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Chronically Ill Adolescents' Involvement in Health Treatment Decision Making

Edna B. Domingo PhD
University of San Diego

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DOCTOR OF PHILOSOPHY IN NURSING

CHRONICALLY ILL ADOLESCENTS' INVOLVEMENT IN HEALTH TREATMENT DECISION MAKING

by

Edna B. Domingo

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Dissertation Committee

Jane Georges, RN, PhD, Chairperson

Donna Agan, EdD

Susan Instone, RN, DNSc

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ABSTRACT

The purposes of this study were to explore preferences for involvement of chronically ill adolescents in health treatment decision-making; describe, explain and predict relationships and differences in self-confidence in decision-making between older and younger chronically ill adolescents; and explore relationships between severity of symptoms and self-confidence in health treatment decision-making among chronically ill adolescents.

Ten to twenty million American children have some type of chronic illnesses with 90% survival to adulthood. There is lack of current literature on adolescent preferences for involvement in health care decisions. Courts and legislators assume that minors lack the requisite capacity for information, and lack competence to make health care decisions.

From a cross sectional research design, descriptive and inferential statistical analysis explored the research questions/hypothesis using SPSS version 11.0. A methodological triangulation was used to ensure corroboration of data and for complimentarity. Eighty participants, 20 from each of the four chronic health conditions; cystic fibrosis, asthma, sickle cell, and leukemia were included. Upon USD-IRB and LLUMC-IRB, LLUMC-NRC and CSUSB approval, convenience samples from LLUMC Health Care that met the inclusion criteria were invited to participate with the help of the primary investigator. The researcher made initial contact with the family through the information letter to invite them join this research study. Upon their consent, the researcher made an appointment to meet with them one hour before their clinic appointment for signing of the informed consent and assent before survey questionnaires were administered. Ninety percent completed survey at the clinic while the 10% finished at home and mailed back or collected by the researcher. The study was limited to chronically ill adolescents 14 to 19 years old who spoke English at a 5th grade level. All the participants were patients at LLUMC health care and specialty clinics.

Five instruments were used for data collection: (1) Adolescent Decision Making Questionnaire (ADMQ) to measure decision-making with .67 internal consistency for validity; (2) Problem Solving Inventory Form-A (PSI) to measure self-confidence has internal consistency of .72 to .90; (3) Coping Skills Inventory (CSI) to measure coping patterns has reliability ranging from .79 to .90; (4) (DK-PSDM) Deber-Kraetschmer Problem Solving Decision Making scale as a measure for preferences for involvement with Cronbach Alpha .71 to .90 reliability; and (5) Memorial Symptom Assessment Scale 10-18 (MSAS) as a measure for symptom severity with internal consistency of .70.

Results revealed that chronically ill adolescents desire involvement in decisions made for their care; that adolescents have high coping ability and self-confidence in decision-making even in stressful situations. Gender, diagnosis, and severity of symptoms did not contribute to the self-confidence of chronically ill adolescents. Overtime, coping ability contributed to self-confidence in decision-making. There were no significant differences in self-confidence in decision-making between younger and older chronically ill adolescents. Comparisons between variables and core perspectives revealed chronically ill adolescents' achieving for involvement in health treatment decision-making significant for evidence-based practice./'

Results imply a paradigm shift in health policy to regulate involvement of chronically ill adolescents in health treatment decision-making. Results imply awareness among health care providers of the chronically ill adolescents' preference to have a voice for oneself in health treatment decision-making. Having a voice reinforces self-actualization among chronically ill adolescents as a part of their maturation process.

CHAPTER 1

Introduction

CJ had renal failure at the age of 12 from reflux nephropathy. She had poor venous access for hemodialysis. The only way to save her from toxic shock was to put her on peritoneal dialysis. Complications made her suffer from repeated abdominal infections. At age 14, she received a cadaveric kidney. As part of her non-compliance with cyclosporine prescription, she developed rejection after six months. Since that time, she has not remembered any episode of being well. She informed her physician that she did not want to return to her dialysis in spite of her understanding that she would die from renal failure. CJ's emphatic mother wanted her to return to dialysis. The legal counsel for the hospital emphasized the mother's legal authority over decisions concerning CJ's health care since she was not yet 18 years old.

Chronic illnesses provide many opportunities for adolescents to make decisions about their health. Being less able to function well can impinge upon the self-confidence of chronically ill adolescents to participate in health care decisions compared to healthy adolescents (Schutingga-Helder, Tuinstra, Groothoff, & Post, 1996). Specifically, chronic illnesses are disease conditions that interfere with a person's ability to function for more than three months (Perrin & Hobbs, 1985). Furthermore, chronic illnesses require hospitalization for more than one month in a year (American Academy of Pediatrics [AAP], 1993; Wong, Hockenberry, Wilson, Winkelsten, & Kline, 2003) and expected to last a lengthy duration (Meng Goh, 1999), of extensive hospitalization, or in-home services (AAP, 1993).

These chronic health conditions, according to Perrin and Hobbs (1985) include juvenile diabetes, cystic fibrosis, chronic renal problems, spina bifida, sickle cell, asthma, muscular dystrophy, leukemia, congenital heart defects, hemophilia, and cleft palate. Health conditions may vary in course, duration, and severity that last for a number of years from onset to some improvement, which become stable and/or progressively worst (Perrin & Hobbs). Severity refers to the impact a condition has on a child's intellectual, psychological, physical, or social functioning (AAP, 1993). Perrin and Hobbs defined the criteria for severity of illness that involves large financial burdens, restriction of child's physical development, limited functional ability, maladaptive emotional or coping behaviors, and disruption of family life. The symptom severity is an aspect of quality of life assessment on the physical and emotional functional ability, and global quality of life (Collins, Byrnes, Dunkel, Lapin, Nadel, Thaler, et al., 2000). Therefore, severity of illness among chronically ill adolescents can impinge upon their preferences for involvement in health treatment decision-making.

Involving chronically ill adolescents in health treatment decisions is in their best interest (Runeson, Elander, Hermeren, & Hallstrom, 2001). The epistemology evolves from the notion that the age of majority demonstrates decisional capacity. Decisional capacity implies that persons at the age of majority have the ability to understand and deliberate on information, and then make a decision (Hartman, 2002). Although parents and physicians traditionally made most medical decisions on behalf of children, there is an increased recognition of their developing autonomy in the health care arena (Harrison, Kenny, Sidarous, & Rowell, 1997). One United Nations (1989) convention, known as the *Rights of the Child*, advocated for the right of every child to self-determination, dignity, respect, non-interference, and right to make informed decisions. This brought about awareness among legislators and health care providers that the rights of the child have taken a stride in societal change. Runeson et al. summarized children's rights into two basic principles: (a) In all actions, the primary consideration is the best interest of the child, and (b) An acceptance of his/her views in accordance with his/her age and assurance of his/her decisional maturity.

Besides dealing with the impact of chronic illness physically, emotionally, cognitively, and socially, chronically ill adolescents go through the same process of growth and development (Brownlow, 1993) just like healthy adolescents. In comparison to healthy adolescents, chronically ill adolescents experience the same process in transition to maturity (Gucray, 2002).

Schevanveldt and Adams (1983) claimed that adolescence is a period with limited experience in terms of problem-solving and decision-making skills. Gucray (2002) presented the notion that within the first decade of a child's life, adults make decisions for them, and that the second decade of life is a period of limited experience in carrying out decision-making responsibilities. He believed that adolescents need protection from their improvident decisions, and need guidance and support in their cognitive processes such as decision-making. Thus, they are not encouraged to make important decisions about their lives, and not given the opportunity to do so. When given the responsibility to make decisions, they get very little support and help resulting to faulty decisions affecting their future. However, he recognized that decision making and problem-solving skills develop with age, and that some cognitive processes can be developed and learned over time.

Mann, Harmoni, and Powers (1989) pointed out considerable changes in the development of decision-making, including revising reasonable information at hand, thinking of the possible consequences, and being faithful to the decision given. When all these changes take place in decision-making, adolescents learn the process of making rationale decisions over time.

Decision-making implies consideration of alternatives based upon information gathered, and making a choice that fits the goal, values, lifestyle, and or desired outcome (Harris, 1998). It is the process of identifying alternatives, reducing uncertainty and doubt about alternatives, and making a reasonable choice. Friedman and Mann (1993) supported the notion saying that while adolescents experience the challenges of rapid increase in physical, emotional, and psychosocial aspects of growth and development, their decision making appear conceptually similar. Their decision-making includes complex processes as identifying and evaluating alternative course of action, and selecting alternatives for the purpose of implementation (Phillips, Pazienza, & Ferrin, 1984). Decision-making is a way of solving problems, as Ross (2000) explicated that health care decision-making by children is in their best interest. Possible solutions to problems emerge based on alternatives despite the burden of chronic illness.

The extra burden of chronic illness and its care are stressors to 15% or 20% of chronically ill adolescents. Patterson and Garwick (1991) explained that chronic illness posits a negative impact on family lives related to family regulatory processes that may lead to developmental distortions. However, many children who have chronic illnesses cope well (Olson, Johansen, Powers, Pope, & Klein, 1993). Coping means fighting with some degree of success or struggling successfully (Barnhart & Barnhart, 2000). Olson et al. described coping as a means of adapting to either positive or negative responses to stressful situations. They further said that one's cognitive appraisals are important elements for emotion-focused coping or problem-focused coping, and vigilant coping (Janis & Mann, 1977). Coping responses, according to Brown, O'Keefe, & Sanders (1986), include focused attention, assessment of coping capabilities, and appraisal of the threatening event. On the other hand, Delamater, Kurtz, and Bubb (1987) asserted that children with illnesses show higher rate of behavioral problems when they use dysfunctional strategies to cope.

The legal presumption on children who have not reached the age of majority assumes, firstly, that minors lack the requisite capacity to make health treatment decisions (Gittler, Quigley-Rick, & Saks, 1990), and therefore need protection from their vulnerability. Another rationale is the lack of experience in confronting issues of decision-making in stressful situations. However, Gucray (2002) believed that when adolescents experience early participation in problem solving and decision-making, these skills will be developed and learned over time.

The ambiguous status of chronically ill adolescent involvement in health treatment decision- making poses a gap in improving a friendly adolescent care. It is a phenomenon not addressed in the health care arena. There are enormous researches found in the literature about health care decisions for abortion and use of contraceptives among adolescents but there are only few literatures dealing with health care decision-making among chronically ill adolescents.

The question of how authority allocates adolescent health care decision-making is far from its reality (Gittler et al., 1990). Olson et al. (1993) made strong emphasis that adolescents' cognitive capacity to make decisions remains intact even while suffering from the effects of chronic illness. It appears incongruous, then, that authorities as well as health care policy makers remain silent about the recognition of adolescent involvement in health treatment decision making. If they cannot either participate or be involved in health care decisions for their welfare now, then at issue is how soon they can participate. At issue is chronically ill adolescents' preference for involvement in health treatment decision-making. There is lack of current empirical evidence regarding adolescents' preferences for involvement in health treatment decision-making. In the light of these circumstances, there is therefore a need for empirical research to unfold preferences of adolescents for involvement in health treatment decision-making.

This research explored the preferences of chronically ill adolescents for involvement in health treatment decision-making. It examined the chronically ill adolescents' self-confidence, decision-making styles, and coping patterns when confronted with difficult situations requiring decisions for their care. It sought to understand the differences between younger and older chronically ill adolescents in health treatment decision-making. It discovered and generated core perspectives and patterns of association that unfolded chronically ill adolescents' preferences for involvement in health treatment decision-making.

Congruent with the chronically ill adolescent's developmental milestones, this research believes in the assumptions that chronically ill adolescents prefer involvement in health treatment decision making. They also have the self-confidence and problem solving capacity to make rational decisions. Although their decision-making styles and coping patterns vary, yet they cope well and are able to make decisions even in stressful situations. In the light of the foregoing assumptions, the research questions below examined the preferences of chronically ill adolescents in health treatment decision-making. It also sought to find the ontological and epistemological realities of the preferences of chronically ill adolescents for their involvement in health treatment decision-making.

- **Research Question 1**: What are the relationships between chronically ill adolescents' self- confidence, problem solving confidence, coping patterns, and preferences for involvement in health treatment decision-making?
- **Research Question 2**: What are the relationships between chronically ill adolescents' age, gender, health condition, or diagnosis, and their preferences for involvement in health treatment decision-making?

- **Research Question 3**: How do older and younger chronically ill adolescents differ in self-confidence in health treatment decision-making?
- **Research Question 4**: How do male and female chronically ill adolescents differ in coping ability and self-confidence in health treatment decision-making?
- **Research Question 5**: How do health condition (diagnosis) and severity of symptoms affect preferences of chronically ill adolescents for involvement and/or non-involvement in health treatment decision-making?
- **Research Question 6**: What are the relationships between severities of symptoms and self-confidence among chronically ill adolescents in health treatment decision-making?

Developmental Theories

Piaget (1969) theorized that, apart from inexperience, most individuals 14 years of age and older show intellectual capacity to reason, generalize beyond experience, deal with abstract ideas and predict potential consequences of actions (Weithorn & Campbell, 1982). Bibace and Walsh (1980) confirmed Piaget's theory with their findings that 42% of children, 11 years of age, understand the physiologic basis of disease. They further stated that adolescents begin to understand disease processes at age 11 and are competent to make decisions at the age of 14.

Kohlberg (1976) based his post-conventional moral developmental theory on Piaget's cognitive theory, that adolescence assumes recognized social responsibility. At this point, adolescents can consider the value of two differing moral approaches and then make a decision. He presents the notion that middle adolescence starting from age 13 have fully attained mature intellectual thought and they can think abstractly to consider different alternatives or outcomes and no longer depend on concrete experiences to find meaning in life. Adolescents rejoice in this new-found ability and spend a great deal of time reading, thinking, and talking about abstract concepts such as justice, beauty, truth, power and morality (Ball & Bindler, 2003).

Erikson's (1968) psychosocial developmental theory correlated with Piaget and Kohlberg's theories, that as the body matures and thought processes become more complex, the adolescent experiences that new sense of identity. S/he examines and redefines self within the context of family, peer group, and community. The adolescent establishes close ties with peers and increasingly leave the home base as a basis for identity formation. In the process, there is generally a strong period of crisis in the quest for self-identity before a strong identity can emerge. Maslow's hierarchy of needs (Brownlow, 1993) proposed that every person has an impulse towards growth, an active will towards health, desire toward achievement of potentialities and self-actualization.

Thompson (1990) stressed that adolescents with chronic illnesses are perceived as cognitively unable to make decisions in comparison to their healthy peers. However, he promoted adolescents' participation in their own care with a shift from disease treatment to health promotion, and prevention of disease exacerbations. He emphasized that it is important for health care providers and parents to provide a positive role modeling in family decisions for the development of decision-making capacity among chronically ill adolescents.

From a feminist perspective, Gilligan (1993) proposed gender differences in moral reasoning based on the context of Kohlberg's moral theory, and Piaget's cognitive theory. Knowing that both Piaget and Kohlberg applied their studies on male population, she claims that there is a difference among females and males in their moral reasoning. She presents the notion that females are not inferior in their personal or moral development; rather, their focus aims towards making connections with other people with a more caring attitude. She emphasizes that females make decisions based on the ethics of care.

Adolescents' transition from concrete to abstract logical reasoning and conception of what is right from wrong (Kohlberg, 1976; Piaget, 1972), egocentrism, and identity (Erikson, 1968) are evidences of maturational progression of adolescents' cognitive maturation to make decisions.

The early stage of adolescence involves peer groups' drive for independence and identity. Bandman and Bandman (2002) explained that in the early stages, adolescents tend to test rules and expectations of parents and authority, and they may live in fantasy with wrong role models and unrealistic goals. This is the period when adolescents indulge in occasional experimentation with restricted activities that expose them to vulnerable situations. Marcia (1980) reinforced Erikson's theory of identity saying that identity is adolescents' definition of which they are, evolving from their understanding of their inherent motivations, previous experiences and personal belief system. He further said that adolescents will be more self-determined if they have developed a strong sense of identity.

The middle adolescence includes self-involvement alternating between poor self-concept and unrealistically high expectations (Bandman & Bandman, 2002). There is a strong emphasis on new peer group superiority, selectivity, and competitiveness. They have greater capacity for setting goals and development of ideals and moral reasoning. Vygotsky (1962) believed that cognitive development including psychosocial identity in adolescence, results from social relationships with parents, teachers, peers, and others who have rich cognitive challenges to make them think. Potts and Mandleco (2002) supported Vygotsky's assertion that adolescents have the ability to consider the moral implications of their own actions, and that, others largely define their social, political and religious identities as crucial to their developing belief system.

The later stage of adolescence demonstrates understanding of sexual identity and intimacy coupled with responsibility as peer relationships mature (Bandman & Bandman, 2002).

Legal Competency to Make Health Care Decisions

Central to existing laws governing health care decision-making, patients under the age of majority (i.e., 18 years old) cannot give informed consent about health care decisions for themselves (AAP, 1995). Neither the courts nor legislators have furnished guidance on the content and meaning of competency in the context of health treatment decision-making. The Supreme Court's concern stems from the assumption that minors do not possess the intelligence, maturity and experience that their parents possess. The court's specific concern explicates that minors do not understand the long- term consequences of their decisions, which could be influenced by interpersonal pressures resulting to decisions detrimental to their welfare. The standard for judging competency is whether the minor is capable of understanding the consequences and nature of proposed surgical or medical treatment and procedures (Gittler et al., 1990).

Bartholome (1985) asserted that children are intelligent, observant, and responsible persons who deserve respect as capable decision-makers. He influenced the AAP Committee on Bioethics (1995) to legislate a policy stating that the decision-making power is a shared endeavor between patients or their surrogates in consultation with the physician as equal partners. The shared decision-making process overrides the vulnerability of minors in making improvident decisions.

Bioethics in Adolescent Health Care

Informed decisions imply an understanding of the person giving consent, the benefits, and risks of the treatment or of refusing treatment. The doctrine of informed consent implies respect for persons by disclosure of accurate information relevant to their rights in making decisions. The American Academy of Pediatrics (AAP, 1995) defined elements of informed decisions such as provision of information regarding nature of ailment, proposed diagnostic tests, risks and benefits, and other alternatives; assessment of patient's level of understanding of information; assessment of the capacity of the patient to make decisions; and assurance of the patient's freedom to choose medical alternatives.

McAbee and Fieldman-Winter (2002) and Broome and Stieglits (1997) believed that assent is the acceptable ethical approach to all health care decisions involving adolescents. Assent means that adolescents acknowledge understanding of their illness and treatment trajectory, and indicate willingness to participate in health care decisions or in research trials (AAP, 1995). It is defined further as helping adolescents achieve an awareness of disease condition, disclosure of test results and treatments, clinical assessment of client's level of understanding of situation and factors affecting responses, influencing an expression of willingness to accept proposed care. It also defines the extent of involving adolescents and children in decision-making that it should include the assent of the patient, as well as the participation of the parents and the physician. AAP (1995) recognized that as minors approach adolescence, there is a need for an independent relationship with the physicians. The greatest fear among adolescents is the disclosure of confidential information to their parents. Although the duty of beneficence provides a starting point to determine what is in the child's best interest, Harrison et al. (1997) asserted that the family-centered ethics is the best model for understanding the collaborative relationship that bears upon the child's situation. They further said that a family-centered approach respects the dependence and vulnerability of the child, his developing decision-making capacity, and the complex nature of parent-child relationships. Shared decision-making implements both justice and care ethics between the parents, the adolescent, and the physicians/nurses for the best interest of the adolescent child.

The president's commission for the study of ethical problems in medicine recommends shared decision making as an important component in informed consent in decisions for the care of adolescents (Beuchamp & Childress, 1994). This approach allows a voice from the parents, the adolescent, and the health care providers. The recognition of the ethical rights of the adolescent precludes an important aspect of their involvement in health treatment decision-making. Runeson et al. (2001) asserted that involving adolescents in health treatment decisions and allowing them to express their opinions is in their best interest. The Belmont Report (Health & Human Services, 1979), and the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1977) confirmed assertion of Runeson et al. by emphasizing the three ethical framework: respect for person, beneficence, and justice.

The case of CJ represents an empiric experience where health treatment decisions were for her best interest. Justice and ethic of care allowed CJ to experience a peaceful death according to her wishes.

Many states permit minors to seek, and consent to care for conditions that include pelvic examinations, counseling for and prescribing of contraception, substance abuse, screening for and treatment of sexually transmitted diseases, prenatal care following sexual assault, mental disorders and HIV testing (AAP, 1995). Rules related to abortion vary among the states. In some states, adolescents can obtain abortion without parental approval or require parental notification or judicial approval (McAbee & Fieldman-Winter, 2002; English, 1990). Federal courts have classified adolescents in relation to exceptions for parental consent and involvement related to their status, and characteristics as exceptions for emancipated or independent minors, and exceptions for mature minors (Clark, 1988; Katz, Schroeder, & Sideman, 1973).

Emancipated minors are minors who have received freedom from parental control. Under common law, emancipation may be complete or partial and may or may not result in having a right to consent to health services. Indicators are a minor's marriage, a minor's establishment of a home away from his/her parents, a minor's induction into the military, a minor's economic independence from his/her parents, and a minor's age (Cady, 1979). Half of the states enacted statutes stating that certain designated acts by a minor or minor's parents or both constitute emancipation (Clark, 1988). The statutes remove the disabilities of minority including parental consent, thus allowing the minor to have the right to consent to health services. Some states enacted statutes authorizing minors who have attained independence or independent minors to consent to health services (Katz et al., 1973). The primary focus of exceptions is not on the minor's capacity to make health care decisions, but rather for the independence of the minor.

Exception of mature minors from parental requirement for decisions made for them was legislated by State courts in the early 1900s (Gittler et al., 1990). The exception of mature minors to parental requirement emerges from the rejection of the presumption of minors' incompetence, and the assumption that minors lack decision-making capacity.

Rothenberg (1986) defined factors that support maturity of minors to make health treatment decisions as undertaking treatment for the minor's benefit not a third party, minor is near the age of majority, considering minors to have sufficient mental capacity to understand fully the nature and importance of proposed treatment plan, for not overly complex procedures. Three states including Arkansas, Mississippi, and New Hampshire have enacted statutes authorizing mature minors to consent to health services (American Psychiatric Association, 1986). The states of Idaho and Nevada enacted mature minors statutes (American Psychological Association, 1986). The exception of mature minors' parental consent requirement applies to minors in middle and late adolescence (Gittler et al., 1990).

Nurses' Role in Adolescent Health Treatment Decision-Making

Chronically ill adolescents' right to make informed consent to medical procedures or treatment remains a controversial issue in the health care arena. The pediatric health care protocol follows an informed consent by the physician. However, the role of the nurse must also be considered. Viewed by the Code of Ethics Project Task Force (American Nurses Association [ANA], 2000), the nurse's goals and values include respect for dignity, worth and uniqueness of each patient, and protecting patients from any threat stemming from incompetent, unethical or illegal practices of others.

Another provision made for the nurse when caught between parents' anger and duties, and the vulnerability and defensiveness of adolescents is to serve as an advocate. According to the American Nurses Association (ANA, 2000), for adolescent care the nurse's major function is to serve as an advocate, a spokesperson, a care provider, an administrative case manager and a volunteer with interdisciplinary approach and multicultural, socioeconomic and multiracial perspective. This means that while giving relevant information to making an informed judgment, the nurse supports patient's self-determination. Self-determination is a direction from within without outside influence of coercion.

The nurse also supports values that help an individual adolescent become a responsible member of society. In situations where there is controversy between parental authority and adolescent autonomy, the nurse may be much like that of a broker trying to reconcile two different viewpoints on certain issues. The issue *what is the nurses' role* becomes a presenting rationale as an advocate to resolve conflict between adversarial parents and adolescents (ANA, 2000).

The ANA (2000) provisions reflect its focus on the responsibilities of nurses leaving ambiguity about their duties in relation to advancing nursing knowledge and improving nursing care as dependent upon their values of the nursing profession. Even in the post-modern era of pediatric health care, there is that ambiguous understanding by nurses of the involvement of chronically ill adolescents in health treatment decisions.

Main Research Variables

Adolescents' self-confidence, decision-making styles, coping patterns, and preferences for involvement in health treatment decision-making were the main variables in this research. It included age, gender, and severity of symptoms as variables affecting self-confidence and involvement of chronically ill adolescents in health treatment decision-making. There were unidentified extraneous variables that may have influenced validity of findings.

Barnhart and Barnhart (2000) defined self-confidence as a belief in one's own ability, power, or judgment. Confidence in oneself implies that one's judgment based on disclosed information and alternatives are morally right. Self-confidence emerges from an individual's belief and motivation, knowledge and skills to reach a goal. It grows with the knowledge that basic motivation and ability to learn progresses over time in any situation. Self-confidence therefore, influences an individual's decision-making capacity in a certain situation.

Decision-making, as defined by Barnhart and Barnhart (2000), is an act of making up one's mind. It implies consideration of alternatives from disclosed information and making a choice that fits the outcomes (Harris, 1998). Janis and Mann (1977) asserted that effective decision making results from a set of processes such as identifying problems, generating alternatives, considering consequences of every decision, gathering information, evaluating alternatives, identifying suitable alternatives, and implementing the decision and making plans. When these processes are considered in making decisions, the behavior is vigilant information processing. Likewise, moderate stress in the process of decision-making results in a more vigilant decision-making.

Patterns of coping are styles experienced with the stress of decision-making. These patterns divide into two categories as adaptive and maladaptive decision-making (Janis & Mann, 1977). The adaptive type focuses on finding solutions to the problem with self-confidence and vigilance, while the maladaptive type focuses more on emotions leading to evasiveness, panic, and complacency. Lazarus and Folkman (1984) defined coping as a cognitive appraisal and reappraisal of a situation. An individual who handles a problem carefully in making decisions will evaluate the alternative courses of action, generate alternatives, and make choices that fit the goal and implements course of action. This kind of decision-making relates to appropriate problem-solving skills and high self-confidence (Friedman & Mann, 1993; Mann et al., 1989; Phillips et al., 1984; Radford, Mann, Ohta, & Nakane, 1993).

Brems and Johnson (2001) explicate that age and gender influence people's appraisal of their ability to solve problems and cope with problem situations. Studies show that men predict success and outcomes more than women who tend to internalize defenses and denial (Erkut, 1983; Frank, McLaughlin, & Crusco, 1984). Rousseau (1979) portrayed that the development of rationality for educational goals belongs to boys not for girls. He believed that in order for a man and a woman to be perfect, they should not resemble each other in mind any more than in looks. The moral imbalance between men and women precludes men's arrogance for their selfish propensities, and of women's servility for viewing themselves as less capable and deserving than men. This inequality can influence the capacity of adolescents to make health treatment decisions.

Decisions made in adolescence pose life-long impact on the individual's psychosocial wellbeing, health status, job, and acceptance into society (McAbee & Fieldman-Winter, 2002). Decisions made in adolescence may generate suitable conditions for life or may impose limitations on life conditions (Mann et al., 1989). Chronically ill adolescents have preferences in relation to the treatment trajectory they deal with in subjection to their body and being. They have to experience pain and discomfort that a treatment trajectory entails besides the discomfort from symptoms of the disease itself.

An individual's severity of illness influences his/her intellectual, psychological, physical, or social functioning (AAP, 1993). In addition, it affects the family's financial resources, child's physical development and functional ability, and emotional and coping behaviors (Perrin & Hobbs, 1985) that may influence preferences for involvement in health treatment decision-making. Several empirical studies in literature on decision-making and problem solving skills of adolescents have revealed a comparable capacity with that of adult decision-making capacity. However, there is lack of empirical studies on chronically ill adolescent preferences for involvement in health treatment decision-making.

Theoretical Framework

The theoretical framework for this research study revolves around the self-confidence, coping patterns, problem solving ability, and preferences for involvement in health treatment decision making of chronically ill adolescents, and the effects of symptom severity on self-confidence in decision-making. Janis and Mann (1977) identified four coping patterns used by adolescents when dealing with stressful decisional conflicts. Their conflict model on decision-making explains that antecedents such as time, pressure and optimism or pessimism precede coping patterns associated with a particular level of psychological stress. These coping patterns divide into two clusters as adaptive and maladaptive strategies. The adaptive coping behavior includes subscales of self-confidence and vigilance, while the maladaptive coping behavior includes subscales of panic, evasiveness, and complacency.

An adaptive behavior pattern is a carefully deliberated behavior, while a maladaptive behavior pattern fails the requirements of a high quality information processing (Janis & Mann, 1977). Embedded with the coping behavior is the cognitive behavioral tradition that is important in information processing, conceptualizing, and problem solving appraisal. Problem solving appraisal includes cognitive activities and rationale thinking (Heppner, Reeder, & Larson, 1983), active coping strategies (Larson, Piersel, Imao, & Allen, 1990; MacNair & Elliott, 1992), and utilization of environmental resources and social support (Elliott, Herrick, & Witty, 1986).

Social support best happens in a shared decision-making environment that bridges the vulnerability of adolescents in decision-making. The inexperience of adolescence in decision-making makes them vulnerable, which means being open to influences such as ridicule or injury (Barnhart & Barnhart, 2000). The shared decision-making allows a triadic collaborative relationship between the adolescent, parents, and physicians or nurses where options are deliberated and information of risks and benefits are considered. A shared decision making environment not only allows a voice of the adolescent but also makes their desires transparent for their preferences when decisions are at stake for their care. It protects the adolescent from coercion, ridicule, or injury, and it serves as an educative process in problem solving and decision-making.

Linked to Janis and Mann's (1977) conflict model of decision making with Piaget's (1972) cognitive development theory on adolescent thinking, adolescents can now consider abstractions rather than concrete deliberations. They now can think about their own thoughts and consider such as real objects for exploration. They begin to recognize between how things are and how things could be. Adolescents' thinking ability begins to conceive of the possibilities and moves beyond the limitations (Potts & Mandleco, 2002). The *what then* deliberations begins to emerge, and out of this ability comes a new sense of idealism in adolescence that unfolds comparison of self with the world around them. Selman (1980) supported Piaget's theory that adolescent's cognitive reasoning continues to become more complex in the context of allowing mutual perspectives to emerge. Mutual perspective taking ability recognizes that the fulfillment of relationship needs involves more than one relationship, thus individual differences can be an asset and not a threat (Potts & Mandleco). Erikson (1968) agreed with the notion of Piaget that, a strong sense of identity among adolescence makes them more self-confident, more secure with who they are, and how they are similar to, and different from those around them. Kohlberg (1976), in reference to Piaget's cognitive developmental theory, reinforced adolescents' acceptance of rules and laws, considering moral implications of their thoughts and others' thoughts, which is crucial to their developing personal belief system that largely defines their religious, social and political identities.

From the feminist's perspective in the context of identity and morality, Gilligan (1993) affirmed that the dominant voice is associated with males' justice perspectives and the inferior voice is associated with females' caring perspectives. This notion builds into the variable of gender differences in self-confidence, decision-making styles, and coping patterns. Besides gender and age, symptom severity can impinge upon the preferences of chronically ill adolescents for involvement in health treatment decision-making. Severity of symptoms can make a chronically ill adolescent less desirous for involvement in decision making than those with less-severe symptoms. Older chronically ill adolescents would tend to prefer more involvement in decisions made for their care than their younger counterparts would. With more experience and exposure to life stressors, older chronically ill adolescents tend to have more self-confidence in making health treatment decisions.

The integration of Janis and Mann's (1977) conflict model on decision making with the developmental theories, provide a strong foundation for involving chronically ill adolescence in deliberated health treatment decision-making. However, the presumed vulnerability of adolescents when afflicted with chronic illness entails a careful and deliberate decision that can only exist in a shared decision making process. A shared decision making environment provides opportunity for adolescent preferences for involvement in health care decision-making. Their decision-making ability continuously grows overtime with their experience when they are involved in the process of decision-making for their care. The collaborative environment in a shared decision making process allows education and learning for the chronically ill adolescent. Over time, their involvement becomes empiric as they participate in shaping their future and self-actualization.

Self-actualization, according to Barnhart and Barnhart (2000), means self-realization. Being able to realize the risks and benefits of treatment options gives meaning and ownership for health care outcomes of the decisions made to the adolescents. Congruent with self-confidence is the feeling of well being through involvement in the decision-making process. Having a voice in the process of decision-making gives them that feeling of ownership when outcomes unfold. On the contrary, if the expected outcome for the adolescent fails, his/her best interest overrides health care decisions.

Figure 1 shows the theoretical model for chronically ill adolescents' decision-making as a function of adaptive and maladaptive coping and problem solving based on Janis and Mann's conflict model in decision-making. It reflects a linear relationship between the existence of a problem with thorough information where problem resolutions undergo both adaptive and maladaptive processes using vigilance, panic, evasiveness, and complacency resulting in problem resolution and decision-making.

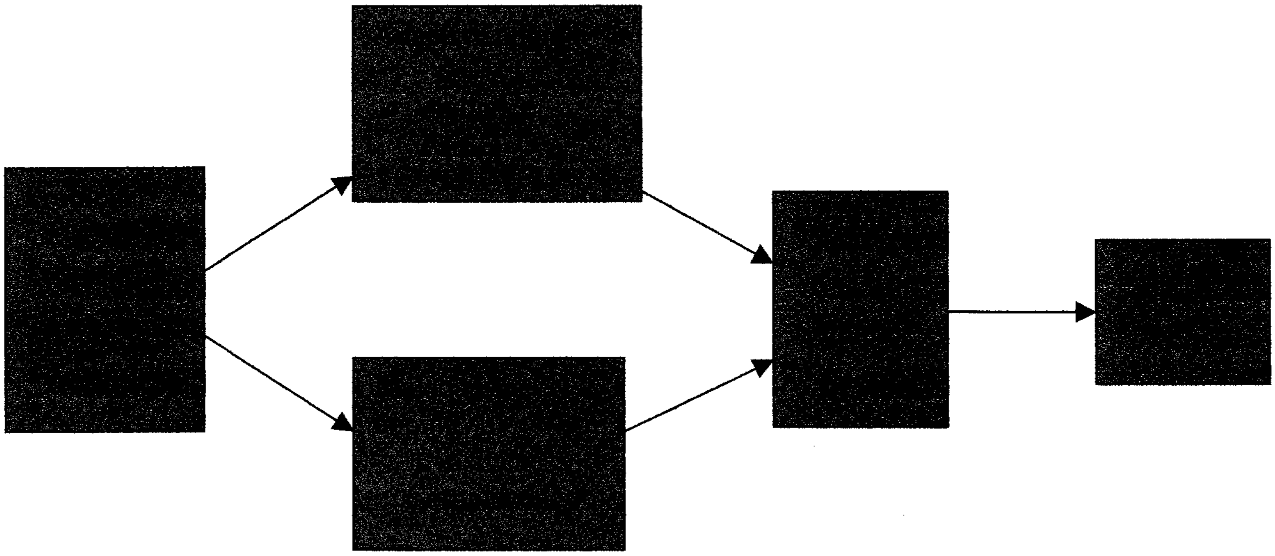

Figure 1. Janis and Mann' (1977) Conflict Model of Decision-making: Decision-making as a function of adaptive and maladaptive coping, and problem solving.

Figure 2 reflects a linear relationship between chronic illness, symptom severity, self-confidence, problem solving confidence, coping pattern, and preferences for involvement of chronically ill adolescents in relation to health treatment decision-making. Other variables that may influence the involvement of chronically ill adolescents in health treatment decision-making are their diagnosis, gender, and age. The notion that chronically ill adolescents' symptom severity, diagnosis, age, and gender affect their self-confidence for involvement in health treatment decision-making becomes the phenomenon to be tested in this research. It also includes variables such as problem solving confidence, coping patterns, and self- confidence in decision-making influencing preferences for involvement.

