Title
Primary health care needs identified by chronically ill adolescents and parental perceptions of those needs

Author
Dragone, Mary Alice

Publication Date
1988

Peer reviewed|Thesis/dissertation

Primary Health Care Needs Identified by Chronically Ill Adolescents and Parental Perceptions of Those Needs

by

Mary Alice Dragone

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA

San Francisco

DEDICATION

This thesis is dedicated to my husband, Thomas Dragone,
who challenged me to grow beyond my expectations,
supported me with his time, patience, and love, and
smiled through it all.

ACKNOWLEDGEMENTS

This thesis could not have come to its completion without the assistantance of many people who gave of their expertise and support. I am grateful for the efforts of my thesis commitee, Drs. Bonnie Holaday, Marilyn Savedra, and Barbara Durand, who skillfully combined critique with encouragement and support during the development of this project.

A special note of thanks is extended to those adolescents and their families who participated in this research and to the physicians and clinic staff who allowed me access to their patients. Over the past two years I have received priceless emotional support from my fellow nurse practitioners, family, and friends who never ceased to show interest in my research through its high and low points.

I would especially like to thank my husband and parents for encouraging me to "reach for the stars" for I'm beginning to touch them.

This research has been funded by a grant from the Alpha Eta Chapter of Sigma Theta Tau.

ABSTRACT

A descriptive research design was used in this study to ascertain both the primary health care needs identified by chronically ill adolescents and parental perceptions of these needs. A noncategorical approach to chronic illness guided the nonprobability sampling of twenty-four 11 to 19 year-olds seen at specialty clinics associated with a university medical center. Utilizing a framework of symbolic interactionism, Lamberton's model of health and illness, and developmental theory, an author-designed Primary Health Care Needs Assessment was administered in written form to the chronically ill adolescents and their parents. The most prevalent and top-ranked primary health care needs identified by the adolescents were boredom, concern about the effect of the illness with increasing age and in childbearing, general concern about their health, not being able to do the things their friends do, headaches, depression, being overweight, not doing well in school, and needing help to decide about the future. The 76% average degree of adolescent-parent agreement did not differ significantly by adoelscent sex, age, or chronic illness grouping. These adolescents most frequently used their parents (42%) and physicians (37%) as resources to need their identified needs; however, 20% of the identified primary health care needs were met by no one. Nurses were utilized for only 8% of the identified needs. Some of the needs which increased significantly in prevalence across early, middle, and late adolescent groups were needing help with future plans, depression, problems sleeping, and concern about the future effects of the illness. The complexity and diversity of chronically ill

adolescents' perceived primary health care needs elicited by this study necessitates access of these adolescents to comprehensive and coordinated primary health care. Future research may focus on correlates of depression expressed by these adolescents, comparison with the primary health care needs identified by "healthy" adolescents, and the means by which adolescents access information related to their needs.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF APPENDICES

Chapter I: Introduction

Effective communication between clients and primary health care providers depends on an understanding of the meanings that clients assign to their own needs. The provider interacts with more than one client when a chronically ill adolescent presents for primary health care -- the adolescent and his or her parents. Because the meanings that each assign to primary health care needs may vary, the purpose of this research is to discern what chronically ill adolescents and their parents identify as the adolescent's primary health care needs.

Primary health care encompasses both the promotion of health and the management of illness (Hansen, 1970) in an accessible, comprehensive, coordinated, continuous, and accountable manner (Institute of Medicine, 1977). Chronically ill adolescents are particularly at risk for receiving primary health care that is less than comprehensive. Specialists have often been looked to as providers of primary health care despite their inherent focus on illness management. In two studies, for example, 31 percent (Palfrey, Levy, & Gilbert, 1980) to 40 percent (Carroll, et al., 1983) of chronically ill adolescents were unable to identify a primary health care provider outside of their illness specialty clinics. Other researchers (Kanthor, Pless, Satterwhite, & Myers, 1974; Pless, Satterwhite, & van Vechten, 1978) have described the lack of coordination and comprehensiveness in the primary health care of this population that had resulted from the fragmentation and duplication of services.

The primary health care provider uses his or her knowledge to prioritize needs by various medical and nursing models. The client provides personal priorities for

the needs that most greatly affect his or her functioning. Symbolic interactionism (Blumer, 1969) posits that an understanding of the meanings an individual assigns to objects and events is crucial to effective interaction. Inattention to clients' needs often leads to decreased participation in the prescribed plan of care (Korsch, Gozzi, & Francis, 1968).

In the past, data concerning the primary health care needs of chronically ill adolescents either (1) have not been gathered in a comprehensive manner with attention to developmental issues or (2) have not been obtained directly from adolescent clients. A model of health and illness, which encompassess developmental and environmental issues as well (Lamberton, 1983), forms the framework for assessing the primary health care needs of adolescents. Knowledge of what chronically ill adolescents identify as their needs is crucial to the provision of comprehensive primary health care.

Statement of the Problem

Little is known about the self-identified primary health care needs of chronically ill adolescents. Without first-hand knowledge of these perceived needs or agendas, primary health care providers cannot expect to provide services that are acceptable to adolescents and their parents. Although certain pieces of research have been able to elicit some of these perceived needs (Carroll, et. al., 1983; Palfrey, et. al., 1980), a comprehensive and developmentally appropriate primary health care needs assessment of this population had not been conducted prior to the current study.

A needs assessment questionnaire was used in this study to ascertain what chronically ill adolescents identify as their primary health care needs. A parallel

assessment was conducted to determine what parents perceive as the adolescents' primary health care needs. This approach has the benefit of directly assessing the presence of specific needs from the perspectives of both primary health care clients--the chronically ill adolescent and his or her parents.

In this study, primary health care is defined as the promotion of health and management of illness (Hansen, 1970). The comprehensiveness of primary health care as it relates to individuals is the specific focus of this study and is derived from the Institute of Medicine's (1977) definition of the components of primary care. This definition of primary health care must be differentiated from the World Health Organization's definition which encompasses health care that is not limited to individual care but also includes the health of the community, i.e., clean drinking water and sanitation (World Health Organization, 1978).

