action-based phases of caring to be considered when applying the ethics of care to health

care. The first phase is caring about the patient, the second phase is taking care of the patient, the third phase is caregiving, and the final phase is care receiving. These four elements require the physician remain attentive to patient needs, the physician acknowledges responsibility for taking care of their patients, physicians possess competence to care for patients on individual levels, and, lastly, that the patient and family are responsive to the care they are receiving and they agree it is being delivered in a caring manner. There are also four elements of caring which are tools necessary to effectively show that one cares. The four elements of caring are: attentiveness, responsibility, competence, and responsiveness of the individual receiving the care. Attentiveness requires the medical staff to focus on the patient and their families as individuals and carefully pay attention to their individual needs. Second, the medical staff is responsible for at least taking care of their assigned patients. Third, there is a level competence expected from the medical staff to show the patient they care. If a care plan is not working for a patient, then physicians must be competent enough to recognize this and suggest a different care plan. Physicians must also continue their education to enhance their skills. Finally, the medical staff members must confirm that the care plan for the individual patient is working and meeting the patient's needs. Caring is necessary for creating relationships, and relationships thrive off caring, especially those at the end of life.³⁰

A central focus of building the doctor-patient relationship should be patient satisfaction. Patient satisfaction has been noted historically as being an important product of the health encounter. In patient satisfaction research it has been found that patients wish to have a compassionate and competent physician who is concerned with both the medical and emotional well-being of the patient. Researchers also found that patients were more satisfied with communication when physicians sought to understand a patient's expectations during the

consultation. Consequently, when patients rate their physicians as having highly effective communication skills they also report being more satisfied with their overall medical care. Yet, there are also communication barriers contributing to patient or surrogate dissatisfaction. Some of those barriers include pediatricians failing to acknowledge parental concerns and expectations, a lack of friendliness from the physician, the over use of medical jargon, and failing to clearly explain the patient's diagnosis. Another central focus of establishing rapport between the patient and physician is patient adherence to recommended treatment. Adherence to treatment is a direct result of physician-patient communication and, thus, the physician-patient relationship.

Research has identified communication to be the most important factor in determining whether a patient will follow their recommended treatment. Patients are more likely to follow through with proposed treatments when physicians who show patients they care by educating them about their prognosis and treatment seek out patient expectations, include patients in the communication interaction, and use empathy and encouragement. Physicians must communicate in a way their patients understand. They must make certain their patients understand their prognosis and treatment options. Doctors must also use communication to seek out what the patient's goals are and how those goals are related to the prognosis and treatment. Physicians must actively include patients in goal planning and treatment options. Lastly, physicians must be empathetic and encouraging towards their patients in order to build a partnership. Research has found that the more satisfied patients are with their physician, the more likely they are to stick to the proposed treatment regimen. When communication is a central focus of establishing rapport with the use of the ethics, research has determined that health outcomes ultimately improve. When the initial doctor-patient is positive and the patient is satisfied then the patient's recovery tends to be better. Positive patient results are affected by their physician's use of empathy and articulation of

support for their patient, the physician's ability to help patients accurately communicate their symptoms, by the physician communicating in an understandable manner, and when physicians actively including patients in the decision-making process. Building relationships through a caring and compassionate manner is considerably associated with increased trust, better communication, and overall better health outcomes for the patient.³¹

ii. Taking responsibility of others through the voice of care

Another way to establish rapport through communication is taking responsibility of others through the voice of care by meeting the needs of those for whom we take responsibility, especially vulnerable populations such as pediatric patients. Caring for someone else means that the individual providing the care is attentive to the emotional and social needs of those they are caring for. The person providing the care is also attentive to their own needs, as they cannot provide proper care for others if they have not first cared for themselves.³² Vulnerable patients are those who are incapable of protecting themselves and their own interests due to their illnesses and/or lack of decision-making capacity.³³ Children are a naturally vulnerable population as they require the care of others to help them prosper. Children become even more vulnerable when they become patients because their health and life depends on care from others.³⁴ Patients are vulnerable because they require assistance from a physician to seek a better state of health, and they are reliant on the physician for treatment. The patient typically has limited choices. They can accept what the physician proposes in terms of treatment, reject the physician's proposal, or seek other expertise. Likewise, patients may only have one chance to get better. On the other hand, the physician is not at any risk from the patient's diagnosis given that there is no negligence or malpractice involved.³⁵

Taking responsibility of others through the voice of care in pediatrics allows children and their surrogates to participate in the caring by creating a more customized approach to care and medicine rather than a one size fits all approach.³⁶ The voice of care also allows pediatric patients, when applicable, to voice what their health condition means to them and how disease progression and treatment affects them. This allows pediatric patients to be somewhat autonomous and participate in decision-making when it is deemed appropriate. There is a fine line between allowing pediatric patients to engage in self-sufficiency and protecting them from harm.³⁷

The voice of care recognizes that there may be cultural and familial differences setting patients apart from what is considered the “norm.” For instance, veracity (which will be further discussed later) is often regarded as being highly important in terms of doctor-patient relationship maintenance. Yet in some cultures partial disclosure may be requested.³⁸ The World Health Organization (WHO) recognizes that health is not only absence of disease, but also the comprehensive wellbeing of the patient including physical, mental, and social wellbeing.³⁹ Physicians should strive to be present with each and every patient to find meaning in what the patient’s diagnosis means to them and how it ostensibly affects others around them. When physicians are present in the moment with their patients it not only shows that they are compassionate and empathetic, but also it demonstrates they care about the patient beyond their diagnosis and instead as an individual person.⁴⁰

b. Managing the Uncertainty of Veracity

Information about one’s health can be uncertain or ambiguous at times especially when the patient’s diagnosis and prognosis are complex.⁴¹ Managing how to authentically and reliably communicate pertinent health care information to parents with pediatric patients is an

intimidating yet essential task. Truth telling is often declared as one of the most important virtues a physician can possess. Even in pediatrics there has been a shift towards comprehensive truth telling with pediatric patients who wish to be informed about their condition.⁴² The problematic integration theory is a generalized theory that focuses on uncertainty in communication. Under the problematic integration theory people have two expectations. There is a probability that in which certain outcomes will arise and there is an array of possible outcomes. How the patient interprets the uncertainty of the situation will be dependent upon the information given to the patient. Physicians can reduce this uncertainty by speaking in a clear and consistent manner and by using as much completeness and accuracy as possible. The language used by the physician to communicate prognosis will inevitably affect the patient's ability to make vital decisions.⁴³ The physician's responsibility to communicate truthfully and how to deal with communication ambiguities in pediatrics will be further explored.

- i. Responsibilities to communicate truthfully

When communicating, especially in the healthcare setting, there is sometimes an assumption that what is being communicated is completely truthful. This, though, is not always the case and must be addressed.⁴⁴ Veracity in healthcare refers to the physician's ability to convey pertinent information to the patient or surrogate decision maker in a way that nurtures understanding in order for fully informed decisions to be made. Although full disclosure is necessary for informed decision-making to take place, veracity also helps foster a solid relationship between the patient and the physician. While a physician bears the responsibility to communicate truthfully, this is not only limited to the broad term lying. Lying is always immoral and occurs when the physician knowingly misinforms the patient or their surrogate. Yet, other forms of deceitfulness can be used such as deception or non-disclosure. When a

physician is being deceptive they may use statements or words to intentionally mislead the patient and their surrogate. For example, by saying the patient has a growth instead of straightforwardly saying the patient has cancer. Physicians may also choose to not disclose pertinent information to the patient or surrogate. This is another form of lying. In terms of pediatric medicine, there is an ethical obligation to communicate truthfully with the patient about their healthcare decisions when they have the capacity to do so. This type of honest communication enhances the relationship between the patient and the doctor, and it gives pediatric patients the skills they need to make healthcare decisions in the future.⁴⁵

Even when the news is determined to be bad news physicians typically must communicate in a truthful manner. Communicating bad news to a patient and their family can range from informing them of a necessary surgery which may be inconvenient and stressful, relaying information regarding a terminal diagnosis, or informing family members of a death of a patient. Effective communication skills are necessary for communicating all forms of associated bad news.⁴⁶ Research shows that physicians sometimes grapple with the hardship of communicating bad news because they feel uncertainty in predicting prognosis, they feel as though they have failed the patient medically, they do not know how to properly deal with their emotions or the patient's emotions, or they lack training in communicating bad news. It is at this juncture the physician-patient relationship is imperative. Rapport that has been built between the physician and the patient can help facilitate affective communication, even when the prognosis is grim. Many researchers have noted the importance of using compassion when communicating bad news and how being uncompassionate can cause patients to view their situations in a very negative manner and undermine their ability to make informed decisions.⁴⁷ Physicians should consider the individual patient and family when conveying bad news. They

should adjust their speaking style and pace based on the needs of the patient and family. Communicating life-threatening news undoubtedly requires empathy. In order to achieve empathy when communicating bad news there are several recommendations physicians should consider. Physicians should choose an appropriate location and time to discuss the news, they should place themselves close to the patient and make eye contact with the patient and family, they should begin communication by finding out what the patient and family already know and gauge how they are likely to react, they should encourage questions and allow ample time for discussion and summarization, physicians should avoid medical jargon, and they should communicate at the patient and their families pace.⁴⁸

Pediatric critical care physicians may also find it burdensome to discuss options of limiting care with patients and family members even when they know the patient is unlikely to survive and current interventions are only prolonging the inevitable. Though this type of deceitful communication may not be done in a purposeful manner it often leads to superfluous medical intervention for the patient.⁴⁹ When a patient is at the end of their life it is not whether or not the physician should tell the patient and family, rather how they should tell them. Physicians should not limit communication during this time as that disregards caring for the patient. While it may be difficult for the physician, the patient, and the family to accept that treatment options are no longer providing any benefit to the patient, it is important to communicate that rather than treatments prolonging life, there will be a shift in care focusing instead on other treatments such as relief of symptoms and maintaining the patient's comfort. Physicians should communicate with patients and families what has previously been done and whether those treatments were useful. It may also be necessary for physicians to discuss the seriousness of the patient's illness again. Physicians should avoid using terms such as futile or

telling patients and families that nothing more can be done. These statements convey notions of vulnerability and desertion. Physicians should use empathy and compassion, but they must remain rational and try to not become too expressively involved.⁵⁰

Telling the truth to achieve truly informed consent is a central issue to medical ethics and patient rights. Patients and their surrogates deserve the truth to make informed decisions as they are presumed to be the best judges of their own interests. The amount of information patients and their surrogates receive regarding prognosis and diagnosis can affect their overall well-being as full disclosure can have both medical and emotional benefits. Researchers have identified seven important criteria necessary for informed decision-making. The criteria include patient participation and communication about patient preferences, discussion about the patient's decision, communication about the risks, benefits, alternatives, uncertainties, and making sure the patient fully understands the diagnosis, prognosis, and treatment options. The optimal way to achieve informed consent is for physicians and patients to work together and communicate about goals and treatments.⁵¹

Communicating in the utmost truthful manner also shows respect for the patient and their family as individuals and not just as patients. Patients have the right to know all information the physician has about them whether or not the physician believes the information will upset the patient. Telling patients the truth rests in the Hippocratic Oath to do no harm. Telling the truth prevents harm by giving patients and surrogates the information they need to make the best possible decisions. Communicating truthfully allows patients to seek the medical attention they need and to make decisions about their lives that they may not have made if they were not fully aware of their condition. When physicians are honest about a patient's prognosis it has been shown to increase patient compliance with treatment plans, increase pain management, and

improve overall health outcomes. It is the physician's responsibility to truthfully communicate in a way that can be understood and applied by the patient or surrogate. When communicated correctly, truth telling can strengthen the relationship between the doctor and the patient despite the severity of the prognosis.⁵² Truth telling also promotes trust within the doctor-patient relationship. Trust manifests when the patient has the confidence that the physician is morally competent. When physicians are deemed as trustworthy health care tends to be more effective.⁵³ While the outcomes of many medical encounters cannot be completely known, it is imperative physicians aid decision-making by using open and honest communication with their patients and family members.⁵⁴

ii. Dealing with communication ambiguity in pediatric medicine

Uncertainty will always be present in medicine. Medicine is science-based and is therefore never truly definitive. Uncertainty has been described as a widespread experience for patients and families facing serious pediatric illnesses.⁵⁵ Prognostic uncertainty is even more prevalent in pediatric medicine as many rare conditions have limited clinical accounts for prognosis. Some neurological and metabolic conditions are so rare that it would not be improbable for a pediatric physician to have little to no experience with these conditions. They must, therefore, rely on their own clinical judgement based on the patient's response to treatment. Relying on prognostic indications from adult medicine often does not work as there are too many different variables between adult and pediatric patients.⁵⁶ How physicians deal with and communicate ambiguity is important in managing the uncertainty in veracity and maintaining the trust of their patients. Physicians can embrace the uncertainty of medicine by acknowledging and addressing it. Sharing uncertainties in medicine by discussing a range of possible outcomes can help patients and families appreciate the complexities of medicine and the

need to continually openly communicate about prognosis and medical intervention.⁵⁷ Medicine can be uncertain in that all the facts cannot be known and the facts that are known may continuously change. Each medical problem and procedure has separate risks. Many patients, especially those who are critically ill, see several providers who may have differing opinions regarding the patient's prognosis. Unfortunately, when the communication is abstruse it may appear that the information the physician(s) is communicating is contradictory.⁵⁸

How a physician communicates about prognosis, even if it is uncertain, is important to the doctor-patient relationship and the overall health of the patient. Research shows that ambiguous diagnosis and prognosis increases psychological anguish in pediatric cancer patients, reduces their overall quality of life, and can increase risk for depression. While ambiguity about a child's prognosis can manifest from the notion that the physician truly does not know the likely outcomes of the disease prognosis, it can also stem from physicians not properly discussing information with pediatric patients for a variety of reasons. Physicians often want to protect hope in patients and families with critically ill children. However, studies have shown that when physicians communicate in a vague manner, in an effort to preserve hope, they actually decrease hope and trust. When children are critically ill physicians often spend less time directly communicating with the pediatric patient to avoid discussions of death and dying. Research suggests that direct communication about prognosis and diagnosis, even when the end result may be unknown, produces positive outcomes by reducing uncertainty in pediatric patients and improving quality of life. Communication, even in abstruse situations, allows pediatric patients to develop an outline to process the course of their illness.⁵⁹

Consequently, research shows that psychological distress is also prevalent for surrogate decision makers when communication about their child's prognosis is ambiguous. Feelings of

anxiety, depression, helplessness, and preoccupation with the disease have been reported by adults caring for a child whose prognosis is unknown. The stressors of an ambiguous diagnosis can make it nearly impossible for surrogate decision makers to make well-informed decisions when there are too many unknowns. Ambiguous communication about disease diagnosis and prognosis compromises a parent's ability to act in their child's best interests and can leave them feeling uncertain and remorseful about the decisions they have made. Furthermore, the ramifications of vague communication can extend beyond just the patient and parents. Parents may pause family plans and events in the midst of doubt.⁶⁰ In pediatrics, the parents are often the main foundation of strength and support for their child. Their well-being is crucial for making decisions for their sick child.⁶¹

Physicians can deal with communication ambiguity in pediatric medicine by truthfully communicating what they know and what they do not know. Physicians should communicate what is happening to the child by giving the patient and parents accurate, clear, and timely information. Doctors should accurately communicate choices such as possible curative measures, life prolonging measures, and comfort measures. Even when the diagnosis and prognosis are unclear physicians can still assert how they will help the patient and family during the course of the illness, as physicians are the main source of professional accountability. Physicians can provide emotional support through empathetic communication.⁶² When a child's diagnosis or prognosis is truly uncertain physicians can focus on what they do know about the patient's disease as well as the clinical indications based upon what they know and what they think is rational.⁶³ Communicating in an empathetic and truthful manner, even in the face of the unknown, can help physicians manage the uncertainty of veracity and thus help to maintain the relationship between the physician and family. This will be further discussed in the next section.

c. Maintaining the Relationships Between the Physician and Family

Thus far how physicians can build relationships between themselves, patients, and parents with good communication skills has been discussed. Maintaining those relationships can improve communication and thus care for patients. This section will discuss how to maintain the physician-family relationships once it has been established.

i. Instituting relationships and enhancing communication

Communication and relationships are tantamount when dealing with interpersonal relationships between the physician and the patient. Open and honest communication helps to institute the initial relationship and thus enhance communication. Likewise, good communication between the physician and the patient also helps to maintain the relationship. Physicians should oblige to develop strong relationships with their patients and develop excellent communication skills. After all, communication is the tie creating and binding the physician-patient relationship.⁶⁴

Effective communication is a necessity for good patient care. Effective communication can determine how much information the physician receives from the patient, whether the patient will adhere to their recommended treatment, it can influence the emotional welfare of the patient, and it is a determining factor in patient approval. The quality of the relationship that develops between the physician, the patient, and their family will influence the effectiveness of the communication transactions. Not surprisingly, efficacious physician-patient encounters will be reliant upon building and maintaining rapport. This is dependent upon effective communication transactions. When used appropriately, communication in the health care setting can help reduce uncertainty. A reduction in uncertainty often leads to more self-disclosure, which leads to more fruitful relationships and overall better health care. Research continually shows that the quality

of the relationship between the patient and the physician is dependent upon the physician's ability to communicate effectively to build trust and their use of empathy. Empathy supports building rapport and enhancing communication by trying to understand what and how the patient and their family may feel. Research also shows that when physicians use empathy it can reduce a patient's pain, blood pressure, and anxiety level. Patients want a physician who is caring, who is non-verbally expressive, who is patient-centered and encouraging.

Patients must also trust their physician. They must trust that their physician is genuine and competent. Patients do not always automatically trust their physician based on their status as a doctor. In many instances trust must still be earned. Communication issues in health care affecting relationships are often derived from physicians making basic errors such as not properly introducing themselves, not asking patients to clarify information, not encouraging patients to ask questions, not inquiring how patient's feel about what has been communicated, and not providing patients with information in a suitable manner. Patients and their families often feel susceptible. When trust is not established it can enhance those feelings of vulnerability. Patients and their families are typically anxious about an admission to the hospital, which can curtail communication and the efficacy of the doctor-patient relationship. Establishing trust with patients helps to ease those feelings of anxiety. Research continues to show that communication issues can be a major source of patient dissatisfaction⁶⁵ When the patient or surrogate deems the physician's communication to be insufficient it can create a feeling of detachment within the relationship. Research shows that patients often report dissatisfaction with their physician when the information communicated was hard to understand or recall. Studies also show that when physician-patient relationships flourish health outcomes are improved.⁶⁶

ii. Family-centered care

Patient-centered care arose in the 1980's when research showed the value of including adult patients in all aspects of their healthcare delivery and decision-making. Family-centered care is in essence the pediatric version of patient-centered care for adults.⁶⁷ Family-centered care is a newer approach to health care delivery that began during the second half of the 20th century when research started to show the effects separating children from their families during hospital stays. Hospitals began to include families in children's hospital stays and encouraged them to be present during medical procedures. Today family-centered care has grown beyond just having family present. It is a method of healthcare that continues to evolve as it recognizes the valuable roles families play in the overall well-being of the pediatric patient. When physicians conform to family-centered care they recognize the importance of treating each patient and family on an individual level, beyond the scope of just treating the child's disease. Physicians who contribute to family-centered care follow a set of principles outlined by the American Academy of Pediatrics (AAP). These principles facilitate excellent communication practices and thus help to harvest and preserve relationships between the physician and the family. Physicians establish rapport with patients and families by listening to them and respecting their ideas and individual backgrounds. Doctors show patients and families integrity by honoring their uniqueness and respecting their race, ethnicity, experiences, and cultural backgrounds when considering healthcare treatment and goals. In a family-centered approach, physicians communicate with patients and families in an honest and timely manner on a continuous basis. Families and patients are always encouraged to participate in dialogue regarding the patient's healthcare to give them the self-assurance they need to make well-informed decisions. Physicians go above and beyond by supporting the patient both formally and casually over the course of their diagnosis and

prognosis. Physicians who participate in family-centered care reap the benefits of improved communication.⁶⁸

The family system theory recognizes that the patient is part of an entire system. They are family and they are a subsystem so what affects them can affect the entire system, or family. Pediatricians, therefore, cannot effectively care for children without creating a partnership with their family. Research shows that these types of family-centered partnerships are beneficial in terms of the patients physical and mental health, satisfaction with the physician, communication, and the overall functioning of the family is better. There are several integral elements to family-centered care: family-centered rounding, peer support, and family-centered facility design. Family-centered rounding is important on the basis that families have the right to all honest information, including information shared during physician rounds. Families also offer knowledge and information about the patient, which is necessary for creating goals of care and should be encouraged to actively participate in rounding not in just being present. When families participate in rounding they are less likely to question patient care plans, they understand discharge instructions better, and they are less likely to need to consult with the physician later in the day. Family-centered care also opens doors for greater peer support for the families of patients. Peer support can occur when families in similar situations can share their experiences together, offer support and advice, and help each other cope. The design of the hospital which children are admitted to can influence the family-centered care. Family-centered care facilities should consider the needs of families and patients to promote their well-being. They should have ample parking for families, green space for families to use, and facilities for patients and siblings to interact together, and accommodations for patients and families to achieve quality sleep together. Overall, family-centered approaches to care promote reinforced relationships between

the physician, the patient, and the family while improving the quality of health care for the patient.⁶⁹

2. Ethical Framework for Pediatric Communication

Research continues to exemplify that physicians having good and effective communication skills is undoubtedly imperative and necessary for operative health care transactions and outcomes. The benefits of physicians having effective communication skills are abundant. Evidence continues to show that poor communication between the physician and patient is likely to produce negative health outcomes and patient dissatisfaction. While a typical physician may conduct between 150,000 to 250,000 patient interviews over the course of their career, very few physicians have had any type of formal communication training. Those who have had training have often received inadequate coaching. Giving physicians the tools they need to be effective communicators with their patients should be a top priority in all medical schools and hospitals as evidence continues to support the need. Physicians need communication training beyond just learning from and modeling more experienced physicians. Physicians need to learn and understand how to properly use patient-centered communication skills.⁷⁰ This section seeks to ground communication skills in a theoretical framework. This section will explore the proposed ethical framework for pediatric communication that can be taught as well as applied to communication transactions, specifically in pediatric critical care. The framework will include the ethics of care specifically, the virtue of caring and using those virtues to communicate caring, veracity for surrogate consent, pediatric surrogate decision-making standards, the ethical duty to communicate honestly, the physician-family relationship, ethical considerations when building relationships, and foundations of family-centered care.

a. Ethics of Care

The doctor-patient relationship typically begins when there is a patient who needs support and needs to be cared for. The physician can offer the care and support the patient needs in order to show their concern for the patient and the patient's individual needs. The physician should balance clinical care with the personal care that the patient may require. This relationship between the cared for and the person caring is fundamental to the ethics of care. The ethics of care recognizes that the patient is often vulnerable as they are dependent upon on the physician for care.⁷¹ The ethics of care focuses on moral values such as being attentive, responsive, and trustworthy in order to establish caring relationships. Moreover, it recognizes the importance of those relationships.⁷² The ethics of care is empathetic towards the suffering and needs of others as it recognizes the reliance of those who are chronically ill.⁷³ The entire basis of the ethics of care is recognizing the need to care and be cared for. The ethics of care proposes that appropriately responding to others emotions with empathy is of utmost importance to the vitality of moral relationships. Good healthcare is often a result of physicians who are attentive to the patient's emotional needs and circumstances.⁷⁴ This section distinguishes the virtues of caring and how the virtues of caring can be used to communicate caring.

i. The virtue of caring

The way healthcare is interconnected suggests that the virtue of caring is imbedded in healthcare itself. The care in healthcare is suggestive of the notion that there is an assurance from the physician to treat their patients compassionately and consider their emotional needs within the realm of care.⁷⁵ Although the main goal of healthcare is typically curative in nature, sometimes cure is no longer an option as conditions become chronic. When conditions become chronic it can change a patient and their entire family's world view. Patients who face a

prognosis in which there are no curative measures often require a lot of care and support. Establishing grounded relationships with providers becomes of utmost importance. Caring for a patient goes beyond the notion of just trying to cure them. Caring for a patient means going above and beyond and showing the patient support, empathy, patience, devotion, and contributing to their overall well-being. Caring for a patient means recognizing the patient as an individual with respect to their sole being.

There are four types of relationships and relationship qualities recognized by means of caring. The first relationship quality is caring about another individual. When a physician cares about a patient they must first recognize that care is necessary and needed. Physicians must also pay attention to the individual needs of the patient. The second relationship quality is taking care of the patient. When a physician agrees to care for a patient they vow to become accountable for the patient's needs and must learn how to meet those needs. Once a physician evaluates how to meet the patient's needs they can begin the process of care giving. Care giving is the labor-intensive work that it takes to physically care for a patient. To give proper care physicians must be both professionally and morally competent. Lastly, the physician must confirm that the care the patient has received has met the patient's needs or else the patient has not really been cared for.⁷⁶ How to use virtues to communicate caring will be discussed next.

ii. Using virtues to communicate caring

It has been established that physicians must communicate that they care in an effective manner in order for the patient to really feel as though they have been cared for. This section will describe how to communicate caring through the use of virtues. A virtue is an attribute of one's character that is highly respected and valued. A moral virtue is an attribute that is communally acceptable. People who are inherently morally sound are likely to understand what

needs to be done to attend to other's needs and more likely to preform those actions to meet those needs. Furthermore, virtues can be noted as traits that create a climate of trust amongst others.

As previously introduced, there are five focal virtues physicians can use to communicate: caring, compassion, discernment, trustworthiness, integrity, and conscientiousness. The virtue of compassion essentially sets the stage for caring to occur. Compassion requires physician to respect the overall well-being of their patient as it focuses on the pain, misery, and/or disability the patient is facing. To respect their patient's welfare physicians must respond with sympathy and empathy to their patient's distress and anguish. Compassion requires physicians to immerse themselves within the patient's position. Physicians must consider the emotional state and experiences of the patient in order to care for the patient and thus suitably treat the patient. The importance of compassion is insurmountable as physicians who lack the ability to feel compassionate or express compassion often fail to aptly treat their patients.⁷⁷ Furthermore, compassion in pediatrics is imperative as most children are not responsible for their medical state and compassion calls for physicians to avoid judging those patients who may be responsible for their need for healthcare.⁷⁸

Discernment is a second virtue of caring requiring for physicians to use their best judgment and understanding to reach decisions to appropriately care for the patient and meet their needs. A thoughtful physician will be able to properly recognize when a patient needs emotional support versus time to themselves. If a patient needs emotional support the physician should be able to recognize how much emotional support to provide without overwhelming the patient.

The third virtue of caring, trustworthiness, is integral to healthcare and shows patients that they are being cared for. Patients are susceptible as they put their viability in the hands of

physicians to properly treat them. Trust in this sense then is confidence in the physician's capability and moral character to appropriately treat the patient. Establishing and maintaining the trust of the patient is of utmost importance in communicating caring within the realm of healthcare.

Another virtue, moral integrity, is also deemed necessary to communicate caring. Integrity means that physicians are dependable, have good moral character, and will act within ethical norms. Integrity is two-fold as it requires the physician to have beliefs, knowledge, and emotions that accompany each other. The second part of integrity requires physicians to stand up for those deeply held beliefs when required. Physicians must also uphold their professional integrity requiring them to conduct themselves in a way appropriately aligned with their professional standards.

The final virtue, conscientiousness, is when a physician is driven to do what is right simply because it is the right thing to do. Conscience prompts physicians to reflect on what they believe to be good, bad, acceptable, or unacceptable. Sometimes those beliefs are so deeply held that they interfere with a patient's care such as a physician who will not withdraw life support. Such conscience decisions may interfere with a patient's right to care. In these instances, the physician has the moral duty to refer the patient to another physician who may perform these procedures. These virtues provide a basis for physicians to communicate that they care about the patient beyond the realm of just physically providing care, but emotional care as well.⁷⁹

b. Veracity for Surrogate Consent

Physicians are required to provide patients and families with honest information regarding the patient's prognosis and diagnosis to attain ethical healthcare outcomes. Patients and families will lack trust in their physician if they suspect they are not being honest with them.

When patients and families are given honest information, they can make informed decisions. A physician's goal must not be just to obtain consent, but to do so in a way that patients and families are well-informed, can understand the information given to them, and can conclusively make well-rounded decisions. Making sure patients and family members understand is not a straightforward task. Health information communicated is often complex and can be uncertain. If the patient and family do not understand the information, diagnosis, prognosis, or treatment options, they cannot be truly informed and, therefore, they cannot make truly informed consent decisions. It is the physician's responsibility to communicate in a way that can be understood by the patient and the family to achieve informed consent.⁸⁰ In an effort to make surrogate consent meaningful and prosperous physicians should seek to first establish a relationship with the patient and their families, only physicians who have directly and consistently dealt with the family should communicate with the family about consent, physicians should assist family surrogates in coming to a decision when necessary, and physicians should support the surrogate's decision.⁸¹ This section will delve into pediatric surrogate decision-making standards and the ethical duty to communicate honestly.

