

THE EXPERIENCES OF ADOLESCENTS CONSENTING TO PSYCHIATRIC MENTAL
HEALTH TREATMENT

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ABSTRACT

ANTHONY JAMES ROBERSON: The Experiences of Adolescents Consenting to
Psychiatric Mental Health Treatment
(Under the direction of Diane K. Kjervik)

Minor consent laws have been enacted without demonstrated and clear understanding of what influences the adolescent to decide to consent to psychiatric mental health treatment in real life situations. Further, minor consent laws are being expanded without understanding their therapeutic and anti-therapeutic effects on treatment outcomes. The purposes of this study were to (a) explore the decision-making process of adolescents who consent to psychiatric mental health treatment in real life situations, and (b) explore the experiences of parents whose adolescent consents to psychiatric mental health treatment.

A four step decision-making model, Therapeutic Jurisprudence, and the Vygotskian concept, *scaffolding*, served as the synthesizing framework for this study. Using a qualitative descriptive method and the four step decision-making model as a guide, adolescents were interviewed about their processes in deciding about outpatient psychiatric mental health treatment. Sixteen adolescents and thirteen parents/legal guardians participated in this study. Adolescent participants ranged in age from 12 to 17 years. At the time of the study, each adolescent was receiving outpatient psychiatric mental health treatment, which included medication, psychotherapy, or a combination of these two interventions. Adolescents and parents were interviewed about their decisions made about initial and continued treatment. Adolescents and parents were also asked their understanding of the current minor consent

laws. Interviews were audio-recorded, and transcripts were analyzed through concept analysis using Atlas/ti® software. Findings were presented in the context of the decision-making steps and research questions, and discussed in terms of the Therapeutic Jurisprudence model and the Vygotskian concept, *scaffolding*.

Most adolescents did not recognize consequences related to psychiatric mental health treatment and did not assimilate and integrate information provided to them about treatment choices. Adolescents and parents disagreed with current minor consent laws that allow minors to consent to certain healthcare treatments without the required consent of the parent. Further, adolescents and parents reported that a collaborative approach in making decisions about the adolescent's psychiatric mental health treatment was most facilitative of achieving the goals of treatment.

DEDICATION

I dedicate my dissertation first to my **Lord and Savior, Jesus Christ**, and second to my **family and friends**. Life with you will always have meaning.

To my late father, **Louie Selwyn Roberson**, who I miss greatly and wish were here to share this exciting time with me. He always encouraged me to strive for excellence. His intelligence and wisdom were remarkable. Most importantly, he was a daddy who loved me dearly. Much of who I am today is because of this man.

To my mother, **Joyce Elaine Roberson**, your faith in God inspired me to persevere when it seemed I could no longer endure. There are countless reasons why you are the best mother anyone could ever hope for. I am most thankful for your unshakable, Christian faith and the loving home that you and daddy provided me. It is because of your support, and the belief that you two have always had in me, that I have thrived and succeeded in life beyond my wildest dreams.

To my two very best friends in this world, **Timothy Charles Bickley**, and **Dr. Patricia Flannery Pearce**. Tim, your friendship and belief in me has meant more than I can ever express. Your calm demeanor in times of upheaval has truly kept me grounded. I am grateful for your never-ending faith in my abilities to complete this program. Trisha, you are my honorary dissertation ‘chair’. You advocated for me, guided me, but most importantly, believed in me when I thought all those around me did not. Tim and Trisha, your love and support are the reasons I was able to complete this program. **Thank you** from the bottom of my heart and from the depths of my soul.

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Finally, to all the children and adolescents who are inflicted with a psychiatric mental health illness, the terrible suffering and pain you experience on a daily basis is heart- breaking. I dedicate the remainder of my life as a researcher, clinician, and educator to making your lives better.

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To my loyal, always fun, and supportive friends, **Drs. Vivian and Dave West, and Kopriva and Sean Marshall**, words cannot express how much you mean to me. Your steadfast friendship has been overwhelming. Thank you for understanding when I could not go out and play, and thank you for encouraging me to play when I needed it the most. I hope we have many more fun, exciting times in the future!

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To my niece, **Lauren Nicole Roberson**, and nephew, **Louie Selwyn Roberson, III**, may the accomplishments of your uncle inspire you to excel in all of your academic endeavors. Education opens many doors of opportunities. In everything you do, strive for the very best.

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CHAPTER ONE

INTRODUCTION

Background

The informed consent rights of minors have been expanded in recent years (Ford & English, 2002). English and Kenney (2003) have provided a comprehensive monograph describing each state's minor consent laws related to healthcare treatments. Although these laws vary in the types of healthcare treatments the adolescent may consent to, most states allow minors to consent to certain medical procedures, such as emergency treatments, sexually transmitted disease testing, abortions, and mental health services, including outpatient and crisis intervention for mental health reasons, without the required consent of the parent or legal guardian (English & Kenney, 2003).

The informed consent process includes two main steps: (a) disclosure by the treating practitioner to the patient about information related to proposed treatment, and (b) the acceptance or rejection of recommended treatment by the patient (Beilder & Dickey, 2001; Scherer & Reppucci, 1988). Although practitioners consider a one time communication between the patient and themselves to be sufficient in meeting the technical and legal requirements of informed consent, the process does not end with the initial exchange between the practitioner and patient (Beilder & Dickey, 2001). The legal and ethical obligations and responsibilities related to the informed consent process continue throughout the treatment relationship.

Adolescents who agree to healthcare treatment must be included in the informed consent

process, especially if they are consenting to treatment without the consent of their parents.

The following are crucial elements that must be considered by the treating practitioner during the consent process: (a) the adolescent's competency level to receive the information provided by the practitioner, (b) the level of understanding of the information by the adolescent, (c) whether a decision by the adolescent about treatment is based on the actual information given by the practitioner, (d) and whether the acceptance, or rejection, of recommended treatment by the adolescent is made voluntarily (Beauchamp & Childress, 1994; Beidler & Dickey, 2001; Scherer & Reppucci, 1988; Wexler & Winick, 1992).

The exchange between those who support and those who oppose the expansion of consent rights for minors has been played out rather aggressively in the legal and empirical literature (Mulvey & Peebles, 1996; Scherer & Repucci, 1988; Weithorn & Campbell, 1982). The empirical support for expanded consent rights for minors has mainly been based on the comparison of competency levels between adults and adolescents. Evaluating competency levels of minors has been a priority in the informed consent literature since the early 1980s (Applebaum & Grisso, 1988; Appelbaum, Mirkin, & Bateman, 1981; Grisso, Appelbaum, Mulvey, & Fletcher, 1995). One group of researchers propose that there are no differences in the competency levels of adults and adolescents when it comes to consenting to certain treatments, such as abortions, acne treatments, and kidney transplants (Ambuel & Rappaport, 1992; Bastein & Adelman, 1984; Kaser-Boyd, Adelman, Taylor, & Nelson, 1986; Lewis, 1980; Scherer & Repucci, 1988; Weithorn & Campbell, 1982). The authors of these studies argue that because there is relatively no difference between adult and adolescent competency levels, the consent laws are too paternalistic and that these laws should be expanded for minors.

Opponents of expanding the consent rights for minors were rather quiet for years, but have recently become as vocal as the proponents of minor consent rights expansion (Scott, 1992; Scott, Repucci, & Woolard, 1995). Those who oppose expanding the consent rights for minors propose the deferment of these rights to the parents or legal guardian (Fundudis, 2003; Luce, 2003). Perhaps the strongest argument from those who oppose expanding minor consent rights is that legal restrictions for minors are in place for one reason: minors are immature in their judgment and decision-making skills (Fundudis, 2003). The stance taken by opponents of expanding minor consent rights is that the logical choice for who decides about whether their child should be consented for treatment lies with the parent, not with the child. Opponents purport that consent decisions should not be the result of a consensus between the parent and child, and that parents know what is best for their child when it comes to consenting to healthcare treatments (Walker, Booke, & Wrightsman, 1999). Some opponents of expanded minor informed consent rights contend that despite the minor's wishes, and perhaps despite whether the minor is competent to provide consent, the welfare of the minor is ultimately the responsibility of the parents or legal guardian (Fundudis, 2003).

Those who oppose expansion of minor consent rights solidify their argument with published critiques of studies that have evaluated and compared the competency levels of adolescents to that of adults (Fundudis, 2003; Mulvey & Peebles, 1996). The opponents of the expansion of minor consent rights claim that these studies evaluated competency levels of minors based on the minors' decisions made in hypothetical healthcare situations, not real life encounters. In addition, the hypothetical vignettes were situations that the minor would most likely never experience (Fundudis, 2003). The generalizability of the studies' results was ultimately in question. The generalizability of a study depends on a number of

parameters, most specifically sample size and power, randomization, control, and overall strong study internal validity (Polit & Beck, 2004), and none of these are represented in the strongly vignette-oriented research. Therefore, the question can be asked: if the competency of minors was measured in real life healthcare situations, and if the results indicated that expanding consent rights of minors would not be therapeutic, would the arguments of those who favor the expansion of informed consent rights of minors be as strong and vocal? The only way to answer this question is to provide the legal and healthcare literature with empirical studies that examine the consent process of minors in real life healthcare situations.

As a discipline, developmental psychology is concerned with closely examining the changes in physical, intellectual, emotional, and social aspects of a person over the life cycle (Steinberg & Schwartz, 2000). Developmental research psychologists have examined and evaluated adolescent development perhaps more than any other group of scientists. Development is defined as “systematic, age-related, universal, predictable, enduring, and adaptive, in the sense that development usually involves some sort of lasting improvement in competencies and capabilities” (Steinberg & Schwartz, 2000, p. 21).

Developmental psychologists generally agree that adolescence is comprised of three phases: early (10 to 13 years), middle (14 to 18 years), and late (17 to 20 years) (Kaplan & Saddock, 1998; Keating, 2004; Santrock, 2006). Adolescence is crucial in the overall development of a person, mainly because the developmental tasks that are achieved in this period of growth are unlike those of any previous or subsequent stage of development. Some of the more significant developmental tasks of adolescence include achieving mature relationships, forming a sex-role identity, contemplating marriage and family life, attempting

emotional independence from parents, and considering a career, which may include education and financial planning (Berger, 1994).

From physiological and cognitive perspectives, adolescence is uniquely different from all other stages of human development, and it can be argued that it is the most challenging of all developmental periods (Berger, 1994). The physical changes that occur during this developmental stage are perhaps more obvious than the cognitive changes. The adolescent experiences genital development, breast development, pubic and axillary hair development, skin changes, and at times rapid changes in height and weight (Berger, 1994). The physiological changes of development will be realized eventually for each adolescent. Further, physiological changes generally occur earlier in girls than boys.

The cognitive changes of adolescents occur with great diversity. “Many adolescents are as egocentric in some respects as preschool children, while others reach the stage of abstract thinking that characterizes advanced cognition” (Berger, 1994, p. 367). Adolescence is the period of development that the individual is usually attempting to break parental bonds, establish themselves in certain social groups, and develop a sense of self (Langer & Warheit, 1992). These changes in relationships with others can be better defined as the adolescent’s attempts to establish an identity and independence. The term ‘identity crisis’ is often used in describing an adolescent who is learning about self and trying to deal with the conflicts experienced during the developmental stages of childhood and adult. The conflicts experienced by adolescents can vary, but overall these are closely linked to their attempts to make sense and find meaning of their world. For example, adolescents seeking to establish an identity experiment with the various conflicting roles related to vocation, politics, sex, gender, and relationships, just to name a few (Santrock, 2006). Most adolescents are

successful in coping with these conflicts and proceed to the next stage of development.

However, some adolescents are not as successful and emerge from adolescence conflicted and confused.

In addition to establishing one's identity, the adolescent is also striving to become more independent. Adolescence is perhaps the phase of development in which the individual is making the most effort to seek independence and control over their lives, which includes the desire to start making more of their own decisions (Bjorklund, 2005; Santrock, 2006).

Parents play a crucial role in the adolescent's ability to establish independence. It is the shrewd parent who does not allow their adolescent to make all decisions independent of them (Santrock, 2006). In order for adolescents to learn how to make wise and well thought-out decisions, they must be instructed and guided by the parents at first. Otherwise, adolescents are more likely to make poor decisions that result in negative consequences. Once the adolescent becomes more competent in making decisions, the parents can safely relinquish control. Eventually the adolescent is making reasonable decisions without the guidance of the parents, resulting in the desired independence (Santrock, 2006).

A crucial part of adolescence is that the individual begins to make significant life decisions without direct input from the parent. Many of the independent decisions an adolescent makes are related to what friends to have, where to go on Friday night dates, what music to listen to, whether to use drugs or drink alcohol, whether to engage in sex, or perhaps what day to skip school with friends (Steinberg & Schwartz, 2000). These decisions require that the adolescent have the ability to think in abstract terms, especially when the adolescent is considering the consequences of the decisions (Bjorklund, 2005). Piaget defines the cognitive developmental stage of formal operational thinking as the phase in which

adolescents age 12 years and older can think about hypothetical concepts and are able to contemplate consequences related to decision choices (Berger, 1994). Part of the cognitive development of adolescents age 12 years and older includes the adolescent's increased ability to solve problems and "speculate about the possible as well as the real" more independent of others (Berger, 1994, pg 51).

One area of decision-making research that has recently been examined more closely is that of adolescents making independent decisions about their healthcare treatment (Ambuel & Rappaport, 1992; Bastein & Adelman, 1984; Kaser-Boyd, Adelman, Taylor, & Nelson, 1986). These researchers suggest that adolescents are capable of making complex healthcare decisions. However, adolescents have shown that they are more interested in having their developmental needs, such as independence and autonomy, met and at times may forgo the recommended treatment in order to meet these needs (LaGreca, 1990).

Research studies support that parents and peers influence the decision-making of adolescents in hypothetical healthcare situations (Emmerich, 1978; Ortiz, 1983; Poole, Cooney, Shook Cheong, 1986). Parents are more influential than peers when the adolescent is making a decision that has a moral or value slant, such as deciding to report someone who has destroyed property or has engaged in stealing. Peers are more influential when the adolescent is deciding on non-life-threatening issues, such as whom to date and what to wear to an event. However, the influence that parents and peers have on the adolescent who is deciding to consent in a real life healthcare situation is not fully understood. Further, we do not understand the influences of parents, family, and peers on outcomes in psychiatric mental health situations.

There are significant adolescent physical health related concerns. Most of these are related to the unhealthy behaviors adolescents engage in, such as smoking, drinking, and the consumption of foods high in fat and cholesterol (Rew, 2005). In all likelihood, the consequences of these risky behaviors will manifest later in life with heart attacks, strokes and cancer. Some propose it is the insidious nature in which the consequences of these behaviors are recognized that contribute to the adolescent continuing to engage in these activities (Holden & Nitz, 1995).

In addition to the physical health concerns, adolescents today face mental health issues. Psychiatric mental health disorders that appear in adolescence are often exacerbated in adulthood (Rew, 2005). Historically, adolescent mental health issues have not received the same level of research focus as the physical health concerns. Consequently, in comparison to what we know about physical health disorders in adolescents, our knowledge is limited when it comes to fully understanding the complexities of adolescent psychiatric mental health illness. However, mental health disorders pose immediate and serious threats to the adolescent population. For example, suicide is the third leading cause of death among adolescents (Bhatia & Bhatia, 2007). Further, depression is the leading cause of suicide and the number one diagnosed mental health disorder among adolescents. Other mental health disorders that are just as debilitating and destructive include disruptive behavior and alcohol and substance dependence and abuse disorders (Bhatia & Bhatia, 2007).

Significance of the Problem in Nursing

The subject of minor consent rights has received considerable attention in the scholarly literature of medicine, social work, psychology, and law (Bruzzese & Fisher, 2003; Geller, Bernhardt, Tambor, Fraser, & Wissow, 2003; McAbee & Feldman-Winter, 2003; Rew,

Taylor-Seehafer & Thomas, 2000; Whitney, McGuire & McCullough, 2004). Increasingly, nurse researchers and clinicians are interested in the various issues related to competency and minor informed consent, such as when an adolescent is competent to decide on treatment options without the parent and when the nurse should involve the parent in the consent process even though the adolescent appears competent. The implications of expanding minor consent rights are extensive, especially considering the responsibilities and obligations of nurses to obtain consent for treatment from the minor.

The collaborative efforts of nursing and legal scholars would be the most effective approach in continuing to address the complexities associated with minor consent decisions. The impact of legal rulings, for example, the expansion of minor consent rights, would be better understood if the results of nursing research were considered prior to the enactment of laws that directly affect the treatment of certain populations and nursing practice. Nursing researchers can make a substantial contribution to examining the impact of legal rulings on practice – from individual to population-based arenas – and especially focus on the evaluation of rulings on the overall treatment process.

Although nursing and legal researchers are now working more closely in addressing complicated healthcare issues, too often nursing and other healthcare disciplines have not fully understood how legal research in combination with their empirical research could greatly augment knowledge, specifically in relation to how policy affects the patients and overall clinical practice. A social science and legal research approach to better understand the experiences of minors consenting to healthcare treatment, and the role parents play when their adolescent consents, would significantly enhance our understanding, our knowledge, and subsequently the body of literature, and perhaps provide legislators the data to make

logical, informed policy decisions.

Problem Statement

Minor consent laws have been enacted without demonstrated and clear understanding of what influences the adolescent to decide to consent to psychiatric mental health treatment in real life situations. Further, minor consent laws are being expanded without understanding their therapeutic and anti-therapeutic effects on treatment outcomes. Moreover, the parents' views on the adolescent consenting without the parents' required consent are not understood. Lastly, no empirical studies have examined the decision-making process of adolescents who consent to healthcare treatment in real life situations.

Purpose and Research Questions

The overall purpose of this study is to explore the decision-making process of adolescents who consent to psychiatric mental health treatment in real life situations. Considering the minor consent laws that provide adolescents the right to consent to psychiatric mental health treatment without the consent of the parent, the following research questions will be addressed:

1. How do 12 to 17 year-old adolescents who consent to psychiatric mental health treatment (medication intervention, psychotherapy, or a combination of both) perceive the process of deciding to accept treatment?
2. How do 12 to 17 year-old adolescents who consent to psychiatric mental health treatment (medication intervention, psychotherapy, or a combination of both) perceive the goals of treatment?
3. What are the parents' perceptions of the roles they play in the adolescent's decision to consent to treatment?

4. What are the parents' perceptions of the roles they play in the goals of treatment?
5. What are the parents' experiences of their child (adolescent) being afforded the right to consent to psychiatric mental health treatment without the parent's consent?

CHAPTER TWO

REVIEW OF LITERATURE

This chapter will provide a literature review of: (a) the synthesizing framework to be used in this study, (b) the adolescents' capacity to decide about healthcare, (c) a comparison of younger and older adolescents' capabilities to make healthcare decisions, (d) how adolescents differ from adults in the decision-making process, (e) the applicability of the decision-making theory to adolescent healthcare treatment decisions, (f) the legal requirements in the State of North Carolina for minors to be considered competent to give their informed consent to medical treatments, and to psychiatric treatments in particular, and (g) parental and peer influences on the adolescents decision-making process.

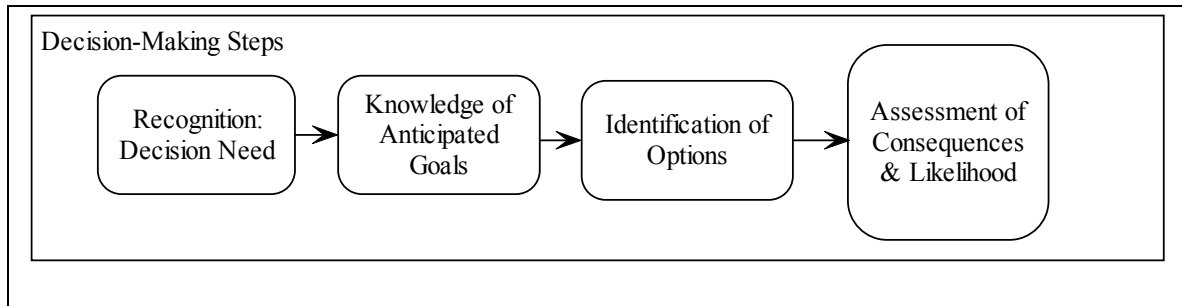
Synthesizing Framework

Decision-making Model

In order to provide a logical and succinct discussion of the adolescent's capacity to decide, the comparison of younger and older adolescents' capabilities to make decisions, and how adolescents differ from adults in the decision-making process, the following decision-making model will comprise one component of the synthesizing framework for this study: (a) recognizing that a decision is required; (b) knowing the purpose(s) and goals of the decision; (c) identifying alternatives and all consequences; and (d) knowing the desirability of each consequence and assimilating all the information (Fischhoff, Crowell, & Kipke, 1999; Janis

& Mann, 1977; Mann, Harmoni, & Power, 1989,). Figure 1 provides a schematic for the decision-making steps:

Figure 1. Decision-Making Steps



In addition to decision-making theory, the theoretical model, Therapeutic Jurisprudence (TJ) (Wexler & Winnick, 1992), and the concept of *scaffolding* (Berk & Winsler, 1995), which is based on the works of constructivist psychologist Lev Vygotsky, will comprise the complete synthesizing framework for this study. An analysis of TJ and *scaffolding*, along with a discussion of how each was integrated into this study, will be provided.

Therapeutic Jurisprudence

Therapeutic Jurisprudence is the collective work of David Wexler and Bruce Winick, both mental health legal scholars. Their scholarly interests are in analyzing the therapeutic impact of legal rules (Wexler & Winick, 1992), specifically what scholars in psychiatry and psychology think about the therapeutic effects of the law. They view law as a system of applied psychology, meaning that law seeks to order human behavior (Winick, 1997). Although mental health law was and still is intended to produce the most therapeutic consequences, Wexler and Winick recognized that law is often misunderstood and misapplied and that the law at times induces dysfunctional behavior. Their focus is on decreasing the negative outcomes of the law and looking toward the law to produce

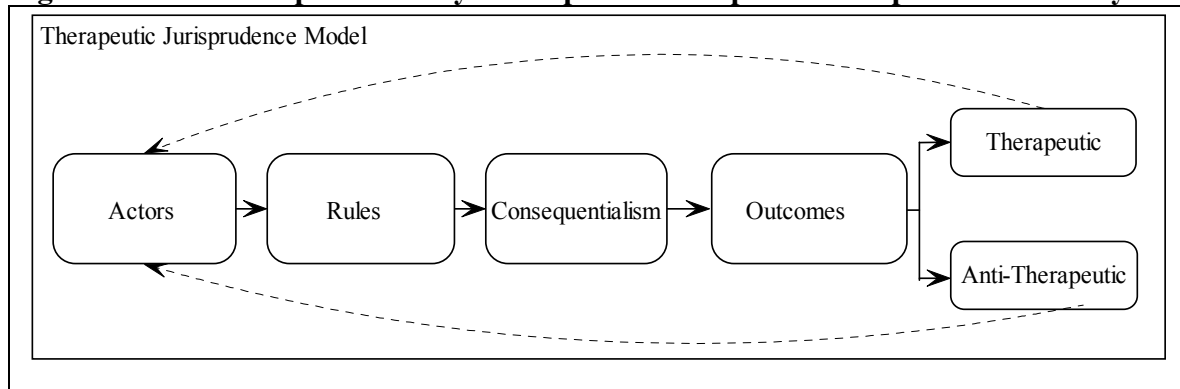
therapeutic effects on the mental health of those affected (Wexler & Winick, 1992). As indicated by Wexler and Winick (1992), TJ was initially intended to be used as a guide in criticizing the various aspects of mental health law that were producing anti-therapeutic results. Although its origins are in mental health law, the use of TJ concepts quickly expanded into other areas of law and TJ is now used as a theoretical model in psychology, social work, medicine, and most recently nursing (Wexler & Winick, 1992).

TJ is interdisciplinary, empirical, and international in its orientation (Wexler & Winick, 1992). The authors of TJ suggest that legal decision-making should not only consider economic factors, public safety, and the protection of patient's rights, but that it should also take into account the therapeutic implications of a rule and its alternatives (Wexler & Winick, 1992). There are six major concepts of TJ; *actors*, *rules*, *consequentialism*, *outcomes*, *therapeutic*, and *anti-therapeutic*. The authors of TJ do not operationalize these concepts clearly but do state that *actors* have direct effects on a legal *rule*. Two of the most important concepts of TJ are *therapeutic* and *anti-therapeutic*. *Rules* can produce *outcomes* that are either *therapeutic* or *anti-therapeutic*. *Therapeutic outcomes* would indicate that a *rule*, or law, is leading to, or influencing, improved overall health of the individual. *Anti-therapeutic outcomes* of a *rule* would be indicated by overall deterioration of the individual's health. *Rules* are determined to be *therapeutic* or *anti-therapeutic* by the *actors* or others who are affected or impacted by the *rule*. *Therapeutic* outcomes are defined as positive or desired results and *anti-therapeutic* are those outcomes that are negative or undesired.

Consequentialism refers to the results of legal *rules* or decisions. This basically includes the rights that are afforded to an individual as a result of the *rule*. *Rules* refer to policies, statutes, or laws. In the early developmental stages of this theory, *actors* referred to the judges and

lawyers who implement the rules. More recently the concept of *actors* has been expanded to include medical and social behavior professionals, family and friends of an individual, and the community as a whole (Wexler & Winick, 1992; Wexler & Winick, 2003; Winick, 1997; Winick & Lerner-Wren, 2002). In healthcare, TJ asks if a particular rule is therapeutic or anti-therapeutic to the patient.

Figure 2. Relationship of Primary Concepts of Therapeutic Jurisprudence Theory



In explaining the relationship between and among the TJ concepts (Figure 2), examples will be provided that are related to this research. *Actors* include parents, nurses, doctors, social workers, attorneys, policy makers, judges. Other *actors* include siblings, peers/friends, teachers, representatives from religious affiliations, or neighbors. This list of *actors* is not comprehensive, but it does provide an idea of the types of persons who can be included in the concept of *actor*. *Rules* are made, enforced, influenced, or even encouraged by *actors*. For example, attorneys and policy makers create and pass *rules* (i.e. North Carolina § 90-21.5), and these *rules* are subsequently enforced by judges and are often carried out by nurses, doctors and/or social workers. Parents are significant *actors* in the adolescent consent process because they are often the ones who ultimately decide for or against the proposed treatment.