Chronically ill adolescents should have the opportunity to receive primary health care that focuses both on health promotion and illness management. The complexity of their illnesses may divert most attention toward illness management. The provision of comprehensive care is made more complex by the inclusion of both parents and the adolescent as clients and consumers of health care. There also exists a potential gap between what these adolescents identify as their primary health care needs and what needs are perceived by their parents.

Purpose

The purpose of this study is to describe both the primary health care needs identified by chronically ill adolescents receiving care at specialty clinics associated with a university medical center and the parental perceptions of these needs. More specifically, answers to the following research questions are sought:

1. What are the primary health care needs identified by chronically ill adolescents who receive care at specialty clinics associated with a university medical center?
2. What are the parental perceptions of these needs?
3. What is the degree of agreement between the needs identified by these chronically ill adolescents and those identified by their parents?
4. What resources are used by chronically ill adolescents to meet identified primary health care needs?
5. What clusters of primary health care needs are identified by early, middle and late adolescents in the sample population?

Significance of the Study

The findings of this study will have widespread importance because chronic illness affects 10 to 20 percent of our childhood and adolescent population (Gortmaker & Sappenfield, 1984; Haggerty, Roghmann, & Pless, 1975). As a result of advanced technology, 90 percent of chronically ill children can be expected to live to the age of twenty (Gortmaker & Sappenfield, 1984). This trend effectively increases the number of adolescents with chronic illnesses that are receiving primary health care.

There are few studies which have sought to describe the primary health care needs of chronically ill adolescents. Those that have are lacking in direct assessment of the adolescent client and use of developmentally appropriate and comprehensive assessment tools. Several studies have directly assessed healthy adolescents to determine their primary health care needs (Sternlieb & Munan, 1972; Parcel, Nader, & Meyer, 1977; Hodgson, Feldman, Corber, & Quinn, 1986; Smith, Turner, & Jacobsen, 1987). Most studies of chronically ill adolescents' primary

health care needs have obtained data primarily from parents (Palfrey, et al., 1980; Schade & Passo, 1981; Passo-Coffman, 1983). Adolescents, however, are also considered as clients and need to be assessed directly in order to meet their expectations for care. A data base which fails to address the perceived primary health care needs of both clients may result in care that is unacceptable to either adolescents or their parents. This study extends knowledge of the similarities and differences in perceptions of primary health care needs between chronically ill adolescents and their parents. These data also enable primary health care providers to anticipate the range of needs common to both client populations.

Attempts to determine the primary health care needs of adolescents must be developmentally appropriate in order to be comprehensive. Frequently, because adolescents have been a subgroup of a larger sample of chronically ill pediatric patients, the assessment tools that were used failed to address specific adolescent health care needs (Schade & Passo, 1981; Passo-Coffman, 1983). Even studies which utilized adolescent target populations did not include a comprehensive review of developmental concerns (Palfrey, et al., 1980; Carroll, et al., 1983). This study contributes to nursing's body of knowledge regarding developmentally appropriate primary health care needs assessments of chronically ill adolescents.

In a primary health care setting, it is often very time consuming to elicit a fully comprehensive data base related to the adolescent's health, illness, and developmental concerns. In specialty clinics where many chronically ill adolescents seek primary health care (Palfrey, et al., 1980; Carroll, et al., 1983), even less time may be allotted for primary health care needs assessments. This study extends clinical knowledge by documenting primary health care needs that are

common to this population, thereby allowing providers to incorporate commonly perceived needs within the plan of care.

In a proposed research agenda for nurse practitioners, Molde and Diers (1985) encouraged practitioners to demonstrate their suitability as health care providers for chronically ill individuals. This study will demonstrate the utility of a nursing model of health and illness in assessing the primary health care needs of chronically ill adolescents. The data will enable nurse practitioners to both direct their care more efficiently and focus future research efforts with attention to the clients' priority concerns for care.

Operational Definitions

1. Primary health care needs: Those specific needs or concerns occuring within the past year that are related to health promotion or illness management as reported on the Primary Health Care Needs Assessment (PHCNA).
2. Chronically ill: Having a "physical or sensory disorder lasting three months or longer" (Pless et al., 1976, p.38) as indicated on the Demographic Data Form (DDF).
3. Adolescent: An individual between the ages of 11 and 19 by self-report on the adolescent's DDF.
4. Parent: The adolescent's biological or adoptive mother or father or his/her legal guardian as reported on the parent's DDF.
5. Parental perceptions: The adolescent's specific needs or concerns, occurring in the past year, that are related to health promotion or illness management as reported on the parent's PHCNA.
6. Resources: Those persons or groups having the ability to meet individual

primary health care needs based on parent and adolescent reports on the PHCNA.

Assumptions

This study has the following underlying assumptions:

1. Adolescents with different chronic illnesses have similar primary health care needs.
2. Primary health care needs encompass the elements of health, illness, development, and environment.

Chapter II: Theoretical Framework and Review of the Literature

Introduction

This chapter will begin with a theoretical framework that addresses both the rationale for studying chronically ill adolescents' self-identified primary health care needs and the scope of a comprehensive and developmentally appropriate assessment of these needs. This will be followed by a review of relevant research literature related to the variables of this study, i.e., primary health care for chronically ill adolescents, a noncategorical perspective on chronic illness, and perceived primary health care needs of both well and chronically ill adolescents.

Theoretical Framework

The framework for this study will (1) validate the need to assess the self-identified primary health care needs of chronically ill adolescents' and their parents' using symbolic interactionism, (2) use Lamberton's model of health and illness to elucidate the areas included in comprehensive primary health care, and (3) place adolescent primary health care within a developmental perspective.

