8-1-1993

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Recommended Citation

Benoit, Catherine, "Perspectives Of Primary Health Care Needs By Chronically Ill Adolescents And Their Parents" (1993). *MSN Research Projects*. 175.
https://athenacommons.muw.edu/msn-projects/175

PERSPECTIVES OF PRIMARY HEALTH CARE NEEDS BY CHRONICALLY ILL ADOLESCENTS AND THEIR PARENTS

by

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A Thesis
Submitted in partial fulfillment of the requirements
for the Degree of Master of Science in Nursing
in the Division of Nursing
Mississippi University for Women

COLUMBUS, MISSISSIPPI

AUGUST, 1993

Perspectives of Primary Health Care Needs by Chronically Ill Adolescents and Their Parents

by

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Abstract

This current descriptive correlational study is a replication of Dragone's (1990) research. Three null hypotheses guided this current study. Ho_1: There is no significant difference in degree of agreement between perceptions of the top five primary health care needs identified by chronically ill adolescents and their parents. Ho_2: There is no difference in degree of agreement of perceptions of primary health care needs among early, middle, and late age groups of chronically ill adolescents. Ho_3: There is no difference in use of health care professionals as resources between parents and chronically ill adolescents. Orlando's Nursing Process Theory (1961) provided a framework for this replication study. A 60-item comprehensive Primary Health Care Needs Assessment was utilized to address issues related to health promotion, illness management, and developmental issues. Agreement between perceptions of specific age groups and between parent and adolescent groups were analyzed. Utilization of health care professionals as resources also was investigated. Adolescents were persons in the age range of 11-19 years, and the parents were primary caretakers to the adolescents. The setting was a major medical center in a southeastern state. A 20-paired sample ($\underline{N}$ = 20) of convenience was accessed and personally interviewed on site in specialty outpatient clinics which included diabetes, pulmonology, rheumatology, hematology, and oncology. Informed consent was obtained from parent and adolescent subjects. Data on the primary health care perspectives were analyzed through descriptive statistics and chi-square analysis. Adolescents identified sociopersonal and behavioral adaptative issues as their primary health care needs. There was a 76% degree of agreement on concerns between parent and adolescent groups. Chi-square analysis indicated a difference in agreement regarding physical concerns between specific age groups of adolescents at .05 level of significance. Descriptive statistics indicated that parents were the resources utilized most frequently by both groups. This research supports Dragone's (1990) original study and the need for further studies on the perceptions of chronically ill adolescents and their parents. It further suggests the study of other influential variables on perceptions in chronically ill adolescents, such as ethnicity, economics, and education. Finally, this research suggests several avenues for study in the role of the nurse in chronic illness affecting adolescent populations.

Dedication

Keep me from the wisdom that does not
weep, and the philosophy that does not
laugh, and the pride that does not bow
its head before a child.

--Kahlil Gibran

This work is primarily dedicated to my children, Chanda and Anthony, and to my brother, Poppy.

Chanda and Anthony, your courage, strength, and resilience have become my own. Thanks for your love and patience. You are truly the wind beneath my wings.

Poppy, you taught us about living in life and in death. Thank you. This accomplishment is ours.

Finally, this work is dedicated to all of those who dedicate their lives to the care of chronically ill children and families. You have been entrusted with the care of a very special garden; and because of you it continues to grow.

Acknowledgments

I wish to thank God for the many blessings which have permitted me to complete this task. Only because of these blessings was this work possible.

I further express my gratitude to my committee members, Lynn Chilton, Dr. Nancy Hill, and Dr. Sheila Adams, for their assistance and guidance. A special thanks to Lynn Chilton, my committee chairperson for her time and efforts. Further appreciation is extended to Dr. Mary Pat Curtis for her expert advice.

I wish to acknowledge the great support of my family and close friends. Without their dedication and love, this program nor this research would have been possible. Your presence and support have been the greatest blessings that God has granted to me.

I must express my profound appreciation to Sigma Theta Tau, Zeta Rho Chapter, for partial support and funding for the conduction of this research.

Sincere appreciation is extended to the staff members of the Medical Center who assisted in this research effort. You have my deepest respect and admiration.

Finally, I am extremely grateful to the adolescents and parents who participated in this study. I see your eyes, and I hear your hearts.

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Chapter I

The Research Problem

Advances in medical technology have altered health care delivery and the populations served. Illnesses which were once considered terminal are now classified as chronic. Hence, health care professionals are called on to define characteristics of populations affected with chronic illness and to assess their specific needs. From this population emerges a unique group of chronically ill adolescents with distinct health care perspectives and needs. A number of issues are presented to the primary care provider of the adolescent client, such as various developmental characteristics of the adolescent client and the influence of parents or caregivers. In order to assess the needs of this population, the prevalence and impact of chronic illness in the adolescent must be recognized.

Establishment of the Problem

Research has documented dramatic changes in incidence and prevalence of childhood illnesses during this century (Newacheck & Taylor, 1992). While infectious diseases have been greatly reduced and somewhat controlled, chronic diseases have been either eradicated as with polio, or prolonged as with leukemia. Studies of chronic illness in children indicated 10 to 20% of the national pediatric population was affected with chronic illness in 1984 (Gortmaker & Sappenfield, 1984). In 1992, 31% of children under 18 years of age were reported to have one or more chronic illness conditions (National Center for Health Statistics, 1990). Although studies have indicated an increase in chronic illness (Gortmaker & Sappenfield, 1984), establishing prevalence is elusive since the health care community has no definite standard by which to measure chronic illness. Due to this lack or standardized, systematic categorization, the definition and incidence of chronic illness will vary.

Reduced mortality rates and increased rates of chronic illness in pediatric populations have direct implications for the prevalence of chronic illness seen in adolescent populations. In effect, as pediatric populations with chronic illness increase, adolescent populations with chronic illness will also increase (Gortmaker & Sappenfield, 1984). Historically, adolescent populations have been underserved regarding age-specific health care sensitivity and interventions (Bearinger, Wildey, Gephart, & Blum, 1992; Cohen, 1982). Recent research has investigated and documented health care perceptions and behaviors in adolescents with chronic illness (Dragone, 1990).

Adolescence is a period of marked development which requires mastering major tasks in identity and self-concept

(Garrison & McQuiston, 1990). Chronic illness may intensify existing stress as well as increase stressors in this already turbulent period. Establishment of independence is a developmental task which may be impeded by the illness condition. Ultimately the adolescent may choose the acting out behavior of noncompliance as a means of asserting independence (Coupey & Cohn, 1984). Peer conformity, self-image, and psychosocial issues will have significant influence on the adolescent's health care attitudes and perceptions. Parents and health care professionals must be aware of the adolescent's perceptions in order to assess and meet the client's needs.

The pilot study conducted by Dragone (1990) was replicated in this present research. Dragone noted the increasing number of adolescents with chronic illness and their unique needs and perspectives on primary health care. Adolescents generally seek health care with parents, and parental views on health care issues may inevitably influence the adolescent's general health care. In addition, it is noted that often health care professionals focus primarily on the needs and perspectives of the parents, as opposed to those of the adolescent. In order to assess the needs and perspectives of both adolescents and their parents, a study of the primary health care concerns and perspectives of both groups was necessary.

Significance to Nursing

Although nurse practitioners traditionally have been involved in primary care to chronically ill young children and their families (Ford, 1992), this has not been the case with adolescent populations. Research has indicated that nurses generally identify a need for more comprehensive education and preparation to adequately serve the adolescent population. Bearinger et al. (1992) found that nurses who routinely worked with adolescents felt they were inadequately prepared for the care of adolescents and often avoided this population due to these feelings of inadequacy. In case work with chronically ill adolescents, Whyte (1992) also cited the need for appropriate educational preparation of nurses. Generic nursing education provides only a foundation for basic nursing skills and does not provide the specialized training to adequately assess and meet the complex needs of chronically ill adolescents. Therefore, this research presents a guide for teaching developmentally appropriate nursing care of chronically ill adolescents, based on the perceptions of these adolescents. By understanding this population, nurses may impart this knowledge of adolescent care in both generic and advanced preparation of nurses.

In order to facilitate education, research must continue to support current knowledge and expand upon that knowledge base. Garrison and McQuiston (1990) noted that of the professional health care providers, nurses have consistently been in the foreground of health care for acutely and chronically ill adolescents, and nursing literature contains the earliest documentation of clinically oriented writings about this population. This research expands on previous research to enhance knowledge of a growing population of chronically ill adolescents. Through replication of existing studies, knowledge is expanded and refined. This knowledge promotes nursing science and continues to contribute to client care through other health care disciplines.

Nursing practice is directly affected by implications of this research. By understanding the self-identified perspectives of primary health care concerns of chronically ill adolescents, nurses may identify potential and actual problems specific to this population. In understanding the age-specific concerns of early, middle, and late adolescents, nurses may implement developmentally appropriate health care interventions on their behalf. Likewise, parental views may directly influence adolescent health care and should be taken into consideration when care is assessed, implemented, and evaluated.

Conceptual Framework

Orlando's Model of Nursing Process Theory promotes a framework for practice which advocates the nurse to assess the client's cues, validate the nurse's and client's perceptions, and plan immediate interventions based on these perceptions. This theory utilizes the nurse-patient relationship as an active instrument contributing to the care of the client. Orlando (1961) based her model on the nurse's ability to avoid making assumptions based on his or her general nursing so that the nurse is able to freely interpret the client's specific needs in the immediate situation.

The client experiences stress due to unmet needs. Often health care providers quickly assume meanings to both verbal and nonverbal cues from clients and proceed to implement interventions to meet those assumed needs. However, the perceptions of the nurse do not necessarily reflect the intent of the client. In order to accurately assess the client's needs, the nurse must reflect his or her interpretation of the situation back to the client. The client can then validate or correct the nurse's interpretation, and appropriate interventions can be implemented.

Orlando (1972) describes nursing as an autonomous profession warranting independent interactions and interventions. A basic concept is nursing care dictates, "The function of professional nursing in conceptualized as finding out and meeting the patient's immediate needs for help" (Orlando, 1972, p. 20). Therefore, nursing process is based on the interactions between (a) the patient's behavior, (b) the nurse's reaction, and (c) the nursing actions which are designed for the patient's benefit. The nursing goal is to relieve the client's stress due to unmet needs and ultimately cause improvement or change in behavior. The nurse's reaction is founded on thoughtful assessment of the given situation instead of an automatic response.

The client's and nurse's perceptions constitute the basis for the nursing process (Marriner-Tomey, 1989). Initially, the client's behavior indicates a need to relieve stress. The nurse then clarifies this perception. In this study of chronically ill adolescents, it is necessary to ascertain the perceptions and meanings of the subjects' behaviors. By expressing his or her feelings or perceptions relevant to the adolescent's behavior, the nurse ensures correct assessment and interventions on their behalf. This is especially important with chronically ill adolescents, since adolescence is a period in which abstract thinking is just beginning to develop.

Dragone's (1990) study of health care concerns of chronically ill adolescents and their parents was a direct application of Orlando's Nursing Process Theory. Traditionally, issues which may reflect concerns of health care professionals or adults with chronic illness are assumed to be those of adolescent populations with chronic illness. Adolescent responses to stress may be mistakenly attributed to factors which are consistent with adult populations.

According to Orlando's theory, this assumption represents the concept of nurse's perceptions. However, in assessing an adolescent's self-identified concerns through a developmentally appropriate tool, the nurse attains clarification of the adolescent's perceptions and related behaviors. This represents the second stage of the nursing process. Parent's perceptions are also clarified in order that the nurse may determine needs and implement appropriate interventions. The degree of agreement or conflict in perspectives on primary health care needs is significant in the nursing assessment, as these concepts will have a direct influence on the client's stress. Finally, through validation and clarification, the nurse is able to identify and implement interventions to meet specific needs of the adolescent client. Outcome is evaluated through observation of the client's behavior which indicates relief or persistence of the client's stress. Only through the nurse-client interaction is the nurse able to be effective as the care provider and client advocate.

Assumptions

This study of primary health care concerns of chronically ill adolescents and their parents is based on the following assumptions:

1. Chronically ill adolescents are cognitively aware and capable of identifying primary health care needs.

2. Parents' and health care professionals' perceptions of adolescents' primary health care needs influence health care which is rendered.

