

A CULTURALLY HUMBLE BIOETHICS PRACTICE MODEL FOR PEDIATRIC
MEDICAL SOCIAL WORKERS

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the Degree

Master of Social Work

In

Individuals, Families, & Groups

by

Emma Marie Claudeanos

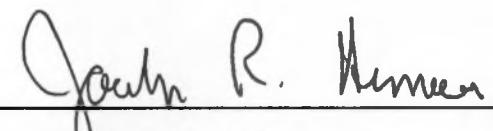
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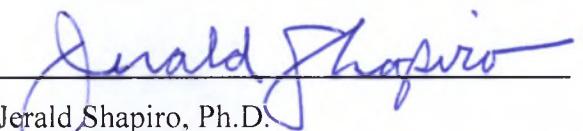
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I certify that I have read A Culturally Humble Bioethics Practice Model for Pediatric Medical Social Workers by Emma Marie Claudeanos, and that in my opinion this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirement for the degree Master of Social Work at San Francisco State University.



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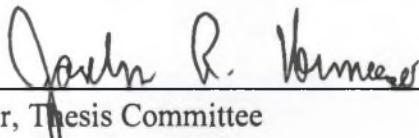
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A CULTURALLY HUMBLE BIOETHICS PRACTICE MODEL FOR PEDIATRIC MEDICAL SOCIAL WORKERS

Emma Marie Claudeanos
San Francisco, California
2019

Ethics in general are a complex and nuanced matter, and this is especially so in medical settings where patients and families are facing decision-making related to health and well-being. The inherently complex nature of ethics in medical decision-making is compounded in pediatric settings when questions arise in the context of the larger family system with multiple players engaged in the process of seeking answers (Ronen & Rosenbaum, 2017). This is especially so in cases of complex and life-threatening illness in children, when intense emotions such as guilt, fear, confusion, misery, and desperation are added to the equation introducing further ambiguity into the ethics of decision-making. The nuanced nature of bioethical considerations and the inherent complexity of medical decision-making indicate the importance of a patient/family-centered culturally humble approach to bioethics consultation. Social workers are uniquely suited to work in this capacity due to the foundational ethical principles that define social work ethos, govern curriculum in academic settings, and guide practice and research within the field. The information and suggested model of ethics consultation presented in this thesis are intended to promote increased engagement of pediatric medical social workers in ethics consultation services in hospital settings, which are currently led primarily by physicians, nurses, and other medical professionals.

I certify that the Abstract is a correct representation of the content of this thesis.



Chair, Thesis Committee

22 May 2019

Date

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This thesis is dedicated to B.R.

I would like to thank my family to whom I will forever be indebted for giving me all that
I have.

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Chapter One: Statement of the Problem

Ethics are a complex and nuanced matter. Often defined across a wide range of interpretations, they are influenced by individual values, beliefs, experiences, emotions, and biases. Ethics play a fundamental role in human interaction between individuals and in individuals' interaction with their environment in both personal and professional settings. Many professional fields develop ethics frameworks to attempt to guide their work; in contemporary healthcare settings, this framework is referred to as bioethics and its purpose is to explore the positive and negative implications of technical advances in western medicine on human well-being.

Bioethics theory seeks to address a wide range of issues from parents' choice to refuse immunizations for their child to an individual's right to medically assisted suicide. The inherently complex and nuanced nature of bioethical considerations presents a fundamental challenge to universal implementation of ethical standards, inevitably giving rise to ethical dilemmas – situations in which there are two (or perhaps more) mutually exclusive options requiring consideration through an ethics lens. Further complexity arises when medical decision-making falls into the hands of proxy decision-makers, something that often occurs when common sense or societal norms have determined that an individual is incapable of making their own medical decisions; examples of this include elderly patients incapacitated by dementia, patients on life support and unable to communicate, and children, as will be discussed in this thesis.

Pediatric health care professionals face ethical considerations on a daily basis (Jacobson, Antiel, & Fischer, 2009). The inherently complex nature of ethics in medical decision-making is compounded in pediatric settings when questions arise in the context of the larger family system with multiple players engaged in the process of seeking answers (Ronen & Rosenbaum, 2017). This is especially so in cases of complex and life-threatening illness in children, such as cancer, blood and lymphatic disorders, renal disease and other chronic illnesses, and serious injury, when intense emotions such as guilt, fear, confusion, misery, and desperation are added to the equation introducing further ambiguity into the decision-making process. The journey of a patient and their family faced with such a diagnosis can include initial shock, ongoing trauma as the disease progresses in expected or unexpected ways, the physical and emotional rigors of treatment, and the gravity of end-of-life considerations. Throughout this journey, families caring for minors and the minors themselves are asked to make many decisions from whether to undergo treatment that may have adverse side effects to withholding or withdrawing life-sustaining support. Further ambiguity may arise if what the family wants does not align with what the medical team believes is best for the patient and/or the greater community.

Another critical factor to consider in these matters is culture. Pediatric diseases affect children and families of every ethnic and cultural background, and professionals in any pediatric medical setting in the U.S. may come into contact with patients from around the country and around the world. This is especially so in medical settings serving

children with complex and life-threatening illness, as programs focused on specific types of treatment will attract families from many different areas seeking specialized care for their children. This brings to the table great variation in views of western medical practice, faith in naturopathy and other non-western healing methods, definitions of death (brain death, cardiac death, spiritual death), and beliefs and traditions surrounding illness, death, and the dying process. Cultural considerations are a critical element of ethics, and a lack of understanding or disagreement between families and medical systems can be grounds for fundamental ethical challenges.

In order to support patients, families, and medical teams in navigating ethical dilemmas, many hospitals designate ethics consultation services (Fox, Myers, & Pearlman, 2007). These services utilize professional expertise and decision-making frameworks to explore ethical dilemmas and develop a plan of action for care. The vast majority of ethics consultation services are led by medical professionals, specifically physicians and nurses, rather than social workers (Fox, et. al., 2007). In fact, a study by Jansson and Dodd (2002) found that many medical social workers do not engage in ethical activism in health care settings.

This thesis will argue that the nuanced nature of bioethical considerations and the inherent complexity of medical decision-making indicate the importance of a patient/family-centered culturally humble approach to bioethics consultation and that social workers are uniquely suited to work in this capacity due to the foundational ethical principles that define social work ethos, govern curriculum in academic settings, and

guide practice and research within the field. The purpose of this project is to promote increased engagement of pediatric medical social workers in ethics consultation services in hospital settings. Through a review of the literature and synthesis of information related to bioethical considerations as well as through a suggested model of practice for ethics consultation in pediatric settings specific to complex and life-threatening illness, this project attempts to equip medical social workers with the ability to assist in navigating bioethical dilemmas with a culturally humble patient/family-centered approach.

This thesis will be organized as follows: Chapter two will review literature relevant to the research topic. Chapter three defines the theoretical framework of this practice model as well as the author's own related positionality and subjectivity. Chapter four defines the variables upon which the model is based. Chapter five lays out the model itself and describes the methodology utilized to create it. Chapter six presents analysis and discussion of the ways in which the problem is being addressed, and chapter seven concludes the project with discussion of implications for social work, limitations of the model, and suggestions for further study.

Chapter Two: Review of the Literature

As noted in the previous chapter, bioethical considerations in medical decision-making are a complex and nuanced matter. This review of the literature will highlight these complexities in the context of general medical settings, pediatric settings, and settings specific to complex and life-threatening illness in children. The information will serve as a foundation for the model presented in chapter five and will provide medical social workers with a basic understanding of bioethics theories and principles that can be applied in the application of the model and in bioethics consultation with interdisciplinary teams.