Symbolic Interactionism. The grand theory of symbolic interactionism broadly holds that effective communication involves an understanding of the meanings that an individual assigns to objects or events within his or her world. This theory provides a rationale for the need to directly assess what meanings chronically ill adolescents assign to their own primary health care needs. These meanings have the potential for being different from those of their parents. The different developmental stages of the respondents have a great potential for influencing the meanings that are assigned to specific needs (see "Developmental

Theory" for discussion). In the paragraphs which follow, both the general theory of symbolic interactionism and a particular middle-range theory that applies specifically to this study will be discussed. Concurrently, the theoretical propositions will be applied to the current study of chronically ill adolescents.

The three basic premises of the grand theory of symbolic interactionism described by Blumer (1969) will be related to the aims of this study. First, individuals act in a particular way toward objects and events based on the meaning they have assigned to them. Adolescents tend to respond more actively when interventions address those concerns that are most important to them. It would be helpful for primary health care providers to know which primary health care needs are most important to chronically ill adolescents. Secondly, social interactions with other individuals are central to the derivation of these meanings. Adolescent development includes the expansion of social networks and the increasing influence of peers. Because the parents of adolescents have social interactions with individuals different from those of their children, there exists a potential difference in the meanings that each derive from their social interactions. Lastly, individuals proceed through a process of self-interaction by which they continue to select and transform past meanings assigned to objects or events based on the current situation. An adolescent with a chronic illness has had, by definition, months to years to transform particular meanings with respect to his or her own specific illness and unique social and environmental situation. This last premise allows for individual differences based on an individual's ability to rely on past life events to shape current meanings.

"Definition of the Situation Theory" is a middle-range theory of symbolic interactionism specified by Burr, Leigh, Day, and Constantine (1979). The meaning that a particular situation has for an individual is the "definition of the situation." This theory states three major propositions: (1) The effect of a situation is determined by an individual's definition of the situation. For example, when an adolescent undergoes chemotherapy, his or her parent may define the situation as a beneficial life-saving measure while the adolescent may define it in terms of his or her loss of control (restriction by an intravenous line, hair loss, swelling from steroids). In determining the effect of the chemotherapeutic treatment, the adolescent may use the outcome measure of amount of control retained while the parent may use tumor reduction alone as a criterion. (2) The greater the value attached to a situation, the greater will be its effect in social interactions. For example, if an adolescent who values being physically active in sports develops kidney failure, the restrictiveness of renal dialysis will have a greater effect on him than on another adolescent who occupies him or herself with activities that can be done in the clinic (i.e., needlework, sketching, reading). (3) If someone defines a situation as being real, its consequences are real for that person. If adolescents believe that they have a hard time making friends because of their chronic illnesses, then future situations in which they are unable to acquire a certain friend may be attributed to the illness and not to a personality fault. The perceived negative effect of their illnesses on friendship building may result in social isolation which removes them from the chance of even meeting new people.

In summary, symbolic interactionism and, more specifically, "definition of the situation theory" state that differing spheres of social interaction can lead to different

meanings assigned to the same situation or event. Adolescent developmental changes with regard to increasing social influences from outside the family may contribute to differing meanings between adolescents and their parents. Because primary health care providers also attach their own meanings to certain needs based on medical or nursing models, they may be unaware of the meanings assigned to the same potential concerns by chronically ill adolescents and their parents. Symbolic interactionism provides the rationale for the focus of this study on a direct needs assessment of the chronically ill adolescents as well as their parents.

Lamberton's Model of Health and Illnes. Lamberton's model of health and illness (1983) is used to describe the components to be considered in any primary health care needs assessment. It elaborates on the classic definition of primary health care which encompassess the promotion of health and the management of illness (Hansen, 1970). The original model is based on the hypothesis that health and illness form separate continua. The absence of health is not synonymous with the presence of illness. That is, "a person may be relatively unhealthy [i.e., sedentary and overweight] and yet free of any illness" (Lamberton, 1983, p.50). The opposite is also true. For example, an adolescent with well controlled diabetes may be classified as having an illness yet be reasonably healthy with respect to development, sleep, mobility, and social skills. One's position on the health continuum is determined by such parameters as mobility, sexual functioning, and nutritional status. The illness continuum is concerned with the course of a pathological condition such as diabetes.

The concepts of development and environment complete the model. Developmental tasks remain despite the absence of health or the presence of illness. This concept must be considered in the delivery of care at each point on the health and illness continua (see "Developmental Theory" for discussion). Lamberton defines the environment as inclusive of but "not limited to internal milieu, family, community, friends, groups, society, place in time, culture, race, politcs, economics, natural resources and climate " (Lamberton, 1983, p.52). A client's interaction with the environment affects where he or she will be on the health or illness continua.

The original model (Appendix A) depicts development as a separate continuum while acknowledging its interactive effects on health and illness. For the purpose of this study, the model has been modified to view development primarily as an interactive factor rather than as a distinct continuum in and of itself (Appendix A).

This model was chosen because it gives equal consideration to health and illness in the provision of care with an emphasis on the interactive effects of development and environment. This has practical import in the provision of primary care to chronically ill adolescents who have many needs related to their development and changing social environment in addition to pressing illness needs. In order to assess primary health care needs, a framework addressing a wide range of possible concerns is crucial.

Developmental Theory. As previously discussed with regard to symbolic interactionism, the meanings that chronically ill adolescents assign to their primary health care needs is greatly impacted by social interactions and concurrently by developmental status. These primary health care needs are best understood from a

developmental perspective. The developmental theory presented in this section is eclectic in nature and is related specifically to the issues of particular concern to early, middle, and late adolescents. It will begin, however, with some notable general theories of adolescence.

Erikson's (1968) stage of "identity vs. role confusion" serves as a broad base for discussing the developmental tasks of adolescence. Identity is achieved through clarification of values, increased autonomy of action, and an awareness of one's sexuality. Aten and McAnarney (1981) described major developmental and behavioral issues that need to be assessed in adolescents: "separation from family; development of peer relationships; emerging sexuality; relationships to school and work activities; planning for the future -- career, adult living, the next generation; and, the presence of social habits which 'test' the environment -- alcohol or other substance use, smoking, etc." (Aten & McAnarney, 1981, 45-46).

