

ADOLESCENT DECISIONAL CAPACITY AND MEDICAL DECISION-MAKING

BY

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A Thesis Submitted to the Graduate Faculty of

WAKE FOREST UNIVERSITY GRADUATE SCHOOL OF ARTS AND SCIENCES

in Partial Fulfillment of the Requirements

for the Degree of

MASTER OF THE ARTS

Bioethics

May 2019

Winston-Salem, North Carolina

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## Introduction

The World Health Organization defines adolescence as the period in childhood between age ten and age nineteen (Csikszentmihalyi 2018). During the adolescent years children enter puberty, gain physical and emotional maturity, and often enjoy gradual opportunities for important decision-making until reaching adulthood on the date of one's eighteenth birthday. Adulthood was first designated at eighteen by The Family Law Reform Act of 1969, which lowered the age of majority from twenty-one to eighteen in the United Kingdom (Wright 2009, p. 238). Two years later in 1971, however, the United States also reconsidered the age marking the beginning of adulthood with the passage of the 26th Amendment, which reduced the eligible voting age for citizens from twenty-one to eighteen (Schamel, 1996). Thus, while the age at which adulthood has been legally recognized has shifted in the U.S. and elsewhere, that point has remained significant as it portends an immediate expansion in one's rights and social status.

Upon becoming adults many adolescents anticipate the ability to live independently, to vote in elections, to travel unsupervised, or to qualify for a job. Adolescents living with an illness, however, often focus on their ability to determine their health care and treatment options, because in most instances they are not legally allowed to give informed consent or informed refusal concerning the direction of their care, even if they possess a thorough understanding of their condition due to their experience of living with a chronic or long-term illness. As a result, discordance between the decisional capacity of adolescents and their legal ability to self-determine medical care arises on occasion, leading to fundamental

questions regarding how decisional capacity distinctions are made for adolescents in health care settings. It is therefore important to continue to consider an adolescent's right to medical self-determination in health care settings as we strive to provide the best protections for the most vulnerable in our society, while also ensuring that a respect for patient autonomy is being honored.

Certain exceptions permitting adolescents to make medical decisions and/or to give or refuse consent for medical care and treatment do exist, however, such as in cases of emancipation. Some of the ways that an adolescent can achieve emancipation are through a legal request and court determination, by marriage, or upon becoming a parent. In addition to emancipation as a means for independently making health care decisions, chronically and terminally ill adolescents are also frequently allowed to choose from various therapeutic interventions that alleviate stress, as well as to provide their assent to participate in research studies. Yet, despite various options and opportunities for adolescents to realize self-determination in a health care setting, conflict still occasionally occurs involving the health care and treatment options that are being provided, and when this happens difficult choices must be made in order to respect patient autonomy while also abiding by the practices of informed consent or refusal, as well as parental consent.

The informed refusal of medical care can often be a much more difficult matter to resolve for an adolescent than the acquisition of informed consent. Informed refusal may be seen most frequently in situations where a religious or spiritual belief is in conflict with the medical treatment in question, such as when a blood transfusion is rejected by a patient who is a Jehovah's Witness. At other times, informed refusal

may occur because the treatment is too burdensome for the patient to endure, because the patient chooses to pursue an alternative or unproven therapy, or because the patient would rather forgo further attempts at a curative treatment that offers a slim margin of success. Regardless of the exact reason for the informed refusal, however, a non-emancipated adolescent typically requires parental consent to stop treatment, which occasionally leads to a dispute between the patient, the family, and/or the medical team providing the care.

Furthermore, when an adult refuses treatment for a terminal or life limiting condition there are multiple European countries, as well as the countries of Colombia, and Canada that offer the option of receiving either euthanasia, or physician-assisted suicide, which are both considered forms of medical assistance in dying (MAID) (Dyer 2015). For terminally ill adults in the U.S., eight different states and the District of Columbia currently permit the physician-assisted suicide form of MAID, while euthanasia remains illegal (ProCon.org 2018). However, only two countries internationally have extended the option for MAID to terminally ill adolescents, with both requiring parental consent and involvement under differing regulatory processes (Chhikara 2017, p. 432). The first country to allow mentally competent adolescents age twelve and older to receive MAID was the Netherlands in 2002, whereas in Belgium, MAID rights were extended to children of any age in 2014 (Ibid). Recently however, there has been a growing support for adolescents to be eligible to receive MAID, and many physicians, despite the criticisms that persist against it, are reporting increases in MAID requests.

One advocate of adolescents receiving MAID rights, Luc Bovens, offers and then

counters five separate arguments against the practice of euthanasia in his article, “Child euthanasia: should we not just talk about it?” (Bovens 2015). According to Bovens, the five primary arguments against allowing euthanasia for minor children are: an “argument from weightiness” which states that the subject matter is simply too important for minors to consider; an “argument from capability of discernment” which holds that an adolescent is not yet capable of making reasoned decisions; an “argument from pressure” which suggests that a terminally ill adolescent would choose to end his or her life due to coercion from family members or medical practitioners; an “argument from sensitivity” which offers that a minor child may be more sensitive to the suffering of his or her family and friends and may therefore choose euthanasia to alleviate that suffering; and an “argument from sufficient palliative care” which calls for better palliative care for terminally ill minor patients rather than providing an option to end their lives.

For many, however, the simplified basis for denying MAID rights to adolescents or requiring terminally ill adolescents to obtain parental consent as well as to pass psychological examinations proving decisional capacity in order to refuse, alter, or discontinue medical treatment stems from the following two presumptions: first, that one is not fully capable of making informed choices prior to becoming a legal adult on the occurrence of one’s eighteenth birthday, and second, that decisions regarding terminal illness are unlike other health care decisions because they involve higher stakes with permanent consequences. Yet, it is well accepted in the medical community that neither cognitive development nor social maturity occurs uniformly during adolescence with regard to the first presumption; therefore it does

not follow that every eighteen year old will suddenly be capable of making informed choices about health care at 12:01AM on his or her eighteenth birthday. For some, it may take longer to develop the ability to make a reasoned decision and thereby give genuine informed consent or refusal, while for others this ability may be present sooner in adolescence, with some suggesting that adolescents can be decisionally capable regarding important health care determinations by ages ten, twelve, or fourteen.

Moreover, an emancipated adolescent who has been deemed an adult as a result of marriage, parenthood, or being independent and self-supporting is also not automatically decisionally capable upon the recognition of a legal adult status, although law may have accorded it. Thus, it is important to carefully consider and distinguish among the ways a minor may receive the legal ability to independently make medical decisions, and whether or not to examine if those ways accurately represent decisional capacity.

With regard to the second presumption concerning higher stakes, it could be argued that many if not all health care decisions carry high stakes and the possibility of permanent consequences. Yet, in the U.S., we do in fact allow minors to independently consent to certain medical treatments under specific conditions that are considered threats to public health, with the exact circumstances varying from state to state. Therefore the arguments underlying the denial of MAID to adolescents with terminal illness may be seen differently in light of minor treatment statutes, which are widely accepted and are present in every U.S. state.

In the subsequent chapters of my thesis I consider the history of decisional

capacity determinations that have allowed adolescents to choose their health care and treatment options, as well as the age parameters and conditions eligible for receipt of medical care without parental consent. I compare the availability of medical treatments that adolescents can currently consent to internationally, including the right to receive MAID, and I examine the legal restrictions and requirements placed on adolescents in health care settings. In addition, I analyze the arguments offered for and against allowing adolescents to receive more robust rights to self-determination in health care settings, and I scrutinize the processes of informed consent, informed refusal, and parental consent when conflict arises between the patient and/or the family and medical team. I conclude my thesis with statistical and qualitative data that are suggestive of future trends in adolescent health care.

In the first chapter, I trace the historical relevance of the period of adolescence, with a critical analysis of the legal certification of decisional capacity. In doing so, I explore the history of legal age requirements, emancipation laws, and the methodologies used to determine decisional capacity. Moving forward, I examine the principal differences between an adolescent's informed consent to medical treatment and informed refusal, and I compare the laws and medical practices governing terminally ill adolescents in the United States and European countries, as well as the therapeutic interventions that are frequently offered.