Ethics

Broadly defined, ethics is a code of conduct used to distinguish between acceptable and unacceptable behavior (Resnik, 2011). At the root of ethical considerations is the phenomenon of relational human existence, whereby our actions influence the people and the environment around us in both positive and negative ways and to varying degrees. In order to manage this influence and to promote peaceful coexistence, human societies have developed clearly defined and widely agreed upon moral codes that set standards for our behaviors and actions. Though legality and ethics don't always align, often the most fundamental elements of a society's ethical code are considered common sense and are governed by law (Resnik, 2011), for example laws against violence, theft, and libel. Other elements of ethical code are more abstract and may be interpreted differently depending on an individual's personal values and life

experiences (Resnik, 2011), for example, the justice of the death penalty, abortion, and physician assisted suicide. Other elements are even broader, more informal, and highly equivocal, for example the “golden rule” that says do unto other as you would have done unto you (Resnik, 2011). These less clearly defined elements of moral code are often at the root of ethical dilemmas.

Bioethics

Historical context.

Consideration of ethical standards is a critical element of numerous areas of scientific inquiry and disciplines of study, including philosophy, theology, psychology, sociology, and medicine (Resnik, 2011). The study and application of ethics in the medical field is called bioethics. Defined literally, bioethics is the “ethics of life”, however the term has come to refer specifically to both the positive and negative implications of technical advances in western medicine on human well-being (Campbell, 2013).

Moral guidelines in medicine remained remarkably consistent from the time of Hippocrates until the middle of the twentieth century (Beauchamp & Childress, 2009). Most historians agree that the earliest documentation of ethical considerations in the context of medicine date back to two foundational texts that continue to influence medical practice in contemporary times, the Charaka Samhita and the Hippocratic Oath. Originally composed in 900 B.C., the Charaka Samhita is a Sanskrit text that outlines theory and practice of traditional Indian ayurvedic medicine (Dev, 1999). The

Hippocratic Oath is an ancient Greek oath dating back to the 3rd century CE that required all physicians to swear to uphold a number of ethical standards including, “to use regimens for the benefit of the ill” and “to not give a drug that is deadly to anyone” (Miles, 2004, p.ii). Though teachers and practitioners of medicine have been considering the ethics of the doctor-patient relationship since ancient times, the earliest notion of medical ethics as a formal concept emerged in the aftermath of the Second World War during the Nazi War Crime Tribunals in Nuremberg that took place from 1945 to 1949 (Campbell, 2013). These tribunals revealed the crimes against humanity perpetrated by Nazi doctors on concentration camp prisoners and led to the creation of pivotal works outlining the doctor’s ethical obligation to their patient (Campbell, 2013). The Nuremberg Code of 1947 put forth fundamental principles for the protection of human subjects in medical research with a primary emphasis on informed voluntary consent (Campbell, 2013). That same year, the World Medical Association was founded, and in 1948 the association produced the Geneva Code of Medical Ethics, an updated version of the Hippocratic Oath that required physicians to hold the health of their patient above all else (Campbell, 2013). This early concretization of medical ethics was an indication of the growing awareness of a need for defined ethical standards in medical practice and an understanding that the safety of the patient must not be left to the assumption of the doctor’s goodwill alone (Campbell, 2013).

Birth of bioethics.

The rapid growth of medical technology in the 20th century led to greater ambiguity in medical moral standards, and scholars and practitioners of medicine faced an ever growing need to focus attention on the ethics of their practice. Advancements in medicine during this time period include the discovery of antibiotics in 1928, the legalization of birth control for unmarried couples in 1972, growth of randomized controlled trials, advancements in childbirth (cesarean section, forceps delivery) that reduced infant and maternal mortality, and the first successful organ transplants – kidney in 1954, liver in 1967, and heart in 1968 (Childs & Kansagra, n.d.). These advancements led to new areas of consideration in the field of ethics including truthfulness, extended life expectancy, privacy, equitable distribution of healthcare resources, and communal responsibility (Beauchamp & Childress, 2009).

In an effort to explore the vast implications of this technological progress on the well-being of humankind, academic institutions began to formalize the study of ethics in medical practice. Founded at Georgetown University in 1971, the Kennedy Institute of Ethics became the first academic institution dedicated to bioethics and is home of the Bioethics Research Library, the world's largest and most comprehensive collection of scholarly resources on the subject ("Founding of the Institute," n.d.). The birth of the Kennedy Institute drew attention to the study of medical ethics and inspired similar endeavors around the world leading ultimately to the birth of bioethics as a recognized field of academic study ("Founding of the Institute," n.d.). It is important to note that the

field of bioethics is dominated by the cultural values, beliefs, and practices of white, middle class populations and is largely informed by western philosophical and legal traditions that emphasize individualism (McCormick, 2011).

Moral principles of biomedical ethics.

In order for medical social workers to successfully engage this practice model, they must have a basic understanding of the four major moral principles of biomedical ethics: *respect for autonomy, nonmaleficence, beneficence, and justice* (Beauchamp & Childress, 2009). Consideration of these principles should be a key element of the exploration of ethical dilemmas, however the individual circumstances of the patient and their family as well as the clinical judgement of the social worker should be employed to determine whether one or more principle is of greater importance or whether other ethical principles beyond these should be considered.

Respect for autonomy.

Broadly speaking, respect for autonomy in the context of biomedical ethics refers to the individuals' right to self-governance and personal decision making in relation to their participation in health care and related research (Beauchamp & Childress, 2009). The notion of respect for autonomy should be understood within the context of social and emotional human nature, whereby autonomy is not purely individualistic (decision-making affects and is influenced by others), not purely reasonable (decision-making is emotional), and not purely legalistic (decision-making is influenced by social norms and responsibilities, in addition to legal systems) (Beauchamp & Childress, 2009). Bioethics

theory purports that in order for medical practitioners to uphold the autonomy of their patients, they must acknowledge the patient's right to hold views, make choices, and take action based upon personal beliefs and values (Beauchamp & Childress, 2009). Medical practitioners' actions must reflect this acknowledgement and encourage autonomy by emphasizing thorough and accurate patient education, truthfulness, protection of privacy, informed consent, and provision of counseling when requested (Beauchamp & Childress, 2009).

When considering autonomy in the context of medical decision-making, it is important to also consider notions of competence, as it is often the dilemma of the medical professional to determine a balance between upholding the patient's autonomy and protecting them from the possibility of their decision leading to poor outcomes (McCormick, et.al., 2014). Medical practitioners and bioethicists often rely on commonsense and social norms to determine whether an individual is competent enough to make autonomous decisions: ability to communicate a preference or choice, understanding of their circumstances, ability to grasp consequences of action or nonaction, ability to display reason, and ability to understand risks and benefits (Beauchamp & Childress, 2009).

Nonmaleficence.

Nonmaleficence refers to an ethical principle that in many senses embodies one of the most fundamental commonly held beliefs amongst humankind, the obligation of the individual not to inflict harm on others; in the context of medicine it is often translated to

the keystone maxim, “Above all [or first] do no harm” and requires medical practitioners to uphold the principle impartially (Beauchamp & Childress, 2009). A common example used to illustrate nonmaleficence is the following hypothetical ethical dilemma: a surgeon has the opportunity to save the lives of two innocent people by killing a prisoner on death row and retrieving his organs for transplantation (Beauchamp & Childress, 2009).

Though there may be disagreement over the ethics involved in this hypothetical situation, and some may argue that killing the prisoner would have higher net benefit as it would save two lives, nonmaleficence states, unequivocally, that the surgeon is morally obligated to act impartially and refrain from harming the prisoner (Beauchamp & Childress, 2009).