Siblings, peers, teachers, and others who are not involved in the direct treatment of the adolescent are also considered *actors*.

Although it is not understood how the various *actors* influence adolescents in real life consent situations, the reported results of some research studies have suggested that *actors* may influence the adolescent's decision-making process in hypothetical situations (Brittain, 1963; Broome & Richards, 2003; Emmerich, 1978; Ortiz, 1983). Some suggest that *actors* (parents) are considered by adolescents instrumental in the adolescent integrating information about healthcare choices and providing the needed guidance in making a competent decision about treatment options (Broome & Richards, 2003; Poole, Sundberg, & Tyler, 1982; Poole, Cooney, & Cheong, 1986; Scherer, 1991).

Therapeutic Jurisprudence is the ideal model for guiding research that examines the effects of health policy on treatment outcomes, especially when this research is a confluence of nursing and law. Considering that adolescents are allowed to consent to psychiatric mental health treatments without their parents' permission, TJ provides the framework for exploring the complexities related to this process. It also encourages the critique of the roles that *actors* play in the creation and implementation of the consent law. Finally, and perhaps of most importance, this model encourages the researcher to consider each component of the policy making process to determine whether the policy is resulting in desired, positive, therapeutic outcomes.

N.C. § 90-21.5, a *rule*, is a North Carolina state statute that allows adolescents to consent to certain medical interventions without the required consent of the parent or legal guardian. *Consequentialism* can be explained in terms of N.C. §90.21-5. This statute is a *rule*, and the *consequence* of that *rule* is adolescents are given the right to consent to recommended

treatments independently. According to TJ, once the adolescent consents to the recommended treatment, the effects of the *rule* can be measured as either *therapeutic* or *anti-therapeutic*. A *rule* is considered *therapeutic* or *anti-therapeutic* based on the treatment *outcomes*. For this research, *therapeutic* could be represented, for example, by a decrease in the level of depression experienced by the adolescent or an increase in the level of focus and concentration.

From a clinical perspective, perhaps two components should be added to the TJ model to clarify what occurs between *consequentialism* and *outcomes*. In healthcare situations, a *decision* about whether to accept treatment must be made by the individual. If the decision is to accept the recommended treatment, the next step is the *intervention*. Of course, adding these steps may take away from the TJ authors' original intent of presenting a parsimonious model, but it does provide the clinician a more comprehensive approach in examining the effects of a *rule*.

TJ is presented in the literature as being linear in nature. Figure 2 represents the relationship among the concepts, but adds a recursive element, as represented by the dashed line in the model. The following explains the rationale for representing the recursive model. Legal *rules* result in legal practices, which are carried out by legal *actors*, which results in *therapeutic* or *anti-therapeutic* outcomes. The underlying assumption is that if a *rule* is truly *therapeutic* in its intent then it should consistently produce *therapeutic outcomes*, with outcomes reinforcing the *rule* as an effective *rule*. If the *rule*, or policy, produces *anti-therapeutic outcomes*, then ideally the *rule* would be considered for amendments, which takes that *rule* back to the *actors* for reconsideration. Therefore, whether outcomes are *therapeutic* or *anti-therapeutic*, the effect of the *outcomes* provides a basis for feedback to

the involved *actors*, who then can initiate changes based on *outcomes*. Note that a loop for the *therapeutic* and *anti-therapeutic* outcome has been included. Although an *outcome* can, and is intended to be, mostly *therapeutic*, it is possible that aspects of the *outcome* may be *anti-therapeutic*, thus requiring the re-consideration of the *actors* to formulate a more *therapeutic rule*. In other words, when discussing *therapeutic* and *anti-therapeutic* in legal terms, and using the TJ conceptualization, the notion is that *outcomes* are more or less black and white. When the terms are considered in the face of reality and practicality in healthcare situations, *therapeutic* and *anti-therapeutic outcomes* occur in varying degrees; they do not necessarily fall into exclusive categories of *therapeutic* and *anti-therapeutic outcomes*.

Based on a review of the literature, TJ has not been used as a theoretical framework to guide social science research. However, TJ has generated a significant amount of research in law, seen primarily in the implementation of law briefings and filing of appeals (Dauer, 2003; Madden and Wayne, 2003; Ronner, 2002; Winick & Lerner-Wren, 2002). Winick and Lerner-Wren (2002) presented what is known as the first TJ brief to appear in an appellate court of law. Prior to the submission of Winick and Lerner-Wren's brief, the Florida constitution stated that a hearing was not required when the commitment of a juvenile in foster care to a psychiatric mental health facility was being considered. The Florida Supreme Court considered a challenge to this constitutional law (*M.W. v. Davis*, 2000). Although the challenge was rejected, the Florida Supreme Court suggested that the Florida Juvenile Rules Committee consider the protections needed for an adolescent during a commitment procedure. The majority of the committee proposed that adolescents should be represented by a guardian *ad litem* during commitment hearings. Winick and Lerner-Wren argued that in order for the hearing to be *therapeutic* in nature, the representative for the juvenile should be

legal counsel, not solely the guardian *ad litem*, foster agency, or foster parent(s). Winick and Lerner-Wren presented an amicus brief to the courts that encouraged the consideration of TJ principles by evaluating the *therapeutic* and *anti-therapeutic* effects of representation in the commitment hearings of adolescents. The judge eventually ruled that a juvenile in foster care would be represented best by legal counsel, but that the input of the foster agency or parents would also be considered in the commitment process (*M.W. v. Davis*, 2001; Winick & Lerner-Wren, 2002). Winick and Lerner-Wren considered the acceptance of this brief a significant move in the direction of TJ being considered a legitimate model (theory) to guide legal research and proceedings.

Kjervik (1999), who is the strongest proponent of the use of TJ in nursing research, has been largely responsible for introducing nursing to TJ and vice versa. She states that the “intersection of nursing and law contains the potential for asking whether a given policy promotes a healthy society” (Kjervik, 1999, p. 5). In 2003, Kjervik examined the way law may affect nursing practice and outcomes. She suggests that nursing scholars “expand their theoretical models to include legal phenomena such as court opinions, legislative decisions, and regulatory authority to health and nursing-sensitive outcomes (Kjervik, 2003, p. 174). Perhaps Kjervik (2003) provides the best argument for the use of TJ as a theoretical framework in nursing research:

Nursing research that examines the relationships between governmental policy, nursing care and patient/community outcomes can provide reality-based grist for the legal decision-making mill. Nursing research in collaboration with legal research draw together two powerful approaches to research that fall clearly within the TJ model (p. 175).

Therapeutic Jurisprudence provides a relevant and useful framework to guide this study primarily because of its focus on outcomes and effects of policy on the mental health of

adolescents. Its concepts are especially applicable when considering how and why adolescents decide to consent to psychiatric mental health treatment. Therapeutic Jurisprudence first encourages the researcher to examine if the *rule* is created with a *therapeutic* intent, or if the *rule* is perhaps the product of negotiations or concessions among or between political or special interest groups. Secondly, TJ encourages the researcher to provide empirical data that support the creation of a certain *rule*. That is, before a law that expands the consent rights of adolescents is created or proposed, the process that adolescents use in deciding to consent should be understood. Lastly, TJ encourages the researcher to measure the outcomes of the *rule*. Is the *rule* creating the anticipated or desired (*therapeutic*) effect or outcome on the individual or, is the *rule* resulting in *anti-therapeutic* outcomes? Is the overall mental health of adolescents improving, declining, or remaining the same as a result of the expanded consent rights? The perceptions that matter in whether a *rule* results in *therapeutic* or *anti-therapeutic outcomes* are those of the adolescent, parent, and nurse. If a *rule* results in *outcomes* that are not desired, then the voice of these *actors* should be considered in modifying the *rule* in an attempt to achieve the desired *outcomes*.

The process of adolescent consent is a rather complex phenomenon. We do not fully understand all the variables involved in this process. TJ provides a parsimonious theoretical framework that would certainly help us to understand the complexities of an adolescent deciding to consent to psychiatric mental health treatment. Although the theory admittedly does not have strong empirical evidence to support it currently, the conceptual statements of TJ literature are clear and precise.

One of the primary concerns in using TJ as a part of the synthesizing framework for this research is that TJ is in its early developmental stages, and it is not well known by most

nursing scholars. Its use as a theoretical framework to guide research outside of the legal discipline is non-existent. Its infancy status and limited use outside of legal circles may provide sufficient reason for some to dismiss TJ as a legitimate research model in nursing. However, others may recognize the potential as a sound and legitimate research framework in spite of its infancy and limited current use in nursing related research, mainly because the concepts and overall ideology of TJ can transcend many disciplines, including nursing.

Another potential problem area in using this theory is related to the concepts. The relationship between and among the concepts of TJ has not been thoroughly examined. Without the presence in the published literature of its concepts, the communication and application of the TJ model is greatly hindered. Although the authors of TJ have made efforts to provide definitions of some of the main concepts, there remains a great deal of room for further development and clarification. Therefore, a study using qualitative methods would be ideal to elucidate the meanings of TJ concepts. For example, this qualitative research study will provide the opportunity to explain TJ concepts as they relate to adolescents consenting to psychiatric mental health treatment.

Vygotsky Cognitive Development Theory

Vygotsky never received formal training in psychology, but it is thought that his fresh, creative, and uninfluenced insights into the field are what led to his great contributions in the area of educational research and clinical practice (Berk & Winsler, 1995). During the time Vygotsky was developing his theory of cognitive development, he wanted to restructure the fields of psychology and education to fit with the changing ideas of his country, which were greatly influenced by Marxist principles. Therefore, his theory had a strong socio-cultural approach, and it was an attempt to explain how social and cultural influences affected

children's development (Berk & Winsler, 1995). With the development of his theory, he chose to address the overwhelming health and social concerns facing his country. To put things in perspective, in the 1920s, Russia had record numbers of orphaned, homeless, mentally retarded, physically disabled, and/or delinquent children. Vygotsky was most interested in ensuring that his theory had relevant clinical applications. He believed that if his theory could not contribute in some way in addressing the terrible state of affairs in his country, then his theory was not worthy (Berk & Winsler, 1995).

One of the primary reasons that Vygotsky's work has not been well known to the world outside of Russia is that shortly after his death, Stalin's rule banned the distribution of his works for the next 20 years. After Stalin's death in 1953, Vygotsky's publications began to spread throughout the Soviet Union. However, they did not reach the United States until after the Cold War. Vygotsky is now considered the father of abnormal psychology in Russia and his prolific writing and research contributions is respected in countries world-wide (Berk & Winsler, 1995).

Vygotsky never completed the work on his theory. His life was cut short by tuberculosis at the age of 33. At the time of his death he had many small, unfinished manuscripts on his theory. Some of these were ideas about his theory, some were working theories, and others included yet-to-be-tested concepts of his overall theory. He had not really combined all the ideas or his separate theories into one comprehensive theory prior to his death (Berk & Winsler, 1995). Today, his theory remains several theoretical ideas and they are often referred to as "Vygotsky's theories".

The overall meaning of Vygotsky's theory can be summarized into eight ideas: (a) *higher mental functions* vary across cultures; (b) in order to understand human behavior, we must

know how it forms developmentally; (c) there are two planes in which child development takes place, *natural* (biological growth of physical and mental structures) and *cultural* (the part of development that is influenced by culture); (d) we have *higher* and *lower* mental functions with higher mental functions being unique to humans; (e) higher mental functions have social origins; (f) language is the *cultural tool* that humans use in forming higher order thought processes; (g) formal education, which is considered *cultural socialization*, along with other *cultural socialization* experiences, helps direct the individual from childhood to adulthood; and (h) the *zone of proximal development* is a hypothetical phenomenon that is defined by the difference between what a child can accomplish on his own and what he can accomplish only with the assistance of an adult, or someone in his culture (Berk & Winsler, 1995; Bjorklund, 2005; Vygotsky, 1978).

Vygotsky viewed children as being actively involved in their learning, yet he placed limited emphasis on self- discovery (Bjorklund, 2005). He theorized that cognitive growth of a child was due to social contributions and that it was these social contributions that lead to higher mental development. The concept of *zone of proximal development* is the cornerstone of Vygotsky's theory (Berk & Winsler, 1995; Bjorkland, 2005; Scrimsher, & Tudge, 2003; Vygotsky, 1978). It is a hypothetical "zone" of learning in which a child is most sensitive to learning and where new cognitive growth and development is most likely to occur. The idea is that the child will begin to internalize problem-solving techniques while collaborating with the parent(s), older sibling, or a more able peer, who will show him how to solve the problem independently. The overall hypothesis is that the child can best learn to problem solve "at the level between their current ability and their ability when assisted by an adult" (Bjorklund, 2005, p. 65).

Scaffolding is a concept closely linked to the *zone of proximal development* (Bjorklund, 2005). The term *scaffolding* was not originally used by Vygotsky, but it has become synonymous with his theory. The idea of *scaffolding* is rather simplistic, but it is a concept that is most intriguing, especially when considering its defining characteristics with that of an adolescent deciding to consent to healthcare treatment. The following example can best describe the meaning of scaffolding. Consider the construction of a new building. In the initial stages of development, surrounding the building site there are many *scaffolding* materials, such as metal lattice-work, that supports planks on which builders work to create the building structure. These materials serve several purposes, but the primary purpose, and of utmost importance, is that of support for the development of the building structure, the building process, and those who actually construct the building. These support structures are often times unsightly but they are providing the framework for something that will eventually be a unique, complete, and useful product. As the upper progress of the building proceeds, the *scaffolding* is slowly disassembled. At times, something may happen to the structure of the building, which may require that the *scaffolding* be reassembled. Hopefully, the structural problems are soon rectified and the disassembling of the *scaffolding* resumes. Eventually, the lead engineer will decide that the building is complete and does not need the support of the *scaffolding*, and the building is ready to stand by itself and accept occupants.

When considering the cognitive complexities associated with adolescents deciding to consent (or not) to healthcare treatments, the important role that experts (parents) play in the adolescent's decision-making process is easily identified. The idea of *scaffolding* provides not only a framework for studying how and why adolescents consent (or not) to healthcare treatment, but also is a technique used by therapist in working with patients, specifically in

cognitive behavioral, rational-emotive, and family therapy approaches. These therapies are among the most commonly used in clinical treatment of adolescents (Corsini & Weding, 2000). The idea of *scaffolding* would provide experts (parents, clinicians) a way to conceptualize their role as guides to the adolescent in the decision-making process. They would, in a sense, become the *scaffold*, and create the environment that supports decision-making.

The most important aspect of *scaffolding* and its relation to adolescent consent is keeping the adolescent in the *zone of proximal development*. That is, parents must be aware of the amount of time required of them in guiding the adolescent through the decision-making process. The amount of guidance time required is ultimately based on the adolescent's competency level (Berk & Winsler, 1995).

There is a respected body of research studies that have used Vygotsky's theories as theoretical frameworks in examining *scaffolding* (Diaz, Neal & Vachio, 1991; McCarthy, 1992; Pratt, Green, MacVicar & Bountrogianni, 1992; Steinberg, Elmen & Mounts, 1989). Because of the practical element of Vygotsky's theory, there are numerous studies that have evaluated the theory as an intervention. These studies have predominantly been in the field of early childhood education (Anton, 1999; Gregory, Kim & Whiren, 2003). Other uses of *scaffolding* as an intervention have occurred in psychiatric mental health related studies (McNaughton & Leyland, 1999; Morelock & Brown, 2003).

Scaffolding concepts are also represented in adolescent research. Elias and Kress (1994) incorporated the idea of constructivist to health promotion in middle-school aged adolescents. Their idea was to enhance the adolescent's decision-making skills by partnering them with teachers and peers who can provide the needed guidance in learning how to make

difficult decisions. Crespi and Generali (1995) considered a constructivist's perspective in better understanding and working with adolescents in counseling settings. Specifically, this approach provided the clinician a framework with which to evaluate the adolescent's development and tailor the counseling according to specific developmental needs and skills.

Vygotskian ideas have been represented in nursing research studies as a rationale or a process orientation for research. Cintra, Delboux-Diogo, and Filomena-Ceolim (2005) have a published abstract indicating they used a Vygotskian orientation with a group of elderly for story-telling about their health. Searches of the literature indicate that only three nursing research studies have utilized Vygotskian ideas as a theoretical framework, as a rationale, or as a process orientation for research. Rushforth (1999) and Pearce (2004) used a Vygotskian orientation to explore the understanding of children. Rushworth (1999) provided a theoretical discussion of how hospitalized children's understandings of health and illness should be considered through a Vygotskian orientation. Pearce (2004) used a Vygotskian orientation to explore middle-school children's (age 10 to 15) understanding of physical activity, and to develop the basis of a computerized questionnaire for children to self-report their physical activity. Sanders and Welk (2005) proposed using scaffolding techniques and ideas in classroom and clinical settings to enhance the learning of nursing students. Their approach was intended to increase the confidence of the student so they could mature into competent clinicians who function independently.

Based on a literature review of its use in research studies, the ideas of Vygotsky are generally utilized in a consistent manner. Vygotsky's theory, especially the *zone of proximal development* concept and how it relates to *scaffolding*, is logical. There are no indications in the literature that researchers are in disagreement about the theory's overall meaning.

However, one scholar suggests that there is no consensus among researchers about how to identify if *scaffolding* is successful (Verenikina, 2004).

Perhaps the most difficult aspect of the logical adequacy of this theory is that of explaining how the concepts relate to one another. The following is one of the best explanations in the literature of the *scaffolding* concepts: “Scaffolding is a much more subtle phenomenon, one that involves a complex set of social and communicative dynamics” (Stone, 1993, p. 180). “The quality of adult support, the interpersonal relationships between adult and child, the meanings expressed, and the value attached to the situation, the task, and its associated behaviors are also important” (Berk & Winsler, 1995, p. 34).

Vygotsky’s theory has contributed significantly to the body of knowledge, especially that of early childhood education research, and research specifically with children (Anton, 1999; Gregory, Kim & Whiren, 2003; Pearce, 2004; Rushworth, 1999). However, other disciplines, such as psychology and nursing, are beginning to gain from its use as an organizing framework in research studies. The *scaffolding* concept fits well with the idea that when adolescents are making life altering decisions they benefit most from the support of parents, and others, who are experienced in making the same type of decisions. Consider an adolescent making an independent choice to initiate Lithium treatment for a bipolar disorder. The idea of initiating long-term medication intervention is most likely not a decision that the adolescent has made previously in life. Although the parents could also be lacking in this experience, typically they have already made decisions that have long lasting consequences, and they are perhaps more experienced than their child in determining the long-term effects of certain healthcare decisions. *Scaffolding* involves the interpersonal relationship between a child and adult, there is a value attached to the task, and the entire process is the complex set

of social and communicative processes. Would this approach to consenting for treatment produce better outcomes than say a policy that allows adolescents to choose treatments without the *scaffolding* of their parents?

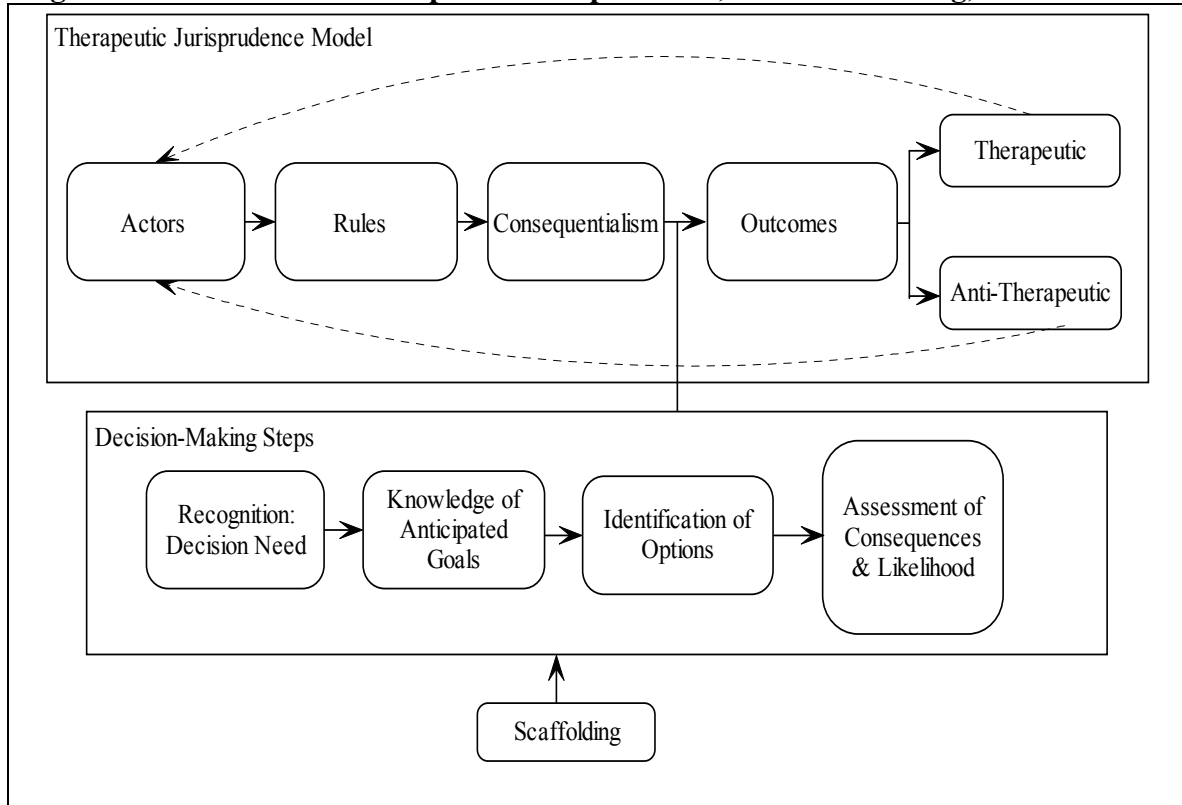
How effective would this theory be in enhancing the explanation of the complex phenomenon of adolescent consent? Vygotsky's theory has been used as a theoretical model in psychiatric mental health settings (Crespi & Generali, 1995). Its use is well documented in studies that represent child, adolescent, adult, and geriatric populations. A Vygotskian orientation, as a theoretical model, or portions of the theory has been used successfully in education. In the healthcare arena, and in nursing specifically, a Vygotskian model seems appropriate. The overall concept of *scaffolding*, when used in terms of the *zone of proximal development*, is closely related to this study. If adolescents are making decisions about consenting to their psychiatric healthcare, *actors* (parents, clinicians, researchers) may provide the *scaffolding* necessary to identify and aid the decision-making process of adolescents faced with decisions they have never made before, and that carry consequences that affect the adolescent's life.

The decision-making steps and concepts of TJ and *scaffolding* are combined and used as a supportive synthesizing framework for this study. There is little published literature regarding adolescent decision-making when consenting to psychiatric mental health treatment. Yet, there is a policy (*rule*) that allows this to occur (*consequentialism*). The decisions adolescents make result in *outcomes* that cover the spectrum of *therapeutic and anti-therapeutic*, which provide a basis upon which to evaluate not only the treatment and effect, but also to serve as feedback to generate further *rules*. The idea of TJ is to encourage the researcher to examine how policy is affecting current *outcomes*; is the policy *therapeutic*

or *anti-therapeutic*? The *actors* of TJ are making the *rules*. These *actors* are also potentially providing the needed *scaffolding* for the adolescent to make a decision about treatment.

Examining the decision-making process, and in that process the expert *scaffolding* to support decision-making, as needed by adolescents, would enhance the adolescent consent literature even more. The following diagram (Figure 3) is the relationship of decision-making among adolescents, TJ, and scaffolding:

Figure 3. Full Model of Therapeutic Jurisprudence, Decision-Making, and Scaffolding



Adolescents' Capacity to Decide

Adolescence is the stage of development during which the individual can form an appreciation for the nature of proposed healthcare treatments (Bjorklund, 2005; Inhelder & Piaget, 1958; Weithorn & Campbell, 1982). However, when it comes to making life-altering

healthcare decisions, the adolescent can be somewhat vulnerable, and his or her developmental needs, such as autonomy and independence, are challenged by the need to make the decision (Christian, D'Auria, & Moore, 1999). Adolescents may go against their parents' wishes and take risks related to their health in order to maintain a sense of control over the situation and independence in ultimately making healthcare decisions (Christian, D'Auria & Moore, 1999; Santrock, 2006).

Inhelder and Piaget (1958) suggest that formal operational thinking allows the person to make choices in a situation after reasoning about the multiple possibilities of the choice. They further propose that the distinguishing feature of adolescence is the ability of the individual to think in terms of possibilities instead of concrete thinking (Berger, 1994). *Competence* and *capacity* are terms often used interchangeably to describe the same concept (Sturman, 2005). However, Sturman (2005) proposes that *capacity* is related to the clinical state of an individual that is determined by healthcare professionals, and *competence* is a legal status that is determined by legal professionals. The *capacity* and *competence* level of an individual can be affected by psychiatric disorders, at times in a pronounced manner (Sturman, 2005). Decision-making, including understanding consequences to the choices made, can be significantly affected by mental health illness (Byrnes, 2002; Sturman, 2005). D'Zurilla and Goldfriend (1971) advise that for an individual to be considered *capable* of making a decision, they must be skilled in understanding the consequences of all proposed treatment. Although most states statutes provide a definition of *capacity* or *competence*, the healthcare professional is frequently left with the responsibility of determining this state of the individual.