It is generally accepted that adolescents can make determinations regarding at least some important life decisions; therefore it is necessary to question which decisions an adolescent is capable of deciding independently and which decisions

require an additional safeguard such as parental consent. In most countries today, the recognition of adulthood applies to everyone who reaches eighteen years old, and once one reaches that age, medical treatment and care becomes completely self-determined provided the person is conscious and cognitively capable. Under certain conditions, however, adolescents become exempt from the standard parental consent requirement. This chapter conducts in depth investigations into the reasons why medicine, society, and the law distinguish between an adolescent's ability to consent to or refuse medical treatment based on numerical age, and if current emancipation laws and the tests used to determine decisional capacity are doing enough for those most in need.

In the second chapter, I elucidate the arguments for expanding the right of self-determination to adolescents in health care settings, as well as the arguments against expanding adolescents' self-determination rights. In addition, I compare the approaches to MAID that are available to terminally ill adolescents in the Netherlands and in Belgium, with the approaches taken in the United States. Following that comparison, I analyze research pertaining to adolescent access to and utilization of medical treatment in order to provide the underpinnings of each argument or approach, as well as providing consideration of case histories to demonstrate the potential for satisfactory outcomes.

Adolescents in need of medical care and treatment experience dramatic differences according to their geographic location with regard to the self-determination rights that are available to them. Yet, a growing body of evidence suggests that many adolescents are decisionally capable regardless of their

background or culture prior to their eighteenth birthday. Nonetheless, the question whether or not adolescent decisional capacity can be extended to the right to die remains fiercely debated. My second chapter focuses on how decisional capacity is determined for adolescents, and the arguments for and against their right to make self-determined medical decisions during, as well as at the end of their lives.

In the final chapter of my thesis, I examine international statistical and qualitative data from a liberationist approach regarding adolescent medical decision-making, and I compare those data with the laws and practices governing the medical care and treatment of adolescents in the United States. I additionally offer an analysis of the current trends in adolescent health care, provide potential solutions for avoiding or easing conflict based on recent concepts, and provide my personal conclusion concerning self-determined end-of-life care for adolescents after conducting a detailed evaluation of the laws and factors contributing to the recognition or denial of adolescent self-determination rights has been considered.

Many countries and multiple U.S. states are now debating legislation allowing MAID for terminally ill adults, and as such, it stands to reason that MAID rights, in addition to other medical decision-making rights are likely to follow for adolescents. Yet, it is undeniable that adolescents are not always decisionally capable persons, despite the existence of certain health care conditions where they are allowed expanded opportunities to act as autonomous agents regarding their treatment options. Thus, while many report evidence suggesting that decisional capacity can be present in adolescents, and legal exceptions to the age of majority rule can be found, it is important to examine how decisional capacity emerges, how it is

determined, and the ways it can be facilitated to provide the best support for minors in health care settings.

# **Chapter One**

## **A Brief History of the Age Requirements and Regulations that Determine Adolescent Medical Decision-Making, and a Comparison of the End-Of-Life Laws Governing Adolescents**

Until recent decades, common law mandated that “a child, which meant anyone under 21, not 18, was a chattel of his or her parent – actually, of his or her father. A father had the right to sue a physician who treated his son or daughter without his permission, even if the treatment had been perfectly appropriate, because such an intervention contravened the father’s right to control the child” (Holder 1989, p. 161). Historical notions of patriarchal dominance aside, however, the right of parents to direct the medical care provided to their minor children, and the requirement of the physician(s) to obtain either written or oral consent from a parent or guardian prior to providing the care remains the legal standard under most conditions.

Exceptions allowing minors to receive medical care without requiring a parent or a guardian’s permission exist, however, in cases of emergency, emancipation, and instances where public health concerns are present. In an emergency situation involving a minor, the statutes that address providing medical treatment are consistent in every state regardless of the ability to obtain consent from a parent or guardian. The unilateral observance of providing emergency care with or without

parental or guardian permission is supported by the “emergency exception rule” or “doctrine of implied consent”, which states, “ED practitioners are bound by an ethical and moral duty to provide emergency treatment to safeguard life, even in the absence of consent” (Benjamin et al, p. 225). In addition to the emergency exception rule, however, EMTALA, or the Emergency Medical Treatment and Labor Act of 1986, also applies, and as a federal law, it supersedes all state laws. EMTALA fundamentally mandates at least some treatment for any person seeking treatment in an emergency department. Therefore, all medical emergencies involving minors directly result in prompt and appropriate treatment, whether consent from a parent or guardian has been given or not.

With regard to providing medical treatment to an emancipated minor, the defining circumstances and laws awarding emancipation vary from state to state. For example, a 14 year old may petition the court for emancipation in the state of California, which if granted would consequently allow for self determined medical decision-making among other things, but in Wyoming he or she must wait until 17 to petition the court for emancipation. Yet, in states like Delaware, Indiana, and New Jersey the age for petitioning the court for emancipation is not specified (Lane, Kohlenberg 2012, pp. 536-538). Further differences in many but not all states include an automatic conferral of emancipation status upon entering into marriage or active military service, or upon becoming a parent. Several states additionally consider a minor emancipated and capable of self-determined medical decision-making under extenuating circumstances such as if his or her parents are deceased or determined “insane” (Lane, Kohlenberg 2012, pp. 535-536), while in other states

like Florida, “a health care provider may accept a written certificate as proof of the minor’s status as an unaccompanied homeless youth to consent to medical, dental, psychological, substance abuse, and surgical diagnosis and treatment, including preventive care” (Benjamin et al, p. 227). As such, emancipation does not offer a reliable standard for deeming a minor capable of self-determined medical decision-making although it legally enables them to independently make medical decisions. In spite of the inconsistent qualifications for emancipation, however, “For at least two hundred years courts in the Anglo-American system have recognized the concept of an “emancipated minor”” as a person below the legal age of majority who is capable of making important life decisions without parental or guardian permission (Holder 1989, p. 162).

In addition, various medical conditions such as sexually transmitted infections and substance abuse issues have been identified as public health concerns, and thus they have allowed an unaccompanied minor to receive medical treatment without the consent of a parent or guardian since the 1960’s under legislation known as minor treatment statutes (Holder 1988, p. 220). Minor treatment statutes were passed as protections for the provision of medical care to treat sensitive health conditions that a minor may not feel comfortable addressing with his or her parent or guardian, but which if left untreated presented a potential for spreading into a community wide epidemic. These statutes have been codified into law in every U.S. state, yet, like emancipation laws, minor treatment statutes vary from state to state in outlining the narrow margins around the types of care provided and qualifying conditions that are applicable. Consequently, these statutes do not provide a

consistent foundation or standard protocol for medical decision-making for minors under the specifically listed circumstances across the U.S., however, under each state's minor treatment statute, it is legal for a minor to receive medical treatment without the permission of a parent or guardian.

Outside of the exceptions for emergency related care, and in cases of emancipation, and a public health concern, minor children are nonetheless often encouraged to participate in their medical decision-making and offer their assent to treatment before the administration of medical care. It is notable, however, that while assent is defined as the agreement of a minor that is accompanied by parental or guardian permission, the procedural act of requesting assent is representative of considering a minor capable of some degree of autonomous medical decision-making. Furthermore, while few argue that parent or guardian permission should not be consistently required for younger children who have not yet entered adolescence, the decisional capacity of adolescents to independently provide consent in medical settings has frequently been debated. In fact, "the Tennessee Supreme Court, in deciding *Cardwell v Bechtol* in 1987, used the "rule of sevens" to uphold the decision-making capacity for a 17-year-old girl receiving spinal manipulation. This "rule" stated that no capacity exists for children younger than the age of 7 years, a lack of capacity is presumed but may be rebutted with appropriate evidence between the ages 7 and 14 years, and capacity is presumed but may be rebutted at age 14 years and older"(Katz et al, p. e7). In addition, "Developmental research in the 1980s concluded that many minors reach the formal operational stage of cognitive development that allows abstract thinking and the ability to

handle complex tasks by midadolescence”(Ibid).

However, there is not consensus among researchers or medical experts regarding the capacity of adolescents to make autonomous health care decisions. In the article “Adolescent Pediatric Decision-Making: A Critical Reconsideration in Light of the Data”, author Brian Partridge writes:

“Most adolescents make decisions differently from most adults both in terms of the character of their decisions, which difference appears generally to be a function of neuroanatomical substrate. There is a growing body of evidence linking differences in neural development to high levels of morbidity and mortality among various adolescents...It is thus important to explore with care how adolescent decision-making differs substantively from that of adults...a study utilizing neural imaging techniques proposed that these differences in decision-making were in particular due to the differential development of the later maturing prefrontal areas of the brain, which are responsible for executive control, as well as the earlier development of the limbic areas of the brain, responsible for affective decisions and reward salience”(Partridge 2014, p. 302).