- i. Pediatric surrogate decision-making standards

Making well-informed decisions in pediatrics is not a straight forward task. It used to be that decisions about one's healthcare were solely in the hands of the physician. Ethics has evolved and the process now includes the patient and their surrogate decision makers. Decision-making in pediatrics has proven to be a very complex process. Decisions in pediatrics are often made by the surrogate decision-makers who are typically the patient's parent(s) or guardian(s).⁸² Assent in pediatrics recognizes that children under the age of 18 typically do not legally have the right to consent to treatment. However, older minors can still participate in the decision-making

process given they have the intellectual ability to do so.⁸³ Physicians must, therefore, seek informed consent of parents before they can administer treatment to the child. Surrogate decision makers have the right to receive all the elements of typical informed consent. Parents have the right to receive all information necessary to make well-informed decisions regarding their child. Parents should have information explained in a way that they can easily understand. They should be able to understand the nature of the diagnosis and the steps needed to treat the patient.⁸⁴

Surrogate decision makers should have valid information regarding the risks and benefits of the proposed treatment. The British Medical Association (BMA) defines risk as the likelihood that something unpleasant will occur.⁸⁵ While risks are not absolute or certain to occur, if they do occur they will likely have negative rather than positive outcomes. Inevitably, there is a risk to everything and therefore it is the physician's responsibility to decide what risks need to be communicated to surrogate decision makers to aide them in their decision-making process. Physicians must also consider the individual patient and their family. What may seem like a minor risk to the physician may appear to be a major risk to the patient and family. To help physicians communicate pertinent risk information there are six questions they should reflect upon: what are the relevant undesirable consequences of the treatment option, how perpetual is the risk, when is the undesirable outcome likely to occur, how likely is it that undesired outcome will even occur, is the unwanted outcome a result of a single exposure or exposures over a period of time, and lastly how much do the undesirable effects matter to the patient and their family? Risk information must be balanced and, therefore, benefits must also be considered. Patients and parents should be privy to all information relevant to the proposed treatment interventions, and it should be communicated in a way which they can best understand the given information.⁸⁶

Parents should also be given alternative options such as no treatment as well as its the risks and benefits. It is the duty of the physician to make sure the surrogate decision maker correctly understands the given information, and it is the duty of the decision maker to act in the best interests of the child.⁸⁷

While surrogate decision makers have the right to make well-informed decisions for patients, they also implicitly have the right to refuse treatment for the child. This refusal can be limited if it puts the child's life at risk or community health at risk. Physicians may seek to overturn a surrogate decision maker's refusal of treatment if their decision appears to be neglectful, puts the patient at risk, or is not within the child's best interests.⁸⁸ The best interests standard requires a surrogate to carefully select the treatment option that will offer the patient the highest net benefit though it does not require that surrogates maximize all benefits and minimize all burdens. To reach the highest net benefit surrogates need to be given the most accurate information available regarding their child's diagnosis and prognosis. To determine the best interests the surrogate can and should consider the physical and emotional impact the medical treatment will have on the child, and the impact the treatment will have on the family. Varying values and goals of different families may mean surrogates may see the risks and benefits of treatments contrarily, even if two patients have a similar prognosis. Overall, the surrogate should choose the treatment option that capitalizes the patient's long-term benefits while minimizing the burdens. While parents have the right to decide what is in the best interests of their child, they are also bound to the duty to afford them a certain level of adequate care based on scientific evidence. What a parent thinks is best for their child must be supported by rational medical indications, not just their opinion. To keep surrogate decision makers from making irrational decisions there is a threshold of suitable care that they must meet. This threshold does

not mean that everyone must agree with the surrogate's decision, but it does mean that the surrogate's decisions must be within reasonable limits.⁸⁹ When surrogate decision makers and physicians adhere to these decision-making standards and communicate in a transparent manner it makes surrogate consent more wholesome and truly considers the well-being of the pediatric patient. The physician's ethical duty to communicate honestly will be discussed next.

ii. Ethical duty to communicate honestly

Communicating in an operative manner is essential to achieving optimal healthcare. Effective communication is not a bonus to healthcare; rather, it is a medical necessity for basic patient care. Effective communication is communication that focuses on the patient, informs the patient, and encourages a trusting relationship between the physician and the patient. Honest and effective communication is therefore ethically necessary in healthcare as honest communication has been found to reduce patient anxiety and dissatisfaction. Patients who are critically ill have lower levels of psychological distress when they receive transparent information regarding their diagnosis. Honest communication allows physicians to reach a more accurate diagnosis and improve the overall quality of healthcare associated with more positive health outcomes.⁹⁰ Honesty and telling the truth are virtues physician-patient relationships are built upon. Communicating honestly in pediatrics is of utmost importance as pediatric patients are vulnerable, meaning there is a moral duty to protect them. However, a moral duty to protect pediatric patients does not entail withholding information from them or communicating information pertaining to their diagnosis or prognosis in a dishonest manner. The AAP and many other pediatric professional associations are steadfast in their belief that pediatric patients should be fully informed when it comes to their diagnosis and prognosis and the nature of their illness. When physicians have information pertaining to a patient that may cause them anxiety

they sometimes wish to withhold that information. This violates their ethical duty to disclose such information. Dishonest communication can lead to feelings of anger and betrayal by the surrogate and the patient. To help promote honest communication physicians, surrogates, and patients should outline what kind of information should be shared and with whom that information should initially be shared. Information must be shared with the surrogate decision maker when the information is necessary for surrogate decision-making. Parents sometimes wish to protect their children from information they believe may be too overwhelming for the child to hear and, therefore, may ask physicians not to discuss such information with them. Sometimes these requests are culturally motivated, as some cultures believe it is the parent's duty to guard their child from harmful news. By not guarding children from such information may worsen the patient's condition. In these situations, physicians should work with parents and develop a plan to discuss diagnostic information with children in an appropriate and honest way when applicable. Physicians should also strive to understand each individual family and their cultural values to understand the type of value they place on transparency in medicine. Understanding individual family cultural values can help physicians communicate in an honest yet respectful way with patients and families.⁹¹

Though discussing the imminent death of a pediatric patient with a life-threatening illness may be one of the most difficult things pediatric physicians may have to do, it is undoubtedly necessary. Children who are dying are extremely vulnerable and physicians and parents may wish to protect them from such information. However, research shows that it is typically in the patient's best interests to know what lies ahead. It was reported that almost all children who had cancer wanted to know when and if their treatment was no longer working and they were likely to die. Pediatric patients who are terminally ill typically know that they will

pass away soon, and keeping such information from them can increase their anxiety and fears. Pediatric patients who are terminally ill need the opportunity to communicate their feelings, to discuss how they will be taken care of, and how their families will handle the impending death. Physicians have an ethical duty to truthfully communicate information regarding death to their pediatric patients. If a patient's parents insist that the patient not be told, then the physician should counsel the parents on the consequences of withholding such information and the benefits of discussing end of life care with their child. If pediatric patients ask their physician questions regarding death the physician has the duty to answer such questions in an honest manner. Communicating honestly in pediatric critical care settings is morally imperative. Deceptive communication regarding the patient's diagnosis should rarely, if ever, occur. If there is a request to not share diagnostic information with the patient, there must be valid reasoning. The surrogate decision maker must always have access to honest communication regarding the patient's diagnosis and prognosis.⁹² The ethical implications of the physician-family relationship will be discussed next.

c. Physician-Family Relationship

Pediatric medicine is unique for many reasons, but one reason is the multiple relationships that must be built with the physician. In pediatrics, there is typically always the presence of at least one parent or surrogate decision maker. Their influence is often prevalent as families are a vital influence in children's lives and there are needs which only families can provide their children. Family-centered care in pediatrics requires that a partnership be built between the patient, the patient's family, and the physician.⁹³ Building a strong physician-family relationship is at the forefront of effective communication in pediatric critical care settings. The

ethical considerations physicians must acknowledge when building relationships and the foundations of family-centered care in pediatrics will be discussed.

i. Ethical considerations when building relationships

Relationships are built and maintained across a series of multiple interactions with a common end goal.⁹⁴ In pediatrics, the physician and the parents both have a fiduciary duty to the patient. This means they are obligated to act on behalf of the patient/child who they represent. Parents are fiduciaries to their child, yet most parents cannot provide the expertise needed for pediatric health care and, therefore, they must seek assistance from a physician. The physician and the parents then become co-fiduciaries of the pediatric patient binding them into a relationship.⁹⁵ Notably, the term fiduciary is a derivative of the Latin word for trust. In the physician-family relationship trust is integral. Physicians should be aware of communication techniques that help elicit feelings of trust such as sitting down when speaking to the patient and family, establishing eye contact, actively listening to the patient and their family members, and showing empathy towards the patient and their family.⁹⁶

When patients and families do not trust a physician, they are less likely to divulge important and necessary information to the physician. When the relationship is not well-established patients and family members may be anxious and are less likely to comprehend the information given to them in a concise manner. The physician-family relationship then has a direct effect on the quality of the treatment and care given to the patient. The relationship is especially important in the pediatric critical care setting as the patients are a vulnerable population, and there is a reliance on the physician's knowledge and skills.⁹⁷ Research has shown that when the physician, patient, and family members are included in triadic communication the treatment outcomes and satisfaction are improved. Research shows that

pediatric patients are more satisfied when their physician is friendly, shows interest, is responsive, pays attention to patient concerns, and is not dominant. Physicians can thus enhance relationships with their pediatric patients and parents by showing acts of friendliness through reassurance and admiration, showing interest by listening to their patient and considering their lived experiences beyond the scope of their disease, being responsive by paying attention to patient and family concerns, limiting dominance by working together with the patient and the family to achieve treatment plans and goals, and by spending adequate amounts of time with the patient and family. The way in which the physician communicates with the patient and family is imperative to building and maintaining relationships as research shows that the physician's communication style may be more imperative than the actual content of the communication.⁹⁸ When physicians and families can work together it can improve health outcomes and the quality of life for the patient.⁹⁹

ii. Foundations of family-centered care in pediatrics

Family-centered care is a novel approach to healthcare delivery that recognizes the important role family plays in a patient's healthcare and the benefits of creating a partnership between the physician, patient, and family. Physicians who provide a family-centered approach to healthcare recognize that families provide imperative emotional, social, and developmental support to pediatric patients, a cornerstone to their healthcare. Pediatricians who implement family-centered care in their practice consequently spend more time with the patient and family. This has been shown to help build relationships between physicians and patients. A family-centered approach to healthcare recognizes that families are the main support system for pediatric patients and, therefore, their perspectives are relevant in the clinical decision-making process.¹⁰⁰ When families participate in their child's care they assume an important role as an

advocate for their child. As an advocate, they are more likely to stay informed and be involved with their child's medical care and feel as though they are a member of their child's medical team. When parents advocate for their child they typically seek a complete and honest diagnosis and they help physicians better manage patient's symptoms. When parents are given the opportunity to actively provide support for their critically ill child it can help to reduce feelings of powerlessness and emphasize the importance of the collaborative nature of the entire medical team.¹⁰¹

Research shows that family-centered care is associated with many positive outcomes. When families can be present for healthcare procedures it can decrease patient anxiety. Research has shown that when pediatric patients undergo surgery they cry less and require less medication when their parents are present and participate in pain management. Not only do patients and families benefit from this type of care, but physicians also reap benefits. Physicians who participate in family-centered care build stronger relationships with the family and thus have better health outcomes for their patients, physicians understand the role families play and the importance of family culture and values in health care, decision-making improves when physicians join forces with families, families are more likely to follow through with the care plan, there is improved communication among all members of the healthcare team, and patients and family members are more satisfied with the care the patient receives.¹⁰²

There are several fundamental principles helping to establish the collaborative relationship between the physician, the family, and the family. The first principle is listening to the patient and their family. Listening goes beyond just considering the scope of the patient's disease. It includes listening about the patient's cultural background, their socioeconomic background, and their experiences that may affect the delivery of healthcare.¹⁰³ Listening to

patient also extends beyond just hearing what they have to say. It requires physicians to read their patient's non-verbal cues and to act on them. Effective listening skills are imperative to gain full comprehension of the patient's ailment. Listening skills also help physicians to be more patient-centered and empathetic.¹⁰⁴ When physicians are flexible in their practice it also helps to build relationships. Physicians should not assume that one size fits all when treating their patients; they should adapt their services to the patient when applicable.

Another important principle is the principle of honesty. Physicians should communicate with patients in families in an honest and unbiased manner. Physicians should communicate in a way that patients and family members can understand and in a family-centered approach where family members are included in physician rounds. An additional foundation of family-centered care is providing patients and families with the formal and informal support they may need over the course of the child's illness. Lastly, physicians should build upon the strengths of patients and families to give them the self-assurance they need to participate in medical decision-making thus enhancing the collaborative effort of family-centered care.¹⁰⁵

Conclusion

This chapter has sought to provide the basis for communication theory and prognosis in the pediatric critical care setting. This chapter has reviewed the importance of establishing rapport with the ethics of care specifically by creating relationships through caring and taking responsibility of others through the voice of care. This chapter has reviewed how physicians can manage uncertainty in veracity by communicating truthfully and how they can deal with communication ambiguity in pediatric medicine. Maintaining the relationship between the physician and family were also reviewed and the importance of instituting relationships in order to enhance communication and provide better family-centered care. This chapter also provided

the basis for the ethical framework for pediatric communication. The ethics of care and the virtues of caring were discussed. The importance of veracity for surrogate consent was discussed with a focus on pediatric surrogate decision-making standards and the ethical duty of the physician to communicate honestly. Lastly, the physician- family relationship was measured in terms of ethical considerations and the foundations of family-centered care in pediatrics. Chapter three will provide a discourse on how to establish rapport with the ethics of care.

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Chapter Three: Establishing Rapport with the Ethics of Care

As it has been noted, establishing solid relationships between the physician, the patient, and the family is a cornerstone to effective and ethical communication particularly in pediatric critical care medicine. Communication is one of the most imperative aspects of human life and it garners special attention to its intricacies. Communication is comprised of both scientific and humanistic methods. Understanding communication theory allows one to appreciate the value of communication and its ability to generate change.¹ Human communication uses symbolic language to describe how people interact together. It is unending and considers feelings and attitudes as well as provides information. Human communication is a process which is transactional in nature; people interact together and are affected by their interactions. Communication also has several dimensions since it considers not only the content of the message, but also the relationship of those communicating. Physicians must recognize the relationships they develop with their patients and family members will have a profound influence on the efficacy of their interpersonal communication. Notably, health communication is considered to be a subcategory of human communication which considers how people think through and communicate about health-related issues.² Communication theory and theoretical frameworks help to highlight the intricacies of communication and communication interaction.³

When physicians have knowledge about communication theory it helps to introduce new perspectives that may have previously gone unnoticed. This helps physicians become more flexible in their method of communication.⁴ The words physicians use have the power to build strong relationships with their patients, or they have the power to destroy the partnership.⁵ This chapter will explore how physicians can build rapport with their patients and their families by examining the ethics of care in conjunction with several human communication theories and

traditions. Symbolic communication traditions such as the semiotic tradition and the sociocultural tradition will first be explored. Next, the ethics of care will be discussed with particular attention given to relational autonomy and meeting the needs of others all in conjunction with how physicians can apply these theories and traditions to establish rapport with the ethics of care.

1. Symbolic Communication Traditions

Symbols are everywhere in our everyday life. People use symbols to make sense of their experiences and to give meaning to what is going on in the world around them. Occasionally, people will share the same symbols and thus reach the same meaning. On other occasions communication may seem vague as symbols are not well understood by everyone in the communication transaction. Symbols are complex as they help others conceive ideas between the symbol, the object, and the person. Symbols communicate perceptions. Sometimes people will share those perceptions and other times communicators will have a private meaning for the symbol communicated. The meaning of symbols exists in the individual's schema and are often based on the context of which the communication is taking place.⁶

In healthcare there are three pertinent categories of semiotics. The first category is the symbolic sign. It is typically gathered during the interview and history-taking process between the physician and patient. In the second category are the indexical signs encompassing nonverbal communication. The third category consists of iconic signs such as x-rays or other visual medical tools. Symbolism in medicine recognizes that while physical patient symptoms are important there is underlying communication taking place that will ultimately affect the physician-patient relationship and patient outcomes.⁷

a. Semiotic Tradition

Semiotics, described simplistically, is the study of signs. Semiotics describes how objects gain meaning from situations, feelings, and ideas.⁸ The semiotic tradition is often referred to as a bridge between each person's worldview and the connotations symbols produce to create a shared meaning between two or more people. When a shared meaning is not elicited a misunderstanding in communication may occur. This solidifies the notion that there needs to be a common language used for complete comprehension to occur.⁹ This section will explore ways to identify the semiotic tradition and provide a connection between the semiotic tradition and establishing rapport.

i. Identifying the semiotic tradition

Symbols within an individual's schema garner meaning because of how those symbols relate to other symbols or how they create larger patterns of understanding. The semiotic tradition is triadic in nature as meaning is created from the relationship among three things: the object, the person, and the sign. Semiotics is then further separated into three areas: semantics, syntactic, and pragmatics. Semantics looks at what symbols stand for or signify. Syntactics review how symbols are formed into meaning through use of both verbal and nonverbal signs. Pragmatics shows the importance symbols have in everyday life.¹⁰ Syntactic codes are pre-established codes necessary for communication, even if the communicators do not share a mutual understanding. Syntactic codes are important when people need to communicate in situations where there is no opportunity to define codes beforehand, yet they are often understood because of the rules of grammar. Syntactic codes are more straightforward as they remove the ambiguity. On the other hand, pragmatic codes can only be understood when the communicators have

shared information about a situation. Pragmatic codes in pediatric health care may take the form of medical jargon.¹¹

Nonverbal communication is of vast importance to the semiotic tradition especially in pediatric health care. Nonverbal symbols often have several properties. The first property of nonverbal symbols is that they are analogic symbols. Analogic symbols are ever changing for example as the volume of a particular sound, the brightness of a light, the tone of someone's voice, or the facial expressions one makes. Nonverbal symbols can also have iconic properties such as demonstrating to someone the size of an object with your hands. Some nonverbal symbols have a common meaning across different cultures and backgrounds. Emotional or intimidating exhibitions that may be biologically inclined are examples of this. Nonverbal codes can also elicit the concurrent transmission of several messages at one time in an unprompted manner. When one is communicating their facial expressions, tone of voice, and body posture can prompt several differing messages at once. Lastly, nonverbal symbols often illicit an automatic response that does not require the receiver to truly think about it.¹²

Nonverbal symbols are also frequently classified by the activity they are used in. Some examples are kinesics, vocalics, proxemics, haptics, physical appearance and artifacts, and chronemics. Kinesics, or body language, is a cornerstone to nonverbal communication. Body language in communication always has the potential to elicit meaning, though those meanings may be varied depending upon different groups and cultures. People are often easily influenced by the body language one communicates. Body language can be both interactive and informative. Interactive body language is intentional such as waving to a patient to greet them. Informative body language may not intend to elicit communication, but may still provide information to the receiver such as trying to avoid communication with a patient or their family

by quickly entering the staff lounge. If the patient and the family who are trying to communicate with the physician see the physician quickly enter the staff lounge, then they may interpret this as an avoidance behavior. In this instance communication has occurred though it may not have been deliberate.¹³

Gestures are an important component to nonverbal communication and kinesics. Gestures are often used in place of words and can help regulate communication and make communication transactions flow more smoothly. Something as simple as the gesture of a head nod can direct the patient to continue speaking.¹⁴ Body language is a very important communication tool in pediatric health care. Something as minor as the way that one sits can communicate caring and sensitivity. For instance, if a physician sits with their legs towards the patient this can mean that they are receptive to what the patient is communicating. If the physician sits with their legs away from the patient it can mean that they are unresponsive to the patient.

Facial behaviors are also important body gestures when communicating. Nonverbal messages can be communicated by how a person moves their face, lips, eyebrows, and forehead. When people are communicating they often look at three principal areas of the face for emotion: the eyebrows and forehead, the eyes, and the lower region of the face such as the cheeks, nose, and mouth. Sadness, fear, and surprise are often seen in the communicators eyes. Anger is often seen in the cheeks, eyebrows, mouth, and forehead of the communicator. Communication cues of disgust are often present on the lower portion of the face. Happiness is often seen in the communicators eyes and/or the lower portion of the face. There are four categories of facial movements used in nonverbal communication. The first is masking. Masking occurs when a person replaces one facial expression with a more appropriate expression such as a facial

expression of disapproval replaced with the expression of approval. The second facial movement is intensification in which facial expressions are exaggerated. Neutralization is another nonverbal communication tool in which facial expressions are defused. Lastly, there is deintensification in which facial expressions are modulated in an effort to show a more appropriate facial expression.¹⁵ Gaze, closely linked to facial expressions, is important to nonverbal kinesics. Gaze acknowledges how people use their eyes to communicate with others. People tend to use their eyes to communicate by monitoring, regulating, and expressing. Monitoring is when a person uses their eyes to assess how another person appears and how others are responding to them. Gaze is often used in healthcare to gather information about how patients are responding to treatment, and physicians may use gaze to monitor any changes in their patient's condition. Gaze also helps to regulate the communication transaction. Communicators may use their eyes to signal whose turn it is to talk and whose turn it is to listen. Gaze also helps communicators express emotions and feelings.¹⁶

Vocalics is the study of the vocal aspects of the voice. It includes the study of characteristics of the voice, tone of voice, pitch of voice, accent, dialect, and silence. The voice can transmit both verbal and nonverbal symbols. People can express positive and negative expressions in their voice by the tone and volume they use. Monotone or harsh vocal expressions can make the communicator appear to be offensive. When a communicator has good vocal delivery, they are typically seen as being more sincere. Good vocal delivery entails speaking at a sensible volume at a reasonable rate while clearly articulating speech in a flowing manner.¹⁷ Vocalics influences how the receiver feels about the messaging from the sender. Vocalics can provide nonverbal information from the sender such as their personality or emotions, their competence, and how they wish to have the message received for example in a

joking manner or in a respectful manner.¹⁸ Vocalics are important to regulating the communication transaction and physicians should pay attention to their vocalics when communicating with patients. Vocalics can influence a patient's perception of the physician and they can affect how well patients recall verbal information.¹⁹

Proxemics is the study of how space is used in communication. Different cultures view the use of space in communication differently. In the United States being able to see and hear the person you are communicating with is considered significant. When communicating there are three rudimentary elements that make up space. The first is fixed-feature space. This includes objects that cannot be removed such as walls and rooms. The second is semifixed-feature space pertaining to removable things like furniture. Third is informal space. Informal space defines appropriate interpersonal distances. The American culture identifies four different sectors of distances. The intimate distance is zero to 18 inches between communicators, personal distance is one to four feet apart, social distance is four to 12 feet apart, and public distance is anything over 12 feet apart.²⁰ Research shows that people often choose their distance zones based on their feelings, the communication transaction, and the relationship between the people involved. Patient age can also influence physician distance choices as research shows that doctors tend to sit closer to middle-aged patients and further from younger patients. While there are no steadfast rules to distance zones, physicians should be aware of distance and how it affects the effectiveness of communication.²¹ People also have both personal space and territorial space. Personal space is the space people create around themselves in which they can choose to expand that space or decrease the amount of space based on whom they are communicating with. Territorial space is the area people are allocated such as a physician's office or a patient's hospital room.²² It is important for physicians to remember that in health care patients

sometimes feel as though medical staff has conquered their personal space. Though it is often necessary for physician's to "invade" a patient's personal space to properly care for them it is important that they remember this can make patient's feel as though they are helpless and have no dignity left.²³ Physicians should be empathetic towards patients and their territorial space as they must leave their own homes and "live" in a new setting with strangers and people constantly in and out of their area. Physicians should recognize when patients need personal space or privacy and their wish should be respected. Physicians should give the patient as much control over their space as they can for example by allowing the patient to decide if their hospital room door should be opened or closed.²⁴

Related to the study of proxemics is haptics. Haptics is the study of touch and what touching communicates. Though many people avoid using touch research has shown that touch is one of the most powerful nonverbal communication tools that can be used.²⁵ Touch has also been noted as one of the most effective tools doctors can use to gain insight about their patient and build rapport.²⁶ Generally, how touch is construed will be determined by the context in which the communication is taking place and the established relationship between the communicators. Touch in health care is very important and sometimes a necessary form of communication when appropriately used. Touch can take on different forms such as positivity or communicating appreciation to someone else; being playful; showing dominance or control, cultural rituals, such as shaking hands; and most often found in healthcare, task related such as examining a patient.²⁷ The very first touch a physician should make when communicating with a patient is a handshake or some sort of gesture indicating friendliness and readiness to communicate and listen.²⁸ Sometimes physicians are eager to grab their patient's chart or test results instead of initially greeting the patient with a touching gesture. Physicians must

remember that touch is an invaluable tool to enhancing communication and thus relationships. Touch can help bridge the gap between physical and emotional pain in patients and can foster trust between the physician and patient.²⁹ In pediatrics, touch has been shown to comfort children in distress and plays an important role in child growth and development. Touch typically helps to improve physician-patient relationships by showing care and concern for the patient. Although, it is important for physicians to remember that touch will not always be well received by all patients.³⁰ Research has identified several factors that influence one's comfort with touch. The first factor is gender. The gender of the physician and the patient may influence whether the patient is receptive of the gesture. Research suggests that male patients may feel that touch invades their privacy more than female patients.³¹ A second factor is the sociocultural background from which the patient comes from. Some families and cultural environments embrace touch, while other cultures prefer limited or no contact. Lastly, the relationship between the physician and the patient will affect whether patients are receptive to touch. When patients and physicians have a well-established relationship, touch is typically viewed as a positive interaction. When the relationship is not well-established touch can create uneasiness for the patient. While there are no clearly defined rules for physicians delineating when to use messages of touch and when not to touch patients, there are several things physicians should consider. Physicians should use a form of touch deemed appropriate for the situation. For example, a patient or family member who is upset by the news of a poor diagnosis may respond well to a physician placing a hand on them to comfort them. On the other hand, patients or family members who are visibly angry may not respond well to touching gestures. Physicians should pay attention to their patient's response to touch. If the patient pulls away then the patient is probably not responding well to the gesture. However, if the gesture relaxes the patient then

the gesture is likely to be well received. Touch can be valuable to health communication when physicians are aware of its effectiveness and how to properly use it.³²

A person's physical appearance and artifacts are often the first message they will send to their receiver. People innately judge others by their physical appearance. If someone views another person's physical appearance as not up to par, then they may not even wish to communicate with that person. Physical appearance includes the way one dresses, clothing style, and the accessories or artifacts worn.³³ Some of the nonverbal messages one communicates through their physical appearance are within one's control such as hairstyle, clothing choices, and jewelry. Other personal appearance features cannot be controlled such as skin color or facial features. Given this information physicians should dress in an appropriate manner for the communication transaction. For example, a physician would probably not send a very good nonverbal message of caring if they dressed in an old T-shirt and shorts to inform a patient and family of a terminal diagnosis, as this is not viewed as a traditional dress code for physicians.³⁴

The environment the patient is in can also influence the communication transaction. There are six dimensions to one's environment that people tend to assess: formality, warmth, privacy, constraint, distance, and familiarity. People tend to base their communication on how the setting of the communication appears to them. Formal settings tend to denote that the communication will be less relaxed and difficult information may be communicated. The warmth of the room where the communication takes place will also influence the entire transaction. Environments appearing to be warm to patients due to wall color or décor, may influence how long patients communicate and how relaxed they are during the communication transaction. Pediatrics hospitals often try to use colorful schemes and sometimes include cartoon characters and encourage staff members to wear bright colored uniforms. Privacy is important to

communication in the healthcare setting as environments that are not closed off or can easily be overheard by others may hinder communication. Rooms providing more privacy foster an environment for more personal communication to occur. Constraint, or a patient's ability to move around freely, can also effect communication. When patients can freely move about their room; opposed to being in bed with machines on them, they are more likely to communicate personal information than patients who are more constrained. The distance the patient's hospital room is from other patient rooms or the nurses station can influence communication. In addition, patients who are in rooms at the end of a hallway tend to feel more isolated from others. Lastly, how familiar the patient and their family are with the environment can affect communication. If patients are unfamiliar with the territory they may be hesitant to communicate in an open manner. These environmental factors offer physicians a way to see how communication can be affected and influenced by things often times overlooked.³⁵

Chronemics is a final factor when considering nonverbal communication. Chronemics is the study of time and what time can communicate. Messages imbedded in chronemics are often culturally sensitive due to the United States being a very time oriented culture. How a person communicates time and their use of time can determine how one person perceives another person. A physician who is habitually late may be seen as uncaring or selfish to the patient and the family.³⁶ The way people use and express time can communicate a lot about their relationship. Spending appropriate amounts of time with patients and their families will communicate to them that they are important.³⁷

Nonverbal messages also function to complement, contradict, accent, repeat, regulate, and substitute communication. Nonverbal messages may complement communication by emphasizing the verbal message such as a proper tone of voice or the use of haptics during

communication. Sometimes nonverbal messages are contradictory meaning the nonverbal message and the verbal message do not mesh together. Nonverbal communication can be used to accent verbal communication such as highlighting verbal communication by changing one's tone of voice. Nonverbal messages can also be used to repeat the verbal message for example by asking a patient if they need assistance and lending them a hand simultaneously. Regulating conversations with nonverbal communication is also important. Nonverbal regulatory techniques include using eye contact, pausing, looking away from the patient, or touching the patients hand. These nonverbal regulatory techniques help to set the pace of the verbal communication. Lastly, nonverbal messages can be used as a substitution for verbal communication. For example, a physician who has just given a family a grim diagnosis may choose to hug the family to reassure them instead of offering any more verbal communication at the time.³⁸ Physicians should also be aware of the nonverbal cues their patients and families are eliciting during communication. They should look for cues confirming that the patient or family members understand what is being communicated such as nodding their head and making eye contact with the physician. If nonverbal communication confirming understanding is missing then this may suggest a lack of comprehension from the patient or family members.³⁹

This portion of the chapter has identified the semiotic tradition as the study of signs in communication; particularly nonverbal signs. The next section will explore how the semiotic tradition allows physicians to establish rapport with their patients.

ii. Semiotic tradition and establishing rapport

Semiotics and nonverbal communication are indispensable in health care communication especially in terms of establishing rapport. Nonverbal communication is a part of the communication process of essentially communication sans words. Instead of words messages

are communicated through body motion, proxemics, use of sounds, and touch. Nonverbal communication can also be vocal or non-vocal as the tone of voice is considered. Nonverbal communication exists to assist communicators in expressing their feelings and emotions, regulating the flow of the communication transaction, validating verbal messages, maintaining self-image, and maintaining relationships.⁴⁰ Research shows that two-thirds of meaning in a communication transaction occurs from nonverbal communication, and the entire communication transaction can sometimes rely solely on nonverbal communication. Nonverbal communication is an innate behavior across all cultures. Discounting the impact of nonverbal communication can impose severe consequences on relationships.

Many physicians fail to become operative communicators because they do not consider the impact of nonverbal communication. Nonverbal communication is always present and continues to be engaging even after verbal communication has ended. Verbal communication is imperative to building relationships, yet it is typically always accompanied by nonverbal communication elements. Nonverbal communication typically has the most impact on the relationship because it elicits the largest impact on the way patients and families feel about their interaction with the physician. Nonverbal communication is also more believable than verbal communication. If the verbal and nonverbal messages contradict each other, the nonverbal message is typically believed over the verbal message.⁴¹ Nonverbal communication is of great importance in the healthcare setting as patients and family members often seek out nonverbal messages when they are fearful and uncertain and seek to lessen their uncertainty about the situation. Patients and family members will sometimes attempt to gather information quickly before any verbal communication takes place by assessing the physician's nonverbal communication. Parents may attempt to observe a physician's nonverbal behavior to determine

whether they will receive good or bad news once verbal communication takes place. If patients or surrogates do not believe the physician is providing transparent information, then they may look for nonverbal clues to confirm their assumptions.⁴² In order to relate to patients and, therefore, to establish rapport, physicians must be able to appropriately use nonverbal communication and read the nonverbal communication of their patients and families. Doctors should be able to recognize if the verbal message a patient is communicating does not match the nonverbal message they are sending.⁴³ Physicians must be attuned to the nonverbal communication of their patients as sometimes it is the only means for gathering information. This is especially true in pediatrics as many times patients are not able to properly communicate with physicians to express their needs.⁴⁴

Nonverbal communication helps to create rapport between physicians and families by establishing immediacy, or the degree of perceived closeness, in a relationship by signaling warmth, availability, and decreasing distance.⁴⁵ Doctors who are nonverbally immediate will appropriately use eye contact, stand closer to their patients and families, listen attentively, use appropriate amounts of touch, smile, and/or use a warm tone of voice. Physicians who are nonverbally nonimmediate may avoid eye contact, keep a distance between themselves and the patient and their family, and avoid using touch. Nonverbally immediate behaviors improve interpersonal relationships and communication. Research has shown that as immediacy behaviors increase interpersonal relationships improve. This suggests immediacy increases the amount someone likes you and, therefore, liking someone inspires more immediacy. Physicians who are immediate are seen as more competent communicators and more responsive to patient's empathetic needs. When physicians use immediacy behaviors it shows patients that there is mutual likeability and value in the relationship.⁴⁶ If physician's wish to build rapport between

themselves and their patients and families they should use immediacy behaviors that will increase their likeability and approachability. Some examples of immediacy behaviors having a positive impact are standing close to the patient and their family, leaning forward and facing the patient directly when seated, using eye contact, and using greetings that require touch such as a handshake. When physician's use immediacy behaviors in their communication style they are seen as being more approachable and help reduce uncertainty about the physician and the situation.

Research also suggests that when physicians use nonverbal immediacy behaviors they are viewed as being more responsive, understanding, and assertive. They are viewed as being good listeners and know when to respond appropriately. When a physician uses nonverbal immediacy behaviors they also decrease the status differences between themselves, the patient, and their family. More effective communication takes place when the physician is able to decrease the status difference without sacrificing their expertise. As immediacy behaviors increase so does the feeling of solidarity; likewise, as solidarity increases immediacy behaviors increase.⁴⁷ Rapport is more likely to increase when a physician uses immediacy behaviors.

Immediacy behaviors have also been shown to decrease patient anxiety and fear regarding their physician. This also leads to more positive medical outcomes. Nonverbal immediacy behaviors, when used appropriately, are exceptional tools for establishing rapport between doctors, patients, and their families.⁴⁸

Northouse and Northouse established a model of health communication accentuating how factors such as relationships, transactions, and contexts can influence communication. Their model defines four major types of relationships in existence in the healthcare setting: professional-professional relationships, professional-patient relationships, professional-patient's

family relationship, and the patient-family relationship. This model emphasizes the importance of the patient and their family when establishing rapport in healthcare, and how those relationships affect the health of the patient. Northouse and Northouse highlight the notion that the relationship between the patient, the family, and the physician will influence the content of the communication and how the message is interpreted.⁴⁹ This model also acknowledges that all interpersonal relationships in the healthcare setting can influence other relationships within the same setting. For example, how a physician communicates with another physician can affect how that physician communicates with their patient and family. The health communication model notes health transactions, or health-related communication, are most operative when verbal and nonverbal messages align with each other. This model also considers the importance of the context in which the communication takes place. The context here considers the setting where communication occurs as well as the participants in the communication transaction. Communication may be one-on-one, triadic, in small groups, or even large groups.⁵⁰

Overall, the importance of semiotics and building rapport is insurmountable in health care. Successful health care transactions rely on developing and maintaining relationships with the patient and their family. The quality of the relationship is dependent upon the quality of the communication transactions. Physicians must be able to garner trust in their patients and their families and establish their credibility by meeting the patients' needs to build rapport and maintain necessary relationships between the patient and their family.⁵¹

This section has identified the semiotic tradition and established how the semiotic tradition can be used to establish rapport between the physician, patients, and their families.

b. Sociocultural Tradition

The sociocultural tradition focuses on how we gain meaning about norms, roles, and rules through communication interaction and how our cultures, groups, and communities effect those interactions. This tradition concentrates on how people create realities together through communication, and, thus, creates meaning.⁵² The sociocultural tradition is focused on conceiving how connections are made between societies and interactions within those societies. Communication is therefore imperative to one's social construction of reality or their worldview. The sociocultural tradition examines the importance of social roles and cultural identity.⁵³

This section will explore the key elements of the sociocultural tradition and how the sociocultural tradition can be used to establish rapport in pediatric critical care.

i. Key elements of the sociocultural tradition

In the sociocultural tradition identity is constructed through interactions in groups and within cultures. Identity defines the roles one plays within communication interactions. Context is a cornerstone to the sociocultural tradition as it recognizes that symbols are important to the communication transaction, but also acknowledges those symbols will have different meanings based on different communicators in differing situations.⁵⁴ When people share the same language, beliefs, values, it makes communication flow in a more straightforward manner. When there is too much diversity among languages, beliefs, and values, it can create conflicts and misinterpretations between the communicators. The sociocultural tradition is important to pediatric critical care medicine because it can assist physicians in dealing with strain in the relationship between patients and families when their backgrounds, beliefs, and values do not align, and when patients and families appear to be uncooperative due to their beliefs and values. The sociocultural tradition recognizes that every person has a distinct cultural background which

may affect communication transactions between the physician, patient, and family.⁵⁵ Culture, in this sense, can generally be defined as a set of beliefs, values, attitudes, and norms that are mutual amongst a certain group of people. Culture is a way of life for a group of people. Multicultural describes the existence of multiple cultures and subcultures that can be defined by race, gender, age, ethnicity, etc. Diversity refers to the different cultures and ethnicities that exist within a group.⁵⁶

Symbolic interactionism is a descendant of the sociocultural tradition focusing on how relationships are created and maintained through communication. Symbolic interactionism notes that the more interaction people have with each other the more they will begin to share meaning and understand realities. Important to the study of pediatric critical care in medicine is the social construction of emotion. Symbolic interactionism recognizes that emotions are created through communication and influenced by culture. People in different cultures may assign different meanings to different emotions such as fear, anger, sadness, grief, etc. How one responds to those emotions and what those emotions look like will be dependent upon culture and social interaction. When people enter new situations in life such as having a critically ill child, how they understand and react to those emotions will change.