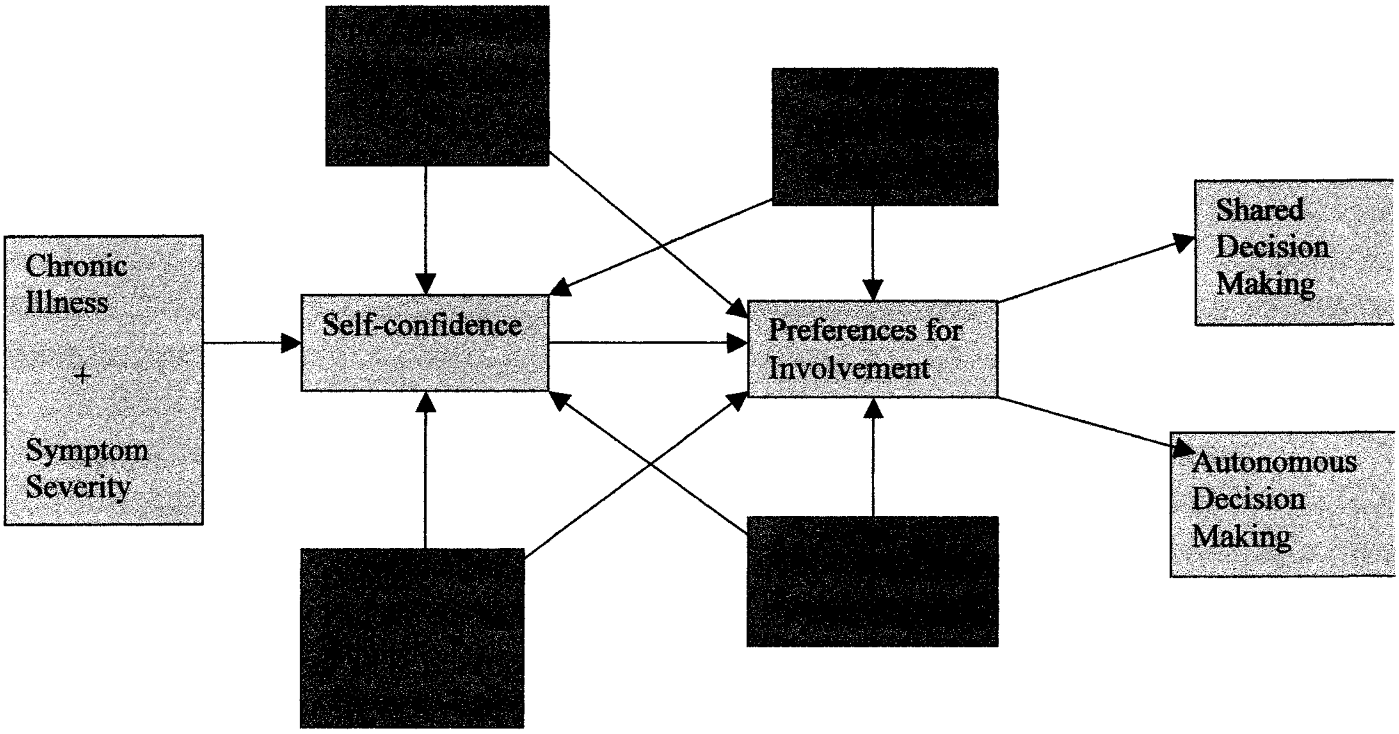

Figure 2. Chronic illness, severity of symptoms, and self-confidence that influence preferences for involvement in health treatment decision-making.

Embedding the two models together builds the theoretical framework for a shared decision-making that provides opportunities for the chronically ill adolescent's involvement in health treatment decision-making. Figure 3 shows the interrelatedness between the variables of interest in this study that influence chronically ill adolescents' preferences for involvement in health treatment decision-making.

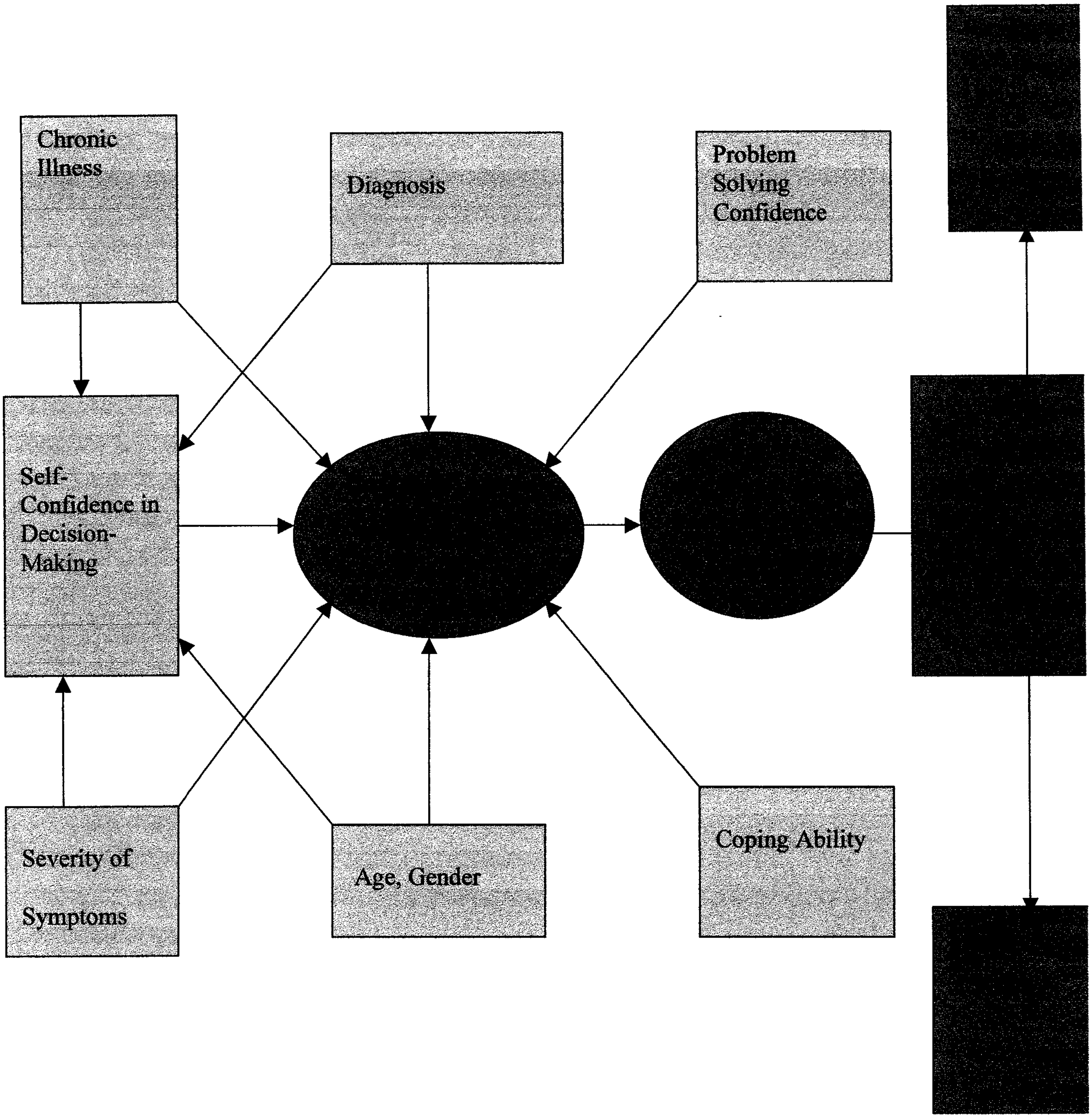

Figure 3. Theoretical model: Shared decision making for chronically ill adolescents' involvement in health treatment decision-making.

Limitations of the Study

This research study was limited to chronically ill adolescents who were representatives of four chronic conditions. Out of eleven chronic health conditions affecting children and adolescents (Perrin & Hobbs, 1985), four chronic health conditions with less severe and more severe sequelae based on severity of symptoms, hospital stay, and frequency of hospitalizations were included: asthma, cystic fibrosis, acute Lymphocytic Lymphoblastic leukemia, and sickle cell disease. Having a combination of less acute and acute chronic disease conditions may unfold variances, associations, and differences between variables on how chronically ill adolescents view or perceive their involvement in health treatment decision-making.

Summary

Chronic health conditions affect many children and adolescents. A health condition entails a characterization of the duration and severity of symptoms. These conditions are illnesses or impairments lasting a month or more with repeated medical attention and care requiring extensive hospitalization, or in-home health services. An estimate of 10 to 20 million children and adolescents diagnosed with chronic conditions or impairments live in the U.S. Current data suggests that 90% of chronically ill adolescents survived to adulthood attributed to medical and research advances that had decreased mortality rates. How adolescents managed to survive to adulthood, in addition to advanced technology and research raises a concern about their involvement in health treatment decision making over time.

The issues of adolescents' involvement in health treatment decisions are more complex than a physician's relationship with the patient and patient's family. The doctrine of informed consent provides evidence for the competence of the adolescent to make health treatment decisions. The principle of respect for a person's right of choice without coercion reflects the principle of informed consent. In the context of maturity, adolescents have moral and intellectual maturity comparable to adults. Many states legitimize adolescents as emancipated minors and mature minors who have the full responsibility to make health treatment decisions without parental consent requirement. However, the law states that each individual is capable of giving consent in the absence of proof to the contrary.

The adolescents' perceived vulnerability poses uncertainty and risk in his/her involvement in health treatment decision-making. An approach that satisfies a defined care of chronically ill adolescents includes an understanding of their interpretation of their expected developmental tasks in relation to their health behaviors. Chronically ill adolescents' vulnerability remains a controversy in involving them in health care decisions. State laws and regulations (AAP, 1995) passed a policy to involve adolescents in health care decisions, based on their maturity and ability to understand risks and benefits of a treatment plan, and a demonstrated understanding of alternatives that may be potentially imperative in their care.

The interplay between the theories of Piaget (1972) on adolescents' cognitive development, Kohlberg's (1976) moral development, and Eriksson's

(1968) identity with Janis and Mann's (1977) decision-making conflict model, provide a foundation for understanding adolescents' strategies in making decisions and their desire or preferences for involvement in health treatment decision-making.

Interwoven into the developmental theories and decision-making conflict theory is shared decision making. Shared decision-making is recommended to assure a well-deliberated decision, thus promoting an educative learning process for the chronically ill adolescent with consideration of his/her views in the decision making process. Their being able to participate in making decisions enhances their cognitive abilities to solve problems, strengthens their self-confidence in decision making, and promotes their feeling of well being and self-actualization.

The implementation of the theoretical model as an approach in the care of chronically ill adolescents initiates a shift in both medical and nursing practices in the plan of treatment for the adolescents and youth. It advances both medical and nursing knowledge about preferences of chronically ill adolescents in treatment decisions for their health and care as it empowers a shift in health policy, and interdisciplinary care approach for the adolescents and youth as well.

CHAPTER 2

Review of Related Literature

A study in 1991 (Meng Goh, 1999) estimated a prevalence of chronic illnesses among adolescents at 31.5% in the United States; 4% of these with one or more chronic health conditions sustained significant functioning limitations. In a 1993 study (AAP, 1993), 10 to 20 million American children, and adolescents had some type of chronic health conditions. Out of 10% children with chronic conditions, 2% have severe conditions enough to impact on their daily lives. Newacheck and Stoddard (1994) estimated that less than 1% children below 18 years old have three or more chronic conditions, and less than 5% have such conditions. Data from the National Health Review (1997) indicated that 8% of children from ages 6 to 18 years experience some degree of limitation in their activities due to chronic conditions and .2% experience severe limitations.

Severe limitations result from persistent symptoms requiring treatments, limitation of activity or mobility, interference with school, recreation and family activities. However, recent medical and surgical advances markedly decreased the mortality rates for children and adolescents with chronic conditions.

Data show that 90% of children and adolescents survived at least to young adulthood (AAP, 1993). Their survival with chronic illness to young adulthood posed a research interest about their involvement in health care decisions over time while they transitioned from adolescence to adulthood. Although research showed that children with chronic illness sustained more emotional trauma, other data has shown that, given the right environment, adolescents could make a smooth transition to adulthood even with chronic illness (Meng Goh, 1999).

Langer and Warheit (1992) found that teenagers tended to be high in sensation seeking, while Jessor's (1987) study revealed that adolescents used risk-taking behaviors to appear mature. Elkind (1985) confirmed Zucherman, Moreno, and Ahronheim (1994) and Jessor's notion asserting that adolescents have high sensation seeking due to heightened egocentrism in their stage of development. The National Research Council (1993) attributed these behaviors to a combination of individual vulnerability, social, and environmental factors. Although some research reported that adolescents had problems managing their health issues, other research findings revealed that chronically ill adolescents did not show increased difficulties and behavioral problems (Woodgate, 1998).

Newacheck, Strickland, Shonkoff, Perrin, McPherson, McManus, et al. (1998) reported that 12.6 million children nationally had developmental, behavioral, physical, or emotional conditions that required health care services beyond what children generally required. Newacheck and Halfon (1998) presented results from the National Health Interview Survey that 6.5 % of children in the United States experience some degree of disability.

The AAP (1993) estimated that between10 and 20 million American children and adolescents had some type of chronic health conditions. Meng Goh (1999) presented an estimate of the impact of chronic illnesses among adolescents in the United States at 31.5%, with 4% sustaining significant limitations in functioning. The Canadian Pediatric Society (2002) presented a similar estimate, that 20% or more adolescents under the age of 17 had chronic illness or disability with 90% survival to adulthood in the United Kingdom. Researches revealed that there were no significant differences in self-confidence among chronically ill adolescents when compared with healthy young people (Ireys, 1994).

Four Chronic Health Conditions Included in This Research

Gortmaker (1985) reported that recent medical advances have increased the survival chances of chronically ill children. Out of eleven chronic conditions in adolescents presented by Perrin and Hobbs (1985), four health conditions were included in this research study: cystic fibrosis, sickle cell disease, leukemia, and asthma. The impetus for the choice of these disease conditions emerged from the unique impact of each health condition to the adolescent's cognitive ability in making decisions in a stressful situation. Likewise, the rationale for including cystic fibrosis, sickle cell disease, leukemia, and asthma in this research emerged from the standpoint that the duration of illness, severity of exacerbations, remissions, and repeated hospital admissions affect the whole being of a person.

Although unique and varied in nature, the sequelae can lead to infections, respiratory compromise, and circulatory collapse. The severity and lengthy duration of illness can dramatically affect the cognitive, psychosocial, and moral development of the adolescents' decision-making abilities. They may prefer to withdraw from the decision-making process or may want to participate in the decision-making process.

Included in this study was leukemia. Although it is chronic in nature, most often patients become acutely ill. However, some research literature has shown that they survive up to the age of 20 (Hollen, Hobbie, and Finley, 1999). Exploring how chronically ill adolescents would like to be involved in treatment decisions for their care and knowing their experience for being involved in decisions for treatment options, as well as the acceptability of risks and benefits, unfolded new knowledge for the improvement of chronically ill adolescent's plan of care.

Lewiston (1985) explained that cystic fibrosis became recognized in 1930 from a marked elevation of sweat chloride concentration that became evident within the first year of life (Dynesen & Flenskborg, 1978) and survival is 70% to age 21. The gene is prevalent among Caucasians in a ratio of 1:1,600 births in the United States. It is present among other races but less common (Thompson, 1990). Advances in medicine increased the life expectancy of individuals with cystic fibrosis. Rosenstein (1999) estimated the incidence of cystic fibrosis among Caucasians at 1:3,200 live births, African-Americans at 1:16,300 live births, Asians at 1:3,200 live births, all with a median expectancy of 31 years. Littlefield (1981) and Lewiston (1985) revealed that 95% of cases predominate among the Caucasian population. Hatziogorou, Karagianni, Vidalis, Bullinger, Tsanakas, and the DISABKIDS-Group (2000) reviewed the health-related quality of life measure that provided information about the impact of cystic fibrosis.

The health-related quality of life measure increased children's views towards treatment and care. Statistics have shown that early diagnosis and treatment increased quality of life and survival to adulthood. Related literature reflected the quality of life and reported increased survival rates up to 34 years old in the United States and 35 years old in Canada. However, there was no mention of how these adolescents were involved in the decision-making process for their treatment trajectories. Since this disease condition greatly influenced family functions and structure, the researcher would like to explore involvement of adolescents in shared decision-making as a collaborative effort between the parents, adolescents, and physicians.

Leung, Steinback, Morris, Kohn, Towns, and Bennett (1997) conducted a descriptive study on chronic illness perception in adolescents and the implications of the doctor-patient relationship. The inter-relationship of chronic severity as perceived by adolescents with the psychosocial well being among adolescents with cystic fibrosis (CF) and insulin-dependent diabetes mellitus (IDDM) showed that patients with CF correlated with the perception of severity and clinical indices, but not to participants with IDDM. Physicians came from a different perspective on the severity of illness; therefore, they did not infer perceptions of illness severity.

The differences in perceptions among adolescents with IDDM and adolescents with CF emerged from the uniqueness of their experiences with the disease. Besides glycemic control in IDDM with diet and insulin injections, adolescents with IDDM most often feel *normal.* On the contrary, adolescents suffering from CF experience abnormality in their breathing pattern that compromised systemic oxygen supply and circulation. There was poor absorption of nutrients leading to malnutrition and poor immune system. With the systemic complications of the disease, the differences in how adolescents with cystic fibrosis differ in their cognitive abilities to make decisions from that of the other adolescents suffering from other chronic illnesses will be considered in this study to see if their perceptions of severity correlate with clinical indices. The severity of illness with respiratory compromise might influence their preferences for involvement in health treatment decision-making.

Another chronic childhood illness that threatens about 4 million children in the USA is asthma, affecting 5% to 10% of the population and a mortality of 5,000 children per year (Ostrum, 2003). Asthma is an inflammatory condition of the bronchial airways resulting from excessive overreaction of the airways caused by triggers producing increased mucous, mucosal swelling, and muscle contraction. These changes produce airway obstruction, chest tightness, coughing, and wheezing. Severe reactions can cause shortness of breath and low blood oxygen concentration (Couriel, 2003). Ostrum reported that with asthma, breathing is restricted. She further said that the airway becomes irritated from triggers, and then becomes constricted from bronchospasm. About 75% to 85% of affected children have some form of allergy. The allergic reaction caused by a specific trigger can result in airway obstruction or bronchospasm. These triggers could include smoke, mite dust, chemicals, pets, exercise, emotional stress, drugs, and air pollution (Ball & Bindler, 2003). Asthma in adolescence is a challenge, because teenagers are more concerned about their schoolwork and social life than their health. Ostrum further stated that teenagers would comply with their treatment regimens if they had a part in the decision-making process and if they were allowed to own the decision-making about their disease. The problems with treatment compliance among teenagers with asthma were the impetus for including this chronic illness in this research.

One of the hematological health conditions among chronically ill children is sickle cell disease (SCD). SCD was first described in 1948, but differentiation between sickle cell trait and sickle cell anemia was elucidated in 1940 (Whitten & Nishura, 1985). There is the mutation and sickling of red blood cells aggravated by poor oxygenation of red blood cells. SCD is a hereditary disease from the gene of both parents of African-Americans with an approximate live birth frequency of 8% for sickle cell trait and .2% for sickle cell anemia. Onset occurs in the latter part of the first year of life (Vaughan, McKay, & Nelson, 1975; Goldenson, Dunham, & Dunham, 1978) with a survival rate at 93% up to age 20 (Murthy & Haywood, 1981). Early diagnosis, therapeutic intervention, and patient education resulted in a dramatic increase in survival (Lukens, 1981). Adolescents with sickle cell have had multiple sickle cell crisis admissions not only to the acute care settings but also to the intensive care units. Over time, they tend to become so familiar with their treatment trajectories (e.g., routines, procedures, medications) that they have a heightened self-confidence in decision-making and an increased desire for involvement in health treatment decision-making. Their desire for pain control becomes a challenge among health care workers. This is the impetus for inclusion of this disease condition. Their decision-making ability could influence the administration of frequent pain medication and requests for breakthrough pain medications. If control is passed onto the adolescents, then that would require nurses to believe they are in pain when they demand their pain medications instead of giving their pain medication every two hours on the hour or question whether they are really in pain. Additional knowledge would help to justify their involvement in health treatment decision-making, to own the decisions for their health and care.

To predict correlations between severity of symptoms and self-confidence in decision-making, the researcher decided to include a more severe form of chronic illness, leukemia. Leukemia is one of the leading causes of death among children aged 1 to 15 years in the United States (Pendergrass, Chard, & Hartman, 1985). An estimated 130 new cases of leukemia have been reported each year for every 1 million children, 30% of which reported leukemia with annual incidence of 40 cases per 1 million under the age of 15 (Young & Miller, 1975). Young (1978) commented that, in the United States, approximately 6,100 new cases of childhood cancer occur each year, including 1,900 cases of childhood leukemia. Onset occurred at the age of 3 to 4 (Vaughan, McKay, & Nelson, 1975) with 50% survival to age 2-from 1970 to 1975 (Szklo, 1978), 30% in remission for 3 years, or relapse after the fourth year, thus increasing the estimate of 50% survival to age 20 (Simone, 1979). Later research demonstrated that the annual incidence was three to four cases per 100,000 Caucasian children (Margolin, Steuber, & Poplack, 2002). Hollen, Hobbie, and Finley (1999) tested the cognitive late effect factors related to decision-making and risk-taking behaviors of cancer-surviving adolescents. A correlational study was carried out from a convenient sample of 52 survivors aged 14 to 19-years-old with all types of cancer, except brain tumors, who were disease free for 5 years and had no treatment for 2 years participated in the study. Results showed that there were no significant differences related to abstract and analytic ability among the participants. They believed that abstract and/or analytic ability influenced decision-making ability and risk taking behaviors of teen survivors. Therefore, they recommended a larger sample for further study.

Hollen and Hobbie (1993) conducted a study adding a decision-making module to risk reduction and other health care programs for adolescents. They focused on teens surviving from cancer. The intent of the intervention booster was to refine adolescent decision-making skills through a teaching life style tool for making decisions related to smoking and alcohol use and other health-related decisions. The intervention module includes a curriculum with video, workbook, and two instruments to measure outcomes. Results illustrated a dampening effect on the upward trajectory of substance use. Hollen and Hobbie believed that it was imperative to have a booster program to refine decision-making skills within a meaningful decision context to reduce risk behaviors among cancer surviving adolescents.

Laikin (1993), in her study on the role of adolescents concerning their cancer therapy, found that their part was to comply with every treatment trajectory. The articles presented an analytic ability of cancer surviving adolescents for all kinds of cancers except brain tumors, but did not address their preferences for involvement in health treatment decision-making. Of interest would be to find out if they prefer involvement that would positively influence their survival and quality of life. Thus, knowing the adolescent's preferences for involvement in health treatment decision-making could promote a better planning of care and serving the best interest of the chronically ill adolescent.

Adolescent Growth and Development

Weithorn and Campbell (1982) compared competency among adolescents 9, 14, 18, and 21 years old in terms of understanding, rational thinking, and reasonable outcomes to make informed treatment decisions. Results showed that 14, 18, and 21-year-old adolescents did not differ significantly in their ability to reason and understand treatment information, even in hypothetical situations. Doig and Burgess (2002) said that adolescents who understood that the consequence of withdrawing life-sustaining medical treatment might result to their death deserved the right to make that decision. The AAP (1994), along with the Canadian Pediatric Society (2002), stated in their guidelines on foregoing life-sustaining treatment that, regardless of legal particulars, parents and physicians should give great weight to expressed views of adolescent patients regarding life-sustaining medical treatment.

Adolescence is a developmental epoch divided in different phases as early, middle, and late adolescence. Piaget and Inhelder (1964) defined early adolescence as between the ages of 12 to 14 years. They said that these children could detach but could not reason abstractly. Bandman and Bandman (2001) characterized early adolescence as the phase of invisible mood swings without obvious factors. They said that middle adolescence was the stage when parental detachment continued to emerge coupled with heightened conflicts between the ages of 14 to 17 years. The adolescent constantly challenged rules and renegotiated them.

Late adolescence, ages 17 to 19, marked the period when sexual identity and peer relationships matured. The future became the dominant perspective with further education, career beckoning, and marriage. Potts and Mandleco (2002) defined gender identity as the way individuals thought about themselves as either female or male and it was a culmination of personal and social expectations, biological makeup, and recommendations as to how males and females should think and behave. Children came to understand the differences between boys and girls and demonstrated strong preferences toward gender-appropriate behavior. Erikson (1968) considered gender as an important part of establishing identity among young people.

Gilligan, Lyons, and Hanmer (1990) agreed with Erikson (1968) in the context that gender was important in developing a sense of identity among early adolescent girls. They contended that males and females experienced different developmental paths. According to them, girls had greater orientation on relationships and interaction with others. In adolescence, girls became aware that their innate relational orientation did not measure with the male-dominated culture of rules-based orientation. Thus, girls silenced their unique perspective, or *different voice*, becoming less assertive with their opinions. However, Archer (1992) and Waterman (1992) found that males and females became increasingly similar in their patterns of identity formation.

The three phases of adolescence reflected a progression of cognitive, physical, emotional/social, moral, and gender identity development based on Piaget's, Kohlberg's, and Freud's theories, as shown on Table 1 (Busen, 2001; Hawley, 1997; Potts & Mandleco, 2002; Wong et al., 2003).

Table 1

Growth and Development: Adolescence from 14 years old to 19 years Old

Three Phases	Cognitive Piaget	Moral Kohlberg	Emotional Social-Erikson	Physical/ Biological
Early 12- 14 years old	Explores newfound limited abstract thought Comparison of abnormality with peers of same sex	Conventional moral reasoning Spiritual and ideological orientation	Strong desire for dependency while trying to detach from parents Mood swings rebellious and defiant behavior	Rapid body changes Self exploration and evaluation Secondary sex characteristics
Middle 14- 17 years old	Developing abstract thinking Enjoys intellectual powers for Philosophic, Political and Social problems	Morality based on equal respect and reciprocity Emphasis on internal aspect of religious commitment	Push for detachment from parents Modifies body image Strong needed for identity More introspective	Reaches 95% of adult height Well-advanced Secondary sex characteristics Exploration of self-appeal Tentative est. of relationship
Late 17-19 years old	Established Abstract thought, intellectual and functional ability Views problems comprehensively	Principled moral reasoning Orientation to justice Reevaluation of beliefs and values of childhood Religious beliefs become more personalized	Emotional and physical separation from parents Constancy of emotions Giving and sharing relationships Emancipation nearly secured	Physically mature Mature sexual identity Intimacy commitment Stability of self-esteem Romantic dating

The majority of physical/biological development occurs in the early and middle adolescence in physical growth, hormonal changes, and sexual maturation. Piaget and Inhelder (1964) reported that adolescent cognition transitioned from concrete to formal operational thought and it influenced all aspects of their psychosocial development. Early adolescents interpreted events literally, while middle adolescents used inductive and deductive reasoning to project into the future, and progressed to late adolescence where abstract reasoning enabled them to apply knowledge to the future with the understanding of consequences. Problem-solving skills were highly developed in middle adolescence, as well as the capacity to analyze and understand complex concepts (Busen, 2001).

Health Care Issues in Adolescents with Chronic

Bryden, Peveler, Stein, Neil, Mayou, and Dunger (2001) conducted a longitudinal cohort study to determine the clinical and psychosocial course of diabetes and its relationship with glycemic control in young adulthood. They found that behavioral problems in adolescence influence glycemic control that required effective interventions for high-risk adolescents. Similarly, Dashiff and Batolucci (2002) investigated autonomy development among adolescents with IDDM. Using the descriptive method, 54 adolescents with IDDM participated in the study. The researchers assessed relationships among behavioral, cognitive, and emotional autonomy and determined relationships between autonomy and metabolic controls. Results of the investigation suggested that the pattern of adolescent autonomy with IDDM corresponded with that of healthy adolescents, and emotional autonomy related to poorer glycemic control. Results also showed that daughters from a one-parent family scored higher on emotional autonomy. The poorer glycemic control relating to emotional autonomy might have an effect on their involvement in health treatment decision-making. There was no mention of how these adolescents were involved in health care decisions in the study.

Urowitz, Deber, and Myers (2002) conducted a study on autonomy, decision-making, and patient's preferences to determine preferred roles in clinical decision-making. They examined factors affecting preferred roles and determined the effects of preferred roles on clinical outcomes to autonomous young adult patients with HIV/AIDS. Results showed that, even with these autonomous patients, they preferred a shared role with their providers. However, the study did not explain the reasons why these autonomists preferred a shared decision instead of autonomous decisions, yet these were young adults presumed competent to make autonomous decisions. Hatzigorou et al. (2000) examined instruments that measured health related quality of life on children with CF. The health-related quality of life measures raised the profile of children's views about treatment and organization care. Including five different chronic health conditions in this research study will allow an exploration of the differences in the self-confidence of chronically ill adolescents as well as their preferences in getting involved in health treatment decision-making.

Empirical Research on Minors' Competency in Health Care Decisions

Seven empirical studies on the age-competence relationship in health care decision-making were conducted by Lewis (1980, 1981); Weithorn and Campbell (1982); Belter and Grisso (1984); Kaser-Boyd, Adelman, and Taylor (1985); and

Ambuel (1989). Their studies tested whether the cognitive development of minors differed in their ability to make health care decisions from adults. They compared children's competency among 9 to 25 year-olds to make health care decisions and age-competence relationship in health care decision-making. Results found few differences in health care decision-making as a function of age for adolescents 14 to 15 years old. On the other hand, their studies found that, as age increased from 12 to 19 years old, an increased awareness of risks and future consequences and caution about the advice of persons interested in the choice were evident. Results also showed that adolescents aged 14, 18, and 21 did not differ in their reasons for their decisions and they did not differ in understanding health problems and consequences associated with alternatives. Thus, these studies showed evidence that patients in middle and late adolescence had competence equivalent to adults even if they were presumed incompetent. Findings likewise showed that adolescents in the early stage, aged 11 to 13 years, needed more assistance in their decision-making.

Results in other studies, including variables of gender, intellectual ability, experience, condition severity, pressure from peers/family, or skill training reflected minors' decision-making capacity. Studies by Lewis, Lewis, and Ifekwunigue (1978), and Lewis, Lewis, and Lorimer (1977) found that elementary school boys and girls did not differ from adults in the utilization of health services. However, they found that girls made use of health services more often than boys did.

Kaser-Boyd, Adelman, and Taylor (1986) found in their study on the effect of ethnicity in decision-making that Caucasian and non-Hispanic adolescents scored higher on the psychological treatment decision vignettes than other participants. They examined the effects of condition severity on competence to decide and found that adolescents not referred for psychological treatments, and adolescents with moderate behavior problems scored higher on the psychological treatment decision vignettes than adolescents under psychological treatment and adolescents with severe behavior problems. Lewis (1981), Weithorn, and Campbell (1982) found that there were no systematic differences in decision-making as a function of the seriousness of the condition. These studies on gender, intellectual ability, and condition severity reflected differences in psychological decision vignettes, higher on those with behavioral problems. Considering the severity of health condition as a variable affecting self-confidence and involvement in health treatment decision-making may unfold new knowledge in the context of adolescent decision-making.

Scherer and Repucci (1998) examined the effects of parental pressure on hypothetical health decisions. They found that the more invasive the treatment choices, the less 14 and 15-year-olds yielded to parental pressure and the more sensitive the condition, the more these adolescents yielded to parental pressures. The exploration on the relationship between age and conformity to social influence in decision-making revealed a decrease from ages 7 to 11 years old, then an increase from ages 11 to 13, and then began to decrease after that. Belter and Grisso (1984) examined the effect of skill training on one's competence to decide. Results showed that adolescents who received briefings showed significantly higher recognition and protection scores than those who did not. The 9 year-olds did not receive any benefit, but 15 and 21 year-olds derived significant benefit. Heremes and Petersen (1986) presented their notion that sixth grade children learned resistance to persuasion leading to a more independent decision-making. The AAP (1995) recommended respect for the voice of the child without the influence of coercion.

The previous studies emphasized the importance of disclosing information that allows adolescents to make competent decisions. They demonstrated empirical evidence of the sensitivity in the middle and late adolescent to recognize social pressures that affected their decision-making skills.

Hollen, Hobbie, and Finley (1997) did a correlational study from a convenience` sample of cancer-surviving adolescents on the cognitive late effects of treatment on their decision making and risk taking behaviors. It included all types of cancers, except brain tumor, among cancer surviving adolescents aged 14 to 19. Results showed that there were no significant differences in abstract and/or analytic ability concerning cognitive threat status.

Empirical studies by Weithorn and Campbell (1982) supported the idea that minors, aged 14, and 15 through 17 years had the same capacity to make health care decisions comparable to adults. The traditional and implicit assumption of the law that minors were unable to make health care decisions as well as adults posited a challenge (Gittler, Quigley-Rick, & Saks, 1990). However, the studies revealed gaps in knowledge to formulate public policy pertaining to adolescent involvement in health care decision-making. The studies did not examine decision-making performance in real stressful situations to see what effects a situation yielded on decision-making performance. Another limitation was that comparisons involved very young adults and minors rather than adolescents of various ages. Therefore, it is imperative to the present study to include adolescents who have experienced the effects of chronic illness physically, emotionally, cognitively, and psychosocially, to examine the empirical meaning of chronic illness to the decision-making abilities of chronically ill adolescents in relation to their preferences for involvement in making health treatment decisions. Including the three stages of adolescence in the population of this study would allow a more inclusive view of adolescents' preferences for involvement in health treatment decision-making in stressful situations.

Bioethics in Adolescent Care

Cohen, Flament, Taieb, Thompson, and Basquin (2000) conducted a study on the ethics of electroconvulsive therapy (ECT) in adolescence. Based on the principles of non-malfeasance, beneficence, and justice, there was no ethical reason to ban the use of ECT in adolescence. Ethical options in clinical practice needed empirical evaluation with respect to the consequences for the patient.

Traugott and Alpers (1997), both practicing attorneys, asserted similar ethical perspectives as did Cohen et al. (2000) on three reported cases of adolescents who refused life-prolonging treatment. Billy Best, 16 year-old, refused chemotherapy for Stage II Hodgkin disease, Benny Agrelo, 15 year-old refused immunosuppressant medications after liver transplantation, Lee Lor, and 15 year-old refused chemotherapy for ovarian cancer. The child welfare services and police were involved in the latter two cases. Related to these three cases, Traugott and Alpers (1997) reported that a sound ethical practice required physicians to respect the dignity of each adolescent patient by listening and understanding the individual values and concerns about medical treatment.

Quality of life and survival should be a priority instead of state and social work involvement. If the court determined that an adolescent's competence for informed decisions, it called for justice. If not, then judges should decide for the best interest of the adolescent. The court could implement judicial bypass to assess the capacity of the adolescent to make mature medical decisions (Traugott & Alpers, 1997).

Judicial bypass allows an adolescent to bypass his/her parents and consent to treatment as a mature minor independently. It functions as a public recognition of an adolescent's concerns, although it also poses significant difficulties in a bureaucratic environment. Beidler and Dickey (2001) stated that advances in chronic illness and genetic disease management and technology created new challenges for patients and health care professionals in informed decisions. The growing interest in children's involvement in their own health care decisions and rebalancing adolescents' rights and responsibilities compounded these challenges. There was a preponderance of support with involving children in the decision making process and a dearth of reasons for excluding them. They recommended further research on children's competence to participate in healthcare decisions including reasons for their increased involvement in health care decisions.

There were variations in decision-making within age groups, thus public policy makers needed to seek an individualized determination of competence by health care professionals or by courts. On the other hand, policy makers could establish a reputable balance of interest between adolescents, parents, health care providers, and the state (Bennett, 1976). There must be a clear definition of adolescent involvement in health care decisions similar to regulations on adolescent decision making in seeking health services.

Adolescent Involvement in Health Treatment Decision-Making

A research study done by Hartman (2002) on physicians' perceptions of adolescents' decisional capacity revealed that more than 50% of physicians reported that adolescent patients understood conditions and medical treatment, engaged in rational deliberations, rendered mature judgments, and communicated choices and concerns clearly. Thirty-three percent involved a parent or guardian only with the adolescents' expressed consent, 90% of physicians who responded emphasized respect for the adolescent patient's confidences, honored confidentiality of conversations, and secured adolescent's trust, 75% honored adolescent decisions about non-life threatening conditions despite parental objections. The majority agreed that adolescents exhibited a stable set of values and emotional stability in the medical decision-making process not different from young adults, even when confronted by hormonal fluctuations and stress. The quality of their decisions did not differ from those of adults. Thus, the study challenged the implicit presumption that adolescents lacked the requisite capacity for quality decision-making. Physicians believed that they were ethically encouraged to involve adolescent patients in treatment decisions.

Runeson, Enskar, Elander, and Hermeren (2001) conducted a study on the perceptions of health care professionals on children's participation in decision-making. Out of 140 participants, 81% were nurses. Results revealed that children's participation affected their situation. Other findings showed that violating actions on children became a practice in the health care arena. Runeson, Elander et al. (2001) found similar results in their study on everyday situations where hospitalized adolescents aged six to 17-years had a voice. Some situations allowed some degree of self-determination. However, staff honored children's choices concerning their care.

McAliley, Hudson-Barr, Gunning, and Rowbottom (2000) found in their research that adolescents 15 to 18 years old felt it very important for someone their age to have a living will. Other findings revealed that there was no developmental significance about turning 18 when it concerned end-of-life decisions. Hollen et al. (1997) agreed with this assertion based on their correlation study on late effects of treatment that predicted decision-making and risk behaviors of cancer-surviving adolescents. Their findings showed that abstract and/or analytic ability of teen survivors revealed a link to their decision-making and risk behaviors.

Advances in chronic and genetic management and technology create new challenges for health care professionals and patients in making informed decisions. These challenges preclude the growing interest in children's involvement in their own health care decisions. The Q'Quigley Report revealed dominant themes including autonomy, confidentiality, and cultural sensitivity in the context of children's views about their medical treatment (Terry & Campbell, 2001). Blum, Resnick, and Stark (1993) recommended in an article, transition from child centered to adult health care systems for adolescents with chronic illness. Their recommendations included professional and environmental support with active participation of the family and patient in the process of decision-making.

Britto, deVilles, Hormung, deFriese, Atherton, & Slap (2004) launched a study on health care preferences and priorities of adolescents with chronic illnesses. They used a mixed-method questionnaire development and survey applied to 155 chronically ill adolescents who had inflammatory bowel disease, rheumatoid arthritis, SCD, and CF. Results revealed that, on average, these adolescents preferred that information be directly given to them rather than their parents but were neutral about physician's inquiries on personal issues. On the other hand, Stenekes (2005) explored relationships between family functioning and adolescent preferences for decision-making among oncology patients. He found that family functioning did not contribute to the preferences for decision-making of adolescents with cancer.