Nonetheless, according to other perspectives on this aspect of the debate, “Neuropsychological research to link adolescent behaviors such as sensation and risk taking to brain structure and function is ongoing but still speculative in many areas”(Katz et al, p. e7). Therefore, although Brian Partridge and others assert neuroanatomical explanations to support their standpoint, many unresolved questions persist regarding the ability of adolescents to functionally self determine

their medical treatment and care.

Due to the disagreement on this topic, “discussions are occurring among pediatric societies regarding the formation of a national agenda for children and adolescent public policy” (Lane and Kohlenberg 2012, p. 535). Unfortunately however, the creation of a national agenda and public policy for children and adolescents has not occurred to date. Therefore, when questions and/or conflicts concerning the ability of a minor to exercise thoughtful, autonomous decision-making in a medical setting arise, the decisional capacity of the minor in question must be determined on an individual case-by-case basis without the benefit of any standard protocol to offer guidance in the overall assessment.

In making determinations regarding adolescent capacity, Brian Partridge suggests that in order for a minor to be considered decisionally capable, he or she must display “(1) an intellectual appreciation of how one’s decisions are tied to their casual outcomes, along with (2) a capacity realistically to evaluate affectively the proximate and distant consequences of one’s choices” (Partridge 2014, p. 301). Yet the methods for determining decisional capacity vary, as do the interpretations of what represents an appropriate response or outcome to effectively demonstrate an adequate level of capacity. While the protocol dictates, “When conflicts about the goals of treatment persist, the healthcare team should enlist the involvement of secondary consultants, an integrated palliative care team, ethics consultation, psychologists, or chaplains”, there is no standard for making decisional capacity assessments that the healthcare team or any of the secondary consultants can reliably follow (Katz et al, p. e11).

“In fact, judgments are often subjective and cannot be objectively verified and may lie outside the physician’s expertise. Even if a child is considered mature or is being assessed for that status, doctors are caught in a paradox. Adolescents are deemed to be competent when they consent to a doctor’s proposal, but “incompetent if they reject professional [or potentially parental] advice””, which on occasion happens to adults as well (Babcock 2016, p. 6). It is important to note, that it is the refusal of a minor to assent or consent to professional or parental advice where medical treatment and care is concerned that frequently provides the primary basis for conflict in these situations. Thus, while a conclusive assessment of adequate decisional capacity results in the legal ability of a minor to both consent and refuse medical treatment, it is most often the refusal of consent that leads to the need for decisional capacity determinations in the first place. One solution that has been offered to mitigate this conundrum is for medical providers to put into practice a framework for “conditional autonomy”, whereby “adolescents are allowed opportunities for choice and involvement in care only when the stakes are lower or when they are perceived to be making the right choice”(Lang and Paquette 2018, p. 535). However, it can easily be argued that autonomy is not conditional, although decisional capacity may be.

Furthermore, as Dr. Abigail Lang and Dr. Erin Talati Paquette write, “Decisions regarding refusal of treatment become more complex as children become older and more involved in the decision-making process. While the AAP recommends obtaining assent “whenever reasonable,” the policy statement also notes that assent should only be solicited in situations in which the healthcare team would be willing

to honor, at least in part, a child's dissent" (Ibid). Yet it is widely reported that physicians and treatment providers find greater difficulty in accepting a minor's refusal than in accepting his or her consent. Some suggest that the fundamental reason behind the higher incidence of reluctance in accepting a minor's refusal of treatment compared with a minor's consent to treatment lies in concerns over reports of medical neglect by the treatment team, while others claim that it stems from the harm principle, "which maintains that society has the duty to protect and care for those who cannot advocate or care for themselves" (Ibid).

According to Dr. Rob Lawlor, "the asymmetries between consent and refusal can be found in the law, with adolescents often having a right to consent to treatment but not always a right to refuse treatment" (Lawlor 2016, p. 748). The legal right of an adolescent to refuse medical treatment has, however, undergone significant reconsideration in some locations, particularly around end-of-life decision-making. While in the United States adolescents have very few formal means to refuse life-sustaining treatment(s), some in fact do exist. For example, Virginia passed a law in 2007 referred to as "Abraham's Law" which provides adolescents age 14 and older with decision-making rights in circumstances involving a life-limiting illness (Katz et al 2016, e11). It is important to note that Abraham's Law was only drafted after its namesake (16-year-old Abraham Starchild Cherrix) was able to successfully refuse the standard treatment therapy for his lymphoma after winning his case in court, with the judge's ruling focusing "on the patient's maturity, understanding of his illness, and parental support of his refusal" (Ibid). Nonetheless, in other states where adolescents have no legal support for treatment refusal, "in circumstances of

a life-limiting terminal illness when only unproven, overly burdensome or likely ineffective treatment options exist, some adolescents may make an informed choice to forgo interventions to address their underlying disease and instead focus on measures that provide comfort or support” (Katz et al 2016, p. e12).

Thus, in instances where an adolescent is facing a terminal illness with a very slim chance of responding to an effective treatment, his or her wishes for the refusal of further curative treatment are oftentimes honored. In fact, in the American Academy of Pediatrics (AAP) recommendations for the refusal of life-sustaining medical treatment, among the guidelines recently issued are the statements: “Each child is entitled to “open and honest” communication of “age appropriate information about his or her illness, as well as potential treatments and outcomes within the context of family decisions” and to be “given the opportunity to participate in decisions affecting his or her care”” (Weise et al 2017, pp. 1-2). Furthermore, “It may be ethically allowable to cease LSMT without family agreement in rare circumstances of extreme burden of treatment when LMST is simply prolonging inevitable death” (Weise et al 2017, p. 2). It is therefore important to recognize that while minors do not have a standard policy outlining their rights to end-of-life medical decision-making in the U.S., the AAP guidelines offer clear support for children and adolescents as active participants in their end-of-life care, while also providing an acknowledgement concerning the ethical permission to cease LSMT in circumstances of extreme burden.

With regard to Europe: “A recent statement from the Confederation of European Specialists in Pediatrics clearly states that pediatric patients may not refuse life-

saving treatment” (Katz et al 2016, e11). Yet, in the Netherlands, and in Belgium, terminally ill adolescents can be considered decisionally capable to forgo life-sustaining medical treatment in order to end their lives under differing regulatory processes.

In the Netherlands, The Termination of Life on Request and Assisted Suicide Act of 2002 made it possible for minors as young as 12 years old to end their lives either through euthanasia or by the ingestion of a lethal dose of drugs prescribed by a physician (Chhikara 2017, p. 342). Important stipulations in the Dutch law require that the patient demonstrate a level of “unbearable suffering” while also offering a notion of a graduated degree of autonomy that comes with age, as it proclaims: “From age twelve to sixteen the minor needs parental consent. From ages sixteen to eighteen, no parental consent is required, but the government requires parental advisement with the decision” (Ibid).

In Belgium, the law governing the receipt of euthanasia for adults was amended on March 22, 2014 “to include competent minors as a category of persons participating in the euthanasia practice” (Chhikara 2017, p. 343). The Belgian law differs from the Dutch law in that it only allows for euthanasia, not physician-assisted death through the prescription of lethal drugs. In addition, it mandates that the minor visit a psychiatrist or psychologist to determine competency, and it requires that the psychiatrist or psychologist perform an evaluation and provide certification of decisional capacity in order for the minor to receive euthanasia (Ibid). The minor and his or her legal representative must then subsequently submit the decision for euthanasia to the minor’s physician in writing (Ibid). However, one

of the most controversial differences between the Dutch law and the Belgian law is that the Belgian law does not have a minimum age requirement for eligibility for medical assistance in dying (Cuman, Gastmans 2017, p. 838). Instead, the Belgian law “focuses on the minor’s capacity for discernment. In fact, the Belgian law states that competent minors can request to receive euthanasia if they are in a “medically futile condition of constant and unbearable physical suffering that cannot be alleviated and that results from a serious, incurable disorder caused by illness or accident that will cause death within a short period of time”” (Ibid). Thus, while the Belgian law is both more specific and narrow in some of its requirements for the receipt of euthanasia, it is also simultaneously less rigid with regard to the age requirement for the legal recognition of the capacity for medical decision-making.