The way in which people present themselves, or the presentational self, is also important to the sociocultural tradition. The presentational self notes that communicators are metaphorically the actors of life; they must decide how to perform when communicating. People must decide how to communicate, how to position themselves, and how to act within the communication interaction. Physicians must present themselves and communicate in a way that their patients and family members will understand and accept. In such a situation, information

must be communicated and collected in a manner that allows everyone within the communication interaction to know what is expected of them.⁵⁷

The communication theory of identity is a fragment of the sociocultural tradition that explores personal identity from the perspective of the individual, the communal, and the societal. Communication bridges the gap between these identities. Identity is established through communication and can always be altered based on the communication situation. Identity is formed when the views of others are assumed during communication, and people communicate their identities by expressing themselves to others. There are four layers of identity recognized by the communication theory of identity. The first layer is the personal layer which is one's sense of self within social interaction. The sense of self consists of how people feel about themselves and how they project themselves in certain situations. The second layer is the enactment layer. The enactment layer allows others to form a perception about you based on what you do, how you act, and what you have. The third layer is the relational layer; it defines who you are in relation to others. Identity is constructed during communication with others. In pediatric critical care there is the patient, who is a son or daughter, and their parents, who are likely the surrogate decision makers. The last layer is the communal layer. This layer is one's cultural identity based on what the community one belongs to thinks and does.⁵⁸

Identity negotiation theory is similar to the communication identity theory as it explores how people convey their identities during communication with others. The theory examines the cultural identity people assume and how communication is affected when communicating among different cultural groups. When people communicate with others from similar cultures they tend to feel more secure, included, and consistently connected. When people communicate with

others from different cultures they tend to feel susceptible, unpredictable, and sense a lack of permanency in the communication transaction.⁵⁹

The next section will discuss how the sociocultural tradition in communication can help establish rapport in the doctor-patient relationship.

ii. The sociocultural tradition and establishing rapport

The sociocultural tradition is an important communication tradition to pediatric ethics guiding physicians to be mindful of their audiences. The sociocultural tradition prompts physicians to see each patient as an individual by recognizing the medical literacy, cultural norms, and values that patients and their families may have. Physicians are not exempt from working with patients and families from many different backgrounds. Sometimes those cultural values and norms affect the way patients and their families view and react to a diagnosis.⁶⁰ In a 1994 report by the AAP Task Force on Minority Children's Access to Pediatric Care, the AAP outlined concern for health care delivered in accordance to the majority culture. When this occurs patients from different cultures may have difficulty in the healthcare delivery potentially causing adverse effects on health outcomes.⁶¹ Demographic changes have already altered how pediatricians provide care for their patients, and changes will continue to occur prompting pediatricians to provide care to many culturally distinct populations.⁶² In fact, the United States Census Bureau estimates that by the year 2020 44.5% of American children will belong to a racial or ethnic minority group.⁶³ Cultural and ethnic backgrounds can strongly influence communicative behaviors. People from different ethnic or cultural backgrounds may speak different languages or dialects. People may even communicate in the same language, but there may be cultural barriers that can create interpretation and understanding issues.

Communication styles also vary among different cultural backgrounds. Individualist cultures tend to be more assertive when communicating while collectivist cultures are more passive and show respect for authority and accommodate others.⁶⁴ In the realm of healthcare, individualist cultures believe that patients and their immediate families should make autonomous clinical decisions. In collectivist cultures individuals are to consider their own needs after first reflecting the needs of the community of which they are a part. Collectivist cultures are also cautious to control their nonverbal communication in ways that will exemplify group solidarity and respect the status of the perceived hierarchy. People from collectivist cultures also tend to avoid situations where conflict may arise. Some cultures, such as the Mexican-American, culture discourage questioning others in conversation and, therefore, patients from this culture may be hesitant to ask questions that may possibly hinder the overall health of the patient.⁶⁵

Cultural and ethnic backgrounds can also affect how people interpret wellness and illness, which will in turn affect the result of the medical encounter. For instance, in the Chinese culture disease is viewed as a disharmony signifying imbalanced health. In the African culture, they tend to use spiritual, magical, and herbal treatments. In Middle Eastern cultures, they view disease as a familial event in which the whole family takes on the illness.⁶⁶ Perceptions of diagnosis and prognosis often differ among different cultures, and these discernments can influence how approachable patients and family members are to certain treatment options. Physicians should be careful not to label patients and family members as non-compliant based on differing cultural views. Physicians should avoid being ethnocentric as it makes them less tolerant of others and, therefore, would be detrimental to building rapport and the ethics of care. When physicians are ethnocentric they give precedence to their beliefs and values over the patient's beliefs and values. When a physician can recognize and acknowledge the different

cultural views of their patients they can seek to better understand them and create a partnership to work within the patient's best interests to help them achieve their healthcare goals.⁶⁷

Religion is also pervasive in healthcare and understanding a patient's religious beliefs can be imperative to establishing rapport with patients and their families. Religious beliefs can strongly influence communication and how the patient and their family view the disease, diagnosis, and prognosis. For instance, people from African cultures view blood as the life of a person and, therefore, typically do not believe in donating blood or organ donation. The Jehovah's Witnesses, a religious group, does not believe in accepting blood transfusions because they believe the Bible forbids it. In pediatrics, this can create an ethical dilemma when a blood transfusion may be necessary for life saving measures.⁶⁸ While religious beliefs are never a basis for refusal to provide necessary medical care, for a child it is imperative for physicians to remember that in these situations, effective communication and being mindful of one's cultural and religious beliefs is necessary to seeking common ground.⁶⁹

Cultural and religious values can have major implications on communication and impact rapport in the pediatric healthcare setting.⁷⁰ Culture can affect how patients and their families interpret communication messages. High-context cultures, such as the United States, tend to interpret communication based on a broad set of culturally appropriate rules. High-context cultures tend to be very focused on the nonverbal message, the nonverbal rules, and the hierarchy status of the communicator. These cultures tend to expect others to be able to interpret what they are thinking without verbalizing their thoughts. On the other hand, low-context cultures, such as China, tend to interpret communication based on the content of the verbal message and give less priority to the status of the communicator. In low-context cultures the meaning of the message is derived from the content of the message.⁷¹

Understanding the different contexts patients can exist within is imperative to establishing rapport with patients and family members. Communication and understanding of all parties involved can be enhanced when physicians can understand context and cultural characteristics and incorporate them into communication. This then improves the relationship. There are three approaches physicians can adopt to improve intercultural communication to establish rapport with patients from different cultural backgrounds. The first approach is recognizing the transactional influence of culture on interpersonal relationships. Each person in the health care transaction has their own set of values, beliefs, and worldviews. These differing perspectives influence communication. Physicians must first identify their own cultural beliefs and values to recognize when cultural conflicts with patients and family members may occur. When cultural conflicts arise, physicians must develop skills allowing them to overcome differing points of view. This is also known as cultural brokerage. Cultural brokerage fosters building rapport between physicians, patients, and families by requiring the physician to simplify and understand the patient's perspective, and to bridge any gaps between the physician's cultural values and the patient's cultural values so that a common understanding regarding the diagnosis and prognosis can be reached.

The second approach notes that physicians should provide culturally sensitive care. Culturally sensitive care is formed on the basis of knowledge, respect, and negotiation. Information about a patient's cultural beliefs should be sought directly from the patient and their family as they are the most well-informed about their own beliefs. Physicians should avoid making assumptions about patients based on the idea that people from the same culture all have the same beliefs. Instead, physicians can foster building rapport by recognizing that each patient and their family are individuals with an exclusive point of view shaped by their cultural values.

Physicians can gain knowledge about a patient's cultural values by asking them to describe what they know about their illness, their treatment preferences, and how they view their prognosis. When physicians show respect to their patients, they can incorporate cultural beliefs and values into the patient's care when deemed appropriate. Moreover, when a patient feels respected they are more likely to show their physician reciprocal respect. When physicians provide culturally sensitive care to their patients it creates a coalition between the physician, patient, and family members resulting in strengthening their overall relationship. Lastly, physicians should implement culturally based resources into patient care. The most obvious resource that can be implemented is a translator or an interpreter to help patients bridge communication gaps.⁷²

The AAP recommends that culturally competent healthcare should be maintained through medical school, residency, and continuing medical education. Such education should increase the physician's knowledge regarding their patient's cultural values to provide care that is receptive to each individual patient's cultural needs resulting in increasing interpersonal communication and overall rapport.⁷³ Physicians should be aware of their hospital's community-based services to different cultural groups and offer those services to patients and families when appropriate. When physicians increase their knowledge about their patient's cultural beliefs and values they become more reverent and sensitive to their patient's wishes. This fosters more effective intercultural communication and thus helps physicians build and establish rapport with patients and family members.⁷⁴

2. Ethics of Care

The ethics of care is undoubtedly necessary for establishing and maintaining rapport between patients and family members. The ethics of care requires physicians avoid objectifying patients by their disease or ailments, and instead view them as a person first. The ethics of care

also notes that respect for patients goes beyond just providing them with informed consent.⁷⁵ When people consider what they ought to do in certain situations, they must consider the relationship and the complexities of the individuals involved. The ethics of care expresses that our responsibilities to others are a direct result of the relationship built between people. A physician's responsibility to their patient's and family members should be grounded in empathy and should be intended to fulfill the needs of the patient and their family. The ethics of care requires physicians to ground their actions and attitudes on the basis of care and not on the value of giving and receiving care.⁷⁶ Empathy forces physicians to care for the patient beyond the means of physical care and to be interested in the patient as a human being.⁷⁷ Care is imperative to survival. Without care no one would survive. Everyone has individual basic needs which must be met. For children to grow sufficiently they must feel cared for and valued by those with whom they engage in relationships.⁷⁸

a. Relational Autonomy

A relational approach to autonomy in healthcare is cemented in the ethics of care and establishing rapport with patients and family members. Relational autonomy can be understood through the relationships and social atmosphere which the autonomous individual exists within.⁷⁹ Relational autonomy is imperative for physicians to understand as it holds in high regard the social context in which patients and family exist. Relational autonomy is thoughtful of the emotional aspect of patient and surrogate decision-making. Autonomy in health care has evolved from a paternalistic approach where the physician was in control of decision-making to a standard approach where physicians provided scientific medical evidence, but provided no regard for the emotional aspect of decision-making, to a relational approach which respects the roles others play in clinical decision-making and the emotions that may be involved. In a relational

approach to autonomy physicians are expected to involve patients and surrogates in the decision-making process in a way that engages their emotional experiences while providing them with clear direction regarding their diagnosis and prognosis. Relational autonomy is especially important in pediatric critical care as parents often must make decisions for their child who is emotionally laden.⁸⁰

This section will provide a comprehensive explore of relational autonomy to understand how relational autonomy is necessary for establishing rapport with the ethics of care.

- i. Understanding relational autonomy

Understanding how relational autonomy has evolved today requires one to understand differing models of autonomy in relation to clinical decision-making. Foremost, personal autonomy in health care encompasses the notion that autonomous patients or surrogates should be able to act freely and choose a care plan without unnecessary intrusion from others or other limitations such as insufficient knowledge regarding the diagnosis, prognosis, or treatment.⁸¹ The first model of autonomy is the individualistic approach. In the individualist approach to autonomy it is assumed that the decision maker is in control and has the ability to disregard emotion and focus on the rational scientific aspects of decision-making. While the individualist approach to autonomy does require patients and surrogates to receive transparent information regarding their diagnosis, prognosis, and treatment options, it is lacking in that it is individualistic and necessitates physicians to ignore any emotional aspects of the decision-making process. The individualist approach assumes decision makers can be cogent and practical and not be influenced by emotional or personal predilections. If the decision-maker elicits to their emotions, then it is considered that their willpower is deficient and their autonomy is therefore destabilized. Under an individualist model of autonomy in pediatrics, pediatricians

are required to provide transparent facts necessary for clinical decision-making, and surrogate decision makers are to interpret the facts and decide on a treatment for their child with regard to the best interests standard. Under this approach if surrogates ask physicians for their opinions in the decision-making process physicians should not provide any recommendations beyond the objective facts. Otherwise, this may be seen as morally inappropriate and reducing the surrogate's autonomy. This model also assumes parents should never consider anyone but the patient when making decisions. The impact of treatment on the family structure should not be considered because it would not be considered in the patient's best interests. The individualist approach appoints surrogates as being "on their own" in the decision-making process. Clinical decisions should always be absent of emotion and defended on a rational scientific basis. The individualist approach to autonomy does not recognize the inclusion of children in medical decision-making as it assumes children cannot offer any significant input.⁸²

The relational autonomy model recognizes that one's identity is formed within their social relationships and that people are not truly isolated individuals as they are a product of their relationships with others. The relational autonomy model considers the emotional aspect of decision-making to be of high importance, particularly in pediatric critical care. The emotional facet of decision-making is not seen as being irrational; rather, those emotions highlight the experience parents with ill children go through. In the relational autonomy model physicians are expected to involve surrogate decision makers in a way that considers the emotional aspects of decision-making. Physicians should also allow surrogate decision makers to consider the impact the diagnosis, prognosis, and treatment will have on the entire patient's family and social structure, as treatments do not just affect the individual patient. The best interests standard under the relational autonomy model supposes that surrogates must consider the best interests of the

patient and meet their needs, but they may also consider the interests of the family. For instance, a parent may make the decision to take their terminally ill child home. This would mean forgoing certain treatments only available in the hospital setting, but it would be in the best interests of the patient and grieving family to have the child home.

Self-sufficiency is gained through patients and surrogates communicating with each other and the physician about the interests of the patient. Physicians are often asked to discuss the scientific aspects of the diagnosis, prognosis, and treatment as well as the emotional implications for the patient and family. Such discussions are not seen as being irrational as the emotional experience is equally important to the decision-making process. Physicians should not reject treatment decisions made by surrogates that consider the rational emotional aspects of treatment. Physicians may even be asked to provide their opinion in the decision-making process. Surrogates may also seek opinions from other important family members such as grandparents. The relational model for autonomy also seeks to include patients who have the capacity to contribute to the decision-making process. Physicians should help parents learn how to appropriately include their child in the clinical decision-making process. Patients who are competent should have some control over their care while parents are still responsible for making certain all decisions are made in the patient's best interests. The relational model differs from the individualist model as it recognizes that impartial facts are not the only basis for decision-making. While the individualistic approach to autonomy protects surrogate decision makers and patients from paternalistic physicians and coercion, it denies physicians the ability to create rapport and it is not in line with the ethics care.⁸³

ii. Relational autonomy and establishing rapport

Relational autonomy and establishing rapport is multifaceted in pediatric clinical decision-making, and how autonomy is theorized will ultimately affect how rapport is established. As previously noted, in pediatrics, the patient often lacks the legal capacity to make decisions and, therefore, a competent surrogate, typically a parent, must make decisions on their behalf. In deliberating, the surrogate might sometimes include the opinions of the competent patient. It is anticipated that pediatric surrogate decision makers will always work within the best interests standard and not be negligent to the patient. However, relational autonomy in pediatrics is further complicated for pediatricians as they must respect the autonomy of the surrogate decision maker and the patient. When physicians adopt the relational autonomy approach it can facilitate rapport between the physician, patient, and family. The physician's role under this model is to provide objective facts, but the role also requires attending to the emotional needs of the patient and their family members. Trust is garnered through conversations about the emotional aspects of the diagnosis, prognosis, and treatment, and forsaking families during these emotional times would void the providers responsibilities. Physicians have a moral obligation to assist families and patients and show empathy through emotionally laden times. This simultaneously helps build and maintain the provider-patient relationship. Undoubtedly, an individualist approach to autonomy would not help build rapport as it discourages physicians from providing any direction during difficult and emotional times. A relational approach to autonomy fosters rapport as it helps families engage in a way that acknowledges valid emotions and encourages parents to include making decisions for their child in a way that acknowledges their best interests and expresses their love for them.⁸⁴

Under the relational model of autonomy physicians are required to show empathy for patients and families. Empathy, in turn, helps foster rapport between the physician, patient, and family members. Empathy is a variable of health communication held in high regard. Empathy affects communication and relational outcomes and is necessary for effective interpersonal communication. Without empathy, there is a lack of understanding between the persons involved. Empathy helps to establish and maintain rapport by allowing physicians to feel what their patients feel and understand their feelings from their patient's perspective. Many times patients and family members express the need to be understood. When physicians show their patients and family members empathy they acknowledge their point of view. When physicians show empathy, it reduces the patients and family members feelings of abandonment or being isolated in their situation. Patients feel more connected to their doctor when they feel as though their physician understands them. Empathy can also help patients and families adjust better to the situation by providing a sense of self-control. Physicians must be cognizant to the meaning the diagnosis has for the patient and family. When physicians show empathy, it helps them to improve their communication with patients, and reduces communication issues between other physicians. Empathy helps physicians interpret their patient's communication in a more precise manner, because they can see things from their patient's point of view. Better communication enhances the relationship.⁸⁵ Empathy also aids communication and thus rapport by forcing physicians to listen to their patients. When actively listening to their patients, physicians can often find hidden clues beyond the patient's main grievance helping to aid the diagnosis and treatment. Such information can also help physicians better understand the patient beyond their symptoms and their diagnosis. This is an important aspect of building rapport in medicine.⁸⁶

b. Meeting the Needs of Others

Meeting the needs of others, particularly in pediatrics, is an integral part of effective health care. Yet, meeting the needs of pediatric patients can pose some difficulties as pediatric patients often differ greatly in terms of age and developmental status. Understanding the different needs of pediatric patients in different development stages can greatly enhance the doctor, patient, and family relationship. Research shows that parents of pediatric patients ages newborn to five years old may have more needs requiring attention in order to cope with pain management for their child. Many children in this age group may have difficulty expressing their pain or what they wish to have done in terms of pain management which can cause anguish for the parents as well as the patient. These families will typically require more empathy and attention regarding pain management, whereas older pediatric patients who also need to have their pain managed can communicate with physicians better in terms of what needs to be done to meet their pain management goals. Families with younger children also typically need more time spent on discharge instructions and reassurance that they can care for their sick child at home in comparison to families with older children. Research outlines that the patient experience, and thus, relationship with the physician, are influenced by the ways in which physicians meet their patients age-related needs in pediatrics.⁸⁷ Meeting the needs of patients requires that physicians imbed themselves within their patient's story by learning what it means to be sick and well to the patient. This allows for physicians to not only provide medical treatment to the patient, but to also build a relationship with them.⁸⁸

This section will review the importance of developing caring relationships and meeting individual patient needs.

i. Developing caring relations

Developing caring relations in healthcare is imperative to establishing rapport with the ethics of care. The ethics of care hypothesizes that others are affected by their relationships with their relations of care. The ethics of care supposes that caring relations should be mutual. When they are it creates an environment where the people in the relationships will work to create relationships with the right motives. When caring relations are developed it not only shows physicians how to respond to their patients, but also why they should respond to them in that manner. This in turn builds trust and rapport between the physician, the patient, and their family members.

The term “care” and what it means to care has some peculiarities that must be defined to understand how caring relations are developed. Although one could assume physicians like all the patients for whom they provide care, when physicians care for a patient they go beyond just providing care from maintaining necessary medical equipment. Care is the work that goes into providing thoughtfulness for patients to meet their needs. Care also encompasses the physician’s motives to meet their patient’s needs. Care is not only the physician’s intent to have concern for a patient, but it also encompasses partaking in developing caring relations with the patient. Care is not something that can be defined as being only good or bad; care must encompass being attentive to patients, being sensitive to patients, and attending to patient’s needs. Care should be seen not only as an exercise, but also as a value. A physician’s caring attitude should be valued by the patient, their family, and the healthcare system. When caring relations are built between each patient and their family members, it can create an entire environment of caring within the healthcare system.⁸⁹

When caring relations are developed it helps to encourage the maintenance of rapport. Caring relations require that those providing the care be sensitive to the feelings of those being cared for. When a physician provides care for a patient they must show empathy towards the patient by paying attention to the patient's feelings, needs, and point of view.⁹⁰ Empathy is essential to caring relations. Patients are unlikely to trust a physician or want to develop caring relations with physicians who are viewed as being detached. Empathetic physicians increase trust by valuing each patient as an individual. Empathetic communication shows patients that physicians care about them, because it requires physicians to listen to patients carefully and set their own personal values aside to see things from the patient's point of view. When physicians are empathetic it encourages caring relations by helping patients feel as though they are understood and valued and have some sort of control over their situation.

Confirmation is another variable in the healthcare setting that displays similarity to empathy. Confirmation can help build caring relationships. It requires physicians to respond to their patients in a way that acknowledges their unique perspective and individuality. Physicians can confirm the importance of each patient's existence by validating their experiences and providing support for their individual problems. Confirming responses helps physicians and patients to maintain a sense of connectedness, especially when patients may feel disconnected from the things they are used to outside of the hospital.⁹¹

Trust is another concept central to building caring relations and establishing rapport through the ethics of care. Trust is imbedded in the relationships between people and cannot be isolated. Respecting others' lives and personal belongings are values contributing to making one trustworthy. Trust is imperative for care as it is an understanding that the physician will have

responsible intents towards their patients. Although trust itself does not provide patients with the care they need, it is necessary to create caring relations between the physician and patient.⁹²

Trust exists when the patient believes the physician will act in ways beneficial to the physician-patient relationship without trying to be in total control of the relationship. Trust is a necessary for building and maintaining all relationships. Trust is especially important in health care as patients often feel vulnerable. Relationships flourish when hen patients trust their physicians. Trust aids communication by creating a climate where patients feel they can openly communicate with their physician. Trust in healthcare is two-fold. Patients tend to trust their physician if they believe they are credible and if caring relations are developed between the physician and patient. Physicians must be aware of the two ways which often fosters trust with patients. Often physicians will spend so much time proving their credibility to patients that they may ignore the interpersonal elements necessary for developing caring relations leading to trust. To develop trust physicians should be sincere in their communication, credible, and predictable when possible. Trust is further enhanced when physicians use supportive communication over defensive communication strategies. If physicians use a defensive tone of voice or communicate defensive content then the patient will often distrust the physician. When a physician tries to control a patient's beliefs, attitudes, or behaviors through communication it often results in distrust. Physicians can use problem-oriented communication instead, which seeks to define the problem and provide a solution without pointing fingers. Patients are also more likely to trust physicians who communicate in straightforward, open, and honest ways. When physicians try to push their superiority on patients in a negative way it often distorts trust, as patients are much more likely to trust physicians who exhibit equality in the problem-solving relationship.⁹³ The

next section will discuss how physicians can meet the needs of others by addressing patient's individual needs.

ii. Addressing individual needs

Meeting the individual needs of patients is imperative to the patient's overall well-being. Attending to a patient's needs involves meeting their basic needs but also meeting their physical, psychological, and cultural needs. When physicians care for their patients it should express care in a way that builds relationships in a morally acceptable way.⁹⁴ Pediatricians should strive to meet their patient's individual needs in a manner allowing them to live as normally as possible given their situation. Meeting individual patient needs should encompass both the physical and emotional needs of the child. Physicians should seek ways to minimize the obtrusiveness of the intensive care unit by encouraging family visits, playing, learning, and other normal activities children may enjoy. One of the main goals of health care is to meet the physical needs of the patient. Physicians should strive to meet the individual physical needs of each patient as they may differ from patient to patient. Comfort is imperative for pediatric patients, especially for those patients who have chronic or life-threatening diseases. Physicians should seek information from the patient and family regarding the patient's physical pain. Parents of children who are intensively or chronically ill are often able to recognize physical discomfort immediately; they also typically know how to comfort their child and can predict how they will react to certain treatments and procedures. Research shows that parents want to be listened to regarding their child's illness, and they want to be recognized as experts regarding their child. When physical pain is not properly dealt with it can cause distress for both the patient and the family and can make pediatric patients uncooperative with other therapies.⁹⁵

Pediatricians should always manage individual patient symptoms based on an individual symptom assessment. Once an individual symptom assessment is completed a care plan should be developed that is tailored to the patient's needs. Physicians must also consider the distinct characteristics of each patient when developing the care plan. Physicians should consider the patient's personality, medical experiences, cultural values, coping mechanisms, age, and competence. Physicians should properly document symptoms and attempt to measure symptoms in a meaningful way to determine if interventions have been successful in the management of symptoms. Physicians should consider less taxing medical interventions when possible. If less burdensome alternatives are not available doctors may consider using complementary medicine such as a child life specialist to assist with relaxation and distraction from physical discomfort. Other forms of complementary medicine include acupuncture, massage therapy, or aromatherapy.⁹⁶

Although it is important to accommodate the physical needs of each patient, it is also imperative to the patient's well-being to address their individual emotional and psychological needs. Physicians should conduct individual psychological assessments to create an all-inclusive plan of care for the patient. Many children will experience emotional side effects as a response to their illness. Pediatricians should include mental health professionals in the child's care when necessary as some children may exhibit signs of depression, anxiety, emotional suffering, or traumatic stress. Physicians should seek to understand the patient's perception of their situation, they should be attentive to the patient's symbolic language regarding their disease, and they should reassure patients it is okay to express their feelings regarding their diagnosis, prognosis, and treatment. Some patients may also be concerned with their appearance and this may cause them emotional distress and feelings of isolation. Physicians should be sensitive and aware of

these types of cues. Doctors should also be aware that different patients may express themselves in different ways, and they should be attentive to the ways in which their patients convey themselves. Some children may express their emotional needs through writing, telling stories, keeping a journal, or even drawing. Sometimes a child's artistic expression can reveal the emotional anguish they feel. Encouraging young children to play and being attentive to their communicative cues during play is also important to meeting the individual needs of each patient. Imaginative play can help children express their emotions.⁹⁷

Caring for patients, especially children, at the end of their life can be extremely taxing for all parties involved. Physicians should be cognizant of the needs of the patient and their family members at the end of the patient's life and should strive to meet those needs. To meet patient's needs at the end of life physicians should refer to the philosophy of palliative care. The philosophy of palliative care aims to improve the patient's quality of life beyond the purpose of healing to prepare them for a good death. It focuses on the patient as a person rather than on the patient's illness. Furthermore, the theory attaches a high degree of value to the partnership between the physician, the patient, and family members.⁹⁸ Meeting the physical and emotional needs of dying children is demanding yet necessary. Physicians, families, and patients, will need to work together to meet those needs. It is also important to note that meeting the patient and family's needs does not halt as soon as the patient passes away. Many times, there will be needs that must be met following the patient's death such as; providing the family with resources for bereavement care.⁹⁹

Meeting the needs of the patient's family has also proven to be important. While the child's pediatrician is not the primary care physician for the patient's entire family, pediatricians should still be attentive to physical and emotional needs of the parents and siblings of the patient.

The wellness of the family unit will affect the individual patient's well-being. The impact of the patient's diagnosis often requires support for both the patient and the family. Physicians should be attentive to the emotional needs of the family and should offer appropriate available resources or referrals to them. If a patient has siblings, the siblings may also have needs that will need to be met as well. Siblings often require emotional support to help them deal with the reality of the patient's illness. Physicians should strive to help siblings understand the illness and address any uncertainties the sibling(s) may have.¹⁰⁰

As previously delineated, the cultural values and needs of patients can have a major impact on communication and, thus, rapport within the physician-patient relationship.¹⁰¹ Physicians should strive to meet their patient's individual needs by addressing cultural values pertinent to the healthcare transaction. The AAP recommends that physicians should meet the needs of their patients by delivering culturally effective pediatric care. Furthermore, pediatricians should strive to provide high quality clinical care as outlined by the Institute of Medicine (IOM). The IOM indicates that pediatricians should provide the type care to their patients and families that does not waiver in quality based on a patient's personal characteristics such as gender, ethnicity, or socioeconomic status. Pediatricians must be prepared to provide healthcare to patients based on their individual cultural needs. To deliver culturally effective care in the pediatric setting physicians should have knowledge and appreciation of their patient's cultural differences in order to lead to ideal health outcomes. When physicians address the individual cultural needs of their patients and families they increase interpersonal communication and strengthen rapport leading to better care for the patient. The AAP outlines several guiding principles to assist pediatricians in providing effective individualized culturally appropriate care to their patients. The first principle recommends physicians should

communicate with their patients that they are open to working with different cultures and cultural differences. The second principle states that pediatricians should be willing to adapt (when applicable and within reason) their clinical practice to meet the needs of their patients and family's cultural values. Third, pediatricians should strive to continuously obtain new knowledge regarding cultural competence. Lastly, pediatricians should consider the individual cultural variables each patient may have.¹⁰² Physicians should also be aware of the religious values of the patient and family in order to meet their spiritual needs. Physicians should respectfully seek out the patient's religious values when appropriate and provide them with referrals to meet their needs. Chaplains or other religious figures can help families cope with their feelings and discuss their beliefs aiding in facilitating feelings of comfort and hope.¹⁰³

Meeting the individual needs of patients is imperative to the ethics of care and can be achieved through developing caring relations with patients and families. As noted, the main focus of the ethics of care is meeting the needs for whom one takes responsibility. The ethics of care recognizes the importance of meeting the individual needs of those who are dependent in order for progress to be made.¹⁰⁴ Focusing on individual patient and family needs is necessary as medicine is not a one size fits all venture. What is deemed appropriate for one patient may not be deemed suitable for a patient in a similar situation given their individual needs. To meet their patient's needs and thus help build and maintain rapport, physicians should focus on the golden rule of how they would want to be treated and have their needs met if they were the patient.¹⁰⁵

Conclusion

This chapter has focused on how physicians can establish rapport with their patients through the ethics of care. This chapter reviewed symbolic communication traditions, specifically the semiotic tradition and the sociocultural tradition and how they can be applied to

establishing rapport between physicians and patients. The ethics of care was also delineated and focused on relational autonomy and meeting the needs of others. Relational autonomy was explored in terms of how it is useful in establishing rapport. Lastly, how physicians can meet the needs of their patients through developing caring relations and focusing on individual patient needs was discovered. Chapter four will provide information on how physicians can manage uncertainty in veracity for surrogate consent.

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Chapter Four: Managing Uncertainty in Veracity for Surrogate Consent

Determining an accurate prognosis is not always a straightforward task for physicians. A physician does not have an exact scientific equation able to accurately calculate every patient's diagnosis and prognosis. Providing prognostic information for pediatric patients is especially challenging as much of the research includes adult patient data. Patterns of childhood disease and death often differ from adult patients. The same disease in adult medicine may follow a completely different course in pediatric medicine depending on how well the pediatric patient can tolerate treatments. Furthermore, some childhood diseases and disorders are so rare that physicians have little to no information regarding the disease or prognostic details. Therefore, physicians must rely solely on their own clinical judgement to treat the patient. When a diagnosis and prognosis are truly uncertain it does not mean the patient does not deserve honest communication about possible treatment and outcomes. While prognostic uncertainty is inevitable in medicine, especially in pediatrics, obtainable prognostic information is necessary for managing uncertainty in veracity for surrogate consent.¹ Research indicates that when uncertainty in communication is reduced satisfaction with the communication transaction increases.² Surrogates of sick children deserve to have all available information regarding their child's condition and prognosis communicated to them. Having accurate prognostic information can influence how medical and lifestyle decisions are made. It is also important for physicians to communicate with patients and surrogates when patients are waiting for a confirmation of a diagnosis. Sometimes there is a period of uncertainty and waiting that occurs as test results are pending or as the disease progresses. Nonetheless, discussing prognostic information requires the physician to be compassionate, have empathy, and engage in teamwork with the patient and their family.³

This chapter will review uncertainty communication theories including management and reduction theories and how they aid veracity for surrogate consent. Framing communication and methods of framing communication in uncertainty will be discussed alongside the effects of framing on surrogate decision-making. Next, veracity for surrogate consent will be considered in detail along with beneficence and best interests. Lastly, disclosure and impartiality will be delineated in reference to how physicians can properly disclose information to patients and families and what it means for a physician to remain a neutral party.