Although studies did not explicitly assert adolescent involvement, empirical research revealed evidences of adolescent competence in making health treatment decisions even in stressful situations. This evidence challenges the legal assumption that adolescents lack the experience and therefore are incompetent to make health treatment decisions.

Summary

With improved management of chronic disorders in childhood, 90% of chronically ill and disabled children survive into their second and third decades of life (Schutingga- Helder et al., 1996). The self-esteem of chronically ill adolescents did not differ from the self-esteem of healthy adolescents. Empirical studies on the age-competence of adolescents in relation to decision making (Ambuel, 1989; Belter & Grisso, 1984; Kaser-Boyd et al., 1985; Lewis, 1980, 1981; Weithorn & Campbell, 1982) showed differences in decision-making competence among older and younger adolescents. They revealed that adolescents aged 14 years and above had decisional competence comparable to adults. Other variables empirically studied were gender, intellectual skills, experience, condition severity, and pressures from peers and family. Results further revealed that intellectual skills, experience, condition severity, and pressure from peers influenced the decision-making of minors. Studies on preferences of chronically ill adolescents in health treatment decision-making revealed that severity of condition and family functioning did not affect their preferences for involvement in health treatment decision-making. Their desire for information about their illness was to receive the first hand information, instead of through their parents. How a stressful situation in chronic illness among chronically ill adolescents influenced their decision-making capacity would be significant to advance nursing knowledge, nursing practice, and health policy.

The shared decision-making process supports the self-confidence of the adolescent while processing information and alternatives in a deliberated but supportive environment. The allocation of adolescent involvement in health treatment decision-making is not clear even in the courts or health-care arena.

While advances in medical treatment and technology through research have increased chronically ill adolescent's survival rates, definition of their involvement in health treatment decision-making remains non-transparent. Digging deeper into the self-confidence, decision-making styles, and coping patterns of chronically ill adolescents in relation to their illness may validate research theories that adolescents could make decisions just as adults do. In spite of the ill effects of the intrusion of chronic illness, adolescents' decisional capacity remains intact. Exploring more into the preferences of chronically ill adolescents in relation to their involvement in health treatment decision-making unfolded their desire to be involved in decisions made for their care. It further illuminated their seeking for involvement and shared decision-making as well as autonomy.

The next chapter presents the methodology and process of exploring and examining the phenomena of self-confidence, decision-making confidence, and coping patterns that influence chronically ill adolescents' preferences for involvement and/or non-involvement in health treatment decision making. It uncovered the extraneous variables as age, gender, and diagnosis, and measured the effect of symptom severity as variables that may influence chronically ill adolescents' self-confidence and preferences for involvement in health treatment decision-making.

CHAPTER 3

Research Methodology

Although this study was a quantitative, two questions for qualitative inquiry were included to unfold the epistemological and ontological underpinnings influencing chronically ill adolescents' preferences for involvement in health treatment decision-making. The research design included cross sectional nonrandomized methodological triangulation.

Methodological triangulation explored the preferences for involvement of chronically ill adolescents in health treatment decision-making to unfold new knowledge for health policy makers, and health care professionals involved in the care of chronically ill adolescents. Methodological triangulation included both quantitative and qualitative inquiries to describe and infer the events and people that are objects of the study, and interpret to propose meanings that go beyond the descriptions (Thomas, 2003). Methodological triangulation or mixed-method, according to Field and Morse (1985) can be simultaneous or sequential. Triangulation ensured corroboration and validation of data. Descriptive and inferential statistical analysis explored associations, sameness, and differences, while the qualitative piece of the inquiry looked for commonalities and linkages of the diverse point of views, experiences, and perspectives of chronically ill adolescents, in relation to their preferences for involvement in health treatment decision-making. According to Munro (2001), Pyrzak (1995), and Antonius (2003), a descriptive statistic aimed at describing situations by summarizing information based on numerical data gathered to get an average. It included measures of central tendency to examine values that represent the bulk of the data. It also measured dispersion through standard deviation, variance, and range, and measures position through quartiles and percentiles, and associations using correlation *r* for prediction.

Furthermore, inferential statistics according to Munro (2001), Pyrszak (1995) and Antonius (2003) aimed at generalizing a measure from a smaller number of cases to a larger set of cases observed. It includes estimation and hypothesis testing. Estimation involved drawing conclusions about the whole population from a known sample. Hypothesis testing predicted a range of values a variable is likely to be on a representative sample. If the value fell within the predicted range, the hypothesis was reasonable. If the observed value fell outside the predicted range, the hypothesis was rejected. Antonius (2003) said that hypothesis testing was the main mode of reasoning in inferential statistics with estimation. He elaborated that it was a process where one proposition was accepted against another that provided the probability of error at the same time.

Munro (2001) presented that if inferences about the population should take place, the following assumptions must exist:

1. The sample to which inferences were made must be representative of the population.
2. Variables must be normally distributed.
3. There must be homoscedasticity or equal variability and/or the same standard deviation.

4. Relationship between X and Y must be linear.

The basic purpose of inferential statistics was to draw conclusions from information collected on a sample about a population. Antonius (2003) explained that inferences always imply a margin of error and a probability of error. He said further that a random sample was likely to be representative, and inferences based on representative samples have a higher chance of being correct.

Both descriptive and inferential analysis explored answers to the research questions prospectively presented in this research study.

Research Questions 1: What are the relationships between chronically ill adolescents' self- confidence, problem-solving confidence, coping patterns, and their preferences for involvement in health treatment decision-making?

Research Question 2: What are the relationships between chronically ill adolescents' age, gender, diagnosis, and their preferences for involvement in health treatment decision-making?

Research Question 3: How do older and younger chronically ill adolescents differ in self-confidence for involvement in health treatment decision-making.

Research Question 4: How do male and female chronically ill adolescents differ in coping ability and self- confidence in health treatment decision-making?

Research Question 5: How do health condition or diagnosis, and severity *of symptoms, affect preferences of chronically ill adolescents in their involvement and/or non-involvement in health treatment decision- making?*

Research Question 6: What are the relationships between severities of symptoms and self-confidence among chronically ill adolescents in health treatment decision-making?

The Deber-Kraetschmer Problem Solving Decision Making Scale (10-18) included closed and open-ended questions to generate participant's perspectives, preferences, and experiences in relation to their involvement in health treatment decision-making. Core perspectives emerged from responses as salient themes unfolded. The closed-ended question included *How much experience have you had with the clinical situation described in the above scenario?* The open-ended questions included *How would you like to be involved in treatment decisions?* Moreover, *How has the nurse made it easier for you?*

Data Collection

Using a qualitative inquiry to a quantitative driven research approach was an inductive approach to ensure corroboration of data and validate findings. This *quant* + *qual* inquiry was based on the ontological and epistemological paradigms for knowing the real worldviews and perspectives of chronically ill adolescents, in relation to their involvement in decisions made for their health and care. Epistemology, according to Rohmann (1999), was knowledge based on the relationship between the knower and the known. He said further that it was the knowledge of what was true. Affirmed by ontological perspective that dealt with what was real or reality, the researcher tried to find the truth and reality through qualitative inquiry. Including a qualitative inquiry allowed the researcher to ground what was the truth, and what was real in the world of adolescence as it related to their preferences for involvement in health treatment decision-making. Sandelowski (2000) believed that conducting grounded theory creates reality, fashioned, or invented from the data. It emerged from the constructivist's assertion that all human discoveries were creation. The use of methodological triangulation ensured corroboration of data, clarified and explained results of analyses, guided the use of additional sampling, data collection and/or analysis techniques as necessary (Greene, Caracelli, and Garham, 1989).

Sampling

Sampling is the process of selecting individuals to represent a larger group from which they were selected for a study (Fain, 1999; Polit and Beck, 2003). It allows drawing inferences and generalizing by the researcher about the population. With a proper conduct of sampling procedure, the characteristics of the phenomena of interest become transparent in all the variables studied.

This study used convenience sampling or nonrandom sampling. Fain (1999), called it accidental because the process included collecting data from subjects who were readily available or easily accessible to the researcher. Polit and Beck (2003) say that convenience sampling used the most conveniently available subjects for the study. They say that although it was known as the weakest form of sampling, it was a sampling method that was most commonly used in nursing studies. The sample subjects were not selected from a larger group, instead the researcher collected data from whoever was available and met the study criteria. With a homogenous population as defined in the eligibility criteria below, strong generalizations applied to the population can be made.

Definition of the criteria for eligibility guided the researcher in identifying participants from the specialty clinics, and medical personnel to support this study. The researcher sent letters to the department heads of the Pediatric Specialty Team Center for Loma Linda University Children's' Hospital and Loma Linda University Health Care. Letters of support were received from physicians for their willingness to support this study. Please see Appendix A.

In compliance with HIPPA and LLU-IRB, a principal investigator (PI) was assigned by the department of pediatrics to help identify participants for Sickle Cell Disease and Acute Lymphocytic Leukemia based on the criteria for inclusion and criteria for exclusion defined below. Pediatric Pulmonology health practitioners also helped identify participants for cystic fibrosis and asthma.

Criteria for eligibility:

1. Adolescents ages 14 to 19 years old.
2. Adolescents diagnosed with cystic fibrosis, asthma, sickle cell disease, and acute Lymphocytic leukemia that were patients at LLU health care.
3. Adolescents who spoke and read English at a fifth grade level
4. Adolescents who were patients at LLU health care ambulatory center.

The following exclusions guided the recruitment for participants into the study.

1). Emancipated minors, and

2). Adolescents hospitalized for acute exacerbations and/or crisis.

Procedure

After the Human Subject Protection Committee and Institutional Review Board (IRB) at University of San Diego (USD) approved the dissertation proposal, the researcher submitted a copy of her proposal to Loma Linda University Medical Center Nursing Research Council (LLUMC-NRC) for review. The researcher met with the members of the (LLUMC-NRC) and successfully defended the research proposal. Copies of the USD-IRB and LLU-NRC approval were submitted to the Loma Linda University-IRB (LLU-IRB) with the application packet including letters of support from the department heads of the Pediatric Health Care. Because of the strict implementation of the new privacy act known as the Hospital Insurance Portability Accountability Act (HIPAA), passing through the gatekeepers was a challenge. There was then a need to change the hospital nursing Principal Investigator (PI) to medicine (PI). LLU-IRB approval was then released. Being a researcher and a faculty at California State University San Bernardino (CSUSB) Department of Nursing, the CSUSB-IRB needed to approve the researchers' proposal. The researcher submitted a copy to CSUSB-IRB for approval before collecting data. Upon receipt of approval from CSUSB, the researcher collaborated with the doctors at LLUMC-HC and the (PI). The identification of participants and data collection for the study was accomplished very carefully in accordance with HIPAA regulations through the designated (PI).

The researcher worked very closely with the principal investigator and with the doctors at the Oncology/Hematology, and Pediatric Pulmonology clinics. Data collection was completed on January 2005. Please see Appendix B for IRB approvals and Appendix C for instruments.

Recruitment

Working very closely with the (PI), eighty participants was included in the study; twenty from each of the four clusters to allow for inferential analysis. After solicitation of participants to enroll into the study through the information letter, the researcher called the family to confirm participation, and scheduled a meeting for a signed consent from the parents and an assent from the participating teenager.

The information letter explained the intent of the study, the informed consent and assent disclosed expectations of parents and the participating chronically ill adolescents. In compliance with (HIPAA), and Protected Health Information (PHI), confidentiality of all information promoted confidence among all participants. The consent form stipulated the purpose of research, expectations, time and duration, and risks and benefits.

The researcher arranged with the families for a place where they felt more comfortable to complete the survey questionnaires. The researcher worked with the families based on their safety and confidentiality. The duration of the survey lasted from 30-60 minutes depending on their speed to answer the questionnaires. The adolescents who willingly participated received a gift of $25 dollars as a token of appreciation for their participation.

Data Gathering

The researcher worked with parents for signed consent and participants for the assent at their clinic visit, then the participants completed the survey questionnaires. Participants who were 18 and 19 years old signed the informed consent. Most of the participants completed questionnaires at the time of their clinic visit. Some participants brought the questionnaires home for completion and mailed back. Others had their responses collected by the researcher from their homes. Some participants who needed more time requested that questionnaires be mailed to their homes with stamped return envelopes. Data collection was completed in three months.

Instrumentation

The Adolescent Decision Making Questionnaire (ADMQ) of Mann, Harmoni, and Powers (1989) on a 4-point Likert Scale measured the decision-making patterns in adolescence. It was a 30-item, 4-point Likert-type scale self-report questionnaire that measured self-confidence in decision making, and four decision making styles, and coping patterns based on Janis and Mann (1977) decision-making styles and self-confidence. The ADMQ reflects Janis and Mann's (1977) theory in five subscales, namely: self-confidence, vigilance, panic, evasiveness, and complacency. Respondents marked one of the four responses to each item: 'not at all true to me' (1) 'sometimes true' (20, 'often true' (3) and 'almost always true' (4). The psychometric analysis showed a Cronbach's Alpha of .73 for vigilance, .70 for evasiveness, and .73 for complacency (Harmoni, 1990). This scale was found to have good test-retest and internal reliability

(Radford, Mann, and Kalucky (1986), and high validity (Burnett, Mann, and Beswick, 1989).

The Adolescent Decision Making Questionnaire (ADMQ) divided into two clusters: adaptive and maladaptive. The Adaptive cluster had two subscales; self-confidence and vigilance while the maladaptive had three subscales, panic, evasiveness and complacency. Summated scores indicated that the higher the scores, a person is more vigilant in decision-making. The summated maladaptive scores indicate that the lower the scores, the poorer the coping pattern. The higher the scores, the better the coping pattern ability. Friedman and Mann (1993) used this instrument to measure coping patterns of adolescent decision making among Israeli and Australian children. Based on results, they hypothesized that adolescents with higher educational levels scored higher in vigilance and coping patterns, and lower in evasiveness, panic, and complacency. Tuinstra J, Sonderen FLP, Groothoff H, and Post D. (2000) applied the ADMQ questionnaires among adolescents in Netherlands to test for reliability and validity. The Cronbach's alpha was .67 for internal consistency confirming validity of the instrument to measure self-confidence of adolescents in decision-making.

Another instrument, the Problem Solving Inventory-Form-A (PSI) by Heppner and Peterson (1982) assessed a person's appraisal of self-confidence in problem-solving ability. This instrument can be applied to both adults and adolescent population. Gender and sex-role orientation affect how people solved problems and how they coped with problem situations. Erkut (1983) found that men are more likely to predict success and positive outcomes for themselves than women, who tend to attribute success to luck and more externally controlled to utilize internalizing defenses and denial (Frank, McLaughlin and Crusco, 1984).

The Problem Solving Inventory (PSI) contained 32 items on a six-point Likert Scale, from 1- strongly agree to 6- strongly disagree (Heppner, 1988). It contained three subscales, namely, problem solving confidence, approach avoidance, and personal control. The problem solving confidence predicted positive emotionality while the personal control predicted negative emotionality, and the approach avoidance assessed the cognitive-behavioral skills in actual problem solving situations. Reliability estimates with internal consistency of Alpha coefficient from .72 to .90 the test re-test correlations ranged from .83 to .89. Validity indicated that the PSI total scores and the subscales significantly related to variety of self-report and observational measures in predicted directions.

Heppner and Peterson (1982) said that higher scores indicated negative perceptions of one's problem-solving ability, while low scores indicated attitudes and behaviors associated with successful problem solving. Elliott, Herrick, and Stephen (2001) applied the Problem Solving Inventory in their study on personality correlates of self-appraised problem solving abilities in correlation with other measures. They found out that persons who report more approach avoidance skills are more systematic in defining problems, generating solutions, implementing resolutions, and evaluating outcomes of problem solving. The findings also suggested that confidence and approach avoidance might be related to emotional expressiveness. Heppner and Krauskopf (1987) affirmed the uniqueness of the problem-solving inventory as a cognitive-behavioral tradition for learning and information processing.

The third instrument, Coping Skills Inventory (CSI) by Jerabek (1996) was a 45-item inventory that assessed a person's coping ability with stress and difficulties. It included seven subscales, namely: reactivity to stress, ability to assess situation, self-reliance, resourcefulness, adaptability and flexibility, proactive attitude and ability to relax. Low scores indicated poor coping skills and high scores indicated good coping skills. Reliability falls from .88 to .94. The inter item consistency in Cronbach's alpha is .94 with standard error of .89. The test was suitable for adult and adolescent population. The text readability showed 67.1 for Flesh Reading Ease, and 6.3 for Flesh-Kincaid Grade level.

Deber-Kraetschmer Problem Solving Decision Making Scale (DK-PSDM) developed by Deber-Kraetschmer and Irvine (1996), measured the adolescents' preferences for involvement and information for problem solving and decision making tasks. The reliability Cronbach's Alpha for the full scale ranged from .71 to .90. The problem-solving scale ranged from .79 to .90 and the decision-making scale ranged from .67 to .93. This instrument explored adolescents' preferences for involvement in health treatment decision-making.

The Memorial Symptom Assessment Scale 10-18 (MSAS) measured symptom severity among chronically ill adolescents who participated in this study. It was a 30-item patient-rated instrument adapted from a previously validated adult version. It was applied to 160 children with cancer ages 10 to 18-years-old. The analyses of the MSAS 10-18 supported the validity and reliability of subscale scores as measures of global, physical and psychological symptom distress. Validation on content analysis, and evaluation of reliability and validity reflected an alpha coefficient of .70 showing an adequate internal consistency. This instrument quantifies symptom severity as a variable that may affect self-confidence and preferences for involvement of chronically ill adolescents in making healthcare decisions.

Sample Size Determination

Cohen (1987) said that sample size relates to power, effect size, and significance level. Power was the possibility of rejecting the hypothesis, while effect, size was the strength of the relationship or the difference between the groups. The significance was the probability of rejecting a true hypothesis. Henkle, Weirsma, and Jurs (1998) added a fourth factor in determining sample size as the population error variance. Lenth (2001) reinforced Cohen's (1987), Henkle, Weirsma, and Jurs' (1998) concepts of sample determination by asserting that the most popular approach involved power analysis. He described the approaches as specifying the hypothesis, significance level, effect size, power of the test, and target value of the power of the test. PASS (2002) defined a statistical test's power as the probability that the test procedure results in statistical significance as the desired outcome. Power related to the sample size, the size of type I error (alpha), actual size of the effect, and the size of the experimental error. Most common target power value was .80, however, as the power increased, the required sample size increased. PASS (2002) aided in the power analysis for effect size and sample size determination. Cohen (1987) provided a formula for determining sample size.

Given an effect size index *L with moderate effect as* R^2 *of 0.13, power of 0.80, and alpha of 0.05 and three independent variables.* The value of *L is 10.90* for three variables.

The formula was:

Where: N= total number size U= number of independent variables

L= effect size index

$$N = \frac{L\,(1-R^2 + U + 1}{R^2}$$

$$= \frac{10.90\,(1-0.13) + 3 + 1}{0.13}$$

$$= 77$$

With N=77, the researcher recruited 100 participants to allow for potential withdrawal over time. Eighty participants were invited from convenience samples of scheduled patients to be seen by the physicians at a certain clinic day. Antonius (2003) said that for a sound generalization, a sample should not be too small. If the population comes from various groups with variables that may differ, a larger sample might be necessary.

Pilot Study

A pilot study was conducted to determine the differences in adolescent decision-making among Pathfinder Club members at Loma Linda Filipino-American Church of the Seventh-day Adventists in Loma Linda, California. These were adolescent children 11 to 19 years old. The Adolescent Decision

Making Questionnaire (ADMQ) was used as a measure of their self-confidence in decision-making.

Eleven club members participated with demographics of 52.9% female, 47.1% male. Fifty three percent were adolescents' ages 11 to 13 years old, 35.3% were 14 to 16 years old, and 11.8% were 17 to 18 years old. The ADMQ consisted scales as adaptive with subscales vigilance and panic, maladaptive with subscales evasiveness and complacency. A high total score indicated higher self-confidence in decision-making, while a lower total score indicated a lower self-confidence in decision-making.

The Pearson Product-Moment Correlation *r* showed that there was a moderate relationship between self-confidence and vigilance of $r=.482$ $p<.05$ levels in a 2-tailed test among the 14 to 19 year olds. There was a strong relationship between panic and self-confidence of $r=.509$ $p<.05$ level in a 2-tailed test. Results indicated that the more panicky and vigilant adolescents were, the higher their self-confidence. On the contrary, the more evasive an adolescent was, the more complacent s/he was in making decisions thus showing his/her low level of self-confidence.

Results confirmed empirical studies done on decision-making of adolescents that adolescent ages 11 to 16 years have high self-confidence in making decisions. Male adolescents in this study showed higher self-confidence in decision-making than female did. Overall results revealed that vigilance and panic were important components for self-confidence in making decisions among the adolescent participants.

Quantitative analysis

According to Kerlinger and Lee (2000), data analysis was the process of categorizing, manipulating, summarizing, and ordering data to answer research questions. Categorizing and manipulating data were employed to reduce them into interpretive form to study and test relations. To interpret was to explain in order to find meaning. Data were entered into the electronic file using the Statistical Package for Social Sciences (SPSS) version 11.0.

The numeric values of responses in five different instruments were explored to find the answers to the research questions/ hypotheses. Firstly, the scores from the Adolescent Decision Making Questionnaire (ADMQ) were summarized. Measures of central tendency displayed frequencies, means, mode, and standard deviation. It measured the coping ability and decision-making confidence where a higher total score indicated higher self-confidence in decision-making while a lower score indicated a lower self-confidence in decision-making. Secondly, the total scores from the Problem Solving Inventory (PSI) were obtained, and measures of central tendency showed the frequencies, mean, mode, and standard deviation. A lower total score indicated a more successful problem solving confidence while a higher score indicated a poorer problem solving confidence. Thirdly, the total scores from the Coping Skills Inventory (CSI) were obtained. A higher total score indicated a better coping ability while a lower total score indicated a poorer coping ability. The fourth instrument DK-Problem Solving Decision Making Scale (10-18) measured the preferences for involvement in health treatment decision-making. The computed scores on 'who decides acceptability of risks and benefits' and 'who decides treatment options' were significant indicators for the preferences of chronically ill adolescents in health treatment decision-making. The Memorial Symptom Assessment Scale was the fifth instrument used to measure symptom severity that would affect chronically ill adolescent's self-confidence in decision-making.

The SPSS version 11.0 was used in the analysis of data. Simultaneously, a qualitative inquiry supplemented an exploration of the research focus with qualitative open-ended questions coded and categorized that answered the hunches or the gaps not explained by the numerical inferences. Through dimensional analysis, Schatzman (1991) believed that this was an alternate method to generate grounded theory. Grounding data, based on a constructivist philosophy created reality of chronically ill adolescents' perspectives about their desire for involvement when decisions were made for their health and care. Constructivist philosophy supported Jean Piaget's theory used in social psychology that mental categories are not innate but rather constructed in response to interactions with the environment during childhood development (Rohmann, 1999). Piaget's theory emanates from Vygotsky's (1962) work on the mind in relation to learning, as a process of creation where a child structures experiences through interplay with his/her social environment.

Data analysis

Descriptive statistics started with measures of central tendency to summarize information and to capture the essential aspects of the variables being studied (Antonius, 2003). Pyrczak (1995) explained that descriptive statistics determine the highest and lowest scores, and indicated how typical a person scored, and how much the scores varied. In addition, inferential statistics used

Analysis of Variance (ANOVA) to find measures of dispersion, non-parametric for measures of opposition, Correlation Coefficient *r* to determine or explain relationships, and multiple regressions to predict causal relationships.

Hinkle, Wiersma, and Jurs (1998) inferred that correlation coefficient not only measures relationships between variables but index of the proportion of individual differences in one variable associated with the differences in another variable. Munro (2001) said that correlation does not show causality but shows association or relatedness between two variables. He said further, that correlation was a method to quantify correlations between two variables, and multiple correlations to measure relationships between three independent variables and one dependent variable. The multiple correlation *r* goes from zero to one. The combination of independent variables predicts the amount of variance accounted for in the dependent variable known as r^2.

Using data from the ADMQ, PSI, and CSI with the use of correlation and multiple regression analysis reflected non-significant and significant relationships between self-confidence, decision-making styles, coping patterns and preferences for involvement in health treatment decision making among adolescents with chronic illnesses.

Pearson Product-Moment Correlation *r* showed the strength of relationships between the independent variables and the dependent variable (Buley, 2002). It was a predictive paradigm for the strength of relationships between adolescents' preferences for involvement in health treatment decision-making and their self-confidence, problem solving skills, and coping patterns.

Correlation explored associations between chronically ill adolescents' preferences for involvement in health treatment decision-making and self-confidence, problem solving skills, and coping patterns. Pearson correlation *r* and multiple regressions explored answers to research question number one.

Research Question 1: What are the relationships between chronically ill adolescents' self- confidence, decision-making confidence, coping patterns, and their preferences for involvement in health treatment decision- making?

The Pearson Product Moment Correlation Coefficient *r* according to Buley (2002) reflected similarities in response to two variables. It did not reflect the cause but it showed the association or relationships between variables (Antonius, 2003). To explore the relationships between adolescents' preferences for involvement in health treatment decision-making, and their self-confidence, problem solving styles and coping patterns, the Pearson Product-Moment Correlation analyzed statistical associations as shown in Table 2.

Independent Variables: Self-confidence, Problem-solving confidence, Coping patterns

Dependent Variable: Adolescent involvement in treatment decision-making.

Table 2

Correlations

	Self-confidence	Decision-making confidence	Coping patterns	Preferences for Involvement in health care decisions
Self-confidence				
Decision-making confidence				
Coping patterns				
Preferences for involvement in health care decisions				

Predicting the strength of association between adolescents' preferences for involvement in health treatment decision-making, and their self-confidence, problem solving confidence, and coping patterns, multiple regressions revealed statistical association represented by the regression line. There could be a negative or positive association based on the regression line between variable x and variable y. Figure 4 shows a predictive paradigm.

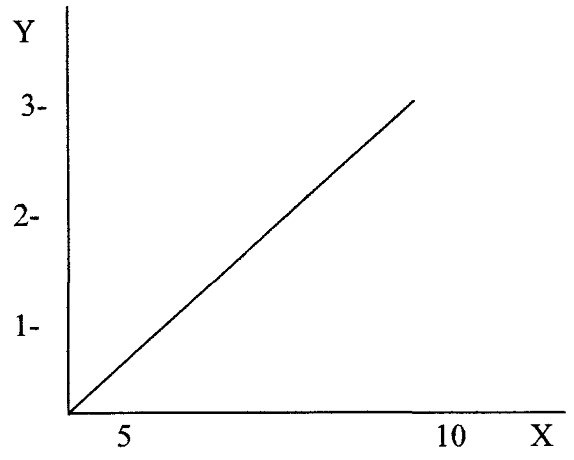

Figure 4. Self-confidence, problem solving confidence, and coping pattern as predictors for preferences for involvement

Pearson Product-Moment Correlation *r* predicts the strength of statistical associations between chronically ill adolescent's age, gender, and severity of symptoms that may influence their preferences for involvement in health treatment decision-making.

Research Question 2: What are the relationships between chronically ill adolescents' age, gender, health condition diagnosis, and their preferences for involvement in health-treatment decision-making?

The Deber-Kraetschmer Problem Solving Decision Making Scale (DK-PSDM) measured the chronically ill adolescents' preferences for their involvement in health treatment decision-making. It assessed chronically ill adolescents' desires and wishes for involvement in health-treatment decision-making in relation to treatment options and acceptability of risks and benefits. Correlations determine if health condition or diagnosis influences chronically ill adolescent's involvement in health treatment decision-making. Analysis of Variance (ANOVA) determines variability in the involvement and preferences of chronically ill adolescents in health-treatment decision-making. Table 3 shows the statistical association.

Dependent Variable: Preferences for involvement in health treatment decision-making

Independent Variables: Age, Gender, and Diagnosis

Table 3

Correlation between age, gender, diagnosis, and preferences for involvement

	Age	Gender	Diagnosis	Involvement in health-treatment decision-making
Age 14- 16				
17-19				
Gender				
Male				
Female				
Diagnosis				
Asthma				
ALL				
CF				
SCD				
Involvement in health treatment decision-making				

According to Buley (2002) correlations measured how two variables were similar or related. It was a way of looking at sameness or commonality. Munro (2001) explained correlation coefficient as a mathematical statement of the strength of relationships between two variables and r^2 represents meaningfulness. She explains that a + 1.00 r^2 indicates a perfect positive relationship, a 0.00 r^2 indicates no relationship, and a -1.00 r^2 indicates a perfect negative relationship. It may show a linear relationship between the adolescent's age, gender, and severity of symptoms with self- confidence in health treatment decision-making. Pearson Product Moment Correlation *r* examined relationships between age, gender, diagnosis, and self-confidence in health treatment decision-making among chronically ill adolescents. Table 4 shows correlation *r*.

Independent Variable: Age, Gender, and Diagnosis

Dependent Variable: Self-confidence in health treatment decision-making

Table 4

Coefficient r

	Age	Gender	Diagnoses	Self-confidence
Age				
14-16				
17-19				
Gender				
Male				
Female				
Dx				
Asthma				
ALL				
SCD				
Self-confidence				

Multiple regressions may be indicated to analyze correlation between two sets of variables. It would predict causal relationships between the variables *x* and *y*. The SPSS version 11.0 (2001) was utilized in the analysis of data. Figure 5

Independent Variables (Y): age, gender, and diagnosis

Dependent Variable (X): Self-confidence and preference for involvement

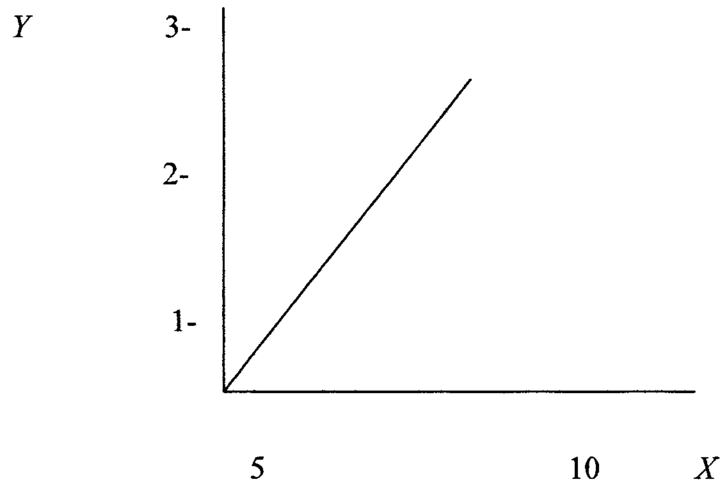

Figure 5. Associations between variable x and variable y in a regression line.

Research Question 3: How do older and younger chronically ill adolescents differ in self-confidence for involvement in health-treatment decision-making?

Data from the Problem Solving Inventory (PSI) and Adolescent Decision Making Questionnaires predict differences in the self-confidence of chronically ill adolescents 14 to 16 years old, as compared with that of the older chronically ill adolescents ages 17 to 19 years old. Analysis of variance (ANOVA) reveals the differences among two or more means. It is also called the F test. The between group is compared with the within group variance. The *df* is determined to find significance of the F ratio, which represents the ratio between the sum of squares and the mean of squares within variance. *P* represents the probability at .05 levels. Table 5 shows the statistical impression of the statistical method.

Dependent Variable:	Self-confidence in health-treatment decision-making.
Independent Variable:	Older and younger adolescents (14 to 16, and 17 to 19 years old.

Table 5

Differences in self-confidence between older and younger chronically ill adolescents

	Sum of squares	df	Mean of squares	F	Sig
Between groups					
Within groups					
Total					

A post-hoc analysis would determine the differences in decision-making styles and coping patterns among adolescents of different cultures from convenient samples.

Another statistical analysis was a non-parametric technique using Chi-square to determine whether a statistically significant relationship existed between two variables. The following assumptions determined the use of chi-square: 1.) Frequency data must be nominal or categorical, and 2.) There must be an adequate sample size based on power, effect size, and significance level. Power is the probability of rejecting the null hypothesis at a significant p<. 05 level. The effect size is the difference of the strength of relationship between the groups. Nominal or categorical data with adequate sample size must be independent from each other, and should have theoretical reason for the categories (Munro, 2001).

The independent sample t-test determined whether two samples drawn independently, are likely to come from the same population (Antonius, 2003). The variables measured in independent t-test were the differences between male and female adolescents in their self-confidence, decision-making styles, and coping patterns in health-treatment decision-making. It examined the differences between older and younger adolescents in their self-confidence, decision-making styles, and coping patterns in health-treatment decision-making.

Research Question 4: How do male and female chronically ill adolescents differ in coping ability and self-confidence in health treatment decision-making?

Analysis of variance (ANOVA) explored the differences between coping ability and self-confidence between older and younger chronically ill adolescents using data from the ADMQ, and the CSI. The total scores from both ADMQ and CSI instruments will be analyzed based on the notion that higher scores reflect good coping ability and higher self-confidence in decision-making, while lower scores indicate poor coping ability and lower self-confidence in decision-making.

The PSI measured the differences in self-confidence among male and female chronically ill adolescents in health treatment decision-making. Total scores from the CSI and ADMQ revealed in paired t-test the differences in decision making styles and coping patterns among male and female chronically ill adolescents in making decisions in stressful health situations.

All the statistical analysis was done utilizing the Statistical Package for Social Sciences (SPSS) for windows version 11.0. Table 6 shows a visual impression of results.

To compare differences among group means, analysis of Variance (ANOVA) examined between-group variations exceeding the within-group variations. Munro (2001) defined the assumptions for ANOVA that the dependent variable should be continuous and normally distributed groups must be independent of each other, and there should be homogeneity of variance. Any variability can be viewed in two ways: first, the scores vary from each other in their group known as *within-group variation*, second, *between-group variation.* The sum from both groups totals the variation. Munro (2001) explained that when the *between-group variance* is greater than the *within-group variance*, the groups must be different. Descriptive statistical analysis was employed first to determine the mean, SD, and confidence interval for mean at 95% then the statistical analysis for ANOVA was used to analyze variance among group means.

Independent Variable: gender (male, female)

Dependent Variable: self-confidence, and coping patterns in health treatment decision-making.

Table 6

Mean differences in self-confidence and coping patterns between male and female chronically ill adolescents

	N	Mean	Std Deviation	Std error
Male				
Female				

Research Question 5: How do health condition or diagnosis, and severity of symptoms affect chronically ill adolescents' preferences for their involvement and/or non-involvement in health treatment decision-making?

Data from the DK-PSDM Scale in a non-parametric statistic determined preferences for involvement and/or non-involvement among chronically ill adolescents in health treatment decision making based on their health condition or diagnosis. It was based on the subscale *who should decide acceptability of risks and benefits and who decides treatment options*. Data from the MSAS quantified symptom severity. The total scores from two variables dealing with decisions were summarized and analyzed based on the weighted response *both equally and me alone*.

Dependent Variable: Preferences for involvement and non-involvement in health treatment decision-making

Independent Variable: Diagnosis, severity of symptoms

Table 7

Effects of health condition and severity of symptoms on preferences for involvement

	Preferences for involvement or non-involvement in health treatment decision-making
Health condition (Diagnosis)	
Asthma	
ALL	
CF	
SCD	
Symptom severity	

Research Question 6: What are the relationships between severity of-symptoms and self-confidence of chronically ill adolescents in health-treatment decision-making?

To describe relationships between severity of symptoms and self-confidence in health treatment decision-making, multiple regressions was used to explore statistical associations between severity of symptoms and self-confidence for involvement in health treatment decision-making. SPSS version 11.0 was utilized in the analysis.

Dependent Variable (x): Self-confidence in health treatment decision-making

Independent Variable (y): Severity of symptoms

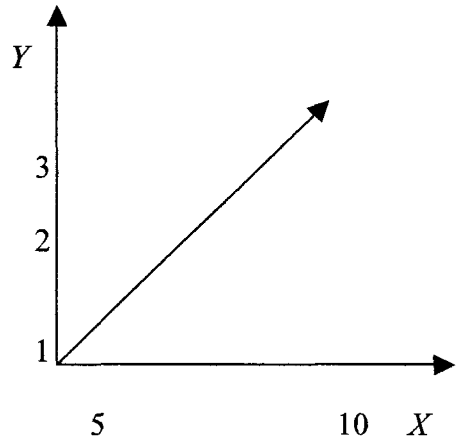

Figure 6. Association between severity of symptoms and self-confidence health treatment decision-making

Inferential statistics, according to Antonius (2003), aimed to draw conclusions from numerical characters of a population when a sample is given. It would make inferences about a population that would imply probability of error and a margin of error. When samples were representative of a population, there was a higher chance of being correct. Inferential statistics would draw conclusions from analyzed data of a sample to the population. For this study, all the statistical analysis used SPSS software version 11.0

Methodological triangulation analysis made descriptions, inferences, and interpretive presentations of results more empiric. A methodological triangulation compared results to fit data together to obtain a comprehensive understanding of the phenomenon in question. Flick (1998) inferred that the combination of two methods would add rigor, depth, richness, breadth, and complexity to an enquiry. Furthermore, Morse (2001) explained that methodological triangulation was conducting complementary projects on one topic using different methods. He suggested that the Quant + qual methodology can be used to generate information from differing perspectives. Quant + qual methodology analysis in this quantitative driven project was a simultaneous conduct of a quantitative and supplemental qualitative study.