The concept of capacity has been the primary focus in the minor informed consent literature (Kaser-Boyd, Adelman, & Taylor, 1986; Lewis, 1981; Scherer, 1991, Weithorn & Campbell, 1982). Some researchers have examined decision-making of adolescents by comparing the capacity of different adolescent age groups to decide (Kaser-Boyd, Adelman, & Taylor, 1986; Lewis, 1981, Mann, Harmoni, & Power, 1989). Others have compared the capacity of the adolescent to decide to that of adults (Kaser-Boyd, Adelman, & Taylor, 1986 Ambuel & Rappaport, 1992; Lewis, 1980; Weithorn, & Campbell, 1982)

Investigators who have compared the capacity of adolescents vary in the way sample populations are grouped by age (Kaser-Boyd, Adelman, & Taylor, 1986; Lewis, 1981; Scherer, 1991). One approach to comparing the capabilities of adolescents to make healthcare decisions has been to compare “younger” and “older” adolescents (i.e. 12 and 16 year-olds), or compare adolescents of different grade levels (9th and 12th graders) (Emmerich, 1978). Some child developmentalists view adolescence as consisting of three phases: younger, middle, and older (Adams, Montemayor, & Gullotta, 1996; Grotevant & Cooper, 1983; Sroufe, 1996). The reasoning for this categorization is that these three phases capture the developmental issues that differ among groups. Others suggest that age-defining categories of adolescents are made arbitrarily and they provide limited purpose in research or the literature other than to conveniently conceptualize a certain group (Bjorklund, 2005; Kaplan & Saddock, 1998). Still others combine all adolescents into one cohort and wash out the developmental effects. Therefore, it is evident by reviewing the developmental literature that there is no universally agreed upon method of categorizing adolescents in research studies.

For this study, adolescence is operationalized according to age: younger (12 to 14 year-olds) and older (15 to 17 year-olds). Three important considerations influenced the decision to categorize adolescents according to these age groups: (a) the legal definition of a minor in the State of North Carolina, and the law (N.C. §90-21.5) that provides adolescents of that state the right to consent to psychiatric mental health treatment without their parents' permission, (b) the cognitive developmental of adolescents as described by Piaget (Bjorklund, 2005), (c) and the emotional development of adolescents. First, the law (N.C. §90-21.5) that was considered in this study applies only to minors, which is defined by North Carolina statutes as anyone who is less than 18 years old. Second, the primary difference in cognitive development between younger and older adolescents is that younger adolescents are more concrete in their reasoning and decision-making, and older adolescents are more likely to consider long-term consequences in their decisions and think in more abstract terms about situations (Gardner, Sherer, & Tester, 1989). Decision-making about healthcare treatment requires abstract thinking on the part of the adolescent. Abstract thinking, which includes the individual considering consequences of their decisions, is representative of Piaget's formal operational cognitive development stage. Individuals 12 years of age and older are expected to be functioning in the formal operational stage of cognitive development as defined by Piaget (Bjorklund, 2005). Adolescents 12 to 14 years old are less experienced in formal operational thinking than those 15 to 17 years old (Bjorklund, 2005). In addition to formal operational thinking, adolescents 12 to 17 years old are seeking increased independence from the parents, specifically when it comes to making certain life decisions (Bjorklund, 2005). Further, 15 to 17 year olds typically are seeking more independence from their parents than 12 to 14 year olds, including more independence in making their own

healthcare treatment decisions (Bjorklund, 2005; Dashiff, 2001). Third, from an emotional perspective, younger adolescents are often more egocentric than older adolescents, and believe they are the persistent focus of others' attention and thoughts (Dashiff, 2001). Considering the tripartite criteria of the legal, cognitive, and emotional aspects of the population of interest, adolescents 12 to 17 years old were included in this study.

Younger and Older Adolescents' Capabilities to Make Healthcare Decisions

Using the four steps of the decision-making process as a framework, this section of the literature review will include an analysis of studies that have examined adolescents' capacity to make decisions. Empirical research and clinical reports will be included for support of the analysis.

Step one: Recognizing that a decision is required. No studies were found that have compared younger and older adolescents' capabilities in recognizing the need, or requirement, for making a decision related to psychiatric treatment. Some researchers have examined the decision-making process of adolescents in other healthcare situations (Christian, D'Auria, & Moore, 1999; Emmerich, 1978; Lewis, 1981; Okwumabua, 1999; Scherer, 1991). However, the examination of whether the adolescent specifically recognized that a decision was required was not included in the research designs of these studies.

Some studies explicitly determined for the adolescent that a treatment decision was required, and in the design of the study, the treatment decision was made for them (Broome & Richards, 2003; Emmerich, 1978; Lewis, 1981; Okwumabua, 1999; Mulvey & Peebles, 1996; Scherer, 1991; Solomon, 1963). To determine whether an adolescent can recognize that a decision is required of him, the researcher could have included specific questioning that would have evaluated the adolescent's capability of recognizing that a decision was

required. One researcher (Okwumabua, 1999) compared at-risk African American adolescents (12 to 14 year-olds, n= 54; 10 to 11 year-olds, n=99) and children (age 8 to 9 year-olds, n=64) to determine if they were capable of recognizing that a treatment decision was required when given a certain healthcare scenario. A Tukey's multiple comparison ($p=.05$) revealed that 12 to 14 year-olds were significantly more capable than 8 to 9 year-olds in recognizing from the scenario that a healthcare choice was required. Although this study is the only one that has examined the capability of the adolescent to recognize that a decision is required, the statistical comparison was made with the capability of children to decide, not with other adolescents. Furthermore, the study included hypothetical instead of real life healthcare situations.

From a clinical perspective, there is a distinct difference between the older and younger adolescent in the outpatient psychiatric mental health clinical setting (Keating, 2004). Usually with the assistance of parents or clinician, the older adolescent is more often capable of recognizing that a decision about treatment is needed and ultimately required. Younger adolescents seem to be less aware than older adolescents that one of the first requirements is acknowledging that a decision about treatment is essential (Byrnes, 2002). At times, the adolescent's lack of awareness that a decision is needed is due in part to the parent not disclosing to the adolescent prior to the session that the overall purpose of the visit is to decide whether or not treatment is needed.

Step two: Understanding the goals. Decision-making includes the adolescent understanding the goals they hope to attain. Without goals, the adolescent would have difficulty identifying desired objectives. Adolescents who are functioning under considerable stress lose capacity to remember and their ability to process situations and problem-solve

effectively and have difficulty identifying goals for treatment (Janis & Mann, 1977). An adolescent presenting with an acute mental health disorder is typically functioning under extraordinary circumstances and stress (Byrnes, 2002). The relationship between stress and the adolescent's capability to understand the goals of treatment has not been studied in psychiatric mental health settings. There is a gap in the literature of what is known about an adolescent's response to goal-oriented treatment decision questions in psychiatric mental health settings and what has been studied by nursing scholars. Research is needed to better understand if adolescents can recognize that a decision must be made, given a set of facts, and whether the adolescent understands the goals to achieve by making a treatment choice. Studies that examine these variables should include comparing younger adolescents to older adolescents along with any gender differences.

Based on clinical experience, younger and older adolescents do appear readily capable of verbalizing goals of medication intervention. It is common for a clinician to ask an adolescent during the initial phase of treatment, "Why are you seeking help at this point?" A typical response from an adolescent who is receiving medication intervention for depression is, "so I can feel better." Similarly, adolescents who are taking medication for ADHD respond, "so I can do better in school." It would be expected, based on developmental theories, that older adolescents would have the ability to think in abstract terms, thus having the ability to identify long-term goals (Byrnes, 2002).

Step three: Determining the consequences. Lewis (1981) was interested in knowing if adolescents were capable of understanding consequences of healthcare treatment choices they made. Adolescents in this study responded to hypothetical treatment choices. The choices were presented to 18 males and 18 females from each of the following grade

categories; 7-8th, 10th, and 12th graders. The ages for the three groups were as follows: (a) 7-8th graders, 12 years 3 months to 14 years 7 months, (b) 10th graders, 14 years and 8 months to 17 years, (c) 12th graders, 17 years 3 months to 18 years 9 months. Some of the healthcare situations were those that the adolescent would most likely never be faced with, such as deciding on whether to receive cosmetic surgery or experimental acne treatment. The researcher reported that the ability to recognize consequences for treatment decisions increased with age. For example, 42% of twelfth graders, compared to 25% of seventh-eighth graders, were capable of identifying risks and consequences of electing cosmetic surgery and experimental acne treatment.

Kaser-Boyd, Adelman, and Taylor (1986) compared younger ($n=37$, 10 to 13 year-old) and older ($n=38$, 14 to 19 year-old) adolescents' capabilities in identifying the risk and consequences associated with participating in psychotherapy, given a single hypothetical therapy situation. The vignettes were created to represent situations that could potentially be experienced by any of the study participants. Examples included being worried about school, feeling angry or sad, or feeling stupid. The authors reported that there was no significant difference between the younger and older adolescents in realizing the positive and negative consequences of psychotherapy. Only one quarter of all participants was able to determine the consequences of psychotherapy. In another study that examined the age differences in the decision-making of 100 pregnant adolescents, younger ($n=45$, 13 to 17 years-old) and older ($n=55$, 18 to 19 years-old) adolescent girls were no different in their capabilities of recognizing both positive and negative consequences for becoming pregnant (Urberg & Rosen, 1987).

It is not known whether older and younger adolescents differ in their ability to identify both positive and negative consequences of treatment options in psychiatric mental health outpatient clinical settings. However, developmentalists would posit that, in general terms, any adolescent functioning in formal operational thinking is more capable of engaging in abstract thinking, thus having the ability to conceive of consequences when given a set of choices. Whether adolescents in psychiatric mental health settings are capable of independently expressing these consequences, specifically in well-defined terms, is not known.

Seldom do adolescents inquire about what a medication can do in terms of the potential negative consequences (Byrnes, 2002). In addition, it is not understood if adolescents have a general awareness that medications they are prescribed have potential adverse side effects. However, most adolescents seem to have an understanding that certain medications are intended to produce positive consequences (Byrnes, 2002). They understand that medication for Attention Deficit Hyperactivity Disorders is intended to improve attention and focus, and that an antidepressant is intended to help them feel less sad (Byrnes, 2002).

Younger adolescents who seek treatment in outpatient psychiatric mental health clinical settings usually require a detailed explanation about the intent of the medications (Byrnes, 2002; Byrnes & McClenny, 1994). This clarification is precursor to the adolescent being capable of understanding the positive and negative consequences of the medications. Although the nurse may explain to the adolescent that a treatment decision is required, and perhaps the nurse assists the adolescent in identifying, clarifying, and establishing goals of treatment, the differences in the abilities of younger and older adolescents to identify the

positive and negative consequences of psychiatric mental health treatment options are not fully understood (Byrnes, 2002).

Step four: Understanding that each consequence is likely to occur. The final step in the decision-making process includes determining the desirability of each consequence, evaluating the probability of each consequence, and assimilating all of the information. There are two studies in which the adolescent's understanding of the desirability of the consequences and likelihood that each will occur was evaluated. Lewis (1981) reported that 43 % of the 12th graders (older adolescents), compared to 11% of the 7th graders (younger adolescents), were able to recognize and discuss future implications of their healthcare treatment choices. The older adolescents were more interested than the younger adolescents in discussing the positive and negative consequences to cosmetic surgery and experimental acne medication. The older adolescents were more likely than the younger adolescents to discuss the effects of the decisions in future terms (how the choices will affect them later in life). The younger adolescents discussed the consequences in present terms (being teased at school, not getting a date). Urberg & Rosen (1987) reported that younger adolescent girls ($n=55$, 13-17 years-old) were not significantly different than older adolescent girls ($n=45$, 18-19 years-old) in their ability to offer future consequences of becoming pregnant.

These two studies tell us very little about how adolescents can assimilate information in real life healthcare situations. They do provide an understanding that adolescents may vary in their ability to assimilate the information related to their decision, primarily based on the type of decision. Most importantly, how adolescents integrate treatment options in psychiatric mental health settings is not well understood.

In psychiatric mental health clinical settings, the older adolescent (15 to 17 years-old) ask more questions about the related consequences when the discussion of these consequences are initiated by the practitioner (Byrnes, 2002). The younger adolescent (12 to 14 years-old) does not seem to contemplate consequences beyond what is told to him or her about the positive and negative consequences. The younger adolescent does not pose questions or make statements related to future implications of the consequences, whereas the older adolescent does ponder the possible future effects of current choices (Byrnes & McClenny, 1994).

Comparison of Adolescent and Adult Decision-making

Using the four steps of the decision-making process as a framework, this section of the literature review will analyze studies that have compared adolescents' capacity to make decisions to adults. To support the analysis, research and clinical reports will be presented.

Step one: Recognizing that a decision is required. Clinically speaking, in psychiatric mental health outpatient settings, the differences between the decision-making process of adolescents and adults are considerable. Most often adults are likely to understand that a decision is required when being evaluated by a PMHNP. Overall, younger and older adolescents struggle with this step in the decision-making process, as they are not skilled in independently recognizing that a decision must be made. This limitation can be explained from a developmental perspective by considering the inexperience of adolescents in making decisions in psychiatric mental health situations (Santrock, 2006). The typical adolescent has not made decisions related to their healthcare. Most decisions that adolescents make are related to friendships, who to date, or what class to take at school. A breadth of experience often contributes to the individual's ability to make competent decisions. Therefore, if the

adolescent does not have experience in making decisions in a psychiatric mental health setting, they cannot be expected to realize that a decision is required of them in the initial phases of treatment.

Another reason for the adolescent's inability to recognize the need to make a decision is that the adolescent is at times not informed about the reason for the visit, or is not told about the role of the Nurse Practitioner prior to the visit. It is not fully understood why the adolescent is uninformed about the visit. Although, parents have provided reasons that information was withheld from the adolescent out of concern that the adolescent would refuse to attend the initial session and ultimately reject treatment. Issues of coercion and deception are in play with this scenario, especially given that adolescents can consent to psychiatric mental health treatment without the required permission of the parents. Regardless, the process that adolescents go through to decide on psychiatric mental health treatment is in need of further examination, especially given that adolescents are usually not experienced in making such decisions.

Step two: Understanding the goals. Goal-setting among adolescents has not been the focus in developmental literature (Byrnes, 2002). However, the results of studies suggest that adults are more likely than adolescents to consider multiple goals or choices (Byrnes & McClenny, 1994; Byrnes & Reynolds, 1999). In clinical settings, adolescents experience a greater challenge than adults in understanding or expressing their desired goals, especially in situations where it is not clear to the adolescent that a decision is even required of them (Wisdom, Clarke, & Green, 2006). When goals are established in psychiatric mental health clinical settings, they are usually the result of collaboration between the adolescent, parents, and the treating practitioner. Frequently, the initial goals of the adolescent are actually

congruent with those of the practitioner, or perhaps the practitioner and parents, mainly because the adolescent has difficulty in establishing goals. Adults commonly seek treatment with goals in mind, which are typically related to general improvement of mental health status (Wisdom, Clark, & Green, 2006). However, the goals of adults are very specific at times (desire for more energy, to feel happier, to have the ability to focus and concentrate, to stop the auditory or visual hallucinations).

Step three: Determining the consequences. Adults are usually capable of identifying options and potential consequences of each treatment option. Adolescents are more limited than adults in considering all options and consequences (Wong, Hser, & Grella, 2002). During the initial stages of treatment in an outpatient psychiatric mental health setting, adolescents tend to focus on the negative consequences of medication intervention (increased feelings of tiredness, decreased sex drive, not feeling energetic, increased appetite) and not the positive consequences to taking medication. Adults are more inclined than adolescents to identify the negative and positive consequences of their treatment decisions (Schulman-Green, Naik, Bradley, McCorkle, & Bogardus, 2006). As treatment progresses, adolescents are more capable of recognizing the positive consequences along with the negative, especially if treatment has produced positive outcomes such as increased focus and attention, feeling less sad, fewer conflicts with parents.

Step four: Understanding that each consequence is likely to occur. One of the more common lines of inquiry by adults in a psychiatric setting is related to the future implications of their decisions. Adults want to know how a particular medication will affect them if taken for several years (Shiloh, Gerad, & Goldman, 2006). In fact, with the assistance of the internet and the accessibility and availability of information, adults are at times as informed

as the practitioner about future implications of long-term medication intervention. Younger and older adolescents are less likely to consider the long-term consequences of taking medication. Most, if any, of an adolescent's concerns about their decisions are related to short term effects, and this fits developmentally with this population (Santrock, 2006).

Summary of Adolescent and Adult Decision-making

There is limited research that provides a thorough comparison of the steps taken by adults and adolescents in making healthcare related decisions. Some researchers have isolated specific steps of the decision-making process, and have evaluated them without considering the remaining steps (Ambuel & Rappaport, 1992; Lewis, 1980; Weithorn, & Campbell, 1982).

Lewis (1980) examined the capability of single female adults ($n=26$) and adolescents ($n=16$, age 17 and younger) to determine the consequences (**step 3**) related to becoming pregnant. Reportedly adults and adolescents in this study were equally capable of considering the positive and negative consequences of becoming pregnant. The differences between these two groups are related to future consequences. Adolescents focused more on immediate consequences of pregnancy, such as the added burden the pregnancy would place on her parents, who would baby-sit when she could not care for the baby, or how she would find employment. Adults focused on long-term consequences such as the overall quality of life for mother and baby.

Weithorn and Campbell (1982) compared the competency levels of two adolescent groups ($n=24$, 12 males and 12 females in each group, 8.5 to 9.5 years-old & 14 years-old) to that of two adult groups ($n=24$, 12 males and 12 females in each group, 18.5 years-old & 21 years-old) in making hypothetical healthcare related treatment choices. One aspect of their

study was to compare adult and adolescent decision-making abilities. The authors reported adolescents as young as 14 years of age were capable of recognizing that a decision was required (**step 1**), verbalizing an understanding of the goals desired (**step 2**), and recognizing the consequences of their decisions (**step 3**). However, adolescents in this study experienced difficulty in assimilating all the treatment information presented to them (**step 4**). The adults were capable of recognizing all four steps in the decision-making process.

Ambuel and Rappaport (1992) were interested in better understanding the process that female adults and adolescents go through in deciding to have an abortion. Adults and adolescents ($n=75$, five participants in each age group between the ages of 14 and 21 years) arriving at an outpatient clinic for a pregnancy test, were asked about how they would go about deciding whether or not to abort their baby if it was determined they were pregnant. This study required the participants to project how they would handle a life altering decision. The investigators found that both adult and adolescent participants were capable of determining the consequences of aborting (**step 3**), and that both groups were interested in the long-term consequences of their decision (**step 4**).

When considering these studies as a whole, in certain situations adolescents assimilate and integrate information provided to them related to making a treatment decision. However, in general, adults recognize the long-term consequences of their decisions more readily than adolescents in certain healthcare situations. Nevertheless, it is not fully understood whether adolescents actually assimilate treatment information when given a set of options. Nor is it known if adolescents readily consider the long-term consequences of the chosen treatment interventions in their decision-making process.

Adequacy of Decision-making Theory

The decision-making theory, which was used as the framework for the analysis in comparing adolescents of different age groups and adolescents to adults, would prove adequate in explaining the components of the decision-making process that adolescents use to make decisions about mental health treatment. It is evident that there is a significant gap in the literature to explain how adolescents make decisions in real life healthcare situations. Although some studies have examined specific steps of the decision-making process of adolescents, no studies were found that comprehensively examined each step of the process in the context of adolescent healthcare decision-making. Thus, the various decision-making steps that adolescents use to decide healthcare choices are not fully understood. Further, there is a dearth of research that has examined the decision-making process of adolescents in real life situations. Whether the adolescent can independently recognize that a healthcare decision is required, understands their goals, can determine consequences of the options, and knows the desirability of each consequence remains unexplored. More specifically, research is lacking that explains age-related differences among adolescents when it comes to understanding whether they employ the decision-making steps in psychiatric mental healthcare situations.

Considering the current minor consent laws of the State of North Carolina (N.C. §90-21.5), where an adolescent can give consent for psychiatric treatment without the consent of parents, it is imperative to understand whether an adolescent is capable of recognizing that engaging in treatment requires a decision on his or her part. It is important for healthcare practitioners to know if adolescents are capable of understanding the goals the adolescent desires to achieve. If the adolescent proves incapable of independently completing these

steps of the decision-making process, the practitioner could assist the adolescent in recognizing that a decision is crucial in order to proceed with the remaining decision-making steps. Assisting the adolescent to identify goals would assist practitioners to adjust the treatment approaches. Most importantly, if researchers determine that adolescents in healthcare situations consistently do not complete the first two steps of the decision-making process, should the consent rights provided to minors by N.C. consent law (§ 90-21.5) be considered for modification?

There is some evidence that older adolescents are more capable than younger adolescents in recognizing the consequences of their healthcare treatment choices (Lewis, 1981; Kaser-Boyd, Adelman, & Taylor, 1986). Other researchers purport that younger and older adolescents are no different in their abilities to recognize the consequences of their treatment choices, and older adolescents are more capable than younger adolescents in considering future consequences to their choices (Urberg & Rosen, 1987). The differences in the results reported in these studies provides support for the argument that further research is required to better understand how adolescents recognize the consequences related to their healthcare treatment choices.

The decision-making model provides a necessary framework for guiding research that attempts to explain how and why adolescents decide to consent to mental health treatments. No study has utilized this framework to examine how adolescents decide to consent to healthcare treatment. Further, no study has examined each step of the decision-making process in a concise and succinct manner when considering adolescent healthcare treatment in general and adolescent psychiatric mental healthcare specifically.

Researchers have examined the adolescent decision-making process (Kaser-Boyd, Adelmanm & Taylor, 1986; Lewis, 1981; Urberg & Rosen, 1987), but their research findings do not increase our understanding of how adolescents decide about treatment in real life healthcare situations. Using the decision-making process as part of a synthesizing framework, research that considers how and why adolescents decide to consent in psychiatric mental health settings has the potential to guide informed consent policy and clinical nursing practice.

State of North Carolina Minors Consent Law

One of the primary routes to fully understand the purpose of a statute is to investigate its legislative history and the political trade-offs required to pass legislation. Although by its very nature a statute is in force as a law, there is no way of knowing the background and rationale for its generation without investigating its history. It is imperative for Psychiatric Mental Health Nurse Practitioners (PMHNP) to understand the law that guides or influences their clinical practice. Statutes that guide practice will ultimately affect, either therapeutically or anti-therapeutically, the health of patients. This relates directly to the notion that nursing practice and law provide the practitioner a framework to ask whether a policy is promoting improved health in the patients we treat (Kjervik, 1999).

Several North Carolina statutes specifically address issues related to informed consent and competency of minors. N.C. § 90-21.5 directly influences the clinical practice of PMHNPs, and it is the statute of most interest in this study. Therefore, it is crucial to understand how this statute not only affects practice, but also what outcomes (therapeutic or anti-therapeutic) are produced.

In order to understand the intent of the N.C. legislature to pass the law about minor consent (N.C. §90-21.5), a concerted effort was made to learn the history of this law with a goal of understanding the reason(s) for its eventual implementation. The original author of N.C. §90-21.5 was contacted and asked if he could provide any information about the origins of this statute. Initially, the legislator expressed an interest in assisting in this study. However, subsequent inquiries by this researcher went unanswered. Therefore, no understanding of the impetus and intent of the law is possible.

The next step in investigating the origins of this law was to conduct an independent research into the bill's history, which included accessing legislative reports located at the North Carolina Legislative Offices in Raleigh, North Carolina. Although this search did not result in knowledge about the impetus and intent of N.C. § 90-21.5, information about the bill's history and series of amendments was obtained. In 1971, North Carolina House Bill 163 entitled "An act to allow a minor 18 years of age to give consent for medical treatment" was introduced and read for the first time in the North Carolina House of Representatives. Later that year the bill was passed into law and became known as the North Carolina § 90-21.5. This statute provided any minor who was 18 years of age or older (the definition of legal adult in North Carolina in 1977 was 21 years-old) the right to consent to medical treatment. The statute also allowed anyone 18 years or older to seek diagnosis and treatment for venereal diseases without the required consent of any other person. Over the years, N.C. § 90-21.5 (West's North Carolina Chapter 90) was amended, ratified and has remained unchanged since 1985. It currently reads as follows:

Minor's consent sufficient for certain medical health services.
(a) Any minor may give effective consent to a physician licensed to practice medicine in North Carolina for medical health services for the prevention,

diagnosis and treatment of (i) venereal disease and other diseases reportable under § 130A-135, (ii) pregnancy, (iii) abuse of controlled substances or alcohol, and (iv) emotional disturbance. This section does not authorize the inducing of an abortion, performance of a sterilization operation, or admission to a 24 hour facility licensed under Article 2 of Chapter 122C of the General Statutes except as provided in § 122C-222. This section does not prohibit the admission of a minor to a treatment facility upon his own written application in an emergency situation as authorized by § 122C-222.

The current legal age of a minor in the State of North Carolina is any person who has not reached the age of 18 years (N.C. § 48A-2; West's North Carolina Chapter 48).

N.C. § 90-21.1 provides for a physician to treat a minor without the consent of the parent or legal guardian for situations in which, (a) the parents cannot be contacted and the child needs medical care, (b) the identity of the child is unknown and seeking it would delay needed treatment, (c) an effort to contact the parents for consent could endanger the child if treatment is delayed, or (d) the parents refuse treatment for their child and the refusal would place the child in serious danger. This final condition (d) would require the opinion of a second physician to confirm that treatment was necessary to prevent further harm to the child. Treatments that can be performed by a physician may include X-rays, the administration of drugs, blood transfusions, use of anesthetics, and laboratory or other diagnostic procedures (N.C. § 90-21.2). N.C. § 90-21.3 provides for a surgeon to perform surgery on a minor without the consent of parents in emergency situations. However, the second opinion of a surgeon is required before surgery can proceed. If the surgeon and child are located in a rural area of the state, if the surgery is needed immediately, and a second surgeon is not readily available to provide an opinion, then the primary surgeon can proceed with treatment.

Guidelines for determining the level of competency of minors are not provided in the

State of North Carolina statutes. In fact, when defining the mental capacity of individuals, the State of North Carolina does not use the term *competence*, but rather, *incompetence* is the preferred term. Additionally, North Carolina incompetence statutes use the term *child* instead of *minor*. A *child* in the State of North Carolina is defined as an individual who has not attained the age of 18 years (N.C. § 50A-102).