1. Uncertainty Communication Theories

Uncertainty in pediatric medicine is expected, yet how the communication surrounding the uncertainty is dealt with can have an impact on the physician-patient relationship. This will in turn influence the perceived reliability of the physician and surrogate consent. Uncertainty communication theories seek to understand how one gathers information about others, why one chooses to gather information about another person, and then what one does with the information gathered. Uncertainty communication theories aid in the management of uncertainty in communication and anxiety when communicating.⁴ The method of framing tends to go into effect in situations where uncertainty is not properly managed and reduced. In these situations, the message is framed in either a positive or negative view and then impacts informed consent and how treatment options are presented.⁵

This section will review uncertainty management, reduction theories, and framing communication in uncertainty.

a. Management/Reduction Theories

Uncertainty management and reduction theories are imperative for physicians to comprehend as they are a cornerstone to understanding how relationships grow during

preliminary interactions between the physician and the patient. When a physician and patient meet for the first time one of their main concerns will be how to reduce the uncertainty surrounding the situation and how to increase the predictability within the communication transaction. This type of uncertainty present is often uncomfortable for both parties and can at times lead to anxiety if not properly dealt with.⁶ Uncertainty reduction theories seek to cultivate relationships by increasing predictability in communication transactions and to help communicators “make sense” of what is going on.⁷ Uncertainty reduction theories are relational communication theories seeking to illustrate how people manage their relationships.⁸ Identifying uncertainty management and reduction theories will be discussed as well as their implications on veracity for surrogate consent.

- i. Identifying management/reduction theories

Uncertainty reduction theory, coined by Charles Berger and Richard Calabrese, focuses on the process of how we gain information about other people. People generally do not like ambiguous situations and, therefore, are motivated to reduce uncertainty to create a more predictable communication environment. Reducing uncertainty is one of the first obstacles of developing a relationship with others.⁹ Uncertainty reduction theories seek to provide an explanation for how and why people communicate to reduce their uncertainty. The theory provides the most rooted explanation of the human communication process during initial communication exchanges.¹⁰ When communicating with others people are often developing a plan to reduce their uncertainty with others. The more uncertain one becomes the more cautious they will become in the communication transaction. When uncertainty is reduced relationships can flourish.

Uncertainty reduction theory has two central focuses. The first concerns what one knows about oneself, self-awareness. The second emphasis is what one may know about others. Self-awareness varies depending on the person and the situation. Some situations require more self-awareness than others. Objective self-awareness, or self-consciousness, notes that the communicator focuses more on themselves than their environment. Subjective self-awareness focuses on the environment where the communicator is located. When a patient is communicating with a family member they may be more calm and relaxed than when they are communicating with their physician. Such self-awareness can also lead to self-consciousness where people tend to monitor the impression they give to others. High self-monitors are very sensitive to feedback, while low self-monitors tend to be less concerned with the impression they are making on others.¹¹

The uncertainty reduction theory notes several assumptions. The first assumption is that when people meet their primary concern is to reduce the amount of uncertainty in the interaction. The second assumption is that uncertainty frequently occurs yet, it is still uncomfortable to deal with.¹² Distance is often created in the relationship when there are high levels of uncertainty. The verbal and nonverbal behavior of the communicators often predicts levels of uncertainty. For example, nonverbal immediacy helps to reduce uncertainty; likewise, a reduction in uncertainty increases nonverbal immediacy behaviors. Reducing predictive uncertainty means that one is interested in reducing uncertainty regarding another individual's behavior in order for them to further reduce explanatory uncertainty, or acquire a better understanding of the other person's actions.

There are different ways in which one might attempt to gather information about another person. Some options are through the use of passive, active, and interactive strategies. The first

passive strategy, is reactivity searching where the communicator is observed reacting to a formal situation. On the other hand, distribution searching is observing how the communicator reacts in more casual situations.¹³ Self-disclosure is an interactive strategy people often use for gaining information and reducing uncertainty about others; the more information you disclose the more information the other person is likely to disclose as well.¹⁴ Self-disclosure is important to reducing uncertainty as it is an essential component to developing and maintaining interpersonal relationships.¹⁵

The uncertainty reduction theory categorizes nine axioms seeking to explain how one goes from entering a relationship with uncertainty to developing a relationship. The first axiom is verbal communication. As verbal communication increases the level of uncertainty should begin to decrease and, thus, communication should continue to increase. The second axiom of uncertainty reduction theory notes that as nonverbal expressiveness increases, uncertainty should begin to decrease. Nonverbal cues such as head nods, perceived closeness, eye contact, and other gestures help to ease uncertainty.¹⁶ Nonverbal cues can also help bring communicators together when uncertainty is reduced.¹⁷ The third axiom is information seeking. As uncertainty decreases the need for information will decrease. In the beginning stages of communication physicians may seek information regarding their patients in terms of occupation and demographic information. The fourth axiom notes that as uncertainty decreases, the level of intimacy in the communication will increase.¹⁸ Initial communication counters are often of low intimacy in the information seeking stage. As uncertainty decreases, communication will reach higher levels of intimacy and more personal and productive health care discussions will take place.¹⁹ Reciprocity is the fifth axiom of uncertainty reduction theory which assumes that lower levels of uncertainty produce higher levels of reciprocity and sharing in communication

transactions. The sixth axiom notes that similarities established between communicators will reduce levels of uncertainty as they provide an explanation for behaviors. Liking, is the seventh axiom to reduce levels of uncertainty in communication. Liking increases when uncertainty decreases. If uncertainty decreases liking is likely to decrease as well.²⁰ Berger and Calabrese noted that people will often seek out similarities in others (axiom six) to increase liking and thus reduce uncertainty.²¹ Axiom eight notes that sharing the same communication channels tends to decrease uncertainty between communicators. The final axiom notes that for communication to be sustaining uncertainty must be reduced by the previous axioms.²²

Anxiety uncertainty management is another uncertainty reduction theory that focuses more on uncertainty reduction in intercultural communication. Anxiety, or being worried or uneasy about the outcome of an interaction, can be an emotional response to the possible negative consequences of intercultural communication.²³ It has been established that people seek to reduce uncertainty in the beginning stages of all relationships, but reduction methods tend to vary from culture to culture based on their context. High context cultures tend to rely on the “bigger picture” for reducing uncertainty, while low context cultures rely on the specific verbal messages being communicated to reduce uncertainty. High context cultures pay more attention to nonverbal cues when seek uncertainty reduction, and low context cultures are more direct in their verbal questions to reduce uncertainty. Uncertainty reduction across different cultures can create feelings of anxiety if the two cultures are not well understood. The less a person knows about another culture the more anxious they will be to communicate in intercultural situations, and in some instances, one may avoid necessary communication altogether. To reduce uncertainty in intercultural communication the communicators may seek to accommodate and/or adapt to one another. The accommodation theory suggests people may

adjust their communication style to mirror the other persons to converge or come together. When communicators use convergence tactics appropriately they may reduce uncertainty by finding one another more predictable and relatable. Divergence, on the other hand, occurs when communicators put too much emphasis on their cultural differences.²⁴

Managing face can also be an important part of anxiety uncertainty management theory. Face-negotiation theory focuses on how people will accomplish face-work in different cultures. Face is essentially how one appears to others. Face-work is what people use to communicate and protect their own face. When face is threatened it can be because of conflicting values or sentiments.²⁵ In some instances, people may insist on only communicating with those who identify with their same cultural background. In such instances separation can occur where people resist communicating with others who are not from their cultural background. When uncertainty is not reduced stereotyping and ethnocentrism may occur.

Physicians should be aware of the consequences when intercultural uncertainty is not properly managed in communication transactions. Physicians should be mindful of patient and family values and attitudes and should seek to apply uncertainty reduction techniques for effective intercultural communication and relationships.²⁶

ii. Management/reduction theories and veracity for surrogate consent

Uncertainty reduction/management theories have been presented from a theoretical perspective. This section will seek to integrate those theoretical views into practical use for physicians when providing authentic information regarding diagnosis and prognosis for informed surrogate consent in pediatrics.

Veracity, or truth telling, denotes the honest disclosure of information to patients when the physician- patient relationships heavily rely on this honesty.²⁷ Veracity for surrogate consent

in pediatrics is unique in that it is triangular. So physicians not only have an obligation to their patients, but also to their patients surrogate decision maker and surrogates, therefore, have an obligation to make the best decision on the patient's behalf. As it has been previously noted, pediatric physicians will often grapple with how much information to divulge to patients and families and what information is worthy of passing on to patients and families. Physicians find these conversations troublesome as they wish to keep hope alive or may find uncertain prognostic information difficult to discuss. Physicians may wish to safeguard parents and patients from bad news and the uncertainty of it all can be distressing for the physician, the patient, and the families.²⁸

However, research continuously shows that veracity for surrogate consent is necessary for ethical health outcomes to occur. The physician-patient relationship is centered around trust and patients and family members will not trust physicians if they do not believe they are being given all the information they need to make necessary decisions for their loved ones.²⁹

Northouse and Northouse have identified four approaches to veracity in healthcare. The first approach is strict paternalism where the physician outwardly lies to the patient and their family presumably for the good of the patient. An example of strict paternalism would be a physician not telling a patient they have cancer because the doctor does not want the patient to worry about cancer when they believe the patient will die from another ailment first. The second approach to truth telling is benevolent deception where the physician provides some truthful details regarding the patient, but still withholds information. An example of benevolent deception would be telling a patient or surrogate they have cancer that can be treated while failing to mention that even with treatment the prognosis will still be poor for the patient. Contractual honesty is the third approach where the physician provides details to the patient and family based on the wants

of the patient. For instance, some patients or surrogates may wish to hear only good news or news offering hope. Lastly, unmitigated honesty involves the physician providing the patient and family members with necessary information, even if they may not want to hear it.³⁰

However, as a surrogate decision maker in pediatrics families have the obligation to hear useful information regarding the patient even though they may not necessarily want to be given the information.³¹ While the truth regarding diagnosis in prognosis can at times be cruel, if physician's are mindful of their communication they can communicate even the most brutal diagnoses in a caring manner. Regardless of which type of honesty patients or physicians may prefer; patients and surrogates must receive any information that any reasonable person would need to know in a similar situation to make autonomous choices.³²

The interpersonal relationship between the physician, the patient, and the surrogate is of utmost importance to authentically discussing necessary information for surrogate consent. Research indicates that if patients trust their physicians they are likely to trust a physician's treatment options and plans. Research also shows that patients or surrogates need to feel comfortable with their physician to provide consent. The relationship between the physician and the patient therefore heavily influences consent. Relationships between patients and physicians are influenced by the deeply held values that all parties have and, therefore, discussions about treatment options cannot authentically occur unless the physician has knowledge of the patient's values. In pediatrics, adding family to the mix of consent creates another layer of values that need to be discovered, considered, and appreciated for relationships to flourish.³³ Reducing uncertainty in the pediatric patient is also necessary as providing surrogate consent can be even more strenuous when the patient is showing signs of uncertainty. Uncertainty in pediatric patients with cancer can cause psychological distress and anxiety for

both the patient and parents. Sources of uncertainty in pediatric patients often stems from their fear of death, fear of treatment side effects, unpredictable long-term prognosis, and interruptions in their typical life.³⁴ Research indicates that illness uncertainty in children with cancer is associated with a lower quality of life. Physicians can aim to reduce such uncertainty by improving their communication and thus relationships with their patients. Physicians should communicate honestly about the patient's prognosis and treatment expectations.³⁵ Patients and surrogates who have not had their uncertainty reduced during initial physician encounters may also be apprehensive to share necessary information with the physician. They may not give detailed accounts of their medical history or provide necessary details about their symptoms. Patients and surrogates may also be hesitant to discuss their preferences for treatment options.³⁶ Uncertainty reduction/management theories can therefore be grounded in health care as key components to establishing physician-patient relationships and aiding surrogate consent. When physician's use uncertainty management/reduction theories in their practice it can open doors to establishing a relationship where all necessary information for surrogate consent can be provided in a comfortable setting based on the interpersonal relationship developed between the physician, the family, and the patient.³⁷ Veracity for surrogate consent can help reduce uncertainty in both the relationship and the prognosis and support hope for patients and families, even when bad news may be involved.³⁸

b. Framing Communication in Uncertainty

Communicating medical information with patients is often a difficult task due to the complexities, uncertainties, and instability of information. Communicating with patients and family members about risks and benefits of treatment options for informed consent also proves to

be challenging as physicians must determine how much information to communicate and what is the best way to present information in a fair manner.³⁹

The British Medical Association (BMA) defines risk as the given likelihood that something displeasing will happen.⁴⁰ There is risk associated with everything one does, especially in health care. The challenge becomes how do physicians present risk in a fair manner so patients and surrogates can make truly informed decisions based on the patient's values.⁴¹ When information is not presented in a fair manner by the physician it gives way to framing communication, which is a risky way to mislead patients into certain treatment options.⁴² Framing is more likely to be used by physicians in situations where they believe that their patient or the patient's surrogates do not have strong feelings regarding one treatment or another.⁴³ The method of framing communication and surrogate decision-making will be further discussed.

- i. Method of framing communication

The method of framing communication involves a physician's presentation of information in a way that influences the patient's perception about the information being presented and can affect their ability to make informed choices. Specifically, in health care, framing is often used to manipulate the patient's view of the risks or benefits of a treatment option. Framing can be done in a positive or negative manner and research indicates that patients are much more likely to choose treatment options that are framed in a positive manner. For example, a positive manner would be telling a patient there is a 90 percent survival rate; whereas, a negative manner would be telling a patient there is a 10 percent morbidity rate. Research also specifies that patient preferences and abilities to interpret information based on how it is presented by the physician will vary. Research has found that when physicians use verbal descriptions of risks and benefits such as "likely," there is a wide variability of

interpretation of what “likely” indicates. In some cases, patients reported that likely could range from a 25 percent likelihood to a 75 percent likelihood. Words such as “common” or “rare” that are often used by physicians to describe risks and benefits are also difficult for patients to interpret. Physicians often must discuss risk reductions or risk increases as treatment goals and options change. Physicians can choose to present this information in relative or absolute terms. For example, a risk reduction from ten percent to five percent could be communicated as a risk reduction of five percent, or as being reduced by 50 percent. Presenting information using the absolute risk format is often recommended as the relative risk format can give way to more misunderstandings.⁴⁴ How the information is communicated significantly influences the patient’s and surrogate’s perception and understanding of the given information.

The order physicians present information also influences patient perception regarding risks and benefits as many people correlate order and perceived importance.⁴⁵ Research confirms that the way risk information is presented also influences perceptions of overall treatment benefit. One study revealed that the presentation of absolute survival led to the perception of the weakest benefit; whereas, relative mortality reduction led to the perception of the utmost benefit.⁴⁶

Research has identified several different ways which physicians frame information when communicating with their patients. The first way is negative versus positive framing of risk information. When presenting risk information physicians can describe it in a negative way or a positive way. For example, a physician may present the chances for mortality from a given treatment option over the chances for survival, or they may present the side effects of a medication versus the positive effects of the medication. Another framing method is loss framing or gain framing. In loss or gain framing the physician presents information about the

consequences of different actions. For example, a physician might emphasize the risks of not adhering to a certain treatment option. How the physician presents the information in terms of presenting numerical or graphical information is another method of framing used by physicians. One more framing method involves physicians presenting more or less data about a given treatment option. How physicians communicate about the risks and benefits associated with the treatment in terms of numerical information or verbally describing the information can influence patient choices. For example, a physician may say there is a 90 percent success rate or they may say there are “rarely” any risks to the treatment. Physicians may also use anecdotal evidence from previous patients to present information instead of using science-based information and examples.

Lastly, the language and jargon physicians use to speak about the treatment options can affect a patient’s likelihood of choosing different treatment options. A physician may use medical jargon making it difficult for a patient to understand, or they may use lay terms more easily understood by the patient.⁴⁷

Framing communication is coercive in nature and any type of consent where coercion has occurred is not binding. Coercion strips the patient and their surrogate from making autonomous choices. Physicians should avoid attempting to convince their patients to participate in treatment options in which the patients are not the primary beneficiary.⁴⁸ Framing communication in health care is not only risky but also unethical. It makes truly informed consent impossible and can increase uncertainty and thereby hinder the physician-patient relationship.

How framing communication effects surrogate decision-making will be further discussed.

ii. Framing communication and surrogate decision-making

Framing and manipulating information influences patient and surrogate perceptions of risk and treatment options. Research continues to support the notion that methods of framing do influence patient and surrogate choices.⁴⁹ Framing makes it nearly impossible for surrogate decision makers to make well-informed decisions, and the manipulation of such information can have implications on patient choices, patient care, and physician-patient relationships.⁵⁰ Framing is often paternalistic in nature and can include forms of influence over the patient such as deception, lying, manipulating information, failing to disclose necessary information, and restricting a patient or surrogate's ability to make autonomous choices.⁵¹ Furthermore, framing raises ethical issues of whether or not physicians should attempt to change patient mindset and behavior by framing information or only provide the necessary information for informed decision-making.⁵²

Physicians should be mindful of their patients and their surrogates when presenting information. Truly informed consent is necessary to preserve the integrity of surrogate decision-making and the physician-patient relationship. While physicians are not obligated to discuss every single possible risk, especially those unlikely to occur or would have limited consequences if they did occur, they should keep in mind their patient's values and individual preferences. Different patients and surrogates will perceive and associate risk differently based on their values. What may seem like an insignificant risk for one patient may seem like a major risk to another patient. There are six questions physicians should consider when they are preparing to communicate risk information with patients and surrogates: what are the unwanted outcomes, what is the permanency of the unwanted outcomes, what is the time frame of the unwanted outcome occurring, how likely is it that the unwanted outcome will occur, how many exposures

will it take for the unwanted outcome to occur, and how much does the unwanted outcome matter to the patient and their surrogate.

Physicians should present information in a fair and balanced manner by providing information about the risks and also the benefits of the treatment options. Physicians should not communicate anecdotal evidence to patients or their surrogates, as information should always be from an up to date scientific source.⁵³ Doctors should also be aware of the ways in which patients and family members wish to have information presented to them. Some patients and families may wish to have information presented in terms of numbers, while others may be more comfortable with descriptive information. When physicians are mindful of their biases and ability to frame information, they can provide surrogates and patients with the entire truth regarding treatment options and care; not just what they perceive to be truthful. Physicians can provide patients and surrogates with more ethically appropriate information for decision-making when they provide accurate and truthful information based on the preferences of each individual patient.⁵⁴ Physicians must also recognize that discussing prognosis and treatment options in vague or overly optimistic terms does not aide surrogate decision-making. Patients and surrogates who are truthfully aware of their prognosis and treatment options are more likely to make cognizant decisions regarding care. This holds especially true for critically ill patients as their treatment decisions will often be based on what is possible given their prognosis. Patients and surrogates who understand the severity of their prognosis are more likely to the choose care they really want, whether it be potentially life prolonging care or comfort measures only. Honest communication about prognosis and unbiased discussion of treatment options promotes trust and enhances the relationship between the physician, patient and surrogate, allowing both the physician and the surrogate to fulfill their fiduciary duty to the patient.⁵⁵

2. Veracity for Surrogate Consent

In general, informed consent serves two purposes: to disclose relevant information to patients and their surrogates and to serve as legal permission before beginning medical interventions. Although in pediatrics the responsibility of consent is delegated to the patient's surrogate, patients should participate in the decision-making process in accordance with their developmental and cognitive abilities. Consent in pediatrics requires collaboration between physicians and surrogates. Physicians must provide necessary information for surrogates to make well-informed decisions.⁵⁶ This section of the chapter will discuss the role surrogate decision makers and physicians play in well-informed and honest pediatric decision-making.

a. Surrogate Consent, Beneficence, and Best Interests

Surrogate consent, beneficence, and best interests are unified when discussing how to maintain veracity for surrogate consent in pediatrics. Since pediatric patients are often limited in legal competence, surrogate decision makers are appointed for them. Surrogate decision makers must act on the principles of beneficence and best interests when making decisions for pediatric patients. Beneficence solidifies that the surrogate must act for the benefit of the patient and within the patient's best interests. What is in the patient's best interests should be based on consideration to the benefits and burdens to the patient, not the family or physician. Understanding these principles is paramount for decision-making in pediatrics and effective communication among all involved groups is necessary for informed consent to occur.⁵⁷ This section will detail the important duty of surrogate consent and the role that beneficence and best interests play in surrogate consent in pediatrics.

i. Surrogate consent

The process of obtaining consent in pediatrics is grounded in both ethical theory and law. The goals of informed consent are to protect and promote the health-related interests of the patient while incorporating the patient, surrogates, and family into the medical decision-making process.⁵⁸ There are three kinds of information ethics requires to be divulged during the consent process. The first is the patient or surrogate must be informed of the risks and benefits of the treatment options. Second, the patient and surrogate must be told about any alternative treatment options including the choice of no treatment and their risks and benefits. Lastly, the surrogate and patient must have knowledge of the patient's diagnosis and prognosis and what may happen if no there is no treatment. When patients and surrogates know all necessary information, they are in the best position to make the best choices regarding their health. Without necessary information, they might choose interventions that they may have avoided had they had all the information they needed.⁵⁹

Pediatric patients typically are not considered to have the legal capacity to make decisions regarding their own care unless they are emancipated from their parents. This task is typically delegated to the patient's parents or guardian.⁶⁰ Parents are typically the patient's surrogate decision maker as it is assumed they understand the needs of their child and family better than anyone else to make well-informed decisions. However, surrogate decision-making by parents is not an absolute right as patients are legally protected from harm. If a surrogate's decision-making process may harm a patient then the authority of the surrogate decision maker may be challenged or revoked. Surrogate decision makers have the responsibility to make decisions regarding their child and their families' best interests. The physician also has a duty to protect and promote the best health interests of their patients without involving their own

interests. The physician and the surrogate then act as co-fiduciaries in the medical decision-making process.⁶¹ Physicians are obligated to protect and promote the health-related interests of their patients while keeping their own self-interest's secondary. Likewise, parents are the fiduciaries of their child who is the patient. However, parents cannot protect and promote the health-related interests of their child without the assistance and expertise of the physician making them co-fiduciaries. Physicians are morally responsible for presenting all medical treatment alternatives and parents are ethically free to select any medically reasonable alternative.⁶² A physician's failure to present all necessary information is immoral, a violation of all health care codes, and in some instances illegal.⁶³ Parents are required to consider their child's values, lifestyle, and other non-health related factors when making decisions. Physicians should typically accept a parent's competence regarding the patient's non-health related interests as physicians do not have the knowledge necessary to make these decisions. Physicians do have the duty to protect their patients from decisions that may cause death or serious irreversible loss of health.⁶⁴

Surrogate consent in pediatrics also differs from practices in adult medicine in terms of substituted judgement. In adult medicine substituted judgement is used by the surrogate decision maker to substitute their knowledge of the patient's values and preferences to reach a treatment option that has the patient's best interests in mind. However, in pediatrics, substituted judgement is difficult to use as many time patients cannot or have not expressed their preferences for treatment due to age or incapacitating disease.⁶⁵ Decisions made in pediatric medicine should be based on the patient's best interests. Best interests can be determined by several factors including the effectiveness of the proposed treatment and the needs of the patient and those who

care for the patient. When there is conflict regarding what is in the patient's best interests, typically the preference of the surrogate decision maker will be favored if within reason.⁶⁶

Obtaining informed consent is not and should not be viewed as simply obtaining a signature on a piece of paper. Accurate information regarding the patient's medical condition is necessary for informed consent to take place. Physicians must explain information to patients and surrogates in a way that is easy for them understand and comprehend. Surrogates and patients must be able to understand the breadth and depth of the illness and the treatment options, the probability of success, the risks associated with the given treatment options, alternative treatment options, and the option for no treatment intervention. Consent should be voluntary as surrogates and patients should have the freedom to choose their treatment option without pressure. Informed consent should be viewed as a process and part of the patient's planned goals of care. Informed consent in pediatrics is often more complex as there are many factors that can influence surrogate decision-making. Factors such as the relationship between the physician and the patient will influence decision-making. Changes in the patient's health, the emotional toll of the patient's health problems, and previous knowledge about the patient's health problems may also affect surrogate decision-making. Distress experienced by the surrogate decision maker can also influence the decision-making process. Parents who have received information regarding their child's life-threatening illness report that such information can make decision-making difficult. Physicians should therefore be cognizant of the effects of the way in which information is communicated to patients and surrogates.⁶⁷

Physicians should be mindful of several factors involving consent of pediatric patients. They should seek to involve patients given developmental maturation and appropriateness. They should explain medical information and treatment plans to patients in a truthful manner and

provide a supportive environment where patients and surrogates can discuss the patient's health and treatment options. They should base their recommendations for treatment options on the benefit to the patient, considering the risks, alternatives, and overall patient prognosis.

Physicians should respect decisions made by surrogates and patients, and if there is a conflict of what is in the patient's best interests they may need to call an ethics committee meeting.

Resorting to the court to resolve disagreements regarding best interests is typically a last resort.⁶⁸

The benefits of providing truthful information to patients and surrogates for consent are numerous, but most notably pediatric patients undeniably benefit from well-informed decisions made by their surrogates, and surrogates benefit by knowing that they have made a decision that is in the patient's best interests based on the information they were presented.⁶⁹

Surrogate consent in pediatrics rests on three ethical concepts: the physician as a fiduciary to the patient, the parent as a fiduciary to the patient, and the physician and surrogate as co-fiduciaries to the patient. For surrogate consent to be truly informed and for decisions to be made in the best interests of the patient each fiduciary must keep the patient's health-related and non-health related interests at the forefront.⁷⁰ Research confirms that while communication alone is not sufficient for informed consent, there is, however, a correlation between the physician's communication abilities, the physician-patient relationship, and obtaining truly informed consent.⁷¹

Some of the intricacies of surrogate consent in pediatrics were discussed. The next section will detail beneficence and best interest in terms of surrogate consent in pediatrics.

ii. Beneficence and best interests

The Hippocratic Oath physician's take confirms vows that physicians should help the sick in accordance with their best judgment but never with the intention to hurt the patient or

cause further illness.⁷² Even today, the Hippocratic Oath continues to imply that physicians should act in the best interests of their patients. The principle of beneficence stems directly from the Hippocratic Oath as it encompasses a duty to protect patients from harm while acting in their best interests. This duty; however, does not imply that physicians have the authority to make decisions for their patients as this does not necessarily benefit the patient.⁷³ Beneficence supposes that physicians should act in their patient's best interests.⁷⁴ Beneficence assumes three obligations: one ought to prevent evil or harm, one ought to remove evil or harm, and one ought to do or promote good. Beneficence requires one to act by either helping, preventing harm, removing harm, or promoting good. Though providing a stringent definition of harm may be difficult, it is agreeable that harm involves physical harm, pain, suffering, death, or hindrances to the interests of the person.⁷⁵

Beneficence is of utmost importance in pediatrics because it not only requires physicians to keep patients free from harm, but also to act in ways benefitting the patient. Beneficence has two categorical principles: positive beneficence and utility. Positive beneficence requires physicians to provide benefit to others. The principles of positive beneficence include protecting the rights of others, preventing harm from occurring to others, removing circumstances which will cause harm to others, help people with disabilities, and rescue those who are in danger. Utility requires physicians to seek the best comprehensive results by balancing risks and benefits. Beneficence can also be broken down into terms of specific and general beneficence. Specific beneficence is important to pediatric ethics as it is directed towards specific groups of people such as children and patients. General beneficence, on the other hand, is directed towards anyone. Specific beneficence calls for physicians to promote the welfare of their patients, not only by avoiding harm for them, but by embodying the goals of medicine to treat them.⁷⁶

Beneficence and autonomy often go hand in hand. They sometimes work seamlessly together, and at other times conflict. Autonomy suggests that the patient's or surrogate's rights to make well-informed decisions regarding their health care are paramount. Autonomy essentially gives patients or surrogates control over their health care decisions.⁷⁷ Autonomy and beneficence work together in the sense that the physician is obligated to act in a beneficial manner towards their patients and, therefore, respect their autonomy.⁷⁸ In some cases autonomy and beneficence can conflict, such as a patient who needs to have their wounds cared for, but instead the patient wishes to be left alone. In such a situation the best interests of the patient may need to be re-evaluated as patient preference can change over time or at times be contradictory.⁷⁹ Respecting a patient's autonomous decisions is however beneficial because it asserts that patients have the right to receive necessary information from their physician, consent or refuse consent to procedures and treatment options, and have their confidentiality maintained.⁸⁰ Autonomy, however does not assert that patients or surrogates can demand treatment from physicians.⁸¹

A key factor with the principles of beneficence and autonomy is the function of communication. Communication is the breadth of ethical decision-making and therefore clear and honest lines of communication are necessary for morally sound decisions to be made.⁸²

While beneficence and autonomy are great principles for physicians to follow, there are also times when the patient's preferences are not well known. There are different reasons a patient's preferences may be unknown. They may have never been competent in the first place or they may have never indicated their preferences towards certain treatments. In the event that the patient's preferences are not well known, the surrogate decision maker is required to use the best interests standard. The best interests standard indicates that the surrogate decision maker

must determine the highest net benefit among the available treatment options. The decision the surrogate makes should protect the patient's well-being. The best interests standards must consider the life of the patient and how the choices will affect the life they will have to live, not the value that the patient's life has on the surrogate.⁸³

In the case of many pediatric patients they may have never been old enough, mature enough, or mentally cognizant enough to express their preferences or wishes. In pediatrics, surrogates have the discretion to decide what is in their child's best interest within limitations, as they must adhere to the duty to provide them with acceptable care. The best interests standard provides guidance to surrogate decision makers of pediatric patients. The best interests standard can be considered in terms of several conditions. The first condition is *prima facie* and notes that surrogates should use available information to assess the patient's interests both long term and immediate. Surrogates should seek to maximize the long-term benefits for the patient while abating the burdens. This condition notes that surrogates should act upon what is reasonable given the patient's situation. What is considered good for the patient must be grounded in scientific evidence, not anecdotal evidence or opinions. When physicians and surrogates have clear lines of communication and surrogates are well-informed, this condition is relatively easy to achieve. The second condition is that surrogates must meet a minimal threshold of acceptable care for the patient when making decisions. What is considered reasonably acceptable is typically based on what a knowledgeable person in a similar situation would choose. The second condition acknowledges surrogates in similar situations may make different decisions for the patient, but they must at least meet the minimal standards of ethically, legally, and socially acceptable care for the patient. Surrogates can consider the patient's values and their family values when making decisions, but decisions must still be reasonably acceptable. What is

considered minimally acceptable care should be based on scientific evidence in medicine and our obligations to care for children. Each patient and their surrogate shapes the best interests standard. What is in the best interests of one patient may not be in the best interests of a similar patient. The best interests standard does not require surrogates to maximize all benefits while minimizing all burdens; instead, the surrogate must make reasonable decisions for the patient who is unable to make those choice for themselves.⁸⁴

b. Disclosure and Impartiality

Communicating with patients and family members about sensitive information can sometimes create a conflict within physicians. Although research continuously highlights the notion that patients benefit from honest communication transactions, telling the truth under some circumstances can still be difficult for physicians. Physicians sometimes wish to withhold the truth for what they believe to be to the benefit of the patient and their family, or because they believe the patient or family members cannot handle the truth. However, patients are entitled to truthful and honest communication necessary for solid physician-patient relationships and, thus, well-informed consent.⁸⁵

i. Disclosing information to families and patients

This section will explore the intricacies of disclosing information to patients and families and what it means for the physician to be a neutral party.