The qualitative inquiry validated hunches and explained gaps from a quantitative perspective while preserving the numbers and words in each data set. The quantitative analysis preceded the qualitative inquiry, as a quant + qual method of exploration and validation.

Summary

An exploratory cross-sectional and survey research design using descriptive and inferential statistics explored relationships and differences between chronically ill adolescents' self-confidence, decision-making styles, coping patterns and their involvement in health treatment decision-making. It compared relationships and differences between age, gender, severity of health condition and their self-confidence in health treatment decision-making. Analysis of Variance (ANOVA) explored differences among group means. Inferential statistics drew conclusions from a sample to the population for estimation and hypothesis testing. While correlation attempted to determine whether variables were similar, regressions predicted an equation through a straight line. The use of five different instruments that measured self-confidence, decision-making, problem-solving confidence, coping patterns, severity of symptoms, and preferences for involvement provided data for quantitative and qualitative inquiries.

The validity and reliability of the ADMQ instrument was evident in the study done to Israeli-Australian adolescents to determine their decision- making abilities in career paths. The PSI measured self-confidence in problem solving and decision-making, while the CSI measured coping patterns of chronically ill adolescents in stressful situations. The DK-PSDM scale explored chronically ill adolescents' involvement and preferences in being involved in health treatment decision-making. A total sample of 80 adolescents who were chronically ill with cystic fibrosis, leukemia, sickle cell disease, and asthma completed the survey questionnaires. They were patients at Loma Linda University Medical Center Health Care.

Chapter 4 presents the findings from a methodological triangulation. The assumption that older chronically ill adolescents have higher self-confidence in decision making in stressful situations, and the assumption that chronically ill adolescents desire to be involved in health treatment decisions when explored through quant + qual inquiries would validate linkages, sameness or associations.

CHAPTER 4

Presentations of Findings

The presentation of findings starts with frequency and demographic data to summarize the number of instances or cases of a particular variable (Nicol and Pexman, 2000).

Perceptions of chronically ill adolescents about their involvement in health treatment decision-making influence their desire to participate in decisions made for their care. Their experience with severity of symptoms influenced their ability to make decisions and the type of chronic illness they have plays a role on how they perceive their ability to be involved as well. Their problem solving confidence and coping ability affect their self-confidence in making decisions, thus affecting their preferences for involvement in health treatment decision-making. The application of methodological triangulation in exploring the preferences of chronically ill adolescents in health treatment decision-making unfolded the desires of these adolescents to meet their care needs. Their answers to the numeric inquiry and subjective inquiry through their written responses present linkages that strengthened the validity of results.

Findings from a methodological triangulation achieved corroboration of data from responses of chronically ill adolescents in relation t their preferences for involvement in health treatment decision-making. The qualitative approach complemented the analysis of data in the numeric approach.

Demographics

Eighty respondents from a convenience sample participated, representing an equal number of 20 participants in each of the disease conditions of Cystic Fibrosis, asthma, Acute Lymphoblastic/Lymphocytic Leukemia (ALL), and sickle cell disease. All the respondents met the criteria for inclusion and each minor participant signed an assent while the parents signed an informed consent. Adult participants (i.e., 18 and 19 year olds) signed informed consents.

These demographics included age, gender, ethnic background, and grade level in school, type of school attended, and diagnosis. With the use of SPSS Version 11.0 software, descriptive statistics provided an understanding of the demographics using measures of central tendencies. Clustering of variables showed results on bar charts for comparisons between respondents' gender and age, respondents' school level and school attended, respondents' ethnic background and school attended, respondents' diagnosis and ethnic background, and the respondents' gender and medical diagnosis.

Descriptions of demographic data

Fifty-seven or (71.29%) were adolescents from 14 to 16 years old and 23 (28.75%) were 17 to 19 years old. Forty-one or (51.25%) were male chronically ill adolescents, and 39 or (48.75%) were female adolescents. Forty-five or (56.3%) participants were in grades 7 to 9, and 35 or (43.78%) participants were in grades 11 to college. Demographic data revealed that 49 or (61.3%) of the participants attended the public school system, while 11 or (13.8%) participants attended the private school system. Eighteen or (22.5 %) participants were home schooled, while 1 or (1.3 %) attended tutoring, and the remaining (1.3 %) attended special school.

As to their ethnic background, the sample included 28 (35%) Whites, nine or (11.3 %) African-American, 53 (41.3 %) Hispanics, and five or (6.5 %) Asian –

Americans. One or (1.3%) Pacific Island and four or (5%) participants did not specify their ethnicity.

Figure 7 shows the respondents' gender and age. Forty-nine percent of the participants were females and fifty one percent were males. The actual number representing 41 male participants, and 39 female participants of which, 51% were ages 14 to 15 years of age, 32.5% were ages 16 to 17 years of age, and 16% were ages 18 to 19 years of age. The bar chart shows a significant representation from the adolescent children age 14, with a least participation from the older adolescents.

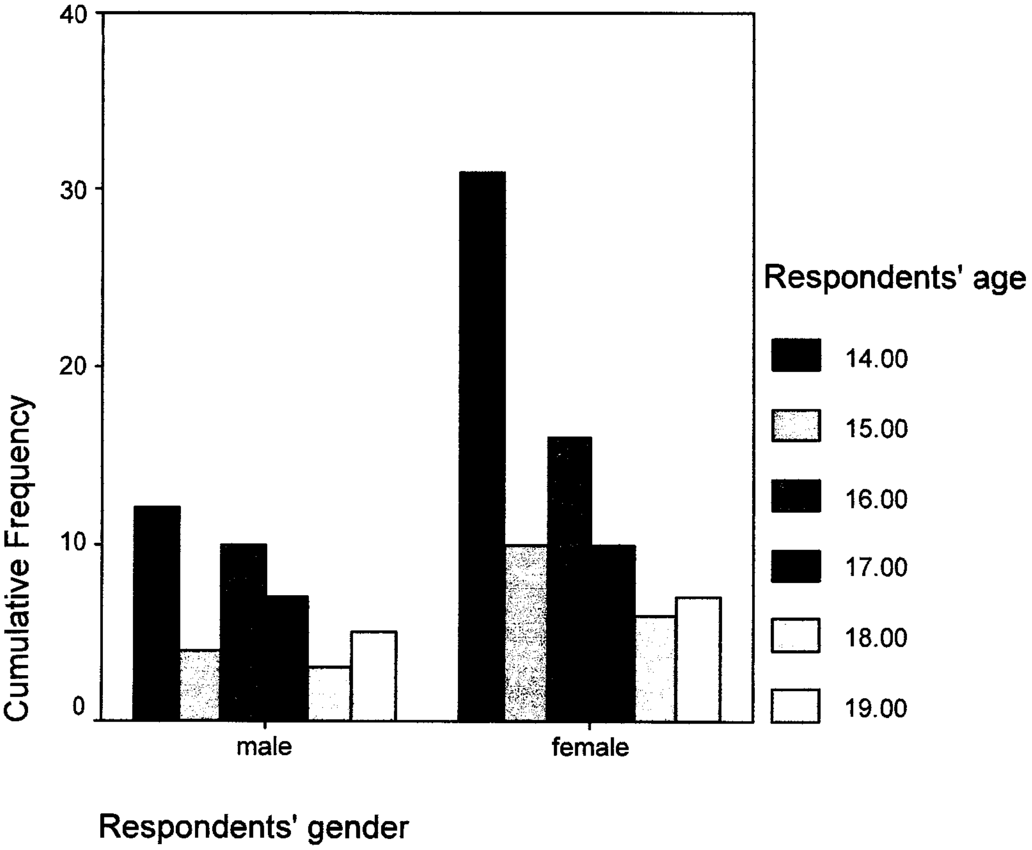

Figure 7. Respondents' Age and Gender

A visual representation of respondents' grade level and school attended is shown in Figure 8. Adolescents who were 18 to 19 years old attended college level that may significantly make a difference in the way they perceive involvement in health treatment decision-making. Among all the participants, 61% attended public school, 13.75% attended private school, 22.5% were in home schools, one attended tutoring classes, and one attended a special school.

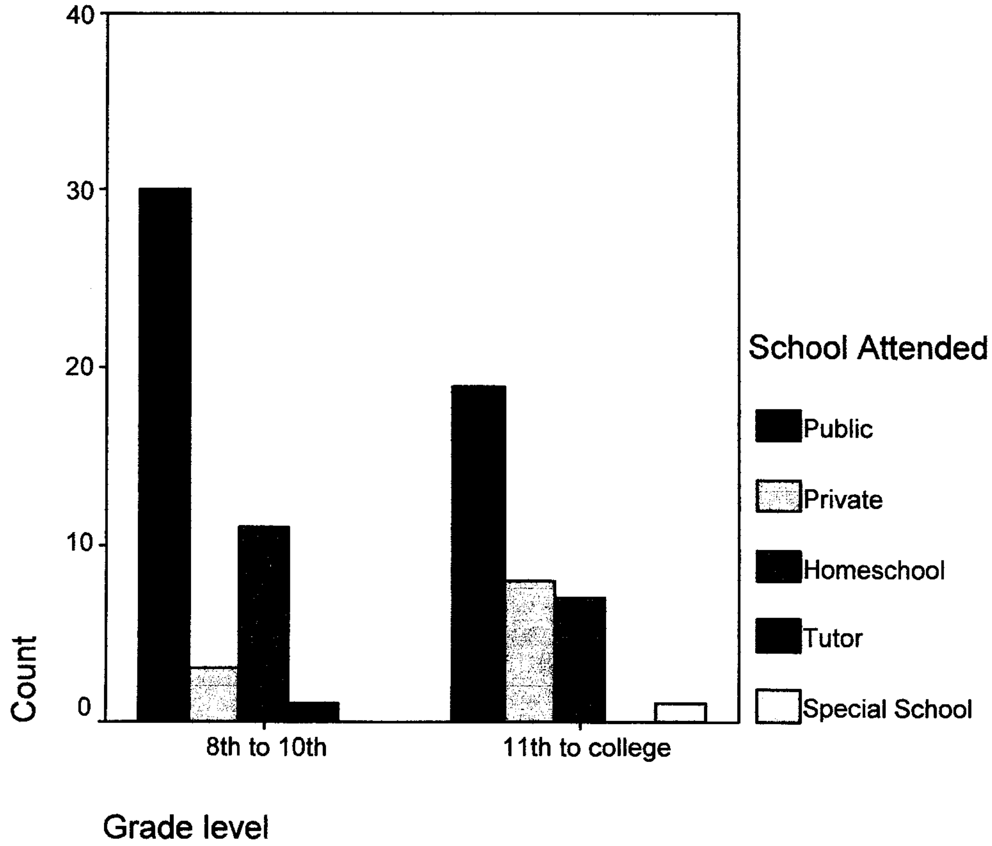

Figure 8. Grade Level in School and School Attended

Figure 9 represents the demographics of respondents' ethnic background and school attended. Black Americans, Hispanics, and White participants attended private and public schools as well as home schooling. One Pacific Islander participant attended special school, and one attended tutoring. Asian-American participants attended both public and private schools.

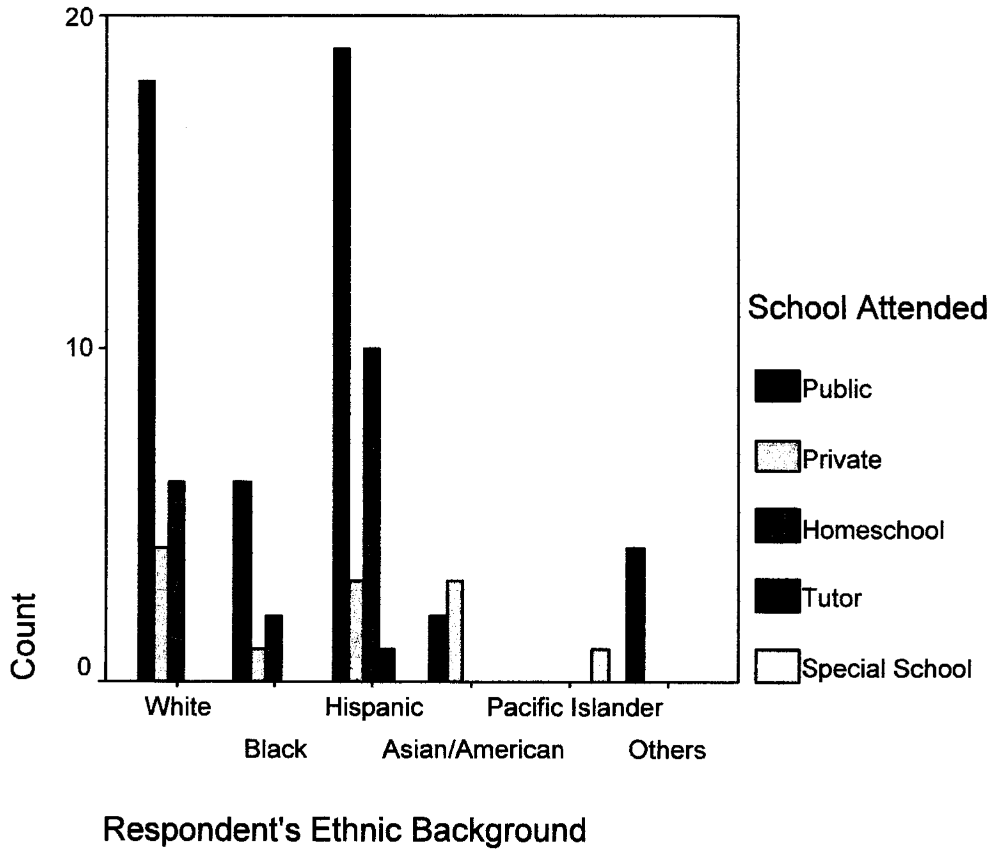

Figure 9. School attended and Ethnic Background

Figure 10 shows the demographic presentation of the ethnic background and diagnoses of participants. The bar chart shows that from a convenience sampling, Acute Lymphocytic/Lymphoblastic Leukemia (ALL) was more prevalent among the Hispanics and Cystic Fibrosis among Whites although found among Blacks and Hispanics as well. Sickle Cell Disease is prevalent among all the ethnic groups, except in the other unidentified ethnic group. Asthma was also prevalent among all the ethnic groups, except the Pacific Islanders that were least represented.

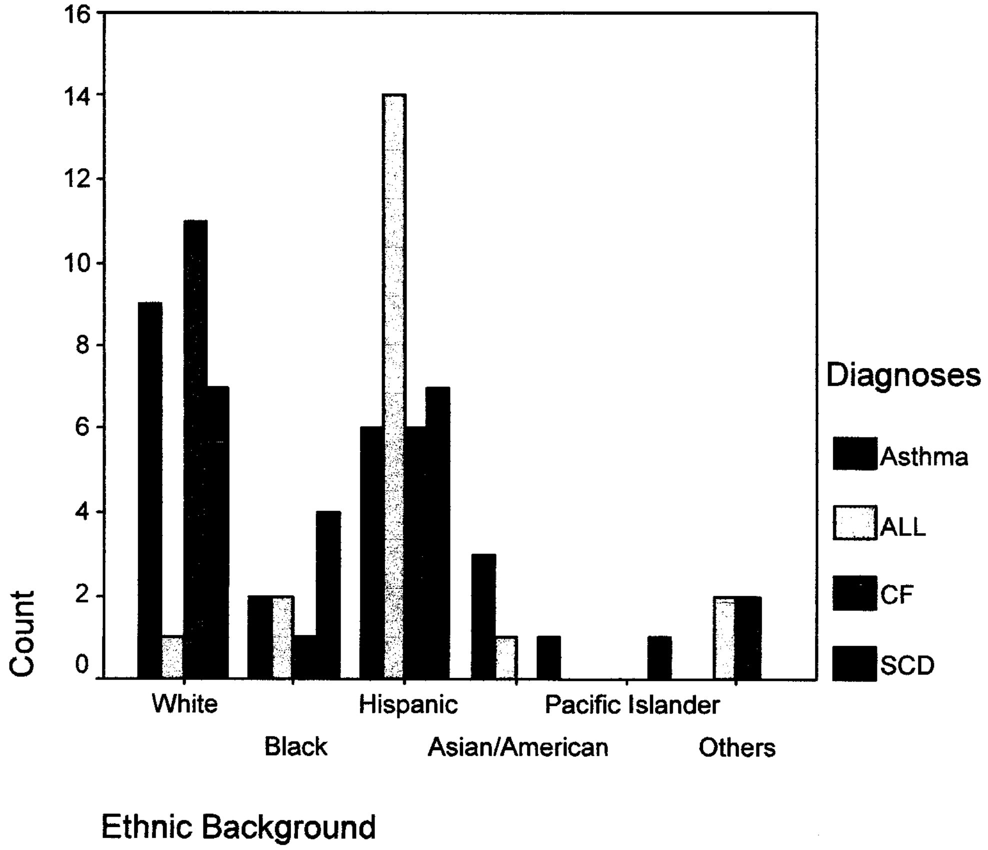

Figure 10. Respondent's Ethnic Background and Diagnoses

It happened by chance that there were more Hispanic participants. Based on the criteria for inclusion, diagnosis and age were stipulated as the bases for convenience sampling.

Figure 11 shows more male adolescents who are chronically ill with Sickle Cell Disease than the female respondents are but not statistically significant. However, the chart shows that there was an equal representation from both male and female for Asthma, Acute Lymphocytic/Lymphoblastic Leukemia, and Cystic Fibrosis. It happened by chance that there were more male adolescent participants with sickle cell. It could be that the number of chronically ill adolescent participants was predetermined to be equal in number based on diagnosis regardless of age and gender.

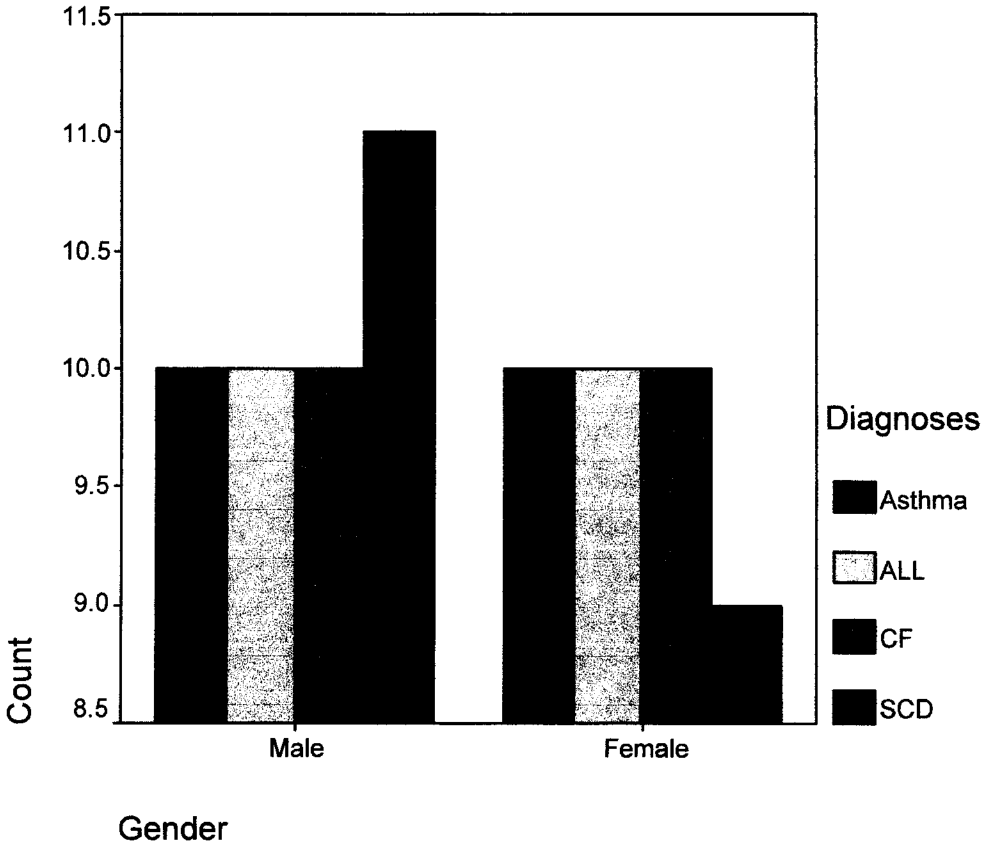

Figure 11. Respondent's Diagnoses and Sex

In the criteria for inclusion, participants were randomly selected from convenience samples. It happened by chance that there were more male adolescent participants with sickle cell. It could be because the number of chronically ill adolescent participants was predetermined to be equal in number based on diagnosis regardless of age and gender.

Quantitative Analysis

The aim of this quantitative research was to unfold chronically ill adolescents' desires or preferences for involvement in health treatment decision-making. Unfolding chronically ill adolescents' perspectives for involvement in making decisions for their health and care provides a justification for health care providers and policy makers to examine protocols for practice in the real world of adolescent care. It gives an affirmation to empirical research as well as the developmental theorists' notion that those adolescents as young as 14 years of age are capable of making rational decisions just like adults even when afflicted with the intrusion of chronic illnesses.

The methodological triangulated analysis explored multifaceted phenomena in the study. It was used to circumvent personal biases as well as to overcome a single-theory method, thus increasing the validity of findings (Denzin, 1989). The variables this research sought to find included relationships between self-confidence, problem solving confidence, and coping patterns of chronically ill adolescent children in relation to age, gender, and severity of illness. It also explored their preferences for involvement and/or non-involvement in relation to their age, gender, self-confidence, problem solving styles, and coping patterns.

Five sets of questionnaires generated data to explore answers to the research questions posed in this research. Descriptive and inferential statistical analyses determined relationships, explained differences, and predicted relationships. A qualitative inquiry provided validation of findings from a quantitative perspective, as it grounded numerical values into the real world experience.

Results

Descriptive, correlational, and inferential statistical interpretations revealed answers to the research questions and research hypotheses explored in this study. For descriptive and correlational analysis, a research question was used. When predicting relationships, a research hypothesis was used.

Research Hypothesis 1: There are relationships between chronically ill adolescent's self-confidence, problem solving confidence, coping patterns, and preferences for involvement in health treatment decision-making.

The Pearson *r* correlation analysis explored data from four sets of questionnaires, the relationships between the self-confidence, problem-solving confidence, coping patterns, and preferences for involvement of chronically ill adolescents in health treatment decision-making. Assigning self-confidence, problem solving confidence, and coping patterns as independent variables, and the dependent variable, as preferences for involvement in health treatment decision-making, correlation coefficient *r* revealed statistical association.

The use of the Adolescent Decision Making Questionnaire (ADMQ) measured self-confidence in decision-making as well as the coping patterns. It included subscales as self-confidence, vigilance, panic, evasiveness, and complacency. The interpretation of scores indicates that the higher the scores, the higher the self-confidence of a person for decision-making. The lower scores indicate poor coping patterns relative to lower self-confidence of a person for decision-making. On the other hand, if the scores were higher, a better coping pattern reflects a higher self-confidence in decision-making. Total scores obtained from participants with the use of this instrument revealed high scores with a minimum of 46 and a maximum of 81 from a total score of 120. Splitting the total scores into two divided score ranges from scores of 46 to 59 for low scores, and from scores of 60 to 81 for high scores. Fifty respondents scored from 60 to 81 while 20 respondents scored from 46 to 59. Seventy-five percent scored high indicating high self-confidence in decision-making. Twenty-five percent scored low indicating a low self-confidence in decision-making. Figure 12 shows a visual representation of total scores.

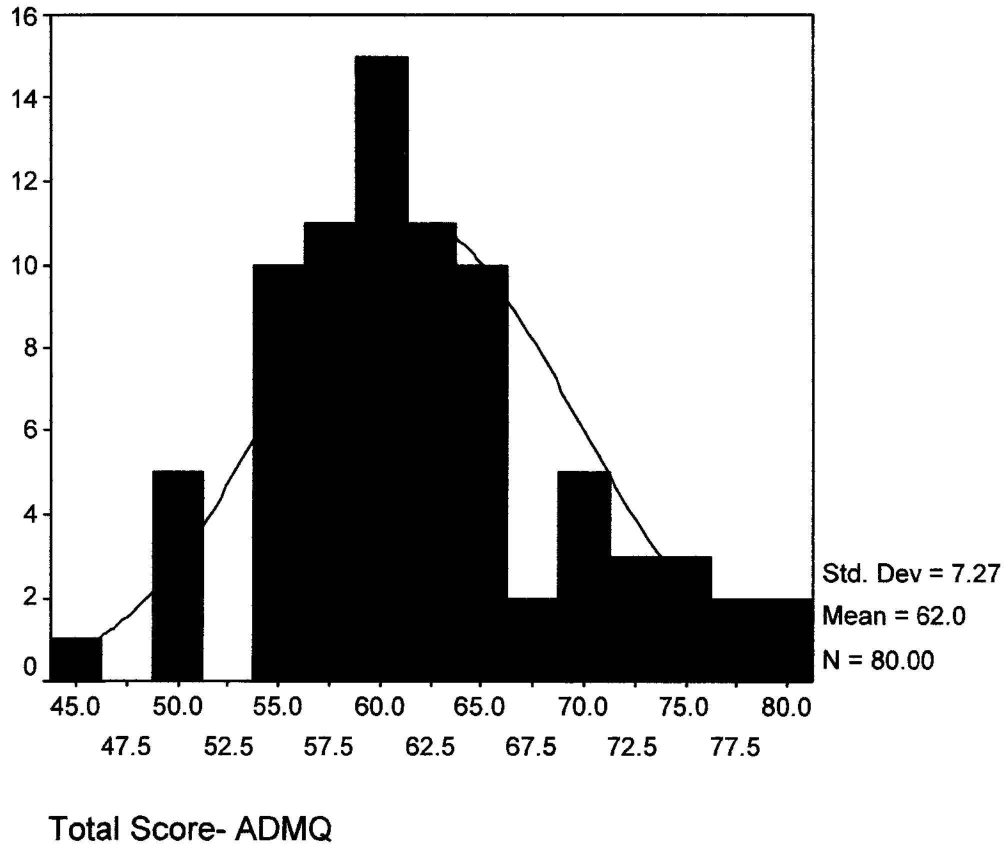

Figure 12. Histogram of ADMQ total scores

The second questionnaire was the Problem Solving Inventory (PSI). It measured the participant's perceptions of their problem solving behaviors and attitudes. It included subscales as, problem solving confidence, approach avoidance, and personal control. The lower scores indicate attitude and behavior associated with successful problem solving ability, whereas high scores indicated a negative perception of one's problem solving ability. Total scores obtained from participants in this survey questionnaire indicated that 87.5% scored lower while 12.5% scored higher. The scores obtained ranged from a minimum of 48 and a maximum of 178 from a total score of 216. Seventy participants scored 48 to 89 while 10 participants scored 90 to 178. The histogram below shows that 87.5% of participants fall on the lower half of total scores. This indicated that 87.5% have an attitude and behavior associated with successful problem solving ability, thus showing a high self-confidence in decision-making. Figure 13 reflects a visual presentation of total scores.

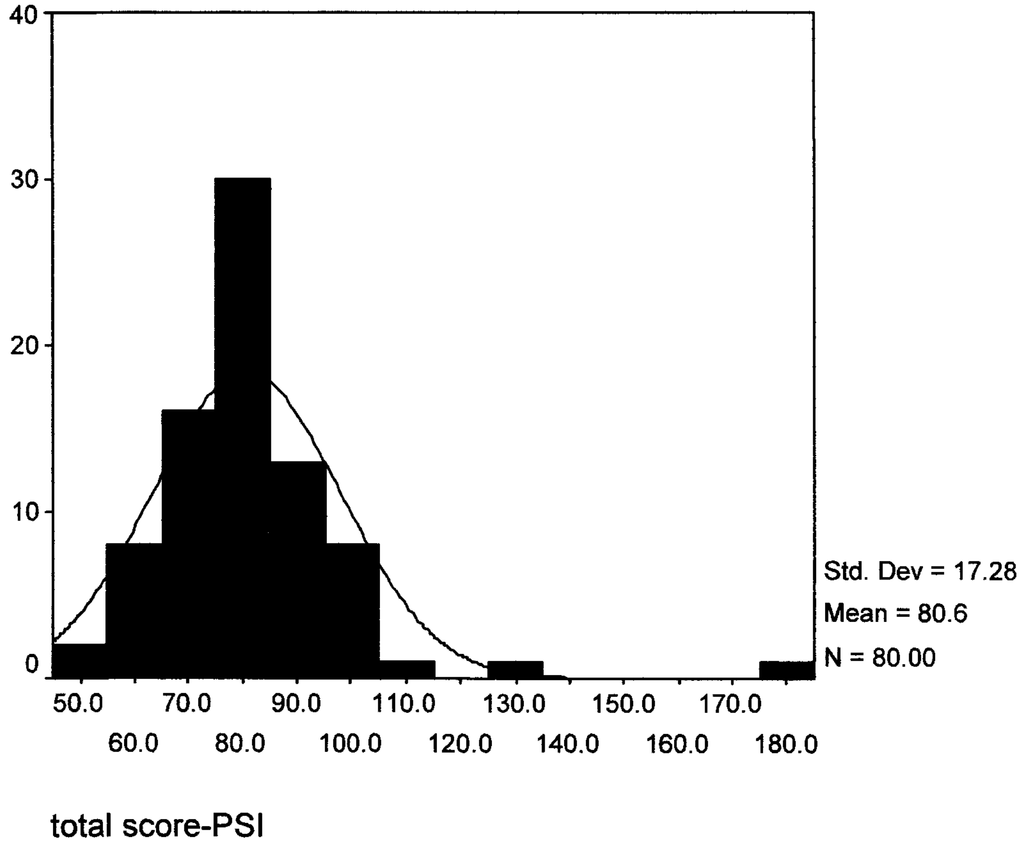

Figure *13.* Histogram of Total Scores from PSI

The Coping Skills Inventory (CSI) was the third instrument that measured the participant's ability to cope with stress. It yielded seven sub-scores from reactivity to stress, ability to assess situation, self-reliance, resourcefulness, adaptability and flexibility, proactive attitude, to ability to relax. High scores indicate good coping skills, while low scores indicate poor coping skills. Total scores obtained from each of the participants revealed high scores with a range of 95 to 187 from a total score of 225.

Ninety percent of participants scored from 120 to 187. Only 10 % scored lower than 120. Results indicated that 90% of the participants have good coping skills despite suffering from the intrusion of chronic illness thus showing 90% have a high self-confidence in decision-making. Figure 14 is a histogram of the total scores.

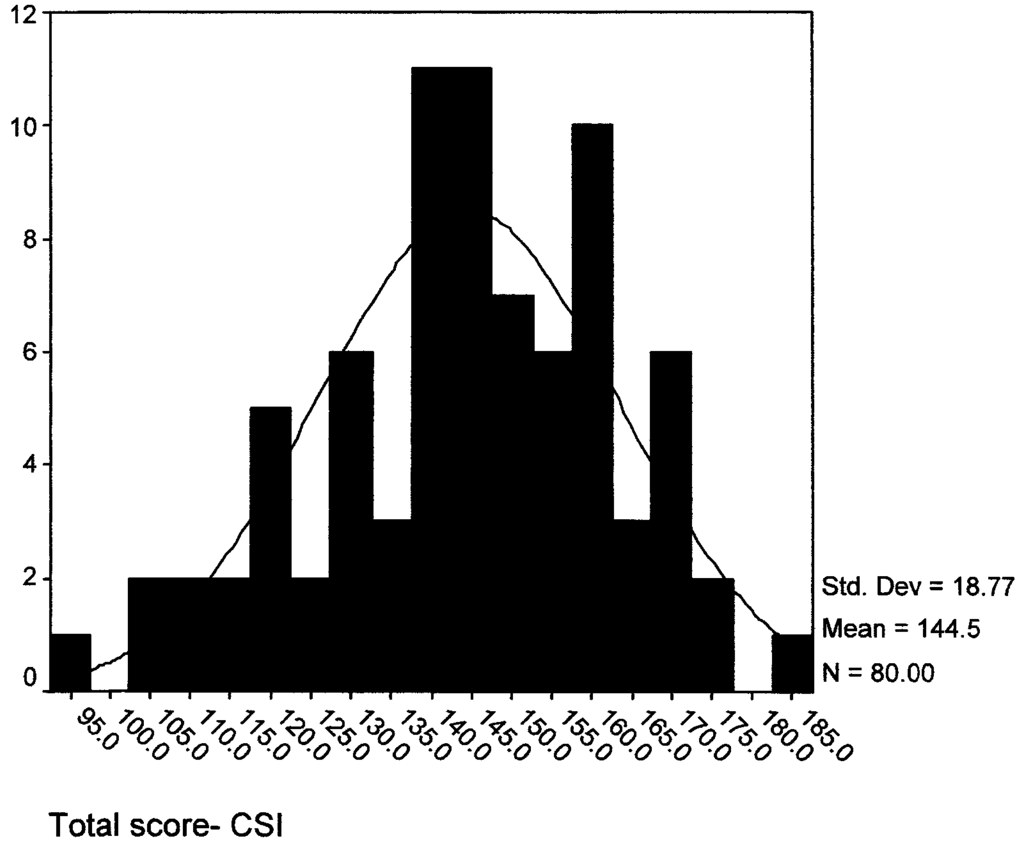

Figure 14. Histogram of total scores from CSI

The fourth instrument, the DK-Problem Solving Decision-Making Scale (DK-PSDM) *morbidity vignette*, is a measure of attitudes and preferences about participation and information. It includes subscales, *who should determine treatment options? Who* *should determine diagnosis? Who should determine risks and benefits? Who should decide acceptability of risks and benefits? Who should determine risks and benefits?* In addition, *who should decide treatment options?* Scores were based on a 4-point Likert scale that includes *doctors only, mostly doctors, both equally, mostly me,* and *me only.* Visual impressions of representations are shown in bar charts. Figure 15 shows representations on *who decides treatment options* and *age* while Figure 16 shows *who decides treatment options* and *gender.*

Clustering respondent's age, and *who should determine treatment options* in a bar graph showed that 36.3% of the chronically ill adolescent participants who were 14 and 16 years old indicated their strong desire to be involved in treatment decisions by indicating that *both equally* decide treatment options. On the other hand, 22.5% of 14-year-old chronically ill participants wanted the *doctors alone* to decide treatment options. Across the age ranges, 16% indicated that *mostly the doct*ors decide treatment options, 17.5% indicated *mostly me* to decide treatment options, and 7.5% expressed *me alone* decide treatment options by the 17-year-old participants. Interestingly, the older adolescents, 18 and 19-year-olds, indicated that *both equally* decide treatment options, and the 19 years old indicated more of *doctors alone* and *mostly me.*

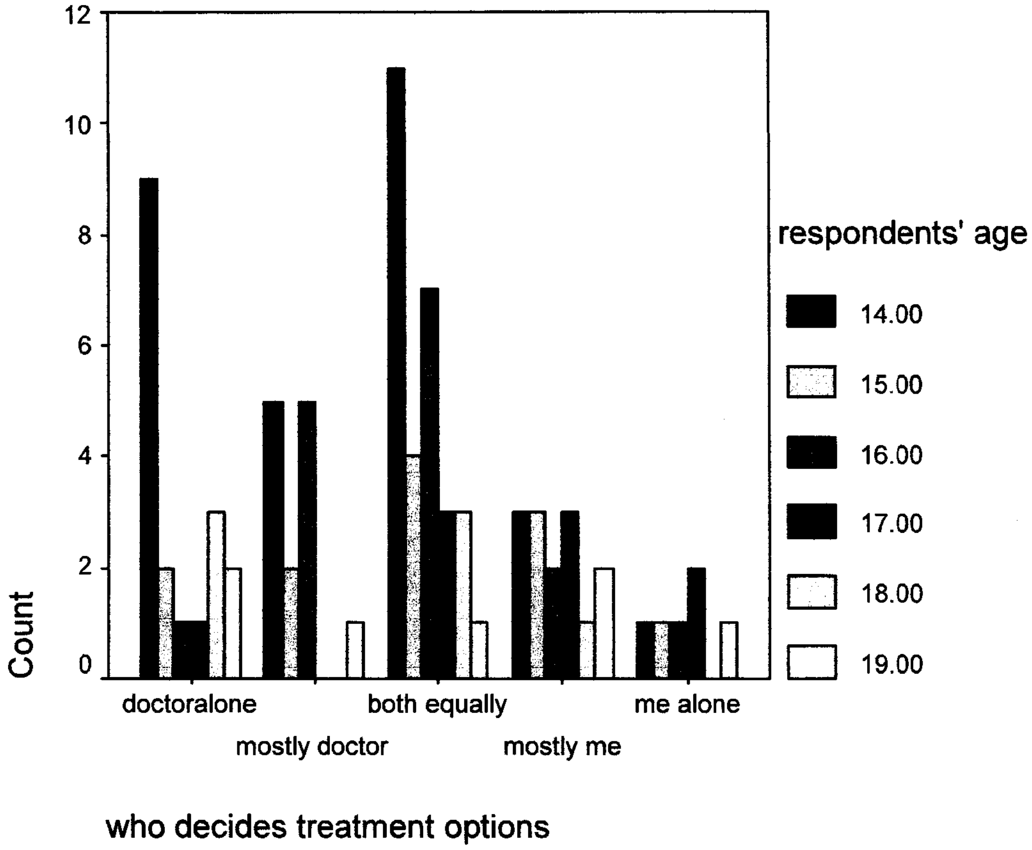

Figure 15. Age and who decides treatment options

The graph on Figure 16 shows 18 females who indicated *both equally* to decide treatment options versus 13 male counterparts. Male respondents indicated an equal desire for *mostly the doctors* and *both equally* to decide treatment options. Figure 17 shows a visual representation of *who decides acceptability of risks and benefits* and *age*, and Figure 19 shows *who decides acceptability of risks and benefits* and *gender.*

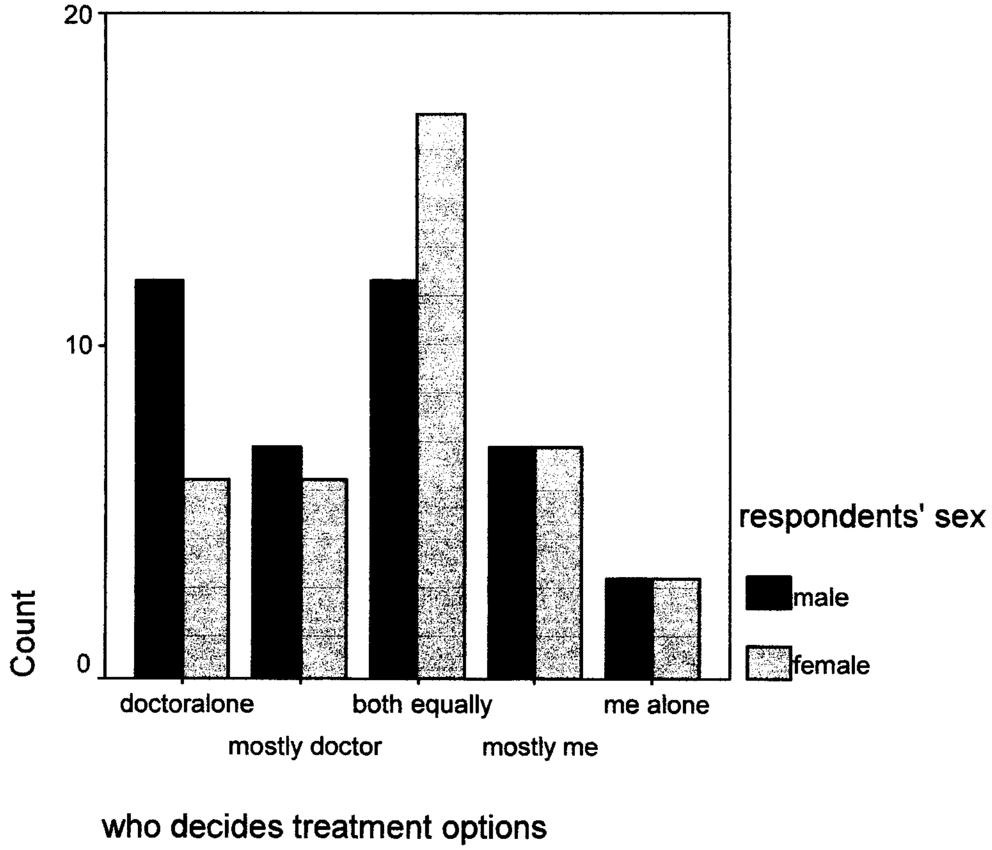

Figure 16. Sex and who decides treatment options

Statistical association between respondents' *sex,* and *who decides acceptability of risks and benefits* likewise revealed *both equally* among all the participants. Figure 17 illustrates a graphic picture of results.