N.C. § 35A-1101(8) (West's North Carolina Chapter 35) defines the incompetent child as someone who, "lacks sufficient capacity to make or communicate important decisions concerning the child's person, family, or property whether the lack of capacity is due to mental illness, mental retardation, epilepsy, cerebral palsy, autism, inebriety, disease, injury, or similar cause or condition." Mental illness is further defined as, "an illness that so lessens the capacity of a person to use self-control, judgment, and discretion in the conduct of the person's affairs and social relations as to make it necessary or advisable for the person to be under treatment, care, supervision, guidance, or control" (N.C. § 35A-1101(12)). Mental illness, as defined by the State of North Carolina, may also be referred to as, "mental disease, mental disorder, lunacy, unsoundness of mind, and insanity" (N.C. § 35A-1101(12)).

Determining the level of competence of an adolescent can be challenging in clinical settings, especially considering there are no clear guidelines that the nurse can follow. It is recognized that in most clinical settings, identifying an adolescent as being "competent" or "incompetent" is a subjective evaluation (Sturman, 2005). Sturman (2005) provides a summary of instruments that can be used in clinical settings to determine "competence" in order to eliminate or reduce the element of subjectivity. However, the presence of certain psychiatric mental health disorders can make it difficult for the clinician to determine if the adolescent meets the criteria of "competent". Further, the results of evaluations of individuals

with psychiatric mental health illness may not accurately reveal their level of “competency” (Sturman, 2005).

The American Nurses Credentialing Center is the primary credentialing body for nurses, including PMHNPs. The North Carolina Boards of Nursing and Medicine regulate the practice of PMHNPs. Neither of these credentialing and regulating bodies provides the nurse clinician guidelines for determining if someone is “competent.” In addition, although “competency” is a legal status, PMHNPs are often times required to make these judgments without the knowledge or experience in making such determinations (Sturman, 2005).

In summary, a minor in the State of North Carolina may consent to the following treatments without the required consent of the parent or legal guardian: (a) emergency care; (b) family planning & contraceptive care; (c) pregnancy related care; (d) STD/VD care; (e) reportable disease care, including HIV/AIDS; (f) drug/alcohol care; (g) outpatient mental health services. N.C. statutes that address competency and informed consent among minors are in place for specific and logical reasons. For example, if a child is in a serious medical situation and the parents or legal guardian cannot be contacted, N.C. § 90-21.1 allows the physician to make a judgment about necessary treatment for the minor, on behalf of the parents, especially when the condition of the minor is in jeopardy of worsening. Thus, the logic of the statute is apparent. An additional intent of N.C. § 90-21.1 is to protect those who live in the most rural areas of North Carolina. If the physician determines that a child living in a rural area of North Carolina is in immediate need of medical care, and if the parents are refusing medical care for the child, the physician is not required to obtain the second physician opinion due to the extreme shortage of physicians in North Carolina rural areas

The State of North Carolina’s approach to mental health treatment for minors is most

intriguing, primarily because of the controversy and ambiguities that are created with the mental health and informed consent statutes. Emotional disturbance (N.C. § 90-21.5 (a) (iv)) is not clearly defined. One question about this statute, from a clinician's perspective, is whether a physician can perform electroconvulsive treatments (ECT) on a minor without the consent of a parent and remain within the guidelines of N.C. § 90-21.5. Mental health treatment has been defined as, "the process of providing for the physical, emotional, psychological, and social needs of the principal for the principal's mental illness" (N.C. § 122C-72). Mental health treatment also "includes, but is not limited to, electroconvulsive treatment, treatment of mental illness with psychotropic medication, and admission to and retention in a facility for care or treatment of mental illness" (N.C. § 122C-72). Also unclear is the use of the terms *emotional* in N.C. §90-21.5 and *mental health* in N.C. § 122C-72. It is not known if these terms are intended to define similar states of health in an individual, since no definitions are provided.

In evaluating the legal requirements of competency and informed consent related to minors, generally speaking the North Carolina statutes are clear and concise. There is little room for misinterpretation, but the consequences and outcomes for minors remain a question. Additionally, are those consequences and outcomes in alignment with the intent of the law?

Research and analysis of N.C. § 90-21.5 generates questions that can only be addressed in empirical research. Was N.C. § 90-21.5 passed into law without knowing how and why minors (adolescents) consent to treatment? Was it known at the time this bill was passed the influences involved in whether the adolescent consents (or not) to treatment? Was research or clinical evidence that examined competency and informed consent of minors completed and published and used as part of the discussion process in the legislative hearings of the original

bill? Were the legal, nursing and medical disciplines in support of this bill? Was this bill passed as part of concessions or agreements between one or more special interest groups? Although the pathway of this bill was perhaps part of the typical legislative process, there is no documented justification for the passage and ultimate implementation of this law, and there is no evidence to thoroughly and accurately answer these questions.

Parental and Peer Influences on Adolescent Decision-making

Researchers have considered the influence of others on adolescent decision-making for over forty years. Early studies (Solomon, 1963; Brittain, 1963; Brittain, 1966; Emmerich, 1978) that considered adolescent decision-making focused primarily on examining parental influences on everyday decisions made by the adolescent, such as whether to date, who to have as friends, following through with promises, or copying a friends' paper during a test. The findings were similar for each of these studies; adolescents were more likely to consult with their parents about decisions that had a value slant or were considered life altering, such as reporting a serious crime, or whether to lie to gain something. Peers were more influential than parents when it came to non-life-threatening decisions, such as what to wear to an event or deciding who to date.

Ortiz (1983) was among the first to consider decision-making influences in a healthcare situation. The study considered the decisions made by 43 Puerto Rican pregnant teenagers who decided either to abort their pregnancy or have their baby. The participants who decided to carry their baby were most influenced by their parents, and those who chose abortion were most influenced by their peers. Brothers and boyfriends of the teenager were more influential than the subjects' sister when it came to deciding to carry the baby. Fathers were the least influential among those who chose to abort and carry their baby.

Two quantitative studies (Poole, Sundberg, & Tyler, 1982; Poole, Cooney, Cheong, 1986) provided an examination of the differences in influences among adolescents of various cultures. Poole et al. (1982) compared the decision-making between adolescents of India, Australia, and the United States. The authors were specifically interested in comparing the perceived autonomy of the adolescent in making decisions. The ages of the adolescents were not clearly identified. Therefore, it is not understood if the definitions of ‘adolescence’ were similarly used across cultures.

A forty-item questionnaire was used for data collection. The instrument consisted of questions that asked the adolescent who decides certain activities in the family. Examples of questions included who decides what the family eats, where the family attends church, and the types of books that should be read. The options for who decides in a particular situation were mother, father, other family members, self, or other. If the adolescent checked more than one response, weights were assigned based upon how many of the responses were chosen.

As hypothesized by the authors, American adolescents evidenced the greatest perceived autonomy in decision-making, with Australians reporting lesser and adolescents from India the least. Australian girls perceived their mothers were significantly less influential in their decision-making than American and India girls ($F = 3.42$, $df = 2,461$, $p < 0.05$). The father had the most influence in the decision-making among India girls and boys than those fathers in Australia and America. The influence of other family members was most evident among the adolescents of India. A limitation of this study design was that the perception of the family members and “others” was not evaluated and compared to that of the adolescent. One question raised is whether adolescents who perceive themselves as having greater autonomy

in the decision-making process would be more or less likely to choose the medical treatment intervention that is considered by standards of practice to be the best.

Poole et al. (1986) modified the 1982 study and included adolescents from Singapore and Australia. He chose subjects from Singapore because of this country's mix of western and eastern cultural influences. He was interested in how influences differed between a western culture (Australia) and an eastern/western culture (Singapore). The questionnaire that was used in the Poole 1982 study was also administered in this study. The authors reported that overall the fathers of Singapore adolescents were more influential than their Australian counterparts. In Singapore and Australia, adolescent girls tended to be more influenced by their mothers than the adolescent boys. In summary, the same limitations and implications for further research that were considered for the Poole (1982) study apply to this study.

Scherer (1991) offered one of the first investigations of others' (non-parents) influence on the adolescent decision-making about medical treatment options. The subjects were assigned to three groups according to age; 9 and 10 year-olds (20 males and 20 females), 14 and 15 year-olds (20 males and 20 females), and 21 to 25 year-olds (20 males and 27 females). The subjects were asked to read vignettes in which they were asked to choose various medical treatment interventions. The choices included wart removal, tonsillectomy, and kidney donation. The participants were asked to either accept or reject the treatment intervention. Parents were not involved in the treatment decisions during this first reading. The participants were then asked to read the vignettes for a second and third time. The second readings were followed by insertions that the parents were slightly in favor or slightly against the treatment option, but that the parent would ultimately follow the choice of the adolescent (parental non-coercive influence). The third readings were followed by either a parent's

strong agreement or disagreement with the treatment (parental coerciveness). The adolescent was basically told in the third readings that the parent would not accept anything but their decision (the adolescent's treatment preference did not matter if it conflicted with that of the parent's). After reading each situation, the adolescent was asked which treatment they thought was the best and to rate their confidence in choosing the best treatment option based on a conviction scale from 1-10. The participants were also asked to describe what they thought made their choice the right one and these responses were recorded verbatim in order to be qualitatively analyzed.

A MANOVA procedure was implemented to identify whether there were age group differences in the degree to which various parental influences affected the adolescent's treatment choices. There were no differences in the conviction ratings with the wart scenario. The most significant finding of this study is that treatment decisions made by adolescents who are faced with parental influences in the wart and tonsillectomy scenario are not distinct from young adults who are reacting to similar influences from parents. The most significant difference in influence was found with the kidney donation scenario ($F(2, 124) = 2.962, p < .055$). Children (9 to 10 year-olds) were least likely to be sure about their treatment decisions when the parents offered no influence, and the young adults (21 to 25 year-olds) were more certain about their treatment decisions given there was no influence by the parents. There was no significant difference between the child, adolescent and young adult groups in the certainty of the participants' choice of treatment when the parent coerced the decision. There was a statistically significant difference in the non-coercive parental influence situations. The young adults' certainty in treatment was significantly different than the child's certainty ($p < .05$) and the adolescents' certainty in treatment choices were different than the child ($p <$

.01). These are important findings because they give us an understanding of the type of healthcare situations that certain age groups of adolescents rely most on their parents to collaborate about before making decisions. The findings of this study suggest that with the more difficult and potentially life-altering healthcare decisions, younger adolescents are more likely than older adolescents to turn to their parents for advice and guidance.

This study was one of the first to include a qualitative component in the analysis section as an attempt to better understand the nature of influences in the decision-making process of adolescents in healthcare situations. The authors presented several themes in the decision-making process that were delineated from the qualitative analysis. They found that the decisions of the adolescents were influenced by avoiding parental and/or family conflict, respecting parent's decision, and feeling that parents know more about the decision than themselves.

Broome and Richards (2003), both nurses, provided the first published qualitative study that examined the influences on the decision-making of children and adolescents in a healthcare setting. The purpose of their study was to describe the various factors that influence children and adolescents to become involved and to continue in a clinical trial research project. The participants were chronically ill children who were diagnosed with cancer, diabetes, or sickle cell anemia. The authors were particularly interested in the influences of the parents and that of the researcher/clinician in the decision of the child to remain involved in the research.

The research design included the use of semi-structured interviews and narrative analytic techniques and the basic framework was narrative inquiry. The participants ranged in age from 8 to 22 years-old and were interviewed about their experiences with the assent/consent

process for a research study. The focus of influences was not limited to that of the parents, but was extended to that of the researcher/clinician. The overall research question was how children's and adolescents' perceptions of their relationships with adults influenced their decision to participate in a research project.

Parents were reported to be quite influential in the participants' decision-making process. Specifically, children and adolescents would relay that there was a level of faith in their parents and that their parents would protect them and obtain the necessary information to make the right decision about their involvement in the research project. Another common theme was that the participants felt that parents respected what they wanted when it came to deciding for or against continued participation in the study. There were two unique aspects of this study when compared to previous similar studies; it included sick participants, not well participants, and the situations were real life and not hypothetical.

In summary, the findings of these studies demonstrate that family members and peers influence adolescents when it comes to the decision-making. The extent that family members and others influence the adolescent is dependent on the type of decision and the significance placed on it by the adolescent. For example, adolescents who are faced with life altering choices tend to rely heavily on their parents for guidance in making the decision. Overall, parents are significantly influential in the adolescent deciding, and adolescents rely heavily on their parents for guidance in making a variety of treatment decisions. However, the extent of parental influence in the adolescent consenting to psychiatric mental health treatment is not fully understood.

Considering the minor informed consent rights that afford the adolescent the right to consent to psychiatric mental health treatment without the required consent of parents, it is

critical to completely understand the influences of family members and peers on the decision-making process. Understanding the influences of adolescents in deciding on healthcare situations will provide nurses and legislators the accurate information to formulate and implement minor consent laws. Based on whether the influences of parents and peers are therapeutic or anti-therapeutic, policy makers could make more informed decisions related to proposing and passing bills. Also, if parents positively influence adolescents in making decisions about their healthcare treatment, then perhaps the expanded minor consent laws should be reconsidered. Legislative decisions and health policy could, thus, be guided by empirical data.

Summary

It is generally agreed that adolescents are as capable as adults in making certain decisions (Ambuel & Rappaport, 1992; Bastein & Adelman, 1984; Kaser-Boyd, Adelman, Taylor, & Nelson, 1986; Lewis, 1980; Scherer & Repucci, 1988; Weithorn & Campbell, 1982). Based on these research findings, it has been argued that adolescents should be afforded the same consent rights as adults. Some have refuted these studies claiming that the adolescent's capacity to decide was evaluated in hypothetical situations and could, therefore, not be generalized so easily to real-life situations (Fundudis, 2003; Mulvey & Peebles, 1996). When placed in the context of real-life healthcare decision-making, there is limited research that has considered the adolescent's perception of the decision-making process.

Parents and peers influence adolescents in certain decision-making situations. Much of the knowledge available on the influences of adolescents' decision to consent to healthcare treatment is based on evaluating the decision-making process of adolescents in hypothetical healthcare situations (Emmerich, 1978; Ortiz, 1983; Poole, Cooney, Shook Cheong, 1986).

However, we do not know the influences on adolescents who consent to life-altering, real-life, healthcare situations, specifically psychiatric treatment.

The North Carolina statute, N.C. § 90-21.5, provides adolescents of that state the right to consent to certain healthcare treatments, including psychiatric mental health, without the required consent of the parent. These rulings were made without really understanding how and why adolescents consent to treatment. Further, the perception of treatment outcomes, whether therapeutic or anti-therapeutic, as a result of an adolescent consenting to healthcare treatment with or without the parents' consent is not known.

To examine the experiences of adolescents who are consenting to healthcare treatment, specifically psychiatric mental health, three models appropriately serve as a synthesizing framework for the research design. First, a decision-making model (Fischhoff, Crowell, & Kipke, 1999; Janis & Mann, 1977; Mann, Harmoni, & Power, 1989) provides a guide in examining the adolescent's decision-making process in consenting to psychiatric treatment. Second, TJ (Wexler & Winick, 1992) provides a legal theoretical model for considering the process adolescents take in consenting to treatment without the required consent of their parents. Third, Vygotsky's concept of *scaffolding* (Bjorklund, 2005) provides the model for considering the influences of parents and peers on the adolescent's decision to consent to psychiatric mental health treatment. The combined models of decision-making, TJ and scaffolding are presented in Figure 3.

Understanding the experiences related to the decision-making process of adolescents who consent to treatment will provide nurses with knowledge of how to support the individual through that process. Clinical and research nurses could play a more pivotal role in identifying the therapeutic and anti-therapeutic outcomes of legal rulings, especially when

these rulings may affect the overall mental health of the adolescent. Understanding how and why adolescents consent to psychiatric mental health treatment has the potential to assist the nurse in presenting treatment information to adolescents so they can make decisions that are based on long-term outcomes, not solely on developmental needs of independence and autonomy.

CHAPTER THREE

METHODS

The overall purpose of this study was to explore the decision-making process of adolescents who consent to psychiatric mental health treatment in real life situations. In addition, this study explored the experiences and views of parents whose adolescent consents to treatment without their consent. Quantitative research that examined adolescents who consent to healthcare treatment have considered one aspect of the decision-making process, such as whether an adolescent can identify goals and consequences of their decision, and not the whole process of decision-making (Kaser-Boyd, Adelman, Taylor, Nelson, 1986; Urberg & Rosen, 1987; Weithorn & Campbell 1982). Published research related to adolescent decision-making in healthcare is substantially limited by: (a) use of small sample sizes; (b) use of hypothetical vignettes that are not necessarily related specifically to healthcare decisions that the individual will face; (c) measuring one aspect of the informed consent process (competence); and (d) inferring that an adolescent who is deemed competent is capable of making complex medical decisions.

Unfortunately, despite articulated standards of practice, specified ethical and moral obligations, and a legal requirement for informed consent, there is no published research that supports adolescents consenting to psychiatric mental health treatment. Namely, there is a lack of empirical data about the decision-making process of adolescents who consent to healthcare treatment, specifically psychiatric mental health treatment. Yet, *informed consent*

is required legally and statutes determine when adolescents are considered capable of executing the consent. Thus, the lack of understanding of the decision-making process of adolescents who consent may undermine the legal requirements.

In order to understand the complexities of the experiences and perspectives of adolescent consent, a qualitative descriptive research study was required (Denzin & Colin, 2005; Sandelowski, 2000; Strauss & Corbin, 1998). The purpose of a descriptive method is to capture the true experiences of an individual given a particular situation, and how these experiences are related to one another (Strauss & Corbin, 1998; Martin, 2006). Interviewing adolescents and their parents provided a better understanding of the specific complex processes that adolescents go through in deciding to consent. In addition, this approach was the best way to capture the experiences of parents whose children had consented to psychiatric mental health treatment. Data collected from interviews with adolescents and parents provided the descriptions needed to understand the influences of parents and others on the adolescent's treatment choices. Descriptive research method also provided the necessary flexibility to explore the multifaceted components of the adolescent consent process. For example, the questions and probes in the interview scripts evolved over time based on participant's responses.

Subjects and Setting

Subjects

Sample size in qualitative research is determined by theoretical data saturation, rather than power analysis, which is associated with quantitative research (Munhall, 2007). The sample size for this study consisted of 16 adolescents and 13 parents or legal guardians. The age range of the adolescents was 12 to 17 years (nine 12 to 14 year-olds and seven 15 to 17

year-olds). These age groups represent the major adolescent developmental stages. The study included a relatively equal number of females (9) and males (7). The intent for this inclusion was to identify any differences between genders in problem solving abilities. The study included 10 African American and 6 Caucasian adolescents.

Both biological parents and/or legal guardians of the adolescent were asked to participate in the study. A total of 13 parents or legal guardians agreed to participate. Ten biological mothers, one biological father and two maternal grandparents comprised the parent/legal guardian participants. The grandmothers were the legal guardians of the adolescents they represented. Among the parents, 6 were at least high school graduates but 6 had no high school diploma or GED equivalent. No child had two biological parents or grandparents residing in the same household. Eight of the fourteen parents/grandparents were single, divorced, or widowed. A comprehensive outline of the demographic information for the adolescent and parent participants is provided in Tables 1-7.

Table 1. Gender and Race Frequency Distribution by Age Group

Age Group Total (<i>n</i>)	Caucasian (<i>n</i> =6)		African-American (<i>n</i> =10)	
	Female (<i>n</i> =1)	Male (<i>n</i> =5)	Female (<i>n</i> =8)	Male (<i>n</i> =2)
12 to 14 (9)	0	3	5	1
15 to 17 (7)	1	2	3	1

Table 2. Diagnosis and Frequency by Age Group

Diagnosis	12 to 14 year-olds (<i>n</i> =9)	15 to 17 year-olds (<i>n</i> =7)
ADHD	3	1
ODD		2
MDD		2
PTSD	1	
Social Phobia	1	
ADHD/DBD	2	
ADHD/ODD	1	
ADHD/MDD		2
ADHD/PTSD/ODD	1	

Note: ADHD – Attention Deficit Hyperactivity Disorder

ODD – Oppositional Defiant Disorder

MDD – Major Depressive Disorder

PTSD – Post Traumatic Stress Disorder

DBD – Disruptive Behavior Disorder

Table 3. Frequency of Current Management Regimen by Age Group

Age Group Total (<i>n</i>)	Medication Only (<i>n</i> =4)	Therapy Only (<i>n</i> = 6)	Combined (<i>n</i> =6)
12 to 14 (9)	2	3	4
15 to 17 (7)	3	2	2

Table 4. Participant Grade Level Progression Frequency By Age Group

Age Group Total (<i>n</i>)	On Time Grade	1-Year Behind Grade	≥2-Years Behind Grade
12 to 14 (9)	4	4	1
15 to 17 (7)	2	4	1

Table 5. Frequency of Marital Status of Parents/Legal Guardians

Total (n)	Single Never Married	Married	Divorced	Widowed
Mother (10)	5	4	1	
Father (1)			1	
Grandmother (2)		1		1

Note: No adolescent participant was residing with both biological parents

Table 6. Frequency of Parent/Legal Guardian Employment Status By Role

Total (n)	Unemployed	Employed*
Mother (10)	5	5
Father (1)		1
Grandmother (2)	2	

Note. *=Full or Part-Time Employment

Table 7. Frequency of Highest Education Attainment of Parents/Legal Guardians By Role

Total (n)	< High School and no GED	GED	High School And some college	College graduate
Mother (10)	5		5	
Father (1)				1
Grandmother (2)	1	1		

Adolescents and parents whose only language was English were recruited and included in this study. All adolescents who participated in this study were from lower socio-economic families. The sample was purposeful in that adolescents recruited for the study had consented to treatment and were receiving out-patient psychiatric mental health treatment. Psychiatric mental health treatment is defined as a combination of medication and psychotherapy intervention.

Only adolescents who were receiving maintenance psychiatric mental health treatment were considered for this study. Maintenance treatment was defined by the American Psychiatric Association (APA) (2006) as a period of treatment when the patient is not experiencing recurrent signs and symptoms of the illness being treated. Although *maintenance phase* is not defined by the number of weeks or months, the criteria established for this study were as follows: over the past four weeks, the adolescent's medications had not been changed or adjusted either in dosing or type, and new issues in therapy were not being addressed.

It was essential to include participants in this project who were in the maintenance phase of treatment, because the individual has the ability to reflect on the treatment decisions that were made and how these decisions have contributed to their current mental health stability. The desire was to capture the entire experience of the adolescent consenting to treatment, which includes reflecting back on the choices that were made in the consent process and how these choices related to the treatment outcomes. To ensure that the participant was in the maintenance phase of treatment, consultation occurred with the treatment team of the facility prior to enrolling the participant in the study. Using the sampling criteria, therapist and nurse practitioners agreed to identify adolescents and their parents for participation in this project. Potential participants were initially approached by the treating nurse practitioner or therapist and were informed about the study. Appendix 11 contains the recruitment flyer that was provided to the interested participant as a brief description of the study. Appendix 12 contains the script used by the nurse practitioner or therapist in discussing the study with the participant. If the participant desired to be contacted by the PI, the script included in Appendix 13 was used during the initial telephone conversation between the PI and the

interested participant. If the interested participant preferred to contact the PI, a script paralleling the one in Appendix 13 was followed to explain the study to the interested participant.

Setting

Data collection took place in a community based out-patient psychiatric mental health practice located in a mid-sized city in the Southeast. Services provided by the facility include medication intervention, individual psychotherapy, group therapy, and case management services. Psychiatric Mental Health Nurse Practitioners provide medication management in addition to individual and family therapy for patients. Master's and doctoral level therapists provide individual and group therapy. Case management is provided by bachelor's prepared therapists.

The treatment team at the facility consisted of nurse practitioners, therapists, and case managers. Treatment teams met once per week to discuss the progress of patients. It was at these meetings that the treatment team determined if a particular patient who was interested in participating in the study was considered to be in the maintenance phase of treatment. The treatment team recommended the inclusion or exclusion of the adolescent from this study based solely on whether they were in the early or maintenance phase of treatment.

All age groups are served by this community mental health center. However, there is a focus on the out-patient psychiatric mental health treatment of children and adolescents from lower socio-economic levels. This researcher is a contracted employee of the facility as a State of North Carolina licensed PMHNP and a board certified (American Nurses Credentialing Center) Family Psychiatric & Mental Health Nurse Practitioner and Adult Psychiatric & Mental Health Nurse Practitioner. To minimize bias, this researcher was not

part of the determination of whether participants met the criteria for inclusion in this study. Further, the treatment team members made initial contact with the participants about participating in this study. It was only after the participant was made aware about the study by the treatment team member that this researcher made contact with the participant about enrolling in the study.

Exclusion Criteria

Adolescents in the early phases of treatment were not included in this study. An adolescent was considered in the early phases of treatment if they were receiving medication changes or if issues related to therapy were recently being disclosed and had not been addressed to any degree. Adolescents who were experiencing returned signs and symptoms of the mental illness were not included in this study. Adolescents whose primary language was other than English were not included in this project. If the treatment team determined, for whatever reason, that the adolescent should not be recruited for this study, the author respected this decision and the adolescent was not included in the study.

Consent Process

Full approval for this research was obtained from the University of North Carolina at Chapel Hill Public Health and Nursing Institutional Review Board. Informed consent was obtained from adolescent and parent participants. First, in order for the adolescent to participate, consent from the parent for the adolescent to be involved in the study was obtained. Second, consent for the parent was obtained. And finally, consent from the adolescent was obtained. Verbal permission to conduct this study at the facility site was received from the organization's owner. As required by HIPAA, this author signed a form

provided by the facility to protect the confidential information gleaned from review of the participant's medical record.