3. The nurse's perceptions of primary health care needs are not necessarily those of the client.

Purpose of the Study

Research into the needs of chronically ill adolescents is limited, and replication of existing studies (Dragone, 1990) is necessary to support theories of current adolescent care. The purpose of this study, in replicating Dragone (1990), is to describe the self-identified primary health care needs of specific age groups of chronically ill adolescents and their parents, the degree of agreement between these populations, and the resources of health care professionals which they utilize.

Hypotheses

The following hypotheses are tested in this study:

Ho_1: There is no difference in degree of agreement between perceptions of the top five primary health care needs identified by chronically ill adolescents and their parents.

Ho_2: There is no difference in degree of agreement of perceptions of primary health care needs between early, middle, and late age groups of chronically ill adolescents.

Ho_3: There is no difference in use of health care professionals as resources between parents and their chronically ill adolescents.

Ha_1: Parents utilize health care professionals as resources more often than chronically ill adolescents to help meet identified primary health care needs.

Definition of Terms

For the purpose of this study, the following terms have been defined:

Degree of agreement: Degree is defined as intensity, extent, or amount. Agreement is defined as agreeing, or to be in harmony with (Guralnik, 1971). Therefore, degree of agreement is the extent of harmony between two or more parties. In this study, degree of agreement will be determined through an item-by-item agreement index between primary health care concerns of parents and chronically ill adolescents as identified by the Primary Health Care Needs Assessment (PHCNA) (see Appendices A and B).

Perceptions: Perception is defined as the elaboration of a sensory impression: the ideational association modifying, defining, and usually completing the primary impression or stimulus (Thomas, 1989). In this study, perception is defined as an awareness of conscious interpretations of an individual's thoughts or feelings relevant to the individual's primary health care concerns. Perceptions will be defined as items which are identified on the PHCNA.

Primary health care is basic or general health care provided through initial contact and ongoing care with a health care system (Thomas, 1989). In this study, primary care is defined as basic or general health care specific to the client's needs.

Health care needs are a client's general concerns, needs, or deficits which serve as a basis for nursing care rendered (Rorden, 1987). In this study, health care needs are those items identified by the PHCNA as areas of health care needs by chronically ill adolescents and their parents.

Chronically ill: Mattson (1972) defined individuals who are chronically ill as those with a disorder that has a protracted course which can be progressive and fatal or associated with a relatively normal life span despite impaired physical and mental functioning. In this study, chronically ill adolescents are defined as adolescents with illness ranging in duration from 3 months to 18 years and will include diabetes mellitus, cancer, sickle cell anemia, systemic lupus erythematous, asthma, cystic fibrosis, and congenital heart disease.

Adolescent: Thomas (1989) defines an adolescent as a young man or woman not fully grown. In this study, adolescents are identified as persons ranging in ages from 11 to 19 years.

Early adolescent: Whaley and Wong (1991) define early adolescents as young people ranging in ages from 11 to 14 years who cast off childhood through rapidly accelerating growth and the exploration of the new self. In this study, an early adolescent is a person between the ages of 11 and 13 years.

Middle adolescent: Whaley and Wong (1991) define middle adolescents as young people ranging in ages from 14 to 17 years who belong to an adolescent subculture and begin to find their places in the larger community. In this study, a middle adolescent is a person between the ages of 14 and 16 years.

Late adolescent: Whaley and Wong (1991) define late adolescents as young people ranging in ages from 17 to 20 years, who crystallize their identities and become adults. In this study, a late adolescent is a person between the ages of 17 and 19 years.

Parent: Thomas (1989) defines parent as a father or mother. In this study, parent is defined as a father, mother, or primary caretaker to the adolescent client. Parents/caretakers are those persons who actually live with the adolescent client and participate in the adolescent's care.

Health (care) professional: Health is defined as physical and mental well-being, freedom from disease, while provider is identified as the individual who makes available supplies or furnishes health care (Guralnik, 1971). Therefore, health care professional is a health care provider involved in delivering care which promotes physical, emotional, and mental well-being in clients. In this study, health care professionals are the resource persons identified as doctor, nurse, or social worker on the PHCNA.

Summary

As technology continues to offer new avenues of treatment to old illnesses, implications of increasing needs escalate with increasing numbers of survivors of chronic illnesses. Children who were once victims of disease mortality are now living to become part of an adolescent population with chronic illness. In the past, this adolescent population has traditionally been grouped with adults or children with chronic illness. However, current trends recognize the uniqueness of this population and promote age and developmentally sensitive methods in caring for this group.

Knowledge of adolescent care is continuously expanding, yet knowledge of chronically ill adolescents is limited. Nurses are aware of the increasing numbers of this group, but have limited education in and preparation for chronically ill adolescent care. Nurses have identified a need for comprehensive training in health care for adolescents in order to meet current needs as well as to anticipate and provide ongoing care.

Orlando's Nursing Process Theory (1961) advocates the nurse-client interaction as an effective instrument in providing client care. Through the Nursing Process Theory, the nurse will recognize his/her own perceptions of the client's concerns and then have the client validate these perceptions by asserting his/her concerns or perceptions. Once these perceptions have been validated, the nurse can implement interventions to provide the client with appropriate care.

This study, which replicated Dragone's (1990) study on perceptions of health care concerns by chronically ill adolescents and their parents, describes those perceptions of these populations as identified on the PHCNA. The degree of agreement between age groups was identified. Finally, the resources most utilized in meeting primary health care needs were identified by all groups.

Chapter II

Review of the Literature

Research on health concerns of healthy adolescents is continuously expanding, but there is very little research documented on health care concerns of chronically ill adolescents. Primary health care concerns of healthy adolescents are being shown to differ from traditional views by health care professionals, parents, and caretakers. A review of the literature described the self-identified perspectives of health care concerns of healthy and chronically ill adolescents as well as those of parents and caretakers.

Perspectives of Health Care Needs by Chronically Ill Adolescents and Their Parents

Dragone (1990) studied the health care concerns of chronically ill adolescents and their parents. Dragone noted that health care providers must assess the specific needs of this population with recognition of their unique characteristics. Adolescents traditionally have been clustered with general pediatric populations, and specific developmental issues have not been recognized. Furthermore, adolescent populations generally seek health care accompanied by parents, which implies the assessment and directed care of more than one client when serving the adolescent client.

This descriptive, correlational study was conducted in specialty clinics of a western university's medical center. A nonprobability sampling of 24 adolescent-parent pairs was interviewed on-site and in the client's home. The adolescent sample consisted of 14 females and 10 males, with a mean age of 15.4 years. Early adolescents were aged 11-13 years. Middle adolescents were aged 14-16 years. Late adolescents were aged 17-19 years. Chronic illnesses included in the study were asthma, end stage renal disease, spina bifida, juvenile rheumatoid arthritis, diabetes mellitus, congenital heart disease, seizures, dystonia, and lupus erythematous. Duration of the illnesses ranged from 1 to 18 years.

The parent sample consisted of 22 mothers and 2 fathers with an average age of 44.7 years. Most parents were married (63%) and working full-time (55%). Of all participating parents, 91% had completed high school, and the majority had completed at least 3 years of college (51%).

The Primary Health Care Needs Assessment (PHCNA), a 60-item questionnaire authored by Dragone, was administered to the parent and adolescent on clinic visits (40%) or at arranged home visits (60%). Adolescent and parent pairs were separated, and the questionnaires were administered individually in separate rooms. Subjects were not allowed to discuss test items or responses in order to enhance validity in the answers. The researcher was available throughout the interview to answer questions for the participants. Items on the instrument addressed health promotion, illness management, and developmental issues congruent with adolescent primary health care needs.

Ranking was utilized to establish respondents' priorities in health care and resources utilized for meeting primary health care needs. Content validity was established with adolescent care experts, and reliability was established at 88% by the test-retest method.

An item was considered prevalent in health concerns if at least 33% of the sample had chosen it, and if 33% of the sample that identified it as a concern also ranked the item as one of their top five concerns. The PHCNA was administered to parent and adolescent pairs. Degree of agreement between parents and adolescents was then determined by an item-by-item index. Resources utilized by subjects were also identified by ranking according to the participant's preferences.

There was no statistical significance in primary health care needs prevalent in specific groups of illnesses. However, primary health care needs which were identified indicated significant trends related to age groups of adolescents. Generally, identified health care needs seemed to focus more on behavioral issues, such as school performance and boredom instead of physical symptoms such as headaches.

Of the three adolescent age groups, early adolescents (11-13 years) were more concerned with physical symptomatology, middle adolescents (14-16 years) were more concerned about the future and sociopersonal issues, while late adolescents (17-19 years) were more concerned with future plans, depression, and adjustment. Late adolescent groups identified more extensive primary health care needs than early or middle age groups. Late adolescents identified depression as a primary care need in 7 out of 10 instances for the total group, and reported symptomatology that may be associated with depression such as fatigue, boredom, and sleep disturbances.

Parents identified primary health concerns similarly to the adolescents. In fact, adolescents and parents indicated a 76% agreement rate on health care concerns. Dragone (1990) suggested the close degree of agreement may have been indicative of the high educational level of parents or the closeness that developed between the parent/adolescent pair as a result of the family's coping with chronic illness. One item of the PHCNA did reflect a marked difference between the pairs. Sexual intercourse was identified as a perceived concern by 25% of the adolescent population and by 0% of the parent population. Resources identified by all groups focused on physicians and parents. Nurses were rarely utilized by either group.

Dragone's (1990) study implied that the prevalence of boredom and fatigue in early and middle adolescents with chronic illness may indicate early signs of depression, which was more directly identified in the late adolescent group. Late adolescents strongly indicated their most prevalent concerns were related to the impact of their illness on daily living and future plans. Dragone (1990) recommended that, while the nurse may utilize these findings as a guide for primary health concerns, recognition of the adolescent's risk for depression enhances holistic care for the client's physical, mental, and psychosocial needs.

Furthermore, although there was a high degree of agreement between parents and adolescents, nurses should not rely on parental reports to assess adolescent care needs. In Dragone's (1990) study, parents were unaware of at least one major risk-taking behavior in their adolescent children. Finally, the study indicated that 21% of these adolescents did not have a primary health care provider outside the specialty clinic.

Dragone (1990) noted the pilot study was limited due to small sample size. Statistical differences between chronic illness groups was not feasible due to the sample size. Dragone (1990) also noted that the use of a nonprobability sampling exposed the study to bias from a potentially unrepresentative sampling.

In this current replication study of Dragone's (1990) research, the setting was a major medical center in a rural southern state. While the population in Dragone's (1990) study was predominantly caucasian and exhibited a higher level of education, the population in this current study was of varied ethnic origins and exhibited a lower level of education. Parent and adolescent pairs were accessed solely in the outpatient clinic setting, which was a contrast to the home testing administered by Dragone (1990). The questionnaire used in this study was the same instrument authored by Dragone (1990). However, the demographic and resource utilization information sheets were modified to a shorter version for the purpose of this study.

Perspectives of Health Care Needs of Healthy Adolescents

A study on health concerns of healthy adolescents by Duchen-Smith, Turner, and Jacobsen (1987) recognized the singularity of adolescents as a population, thereby ascertaining their unique needs. The researchers sought to identify health care concerns specific to this group. A theoretical framework was not identified.

The random sample consisted of 149 ninth-grade students from a middle-sized community in the West. Independent variables were age and sex. Ages ranged from 14-16 years. The sample consisted of 75 males and 76 females.

The tool was a 45-item, self-administered questionnaire which covered a range of health concerns, such as physical functions, appearances, mental health, social/sexual concerns, and interpersonal relationships. Subjects were asked to identify items which concerned them, and then to rank the items according to priority. Results were calculated with chi-square analysis.

Results in the Duchen-Smith (1987) study implied that while adolescent girls' primary concerns focused on their weight and hair, adolescent boys focused on their future and weight, respectively. Collectively, predominant health concerns inclined to those of a social-personal nature and physical appearance concerns. Younger teenagers seemed to have health concerns which were influenced by gender and background, as opposed to more traditional concerns of health care professionals.

While Duchen-Smith et al.'s (1987) study focused on primary health care concerns of healthy adolescents, this current replication study focused on the primary health care concerns of chronically ill adolescents. Duchen-Smith et al.'s study elicited a large random sample of healthy adolescents ranging from age 14 to 16 years. This age group corresponded with the middle-age group identified in the current study. Although the instruments used in the separate studies were different, both used the same structural format and focused on a variety of primary health care concerns faced by adolescents. Although several variables differed between the Duchen-Smith et al. (1987) study and the current research, the significant difference between the studies is the health status of the adolescent subjects.