Elkind (1967) concentrated on the egocentrism demonstrated by adolescents. Adolescents seem to believe that they are constantly the focus of attention among their peers resulting in either admiration or criticism. Because this audience exists primarily in the adolescent's mind, Elkind has termed it the "imaginary audience". The concept of "personal fable" is closely related and refers to the adolescent's belief in his or her uniqueness and also a belief in his or her indestructibility.

Adolescence is separated into early, middle, and late stages. In early adolescence (ages 11 to 13), individuals experience the beginnings of physical sexual maturation. They are frequently preoccupied with their bodies and compare the normalcy of their development with their peers. The increasing importance of peer relationships may be accompanied by decreased compliance with family rules,

values, or routine events. Abstract cognitive thought begins to emerge at this time and develops more fully throughout adolescence.

During middle adolescence (ages 14 to 16), "young people are concerned primarily with achieving psychological independence from their parents and learning to handle dating and heterosexual relationships" (Elkind & Weiner, 1978, 564). Standards for behavior are often set by the peer group (Irwin, 1982). Physically they have attained much of their adult height and have the capacity to reproduce.

Late adolescence (ages 17 to 19 and beyond) continues until the individual has "formed a reasonably clear, consistent sense of personal identity and has committed him or herself to some fairly definite social roles, value systems, and life goals" (Elkind & Weiner, 1978, 564). At this time there appears to be less overt conflict with parents as the adolescent integrates parental values with his or her own (Aten & McAnarney, 1981).

In summary, developmental theory interfaces with both symbolic interactionism and Lamberton's model of health and illness. Developmental issues are influential in the formation of meanings that chronically ill adolescents assign to their primary health care needs. Consideration of physical, cognitive, psychological, and social aspects should also be part of a developmentally appropriate and comprehensive assessment that addresses the continua of both health and illness.

Review of Relevant Research Literature

This review will more fully develop the major dependent variable of this study: primary health care needs of chronically ill adolescents. The review begins with a

discussion of primary health care utilization by chronically ill adolescents. Issues related to a definition of chronic illness will follow in order to substantiate the noncategorical approach taken by this study. A discussion of current research documenting adolescent primary health care needs will be followed by studies focused specifically on chronically ill adolescents.

Primary Health Care Related to Chronic Illness. To gain an understanding of primary health care as it relates to chronic illness, it is necessary to define this type of care and to describe its utilization by chronically ill adolescents. The Institute of Medicine (1977) identified the essential components of primary health care as accessibility, continuity, comprehensiveness, and accountability. The literature shows widespread use of this definition (Featherstone & Petersdorf, 1978; Levy et al., 1979; Palfrey et al., 1980). The domain of primary health care in pediatrics includes health promotion and illness management. However, authors tend to vary the emphasis placed on the domain of health concerns (Aiken et al., 1979; Burns & Thompson, 1984; Hansen, 1970).

Despite Battle's (1972) designation of the pediatrician as ombudsman or coordinator of primary health care, these physicians have not been able to maintain this role with many chronically ill children and adolescents. Pless, Satterwhite, & van Vechten (1976) found that many physicians have not taken a major role in counseling, advising, and coordinating adjunct services. The physician's assumption of primary responsibility for these children varied with the condition involved (i.e., 57% for cerebral palsy and 93% for asthma). Although specialists have generally not gained expertise in the provision of primary health care, they are being called upon to provide this care for over one-third of chronically ill adolescents

(Carrol et al., 1983; Palfrey et al., 1980). In an evaluation of health care utilization, children with no primary health care source were those most likely to be seen at subspecialty clinics (Levy et al., 1979).

To conclude this discussion of primary health care among chronically ill adolescents, it has been demonstrated that interprofessional conflicts abound in the territorial arena of primary health care for chronically ill children and adolescents (Klerman, 1985). Resultant gaps have occurred particularly in the areas of comprehensiveness and coordination between specialty providers and pediatricians/ pediatric nurse practitioners. Health professionals have unique and overlapping functions which must be coordinated to prevent the duplication and neglect of services (Klerman, 1985). Hymovich (1985) identified the pediatric nurse practitioner in specialty chronic illness care as a professional who may help to coordinate primary health care services for these children and adolescents.

Noncategorical Approach to Chronic Illness. Since the 1970's an approach has been developing to define chronic illness in terms of concerns and characteristics common to all chronically ill children rather than by specific disease categories. The development and benefits of this approach will be expanded in the paragraphs to follow.

Mattson (1972) referred to chronic illness in childhood as a "disorder with a protracted course which can be progressive and fatal, or associated with a relatively normal life span despite impaired physical or mental functioning" (p. 801). Pless, Satterwhite, and Van Vechten (1976) defined chronic illness as a "physical or sensory disorder lasting three months or longer" (p.38). Both definitions consider the general attributes of a chronic illness that may be applied to a wide range of

specific conditions.

Pless and Pinkerton (1975) were among the original proponents of a noncategorical approach to chronic illness. They noted "certain problems common to all chronic illnesses over and above particular challenges posed by individual needs" (p.52). In substantiation of this position, Stein and Jessop (1982) found marked commonalities across different chronic disease categories in evaluations of the impact of the illness, burden imposed on the family, and other measures. Similar findings were noted among chronically ill adolescents (Coupey & Cohen, 1984). Demanding routines of care and developmental changes are among the problems common to chronically ill children and adolescents (Ireys, 1981, Perrin, 1985).

In conclusion, the usefulness of a noncategorical approach to chronic illness has been repeatedly documented in the literature. Attention to areas of commonality among various conditions can be helpful to the many practitioners who do not see large numbers of any one chronic illness in their practice. Additionally, this approach allows research efforts to serve the widest possible target population.

Primary Health Care Needs of Adolescents. As was previously discussed in the theoretical framework, the primary health care needs of adolescents must be viewed from a developmental perspective in order to give holistic care. The studies that will be evaluated in this section will focus on the documentation of adolescent health care issues that are biopsychosocial in nature.