Reconsiderations concerning the medical decision-making ability of adolescents are, however, emerging internationally. While the history, list of exceptions, fundamental disagreements, and cultural differences surrounding the decisional capacity of minors provides an interesting background, it may be of even more interest to speculate what changes are yet to come for this controversial issue. In the following chapter, I examine the key arguments underlying this topic and consider how various bioethical opinions are informing public debate and influencing the creation of new legislation.

## **Chapter Two**

### **The Arguments For and Against Expanding Medical Decision- Making Rights for Minors: A Review of the Legislation, Research, and Divergent Attitudes**

In 1987, the Tennessee Supreme Court issued a decision referred to as the “rule of sevens”, which acknowledged an increasing capacity for medical decision-making in minor children (Katz 2016, p. e7). According to the “rule of sevens”, children under seven years of age possess no capacity for medical decision-making, children between seven and fourteen years of age are presumed not to have decisional capacity although a rebuttal is possible, and children fourteen years and older are presumed to have decisional capacity for medical decision-making, although the presumption of capacity may also be rebutted (Ibid).

In 1989, The United Nations Convention on the Rights of the Child recognized children’s “participation as its underlying principle, it implies an obligation to acknowledge and respect the views and opinions of children” (Jeremic et al 2016, p. 526).

Eight years later in 1997, The European Convention on Human Rights and Biomedicine wrote, “the opinion of the minor should be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity” (Ibid).

Currently, U.S. state laws allow the following: “in South Carolina, when a person has reached the age of 16 she may give formal, legal, consent to medical treatment”,

and in New Mexico, decision-making capacity in medical settings is accepted for “minors who can display that they “understand the nature of that unemancipated minor’s medical condition, the risks and benefits of treatment and the contemplated decision to withhold or withdraw life-sustaining treatment”” (Baker 2013, p. 312).

Thus, although a legal age of majority exists, as well as mature minor statutes, and various emancipation laws listing rules and requirements for when and under what circumstances a minor can autonomously exercise medical decision-making, the guiding principles for the treatment of minors are increasingly supporting the inclusion of non-emancipated minor patients in all manner of medical discussions. Furthermore, “Legislation across the world acknowledges that the (clinical) capacity to make medical decisions does not suddenly appear when a person reaches the age of majority” (Ruhe et al 2016, p. 517). It is well accepted in the medical community and elsewhere that children mature at different rates physically, mentally, and emotionally, which can lead to different levels of decisional capacity for children of the same age and even for those born on the same day. However, while children are being included more frequently in medical decision-making, vastly different treatment options and medical outcomes result even for very similar cases due to location, provider discretion, inconsistent legislation, and subjective measurements for determining decisional capacity.

## **Arguments Supporting an Expansion of Medical Decision-Making Rights**

The arguments for expanding medical decision-making rights to minors can be

found on various fronts, however, with some asserting that an expanded protocol of medical decision-making is not only possible, it is necessary in order for minors to be fundamentally respected as persons in health care settings. Yet, as the authors of the article “Participation of Children in Medical Decision-Making: Challenges and Potential Solutions” point out, “There is generally agreement that children should have their voice heard with regards to “minor” medical decisions...disputes appear when it comes to “major” medical decisions, like deciding on treatment or selecting treatment alternatives” (Jeremic et al 2016, p. 531). Consequently, most arguments supporting an expansion of medical decision-making rights focus on the rights of minor children during the period of adolescence due to the minor’s presumed advanced cognitive development compared with that of a younger child.

With considerations of decisional capacity and arguments for medical decision-making often focusing on the minor’s age as it is represented in legislation, however, another important influence contributing to this discussion is Piaget’s theory of child development, which shaped “[e]arly bioethical, legal, and psychosocial literature on children’s ability to consent to treatment” (Ruhe et al 2016, p. 517). According to Piaget, “children go through a series of discrete, invariable, and universal cognitive stages. Each stage is marked by several qualitative changes in children’s thinking and reasoning” (Ibid). Moreover, Piaget’s theory “closely linked these stages to age and argued that at fourteen children usually have the same information processing abilities as adults” (Ibid). As such, Piaget’s theory of child development, and his argument concerning the information processing abilities of fourteen-year-olds, both support the acceptance of the decisional capacity of

adolescents in medical settings, and line up with court decisions like Tennessee's "rule of sevens".

Yet there are critics of Piaget's theory who support expanding medical decision-making rights for minors and who argue that decisional capacity doesn't in fact appear at a set age, but rather is "something that develops through communication, explanation, and interaction with others" (Ibid). For some, Lev Vygotsky's "Zone of Proximal Development" presents a better model for understanding how decisional capacity develops in children and how it should be assessed. In Vygotsky's theory, "all higher cognitive functions (e.g., thinking, memory, consciousness) have their origin in social cooperation and are generated by an initial exchange between the child and adults or peers" (Ruhe et al 2016, p. 518). Therefore, unlike Piaget's theory, which posits that decisional capacity in children coincides with age and stages of development, Vygotsky's Zone of Proximal Development theory roots itself in context, the social environment, and the constant engendering of potential for children to learn and improve upon their decision-making skills.

In order to effectively utilize Vygotsky's theory, the focused effort of family, friends, and medical providers is required to assist in the development of the minor patient's decisional capacity. For this to be actualized, Vygotsky recommends using guided participation techniques, various social cues concerning thoughtful reasoning, and the creation of an open and supportive environment by the adults. When practiced consistently, these efforts should lead to a full participation on the part of the minor. By using this method, the minor's decisional capacity "is seen as originating from and being shaped by social interactions...It is no longer the child's

responsibility to “perform” her capacity but that of the adults to create an environment that allows her to exercise and learn to make decisions” (Ruhe et al 2016, p. 522). As such, Vygotsky’s theory is “more concerned with what children are able to achieve in collaboration than with what they are capable of doing alone” (Ruhe et al 2016, p. 518). Furthermore, according to the framework of Vygotsky’s theory, adolescents as well as younger minor children could be assisted in developing their decisional capacity provided that collaborative communication and competent facilitators are in place.

However, in order for Vygotsky’s theory to achieve its postulated outcome of enhanced collaborative agreement between children and adults, it would need to be implemented early in the minor patient’s life or illness, and be the ongoing accepted protocol by all involved parties. Thus, while Vygotsky’s theory presents a gradual method for developing decisional capacity that may limit or negate future conflict in medical decision-making situations involving minors, it is not necessarily applicable where conflict is already present.

Beyond arguments based on age, cognitive development, and decisional capacity assessments, however, there are still others who assert that minors’ basic human rights obligate society as well as medical providers to respect the minor patient’s agency and personal autonomy. These arguments reason, as Jennifer Baker states in her article “Children’s Agency, Interests, and Medical Consent”, that while “we take the difference between childhood and adulthood to be self-evident...if we look to practice, we see very little to support that idea” (Baker 2013, p. 311). Moreover according to Baker, although children may not “have the ability to think of “their

lives as a whole”...they are also unlike the merely sentient” (Baker 2013, p. 320). “Standardly developing young children have “a capacity for self-awareness and an ability to plan for the future and have meaningful relationships with others”” (Baker 2013, p. 316). Thus, according to the argument made by Baker, although minor children may not always possess the same level of reasoning that an adult has, it does not mean that their opinions should be overlooked or excluded from participating in the direction of their care.

Support for Baker’s argument concerning children’s agency in medical settings can be found in international legislation such as the U.N. Convention on the Rights of the Child (UNCRC), which emphasizes among other things, children’s “freedom of expression” (Attiah, 2014). To date, the UNCRC stands as “one of the most ratified treaties in the world” although it is notable that the U.S. has not ratified the 1989 treaty, which according to Michael P. Farris of the group “ParentalRights.com” is due to the fact that “[o]ur constitutional system gives the exclusive authority for the creation of law and policy on issues about family and children to state governments” (Ibid). Farris’s group, however, has been opposed to U.S. ratification because of what it sees as “dangerous U.N. conventions that threaten parental rights” (Ibid). Farris’s group’s standpoint, which views the UNCRC as a threat to parental rights, is not one that many other countries around the world have shared. As it stands, the U.S. is only one of three countries internationally that have chosen not to ratify the UNCRC protections.