Relatively speaking, no one ever wants to see a child be critically ill or face death, yet it is an unavoidable part of life. How physicians communicate about end of life issues can affect the quality of care pediatric patients and their families receive. In a 1997 survey examining communicating pediatric deaths in the emergency department, 66 percent of 122 physicians reported that communicating a pediatric death to families was the most difficult thing they had

done in medicine. Ninety-two percent of respondents felt that a course on communicating bad news to families would be helpful.⁸⁶ Training in medical school often does not cover disclosure practices and as a result many physicians learn from a system of trial and error.⁸⁷

Children are often viewed as especially resilient and cherished and therefore talking about unfavorable prognosis with children can be a daunting task for most. Those medical professionals who care for children with life threatening medical conditions often commit themselves to pursuing every curative measure possible. While the intention is essentially good, this is not always the most honest way to treat pediatric patients and their families.⁸⁸ Even in the age of informed consent pediatricians often disagree and struggle with the appropriateness of disclosing distressing information to parents and children. Another difficulty in pediatrics is deciding how much information to give parents and children about medical conditions in which the prognosis is uncertain.⁸⁹ Physicians will sometimes engage in avoidance behaviors instead of disclosing necessary information due to the emotional impact the conversation may have on the patient or physician. Avoidance behaviors cause emotional distress for both the physician and the patient and can create hindrances in further communication possibly affecting treatment and recovery.⁹⁰ A final challenge with veracity in pediatrics is deciding how much information a child should know about their condition. It is not unreasonable to think that parents may want to protect their chronically ill children from the entire truth about their prognosis, yet research shows that this type of deception is often not clinically helpful. Not disclosing the truth to children may cause them to have increased anxiety about what is going on, why they are in the hospital, etc. It can also create isolation between the parents, the medical staff, and the child.⁹¹

There are several recommendations physicians can act upon when disclosing information to patients and families. Physicians should choose an appropriate location that is quiet,

comfortable, and private. A convenient time for all parties involved should be chosen so that there will be no interruptions and there will be a substantial amount of time available without the physician being rushed.⁹² Physicians should sit close to patients and their surrogates and engage in nonverbal immediacy behaviors such as eye contact. They should also use a warm tone for communicating and exhibiting empathy and respect. Physicians should seek to find out what the patient and surrogate already know, how they may react to the information, and they should seek to gauge at what pace they should disclose the information. Physicians should encourage questions and be sure to summarize key points at the end. Physicians should also be mindful of the language they are using and communicate in a manner which patients and surrogates can understand. Physicians should listen to their patients and determine if there is anything more their patients may want to know or need to know. The presence of family may be therapeutic for the patient and physicians should use family members to help the patient cope. Physicians should be sure not to frame information and they should speak in a direct manner instead of using euphemisms to downplay the severity of the information.⁹³ Doctors can also collaborate with patients and surrogates. Collaborative communication encourages a reciprocal relationship where the physician and patient discuss treatment options and choices tailored to the patient and their specific circumstance.⁹⁴

Physicians should pay close attention to the patient's and surrogate's nonverbal communication during the disclosure of information. Research has indicated that in some instances, when a patient becomes anxious during disclosure the physician may need to pause to allow the patient to disclose vulnerable information or ask vulnerable questions regarding their diagnosis. If physicians are not attuned to this type of nonverbal behavior than patients are less likely to share vulnerable information with their physician.⁹⁵ Research has indicated that when

physicians show empathy when communicating bad news patients cope better with the diagnosis over the course of time.⁹⁶ When physicians use patient and surrogate's emotions as a guide for communication a more robust exchange is likely to take place.⁹⁷

Disclosing information to patients who have a terminal diagnosis can be extremely challenging for physicians. In fact, communicating terminal diagnosis can sometimes cause physicians to retreat and avoid communication, which can leave the patient feeling abandoned and fearful. Patients who have a terminal diagnosis should be given the news in a sympathetic and rational manner. Research continually shows that the quality of communication that occurs at the end of life is directly related to providing effective care to dying patients. Patients and surrogates should be reassured that while death may imminent they will be kept comfortable and cared for.

Another challenge for physicians is breaking the news of an unexpected death to families. Unexpected deaths can be challenging as physicians may not have all the relative information regarding the circumstances of the death that families may seek. In these circumstances physicians should be empathetic and repeat the information they have as necessary.⁹⁸ Although disclosing certain information to patients and families can be a difficult task for physicians, if it is done well it can increase patient satisfaction and decrease the emotional toll of the information. Research shows that the way in which physicians break bad news to patients can affect how the patient reacts to the news. Information that is not properly disclosed to patients and families can have lasting effects on the physician-patient relationship and patient treatment adherence.⁹⁹ While there will always be unknowns in medicine and patient prognosis is not always clear, physicians can help patients make well-informed decisions through transparent communication practices.¹⁰⁰

ii. The physician as a neutral party

To maintain veracity for surrogate consent and to meet the ethical and legal criteria for surrogate consent physicians should strive to maintain a neutral position with patients and their families. Value neutrality calls for physicians to suppress their personal beliefs and values in their professional lives by allowing patients to make autonomous choices. Some associate this mean that physicians cannot show empathy or sympathy; however, this is not true. Others argue that this requires physicians to participate in treatment or care they may find to be immoral, this, however, is also not true. When a physician takes the stance as a neutral party they can share religious or moral values that may interfere with patient care. Physicians should inform patients at the beginning of care if they feel that their moral or religious values will conflict with patient treatment options. Physicians should explain in detail treatment options they will not participate in. This will help in their effort to abstain their moral beliefs and patient autonomy simultaneously. Patients and surrogates then have the choice to refuse to enter a relationship with the physician unless in emergent situations. If a difference in moral beliefs is discovered in the midst of treatments physicians may suggest patients seek another physician on the basis of personal moral values. Physicians should never attempt to explain why they believe treatment options are immoral or attempt to force their beliefs on the patient or surrogate. While respect for patient autonomy would not require physicians to assist patients in finding a doctor who will perform the treatment options, they are, though, responsible for continuing to care for the patient until another suitable physician is found. In emergent situations, or in situations where a suitable replacement for the physician cannot be found, the physician must continue to provide treatment for the patient despite their moral beliefs. When physicians disclose possible moral conflicts at the beginning of communication it allows patients to find physicians who may have shared

values, it allows treatment to continue without disruption, and it allows the physician to maintain their moral values and the patient or surrogate to maintain their autonomy when making decisions.¹⁰¹

Physicians should also avoid being overly involved in patients, but they should remain empathetic. Physicians must find this fine line of neutrality as they must be able to care for their patients without becoming overly involved and integrating personal feelings in medical treatment. In medicine, being an empathetic physician requires the physician to acknowledge the emotional state of the patient and family without experiencing what they are feeling. Empathy does not require the physician to live vicariously through the patient or surrogate; instead, it calls for physicians to put their focus on the patient, what the patient may be feeling, and what their emotions are communicating about their situation. Neutrally empathetic physicians should be able to treat their patients without feeling grief, regret, or becoming overly emotional. Since emotions are human nature, it would be impossible to assume that physicians can overcome all emotions when treating patients. The key is that they maintain objectivity when treating patients to preserve patient and surrogate autonomy for consent.¹⁰²

There are four ways physicians can enhance medical care for patients by attuning to their emotional needs. The first method is to recognize that empathy involves associative reasoning. Being aware of the patients helps physicians understand the meaning of the patient's communication. A physician who is emotionally attuned to their patients will recognize when certain words provide different connotations for patients. The second way is for physicians to recognize that emotions help guide physicians to know what is significant to the patient. Physicians should pay attention to what their patients seem anxious or worried about and use this emotional attunement to figure out what else may be going on with the patient. Third, empathy

facilitates trust and disclosure between the physician, surrogate, and patient. When patients feel that their physicians are empathetic and attuned to their needs they are more likely to communicate more medical history information and feel more comfortable with their physician. Empathy can also enhance medical outcomes. Empathetic communication decreases patient anxiety and a decrease in patient anxiety has been linked to better therapeutic outcomes for patients. Lastly, being empathetic makes being a physician more meaningful. Research has indicated that physicians who have a more empathetic communication style tend to burn out less often than physicians who do not have empathetic communication styles. When used correctly, empathy can enhance the medical encounter and foster trust between the physician, patient, and the surrogate. It is important for physicians to recognize that they can be empathetic towards their patients while also remaining neutral to maintain patient autonomy.¹⁰³

Conclusion

This chapter has focused on managing uncertainty in veracity for surrogate consent. Uncertainty communication theories were reviewed in conjunction with veracity for surrogate consent. Framing communication and its role in uncertainty was also discussed. How framing effects surrogate decision-making was delineated. Veracity for surrogate consent was also considered. The meaning of surrogate consent and the principle of beneficence and the best interests standard were reviewed. Lastly, disclosure and impartiality were discussed. How physicians should disclose information to patients and families was deliberated as well as what it means for a physician to be a neutral party in the transaction. The next chapter will examine the maintenance of the physician-patient relationship.

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Chapter Five: Maintaining the Physician-Family Relationship

1. Relational Communication Theories

Relationships and communication are intricately intertwined. The relationship is the focus of interpersonal communication theory, and can be defined as an established set of expectations two people or more have regarding their behavior based on patterns of interaction between them.¹

Relationship development includes the very first encounter through increasing participation in the relationship.² The relationship between the communicators will affect the context and patterns of communication transactions, which will ultimately affect the relationship.

Relationships can vary. Some relationships are relaxed while other relationships are difficult.³

Relationships of all kinds must be sustained and maintained, and it is often discovered that creating the initial relationship is much easier than maintaining the relationship. Most patients in health care organizations are only satisfied when they receive personalized care and attention from their physicians with whom they have created relationships.⁴

Relational communication theory is grounded on fundamental common assumptions. The first assumption is that relationships are always interconnected with communication and cannot be divided. Second, the nature of the relationship is defined by the communication transactions that take place between the communicators. Third, relationships are typically defined indirectly rather than overtly. The final assumption is that relationships are dynamic as they develop over the course of time through cooperation and interaction. Relationships in communication are systematic and thus require two people to communicate to define their relationship. Creating new expectations, emphasizing old expectations, or changing the current pattern of interaction defines them. Relationships in communication are important as one is always influencing others' perceptions of themselves, whether intentionally or unintentionally. Communicators are always

conveying something about their relationship with the other person. Communication interactions are comprised of verbal and nonverbal communication, and these communication behaviors and interactions help define the meaning of the relationship.⁵

In established relationships interaction patterns can become more steady overtime; however, certain actions can send these relationships into unforeseen directions, exemplifying the dynamics of communication in relationships. Communicators within a relationship must also decide how much information they will share with the other parties in the communication transaction. In some relationships communicators will share a wealth of information about themselves, in others they will be more reserved and share less information. Information sharing in relationships creates a challenge between how much information to share and what information to keep private.⁶ Managing the information one shares forges relationships. Researchers have identified five qualities that change as relationships continually develop. The first quality is amplitude. Amplitude is the strength of feelings and/or behaviors within the relationship. At some points in the relationship there may be strong feelings about something whereas at other times the relationship may be calmer. The second quality is salience or the past, present, and future. At some points in the relationship there may be a focus on what happened in the past, at other times the focus may be what is going on currently, or there may be communication regarding the future. The third quality is scale. Scale entails the length of time communication patterns last. Fourth is sequence or the order of actions in the relationship. Sequence involves how the communicators manage their actions and behaviors. The final quality is the pace of the relationship. At times things in the relationship may happen very quickly, at other times things may occur much more slowly. Relationships are ever evolving and

take practice. Relationships are not one sided; instead, they are created through communication with others.⁷

Relational communication theory helps to make sense of the different types of interpersonal relationships and the process of developing relationships. These theories examine the how and why of relationship development and maintenance.⁸ Effective relational communication can help maintain relationships by using empathy, engaging in open communication, and being culturally sensitive. Effective relational communication also engages in suitable amounts of self-disclosure and active listening.⁹ This section will explore two relational communication theories, the social penetration theory and the sociopsychological tradition, and their relations to maintaining the physician-family relationship.

a. Social Penetration Theory

The social penetration theory is a relational communication theory developed by Irwin Altman and Dalmas Taylor to understand the relational closeness between two people. The social penetration theory examines how a communicator's decision to disclose or withhold information will affect the relationship. Social penetration is the progression of connecting communicators in a way that forges the relationship from an artificial and closed relationship to a more friendly and open relationship. The process of social penetration includes verbal communication, nonverbal communication, and the physical environment of the communication transaction.¹⁰ The social penetration theory typically applies to romantic relationships, but it can easily be applied to other relationships, such as a physician-patient or family relationship, as different relationships involve different levels of closeness and understanding.¹¹ Social penetration theory is based on the notion that relationships will continue to grow when they are rewarding, they will decline when they are no longer rewarding, and the individuals in the

relationship will continue to assess the benefits and disadvantages of the relationship throughout the relationship.¹² The social penetration theory also notes that relationship development is complex, rarely static, and evolves over the course of time.¹³ This section of the chapter will explore some of the key characteristics of the social penetration theory and how the social penetration theory affects physician-family relationships.

- i. Characteristics of the social penetration theory

The social penetration theory is guided by four assumptions. The first assumption is that relationships tend to progress from non-intimate to intimate, although not all relationships are non-intimate or intimate as some relationships fall in the middle. This assumption notes that when relationships begin they tend to be rather artificial, and as they develop they become closer. However, while initial communication may seem superficial it marks the beginning of relationship development. The second assumption of the social penetration theory is that relational development is typically predictable and occurs in a systematic way. While communication relationships are very dynamic and always changing, they typically follow some sort of acceptable pattern of growth. Variables such as the communicator's time and personalities may affect the evolution of the relationship. The third assumption is that relational development also includes depenetration and termination. While the focus of the social penetration theory is on relationships developing, it is notable that relationships do sometimes fail to further progress and end. Communication allows relationships to develop but it can also cause relationships to end as a result. Relationships may end when communication is conflicting or destructive to the nature of the relationship. If communication does not cause the relationship to end completely, the relationship may become less close. Depenetration also tends to happen in systematic and predictable way.¹⁴ Dissolution of a relationship in medicine may occur when

the patient or physician have different expectations, the goals of the relationship are not clear, or the patient's values have been neglected. Patients may choose to stop receiving care from a physician or the physician may view their patients as difficult to work with.¹⁵ If deterioration of the relationship does occur repair may be possible. Steps to attempting to fix the relationship include an acronym for REPAIR. The first step is recognizing and addressing the problem. If this step does not occur then repairing the relationship is most likely not possible. The second step is engaging in productive conflict resolution. Often it is not the conflict itself, but how the conflict is managed that determines the result of the conflict. The third step is proposing possible solutions to the problem. The fourth step includes affirming each other or engaging in positive communication. The fifth step to repair is integrating solutions into normal behavior. The last step is risk. Risk includes taking chances to improve the relationship such as engaging in new or different communication strategies.¹⁶ The final assumption is that self-disclosure is central to relational development. Self-disclosure can be defined as the process of revealing information about yourself to others. The breadth and depth of the information that is revealed during self-disclosure will affect the development of the relationship. Non-intimate relationships progress to intimate relationships through self-disclosure. Self-disclosure can either be done strategically or spontaneously. In some relationships, there is a strategic manner to which people choose what to communicate about themselves. In other relationships, what is communicated is more spontaneous as one may communicate information about themselves to a stranger.¹⁷

Individuals do not always automatically decide whether a relationship will be sustaining and whether they want to remain in the relationship as there are four different stages to the social penetration process.¹⁸ The first stage of the social penetration process is orientation. The orientation stage is the earlier stage of the communication interaction. In this stage, the

communication that occurs is at a more public level. Conversations are typically superficial and only limited information is revealed about each other. In this stage people tend to adhere to the norms of societal interaction. In the orientation stage people tend to not evaluate the other communicators as this could create conflict and prevent future communication interactions.¹⁹ However, the orientation stage must be rewarding to the communicators to proceed to the next stage.²⁰ The second stage is the exploratory affective exchange phase. In this stage, individual personalities begin to reveal themselves though the communicators are still cautious about sharing too much personal information. However, communication in this stage becomes more spontaneous as the communicators become more comfortable with each other. Nonverbal communication such as touch and facial expressions become part of the communication. This stage is akin to the relationship one may have with an acquaintance. Many relationships do not go past this stage. The third stage is the affective exchange stage. This phase is categorized by close friendships and intimate relationships. The interactions in this stage are more spontaneous and casual as the communicators are more comfortable with each other. This stage includes the unique communication of people in relationships. In the affective exchange stage individuals may still feel the need to protect them from becoming overly vulnerable. However, during this period there may be conflicts, but the significance of the relationship typically keeps the relationship going.²¹ This stage will generally not be entered unless the rewards of the relationship seem to outweigh any costs of the relationship.²² The final stage is the stable exchange stage. The stable exchange stage is characteristic of openness and spontaneous communication between individuals. In this stage behaviors become predictable. Communication in this stage is often very efficient and clear-cut. This phase boasts unique relational qualities such as the use of sarcasm or humor.²³

The social penetration theory is often likened to the metaphor of onion layers. In order to get to the center where personal disclosure occurs the outer layers must first be peeled back. Communication that takes place on the surface is very superficial, but the layers to get to the center are more difficult to access.²⁴ The outer layer of the onion is often noted as the public image of the individual, or what is accessible to anyone. The public image might include things such as race, ethnicity, height, weight, hair color, etc. Through reciprocity of sharing information with each other the layers of the onion are peeled away. The breadth and depth of the communication also affects the amount of self disclosure that occurs. Breadth is the number of topics discussed and depth refers to the degree of intimacy within those topics. The greater the depth of the communication the more likely a person may begin to feel vulnerable in the conversation. Self-disclosure in relationships can progress the relationship towards more closeness, or it can cause the relationships to be terminated. If too much information is revealed during the initial stages of the relationships than the relationship may end as the other person may be underprepared to know the other individual on such a personal level so quickly.²⁵

The social penetration theory is also based on a cost-benefit analysis. According to the social penetration theory the closeness of a relationship can be based on the rewards and costs of the relationship that each individual performs. This analysis will predict if individuals will engage in self-disclosure. Similar to the principle of utility, the social penetration theory claims that individuals want to maximize their benefits and minimize their costs. Individuals decide whether to disclose information with one another based on the cost-benefit ratio. In initial encounters individuals will view things such as appearance and backgrounds that fit their norms as benefits and any deviance from those norms as will be considered negatives. As the relationship progresses the costs and benefits will also change. Benefits in a closer relationship

may include common values.²⁶ If a relationship entails more reward or benefits than costs, then the relationship is likely to flourish. However, if the relationship has more costs than benefits, then the relationship is likely to end. Relationships that have a stockpile of rewards are likely to make it through costs such as conflict. A single conflict is unlikely to outweigh a surplus of rewards in any given relationship.²⁷

This section has explored the intricacies of the social penetration theory. The next section will apply the social penetration theory to physician-family relationships.

ii. Social penetration theory and physician-family relationships

While the social penetration theory was not developed specifically for health care transactions or the physician-family relationship, it can be applied to non-romantic relationships in a way that benefits the physician-family relationship.²⁸ Providers should be aware of the social penetration theory to reduce uncertainty amongst patients and family members in an effort to forge relationships where communication is prosperous and patients are willing to disclose personal information from their central layers which can affect the care they receive such as emotions, values, and beliefs. In health care transactions, the relationship may move more quickly as surface layer information may quickly be discussed such as age, height, weight, etc. Conversations may quickly include questions about patient's sexual behaviors or drug and alcohol use when applicable.²⁹

The rule of reciprocity is often violated in the physician-family relationship, as it is typically the patient or family divulging information and not the physician. When reciprocity is not repaid it may be viewed negatively by the patient or family members. Physicians who are aware of the social penetration theory and the rule of reciprocity may strive to acknowledge reciprocity by thanking the patient or family members for providing personal information. The

family and patient may then view the physician's acknowledgement as a benefit to the relationship.³⁰ While physicians will likely not share the same information the patient is sharing, they can still foster feelings of reciprocity in the relationship by communicating their honest feelings with their patients in an empathetic manner. Physicians can seek to show patients that they understand how they are feeling in their given situation. The focus should always remain on the patient even if the physician is sharing some of their feelings regarding the situation.³¹

Physicians who have knowledge regarding the social penetration theory will also understand the importance of self-disclosure and the physician-family relationship. Self-disclosure is necessary for open communication and open communication is necessary for building and maintaining interpersonal relationships. Self-disclosure benefits the patient and the relationship between physician and the patient. Self-disclosure is comprised of five dimensions. The first dimension of self-disclosure is the intention. The intention is the person's willingness to disclose information to others. The second dimension is the amount of information a person chooses to communicate. Patients who share a lot of information about themselves are participating in greater self-disclosure, while patients who share little about themselves are participating in low self-disclosure. The third dimension is valence which is whether the content of the disclosure is positive or negative. If people disclose good things about themselves then the disclosure is positive; however, if people disclose undesirable things about themselves then the disclosure is negative. The fourth dimension is honesty. Honesty measures how accurate the information disclosed is. Some people may find it difficult to communicate exactly how they think or feel while others are more to the point. The final dimension of self-disclosure is depth. Depth refers to how much personal information is shared. Depth increases as more personal information is shared. Self-disclosure is important to patients and families as it allows them to

communicate about the emotions that often accompany an illness. Self-disclosure also allows patients and families to receive feedback from physicians ensuring that their reactions to their illness are normal. Lastly, self-disclosure can help patients and family members see their illness from a more detached viewpoint. Self-disclosure gives patients and family members an opportunity to talk about the illness as research indicates that patients and family members do not always discuss the illness with friends and family. It can also help patients adjust to the reality of their illness. Self-disclosure in health care can be difficult if a relationship is not established as patients and family members may feel vulnerable and uncertain about what information they should share with their physician. Patients often wonder whether their feelings regarding their illness are normal, and they worry others may find them to be weak if they divulge how they are feeling about their illness. Patients and family members may also worry that self-disclosure will negatively affect the physician-family relationship if the self-disclosure is viewed negatively by the physician. Patients disclose more information to their physicians when they feel that their physicians are compassionate and accepting.³² Pediatric physicians must also understand that children of all ages appreciate privacy and the ability to trust their physician. For example, toddler patients may be embarrassed to get undressed and adolescents may be hesitant to provide information regarding their risk-taking behaviors.³³ Patients also tend to disclose more information when physicians prompt patients to tell them more about themselves. Physicians must be aware that patients and family members need a trusting relationship and privacy to participate in self-disclosure. For example, when a physician gives family members information in a waiting room in front of others or in a hallway they are not fostering an environment where self-disclosure is likely to occur. Physicians must work to create an environment where self-disclosure can occur and relationships of trust can be fostered.

Health care organizations that support open communication between physicians, patients, and family members will create environments where self-disclosure can occur and, thus, positive relationships will be developed and maintained.

The social penetration theory and the physician-family relationship has been reviewed, the sociopsychological tradition will be reviewed next.

b. The Sociopsychological Tradition

The sociopsychological tradition is mainly concerned with how others express themselves, interact, and with external influences. This communication tradition focuses on how behavior, attitudes, and personality traits affect interactions. The sociopsychological tradition is important in deciphering how individual personalities, beliefs, and feelings influence communication and decision-making.³⁴ The sociopsychological tradition seeks to depict individuals and the relationships they are in. This tradition examines what individuals are like within a relationship and what the relationship itself is like.³⁵ The sociopsychological tradition is focused on the participants in the communication transaction, the roles they play, and the cultural context of the communication transaction. The sociopsychological tradition also includes how friendly or unfriendly the communication is, and the formality of the communication.³⁶ This section of the chapter will seek to identify key features of the sociopsychological tradition and identify the importance of family dynamics in pediatrics.

i. Features of the sociopsychological tradition

While the sociopsychological tradition was not developed solely for use in the field of healthcare, in order for physicians to increase the effectiveness of their health communication can undeniably use it. Although communication in the sociopsychological tradition is reflective of individual personalities and beliefs, it is important to keep in mind that humans are

intrinsically rational beings. Communicating about an illness to a patient and their family members is more than just explaining the illness and the process the illness may take. It is about addressing the patient's beliefs, uncertainties, and working within the context of their relational roles with their families and others.³⁷

One of the focal features of the sociopsychological tradition is its attention to the relationships people are in and how they interact within those relationships. Relational schemas are important to deciphering how individuals interact within their families. Relational schemas provide insight into different family types and reasons for the differences. Relational schemas are based upon the information one has about themselves, relationships, and how to interact within those relationships. Schemas are systematized memories that individuals will access whenever they interact with others. The information one gains from their schema will direct their behavior within relationships. Relational schemas are organized from general knowledge about relationships to specific knowledge about relationships. Family schemas include what one knows about relationships on a general level, what one knows about family relationships, and what one knows about their relationship with their family.³⁸

According to the sociopsychological tradition and family schemas communication within a family is not random, but follows an outline that will determine how family members communicate. Communication within a family will be based off how close the family is, the individuality within the family, and external factors affecting the family such as location, work, and other external concerns. Each family's schema will include an orientation to communication, conversation orientation, or conformity orientation. Families that have a high conversation schema generally enjoy conversing, whereas families with a low conversation schema do not enjoy conversing as much. Families that have a high conformity schema obey

family authority, whereas families with a low conformity schema tend to exhibit more individuality. The different schema patterns exhibit then create different types of families. Understanding the different family patterns is key to understanding how families function and think about relationships.³⁹

Four different types of families can be identified. The first type of family is a consensual family. Consensual families are both high in conversation and conformity meaning they like to engage in conversation, but the authorities in the family, typically the parents, make the decisions. In a consensual family, parents will hear what their children have to say, but they will make the final decisions. Consensual families will often explain parental choices to the children to help the children understand the reasoning behind the decision-making process. Consensual families tend to enjoy each other's camaraderie. When disagreements occur in consensual families they are typically not overly forceful; however, they do not seek to avoid conflict. Marriage in consensual families tends to be traditional and stable.⁴⁰ Consensual families strive to spend as much time together as possible and they are more likely to place a high amount of value on participating in family rituals. A consensual family values the importance of family involvement and traditionalism.⁴¹ The second type of family is a pluralistic family. Pluralistic families tend to be high in conversation and low in conformity. In pluralistic family's communication is abundant, but everyone makes decisions for themselves. Pluralistic parents do not control their child's decisions; instead, they allow children to have an opinion and allow them to contribute to decision-making.⁴² In pluralistic families differing opinions are welcome and members of the family do not feel the need to hide their differences. Pluralistic family members are more likely to have differences amongst one another, but they are also more likely to confide in each other when they need help. Pluralistic families embrace each other's

differences.⁴³ Marriage in pluralistic families tends to be autonomous and eccentric, as parents do not rely on each other for decision-making. The third family type is protective families. Protective families are low in communication, yet high in conformity meaning communication is minimal but the children abide by authority. Parents in protective families make the decisions and do not find it necessary to provide their children with an explanation for their decisions. Marriage in protective families tends to be traditional, but separate as the parents do not share much. The final type of family is the laissez-faire family. The laissez-faire family is low in both conversation and conformity. These types of families are not concerned with what other members of the family do and they do not wish to participate in communication about their decisions.⁴⁴ Laissez-fair families tend to want little to do with each other and they often develop stronger relationships with people outside of their family. Laissez-fair families are typically conflict free, but they also do not turn to other family members for advice.⁴⁵ Marriage in lassiez-faire families tends to be a mix of different orientations, but is also known to be dysfunctional.⁴⁶ Parents in laissez-faire families typically have different ideas of what their relationship entails, making it difficult to set clear expectations for the family as a whole.⁴⁷

This section has outlined the importance of family dynamics within the realm of the sociopsychological tradition. The next section will describe the importance of family dynamics in pediatrics.

ii. The importance of family dynamics in pediatrics

Understanding how different families communicate and interact is imperative to providing excellent pediatric care as families and healthcare are intertwined in pediatrics. Physicians must understand the different family types and how they interact to know how to best communicate with each family type. American families come in many different shapes and sizes

and continue to change and evolve.⁴⁸ Roles in some families are fluid and changing, while in other family's roles do not change. Some families have access to necessary resources while other families do not. Regardless of the family structure pediatric physicians must understand how to help families make decisions based on each family's unique and distinctive make up.⁴⁹

Many children now live in single parent households and that number is increasing. Some children also live in families where their parents are not married. Also evolving is the number of children who have parents in a domestic partnership.⁵⁰ There are also some children who do not live with their parents and instead live with a guardian(s). There are step-families who developed from divorced parents, and some children live in adoptive families.⁵¹ There are several different types of relationship dynamics pediatricians may encounter and should be aware of. The first is traditional couples. Traditional couples share a similar belief system that brings them together as an interdependent couple. Traditional couples typically do things together and make decisions together. They typically do not engage in conflict as they stick to their roles within the relationship. Interdependent couples on the other hand are more attuned to their individual identities. Interdependent couples spend a significant amount of time together, but do not necessarily prioritize their time together. Interdependent couples engage in conflict and self-disclosure. Separate couples live together often for the sake of convenience. They typically see themselves as individuals and distinct from being a couple. Combinations of these different relationship types can also be created.⁵²

Understanding family dynamics is imperative as the patient's family is the main source of support for the patient. Each family's dynamic and perception will also play a role in their decision-making process. Positive experiences will increase parental satisfaction with their roles in the health care transaction which will over time make patient's more competent when it comes

to making their own health care decisions.⁵³ When pediatricians are aware of the family dynamics of their patients they are able to tailor their communication to best fit the subtleties of the family and, therefore, increase the likelihood of effective communication taking place. Pediatricians are in a unique situation where they must assess their pediatric patients within the context of their family situation, as the values, beliefs, and attitudes of the family will affect the patient's physical and emotional wellness. Understanding the patient's family dynamics also helps pediatricians navigate the strengths and weaknesses of the family, and it can help physicians gauge the amount of knowledge parents have about their child's situation. It can also help pediatricians assess what is developmentally appropriate for the patient so that the physician can tailor communication to the patient and their family for effective communication to take place.⁵⁴ Pediatricians must also conduct an interview of family medical history. In addition, understanding the family dynamics can foster more effective communication and disclosure regarding medical history. Pediatricians should be aware of topics during the medical history assessment that may be sensitive to the family such as questions about abuse or neglect.⁵⁵

Family dynamics may also affect how parents deal with their child's diagnosis and prognosis. Families may be reluctant to accept a terminal diagnosis or they may hold conflicting goals for their child. Sometimes families need additional members of their child's health care team available for information and to facilitate effective communication. Physicians must always remember that communication is ongoing and interactive, and they may need to re-evaluate what families and patients know or need to know about their prognosis and diagnosis. Pediatric physicians should also be aware of families who are likely to communicate information regarding prognosis and diagnosis to other family members or friends as they may need support in doing so. Families may also need assistance navigating the health care system to get the best

care for their child as they may not understand the complexities of medical specialties necessary to treat their child.⁵⁶ Overall, family dynamics in pediatrics are of utmost importance.

Communication in the pediatric setting is dynamic. Effective communication in the pediatric setting takes knowledge of the patient's family structure and dynamics and encouraging parents to participate in communication transactions. Understanding the basic family elements is essential to effective communication in pediatrics.⁵⁷

2. Physician-Family Relationship

The physician-patient relationship and its construction through effective communication has been historically described in medicine from the time of the Greeks. However, the integration of more science and less focus on humanities has hindered communication that incorporates both the patient's illness and the patient's perspective regarding the illness.⁵⁸ Building and maintaining relationships are an important aspect to healthcare especially in pediatrics. Relationship maintenance is the process of keeping the relationship intact through positive communication strategies.⁵⁹ Long term relationships between the physician and family are often forged when physicians pay attention to close details such as showing interest in the patient and their family members beyond the patient's disease, allowing the patient and family members to actively participate in treatment plans, and making sure there is adequate time and privacy during visits with the patient. Research continues to indicate that the quality of the relationship between the physician and the family is a direct effect of the communication transactions that occur. Physician friendliness in their communication transactions is associated with higher parental satisfaction. Research also shows that parents of chronically ill children are more satisfied with their child's care when reporting a quality and sustainable relationship with their physician(s).