Psychosocial issues are frequently the concern of adolescents and their parents. Parents of healthy children and adolescents identify many of their concerns in the areas of development, discipline, and preventive care (McCune, 1984; Ryberg &

Merrifield, 1984). Consistent with this perspective, Haggerty, Roghmann, and Pless (1975) noted a "new morbidity" that includes behavior problems, school functioning, and adjustment to adolescence.

Sternlieb and Munan (1972) studied the health problems identified by 15 to 20 year old Canadian youth (N=1346) to aid in the planning of a youth clinic. The stratified random sample was drawn from secondary schools, colleges, and workplaces. The questionnaire, divided into sections on health problems (8 items) and personal problems (10 items), was not based on a theoretical framework and neither reliability nor valididty data were included. The "health problems" scored with the highest frequencies were nervousness (29%), dental (27%), and acne (18%). The most frequent "personal problems" in the overall sample were school (30%) and family (21%). The subgroup of secondary students most closely matched the sample totals as they represented 56 percent of the subjects. Differences were evident in the other subgroups; for example, among the workers, family (26%), religion (16%), and communication with adults (16%) were the top concerns while among junior college students, family (21%), school (20%), and "psychological" problems (18%) predominated. Despite the small number of items related to health concerns, those that were included did cover a great many of the common health and developmental issues of adolescents; however, some of the item labels were vague and may have challenged the reliability of these items.

A sample of 3255 fifteen to eighteen year-olds, representing 71% of the target population, was studied by Parcel, Nader, and Meyer (1977) to determine adolescent health care utilization, health concerns and problems. Extensive demographic data on the sample is beneficial in the application of results despite the

time elapsed since the study's completion. Although the data base related to health needs was fairly extensive, inconsistencies in the wording of questions could have created confusion among the subjects. Of the nine items listed, the most frequent "health concerns" were school (44%), drugs (39%), sex (38%), and parents or family (35%). When the subjects were asked which problems they wanted help with, 20 to 30% listed these areas (in order of increasing frequency): nervousness, dental, worries about their health, getting along with parents, overweight, depression/ sadness, how far to go with sex, and acne/pimples. Variations between ethnic groups were not remarkable. The most frequent source of health care was the family physician (57%) followed by the emergency room (16%), medical center clinic (15%), public health clinic (10%), and the high school clinic (2%). Regardless of socioeconomic status, black students relied more on public health facilities. The weaknesses of this study are that no conceptual/ theoretical framework for instrument development was presented and that reliability data on the instrument were not obtained.

In Hodgson, Feldman, Corber, and Quinn's (1986) study of 730 Canadian adolescents (ages 12 to 20), a mailed survey was used to elicit information about the subjects' health care utilization. A list of sixteen health concerns was included and identified the major concerns of this population: acne (47%), menstruation (32% of females), nervous/emotional (26%), dental (26%), and overweight (26%). The lack of an explicit theoretical rationale and specific objectives, no reliability or validity data concerning the instrument used, and inappropriate labeling of the sample as randomly drawn are among the limitations of this study.

The only nursing study which assessed the self- identified health concerns of adolescents was completed by Smith, Turner, and Jacobsen (1987). One hundred forty-nine ninth graders were given a 45 item author-designed questionnaire covering the categories of physical functions, physical appearance, mental health, interpersonal relations, and social/sexual concerns. Although no information was given regarding instrument development, the items addressed a broad range of biopsychosocial concerns that have appeared consistently in the literature. The data reflected a difference in the frequency of health concerns perceived by males and females. The most prevalent concerns among male subjects were the future (48%), body build (44%), vision (44%), muscles (41%), and teeth (39%). Girls most frequently checked concerns about body weight (73%), the future (69%), hair (62%), figure (60%), skin (60%), teeth (54%), and emotions/feelings (51%). The researchers presented conflicting data with regard to the age of subjects, once stating them as 12 to 15 years of age and at another time as 14 to 16 years of age. This is of particular importance in the interpretation of the prevalence of certain health concerns and in the application of the results to other groups of adolescents. Neither reliability data nor an evaluation of this first piloting of the instrument was provided.

In summary, assessments of adolescent primary health care needs in the research literature have become more comprehensive and developmentally focused. Major deficits remain the lack of specific theoretical or conceptual frameworks and the omission of reliability and validity testing of new instruments.

Primary Health Care Needs of Chronically Ill Adolescents. In studies which have assessed the primary health care needs of chronically ill adolescents, the

adolescents have most often been a subgroup of a larger pediatric sample composed of infants through adolescents. Only one study, presented in the paragraphs to follow, focused specifically on an adolescent population. Variations have also occurred in the use of parents and/or adolescents as reporters of identified needs.

The purpose of Schade and Passo's (1981) study was to develop an instrument to assess the needs of parents and children who were seen in sixteen pediatric specialty clinics. Parents of 178 patients (0 to 21 years of age), twenty-two percent of whom were adolescents, completed an author-designed needs assessment survey consiting of 12 illness/handicap related items and 11 related to health maintenance concerns that the parents would want to discuss with a nurse. Over 30 percent of parents desired to speak with a nurse concerning medications that the child received, how the child's development was affected by the illness, and additional help in understanding the child's illness or handicap. Although the relatively large sample size enabled the authors to specify particular needs of their target population, demographic data concerning socioeconomic status, race, and specific illnesses within the sample would not allow accurate replication. Despite the authors' instrument development, no theoretical framework, reliability data, or evaluation of the instrument were presented.

Passo-Coffman (1983) expanded the survey items of the previous study to include 31 items worded specifically for parents (N=203) of cerebral palsy patients (infants through adolescents) seen in an ambulatory clinic. The purpose of this study was to prioritize the needs of parents in order to direct the energies of clinic nurses. Twenty-four percent of the patients were adolescents. The most frequently chosen (27 to 33%) topics of concern to parents were a lack of

understanding of the illness, how the child's development was affected by the illness, lack of knowledge about community resources, and colds/respiratory problems. As with the previous study, the restriction of parents to those items they would want to discuss with a nurse does not allow for the identification of those items a parent would want met by a different member of the health care team. The nurse is, however, in an ideal role to facilitate this. The statistical methods were appropriate for the data obtained but reliability tests were not included. The post hoc relationships drawn between number of parental concerns and demographic data did not relate clearly to the study's objectives. The limitations of the study included wide range and lack of specification of the exact range of patient ages. The data from the large and homogeneous sample, however, do provide useful guidelines for future research.