With regard to the expansion of medical decision-making rights to terminally ill minors in order to allow them the right to choose medical aid in dying (MAID), the

issue remains much more controversial. While the Netherlands and Belgium have both extended the right to actively and voluntarily end life to minor children age 12 and older, they are currently the only countries to do so. However, there is growing international support for terminally ill minor children, especially those who have reached adolescence, to be granted the option to refuse treatment or receive MAID. In the U.S., law professor Susan E. Zinner, from the School of Public and Environmental Affairs at Indiana University Northwest, recently argued that “children should get involved in the decision-making process much earlier than we allow them to...Minors have the right to create their own directives letting their providers and parents know what their wishes are at the end of their lives” (Harris 2009, p. 32). In addition, according to Zinner, “As children get to 11 or 12, and especially when they’re in their teens, there should be a presumption that they should carry the greater weight when balancing the interests of the parents, child, and provider” (Ibid). Thus, with these assertions Zinner not only validates the decisional capacity of adolescents, she also makes the same age distinction that Belgium and the Netherlands have, which is to allow adolescents age 12 and older to make their own end-of-life determinations.

Furthermore, as author Neelam Chhikara states in her article, “Extending the Practice of Physician-Assisted Suicide to Competent Minors”: “Children under the age of eighteen should not be deprived of the same level of patient autonomy afforded to adults simply based on their age. Age is merely a factor to consider in deciding whether a patient may give consent to a medical procedure” (Chhikara 2017, p. 441). With this being noted, Chhikara’s argument highlights another

important aspect of this issue that stems from the recognition of one's basic human rights. From this angle, minor children are considered persons with agency and important opinions, regardless of the amount of life they have lived or their ability to demonstrate decisional capacity. As such, Chhikara's argument echoes the sentiment put forward in the UNCRC, which emphasizes children's right to participation, rather than focusing on how decisional capacity may correspond with a specific age requirement.

Therefore, while the arguments supporting the expansion of medical decision-making rights to minors substantively differ, the conclusion that advocates of expansion reach is the same, which is that minor children fundamentally deserve a voice in the direction of their medical treatment and care. In addition, many involved in this debate increasingly feel that the right of minors to make medical decisions includes the right to refuse life-sustaining medical treatment(s) (LMST) in order to end life, when their suffering from an incurable terminal illness becomes too burdensome.

## **Arguments Against the Expansion of Medical Decision-Making Rights**

Yet, disagreement concerning the expansion of medical decision-making rights to minors can also be found from various standpoints. According to Brian Partridge, who has written extensively on this topic, "Adolescents and younger children are different from adults in having faulty perceptions of risk, inadequate capacities to gauge the long-term outcomes of their decisions, and more limited control of their

impulses” (Partridge 2014, p. 300). Furthermore, Partridge maintains, “These disparities in decision-making have been shown to reflect differences in the neurophysiological character of the adolescent brain” (Ibid). Thus for Partridge, the argument against expanding medical decision-making rights to minors centers on physical maturation and its purported relationship to decisional capacity.

Citing data from several sources, Partridge argues that adolescents are typically not capable of the adequate risk assessment necessary for medical decision-making due to “lower activation of regions of the brain critical to the executive dimensions of decision-making” (Partridge 2014, p. 302). Consequently, he concludes, that parents or guardians should occupy the primary role in medical decision-making for adolescent children, as “the brains of adolescents are generally different from the brains of adults” (Partridge 2014, p. 304).

In addition, Partridge notes, “studies have shown a desire on the part of most adolescents for parental involvement...parents are recognized as the best authorities regarding the best interests of their adolescents, as well as regarding their adolescents’ capacity to make particular decisions in particular circumstances” (Partridge 2014, pp. 305-306). Yet it could be argued that Partridge simultaneously contradicts his position as well as the data that he bases his argument on, as he also recognizes the value of collaborative decision-making with adolescents. In the same article, according to Partridge, adolescents should be viewed as “apprentice decision makers who should make decisions in collaboration with their parents until at least the age of 18” (Partridge 2014, p. 299). Thus, while Partridge repeatedly asserts that adolescents are not physically capable of medical decision-making, and that their

parents or guardians should have the overall authority when making medical decisions, he also considers adolescents decisionally capable of collaboration and of having some measure of meaningful input in the direction of their care.

In another article Partridge authored in 2013, he clarifies his position concerning adolescent decisional capacity with regard to the application of the mature minor doctrine. In “The Decisional Capacity of the Adolescent: An Introduction to a Critical Reconsideration of the Doctrine of the Mature Minor” Partridge analyzes, elaborates on, and concurs with the arguments put forward by Evan Williams, Valerie Reyna, Laurence Steinberg, Rachel Barina, Jeffrey Bishop, Mark Cherry, and Ana Iltis, who each find that substantial qualitative differences exist between an adolescent’s decisional capacity and the decisional capacity of an adult. In doing so, Partridge points out the “seemingly contrary view of the decisional capacity of minors developed in American criminal law” which according to Partridge conflicts with the notion that adolescents possess the appropriate level of decisional capacity needed for important medical decision-making (Partridge 2013, p. 249). In his argument Partridge considers the general rule whereby “courts have accepted the view that the decisional capacity of adolescents is not fully developed and that as a consequence adolescents cannot have the same degree of criminal culpability as adults” (Ibid). Incidentally, however, Partridge fails to mention that courts do in fact frequently make exceptions to this view and that in certain cases adolescents are considered to have the same criminal culpability as adults. Despite this omission, however, in the conclusion of the article, Partridge acknowledges exceptions to what he sees as a general lack of decisional capacity in most adolescents. In doing so

he writes, “judgments regarding the decisional capacity of an adolescent will depend on the particular adolescent and the particular context...persons do not take a uniform journey from infancy to mature adulthood. Some persons become mature decisionmakers much earlier than others, while others appear never fully to achieve this status” (Partridge 2013, pp. 253-254).

Other critics of expanding medical decision-making rights to adolescents, like Lainie Friedman Ross, however, place less value on respecting minors’ opinions in a collaborative decision-making process. Ross argues that while efforts should be undertaken to guide a child toward a consensual agreement in medical settings, “the child’s preferences for or against treatment are nonbinding...the adolescent’s current autonomy can be overridden to promote his long-term autonomy” (Ross 2009, p. 310). The basis for this viewpoint, according to Ross, is that an “adolescent’s relative lack of worldly experience “distorts his capacity for sound judgment”” (Ibid). Thus, Ross’s argument differs from Partridge’s in that she asserts that adolescents have not yet had enough life experience to provide the appropriate foundation for making medical decisions, whereas Partridge focuses primarily on neural development and its relationship to decisional capacity.

Moreover, Ross finds her conclusion regarding the lack of life experience to be an especially crucial factor when considering the decisional capacity of terminally ill minors. However, it is notable that Ross does not consider the actual lived experience of terminally ill minors to be adequate for making medical decisions, despite the fact that living with a terminal illness routinely involves an extensive knowledge of one’s disease, as well as the protocols, and potential health related

outcomes. In fact, according to research conducted in 2007, “There is evidence that even young children with chronic illness can possess high degrees of understanding and sufficient appreciation about their condition...which the children gain through the experience of their chronic illness”(Jeremic et al 2016, p. 529).

The basis for Ross’s argument against the expansion of MAID rights to minors can be found in a decision-making model that she refers to as “constrained parental autonomy” which “presumes that parents should have the authority to make life-saving treatment decisions for their children” even when the minor child clearly expresses refusal (Ibid). With that being noted, however, Ross does allow for an exception in situations where an effective therapy does not exist. According to Ross, “if we were to consider the case of a life-threatening illness for which treatment is not highly effective (e.g., prognosis is <10% overall survival) or an illness for which only experimental treatment exists, then parental discretion and the adolescent’s dissent would have a more determinative role” (Ross 2009, p. 311).

Yet, for Christopher Kaczor, there are additional considerations regarding the expansion of medical decision-making rights to adolescents at the end of life apart from whether or not any treatment is deemed effective in curing the illness. In his article “Against euthanasia for children: a response to Bovens” Kaczor defends five arguments made and countered by Bovens, thus rejecting the extension of euthanasia to minors. The five arguments Kaczor offers against euthanasia are as follows: an *argument from weightiness*, which reasons that “we do not let minors vote, buy cigarettes or alcohol”, therefore “we should not let them make even more serious decisions, such as whether to live or die” (Kaczor 2016, p. 57); an *argument*

*from capability of discernment*, which asserts that “a minor seeking euthanasia is incapable of giving informed consent because minors lack the capability of discernment” (Ibid); an *argument from pressure*, which Kaczor contends could be surreptitiously applied by family and friends, who “may be seeking to alleviate their own emotional suffering” by encouraging euthanasia for the terminally ill minor (Ibid); an *argument from sensitivity*, which according to Kaczor may lead a minor to choose euthanasia in order “to satisfy what they rightly or wrongly view as the expectation of parents” who are suffering as a result of caring for their sick child (Ibid); an *argument from sufficient palliative care*, which reasons that “euthanasia is unnecessary for minors because the physical and mental sufferings that a minor may undergo at the end of life can be alleviated by palliative care” (Kaczor 2016, p. 58).