In addition to the medical practitioners’ obligation not to inflict harm, the obligation not to impose *risks* of harm is also a critical element of nonmaleficence (Beauchamp & Childress, 2009). To uphold this obligation, medical practitioners must always act with sufficient and appropriate care, they must justify their recommendations in light of inherent unavoidable risks of medical procedures, and they must ensure that their patients fully understand the risk/benefit analysis of the proposed treatment plan (Beauchamp & Childress, 2009). Nonmaleficence is often a foundational principle in cases of serious terminal illness and injury where medical practitioners, individuals, and families are faced with consideration of nontreatment. Nontreatment can include consideration of *withholding* or *withdrawing* life-sustaining treatment, the concept of *killing* versus *letting die* (e.g. withholding medically administered nutrition and

hydration), and implementing *extraordinary/heroic* efforts (e.g. life support) beyond *ordinary* treatment (e.g. pain management) - it is often thought that it is morally sound to forgo extraordinary/heroic treatment if the patient desires, if risks outweigh benefits, or if treatment is futile and/or would significantly impact quality of life; however, it is not morally sound to forgo ordinary treatments (Beauchamp & Childress, 2009).

Beneficence.

In the context of biomedical ethics, beneficence refers to the medical practitioner's obligation to actively contribute to the welfare of their patients (Beauchamp & Childress, 2009). Beneficence may be considered the most straightforward of the principles, as the medical profession is built around the notion of healing, and, throughout the history of health care, the practitioner's commitment to helping others has been of utmost importance (Beauchamp & Childress, 2009). In the literature on beneficence within the field of bioethics, the principle is often defined as having two components: *positive beneficence* and *utility* (Beauchamp & Childress, 2009). Positive beneficence requires the medical practitioner to take proactive measures to provide benefits to their patients, for example remaining informed of the most recent research within their field in order to be able to provide the best care; utility refers to the obligation to balance benefits, risks, and costs in order to ensure the best overall results of a course of action (Beauchamp & Childress, 2009).

Traditionally, the doctor-patient relationship has been viewed as paternalistic, whereby the patient is expected to accept the expertise of the physician in decision-

making related to their health (Beauchamp & Childress, 2009). Recently, however, there has been increased emphasis placed on the autonomy of the patient, and the medical field has been grappling with assertions of the patient's right to make independent judgements (Beauchamp & Childress, 2009). This development has led to the development of a conflicting paradigm that has become a central source of dispute in bioethics: whether beneficence takes primacy over respect for autonomy or vice versa (Beauchamp & Childress, 2009). In other words, if what the patient wants does not align with what the doctor recommends based on their expertise and their commitment to beneficence, what is the morally correct course of action?

Justice.

Justice, in the context of medical ethics, is defined much the same as it is in a general context: the distribution of fair, equitable, and appropriate treatment in light of what is due or owed to a person (Beauchamp & Childress, 2009). Bioethicists approach justice with the understanding that the principle is deeply complex and nuanced and is often interpreted differently by different people depending upon personal beliefs, values, and biases (Beauchamp & Childress, 2009). Additionally, bioethics theory recognizes that sufficient reflection on the subject requires consideration of multiple theories of justice including egalitarian (all people are equal and deserve equal rights, health care should be universal), communitarian (emphasis on responsibility of the community to the individual and vice versa), libertarian (maximize autonomy, distribution of health care is best left to the free market), and utilitarian (maximize social welfare by enforcing policies

that benefit the greatest number of people in the greatest possible way); bioethics theory primarily approaches the principle of justice from an egalitarian and utilitarian viewpoint (Beauchamp & Childress, 2009).

Many of the debates surrounding justice in the medical field center around access to health care, health insurance, health status, and the recent dramatic increase in cost of health care services; these issues give rise to ethical questions of whether access to health resources should be based upon need or whether they should be distributed equally among all as a right (Beauchamp & Childress, 2009). Furthermore, bioethics theory recognizes the disparities in health care based on race, ethnicity, and gender, and, though largely unsuccessful, the field has inspired research and efforts into calling attention to and correcting these disparities (Beauchamp & Childress, 2009). One such report, published in 2003 by the Institute of Medicine, identifies a number of racial and ethnic disparities across a wide range of health care services and medical conditions in the U.S. that ultimately lead to overall “worse health outcomes” for racial and ethnic minorities (Smedley, Stitch, & Nelson, 2003).

Professional-patient relationships in bioethics theory.

In light of certain failings of traditional literature, bioethicists have determined the need for specification of certain rules to govern the professional-patient relationship that further illuminate the four principles outlined above. The first is *veracity* and describes the health care professional’s obligation to be candid, honest, and truthful in all aspects of their relationship with their patient; this includes comprehensive, accurate, and objective

transmission of information that fosters the patient's understanding and ability to make autonomous decisions (Beauchamp & Childress, 2009). The second rule is *privacy* and refers to the patient's right to determine who has access to their information (informational privacy), their person and personal spaces (physical privacy), their personal choices (decisional privacy), and their property (proprietary privacy) (Allen, 1997). In addition, Beauchamp and Childress (2009) propose a fifth form of privacy (relational privacy) that recognizes the influence of intimate relationships, such as family, on the individual's decision-making process. The third rule is *confidentiality* and is a subset of informational privacy (Beauchamp & Childress, 2009). It refers to the patient's right to maintain protected information and to control the authorization of access to that information through consent policies (Beauchamp & Childress, 2009). The final rule is *fidelity* or *loyalty* and refers to the medical professional's obligation to maintain involvement in a patient's care once a significant relationship has been established between them and requires the professional to favor the patient's interest over self-interest and the interest of others (Beauchamp & Childress, 2009).

Bioethics in Pediatrics

Principles specific to pediatrics.

Ethical questions are deeply challenging because they force us to confront our core principles and our most fundamentally held beliefs about ourselves and others; this already complex equation becomes even more challenging when ethical questions arise in the context of the larger family system with multiple players engaged in the process of

seeking answers, as is the case in pediatric medical settings (Ronen & Rosenbaum, 2017). Likely a result of the fact that bioethics is a relatively young field of study, there is a gap in literature that addresses the ethical issues specific to pediatrics, with the vast majority of material approaching bioethics from either a general or adult-specific perspective. Though the principles and rules outlined above can be applied to pediatric practice, certain specific ethical issues arise when medical decision-making falls into the hands of someone other than the patient, as is the case with minors in the United States. According to the literature, pediatric practice gives rise to the following areas of ethical consideration: *autonomy and moral status of the child, nature of decision-making, and best interest of the child.*

Autonomy & moral status of the child.

The study of bioethics explores morality in the context of medical practice, and it assumes the widely accepted moral status of adults as endowed with human rights and deserving of dignity, freedom, and autonomy; pediatric bioethics thus begs the questions, are children moral equals of adults (Weisermann, 2016)? There is much variation in opinion on the answer to this question, and while there is a growing worldwide trend in philosophical musings as well as social ethos that places children as moral equals to adults, the justification and practical consequences of this idea are complex (Weisermann, 2016).

A person's moral status is intimately linked with the personal autonomy afforded them. For adults, this is straightforward – once a person reaches the age of legal majority,

they gain control of their persons, actions, and decisions, thus granting them complete autonomy and terminating the control and legal responsibility of their caregivers. For children, personal autonomy is greatly limited by law and by social and cultural norms, and though the United Nations put forth the Declaration of the Rights of the Child in 1959 and most modern societies emphasize the value of children and invest resources in their protection and upbringing, paternalism remains the default (Weisermann, 2016). Children, after all, are vulnerable and, many argue, incapable of employing the reason and intellect necessary to afford them the same freedoms as adults, for example staying out late, travelling alone, or making potentially life-altering decisions. This limitation of freedom, though carried out in the best interest of the child, implies that children's moral status differs from that of adults; meaningful consideration of the ethical implications of this on the child, their autonomy, and their healthcare is a primary goal of bioethics in pediatric settings, because, while for an ill child, it is their disease, their emotional involvement, and their life, proxy decision-makers are often hold the majority of power (Weisermann, 2016).