Another research study by Baker (1991) looked at the self-identified primary health care concerns of healthy adolescents with a focus on early, middle and late age grouping. Baker (1991) cited the developmental transitions characteristic to early, middle and late age adolescent populations and the effects of those transitions on their individual needs.

The rhetorical framework for Baker's (1991) study was Modeling and Role-Modeling by Erickson, Tomlin, and Swain with contributions from Maslow's Theory of Basic Needs Satisfaction and Erickson's Theory of Growth and Development. The theory contains two major components. Modeling is the nurse's reflection of a situation from the client's viewpoint, as well as investigation of the client's model which is based on the client's perceptions of his/her past. Role-modeling is the planning and implementation of nursing interventions determined individually for each client. The concept of modeling and role-modeling allowed the nurse to enter and assess an adolescent client's world and help him/her to meet perceived needs.

The study by Baker (1991) was of a univariate descriptive research design. The setting for the study was a middle school and a high school in a rural southern state. A convenience sample of 25 to 30 students from Grades 6, 9, and 12 was selected by the school principals to access early, middle, and late adolescent age groups. Early adolescents were identified as aged 11 to 12 years; middle adolescents were identified as aged 14 to 15 years; and late adolescents were identified as aged 17 to 18 years.

The instrument utilized in Baker's (1991) study was the Adolescent Health Questionnaire developed by Duchen-Smith et al. (1987) which consisted of 44 possible health concerns ranked in order of importance. Adolescents first selected items of most concern to him/her and then prioritized these concerns on a scale of 1 to 5. One was indicative of the most important item, and 5 was indicative of the least important item. Percentages were used to report the five most prevalent health concerns of each group of adolescents.

Of the early adolescent age group, 69% identified weight as most significant health concern by males and females. Weight was followed by relationships, self-concept, and nervousness. Both sexes identified concerns for the future as the last of their top-ranked health concerns. Sources for health information for this group were doctors, parents, and school nurses, respectively.

In the middle adolescent age group, personal appearance was cited as the primary concern of both sexes (82%). Personal appearance was followed by weight, future, emotions, and physical functions. Physical functions ranked last in concerns by females, while emotions ranked last by males. Sources for health information for this group were doctors, parents, family, friends, and teachers, respectively.

In the late adolescent age group, the future was cited as the primary concern of both sexes (57%). Personal appearance and weight ranked second and third. Emotions were ranked last by males, while relationships were ranked last by females. Sources for health information for this group were doctors, mothers, agency, and brothers.

Baker's (1991) study suggested that although each age group determined different priorities of concerns, the three age groups of early, middle, and late adolescents held similar concerns in health care issues. These concerns were not in agreement with current concerns considered to be important by health care providers, such as drugs, pregnancy, and venereal disease. Although early adolescents prioritized weight, middle adolescents prioritized personal appearance, and late adolescents prioritized the future as health concerns, all groups identified relationships with others, self-concept, emotions, and nervousness as concerns. All three groups identified doctors, mothers, and fathers as persons selected to provide health information.

Additionally, Baker (1991) cited the difference in perceptions of health care concerns by healthy adolescents and health care providers. Baker (1991) noted the need for continued research into adolescent's perceptions to compare with other adolescent populations of varying backgrounds and to the parents/caretakers of healthy adolescents. The investigation suggested that data from this research could offer insight into the perceptions and needs of adolescents and could serve as a guideline to nurses in establishing developmentally sensitive nursing care interventions.

The study by Baker (1991) focused on primary health care concerns of healthy adolescents of varying ages. The current research differed in that it focused on the primary health care concerns of chronically ill adolescents of varying ages. While Baker (1991) accessed adolescent populations through schools in a rural state, this current research accessed adolescent populations through a major medical center in a rural southern state. Baker's (1991) study differed from the current research in the health status of the populations being studied.

A comparison of the studies found in the literature that focused on perspectives of health care needs of healthy adolescents revealed various similarities. The findings of

Baker's (1991) study on health care concerns of middle-aged healthy adolescents were similar to the findings of Duchen-Smith et al.'s (1987) study on health care concerns of middle-aged adolescents. Collectively, health concerns were inclined to be those of a sociopersonal nature, physical nature, and of physical appearance, although male and female subjects prioritized concerns differently. The concerns of this adolescent group, physical and sociopersonal, reflect some of the health care concerns of the corresponding middle-age adolescent group in Dragone's (1990) study.

A comparison of the studies in the literature concerning perspectives of health care needs of healthy adolescents and chronically ill adolescents revealed various similarities as well as some differences. Dragone's (1990) study of chronically ill adolescents, like Baker's (1991) study of healthy adolescents, focused on the health care concerns of the three age groups of adolescence. Early-aged adolescents of Dragone's (1990) study identified issues of physical symptomatology, while the early-aged adolescents of Baker's (1991) study identified weight as a primary concern.

Middle-aged adolescents with chronic illness studied by Dragone (1990) identified concerns of the future and sociopersonal issues. Healthy middle-aged adolescents of Baker's (1990) study identified physical appearance and sociopersonal issues as health care issues. This trend was also noted in the middle-aged adolescents of Duchen-Smith et al.'s (1987) study.

Late adolescents of Dragone's (1990) study identified concerns of future plans, depression, and adjustment while the late adolescents of Baker's (1991) study focused on concerns related to the future. The chronically ill adolescent population of Dragone's (1990) study showed increased evidence of risk for depression as compared to the healthy adolescents in Baker (1991).

A comparison of studies on healthy and chronically ill adolescents indicated that although chronically ill adolescents shared some health care concerns with their healthy counterparts, they also expressed a unique perspective of needs which were inherent to this population. A correlation of the studies also supported that there were differences in health care perspectives identified by the three age groups of adolescence.

Dragone (1990), Duchen-Smith et al. (1987), and Baker (1991) submitted similar implications for continued nursing research. They recommended that health care providers must be aware of these youths' perceptions and be able to use this information in forming plans of care to meet their needs. They further suggested that support and expansion of this recent knowledge could only be attained through replication of existing studies and formation of additional research.

Perspectives of Health Care Needs by Parents and Caretakers

Few studies have been identified in the literature that deal with perspectives of health care needs of adolescents as identified by parents and caretakers. While healthy adolescents may view health issues on a personal scale, parents may present a more global view of adolescent health care issues based on traditional medical health care beliefs. A study of parents' views of adolescents' health issues by Fisher (1992) investigated the importance perceived by parents of adolescent health issues and the involvement they would like from schools and physicians in adolescent health care.

Fisher (1992) cited comparison studies which indicated that adolescents of various socioeconomic backgrounds reported significant unmet health care needs. Many pediatricians and physicians surveyed indicated discomfort in providing comprehensive health care to adolescents, especially in those areas which represented greatest concerns to them. These health care professionals disclosed concerns related to the parent's approval of comprehensive care in areas such as contraception, substance abuse, or pregnancy. Fisher noted that although literature reviewed parents' and adolescents' opinions of current issues, there was no research documenting parents' identified concerns of adolescent health care issues. Therefore, the purpose of this study was to determine the importance parents perceived of adolescent health issues and what kind of involvement they desired from physicians and schools.

The nonprobability sampling of 1,090 families was chosen from two public high schools in a suburban community outside New York City. The adolescents were in Grades 9 through 12. Mailing lists were obtained from the participating school districts, and subjects were selected by obtaining every other name from the list. Either parent or caregiver was requested to complete the questionnaire with the eldest adolescent child in school to be used as the reference subject.

Of the 1,090 families contacted, 438 parents participated in the study (40% response rate). Adolescents were 14 through 18 years of age, with a mean age of 16.2 years. There were slightly more males than females in the adolescent group. Ninety-three percent of the adolescents received private medical care, 70% received care from a pediatrician, and 92% of parents reported that their adolescent child visited the doctor at least once a year.

The questionnaire was composed of three sections. The first section addressed demographics, health care information about the adolescent, and whether the parent believed the adolescent participated in the health risk behaviors involving areas of substance abuse, sexuality, or mental health. The second section sought information regarding the parent's behavior on the same issues, both currently and as an adolescent. The final section asked the parent to respond either yes or no to 20 questions regarding 13 specific health issues. These 13 issues were elicited from areas of (a) substance abuse, (b) sexually-related concerns, (c) mental health issues, (d) general medical concerns, and (e) nutritional issues. The questions attempted to identify areas of concern to parents, communication of these concerns to adolescents, the knowledge they believed that their children had on these issues, and education and involvement they desired from physicians and schools.

All questions were coded and keypunched for computer tabulation and chi-square analysis. Mean responses were calculated for the questions in each of the content domains. Results of this study indicated parental concerns for adolescent health issues and receptivity to assistance from professionals in areas of adolescent care.

In Fisher's (1992) study, parents were questioned about the health risk behaviors they believed their adolescents practiced, the health risk behaviors in which the parents participated when they were adolescents, and the health risk behaviors they participated in as adults. In areas of substance abuse, sexually-related activities and mild overweightness, parents consistently rated adolescents as having lower activities of involvement than the parent had as an adolescent with the same issues, despite the fact that substantial percentages of these parents continued to participate in the activities as adults.

The questionnaire addressed parental concerns for adolescent issues on a local and national scale. Substance abuse was identified as a primary concern on a national level by 92% of the parents. Sexuality-related issues were ranked as a nationally important issue by 85% of the parents while nutritional concerns were identified by 74% and general medical issues by 64%.

Fisher (1992) found that parents felt local implications of these concerns were less important than on the national level. Although substance abuse was still considered an issue of primary importance by parents, only 87% of the adults identified it as important on a local level as compared to 92% citing its importance on a national level. While 85% noted sexually-related concerns on a national level, only 63% considered this an important issue locally.

Fourteen to 19% reported that their adolescents required attention for nutritional, general, medical, and mental health problems. Only 8 to 10% said their adolescents required attention for substance use or sexually-related issues. More than 20% said they would be interested in having their adolescent receive help for any of these issues, although they did not specify what kind of help they would desire.

More than 95% of the parents indicated that parents should discuss health issues with adolescents, and more than 80% believed their teenagers had as much knowledge as most teenagers on these topics. Parents indicated that they felt these issues should be discussed in schools. Substance abuse and sexuality-related topics were supported by 90% of the parents for school discussion.

Fisher (1992) addressed parental perspectives on medical management in adolescent care. Approximately 75% of parents indicated the following:

1. They would take their adolescents to their regular doctors for care related to these issues.
2. Their physicians would feel comfortable managing these issues.
3. Their physicians should routinely discuss these issues.
4. These discussions should take place before age 14.

This study indicated that parents of adolescents are concerned about behavioral and psychosocial issues as well as physical concerns. Parents indicated that they would like help from schools and physicians in management of these issues. Parents also indicated they desired physician management in adolescent health, although they did not want physician/adolescent confidentiality or higher fees which may occur with longer time mandates.

Fisher's (1992) study focused on health care issues of healthy adolescents as perceived by their parents. There are substantial differences between Fisher's (1992) study and the current study with parents of chronically ill adolescents. While Fisher's (1992) study addressed perspectives of health care needs by parents of healthy adolescents, the current study addressed perspectives of health care needs by parents of chronically ill adolescents. Furthermore, Fisher's (1992) study consisted of yes, no, and unsure forced choice answers to questions specifically focused on traditional areas of health concerns. The questionnaire used in this current study of chronically ill adolescents and their parents presented a self-identification format which allowed respondents to identify areas of primary concerns and to rank their importance. Thus, the very format of the questionnaire changed the focus from those concerns as identified by the health care professionals to the concerns as identified and prioritized by the clients.

The populations accessed by Fisher (1992) were predominantly Caucasians from a suburban community. A majority of the respondents were well educated, and more than half reported an annual income greater than $50,000. The populations accessed in the current research were of diverse ethnicity, less educated, of poor socioeconomic status, and lived in areas ranging throughout a rural southern state. Therefore, the adolescent/parent pairs varied in education and socioeconomic background.

While research on adolescents with chronic illness is limited, there is documentation of perceptions of health care needs of chronically ill adults and their caregivers. In a descriptive study by Hileman and Lackey (1990), self-identified needs were addressed by patients with cancer and their caregivers. Chronic illness was often treated in the home with family caregivers serving as health care providers. This study was conducted in order to identify this population's needs.

The sample consisted of 15 clients with cancer and their caregivers randomly selected through a nonprofit agency. Clients were age 18 or older and had been diagnosed for a minimum of 3 months. Subjects were given two object content tests which reflected the subjects' views and what they perceived to be their counterparts' views. The 505 needs statements were computer Q-sorted into a set of need categories by oncology nurse researchers and oncology clinical nurse specialists.