Kaczor’s analysis goes the furthest, however, with regard to his position stemming from the argument from sufficient palliative care. According to Kaczor, “The more people who choose euthanasia instead of palliative care, the smaller is the market for palliative care. Once there is a legal option for ending pain other than palliative care, the pressure from patients, families and doctors to improve palliative care is lessened” (Ibid). Thus, Kaczor interprets and presents a view of palliative care that acts in opposition to euthanasia, rather than viewing euthanasia as an option that may be included with the provision of sufficient palliative care at the point when patients find that their suffering has become too burdensome.

### **Divergent Attitudes Leading to Different Approaches**

Furthermore, it is important to note that Kaczor’s predictive argument regarding

a reduction in palliative care utilization has not come to fruition in the Netherlands, where active euthanasia has been available since 2002 for minors age 12 and older (Brouwer et al 2013, p. 376). Yet, even prior to the passage of the 2002 legislation, which legalized voluntary active euthanasia, Dutch attitudes toward end of life care regarded withdrawing or withholding treatment, “as being a part of a normal medical procedure” with physicians “not obliged to make an official report” (Brouwer et al 2018, p. 378). In fact, the withdrawal or withholding of life sustaining medical treatment has long been viewed as morally acceptable and legally permissible in the Netherlands, including for terminally ill minors. While in America, withdrawing or withholding treatment still remains controversial, especially in cases involving minors. As such, the Dutch approach to end-of-life care has differed from the American approach for quite some time, primarily because in “the Netherlands it is generally accepted that not everything that can be done, should be done” (Brouwer et al 2018, p. 380).

With the passage of the 2002 Euthanasia Act, however, the approach in the Netherlands differentiated itself further, as “the Dutch guidelines introduce a close relationship between palliative care and dying” by “stating that palliative care is not just about quality of living but about quality of dying as well” (Brouwer et al 2018, 379). Within this framework, the Euthanasia Act therefore considers voluntary active euthanasia, which involves the intentional ending of life through either physician administered drugs or the ingestion of physician provided drugs, as being an option that should also be available for terminally ill minors in order for them to end suffering and experience a dignified death. Specifically, “The guidelines see

palliative care and death as part of the same continuum: death is seen as an integral part of having a life-limiting illness” (Ibid). From this position, and contrary to Kaczor’s argument, “active ending of life is not –as some authors suggest- an alternative to palliative care, but rather its final chapter” (Brouwer et al 2018, p. 383).

Moreover, it could be argued that the expanded approaches to MAID for terminally ill minors taken in the Netherlands, and in Belgium, which is the only other country currently permitting minors to choose voluntary active euthanasia, at least partially stem from the principles of participation that are espoused in the UNCRC. As previously noted, however, the United States has not ratified this document. Consequently, due to the political structure in the U.S., and the predominant attitude concerning minor children’s lack of decisional capacity, terminally ill minors who would otherwise choose to actively end their lives are often forced to endure a protracted and painful dying process rather than being given the option to alleviate the burden of their pain and suffering with medical assistance.

For terminally ill minors like “Sara” a fictional character used by Neelam Chhikara “whose experience as a terminally ill minor mimics the real experience of a terminally ill minor” the age requirement for the receipt of MAID resulted in a series of tragic circumstances in her final days due to the fact that she was legally prohibited from receiving medical assistance to voluntarily end her life (Chhikara 2017, p. 13). At sixteen, “Sara” was diagnosed with a malignant brain tumor and given four months to live. The details of “Sara’s” case speak to the inconsistency

found in the Death with Dignity Act in Oregon (where Sara lived), as well as in the other U.S. states that permit physician-assisted death for adults over the age of eighteen. “Sara” “had a 3.8 grade point average...worked twenty hours a week...took care of her two younger siblings by cooking dinner and helping with their homework...had a driver’s license and bought herself a used car” (Chhikara 2017, p. 431). Yet, while “Sara” exhibited an adult level of maturity and a comprehensive understanding of her condition “[s]he was not awarded the decision of legally limiting the duration and extent of her pain through physician-assisted suicide, whereas someone who is just as competent as Sara, or even less competent, but a little older, may pursue this option” (Ibid).

In fact, if Sara had been just a year and a month older when she sought the ability to end her life, she would have been granted her request to receive a physician’s assistance in doing so, but instead the last “four months of Sara’s life were filled with depression and anxiety...she lost her motor skills, leaving her unable to speak. Then, she lost her language-recognition abilities and could no longer express herself...after four months of mood swings, painful headaches, and seizures, Sara passed away” (Ibid).

Unfortunately for the character of “Sara”, and in similar cases involving mature minors, there is no current protocol or pending legislation within the U.S. to address the asymmetrical perspective regarding the option to receive a physician’s assistance in dying when a terminal illness is present. However, with an acceptance of physician-assisted death growing internationally, many feel that in cases involving mature adolescents, if “terminally ill adults are awarded the option of

ending their life as an effort to preserve their quality of life, then minors should also be awarded the choice to circumvent the mental and physical anguish” (Chhikara 2017, p. 431).

Yet, as Chhikara importantly notes, “In order for minors to participate in physician-assisted suicide, they must be deemed legally competent to give consent for the treatment” (Chhikara 2017, 442). Notably, however, while “the legal issues of when and under what circumstances minors can refuse or consent to medical treatment remain unresolved, it is also significant that lawyers and judges increasingly assume that the mature minor must be treated differently by physicians and the courts” (Derish et al 2000, pp. 113-114). Thus, until a clear and standardized protocol is established concerning whether or not minors can adequately possess the capacity for medical decision-making, vastly disparate options will continue to persist in the medical treatment of those under the legal age of majority, both at the end-of-life and in non-life threatening situations as well.

In the next and final chapter of my thesis, I consider the issue of medical self-determination rights for minors further through additional analysis of international data, as well as examinations of current trends in medical care. I also offer potential solutions to ease or avoid conflict between the various stakeholders and make my own perspective clear after the conclusion of my research.

## **Chapter Three**

# **A Review of the Data, a Comparison of Methods for Reaching Consensus and Resolving Conflicts in Medical Decision-Making with Minor Children, and an Analysis of the Current Trends**

According to the 2016 article “Participation of Children in Medical Decision-Making: Challenges and Potential Solutions” “Research has shown that allowing children to participate in decision-making regarding their clinical care is beneficial in a number of ways. It may help them develop competence, confidence, and responsibility, leading to greater participation in society later in life” (Jeremic et al 2016, p. 527). Furthermore, according to recent data cited by the international team of researchers who collaborated on the article, “Several qualitative studies assessing children’s views and attitudes on participation show that they usually want to be consulted and included in making decisions about their treatment” along with the added benefit that, “Participating in medical decision-making can instill children with a sense of control, which results in better adjustment to treatment” (Ibid).

One of the sources providing the foundation for the researchers’ assertions is a study that was conducted in 2011, in twenty-two European states. In the study, 2,275 children were surveyed and reported that being involved in their medical decision-making helped them to “better understand the illness and to prepare themselves for procedures. They felt happier, more reassured and valued when they

were consulted, had the opportunity to ask questions, and felt their wishes were being heard” (Jeremic et al 2016, p. 528).

Yet, as previously noted, divergent opinions regarding the inclusion of adolescents and minor children in medical decision-making continue to present barriers to those minors who wish to participate in or self-determine the direction of their medical care. In fact, in one 2007 study of children “who were admitted for planned medical interventions, 30 percent indicated they were not adequately informed about the procedure and 61 percent did not have a chance to participate in decision-making” (Jeremic et al 2016, p. 527). In a different 2007 study, the same researchers found that 65 percent of children “had passive roles in consultations” (Ibid). Moreover, while it is important that these studies relay data which show that it is a common occurrence for children to be excluded from discussions related to their medical care, it also is notable that the participation of children in medical decision-making has long been encouraged by international legislation such as the UNCRC, in guidelines issued from the AAP, in various approaches such as Vygotsky’s Zone of Proximal Development, and in decades old analyses of developmental psychology literature such as the research conducted by Thomas Grisso and Linda Vierling, who concluded that “minors are entitled to have some form of consent or dissent regarding the things that happen to them in the name of assessment, treatment, or other professional activities” (Weir and Peters 1997, p. 31).