Procedure

After the appropriate informed consents (Appendices 1 – 4) were obtained by this researcher, adolescents and their parents were interviewed by this researcher using a semi-structured interview script (Appendices 5 & 6). Although the intent was to consistently follow the interview script, participants were encouraged to discuss other matters not included in the interview questions that were related to the research topic. The interview script was formulated with the assistance of the dissertation committee members and experts in the field of psychiatric mental health. The final interview script was pilot tested with three adolescents and two parents of adolescents to ensure that the interview questions could be understood and comprehended. The adolescents and parents who participated in the pilot test were not included in the final data analysis of this study.

Interviews with the adolescent and parents were audio recorded with the use of an Olympus digital recorder. Adolescents and their parents were interviewed separately in a private, sound-proof room at the study facility. Parents were interviewed first followed by their adolescent. Each interview lasted for approximately one hour. Specific consent for this author to read the medical records of the adolescents was obtained (Appendices 7 & 8). The information extracted from the medical records included demographic data about the adolescent, such as year of birth, ethnicity, mental health diagnosis, medical diagnosis, and education level (Appendix 9). Parents were asked to complete a short demographic form related to their gender, age, ethnicity, socio-economic status, marital status, and education

level (Appendix 10). Appendices 11-13 include an example of the flyer and supplemental scripts used in the recruitment process.

Data Management and Analysis

Data analysis was a continuous process throughout the study (Ulin, Robison & Tolley, 2005). The researcher transcribed the data after each interview. After each interview was transcribed, the researcher listened to each interview while reading along with the text to ensure the accuracy of the transcribed interviews. This approach was extremely helpful in getting to know the details of the interviews, in keeping the researcher immediately aware of any new discoveries from interview to interview, and providing alerts to make necessary modifications to the interview questions. One change that occurred in the original interview script was related to the use of the word “influence”, in terms of those who influenced the adolescent to remain in treatment. The first two adolescents who were interviewed interpreted “influence” as having a negative connotation. However, when the word “encourage” was used in place of “influence”, the adolescent responded with a range of positive to negative descriptions.

All field notes were transcribed by this author. Field notes contained a detailed description of the events that occurred during the interview, such as the location, date and time of the interviews and any events that were observed during the interview. These notes also included what was learned by this author from one interview to the next. The field notes were organized chronologically in a loose-leaf binder (Munhall, 2007).

Each participant was assigned a number that was only identifiable by this researcher. Each document that included data (transcripts from adolescent and parents, demographic information, field notes) was assigned the participant number. All parent information

collected was linked to the respective number assigned to their adolescent. No participant identifying information was linked to the transcripts, audio-tapes, field notes or demographic information. All collected data were categorized according to date and time of interview, and the de-identifying number assigned to each participant. The data remained in the possession of this author only throughout the study and will remain in the possession of this author for five years upon completion of this study.

Recorded interviews and field notes were transcribed into a laptop computer, using Microsoft Word, immediately following the interview. Interview transcripts were catalogued in computer files, a USB mass storage device, and hard copy notebooks to include participant number, date of transcription, and name of transcriber. Hard-copy interview transcripts are organized in a loose-leaf binder. Copies of all computer files are stored separately from the original files.

Word documents were converted to Atlas/ti©, a qualitative software package that provides a way of reading, maintaining and analyzing data (Martin, 2006). Atlas/ti© assisted in the management of the data by reassembling the large amount of text that was produced from this study into one document. This provided a means of examining the data in a more comprehensive and complete manner (Martin, 2006). A codebook was developed to identify the key concepts and sub-concepts in the adolescent and parent interviews.

The data analysis process was completed using several components. Verbatim transcripts were read iteratively (Parse, 2001). A system of data reduction, through open, *in vivo*, and axial coding (Strauss & Corbin, 1998) techniques were used when appropriate. Members of the dissertation committee and psychiatric mental health therapist and nurse practitioners assisted in evaluating the coding schemes. The components and sub-components of coded

data were analyzed to develop themes, and then the themes were related to the research questions and synthesizing framework (Denzin & Lincoln, 2000; Krippendorff, 2004; Parse, 2001). Collected field notes were used to enhance the insights provided by the transcripts (Parse, 2001).

Content analysis of the data was completed for this study. This approach was helpful considering the limited knowledge on the topic of the decisions adolescents make in psychiatric mental health situations (Rew, 2005). This study involved manifest content analysis, meaning that the data were categorized, in this case according the interview questions (Rew, 2005). The categories were further separated into indexes and ultimately represented by exemplaries which were included as support for the findings. The units that were analyzed in this study were primarily phrases and sentences from the adolescent and parent interviews.

To increase the credibility of this study, thick rich detail of the setting, the participants, and the themes that emerge from the data were provided (Creswell & Miller, 2000). Validation of data was crucial to ensure the accuracy of the data and reliability of the findings. To make certain validity was optimized, accuracy of the transcripts was thoroughly scrutinized by this researcher. Creswell and Miller (2000) state that validity in qualitative studies is defined by how accurately the account of the study participants' realities is presented in the data analysis. The researcher was most concerned with the inferences drawn from reported study results and whether the realities of the participants were provided. Therefore, validity of the findings was checked by asking the study participants themselves if the interpretations by this author truly captured the essence of their experiences (Parse, 2001). Another test of validity involved this author sharing the descriptions and the steps of

analysis with qualitative experts, including those on the researcher's research committee (Munhall 2007, Parse, 2001).

CHAPTER FOUR

FINDINGS

The focus of this study was to explore the experiences of adolescents consenting to psychiatric mental health treatment and the experiences of parents whose adolescent has consented to psychiatric mental health treatment. Research Question #1 asked how 12 to 17 year-old adolescents who consent to psychiatric mental health treatment (medication intervention, psychotherapy, or a combination of both) perceive the process of deciding to accept treatment. This question will be addressed by presenting findings related to the (a) adolescent decision making steps in treatment, and (b) the adolescent initial treatment decisions. Research Question #2 asked how 12 to 17 year-old adolescents who consent to psychiatric mental health treatment (medication intervention, psychotherapy, or a combination of both) perceive the goals of treatment. This question will be addressed by presenting findings related to the (a) adolescent continued treatment decisions, (b) adequacy of adolescent treatment decisions, (c) best treatment decisions as perceived by the adolescent, (d) parental influences from the adolescent's perspective, (e) adolescent definition of "consent to treatment", and (f) adolescent evaluation of minor consent laws.

The experiences of parents whose adolescent consented to treatment were also explored. Research Question #3 asked about the parents' perceptions of the roles they played in the adolescent's decision to consent to treatment. This question will be addressed by presenting the findings related to the parent views of their adolescent's initial treatment decisions.

Research Question #4 asked about the parents' perceptions of the roles they played in the goals of treatment. This question will be addressed by presenting the findings related to the (a) parents' views of their adolescent's continued treatment decisions and (b) the parents' views of their influence on their adolescent's treatment decision. Research Question #5 asked about the parents' experiences of their child (adolescent) being afforded the right to consent to psychiatric mental health treatment without the parent's consent. This question will be addressed by presenting the findings related to the (a) parent definition of "consent to treatment", (b) parent knowledge of minor consent laws, and (c) parent evaluation of minor consent laws. Names used are not actual names of the participants. Phrases in bolded italic quotation marks are direct quotes from participants.

Adolescent Interviews

Research Question #1 – Adolescents' perceptions of their decision-making process about treatment

Decision-making Steps in Treatment

The following decision-making step model was used as the framework in formulating the interview questions and will serve as a guide to present the findings: (a) the adolescent's recognition that a treatment decision is required, (b) the adolescent's understanding of treatment goals, (c) the ability of the adolescent to determine the consequences of the treatment decisions, and (d) the adolescent's ability to understand that each consequence is likely to occur, which includes assimilating and integrating the information provided about treatment options (Fischhoff, Crowell, & Kipke, 1999; Janis & Mann, 1977; Mann, Harmoni, & Power, 1989).

Recognizing that a treatment decision was required. Adolescents were first asked about the decisions they made in initiating psychiatric mental health treatment with the following: “Tell me about the initial decisions you made about getting treatment” and “how did you decide that you needed treatment?” The researcher was specifically interested in how the adolescents came to the decision that they were in need of treatment. Particular attention was given to those decisions that the adolescent made without the parent or legal guardian to initiate treatment. It was important to distinguish between those decisions that the adolescent made without others and those made with others in order to fully understand if the adolescent recognized that a decision about their mental health treatment was required.

“I knew I needed to get some help, I had to.” All adolescents reported that during the initial meeting with the nurse practitioner or therapist, they realized that a decision about treatment choices would be needed. Most ($n=12$) adolescents stated that the initial decision to seek treatment was completed in collaboration with their parent or legal guardian. Some adolescents ($n=4$) reported that decisions made about initiating treatment were made without the parent. All adolescents felt their own input was taken seriously by their parent and nurse practitioner, whether in making independent decisions or decisions in conjunction with their parent or legal guardian.

There was strong evidence to support the adolescent’s ability to identify that a decision about treatment was needed or ultimately required. For example, a common response among adolescents was that they knew when the initial appointment was made at the treating facility there would ultimately be a decision made about accepting or rejecting treatment. All adolescents identified that the general purpose of the initial visit to the facility was to receive psychiatric mental health treatment, and that a decision about their treatment would be

required. Although all adolescents engaged in discussions about their initial decisions to seek treatment, the older adolescents (15 to 17 years-old) provided more detailed and focused descriptions regarding their perceptions of need for treatment.

The interview questions included asking adolescents about the initial treatment-related decisions. Each adolescent was asked about the purpose of seeking treatment and more specifically about starting treatment. The purpose of posing questions in this manner was to determine exactly what decisions the adolescents made about their treatment. It is evident that all adolescents could recognize that a decision to seek mental healthcare was needed, based on their negative experiences behind and ahead of them:

I was on drugs real bad and I started, when I, I felt real bad one day. I was like crying all of the sudden, I don't know. I had this feeling that something weren't right so I went to [private hospital]. I told my mom that I wasn't feeling great, so she took me to the hospital and I was the one who wanted to go but she kind of helped me out with that. Then I wanted to come here because [private hospital] didn't think I needed to be in the hospital. So, I knew I needed to get some help, I had to. (John, 17 year-old male)

I needed to get help with my problems...I had a bad attitude and behavior, and I wanted to get help with all that. So, I knew that coming here was something I had to do. My mom said to me that she thought it would help me to come here, so I came here. (Kay, 13 year-old female)

Understanding the goals of treatment. Adolescents were asked specific questions related to their goals of treatment to understand whether the adolescent could identify personal treatment goals, rather than those established by others (i.e. nurse practitioner, therapist, parents). Each adolescent voiced specific goals for treatment, including those independently formulated and those that seemed influenced by others.

“I just wanted to feel better.” Most adolescents based their goals of treatment on the struggles experienced in living with their mental illness. One 17 year-old male diagnosed with a Major Depressive Disorder, severe type, communicated that his goal in treatment was

to, “feel better and to not be so depressed...I was not doing well in school because of the depression and I needed to get my grades better...but I had to get over the depression first.”

Other examples of goals were:

I wanted to, uh, stop stressing all the time and stop fighting and stuff and fighting to my little sister (Lauren, 15 year-old female).

I wanted to be able to control myself better and bring my grades up...I was feeling real bad and I just wanted to feel better (John, 17 year-old male).

I wanted to start feeling better about myself and um, feel better about the past and get over the death of my grandfather (Joe, 13 year-old male).

“To not end up like my mother.” It was evident in some responses ($n=3$) that some adolescents may have formulated an answer about their goals in treatment based on what they had been told by others. For example, a 12 year-old male who had been sexually molested by his mother for many years reported his goal in treatment was, “to not end up like my mother because she molested us [siblings] when we were little and I don’t want to molest my kids when I get older.” The concept that certain behaviors, such as molestation, are somehow ‘passed down’ are at a higher level of logic and abstraction that would normally be expected of an older adolescent, but not of a 12 year-old’s thought pattern. This response suggests that an adult discussed this particular goal with him. Regardless of his age, this adolescent was capable of stating a treatment goal and he had learned from prior experiences.

“To feel better now.” Initially, questions about their short-term goals and responses were highly detailed. However, when questioned about any long-term goals that were established in the initial stages of treatment, adolescents would consistently refer back to the short-term goals of feeling better now, improving grades, or to stop being angry. The

adolescents were unsuccessful in identifying long-term goals established at the onset of their treatment. But, they were successful in discussing immediate goals such as to feel better now.

Determining the consequences of treatment decisions . To understand whether adolescents could determine the consequences and risks associated with taking medication or engaging in individual or group psychotherapy, the participants were asked to identify the reasons for taking the medications or receiving psychotherapy.

“The medication helps me calm down.” Identifying the reasons for any treatment is an important step to being able to identify the consequences. All adolescents spoke easily about their reasons for taking medication. Each rationale was linked with past behavioral experiences that were perceived as negative with positive medication effects. Each related to a context important to the adolescent – school performance, emotions, and relationships. The extent of knowledge about the specific reasons for the medications and the elaboration provided by the participants varied, but not by a specific age group. The following are examples of responses when the adolescents were asked to identify the reasons for taking the medications:

Cause it [Adderall] help me focus...it help me slow down and focus so I can do my work at school, it just help me focus a lot, I can really tell the difference since being taking it because it help me focus more. I was hyper AD ? [sic] I was also depressed, so I taken that Lexapro so it'll help my attitude...my mood was not good and it made me feel better, I've been feeling better while taking that (John, 17 year-old male).

I'm taking it [Zoloft] because it won't, I won't be so sad and stuff like I used to be after what happened and stuff. I was depressed and not myself, and I needed to feel better, so the medication took, it took, it made me feel better, it took away that depression, so that's the reason I need to take it (Angela, 15 year-old female).

I take Metadate so, it help keep me calmed down a little bit and help me in school...I do better in school, my grades are better...it were given to me because I were hyper a lot, and were gettin' in trouble at school a lot (James, 12 year-old male).

I know the medicine, it [Concerta] helps me concentrate more (Sue, 14 year-old female).

“Wellbutrin influences dopamine levels.” One 16 year-old adolescent provided a more technical response as to the reason and purpose of the medications he was prescribed. His response differed from other adolescents because he made no mention of how the medication helped him feel better or for what purpose the medication was intended. Even with the use of probes, the adolescent did not seem to make the connection between the goal to feel better and taking an antidepressant. Discussion by the adolescent about the intended purpose and reason for the medication remained at a medical terminology level:

Um, Wellbutrin, um, influences your dopamine levels, while Lexapro is an SSRI, which focuses more on serotonin, but it does, I think, influence overall levels...like all three brain chemicals (Tim, 16 year-old male).

This adolescent's father is a healthcare professional and frequently discusses with his son the reasons for the medications, perhaps on a more technical level than an emotional one.

“Therapy can relax you.” Adolescents were also capable of identifying reasons for receiving therapy:

He's [therapist] teaching me like, um, stuff like tell me don't do bad stuff and what not do and what is good to do. Like he told me I got, um gotta start talking and stuff about stuff that could help me (Lauren, 15 year-old female).

I feel that therapy can relax you, and it can make you feel better. And it can open up your community skills and how you communicate with other people (Barbara, 14 year-old female).

“Antidepressants increase risk for suicide.” In terms of adolescents identifying consequences and risks associated with medication or psychotherapy intervention, the responses varied according to age. Each adolescent understood the meaning of *risk* as they were asked to provide a definition of the word and an example of ‘taking a risk’. For

example, one adolescent (13 year-old male) defined “taking a risk” as “taking a chance”. He further provided an example by describing, “if you drink and drive, that’s a risk of getting a ticket for driving drunk, or it’s a risk of hitting someone while you’re drunk...having a car accident.” Out of the 11 adolescents taking medications, only one (16 year-old male) provided a clear understanding of the risks involved with taking the medications he was prescribed. This was also the adolescent (**Tim, 16 year-old male**) who discussed the goals of the medication in more technical terms.

*Um, Lexapro, like it has a side effect of, like, like tiredness, which at the beginning I felt a lot, like collapsing in the middle of class until we the times I given[sic] it were switched. I know that Wellbutrin can, is like, has a real risk for seizures....so you always have to be careful about your dose. I know that all antidepressants, especially for adolescents, can increase, like, risk of suicide, well for all ages, but particularly focusing on adolescents because you suddenly have that energy to do things, while it’s (antidepressant) not necessarily treating your behavior yet (**Tim, 16 year-old male**).*

“There are no risks.” Tim’s identification of risks associated with taking medications was not typical. In fact, a common theme among the adolescent participants was their inability to identify risks associated with taking the medications they were prescribed. Out of the remaining ten adolescents taking medications, eight stated the medication(s) they were taking had no risks. Two adolescents responded with, “I did not know” when asked if the medication(s) they were taking had any risks. The examples reflect that the notion of no risks may be related to the adolescent’s perception that they had not experienced any side effects or adverse events, thus there must not be any risks involved in taking the medication:

*No, there ain’t no risks...it [Concerta] hadn’t done anything wrong to me for the past two years that I been taking it (**James, 12 year-old male**).*

*I don’t know of any [risks] ...it help me, it don’t hurt me (**Jean, 12 year-old female**).*

Nothing really...I don't remember what the risks was if there was any...cause I guess they really weren't that bad even if there was em [risks]. I don't know of any [risks]
(Angela, 15 year-old-female).

One 15 year-old female adolescent identified a side effect of taking Zoloft by stating, "I think I've got to eat with it [Zoloft] so I won't get sick." One adolescent provided the following response to the risk associated with her medication. Similar responses were shared by others ($n=6$), but this was the only response this particular adolescent provided in explaining the risks associated with taking Zoloft:

If I take, if I take a lot of them I know it can do, make an overdose **(Sue, 14 year-old female).**

"If therapy is helping, how could it hurt?" No adolescent receiving psychotherapy was able to provide a description of any risks involved in this form of treatment. Each adolescent was asked why they did not think there were any risks associated with receiving therapy. The overwhelming response was similar to, "if therapy is helping, how could it hurt?"

In summary, most adolescents did not identify risks associated with taking certain psychotropic medications or receiving psychotherapy. No adolescent identified risks associated with receiving therapy. However, in the adolescent's eyes, the positive effects of improving sadness, providing increased ability to focus, and improving energy levels, satisfied their goals without any thought or consideration to risks or consequences.

Understanding that each consequence is likely to occur. This step of the decision-making process involves the adolescent assimilating all of the treatment options presented and deciding on the desirability of each consequence. Each adolescent involved in this study was receiving medication, psychotherapy, or a combination of both. To obtain information about the process of assimilation, adolescents were asked questions about their initial

treatment decisions in addition to those decisions made about continued treatment. The information gleaned from this interview approach provided an understanding of the process the adolescent went through to incorporate the psychiatric mental health treatment information presented.

Initial Treatment Decisions.

“We made them together.” Most ($n=12$) adolescents perceived that they made the initial decisions about treatment with their parents. Adolescents spoke of the collaboration with their parents in the initial phase of treatment. This collaboration consisted of discussions about whether or not to start medication or psychotherapy intervention.

We decided that I was going to get treatment and that I would take the medicine that I’m taking (Joe, 13 year-old male).

We [mother and adolescent] talked about if I wanted to get treatment, so that’s something we decided together (Jill, 13 year-old female).

She [grandmother] wanted me to take the medication and I wanted to take it too, so we decided that together (Mack, 15 year-old male).

“I made the choice.” Other ($n=4$) adolescents perceived that they were the ones who decided upon initial treatment, including what kinds of interventions they would consider:

I’m the one that told them [parents] that I wanted to go [to treatment] and everything (Jim, 17 year-old male).

I made the choice about me getting into group therapy (Jill, 13 year-old female).

I decided to not take medication and just to get therapy (Elaine, 17 year-old female).

I decided to take the Risperdal...it was me who decided that the first time around, because my mother weren’t no where around (Joe, 13 year-old male).

Research Question #2 –Adolescents’ perceptions of the goals of treatment

Continued Treatment Decisions.

“We made those together too.” The perception among all adolescents was that most decisions made related to continued treatment (those made after the initial treatment decisions) were made with their parents. Examples of continued treatment decisions included goals related to making changes in medications, either in type, dosing levels or timing, or discontinuing therapy.

Um, I was asked if I wanted to be switched to a different dose and me and my parents talked about that to see if I needed (Tim, 16 year-old male).

My mother asked me if I wanted to stay here [treatment facility], because she would have take me somewhere else if I really wanted to, because I wanted to go to therapy (Jill, 13 year-old female).

We made all those together...because after I was taking the medication for a while we decided if it were working and we decided that it was, so that’s what we decided together (Sue, 14 year-old female).

“I decided on the mentor I wanted.” Some ($n=6$) adolescents reported making some decisions about continued treatment without their parents. These decisions included those made about staying on medications, choosing a mentor, or getting to the appointments at the facility:

I think the biggest choice I made [about treatment] was not making a big deal out of it, I just kind of went along, but the fact that I just stayed on it [medication], that was not really influenced by my parents (Tim, 16 year-old male).

I decided on the mentor that I wanted (Sue, 14 year-old female).

I decided if I’m feeling something, to just tell my therapist and not hold back like I usually do (Barbara, 14 year-old female).

Mainly to stay on medicine and to keep taking it every day, and I kind of like it because I kind of get focused on that and I’m a little better (Dave, 13 year-old male).

Adequacy of Adolescent Treatment Decisions

Given the significant decisions made about their treatment, it was important to understand the adolescents' perceptions about the best decisions that were made in treatment. Adolescents were asked, "Which decisions about your continued treatment do you consider the best; those made without your parent, by your parents without you, or with you and your parents?" "Best" was defined as those decisions that have most led to the adolescent's current psychiatric stability.

The best treatment decisions. The overwhelming theme was that the adolescents ($n=16$) perceived that the best decisions made about their continued treatment were the ones made in collaboration with their parents. When asked about why they perceived that the best decisions about treatment have been made with their parents, a common response was that collaboration with parents provided them with the opportunity to reflect on the information about treatment more effectively and that some of the treatment decisions could not have been made without their parent. The time spent to mull over the information with their parents prior to deciding was described as important. The discussions with parents about treatment were viewed as helpful in the process and supportive for decision-making.

"The decision me and my grandmom have made." Among those ($n=11$) taking medications, most ($n=8$) relayed that they would not have been able to make a decision about what type of medication to agree to if this decision would have been made independent of their parent(s)/legal guardian. Although some adolescents ($n=2$) taking medications relayed that initial decisions related to their treatment were made primarily by their parents, these adolescents perceived that their parents played an integral role in the decisions made about

the adolescent's continued treatment. The following is a representative response of the adolescents when asked about the best decisions made related to their continued treatment:

Definitely the decisions me and my grandmom have made because, well, they (parents) give me an opportunity to learn from them after the good decisions they make. So I make more decisions, more better decisions than I do [now] (Sue, 14 year-old female).

Parental Influence from the Adolescent Perspective

When adolescents were asked if parent(s)/guardians were influential in their remaining on the prescribed medication(s) and remaining in therapy, the adolescents' comments indicated the important roles of parents in facilitating treatment through a variety of mechanisms. The adolescents' description of these roles is represented by the following labels: *encourager*, *transporter*, *administrator*, and *purchaser*.

"She [mother] just helps me." Fifteen adolescents viewed the most influential role of the parent as that of *encourager*. The adolescents contributed their continued commitment and follow-up to treatment to the consistent encouragement that their parents provided them throughout treatment. Adolescents voiced a strong need for parental encouragement during treatment and discussed this particular role of the parent as essential to their continued stability:

She just tells me, um, the medication ain't nothing bad to take...so you shouldn't feel bad about taking stuff that's going to help you (Lauren, 15 year-old female).

Sometimes I didn't want to be in there [group room] with one of the people who were making me mad, I didn't want to go be in there when she [mother] said that if you go you can get some stuff off your chest and talk to the person that you're mad at (Joe, 13 year-old male).

She [mother] just helps me because she tell [sic] me it's good to be in it [therapy] and get help for myself (Jill, 13 year-old female).

My mom, she tells me that I should go more often because she sees a change in my attitude (Barbara, 14 year-old female).

“She makes sure I get there [mental health facility].” Several adolescents ($n=7$) described that one manner in which their parents/guardians were influential in contributing to their stability was the role the parent played as a *transporter*. Although this role did not receive the emphasis of the *encourager* role, adolescents from both age groups identified this role as an essential component to their overall continuation in treatment.

She makes sure I get there [mental health facility] **(Elaine, 17 year-old female).**

My grandma, she makes it possible for me to come [to the mental health facility]. Even if she’s busy on Tuesdays, she makes a way for me to come to therapy **(Sue, 14 year-old female).**

“She [mother] makes sure I take it [medication] everyday.” Adolescents also identified their parent as the *administrator* of their medications. Of the eleven adolescents currently receiving medication intervention, six discussed this particular role of their parent/guardian in terms of the significant influence on their continued stability. Further probes provided information on how the adolescent perceived this particular role. Among those taking medications, four viewed this role in a positive light, stating that the reminders from parents to take their medication(s) were helpful, while the remaining two viewed the parent’s reminders as annoying.

She [mother] makes sure I take it [medication] everyday **(Angela, 15 year-old female).**

My mother, she actually give me, like, almost all the doses, if not all, yes, she hands them [medication] to me so I’ll remember to take them **(Mack, 15 year-old male).**

When I wake up, she [mother] tell me to take it [medication] every, every morning...that way I don’t forget, which I had forgot some, but she help me remember **(Tim, 16 year-old male).**

My grandmom, she checks the cups now to make sure I take it [medication]. I used to try to trick her and act like I swallowed it but the pill be in the cup the whole time and she don't even know it...but she check my mouth now to make sure I take it (Sue, 14 year-old female).

“She buys it for me.” Another influential parental role described by adolescents ($n=3$) was that of a *purchaser*. The adolescents considered the task of their parents purchasing the medications as a positive influence on them remaining stable and continuing in treatment:

She calls over here [mental health facility] and gets the prescription and then she buys it for me. If she didn't do that I wouldn't have 'em...that would not be a good thing for me, so, that's important for me to stay stable (John, 17 year-old male).