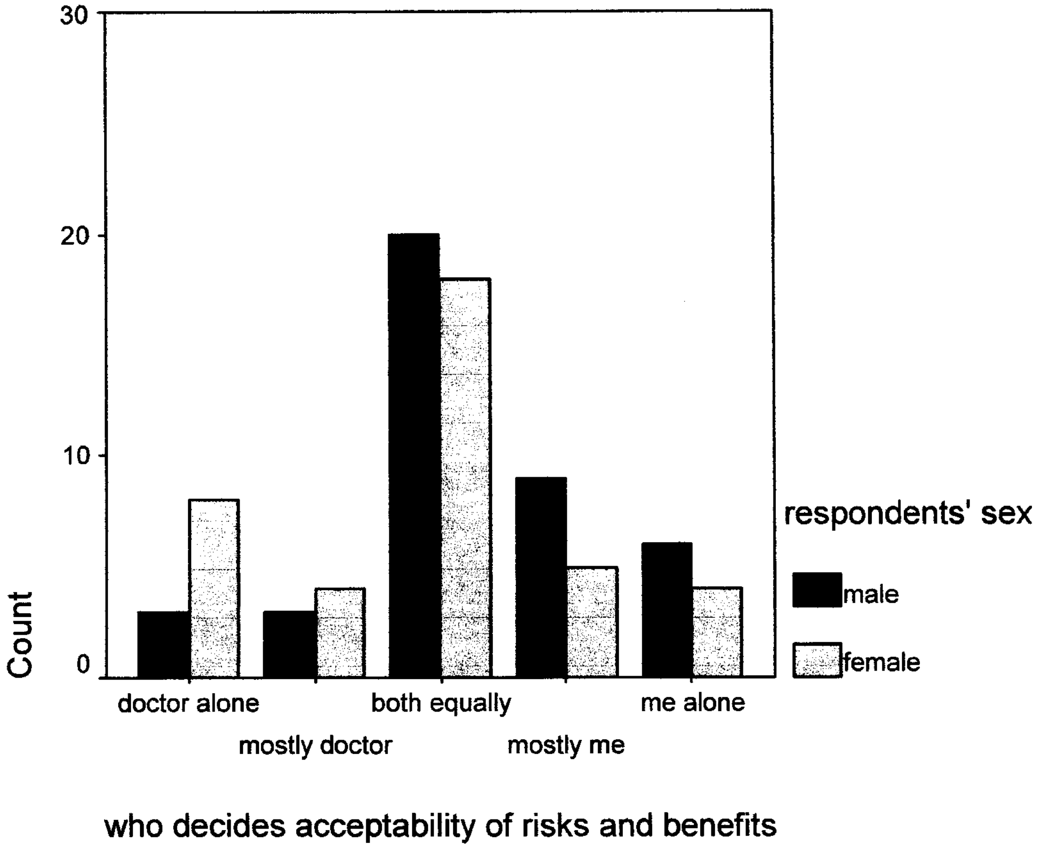

Figure 17. Gender and who decides acceptability of risks and benefits

Results also showed that male and female respondents desired *both equally* to decide acceptability of risks and benefits of treatment options. Overall, 47% of male and female respondents indicated their desire to be involved when making decisions for the acceptability of risks and benefits of treatment options. Interestingly, 14 and 16-year-olds indicated *both equally* to decide acceptability of risks and benefits of treatment options. Figure 18 shows a graphic picture of results.

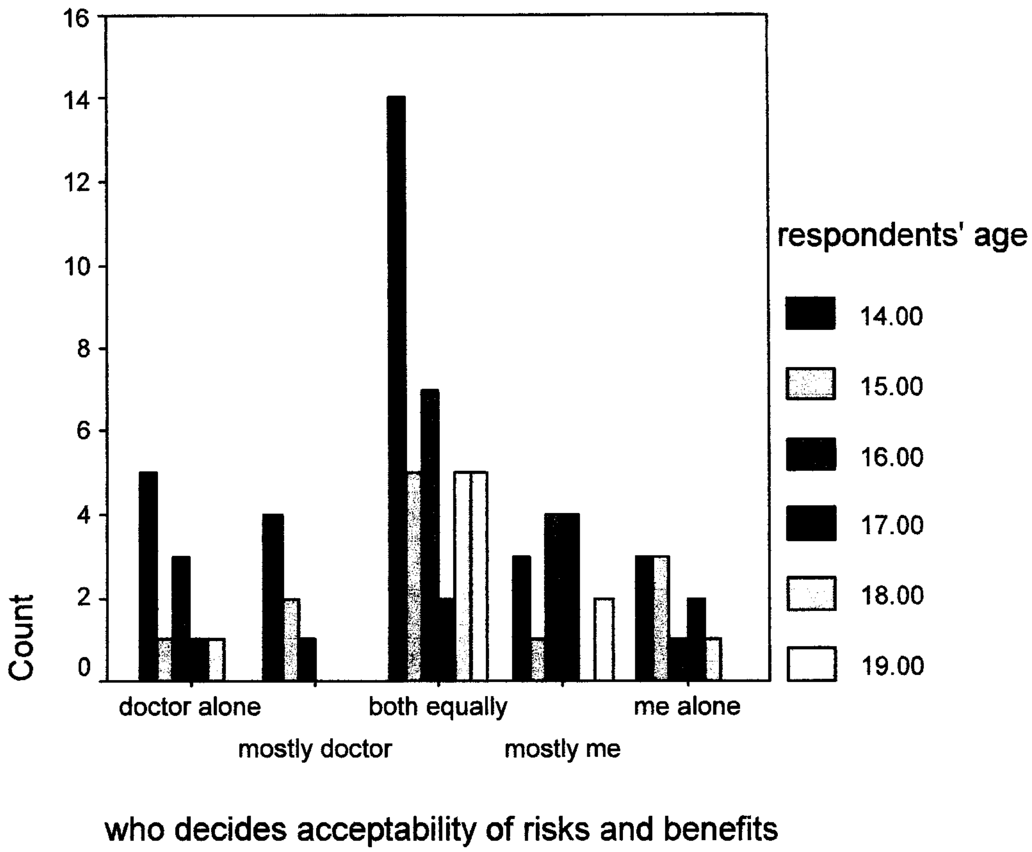

Figure 18. Age and who decides acceptability of risks and benefits of treatment options

Results from the DK-Problem Solving Decision -making Scale (DK-PSDM), show that 38% of chronically ill adolescents who participated indicated a desire that doctors alone determine diagnosis, 35% indicated both equally to determine diagnosis, and the 30% were spread across the spectrum for, *mostly me*, *me alone*, and *mostly doctor*. Relating to the variable *who should determine risks and benefits* with age, 80% of participants indicated *mostly the doctor, both equally*, and *doctor alone*, 20% were spread across between *mostly me*, and *me alone*. In relation to sex and *who should determine risks and benefits*, results showed that 80% of male and female respondents indicated their desire for *both equally, mostly the doctor*, and *doctor alone*. More female respondents indicated *both equally* to determine risks and benefits.

Data from the Adolescent Decision Making Questionnaire (ADMQ) were statistically analyzed using correlation coefficient (r) to predict for statistical association between age, gender, diagnosis, and coping patterns for self-confidence in decision-making. Table 8 shows a visual impression of relationships. Results showed correlations at alpha level .01 and .05 in a 2-tailed test. The association between complacency and evasiveness of ($r = .576$) symbolized being careful in making decisions. Having a correlation between panic and evasiveness of ($r = .416$) indicated self-confidence but carefully examined all angles when involved in making decisions. Correlations (r= .355) between panic and complacency indicated a high level of self-confidence, however, tend to put off or wait before making decisions. Correlation between vigilance and complacency (r= -. 285) showed a very little relationship, meaning that being vigilant did not contribute to self-confidence, however allows time before making a decision. There was no correlation at all between self-confidence, evasiveness, and complacency. This signifies that self-confidence in decision-making is not associated with factors that make a person more careful, or weighs the pros and cons before making a decision.

The Problem Solving Inventory (PSI) examined the relationships between the cognitive behavioral learning and information processing of chronically ill adolescents in relation to self-confidence in health treatment decision-making. The instrument used descriptors as problem confidence, approach avoidance, and personal control.

Table 8

Correlations between self-confidence, vigilance, panic, evasiveness, and complacency in ADMQ

		Self-confidence	Vigilance	Panic	Evasiveness	Complacency
Self-confidence	Pearson Correlation	1				
Vigilance	Pearson Correlation		1			-.285*
Panic	Pearson Correlation			1	.416**	.355**
Evasiveness	Pearson Correlation			.416**	1	.576**
Complacency	Pearson Correlation		-.285*	.355**	.576**	1
	N	80	80	80	80	80

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

The PSI examined the relationships between the cognitive behavioral learning and information processing of chronically ill adolescents in relation to self-confidence in health treatment decision-making. The instrument used descriptors as problem confidence, approach avoidance, and personal control. Problem solving confidence indicated positive emotionality, while personal control indicated negative emotionality. The approach avoidance reflected cognitive behavior skills as it applies a more systematic process in defining problems and generating solutions to problems, and evaluating outcomes. A higher cumulative score reflected a negative perception of one's problem solving ability while a lower cumulative score reflects an attitude and behavior associated with successful problem solving. Results indicated higher scores in approach avoidance with lower scores in personal control. A lower score in personal control indicated a desire among chronically ill adolescents to be in control to give them the self-confidence for solving problems. Table 9 shows correlation analysis of data with the aid of SPSS version 11.0

Table 9

Correlations between problem solving confidence, approach avoidance and personal control in PSI

		Respondents age	Respondents	Problem solving confidence	Approach avoidance	Personal control
Respondents age	Pearson Correlation	1	-.219			.231*
Respondents sex	Pearson Correlation	-.219*	1			
Problem solving confidence	Pearson Correlation			1	.439**	
Approach avoidance	Pearson Correlation			.439**	1	.344**
Personal control	Pearson Correlation	.231*			.344**	1
	N	80	80	80	80	80

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Bivariate correlations between problem solving confidence and approach avoidance showed a low to moderate relationship (*r*= .439) at (p<. 05) level in a 2-tailed test. Age and personal control a low relationship (*r*= .231) at (p<. 05) level in a 2-tailed test. Personal control and approach avoidance show a low relationship at (p<. 01) level in a 2-tailed test.

A scatter plot in Figure 19 reveals that approach avoidance contributed moderately to the problem solving confidence of chronically ill adolescents.

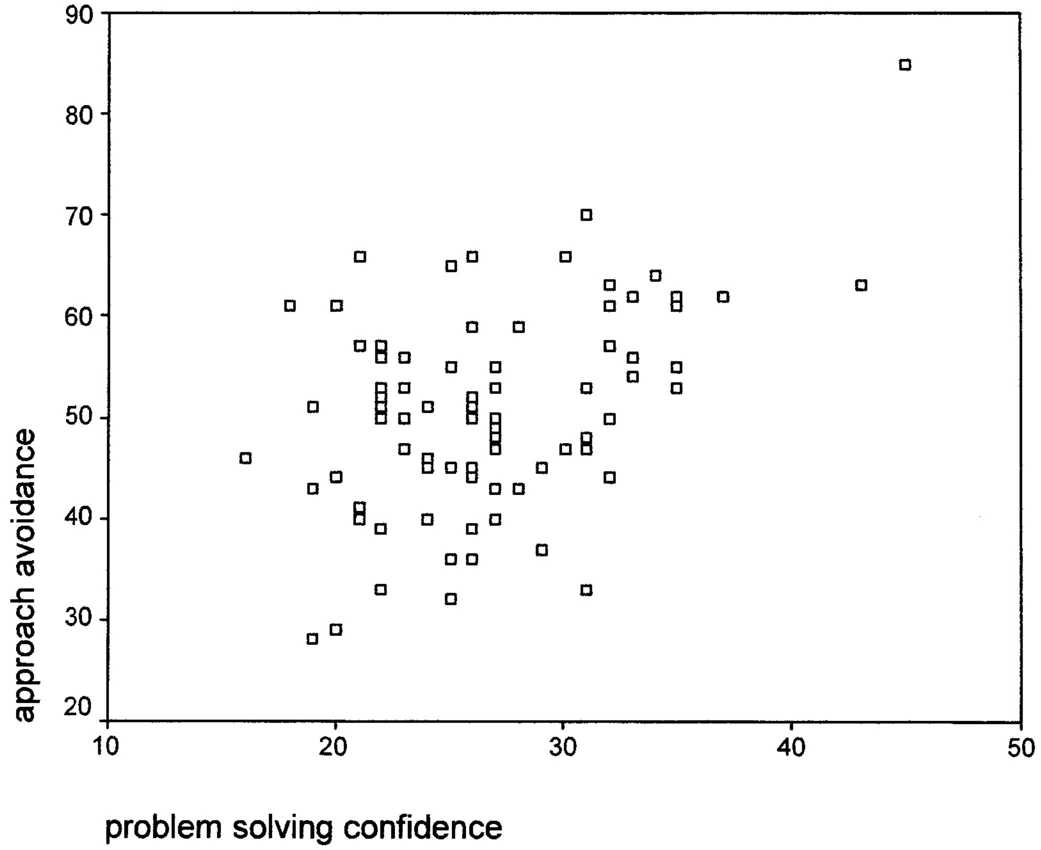

Figure 19. Approach Avoidance as a predictor for Problem Solving Confidence

Pearson correlation *r* determined relationship between the Problem Solving Inventory (PSI) for problem solving confidence, and the Adolescent Decision Making Questionnaire (ADMQ) for self-confidence of chronically ill adolescents in health treatment decision-making. Results showed a non-significant relationship between problem-solving confidence and self-confidence in decision-making among the chronically ill adolescents.

Analysis of data from the PSI for problem solving confidence, and from the ADMQ for self-confidence did not show a significant relationship. It implied that problem-solving confidence did not contribute to self- confidence in health treatment decision-making among chronically ill adolescents. Correlation analysis showed a negative correlation between problem solving confidence and self-confidence.

Figure 20 presents a scatter plot of the association between coping patterns and self-confidence. It showed that although there was no linear association, there was a scattered association along the line. In some ways, coping patterns contributed to self-confidence in decision-making among chronically ill adolescents. Correlation analysis between coping patterns and self-confidence showed a very low, if any, relationship.

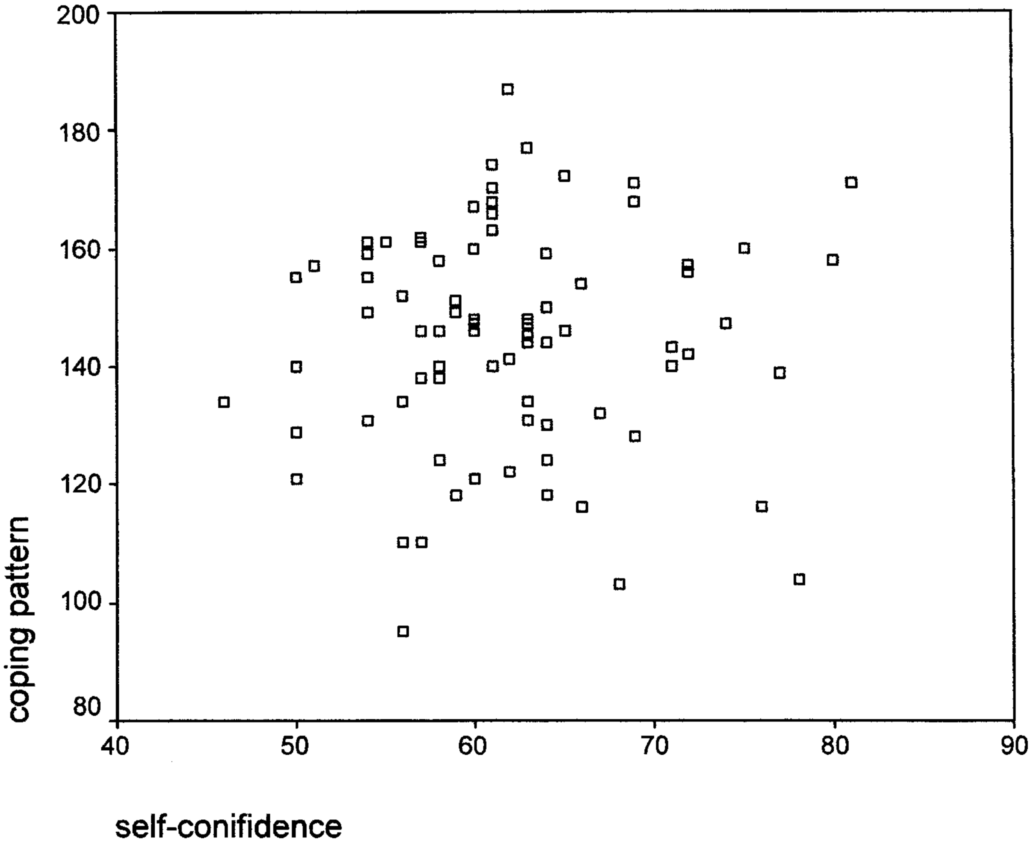

Figure 20. Coping pattern as a Predictor for Self-confidence

Another instrument used to explore chronically ill adolescent's coping patterns in relation to health treatment decision-making was the CSI. This 45-item inventory assessed the chronically ill adolescent's ability to cope with stress and difficulties with illness. The instrument included descriptors as: reactivity to stress, ability to assess situation, self-reliance, resourcefulness, adaptability and flexibility, proactive attitude, and ability to relax. The high scores indicated good coping skills while the low scores indicated poor coping skills.

Correlations between respondents' age, reactivity to stress, ability to assess situations and self-reliance, resourcefulness, adaptability and flexibility, proactive attitude and ability to relax have been entered in SPSS version 11.0.

Results indicated that when chronically ill adolescents have the ability to assess situations, and at the same time proactive with a strong reactivity to stress, they cope well with self-confidence to be involved in decisions made for their health and care. Table 10 shows significant correlations at ($p< .01$) and ($p< .05$) levels in a two-tailed test. A multiple regression ($r^2=. 513$) between reactivity to stress and the ability to assess situations predicted that, when a person has a high reactivity to stress, s/he has a higher ability to assess situations indicating a higher coping ability. A proactive attitude showing correlation with resourcefulness ($r^2= .410$) indicated that a change in proactive attitude could influence 41% change in resourcefulness. On the other hand, results showed that the ability to assess situations moderately correlates with self-reliance ($r^2=. 391$) that predicted a good coping ability. Moderate correlations between reactivity to stress and self-reliance ($r^2=. 375$) indicated that vigilance could influence a 38% change in self-reliance that strengthen adaptive coping. There is a moderate correlation between self-reliance and ability to relax ($r^2=. 360$) indicating that with self-reliance a person can have self- confidence to cope well without panic. The correlation between proactive attitude and ability to relax ($r^2 =. 351$) indicated a moderate association meaning that when a person has a proactive attitude, he is able to confront issues without panic as well. The ability to assess situations and self-reliance showed a moderate correlation ($r^2=. 391$) indicating that assessment of a situation is imperative to self- reliance or self-confidence and predicted good coping ability. Munro (2000) said that r^2 or coefficient of determination was used as a measure of the meaningfulness of *r*.

Table 10.

Correlations between Variables for Coping Pattern

		Reactivity to stress	Ability to assess situations	Self reliance	Resourcefulness	Adaptability and flexibility	Proactive attitude	Ability to relax
Reactivity to stress	Pearson Correlation	1	.513**	.371**	.229*			.265*
Ability to assess situations	Pearson Correlation	.513**	1	.391**				.360**
Self -reliance	Pearson Correlation	.371**	.391**	1				.299**
Resourcefulness	Pearson Correlation	.229**					.410**	.247*
Adaptability and flexibility	Pearson Correlation							
Proactive attitude	Pearson Correlation				.410**			.351**
Ability to relax	Pearson Correlation	.265*	.360**	.299**	.247*		.351**	1
	N	80	80	80	80	80	80	80

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

The use of coefficient and construction of Confidence Interval around *r* were used to determine the meaning of the calculated *r*. Table 11 shows a visual representation of coping patterns and diagnoses as predictors for self-confidence. A correlation coefficient between diagnosis and self-confidence *tv= .168* when compared to the critical value *tcv=1.999* at ($p<.05$) level and a critical value *tcv= 2.658 at* ($p<.01$) level, showed that diagnosis did not contribute to self-confidence while a correlation coefficient tv= *.812* between coping patterns and self-confidence when compared to the critical value *tcv=1.99* at ($p<.05$) level and critical value *tcv=2.658* at ($p<.01$) level of significance (Henkle, Wiersma, and Jurs, 1998) was found that coping patterns had a moderate contribution to self-confidence. This confirmed the results shown in Figure 20 that reflects a moderately low association between coping patterns and self-confidence.

Table 11.

Coefficient r for coping pattern, diagnosis, and Self-confidence

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B	
Model	B	Std. Error	Beta			Lower Bound	Upper Bound
1 (Constant)	63.002	6.785		9.286	.000	49.492	7 6.512
Coping patterns	1.044E-02	.044	.027	.239	.812	-.077	.098
Diagnosis	-1.014	.729	-.157	-1.390	.168	-2.466	.438

a Dependent Variable: Self-confidence

Likewise, results from ANOVA showed a calculated *F ratio of* 1.034 which when compared to the *F ratio* 4.916 ($p<.05$) and *F ratio* 3.072 ($p<.01$) alpha level of significance (Henkle, Wiersma, and Jurs, 1998), indicated a moderate association between diagnosis and self-confidence as well as coping patterns and self-confidence. Table 12 shows the *F ratio* from ANOVA.

Table 12.

Variance between Coping patterns, Diagnosis, and Self-Confidence

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	109.094	2	54.547	1.034	.360
	Residual	4060.856	77	52.738		
	Total	4169.950	79			

a Predictors: (Constant), Diagnosis, Coping patterns
b Dependent Variable: Self-confidence

Data from the DK-Problem Solving Decision Making Questionnaire (PSDM) were analyzed using statistical association to reflect associations between respondents' age, gender, and diagnosis with their desire to be involved in health treatment decision-making. Results indicated a significant correlation at p< .05 and p< .01 in a 2-tailed test. Table 13 shows a visual impression of statistical association.

Results show that the correlation of .257 (p < .05) between *who should determine diagnosis* and *who should decide treatment option* indicated a little, if any, relationship. Calculated correlation of .336 indicated a low relationship between *who should determine treatment options* and *who should decide treatment options* at (p< .05) in a 2-tailed test (Munro, 2000). *Who decides acceptability of risks and benefits,* and *who decides* *treatment options* have a little if any relationship of .294 at p< .01 in a 2-tailed test (Munro, 2000).

Table 13.

Inter-item correlations for preferences for involvement in health treatment decision-making in the PSDM

		Who should determine dx	Who determines treatment options	Who determines risks and benefits	Who decides acceptability of risks and benefits	Who decides treatment options	Preferences for involvement
Who should determine dx	Pearson Correlation	1	.202	.257*			
Who determines treatment options	Pearson Correlation	.202	1			.336**	
Who determines risks and benefits	Pearson Correlation	.257*					
Who decides acceptability of risks and benefits	Pearson Correlation				1	.294**	.244*
Who decides treatment options	Pearson Correlation		.336**		.294**	1	.290**
Preferences for involvement	Pearson Correlation				.244**	.290**	1
	N	80	80	80	80	80	80

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

A coefficient correlation *r* on Table 14 confirmed that the chronically ill adolescents were more concerned about *who decides treatment options and who decides* *acceptability of risks and benefits*. Most of the respondents expressed their desire to be involved by indicating *both equally,* for *who decides treatment options,* and *who decides acceptability of risks and benefits*. The calculated *t* value of 1.466 for *who decides acceptability of risks and benefits* when compared with the critical t value of 1.986 at (p< .05) and 2.631 at (p< .01) indicated significant relationship between chronically ill adolescents' preferences for *who decides acceptability of risks and benefits* (Munro, 2000). Results based on *who decides treatment options,* the calculated *t value* of *1.740* when compared with the critical *t* value of *1.986* at (p<. 05) and *t* value of *2.631* at (p<. 01), indicated a significant relationship between the chronically ill adolescents' preferences for involvement and *who decides treatment options* (Munro, 2000).

Table 14.

Coefficient r for Preferences for Involvement among Chronically ill Adolescents

		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
Model		B	Std. Error	Beta		
1	(Constant)	.801	2.260		.354	.724
	Who should determine diagnosis	-.679	.561	-.142	-1.211	.230
	Who determines treatment options	.405	.628	.076	.644	.521
	Who determines risks and benefits	-.308	.540	-.066	-.571	.569
	Who decides acceptability of risks and Benefits	.679	.463	.167	1.466	.147
	Who decides treatment options	.821	.472	.214	1.740	.086

a. Dependent Variable: Preference for involvement

Statistical Correlations between total scores from the Problem-solving Inventory (PSI), Adolescent Decision Making Questionnaire (ADMQ), Coping Skills Inventory (CSI), and the DK-Problem Solving Decision Making Scale (DK-PSDM), revealed a negative and non-significant correlation. Correlation coefficient of .089 indicated no relationships between decision-making capacity and preference for involvement; correlation coefficient of -.103 showed a negative relationship between self-confidence and preference for involvement, and correlation coefficient of .045 did not show any relationships between coping ability and preferences for involvement in health treatment decision-making. Coping patterns and self-confidence showed a minimal or very little if any relationship. There were some associations but not very significant.

A regression analysis demonstrates whether decision-making, self-confidence and coping ability influence preferences for involvement in health treatment decision-making among chronically ill adolescents.

The calculated *F* .036 when compared with the critical value of *fcv*= 2.72 ($p < .05$) shows a non-significant statistical associations meaning the decision-making capacity, self-confidence or coping ability of chronically ill adolescents do not contribute to their preferences for involvement in health treatment decision-making.

Another statistical analysis using correlation coefficient to confirm relationships between decision-making capacity, self-confidence, coping ability, and preference for involvement in health treatment decision-making was the ANOVA. The calculated *t* value of .536 for constant, *t* value of .242 for decision-making, *t* value of -.076 for self-confidence, and *t* value of - .200 for coping ability when compared with the critical value of *tcv*= 2.003 at ($p < .05$) showed non-significant relationships.

Results revealed that neither decision-making confidence, self-confidence, nor coping pattern influence and/or predict the chronically ill adolescent's preference for involvement in health treatment decision-making. Having the capacity to decide with self-confidence to cope does not guarantee that chronically ill adolescents prefer involvement. There could be extraneous variables that may influence chronically ill adolescents' preferences to be involved.

> *Research Hypothesis 2: There are relationships between chronically ill adolescents' age, gender, health condition or diagnosis, and preferences for involvement in health treatment decision-making.*

The Deber-Kreatschmer Problem Solving Decision Making Questionnaire and the Memorial Symptom Assessment Scale (10-18) were used to aid in the exploration of relationships between age, gender, severity of symptoms, diagnosis, and preferences for involvement in health treatment decision-making. Pearson Product-Moment Correlation r examined the inter-item associations between the DK_PSDM subscales *who should determine diagnosis? Who should determine treatment options? Who should determine risks and benefits? Who decides acceptability of risks and benefits? Who decides treatment options?*

Correlations showed .286 correlations that reflected a very little if any associations between *who should determine risks and benefit* as well as *who should determine treatment options* among chronically ill adolescents. A correlation of .355 between who *determines treatment options* and *who decides treatment options* indicated low if any statistical association, and likewise a correlation of .306 between *who decides* *acceptability of risks and benefits* and *who decides treatment options* indicated very little if any statistical association (Munro, 2000).

On the other hand, correlation coefficient revealed a negative relationship between age and gender in relation to preferences for involvement. Results also indicated that severity of symptoms, as well as diagnosis did not contribute to preferences for involvement in health treatment decision-making among chronically ill adolescents.

However, analyzing the subscale variables separately, a Pearson Correlation *r* of .135 between *age* and *who decides treatment options* showed little if any statistical association, likewise, a Pearson Correlation *r* of .129 between *gender* and *who decides treatment options* indicated little if any statistical association (Munro, 2000).

Table 15 shows a significant relationship between *age, gender*, and *who should decide treatment options* (p< .05) in a 2-tailed test.

Table 15

Pearson Correlation r between age, gender, and who decides treatment options

		Respondent's age	Respondent's sex	Who decides treatment options
Respondent's age	Pearson Correlation	1	-.262	.135
Respondent's sex	Pearson Correlation	-.262	1	.129
Who decides treatment options	Pearson Correlation	.135	.129	1
	N	80	80	80

* Correlation is significant at the 0.05 level (2-tailed).

Multiple regressions explored statistical associations between *gender*, *age,* and *who should decide acceptability of risks and benefits*? Table 16 shows a significant relationship between *age*, *gender,* and *who should decide acceptability of risks and benefit?*

Table 16

Age and gender as predictors for who decides acceptability of risks and benefits

		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
Model		B	Std. Error	Beta		
1	(Constant)	2.733	1.406		1.944	.056
	Respondent's age	6.084E-02	.079	.088	.766	.446
	Respondent's sex	-.419	.263	-.183	-1.592	.115

Dependent Variable: who decides acceptability of risks and benefits

The calculated *t* value .766 for age when compared to the critical *t* value (*tcv*= 3.11), showed non-significant association between age and *who decides acceptability of risks and benefits* while the calculated *t value* –1.592 for gender and *who decides acceptability of risks and benefits* at (p< .05 and p< .01) showed a negative association or correlation (Munro, 2000).

However, most participants indicated that *both equally* meaning the doctor and the patient would equally have a voice in the decisions made for treatment options and acceptability of risks and benefits. Figures 21 and 22 visually show strong preferences for chronically ill adolescents to be equally involved in decisions made for their care in relation to their age, gender, and diagnosis.

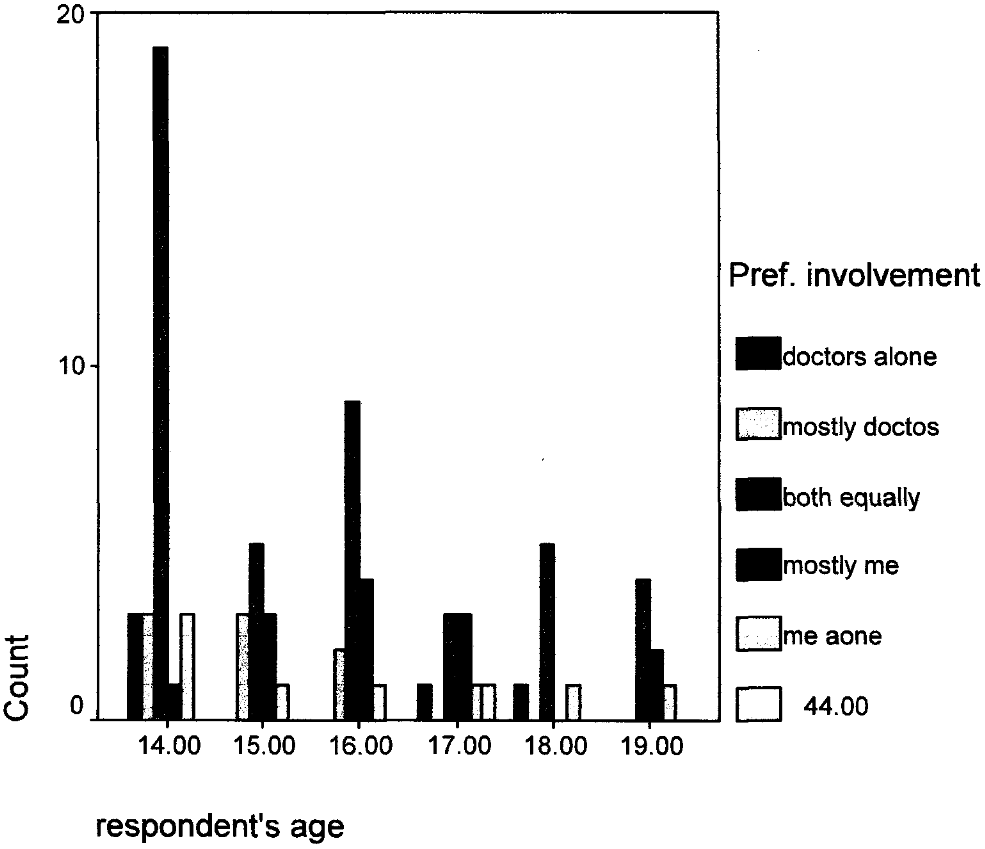

Figure 21. Preferences for Involvement in relation to Age

Between respondent's age and preference for involvement, Figure 21 shows that across the age groups represented from 14, 15, 16, 18, and 19 years old indicated their preference to be involved by indicating *both equally.* This means that the doctors and they would be involved in making health treatment decisions for *treatment options* and *for acceptability of risks and benefits*. However, the 17 years old indicated equal proportions of *both equally* and *mostly me.*

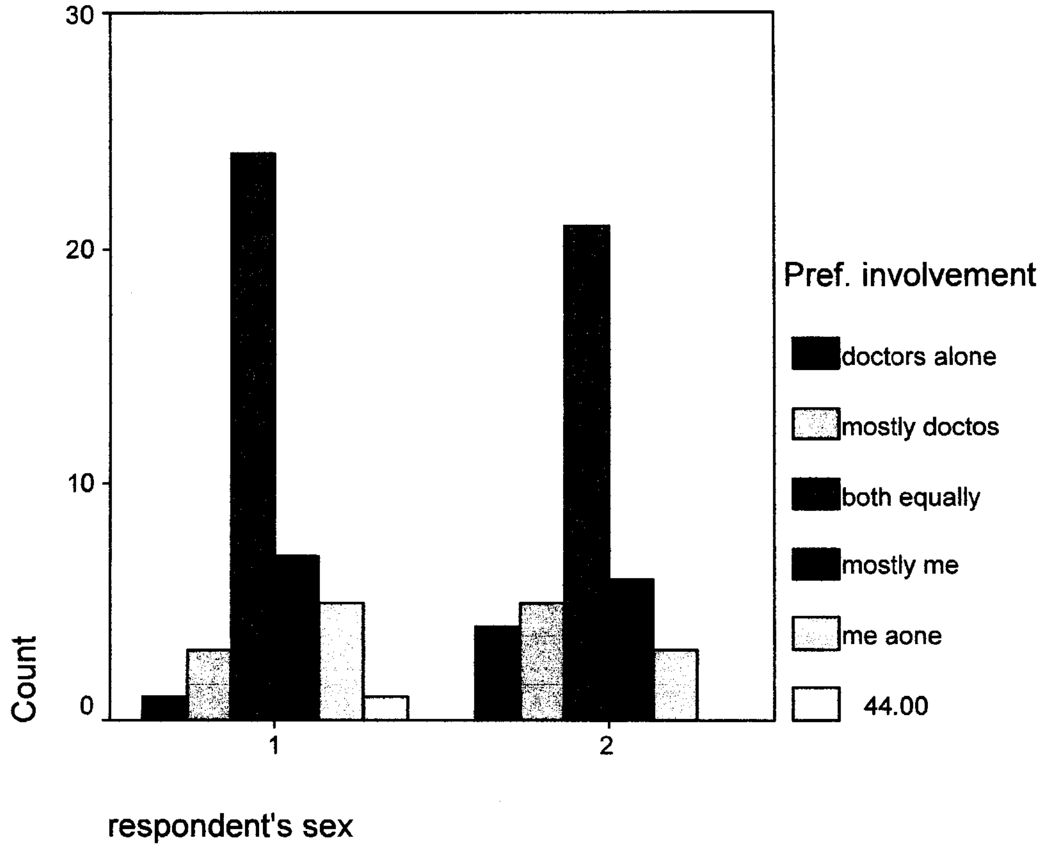

Figure 22. Preference for Involvement in relation to Gender

Between gender and preference for involvement, both male and female respondents indicated their strong desire to be involved by indicating *both equally* as their preference in relation to making health treatment decisions. Figure 22 shows a visual impression of the preferences for involvement among male and female respondents in health treatment decision-making in relation to *who decides treatment options* and *who* *decides acceptability of risks and benefits. Both equally* prevailed among all the responses meaning that both male and female chronically ill adolescents prefer to be involved.