Furthermore, according to research conducted in 2006 and in 2011, evidence suggests that not including minor children in the discussions concerning the direction of their medical care may actually have adverse effects on their mental and

physical health. Using data collected through interviews with hospitalized children, research has revealed that “although many children state that they get accustomed to not being consulted, they still experience feelings of anger and distress when they are ignored by health professionals, particularly in difficult situations (Coyne 2006). Lack of involvement can also lead to increased fear, anxiety, feeling unprepared for procedures, and reduced self esteem (Coyne and Gallagher 2011)” (Jeremic et al 2016, p. 527). Thus, considering the potential benefits of increased participation and the detriments of exclusion, advocates of expanding medical decision-making rights for minors have begun asking, aside from changing legislation, “What can be done in clinical settings to enhance the decisionmaking of adolescents, and to increase the chances that their decisions will be carried out?” (Weir and Peters 1997, p. 31).

## **Methods for Increasing Child and Adolescent Participation in Medical Decision-Making**

Although the debate continues over what degree of inclusion minors should receive in medical decision-making, some pediatric health care providers have already begun utilizing various tools to clarify and practically implement a shared decision-making process that gradually facilitates the development of independent decision-making of their minor patients. The goal of these decision-making tools, which are called patient decision aids, is to both assist in the minor patient’s understanding of the potential outcomes related to the proposed treatment(s), and to also respect the minor patient’s opinions in the direction of their care.

Designs for pediatric patient decision aids may vary according to the patient’s

age, treatment protocol, and delivery format, and range from a decision aid that primarily consists of pictures on a paper pamphlet, to a pamphlet that includes a list of questions for the patient to answer, to a short video for the patient to view.

However, regardless of the specific design, every patient decision aid includes three important features. “Firstly, they provide further details of the healthcare decision, the options available, and the costs, benefits and uncertainties associated with these options. Secondly, they encourage patients to recognise their own values attached to these various options, risks, benefits, and uncertainties. Finally, they encourage the sharing of these values with the healthcare practitioner and others who may be involved in the decision-making process” (Hulin et al 2016, p. 345).

Yet, within the pediatric setting, while patient decision aids have been developed to enhance children’s understanding of treatment and to include them in the medical decisions that determine their care, the patient decision aids themselves are nonetheless largely employed collaboratively, with parents or guardians sharing in the deliberation process. For some, this model of shared decision-making represents the ideal method for realizing the minor patient’s participation in medical decision-making discussions; however, for others this particular aspect of the decision aid’s utilization has been deemed problematic. According to the authors of the 2015 article “Shared Decision Making in Pediatrics: A Systematic Review and Meta-analysis”, “Perhaps the most provocative and surprising finding of our review was that interventions rarely targeted patients (ie, children) but focused mainly on parents” (Wyatt et al 2015, p. 577). Moreover, the “interventions reviewed generally did not attempt to empower children with a voice, with only 7% of the interventions

targeting the pediatric patient alone and 19% targeting the pediatric patient with another party...children were not directly targeted in many decisions they could arguably be capable of participating in” (Wyatt et al 2015, p. 579). Thus, the authors conclude that pediatric patient decision aids are often not as effective in clarifying or developing decision-making skills for the pediatric patient, although they may suggest otherwise. Consequently, the authors propose the development of separate decision aid components for the minor patient and the parent or guardian, which would give each party the opportunity to independently consider options and outcomes, but would still work together collaboratively in the final decision-making process. In the conclusion of their research, the authors therefore acknowledge that although limited evidence suggests that the shared decision-making model most pediatric patient decision aids use may “improve parent knowledge and decisional conflict, further studies are needed to advance the science” (Wyatt et al, p. 580).

Despite the criticism concerning parent and guardian involvement in the use of pediatric decision aids, however, it is important to recognize that the input of parents and guardians is included and often required, not only as the standard in traditional health care settings, but also in very progressive environments such in Belgium and the Netherlands where adolescents and minor children are given the most expanded role in the direction of their end-of-life medical treatment and care. Considering this fact, it is therefore critical to understand how the input of parents and guardians may be affected under the difficult conditions that are inherent to caring for a sick child.

According to the AAP Committee on Bioethics, “Informed Consent in Decision-

Making in Pediatric Practice”, “Parental distress presents a challenge for good informed decision-making. Parents who receive new diagnoses of cancer or other life-threatening illnesses in their children report burdensome emotional and psychological stress that can interfere with decision-making” (Katz et al 2016, p. e5). Thus, while this finding does not question parents and guardians playing a collaborative role in the deliberation of medical decisions for their minor children, the committee conclude: “Parental decision-making should primarily be understood as parents’ responsibility to support the interests of their child and to preserve family relationships, rather than being focused on their rights to express their own autonomous choices” (Ibid). Furthermore, the researchers submit that a contextual reframing of parental and guardian expectations is necessary in order to achieve a new understanding of this role, and to facilitate this reframing, the researchers emphasize the importance of the role of the medical providers. In the conclusion of their argument the researchers of the article maintain: “By moving the conversation from parental rights toward parental responsibility, clinicians may help families minimize conflicts encountered in the course of difficult medical decision-making” (Ibid).

With regard to how parents and guardians may best demonstrate their responsibility through supporting their child’s end of life wishes, one group of researchers assert that “a multidisciplinary approach to improving the capacity of children to express their values constitutes one potential advance” (Barfield et al 2010, p. 29). In the article “Mind the Child: Using Interactive Technology to Improve Child Involvement in Decision Making About Life-Limiting Illness” the researchers

detail the results of a survey that was conducted of health care workers at a children's hospital in order to document opinions surrounding the inclusion of minor children in medical decision-making near the end-of-life. The results of the survey revealed "a disconnection between when children wish to be involved in decision making and when they actually are involved in decision making" (Ibid). In addition: "While 72.2% of respondents said that children begin voicing their opinions about a major treatment decision at age 9 years or younger, when asked about when parents typically start considering a child's opinion before a major treatment decision, only 29.3% said that this occurs at age 9 or younger" (Ibid). It is important, however, to recognize that children at age 9 or younger are rarely considered decisionally capable of making medical determinations, as noted in legislation such as Tennessee's "Rule of Sevens", in Piaget's Theory of Child Development, or in the minimum age requirements of 12 years or older for the receipt of MAID in Belgium and the Netherlands. With this in mind, the researchers therefore recommend the development of a flexible method to solicit the minor patient's participation regardless of specific age.

For implementation of the minor child's participation, the researchers suggest the following: "Interactive media-based decision-making aids and qualitative, child focused data collection could be used to create a tool aimed at enhancing a child's ability to prioritize and express goals...Such tools might be used as part of a larger process to explore the ability of children to express their ideas, goals, priorities, and desires, related to quality-of-life planning near the end of life" (Ibid). In addition, the computer and video game format would utilize developmentally appropriate

information, consisting of “different graphical themes (both realistic, as with sports motifs, and abstract, as with geometric patterns)” in addition to presenting ideas and concepts that asked children “open-ended questions about their preferences” (Barfield et al 2010, p. 30). As such, with the establishment of this approach, the researchers consider even very young minor children capable of being included in medical decision-making at the end-of-life. Consequently, they maintain that “it is our ethical imperative to search for methods to incorporate children’s preferences into the decision-making process near the end of life...there is no one appropriate time or correct age for children to begin to play a role in decision making about medical treatment” (Barfield et al 2010, p. 29).