Researchers have identified four facets of relationships that are associated with patient and family satisfaction. The first aspect is the relationship between the parent and the physician, the second aspect is the relationship between the patient and the physician, the third aspect is the parents comfort with asking the physician questions, and lastly, the parent's level of trust in the physician. When physicians pay attention to their communication style they can enhance the relationship between the physician and the family. Enhanced relationships tend to lead to more self-disclosure and higher rates of parental satisfaction.⁶⁰

This section of the chapter will explore the physician-family relationship through the avoidance of paternalism and the importance of creating a partnership and exploring patient autonomy as a minor.

a. Paternalism and Partnership

This section will explore the importance of physicians avoiding paternalism and instead creating a partnership with patients and their families. Patient autonomy as a minor will also be discussed as a way for physicians to avoid paternalism. Deciding when to include children and adolescents in their care will be delineated along with how to include children in goal planning.

i. Avoiding paternalistic behavior

Paternalism in the context of healthcare is the deliberate superseding of a person's preferences by another person on the basis that the person who supersedes the preferences rationalizes their actions by assuming they are benefiting the person or preventing harm from occurring to the person whose preferences were overruled.⁶¹ Paternalism says that one person knows what is better for another person, regardless of whether or not they have asked for help.⁶² Paternalism stems from the notion that the father of the family accepts a paternal role and,

therefore, makes at least some of the decisions regarding his children's well-being. In healthcare, this is likened to a physician who has medical training and knowledge and, therefore, is in the best situation to make decisions regarding the patient's best interests.⁶³ Paternalistic physicians decide what they believe to be in the patient's best interests with little to no regard of the patient's beliefs and values. Essentially, the physician assumes the patient's values and beliefs are the same as the physicians.⁶⁴

The structure of our health care system typically gives physicians more power since they are in a dominant position that can sometimes result in paternalistic behavior.⁶⁵ Paternalism has long been a part of medicine. In the Hippocratic tradition physicians relied on their findings to decide how much information they felt their patient needed and what treatments would work best for the patient. Traditionally, physicians felt they were benefitting the patient or family members by not disclosing information that may cause harm to patient because physicians have a moral obligation to do no harm. However, over the last few decades the autonomous rights of patients have emerged making paternalism problematic. Paternalistic behavior in healthcare is often problematic as forms of deception, influence, force framing information, not disclosing information, or outright refusing to treat a patient based on their wishes often occurs. This confines a patient or family member's ability to make autonomous choices.⁶⁶

Paternalism can be categorized as being hard paternalism or soft paternalism. In soft paternalism, the physician would intervene with the patient or surrogate's choices based on beneficence to prevent the patient from engaging in nonvoluntary treatment on the basis that the patient or surrogate were not well-informed, the patient or surrogate are severely depressed interfering with their decision-making capabilities, or the patient or surrogate have an addiction which can interfere with their ability to make autonomous choices. Soft paternalism claims to

respect the autonomy of the patient or surrogate by trying to prevent the patient from experiencing consequences they did not autonomously choose. Hard paternalism entails a physician intervening to prevent a perceived harm which they believe would be beneficial to the patient, even if the patient or surrogate are well-informed and making decisions voluntarily and autonomously. A physician who is a hard paternalist will limit the amount of information available to the patient or surrogate. Both soft and hard paternalism can be ethically problematic as they interfere with a patient's ability to make autonomous choices by attempting to sway patients in a different direction. While some forms of paternalism may appear to be beneficial *prima facie*, they often disrupt the need to respect the patient's autonomy.⁶⁷ Both soft and hard paternalism intend to make the patient do something. A hard paternalist claims to know what they think is best for the patient and intends to make them adhere to that. A soft paternalist claims the patient knows what is best for them and will make them act in their perceived best interest. Soft paternalists may participate in framing information to get patient's or surrogates to choose a certain treatment option. While soft paternalism may appear to be beneficial or not harmful, it can often lead to hard paternalism.⁶⁸

Some researchers argue that medical paternalism is sometimes necessary. Goldman argued that there might be two situations in which medical paternalism may be permissible. The first situation is if communicating information regarding a patient's diagnosis or prognosis would cause the patient direct harm such as depression or unwillingness to live. The second condition is when informing a patient of their condition may cause them to choose the wrong treatment or refuse treatment. However, as a counterargument Goldman concluded that providing a patient with honest information regarding their diagnosis or prognosis is unlikely to lead to harm. Even if a patient would experience depression, that is better than denying a patient their autonomous

rights as patients typically want full disclosure of information.⁶⁹ Others argue that paternalism is sometimes necessary as patients sometimes wish to make decisions that have the potential to be dangerous or irreversible as they may not accurately understand the dangers of their choices. In such situations, especially in pediatrics, there may be an approval for others to step in and take control of the actions of others to protect the patient from harm. Paternalism in health care can be justified on the following basis: a patient is at risk for a substantial harm which is avoidable and the paternalistic action will prevent the harm from occurring, the benefits of the paternalistic action outweigh the risks to the patient, or there is no alternative to the paternalistic action.⁷⁰

In some instances, physicians must deny patient or family requests for medically ineffective treatment, which may be viewed as paternalistic. Medically ineffective treatment is treatment that will no longer produce benefit to the patient that the patient or family is seeking.⁷¹ In order to avoid paternalistic behavior physicians must remember that parents may naturally want to explore every medical option available to save or pro long their child's life. Therefore, clinicians have a moral and ethical responsibility to educate themselves about these issues so they can provide virtuous care to seriously ill children and their families. Clinicians must be able to recognize when they are bringing suffering to children without benefit and how to work with families to create revised goals of care without involving paternalism.⁷² The notion of futility or medical ineffectiveness also becomes problematic when the physicians and parents of a child do not agree about the degree of ineffectiveness. In absence of consensus regarding medically ineffective treatment, physicians must have strong evidence to override the parents' wishes. For example, if a patient is on a ventilator and meets brain death criteria, then the patient will need to be removed from the ventilator. Yet, if a patient is on a ventilator with severe neurological damage and will require long-term chronic ventilation, but the family wishes to keep that child

on the ventilator, it would be hard for the physician to override this decision unless they have evidence this is harmful to the child. Sometimes these types of situations just take time, counseling, ethical reasoning, and good communication with the families. In other instances, the families want to keep their children alive at all costs.⁷³ The World Health Organization (WHO) and the American Academy of Pediatrics (AAP) have both issued policy statements regarding the physician's obligation to recognize, prevent, and/or relieve pain in children in such a way that the benefits are numerous and the harms are minimal.⁷⁴ It is also ethically imperative for physicians to realize that each child may take a different passageway to their death as families will have varied opinions about what is best for their child. Some families may choose to prolong a child's life while other families may choose to provide the child with comfort measures only. If it is in the child's best interests different opinions should be welcomed and autonomous choices should be granted.⁷⁵ This section has detailed paternalism and arguments for sometimes accepting paternalism have been delineated; however, counterarguments have been provided to assert that paternalistic behavior should generally be avoided. The next section will explore the benefits of creating a partnership over paternalism.

ii. Creating a partnership

Creating a partnership in the pediatric healthcare setting is paramount to overcoming paternalism. A partnership is imperative because in pediatrics the patient can never be viewed in seclusion as the patient and the surrogate are intertwined. The physician's role in the partnership is to cooperate with the patient and parents of the patient and to promote the child's best interests. Children are dependent upon their parents and family and the partnership and communication developed between the physician and the parents can have a direct effect on the care the child receives from their family. If parents feel comfortable with the physician then they

are more likely to communicate with the physician and ask necessary questions, which can ultimately affect the patient's physical and emotional health.

Six steps for building a partnership in pediatrics have been outlined. The first step focuses on using respectful communication to establish trust and exhibit empathy. The second step includes the physician listening to the patient and their family members and asking appropriate questions to identify health concerns. The third step is for the physician to praise the patient and their family for their achievements and to identify the strengths of the patient and family. The fourth step includes supporting the partnership by communicating shared goals between the patient, family, and physician. Supporting the partnership also entails referring the patient and their family to appropriate outside resources when necessary. The fifth step involves creating an achievable plan based on the previously identified shared goals. Lastly, the efficiency of the partnership should be evaluated frequently. The partnership in pediatrics is so imperative as the physician is a position to create a constructive health care experience for the patient and family. The physician will influence the patient and family's perception of their confidence and competence through teaching and offering encouragement. Pediatric physicians must also remember they are treating the entire family and, therefore, creating a trusting and caring partnership with the patient and family will lead to healthier outcomes for the child.⁷⁶ Physician's should encourage parents and patients to participate in the partnership and communication. Active participation by parents and patients has been shown to accelerate the visit and parents often feel more satisfied with the visit. Whereas parents who are not included in partnership communication often feel frustrated, rushed, and left out of the communication transaction. Physicians can encourage pediatric patients to participate in the partnership by asking open ended questions and using encouraging communication.⁷⁷

In pediatrics decision-making about chronic conditions requires a partnership as the decision-making process can be time consuming and intricate. It is required that the physician, the patient, and the family all be involved. Researchers in adult medicine have indicated that establishing a partnership is beneficial to reducing patient anxiety, reducing decision-making regret, and reducing decision-making conflicts by communicating about the goals of care in a collaborative manner. Creating a partnership allows the physician to present necessary information in a manner that provides scientific medical information while also including the patient and family's values, beliefs, and preferences.

Collaborative communication within the partnership can be done by exhibiting three different types of "talks." The first is choice talk. In choice talk the physician provides a summary of the patient's diagnosis and prognosis, explain that different treatment options will be provided, and reminds the family and patient to be mindful of their values and beliefs. The physician can then assess everyone's reaction and determine if they are prepared to move to the next step referred to as option talk. In option talk the different treatment choices are explored. To keep the partnership honest and open the physician should communicate treatment options, explore patient and family preferences, and outline harms and benefits. Physicians should always assess the patient and families' understanding of the treatment options provided and should provide more discussion or tools if necessary. The final step focuses on helping the patient and family move to a decision based on their preferences and providing an opportunity to review their decision in the future if need be. This step concentrates on helping the family reach a decision they are comfortable with and if they cannot reach a decision revisiting what information they may be lacking. In a partnership, the information exchange and communication should be fairly even as physicians should prompt communication from parents and patients, and

parents and patients should feel comfortable enough in their relationship with their physician to discuss necessary information and questions with them.⁷⁸ A partnership in pediatrics also recognizes that decision-making in pediatrics is often longitudinal, and a lasting partnership will be necessary as information and decisions will need to be revisited frequently over the course of the patient's illness.⁷⁹

At times in pediatrics, there is much uncertainty regarding the patient's diagnosis, prognosis, and trajectory to life or death. A partnership between the physician, family, and patient is especially important in uncertain situations. In a partnership, physicians should strive to understand where families and patients are coming from in their decision-making process. Understanding patient and family reasoning can create opportunities for necessary communication to occur and can lead to more information sharing. Physicians must also remember that the partnership is unique to that particular patient and family. Two different sets of parents in similar situations may reach completely different, but supportable decisions. To have a sustainable partnership physicians must put aside their own personal biases and opinions and support the patient and families' informed decision.⁸⁰

This section has explored the importance and intricacies of forging a partnership in pediatric medicine. The following section will explore patient autonomy as a minor.

b. Patient Autonomy as a Minor

Pediatric patients typically do not have the legal right to make autonomous choices regarding informed consent as they lack decision-making capacity due to their age, which legally disempowers them from any decision-making authority in health care. However, the AAP has argued that older children and adolescents should be involved in their health care decisions. When parents and patients actively participate in decision-making management of the illness

then compliance with treatment often improves. Although pediatric patients are vulnerable decision-makers as they lack experience and maturity at times, the value of including pediatric patients in their care is insurmountable. Including pediatric patients in their care shows them respect as contributors to the autonomous medical decision-making process.⁸¹ In rare circumstances parental authority to provide consent can be overridden. Such circumstances may include when a pediatric patient disagrees with the parent's chosen treatment option; when a parent chooses to withhold lifesaving treatment to the child; or when there is a conflict of interest involved, such as an abusive parent-child relationship, or when the parent is deemed incompetent to make informed decisions. Under such circumstances a compromise should be sought between the physician, patient and the parent. At these times an ethics committee may be necessary to aid the decision-making process. A minor is typically never granted the right to be the primary decision-maker unless the minor is emancipated or the parent of a child.⁸² While parents typically have the authority to make decisions on behalf of their child this does not mean pediatric patients should not be involved in decisions regarding their care.⁸³

- i. Deciding when to include children and adolescents in their care

Deciding when and how to include pediatric patients in their care can be a daunting task. While it used to be common practice to hide a poor prognosis or diagnosis from a child, research continues to indicate that children with life-threatening medical conditions should be included in the communication regarding their care in accordance with their cognitive ability to understand and emotional intellect.⁸⁴ Research also suggests that patients should be included in regarding goals and plans of care, even when dealing with issues at the end of the patient's life.⁸⁵ At times, pediatric patients lack the ability to understand their illness or illness in general, they often lack life experiences and their cognitive and communication abilities are always changing making

communication difficult. Although communication with pediatric patients may be ambitious, research has indicated that it is imperative for children to be included for a positive experience regarding their health. Children who understand their illness are thought to adhere to medical advice better, have better self-management, and experience less stress. How effective the communication with the pediatric patient is can affect their responses to treatment and procedures and their compliance with their health care.⁸⁶ Children should generally be included in their care as they are experts about themselves and can sometimes provide information that only they can offer, especially regarding their symptoms.⁸⁷

While the consent of the parent is necessary in most medical situations it is also acceptable to consider the assent of the patient given that the patient has reached a reasonable level of maturity and is competent. Including pediatric patients in the decision-making process when possible gives them an appropriate awareness of their condition and the ability to better understand their treatment options and goals. This should be a collaborative process in which information and values are openly discussed and shared. An adolescent patient's refusal for treatment should also be considered and may be an indication that better communication needs to take place to understand the patient's fears or other concerns regarding their health care. In all instances, the decision-making process should remain in the best interests of the pediatric patient at all times.⁸⁸ Assent with pediatric patients should include several fundamental steps. First, the patient should have a developmentally appropriate awareness of their medical condition, second patients should be told what to expect in terms of treatments, third physicians should seek to understand how well the patient understands their condition and treatment options, lastly physicians should gauge if patients are in agreement with the proposed treatment plan. Assent in pediatrics should never be considered when the treatment is obligatory and patients should

always know that they are not the final decision-maker.⁸⁹ Ethical issues can manifest when pediatric patients are led to believe that they have the final say in their choices, when in reality their choices may superseded by their parents.⁹⁰

At times parents may request that their child not be included in discussions regarding their diagnosis and prognosis, especially if the patient's diagnosis is life threatening. Reasoning for not including pediatric patients in such discussions may also be driven by cultural values and preferences. Some cultures believe that discussing the child's future is not appropriate. In such situations parents should be made aware of the vast amount of research that supports including children in such conversations. Parents should be aware of the ramifications of not including children in such discussions such as pediatric patients feeling anxious and isolated and a lack of gratitude for the child's values and goals. Pediatricians should work with families to decide how they can respect their cultural values and religious beliefs while still including children in their care. However, if parents still insist that their child should not be included in discussions regarding their care based on cultural or religious values than those preferences should generally be respected.⁹¹

ii. Including children in goal planning

It has been established that including children in their care and goal planning typically enhances the health care experience for parents and patients. However, to include children in their care and goal planning pediatricians must have the necessary knowledge to be able to communicate with their patients of all ages and developmental stages. The physician must understand the temperament of the child and their developmental abilities to assess if the child is able to actively participate in their care. Even when children are included in goal planning they must still be considered in the context of their family, family values, and social situation.⁹²

Including children in their pediatric care will take more time and patience than discussions in adult medicine. Pediatricians should use communication tailored to the patient's age and include the entire family to ensure smooth communication transactions. Physicians should strive to build rapport with pediatric patients to ease their fears and make them feel included in their health care. There are several recommendations for physicians to help build rapport with their pediatric patients. The first recommendation is that physicians should attempt to be eye level with the patient when communicating with them. Being on the patient's level is important to making them feel included. Getting on the patient's level encourages communication. Next, physicians should try to connect with the patient by asking the patient about their favorite toy or character. Physicians should use a calm and leisurely manner when communicating with pediatric patients, and they should be attentive not to interrupt the patient's family members when they are speaking. Physicians should always listen to patients and give them their undivided attention. Empathy should always be used and physicians should inquire about any emotions the patient may be feeling. Lastly, physicians should summarize what the patient has said so that the patient can confirm what has been communicated. Communication should be based around the patient's developmental capacity and feelings. Physicians should ask questions in developmentally appropriate ways. Open ended questions tend to facilitate the most communication in pediatrics. For younger children, the physician may provide different options for answers the child can choose from.⁹³

To be effective pediatric physicians should understand how to communicate with all pediatric patients based on their age and developmental abilities. Understanding developmental differences at each age, including infancy, allows for more inclusive communication to occur. Although infants will not be developmentally or cognitively able to participate in goal planning

or care decisions, physicians can still include them in the communication transaction. Infants will communicate through crying, cooing, grunting, smiling, facial expressions, and other nonverbal means. Infants like close contact with adult faces and eye contact when communicating. They also enjoy high-pitched voices, smiling, and singing. Older infants may experience separation anxiety and should always be in direct sight or contact with their parents when possible. It may be necessary for parents to interpret their infant's nonverbal communication cues for the physician. Toddlers tend to communicate with sentences made up of a few words or nonverbal communication. Toddlers may point or push a physician away when something is uncomfortable. Toddlers will also use nonverbal facial expressions to express happiness, sadness, pain, etc. Toddlers may be the most difficult age group for physicians to communicate with when trying to include them in the health care transaction. To engage toddlers, creative communication techniques may be necessary. Toddlers may often cry when they are displeased and they may not respond positively to communication efforts by the physician. To better communicate with toddlers pediatricians should recognize that cognitively toddlers see things from their point of view and communication should be focused directly at the toddler. Physicians should also strive to build upon a toddler's one or two-word sentences to connect with the child and concede that they understand what the toddler is trying to communicate. Toddlers should be given only one succinct direction at a time when it comes to their health care and physicians should always explain what they are going to do to the patient before they do it. Toddlers should have their parents or a security object close by during encounters. Preschoolers can communicate in full sentences and engage in some conversation, especially regarding things they can relate to such as toys, favorite colors, cartoon characters, etc. Preschoolers can be included in the health care transaction and goal planning by asking them

simple questions. Preschoolers may have many fears regarding their health care treatments and transactions and, therefore, a parent or security object should be present. Physicians must remember when communicating with preschoolers that they interpret communication plainly. Physicians must communicate literally with preschoolers to avoid added confusion and anxiety. Physicians should also use reassuring, simple, jargon-free communication. School-aged children are easier to include in goal planning and health care transactions as they can understand and communicate about health information more easily and provide answers to direct questions. Including school-aged children in goal planning and health care transactions makes them feel included and accountable for their health. School-aged children can understand their body, illness, and hospitalizations. Physicians should explain procedures and medications in ways they can understand, and allow time for the patient to ask questions. Adolescents are the final group of pediatric patients. Adolescents should be included in their care as they are not yet adults, but also no longer children. Physicians should always speak directly to adolescents regarding their health care. Adolescents are generally more aware of their bodies and health, and in order to feel a sense of accountability they want to be included in goal planning. There are several methods for communicating with adolescents and including them in the health care transaction have been outlined. Physicians should build rapport with adolescents by establishing trust and being honest with patients. If pediatricians are honest with adolescents they are more likely to be honest with their pediatrician. Pediatricians should actively listen to what adolescents have to say and they should not express disapproval. Pediatricians should offer adolescents choices and encourage questions.⁹⁴ Some states allow for adolescents to communicate with their physician about sensitive matters in a confidential manner without a parent present. Physicians should

always be certain to clarify what topics will be discussed and the state confidentiality laws before engaging in such communication.

This section has confirmed that all age ranges of pediatric patients can be included in goal planning and health care transactions in one way or another. While communication in pediatrics is dynamic, it can be prosperous if the physician has adequate knowledge regarding pediatric-specific communication across all age levels and cognitive abilities.⁹⁵

Another way to include pediatric patients in their goal planning and care decisions is through play. Important information can be revealed through play if it is utilized correctly. Through play pediatric patients can better communicate and interpret complex information.⁹⁶ Not surprisingly, play is one of the most important and effective communication techniques with pediatric patients. Play can facilitate communication by producing a familiar environment the child is comfortable in. Puppets or dolls can be used to demonstrate different treatment options to patients. Encouraging the patient to tell stories, draw pictures, or play games such as complete the sentence can also facilitate communication and inclusion in the health care process. Drawings and stories may have hidden information imbedded in them that the patient may otherwise be uncomfortable discussing. Sentence completion can help physicians determine the values of the child such as asking a child what their favorite things to do with their family are.⁹⁷ Play is a common language among all children. Play can be used to communicate with even infants who may enjoy clapping or games of peek-a-boo to establish trust during medical assessments and procedures. Play can be pivotal to helping physicians understand patient relationships between their family and other physicians.⁹⁸

Physicians should also be aware of blockades to communication that would interfere with a pediatric patient's ability to participate in goal planning and health care decision-making.

Physicians should avoid using medical jargon when communicating with pediatric patients as it may be difficult for them to comprehend and can cause confusion. Furthermore, parents may be too embarrassed to admit that they do not understand the terminology the physician is using and avoid asking for an explanation. Sometimes children may wish to avoid communication with physicians of certain genders due to negative past experiences. Children can also detect physicians who appear to be insensible instead of empathetic and they may avoid communication with a physician they view as uncaring. Parental communication can also affect the communication of the patient. High levels of stress can lead to ineffective parental communication, which will inevitably lead to a lack of communication from the pediatric patient.⁹⁹ For this reason, physicians should avoid overloading both parents and patients with information. If information overload occurs physicians must recognize the need to slow down and clarify information that has already been communicated.¹⁰⁰ Physicians should be mindful that just including patients and their families in goal planning and decision-making is not enough. They must be mindful of their communication techniques and tactics to establish a trusting relationship which is essential to achieving treatment goals.¹⁰¹

Conclusion

This chapter has explored how to maintain the physician-family relationship in pediatrics. First, relational communication theories, the social penetration theory, and the sociopsychological tradition were explored in accordance with their impact on physician-family relationships and family dynamics in pediatrics. Next, the physician-family relationship was explored in terms of avoiding physician paternalism and instead creating a partnership with patients and families. Lastly, patient autonomy as a minor was discussed and the importance of

including pediatric patients in their care and goal planning. The next chapter will provide the ethical framework for communication of prognosis in pediatric critical care medicine.

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Chapter Six:

Ethical Framework for Communication of Prognosis in Pediatric Critical Care Medicine

1. Establishing Rapport with the Ethics of Care

Establishing and building rapport with pediatric patients and their families is the foundation for building the ethical framework for communication of prognosis in pediatric critical care medicine. Communication is a fundamental necessity for all relationships in society including those in medicine. When rapport breaks down it is typically due poor or a lack of to a communication.¹ Relationships are developed, maintained, and even broken through with good communication.² If a positive relationship between the physician, patient, and family is not first established, then guidelines for the framework will not produce the intended results. Building rapport with patients and families takes time, and appropriate amounts of time should be spent on building rapport, as it is the gateway to forming a trusting relationship. Physicians must allow appropriate amounts of time for questions. A solid relationship between the physician, patient, and family will be the base for good communication to be built upon. To build and establish rapport physicians must refrain from being judgmental, they must always be respectful, they should acknowledge patient and family beliefs and values, and engage in transparent communication. Building rapport specifically with children may take extra communication and interaction. Physicians may need to engage in conversation relatable to the child by engaging in conversation through the child's favorite toy, color, tv show, etc.³

This section of the framework will review how physicians should establish rapport with the ethics of care. This will be done by specifically reviewing the importance of communication and the ethics of care as well as the moral obligations stemming from the ethics of care.

a. Communication and the Ethics of Care

Good communication and a well-established relationship are necessities to the ethics of care. Communication is imperative to ethics of care because it requires one to be responsible for those who are vulnerable or weaker. Care understood in the context of the ethics of care, requires the physician to not only care for those who are in distress, but also to form a relationship between the caregiver and the one being cared for. There must be a course of action in place for the one providing the care.⁴ If physicians are to establish rapport through the means of the ethics of care then they must have knowledge of the mechanisms to communication what is applicable to the ethics of care. This section will review symbolic communication traditions and their importance in communicating through the virtues of caring.

i. Symbolic Communication Tradition

For physicians to adhere to the ethical framework for communication of prognosis in pediatric critical care medicine they must be able to build and establish rapport with the ethics of care, and in doing so they must understand the symbolic communication tradition.

Communication cannot occur or be fruitful if one is unable understand the messages others are trying to communicate, or if others cannot understand the messages being communicated.

Understanding the message process allows one to consider how their messages are sent and how others might interpret our messages.⁵ The messages one communicates are symbolic in nature meaning that people inherently attach to symbols words. Therefore, words are subjective symbols that have no intrinsic meaning because symbols have a learned meaning and value.⁶

Words are symbols for concepts and things, although they may be vague. Symbols can take the form of verbal or nonverbal communication. Symbols can be abstract and stand for a thought or

idea, or they can be concrete and represent an object. Meaning also relates to symbols as meaning is derived from the message. Messages may have multiple meanings and meanings may not always be shared.⁷ It is important for physicians to acknowledge that once the message is sent the same message is not always received. If the message is not understood by the receiver, then although a message has been sent, no communication has occurred.⁸

There are two symbolic communication traditions encouraging physicians to have a basic understanding of the ethical framework for communication of prognosis in pediatric critical care medicine. The two communication traditions are semiotics and the sociocultural tradition. Physicians must understand the semiotic tradition as it is the study of signs and what they communicate. Specifically, semiotics studies words as symbols and how words work.⁹ Understanding semiotics is a tool that physicians need to be able to aide their communication with their patients and family members as semiotics gives meaning to interaction. Semiotics also helps communicators understand the importance of nonverbal communication necessary for effective communication in health care.¹⁰

For physicians to establish and maintain rapport with their patients and families they must understand the implications of nonverbal communication and the different types of nonverbal communication. An understanding of nonverbal communication is imperative to the framework as nonverbal communication is often more powerful and holds more weight than verbal communication. People tend to believe a communicator's nonverbal communication over their verbal communication when the two do not match. However, nonverbal communication can be easily misconstrued. More positive interactions can occur with patients when physicians understand their patient's nonverbal cues and can assess their own nonverbal communication.¹¹ Many physicians who fail at effective communication do so because they are nonverbally

illiterate. Nonverbal communication is an imperative piece to the entire communication process as nonverbal communication is always present and leaves the biggest impact on the entire communication transaction. Nonverbal communication continues even when verbal communication has halted. Even when physicians and patients are not verbally speaking they are still communicating.¹²

The ethical framework for communication of prognosis in pediatric critical care medicine requires physicians to have a basic understanding of what is entailed by nonverbal communication. Physicians must understand paralanguage, or the vocal elements they use when communicating. Paralanguage can include pitch, rate, volume, quality, and so forth of the communicator's voice. Correct use of paralanguage can help physicians when communicating about good or bad news. Paralanguage is also helpful when physicians must have telephone conferences with patients or family members. A second type of nonverbal communication essential to health care communication is the environment where communication takes place. Physicians typically do not have control over the environment where they encounter their patients. Nearly all doctor-patient meetings occur in a hospital setting. However, understanding how environment affects communication is necessary to fostering positive communication outcomes. Environmental factors might include the size of the room, the number of people in the room, the temperature, the lighting, the amount of noise, and so forth. Distractions are an environmental factor that can cause blockades to communication. Distractions often make the communicators feel frustrated and can cause the patient or family members to cease communication. One's appearance will also affect the communication transaction. Physicians should always present themselves in a professional manner. Appearance is particularly important in pediatrics., In pediatrics, the physician may wish to consider wearing character pins,

lab coats that might appeal to children, or colorful stethoscope covers. This type of nonverbal communication can positively impact pediatric patients by sending the message that the physician is approachable, friendly, and non-threatening. Lastly, physicians should be aware of their body language, both voluntary and involuntary. Body language is especially important in pediatrics, as it is the main form of communication for patients under the age of five. Body language also reduces tension and frustration in children and leads to more communication with pediatric patients. Physicians should strive to keep their arms opened rather than crossed when communicating with patients and family members. Open arms often signal friendliness and a readiness to communicate. Closed arms may indicate that the physician is not interested in communicating. They should also be aware of where and how they sit and what this communicates. Physicians who sit behind their desk often communicate that they are trying to distance themselves. Physicians who stand are often portrayed as being in a hurry.¹³ Patients typically perceive physicians who sit down next to them when they talk as more empathetic. It is also perceived that physicians who sit down spend more time with the patient than those physicians who stand to talk.¹⁴ Physicians should also maintain appropriate amounts of eye contact. Too little eye contact can signal that the physician is trying to hide something or is uninterested. Too much eye contact can signal aggression or hostility. Appropriate amounts of eye contact can communicate honesty and readiness to communicate. Lastly, physicians must be cognizant of their gestures and whether their gestures are sending a positive or negative message. A physician nodding their head while a patient or family member is speaking generally communicates affirmation, while pointing might send the message of aggression. Physicians must be conscious of their nonverbal communication in pediatrics. Nonverbal communication that conveys boredom, judgement, or distraction will ruin rapport.¹⁵

Nonverbal communication is not only the study of body language. It also entails listening. Listening is especially important in pediatrics because all children have a desire to be listened to without interruption. Active listening is an integral component of the communication process. Active listening can uncover fears or concerns that the pediatric patient may have and it can unveil critical information needed for treatment.¹⁶ Active listening requires the full attention of the physician and it requires that the physician be free from distractions. Physicians should use nonverbal cues such as eye contact to communicate to the speaker that they are listening. Physicians must also be aware to neutralize nonverbal cues that may signal judgement. Physicians should always avoid ignoring patients such as evading questions the patient or family may have. Physicians should also avoid recording notes while the patient is speaking as it hinders their ability to actively listen. Pediatricians should always listen to children with empathy and they should always attempt to confirm what the child has attempted to communicate.¹⁷

The sociocultural tradition is another symbolic communication tradition pediatric physicians must be aware of in order to adhere to the framework standard and aides in establishing rapport with the ethics of care. Physicians must understand that the sociocultural tradition suggests one's views are strongly shaped by their cultural influences. A culture's language will shape how people communicate, what they think, and what they do. Communication is used in the sociocultural tradition to establish a reality where the culture gap can be bridged and communication can be prosperous.¹⁸

As immigration trends are on the rise in the United States pediatricians must be culturally competent if they hope to create relationships with patients and families across different cultural backgrounds and deliver appropriate care. Furthermore, pediatricians must understand each

individual patient's cultural background to accurately incorporate it into their care.