In Palfrey, Levy, and Gilbert's (1980) descriptive study of the parents of 158 children seen at the specialty clinics of a university medical center, an interview was used to elicit the use of primary health care and perceived health care needs. This nonrandom sample consisted of 35 adolescents (age 13 and over) who were also invited to participate in the interview with their parents. Data for the entire sample revealed that thirty-one percent had no source of primary care compared with 43% of the adolescent subgroup. The review of systems used to assess perceived health care needs did not include many of the developmental issues of great import to adolescents (i.e., body image, sexual development, stature, future plans, interpersonal relationships). The inclusion of both parents and adolescents in the same interview did not provide the confidentiality for eliciting a wider range of perceived health needs. It was significant that one or more health problems were

not discussed with any health care provider among 38 percent of the sample. No reliability or validity data were provided for the assessment of perceived health care needs. Neither a theoretical nor a conceptual framework was provided for this study.

The most recent study directly assessing the health care needs of adolescents was conducted by Carroll et al. (1983). The subjects (N=61), aged 14 through 18 years, attended six specialty clinics at a Canadian teaching hospital. Diagnoses included diabetes, asthma, seizure disorders, renal failure, juvenile rheumatoid arthritis, and inflammatory bowel disease. An author-designed questionnaire was pilot tested before its use in this study but no reliability data were presented. Some instrument error was noted in varying totals (n) for various items from the questionnaire. A developmental framework was implicitly utilized in this assessment of adolescent health care needs. As the entire tool was not presented, however, it is difficult to evaluate the comprehensiveness of the instrument. Sexual activity and drug use were included as part of the demographic data. Although 78 percent of this convenience sample (80% of the target population) identified the specialist as their "personal physician", only 29 percent of them spoke to the specialist about their general health. Forty percent of the sample did not go to any other physician outside the specialty clinics. The health care concerns most frequently noted by these adolescents were menstrual problems (70% of females), anxiety (50%), actual or expected difficulties finding work (43%), weight (40%), acne (37%), and height (36%). Appropriate descriptive statistics were used and adequate demographic data were presented to make appropriate generalizations. The narrow range of ages covered in the sample is beneficial in the consideration of

the study's practice implications.

In conclusion, the assessment of chronically ill adolescents' self-identified primary health care needs has lagged behind the general adolescent research presented earlier. Similar deficiencies are present in instrument testing and sound frameworks for study. Major changes have occurred, however, by the increased inclusion of adolescents in the delineation of primary health care needs.

Summary

The rationale for studying chronically ill adolescents' self-identified primary health care needs flows from symbolic interactionism and the premise that an understanding of the meanings an individual assigns to objects and events is crucial to effective communication. The primary health care provider and client need a positive communicative relationship in order to better ensure care which meets the client's needs. An adaptation of Lamberton's model of health and illness was used to define the scope of a comprehensive and developmentally appropriate author-designed assessment of the meanings adolescents and their parents ascribed to primary health care needs. Developmental theory was discussed with emphasis on the major role it plays in defining the issues influencing both health and illness concerns of adolescents. The review of the literature documents great concern with the primary health care needs of chronically ill adolescents. However, these studies fail either to directly assess adolescents' perceptions of their primary health care needs or to address the comprehensive issues inherent in their primary health care. Additionally, previous

instruments used to assess the primary health care needs of chronically ill adolescents have not been documented as reliable and valid. This study will build

on previous research by assessing chronically ill adolescent clients directly with regard to their self-identified primary health care needs.

Chapter III: Methodology

Introduction

The discussion of methods used to conduct this research will commence with the research design of the study, considering threats to validity. Following a description of the research setting and sample obtained for study, the derivation of instruments for data collection will be detailed. Finally, data collection and data analysis procedures will be presented.

Research Design

The research design used in this study is descriptive. The study describes what chronically ill adolescents identify as their primary health care needs and also what their parents perceive as the adolescents' primary health care needs. Issues of internal and external validity as they pertain to the chosen research design will be discussed.

Internal Validity

Internal validity of the research design is related to the presence of alternative explanations for the results that are subsequently obtained (Polit & Hungler, 1983). The presence of a control group and random assignment to groups are methods used to decrease threats to internal validity in experimental studies. In descriptive studies, extraneous variables that account for competing explanations of the data should be enumerated or controlled. In this study, an assumption was made as to the validity of a noncategorical approach to chronic illness. Thus, the type of illness represented among subjects was controlled only in that it met the definition of "chronic illness" used by the study and that the adolescents had been seen at

those illness specialty clinics associated with the university medical center.

Other variables which were controlled were the absence of cognitive impairments, ability to read the instruments in their written form, and continued close ties to the home environment as defined by habitation with one or both parents. This last variable was crucial for accurately interpreting results of the degree of agreement between parental and adolescent perceptions of primary health care needs. If the adolescent were not living with the parent who filled out the companion questionnaire, lack of agreement as to perceived needs may have been more greatly influenced by minimal contact between family members. The sex of the parent who completed the questionnaire was not limited to mothers or fathers exclusively due to a potential decrease in the already limited subject pool. It was presupposed, however, that mothers would predominate within the sample. The sex and age of adolescents within the sample were not contolled due to a limited sampling frame. The cross-sectional nature of the study in selecting adolescents between 11 and 19 years of age does not control for potential changes over time in perceptions of primary health care needs but was done in this manner due to the lack of feasibility for a longitudinal study. Selection was a particular threat to internal validity in this study as subjects were volunteers. Use of a matched control group of other chronically ill adolescents and their parents would have greatly decreased threats to internal validity but was not feasible in this study due to limited resources and a small sampling frame.