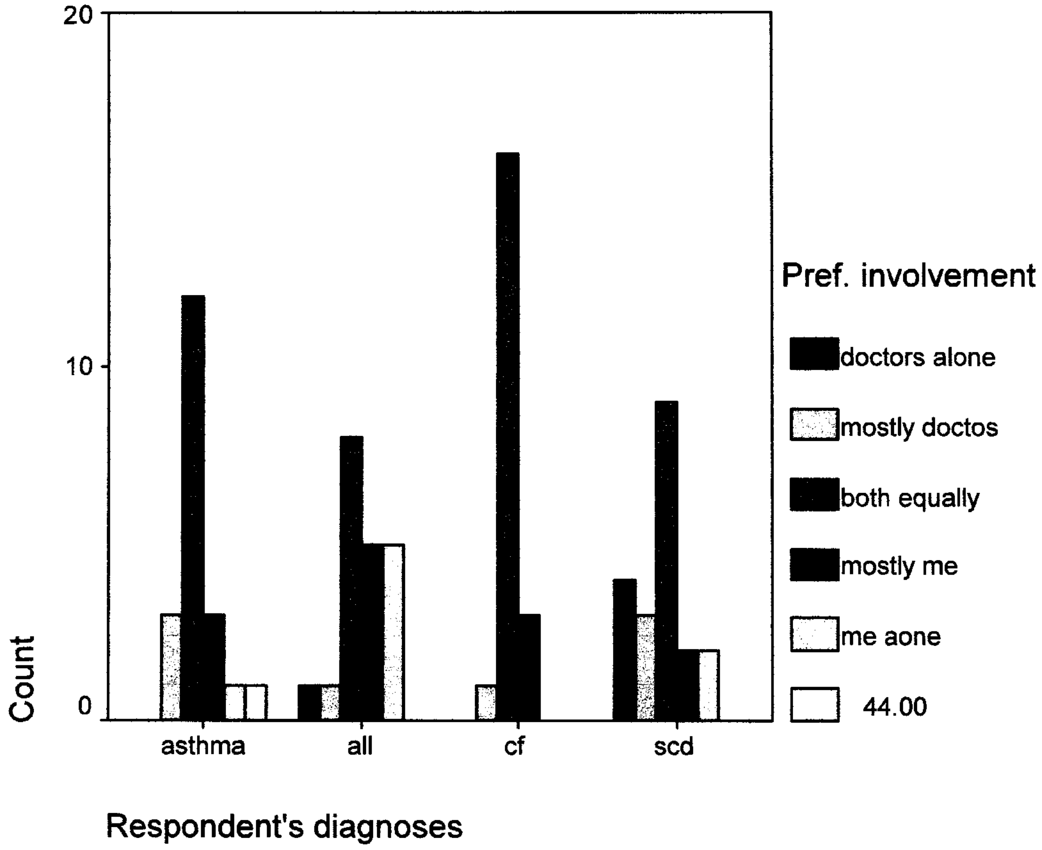

Figure 23. Preferences for Involvement in relation to Diagnosis

Figure 23 shows a representation of chronically ill adolescents' preferences for involvement in relation to their diagnosis. *Both equally* emerged as a significant indicator among the responses of chronically ill adolescents irrespective of their diagnosis that they want to be involved in decision-making for their health and care.

Pearson Product-Moment Correlation *r* -.262 between gender and age indicated a negative correlation at p<. 05 levels Likewise, a correlation *r* -.186 between diagnosis and preference for involvement showed a negative correlation. Correlation *r* -.142 between gender and preference for involvement also showed a negative correlation. The correlation *r*.122 between age and preference for involvement indicated a non-significant relationship at (p< .05, p< .01) in a 2-tailed test (Munro, 2001). The results indicated that age did not significantly contribute to preferences of chronically ill adolescents for their involvement in health treatment decision-making.

Research Question 3: How do o*lder and younger chronically ill adolescents differ in self-confidence in health treatment decision-making.*

The Problem Solving Inventory (PSI) and the Adolescent Decision Making Questionnaire (ADMQ) explored the differences of chronically ill adolescent's self-confidence in decision-making in relation to health treatment decision-making. Descriptive statistical analysis of the total scores from the Problem Solving Inventory (PSI) and the Adolescent Decision Making Questionnaire (ADMQ) revealed a high self-confidence in decision-making among younger and older adolescents.

Figure 24 shows a different perspective where the 18-year-olds chronically ill adolescents indicated a lower self-confidence with a high score than the other age groups who did not at all differ in decision-making confidence.

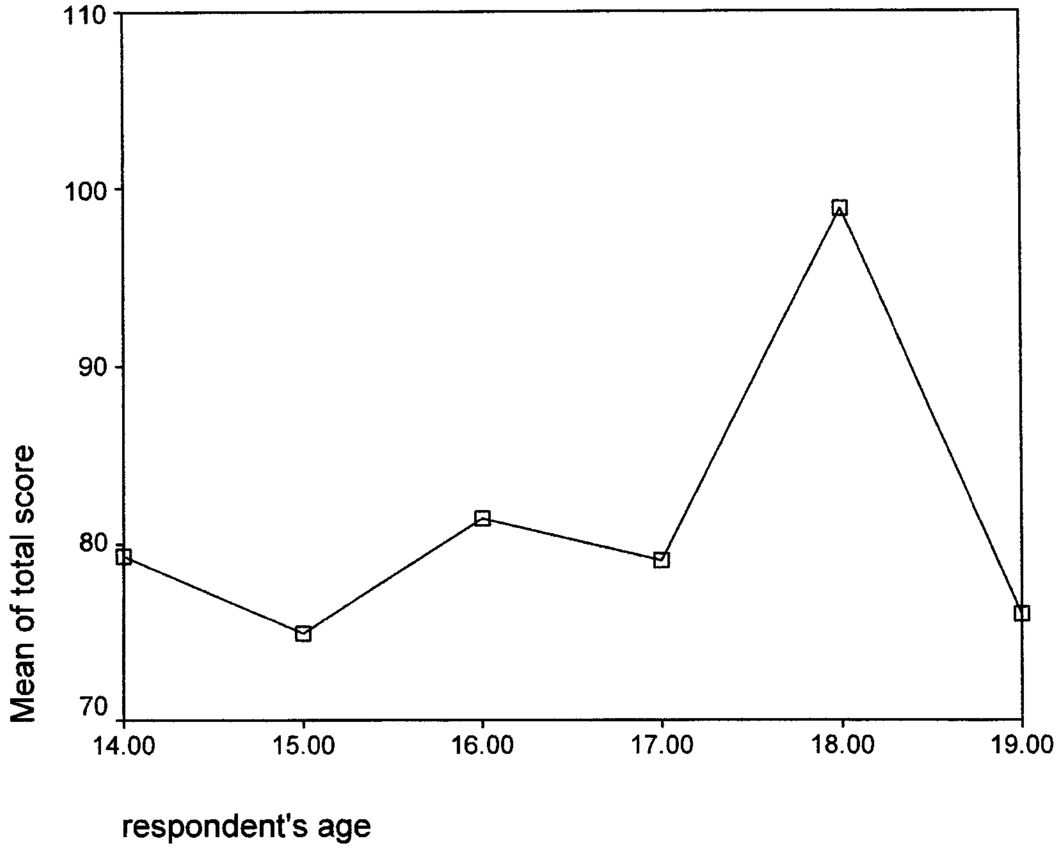

Figure 24. Self-confidence in Problem Solving in relation to Age

Table 17 below shows an objective numerical representation of self-confidence based on total scores from the ADMQ, and from the PSI. Higher scores from ADMQ represent higher self-confidence in decision-making. Lower scores from the PSI indicate a more successful problem solving confidence. The ADMQ scores at a confidence interval of 95% calculated mean scores based on the lower and upper bound at a range of 60.36 to 63.59. Results show that respondents who were 17 years old that represent 12.5% of participants have a mean score of 58 indicating a lower self-confidence in decision-making. Seventy respondents, ages 14, 15, 16, 18 and 19 years old representing

87.5% had mean scores between 61.4 and 65.20. This indicates that 87.5% of respondents have a moderately high self-confidence in decision-making. The calculated PSI scores show a lower and upper bound at a range of 76.72 to 84.42. Results show that 7 respondents, representing 8.75% of participants who are 18 years old indicated a poor problem solving confidence. The 73 respondents, ages 14, 15, 16, 17, and 19 years old that represent 91.24% had mean scores of 74 to 81.37. Having the majority with mean scores at the lower bound indicates that they have more successful problem solving ability.

Table 17

Differences in self-confidence among younger and older chronically ill adolescents in PSI and ADMQ

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
ADMQ									
Total Score	14.00	31	62.32	8.542	1.534	59.19	65.46	46	80
	15.00	10	65.20	6.033	1.908	60.88	69.52	56	78
	16.00	16	61.44	5.796	1.449	58.35	64.53	51	76
	17.00	10	58.80	5.203	1.645	55.08	62.52	50	64
	18.00	7	61.14	6.543	2.473	55.09	67.19	54	72
	19.00	6	62.50	9.268	3.784	52.77	72.23	57	81
	Total	80	61.98	7.265	.812	60.36	63.59	46	81
PSI									
Total score	14.00	31	79.2581	12.56972	2.25759	74.6475	83.8687	57.00	107.00
	15.00	10	74.9000	11.85514	3.74893	66.4193	83.3807	51.00	91.00
	16.00	16	81.3750	15.54295	3.88574	73.0927	89.6573	48.00	100.00
	17.00	10	79.0000	6.07362	1.92065	74.6552	83.3448	72.00	93.00
	18.00	7	98.8571	41.20044	15.57230	60.7531	136.9612	63.00	178.00
	19.00	6	76.0000	10.71448	4.37417	64.7558	87.2442	58.00	90.00
	Total	80	80.5750	17.28230	1.93222	76.7290	84.4210	48.00	178.00

Analysis of Variance (ANOVA) on Table 18 statistically analyzed the differences between group means of chronically ill adolescents, ages 14 to 15, 16 to 17, 18 to 19 years old, and their self-confidence in decision-making. Results from ANOVA indicated the probability that the differences observed in the population means are equal. The calculated value of *fcv*= 2.054 for the Problem Skills Inventory when compared to the critical value of *Fcv* = 3.25 (p< .01) and *Fcv* = 2.33 (p< .05), did not show any differences in self-confidence among younger and older adolescents differing in self-confidence for decision-making. The calculated value of *F* .823 in the adolescent decision making questionnaire when compared with the critical value of *Fcv* = 3.25 (p< .01) and *Fcv*= 2.33 (p< .05) did not show any differences in self-confidence of chronically ill adolescents in decision-making (Henkle, Wiersma, and Jurs, 998).

Table 18

Group Mean Differences in self-confidence among younger and older chronically ill adolescents

		Sum of Squares	df	Mean Square	F	Sig.
ADMQ Total Score	Between Groups	219.681	5	43.936	.823	.537
	Within Groups	3950.269	74	53.382		
	Total	4169.950	79			
PSI Total score	Between Groups	2876.107	5	575.221	2.054	.081
	Within Groups	20719.443	74	279.992		
	Total	23595.550	79			

Analysis of Variance (ANOVA) and measures of central tendencies showed that there were no differences in self-confidence among younger and older chronically ill adolescents.

Results in a clustered bar graph showed a very interesting visual representation of coping patterns, problem solving confidence, and self-confidence among chronically ill respondents.

Coping pattern predominated as a strategy for these chronically ill adolescents to deal with the suffering they go through in relation to treatment options with its risks and benefits. It reflected a deeper understanding of how the intrusion of chronic illnesses made them able to cope in spite of their suffering. On the other hand, the transformed score reflects that coping patterns exceeds among the 17-year-olds while coping pattern is lowest among the 15-year- old respondents exceeded by their high self-confidence. Problem solving confidence was higher among the 16-year-old with good coping pattern and good self-confidence. The 19 years old indicated higher self- confidence and problem solving confidence than coping patterns. The 18- year-olds indicated higher problem solving confidence and self-confidence than coping patterns while the 14 years old indicated non-significant difference between their self-confidence, problem solving confidence, and coping patterns. Figure 25 shows a visual impression of how chronically ill adolescents differ in their coping, problem solving, and self-confidence in decision-making for their health and care.

Further investigation accounted for the differences between male and female chronically ill adolescents in relation to their coping patterns and self-confidence in health treatment decision-making.

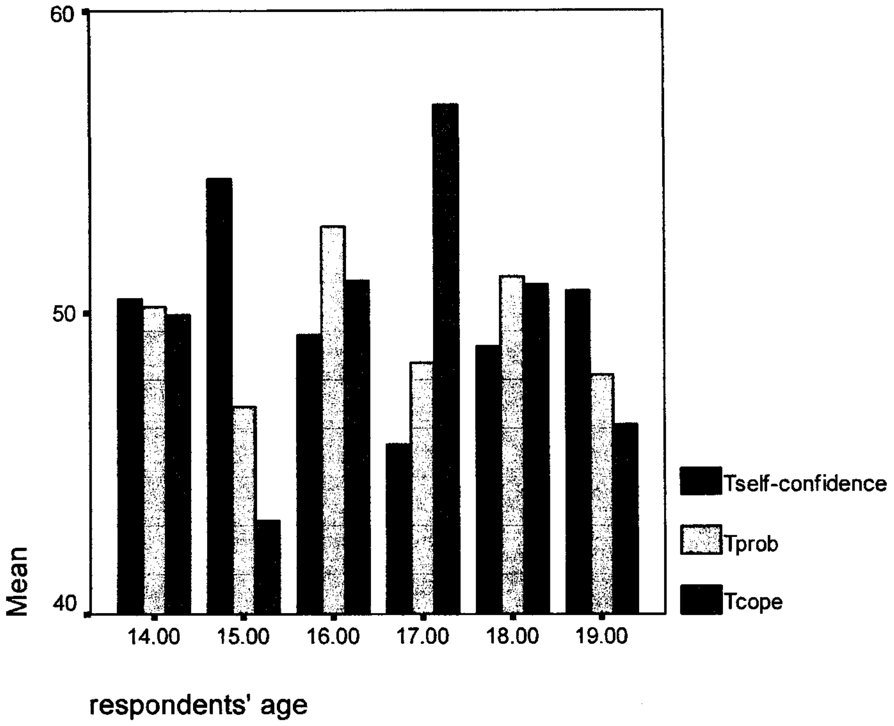

Figure 25. Age and differences in coping patterns, problem-solving confidence and self-confidence

Research Question 4: How do male and female chronically ill adolescents differ in coping patterns and self-confidence in health treatment decision-making.

Analysis of Variance (ANOVA) analyzed the mean differences in self-confidence among male and female chronically ill adolescents in health treatment decision-making from data gathered with the use of three instruments, Adolescent Decision Making Questionnaire (ADMQ), and Coping Skills Inventory (CSI). Based on total scores from the three instruments, the minimum and maximum scores indicate coping ability, problem solving confidence, and self-confidence in decision-making of respondents. A higher score on the ADMQ and CSI indicated higher self-confidence in decision-making. Table 19 shows that the mean differences between male and female respondents did not show any significant differences in scores. The ADMQ mean score of 63 for male and 60 for female did not show a significant difference. PSI results showed a non-significant mean difference based on mean score of 80 for male and 81 for female. Results from the CSI indicated a mean score for male of 146 and 142 for female that did not show significant difference at 95% confidence intervals.

Table 19

Mean differences in self-confidence, and coping patterns between male and female chronically ill Adolescents

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
ADMQ									
Total Score	Male	41	63.00	8.195	1.280	60.41	65.59	50	81
	Female	39	60.90	6.060	.970	58.93	62.86	46	77
	Total	80	61.98	7.265	.812	60.36	63.59	46	81
PSI									
Total score	Male	41	80.1707	15.26745	2.38438	75.3517	84.9897	48.00	131.00
	Female	39	81.0000	19.37035	3.10174	74.7209	87.2791	51.00	178.00
	Total	80	80.5750	17.28230	1.93222	76.7290	84.4210	48.00	178.00
CSI									
Total score	Male	41	146.4146	18.22358	2.84604	140.6626	152.1667	104.00	187.00
	Female	39	142.4615	19.34839	3.09822	136.1895	148.7336	95.00	174.00
	Total	80	144.4875	18.76638	2.09815	140.3112	148.6638	95.00	187.00

Analysis of Variance (ANOVA) for between group and within group differences showed a calculated F value of 1.689 from ADMQ, and calculated F value of .045 from PSI, and calculated F value of .886 from CSI. Comparing the calculated F values with the critical value $Fcv = 3.86$ (p< .05) levels and $Fcv = 6.96$ (p< .01) level confirmed a non-significant difference in self-confidence between group means among male and female chronically ill adolescents (Munro, 2000). Table 20 shows a visual representation of results.

Table 20

Male and female differences in self-confidence

		Sum of Squares	df	Mean Square	F	Sig.
ADMQ						
Total Score	Between Groups	88.360	1	88.360	1.689	.198
	Within Groups	4081.590	78	52.328		
	Total	4169.950	79			
PSI						
Total score	Between Groups	13.745	1	13.745	.045	.832
	Within Groups	23581.805	78	302.331		
	Total	23595.550	79			
CSI						
Total score	Between Groups	312.344	1	312.344	.886	.350
	Within Groups	27509.644	78	352.688		
	Total	27821.988	79			

Results from the Problem Solving Inventory (PSI) showed that there were no significant mean differences in problem solving confidence among male and female chronically ill adolescents. The calculated F value of fv= 2.23 for problem solving confidence, fv= .032 for approach avoidance, and fv=. 708 for personal control were less than the critical value of $Fcv = 2.37$ $(p < .05)$ and critical value of $Fcv = 3.37$ $(p < .01)$ level.

ANOVA results showed a non-significant mean difference in problem solving confidence among male and female chronically ill adolescents. Table 21 shows results.

Table 21

Group mean differences in self-confidence and problem solving between male and female chronically ill adolescents

			F	Sig.
Problem solving Confidence	Between Groups	Combined	2.23	.139
	Within groups			
Respondent's sex	Total			
Approach avoidance Respondent's sex	Between groups	Combined	.032	.858
	Within groups			
	Total			
Personal control	Between groups	Combined	.708	.403
Respondent's sex	Within groups			
	Total			

The calculated value of $fv = 1.496$ on problem solving confidence, $fv = .692$ on approach avoidance, and $fv = .755$ on personal control are less than the critical value of $Fcv = 1.75$ at $(p < .05)$ level and $Fcv = 2.20$ $(p < .01)$ level. This means that self-confidence in health treatment decision-making did not differ among male and female chronically ill adolescents. Table 22 shows results.

However, results from the Adolescent Decision Making Questionnaire shows that the mean differences in self-confidence among male and female chronically ill adolescents were significant. A calculated F value of $fv=2.542$ compared with the critical value of $Fcv=1.99$ ($p<.05$) level shows a significant group mean differences in self-confidence among chronically ill adolescents. On the other hand, ($p<.01$) level with a critical value of $Fcv=2.63$, confirms a non-significant group mean differences (Munro, 2000).

Table 22

Mean differences between problem solving and self-confidence in decision-making in relation to gender.

	Sum of Squares	df	Mean Squares	F	Sig
Problem solving					
Between groups	7.024	21	.334		
Within groups	12.964	58	.224	1.496	.115
Total	19.987	79			
Approach avoidance					
Between groups	6.404	32	.200	.692	.862
Within groups	13.583	47	.289		
Total	19.987	79			
Personal control					
Between groups	4.511	22	.205	.755	.763
Within groups	15.476	57	.272		
Total	19.988	79			

A descriptive analysis of data from the Coping Skills Inventory revealed non-significant group mean differences in self-confidence, and coping patterns among male and female chronically ill adolescents. Table 23 shows the results.

Table 23

Mean differences in coping patterns among male and female chronically ill adolescents

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Male	41	80.1707	15.26745	2.38438	75.3517	84.9897	48.00	131.00
Female	39	81.0000	19.37035	3.10174	74.7209	87.2791	51.00	178.00
Total	80	80.5750	17.28230	1.93222	76.7290	84.4210	48.00	178.00

The groups mean differences in coping patterns among male and female chronically ill adolescents from the Coping Skills Inventory (CSI) showed a non-significant difference. The calculated F value of .045, when compared to the critical value of $Fcv = 4.00$ at ($p <. 05$) level, and critical value of $Fcv = 7.08$ at ($p <. 01$) level, results indicated that between group means, male and female participants did not differ in coping patterns and self-confidence (Munro, 2000). There were no differences in coping patterns and self-confidence between male and female chronically ill adolescents.

From a transformed score, Figure 26 shows a visual impression of the differences in coping patterns, problem solving confidence, and self-confidence between male and female chronically ill respondents. Results showed that there were slight differences in self-confidence as well as problem solving confidence and coping patterns among male chronically ill adolescents. They have higher problem solving confidence but lower self-confidence and coping patterns. Among the female chronically ill adolescents, their problem solving confidence is lower than their self-confidence although they have higher coping patterns. Results indicated coping patterns as a predominant variable with chronic illness among female respondents. In contrast with the original scores, coping pattern scored highest among all the respondents as an important component in dealing with the intrinsic and extrinsic stressors of their illnesses.

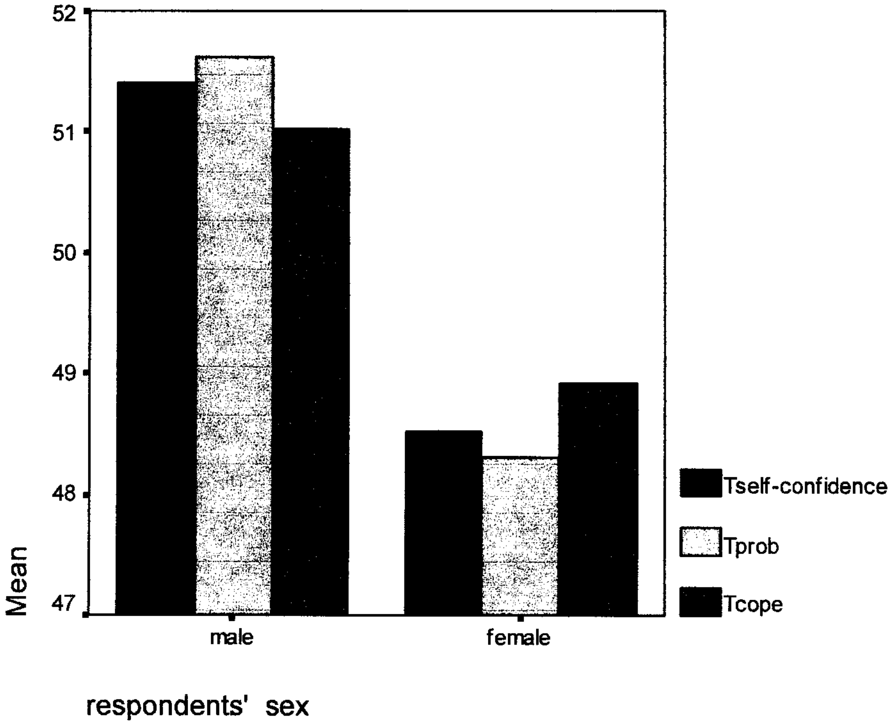

Figure 26. Gender differences in relation to problem solving, self-confidence and coping patterns

Research Hypothesis 5: Health condition or diagnosis, and severity of symptoms affect chronically ill adolescents' preferences for involvement and/or non-involvement in health treatment decision-making.

Pearson Product-Moment Correlation *r explor*ed data from the Problem Solving Decision Making Scale (DK-PSDM), and data from the Memorial Symptom Assessment Scale (MSAS) to determine relationships between severity of symptoms of chronically ill adolescents with their preferences for involvement and/or non-involvement in health treatment decision-making.

Two of the subscales in the DK-Problem Solving Decision Making Scale (DK-PSDM), 'who should determine treatment options' and who should determine acceptability of risks and benefits emerged as significant variants to be discussed further in Chapter 5. Respondents indicated interest that they want to be involved in determining acceptability of risks and benefits and in determining treatment options.

Further exploration of the preferences of chronically ill adolescents in the Memorial Symptom Assessment Scale explored with *who decides treatment options* and *who decides acceptability of risks and benefits*. Results revealed that all the participants preferred involvement by a predominant response *both equally.*

Results from post hoc multiple comparisons of respondents' responses between diagnosis and symptom severity showed that the severity of symptoms affected chronically ill adolescents with physiological symptoms except for adolescents with CF and ALL, whose concentration remained intact, even with the intrusion of illness.

Likewise, results from chronically ill adolescents with CF, SCD, and ALL showed that their lack of energy did not significantly affect their decision-making capacity. Results also showed that frequency of nervousness to adolescents with ALL, Asthma, and SCD was not significant although the same group experienced moderate severity of nervousness in the acute stage of illness.

Pearson correlation *r* calculated value-.186 for diagnosis and preference for involvement showed a negative relationship while the *r* value.033 for symptom severity and preference for involvement showed little if any significant relationship (Munro, 2000).

Further analysis shown in Table 24 using multiple regressions for symptom severity and diagnosis as predictors for preferences for involvement showed a calculated *F* of *fv*=1.393. When compared with the critical value of *Fcv*=3.11 (p<= .05) level, and *Fcv*= 4.88 (p<=. 01) level, significant relationship emerged (Munro, 2000). This means that symptom severity and the diagnosis of the chronically ill patient affect their preferences for involvement in health treatment decision-making.

Table 24

Symptom severity and diagnosis as predictors for involvement

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	60.061	2	30.031	1.393	.255
	Residual	1660.139	77	21.560		
	Total	1720.200	79			

a. Predictors: (Constant), symptom severity, Respondent's diagnoses
b. Dependent Variable: Preference for involvement

Table 25 reflects calculated values from correlation coefficient *r* between diagnosis, and symptom severity with preference for involvement in health treatment decision-making. The calculated value of *tv*=-1.633 for respondent's diagnosis and preference for involvement showed a negative relationship, while calculated value of *tv*= .189 for symptom severity and preference for involvement showed a non-significant relationship when compared with the critical value of *tcv*=1.989 (p< .05) level, and *tcv*= 2.638 (p< .01) in a two tailed test. This means that there is a 5% and 1% probability of error in accepting a non-significant relationship between symptom severity and preferences for involvement as well as a negative effect of the diagnosis of respondents to their preferences for involvement in health treatment decision-making (Henkle, Wiersma, and Jurs, 1998).

Table 25

Effect of respondent's diagnosis and symptom severity to preferences for involvement

		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
Model		B	Std. Error	Beta		
1	(Constant)	5.421	1.510		3.591	. 001
	Respondent's diagnoses	-.762	.466	.184	-1.633	.107
	Symptom severity	9.990E-03	.053	.021	.189	.850

a Dependent Variable: Preference for involvement

Research Hypothesis 6: There are relationships between severities of symptoms and self-confidence in health treatment decision-making among chronically ill adolescents.

Multiple regression analysis predicted relationships between severity of symptoms and self-confidence of chronically ill adolescents in relation to their involvement in health treatment decision-making. Data from the Adolescent Decision making Questionnaire (ADMQ), and the Memorial Symptom Assessment Scale (MSAS) instruments revealed statistical associations between severity of symptoms and self-confidence in decision-making. Tables 26 and 27 show a visual presentation of statistical association.

Table 26

Symptom severity as a predictor for self-confidence in decision-making

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	12.950	1	12.950	.241	.625
	Residual	4131.937	77	53.662		
	Total	4144.886	78			

a. Predictors: (Constant), symptom severity
b. Dependent Variable: Self-confidence

The calculated value of *F*= .241 when compared with the critical value of *Fcv= 3.96* (p< .05) level and *Fcv*= 6.96 (p<. 01) level indicate that symptom severity minimally contributes to self-confidence in decision-making (Munro, 2000). Symptom severity affects self-confidence of chronically ill adolescents in their decision-making capacity but not very significantly. There is a 5% percent and 1% probability of error in rejecting a non- significant relationship between severity of symptoms and self-confidence in decision-making.

Table 27

Coefficient r symptom severity and self-confidence

		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95% Confidence Interval for B	
Model		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	62.588	1.390		45.026	.000	59.820	65.356
	Symptom severity	-4.094E-02	.083	-.056	-.491	.625	-.207	.125

a. Dependent Variable: Self-confidence

The calculated value *tv*= -.491 compared to the critical value of *tcv*= 3.96 indicates that severity of symptoms has a little if any contribution to self-confidence in health treatment decision-making.

The scatter plot below in Figure 27 reflects a minimal relationship between symptom severity and self-confidence in a scatter plot. Symptom severity and self-confidence in decision-making showed a non-significant statistical association along the regression line. It means that severity of symptoms does not contribute to self-confidence in health treatment decision-making.

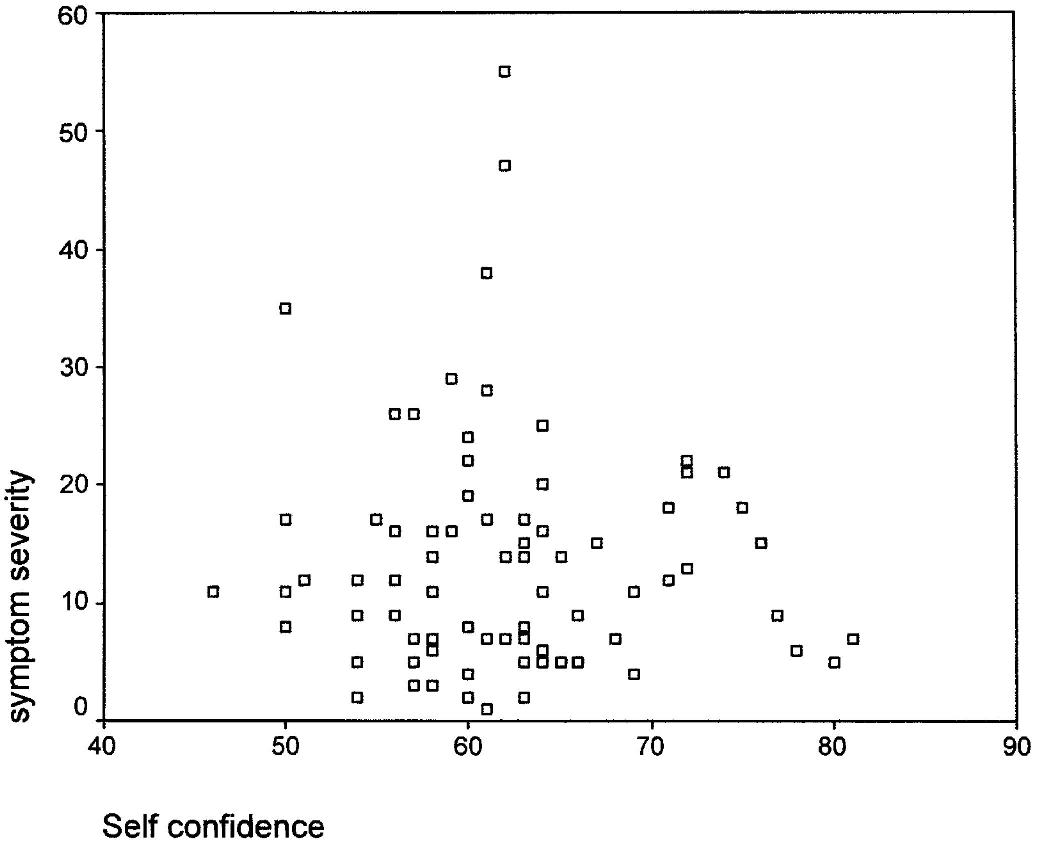

Figure 27. Negative correlation between symptom severity and self-confidence

Since there were no associations between severity of symptoms and self-confidence, multiple regression equation cannot be developed to predict relationships between the two variables. Instead, the mean as the center of the data served as a means for further exploration.

Regression reflects falling back toward the mean (Munro, 2000). Since there was no association between severity of symptoms and self-confidence, the predicted scores are the same as the predictor.

The answers to research question 6 indicated that symptom severity does not contribute to self-confidence of chronically ill adolescents. Regardless of symptom severity, chronically ill adolescents possess the self-confidence to be involved in health treatment decision-making.

The Deber-Kraetschmer Problem Solving Decision Making Scale included a closed-ended question relating to the experience with decision-making. The question states *how much experiences have you had with decision-making.* Respondents circled their responses based on options such as; (*a*) *I have had experience with it*, (*b*) *I know of family member who have the experience, (c) I have read about it, and (d) I do not know much about it.*

A descriptive analysis based on responses revealed that 71.3% had the experience of being involved, 17.5% did not know much about it, 7.5% family and/or friend experienced it, and 3.8% read about it. Analysis of Variance showed a calculated value of *Fv* 1.303 for *age* and *personal experience* when compared to the critical value of *Fcv* =2.72 (p< .05) level, and critical value of *Fcv*=4.04 (p< .05) level, indicated no mean differences in their experience. The groups mean differences on experience and diagnosis showed a calculated value of *Fv*=. 192, which indicated no group, mean difference. Gender and experience revealed a calculated value of *Fv*=1.115 that indicated no group mean differences when compared with critical value of *Fcv*=2.72 (p=. 05) level, and critical value of *Fcv*=4.04 (p< .01) level. Table 28 shows statistical group mean differences.

Table 28

Group mean differences between age, diagnosis, gender, and experience

		Sum of Squares	df	Mean Square	F	Sig.
Respondents' age	Between Groups	10.526	3	3.509	1.303	.280
	Within Groups	204.674	76	2.693		
	Total	215.200	79			
Respondents' diagnosis	Between Groups	.751	3	.250	.192	.902
	Within Groups	99.249	76	1.306		
	Total	100.000	79			
Respondents' sex	Between Groups	.841	3	.280	1.115	.348
	Within Groups	19.109	76	.251		
	Total	19.950	79			

Results on the question *how much experiences have you had with decision-making process* revealed that 71.3% had the experience. The question did not clearly define if experience was involvement in health treatment decision-making or experience with decision-making per se. Two qualitative questions to supplement the numeric inquiry about knowing how these chronically ill adolescents prefer to be involved in health treatment decision-making unfolded patterns of association.

Findings revealed that when chronically ill adolescents use both the adaptive and maladaptive strategies in decision-making, they gain better self-confidence at confronting problems with their illnesses. However, problem solving confidence and coping patterns did not contribute much to their self-confidence in health treatment decision-making.