Understanding individual patient cultures helps to establish trust within the relationship. Culture is so imperative to health care and rapport as culture will guide how patients and families view their illness, the treatment options they choose, and how they will engage in communication transactions.¹⁹ Research has shown that differences in understanding cultural communication styles often affect the outcome of medical care.²⁰ The ethical framework for communication of prognosis in pediatric critical care medicine calls for pediatric physicians to be aware of several key aspects of cultural communication. Physicians must understand that culture is a learned phenomenon and is often extended from the beliefs and values of the child's parents. Many cultures also belong to subcultures such as their religious affiliation or socioeconomic background. Cultural beliefs are often shared by a group of people and integrated in such a way that their beliefs will influence every decision and action the person makes. Cultures are also dynamic and can be modified to different environments.²¹ Sociocultural communication also prepares physicians to work with patients or family members who may have low levels of literacy, low IQ, or learning disabilities. In such cases physicians should keep their communication clear, concise, and free of any medical jargon. They should use repetition for key points. Physicians must be mindful not to speak loudly or show signs of impatience when communicating.²²

The framework calls for pediatric physicians to be culturally competent. Cultural competence ensures the individual patient and their family are being cared for in a culturally appropriate way. Culturally competent care includes a physician's ability to treat patients and respond to their cultural needs. Cultural competence also entails being able to interact with others outside of one's own cultural beliefs.²³ There are six elements demonstrating a physician

is culturally competent. The first element is to alter one's worldview, or become more aware of one's inherent biases. The second element is for physicians to learn about the different cultural groups with whom they frequently work. The third element suggests physician should develop a trusting relationship with the patient and their family. This can be achieved by making sure the physician can either speak the patient's language or has access to an interpreter who can communicate with the patient and family, making certain there is learning material available that the patient and family can understand, and assuring the patient and family they are culturally aware. The fourth element requires pediatricians to learn about the patient's cultural beliefs surrounding health and illness. Fifth, the physician must be able to develop goals of care that are mutually acceptable by both the physician, the patient, and the family. Lastly, physicians should have knowledge of central issues regarding a culture such as verbal and nonverbal communication patterns, child-rearing beliefs, family roles and relationship, who makes decisions in the family, and so forth.²⁴ Physicians must be sensitive and aware of different cultural and religious backgrounds, especially when they differ from their own views. Being cognizant of these differences can help forge respectful relationships and build rapport between the pediatrician, the patient, and the family. Pediatricians must always bear in mind that cultural misinterpretations are difficult to overcome and can have a profound effect on the relationship.²⁵ Cultural and religious beliefs are especially important in the pediatric intensive care unit as families in crisis will often turn to their religion or other beliefs to help them cope. Physicians should be accepting and welcoming of this if it does not interfere with the well-being of the patient.²⁶

This section has reviewed the importance of the symbolic communication tradition in terms of establishing rapport with the ethics of care for the ethical framework for communication

of prognosis in pediatric critical care medicine. The following section will explore the necessary skills pediatricians will need to communicate through the virtues of caring.

ii. Communicating Through the Virtues of Caring

Once physicians have mastered the two symbolic communication traditions discussed, they will be better situated to communicate through the virtues of caring. Pediatricians who work in a hospital will have virtues and standards that are attached to their role as a physician at a given health care institution. However, the virtue of caring will guide physicians to establish rapport with their patients and facilitate communication. The virtue of caring is central for building relationships in health care as it calls for the physician to take care of and care for the patient and their family. Communicating through the virtues of caring builds off the symbolic communication tradition. Some of the central tenants of the practice are encouraging physicians to submerge themselves in their patients by getting to know them and their beliefs and having empathy, which aids in building ethical relationships.²⁷ Most physicians would admit they strive to be a good doctor, but what being “good” means must be defined. Virtue recognizes being good as character trait of a physician whose actions are consistently right and good, and allows the physician to perform their job well. Four goals for a physician to perform their job well have been distinguished: preventing disease and injury while promoting and maintaining health, relieving pain and suffering, caring and curing those who can be cured and caring for those who cannot be cured, and evading premature death or helping patients have a peaceful death.²⁸

Physicians must master the five focal virtues, compassion, discernment, trustworthiness, integrity, and conscientiousness, to communicate with patients through the virtue of caring. Physicians must first exhibit compassion because it is the precursor to caring for someone. Compassion requires that physicians understand the distinct emotional state and experiences of

each patient to be able to respond appropriately to them, thus, requiring empathy.²⁹ Empathy is imperative for pediatric physicians to understand because it requires physicians care for the patient, both physically and mentally, on an individualized level.³⁰ Having empathy in pediatrics is especially important to building rapport with patients and families. Physicians must have a basic understanding of empathy and the effects of an empathetic relationship. Understanding empathy essentially allows the physician to place themselves in the shoes of the patient and family member. Empathy does not connote that the physician agrees with the patient or family members, rather that they can understand where they are coming from on individualized perspective. Patients and families can perceive empathy through verbal and nonverbal communication from the symbolic communication traditions. Empathy in pediatrics requires the physician understands the phases of pediatric development to be able to understand where the patient is coming from.³¹ Care without compassion will not create an environment where relationships between the physician, patient, and family will be built or maintained. Pediatric physicians must also learn to be discerning in that they will be able to treat the patient without outside influence, and they will understand how to appropriately respond to their patient's needs. Pediatric physicians must also be trustworthy, which is key to building rapport. Trust entails that physicians be morally competent, two things for the right reason, and with the right motives in mind. Establishing rapport with the ethics of care also requires physicians to have integrity. Integrity requires physicians to adhere to ethical norms and refrain from being hypocritical, insincere, or deceptive. Lastly, pediatric physicians must be conscientious. A conscientious physician determines what is right through due diligence and does what is right because it is right.³² When physicians routinely communicate through the virtues of caring they create habits of character that give them the necessary qualities to be "good" physicians

providing the groundwork to build rapport with their patients and family members and promote patient healing in a physical and emotional sense.³³

The next portion of this chapter will explore the moral obligations of the ethics of care in accordance with establishing rapport with the ethics of care.

b. Moral Obligations of the Ethics of Care

The ethics of care is a moral perspective accentuating the importance maintaining relationships. The ethics of care can help to identify and address ethical issues resulting from poor communication in health care.³⁴ The ethics of care requires a relationship first be established, empathy is used to establish the needs of the patient, and the physician respond to the needs of their patients. The ethics of care notes that physicians hold a responsibility to their patients based on the rapport they have built.³⁵ Therefore, the moral obligation of the ethics of care supposes one should care for and take care of others.³⁶ In order to adhere to the ethical framework for communication of prognosis in pediatric critical care medicine, pediatric physicians must recognize their moral obligations to the ethics of care. By doing so they will be able to establish rapport with their patients and families.

This section will provide insight on establishing relational autonomy and what it means to meet the needs of patients and families.

i. Establishing relational autonomy

If pediatric physicians are to successfully use the proposed framework for communication of prognosis in pediatric critical care medicine, then they must understand the importance of relational autonomy. Relational autonomy suggests individuals do not exist in isolation, but that their identity extends beyond them to and to their family, ethnic groups, education, occupation, and so forth. The patient's identity will be part of the relationship they

enter with the physician.³⁷ Pediatric physicians must understand the role relational autonomy plays within the social context where the patient and family member(s) exist. Relational autonomy notes that family members play a large role in the decision-making process, and physicians must consider the patient and their family member's emotional experiences and needs when making decisions. Physicians must be sure not to employ an outdated individualistic approach to autonomy where the physician assumes that the patient and their family members should be able to make decisions free from any emotional influence.³⁸ Instead, physicians should be aware of relational autonomy and how it intertwines family and medicine. Involving the family in the health care transaction is beneficial to the patient because families often know the patient's values and beliefs best. Furthermore, in pediatrics, the best interests standard is required by surrogate decision makers, which entails that surrogate decision makers must consider the patient's values and beliefs when determining the best interests of the patient. The relational autonomy model is also culturally sensitive as many collectivist cultures have strong bonds with their families and value family-centeredness.³⁹ As noted, one of the central focuses of the ethics of care is empathy. The ethics of care emphasizes the connection between relationships and emotion, especially in health care. Physicians must learn to feel for their patients and take part in their emotional well-being. A good physician will have insight into the needs of their patient and pay attention to their patient's circumstances.⁴⁰ If pediatric physicians are to follow the moral obligations of the ethics of care to establish rapport with their patients and families then they must appreciate that relational autonomy brings emotion and rationality together. Physicians, particularly in pediatrics, must acknowledge the emotional toll decision-making can have on surrogates. Emotions should never go unappreciated and should be discussed in accordance with decision-making. The pediatrician's role then becomes to facilitate

communication regarding the facts of the patient's diagnosis and prognosis, but also to attend to the emotional needs of the patient and family. Thus, physicians have a moral obligation to help patients and families through the emotional turmoil of their disease progression. This is a period where trust evolves and relationships flourish.⁴¹

The following section will explore the importance of meeting the needs of patients and families in accordance with the moral obligations of the ethics of care and establishing rapport with the ethics of care.

ii. Meeting the needs of patients and families

One of the most profound moral obligations of the ethics of care is to meet the needs of the person being taken care of.⁴² The patient and the patient's family, therefore becomes one of the physician's primary responsibilities. Physicians must work closely with families to identify their goals and plans. They must support the patient and their family and assist them in making informed decisions within the patient's best interests. Pediatricians must keep the patient and family well-informed in all aspects of their health care regarding their treatments, procedures, and additional services available to them. Physicians must provide personable care to the patient and to their family by demonstrating compassion and empathy. To meet patient and family needs physicians must strive to deliver atraumatic care, which entails using interventions that abate the physical and psychological stress experienced by patients and their families. Physicians can provide atraumatic care and meet their patient's and family's needs by adequately explaining treatments and procedures or assuring parents they will have space to stay with their child overnight. Physicians should strive to keep patients and their families together as much as possible to enhance the parent-child relationship during the hospital stay, and should allow the family to have privacy as needed. Physicians should meet their patient's needs by providing

them with appropriate activities to play and express themselves. Meeting patient and family needs also requires physicians respect a patient and their family's cultural beliefs and values. Physicians must also provide personable care to patients and families. Personable care includes listening to the patient and family, making the family feel welcome, involving both the patient and family in the care of the child, and customizing care for the patient. Providing personable care is integral to meeting the needs of the patient and their family and necessary for establishing rapport with the ethics of care as personable care helps establish constructive relationships.⁴³

This section of the framework for communication of prognosis in pediatric critical care medicine has explored the necessity of establishing rapport with the ethics of care and the various concepts and theories pediatric physicians must know in order to establish a relationship. The next section will explore how pediatricians can manage the uncertainty in veracity for surrogate consent.

2. Managing the Uncertainty in Veracity for Surrogate Consent

How pediatric physicians manage uncertainty in veracity for surrogate consent will be paramount to the ethical framework for communication of prognosis in pediatric critical care medicine. Uncertainty is common during any illness. How physicians manage uncertainty will affect the relationship between the physician, the patient, and the parent's ability to provide thoughtful surrogate consent.⁴⁴ Uncertainty in diagnosis or prognosis is common in pediatrics as there may be limited amounts of family history available or there may be limited information or studies regarding similar pediatric cases. This type of uncertainty can cause parents great amounts of anxiety; however, diagnostic uncertainty should not affect medical management or negate honest communication. In pediatrics uncertainty is heightened by the amount of rare conditions pediatricians may encounter. There are many pediatric neurological and metabolic

disorders physicians have little to no information about. There are also progressive conditions in which the course of the ailment varies widely from patient to patient. Many disorders in children do not follow the same course of action in adults and so research in adult medicine does not typically pertain to pediatric medicine. In such cases where uncertainty is prevalent physicians must use their best clinical judgement to treat the patient while monitoring the course of the illness to give parents their best judgement regarding the future of the illness and the child. To communicate with patients and families in an honest manner for surrogate consent, physicians must be able to face an unknown or poor diagnosis for their patient. If pediatric physicians are not competent in communication regarding poor or unknown diagnosis then they will not be able to communicate with families in an honest manner. This can result in having a series of effects on the relationship between the physician, the patient, and the family, and the care that the patient receives.⁴⁵ When physicians are not equipped with the communication tools they need to discuss the poor or unknown diagnosis of a patient, communication tends to occur later than it should possibly leading to decisions that are hastily made by surrogates.⁴⁶

This section of the framework will review the communication theories, skills, and knowledge physicians must possess to manage uncertainty in veracity for surrogate consent and their ethical responsibility to communicate honesty regarding surrogate consent.

a. Communication and Managing Uncertainty in Veracity for Surrogate Consent

Difficult conversations are an inevitable in medicine and they often create apprehension in physicians. Grim conversations with patients and families tend to occur when a prognosis is unknown or the life expectancy for a patient is poor. These types of conversations require physicians to have adequate communication skills. If communication regarding the diagnosis and prognosis is poor between the physician, the patient, and the family then it can cause

psychological difficulties for the patient and their family.⁴⁷ Physicians must circumvent engaging in uncertainty avoidance. This typically happens by attempting to avoid situations and communication regarding patients for which the diagnosis or prognosis is uncertain because they feel that the uncertainty is uncharted territory.⁴⁸ When patients are uncertain it often leads to a poor relationship with their physician. Patients who are uncertain typically will not initiate communication regarding health concerns which may lead their physician to believe they have no concerns. Patients who are uncertain tend to only discuss physical concerns and not emotional concerns necessary for informed surrogate consent to occur.⁴⁹

This section will review the uncertainty communication theories pediatric physicians must possess to be able to adhere to the framework for communication of prognosis in pediatric critical care medicine, and the importance of recognizing communication biases will be outlined.

- i. Uncertainty Communication Theories

Pediatric physicians must understand uncertainty communication theories for the framework for communication of diagnosis in pediatric critical care medicine to be useful. Uncertainty communication theories provide the landscape for allowing relationships to flourish by reducing and managing uncertainty. They also aide communication when uncertainty is present. The uncertainty reduction theory is the first theory pediatric physicians must know in order to be in accordance with the framework. The uncertainty reduction theory was created to explain how communication could be used to reduce uncertainties during preliminary encounters for relationships to forge and prosper. Humans by nature want to engage in communication and relationships that are predictable and explainable. The uncertainty reduction theory helps to make communication more foreseeable. People want to reduce their cognitive uncertainty, or the uncertainty surrounding one's beliefs and attitudes and their behavioral uncertainty, or the

uncertainty regarding one's behavior. A reduction in uncertainty also leads to more self-disclosure imperative in pediatric medicine. More self-disclosure leads to closer relationships, aiding both physicians and patients in having honest conversations, even when uncertainty regarding prognosis or diagnosis is present. There are several assumptions of uncertainty reduction theory pediatric physicians must understand. The first is that people generally experience uncertainty in interpersonal settings. A main concern when people meet is to reduce their uncertainty. Uncertainty that is not reduced can lead to feelings of stress. Effective interpersonal communication is the primary means for reducing uncertainty, but interpersonal communication is developmental in nature and may take time. Effective interpersonal communication requires the physician to have mastery of the skills from the symbolic communication tradition such as listening skills, nonverbal communication skills, shared language, and cultural context. Lastly, as uncertainty is reduced the amount of information people share will change.⁵⁰

Pediatric physicians must also understand the nine axioms of uncertainty reduction. The first axiom is that as uncertainty decreases interpersonal communication will increase. Second, effective nonverbal communication is imperative to decreasing uncertainty. Nonverbal assurance such as smiling, eye contact, and tone of voice can aid in the reduction of uncertainty. Third, when uncertainty levels are high, the desire for information about the other person will also be high. People begin to relax in the communication transaction when the relationship becomes more predictable. Fourth, the higher the amount of uncertainty the less likely someone is to disclose personal information. As uncertainty is reduced disclosure increases, creating an environment where relationships can be built and sustained. The fifth axiom notes that the communicators will attempt to match each other's reciprocity.⁵¹ In health care it is important

for physicians to recognize the importance of reciprocity in relationship building. Reciprocity in health care is different than in typical interpersonal communication, as physicians typically do not divulge the same types of information as patients and family members. However, physicians can create mutual feelings of reciprocity by acknowledging the depth of what their patients have shared and communicating with them in an empathetic manner.⁵² The sixth axiom calls for physicians to get to know their patients on such a level that they can highlight similarities between themselves and their patients. Similarities reduce uncertainty and dissimilarities increase uncertainty. The seventh axiom states that when people become more familiar with each other uncertainty levels decrease and liking increases. If communicators remain unfamiliar with each other than uncertainty levels will not decrease leaving little room for liking to increase or relationships to be established. The eighth axiom states that shared communication networks reduce uncertainty. The last axiom notes that uncertainty reduction follows deductive logic because if each axiom is accomplished then uncertainty in the communication transaction should be reduced and relationships should therefore be able to prosper.⁵³ While most uncertainty reduction theory focuses on the initial encounters in a relationship, pediatric physicians must recognize that uncertainty can develop in established relationships. Uncertainty in established relationships can create tension. In pediatric health care uncertainty may arise over the future of the relationship between the physician, the patient, and the family. If this uncertainty is not managed or reduced like it is in the initial encounters, then feelings of distrust may form causing detriment to the relationship.⁵⁴ The ethical framework for communication of prognosis in pediatric critical care medicine calls for physicians to be able to manage their uncertainty and communicate with patients and families in a truthful manner so relationships can be forged.

Once relationships are forged more honest communication can occur leading to better-informed surrogate consent.

The next section will explore the pediatric physician's need to recognize their communication biases.

ii. Recognizing communication biases

When uncertainty is not reduced and stable relationships are not established it can create a climate of communication where physicians feel the need to imply their own biases and frame information in a way that agrees with their own biases. The ability to recognize one's biases is a skill that should be learned from a development of cultural competence in establishing rapport with the ethics of care, as cultural competence requires physicians first examine their own biases.⁵⁵ For the ethical framework for communication of prognosis in pediatric critical care medicine to be moral, physicians must recognize their own inherent biases and avoid unethically framing information. When discussing information with patients and family members regarding treatment, diagnosis, and prognosis physicians must strive to remain neutral to avoid any type of framing since framing is manipulative.⁵⁶ Physicians must be aware of their inherent biases especially when dealing with ethical issues in the pediatric intensive care unit such as withholding or withdrawing care at the end of life. A physician's attitude regarding life sustaining medical interventions may be influenced by factors such as their own cultural or religious beliefs, emotional responses to the child's illness, misinterpretation of the benefits and burdens of the treatment, or insufficient education about end of life ethics and life sustaining treatment.⁵⁷ Physicians must be aware of any biases they have regarding end of life care as they may frame the risks and/or benefits of these life sustaining interventions which influences the perception of treatment for physicians, families, and patients alike.⁵⁸ Furthermore, clinicians

should be aware of how the patient's biases or ethnic, cultural, and religious values might affect their decisions and relationship.⁵⁹ All variations of framing are manipulative and influence the patient and family member's perceptions of risk resulting in inhibiting informed surrogate consent. It should be the goal of the physician to facilitate informed consent, not to get the patient or their family members to agree with the physician's biases.⁶⁰

Recognizing and communicating biases with patients and their families is necessary in the ethical framework for communication of prognosis in pediatric critical care medicine. This framework does not assume physicians must be free from their own beliefs and values to treat patients. However, when a physician recognizes that their beliefs and values may hinder the care they can provide to a patient or their family, they must recognize this bias and act on it without attempting to influence the patient or family to see things their way.⁶¹ When biases arise physicians are required to be open with patients and explain the types of treatments or interventions they will not participate in. However, they should never attempt to provide an explanation as to why they will not participate in the treatments or interventions as that can influence the patient or family members.⁶² This predisposition can also be referred to as moral distress in health care. When physicians feel morally distressed by a surrogate's choices they can have respectful conversations with the family regarding this distress. If the moral distress continues physicians can seek to remove themselves from the situation by reassigning the patient to another physician when applicable and possible.⁶³

This section has reviewed the importance of the physician's ability to manage their uncertainty in veracity for surrogate consent specifically by requiring pediatric physicians to have knowledge of uncertainty communication theories, and to have the skills to recognize their

own communication biases inhibiting informed surrogate consent. The next section will review the physician's ethical responsibility to communicate honestly regarding surrogate consent.

b. Ethical Accountability to Communicate Honestly Regarding Surrogate Consent

If the ethical framework for communication of prognosis in pediatric critical care medicine is to be a truly moral framework then physicians must recognize their ethical responsibility to communicate honestly, especially in terms of surrogate consent. The National Communication Association illustrates several principles to ethical communication that physicians should know. The first principle states that truthfulness, accuracy, and honesty are necessary in communication transactions as there is an obligation to be honest. Second, physicians must accept responsibility for the consequences of their communication regardless of it being good or bad. Communication used by physicians should benefit the patient and not harm them. Third, physicians should understand their patient and their family member's beliefs, values, attitudes, and character, and be willing to view their communication from an empathetic point of view. Fourth, physicians must promote access to communication resources for their patients and families. Fifth, physicians must avoid any communication that is degrading, coercive, disproportionate, or intolerant. Sixth, physicians must communicate in a just and fair way. Seventh, physicians must provide information to their patients and family members in an honest manner while respecting their privacy and confidentiality. Lastly, physicians must allow patients and their family members to communicate freely, regardless of differing opinions or perspectives, and allow informed decision-making to occur.⁶⁴

i. Understanding Surrogate Consent Standards

For physicians to communicate honestly regarding surrogate consent, they must first understand surrogate consent standards and what being a surrogate decision-maker in pediatrics

entails. There are some key elements of surrogate consent standards pediatricians must be aware of. Pediatric patients are typically minors and, therefore, do not have the legal capacity to make decisions regarding their own health care. In special circumstances, the minor may be emancipated for their parents and, therefore, may be able to provide consent for their own care.⁶⁵ Since pediatric patients cannot consent to treatment they need and so a surrogate must do this for them. Parents are typically delegated as the patient's surrogate decision maker, because it is presumed that parents have the best understanding of their child's values, beliefs, and family needs. Surrogate decision makers must act as a fiduciary to the patient and have the responsibility to act in their child's best interests when making all decisions. Acting in the patient's best interests requires the surrogate to maximize benefits while minimizing harms to the patient.⁶⁶ Physicians must remember that each patient and family unit are unique in terms of culture, religion, and values, and what is in the patient's best interests will vary from patient to patient.⁶⁷ The physician must also act as a fiduciary to the patient as they have the duty to act in the patient's best health interests by providing information free from their own biases. The physician and the surrogate then become co-fiduciaries in the medical decision-making process. The primary elements of informed consent in pediatrics require physicians to discuss the nature of the patient's illness or condition; the available diagnostic steps or available treatments and their rate of success; the potential risks, benefits, and uncertainties of the treatment options; and the option to refuse treatment and adhere to comfort measures only. Physicians must also be sure that patients and family members have correctly understood the information they have communicated. They should also leave ample amounts of time for patient and surrogate questions. Lastly, physicians must be assured the surrogate is acting in a voluntary manner, free of coercion.⁶⁸ It is notable that physicians can challenge parental authority. This typically

occurs when parents refuse a treatment option recommended by the physician, or when physicians feel parents are not acting in their child's best interests.⁶⁹ The American Academy of Pediatrics offers several recommendations for informed consent and decision-making in pediatrics pertinent to the framework. To respect autonomy parents should typically be deemed the appropriate decision-makers for their child. Surrogates must seek treatment options that maximize the benefit to their child while considering their values, beliefs, and emotional well-being. Physicians are morally required to make certain the surrogate is not putting the patient in significant risk of harm. Although pediatric patients have surrogate decision-makers physicians should strive to include patients in the decision-making process in a developmentally appropriate manner. Lastly, physicians must recognize that informed consent is generally an on-going process of communication.⁷⁰

The ethical framework for communication of prognosis in pediatric critical care medicine calls for physicians to uphold their duty to provide honest information to patients and surrogates for informed consent to occur. Professional codes of ethics require physicians to disclose information in an honest manner. This is especially important in pediatrics as the vulnerability of the pediatric patient obligates physicians to protect them.⁷¹ One of the hardest aspects of pediatrics is that pediatricians must have difficult conversations regarding diagnosis, prognosis, and treatment with families and patients in an honest open manner. Strong relationships and open lines of communication between the physician, the patient, and the family are necessary so physicians can feel comfortable facilitating such discussions, and parents can make well-informed decisions regarding their child's care. Physicians must remember that their anxiety about such discussions can lead to poor communication and a breakdown of the relationship.⁷²

Overly optimistic or dishonest diagnostic information does not allow parents to properly make decisions regarding informed consent and can be harmful to the overall health of the patient.⁷³

This section has provided information on the importance of understanding surrogate consent standards in terms of the ethical duty of the physician to communicate honestly regarding surrogate consent. The following section will review physician neutrality.

ii. Physician neutrality

The framework for communication of prognosis in pediatric critical care medicine requires physicians to maintain neutrality. Physicians are essentially the advisors to the patient and their family members when providing informed consent. Pediatricians should strive to support patients and their surrogates in the decision-making process, but they must do so in a neutral manner. Physicians should remain objective when providing information regarding diagnosis, prognosis, and treatment options. However, they should not be so objective that they forget the importance of their relationship with the patient and family. Physicians do not have to refuse to offer any guidance on what is medically or ethically permissible, but they should not offer opinions that are manipulative or deceptive to get surrogates to agree to a certain decision.⁷⁴ It is not unlikely that situations will arise where the beliefs of the physician and the patient will conflict. In these cases, the physician can typically decline to provide medical services that go against their beliefs. However, in such situations physicians must remain neutral, nonjudgmental, and respectful.⁷⁵ Physicians must also remain objective to avoid becoming overly involved with their patients and their families. Physicians must accept this neutral position to avoid allowing their personal feelings to enter the relationship, which can affect the medical-decision-making process and cloud judgement. Physicians can practice empathy while

remaining neutral.⁷⁶ Empathy allows physicians to be compassionate without the perils of too much emotional involvement with their patients.⁷⁷

This section has reviewed the physician's ethical accountability to communicate honestly regarding surrogate consent. Maintaining the physician-family relationship will be discussed next.

3. Maintaining the Physician-Family Relationship

The final part of the ethical framework for communication of prognosis in pediatric critical care medicine requires physicians to take the necessary steps to maintain the physician-family relationship once it has been established. The physician-family relationship is the foundation for which communication takes place regarding prognosis, diagnosis, and treatment. The physician-family relationship also fosters healing the patient and provides support to the patient and their family. The relationship between the physician and the family directly affects care. If the previous steps of the ethical framework for communication of prognosis in pediatric critical care medicine are not met then the relationship will not flourish. Patients who do not trust their physician will not disclose pertinent information. Patients who are uncertain and anxious will not comprehend information correctly. The relationship determines the quality of the medical encounter and patient satisfaction. Research continues to indicate that patients and family members who are active in their care do better clinically. The physician-family relationship is even more imperative in pediatric critical care medicine as the patients are vulnerable and rely on the physician and, therefore, their relationship with them.⁷⁸

a. Communication Strategies for Maintaining Physician-Family Relationships

This section will review the communication strategies necessary for maintaining the physician-family relationship and the ethical considerations of the physician-family relationship.

Building and maintaining the physician-family relationship is crucial to positive health care outcomes. When physicians and families have a well-established relationship patients are more likely to adhere to their treatments and tend to cope better with their illness. Including the family in the relationship is particularly important in pediatrics as the family members will be the main support system for the patient and play a substantial role in encouraging positive health outcomes for the patient. If family members are to maintain their relationship with the physician then they need effective modes of communication.⁷⁹ Research has indicated that physicians who create and maintain a welcoming relationship with their patients are found to be more effective as a physician.⁸⁰

- i. Relational communication theories

This section will review the importance of relational communication theories and family-centered care in accordance with the framework for communication of prognosis in pediatric critical care medicine.

It is necessary for pediatric physicians to have knowledge of relationship-centered communication theories to adhere to the framework. Understanding a relational approach to interpersonal communication will help physicians develop and maintain relationships.⁸¹ The relational communication strategies for maintaining relationships are similar to the communication strategies necessary for effective communication. They include empathetic, positive, immediate, and culturally sensitive communication. When these communication skills are paired with self-disclosure and active listening it creates an environment where relationships become sustainable.⁸²

One relational communication theory pediatric physicians must understand is the social penetration theory. The social penetration theory guides physicians in how to communicate once

the relationship is developed.⁸³ The social penetration theory explores how relationships become deeper and develop over time as disclosure increases. The theory claims that rewarding relationships are sustained, whereas costly relationships tend to decline. The social penetration theory suggests that people are represented in layers including both breadth and depth. The outer layers of a person are impersonal and visible, for example one's gender, height, and weight. As the relationship develops the inner layers will be revealed. The inner layers of a person consist of their personal feelings and thoughts.

There are four stages of relationship development that pediatric physicians should be aware of. The first stage is orientation, where impersonal communication takes place. The second stage is the exploratory affective exchange where communicators begin to share more personal information. The third stage is the affective exchange where deep feelings are shared. This stage will only be entered if the relationship appears to be rewarding. The final stage is the stable exchange where communication is personal and predictable. Relationships will go back and forth between these stages as the needs for information or privacy change.⁸⁴

The sociopsychological tradition is another relational communication theory pediatric physicians must know. The sociopsychological tradition seeks to characterize individuals and the relationships they exist within. Relationships that are of importance in pediatric health care are the patient's family relationships. Pediatricians must understand the importance of family schema, the different types of families they may encounter in the pediatric critical care unit, and the affect it will have on communication transactions. Relational schemas determine what patients and family members know about relationships in general and what they know about family relationships. Communication patterns within a family are not arbitrary and will follow a pattern. Pediatric physicians must understand the different communication orientations families

will fall under. They will affect their communication and decision-making style. The different communication orientations are conversation orientation and conformity orientation. Families that have high conversation orientation will like to talk, whereas families with low conversation orientation will not enjoy engaging in conversation as much. Families with high conformity go along with whatever the authority figure in the family says, whereas families who have low conformity allow for more individuality. Pediatricians must also understand the different family types: consensual, pluralistic, protective, and laissez-faire. Consensual families like to communicate, but an authority figure will make decisions. Pluralistic families also enjoy conversation but decisions are made on an individual basis. Protective families do not enjoy communicating as much; however, the authority figure in the family tends to make decisions without much communication about it. Lastly, there are laissez-faire families who do not enjoy conversation and are generally uninvolved in making decisions together. When pediatricians understand the sociopsychological tradition and how familial relationships work they can understand and appreciate the differing interaction patterns of each patient and their family.⁸⁵ Relational communication theories and their pertinence to the ethical framework for communication of prognosis in pediatric critical care medicine have been discussed.

The notion of family-centered care will be discussed next.

ii. Family-centered care

For the framework for effective pediatric physicians must have knowledge of family-centered care and how to affectively engage in it. Family-centered care in pediatrics is grounded in the relationship between the physician, the patient, and the family. Family-centered care is relative to relational communication theories as it recognizes the importance of relationships and family. Family participation in the health care transaction is crucial to the well-being of the

pediatric patient. Pediatric physicians must know and apply the core principles of family-centered care. The core principles are summarized as follows. Physicians should listen to and respecting the family in terms of background, beliefs, values and culture. Physicians must tailor the health care transactions to the needs of the patient and their family. Physicians must communicate with the family and patient in a complete, honest, and unbiased manner. Physicians must make sure patients and families have access to both formal and informal support networks. A collaborative relationship should be established to deliver appropriate care. Lastly, physicians should seek to empower patients and their families by building on their individual strengths.⁸⁶

Even in the pediatric intensive care unit where tensions typically run high, physicians can do things to make the experience more family-centered and positive for the patient. Families like to be in an environment where they can remain close with the patient in a private setting. Physicians can also help parents feel as though they are actively taking care of their child, even if they cannot administer medical care. Parents can still participate in bathing, clothing, and feeding their child when applicable.⁸⁷ A family-centered approach to care encourages families to stay with their child in the hospital, be present during physician rounds, and be present during medical procedures.⁸⁸ However, family-centered care also encourages parents of the patient to enjoy life outside of the hospital. Parents should be supported and know that they must take care of themselves and the patient's siblings too. Parents should be supported in this way by encouraging them to leave the hospital momentarily to go out to dinner, see a movie, or even sleep in their own bed. Parents should know that taking care of themselves will not change the course of their child's illness or treatment.

There are suggestions for creating a more family-centered approach in the pediatric intensive care unit. Some of those suggestions include keeping families involved in the patient's care by arranging specific times to communicate with the family about the condition and progress of the patient, asking patients and family members for their input, respecting the cultural and religious values of the family, and empathizing with the family.⁸⁹ Pediatric physicians in the intensive care unit must adopt a family-centered approach as the benefits to the relationship, communication, and well-being of the patient and family are insurmountable. Family-centered care increases satisfaction for everyone involved in the relationship including the pediatrician, it helps patients and their families bond and builds upon their strengths, it decreases health care costs by a more effective use of resources, and it decreases anxiety in the patient and family. Research also indicates that the pediatrician will benefit from family-centered care by improved communication skills, professional satisfaction, an enhanced learning environment as pediatricians will learn how family systems truly work. In addition, patient safety is improved when physicians and families collaborate for informed consent. While this type of family-centered care takes additional time, the period pediatric physicians invest will be repaid by improved patient outcomes and better relationships with patients and families.⁹⁰

Family-centered care and its role in the ethical framework for communication of prognosis in pediatric critical care medicine and relationship maintenance has been discussed. The next section will explore some ethical considerations of physician-family relationships.

b. Ethical Considerations of Physician-Family Relationships

Relationships must be morally sound or physicians to maintain physician-family relationships in accordance with the framework for communication of prognosis in the pediatric critical care medicine. There are some ethical considerations physicians should be mindful of

when working within the physician-family relationship. Physicians should make certain patients and families have accurate information regarding the patient, and that they have a clear understanding of the patient's illness and prognosis. Physicians should encourage communication about family beliefs and values and the role they play in patient care. Physicians should support patients, families, and surrogates in the role they play in the health care process, and they should recognize when patients and families may need outside support. Lastly, physicians should develop care plans that are patient-centered.⁹¹ The framework for communication of prognosis in pediatric critical care medicine also requires physicians to make other ethical considerations in terms of the physician-family relationship such as creating partnership with families over a paternalistic relationship and respecting pediatric patient autonomy which will be discussed next.