External Validity

In order to determine the extent to which the findings from this study may be generalized, threats to external validity must be identified. Nonrepresentativeness is

a threat in that the specific clinics from which subjects were drawn were not chosen randomly but were based rather on the acceptance of the research proposal by clinic staff. Subjects were obtained from clinics that represented the most common chronic illnesses such as asthma. The Hawthorne effect may have influenced external validity by encouraging subjects to respond in a particular manner because they were part of a research study. The design of the instruments used in this study in conjunction with reliability studies of the results will help to determine the extent of this effect. Experimenter effects were reduced by the administration of a questionnaire by only one researcher. The use of an interview to collect data would allow greater potential for effects related to the characteristics of the researcher. Measurement effects resulting from the length of the instruments and item placement may affect the generalizability of the data to a population that had not been subjected to the same data collection procedures.

Research Setting

Chronically ill adolescents and their parents were recruited from the cardiac, diabetes, renal, immunology, neurology, and teen (asthma patients) clinics within an ambulatory care center. These facilities are associated with a university medical center in a metropolitan city in the western United States.

Sample

A nonprobability convenience sampling technique was used to obtain the final sample of 24 adolescent-parent pairs. The criteria for inclusion in the study were:

1. Age of the specialty clinic client between 11 and 19 years of age (inclusive).
2. Presence of a physical or sensory impairment lasting for at least three months.
3. Current habitation with at least one of his/her parents.

4. Absence of any cognitive impairments.
5. Ability of the adolescent and parent to speak and read English fluently.
6. Home address within 40 miles of the medical center.
7. Agreement by both the adolescent and his or her parent to participate in the study shown by signing the assent and consent forms.

A discussion of the procedure for subject recruitment will be presented in the "Data Collection Procedure" later in this chapter. A description of sample characteristics will appear in Chapter IV: Findings.

Instrument Development

Primary Health Care Needs Assessment (PHCNA)

This author-designed tool was created to address the variables "primary health care needs identified by chronically ill adolescents," "parental perceptions of these needs," and "resources used by chronically ill adolescents to meet identified primary health care needs." Adolescent (Appendix B) and parent (Appendix C) forms exist to obtain the data and to serve as a basis for determining the "degree of agreement between needs identified by these adolescents and those identified by their parents." The instrument encompasses a wide range of primary health care needs related to health, illness, development, and environment. An adaptation of Lamberton's model of health and illness serves as the framework for the scope of this instrument. The PHCNA was designed for this study because a comprehensive and developmentally appropriate needs assessment for this population did not exist in the studies reviewed. In the following paragraphs, a more detailed description of the instrument, item development procedure, rationale for and limitations of the instrument format, and validity and reliability information will be discussed.

Instrument description. The adolescent and parent forms of the PHCNA each contain a listing of 60 primary health care needs common to adolescents in general, and to chronically ill adolescents in particular. As will be more fully detailed later, the items were drawn from current research literature, textbooks, and from personal experience with this population. Additional information was also obtained to determine which resources were used to meet the primary health care needs of chronically ill adolescents. The items were listed in the final instrument according to random number table assignments.

In the first half of the instrument, adolescents and their parents were instructed to place a check mark next to any primary health care need which was a reality for the adolescent in the past year. To ascertain their perceived priority needs, each respondent was asked to rank the five identified needs, out of all identified needs marked, that were of greatest concern to them (i.e., 1 denoting the item the respondent was most concerned about, 2 denoting the second most concerning item, and so on). The intent of this ranking procedure was to identify the top five primary health care needs for each pair as a group. A decision was made not to weight the primary health care need marked with a "1" any greater than the need marked with a "5" because it was assumed that there would be a large variance in the total number of needs from which the five were chosen for different respondents. For example, the number "3" need from the list of a subject with a total of only 6 items marked would most likely have a different relative weight than the same "3" from a subject who identified a total of 20 needs. This variation between subjects based on the total number of items identified was not considered by Smith et al. (1987) and inappropriate overall rankings were made as a result. Ideally, a

Likert-type scale for each item ("not important to me" to "very important to me") could have been used to provide more accuracy in individual relative weight of perceived primary health care needs. If this type of scale had been used for all 60 PHCNA items, it would have increased the time for administration beyond the desired time frame. It was decided that the chosen method of ranking would be sufficient to meet the research aim of determining those primary health care needs most common to chronically ill adolescents.

The second half of the PHCNA asked adolescents and their parents to identify the resources used by the adolescent to meet identified primary health care needs. These resources -- doctor, nurse, parents, friends, teacher, social worker, and other -- were taken from research literature (Carrol et al., 1983; Pless et al., 1978) which addressed resources used to meet identified primary health care needs. Subjects could check any number of resources used by the adolescent to meet identified needs. A choice of "no one" was also given to both adolescents and parents, and "I don't know " was a choice on parent forms.

Rationale for and limitations of the instrument format. This questionnaire, composed of fixed alternative items, was used to obtain data on perceived primary health care needs of chronically ill adolescents. There are several advantages of this method: (1) questions may be clarified by giving fixed answer options, (2) subjects may respond to more questions of this type in a given period of time when compared with open-ended questions, and (3) subjects who have difficulty verbally expressing themselves may be able to provide a wider range of information than if faced with questions requiring a written response (Polit & Hungler, 1983).

Disadvantages of this method lie in the potential for overlooking important alternative responses and in the sometimes superficial nature of items. This method was chosen, however, to enhance the responsiveness of adolescents to a rather extensive list of potential primary health care needs. The time available for data collection and the reluctance of many adolescents to verbally identify needs to an unknown health professional necessitated the use of this method of data collection. An additional problem may be encountered in the exclusion of other items related to the primary health care needs of chronically ill adolescents. In order to deal with this potential problem, the questionnaire included the opportunity for subjects to add any other health care needs they felt were important in their lives.

Procedural difficulty was encountered in two areas: ranking of the top five items and identifying resources used for each identified problem. Parents seemed to have greater difficulty ranking the adolescents' primary health care needs that they, as parents, were most concerned about. The rather frequent failure to note resources used for an identified need seemed to stem more from the format of the instrument than from a fundamental lack of understanding. An attempt to anticipate this problem was made by placing identifying numbers for particular primary health care needs next to the line where resources were checked off. Each of these problems was dealt with by verbally explaining the directions to subjects until it was clear that they understood. Each questionnaire was checked for missing data (i.e., resources used) before the end of the data collection session in order have subjects fully complete the instrument.