In the Hileman and Lackey (1990) study, client's primary identified needs were psychological, physical, and informational. Primary caregivers' needs were listed as psychological, informational, and household. Of all needs identified by all subjects, 41.98% referred to a need for social ties with families or friends. While identified needs were congruent between clients and caregivers, they were not identical in content or degree of agreement.

Hileman and Lackey (1990) focused on health care issues of chronically ill adults as perceived by the adults and their caregivers. This concept differed from the current study regarding the variable of age, since the current research focused on the self-identified needs of chronically ill adolescents and their parent/caregivers. The instruments of Hileman and Lackey's study allowed clients and caregivers to describe their health care needs in open-ended questions which were then Q-sorted by various experts. The current research utilized a questionnaire which listed various health care items from which the respondents chose appropriate statements which reflected their perceptions. Both studies focused on the needs as assessed by the client's perceptions instead of the traditional perceptions held by health care professionals.

A comparison of the research studies identified in the literature that focused on parent/caregiver's health care concerns revealed several differences. Specifically, there were differences between the parent/caregivers' concerns for healthy and chronically ill adolescents, and between the parent/caregivers' concerns for chronically ill adolescents and chronically ill adults.

While parents of healthy adolescents in Fisher's (1992) study focused on areas of traditional health concerns such as substance abuse and sexuality-related issues, parents of chronically ill adolescents in Dragone's study concentrated more on behavioral issues such as school performance, boredom, and future concerns. The parents in Fisher's (1992) study tended to underestimate their teenager's behaviors. In Dragone's study , a 76% agreement rate existed between parents and teenagers on health concerns. There was a marked difference in the focus of primary health care concerns identified by parents of healthy adolescents and the primary health care concerns identified by parents of chronically ill adolescents. A comparison of these studies may have implied that like the parents of chronically ill adolescents, parents of healthy adolescents perceived health care needs for adolescents which are unique and different from their counterparts.

Fisher (1992) investigated utilization of schools and physicians as resources, while Dragone (1990) investigated health care professionals and personal support systems as resources. Both studies implied a receptivity to possible resources in health care issues by parents. Both of these studies indicated an absence of utilization of nurses as resources in an area for which nursing applications are well-suited.

Although health care views by parents in Fisher's (1992) study were not directly correlated with the views of their teenagers, a difference in parents' perceptions and actual prevalence of health care issues in adolescents was substantiated by statistical analysis of community characteristics. The significance of these findings may have been related to the design of the studies or to a closer relationship experienced between caregivers and chronically ill individuals.

A comparison of caregivers' health care concerns for chronically ill adults in Hileman and Lackey's (1990) study and parent/caregivers' health care concerns for chronically ill adolescents in Dragone's (1990) study indicated a close association in the assessments of needs by the caregiver and the chronically ill individual. However, the health care concerns of the two age groups differed. While the adults cited in Hileman and Lackey's (1990) study identified psychological and informational needs as being significant, the adolescents in Dragone's (1990) study focused on behavioral issues such as a school performance and boredom. These findings support the level of congruency noted between perceptions of chronically ill individuals and their caregivers as well as the individuality of the chronically ill groups as related to age.

Adolescents and adults in studies by Dragone (1990), Fisher (1992), and Hileman and Lackey (1990) indicated utilization of physicians and parents/caregivers as primary resources for meeting health care needs. This may have indicated a perception of physicians being considered the primary health care provider, or it may have reflected structure of the research designs.

Dragone (1990), Fisher (1992), and Hileman and Lackey (1990) have noted the limitations of current research into the needs of adolescent clients, chronically ill clients, and caregivers to these populations. Each researcher proposed continuing research into the needs of these clients and the replication of existing studies to support or disclaim the findings of current research.

Summary

This current study replicated Dragone's (1990) study to identify perceptions of primary health care issues in adolescents with chronic illness and their parents. Current research is limited to studies on pathology-focused issues in specific disease conditions or mental/emotional arenas. There is very little research on primary health care issues in this growing population. In replication of the original Dragone (1990) research, this study may indicate generalization of findings for other chronically ill adolescents and their parents.

Chapter III

The Method

The purpose of this study was to identify the self-perceived primary health care needs of chronically ill adolescents and their parents, the degree of agreement between these populations, and the resources they utilize. A discussion of the methodology utilized in this study will encompass the design of the study, discussion of the methodology, and procedures for data collection and analysis.

Research Design

The research design of this study was descriptive correlational. Polit and Hungler (1991) define descriptive research as "[r]esearch studies that have as their main objective the accurate portrayal of the characteristics of persons, situations, or groups, and the frequency with which certain phenomena occur" (p. 643). This study identified the self-perceived primary health care needs of chronically ill adolescents as well as the parents' perceptions of the adolescents' primary health care needs.

Descriptive correlational research, as defined by Polit and Hungler (1991), is research aimed at describing a relationship among variables rather than attempting to infer a cause-and-effect relationship. This design was applicable to this study as this study further identified possible correlations between variables of age and perceptions of primary health care needs in adolescents, as well as the degree of agreement between adolescents and parent groups. This design allowed the researcher to describe certain perceptions which may have applied age-specified health care concerns of a population which has been traditionally underserved.

Research Setting

The setting of this research was a rural southeastern state. Outpatient clinics in a major medical center were utilized to access the sample. The specialty pediatric outpatient clinics in this study included diabetes, renal, rheumatology, pulmonology, oncology, hematology, and cardiology. Questionnaires were administered on-site by the researcher.

Sample

A nonprobability sample of convenience was used in this research. Convenience sampling, selection of the most readily available persons as subjects of a study (Polit & Hunger, 1991), was appropriate for this study based on the nature of the research and the characteristics of the population being researched. The sample of chronically ill adolescents lived in various areas of the state, and accessibility was best achieved on days of clinic appointments. Since adolescents were usually clustered with other pediatric populations within the clinics, subjects were obtained by chance scheduling of the day.

The criteria for inclusion in this study were as follows:

1. Adolescent client was aged between 11 and 19 years.
2. Chronic illness was diagnosed for a period between three months to 18 years.
3. Adolescent client lived with parent or caregiver.
4. Adolescent client was free of cognitive impairment.
5. Adolescent client and parent were capable of reading and speaking English fluently.
6. Mutual agreement of adolescent client and parent to participate in the study as evidenced by signing the informed consent.

Subjects were accessed at routine clinical visits. Purpose and procedure of the study were explained to the adolescents and parents by the examiner. Parent and adolescent pairs were then separated for administration of the questionnaire with the researcher available for questions as needed.

Data Collection

Instrumentation. The Primary Health Care Needs Assessment (PHCNA), a 60-item questionnaire authored by Dragone (1990), was designed to assess primary health care needs in chronically ill adolescents. Permission to use the questionnaire was obtained in writing from Mary Alice Dragone, a pediatric nurse practitioner (see Appendix C). The PHCNA was composed of three sections. The first section was a questionnaire for demographic information. The second section consisted of the PHCNA which was used to assess variables of primary health care needs of the chronically ill adolescents. The third section consisted of a resource utilization form.

Demographics. The demographic information form requested information which included personal data of the adolescent's physical and social status. Information included age, sex, ethnicity, religion, education level, illness condition, and length of time since diagnosed. Parent groups were asked for similar information, as well as information pertaining to marital status, employment status, and area of residence.

The demographic information form differed from the original authored by Dragone (1988) regarding inquiry of the adolescent's number of hospitalizations during the previous year. In the original study, Dragone (1988) noted that this item produced some confusion for the adolescents. Adolescents tended to estimate these instances more frequently than their parents. This item was not directly implicated in the purpose of the study, and thus was not included in the demographics of the current study.

Primary Health Care Needs Assessment. The adolescent and parent forms consisted of 60 primary health care needs common to adolescents in general and chronically ill adolescents in particular. Items on the questionnaire addressed health promotion, illness management, and developmental issues congruent with adolescent primary health care needs. The items represented on the instrument were issues of primary health care concerns derived from current literature review in adolescent care, textbooks, and personal experiences identified by Dragone (1990).

Content validity for the PCHNA was supported by evaluation of three experts in the fields of chronic illness, primary health care, and adolescence. Reliability was established at 88% by test-retest method. In this current study, slight variations were made in the demographic and resource utilization forms based on recommendations of the author of the original instrument in order to adapt it to a different sample and setting. The list of primary health care needs assessment is identical to that authored by Dragone (1990).

Subjects were instructed to place a check mark next to any primary health care need which the adolescent experienced in the previous year. Priority of the top five needs were then ranked according to the subjects' perceptions. An item was considered prevalent in health concerns if at least 33% of the sample had chosen the item, and if 33% of the sample that identified the items also ranked it as one of their top five concerns. The top five concerns were not weighted according to ranking.

A few advantages offered by this format included the controlled time frame of a fixed-answer format as compared to open-ended questions. Also, fixed-answer options may have facilitated expression of thoughts which these age groups may have had difficulty expressing otherwise. A potential disadvantage of this fixed-answer format was the exclusion of a pertinent health issue as perceived by the adolescent or parent. Therefore, the questionnaire included an opportunity for subjects to write in any other health care need which they identified.

Resource utilization. The resources utilized to meet primary health care needs were assessed through a form similar to the 60-item PHCNA (see Appendix A). Subjects were instructed to place a check mark next to as many resource persons as utilized by the subjects. Choices of resource persons included parents, doctor, nurse, social worker, teacher, friend, or no one. The subject was also instructed to rank resources in accordance of their use.

This format differs from the resource utilization form utilized by Dragone (1988). In the original study, participants were directed to identify resource persons utilized for each identified primary health care need listed on the PHCNA (see Appendices A and B). Dragone (1988) noted that subjects frequently failed to note the resource used for an identified need. This was felt to be related to the format used in the instrument. In this current study, a generalized approach was taken in determining resources these populations may have accessed for primary health care needs. Therefore, the questionnaire only offered a list from which the subject could select an appropriate choice.

Procedure. Approval of the Committee on Use of Human Subjects in Experimentation (see Appendix D) was obtained through the Mississippi University for Women prior to initiating this research, in order to protect the human rights of the subjects. The medical center was contacted through the Department of Nursing Research (See Appendix E). Permission was then obtained from the medical center (see Appendix F) and the individual outpatient clinics for access to adolescent and parent populations. The original informed consent (see Appendix G) was revised by the medical center to meet institutional requirements (see Appendix H). Appointments for single days in each clinic were established with clinical coordinators. These days ranged over a five-week period due to the conflicting schedules of the various clinics.

In the clinical setting, subjects were approached by the researcher and the purpose and procedure of the study were explained to adolescent and parent pairs. Informed consent (see Appendix I) was signed by the parent and the adolescent, and each individual was administered the questionnaire in separate areas. Subjects were advised not to discuss questionnaire items or their responses in order to enhance validity. The researcher was available during the procedure to answer questions as needed. Subjects were advised that they could discontinue participation in the study up to the point of data analysis. Although individual questionnaire items would not be revealed, the grouped results of the study would be disseminated to interested parties.

Limitations

There were two primary areas of limitations identified in this research study. They consisted of internal and external validity. A discussion of these limitations follows.

Internal validity. Polit and Hungler (1991) described internal validity as findings of a study which can be attributed only to effects caused by the independent variables of interest without reflection of extraneous variables. In order to enhance internal validity in research, methods such as use of control groups, random assignment or stratified random sampling may be utilized. Thus, greater control of extraneous variables strengthens the internal validity of the study. Limitations to internal validity in this study were primarily associated with the small sample size. Although use of parent/adolescent pair matching or disproportional random stratified sampling would have allowed greater homogeneity of the sample subjects, such methods were not feasible due to the sample's small size.

Another possible limitation of the study was related to the limited time frame of the study. Chronically ill adolescent clients were integrated into regular pediatric clinical schedules. A longitudinal study would have allowed more opportunity to access increased numbers of adolescent clients. Furthermore, adolescents seen in the outpatient clinics may have represented a small portion of chronically ill adolescents since clinical visits are spaced at various intervals. Visits into the subjects' homes may have produced a larger sample, but was not feasible due to the extent of areas ranging in this rural state.

In this study, homogeneity of population was supported through the criterion established for chronic illness. Only adolescents who had illness conditions which persisted in a range from three months to 18 years were considered for this study. A variety of disease entities may have qualified for these criteria; however, the requirement of treatment in the outpatient specialty clinics as a criterion for selection, promoted a group of subject illnesses which might have been more debilitating than those routinely treated for a shorter period in non-specialty clinics.