Nature of decision-making.

Bioethicists describe decision-making in adult medical care settings as heavily reliant upon discussion within the patient-provider dyad whereby accurate conveyance of information and discussion of benefits and risks allows the competent patient to make informed decisions about the course of their care (Lyren & Ford, 2007). Secondary input from a network of stakeholders surrounding the patient (family, friends, etc.) may be

considered and may influence outcomes, however the primary decision-making agent is the patient; this is even the case when the patient is incapacitated or unable to communicate desires, as health care systems emphasize the role of surrogate decision-makers as, first and foremost, executors of the presumed will of the patient (Lyren & Ford, 2007). For adults, decision-making processes are refined through a lifetime of experiences and relationships that support the development of beliefs, values, and understanding of cause and effect; children, on the other hand, are still in the process of developing these value set, and it is likely that most if not all of the significant decisions made in their lives have been made for them by their caregivers (Lyren & Ford, 2007). Therefore, the law prohibits minors from making independent health care decisions in most cases, and it is often a triad of stakeholders (medical team, caregivers, and child) participating in an inherently more complex and potentially fallible decision-making process (Lyren & Ford, 2007).

Weisermann (2016) argues, however, that most chronically ill children are experts of their disease, and a child's report of definitions of quality of life and related desires can vary greatly from caregivers' reports. Of course, the child's participation in the decision-making process is highly contingent upon their developmental level (Lyren & Ford, 2007) – an infant need not be consulted as to whether or not they want to pursue a certain treatment, whereas an older adolescent may have very strong opinions that could potentially determine the course of action even if they differ from the opinions of caregivers. Furthermore, it is inherently difficult to measure a child's ability to

participate, as age doesn't necessarily indicate capacity and myriad factors like personal, environmental, and historical circumstances affect the cognitive, social-emotional, and spiritual traits that influence decision-making (Lyren & Ford, 2007).

Best interest of the child.

In light of the nature of the child's moral status and the assumption of their underdeveloped decision-making capacity, the best interest of the child is often used as justification for proxy decision making; the nebulous nature of this concept poses unique challenges for bioethicists (Weisermann, 2016). Caregivers are given the role of primary decision-makers in their children's health care decisions because it is assumed that, due to their intimate knowledge of the child and their developing values, they are the foremost experts of their child's best interest (Lyren & Ford, 2007). Given the caregivers' intense emotional connection to the child, however, the possibility of biases entering the equation, especially in decision-making related to serious illness, becomes highly likely and may influence or cloud the best interest of the child (Lyren & Ford, 2007). Thus, it often becomes the medical team's role to analyze the caregivers' decision-making and to employ whatever means necessary (e.g. legal system) to ensure the child's best interest is upheld (Lyren & Ford, 2007). The convergence of the ambiguous nature of the best interest of the child, the influence of caregiver biases, and the participation of the medical team creates a uniquely challenging environment for ethical considerations.

Pediatric bioethics in the context of complex and life-threatening conditions.

Thus far, this review of the literature has addressed principles in biomedical ethics that apply universally to the greater population as well as to the general population of children treated in pediatric medical settings. Alongside these foundational principles, specific ethical considerations must be taken into account in the case of children with complex and life-threatening conditions including cancer, blood and lymphatic disorders, renal disease and other chronic illnesses, and serious injury. Areas for ethical consideration in these circumstances are: *quality of life, obligatory versus optional treatment, and life-sustaining treatment at end-of-life.*

Quality of life.

Quality of life is a critical consideration in the context of complex and life-threatening illness in children, as this type of illness and related treatment can result in significant physical and cognitive impairment, chronic pain, fear, anxiety, lack of normalcy and routine, and social isolation due to hospital stays, among many other challenges. Bioethics recognizes the inherently amorphous and variable nature of attempting to define quality of life, and within the field there is much emphasis placed on respecting the patient's and family's own interpretation of the concept. There are, however, widely accepted measures within the medical field that help ground a definition; these measures include physical mobility, freedom from pain and distress, and capacity to at least minimally participate in human experience through performance of daily activities and engagement in social interactions (Beauchamp & Childress, 2009).

While these notions can provide some structure to the measurement of quality of life, the ambiguity of the concept invites influence from personal biases, especially in pediatric contexts of complex and life-threatening illness where families may be asked to measure quality of life and consider short and long-term potential outcomes in the face of the potential loss of a child.

Furthermore, bioethics literature emphasizes the importance of defining quality of life solely for the person who must live it and their best interest, not for their value in enhancing another's quality of life (Beauchamp & Childress, 2009). This can be especially difficult for caregivers facing the potential loss of a child, as the child often holds great value in enhancing the family's quality of life, a reality that has high likelihood of clouding the caregivers' judgment in decision-making related to the child's healthcare. For this reason, many bio ethicists argue that there is a need for the development of instruments that can provide more concrete and meaningful measures of health-related quality of life (Beauchamp & Childress, 2009).

Obligatory versus optional treatment.

In light of the understanding that there are many health conditions that even contemporary medicine cannot fix, questions often arise around what type of treatment to pursue to support improvement of life trajectories and quality of life, as well as whether to pursue treatment at all (Ronen & Rosenbaum, 2017). In the context of complex and life-threatening illness in children, this is especially relevant in cases of incurable disease where multiple treatment options are available and where questions arise over whether

treatment is obligatory or optional. Obligatory or ordinary treatment is a *prima facie* obligation of both the medical team and the caregivers; this means that it is considered morally wrong to forgo this type of treatment unless the treatment conflicts with an equal or stronger obligation (Beauchamp & Childress, 2009). Examples of obligatory treatment include nutrition, hydration, pain medication, and use of life-sustaining treatment when the patient is likely to recover. Optional treatment is often defined as extraordinary – unusual or uncustomary for medical practitioners to use in the relevant context; standards of measurement for determining whether a treatment is ordinary or extraordinary often include whether it is simple or complex, natural or artificial, noninvasive or highly invasive, inexpensive or expensive, and routine or heroic (Beauchamp & Childress, 2009).

Bioethicist point to specific conditions that override the *prima facie* obligation to treat. The first is *futile* or *pointless treatment*, and is defined as treatment that is determined to have no or very little physiological benefit, is statistically unlikely to be successful in reversing expected outcomes, is highly likely to become more burdensome than beneficial, and/or is speculative due to lack of proven results (e.g. phase 1 clinical trials) (Beauchamp & Childress, 2009). An illustration of this concept can be seen in cases of historically incurable diseases with poor prognosis, for example certain rare pediatric brain tumors such as diffuse midline gliomas which affect the brainstem and spine. In these circumstances, families are offered multiple treatment options including radiation therapy and clinical trials; however, due to the overwhelmingly low survival

rate of children with this disease, all forms of treatment are presented as optional, and caregivers are also counseled on the option of rejecting all treatment and keeping their child home with hospice and/or palliative care.

Life-sustaining treatment at end-of-life.

With advancements in medical technology for critically ill patients, when an ill child is determined to be imminently dying, caregivers are often asked to make decisions about withholding and withdrawal of life-sustaining treatment. These deliberations can be highly emotional and may give rise to ethical dilemmas. In a national study of pediatricians' experiences with and access to clinical ethics consultation, Morrison, et. al. (2015) found that the most frequently reported issues initiating consultation requests concerned end-of-life care. Life-sustaining treatments are defined as all therapeutic interventions aimed at prolonging the life of the patient, including surgical procedures such as organ transplantation, mechanical interventions like ventilators and dialysis, medications like antibiotics and chemotherapy, and medically administered nutrition and hydration (Michelson & Frader, 2011). Debates surrounding withholding and withdrawal of life-sustaining treatment are inherently problematic, as there are multiple and varying opinions on the ethical permissibility of forgoing this type of treatment; some site the "sanctity of life" as a reason why every effort should be made to maintain it, while others believe that allowing nature to take its course and ending pain and suffering should be the primary concern for critically ill patients (Michelson & Frader, 2011). Debates can also arise over the moral implications of withholding or withdrawing life-sustaining treatment;

does it mean that you are actively killing the child or is it seen as letting them die (Beauchamp & Childress, 2009)?