Júlia Martín Badia shares the notion that children of any age may play an important role in medical decision-making in her 2015 paper, “Minor Patients’ Autonomy. Recognizing The Dignity To Create Capabilities”. According to Badia, “autonomy has to be understood not as a state, but as a process that needs support” (Badia 2015, p. 53). The argument Badia makes, which echoes the underlying principle found in Vygotsky’s Zone of Proximal Development theory, asserts that minor children can be supported in acquiring decisional capacity through increased participation in medical decisions over time, instead of viewing decisional capacity as something that appears at a set age. Badia, draws upon the work of Amartya Sen and Martha Nussbaum, which follows that “everybody has different needs and different abilities to transform their capabilities into results” and thus asks, “what each person is capable to do...and to help him/her to acquire those capabilities that he/she lacks” (Badia 2015, p. 60). This approach, referred to as the “capabilities

approach” by Nussbaum, focuses on achieving equal opportunities through recognizing a minimum threshold of capability, in order to assist the individual in achieving a maximum threshold of capability. The foundation for Badia’s argument stems from her proposal that “support should be based on recognizing minors as vulnerable persons, that is to say, as persons with emotional needs, who are the subjects of rights and duties, and who have social needs of self-fulfillment” (Badia 2015, p. 53). Furthermore, Badia argues that the “most important step is to create a sphere of recognition, which should have several characteristics: it should be based on mutual confidence; the caregiver has to avoid both paternalism and placing adult responsibilities on minors; he/she has to assist minors’ vulnerability not as a weakness, but as a chance for their empowerment...he/she has to synchronize his/her professional time with the minors’ experiential time; he/she has to listen to the minors’ account of their problem” and “he/she has to assist minors’ needs and detect any lack of family recognition” (Badia 2015, pp. 63-64). Doing so, Badia concludes, “leads to a supported decision-making process based on an attentive listening” (Badia 2015, p. 64).

It is important to recognize that the process that Badia advocates is already in place within the construct of many therapeutic interventions for minors, which aim to reduce stress and alleviate anxiety in medical settings. In using attentive listening techniques and soliciting participation from minor patients, health care professionals often allow minor children to express their wishes, opinions, fears, and goals for treatment during psychological counseling and various other interventions such as art therapy. One example of this can be found in the work of

Martha Driessnack, who began making masks with pediatric oncology patients when she was a young nurse in the late 1970's. According to Driessnack, whose work does not explicitly result in determining medical decisions for minor patients, one of the benefits of the therapy that she provides, however, is that it does offer "children an opportunity to gain some control over their environment and thus heal themselves, even in the worst of circumstances" (Driessnack 2004, p. 211). For Driessnack, the process of mask making with chronically and terminally ill children, which she refers to as *making special*, allows us to learn who children "are and stand more ready to advocate for and empower them as they and their families transition through the stages of their living and their dying" (Driessnack 2004, p. 213). Thus, the approach that Driessnack takes is similar to what Badia asserts, in that she recognizes minor children as vulnerable persons who may be empowered through a therapeutic intervention in order "to gain some control over what otherwise is an overwhelming environment and circumstance" (Driessnack 2004, p. 211). Furthermore, Driessnack sees mask making as a "method that can help even the youngest of children to heal themselves", which speaks to an acceptance of young children as capable of fundamentally understanding their condition. Considering this, it is not unreasonable to suggest that art therapies such as Driessnack's may also be useful in ascertaining minor patients opinions regarding the direction of their medical treatment, especially when used in conjunction with the previously mentioned patient decision aids and multidisciplinary interactive technologies.

### **An Analysis of Current Trends**

According to the argument presented by Aviva Katz and Sally Webb in 2016,

“Pediatric health care providers have legal and ethical duties to provide a standard of care that meets the pediatric patient’s needs and not necessarily what the parents desire or request” (Katz et al 2016, p. e7).

From the 2013 perspective of Jennifer Baker, in the debate over whether or not a minor patient has the capacity to provide informed consent in medical settings, “Parental rights have occupied far more of our focus. Yet even when states proclaim parental rights must be as “unfettered” as possible, courts have determined that a child’s interests can trump parental rights” (Baker 2013, p. 313).

And, from an article written over two decades ago by Robert Weir and Charles Peters, “No longer are adolescents regarded as merely the recipients of paternalistic decisions made on their behalf by physicians and parents in health care settings. Over the past three decades physicians with adolescent patients, pediatric task forces, interdisciplinary national commissions, state and federal legislators, judges, and numerous adolescents and parents have expanded the boundaries of adolescent decisionmaking” (Weir et al 1997, p. 29).

Furthermore, with the passage of MAID rights for adolescents in the Netherlands and in Belgium, and as the authors of the 2018 article “Medical Assistance in Dying at a paediatric hospital” note, with pediatric MAID rights currently being debated in Canada, it is inarguable that the provision of medical care for minor children is trending toward the recognition that minor patients often have the decisional capacity to participate in, as well as to independently make important medical decisions, even at the end of life (DeMichelis et al 2019). Yet international legislation varies, and many questions persist regarding the rights of minor patients in medical

settings, as well as the assessment of their decisional capacity for medical decision-making.

Thus, in conclusion, I argue that there is an urgent need for more research concerning the best methods for recognizing the decisional capacity of those under the legal age of majority. In my opinion, it is clear that decisional capacity does not suddenly appear at any designated age, and as such, standardization is needed in the evaluation process of minors for decisional capacity although individual assessment is still required. Moreover, as it appears that this debate will probably lead to an expanded understanding of minor patients' decision-making rights in many locations, I further agree with those calling for the immediate development of national certification standards for patient decision aids, which were included as a provision in the 2010 Affordable Care Act, but have not been funded to date (Elwyn et al 2018, p. 703).

With an early implementation of methods to include children in medical decision-making, such as those suggested by Vygotsky's Zone of Proximal Development, and the use of targeted interventions like age appropriate patient decision aids to assist in the understanding of options and the expression of goals, much of the conflict involving minor patients and the delivery of their medical care may be avoided or greatly eased.

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## Education

*Wake Forest University Graduate School of the Arts, Winston Salem, NC*

*Major: Bioethics, GPA 4.0*

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- Awarded a 35% scholarship upon entry
- Completed an independent study on organ regeneration and transplantation, Summer 2017
- Awarded additional Thesis scholarship during the Fall 2018 semester
- Concentration: End of life
- Relevant Coursework: Law and Medicine, Justice, Research Ethics, Observation of Wake Forest Baptist Medical Center IRB, Health Communication, End of life Decision Making, Independent Studies completed on Uterine Transplantation and Regeneration, and a Performable Case Study

*University of North Carolina Asheville, Asheville, NC*

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## Research and Presentations

*Graduate Research, "Adolescent Decisional Capacity and Medical Decision-Making" August 2018-May 2019*

- Researched and analyzed bioethical arguments, international legislation, and statistical and qualitative data related to adolescent decisional capacity in medical settings
- Presented Thesis research at 525@Vine Street/Wake Forest University Downtown, March 2019

*Undergraduate Research, "Racial Disparities in Hospice Utilization within the United States." September 2015-November 2015*

- Researched and analyzed statistical and qualitative data related to hospice

utilization rates within the United States

- Conducted interviews with hospice care educators and a faith-based leader in Asheville, NC
- Presented at University of North Carolina Asheville Research Symposium, November 2015

## **Employment Experience**

*Senior Care*

*In Home and Community Support Caregiver* December 2018-present

- Provides daily in home care and support for a senior with cardiac disease.
- Duties include personal care, light housekeeping, meal preparation, companionship, and transport for medical appointments and personal errands, medication administration and financial oversight

*In Home and Community Support Caregiver* April 2008-April 2014

- Provided daily in home care and support for a senior with dementia and various other health challenges.
- Duties included personal care, light housekeeping, meal preparation, companionship, and transport for medical appointments and personal errands, medication administration and financial oversight

*Crisis Behavior Technician, CNC Access, Asheville, NC* August 1999-October 2005

- Provided community and home based peer support for individuals with developmental disabilities, mental illness, and/or substance abuse issues
- Identified strategies to encourage and successfully meet each individual's behavioral, financial, educational, and personal care goals
- Promoted increased community involvement, wellness, and appropriate social interaction through behavioral modeling and the organization of daily activities
- Worked closely with families to reduce interpersonal tensions and improve healthy communication skills

*Children's Department Head, Books-A-Million, Asheville, NC* November 1998-August 1999

- Organized shipment orders and designed merchandise displays
- Assisted customers by answering questions and locating desired materials
- Operated cash register, cleaned store, and restocked merchandise to ensure a high quality shopping experience for the customer

## **Community Service Experience**

*Community Activist/Social Justice Advocate, Asheville, NC* February 2010-Present

- Organized and assisted with numerous community events and fundraisers to raise awareness for issues such as access to clean water, racial and gender equality, immigration, and living wage certification

*Asheville Buncombe Youth Soccer Association, Asheville, NC* March 2013-May 2013

- Served as a volunteer head coach in the coed youth soccer league. Worked to develop team growth, athleticism, and individual character building skills