Sample homogeneity was further supported through the criteria established for sample characteristics. Eligibility of the sample population for this study included that adolescents be aware of their needs and capable of identifying those perceptions. Criteria also required that adolescents live with the identified parent/caregiver to insure that the parent was in contact with the adolescent and cognitive of his/her perceived needs.

External validity. Polit and Hungler (1991) described external validity as the generalization of the research findings to other samples or settings. Therefore, the largest threat to external validity may have been due to lack of representation of chronically ill adolescents resulting from access of this small convenience sample of adolescents with more debilitating illnesses. Furthermore, the environment of the clinical setting may have influenced participants' resources. Threats to external validity were minimized through design of the instrument.

Data Analysis

Data were analyzed through the use of descriptive statistics. Frequencies were tabulated (a) for the primary health care need items as identified by chronically ill adolescents and their parents and (b) the resources that are identified to meet primary health care needs. Data analysis for degree of agreement between perceptions of adolescents and their parents were based on items which were identified as relevant and top-ranked in importance by the subjects through descriptive statistics. At least 33% of the sample must have identified a concern to qualify as a prevalent issue for this group. An item must have ranked in the top five list of priorities to qualify as top-ranked. Items of agreement between adolescent and parents were then calculated into the total number of items.

Degree of agreement of perceptions of primary health care needs between early, middle and late adolescent age groups was determined by chi-square analysis. Level of significance was set at $p = .05$.

Utilization of health care professionals as resources was determined as indicated on the resource questionnaire. Professional resources utilized by adolescents and parents were determined by the frequency that "doctor, nurse or social worker" was indicated. Resource items were not tested for rank according to use; therefore, percentages were used to determine the resources utilized.

Summary

The format of this study was initially conducted in a pilot study by Dragone (1990). The original Dragone (1990) study was set in a metropolitan area of a southwestern state. The populations accessed were generally educated and in a middle class socioeconomic bracket. This replication study, accessed chronically ill adolescents and their parents through specialty pediatric outpatient clinics in a medical center setting in a rural southeastern state. The populations accessed were generally less educated and in a poorer socioeconomic bracket.

Samples were accessed over a 5-week period. Informed consent was obtained from parent and adolescent clients. The PHCNA, a 60-item questionnaire authored by Dragone (1990) was administered to parent and adolescent pairs to assess the primary health care needs they perceived for the adolescent. Demographic information and resources utilized were also identified. Data were analyzed through descriptive statistics to determine the identified primary health care needs of chronically ill adolescents and their parents, the degree of agreement between these groups and the resources which they utilized.

Chapter IV

The Findings

The purpose of this study was to identify the perceptions of primary health care needs of chronically ill adolescents as expressed by the adolescents and their parents, the degree of agreement of perceptions between these populations, and the differences in their utilization of health care professionals. The research design of this study was descriptive correlational. The results of this study are described as follows.

Description of Sample

The convenience sample ($N = 20$) of adolescent and parent pairs was accessed through a major medical center in a rural state. Each parent subject was identified as mother to the adolescent. Fourteen of the 20 parents indicated they were married (70%) while the remaining 30% were equally divided between being single or divorced. Of the 15 parents that identified their areas of residence, 46.7% indicated living in urban areas while 53.3% indicated living in rural areas.

Parents' educational levels ranged from nine to 16 years. Forty percent ($n = 8$) of the parents indicated education beyond high school, 25% ($n = 5$) indicated a high school education, and 35% (n = 7) indicated less than an high school education.

Parental religious preference was identified by 85% (n = 17) of the subjects: 64.7% (n = 11) were Baptist and 11.8% were Pentecostal. The remaining 23.5% of the sample was divided evenly between Methodist (n = 1), Church of Christ (n = 1), Presbyterian (n = 1), and Charismatic (n = 1).

Although information regarding income was not requested on the demographic form, employment status was included. Several outpatient clinics in this setting were divided by private pay or Medicaid pay status. Due to this policy, several of the clinics accessed for this study saw clients who were Medicaid recipients only. Therefore, a majority of these adolescent/parent groups was eligible for Medicaid and/or financial assistance. Eleven parents (55%) indicated full-time employment, 2 parents (10%) indicated part-time employment, while 7 parents (35%) indicated unemployment.

Adolescent subjects (n = 20) were classified into three age groups. Early adolescents were ages 11-13 years. Middle adolescents were aged 14-16 years. Late adolescents were aged 17-19 years. The early adolescent group consisted of 5 male subjects and 2 female subjects, with a mean age of 11.5 years. Ten adolescents were placed in the middle adolescent group, which consisted of 3 males and 7 females, whose mean age was 14.5 years. Three adolescents, 2 males and 1 female, constituted the late adolescent group. The mean age of this group was 18 years. Adolescent information of race and religion across all age groups was consistent with the parent.

Sixty-five percent (n = 13) of the adolescents were diagnosed with chronic illness for periods ranging from 2 through 16 years, with a mean age of 7.4 years. Thirty-five percent (n = 7) of the adolescents were diagnosed for a period of 3 months to one year. Educational levels of these adolescents ranged from a minimum of 2 years to a maximum of 12 years. One adolescent received homebound education from the parent. Chronic illnesses identified by diagnosis are presented in Table 1.

Table 1

Chronic Illnesses Affecting Adolescents

Illness	n	%
Diabetes	4	20.0
Sickle cell anemia	4	20.0
Osteoblastic sarcoma	1	5.0
Arthritis	2	10.0
Leukemia	4	20.0
Hodgkin's	2	10.0
Cystic fibrosis	3	15.0
Total	20	100.0

Results of Data Analysis

This study generated four hypotheses which were addressed in this research. These hypotheses, data analysis, and findings follow.

Ho_1: There is no significant difference in degree of agreement between perceptions of the top five primary health care needs identified by chronically ill adolescents and their parents.

The PHCNA consisted of 60 items. The item identified most frequently within the adolescent sample (90%) was "Had a sore throat", although only 11% referred to this symptom as a top five concern. Items of psychosocial or behavioral adaptation were much more prevalent as primary health care needs and were consistently identified in the top five concerns. For example, "been bored a lot" was identified by 70% of the sample as a primary health care concern while only 33% rated it as a top five concern. Table 2 presents the adolescent primary health care needs prevalent and top-ranked in importance by adolescents.

Table 2

Adolescent Primary Health Care Needs Prevalent and Top-Ranked in Importance by Adolescents

PHCNA Item	Primary health care need *n*	Primary health care need %	Top five concerns *n*	Top five concerns %
Had a sore throat	18	90	2	11
Been bored a lot	14	70	6	33
Wondered how my ______ will affect me when I'm older	10	50	6	60
Not been able to do the things that my friends can do	9	45	4	44
Had a hard time explaining my ______ to people at school	8	40	5	62
Had trouble explaining my _______ to my friends	8	40	3	37
Been nervous a lot	8	40	3	37
Wanted someone to listen to what bothers me	7	35	5	71
Not been doing well in school	7	35	4	57
Been worried about my health	7	35	4	57
Concerned about being too short	7	35	3	42
Wondered what makes my body go through these changes as a teenager	7	35	3	42
Had a hard time adjusting to school after being absent	7	35	2	28
Been tired a lot	7	35	2	28
Had a lot of headaches	7	35	2	28

Criteria for statistical analysis were identical among parent and adolescent groups. Although parents identified physical symptomatology (headaches, sore throats, and breathing problems) more frequently than did the adolescents, they agreed with adolescents regarding psychosocial and behavioral adaptation as general health care concerns. Table 3 presents the adolescent primary health care needs that were prevalent and top-ranked in importance by parents. A comparison of Tables 2 and 3 demonstrates the closeness in perceptions by these two groups and the priority the groups placed on these perceptions. An item was classified as a prevalent concern if at least 33% of the sample had chosen it as a concern and then also identified it as one of the top five concerns. Therefore, prevalence was determined by the frequency with which an item was identified and the priority it was given by the subject. Parent/adolescent groups indicated agreement on 46 of the 60 items on the PHCNA.

The 76% rate of agreement between parent and adolescent groups supports the assertion that there is no difference in degree of agreement between the perceptions of the top five primary health care needs of chronically ill adolescents and their parents. Therefore, the researcher failed to reject Hypothesis 1.

Table 3

Adolescent Primary Health Care Needs Prevalent and Top-Ranked in Importance by Parents

	Primary health care need		Top five concerns	
PHCNA Item	n	%	n	%
Had a sore throat	15	75	5	33
Been bored a lot	15	75	5	33
Not been able to do the things that my friends can do	13	65	9	69
Had a lot of headaches	10	50	5	50
Wanted to learn more about treatments	10	50	3	30
Wondered what makes my body go through these changes as a teenager	10	50	3	30
Had a toothache	10	50	2	20
Not been doing well in school	9	45	5	55
Been tired a lot	9	45	4	44
Been depressed	9	45	2	22
Had a hard time explaining my ______ to people at school	9	45	2	22
Had a hard time fitting medicine into regular schedule or routine	8	40	2	25
Had breathing problems	7	35	4	57
Had hard time explaining my _______ to my friends	7	35	4	57
Wanted someone to listen to what bothers them	7	35	4	57

Ho_2: There is no difference in degree of agreement of perceptions of primary health care needs among early, middle and late age groups of chronically ill adolescents.

Differences between early, middle, and late adolescent groups were determined by chi-square analysis. Of the PHCNA's 60 items, only three items were significantly different. Skin rash and constipation were identified as concerns between middle and late adolescents, χ^2 (2, 20) = 7.71; p = .02. "Been tired a lot" was identified by all three age groups, but showed marked significance among middle and late adolescents, χ^2 (2, 20) = 7.00; p = .03. Since subjects expressed significant difference in agreement regarding these three concerns, Hypothesis 2 was rejected.

Ho_3: There is no difference in use of health care professionals as resources between parents and their chronically ill adolescents.

Both groups indicated parents as the primary resource utilized by adolescents. Adolescents indicated referring to their parents 100% of the time and friends over 50% of the time. These resource persons were followed by teachers, doctors, and nurses, respectively. Nurses were utilized as a resource only 18% of the time.

Parents indicated that adolescents referred to teachers, friends, and doctors at a near equal rate of 50%. Nurses were identified as resources 38% of the time. Parents indicated utilization of health care professionals while adolescents clearly placed emphasis on parents and friends as resources. The directional hypothesis is supported as parents identify health care professionals as resources for meeting primary health care needs more often than do their adolescent children. The graph on Figure 1 represents resources used to help adolescents' primary health care needs as identified by parents and adolescents. All resources which were identified are represented without ranking.

Additional Findings

This study focused on primary health care needs of adolescents with chronic illness. Although the sample size did not facilitate comparative studies between illness groups or gender, several items emerged as important. Of the 60 items on the PHCNA, only one item had statistical difference related to gender as determined by chi-square test. "Been nervous a lot" was identified as a concern by 54.5% of males participating in this study, while no females identified this item.

Other items were chosen by the combined adolescent group which were not chosen by the parent group. Two adolescents (10%) indicated they had gotten drunk in the previous year while this item was not identified by the parent group. Similarly, "not known how far to go with sex" was identified by 2 adolescents (10%). Two items were identified by at least two parents and no adolescents. "Being concerned about being pregnant" was chosen by 2 (10%)

parents. Parents also identified "Had questions about sex" at a ratio of 4:1 with only one adolescent identifying this item.

Summary

The primary health care needs of adolescents with chronic illness tended to focus on psychosocial and behavioral adaptation issues more frequently than on physical symptomatology. Parents tended to place more emphasis on physical symptomatology than did adolescents, but were generally in agreement with the psychosocial issues identified by the adolescents. This closeness in perceptions is further supported by the frequency with which adolescents utilize parents as resources for primary health care needs rather than health care professionals. Finally, statistical differences were noted between early, middle, and late adolescents with chronic illness.