Furthermore, decisions surrounding life-sustaining treatment for imminently dying children can give rise to ethical dilemmas when caregivers' desires conflict with medical recommendations. Due to the intense emotions involved in withdrawing or withholding life-sustaining treatment for a child, caregivers may want to prolong life as part of their own grieving process, even if it goes against the best interest of the child (Michelson & Frader, 2011). In these cases, though caregivers legally have the power to decide (unless they are deemed incapable by the law), medical teams and other helping professionals are obligated to provide information, counseling, and concrete recommendations based on their expertise (Michelson & Frader, 2011).

Cultural considerations for complex & life-threatening illness in pediatric bioethics.

Cultural considerations are critical in the context of healthcare because belief systems play a central role in an individual's perceptions, preferences, and choices related to medical treatment. For the purpose of this paper, cultural considerations include religious beliefs as well as social customs and institutions that contribute to an individual's worldview, lifestyle, and decision-making. Cultural considerations can be especially poignant for families facing the complex and life-threatening illness of a child, as the environment of death and dying is a powerful stimulant of deep emotion and reflection, and it is human nature to turn towards belief systems when confronting these

fundamental phenomena (O'Connell, 1995). A number of studies have been made into the role of culture in health-related decision-making related to life sustaining treatment and end-of-life care. Blackhall et. al. (1999) surveyed 200 participants from four American ethnic groups and found that ethnicity is strongly related to attitudes about and personal wishes for end-of-life care in the face of terminal illness. Furthermore, Klessig (1992) surveyed patients from six different ethnic backgrounds (African-American, Chinese, Jewish, Iranian, Filipino, Mexican-American, and Korean) on beliefs about end-of-life care and found that ethnic background, past experiences, and societal traditions all played a role in patients' decision-making.

Belief systems contribute to healthcare experiences in a number of ways. First, they provide solace and a source of emotional stability for patients and families facing fear and instability related to their own illness or the illness of a loved one; religion and other cultural beliefs can also provide a defense against the emotional upheaval associated with death and dying (O'Connell, 1995). Second, the medical team's understanding of their patient's cultural beliefs is critical in building and maintaining a successful and trusting relationship; this is especially so for medical practitioners who adhere to specific doctrines themselves and may intentionally or unintentionally impose their own worldviews on their patients (O'Connell, 1995). For these reasons, knowledge about and respect for the religious and cultural beliefs of patients and their families is fundamental in enhancing the meaning-laden experience of dying patients in the medical setting (O'Connell, 1995).

Influence of culture in medical decision-making can give rise to ethical dilemmas when individual beliefs contradict recommendations made from the traditionally scientific and reason-driven ethos of the medical model (O'Connell, 1995). For example, consider a case in which a child is critically ill on life-sustaining treatment, and medical indication is such that all further treatment would be futile. The medical team recommends withdrawal of respiratory support; however, the family would like to continue life-sustaining treatment with the belief that God may work a miracle and save their child (O'Connell, 1995). Situations such as these bring up ethical questions of how to uphold autonomy and respect religious freedom while also supporting the best interest of the child and upholding other ethical obligations such as beneficence (O'Connell, 1995).

Furthermore, with regard specifically to circumstances of complex and life-threatening illness in children, cultural considerations related to individual definitions of death and rituals surrounding the dying process are an important element of ethical exploration. Death is defined differently in different cultures, and socially constructed definitions of death often differ greatly from scientific ones (Koenig & Gates-Williams, 1995). Some cultures view the state of being unconscious as death, while others view organ failure as the defining characteristic (Koenig & Gates-Williams, 1995); moreover, discernment can be made between cardiac and brain death, with different cultural and societal norms recognizing one over the other as indicative of death (Miller, 2011). Additionally, some cultural traditions have strict ritualistic requirements during and after

the dying process that influence how families make decisions and may elicit ethical dilemmas if these rituals contradict Western medical practice, conflict with hospital regulations, and/or interfere with care of other patients on the floor. Examples of these rituals include Jewish body cleansing rituals, Islamic wailing rituals, and Hindu offering rituals (O'Connell, 1995). Varying definitions of death and culturally significant rituals surrounding the dying process are important factors in ethical consideration for critically ill pediatric patients and their families.

Social Work and Ethics Consultation in Medical Settings

Social workers have played a role in the healthcare field since social work was first established as a formal profession, and while there is increased attention focused on social workers' role in complex moral questions in medical decision-making (Reamer, 1985), there is still a significant lack of social work representation in ethics consultation in hospital settings. Formal ethics consultation services (ECSs) are a widely utilized method of resolving ethical dilemmas in medical settings throughout the United States, with one national study indicating that 80% of U.S. general hospitals have ECSs in place with an additional 14% in the process of developing them (Fox, et. al., 2007). Ethics consultation in hospitals is defined as services provided by an individual, team, or committee that address ethical issues related to patients and families currently treated in that hospital (Fox, et. al., 2007). This same study reports the ratio of professionals participating in these ethics consultations: physicians (34%), nurses (31%), social workers (11%), chaplains (10%), and administrators (9%) (Fox, et. al., 2007).

With social workers comprising only 11% of professional participation in ethics consultation in hospital settings, and with social workers being uniquely suited to work in this capacity due to the foundational ethical principles that define social work ethos, govern curriculum in academic settings, and guide practice and research within the field, there is much room for expansion of social work's role in these matters. The following chapter will outline the theoretical framework of the bioethics practice model presented in this thesis as well as the author's own related subjectivity and positionality.

Chapter Three: Theoretical Framework & Positionality

Introduction

The literature shows that bioethical considerations in medical decision-making are nuanced, complex, and require thoughtful analysis by professionals working to support patients and their families, however there is a lack of emphasis on the importance of social work participation in ethics consultation in medical settings. This chapter outlines the theoretical framework that serves as a foundation for the model of practice presented in this thesis, the purpose of which is to increase social work engagement in ethics consultation in medical settings. This chapter also reviews the author's own related positionality and subjectivity.

In conducting research and considering its implications, it is important to understand the theoretical framework of the project as well as the researcher's positionality and subjectivity as these philosophical underpinnings often define the overarching intentions of the work. In the case of this exploration, the intention is to approach ethics consultation in pediatric medical settings utilizing an alternative paradigm, alternative being defined as non-positivist. Positivism, widely accepted in the scientific world as the only true lens through which to view phenomena, is defined by Guba (1990) as the belief that natural immutable law governs a reality that exists objectively, beyond the individual experience. The aim of science, therefore, is to understand, define, and ultimately control these laws (Guba, 1990). To view pediatric bioethics through a positivist lens would be to assume that human experience is objective,

that definable ethical laws should be applied universally in the hospital setting, and that this universal application should therefore serve all families comprehensively and equitably. This paper argues that, while a universal model for ethical behavior and decision-making can be used to help guide professionals in a medical setting, human experience is subjective and ethical decisions related to treatment of complex and life-threatening illness in children are more accurately made on an individual, case-by-case basis with an emphasis on the implications of culture in patient and caregiver decision-making.

Theoretical Framework

It is important to ground research in a theoretical framework in order to define the values of the project that guide the research process. The theoretical framework of this project is based upon the following theoretical models: humanism, systems theory, and relativism.