Their decision-making capacity did not contribute to their preferences for involvement and did neither self-confidence nor coping patterns. Likewise, self-confidence showed a negative correlation with preferences for involvement among chronically ill adolescents. On the other hand, chronically ill adolescents indicated their coping ability contributory to their self-confidence in health treatment decision-making.

Gender in relation to chronically ill adolescent's preferences for involvement in health treatment decision-making showed a negative relationship. Diagnosis and preference for involvement among chronically ill adolescents showed a negative relationship. On the other hand, age and preference for involvement showed little if any relationship. When descriptors for *who decides treatment options,* and *who decides acceptability of risks and benefits* were correlated with age, diagnosis, and gender, a significant relationship emerged. Regardless of diagnosis, gender, and age, chronically ill adolescents indicated their preferences to be involved in deciding treatment options and deciding acceptability of risks and benefits.

Findings showed that male and female chronically ill adolescents did not differ in coping patterns and self-confidence in health treatment decision-making. However, coping patterns predominantly indicated a significant phenomenon among chronically ill adolescents between male and female respondents. Between coping patterns, problem solving confidence, and self-confidence, and age, results showed some differences among chronically ill adolescents. Although coping pattern exceeded among the 17 years old, self-confidence predominated among the 19- year-olds respondents and coping pattern was lowest among the 15-year-olds in the transformed scores. The primary scores showed a high coping pattern among all the age groups.

The diagnosis and preferences for involvement showed a negative relationship, while severity of symptoms and preferences for involvement showed a non-significant relationship. This means that regardless of diagnosis, symptom severity did not contribute much to the preferences of chronically ill adolescents for involvement in health treatment decision-making. Symptom severity showed moderate relationship with self-confidence. It implies that the severity of symptoms contributed to the self-confidence of chronically ill adolescents in health treatment decision-making. Figure 28 shows the theoretical model based on hypotheses testing. It represents results of significant relationships, non-significant relationships, and negative relationships between variables that were statistically tested.

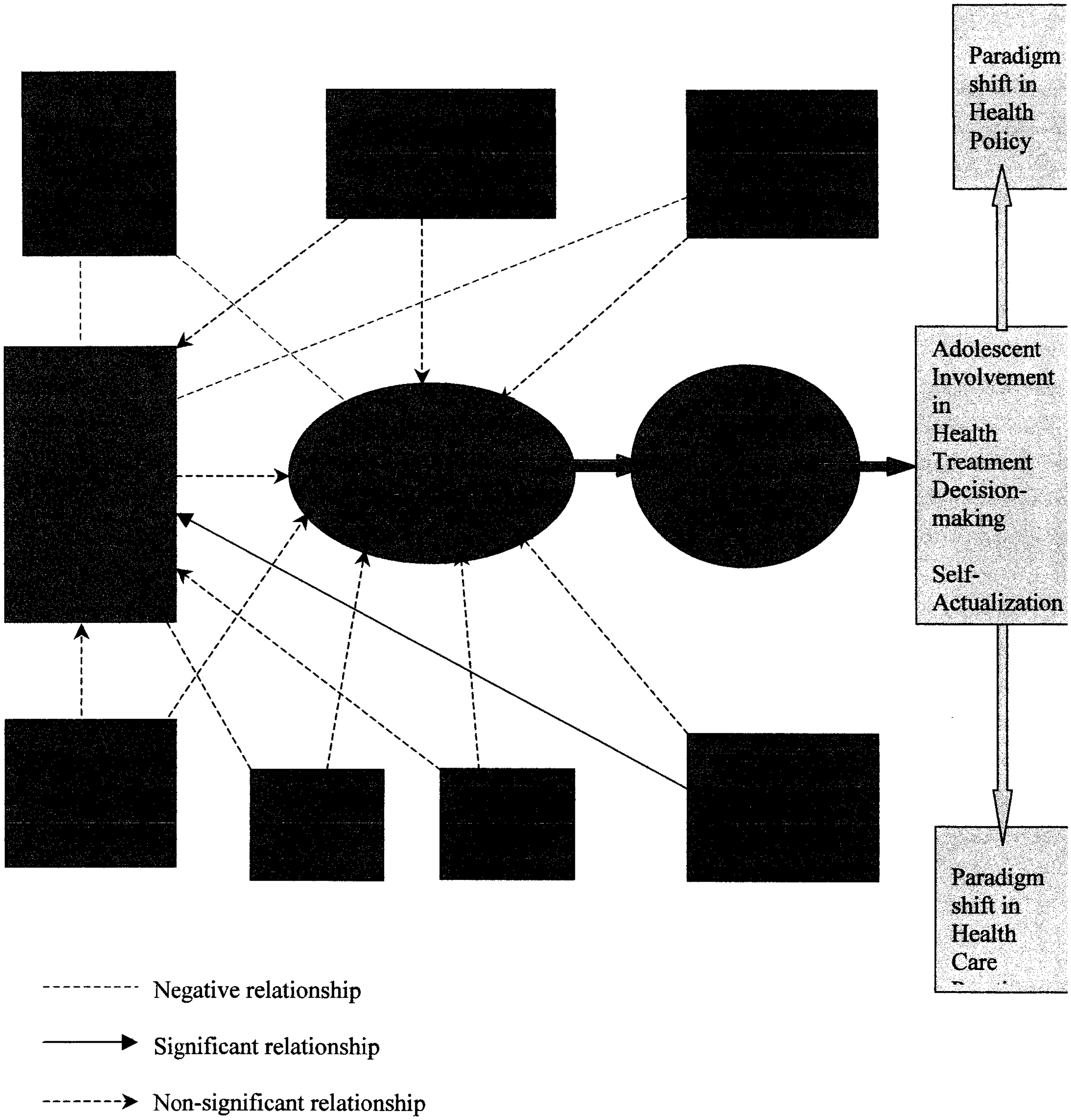

Figure 28. Theoretical Model: Shared Decision Making for Chronically Ill Adolescent's Involvement in Health Treatment Decision Making

Summary

Objective findings based on numeric data revealed significant and non-significant relationships as well as negative relationships. Linkages show that self-confidence and coping ability influence preferences for involvement in health treatment decision-making. Severity of symptoms, age, gender, and coping patterns contribute to the self-confidence of chronically ill adolescents in health treatment decision-making.

On the other hand, chronic illness, diagnosis, and gender showed negative correlation with preferences for involvement while age, severity of symptoms and problem solving confidence showed non-significant correlation with preferences for involvement in health treatment decision-making. Likewise, chronic illness, diagnosis, and problem-solving confidence showed negative correlation with self-confidence in health treatment decision-making. The qualitative inquiry with the aid of grounded theory (Straus and Corbin, 1965; Glaser and Straus, 1967) further validated the numeric findings with a more meaningful base of knowledge on the reality of chronically ill adolescents' preferences for involvement in health treatment decision-making.

Qualitative Analysis

While quantitative inquiry looked at probability and causality, qualitative inquiry aimed at looking for commonalities and associations from a diverse point of view, experiences, and perspectives of chronically ill adolescents about their perceptions on their involvement in health treatment decision-making. It complimented an objectivist view from a quantitative standpoint to a constructivist positivist view. Strauss and Corbin (1990, 1998) positivist view moves towards giving a voice to their respondents, to accurately acknowledge their views of reality, and create empirical reality grounded on the data. On the other hand, Guba and Lincoln (1994) and Schwandt (2001) underpin the relative importance of constructivist grounded theory by creating knowledge through interpretive understanding by the viewer and the viewed. Looking more in depth into the personal social processes, and coding salient themes allows grounding data into the phenomenon in question (Flick, 1998). A supplemental qualitative inquiry intends to identify gaps in a quantitative driven inquiry in relation to the commonalities of perspectives among chronically ill adolescents on their preferences for involvement and/or having a voice in decision-making for their health and care.

Straus and Corbin (1965) introduced grounded theory as a way of explaining human behavior elicited from the reality of experience. Thus, individuals are involved in creating meaning in a situation. Blumer (1969), and Mead (1934), consider grounded theory as a sociological perspective originating from symbolic interactionism. They believe that human beings act according to the meanings things have for them. People create symbols as they interact with each other and at the same time construct their own realities based on the constructivist philosophy (Sandelowski, 2000). Mead (1934) says that reality is created by attaching meanings to words, objects, and clothing as the basis for actions and interactions. These interactions bear theoretical significance as the focus of observations in grounded theory research.

Schatzman (1991) elaborated the concept of symbolic interactionism by introducing dimensional analysis. He says that dimensional analysis is a process that allows the ability to derive meaning through interpretation of the component parts of a phenomenon. The process includes noting the attributes, context, processes, and meanings. Blumer (1969) posits that symbolic interactionism is an approach to yield knowledge of human behavior and the essence of life's choices, while Schatzman (1991) asserts that dimensional analysis is an alternate method to interpret actions that a person naturally and commonly employs in everyday situations. While the objective of grounded theory method focuses on the question *what is the basic social process* underlying the phenomenon? (Glaser and Strauss, 1967), Schatzman (1980, 1986, 1991) asserts that dimensionalizing attempts to address the question *what all is involved here?* He believes that this question guides the researcher's interaction with the data in conceptualizing the meanings of interactions in a situation through natural analysis.

Natural analysis according to Schatzman (1991) is a cognitive process used by people to interpret and understand problematic daily experiences. He says that these experiences allow learning through early socialization that provides individuals with a plan to structure analysis of ordinary life as well as scientific complex problem solving processes. Ordinary life phenomenon requires simpler sets of dimensions, thus analysis in the context of research that intends to generate theory links interpretive actions, fashioned by everyday life experiences (Schatzman, 1991) through the process of dimensional analysis.

Embedding dimensional analysis in symbolic interactionism as a qualitative inquiry in this research, dominant themes emerged from responses to the open-ended questions in the DK-PSDM questionnaires. Charmaz (1990) says that quality of insights generated from personal views is what matters in qualitative inquiry. Reality construction emerges from the interpretation of data through symbolic interactionism and dimensional analysis perspective. Personal insights of respondents in response to the question *how would you like to be involved in decisions made for your care* unfolded salient themes.

These salient themes unveiled the inner voices of chronically ill adolescents from inside out.

Thematic categories

Transforming responses by coding, dominant themes emerged. Twenty-four or 30% of respondents indicated the need to be informed. Twenty-three or 28.75% wanted to be involved, ten or 12.5% indicated their need to be heard. Sixteen or 20% wanted to have a choice with two or 2.5% emphasizing help from the doctors and parents. Two or 2.5% indicated appropriateness of care, one 1.25% indicated assistance and help, while one or 1.25% did not really care. Themes that emerged unfold meanings into the covert perspectives of chronically ill adolescents such as, *being heard, being informed, being involved, and autonomy, shared decision-making, having a choice and decide.*

Being Heard

> *I would like to give my personal opinion and input on things that may be done for me.*
>
> *I like when people listen to me.*
>
> *I would like to know what is going on and have a say in the decision-making process affecting me.*

Being heard (Webster, 1999) is defined as to be listened to with careful attention, be informed of, to be listened to officially, hearkened to, perceived, detected and regarded. Interpreting these definitions of *being heard*, these chronically ill adolescents are asking that the world or the adult world will listen to what they are saying. It reflects an assertion that yes, they are young and may be vulnerable but they have now developed that cognitive ability to dissect abstract information into pieces to put meaning into it, and analyze situations in relation to their condition. Piaget's cognitive theory posits that children, 14 years old and above are capable of making inferences from abstract information.

Being Informed.

> *I would like them to talk about the treatment with me.*
>
> *I want to know what is going on to harm me and the pros and cons of the problem.*
>
> *I would like to be told the problem and say what I think.*
>
> *I would like to know about things done to my body, and what they are talking about.*
>
> *I would like to know what is exactly going on and what is happening to me and ask questions.*
>
> *I just want to understand the decisions for me.*
>
> *Decision and roadmaps should be better-explained run through me first.*

Being informed (Barnhart and Barnhart, 2000), means having knowledge or information, having been instructed or educated. Being informed is a key factor for making good judgment and decision-making. The chronically ill adolescents indicated a universal primary need inherent to every individual whether old or young to be informed. Knowing is not only to a select group. Belenky, Clinchy, Goldberger, and Tarule (1997) in their book Women's Ways of Knowing, indicated that women still feel silenced whether at home, school, in the community or at church. In their book, they reinforced the development of self, voice, and mind among women.

To chronically ill adolescents, patterns of knowing reflect understanding of facts and information influenced by their cognitive ability to understand medical terminologies or drugs. Nevertheless, as their cognitive ability expands, keeping them informed motivates them to look forward to being involved in their treatment trajectory. As Piaget has asserted in his cognitive theory, adolescents age 14 years old and older understand abstract thought just as adults do, and are cognizant with the consequences of their actions. The chronically ill adolescents expressed their desire for information in spite of their awareness that they are living in a society dominated by patriarchal power, parents and doctors. Britto et al (2004) confirms this construct in their findings that adolescents prefer information to be directly given to them rather than to their parents. Their desire to be informed indicates a desire to make good judgments when involved in decisions made for their health and care.

Being Involved

> *I would like to give my opinion.*
>
> *I would like to have more say about what is going on with me and why.*
>
> *I would like to know and be involved about my care.*
>
> *I like it when people involve me in my care.*
>
> *I want to be very involved when decisions are made for my care.*
>
> *I would strongly envy being involved with decision-making.*
>
> *I would like to be involved a lot, because I feel I have the most to do with it. It is hard sometimes but I feel I am in good hands and that the Lord will be there with me the whole time having nothing to fear.*
>
> *I would like my input to be considered.*

Being involved means having a part, participate, to be included (Barnhart and Barnhart, 2000). From a human perspective, individuals need the experience of having a part to develop that feeling of belonging. When a person feels he belongs, he develops and maintains that self-identity in relation to others. With others, a person feels an acknowledgement of who s/he is. Chronically ill adolescents indicated their desire to be involved with the assertion that their body suffers from the consequences of the decisions made for their care. This is a voice from the adolescents, wanting to have a voice and a choice for decisions made for their health and care. When they have been involved with a voice and had the choice for decisions made for their health and care, they take the responsibility for the consequences of that choice. This will help them become more mature in making decisions that will prepare them to confront more challenges that are complex in the future.

Autonomy

> *I would like to continue having choices.*
>
> *I like to have choices.*
>
> *I feel the doctors should diagnose the problem and provide me with reasonable options, pros, and cons, and then ultimately make me decide which is best for me.*
>
> *I want to decide how much of a dosage I should take for my meds.*
>
> *I want to be allowed to make choices for myself.*
>
> *I would be the one to make these important decisions that mainly concerns my care and me.*
>
> *Ask me then I will figure it out.*

I want to make decisions for my care.

By deciding when I could take my blood test to see if I am going to get better.

I would like to have a big part in the decisions regarding myself.

I would like to make decisions about my health without my parents' interference.

I would like to talk directly to the doctors and hear about the different options. I would like to be able to ask questions and what the doctors' educated opinion and make decisions with the help of my family.

Autonomy means independence and self-governance. Based on subjects' responses, this phenomenon emerged from the older chronically ill adolescents; age 17 to 19 year olds. It indicates that older adolescents want their independence to challenge the world and explore their capabilities to handle situations. They want self-governance that will make them more mature in confronting the environment around them. When given the autonomy in finding out what meanings their condition is to their quality of life, they can make better decisions related to plans of care for them. Being informed is a key to helping them find meaning into their health condition.

Shared decision-making

I think my parents are the best to make decisions but I like to be involved.

By talking to other people and see, what they think about my decisions.

I just want to be healthy and not be messed up by the drugs that they have given me.

I like Dr. F ask me how I am doing and ask me what is going on instead of talking to others about me.

S*hared decision-making* means coming to a resolution from differing perspectives.

Shared decision-making involves decisions shared by parents, doctors/nurses and the patient. It is a process where alternative solutions are determined to assure least complications, and maximize effectiveness of care.

Having choices

I would like to continue having choices.

I like to have a choice.

I want to be allowed to make choices for myself.

Having a *choice and decide* implies *an* act of choosing in order to settle. It is further defined as making a choice and making a decision linked with the other salient themes above. The safety of being able to make an acceptable decision becomes possible if adequate information and involvement exist. Being heard comes in when an adolescent is given the opportunity to make a choice and then allowed to make a decision. All salient themes that emerged are symbols that shape people's behavior that ground chronically ill adolescents' perspectives for their involvement in health treatment decision-making.

From the chronically ill adolescent's perspectives, independence and self-governance are very important factors for their success in striving for self-identity and self-actualization. To be involved entails an expression of their views that demand listening with enough information and instructions.

Another open-ended question included in the Deber-Kraetschmer Problem Solving Decision Making Scale was, *how did the nurses make it easier for you.* Out of eighty respondents, only seventy-seven indicated their perspectives in relation to the second question. Transforming the responses through symbols to dig deeper into the data, the following salient themes emerged; *talk to me, explain to me, ask me to make a choice, helpful and nice, involve me, and reinforcement.* Other important themes that captured interest were *older nurses and float nurses.*

Talk to Me

> *I made it easier because the nurse talked about it.*
>
> *The nurses in this office do it well because they also talk to me.*
>
> *The nurse makes it easier when she talks to me as well as the doctors.*
>
> *She made it easier by telling me to make decisions.*
>
> *Talk to me, had a conversation made me feel good.*
>
> *The nurse talks to me and I like it.*
>
> *They have made it partly because now they talk to me instead of my mom.*

Talk to me means the act of communicating with spoken words. Speak with use of words (Barnhart and Barnhart, 2000). While adolescents have learned abstract reasoning, they now want to talk and reason. Their abstract reasoning emerged and their logical thought can be challenged. Hence, words rightly spoken are soothing to the ears of a chronically ill listener yearning for news or solutions to a health problem. Instead of doctors and/or nurses talking to the parents, chronically ill adolescents indicated their desire that doctors and nurses talk to them as well. Twelve percent indicated that nurses made it easier for them to understand and cope with their illness when the nurses talked to them.

Explain to Me

> *By explaining the risk, they are.*
>
> *By telling how so I understand.*
>
> *The nurse has encouraged me with many things such as PICC line placement.*
>
> *The nurse explains the procedures and makes it easier for me to cooperate.*
>
> *They tell me what good for my health are.*
>
> *The old nurses made it easier for me to participate when she sat down with me and told me what they want me to do to help me, tell my parents, doctors what I feel when I get seizures.*
>
> *By explaining each option.*
>
> *By explaining what treatment, options are best for me.*
>
> *By letting me know what they are doing and help me understand.*
>
> *By explaining the situation so, I can make decisions.*

Explain to me means to tell the meaning of or to tell how to do something. Explaining is making an explanation is making it clear for a phenomenon to be understood. In health care, many explanations are needed to clarify procedures, implications of laboratory results, effects and side effects of drugs, what to expect, signs of overdose and symptoms expected from the drugs. One of the chronic illnesses is cancer. Teaching is a big part of nursing. Adolescent children need to know about the side effects of chemo, the falling of the hair, the expected nausea and vomiting, and loss of appetite. Chronically ill adolescents indicated their need to be taught by explaining to them expected outcomes and consequences of treatment trajectories. If decisions have to be made, they want to have the chance to speak up. Thirteen percent indicated that nurses made it easier for them when the nurses explained took the time to explain to them about what is going on.

Ask Me to Make a Choice

> *Actually, they make it very simple because they ask me first.*
>
> *Makes me more aware of the fact that I have choices.*
>
> *By allowing me to give my honest opinion on who should make the opinion.*
>
> *I would like to have a choice as if I want something to get me out of float nurses.*

Ask me to make a choice means to inquire or to seek for the answer. Inquire from the chronically ill child if s/he wants to make a choice and decide. One of the rights of the child is the right to make a choice. (AAP, 1995). Adolescents regardless of their health condition, whether they are chronically ill or not, must have the chance to make a choice and decide based on their cognitive ability to make decisions. They assert that since the focus involves intrusion into their body, they need to have a part in the decisions, and choices made for their treatment trajectory. Their body suffers the consequences. Thus, 7% indicated that nurses made it easier for them by asking them to make a choice.

Helpful and Nice

> *The nurses helped me to feel good.*
>
> *The nurses are very nice. They helped me to feel good.*
>
> *All my nurses have made it easier in treatment decisions by being nice and*

helpful.

They help you along on the little things that you cannot do on your own.

Waiting makes more difficult. The nurses make it easier by helping doctors.

Nurse treated me well, made it easier in difficult times.

Nurses made it easier to where I can.

Nurses made it easier by making me laugh and being so nice.

Helpful and nice means giving help or service. Nice means thoughtful and kind. Putting these two together would mean giving a thoughtful service. Twelve percent of the perspectives indicated that the nurses made it easier for them by being helpful and nice. Having received a very thoughtful service gives them that good feeling in spite of their illness.

Honesty, Caring, and Reinforcement

All the nurses are very caring, smart and might I say some are beautiful! (Ha! Ha!

Ha!) They helped me a lot and I appreciate it. I will never forget what you people have done.

The nurse made it easier by treating me equally and letting me know important information.

Nurses made it easier for me because they give me advice.

She has made it easier by encouraging me and telling me what is going on.

By telling me the truth than lies. Not sugar coat things.

Reinforcement is the act of strengthening a learning behavior or response. Thirteen percent indicated that nurses made it easier for them because they encouraged them more on the positive side of the spectrum of care.

Involve me means being a part of, being included. It means having a part or a voice. Five percent indicated their perspective about how the nurses made it easier for them. When the nurses involved them, it made it easier for them to comply, cooperate, and cope with the intrusion of their illness in relation to the treatment plan.

Honest, truthful, respect, friendly, caring and treats me well. Being truthful and honest are synonymous. Having respect for someone is linked with a caring attitude that treats everybody well. Fourteen and two tenth percent indicated that when nurses are honest, truthful, respectful, caring, and wonderful to them, it makes it easier for them to cope with the intrusion of their illness.

Older and Float Nurses

> *I would like to have a choice as if I want something to get me out of float nurses.*
>
> *When I was little, I would like to have said something to get me out of float nurses.*
>
> *The old nurses really made it easier for me; they tell me what I need to tell the doctors when I come for the doctors' appointment.*

No float nurses, older nurses are nice. Most chronically ill adolescents had repeated hospitalizations within a year that allowed them to know the differences between the care given by a regular nurse on the unit who knows the routine and protocol and a float nurse who is lost and at a high risk to make mistakes. It turns out that the patient would even know more than the float nurse in relation to the treatment trajectory would. *Older nurses are nice*. This is incredible! It indicates here that with a long experience in nursing practice, older nurses present a more caring attitude that transcends the inner feelings of adolescents. Chronically ill adolescents perceive older nurses more competent than brand new ones, thus it makes them more confident that having a more experienced nurse will reinforce their autonomy and recognize their ability as adolescents to make good choices and decisions.

Major themes and sub themes emerged that shaped the core perspectives. The core perspectives defined achieving involvement in health treatment decision-making. The core perspective emerged from the chronically ill adolescent's needs category as, seeking for involvement, seeking for shared decision-making, and seeking for autonomy in health treatment decision-making. Table 29 presents the core perspectives and their dimensions.

A grounded theoretical framework based on methodological triangulation through comparisons of model variables and core perspectives, reflect a shift in paradigm for health policy as well as for health care practices in the planning and implementation of care for the chronically ill adolescents in relation to health treatment decision-making. Figure 29 in Chapter 5 shows the theoretical model.

Table 29

Major Themes and Sub Themes that Emerged from Chronically ill Adolescent's Responses

Core Perspective: Achieving Involvement in Health Treatment Decision Making

Seeking for Involvement
Seeking for shared decision-making
Seeking for Autonomy

Context	Conditions	Process	Outcome
Chronic Illness	**Patterns of Knowing**	**Having a voice for Oneself**	**Paradigm Shift in Health Policy & Health care Practice**
Self-confidence	Talk to me	Having choices	Self-actualization
Coping pattern	Being heard	Explain to me Talk to me	Involvement
Problem Solving	Being informed Being Involved	Listen to me	Involvement Involvement
Symptom severity	Being asked to make a choice	Asked to make a choice	Self-actualization
Preferences for Involvement	Both equally	Have a voice	Shared decision-making Involvement
Age Gender	Explain to me Talk to me	Autonomy Both equally	Self-actualization

CHAPTER 5

Discussion of Findings

Although the American Academy of Pediatrics (AAP, 1997) had made a great stride in the improvement of health care to children and adolescents including those with chronic illnesses, there is non-disclosure in health policy and health care protocol for chronically ill adolescents' involvement in health treatment decision-making. Living with uncertainty posed by the severity of their health condition, chronically ill adolescents have expressed a great desire to be involved in decisions made for their health and care in spite of the intrusion and ill effects of symptoms to their quality of life.

To unfold new knowledge for theory development and achieve an empiric understanding of chronically ill adolescents' perspectives in relation to involvement in health treatment decision-making, methodological triangulation explored the phenomenon. Figure 5.1 presents a theoretical framework for the involvement of chronically ill adolescents in health treatment decision-making. According to Breitmeyer, Ayres, and Knaft (1993), triangulation increases credibility and validity of results owing to convergence and corroboration of data (Duffy, 1987, Rossman and Wilson, 1985) as it elaborates and enriches the database and unfolds new dimensions and details about the phenomenon of interest (Morse, 1991).

Table 30 shows a comparison of model variables and the core perspectives from methodological triangulation that supported linkages unfolding credibility of research outcomes. The linkages revealed chronically ill adolescents' seeking for involvement in health treatment decision-making.

Table 30

Comparison of model variables and core perspectives for achieving involvement in health treatment decision-making

Model variables	Core perspectives	Linkages
Preferences for involvement, Both equally	Achieving for involvement	Having a voice for oneself, being heard, being involved, asked to make a choice, being informed.
Severity of symptoms	Seeking for involvement	Severity of symptoms, self-confidence and involvement
Age, gender and self-confidence	Seeking for autonomy and involvement	Asked to make a choice, asked to decide, having a voice
Problem solving Coping ability	Seeking for a shared decision-making	Having a voice and both equally Shared decision-making
Age and gender	Seeking for involvement	Parents, doctors, nurse, and adolescent Equal participation

Mitchell (1986) explained that combining results, each component is resolved if findings are interpreted within the context of present knowledge. A mixed method served as an informed thought processes that involved wisdom, creativity, judgment, and insight that could modify or create a theory.

Chronic Illness and Adolescence

The adult world perceives the decision-making capacity of adolescents based on the assumption that they lack the experience in terms of problem solving and decision-making skills thus posing them vulnerable to wrong decisions. Piaget's (1972) theory as confirmed by Weithorn and Campbell's (1982) empirical findings about adolescent decision-making explains that apart from inexperience, most individuals at age 14 years old and older show intellectual capacity to reason, deal with abstract ideas, generalize beyond experience, and predict potential consequences of actions. It simply means that the lack of experience does not make a chronically ill adolescent less competent in decision-making. As their exposures to varied experiences expand, they develop a contextual coping approaches to decision-making. In fact, Bibace and Walsh (1980) confirmed in their research findings that 42% of children 11 years old understand the physiologic basis of disease. Andrews, Ainley, and Frydenberg (2004) underpin that adolescents draw on their coping resources to deal with the demands that confront them. When adolescents learn adaptive coping skills, their self-confidence with problem solving enhances one's own capabilities in decision-making. Looking at all angles of the pros and cons, and wanting to have adequate information about their treatment trajectory, an inner voice emerged from the written responses of chronically ill adolescents. Their inner voice reflected a message that says, *yes,* we have the capacity to understand the physiological alterations happening in our lives, thus we deserve to have a voice in decision-making because we suffer the consequences of decisions affecting our health.

This implies a very powerful indication of their seeking for involvement in health treatment decision-making either in a shared decision-making with the doctors and with parents or *both equally.* The reality of their experiences of non-involvement when decisions were made for treatments options and decisions for acceptability of risks and benefits of treatment options made them more vigilant and cautious about what plans were designed for their treatment trajectory.

In spite of severity of symptoms posed by their chronic illnesses that preclude their feeling weak, nauseated, and anorexic, their desire for involvement in decisions for treatment options and acceptability of risks and benefits still emerged. In fact, findings show that their coping exceeds their problem solving confidence and self-confidence. This shows that suffering from the consequences of the intrusion of their chronic illness had made them learn to cope over time and does not stop them from seeking for involvement in health treatment decision-making.

Having a Voice for Oneself

Preferences for involvement among chronically ill adolescents in relation to their problem solving confidence were negatively correlated. It implies that the problem solving confidence of chronically ill adolescents had no influence on their preferences for involvement in health treatment decision-making. Their self-confidence in making decisions had no contribution either to their preferences for involvement in health treatment decision-making. However, when the same variables were explored quantitatively and qualitatively with the emphasis on *who decides treatment options*, and *who decides acceptability of risks and benefits* a meaningful theme evolved. Regardless of *age, gender*, and *diagnosis*, the chronically ill adolescents indicated *both equally* on variables *who decides treatment options,* and *who decides acceptability of risks and benefits*. *Both equally* emphasize their need to have a part when decisions were made for treatment options so they can have a voice if risks and benefits of treatment options were acceptable or not acceptable to them. It implies seeking for involvement in health treatment decision-making that emanates from their need to be heard, need to be informed, need to be involved, being asked to make a choice, and being left without parents' interference. It means having an equal share of insights from the doctors and the patient in relation to decisions made for treatment options and acceptability of risks and benefits.

The chronically ill adolescents did not really care about who would determine diagnosis or treatment options but made a clear view that whoever determines treatment options would decide treatment options with the chronically ill adolescent. Likewise, whoever determines treatment options would decide acceptability of risks and benefits with the chronically ill child. This stance evolves from ownership of this body that suffers from the consequences of treatment options. Their desire to be involved by indicating *both equally* pronounces a message of their capability as chronically ill adolescents to make judgments, and decisions based on their understanding of the consequences of their actions.

From the inscriptions, salient theme as *I like when people listen to me* gives a meaningful announcement of their need to be heard. They are saying, *listen to me because this is my body that feels the aches, pains and hurt so please listen to me, I understand what is going on can I have a voice.* These confirm the cognitive theorist's stance (Piaget) those adolescents' ages 14 years old and above are capable of making abstract reasoning and are capable of understanding the consequences of their actions. The body that suffers from the consequences of treatment options has the right to say *no* (Doig and Burgess, 2000) in relation to the risks and benefits of treatment options. On the other hand, the body that suffers from the benefits of treatment options has the right to say *yes* if the benefits exceed the risks.

Covert perspectives of chronically ill adolescents in relation to their treatment trajectory unfold seeking for autonomy. Their need to know and understand what is going to happen and what is going on with them were all implied in their written responses such as: *talk to me,* and explain *to me* as well as *ask me and I will figure it out.* Another indicator of their great desire to be autonomous was a statement *I would like to talk directly to the doctors and hear about the different options.* These statements gave an essence that these chronically ill adolescents want self-governance that prepares them to confront difficult decisions in the future. Seeking for involvement in health treatment decision-making emerged from both the inscriptions and numeric responses of chronically ill adolescents.

Patterns of Knowing

Chronically ill adolescents are unique in nature for sometimes they are stereotyped for being chronically ill. Irrespective of the stage of growth and development they are in, and the severity of their symptoms, their abilities and capabilities to learn follow patterns of knowing and learning. Belenky and colleague (1986) defined different types of knower as silent, received, subjective, procedural, and constructive. Chronically ill adolescents can be designated as subjective knower because they depend on their own inner voices and inner feelings. Knowledge is personal, private and subjectively known and intuited based on their experiences with their illness. It is an intuitive reaction from something experienced rather than actively pursued or constructed (Belenky, Clinchy, Goldbeger and Tarule, 1986). However, as they grow with their experience, they can become constructed knower who can view knowledge as contextual. They become creators of knowledge and value both subjective and objective strategies of knowing. They integrate the different ways of knowing and the different voices that make them a part in constructing the knowledge and become the intimate part of the known (Belenky, Clinchy, Goldbeger and Tarule, 1986). Just like what Carper (1978) had originally designed for nursing, as a fundamental pattern of knowing would lend to the specific responses such as *I want to know what is going on to harm me and the pros and cons of the problem*, which relatively explains the constructive knower. Carper introduced the aesthetic pattern of knowing that helps nurses understand unique and hidden experiences. Active knowing of perceptions through gathering of details, which would be beyond recognition, unfolds what is there (Holmes and Gregory, 1998).

Another inscription that gives an example of a constructive knower that would help health care practitioners and health policy makers recognize the voices of adolescents was *decisions and roadmaps should be better explained and run through me first.* Digging deeper into the inner thoughts of chronically ill adolescents create an image of the truth. One response said *I feel the doctors should diagnose the problem and provide me with reasonable options, pros and cons, and then ultimately make me decide which is best for me.* Britto, et al (2004*)* support these adolescent's views based on their findings on the adolescent preferences that information about their illness be directly given to them rather than to their parents. Seeking for involvement in health treatment decision-making involves patterns of knowing as a part of becoming a part of the known. The known in relation to chronically ill adolescents' preferences for involvement in health treatment decision-making unfolded seeking for involvement. This is the knowledge that emerged. Therefore, health care providers and health care policy makers need to become cognizant to the needs of these chronically adolescents to learn and grow as they become active participants in decision-making for their plan of care and treatment trajectories, and eventually become the sole decision-makers for themselves.

Paradigm Shift in Adolescent Health Care

Findings pose a great challenge to the health care arena for children and adolescents. Even though the self-confidence and the ability of the chronically ill child to solve problems do not influence directly their preferences for involvement in health treatment decision-making, they have indicated specifically a preference for involvement when decisions are made for their treatment options and for the acceptability of risks and benefits of treatment options. The numeric value from a quantitative inquiry *both equally* matched the theme that emerged from inscriptions written in the responses, *having a voice for oneself.* Recognizing the patterns of knowing among chronically ill adolescents allows health care providers provide a more empiric experience to chronically ill adolescents in their experience with having a chronic ailment by involving them in decision-making. Weir and Peter (1997) say that when adolescents are given an increasing recognition of their capacity to participate in decisions about their healthcare, parents and physicians have shown a greater willingness to include them. Having a part with decisions, make them feel that ownership while they go through the hurts and pains of the process but gives them that joy for having control over their treatment trajectory.

Grounding the preferences for involvement with the dominant theme of having a voice for oneself entails a shift in health care practice and a shift in health care policy for chronically ill children and adolescents. Stenekes (2005) found that even with family's capability of funding hospitalization, adolescents' preferences for decision-making with cancer did not change. Meaning these adolescents wanted an equal opportunity to have a voice for oneself. One important theme that emerged was the statement; *I would like to have a choice as if I want to get out of float nurses.* Similar statement says, *when I was little, I would like to have said something to get me out of float nurses.* These statements only show how sensitive these adolescents are in knowing who could give them the best care and who could possibly hurt them. In real world scenarios, patients do suffer because of the carelessness of health care providers.

A paradigm shift in health policy concerning the care of chronically ill adolescents needs to take place in relation to health treatment decision making, as there are more than 20 million children and adolescents inflicted with chronic illnesses. This means that there are children and adolescents out there who need to be proactive with the decisions for their treatment options and who would seek to decide acceptability of risks and benefits of treatment options before consenting for the treatment. The rate of survival among chronically ill children and adolescents has increased dramatically due to the inventions of new technology that had improved their quality of life. The voices from the chronically ill children hope to influence a shift in health policy for the care of children and adolescence. It also hopes to affect a shift in the practices of care or health care protocols for the chronically ill adolescents.

Health policy regulating involvement of chronically ill adolescents in health treatment decision-making that defines boundaries and scope of care provides a springboard for the improvement of health care approaches to the chronically ill adolescents. The involvement may mean shared decision-making or autonomous decision-making implying respect to the owner of that body inflicted by chronic illness. Successful achievement of involvement in health treatment decision-making whether shared decision-making, consultative, or autonomous, promotes self-actualization to the chronically ill child overtime.

When respect for autonomy, for involvement, and for having a voice for oneself exist in the health care arena, the success of treatment outweighs the risks and adverse consequences. It allows the adolescent child a chance to express his/her inner voice to make known what his/her body can and cannot accept in relation to risks and benefits of treatment options. This process develops the decision-making capacity of chronically ill adolescents into a more contextual approach, shaping their abstract reasoning by being involved in intelligently weighing pros and cons, thus giving them that feeling of self-actualization. Having them involved when decisions were made for treatment options as well as the risks and benefits, their experience allows a cognitive development with creation or construction of contextual decision- making approach overtime. Figure 29 reflects the theoretical model for chronically ill adolescents' achieving for involvement in health treatment decision-making.