“I encouraged myself.” Seven adolescents (four 12 to 14 year-olds and three 15 to 17 year-olds) stated that in addition to their parents, their own influence led them to remain in treatment:

I just wanted to stay in therapy because I think it helps me...so I guess you could say that I encourage myself because I see what good it does for me (Angela, 15 year-old female).

Others who influence

Two 12 to 14 year-olds and one 15 to 17 year-old identified the nurse practitioner as influential in their remaining on medication(s) and two 12 to 14 year-old participants identified their therapist as influential in them remaining in therapy. Mentors were identified as influential in the adolescent remaining in treatment by three 12 to 14 year-olds, and two 15 to 17 year-olds identified a relative who was influential in them remaining in treatment.

Definition of “Consent to Treatment”

The minor consent law (N.C. § 90-21.5) in the State of North Carolina affords adolescents the right to seek and receive psychiatric mental health treatment without the permission of their parents. Given these adolescents have consented to medication therapy,

psychotherapy, or both, exploring their understanding of consent to treatment is integral to understanding the decision-making process of adolescent consenting. Eleven participants (six 12 to 14 year-olds and five 15 to 17 year-olds) provided examples to explain their understanding of the minor consent laws.

“You say you want to come to treatment.” Of the eleven adolescents who provided a definition of “consent to treatment”, five provided examples that paralleled the technical definition of “consent to treatment”:

It’s like you allow...you say that you want to go to treatment and you’re willing to go
(John, 17 year-old male)

That you say you want to come to treatment...that you say that you want to get help
(Jill, 13 year-old female).

It’s like you get, you say ‘okay’, I will do it [receive treatment] ...that it means I will do something or do it and I agree to it
(Dave, 13 year-old male).

Two adolescents provided a definition of “consent to treatment” that were partly correct.

Based on the current North Carolina minor consent law, the sections identified by italic bold are not accurate:

Well, it means that you have to be willing to have treatment, and no one can force you into doing anything...you have to have a parent or a guardian with you to sign the papers and everything
(Barbara, 14 year-old female).

Consent to treatment, is, um, like not only, um, not only affirmative, but just kind of like an agreement to, um, carry out all the, all of the components, like, well, the ask, well the assent of the, um, minor is just kind of agreeing with the consent [of the parent]
(Tim, 16 year-old male).

“Somebody can make you take it.” The responses of the remaining four participants who provided a definition of “consent to treatment”, spoke of this concept in terms of what was required or expected of them related to continued treatment, or what services they might receive at the facility:

It means that like the doctor give you some medication and you have to take it...that you just do what they [doctor] tell you to do (Mack, 15 year-old male).

Consent mean [sic] that somebody can make you take it [medication]. But parent consent means parent permission (Elaine, 17 year-old female).

It means that I will get a mentor and sign up for anger management (Jill, 13 year-old female).

Consent to me means that I will accept it [medication and/or therapy], that I will take whatever they [treatment facility] give me without any problem, that I won't make a big deal about it or fight about it...that I will come and whatever they suggest, I will agree to, like if they think it's best to have you put on medication, I'll take it (Lauren, 15 year-old female).

"I don't know." When asked, "What does 'consent to treatment' mean to you?", five of the adolescent participants answered, "I don't know." Further probes included, "what does it mean to you when you agree to treatment?", or "what is involved in your agreeing to treatment?" These five respondents (three 12 to 14 year-olds and two 15 to 17 year-olds) held to their original answer, "I don't know." It was clear from this response that these participants either did not understand the question, or the adolescent was not aware that there was some level of required agreement on their part in consenting to treatment. As indicated by these examples, younger and older adolescents were equally represented among those who understood and those who did not understand the concept of "consent to treatment."

Evaluation of Minor Consent Laws

Adolescents were asked to describe their thoughts about a law that provides minors the right to consent to psychiatric mental health treatment without their parent's permission.

"Kids should not be making those type of decisions." An overwhelming number of adolescent participants ($n=13$) did not agree with a law that allows someone their age to

consent to treatment without their parent's permission. The most common theme among these respondents ($n=11$) was they did not possess the **confidence** in making healthcare decisions without their parent's input. In addition to lack of confidence, some adolescents ($n=5$) discussed their opposition to the minor consent law solely on the **age** of the adolescent. For example, "older than 16 or 17" was a representative response among those who referred to age as a strict determinant of when a minor should be allowed to consent without their parent's required permission:

Some kids should not be making those type of decisions without their parent...they just don't know what to ask about and they may end up not asking about something or telling the doctor something that's important (Vivian, 16 year-old female).

Well, I think deciding about something like that should be a family thing...that's how we did it, so we decided as a family to do the treatment, to come here, so that's why I did it because it was a family thing (James, 12 year-old male).

I don't think anyone younger than fifteen could decide on that stuff without their parent, not no 12 year or 13 year-old, for sure. I don't even know about a fifteen year-old, if they could do it [decide on treatment without parent]. Cause they still don't know what's good for them at that age [fifteen], and then maybe there's some 12 year-olds who think they know a lot but they be having babies and stuff... they don't know nothing, but I think maybe 16 year-olds could, maybe, it just depends on what they have to decide, maybe therapy, but I sure don't know about medicine (Elaine, 17 year-old female).

Our parents should let us pick what we want to be in, like group and stuff, but they (parents) should be, should know about my health, because they have to know about what's going on with me and my health, because if something goes bad and they don't know what's goin' on, then I could be in trouble (Barbara, 14 year-old female).

Only one adolescent (17 year-old male) emphatically believed that adolescents should be allowed to consent to psychiatric mental health treatment without the required permission of parents, regardless of age, mental health diagnosis, or treatment involved. Two adolescents considered the **type of treatment** involved when expressing their perception of whether it was acceptable for an adolescent to consent to treatment without their parent's permission:

I think it's okay with some things, like therapy maybe, it's okay with if they decide on their own, but they may not be in the position to do it on their own, like when medicines involved, then they can't, I can't see how they decide on that, that's something more serious, taking medicine, and they then the parent should decide, that's what I think (Elaine, 17 year-old female).

Like medicine obviously, I think the parent should be there when deciding on that. If it were up to me I would have never taken the medicine, and I'd probably still be failing every class, or I'd probably be dead if it were up to me to not do the treatment (Lauren, 15 year-old female).

Voice in treatment decisions. Eleven adolescents (six 12 to 14 year-olds and five 15 to 17 year-olds) discussed that they should be allowed a voice in treatment decisions, but the inclusion of parents in the decision-making process was important to them:

I think that would be good [a law that allows her to decide on her own healthcare without her parent], that's kind of good, because I get to make my own decisions, but I think asking my mom would help out a lot... asking her about the treatment first before I do it, that would be helpful (Jill, 13 year-old female).

You know, we should be able to make our own decisions about our healthcare, but we do need our parents... they can help us out with that kind of stuff (Dave, 13 year-old male).

It would be okay to have something like that [a law that allows her to decide on her own healthcare without her parent] cause I like to make my own decisions, but I don't think I could make those decisions without my mom, like treatment stuff (Jean, 12 year-old female).

Yeah, I like that idea [a law that allows her to decide on her own healthcare without her parents], yeah the child should have some rights, but the child ain't so smart she know everything that the parent know...the parent, they look into things a little bit more then their child do (Vivian, 16 year-old female).

I think maybe the kid should have opinions in the situation, like, if the child really thinks that he doesn't need whatever, then they should consider that. But, if they really need it, therapy and stuff, if they think they don't need therapy and they have scars going all up and down their arm and they're threatening suicide, then obviously they need some help, so I think the parent should definitely be involved when it comes to that type of stuff, especially with the medicine stuff (Lauren, 15 year-old female).

Further probing about inclusion of parents provided more detailed information about this aspect of consenting. One adolescent (17 year-old-male) viewed requiring permission from

the parent as unnecessary when it came to deciding on his psychiatric mental health treatment, and that the input from his parents would most likely not make a difference in the decisions he made about treatment. One adolescent (12 year-old male) stated, “I think it [treatment decisions] should be talked over with the kid and they decide about things with the parent.” Three adolescents (two 12 to 14 year-olds and one 15 to 17 year-old) argued that the reason the current minor consent law should not exist is that the parent should be the one who decides on healthcare treatment and that the minor is not capable of making such decisions. When the term “capable” or similar terms were used by the adolescent, they were further asked to explain their meaning of “capable”. The adolescents described capable in terms of their inability to make decisions about issues that they had limited knowledge about, specifically related to choosing between different medications.

Parent Interviews

Under North Carolina law, minors have the right to consent to treatment without parental consent, or parental involvement. Parent interview questions were framed to glean information about their perceptions of roles they played in their adolescent’s decision to consent to treatment and the parents’ perceptions of the roles they played in the goals of treatment of their adolescent. In addition, questions were used to explore the parent’s knowledge and views of current minor consent laws that support adolescents’ right to consent to psychiatric mental health treatment independently of parental input.

Research Question #3 – Parents’ perceptions of their roles in the adolescent decision to consent to treatment

Initial Treatment Decisions

“There was no question.” In terms of making the initial decision to seek treatment, an emerging theme among the parents/legal guardians ($n=10$) was that they were comfortable in seeking treatment for their adolescent. Parents who decided on treatment without much hesitation stated reasons such as their child needing to get help quickly or that there was no question about whether they should receive help:

She was hearing voices and stuff, running out of school, just different things, so there was no question I weren’t gonna not get her help (mother of Lauren, 15 year-old female).

It was a good decision because I knew my child was going through some things ‘cause she has a lot of anger built up that she wasn’t yet decided to talk about...so getting that anger out was needed...it was no problem with me helping her to get treatment (mother of Elaine, 17 year-old female).

I thought it would help her...you know, more than what I was doing at home and I thought maybe the group would help her out a little bit, so there was no question about what I wanted to do...she needed to get help (mother of Barbara, 14 year-old female).

“It’s hard to think your kid needs mental health.” Other parents ($n=6$) discussed fear, inner conflict and apprehension in making the initial decisions to seek treatment for their child.

It was emotional for me...I had a sense of desperation...and we were fearful for his safety and his health...and we were afraid we would not meet the right professional but then again we were hopeful that we would, um, that we would meet up with the right professionals who were qualified and really knew how to handle the situation (father of Tim, 16 year-old male).

I didn’t want my daughter to be medicated so we were trying to do everything possible before we went that route, so we weren’t too sure about the medication when it was talked about...we were a little afraid (mother of Jill, 13 year-old female).

It was very difficult because it's, it's hard to, you know, think that your kid needs mental help, you know? (mother of Vivian, 16 year-old female).

Research Question #4 – Parents' perceptions of their role in goals of treatment

Continued Treatment Decisions

A further component of decision-making from the parental perspective is related to continued treatment. Decision-making patterns, including those decisions the adolescent made independently, those made independently by the parent, and those made with their adolescent and parent were explored with the parents of the adolescents. All parents perceived that most of the decisions about continued treatment were made in collaboration with their child. The descriptions provided by the parents indicated that the communications between the parent and child before and during treatment were very open, and significant discussions about treatment options took place between the parent and child. Some responses indicated that the parent was attempting to allow the adolescent to have more of a say in the treatment process, perhaps an attempt to prepare them to make treatment decisions independently:

Well, we [mother and adolescent] talk about her staying in treatment and staying on the medication, and if it's helping or not and we talk about how she and I think the medicine is helping her (mother of Lauren, 15 year-old female).

She's sixteen and she wants to be treated as a 16 year-old, and one time when I was just making the decisions by myself she thought I was treating her like a bitty child, like a five or six year-old, and us making the decisions together she feels better with the decisions, like she was part of making the decisions, you know, and that she has some choices (mother of Vivian, 16 year-old female).

Influences on Treatment Decisions

Continued treatment is integral to successful mental healthcare, and the decision to continue treatment can be influenced by many factors. To better understand parental

perceptions of external influences on their children, parents were asked about any thing or person who they perceived as influential in their child remaining on medication. Parents identified a variety of influential sources as follows:

“I have influenced her.” Parents identified themselves ($n=10$) as having the most influence on the adolescent remaining on medication(s). Specifically, the parents identified their verbal encouragements, completing tasks of scheduling appointments, and transporting the child to the appointments as influential in their child remaining on medications. These descriptions concur with those of adolescents in which the roles of *encourager*, *transporter*, and *administrator* were described:

I think I have influenced her, because I talk to her and just encourage to keep coming...we talk about how it's [medication] helping her, and I just keep telling her that there's nothing wrong with taking it...I just try to encourage her (mother of Lauren, 15 year-old female).

I think something that really is influencing to him, I mean influencing to stay with the medications that I make sure he's here every week...if I didn't get him here, I think that would probably influence the whole program in a bad, um, negative way, don't you think? (grandmother of James, 12 year-old male).

“No one knows.” Some parents ($n=5$) stated that no one other than themselves and the prescribing practitioner was aware of their adolescent taking medication. One mother stated, “No one knows outside of me and the nurse practitioner...we just don't want anyone to know...you know, it's still that stigma thing.” When asked further about the stigma, the mother spoke of how she and her daughter have avoided talking with others, even close family members, about the mental health treatment her daughter was receiving.

“He influences himself.” The concept of self-influence by the adolescent was introduced and discussed by four of the parents. Seven adolescents identified themselves as being influential in remaining in treatment. In terms of self-influence, parents perceived that

their adolescent had the capability of recognizing the positive effects and outcomes to taking medication. They further surmised that with the ability of the adolescent to recognize the positive outcomes of treatment, this, in turn, influences and motivates the adolescent to continue with the recommended treatment regimen.

I think he sees the difference in his grades because he was and, failing ninth grade twice...so getting better grades has influenced him to continue it (medication) (mother of John, 17 year-old male).

He's a smart kid, and I think that he understands the evidence that the medications can change things for the better...I think he has seen that for himself and that influences him to stay on it for now (father of Tim, 16 year-old male).

He knows it [medication] helps him focus better, he tells me that, so he's doing better in grades and he gets encouraged by that, so he makes sure he takes the medication...that influences him, he does it for himself (grandmother of James, 12 year-old male).

“The nurse practitioner talks to her like she’s human.” The manner in which the prescribing practitioners discussed the medication(s) with the adolescent was identified by the parents ($n=4$) as being influential in their child remaining on medication. For example, one mother stated, “her nurse practitioner talks to her like she is human, and she [NP] really tells her [adolescent] what is going well and what is not as far as the medications are concerned.” Another parent relayed, “he [adolescent] has a good rapport with the nurse practitioner and they talk about what’s working and what’s not...I really think that has been a big influence, you know, the way the nurse practitioner talks to him.”

Parental influences on therapy. Every parent identified themselves as instrumental in their adolescent continuing with this form of psychiatric mental health treatment. The explanations for how they were influential included *transporting* the adolescent to appointments, and *encouraging* the child when there were noticeable signs of improvement in the adolescent’s psychiatric mental health. These are further examples of how the parents’

perceptions mirror that of the adolescents when it came to identifying the critical roles of *transporter* and *encourager* that the parent plays.

“His therapist influences him.” In addition to their own influences, parents identified psychotherapist and mentors of the adolescent as influential in the adolescent remaining in therapy. Ten of the eleven parents whose adolescent was receiving psychotherapy and two out of three whose adolescent had a mentor recognized these “other” individuals as instrumental in their adolescent deciding to continue with the psychiatric mental health treatment. Parents relayed that the intimate relationship commonplace between the therapist and adolescent as the main reason the therapist was influential in the adolescent continuing in treatment. The same strong relationships were recognized by the parents as the reason the mentor was influential in the child remaining in therapy.

Mentors were assigned by the mental health agency to some of the adolescent participants. Mentors were considered by parents as a substitute parent to the adolescent, especially in situations where the adolescent had a single parent. The bonds that are established between the mentors and adolescents were described as very close and tight. Mentors were considered to be extremely influential figures in the adolescent’s life.

Others identified by parents as being influential in the child remaining in therapy were teachers ($n=3$), siblings ($n=3$), and peers ($n=2$). One mother stated she was a role model for her adolescent to remain in therapy because she was engaged in therapy herself. This mother discussed frequently with her child her own continued recovery from drug addiction and the importance of seeking therapy.

Research Question #5 – Parents’ experiences of the adolescents’ right to consent to treatment absent the parents’ consent

Definition of “Consent to Treatment”

Given that N. C. § 90-21.5 allows an adolescent to receive psychiatric mental health treatment without the permission of the parent/legal guardian, understanding the position of parents regarding the statute was essential. However, in order to understand the stance of the parent, it was important to know if parents could provide their own definition of the consent process. The findings suggest whether or not the parents had a general understanding of “consent to treatment.”

Parents understood “consent to treatment” in two ways: as a process ($n=10$), and as a required legal document ($n=2$), without overlap. Of those parents who described “consent to treatment” as a process, eight described the process further as the patient giving permission or agreeing that someone else could do something:

You give permission for someone to treat you or to find out the problem and to find the solution to the problem, so you’re giving permission (mother of Jill, 13 year-old female).

It means giving someone permission to do something, like give you medication and stuff like that (grandmother of Mack, 15 year-old male).

Included in the notion of consent as a process, two described the process of “consent to treatment” as a way for the practitioner to receive permission, rather than the patient to give permission:

Whoever is treating you, like the doctor, that’s how he gets permission to treat you...he’s getting consent, that means he’s getting the permission, the go ahead (grandmother of Clifton, 13 year-old male).

One parent captured the most complete meaning of “consent to treatment” in his description. This parent is a physician assistant and the father of a 16 year-old male participant. He was the only parent that viewed ‘consent to treatment’ in terms of it involving legal documents and as a process, and integrating both patient and provider:

Consent to treatment is the authorization by the person being treated, or the responsible adult for that person who needs treatment to accept the treatment or intervention, um, advised by the healthcare professional team, and informed consent...a complete understanding of all the, you know, the benefits and possibly the risks, and uh, understanding of what the intervention actually entails. Of course, this is all placed in a document that is signed by the person agreeing and the person seeking (father of Tim, 16 year-old male).

Knowledge of Minor Consent Laws

In order to establish whether parents in this study had an understanding of the minor consent laws in the State of North Carolina, specifically related to their child receiving mental health treatment, parents were asked about their knowledge of the minor consent laws when it came to their child receiving psychiatric mental health treatment. No parent had an accurate understanding of the minor consent laws, especially when it came to psychiatric mental health treatment. Most parents ($n=9$) had no understanding of the minor consent laws and provided no description of what was included in those laws. Only four parents had some knowledge of the minor consent laws:

The minor consent laws are what the courts have set up, and it is about who can, I imagine, treat my child, particularly a doctor, but I would imagine that it tells in there somewhere that I have to be a part of it, him getting treatment (grandmother of Clifton, 13 year-old male).

I'm pretty sure that a minor cannot sign off on certain things without a parent or guardian, such as getting a pregnancy test or getting an abortion...a minor can't do that without a parent I think, but I know they can't get an abortion without a parent (mother of Kay, 13 year-old female).

Evaluation of Minor Consent Laws

Perhaps the most vocal, descriptive, and detailed responses from the parents in this study was to the inquiry, “What are your thoughts about a law that currently exists that allows your child to receive psychiatric mental health treatment without your permission?” The grandmothers were encouraged to respond to this question with their specific adolescent in mind, hence, sixteen responses were recorded in order to represent each adolescent participant. Nine parents/legal guardians were against their adolescent being afforded the right to consent to treatment without their permission, and seven parents/legal guardians were in favor of the current minor consent law (Refer to Table 8).

Table 8. Frequency of Parents’ Views on Minor Consent Laws by Participant Age Group and Medication and Therapy Status

Parent View of Current Consent Laws (n)	Adolescent Age Group	Medication Only (n)	Therapy Only (n)	Combination Med/Therapy (n)
Favoring (7)	12 to 14 years	0	2	2
	15 to 17 years	1	0	2
Opposing (9)	12 to 14 years	2	2	1
	15 to 17 years	1	2	1

“She’s not mature enough.” A common theme among parents of younger and older adolescents who voiced opposition to N.C. § 90-21.5 was concern about their child’s maturity level and how maturity level would affect their child’s ability to make certain healthcare decisions. Some parents (n=3) made reference to the age of their child as the

reason they were opposed to the law. Further discussion with these parents highlighted that the parents were referring to maturational level, and not chronological age.

I don't think she mature enough to make those decisions without me...she is so easily persuaded, someone could tell her the moon was coming down and she'd believe it...so she just ain't at that maturity level yet...she has enough problems making decisions everyday, sure couldn't make them about medicines **(grandmother of Sue, 14 year-old female).**

I don't think, say at 15 years-old, that's an ageable [sic] to make that, you know decisions, specially all by theirselves because see he ain't mature completely yet and he could make the wrong decision...it's best I am a part of that for now **(grandmother of Mack, 15 year-old male).**

“Family is important.” Eight of the parents who opposed the law based their decision partly on the importance of maintaining the parent/child relationship and family bonds during times of critical decision-making. These parents emphasized the importance of family support during the decision-making process:

As long as the parents are doing the right thing by the child for the right reasons, and they have a family that cares, and a good relationship with the parent, they needs to include me as the parent in that decision, yes sir **(mother of Elaine, 17 year-old female).**

I think it is damaging to the family, just the stability of the family and the child if you take the parent out of those decisions...they [decisions] are too tough to make without a parent or family there to help out **(mother of Jill, 13 year-old female).**

“I think it's a good idea.” Most parents ($n=6$) in favor of a law that allows the adolescent to consent without parental permission stated reasons for their support were related to the immediate needs of the child. More specifically, they argued that if a child was in need of help and could recognize for themselves that it was needed, and that treatment was accessible, then he/she should be afforded the right to seek the help, even if this meant that the parent would not be a part of the treatment decisions:

If a child is seeking help, and he knows there is a problem then I think it's a good idea...at least he's seeking help from someone (father of Tim, 16 year-old male).

If they got something they want to talk about and it's on their mind and they want to get it out, and they want to get it out to someone other than in the family, then I think that's very appropriate (grandmother of Clifton, 13 year-old male).

“He’s old enough.” Some parents ($n=4$) in favor of the law spoke of the maturity levels of their adolescent as being partly the reason they approve of their child consenting to treatment without their permission:

I think he [adolescent] could make that decision, he's old enough, he's almost eighteen, he's really decided on the medications so far by himself, between him and his nurse practitioner, so I trust him so far...but, if he were 12 or even 16 I don't think I would like that...they just too young to know what to decide on about medicines...I hate to think that he would be doing that at 14 or 15 years-old (mother of John, 17 year-old male).

Well if the child is mature enough to think that they, uh, you know, should consent to something, you know, that's going to help them, I think that should be alright (mother of Barbara, 14 year-old female).

“No, not just any medicine.” The initial interview questions about consenting to treatment referenced three possible psychiatric mental health interventions; therapy, medication, or a combination of therapy and medication. Further discussion with the parents about these interventions involved asking questions about their thoughts of their adolescent consenting to any medication and/or other psychiatric mental health treatments, such as electroconvulsive therapy (ECT) or aversion therapy. Parents ($n=15$) were adamantly opposed to allowing their adolescent to consent to any medication or “other” psychiatric mental health interventions without their permission. Even those parents who were in agreement with their adolescent consenting to some forms of medication intervention without them were not in agreement with all interventions. For example, some parents ($n=3$) who were in support of the minor consent law and whose child was currently taking medication,

were concerned about their adolescent consenting to taking scheduled medications, primarily ADHD medications, without their permission. After thorough probing and evaluating the responses of the parents, ultimately the mother of a 17 year-old male agreed with the current law in its entirety that allows minors to consent without parental permission.

Summary

Understanding the experiences of adolescents who consent to psychiatric mental health treatment was an aim of this study. Specifically, understanding the steps that adolescents take in consenting to psychiatric mental health treatment. A decision-making model (Fischhoff, Crowell, & Kipke, 1999; Janis & Mann, 1977; Mann, Harmoni, & Power, 1989) served as the framework for this study and provided a guide in formulating the interview questions and presenting the findings. The steps of the decision-making model include, (a) the adolescent recognizing that a decision about treatment is required, (b) the adolescent understanding treatment goals, (c) the ability of the adolescent to determining consequences of the treatment decisions, and (d) the adolescent understanding the each consequence is likely to occur, which included assimilating and integrating about treatment options. Another aim of this study was to understand the experiences of parents of minors who consent to psychiatric mental health treatment. When asked about the process of deciding on treatment, younger and older adolescents were able to recognize that a decision was required of them in the early phases of seeking treatment. Adolescents were also clear about the purpose of treatment, although younger adolescents were less detailed in their descriptions related to what prompted them to seek treatment.

The second step in the decision-making process is the ability to understand and establish goals of treatment. Adolescents articulated goals in treatment, although older adolescents

were more detailed in stating their goals. Some younger and older adolescents stated goals that were rehearsed, perhaps selected from those stated by parents or others. Regardless, younger and older adolescents stated goals of treatment that were consistent with diagnosis, reason for treatment, and current interventions. For example, adolescents who were diagnosed with ADHD and taking medication(s) typically prescribed for this disorder offered goals of treatment, such as improving grades or increasing concentration and focus.

Adolescents consistently did not identify risks associated with taking medication(s) or engaging in therapy. Most adolescents taking medications stated the reason the medication had no risks was that it had not caused any harm to them. None of the adolescents identified risks associated with engaging in therapy.

When it came to assimilating and integrating information provided to them about treatment, adolescents accomplished this only in collaboration with their parent/legal guardian. In fact, younger and older adolescents described discomfort and lack of confidence and knowledge in making treatment decisions such as agreeing to or choosing among the various treatment options. Adolescents considered the implementation of medication intervention to be a decision that should only be made with their parent. Adolescents overwhelmingly felt that the best treatment decisions were those made with their parents, not those made by their parents without them or those made independent of their parents. Further, younger and older adolescents and their parents identified the parent as being most influential when it came to the adolescent remaining on medication and in therapy. Therapists were considered by the adolescents and parents as second most influential in the adolescent remaining in therapy. In terms of the current level of psychiatric mental health

stability of the adolescent, both adolescents and parents identified the parent as being most influential.