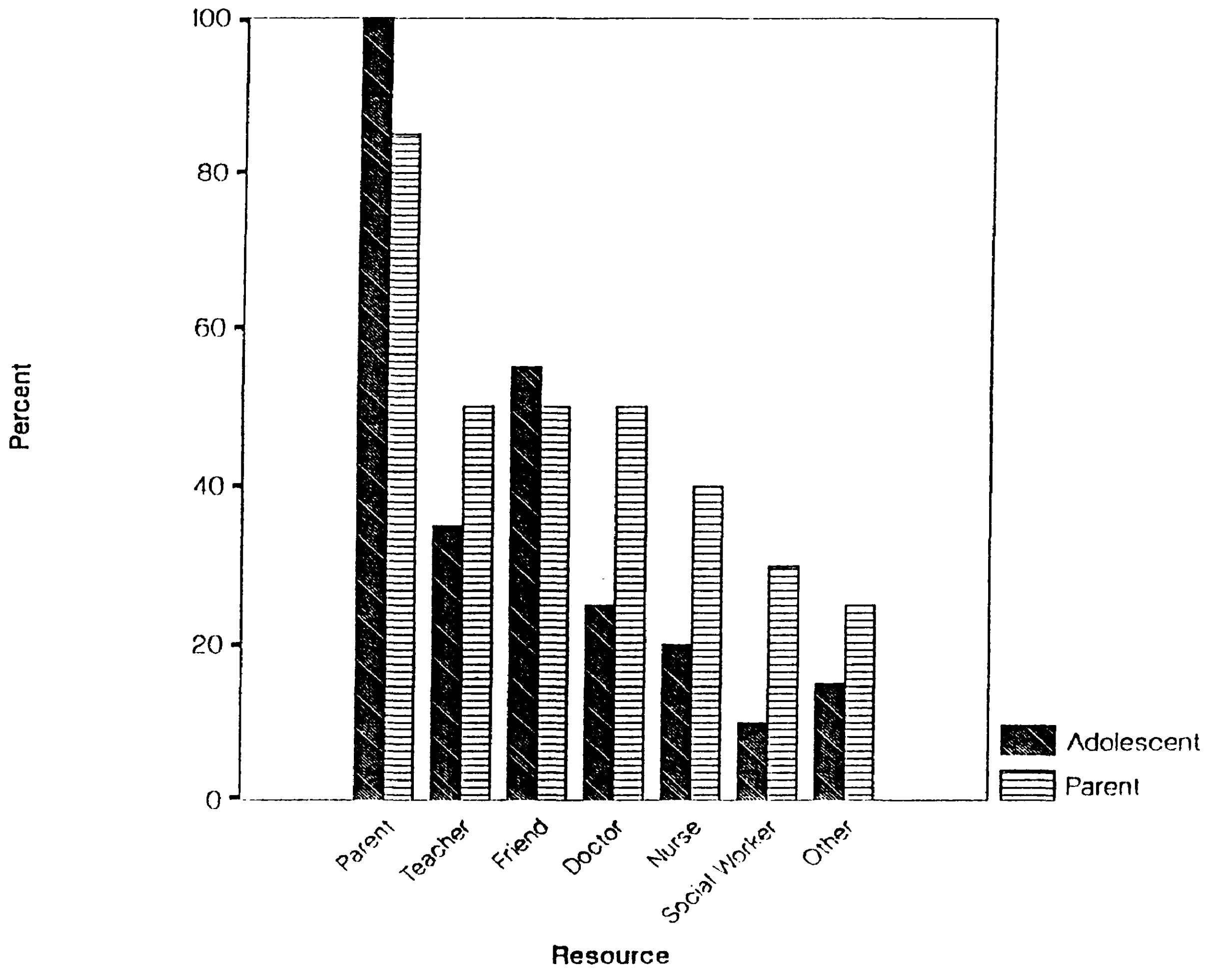

Figure 1. Comparison of adolescent and parent reports on resources used to meet adolescents' primary health care needs.

Chapter V

The Outcomes

The preceding chapters described the problem related to primary health care in chronically ill adolescents and the purpose of this study. Methodology and findings of this study have also been presented. This chapter discusses the outcomes, implications, and recommendations as outcomes of this research.

This replication study sought to identify the perceptions of primary health care needs of chronically ill adolescents and their parents as expressed by these groups. The researcher further sought to identify the resources utilized within this population. A convenience sample of 20 adolescent/parent pairs were accessed through a major medical center in a rural state. Subjects were asked to identify their primary health care needs and to prioritize those needs according to their top five concerns.

Both groups indicated concerns of sociopersonal or behavioral adaptative nature as predominant issues. Adapting to the illness in every day life was a reoccurring theme among adolescents. Several social and personal adjustment items were both prevalent and prioritized by adolescent subjects. Parents indicated more concern for physical symptomatology, such as headache, breathing problems, and toothaches, than did the adolescents. However, parents were generally in close agreement in the frequency of sociopersonal and behavioral issues.

Adolescents consistently describe concerns which referred to "explaining their conditions to peers" or being able to perform activities which were comparable to their peers' (such as doing well in school or doing what peers do) as primary health concerns. In general, parents seemed to be more focused on immediate needs related to the adolescent's physical condition, such as medications, treatments, and symptomatology. Parents agreed with adolescents on issues such as boredom and tiredness.

Both groups chose parents as the resource utilized most frequently. Parents tended to utilize health care professionals more often than did the adolescents and nurses were infrequently utilized by both adolescents and parents.

Discussion

This replication study found several similarities to Dragone's (1990) research on primary health care needs in chronically ill adolescents. In both studies, adolescents generally identified primary health care needs which seemed to focus more on sociopersonal and behavioral adaptative issues, such as school performance and boredom, instead of physical symptomatology, such as headaches and toothaches. In fact, 73% (n = 11) of the 15 top-ranked primary health care concerns addressed psychosocial or behavioral concerns. Issues such as "been bored a lot" (70%), "wondered how my illness will effect me when I'm older" (50%), and "not being able to do what my friends do" (45%) were both prevalent and top-ranked in adolescent groups. These concerns indicated a predisposition to sociopersonal issues which may have reflected anxiety, risk for depression, or fears for the future as related to their health.

Dragone's (1990) findings regarding the closeness in perceptions between parent and adolescent groups were validated in this study. Like Dragone's (1990) study, the current study indicated a 76% rate of agreement between the parent and adolescent subjects. Of the 15 prevalent needs identified on the PHCNA, parents chose only five issues based on physical symptomatology and treatment regimens which differed from their children's selection.

The close level of agreement noted in chronically ill adolescents from Dragone's (1990) study and the current study may have been due to the codependent bonds formed in these parent/adolescent pairs. Chronically ill adolescents may have related primarily to their parents instead of peers due to isolation induced by chronic illness. Furthermore, concerns identified in the current study suggested that adolescents had difficulty explaining their illness to friends and at school while parents may have represented safety and security to chronically ill adolescents as a consistent source of unconditional acceptance.

Dragone (1990) determined that both adolescents and parents focused on utilization of parents and physicians as primary resources, while nurses were rarely utilized by either group. In this current study, parents were cited by both groups as primary resources. Adolescents then followed with friends, while parents referred to physicians. Ironically, adolescents and their parents in this current study reported health care needs which may be effectively managed by nurses as primary health care professionals. Yet, nurses were rarely used to help meet those health care needs. While parents indicated an awareness of nursing potential in health management, adolescents actually recognized nurses less often than other health care professionals as resources for health care.

While the chronically ill adolescents in Dragone's (1990) study shared commonalities with adolescents in the current study, a few differences were noted. One such difference was the increase in the number of top-ranked concerns described by adolescents and parent groups in the current study. The original study identified 12 top-ranked items by parents and 11 items by adolescents, while this replication study found 15 top-ranked items by both parents and adolescents. Adolescents in the current study may have been susceptible to increased potential for high-risk behaviors as evidenced by identification of factors on the PHCNA of increased anxiety (54%) and alcohol consumption (10%). Dragone (1990) did not address to this issue.

Another difference related to sample composition is subjects of Dragone's (1990) study were predominantly educated Caucasians of a high socioeconomic bracket who resided in an urban southwestern state. The subjects of this study were of various ethnic groups (predominantly Afro-American) and lived in a rural southeastern state. Although 65% of the parent group had an educational level of 12th grade or higher, the majority of subjects were eligible for financial assistance or Medicaid. Most subjects were required to drive excessive distances for appointments in the outpatient clinics, while the subjects of Dragone's (1990) study were limited to a 75-mile radius from the participating hospital.

As an extraneous notation, distance may have impacted sample selection on several occasions in which the adolescent desired to participate in the current study while the parent declined. This choice may have been due to fatigue or stress which occurred when parents were forced to commute long distances to health care facilities. Adolescents in the clinical setting were open and often anxious to express their feelings and concerns. In fact, on four occasions, staff and/or parents maintained that adolescents probably would not participate in the study.

However, when approached, adolescents agreed to participate and were open in their responses, which may imply that adolescents with chronic illness felt a need to express their needs and desires and sought avenues to do so. The PHCNA provided a method of relating these needs for the adolescent who may have had difficulty verbalizing.

Of the 15 prevalent needs identified on the PHCNA, adolescents differed from parents on five issues. The adolescents indicated the following concerns of top priority: (a) worried about health, (b) difficulty adjusting to school after absences, (c) how will the illness affect me when I'm older, (d) been nervous a lot, and (e) concerned about being too short. These concerns may have indicated a predisposition to sociopersonal issues which may have reflected anxiety, risk for depression, or fears for the future as influenced by their health.

Of the 15 prevalent needs identified on the PHCNA, parents indicated the following concerns: (a) had breathing problems, (b) been depressed, (c) had a hard time fitting medicine into regular schedule or routine, (d) wanted to learn more about treatments, and (e) had a toothache. These concerns represented more issues related to physical symptomatology than those expressed by adolescent subjects.

Another difference between the current study and Dragone's (1990) study was the inclusion of early, middle, and late adolescent groups within the study. This representation allowed perceptions to be correlated among age groups. Early adolescents presented concerns more related to physical symptomatology; middle adolescents presented concerns related to future and sociopersonal issues; and late adolescents presented concerns related to future plans and depression. However, in this current study, adolescents across age groups indicated concerns related to physical symptoms of constipation, skin rash, and tiredness compared to the trend as noted in the middle and late adolescent groups in the original study. This factor may have been due to the disproportionate numbers representing each age group (early, $\underline{n} = 7$; middle, $\underline{n} = 10$; and late, $\underline{n} = 3$).

Another influential factor for differences between the studies may have been the cognitive abilities of the sample for understanding terminology and in expressing views. Both parent and adolescent groups had some difficulty in completing the questionnaire. Adolescents had difficulty with some words and concepts such as "constipation" and "contraception." This confusion may have been due to poorer education noted in the sample (one 11-year-old indicated a second grade level of education) and the general sample characteristics. However, the researcher explained and defined all concepts which presented problems for adolescents to assure understanding and accuracy in testing. Adolescents also seemed to have difficulty with the length of the tool as the first two pages were often completed with fervor, but adolescents seemed to tire by the time they started on the third page of the questionnaire. The PHCNA required a level of concentration which seemed to pose a problem for some adolescents, which may have been due to the activity in the clinical setting or the individual's attention span.

Parents had less difficulty with terminology used on the questionnaire, but seemed to have general difficulty in ranking. This tendency also was noted in the parents of Dragone's (1990) study. The PHCNA was effective for time management and comprehensiveness in adolescent health care issues. There were few additional entries of concerns by parents or adolescents.

Dragone's (1990) study found only one significant difference related to gender. Girls in the original study expressed concerns regarding weight. In the current study, there was an increased incidence of anxiety in males (54%) over females (0%). Perhaps the adolescent males in this rural setting felt a higher need to model or perform traditional perceived male roles. In this case, chronic illness might have represented higher stress for role expectations and future concerns. This supposition was highlighted on Duchen-Smith et al.'s (1987) study of healthy adolescents which determined adolescent males' concerns focused on their future and weight, respectively. However, chronically ill adolescent males indicated a higher level of anxiety than their healthy counterparts (Baker, 1991; Duchen-Smith et al., 1987) or his chronically ill counterparts (Dragone, 1990).

Relating findings to the scarcity of similar research, the following comments are offered. Parents of chronically ill adolescents in Dragone's (1990) study and in the current study generally exhibited a closer agreement of perceptions with their adolescent children than the parents of healthy adolescents described in Fisher's (1992) study. In Fisher's (1992) study, parents tended to concentrate on issues which were similar to traditional health care beliefs. This conclusion contrasted with the perceptions identified by the healthy adolescents in Duchen-Smith et al. (1987) and Baker's (1991) studies, as adolescent subjects in these studies reported concerns related to physical appearance and sociopersonal issues.