Humanistic theory.

Pilkinghorne (1982) asserts that one of the basic assumptions of humanistic theory is the understanding that, “human beings exist within an experience of meaning and retain the possibility of acting with self-determined purpose.” It is precisely this that implies the need for a client-centered bioethics practice model for pediatric social workers working with families experiencing the complex and life-threatening illness of a child. The ethical issues that arise under these circumstances are often existential in nature as caregivers navigate complex processes and decision-making surrounding

treatment options, decline or withdrawal of care, and end-of-life decisions. Developing this practice model through a humanistic lens encourages consideration of the emotional and deeply personal human experience of a family facing the complex and life-threatening illness of a child, and it provides a foundation for the model to guide social workers in addressing ethical dilemmas through a client-centered approach.

Systems theory.

Alongside the humanistic and existential phenomena that come into play for families facing the complex and life-threatening illness of a child, mezzo and macro level systems also play a role in how families approach decision-making under these circumstances. Hudson (2000) asserts that systems can be defined as, “a complex of components in mutual interaction.” Many schools of thought within the field of social work ask the professional to view the “the whole client” implying a need to consider every element of the client’s life including all of the systems that influence their daily lived experience, e.g. the family system, neighborhood system, school system, cultural system, political system, and, in this case, the hospital system. This practice model asks pediatric social workers to consider how systems impact ethics when caregivers are asked to make decisions related to the care of a child with a complex life-threatening illness. Systems can often encourage families to make decisions that may not truly reflect their desires. This can come in the form of pressure from medical teams, cultural norms, and from extended family members that can influence how and why caregivers make decisions and how those decisions are viewed from an ethical standpoint.

Relativist theory.

At the core of this model is the role of culture within the family unit, specifically how cultural experience impacts decision-making on issues of medical care and end-of-life planning for a child. The model approaches ethics from a relativist-leaning standpoint. In other words, this research assumes that, while universality in ethical law should not be entirely discounted, an individual's culture and systemic context should be weighted and emphasized when considering ethical dilemmas (Healy, 2007). The implications of this assumption are that this practice model does not propose universal rules for addressing bioethics for pediatric social workers, but rather presents a guide for how to effectively navigate this process in working with families in a hospital setting and in the context of the complex and life-threatening illness of a child. The model is designed to directly serve medical social workers and thus benefit their clients and the hospital system as a whole with the goal of improving patient care and alleviating uncertainty that arises from ethical dilemmas.

Researcher's Positioning & Subjectivity

The inspiration for this project came from the author's work as a pediatric social work intern in the neuro-oncology department of a leading children's hospital in the California Bay Area. This placement has brought to light the immensely challenging decisions caregivers are asked to make related to their child's treatment and how ethics come into play in the decision-making process. As a white, able-bodied, cisgender woman, it is critical for the author to acknowledge her privilege in participating in this

field placement and conducting this research. The medical social workers at this field site are majority white women, which has made the author's integration into practice relatively easy, giving her the opportunity to grow, gain confidence, and conduct inquiry into this subject without major barriers. The author's identity also influences the way in which this research is conducted, as her personal opinions and biases impact what is determined to be relevant and worthy of inclusion. Furthermore, the author's positionality as a social work student and the author's own personal philosophy of the importance of culturally humble and family-centered practice has influenced the way in which this model has been developed.

This chapter has outlined the theoretical framework that serves as a foundation for the model of practice presented in this thesis and has reviewed the author's own related positionality and subjectivity. The following chapter will define for the reader the variables and terms utilized throughout this thesis.

Chapter Four: Variable Definition

This chapter defines concepts relevant to the research and practice model outlined in this project. The purpose of this chapter is to assist the reader in understanding the terms and concepts utilized throughout this paper as they are defined through the lens of the researcher. The theoretical framework outlined in the previous chapter as well as the researcher's positionality and subjectivity are foundational elements of these definitions.

Variable Definition

Bioethics.

Bioethics refers the field of study dedicated to exploring the positive and negative implications of technical advances in western medicine on human well-being.

Bioethics practice model.

For the purpose of this project, a bioethics practice model is defined as a model upon which medical social workers can base their practice of working with patients, families, and medical teams to resolve ethical dilemmas that arise during decision-making processes related to treatment.

Child/children.

According to California law, as well as law in most other U.S. states, a child refers to any individual under the age of legal majority (18 years) as defined by family code §6502 (Flaherty, 2011). Distinction between child and adolescent is only made when necessary for the author's argument.

Complex & life-threatening illness.

Complex and life-threatening illness refers to any medical condition that threatens the life of the child including cancer, blood and lymphatic disorders, renal disease and other chronic illnesses, and serious injury.

Cultural considerations.

In the context of this paper, cultural considerations include religious beliefs as well as social customs and institutions that contribute to an individual's worldview, lifestyle, and decision-making.

Cultural humility in social work practice.

Cultural humility is defined as the understanding that culture is defined, practiced, and experienced differently by every individual and that the individual's personal experience of their culture plays an influential role in their self-determination and decision-making. Working to understand the individual's personal experience of their culture should be the social worker's primary goal.

Ethics.

The term ethics refers to codes of conduct that attempt to universally distinguish between acceptable and unacceptable behavior in the context of the individual's interaction with others and with their environment. Ethics includes consideration of personal, cultural, and societal values that influence human behavior.

Ethics consultation.

Ethics consultation in hospitals is defined as services provided by an individual, team, or committee that address ethical issues related to patients and families currently treated in that hospital.

Ethical dilemma.

Ethical dilemmas refer to situations (problems) in which there are two (or perhaps more) mutually exclusive options requiring consideration through an ethics lens.

They/their/them.

They/their/them pronouns are utilized throughout this paper to universally indicate individuals of all gender identities in an effort to achieve gender neutrality.

Western medicine.

Western medicine refers to the scientifically driven system of medical practice in which practitioners (physicians, nurses, etc.) utilize evidence-based interventions to diagnose and treat symptoms and diseases primarily with pharmacological drugs and surgical procedures.

This chapter has defined for the reader the terms and concepts utilized throughout this thesis. The following chapter describes the methodology utilized in carrying out this research and it presents the author's proposed bioethics practice model for pediatric medical social workers.

Chapter Five: Methodology & Practice Model

Methodology

Having defined the variables relevant to this thesis, this chapter will now present the methodology employed to create the model as well as the model itself. The information utilized to develop this model was gathered from a range of relevant sources including review of scholarly articles and bioethics trainings with key informants. It also draws upon the author's own experience as a pediatric social work intern in the neuro-oncology department of a leading California Bay Area children's hospital, though research was not conducted directly with clients. The model was created with the assumption that pediatric settings in which children are experiencing complex and life-threatening illness are grounds for uniquely challenging ethical dilemmas that often present as gray areas for families and medical professionals and that social and cultural institutions and personal biases are critical factors of influence on patient and caregiver decision-making. Table 5.1 below outlines the theory of change logic model that is a foundation for the practice model proposed in this thesis.