- i. Partnerships over paternalism

The framework for communication of prognosis in the pediatric critical care medicine requires physicians to act in a moral manner by refraining from paternalistic behavior. Instead, they should engage in a partnership with the patient and the family. Paternalism is typically viewed as unethical and negative and is generally no longer accepted in the medical decision-making process. When physicians use the interpersonal communication skills they have acquired from the framework they are less likely to engage in paternalistic behavior. Also, when physicians share information with patients and include them in the health care transaction they are less likely to exhibit paternalistic behaviors. Physicians must understand the problems of paternalism and strive to create a trustworthy partnership. Physicians can still care for their patients, guide their patients, and offer their expertise without being paternalistic. When physicians, patients, and family members come together in a partnership they create a

relationship where the physician can share their expertise while guiding the family to make well-informed decisions. To act in an ethical manner physicians must recognize that final decisions rest with the patient and their family, but the physician has the responsibility to empower them to make decisions that are within the patient's best interests. For this type of partnership to come to life a trustworthy relationship and patient-centered communication must unite.⁹² Paternalism is not compatible with this framework because it assumes that physician's values are superior to the patient's values or that the patient and physician have the same values. Therefore, a partnership is a more ethical approach to maintaining the physician-family relationship. A partnership allows a caring physician to provide the patient and their family with informative care while including the patient's values and beliefs.⁹³ The framework requires physicians to establish and maintain rapport through the ethics of care and by creating trusting relationships through veracity for surrogate consent. None of which are well suited for paternalistic views.

ii. Autonomy as a minor

The framework requires physicians to consider the autonomy of their pediatric patients. While most pediatric patients will not have the legal capacity to provide informed consent, they can still be included in the health care transaction, which will subsequently have positive effects on the relationship. The AAP recommends that older children and adolescents should be involved in the health care decision-making process. Including them in their care communicates respect.⁹⁴ However, this framework suggests that all minor patients, from infancy to adolescence, should be included in their care in some way. Research indicates that children can sometimes provide pertinent health information about themselves that may not otherwise be revealed if the child is not included in the health care transaction.⁹⁵ Children who are involved in their care have less stress, better adherence to treatments, and leads to better outcomes.⁹⁶ The

framework necessitates that pediatric physicians should have an understanding of how to include pediatric patients of all ages in their care. Infants will communicate with physicians mainly through nonverbal means. Infants can sense tension; therefore, the physician-family relationship is important even in infant care. Physicians can engage infants in the relationship and health care transaction by using a high-pitched voice or exaggerated facial expressions. Parents will typically need to translate infant communication for the physician. Toddlers typically have an innate desire to exhibit autonomy and independence. Pediatric physicians should use tools such as play and arts and crafts to involve toddlers in their care. Physicians should immediately respond to toddler attempts to communicate and should engage them in the health care transaction by giving them concise directions and explanations for their treatment.⁹⁷

Preschoolers will also appreciate communicating through play; however, they are better situated to understand their health than toddlers. Preschoolers appreciate honest and concise communication and in some circumstances it may be appropriate to give the patient choices and allow them to exercise their autonomy in that way. School-aged children should be provided with diagrams and pictures to explain their condition and treatment options. School-aged children should be able to honestly express their feelings regarding care and they should be able to ask questions and have their questions answered appropriately. Adolescents should be included in their care and should be offered choices when applicable. The physician should encourage the adolescent to ask questions and questions should be answered appropriately.⁹⁸

In some circumstances, typically for cultural or religious values, parents may request that their child not be included in discussions regarding their health care. In such situations physicians should engage in respectful communication regarding the research findings and inclusion of children in their health care. Typically, a parent's wish to keep their child

uninvolved in the health care transaction should be respected.⁹⁹ Pediatric physicians must remember that children across all age and developmental spans can appreciate being included in the health care transaction. Children appreciate being listened to and may reveal pertinent information. Including children in the health care transaction allows them to feel empowered in the physician-family relationship.¹⁰⁰

Conclusion

This chapter has systematically reviewed the ethical framework for communication of prognosis in pediatric critical medicine. This chapter reviewed all the necessary components for the framework to be successful when in use. The first component was the importance of establishing rapport with the ethics of care. Communication and the ethics of care were reviewed with specific attention paid to symbolic communication traditions and communicating through the virtues of caring. Next the moral obligations of the ethics were reviewed, specifically how one can establish relational autonomy and meet the needs of patients and their families. The next component was managing the uncertainty in veracity for surrogate consent. Communication and managing uncertainty in veracity for surrogate consent was reviewed with specific attention paid to uncertainty communication theories and recognizing communication biases. What it means to be ethically accountable to communicate honestly regarding surrogate consent was discussed. Understanding surrogate consent standards and the importance of physician neutrality were reviewed. The final component, maintaining the physician-family relationship, was also discussed. Relational communication theories and family-centered care were reviewed. Lastly, ethical considerations of physician-family relationships were discussed with attention to creating partnerships over paternalism and what it means to be an autonomous minor. The ethical framework for communication of prognosis in pediatric critical care medicine

is deductive in nature. Therefore, all components must be met by the physician to possess the skills they need to ethically communicate with patients and families regarding prognosis in the pediatric critical care unit.

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Chapter Seven: Conclusion

This dissertation has identified the need for an ethical framework for communication of prognosis in pediatric critical care medicine. The thesis was to present an ethical framework for communication of prognosis in the pediatric critical care setting. The main point was that ethical communication transactions are necessary insofar as they lead to better care for pediatric patients in critical care by enabling surrogate decision makers to make well-informed decisions. Communication techniques are essentially tools physicians have in addition to their typical medical devices. This dissertation calls for physicians to have a protocol to guide them when communicating with a vulnerable population such as pediatric critical care patients about prognosis.

The need for framework of interaction was explained by exploring the notion of communication theory and how a lack of ethical communication can have a detrimental effect on all aspects of care in the pediatric critical care setting. Communication theory as it specifically relates to pediatric medicine was reviewed. Next, this analysis explored how communication theory can be enlightened by related bioethics topics. How to establish rapport through the ethics of care, how to manage uncertainty in veracity for surrogate consent, and how to maintain the physician-family relationship was discussed by integrating bioethics and communication theory. Lastly, the discussion provided an ethical framework of communication of prognosis in the pediatric critical care setting. The framework aligned communication theories and bioethics by creating a practical communication protocol.

The lack of an ethical communication framework in pediatric critical care medicine is problematic as pediatric physicians often experience difficulty in having authentic conversations regarding prognosis. When physicians find it difficult to honestly discuss the prognosis of their

pediatric patients it makes truly informed consent nearly impossible for the surrogate decision maker. The lack of candid communication about prognosis can also give way to deceitfulness and false hope. This type of dishonest communication about prognosis in the pediatric critical care setting often leads to uninformed and unfair treatment for children and their families as it can leave them unprepared for what lies ahead. While physicians may not deliberately engage in dishonest communication strategies they are nonetheless problematic.

The relevance of this dissertation was clear insofar as the literature identified the communication problem without providing a truly solid recommendation to resolve the issue. This dissertation was also noted as being distinctive because it applies specifically to the discussion of prognosis in pediatric critical care medicine where there are often numerous ethical issues.

Pediatric critical care was chosen as the focus for the communication framework due to the intricate nature of the pediatric intensive care unit. The pediatric intensive care unit was described as a fast-paced, often tense, environment where ethically loaded decisions must be made. Patient care often involves many physicians in the pediatric intensive care unit, making communication and relationships even more imperative to patient care. The need for such a framework in pediatric critical care medicine has been initiated from the notion that pediatric physicians may experience significant difficulty when it comes to having challenging conversations and communicating unfavorable diagnoses with patients and families. This difficulty often stems from the physician's empathetic nature, but it can result in paternalistic behaviors which can negatively influence a surrogate's ability to make truly informed decisions regarding the patient.¹

Ethical communication transactions are necessary insofar as they lead to better care for pediatric patients in critical care by enabling surrogate decision makers to make well-informed decisions. If pediatric physicians do not have the proper education and tools to communicate information with patients and families then informed decisions will be impossible.²

Communication techniques are essentially tools physicians have in addition to their physical medical tools. The proposed framework gives physicians the tools they need to guide them when they are communicating with a vulnerable population such as pediatric critical care patients and their families about prognosis, diagnosis, and treatment options. The framework for communication of prognosis in pediatric critical care medicine is necessary. There has been a decline in the importance of communication in the health care process as medicine is greatly dominated by science. The lack of significance placed on communication has led to a decline in the physician's ability to build rapport with patients and their families and this in turn has a ripple effect of significant problems.³

Effective communication should not be viewed as a bonus to quality health care. It is the core of quality health care. Effective communication skills allow for relationships to be forged and for health information to be exchanged in an effective and productive manner. The issue lies in communicating effectively versus just communicating. Communication is a complex and multifaceted process that is not simply learned but must be taught. The process of communication requires senders and receivers to share meaning through different channels, but messages can become contradictory as nonverbal communication negates verbal communication. All physicians must communicate with patients and families regardless of their ability. In fact, communication literature notes that communication is so prevalent that one cannot not communicate. Everything the sender does will convey a message to the receiver.

Communicating effectively means the physician will have the knowledge to communicate with the correct people, in the right way, and at the right time. Effective communication in health care is patient-centered, helps build trust and rapport, and is informative. Relationship breakdowns typically occur when communication is not effective. Effective communication must begin with the physician-patient encounter, as the initial encounter will set the stage for all future communication transactions. Evidence continually indicates that physicians who communicate effectively with patients do better for their patients. Patients are more likely to have an accurate diagnosis and improved recovery rates, patients are more satisfied and less stressed, and patients are more willing to follow treatment regimens. Research also shows that ineffective communication leads to negative outcomes. Patients who have a physician who is ineffective at communicating do not engage with their physician, they tend to not follow through with necessary treatment, they do not cope well with their diagnosis or prognosis, and in some cases, they may experience psychological harm. Ineffective communication is a serious problem as it can even lead to death.⁴ Ineffective communication also negatively affects physicians. It has been linked to physician distress, burnout, professional dissatisfaction, and an increase in medical malpractice law suits.⁵

Previous research and this dissertation have both acknowledged several key points regarding effective communication and patient health outcomes. First, communication problems in health care are important to address as they occur commonly. Second, communication issues lead to patient anxiety and dissatisfaction with the physician. Most of the anxiety and dissatisfaction stems from patient uncertainty, a lack of information, and a lack of feedback. Third, physicians often misjudge the amount of information patients want to receive and the type of information they wish to receive. Fourth, when effective communication is exercised it

improves the health care transaction which improves health outcomes for the patient. Fifth, when patients feel comfortable participating in the health care transaction their satisfaction level and treatment adherence increase. Sixth, patient anxiety reduces when physicians take time to empathize with patients and their concerns. Seventh, psychological distress decreases in critically ill patients when they feel they have received satisfactory amounts of information regarding their illness and treatment options. Lastly, if physicians are properly educated about relevant communication techniques they can easily integrate them into the clinical encounter. Research continuously indicates that when physicians adhere to these key points their patients do better. Patients have a more accurate diagnosis, they have less emotional stress and anxiety, they agree with the treatment plan and follow it properly, and they have better recovery rates.⁶

The need for such a communication framework was explained by exploring the notion of communication theory and how a lack of ethical and effective communication can have a detrimental effect on all aspects of care in the pediatric critical care setting. Communication theory as it specifically relates to pediatric medicine was reviewed. Next, this analysis explored how communication theory can be enlightened by related bioethics topics. How to establish rapport through the ethics of care, how to manage uncertainty in veracity for surrogate consent, and how to maintain the physician-family relationship was discussed by integrating bioethics and communication theory. Lastly, this dissertation provided an ethical framework of communication of prognosis in the pediatric critical care setting. The framework aligned communication theories and bioethics to create a practical, easy to integrate communication protocol for pediatric intensive care physicians to implement into their daily work. The relevance of this dissertation was explained as research identifies a communication problem without giving a suitable recommendation to resolve the problem. This dissertation was

distinctive because it applies specifically to the discussion of prognosis in pediatric critical care medicine where there are often numerous ethical issues. This dissertation is unique in that it takes relevant communication theories and applies them to bioethical issues found within the pediatric intensive care unit to create a framework for communication of prognosis. This type of framework can be easily taught and implemented to all physician's and residents working the pediatric intensive care unit in any given hospital or in medical school. An overall conclusion of each chapter will be outlined next.

The first chapter introduced the problem noting that the quality of communication in pediatric medicine is troublesome. Understanding the connection between communication theory and prognosis in pediatric critical medicine is imperative to the foundation of an ethical framework for communication of prognosis. Communication was defined in terms of its meaning to the framework for ethical communication of prognosis in pediatric critical care medicine. While a distinct definition of communication could not be identified there were elements of communication deemed necessary for the communication transaction to be effective. Communication is a transactional process requiring two or more people to construct a shared meaning through the use of symbols that can take the form of verbal or nonverbal communication.⁷ The first chapter also explored the importance of connecting bioethics to communication theory for the purpose of this framework. Communication theory for pediatric medicine was reviewed. Communication theories help one to understand how we interact with others and our relationships with others. Understanding communication theory allows one to better understand how people work together. Theories are essentially a map to guide us through unfamiliar territory.⁸ For the purpose of this framework it was suggested that physicians should know relevant communication theories and research related to the theory and communication in

medicine. Next, bioethical issues were introduced such as establishing rapport with the ethics of care, managing uncertainty in veracity for surrogate consent, and maintaining the physician-family relationship with the main goal of creating an ethical framework for communication of prognosis in pediatric critical care medicine. This chapter was integral in establishing the relevance, uniqueness, and importance of the dissertation.

Chapter two explored communication theory for pediatric medicine. Relevant communication theories and ethical indications that could be used by physicians to promote the discussion of prognosis in pediatric critical care medicine were discussed in this chapter. The significance of communication in health care was also discussed. Effective health communication was noted as having a significant impact on the patient's disease and well-being. Health communication was also noted as important because it attempts to explain what the disease means to the patient and family. This integral to informed decision-making. When physicians understand communication theories they can apply those theories to practical patient encounters.⁹ Chapter two also outlined some of the issues pediatricians have with communicating honestly and effectively in pediatric critical care. Physicians are often uncomfortable communicating about prognosis because they lack guidance for how to communicate prognosis to patients and families. Often, they are unsure how much information to communicate, when to communicate the prognosis, and how to properly communicate about the prognosis. Sometimes physicians fear disclosing too much information will cause patients to lose hope and experience anxiety.¹⁰ However, those beliefs were refuted as it was shown that proper disclosure of information is productive and necessary. Establishing rapport with the ethics of care was discussed next. Establishing rapport between the physician and patient was noted as being a central element to effective health care. Establishing rapport leads to strong

physician-patient relationships and strong relationships allow for more effective communication transactions to take place; however, good interpersonal communication skills are also necessary to establish rapport.¹¹ The ethics of care was discussed in terms of it being a moral theory requiring one to meet the needs for who they are accountable. The link between building rapport and the ethics of care was discussed as the ethics of care considers interpersonal relationships to be vital to morality.¹² What it means to create relationships through caring was discussed next. It was determined that creating rapport and caring for someone both requires effective interpersonal communication to take place. Subsequently, the ethics of care seeks to build relationships by focusing communication on the individual. It was established that caring is necessary for creating relationships, and that effective interpersonal communication is necessary to appropriately communicate caring.¹³ Building relationships through caring in health care was noted as important due to increased trust, better communication, and overall better health outcomes for the patient.¹⁴ Taking responsibility of others through the voice of care was discussed as another way to establish rapport with the ethics of care. Caring for someone through the voice of care means that one must provide physical and emotional care for the patient, and that the physician must care for oneself so he or she can nurture others. This was determined to be especially important when caring for vulnerable populations such as children.¹⁵ The voice of care requires physicians to exhibit empathy and to see their patients for who they are beyond the scope of their illness.¹⁶ The virtue of care connects with communication as it paves the way for providers to learn how to communicate with patients and families in a more compassionate and caring way and calling for them to see the patient and their families as individuals with distinct values and beliefs. The next section of chapter two focused on how physicians can manage the uncertainty of veracity and the physician's responsibility to

communicate truthfully. It was determined that many times in pediatrics diagnosis or prognosis may be uncertain, or the physician may feel uncomfortable communicating bad news with patients and families. However, in such situations physicians have a moral obligation to communicate in a truthful manner as consent cannot truly be informed if the communication is not accurately informative. Moreover, a solid relationship with the patient and family can help facilitate those difficult conversations in a more informative and meaningful way. How physicians can deal with communication ambiguity in pediatric medicine was also discussed. Prognostic uncertainty is prevalent in pediatrics for many reasons such as a lack of information regarding rare diseases and the inability to compare adult disease with pediatric disease due to the number of variables in pediatric medicine.¹⁷ It was determined that communicating about a patient's diagnosis in a truthful manner, even when it is uncertain, is necessary to uphold the validity of the physician-patient relationship. When physicians communicate about diagnosis in a vague manner they create a climate of distrust. The next section of chapter two explored how relationships between the physician and the family can be maintained. It was noted that interpersonal relationships in health care and communication go hand in hand. A physician cannot have an effective relationship with their patient without effective communication, and effective communication is needed to build relationships. Effective communication is also necessary for good patient care as effective communication between the physician and the patient has been shown to lead to better health outcomes for the patient.¹⁸ The importance of family-centered care was also discussed. A family-centered approach to care is advocated by the AAP and is necessary for building strong relationships in the pediatric intensive care unit. Family-centered care recognizes the patient and their family are an integral part of the health

care team, and the physician cannot care for the patient in an effective manner without considering the importance of their family and the role the family plays in the patient's care.

The second portion of chapter two explored the ethical framework for pediatric communication from the perspective of ethical issues. The ethics of care, the virtue of caring, and how those virtues can be used to communicate caring were discussed. The ethics of care and the virtue of caring recognize that caring for a patient go beyond just providing necessary medical care to the patient, but also attending to their emotional needs and experiences. The virtue of caring respects each person on an individual level and requires that care should be tailored to the individual patient.¹⁹ It was also determined that virtues can be used to communicate caring in health care. Five focal virtues pediatricians can use to communicate caring were discussed in detail. Those five focal virtues were compassion, discernment, trustworthiness, integrity, and conscientiousness. These virtues were deemed important to communication in health care as they allow the physician to communicate that they care for the patient beyond the realm of just physical care.²⁰ The veracity for surrogate consent was discussed in terms of pediatric surrogate decision-making standards and the physician's ethical duty to communicate honestly. The intricacies of surrogate consent in pediatrics were discussed as many pediatric patients are legally not permitted to consent for themselves. Therefore, pediatric patients must have a surrogate decision-maker, typically a parent.²¹ The surrogate is required to always act within the best interests of the pediatric patient. The best interests are determined by maximizing benefit and minimizing harm to the patient.²² For truly informed consent to occur pediatricians have an ethical duty to communicate honestly about all necessary information regarding the patient's diagnosis, prognosis, and treatment options. Lastly, chapter two discussed the physician-family relationship, the ethical considerations physician's must make

when building relationships, and the foundations of family-centered care. In pediatrics, the physician-family relationship is of utmost importance. The physician and the parents are all fiduciaries to the patient, and must act within the patient's best interest.²³ It was determined that when a relationship is not forged between the physician and the family it can have detrimental effects on the patient and their health outcomes. A family-centered approach to care provides many benefits such as better relationships with the patient and their family, positive outcomes for the patient, less anxiety for the patient and their family, and numerous physician benefits as well.²⁴ This chapter provided the basis for communication theory and prognosis in pediatric critical care medicine while integrating ethical theories and virtues necessary for the framework for communication of prognosis in pediatric critical care medicine.

Chapter three focused on establishing rapport with the ethics of care. The first section of this chapter focused on integrating specific communication theories and their validity in establishing rapport. Two symbolic communication traditions, the semiotic tradition and the sociocultural tradition, were identified and discussed. Symbolic communication traditions were chosen because symbols are what gives meaning to communication, but symbols are complex and the same symbol may have different meanings for different people. Symbolic communication traditions express the need to get to know a patient on a personal level to be able to create a relationship with them. The semiotic tradition was defined as the study of signs. The semiotic tradition was important to discuss as it defines how people create and share meaning, and how misunderstandings occur when meaning is not shared.²⁵ The importance of nonverbal communication was discussed in terms of the semiotic tradition. The different classifications of nonverbal communication were each discussed which included kinesics, vocalics, proxemics, haptics, physical appearance and artifacts, and chronemics. Understanding nonverbal

communication and the theory behind it is necessary for the framework for communication of prognosis in pediatric critical care medicine. Much of what one communicates is done through nonverbal means. Nonverbal messages seek to complement, contradict, accent, repeat, regulate, and/or substitute communication.²⁶ The semiotic tradition and establishing rapport was discussed next. Nonverbal communication was noted as being imperative to establishing rapport as it has the largest impact on the relationship because it determines how patients and families feel about their interaction with the physician.²⁷ Nonverbal communication can also be used to establish immediacy which can enhance the relationship by signaling closeness with the patient and their family.²⁸ It was determined that nonverbal communication is necessary to establish rapport. Therefore, physicians must be able to appropriately use nonverbal communication and read the nonverbal communication of their patients and families.²⁹ The sociocultural tradition was discussed next. This tradition focused on how people use communication to create meaning and realities.³⁰ The sociocultural tradition was discussed due to its importance in recognizing the cultural beliefs and values of others and how those cultural intricacies will affect communication. The sociocultural tradition is necessary for establishing rapport with patients and families since pediatricians will have to work with patients from all different cultural and religious backgrounds. Physicians must be knowledgeable of different cultural backgrounds and how culture might influence or effect communication. These different cultural backgrounds should not hinder a physician's ability to build relationships with their patients and their family members. When physicians are cognizant of the sociocultural tradition they can increase their knowledge about their patient's cultural beliefs resulting in being more sensitive to their individual needs. This will assist physicians in establishing rapport with patients and family members.³¹

The second portion of chapter three reviewed the ethics of care in terms of relational autonomy and meeting the needs of others. The ethics of care is paramount to establishing rapport because it requires physicians to be empathetic and get to know their patients on a personal level. Relational autonomy was discussed in terms of establishing rapport. It was determined that relational autonomy was necessary for establishing rapport with patients and families as it requires physicians to acknowledge that their patients are not isolated individuals, but are a product of the relationships they exist within. Physicians therefore must not only consider the needs of the patient, but also the needs of their family. Relational autonomy also requires physicians to consider the emotional aspect of decision-making and how the patient's emotions and their family's emotions will impact the decision-making process. Relational autonomy serves as the social framework patients and their families exist within.³² Therefore, the relational model of autonomy requires physicians to show empathy, and it helps to create a bond between the physician, the patient, and the family members. Meeting the needs of others in terms of developing caring relationships and addressing individual needs was discussed next. Meeting the needs of others was discussed in terms of pediatric medicine. It was determined that pediatric physicians must understand the intricate needs of their pediatric patients to develop caring relations with them. Caring for a patient requires physicians to understand and meet those individual needs since care is a personal endeavor. Developing caring relations also requires physicians to be trustworthy and instill trust in the patient and their family. Meeting individual needs was also determined to be an important facet of the ethics of care and building rapport. Physicians must strive to meet the individual, emotional, and psychological needs of their patients as it will impact the overall well-being of the patient. Chapter three exemplified how

physicians can establish rapport with their patients through the ethics of care by merging symbolic communication traditions with the ethics of care.

Chapter four explored how physicians can manage uncertainty in veracity for surrogate consent through the means of understanding uncertainty communication theories and surrogate consent standards in pediatrics. Understanding uncertainty communication theories when dealing with veracity is essential because, uncertainty communication theories seek to describe how individuals cope with ambiguous situations. This chapter outlined the issue of uncertainty in pediatrics. Uncertainty can be present in attempting to determine an accurate diagnosis or prognosis for a patient due to the intricacies of pediatric medicine. Uncertainty can also be present in initial communication encounters. This chapter noted that while uncertainty is inevitable, physicians must have the right tools to deal with ambiguous situations in the correct way. Uncertainty communication theories were discussed as the first tools necessary for dealing with vague situations. Uncertainty management/reduction communication theories were deliberated. Uncertainty communication theories are useful in understanding how one gathers information about others, why one chooses to gather information about another person, and then what they do with that information.³³ Uncertainty reduction theories help to increase predictability. An increase in predictability in communication allows for effective communication to occur. When more effective communication occurs relationships flourish. When relationships flourish physicians feel more comfortable discussing information with patients and their families, regardless of the nature of the information. This allows for well-informed decisions to be made. The physician-patient relationship is centered around trust and patients and family members will not trust physicians if they do not believe they are being given all the information they need to make necessary decisions for their child.³⁴ Framing

communication in uncertainty was discussed next, specifically the method of framing communication and the impact framing communication has on surrogate decision-making. The method of framing communication is a manipulative tactic used by physicians to present information in a way that influences patient and surrogate perception and then hinders their ability to make truly informed choices. In health care framing is typically used to alter the benefits or risks of a treatment option.³⁵ Several different tactics for framing information were discussed. Framing information in any way is immoral because it is manipulative and coercive and should always be avoided by physicians. Honest communication is necessary at all times for the physician-family relationship and for surrogate consent to be truly informed.

The second part of chapter four discussed veracity for surrogate consent, specifically surrogate consent, beneficence, and best interests. Disclosure and impartiality were also discussed in terms of surrogate consent. Surrogate consent requires collaboration and a relationship to be established between the physician, the patient, and the family. Physicians must provide necessary information for surrogates to make well-informed decisions, and surrogates require that information to make their decisions.³⁶ The role of beneficence and best interests were discussed in terms of providing well-informed surrogate consent. Beneficence supposes that physicians should act in their patient's best interests.³⁷ What is in the patient's best interests is for the patient and their surrogate to be well-informed to make decisions for the patient. The importance of properly disclosing information to patients and families was also discussed. Disclosing the necessary information, to the correct people, in an ethical way is essential for well-informed surrogate consent to occur. The harms of not properly disclosing information was discussed along with techniques for properly disclosing information to patients and their families. This chapter also deliberated the importance of the physician remaining a neutral party.

Physician neutrality was determined to be important as it calls for physicians to allow patients and their family members to make informed choices free of any input regarding the physician's beliefs or values. Physician neutrality also requires physicians to respectfully communicate any biases or conflicts they may have when treating a patient due to cultural, religious, or other deeply held beliefs. Chapter four provided some necessary tools for dealing with uncertainty for physicians to help patients reach truly informed decisions.

Chapter five discussed how the physician-family relationship can be maintained. Relational communication theories and their importance in maintaining the physician-family relationship were discussed first. Relationships and communication are woven together as communication will affect the relationship and the relationship will affect the communication. Relational communication theories are important in identifying how relationships are developed and sustained over time.³⁸ The social penetration theory is the first relational communication theory that was explored. The social penetration theory focuses on disclosure in the relationship, the rate at which disclosure occurs, and the breadth and depth of the disclosure. The more self-disclosure that occurs the more effective the relationship is. The social penetration theory works simultaneously with the uncertainty reduction theory as self-disclosure reduces uncertainty and increases communication, thus leading to a more fruitful relationship. Self-disclosure is also necessary for open communication to occur and open communication is necessary for building and maintaining interpersonal relationships. Sociopsychological tradition was also discussed. The sociopsychological tradition focuses on the relationships people are in and how one interacts within that relationship. The sociopsychological tradition explored four different family types: consensual, pluralistic, protective, and laissez-faire. Understanding these different family types is integral to physicians understanding how families function, communicate, and view

relationships.³⁹ The importance of family dynamics in terms of sociopsychological tradition was also discussed. Families are often the main source of support for the patient and understanding how each individual patient's family system works can be integral to maintaining the relationship. Family dynamics, values, beliefs, and attitudes will also affect how decisions are made and what kind of decisions are made. Family dynamics are also a good predictor of how patients and families will deal with the diagnosis and prognosis of the patient.

The second portion of chapter five explored the physician-family relationship. First paternalism and partnership were discussed in terms of avoiding paternalism and instead creating a partnership. What it means to be a paternalistic physician and different types of paternalism were defined. Some arguments for the use of paternalism in medicine were presented and counter-arguments against paternalism were also discussed. It was determined that a partnership is more ethical and effective in maintaining the physician- family relationship. The patient can never be viewed in seclusion without the surrogate decision-maker rendering a partnership necessary in pediatrics. The physician's role in the partnership is to cooperate with the patient and parents of the patient and to promote the child's best interests. Parents who feel comfortable with a physician are more likely to ask necessary questions and communicate openly with the physician, both of which will affect the overall health of the patient.⁴⁰ A partnership also encourages patients to be involved in their health care and can result in positive outcomes. Partnerships are important in the pediatric intensive care unit as discussions regarding diagnosis, prognosis, and treatment will need to be revisited frequently.⁴¹ Patient autonomy as a minor was discussed next. Deciding when to include children and adolescents in their care was discussed. While pediatric patients do not have the legal capacity to make decisions on their own, it does not mean they should not be included in the health care transaction. Research has indicated that

it is appropriate and beneficial to include pediatric patients in their health care. It was argued that children from infancy through adolescents should be included in the health care transaction in some form. It was also recognized that under certain circumstances parents may wish to keep their children out of the health care transaction usually for religious or cultural beliefs. In such circumstances, parental wishes should typically be granted.⁴² Including children in goal planning was discussed next. It was determined that physicians must know how to properly communicate with all pediatric patients across all developmental levels to include children in their health care and goal planning. Different strategies and techniques for communicating with each age group were discussed. Chapter five explored how to maintain the physician-family relationship. Once the relationship is built sustaining the relationship is imperative in pediatric critical care as communication regarding the patient and their diagnosis and treatment will be continuous.

Chapter six discussed the ethical framework for communication of prognosis in pediatric critical care medicine. This chapter pulls the literature and research from the previous chapters to assert that communication greatly impacts healthcare transactions in pediatric critical care, yet many health care institutions do not have procedures for such communication transactions in place, and many physicians lack the necessary tools to properly have these conversations. The ethical framework for communication of prognosis in pediatric critical care medicine states that physicians must first establish rapport with the ethics of care. In doing so they must understand the necessary symbolic communication traditions and how to communicate through the virtues of caring. Next physicians must understand the moral obligations of the ethics of care, they must know how to establish relational autonomy, and know how to meet the needs of their patients and their families. Second, physicians must be able to manage the uncertainty in veracity for

surrogate consent. They must understand the role communication plays in managing uncertainty in veracity for surrogate consent by applying relevant uncertainty communication theories and the importance of recognizing their communication biases. Pediatric physicians must also recognize that they have an ethical accountability to communicate honestly regarding surrogate consent. Therefore, physicians must understand pediatric surrogate consent standards and what it means to be a neutral physician. The final portion of the framework for communication of prognosis in pediatric critical care medicine requires physicians to know how to properly maintain the physician-family relationship. Physicians must understand communication strategies necessary for maintaining the physician-family relationship such as relational communication theories and the importance of family-centered care. Lastly, physicians must consider the ethical considerations of the physician-family relationship. Pediatricians must strive to create a partnership instead of engaging in paternalistic behavior and they must know how to properly respect autonomy as a minor.

If physicians are going to be able to properly use the proposed ethical framework then they must understand both the communication and moral implications of establishing rapport with the ethics of care, managing the uncertainty in veracity for surrogate consent, and maintaining the physician-family relationship. Symbolic and semiotic communication traditions are important when initially establishing rapport with patients and families. These communication traditions are mindful of the risks of miscommunication and the role of nonverbal communication. Once physicians master the symbolic communication traditions they can better communicate through the virtues of caring. The virtues of caring call for physicians to treat the patient not only for their physical condition, but also to consider the emotional aspect. Physicians should be aware of the symbolic communication generated between the physician and

the patient and they should try to be more aware of the patients experience from their perspective instead of generalizing medicine. The framework requires physicians to understand their moral obligations to the patient and the family through the ethics of care. Physicians should establish relational autonomy to effectively meet the needs of pediatric patients and their families. Physicians should also strive to meet the needs of their patients beyond what they require medically. They should consider their patients cultural, religious backgrounds, and values. Pediatric physicians should also consider their patients age and intellectual ability. When physicians take the time to meet these needs on an individual level they build trust and rapport with the patient and their family. A key component of the ethical framework for communication of prognosis in pediatric critical care medicine is effectively managing uncertainty in veracity for surrogate consent. Physicians should first understand uncertainty communication theories and how to integrate them when necessary. Understanding these theories is pivotal as physicians have an ethical obligation to communicate truthfully with patients and surrogates. Uncertainty reduction theories also help to facilitate important conversations requiring self-disclosure from the patient or surrogate. When uncertainty is not reduced communication tends to be hindered, and when physicians are not trained to deal with ambiguous situations they may attempt to avoid the conversation. Lastly, the framework calls for physicians to not only establish a physician-family relationship, but to maintain it. Maintenance of the relationship is imperative and relational communication theories can aid in sustaining the relationship. Adopting a family-centered approach to care also helps to maintain the physician-family relationship. In this approach physicians strive to treat the entire family by providing emotional, social, and developmental support to improve the overall patient experience. The framework notes that from a moral standpoint, physicians should avoid paternalistic behavior as paternalism is not

compatible with a family-centered approach. The framework also provides guidance to physicians for inclusion of autonomous minors. Including pediatric patients in their care, when appropriate, not only improves communication, but it also gives patients the opportunity to discuss their fears and needs. Not including the patient can restrict a coherent understanding of the patient's goals and values. This framework is deductive in nature. All steps and must be satisfied for ethical communication of prognosis in pediatric critical care medicine to occur.

A patient would not allow a physician to perform a surgery on them with only part of the tools they need to successfully complete the surgery, so why is it that we continue to allow physicians to treat patients with minimal tools for effective communication, especially when research continuously indicates that communication matters and has a direct effect on health care outcomes. Treating patients is not a "one size fits all" endeavor. Each patient and their family deserve and require specialized treatment and communication tailored to their needs. Communication is the most common, yet least taught procedure in medical school and it deserves more attention.⁴³ The ethical framework for communication of prognosis in pediatric critical care medicine gives communication the attention it deserves in way that is both easy to understand and easy to apply. These skills can be explicitly trained.

Effective communication is perhaps the best treatment physicians can give their patients. Effective communication strategies and family-centered care can be the difference between parents accepting a diagnosis and making well-informed decisions, or children getting lackluster care because physicians have given parents a precarious sense of false hope.⁴⁴ While adults strive to teach children the importance of honesty, it is time to "practice what we preach" and be more honest with children and their families in pediatric medicine critical care medicine.

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