In summary, adolescents' health care needs have traditionally been categorized by society and health care professionals. The primary health care needs which society identifies with this population have been credited as the standard. However, this study has presented evidence which requires an active search for realistic identification of the adolescent's needs. In the case of the chronically ill adolescent, implications are compounded since these adolescents present a unique agenda of primary health care needs which differs from that of healthy adolescents or chronically ill children and adults.

Orlando's Nursing Process Theory (1970) asserts that the nurse must not assume initial perceptions of client's behaviors to be fact. Only through the nurse/client interaction can the nurse validate and clarify the client's perceptions and subsequently postulate goals and interventions. This concept is appropriate in general nursing strategies and is especially effective in nursing of the adolescent client. The literature has supported the idea that the assumptions which health care professionals have placed on adolescents are often not the perceptions identified by adolescents. Furthermore, adolescence is a period marked with transition and acquiring advanced socialization skills. Therefore, the adolescent is trying to acquire skills which facilitate communication of his/her specific needs and may not yet be proficient in expressing his/her perceptions. Through the nursing process theory, the nurse validates the adolescents's perceptions and uses this knowledge in assisting the client in meeting specific health care needs.

Adolescence is a developmental stage of learning in which learning identity and asserting self are important. Adolescents with chronic illness may be delayed in developing these skills due to health-imposed limitations, lack of socialization, and increased dependence on others.

Through the nursing process, nurses may assist clients in identifying and asserting their concerns. Subsequently, the nurse is using self as a tool for assessing the client's needs and intervening on the client's behalf. This may infer sociopersonal needs, such as teaching coping skills, or more pathophysiological needs, such as interventions for managing nausea associated with chemotherapy. However, adolescents only rarely use nurses as resources. Therefore, nurses need to better explain their role as a resource to adolescents in an effort to be more effectively utilized.

Care of the chronically ill adolescent has additional implications since the parent must be considered as an integral part of the client dyad. Since the adolescent is largely dependent on the parent for care, the parent's perceptions are equally important in assessment and determination of health care needs. This denotes that the adolescent and parent pair must be given equal consideration by the nurse provider. Nursing skills may be required not only on the parent's and adolescent's behalf, but also as a liaison between the two as the adolescent proceeds through growth and development. Thus, as the adolescent client's situation evolves, the nursing process provides an evolving framework for assessment, intervention, and evaluation of client outcomes.

Through use of Orlando's Nursing Process Theory (1970), the professional nurse assesses the client's needs by first identifying and validating the client's perceptions. Dragone (1990) studied perceptions of primary health care needs in chronically ill adolescents and their parents in order to identify the concerns specific to this population. This current research attempted to further study these findings and to assess generalization to other chronically ill populations.

Conclusion

In this replication study, the researcher found support for the findings of Dragone's (1990) study on perceived primary health care needs by chronically ill adolescents and their parents, the level of agreement between these groups, and the resources they utilize to meet these perceived needs. Dragone's (1990) study found a 76% degree of agreement between chronically ill adolescents and their parents on primary health care needs. These were the same findings in degree of agreement in the current study.

Adolescents in Dragone's (1990) study identified issues of sociopersonal and adaptative concerns as their primary health care needs. This current study supported the assertion that chronically ill adolescents perceive primary health care needs which are of sociopersonal and behavioral adaptative concerns. These adolescents were most concerned with issues, such as boredom, fatigue, adapting at school and with friends, and wishing for someone to talk to.

This current study further indicated that parents generally agreed with their adolescent children's perceptions on 76% of the identified items. This is identical to the 76% degree of agreement between adolescent and parent groups in Dragone's (1990) study. While more concerns were identified in the current study as compared to Dragone's (1990) study, the degree of agreement between these populations was unchanged. This further supports the notion that although the identified items may vary, the agreement in perceptions between parent and adolescent groups remain constant.

Dragone (1990) noted significant differences and trends between early, middle, and late adolescent age groups. Although the current study did not identify specific trends among age groups, a difference in perceptions of primary health care needs was noted among early, middle and late adolescent age groups. This may be due to the unequal representation among the three age groups in the current study as opposed to the equal age representation in Dragone's (1990) study.

Finally, the current study supports Dragone's (1990) findings of resources utilized by adolescents and parents. Both studies indicated that adolescents most often utilized parents to meet primary health care needs. Both studies further indicated that these populations were more apt to utilize other health care professionals than nurses to meet perceived needs.

This study has supported Dragone's (1990) findings regarding the perceptions of primary health care needs of chronically ill adolescents and their parents. Orlando (1966) postulates that the professional nurse must interact with the client and validate the client's perceptions of their specific needs before formulating diagnosis and interventions to meet those needs. Dragone's (1990) original study and the current study present evidence which permits the clinician to assess and validate those perceptions.

Implications for Nursing

This study is significant to nursing education, research, and practice in various capacities. Adolescence has been recognized as a unique period of transition, yet understanding and knowledge of the adolescent client remain limited among health care professionals. Nursing has traditionally been involved in adolescent care, but nursing education and preparation have not been designed to assess and meet adolescent needs.

With the increase of chronic illness and survival rates in pediatric populations, nursing must not only recognize this emerging adolescent population, but also accept the responsibility of adequately educating nurses for this realm of care. The increased demands presented by adolescent clients and nurses' assertions that they lack adequate education preparation have been supported in the literature (Bearinger et al., 1992; Whyte, 1992). The dilemma has been recognized, and the need has been documented. Therefore, this study serves as a reservoir of information which supplies nurses with information to understand and perform comprehensive care in chronically ill adolescents.

This knowledge will be useful in various nursing roles and settings. In generic nursing preparation, the novice may establish a baseline understanding of implications of chronic illness in adolescence. In specialty settings, this information presents a floor of knowledge on which nursing standards may be founded. In the advanced practice setting, this information forms guidelines which could direct care and further evolution of nursing theory, knowledge, and practice. Nurse practitioners can be well-utilized as primary health care providers to adolescents who are routinely followed by medical specialists.

This study is also significant to nursing research. The original study was conducted as a nursing exploration into a newly developing arena of health care. In replicating the original work, this study has offered support to existing nursing research and suggested alternative information for deliberation and study. Moreover, the completion of this research has suggested further questions for continuing research. By reviewing these studies, nursing may find direction for continued nursing research, knowledge for further education of nurses, and implications in nursing practice.

This research has indicated that adolescents have a different perception of needs than those portrayed by traditional health care professionals. It further intimated that these adolescents were desiring comprehensive management or assistance in meeting their needs. Perhaps an unexpected finding in this research was the absence of nursing as a resource for this population. Thus, this study has identified a deficit in nursing availability in a needful population.

Recommendations

Based on the findings of this study, the following recommendations were made:

1. Replication to further establish findings with larger samples, in diverse settings, and by adolescent cohort groups.

2. Replication to further investigate the impact of specific variables, such as race, economics, education, and gender.

3. Conduction of research to identify perceptions of barriers to primary health care by chronically ill adolescents and their parents.

4. Conduction of qualitative research that examines adolescent perceptions of illness and health.

Nursing

1. Education of adolescent clients from diverse age groups regarding the role of the nurse as a health care resource.

2. Utilization of tools such as the PHCNA to assess chronically ill adolescents and parents' perceptions about health care needs.

3. Publication of findings from research examining chronically ill adolescents.

4. Education and preparation of nurses in the care of healthy and chronically ill adolescents.

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APPENDIX A

PRIMARY HEALTH CARE NEEDS: PARENT

Primary Health Care Needs: Parent

Part I. Demographics

Please give the following information about yourself which will help identify your characteristics as compared to other adolescents with chronic illness and their parents. Please do not include your name.

Parent Information

Age:__________________

Sex: Male______ Female______

Race:
____ Caucasian
____ Afro-American
____ Hispanic
____ Other

Religion:____

Marital Status:
____ Married
____ Divorced
____ Single

Highest education completed:
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15

More than 16 years:_____

Employment Status:
____ Full-time
____ Part-time

City/town of residence:________________________________

Part II. Primary Health Care Needs

This is a list that many young people say have happened to them or have concerned them.

1. Read each item listed below. Place a check (✓) in the space in front of each item that you believe has happened to your son/daughter in the last year.

   For example:
   If your son/daughter had a toothache in the last year, put a check (✓) in the space next to "had a toothache."

2. After you have finished this, find the five items on the list that you are most concerned about. Using the red pen, put a "1" in the space next to the item you are the very most concerned about, put a "2" next to the item you are concerned about next, and so on until you get to 5.

If you do not understand any of the questions, you can ask the nurse researcher for assistance. Your honest answers will help doctors and nurses to understand more about young people with chronic health problems.

In the past year, my son/daughter has . . .

_____ 1. had a toothache.

_____ 2. had breathing problems.

_____ 3. had a sprained ankle.

_____ 4. smoked a cigarette.

_____ 5. been concerned about being too thin.

_____ 6. not been able to do the things that his/her friends can do.

_____ 7. been concerned about VD (venereal disease).

_____ 8. had a sore throat.

_____ 9. wondered what makes his/her body go through the changes of being a teenager.

_____ 10. had a lot of headaches.

_____ 11. had problems getting along with his/her parents.

_____ 12. had a skin rash.

______ 13. had problems with his/her teeth.

______ 14. been constipated.

______ 15. had problems from wetting the bed or his/her underwear.

______ 16. wondered if he/she will be able to have children when he/she gets older.

______ 17. been bored a lot.

______ 18. been concerned about being pregnant.

______ 19. had hearing problems.

______ 20. had problems getting along with his/her teachers.

______ 21. had a hard time explaining his/her ______________ to brothers and/or sisters.

______ 22. been tired a lot.

______ 23. had a hard time adjusting to school after being absent.

______ 24. not been able to see very well.

______ 25. wanted to learn more about his/her ____________.

______ 26. been depressed.

______ 27. had a hard time fitting his/her treatments into his/her regular schedule or routine.

______ 28. had a hard time fitting his/her medicines into his/her regular schedule or routine.

______ 29. had a broken bone.

______ 30. had an earache.

______ 31. wanted to learn more about his/her treatments.

______ 32. had trouble explaining his/her _____________ to friends.

______ 33. used drugs.

______ 34. had questions about what to expect when he/she is in the hospital.

_____ 35. not been doing well in school.

_____ 36. had problems finding a job.

_____ 37. been worried about being overweight.

_____ 38. had a hard time explaining his/her _____________ to people at school.

_____ 39. had questions about sex.

_____ 40. been worried about his/her health.

_____ 41. been concerned about being too tall.

_____ 42. wondered how his/her _________________ will affect his/her when he/she gets older.

_____ 43. had questions about contraceptives.

_____ 44. had diarrhea.

_____ 45. wanted someone to listen to what bothers him/her.

_____ 46. had trouble getting along with his/her brothers and/or sisters.

_____ 47. had acne (pimples).

_____ 48. had a hard time making friends.

_____ 49. had problems sleeping.

_____ 50. had problems with her period (a lot of pain or bleeding).

_____ 51. been nervous a lot.

_____ 52. needed help to decide about his/her future.

_____ 53. had problems urinating (pee).

_____ 54. been concerned about being too short.

_____ 55. been anxious a lot.

_____ 56. not known how far to go with sex.

_____ 57. wanted to learn more about his/her medicine.

_____ 58. had sex (sexual intercourse).

_____ 59. gotten drunk.

_____ 60. not been able to learn how to drive.

If you have any other concerns, please write them on these lines:

____
____
____
____
____

Part III. Resources

Please identify the resource person whom your son/daughter utilizes to help them meet their health care needs, such as parents, doctors, nurses, friends, teachers, social workers, others, or no one.

Put a check (✓) in the space next to the person whom your son/daughter utilizes as a resource person. Choose as many as may apply. Using the red pen, put a "1" in the space next to the person whom your son/daughter utilizes the most, and so on until you have ranked the persons that you have identified.

_____ Parents
_____ Teachers
_____ Friends
_____ Doctor
_____ Nurse
_____ Social worker
_____ Others: Please write in:____________________________
_____ No one

APPENDIX B

PRIMARY HEALTH CARE NEEDS: ADOLESCENT

Primary Health Care Needs: Adolescent

Part I. Demographics

Please give the following information about yourself which will help identify your characteristics as compared to other adolescents with chronic illness an their parents. Please do not include your name.

Adolescent Information

Age:______

Sex: Male _______ Female______

Race:
_____ Caucasian
_____ Afro-American
_____ Hispanic
_____ Other

Religion:____

Education/Grade Level:_________________________________

What is your illness?__________________________________

How long have you been diagnosed with this problem?
______ Years
______ Months

Part II. Primary Health Care Needs

This is a list that many young people say have happened to them or have concerned them.