Table 5.1: Theory of Change Logic Model

Research, Practice, Theory	Assumptions	Strategies	Results
<ul style="list-style-type: none"> • Review of scholarly books and articles • Bioethics trainings with key informants • Firsthand field placement experience as pediatric neuro-oncology social work intern at leading California Bay Area children's hospital 	<ul style="list-style-type: none"> • Advancement in western medical practice has given rise to complex ethical issues related to the positive and negative implications of these advancements on human well-being • Ethical issues that arise in pediatric settings are uniquely complex due to the role of the larger family system in the decision-making process • There are specific considerations for addressing ethical issues in the context of complex and life-threatening illness in children • Cultural factors play a leading role in these issues • Ethics consultations in medical settings are most commonly led by medical practitioners • Social workers are uniquely suited to lead ethics consultations due to their training 	<ul style="list-style-type: none"> • Propose a culturally humble model of practice that provides pediatric medical social workers with a framework for ethics consultation in the context of complex/life-threatening illness in children • Empower social workers to take a leading role in ethics consultation in pediatric medical settings 	<ul style="list-style-type: none"> • Pediatric medical social workers will be able to address ethical dilemmas related to treatment of complex/life-threatening illness through a culturally humble lens • Pediatric medical social workers will be empowered to take a leading role in ethics consultation • Pediatric medical social workers will be able to advocate on behalf of their clients, taking into account individual cultural considerations

Purpose of the Practice Model

The purpose of this project is to empower pediatric medical social workers to draw upon their training to take on leading roles in ethics consultation services for patients and families. The practice model presented below provides a framework for social workers to address ethical dilemmas from a culturally humble and client-centered approach. In no way is the intention of this model to deemphasize the importance of including bioethics experts in the process of ethical decision-making and especially in the exploration of ethical dilemmas. Social workers are not trained bioethicists, and the information that this paper provides on bioethics theory is merely summative and is meant to provide a foundation of knowledge for social workers to use in approaching ethics consultation with their clients and their medical teams.

Additionally, this model is designed to ensure that clients' voices are heard within the deeply hierachal hospital system that universally places doctors in positions of power and authority in the treatment of illness. This hierarchy creates barriers for families facing immensely challenging decisions related to their child's care, barriers that can often silence families' voices. This model seeks to equip medical social workers with tools to help their families overcome these barriers and advocate for their wants and needs. It does so by informing social workers of bioethics considerations, providing a guide for gaining insight into a family's unique perspective, and bridging the gap between the family and the medical team in navigating ethical dilemmas.

Practice Model

Guided by scientific principles, the medical model has a tendency to approach decision-making from a perspective that views right and wrong as clear-cut and unequivocal. Alternatively, this model acknowledges the complex, varying, and often fluid process of decision-making, and it is meant to serve as a guideline to inform social workers as they work with families to address ethical dilemmas. It is not a decisive model and should not be utilized in an attempt to achieve unequivocal results. This model relies upon the intuition and clinical judgement of the social worker and their ability to remain client-centered; proper use requires acknowledgment of human differences, cultural humility, respect for human rights, and a commitment to the unique experience of the client and their self-determination. Table 5.2 below outlines the proposed model of practice.

Table 5.2: Bioethics Practice Model for Pediatric Medical Social Workers**1. BUILD RAPPORT**

- Develop relationship with the patient & family.
- Build trust.
- Gain consent.

Consider:

- **Importance of human relationships** – The quality of your relationship with the family plays a role in how and what they share with you, especially during times of increased vulnerability (illness of a child).
- **Family dynamics** – If the patient is an older adolescent they may have wants/needs that contradict those of the family unit. Can you maintain neutrality?

2. GATHER INFORMATION

- Who in the family makes decisions about matters of importance (Klessig, 1992)?
- Assess family's understanding of the child's condition.
- How does the family define health and quality of life? How does the patient define health and quality of life?
- How does the family define death (brain death, cardiac death)? What do they think about the sanctity of life (Klessig, 1992)? What are their rituals surrounding death and the dying process?
- What are the family's beliefs of the causal agents of illness (Klessig, 1992)?
- Consider trauma history. What is the family's past experience with complex and life-threatening illness? Hospice/palliative care? Death and dying?
- Define cultural considerations relevant to the family.

Consider:

- Does the **medical team's definition of health and quality of life** differ from the family's and patient's definitions? If so, how?
- Does the **medical team's definition of death** differ from the family's and patient's definitions? If so, how?
- Despite the fact that certain belief systems outline specific definitions of death and ritualistic requirements surrounding the dying process, don't assume that your client adheres to them in a traditional way or at all. Try to gain an understanding of what their traditions mean to them and how they envision those traditions playing out in the context of their child's illness and potential death.

3. DEFINE GOALS

- In the context of illness, treatment, and quality of life, what are the goals of the patient? The family? The medical team?
- Honor alternative viewpoints. Remember that medical practitioners are centered upon “evidence-based” western/mainstream interventions – the family may have interest in other options that western doctors may have biases against (naturopathic medicine, Ayurveda, Chinese medicine, etc.).

Consider:

- Do the patient’s goals align with those of the family as a whole? Do different family members have different goals? How do patient and family goals align with those of the medical team?

4. DEFINE & ANALYZE THE DILEMMA

- What is the ethical dilemma? Define the situation (problem) in which there are two (or perhaps more) mutually exclusive options requiring consideration through an ethics lens.
- Working with the family and the medical team, describe each of the options and all potential outcomes. Consider feasibility and legality.
- Analyze the case in the context of the principles of biomedical ethics (*respect for autonomy, nonmaleficence, beneficence, justice*).
- Analyze the case in the context of bioethical principles specific to pediatrics (*autonomy and moral status of the child, nature of decision-making, best interest of the child*).
- Analyze the case in the context of ethical principles specific to complex and life-threatening illness (*quality of life, obligatory versus optional treatment, and life-sustaining treatment at end-of-life*).
- Are there other ethical principles beyond these that come into play for the family?

Consider:

- What are the underlying values at stake?
- What role do **cultural considerations** play in definition and analysis of the dilemma?

This chapter has presented the theory of change logic model related to this project as well as the culturally humble bioethics practice model itself. The following chapter will present analysis and discussion of the model in relation to the literature.

Chapter Six: Analysis & Discussion

As previously mentioned, the primary means of addressing ethical dilemmas in medical settings is through ethics consultation services led primarily by physicians and nurses (Fox, et. al., 2007), and the role of medical social workers in ethical activism in hospital settings is limited (Jansson & Dodd, 2002). Ethics in this context, however, involves value-driven consideration of complex human emotions and fundamental internal and external phenomena, including patient autonomy and interpretation of nonmaleficence, beneficence, and justice (Beauchamp & Childress, 2009). The literature has also shown that further complexity arises in pediatric medical settings and in the context of complex and life-threatening illness in children where issues of autonomy and moral status of the child, the nature of decision-making, best interest of the child, quality of life, obligatory versus optional treatment, and life-sustaining treatment at end-of-life become central elements of ethical consideration. This chapter will discuss the unique strengths that qualify social workers to participate in ethics consultation in pediatric medical settings with an emphasis on the ways in which social work values, principles, and standards govern curriculum in academic settings, guide practice and research within the field, and contribute to the ethos of the field.

Social Worker Qualifications for Ethics Consultation

Ethics consultation in medical settings requires exploration of the ways in which specific moral principles are interpreted and upheld in the context of the patient's relationship with healthcare systems. The nuanced nature of these considerations and the

inherent complexity of medical decision-making indicate the importance of a culturally humble patient/family-centered approach to bioethics consultation; social workers are uniquely suited to work in this capacity due to the foundational ethical principles that are the define social work ethos, govern curriculum in academic settings, and guide practice and research within the field.

The National Association of Social Workers (NASW) has defined a code of ethics that outlines values, principles, and standards that serve as building blocks for social work training and practice throughout the United States. The code of ethics identifies six social work values and related ethical principles which are outlined in Appendix 1 and include: *service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence* (NASW, 2017). These values and principles contribute to the ethos of social work practice with an emphasis on a client-centered and service-driven approach to working with people. This approach lends itself uniquely to serving families experiencing the complex and/or life-threatening illness of a child and are especially relevant to effectively working through ethical dilemmas in this context which requires an ability to support a family-driven approach to decision-making and an ability to maintain respect for the emotional and nuanced nature of the work.