Adolescents and parents were asked questions about the minor consent laws in the State of North Carolina. Specifically, the intent was to understand the knowledge level of adolescents and their parents when it came to defining “consent to treatment.” The understanding of adolescents and their parents of the existing minor consent laws, along with their views of a law that allows a minor to consent to treatment without their required permission of the parent, was also explored. Most adolescents and all parents provided definitions of “consent to treatment” that would indicate a general understanding of this concept. Very few adolescents and parents were aware of a law that exists that allows a minor to consent to certain healthcare treatments, specifically psychiatric mental health intervention, without the required permission of their parent. Most adolescents and approximately half of the parents disagreed with a law that allows minors to consent to psychiatric mental health treatment without the required permission of the parent. Fifteen of sixteen adolescents and all parents disagreed with a law that allows the minor to consent to any medication intervention without the required consent of the parent. Parents who agreed with the current minor consent laws argued that if the adolescent was “mature” or was able to recognize that they needed intervention, then seeking psychiatric mental health assistance without their permission or knowledge would be acceptable. However, adolescents and parents consistently voiced their preference for collaboratively deciding about psychiatric mental health treatment decisions.

CHAPTER FIVE

DISCUSSION and CONCLUSIONS

The findings will be discussed in terms of the synthesizing framework of the study; the decision-making model (Fischhoff, Crowell, & Kipke, 1999; Janis & Mann, 1977; Mann, Harmoni, & Power, 1989), Therapeutic Jurisprudence (TJ) (Wexler & Winick, 1992), and the Vygotskian concept, *scaffolding* (Vygotsky, 1978). Research implications, nursing practice and education implications, limitations of the study, and conclusions will also be presented.

Discussion

Therapeutic Jurisprudence has its origins in mental health law. The intent of TJ is to provide researchers, legislators, and practitioners a systematic way to analyze a law's therapeutic and anti-therapeutic effects on a person's mental well-being (Wexler & Winick, 1992). Vygotsky's theory proposes that a child's learning and problem-solving abilities are developed in a hypothetical 'zone of learning.' A premise of the 'zone of learning' is that children learn best when assisted by others who are more knowledgeable in solving certain problems, a concept referred to as *scaffolding* (Bjorklund, 2005; Vygotsky, 1978).

N.C. § 90-21.5 provides minors the right to consent to psychiatric mental health treatment without the permission of their parent/legal guardian. There is controversy specifically regarding whether or not adolescents should be afforded the right to consent to treatment without their parent's permission (Mulvey & Peebles, 1996; Scherer & Repucci, 1988; Weithorn & Campbell, 1982). Those opposing such a law argue that it excludes the parents

from the decision-making process, eventually diminishing the crucial and essential role the parents play in positively influencing their child in important decision-making situations (Fundudis, 2003; Luce, 2003; Scott, 1992; Scott, Repucci, & Woolard, 1995; Walker, Booke, & Wrightsman, 1999). Those in favor of the law argue that it provides a means for adolescents to seek treatment in situations where they would normally not seek it (Ambuel & Rappaport, 1992; Bastein & Adelman, 1984; Kaser-Boyd, Adelman, Taylor, & Nelson, 1986; Lewis, 1980; Scherer & Repucci, 1988; Weithorn & Campbell, 1982). From the perspective of TJ, consideration would be given to whether N.C. § 90-21.5 is *therapeutic* or *anti-therapeutic*. To recognize the complexities of N.C. §90-21.5, it is important to understand the steps that adolescents take in making healthcare treatment decisions. Considering that N.C. §90-21.5 has the potential to exclude parents and others in the decision-making process, it is also important to understand the influences of parents and others on the adolescent deciding to consent to treatment.

N.C. § 90-21.5 is momentous in terms of what it affords; the right for minors to make potentially life-altering healthcare decisions without the permission of their parent/legal guardian. It is understood that the effects of this law could be far reaching and long lasting. There is no identifiable research that has attempted to understand the *therapeutic* and *anti-therapeutic* effects of N.C. §90-21.5 on treatment *outcomes*. And because minor consent laws allow adolescents to consent to healthcare treatment independently, an important aspect of completing this study was to understand the steps that adolescents take in deciding on their healthcare treatments. Understanding the steps that adolescents take in deciding on interventions and the influences on their decisions contributes to the overall body of literature of adolescent decision-making.

The findings of this study suggest that younger and older adolescents are successful in completing the first two steps of the decision-making process (recognizing that a decision is required and understanding the goals). Adolescents in this study readily recognized that a decision from them about initial treatment and goals was necessary. However, it was typical for adolescents to complete the first two steps of the decision-making process in collaboration with their parents.

One consistent finding related to the first two steps of the decision-making process was that adolescents discussed the decisions they made and the desired goals of treatment in specific terms of their psychiatric mental health symptomatology, such as the desire to feel or act better now. For example, adolescents spoke of deciding on treatment and establishing short-term goals based on their desire to decrease sadness and tearfulness, and increase their ability to focus and concentrate in school. Although, adolescents consistently made strong connections between what they were feeling or experiencing and the initial decisions made about treatment, the goals never moved beyond those of the short term goals to feel better and act better. From a developmental perspective, this would be expected given that adolescents generally focus on the here and now when it comes to making decisions (Santrock, 2006).

In relation to the first two steps of the decision-making process, the findings of this study are in contrast to what is observed in clinical settings (Sturman, 2005). In outpatient psychiatric mental health settings, younger adolescents seem to be less aware than older adolescents that a decision about treatment is needed. However, based on the findings of this study, younger and older adolescents equally recognize that decisions about their treatment are needed. One explanation for younger adolescents appearing to be less likely to recognize

the requirement of a decision may be as simple as the clinician not consulting with the younger adolescent about this step, but with the parent instead. With older adolescents, clinicians may discuss initiation of treatment directly. However, when it comes to addressing the initial treatment decisions of the younger adolescent, the clinician may direct the discussion to the parents only, thus taking the younger adolescent out of the communication forum. This study provides greater insight into the ability of younger and older adolescents to recognize that treatment decisions are required, stating treatment goals, and verbalizing the details of these two decision-making steps in their own words.

Although younger and older adolescents readily identified the benefits of taking the medications and receiving psychotherapy, their ability to identify the risks and consequences related to these interventions was limited. The findings from this study are similar to researchers (Kaser-Boyd, Adelman, & Taylor, 1986; Lewis, 1981) who examined risks identification of adolescents in healthcare situations. Adolescents in these studies did not readily identify risks of healthcare interventions, especially if the adolescent had not experienced previous side effects or adverse reactions to the intervention. From a cognitive developmental perspective, the expectation would be that younger adolescents would not think at a level other than immediate (Rew, 2005; Santrock, 2006). Therefore, the findings of this study are in line with what others have reported in that younger adolescents experience difficulty in identifying the risks and consequences of treatment choices.

Identifying future consequences requires the adolescent to think in abstract terms, which is a defining characteristic of the formal operational stage of development (Rew, 2005). Bloom (1956) identifies six levels of learning. Within these levels, consideration is given to the concept of critical thinking. It is important for the adolescent to develop critical thinking

skills in order to make decisions (Rew, 2005). The development of critical thinking skills is dependent on the adolescent's ability to analyze, synthesize, and evaluate information (Bloom, 1956). For example, in the current study, in order to understand the future consequences of psychiatric mental health treatment choices, and assimilate and integrate information about treatment options, the adolescent had to be able to analyze and synthesize the information presented. Based on the participants' ages (12 to 17 years-old), it was expected that the older adolescents (15 to 17 year-olds) would respond more than younger adolescents (12 to 14 years olds) to interview questions from a formal operational stage of development perspective, which includes the ability of the adolescents to synthesize and evaluate the initial treatment information presented to them (Sturman, 2005).

Adolescents in this study did not recognize the future consequences of their treatment decisions. Most importantly, adolescents did not assimilate and integrate the information presented to them about their treatment options. These findings are similar to those of Lewis (1981) and Urberg and Rosen (1987) who reported that younger and older adolescents in their study were not capable of integrating information about the treatment interventions represented in their studies. The findings of this study are similar to the findings of others in that adolescents do not independently inquire about future implications of the treatment options. Further, adolescents in this study did not assimilate and integrate information unless this process was completed in collaboration with their parents. There was no evidence that adolescents in this study were functioning in the formal operational stage of development, nor were they using critical thinking skills (synthesis and evaluation) when it came to consenting to psychiatric mental health treatment.

One of the major findings of this study was the relationship between the third and fourth steps of the decision-making process and the adolescents' and parents' perceived influences in making healthcare treatment decisions. Parents identified themselves as playing a vital role in the adolescent initially seeking and connecting to psychiatric mental health resources. Adolescents spoke of the importance of their parent(s) being involved in the initial phases of treatment. Adolescents also described how their commitment to continued treatment and current psychiatric stability was influenced by their parent's input and guidance.

The most resounding discussions of parents and adolescents were related to the overall treatment decisions. The perception among parents and adolescents was that, retrospectively, the best treatment decisions were those made together. One of the most important findings of this study is that adolescents perceived they could best perform the task of integrating all of the treatment information (step 4) with parental input. Adolescents and their parents placed great importance on their collaboration in deciding on the overall psychiatric mental health needs of the adolescent. This is closely associated with the Vygotskian concept of *scaffolding* (Berk & Winsler, 1995) in that adolescents who participated in this study were more likely to decide on the critical, difficult, and life-altering decisions related to psychiatric mental health treatment when assisted by their parents. Adolescents and parents both identified the importance of parental *scaffolding* in making the difficult decisions related to consenting to psychiatric mental health treatment.

The findings of this study indicate that even with the ruling on the books, the capability of adolescents to make informed decisions on their own about their psychiatric mental health treatment should be questioned. Thus, the law may be enabling and reinforcing questionable decision-making on the part of the adolescent. TJ analysis included a closer examination of

N.C. §90-21.5 to determine if excluding the parents, and others, who are positively influential in the adolescent deciding on psychiatric mental health treatment represents what is desired by adolescents and their parents in psychiatric mental health settings. The concept of scaffolding is supported by the findings that adolescents and parents consistently voiced that they prefer a collaborative approach when deciding about psychiatric mental health treatment options.

In summary, findings of this study suggest that, unless completed in collaboration with their parents or legal guardians, 12 to 17 year-old adolescents do not identify consequences **(step 3)** and assimilate and integrate information **(step 4)** when it comes to deciding about psychiatric mental health treatments. These findings support the argument of those who oppose the expansion of the minor consent laws. However, the extraordinary experiences of adolescents gleaned from the current study provide support for those arguing in favor of minor consent laws. For example, the description of one particular adolescent's experiences reverberates. James is the 12 year-old male participant who was sexually molested by his mother, and friends of his mother, for several years. James had a supportive and caring grandmother to disclose the details about the sexual abuse inflicted upon him. However, the possibility of James living with this abuse without a confidante is easily contemplated. Proponents of the current minor consent law would argue that James represents those for whom N.C. §90-21.5 was intended. Specifically, proponents of the law would posit that adolescents like James benefit from N.C. §90-21.5 because the law allows the adolescent to consent to psychiatric mental health treatment when it is the parent who is instigating the problem, or substantially contributing to the adolescent's mental health issues. In the case of parental abuse, it is unlikely that the parent would agree to the adolescent receiving

psychiatric mental health treatment. N.C. §90-21.5 would allow the adolescent to seek treatment without the parent knowing, which is perhaps the only way that some adolescents would seek refuge when it is the behaviors of the parents that are contributing to their mental illness. The overall findings of this study support those who oppose the current minor consent law in the State of North Carolina. However, based on the experience of James, which is representative of many adolescents, the negative implications of changing this law cannot be overlooked.

Implications for Research

This study was limited to 16 adolescents who had consented to outpatient psychiatric mental health treatment at one facility. This study should be replicated to include a larger, more diverse sample. In addition, data collection from multiple sites should occur. This approach would provide a more thorough understanding of how adolescents in a variety of settings and circumstances decide to consent to psychiatric mental health treatment.

Various diagnoses were represented among the adolescents of this study. One focus of future research would include examining the differences in decision-making among adolescents based on diagnostic criteria. For example, it would be important from a clinical perspective to know if adolescents diagnosed with a bipolar disorder decide on treatment options differently than those diagnosed with, for instance, ADHD.

Further research is warranted that includes greater representation of fathers, or both mothers and fathers. This would provide a better understanding of the experiences of fathers whose adolescents consent to psychiatric mental health treatment, along with knowledge about any differences among fathers' and mothers' perceptions related to the consent process and minor consent laws. Additionally, including fathers would provide an understanding of

the influence they have on their adolescent's decisions to accept certain healthcare choices. It is unknown if the inclusion of two biological parents in the adolescent decision-making process would be any different from the adolescent who has one parent involved.

This study included adolescents who had consented to treatment and were following treatment recommendations, and were stabilized in their current treatment regimen. Future studies should consider those adolescents who have decided against treatment and ultimately experienced difficulties due to their decisions. If differences are recognized among these groups, then clinical interventions could focus on identifying those adolescents at greatest risk of experiencing continued psychiatric mental health challenges. Also, research that examines adolescents consenting in inpatient settings would provide an understanding of any differences to those adolescents consenting in outpatient settings. Any differences would provide an understanding of needed interventions to enhance care and ensure positive outcomes for the adolescent.

Perhaps the most important future research should be to understand the effects that laws have on nursing education, research and practice, especially when considering issues related to treatment access and outcomes. It is a rare to find research that examines the results of legislative action; yet laws are implemented that affect the nursing profession in considerable ways. This study provided one example of a law (N.C.§90-21.5) that has significant and potentially long-lasting consequences in terms of a minors' access to treatment, parental involvement in the treatment process of their adolescent, and the nursing practice of treating minors. Further, the positive and negative outcomes of this law have not been examined since its' implementation. It is therefore strongly suggested that any legislation that significantly impacts healthcare be supported by research.

Finally, a longitudinal study that examines the adolescent consent process and decision making throughout treatment is warranted. This type of study would provide an understanding of how the adolescent makes decisions about their psychiatric mental healthcare over time. In addition, further analysis of the data collected for this study could include a comparison of pairs of parents and adolescents. Specifically, examining the relationship of a particular adolescent's responses to that of their parent's would increase our understanding of how adolescents and their parents are similar and different in perceiving the process of consenting to psychiatric mental health treatment.

Implications for Nursing Practice and Education

The findings of this study have important implications for nursing practice and education. Minor consent laws affect nursing practice in that they identify the treatments that nurses can provide the adolescent without the parent's consent, the situations in which information about the adolescent's treatment must be held in confidence by the nurse, and what information the nurse can disclose to the parents regardless of the adolescent's wishes. Complexities in adolescent consent rights are especially evident in advanced practice nursing, specifically with PMHNP. It is often the PMHNP who guides the adolescent through the consent process and is ultimately responsible for ensuring that this process is completed (Weisz & Melton, 1995). However, the PMHNP struggles with agreeing with the adolescent to consent to psychiatric mental health treatment without the parent's permission, and the desire to disclose to the parent that the adolescent is engaging in treatment because *therapeutic* outcomes are maximized when both the adolescent and parent are involved (Weisz & Melton, 1995). This situation is further complicated if adolescents do not assimilate and integrate all the information related to treatment options in psychiatric mental

health settings. This study provides nurse practitioners in clinical settings an initial understanding of how adolescents make treatment choices, especially when the treatment decisions are made without their parents. With this knowledge, steps can be taken by the nurse to ensure that the adolescent proceeds through the consent process successfully, albeit with the understanding the adolescent benefits most from guidance and assistance from others in assimilating and integrating treatment information. If treatment can be enhanced with parental involvement, then the nurse should discuss this option with the adolescent.

A controversial nursing implication is whether to involve the parent in the consent process even though the adolescent chooses to independently seek treatment and wishes to proceed in treatment without the parent(s) being notified. This is possibly the most difficult decision that a nurse in clinical practice could encounter when it comes to minor consent issues. From a legal perspective, N.C. §90-21.5 gives the adolescent the right to consent to treatment without the permission of parents. However, from a clinical perspective, the findings of this study suggest that the adolescent does better in assimilating and integrating information about treatment in psychiatric mental health settings when the parent is included. Therefore, whether the parent should be included in the consent process is controversial in light of the understanding that adolescents and parents perceive that the best treatment decisions are made together. With one exception, adolescents in this study consistently emphasized the importance they place on parental guidance and direction in making decisions about psychiatric mental health treatment options. In addition, in this small sample, the adolescents' perception about the best treatment decisions were those made with their parents. The exception in the instance of the adolescent who reported being sexually

molested by his mother cannot be overlooked as the situation in which consultation with the parent might actually be harmful to the adolescent.

Since nursing practice is guided by policy, and based on the findings of this study, the following points related to N. C. §90-21.5 might be considered in terms of policy. Given that most adolescents in this study perceived that the best treatment decisions are made with their parents, policy change should be considered that would provide the nurse practitioner provisions for including the parent in decisions about treatment when appropriate, especially when the involvement of the parent is determined by the nurse to be most beneficial to the adolescent's overall treatment progress. The second proposed policy change is related to medication intervention. Considering that adolescents in this study do not feel confident in making independent decisions about medication interventions, and that the adolescent prefers to collaborate with their parent about medication treatment decisions, N.C. §90-21.5 could be changed to exclude medication intervention as a treatment option the adolescent can consent to without their parents in appropriate circumstances.

Few states allow adolescents to consent to research without the permission of the parent/legal guardian (English, 2003). However, considering the expressed need and impetus to increase and expand adolescent health research, understanding the process of consent and decision-making regarding treatment options is crucial. If state minor consent laws are to be considered for expansion to include decreased involvement of the parent or others who are positively influential in the adolescent decision-making process, strong consideration should be given to the findings of this study, especially given that adolescents in this study experienced difficulties in assimilating information related to treatment options.

It is crucial that nurse educators are knowledgeable about consent laws, especially given that minor consent laws vary considerably among states (English, 2003). Further, it is important for the nurse educator to understand the process of consent, and that consenting to treatment is not a one time procedure. Perhaps most important for the nurse educator and the nursing student is in understanding the complexities associated with adolescent consent to healthcare. Finally, nurse education programs should incorporate into curriculum a strong, thorough examination of consent issues related to minors and how these issues appear in various practice settings.

Limitations

The sample of this study was limited to sixteen adolescents 12 to 17 years-old who were receiving outpatient psychiatric mental health treatment at a facility in the Southeast. It is unknown how adolescents of other age groups or from different regions of the country would respond. Also, it is not known how adolescents in inpatient settings and their parents would perceive the experiences of consenting to psychiatric mental health treatment.

All adolescents in this study had a parent or grandparent involved in the decision making process and who consented to participate in this study. Some adolescents seek psychiatric mental health treatment without their parent. Therefore, a limitation of this study is the inclusion of only those adolescents whose parent was involved in the adolescent's treatment process.

All adolescents were from families of lower socioeconomic status. In addition, most parents were unemployed with limited education. Therefore, it is unknown whether adolescents from higher socioeconomic levels of employed and more educated parents would differ from those represented in this study.

The inclusion of grandparents in this study was not anticipated. However, two grandmothers were the legal guardians of five adolescent participants. The information gleaned from the grandmothers' interviews contributed to the overall understanding of parents' experiences of adolescents consenting to treatment. However, because of the limited number of grandparents included in this study, the findings related to the grandmother interviews may not be representative of other grandparents who are also the legal guardians of adolescent grandchildren.

Conclusions

This study addressed the experiences of adolescents and parents of adolescents who have consented to psychiatric mental health treatment. Findings indicate that policy makers enact laws that support adolescents to make important, critical decisions about their healthcare. Although adolescents demonstrate they can make initial decisions to seek treatment, once into that care, this study showed that adolescents are faced with making decisions with consequences that they cannot assimilate and integrate. Thus, sought after goals may not be enhanced, and in fact, this policy may endanger the health of the adolescent by not including the parent or appropriate guardian such as grandparent in the treatment decision process. Clinicians need to know when and how to protect the rights of adolescents and when to include parents in the treatment plan.

The state of adolescent mental health is not encouraging. It is estimated that at any given time, 5-8% of adolescents in the United States meet the criteria of a Major Depressive Disorder (MDD) as defined by the DSM-IV-TR (Bhatia & Bhatia, 2007). Three percent of adolescents at any given time meet the criteria for a Dysthymic Disorder (Bhatia & Bhatia, 2007). The leading cause of adolescent suicidal behavior and successful suicide is MDD.

Suicide is the third leading cause of death among adolescents and the fourth leading among children. Two-thirds of adolescents diagnosed with a MDD also have another mental health diagnosis (Bhatia & Bhatia, 2007).

The health of adolescents has only recently begun receiving the attention it deserves. Nurses in clinical and research settings have been instrumental in bringing to the forefront some of the unique health challenges faced by this population. Therefore, it is only logical that nurses should have a greater voice and influence on legislation that affects the nursing roles with adolescents. The findings of this study provide information to better inform nurse educators, researchers, and clinicians of the decision-making steps that adolescents take in choosing healthcare treatment. On a more global level, the findings should serve as a way to increase the awareness of nurses about the importance of understanding how laws affect practice and that the ultimate responsibility nurses share involves examining, influencing, and guiding the development of legislation and policy that profoundly affect the nursing profession.

Finally, the findings of this study indicate that knowledge and understanding of the minor consent laws by adolescents and parents is significantly limited. Most adolescents and parents in this study were not aware of an existing law that allows minors in the State of North Carolina to consent to psychiatric mental health treatment without their parent's permission. Considering the findings of this study, there is a need for increased dialogue among adolescents, parents, nurses, and legislators related to this law. This dialogue should focus on three main topics. First, for clinical and legal reasons, societal awareness of N.C. §90-21.5 should be increased. If increased awareness leads to more adolescents seeking treatment without their parents, then further research, guided by a TJ theoretical model, is

warranted in order to thoroughly evaluate the *therapeutic* and *anti-therapeutic outcomes* of the law. Second, if further research supports the findings of this study, that adolescents make their best decisions in psychiatric mental health settings when collaborating with parents, then N.C. §90-21.5 should be considered for amendment to better reflect the decision-making process and cognitive development of adolescents. Third, consideration should be given to the voice of the parents. The parents in this study were somewhat in favor of their adolescent seeking psychotherapy intervention on their own but not medication intervention. Perhaps a change in the law would not only reflect the concerns expressed by the parents, but also provide clear legal and clinical guidelines related to adolescents consenting to psychiatric mental health treatment.

Appendix 1: Adolescent Participants age 12 to 14 Assent Form
University of North Carolina-Chapel Hill Social Behavioral Form

IRB Study # _____
Consent Form Version Date: _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Person in charge of study: Anthony James Roberson
Where they work at UNC-Chapel Hill: School of Nursing

Study contact phone number: 919-451-8731
Study contact Email Address: ajrobers@email.unc.edu

The people named above are doing a research study.

These are some things we want you to know about research studies:

Your parent needs to give permission for you to be in this study. You do not have to be in this study if you don't want to, even if your parent has already given permission.

You may stop being in the study at any time. If you decide to stop, no one will be angry or upset with you. Your nurse practitioner and therapist will continue to take good care of you.

Sometimes good things happen to people who take part in studies, and sometimes things we may not like happen. We will tell you more about these things below.

Why are they doing this research study?

The reason for doing this study is to help me understand how and why you decided to start taking medications and/or start talking to a therapist. I also want to understand who and what influenced you to decide taking medications and/or start talking to a therapist.

Why are you being asked to be in this research study?

You are being asked to be in this study because you get treatment.

How many people will take part in this study?

If you decide to be in this study, you will be one of about 45 people in this research study.

What will happen during this study?

The interview will take place at B&D Behavioral Health Services. The interview will last for one hour. With your permission I will be tape recording this interview. You can ask

Appendix 1 Continued:

for the tape recorder to be turned off at anytime during the interview. If you do not want to be recorded you will not be able to participate in the study. If it is OK with you I will call you about 3-4 weeks after the one hour interview to ask you some questions about your interview. This phone call will last about 15 minutes.

During this study I will ask you questions about what it was like for you to get treatment and how you decided to get treatment. The questions will also be about the medications you are taking and the therapy you are getting. I will not share any information I hear unless there is indication that you are at risk and in need of help.

Who will be told the things we learn about you in this study?

Your parents will not be told what you say to me during your interview. Nobody will be told what you say to me unless you tell me that you want to hurt yourself or someone else. I will be the only person who has access to the information that you provide me. No one who reads the reports will be able to know who you are.

What are the good things that might happen?

People may have good things happen to them because they are in research studies. These are called “benefits.” There is little chance you will benefit from being in this research study, but it will help researchers and nurses understand how and why adolescents decide about treatment.

What are the bad things that might happen?

Not all of these things may happen to you. None of them may happen or things may happen that the researchers don’t know about. You should report any problems to the researcher. Sometimes talking about bad things that happened to you in the past may cause you to feel bad and unhappy. If the questions I ask you in the interview make you feel bad in any way, I will make sure that you have someone to talk to about these feelings and you will get help. If you do start to feel sad during our interview I will ask your therapist or nurse practitioner to talk with, if that is OK.

Will you get any money or gifts for being in this research study?

You will receive \$15.00 cash for being in this study.

Who should you ask if you have any questions?

If you have questions you should ask the people listed on the first page of this form. If you have other questions about your rights while you are in this research study you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Appendix 1 Continued:

If you sign your name below, it means that you agree to take part in this research study.

Sign your name here if you want to be in the study

Date _____

Print your name here if you want to be in the study

Signature of Person Obtaining Assent

Date _____

Printed Name of Person Obtaining Assent

Appendix 2: Adolescent Participants age 15 to 17 Assent Form
University of North Carolina-Chapel Hill
Social Behavioral Form

IRB Study # _____
Assent Form Version Date: _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Principal Investigator: Anthony James Roberson
UNC-Chapel Hill Department: School of Nursing
UNC-Chapel Hill Phone number: 919-966-4269
Email Address: ajrobers@email.unc.edu
Faculty Advisor: Diane Kjervik, JD, RN, FAAN
Funding Source: None
Study Contact telephone number: 919-451-8731
Study Contact email: ajrobers@email.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. Your parent, or guardian, needs to give permission for you to be in this study. You do not have to be in this study if you don't want to, even if your parent has already given permission. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is for me to understand what it was like for you to agree to mental health treatment. I am also interested in understanding how and why you decided on the treatment you are receiving right now.