1. Read each item listed below. Place a check (✓) in the space in front of each item that has happened to you in the last year.

   For example:
   If you had a toothache in the last year, put a check (✓) in the space next to "had a toothache."

2. After you have finished this, find the five items on the list that you are most concerned about. Using the red pen, put a "1" in the space next to the item you are the <u>very</u> most concerned about, put a "2" next to the item you are concerned about next, and so on until you get to 5.

If you do not understand any of the questions, it is okay to ask the nurse researcher for help. Your honest answers will help doctors and nurses to pay better attention to the things that are happening in your life.

In the past year, I have . . .

_____ 1. had a toothache.

_____ 2. had breathing problems.

_____ 3. had a sprained ankle.

_____ 4. smoked a cigarette.

_____ 5. been concerned about being too thin.

_____ 6. not been able to do the things that my friends can do.

_____ 7. been concerned about VD (venereal disease).

_____ 8. had a sore throat.

_____ 9. wondered what makes my body go through these changes as a teenager.

_____ 10. had a lot of headaches.

_____ 11. had problems getting along with my parents.

_____ 12. had a skin rash.

_____ 13. had problems with my teeth.

_____ 14. been constipated.

_____ 15. had problems from wetting the bed or my underwear.

_____ 16. wondered if I will be able to have children when I get older.

_____ 17. been bored a lot.

_____ 18. been concerned about being pregnant.

_____ 19. had hearing problems.

_____ 20. had problems getting along with my teachers.

_____ 21. had a hard time explaining my _________________ to my brothers and/or sisters.

_____ 22. been tired a lot.

_____ 23. had a hard time adjusting to school after being absent.

_____ 24. not been able to see very well.

_____ 25. wanted to learn more about my _________________.

_____ 26. been depressed.

_____ 27. had a hard time fitting my treatments into my regular schedule or routine.

_____ 28. had a hard time fitting my medicine into my regular schedule or routine.

_____ 29. had a broken bone.

_____ 30. had an earache.

_____ 31. wanted to learn more about my treatments.

_____ 32. had trouble explaining my _____________________ to my friends.

_____ 33. used drugs.

_____ 34. had questions about what to expect when I am in the hospital.

_____ 35. not been doing well in school.

_____ 36. had problems finding a job.

_____ 37. been worried about being overweight.

_____ 38. had a hard time explaining my ________________ to people at school.

_____ 39. had questions about sex.

_____ 40. been worried about my health.

_____ 41. been concerned about being too tall.

_____ 42. wondered about how my ____________________ will affect me when I get older.

_____ 43. had questions about contraceptives.

_____ 44. had diarrhea.

_____ 45. wanted someone to listen to what bothers me.

_____ 46. had trouble getting along with my brothers and/or sisters.

_____ 47. had acne (pimples, zits).

_____ 48. had a hard time making friends.

_____ 49. had problems sleeping.

_____ 50. had problems with my period (a lot of pain or bleeding).

_____ 51. been nervous a lot.

_____ 52. needed help to decide about my future.

_____ 53. had problems urinating (pee).

_____ 54. been concerned about being too short.

_____ 55. been anxious a lot.

_____ 56. not known how far to go with sex.

_____ 57. wanted to learn more about my medicines.

_____ 58. had sex (sexual intercourse).

_____ 59. gotten drunk.

_____ 60. not been able to learn how to drive.

If you have any other concerns, please write them on these lines:

____
____
____
____
____

Part III. Resources

Please identify the resource person whom you utilize to help you meet your health care needs, such as parents, doctors, nurses, friends, teachers, social workers, others, or no one.

Put a check (✓) in the space next to the person whom you utilize as a resource person. Choose as many as may apply. Using the red pen, put a "1" in the space next to the person whom you utilize the most, and so on until you have ranked the persons that you have identified.

_____ Parents
_____ Teachers
_____ Friends
_____ Doctor
_____ Nurse
_____ Social worker
_____ Others: Please write in:______________________________
_____ No one

APPENDIX C

PERMISSION LETTER TO USE TOOL

15482 Waters Creek Dr.
Centreville, VA 22020
(703) 378-6331
February 1, 1993

Dear Ms. Benoit,

I give you permission to use my tool entitled "Primary Health Care Needs Assessment (Adolescent and Parent forms) for your research. I have enclosed one copy of each tool as well as the methodology section of my Master's thesis from which the article in <u>Pediatric Nursing</u> was derived.

In order to refine this tool in the future, I require that those who use it send me a copy of their findings using the instrument. I would like to give you some information regarding the instrument by phone, as it will help you use it more effectively. I may be reached at the above number most often in the evenings.

I wish you much luck in your research pursuits and am very interested in your and your daughter's impression of the full instrument. I look forward to speaking with you.

Very truly,

Mary Alice Dragone

Mary Alice Dragone, MS, RNC, PNP

APPENDIX D

APPROVAL OF MISSISSIPPI UNIVERSITY FOR WOMEN COMMITTEE ON USE OF HUMAN SUBJECTS IN EXPERIMENTATION

MISSISSIPPI
UNIVERSITY
FOR WOMEN
Columbus, MS 39701

Office of the Vice President for Academic Affairs
Eudora Welty Hall
P.O. Box W-1603
(601) 329-7142

February 11, 1993

Ms. Catherine Benoit
c/o Graduate Nursing Program
Campus

Dear Ms. Benoit:

I am pleased to inform you that the members of the Committee on Human Subjects in Experimentation have approved your proposed research.

I wish you much success in your research.

Sincerely,

Thomas C. Richardson
Vice President
for Academic Affairs

TR:wr

cc: Mr. Jim Davidson
Ms. Jeri England
Dr. Nancy Hill
Dr. Rent

APPENDIX E

LETTER REQUESTING AGENCY CONSENT

6954 Kiln Delisle Road
Pass Christian, MS 39571
(601) 255-5904

March 19, 1993

Dear Dr. Rodgers,

My name is Catherine Benoit. I am a registered nurse and a graduate student in the Family Nurse Practitioner program at Mississippi University for Women, in Columbus, Mississippi. Research is a major component of my studies, and I am replicating a study on Perspectives of Chronically Ill Adolescents and Parents on Health Care Needs which was done by Dragone (1990).

I am requesting access to the pediatric outpatient clinics at the University Medical Center in order to conduct this research. I request access to adolescent populations between the ages of 11 to 19 years who are seen in the pediatric specialty clinics with their parents. The areas I wish to include in this study are: diabetes, cystic fibrosis, rheumatology, ESRD, asthma/pulmonology, hematology/oncology, and congenital heart disease.

Criteria for participation in this study are as follows:

1. Adolescents have been diagnosed for a period of 3 months to 18 years,
2. Adolescents are between the ages of 11 and 19 years, and
3. Adolescents are accompanied by parents/caretakers.

The questionnaire utilized in this research has been authored by Mary A. Dragone, a pediatric nurse practitioner. Content encompasses a variety of possible health concerns to be identified by adolescent and parent/caretaker.

I will certainly accommodate the most convenient scheduling the clinic coordinators are able to allow me; however, I have a time limitation imposed with this study. I hope to begin data collection by late April and have all areas covered in a 4- to 5-week period. Therefore, I request response to this application by April 7, 1993.

I am enclosing the Primary Health Care Needs Assessment instrument, a copy of the informed consent, and a copy of the IRB approval for human rights from the Mississippi University for Women. Please advise me if any further information is necessary.

I wish to extend my appreciation for your efforts, as well as those of the medical and nursing staff, in assisting with conduction of this research. Results of this study will be disseminated to all interested parties.

Sincerely yours,

Catherine Benoit, RN, BSN

APPENDIX F

PERMISSION LETTER FROM THE UNIVERSITY OF MISSISSIPPI MEDICAL CENTER IRB

THE UNIVERSITY OF MISSISSIPPI MEDICAL CENTER
2500 North State Street
JACKSON, MISSISSIPPI 39216-4505

School of Medicine
Department of Medicine
Division of Digestive Diseases

Area Code 601
984-4540

April 13, 1993

Ms. Catherine Benoit
UMC School of Nursing
University Medical Center
Jackson, Mississippi 39216-4505

Re protocol: Perspectives of Health Care Needs by Chronically Ill Adolescents and Their Parents

Dear Ms. Benoit:

Thank you for submitting the above protocol. I find it exempt from UMC IRB review so long as anonyity is preserved. No further contact with the IRB will be necessary.

Your protocol and correspondence will remain in our "exempted" file.

Sincerely,

James L. Achord, M.D., Chairman
Institutional Review Board

JLA:bj

APPENDIX G

INFORMED CONSENT FORM

Informed Consent Form

In signing this document, I am giving consent for myself/adolescent minor to participate in a study conducted by Catherine Benoit, RN, a graduate student at Mississippi University for Women in Columbus, Mississippi. I understand that I/adolescent minor will be part of a research study that will focus on the primary health care concerns of adolescents with chronic illness and their parents.

I understand that I/adolescent minor will be interviewed during a clinic visit about health problems, general health issues, and people I utilize to help with those health concerns. I also understand that both adolescent and parent will be interviewed by questionnaire, and neither person will discuss the information being gathered with the other person. All information is confidential. The interview will take less than an hour to complete.

This interview is granted freely. I have been informed that the interview is entirely voluntary, and that even after the interview begins I can refuse to answer any specific questions or decide to terminate participation in this study up to the point of data analysis. I have been told that my answers to questions will be disclosed only as part of the group study, and no reports of this study will ever identify me in any way. I have also been informed that my participation or non participation, or my refusal to answer questions, will have no effect on services that I or any member of my family may receive from health or social service providers at this hospital. I will not receive any direct benefits as a result of my participation in this study. This study will help to identify the primary health care needs of chronically ill adolescents and their families in order to assist health care workers to better understand and meet those needs. There are no identified risks.

I understand that the results of this research will be given to me if I ask for them and that Catherine Benoit, RN is the person to contact if I have any questions about the study or about my rights as a study participant. Ms. Benoit can be reached at (601) 255-5904.

______________________________ Parent/Guardian	________________________ Interviewer
______________________________ Adolescent Minor	________________________ Date

APPENDIX H

INFORMED CONSENT FORM (REVISED)

Informed Consent Form (Revised)

In signing this document, I am giving consent for myself and my adolescent minor to participate in a study conducted by Catherine Benoit, R.N., a graduate student at Mississippi University for Women in Columbus, Mississippi. I understand that I and my adolescent minor will be part of a research study that will focus on the primary health care concerns of adolescents with chronic illness and their parents.

I understand that I and my adolescent minor will be interviewed during a clinic visit about health problems, general health issues, and the people I utilize to help with those health concerns. I also understand that both adolescent and parent will be interviewed by questionnaire, and neither person will discuss the information being gathered with the other person. All information is confidential. The interview will take less than an hour to complete.

This interview is granted freely. I have been informed that the interview is entirely voluntary, and that even after the interview begins I can refuse to answer any specific questions or decide to terminate participation in this study up to the point of data analysis. I have been told that my answers to questions will be disclosed only as part of the group study, and no reports of this study will ever identify me in any way. I have also been informed that my participation or non participation, or my refusal to answer questions, will have no effect on services that I or any member of my family may receive from health or social service providers at this hospital. I will not receive any direct benefits as a result of my participation in this study. This study will help to identify the primary health care needs of chronically ill adolescents and their families in order to assist health care workers to better understand and meet those needs. There are no identified risks.

The University of Mississippi Medical Center has no mechanism to provide compensation for subjects who may incur injuries as a result of participating in biomedical and behavioral research. This means that while all investigators will do everything possible in providing careful medical care and safeguards in conducting this research, there is no way in which the institution can pay for the unlikely occurrence of injury resulting solely from the research itself. We will, of course, provide our best medical treatment to which you are entitled for the illness, if any, for which you consulted us whether or not you participate in this study and whether or not you decide to withdraw from the study.

I understand that the results of this research will be given to me if I ask for them and that Catherine Benoit, RN, or Barbara P. Rogers, PhD, RN are the persons to contact if I have questions about the study. Ms. Benoit can be reached at (601) 255-5904 and Barbara P. Rogers at (601) 984-6233.

Question regarding my rights as a study participant can be answered by Dr. James L. Achord, Institutional Review Board, who can be reached at (601) 984-4540.

______________________________ Parent/Guardian

______________________________ Interviewer

______________________________ Adolescent Minor

______________________________ Date