Furthermore, the NASW code of ethics defines standards of ethical responsibility that govern the professional activities of social workers. These standards include social workers' responsibilities to clients and colleagues in the context of their work within the profession and in the context of broader society (NASW, 2017). The standards of ethical

responsibility outlined in the code of ethics are broad; there are specific standards that are particularly relevant to this project, and they include: *commitment to clients, self-determination, cultural awareness and social diversity, and inter disciplinary collaboration* (NASW, 2017). In ethics consultation in medical settings, commitment to clients is critical, as patients and families often need representation and advocacy in the hierarchical hospital setting. The social workers commitment to self-determination is also an important element of effective ethics consultation, as the needs and desires of the patients and families must be at the center of decision-making and ethical exploration. This helps to ensure that ulterior motives are not the driving force behind ethics consultation, which can arise in medical settings where physicians may be influenced by biases in favor of western medical practice, research agendas, and/or a desire to protect their licensure and avoid legal repercussions such as malpractice suits. Furthermore, the field's commitment to cultural awareness and social diversity means that social workers are trained to keep these considerations at the forefront of their work with clients. As has been discussed, cultural considerations are a central and highly influential element of medical decision-making (Blackhall et. al., 1999 and Kelssig, 1992), especially in the context of complex and life-threatening illness. Finally, interdisciplinary collaboration is a critical element of effective ethics consultation in medical settings. As noted, social workers are not formally trained bioethicists, and the ability to consult with colleagues from other professions is necessary to ensure competent and informed practice.

In conclusion, the field's approach to service and commitment to awareness of human differences allows social workers to address ethical dilemmas in a way that respects client self-determination and cultural considerations. For these reasons, social workers are uniquely suited to participate in and even lead ethics consultation in medical settings and should be empowered to utilize the practice method proposed in this thesis to support medial teams, patients, and families in resolving ethical dilemmas. This chapter has presented analysis and discussion of the model presented in this thesis in relation to the literature. The following chapter will conclude this project with discussion of implications for social work, limitations of the project, and suggestions for further study.

Chapter Seven: Implications for Social Work, Limitations, & Suggestions for Further Study

This project has argued that the nuanced nature of bioethical considerations and the inherent complexity of medical decision-making indicate the importance of a patient/family-centered culturally humble approach to bioethics consultation and that social workers are uniquely suited to work in this capacity due to the foundational ethical principles that define social work ethos, govern curriculum in academic settings, and guide practice and research within the field. Additionally, the author has presented a model of practice for ethics consultation in pediatric settings specific to complex and life-threatening illness that emphasizes the importance of navigating bioethical dilemmas with a culturally humble patient/family-centered approach. This chapter will outline the implications of this project on social work practice, education, research, and policy as well as limitations of the model and suggestions for further study.

Implications for Social Work Practice, Education, Research, & Policy

With regard to implications for social work practice, the purpose of this project is to promote increased engagement of pediatric medical social workers in ethics consultation services in hospital settings by equipping them with a basic understanding of bioethics and a model for approaching ethics consultation with medical teams, patients, and families. By utilizing the information and the model presented here, medical social workers practicing in pediatric settings should be able to more fully support their clients through thoughtful and client-centered exploration of ethical dilemmas. Social workers

should also be able to more deeply engage with interdisciplinary teams as they will have an understanding of basic bioethical principles as well as those specifically relevant to pediatric practice.

With regard to social work education, there is much room in MSW and BASW curriculum to expand upon classroom content related to ethical decision-making. While this model is specific to pediatric medical settings, ethical dilemmas are an inherent part of social work practice on micro, mezzo, and macro levels. For this reason, the general concepts presented in this research can be utilized and adapted to enrich social work educational content. It is also worthwhile to note that students can engage a number of core social work competencies including, engaging diversity and difference, advancing human rights and social justice, and engaging, assessing, and intervening with individuals, families, groups, and organizations, (Council on Social Work Education, 2015) when exploring ethical decision-making.

With regard to research, this project might imply a greater need for research into biomedical ethics from a social work perspective as well as the ways in which patients and families can be more effectively supported by medical professionals including medical social workers. The project may also imply a need for greater research into cultural considerations in the context of complex and life-threatening illness in pediatric medical settings and the implications of these considerations on medical social work practice. With regard to policy, ethics consultation in medical setting is governed primarily by legislation that manages the physical risk and safety of patients (Lewis,

2012). Beyond physical safety, patients' and families' human rights must be upheld on a broader level including the right to self-determination and cultural freedom. This study might imply the need for policy that governs patients' and families' right to access to social services in medical settings in order to ensure that these human rights are upheld, especially in the context of ethical dilemmas.

Limitations & Suggestions for Further Study

The most significant limitation of this study is the researcher's rudimentary knowledge of bioethics theory which has come primarily from a review of the literature and a nine-month practicum in a pediatric oncology setting. For this reason, this project does not claim to present comprehensive expert knowledge of bioethics theory but rather offers summative information to bolster the social worker's training, intuition, and clinical judgment in supporting medical teams, patients, and families with ethics consultation. To further the depth of this study, it would be worthwhile to invite bioethics experts and other social workers and social work theorists with knowledge of bioethical considerations in the expansion of this project. Additionally, further study should be made into social workers' role in ethics consultation in contexts beyond complex and life-threatening illness in children. Social workers have great potential to participate in ethics consultation in medical settings in pediatric primary care as well as with adults in both primary care and specialties, and the model presented here could be modified to support this work.

Conclusion

Ultimately, ethics are a complex and variable matter requiring respect for the individual's own unique perspective and definition of the moral implications of behavior and decision-making. Social work is a field dedicated to awareness and respect for human differences, and social workers are therefore uniquely suited to explore and address ethics in medical settings. The model presented here should be utilized as a guideline for ethics consultation but should not be considered a universal means of achieving results. The success of this model hinges upon the social worker's ability to implement the model in a way that fits best with the needs of the individual client and their unique situation.

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Appendix 1.

Value: Service

Ethical Principle: *Social workers' primary goal is to help people in need and to address social problems.*

Social workers elevate service to others above self-interest. Social workers draw on their knowledge, values, and skills to help people in need and to address social problems. Social workers are encouraged to volunteer some portion of their professional skills with no expectation of significant financial return (pro bono service).

Value: Social Justice

Ethical Principle: *Social workers challenge social injustice.*

Social workers pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. Social workers' social change efforts are focused primarily on issues of poverty, unemployment, discrimination, and other forms of social injustice. These activities seek to promote sensitivity to and knowledge about oppression and cultural and ethnic diversity. Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people.

Value: Dignity and Worth of the Person

Ethical Principle: *Social workers respect the inherent dignity and worth of the person.*

Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity. Social workers promote clients' socially responsible self-determination. Social workers seek to enhance clients' capacity and opportunity to change and to address their own needs. Social workers are cognizant of their dual responsibility to clients and to the broader society. They seek to resolve conflicts between clients' interests and the broader society's interests in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession.

Value: Importance of Human Relationships

Ethical Principle: *Social workers recognize the central importance of human relationships.*

Social workers understand that relationships between and among people are an important vehicle for change. Social workers engage people as partners in the helping process. Social workers seek to strengthen relationships among people in a purposeful effort to promote, restore, maintain, and enhance the well-being of individuals, families, social groups, organizations, and communities.

Value: Integrity

Ethical Principle: *Social workers behave in a trustworthy manner.*

Social workers are continually aware of the profession's mission, values, ethical principles, and ethical standards and practice in a manner consistent with them. Social workers act honestly and responsibly and promote ethical practices on the part of the organizations with which they are affiliated.

Value: Competence

Ethical Principle: *Social workers practice within their areas of competence and develop and enhance their professional expertise.*

Social workers continually strive to increase their professional knowledge and skills and to apply them in practice. Social workers should aspire to contribute to the knowledge base of the profession.