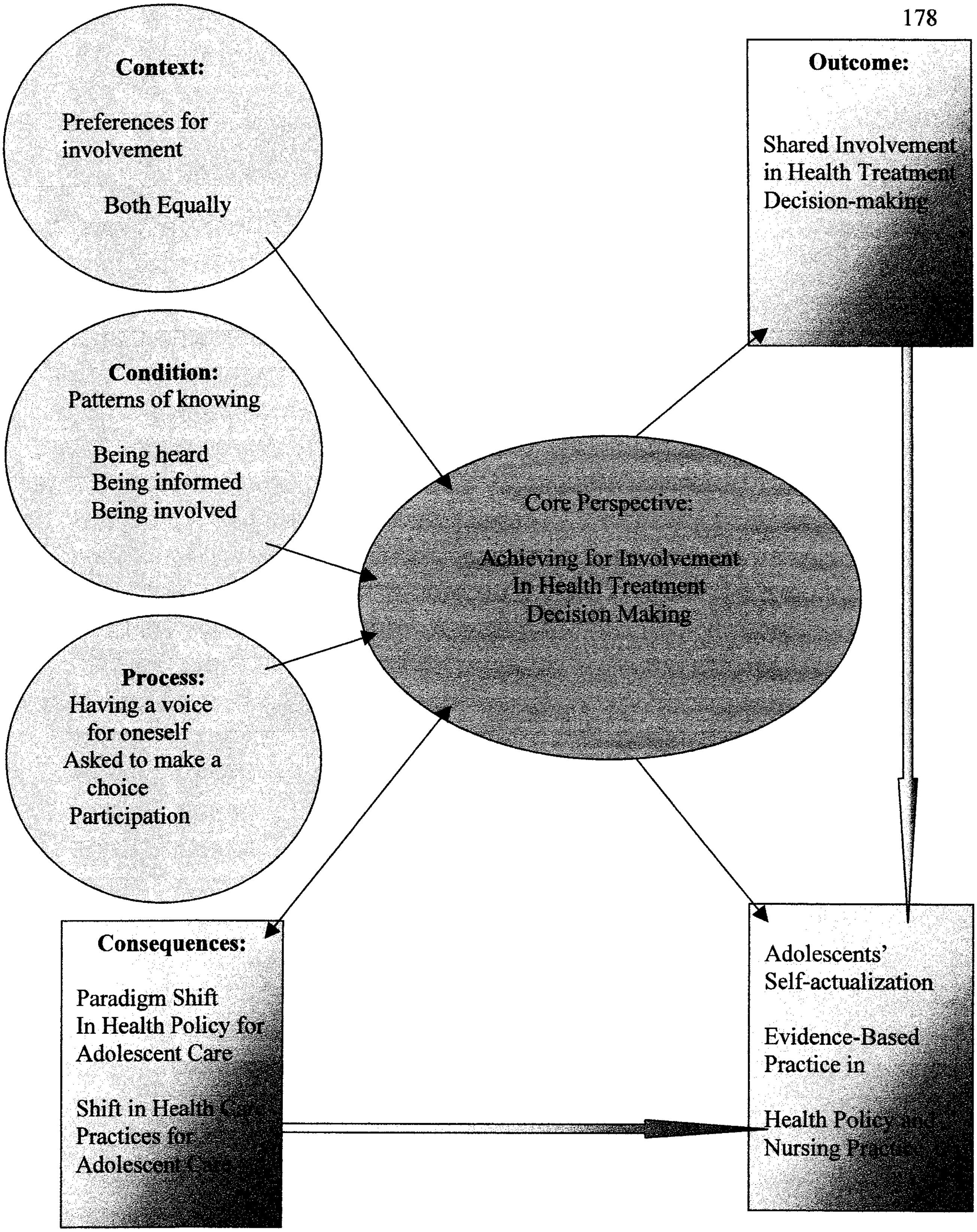

Figure 29. Achieving for Involvement in Health Treatment Decision Making

Summary

The linkages that unfolded from a triangulated process increased the understanding that chronically ill adolescents' self-confidence, problem solving confidence, and coping patterns do not influence their preferences for involvement in health treatment decision-making. However, it was evident that these chronically ill adolescents have developed strong coping ability to the stressors of their illnesses overtime to improve their quality of life. It also became transparent that age, gender, and diagnosis influence the self-confidence of chronically ill adolescents in relation to health treatment decision-making.

Chronically ill adolescents' preferences for involvement irrespective of their age, sex, and diagnosis revealed *both equally* as an indicator for their desire to be involved in decisions made for treatment options, and acceptability of risks and benefits. *Both equally* matched with results from a qualitative deductive approach for *being involved, being informed, and being heard.* Matching of results from a quant + qual inquiries reflected seeking for involvement as a core perspective for wanting to have a voice for oneself.

Seeking for involvement regardless of age, sex, diagnosis, and symptom severity emerged as a context of respondents' preferences for involvement in health treatment decision-making. Seeking for shared decision-making reflects respect and honor for educated and authoritative perspectives of doctors/nurses and parents while their inferior perspective becomes a part of the decision-making process. On the other hand, seeking for autonomy as a core perspective that emerged reflects an assertion of their capacity to make rationale decisions. Preferences for involvement emanated from the reality of their need to know the implications of treatments specifically for the risks and benefits of treatments. Their unique pattern of knowing means a journey to a better knowledge of their illness trajectory, and a meaningful experience with the remaining years of their life's journey.

The existence of a shared decision-making process for the chronically ill adolescents' treatment trajectory in turn would create a shift for health policy makers to regulate involvement of chronically ill adolescents in health treatment decisions. It would also serve as an impetus for a change in nursing policy to involve chronically ill adolescents in health treatment decision-making for evidence based nursing practice. Knowing the inner voice of chronically ill adolescents in relation to their desire for involvement in health treatment decision-making may make a difference in the care of children, adolescents and youth.

CHAPTER 6

Critique and Implications of the Study

A nursing research study no matter how carefully delineated it may be would always benefit from criticisms to further validate findings and create meaningful implications to nursing practice as well as in health policy. There are several considerations identified that may enrich this research of interest as it relates to evidence-based nursing practice.

Implications of the Study

Implications include a challenge to the health care providers and the health policy makers the need to listen to the inner voices of the adolescents and youth. Whether these adolescents and youth are ill or well, they are saying that they can make decisions like those that adults do. For an evidence-based practice, chronically ill adolescents expressed a strong desire to be involved in decisions made for their care regardless as to whether the process was autonomous or shared decision-making. All they cared about is being involved in the decision-making process. Their desire to come out from being passive participants and recipients of set decisions for them became transparent through their responses for seeking involvement in decisions made for their health and care. *Both equally* were indicators for their need to be involved in health treatment decision-making process. Their inner voices reveal their paramount desire for involvement when decisions are made for treatment options, and for the acceptability of risks and benefits of treatment options. This implies that these chronically ill adolescents have developed medical consciousness and understanding shaped by the processes of their experience with the physiological alterations and consequences of treatment options in managing their treatment trajectories.

How then can the health care system ignore the inner voices of these chronically ill adolescents? The reality is that they suffer the ill effects of treatments and procedures. Their sentiments reveal that their physiological and intellectual needs deserve sensitivity by the health care providers to support them move towards a meaningful experience and a better quality of life with their chronic illnesses. While in transition from young adulthood to becoming adults in the future, their early involvement reinforces the development of their critical thinking skills as they move towards becoming in-charge and independent decision makers for their treatment trajectories in the future. Their ability to contribute gives them that feeling of belonging, responsibility, and ownership of the outcome. Thus, their involvement contributes to their maturation process in relation to problem solving and decision-making.

From a qualitative standpoint, the chronically ill adolescents validated their numeric responses with their written responses unfolding core perspectives of seeking for involvement as described in the areas of patterns of knowing (being heard and informed), and having a voice for oneself. They are saying that their voices are significant for their health, survival, and quality of life. Having a voice is significant for their existence and self- actualization.

Being heard and informed is critical to making an informed decision. An informed decision is critical to making decisions for treatment options and/or plan of care, and critical to expected outcomes and consequences. To them, it means that a well-informed decision results to a better health care outcome and improved quality of life. To them, having a voice is asserting for oneself for the purpose of expressing inner thoughts and feelings, expressing fears and concerns, and making a dialogue for a better understanding of treatment plans, outcomes and consequences. This means that it is only then when their voices and the pros and cons were thoroughly deliberated that health treatment decisions become imperative.

What does this mean to health care providers, health care educators, and health care policy makers? This means that health policy needs to consider the significance of adolescent involvement in heath treatment decision-making. It also implies that health care providers need to recognize and respect the voices of adolescents and youth significant to their health and wellness. There would be a phenomenal difference in adolescent health care and a friendlier approach for adolescent care if they were allowed involvement. There would be a more competent and effective health care environment as well as a healthier community if adolescents and youth whether they were ill or well, were involved in health treatment decision-making. The health care system for the adolescents and youth would be more effective if health policy makers took action in regulating the early involvement of chronically ill adolescents in health treatment decision-making. Adolescent health care would be more efficient if healthcare educators included involvement of chronically ill adolescents in protocols as an important aspect of care for the adolescents.

What difference would it make if chronically ill adolescents were involved in health treatment decision-making upon their lives? Chronically ill adolescents' early involvement would give them a better insight about their problem and the alterations involved, and help them gain a better perspective about the significance of diagnostic tests, procedures and drugs in relation to their problems, and their compliance to treatment trajectories would be rewarding having that feeling of control and responsibility when involved. There would be increased effectiveness of treatment options. They develop independence in problem solving and decision-making, achieve self-actualization, and experience a better quality of life.

Findings in this study provide for evidence based practice for involvement of chronically ill adolescents in health treatment decisions in any health care setting like the clinics, hospitals, school health centers, community health centers, as well as in churches where adolescent decisions benefit church programs that can make a difference in the lives of the youth.

Critique of the Study

Limitations that may affect the validity of results emanate from the unequal number of participants in relation to age. There should have been a balance in number of respondents for each of the age groups to ensure validity of results on research question 3 about the differences in self-confidence among the older and younger chronically ill adolescents. The criteria included the disease entity regardless of age and gender representations. There should have been an equal representation based on gender to ensure validity of results on research question 4 about the differences in coping pattern and self-confidence among male and female chronically ill adolescents.

In addition, the presence of the parent while younger respondents filled up the survey questionnaires may have influenced a different response. Respondents with severe symptoms may have responded differently if they were feeling better, however, most of the respondents were on remission as ambulatory care patients. One-half should have increased sample size to 120 respondents to ensure solidity of results. There were only 29% of the respondents who spoke, read, and wrote in Spanish. The remaining seventy-one percent of the chronically ill participants read and spoke English at a 5th grade level.

Gaining Entry into the Study

With the New Privacy Act known as Health Insurance Portability Accountability Act (HIPAA) that implements strict confidentiality of information about patients and families in both ambulatory and acute care settings; the researcher had trouble gaining entry for the identification of participants. After passing through three different Institutional Review Boards, including the Nursing Research Council at Loma Linda University Medical Center, the involvement of the primary physicians opened the door for reaching out to the families and participants. The participation of the primary physicians facilitated willingness of families and respondents to participate and hastened the completion of data collection. Strict observance of HIPAA prevented any untoward reactions from families and from the chronically ill adolescents. The $25 gift was a source of inspiration for the participants having to save some money for CD player or savings in the bank.

Risk and Benefit Ratio

Chronic illness in itself is stressful enough to adolescents who are already vulnerable and at risk for making faulty decisions. However, they need an early understanding of their illness by involving them in decisions made for their care as they transition from childhood to adulthood. Their early involvement in decision-making prepares them cognitively, physically and emotionally to resolve more stressful health care issues in the future. This study strictly observed the regulations of HIPAA and PHI in the implementation of research and in safeguarding the data. Assents were obtained from participants and their parents signed consents.

The benefits for involving chronically ill adolescents in this study outweigh the risks. Their honesty in both study paradigms significantly would make a difference in clinical practice affecting their care. It would affect health policy to regulate adolescent involvement in health treatment decision-making.

Implications for Further Study

Arising from this current study, implications for further research unfold the need to expand the scope of this research and test the newly conceptualized theoretical framework. Testing the model generated in this study with greater sample size strengthens the validity and relevance of findings. The conduct of a purely qualitative inquiry for relevance and validity, and adding reflexivity as an equally important measure mirror the inner voice of chronically ill adolescents. For reflexivity, a qualitative research study on chronically ill adolescents' roles in health treatment decision-making may be necessary. There is a need to investigate chronically ill adolescents' involvement in health treatment decision-making using purely phenomenological research tradition through personal interviews, and tape-recorded verbatim responses that may unfold inner voices from inside out. This inquiry may shed more light into the meanings of chronically ill adolescents' need to be involved in decisions made for their health and care. Such study may warrant substantive basis for instrument development.

I see this research moving into a wider spectrum of curiosity in relation to the involvement of chronically ill adolescents in health treatment decision-making that would include all chronic illnesses among children and adolescents. Specifically looking at the role of adolescents in health treatment decision-making, and the extent of their involvement in future research may unfold results for evidence-based practice. Another area of exploration would be the factors that make chronically ill adolescents competent as participants in health treatment decision-making. Looking at the role of the physicians and nurses in making chronically ill adolescents participate in health treatment decision-making would also be an area of interest. Finally, it would also be helpful to examine the perspectives of parents in involving chronically ill adolescents in health treatment decision-making.

Dissemination of the Study

A research report was submitted to LLUMC-PI. It will be presented at the LLUMC nursing research council on January 09, 2006. A copy of the research report will be submitted for publication at the hospitals' journal. The researcher hopes to publish three articles from this research. Copies of this dissertation will be given to each of the physicians who had given their letters of support.

In 2003, a poster presentation was presented at the Sigma Theta Tau Nursing Honor Society. It won the second prize. In 2004, a presentation was done at the First Asia Pacific Adolescent Congress in Hong Kong. Another presentation was done in Akron Ohio, at the Children's Hospital in 2004. The researcher plans to present this study at the Sigma Theta Tau Nursing Honor Society in 2006.

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Appendix A

INSTRUMENTS

Participants' Demographic Data

1. Code ________________ 2. DOB ____________ 3. Age ________

4. Wt.__________ Kg. 5. Ht. __________inches

6. Gender: 1______Male
2______ Female

7. Ethnic Background
1______White
2______ Black
3______Hispanic
4______Asian/American
5______Pacific Islander
6______Others: Specify

8. School Attended
1______Public
2______Private
3______Home School
4______Tutor
5______Special School

9. Grade Level _________

10. Diagnosis

1________Asthma
2________Acute Lymphocytic Leukemia
3________Cystic Fibrosis
4________Sickle Cell Disease

(ADMQ) Adolescent Decision Making Questionnaire (ADMQ)

	1 Not at all	2 Sometimes true	3 Often true	4 Almost always true
Self- Confidence				
1. I feel confident about my ability to make decisions				
2. I am not as good as most people in making decisions				
3. I think that I am a good decision maker				
4. I feel so discouraged that I give up trying to make decisions				
5. The decisions I make turn out well				
6. It is easy for other people to convince me that their decision is the correct one				
Vigilance				
8. I take a lot of care before making my choice				
13. Once I had made a decision then I don't change my mind				
16. I like to think about a decision before I make it				
20. When I make a decision, I feel I made the best one possible.				
23. I like to make decision myself				
27. When I decide to do something. I get right on with it				
Panic				
11. I panic if I have to make decisions quickly				
18. I feel as if I am under tremendous time pressure when making decisions				
19. I can't think straight if I have to make a good decision in a hurry				
22. The possibility that some small thing might go wrong cause me to immediately change my mind about what I am going to do.				

	1 Not at all	2 Sometimes true	3 Often true	4 Almost always true
Evasiveness				
7. I avoid making decisions				
9. I put off making decisions				
12. I'd rather make someone else make a decisions for me so that it won't be my problem				
14. I prefer to leave decisions to others				
17. When I have to make a decision, I wait a long time before starting to think about it.				
10. When faced with decisions, I go along with what others suggest.				
15. Whenever I get upset by having to make a decision, I choose on the spur of the moment. 21. I put little into making decisions 24. When I am forced to make a decision, I could not care which way I choose.				
25. I choose based on some small thing.				
26. When making decisions, I tend to choose the first alternate that comes to mind.				
29. I tend to drift into decisions without thinking about them.				
30. I prefer to do what others choose because I do not want to be different.				

Problem Solving Inventory (PSI)

	1 Strongly agree	2 Mod. Agree	3 Fairly Agree	4 Fairly Disagree	5 Mod. Agree	6 Strongly Disagree
Problem Solving Confidence						
5. I an usually able to think up creative and effective alternate to solve problems						
10. I have the ability to solve most problems even though initially no solutions is immediately apparent						
11. Many problems I face are too complex for me to solve						
12. I make decisions and am happy with them later.						
19. When I make plans to solve a problem, I am almost certain that I cab make them work.						
23. Given enough time and effort, I believe I can solve most problems that may arise.						
24. When faced with a situation I have confidence that I can handle problems.						
27. I trust my ability to solve new and difficult problems.						
33. After making a decision, the outcome usually matches the expected outcome.						
34. When confronted with a problem, I am unsure whether I ca handle the situation.						
35. When I become aware of a problem, one of the first things I do is to find exactly what the problem is.						

	1 Strongly Agree	2 Mod. Agree	3 Fairly Agree	4 Fairly Disagree	5 Mod. Disagree	6 Strongly Disagree
Approach Avoidance						
1. When a solution to problem was unsuccessful, I do not examine why it did not work.						
2. When I am confronted with a complex problem, I do not bother to develop a strategy to collect information so I can define exactly what the problem is.						
4. After I have solved a problem, I do not analyze what went wrong or what went right.						
6. After I have solved a problem, with a certain course of action, I take time and compare the actual outcome to what I thought should have happened.						
7. When I have a problem. I think up as any as possible ways to handle it as I can until I can't come up with anymore ideas/						
8. When confronted with a problem, I consistently examine my feelings to find out what is going on in a problem situation.						
13. When confronted with a problem, I tend to do the first thing that I can think of to resolve it.						
15. When deciding on an idea or possible solution to a problem, I do not take time to consider the chances of each alternative being successful.						
17. I usually go with the first good idea that comes to my mind						
18. When making a decision, I weigh the consequences of each alternative and compare them against each other						

	1 Strongly Agree	2 Mod. Agree	3 Fairly agree	4 Fairly Disagree	5 Mod. Disagree	6 Strongly disagree
20. I try the overall result of carrying out a particular course of action.						
21. When I try to think up possible solutions to a problem, I do not come up with many alternatives.						
28. I have a systematic method of comparing alternatives and making decisions.						
30. When confronted with a problem, I do not usually examine what sort of external things my environment maybe contributing to my problem.						
When I am confused by a problem, one of the first things I do is survey the situation and considers all the relevant pieces of information.						
Personal Control						
3. When my first effort to solve a problem fails. I become uneasy about my ability to handle the situation.						
14. Sometimes I do not stop and take time to deal with my problems but just kind of muddle ahead.						
25. Even though I work on a problem, sometimes I feel like groping and wandering and am not getting down to the real issue.						
26. I make snap judgement and later regret them.						
32. Sometimes I get so charged up emotionally that I am unable to consider many ways of dealing with my problems.						

Coping Skills Inventory (CSI)

	1 Almost never	2 Rarely	3 Sometimes	4 Quite often	5 Most of the Time
1. I enjoy and accept expansions of warm feelings from others					
2. Having time for myself is important to me.					
3. I trust my judgement					
4. When I am stressed, my mind goes blank					
5. I have troubles controlling my impulsiveness					
6. I know where to find the information that I need.					
7. It's difficult to forget about my problems and worries and just have fun.					
8. When needed, I am able to accept support from others.					
9. I find myself in overwhelming situations.					
11. I like finding out about new things.					
11. I believe that there is a way out of every situation.					
12. When needed, I use objects for purposes other than those for which they are originally designed.					
13. I am able to apply what I have learned to new situations.					
14. When I am in trouble, It's hard to find someone to talk to					
15. I perceive other people's emotions					

	1 Almost never	2 Rarely	3 Sometimes	4 Quite Often	5 Most of the time
16. I am capable of developing strategy that would get me where I want to be.					
17. Before making a decision, I am able to foresee the outcome and possible consequences.					
18. I prefer being the observer rather than taking risk by initiating an action.					
19. I accept my mistakes and learn from them					
20. I get easily discouraged					
21. When the situation changes, I adjust my plans.					
22. I am able to mobilize the physical, emotional, and mental energy I need to accomplish task.					
23. I react inappropriately when iI am caught by surprise.					
24. I take time to relax					
25. It's difficult for me to find the appropriate response in a given situation					
25. I set goals that I am able to achieve					
26. I prefer routine to being surprised					
27. When I fail, I am devastated.					
29. When I have problems, I prefer to keep them to myself					
30. I hate changing environment (moving, school/ job)					

Deber-Kraetschmer Problem Solving Decision Making Scale (DK-PSDM)

	1 The doctor alone	2 Mostly the doctor	3 Both equally	4 Mostly me	5 Me alone
1. Who should determine diagnosis?					
2. Who should determine what treatment options are?					
3. Who should determine what the risks and benefits are to happen?					
4. Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?					
5. Given all the information about risks and benefits of the possible treatments, who should decide which treatment options should be selected?					

Closed ended question:

How much experience have you had with the clinical situation described in the above scenario?

a. I have had personal experience with it
b. I know of family member s or close friends who have experienced it
c. I have read about it
d. I do not know much about it

Qualitative Questions

Open – ended questions

1. How would you like to be involved in decisions made for your care?

2. How has the nurse made it easier or more difficult for you to participate in health treatment decision-making.

Memorial Symptom Assessment Scale (MSAS 10-18)

Section 1

Instructions: If you had the symptoms during the past week, circle ***YES,*** If you circled ***YES***, let me know how often you had it, how severe and how much it bothered you by putting a check mark on 1, 2, 3, 4, and 5…Circle ***NO*** if you never had any symptom.

During the Past week, did you any of the following?

	1 A little bit	2 Sometimes	3 Quite a bit	4 Almost always	5 Very much
1. Cough *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it distress you or bother you?					
2. Feeling of being nervous *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother you?					
3. Dry mouth *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother or distress you?					
4. Nausea or feeling of throwing up *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother or distress you?					
5. Numbness/ Tingling *NO* *YES* *If yes* How often did you have it? How severe usually? How much did it bother or distress you?					

	A little bit	2 Sometimes	3 Quite a	4 Almost always	5 Very
6. Difficulty Sleeping *NO* *YES* *If yes* How often did you have it? How severe was it usually How much did it bother or distress you?					
7. Problems with Urination *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother you?					
8. Shortness of breath *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother or distress you?					
9. Loose Bowel Movement *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother or distress you?					
10. Feeling of Sadness *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother or distress you?					
11. Sweats *NO* *YES* *If yes* How often did you have it? How much did it bother you?					
12. Worrying *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did bit bother or distress you?					

	1 A little bit	2 Somewhat	3 Quite a bit	4 Almost always	5 Very Much
13. Itching *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother you?					
14. Lack of appetite *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother or distress you?					
15. Dizziness *NO* *YES* *If yes* How often did you have it? How severe was it usually? How much did it bother you?					
16. Difficulty Swallowing *NO* *YES* How often did you have it? How severe was it usually? How much did it bother you or distress you?					
17. Feeling of being irritable *NO* *YES* How often did you have it? How severe was it usually? How much did it bother you?					

Section 2

If you have had the symptom, circle *YES* and put a check mark under 1, 2, 3, 4, or 5 to tell me how bad the symptom you are feeling. If *NO symptom,* circle *NO.*

During the week, did you any of the following?

	1 A little bit	2 Somewhat	3 Quite a bit	4 Almost always	5 Very much
1. Mouth sores *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					
2. Changes in food taste *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					
3. Weight loss *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					
4. Hair loss *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					
5. Constipation *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					
6. Swelling of arms and legs *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					
7. I don't look like myself *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					

	1 A little bit	2 Somewhat	3 Quite a bit	4 Almost always	5 Very much
8. Changes in skin *NO* *YES* *If yes* How severe was it usually? How much did it bother or distress you?					

INSTRUMENTOS

Datos Demograficos de Participantes

1. Codigo ____________________ 2. Fecha de Nacimiento ____________________

3. Edad _____________ 4. Peso _________Kg. 5. Estatura _________ pulgadas

6. Genero: 1________Masculino

2 ________Femenino

7. Origen:

1_________Blanco

2 ________Negro

3 ________Asiatico

5 ________Isleno del Pacifico

6 ________Especificar Otro

8. Escuela Asistida:

1 _______Publica

2 ______Privada/ particular

3 ______Instructor privado

4 ______Esculea espesyal

9. Nivel de grado __________

10. Diagnosta: 1_________Asmatico 3 ____________Sibrosis quistica

2 ________ Leucemia aguda 4 _________Enfermidad de las celulas

Cuestionario de las Decisiones que Toman los Adolescentes

	Nunca	Alguna vez	Muchas veces	Siempre
Confianza en sí mismo				
1. Me siento seguro en mi abilidad de tomar decisiones.				
2. No soy tan bueno como muchas personas en tomar decisiones.				
3. Yo pienso que tomo buenas decisiones.				
4. Me siento muy desanimado que dejo de tratar de tomar decisiones.				
5. Las decisiones que tomo salen bien.				
6. Es muy fácil de que otras personas me convensan que la decisión que ellos toman es la correcta.				
Vigilancia				
8. Tomo mucho cuidado antes de tomar una decisión.				
13. Una vez que he tomado una decisión ya no cambio de opinión.				
16 Me gusta pensar antes de tomar una decisión.				
20. Cuando tomo una decisión siento que he tomado la mejor posible.				
23. Me gusta tomar decisiones por mí mismo.				
27. Cuando decido hacer algo comienzo inmediatamente.				
Pánico				
11. Me da terror si tengo que tomar decisiones rápidas.				
18. Siento estar bajo tremenda presión de tiempo cuando trato de tomar una decisión.				
19. No puedo pensar claramente si tengo que tomar una decisión a la ligera.				
22. La posibilidad que alguna cosa pequeña pueda salir mal, hace que inmediatamente cambie de opinión en lo que voy hacer.				

	Nunca	Alguna vez	Muchas veces	Siempre
Evasividad				
7. Yo evito tomar decisiones.				
9. Yo retraso el tener que tomar decisiones.				
12. Yo prefiero que alguien más tome una decisión por mi para que no sea mi problema.				
14. Yo prefiero dejar las decisiones a otros.				
17. Cuando tengo que tomar una decisión, espero un buen tiempo antes de comenzar a pensar en que voy hacer.				
10. Cuando tengo que tomar una decisión, yo voy con lo que sugieren otros.				
15. Cuando me molesto porque tengo que tomar una decisión, tomo una por impulso en ese momento.				
21. Pongo un poquito de esfuerzo en tomar decisiones.				
24. Cuando me fuerzan a tomar una decisión, no me importa lo que decido.				
25. Yo tomo decisiones en base de cosas pequeñas.				
26. Tengo la tendencia de dejarme arrastrar en decisiones sin pensar en ellas.				
29. Cuando tomo decisiones, me dejo llevar y escojo la primera alternativa que se viene a mi mente.				
30. Yo prefiero hacer lo mismo que otros hacen para no ser diferente.				

Inventario Para Resolver Problemas

	Totalmente de Acuerdo	De Acuerdo	Un Poco De Acuerdo	Un Poco en Desacuerdo	En Desacuerdo	Totalmente Desacuerdo
Confidencia en resolver problemas						
5. Usualmente puedo pensar en alternativas creativas y efectivas para resolver problemas.						
10. Tengo la abilidad de resolver la mayoría de los problemas aun cuando inicialmente ninguna solución es aparante.						
11. Muchos de los problemas que enfrento son muy complicados para que yo los resuelva.						
12. Tomo decisiones y estoy contento con ellas después.						
19. Cuando hago planes para resolver un problema , estoy casi seguro que va a funcionar.						
23. Dado suficiente tiempo y esfuerzo, yo creo que puedo resolver la mayoría de los problemas que pueden resultar.						
24. Tengo la confianza que puedo manejar los problemas al enfrentar una situación.						
27. Confío en mi abilidad de resolver problemas nuevos y difíciles.						

	Totalmente de Acuerdo	De Acuerdo	Un Poco De Acuerdo	Un Poco en Desacuerdo	En Desacuerdo	Totalmente Desacuerdo
33. Después de tomar una decisión el resultado usualmente es igual a lo esperado.						
34. Cuando confronto un problema no estoy tan seguro de poder enfrentar la situación.						
35. Cuando me doy cuenta de un problema, una de las cosas que primero hago es tratar de saber exactamente que es el problema.						
Evitar Aproximación						
1. Cuando la solución de un problema no es éxitoso, yo no examino la razón porque no funcionó.						
2. Cuando enfrento un problema complicado, no me molesto en desarrollar una estrategia para reunir información que pueda definir exactamente que es el problema.						
4. Después de resolver un problema, no analizo que salió bien o que salió mal.						
6. Después de haber resuelto un problema de alguna manera, tomo tiempo y comparo el resultado actual con lo que pensé que pasaría.						
7. Cuando tengo un problema, pienso en muchas formas posibles para solucionarlo hasta que no se me ocurra algo más.						
8. Al enfrentar un problema examino constantemente mis sentimientos para saber que esta pasando en ese problema.						

	Totalmente de Acuerdo	De Acuerdo	Un Poco De Acuerdo	Un Poco en Desacuerdo	En Desacuerdo	Totalmente Desacuerdo
13. Cuando enfrento un problema tengo la tendencia de hacer lo primero que se me ocurra para resolverlo.						
15. Cuando pienso en una idea o solución para resolver un problema, no tomo tiempo para pensar en cada una de las alternativas que funcione éxitosamente.						
16. Cuando enfrento un problema paro y pienso antes de decider el siguiente paso.						
17. Generalmente voy con la primera buena idea que se me ocurre.						
18. Cuando tomo una decisión evaluo las consecuencias de cada alternativa y las comparo.						
20. Trato de predecir el resultado total si llevara a cabo una acción particular.						
21. No se me ocurren muchas alternativas cuando trato de solucionar algún problema.						
28. Tengo un método sistemático para comparar alternativas y tomar decisiones.						
30. Cuando enfrento un problema generalmente no examino que tipo de cosas externas en mi medio ambiente pueden estar contribuyendo a mi problema.						
31. Cuando estoy confundido por un problema, una de las cosas que primero hago es estudiar la situación y considerar todas las piesas de información relevantes.						

	Totalmente de Acuerdo	De Acuerdo	Un Poco De Acuerdo	Un Poco en Desacuerdo	En Desacuerdo	Totalmente Desacuerdo
Control Personal						
3. Me siento intranquilo en mi abilidad de controlar situaciones cuando mi primer esfuerzo de resolver un problema fracaza.						
14. De vez en cuando no paro para tomar tiempo y resolver mis problemas y solo me confundo mas adelante.						
25. Aunque trabaje en un problema, muchas veces siento estar confundido y nunca llegar al fondo del verdadero problema.						
26. Hago decisiones a la ligera de las cuales me lamento después.						
32. Algunas veces me emociono demaciado que no puedo considerar muchas formas de tratar con mis problemas.						

Inventorio de Abilidad para Adaptarse

	Nunca	Casi Nunca	Algunas Veces	A Menudo	Siempre
1. Disfruto y acepto los buenos sentimientos de otros.					
2. Es muy importante para mi tener tiempo para mí mismo.					
3. Mi mente se pone en blanco cuando estoy tenso.					
4. Confio en mi opinión/juicio.					
5. Tengo problemas controlando mi impulsivilidad.					
6. Yo sé donde encontrar la información que necesite.					
7. Es muy difícil olvidarme de mis problemas/preocupaciones y solo divertirme.					
8. Cuando lo necesito puedo aceptar el apoyo de los demás.					
9. Me descubro en situaciones arrolladoras y abrumadas.					
10. Me encanta aprender acerca de cosas nuevas.					
11. Creo que toda situación tiene una salida/solución.					
12. Cuando lo necesito uso cosas que no fuerón creadas originalmente para esos propositos.					
13. Tengo la abilidad de aplicar en situaciones nuevas lo que he aprendido antes.					
14. Cuando estoy en problemas es dificíl encontrar a alguien con quién hablar.					
15. Yo persibo las emociones de otras personas.					
16. Yo soy capaz de desarrollar una estrategia que me ayude a llegar donde quiera estar.					
17. Antes de tomar una decisión puedo ver el resultado y las posibles consecuencias.					
18. Prefiero ser el observador a tomar un riesgo si tomo la iniciativa.					
19. Acepto mis errores y apriendo de ellos.					
20. Me desanimo fácilmente.					
21. Ajusto mis planes cuando la situación cambia.					
22. Cuando necesito lograr una meta tengo la abilidad de movilizar mi energía mental, física y emocional.					

	Nunca	Casi Nunca	Algunas Veces	A Menudo	Siempre
23. Reacciono inapropiadamente cuando soy sorprendido.					
24. Tomo tiempo para relajarme.					
25. Es difícil para mi de encontrar la respuesta apropiada dada una situación.					
26. Me pongo metas que puedo lograr.					
27. Prefiero la rutina a ser sorprendido.					
28. Cuando fracaso me pongo triste.					
29. Cuando tengo problemas prefiero guardarmelos y no decirle a nadie.					
30. Odio el cambio de ambiente (moverme, escuela/trabajo)					
31. Encuentro difícil aprender cosas nuevas.					
32. Endiendo lo que otros esperan de mí.					
33. Cuando algo que yo quería no funciona me repongo rápido.					
34. Otras personas ven las relaciones entre cosas o situaciones que yo no puedo ver.					
35. Me siento libre para divertirme.					
36. En una situación dada reacciono de las misma manera no importa las circunstancias.					
37. Yo disfruto las diversiones activas (afuera, deportes, lectura)					
38. Confío en otros para tomar decisiones y resolver mis problemas.					
39. Tengo la abilidad de comunicar todos mis problemas.					
40. Para resolver un problema muy importante hago una lista de estrategias y escojo la que mejor parece.					
41. Detesto compromisos.					
42. Uso mi abilidad mental a lo máximo.					
43. Cuando una situación requiere un cambio de plan o estrategia me confundo.					
44. En caso de nuevos desarrollos o avances estoy dispuesto a cambiar de opinión.					
45. Encuentro razones para sonreir.					

Deber-Kraetschmer Escala de Decisiones Para Resolver Problemas

	Solamente el Doctor	Casi Siempre el Doctor	Los Dos Igualmente	Casi Siempre Yo	Solamente Yo
1. ¿Quién tiene que determinar (diagnósticar) lo que causa tus problemas?					
2. ¿Quién tiene que determinar que son las opciones de tratamiento?					
3. ¿Quién tiene que determinar los riesgos y beneficios que pueden pasar?					
4. Dados los riesgos y beneficios de estos posibles tratamientos, ¿quién tiene que decidir que tan aceptables son estos riesgos y beneficios para ti?					
5. Dada toda la información de los riesgos y beneficios de los posibles tratamientos, ¿quién tiene que decidir cual tratamiento es elegido?					

¿Cuanta experiencia has tenido con la situación clínica descrita en los casos previos?
(Por favor circula todas las letras que apliquen)

a. Lo he vivido personalmente .
b. Yo se de miembros de mí familia o amigos cercanos quién han vivido eso.
c. He leido acerca de eso.
d. No se mucho acerca de eso.

Preguntas Importantes:

1. ¿Cómo te gustaría participar en decisiones para tu cuidado?

2. ¿Cómo la enfermera ha hecho fácil o más difícil tu participación en decisiones acerca de tratamientos de salud?

Evaluación de Síntomas de la Memoria (10-18)

Parte 1

Instrucciones: Si has tenido el síntoma durante la última semana, circula *SI. Si circulas SI,* dejame saber que tan seguido lo has tenido, que tan severo y cuánto te molestó poniendo una marca en 1, 2, 3, 4, y 5... Circula *NO si nunca has tenido ningun síntoma...*

Durante la última, ¿Tuviste algo de lo siguiente?

	Un Poquito	Más o Menos	A Menudo	Casi Siempre	Siempre
1. Dificultad concentrandote NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Dolor NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Falta de Energía NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Tos NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					

	Un Poquito	Más o Menos	A Menudo	Casi Siempre	Siempre
1.Sentirse Nervioso NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Boca Seca NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Náusea o Ganas de Vomitar NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Cansancio NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Entumecimiento/Hormigueo NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Dificultad Durmiendo NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					

	Un Poquito	Más o Menos	A Menudo	Casi Siempre	Siempre
1. Problemas Orinando NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Dificultad Respirando NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Intestino Flojo NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Tristeza NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Sudar NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Preocupaciones NO SI *Si, SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					

	Un Poquito	Más o Menos	A Menudo	Casi Siempre	Siempre
1. Picazón NO SI *Si. SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Perdida de Apetito NO SI *Si. SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Mareos NO SI *Si. SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Dificultad Tragando NO SI *Si. SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
1. Irritabilidad NO SI *Si. SI* ¿Qué tan seguido? ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					

Parte 2:

Si has tenido el síntoma, circula *SI* poniendo una marca en el 1, 2, 3, 4, o 5, para decirme que tan mal es el síntoma que sientes. *Si no hay síntoma* circula *NO.*

Durante la última semana, ¿Tuviste algo de lo siguiente?

	Un Poquito	Más o Menos	A Menudo	Casi Siempre	Siempre
2. Inflamación en la Boca NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
2. Cambio en el Sabor de la Comida NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
2. Perdida de Peso NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
2. Perdida de Cabello NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
2. Estreñimiento NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
2. Hinchazón de los brazos y piernas NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					

	Un Poquito	Más o Menos	A Menudo	Casi Siempre	Siempre
2. No paresco yo mismo NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					
2. Cambio en la Piel NO SI *Si, SI* ¿Qué tan severo usualmente? ¿Qué tanto te molestó o te afligío?					