Appendix 2 Continued:

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 45 people in this research study.

How long will your part in this study last?

The interview will take place at B&D Behavioral Health Services. Your interview will last for approximately one hour. One follow-up interview will be included, which will last for approximately 15 minutes. The follow-up interview can be completed in person or by telephone, whichever is most convenient for you. There may be a couple of weeks between your initial interview and being contacted for the 15 minute interview. Therefore, your participation in this study will last about 3-4 weeks with the one hour interview and 15 minute follow-up interview being the actual activities.

What will happen if you take part in the study?

You will be asked some questions about your mental health treatment. There are no right or wrong answers, so I want you to answer the questions as honest as possible and to the best of your ability. The questions will be about the medications you are taking and the therapy you are receiving, along with questions about how you and your parents decided to start mental health treatment for you. This interview will last for one hour. With your permission I will be tape recording this interview. You can ask for the tape recorder to be turned off at anytime during the interview. If you do not want to be recorded you will not be able to participate in the study. You will be asked to participate in one fifteen minute follow-up visit or telephone conversation, whichever is most convenient for you. I will not share any information I hear unless there is indication that you are at risk and in need of help.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You may not benefit personally from being in this research study. Interviewing you about your treatment is not likely to help you personally, but it will help researchers and clinicians in better understanding how and why adolescents like yourself make certain decisions about your healthcare treatment.

What are the possible risks or discomforts involved from being in this study?

There are no known or anticipated risks for you to participate in this study. However, talking about bad things that happened in the past may cause you to feel unhappy and distressed. If this does occur, I will make sure that the appropriate referral is made so you can get the help that you need. If you prefer I will talk with your therapist or nurse practitioner so they can talk to you about these feelings.

Appendix 2 Continued:

How will your privacy be protected?

Your privacy and the confidentiality of the information you provide are very important. Privacy and confidentiality will be maintained by assigning ID numbers that can only be identified by me. Your information will be locked in a file cabinet when not used by me and only I will have access to any identifiable information obtained by me.

You will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

Your interview will be audio taped by the use of a digital recorder. After our interview, I will transcribe what you said to me. The audio tape of your interview will be manually deleted by me once the study has been completed. The audio tape will remain in my possession at all times. When not in use, your taped interview will be locked in a cabinet only accessible by me.

Will you receive anything for being in this study?

You will be receiving \$15.00 cash for taking part in this study.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Appendix 2 Continued:

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time.
I voluntarily agree to participate in this research study.

Your signature if you agree to be in the study

Date

Printed name if you agree to be in the study

Signature of Person Obtaining Assent

Date

Printed Name of Person Obtaining Assent

Appendix 3: Parental Permission for a Minor Child to Participate in a Research Study
University of North Carolina-Chapel Hill
Social Behavioral Form

IRB Study # _____
Consent Form Version Date: _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Principal Investigator: Anthony James Roberson
UNC-Chapel Hill Department: School of Nursing
UNC-Chapel Hill Phone number: 919-966-4269
Email Address: ajrobers@email.unc.edu
Faculty Advisor: Diane Kjervik, JD, RN, FAAN
Funding Source: None

Study Contact telephone number: 919-451-8731
Study Contact email: ajrobers@email.unc.edu

What are some general things you should know about research studies?

You are being asked to allow your child to take part in a research study. To join the study is voluntary. You may refuse to give permission, or you may withdraw your permission for your child to be in the study, for any reason. Even if you give your permission, your child can decide not to be in the study or to leave the study early.

Research studies are designed to obtain new knowledge. This new information may help people in the future. Your child may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you and your child can make an informed choice about being in this research study.

You will be given a copy of this permission form. You and your child should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to learn more about what it was like for your child to agree to mental health treatment. I am also interested in understanding how and why you and your child decided on the treatment he/she is receiving right now. Your child is being asked to be in the study because they are receiving mental health treatment.

Appendix 3 Continued:

How many people will take part in this study?

If your child is in this study, your child will be one of approximately 45 people in this research study.

How long will your child's part in this study last?

The interview with your child will last for approximately one hour. One follow-up interview will be included, which will last for approximately 15 minutes. The follow-up interview can be completed in person or by telephone, which ever is most convenient for you and your child. There may be a couple of weeks between your initial interview and being contacted for the 15 minute interview. Therefore, your participation in this study will last about 3-4 weeks with the one hour interview and 15 minute follow-up interview being the actual activities.

What will happen if your child takes part in the study?

The interview will take place at B&D Behavioral Health Services. Your child will be asked some questions about their mental health treatment. There are no right or wrong answers, so I want your child will be encouraged to answer the questions as honest as possible and to the best of your ability. This interview will last for one hour. With your permission I will be tape recording the interview with your child. Your child can ask for the tape recorder to be turned off at anytime during the interview. If your child does not want to be recorded he/she will not be able to participate in the study. The questions will be about the medications your child is taking and the therapy your child is receiving, along with questions about how you and your child decided to start mental health treatment for your child. Your child will be asked to participate in one fifteen minute follow-up visit or telephone conversation, which ever is most convenient for you and your child. You and/or your child may refuse to answer any of the questions I ask during these interviews. I will not share any information I hear unless there is indication that your child is at risk and in need of help.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. Your child may not benefit personally from being in this research study. Interviewing your child about their treatment is not likely to help you or your child, but it will assist researchers and clinicians in better understanding how and why adolescents make certain decisions about their healthcare treatment.

What are the possible risks or discomforts involved from being in this study?

There are no known or anticipated risks for your child to participate in this study. However, recalling difficult transition times or questionable satisfaction in treatment may result in emotional distress for your child. If this does occur, I will make the appropriate referral for your child to receive help, preferably to their therapist or nurse practitioner.

Appendix 3 Continued:

How will your child's privacy be protected?

The privacy of your child and the confidentiality of the information your child provides are very important. Privacy and confidentiality will be maintained by assigning ID numbers to the information collected that can only be identified by me. Your child's information will be locked in a file cabinet when not being used by me. Only I will have access to any identifiable information obtained by me.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

Your child's interview will be audio taped by the use of a digital recorder. After our interview, I will transcribe what your child said to me. The audio tape of your child's interview will be manually deleted by me once the study has been completed. The audio tape will remain in my possession at all times. When not in use, your child's taped interview will be locked in a cabinet only accessible by me.

Will your child receive anything for being in this study?

Your child will be receiving \$15.00 cash for taking part in this study.

Will it cost you anything for your child to be in this study?

There will be no costs for being in the study other than time and travel expenses.

What if you or your child has questions about this study?

You and your child have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact the researchers listed on the first page of this form.

What if you or your child has questions about your child's rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your child's rights and welfare. If you or your child has questions or concerns about your child's rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Appendix 3 Continued:

Parent's Agreement:

I have read the information provided above. I have asked all the questions I have at this time.
I voluntarily give permission to allow my child to participate in this research study.

Printed Name of Research Participant (Child)

Signature of Parent

Date

Printed Name of Parent

Signature of Person Obtaining Permission

Date

Printed Name of Person Obtaining Permission

Appendix 4: Adult Participants Consent Form
University of North Carolina-Chapel Hill
Social Behavioral Form

IRB Study # _____
Consent Form Version Date: _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Principal Investigator: Anthony James Roberson
UNC-Chapel Hill Department: School of Nursing
UNC-Chapel Hill Phone number: 919-966-4269
Email Address: ajrobers@email.unc.edu
Faculty Advisor: Diane Kjervik, JD, RN, FAAN
Funding Source: None

Study Contact telephone number: 919-451-8731
Study Contact email: ajrobers@email.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to learn more about what it was like for your child to agree to mental health treatment. I am also interested in understanding how and why you and your child decided on the treatment he/she is receiving right now.

You are being asked to be in the study because your adolescent is receiving mental health treatment.

Appendix 4 Continued:

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 45 people in this research study.

How long will your part in this study last?

Your interview will last for approximately one hour. One follow-up interview will be included, which will last for approximately 15 minutes. The follow-up interview can be completed in person or by telephone, which ever is most convenient for you. There may be a couple of weeks between your initial interview and being contacted for the 15 minute interview. Therefore, your participation in this study will last about 3-4 weeks with the one hour interview and 15 minute follow-up interview being the actual activities.

What will happen if you take part in the study?

The interview will take place at B&D Behavioral Health Services. You will be asked some questions about your adolescent's mental health treatment. There are no right or wrong answers, so I want you to answer the questions as honestly as possible and to the best of your ability. This interview will last for one hour. With your permission I will be tape recording this interview. You can ask for the tape recorder to be turned off at anytime during the interview. If you do not want to be recorded you will not be able to participate in the study. The questions will be about the medications being taken by your child and the therapy your child is receiving, along with questions about how you and your child decided to start mental health treatment for your child. You will be asked to participate in one fifteen minute follow-up visit or telephone conversation, which ever is most convenient for you. You may refuse to answer any of the questions I ask during these interviews. I will not share any information I hear unless there is indication that you are at risk and in need of help.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You may not benefit personally from being in this research study. Interviewing you about your child's treatment is not likely to help you or your child, but it will assist researchers and clinicians in better understanding how and why adolescents make certain decisions about their healthcare treatment.

What are the possible risks or discomforts involved from being in this study?

There are no known or anticipated risks for you to participate in this study. However, recalling difficult transition times or questionable satisfaction in treatment may result in emotional distress. If this does occur, I will make the appropriate referral to get you the needed help.

How will your privacy be protected?

Your privacy and the confidentiality of the information you provide are very important. Privacy and confidentiality will be maintained by assigning ID numbers that can only be

Appendix 4 Continued:

identified by me. Your information will be locked in a file cabinet when not used by me and only I will have access to any identifiable information obtained by me.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

Your interview will be audio taped by the use of a digital recorder. After our interview, I will transcribe what you said to me. The audio tape of your interview will be manually deleted by me once the study has been completed. The audio tape will remain in my possession at all times. When not in use, your taped interview will be locked in a cabinet only accessible by me.

I will not share any information I hear unless there is indication that you are at risk and in need help.

Will you receive anything for being in this study?

You will be receiving \$15.00 cash for taking part in this study.

Will it cost you anything to be in this study?

There will be no costs for being in the study other than time and travel expenses.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Appendix 4 Continued:

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time.
I voluntarily agree to participate in this research study.

Signature of Research Participant Date _____

Printed Name of Research Participant

Signature of Person Obtaining Consent Date _____

Printed Name of Person Obtaining Consent

Appendix 5: Adolescent Interview Guide
University of North Carolina-Chapel Hill

IRB Study # _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Principal Investigator: Anthony James Roberson
UNC-Chapel Hill Department: School of Nursing
UNC-Chapel Hill Phone Number: 919-966-4269

Participant number:

Date:

Person conducting the interview:

Thank you for agreeing to talk with me today. I am very interested in knowing what it was like for you to receive treatment here at B&D Behavioral Health Services.

First I want to ask some questions about when you started treatment. What was it like when you started treatment at B&D? Thinking back when you first started treatment how much of a say did you have in getting treatment? Tell me about what kinds of treatment you are receiving. **Probe: Tell me about the medication treatment you are receiving. Tell me about the therapy that you are receiving. Tell me about the reasons you are receiving treatment.**

Tell me about the decisions you made to start treatment. Did you make these decisions on your own? Do you think anybody influenced those decisions? **Probe: Who influenced you to get treatment? How did these people influence you to get treatment? What were the ways they influenced you?**

When you first started treatment, what was your understanding of the purpose of treatment? What did you want to achieve by coming here for treatment? **Probe: Did you and your therapist (or nurse practitioner) talk about what you might want to achieve by coming here for treatment? Tell me about the medication(s) you are taking. Tell me why you are taking the medication(s). Tell me why you are in therapy. Do you know why the medication is being prescribed? Did the person who prescribed the medication talk with you about the reasons for taking the medication?**

Now I want to ask you a few questions about the medication you are taking. OR Now I want to ask you a few questions about the therapy you are receiving. (If the subject is receiving both medication and therapy intervention, I will start with asking about the medication first then move into the therapy questions). Tell me your understanding of any risks from taking the medication(s) you are taking. **Probe: Do you know of any risks from taking “insert name of medication here”?** Tell me your understanding of any

Appendix 5 Continued:

IRB Study# _____
Adolescent Interview Script

risks from engaging in/receiving therapy. **Probe: Do you know of any risks from receiving therapy? How did you find out about the risks of taking medications? How did you find out about the risks of receiving therapy? What kind of information did you find out about the risks of the medication(s) you are taking? What kind of information did you find out about the risks of therapy? Perhaps if they found out information online – What web site did you use to get the information about the medication(s)/therapy?** Has anyone influenced you about the decisions you made in continuing taking the medication(s) and/or therapy? **Probe: Who has influenced you in the decisions you have made about continuing the medications? Who has influenced you in the decisions you made about continuing therapy? Who do you think has influenced you the most to stay on medication(s)? Who do you think has influenced you the most to stay in therapy?**

Now I would like to talk with you about the role your parents have played in you receiving treatment. Tell me about the role your parents have played in you remaining on medications. Tell me about the role your parents have played in you remaining in therapy. **Probe: Do you think your parents had an influence on you staying on the medication(s)? Do you think your parents had an influence on you staying in therapy? Tell me how your parents influenced you (if they respond ‘yes’). What did they (parents) say?**

Now that you have been in treatment for a while and you are stabilized, I want to ask you some questions about the decisions you and your parents have made since you have been in treatment. What decisions did you make about your treatment that did not include your parents? What decisions did your parents make about your treatment that did not include you? What decisions did you and your parents make together about your treatment? **Probe: Which do you think has contributed to where you are today in your treatment (stability); the decisions you made without your parents, the decisions your parents made without you, or the decisions you and your parents made together? Based on what response the subject provides – Tell me how your decision without your parent (or the decisions your parent made without you or the decisions you and your parents made together) led to your stability.**

Tell me what you know about the consent laws in the State of North Carolina. Tell me in your own words what it means when I say “consent to treatment”.

What do you think about adolescents like yourself deciding about their healthcare without their parents? **Probe: Do you think there should be laws that give the adolescent the right to decide on their healthcare or should laws require that the adolescent get permission from their parent before they can receive healthcare?**

Appendix 5 Continued:

That concludes my questions for you. What would you like to add to our interview? What questions about this interview do you have? I appreciate your time and your answers. Thank you.

Appendix 6: Parent Interview Guide
University of North Carolina-Chapel Hill

IRB Study # _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Principal Investigator: Anthony James Roberson
UNC-Chapel Hill Department: School of Nursing
UNC-Chapel Hill Phone Number: 919-966-4269

Participant number:

Date:

Person conducting interview:

Thank you for agreeing to talk with me today. I am very interested in knowing what it is like for you to be involved in the mental health treatment of your child at B&D Behavioral Health Services.

Tell me the reason your child is receiving mental health treatment

Is your child receiving medication intervention, therapy, or both?

Tell me the decisions you made about the treatment your child was going to receive? **Probe: What was it like to decide if your child would take medications or receive therapy?**

When your child started treatment what was their understanding for the reason they were being brought to treatment? What did you tell them regarding the reasons they were being brought to treatment?

What do you think influences your child to take medications? What do you think influences your child to stay in therapy? Who do you think influences your child's decision to remain on medications or stay in therapy? How do you think you have influenced your child to stay on medications or stay in therapy? **Probe: Do you think anybody other than you has influenced your child to remain on medication(s) or in therapy?**

Now that your child has been in treatment for a while and they are stabilized, I want to ask you some questions about the decisions you and your child have made since he/she has been in treatment. What decisions did you make about the treatment of your child that did not include your child? What decisions did your child make about his/her treatment that did not include you? What decisions did you and your child make together about his/her treatment?

Appendix 6 Continued:

Probe: Which do you think has contributed to where your child is today in their treatment (stability); the decisions you made without your child, the decisions your child made without you, or the decisions you and your child made together? Based on what response the subject provides – Tell me how your decision without your child (or the decisions your child made without you or the decisions you and your child made together) led to their stability.

Tell me what you know about the minor consent laws in the State of North Carolina. Tell me in your own words what ‘consent to treatment’ means to you. **Probe: What is involved in someone agreeing to treatment?**

Tell me what you think about a law that allows your child to consent to psychiatric mental health treatment without your required permission? **Probe: Do you think there should be laws that allow adolescents to get treatment without needing the permission of the parent? What do you think about a law that currently exists that allows your child to get psychiatric mental health treatment without your permission?**

That concludes my questions for you. What would you like to add to our interview? What questions about this interview do you have?

*I appreciate your time and your answers.
Thank you.*

Appendix 7: HIPAA Authorization Child Assent for Use and Disclosure of Health Information for Research Purposes
University of North Carolina-Chapel Hill

IRB Study # _____

UNC-Chapel Hill Principal Investigator (Researcher):
Anthony James Roberson
University of North Carolina at Chapel Hill
School of Nursing
Chapel Hill, NC 27599

This is a permission called a “HIPAA authorization.” It is required by “The Health Insurance Portability and Accountability Act of 1996” (known as “HIPAA”) for us to get information from your medical records or health insurance records to use in this research study.

1. If you sign this HIPAA authorization form you are giving your permission for the following people or groups to give the researchers certain information (described in #2 below) about you:

B&D Behavioral Health Services

2. If you sign this HIPAA authorization form, this is the health information about you that the people or groups listed in #1 may give to the researchers to use in this research study:

Mental Health Diagnoses _____ (initials of participant)

Medical Diagnoses _____ (initials of participant)

3. The people or groups listed in #1 on this form may give this health information to the researcher listed at the top of this form (UNC-Chapel Hill Principal Investigator) or to another researcher working on this research study. This information may also be shared with, used by or seen by the sponsor of the research study, the sponsor’s representatives, officials of the IRB, and certain employees of the university or government agencies if needed to oversee the research study.

4. The HIPAA rules that apply to your medical records will not apply to your information in the research study records. The informed consent document describes the procedures in this research study to protect your personal information. You can also ask the researchers any questions about what they will do with your personal information and how they will protect your personal information in this research study.

Appendix 7 Continued:

5. If you want to participate in this research study, you must sign this HIPAA authorization form to allow the people or groups listed in #1 on this form to give access to the information about you that is listed in #2 on this form. If you do not want to sign this HIPAA authorization form, you cannot participate in this research study but not signing the authorization form will not change your right to treatment, payment, enrollment or eligibility for medical services outside of this research study.

6. This HIPAA authorization will stop the date of your follow-up interview.

7. You have the right to stop this HIPAA authorization at any time. HIPAA rules are that if you want to stop this HIPAA authorization, you must do that in writing. You may give your written stop of this HIPAA authorization directly to the people or groups listed in #1 on this form or you may give it to the researcher and tell the researcher to send it to any person or group the researcher has given a copy of this HIPAA authorization. Stopping this HIPAA authorization will not stop information sharing that has already happened.

8. You will be given a copy of this signed HIPAA authorization.

Signature of Research Subject Date

Print Name of Research Subject

For Personal Representative of the Research Participant (if applicable)

Print Name of Personal Representative: _____

Please explain your authority to act on behalf of this Research Subject:

I am giving this permission by signing this HIPAA Authorization on behalf of the Research Participant.

Signature of Personal Representative Date

Appendix 8: HIPAA Authorization Parent Consent for Use and Disclosure of Health Information for Research Purposes
University of North Carolina-Chapel Hill

IRB Study # _____

UNC-Chapel Hill Principal Investigator (Researcher):
Anthony James Roberson
University of North Carolina at Chapel Hill
School of Nursing
Chapel Hill, NC 27599

This is a permission called a “HIPAA authorization.” It is required by “The Health Insurance Portability and Accountability Act of 1996” (known as “HIPAA”) for us to get information from your child’s medical records or health insurance records to use in this research study.

1. If you sign this HIPAA authorization form you are giving your permission for the following people or groups to give the researchers certain information (described in #2 below) about your child:

B&D Behavioral Health Services

2. If you sign this HIPAA authorization form, this is the health information about your child that the people or groups listed in #1 may give to the researchers to use in this research study:

Mental Health Diagnoses _____(initials of participant)

Medical Diagnoses _____(initials of participant)

3. The people or groups listed in #1 on this form may give this health information to the researcher listed at the top of this form (UNC-Chapel Hill Principal Investigator) or to another researcher working on this research study. This information may also be shared with, used by or seen by the sponsor of the research study, the sponsor’s representatives, officials of the IRB, and certain employees of the university or government agencies if needed to oversee the research study.

4. The HIPAA rules that apply to your child’s medical records will not apply to your child’s information in the research study records. The informed consent document describes the procedures in this research study to protect your child’s personal information. You can also ask the researchers any questions about what they will do with your child’s personal information and how they will protect your child’s personal information in this research study.

Appendix 8 Continued:

5. If you want your child to participate in this research study, you must sign this HIPAA authorization form to allow the people or groups listed in #1 on this form to give access to the information about your child that is listed in #2 on this form. If you do not want to sign this HIPAA authorization form, your child cannot participate in this research study but not signing the authorization form will not change your child's right to treatment, payment, enrollment or eligibility for medical services outside of this research study.

6. This HIPAA authorization will stop the date of your child's follow-up interview.

7. You have the right to stop this HIPAA authorization at any time. HIPAA rules are that if you want to stop this HIPAA authorization, you must do that in writing. You may give your written stop of this HIPAA authorization directly to the people or groups listed in #1 on this form or you may give it to the researcher and tell the researcher to send it to any person or group the researcher has given a copy of this HIPAA authorization. Stopping this HIPAA authorization will not stop information sharing that has already happened.

8. You will be given a copy of this signed HIPAA authorization.

Signature of Parent

Date

Print Name of Parent

For Personal Representative of the Research Participant (if applicable)

Print Name of Personal Representative: _____

Please explain your authority to act on behalf of this Research Subject:

I am giving this permission by signing this HIPAA Authorization on behalf of the Research Participant.

Signature of Personal Representative	Date
--------------------------------------	------

Appendix 9: Adolescent Demographic Form
University of North Carolina-Chapel Hill

IRB Study # _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Principal Investigator: Anthony James Roberson
UNC-Chapel Hill Department: School of Nursing
UNC-Chapel Hill Phone Number: 919-966-4269

Participant number:

Date:

Person collecting data:

Are you male or female _____

What year were you born? _____

Ethnicity _____

Education Level _____

The following information is extracted from the patient's medical record (HIPAA consent obtained and included with this form):

Mental Health Diagnoses _____

Medical Diagnoses _____

Appendix 10: Parent Demographic Form
University of North Carolina-Chapel Hill

IRB Study # _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Principal Investigator: Anthony James Roberson
UNC-Chapel Hill Department: School of Nursing
UNC-Chapel Hill Phone Number: 919-966-4269

Participant number:

Date:

Person collecting data:

Are you male or female? _____

What is your marital status? _____

What is your race? _____

Do you receive Medicaid or Medicare? _____

Does your adolescent receive Medicaid or Medicare? _____

Are you employed? _____

If you are employed, is it full time or part time? _____

What is your education level? _____

Recruitment Flyer

University of North Carolina at Chapel Hill

School of Nursing

What? A study about adolescents who are receiving psychiatric mental health treatment.

Who can participate? Adolescents and their parent(s).

What will it require of you? One hour to interview the adolescent and one hour to interview each parent.

Where? Each interview will take place at B&D Behavioral Health Services at your convenience.

Reimbursement: Each participant will receive \$15.00.

Principal Investigator: Tony Roberson, Doctoral Candidate

Contact Number: XXX-XXX-XXXX

University of North Carolina at Chapel Hill
IRB Study# _____

**Appendix 12: Supplemental Initial Recruitment Script Form
University of North Carolina-Chapel Hill**

IRB Study# _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Script to be used by the nurse practitioner or therapist who is recruiting the parent and child for this study on behalf of the PI:

Hi, *(parents' and adolescent's name here)*. Tony Roberson is a doctoral student at the University of North Carolina at Chapel Hill School of Nursing. He is conducting a study as part of his doctoral program and would like to interview adolescents and their parents about the adolescents mental health treatment. Would you be interested in participating in this study?

If parent and adolescent respond with 'yes': Would it be alright if I give him your name and number so he can contact you about setting up a time to interview you for his study? Yes? Ok, thank you, I will give him your name and number and he will be contacting you within the next 24 hours. Here is information *(recruitment flyer given to child and parent)* about the study.

Appendix 13: Supplemental Telephone Script Form
University of North Carolina-Chapel Hill

IRB Study# _____

Title of Study: The Experiences of Adolescents Consenting to Psychiatric Mental Health Treatment

Script to be used by the PI when parents and child are contacted by telephone:

The PI will ask to speak with the parent when he makes initial contact: Hi, my name is Tony Roberson and *(Insert name of nurse practitioner or therapist here)* gave me your name and telephone number stating that you would be interested in participating in my study. Would you still be interested in participating in this study?

If they answer “yes, I am interested”, or something similar, I will then state: Thank you very much. Can we set up a date and time for you and your child to come in for an interview? The interview will last for about one hour for your child and one hour each for you and your husband/wife **(this inclusion depends on whether both parents are involved in the child’s life)**. We can arrange for you to come it at separate times if that is more convenient for you.

The PI will work around the parents’ and adolescent’s schedule to arrange a meeting time that is most convenient for them.

If the parent asks on the phone about the details about the study, the PI will respond: I will be asking you and your child questions about your child’s psychiatric mental health treatment and the interview will last about one hour.

The PI will close the telephone conversation with: I appreciate your willingness to participate in this study. Let me provide you with some details about the interview. The interview will take place at B&D Behavioral Health Services. I will meet you at B&D. If you need to contact me to cancel or change your interview time, I can be reached at 919-451-8731. That is a private phone and you can leave a message if you reach my voice mail. I will see you and your child on *(insert date and time scheduled along with reiterating that the interview will take place at B&D Behavioral Health Services)*.

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