Item development. Items were developed from existing studies of the primary health care needs of chronically ill adolescents (Carroll et al., 1983; Lau, Williams,

Williams, Ware, & Brook, 1982; Orr, Hoffmans, & Bennetts, 1984; Palfrey et al., 1980; Parcel et al., 1977; Pless et al., 1978; Ryberg & Merrifield, 1984; Schade & Passo, 1981; Starfield et al., 1980), current texts on pediatric primary health care (Chow, Durand, Feldman, & Mills, 1984), and from personal experience with this population. Detailed documentation for each item on the PHCNA may be found in Appendix D.

Validity and reliability. Content validity of this tool was established by submitting the tool to three experts in the fields of chronic illness, primary health care, and adolescence. Construct and criterion-related validity were not a concern at this time because the tool was designed for descriptive rather than predictive purposes. Clarity of the questions was evaluated by the first five adolescents-parent pairs entered into the study and no difficulties were noted.

Reliability was evaluated within the study sample by documenting test-retest stability over time. With their permission, ten adolescent-parent pairs were contacted by phone two weeks after they had completed the instrument. They were asked a subset of 10% of the items on the PHCNA chosen by random number table assignment. Parents' responses on the item subset were in agreement with 85% of their initial responses. Adolescents' responses on the item subset were in agreement with 88% of their initial responses. The lack of variance in the items randomly selected for the retest would not allow a meaningful use of the Cohen's Kappa statistic.

Demographic Data Form (DDF)

This tool was constructed by the author to collect demographic data from chronically ill adolescents and their parents and to determine the adolescent's

developmental stage (early, middle, or late adolescence) based on age. It was created in both adolescent (Appendix E) and parent (Appendix F) forms. In the following paragraphs, the instrument will be described in greater detail, limitaions of the instrument format will be discussed, and validity and reliability information will be presented.

Instrument description. The adolescent form requested information about age, sex, grade in school, jobs, ethnic and religious background, the duration of the illness, and number of hospitalizations in the past year. The parent form requested the same data concerning both the parent attending the clinic with the adolescent and the other parent, if applicable. The parents were also asked to estimate the family's yearly income (optional) and to provide information concerning primary health care utilization in the past two years. The items were drawn from the previously cited research studies used to develop the PHCNA and from consultation with faculty who are experts in the field and who have developed similar instruments.

Limitations of the instrument format. The only item on the DDF which produced some confusion for adolescents asked them to state how many times they had been in the hospital this year. It was clarified verbally with each subject that this question did not refer to their clinic appointments but rather to overnight hospital stays. The item regarding school absence was not sensitive to the one adolescent who reported not being absent but already had a special schedule which was shorter than a 5-day school week.

Validity and reliability. Content validity of this instrument was established by submission of the instrument to three research experts in the fields of chronic illness, primary health care, and adolescence. Although test-retest was not established for

the instrument, certain items were asked on both adolescent and parent DDF's: duration of the chronic illness and number of hospitalizations in the past year. Twenty-three of 24 adolescents gave a duration for their chronnic illness which was within one year of that given by their parents. The fact that adolescents tended to state a number of hospitalizations that was higher than that stated by their parents may be due to a misunderstanding of what "hospitalization" entailed as described in the previous section.

Procedure

Recruitment of subjects began by contacting the physicians and nurse practitioners/clinical nurse specialists in charge of various chronic illness specialty clinics associated with the university medical center. The oncology clinic was not accessed due to concerns that patients might become "over-researched." Six specialty clinics agreed to grant access to their records regarding patients between 11 and 19 years of age.

Sixty-four adolescent/parent pairs met the study criteria and were subsequently mailed an explanation of the study from the researcher (Appendix G), a letter of introduction from the adolescent's specialty clinic physician, and a postcard (Appendix H) that was to be returned if either the adolescent or the parent did not want to be contacted concerning the study. The letter also explained that the parent or adolescent could decide not to participate in the study once they read the consent forms at the time of data collection. Telephone contact was then attempted to further explain the study to the subjects and to set up a time for data collection at a clinic appointment or at the subjects' homes, whichever was more convenient for them. Twenty-four adolescent-parent pairs were enlisted from the target population of 64

pairs who met the study criteria. Forty pairs were not included secondary to refusal to participate (26), mail which was no longer forwarded (5), inability of the researcher to obtain telephone contact (8), and hospitalization of the adolescent (1).

Forty percent of the data collection took place in the clinics and 60 percent at adolescents' homes. At the time of data collection, questions concerning the study were answered, parental consent (Appendix I) and adolescent assent (Appendix J) were obtained, and each was given a copy of these forms with the "Experimental Subject's Bill of Rights." Parents and adolescents were instructed not to confer with each other regarding their responses on the questionnaires and each was reminded that their data would be kept confidential. In all cases, the adolescent and the parent did not complete the PHCNA and DDF in close proximity, thus confidentiality was maintained. In addition, the researcher was always present during the completion of instruments. Due to time constraints with most subjects, this entailed having the adolescent and parent sit at opposite sides of a room at home or several seats apart at the clinic. The Primary Health Care Needs Assessment and Demographic Data Forms were administered over 20 to 30 minutes. The researcher answered questions as they arose during instrument administration.

All subjects were told of the possibility that they would be contacted two weeks after the data collection meeting to answer a small subset of the PHCNA items (for test-retest reliability). Within twelve to fourteen days after data collection, the second 10 adolescent/parent pairs entered into the study were contacted by telephone. Each was asked if the following items had happened to the adolescent in the past year: item number 4, 5, 29, 32, 37, and 38. The result of the test-retest is presented in the discussion of reliability of the PHCNA.

Data Analysis

Descriptive statistics were used to analyze the data. Demographic data were compiled in this manner to describe the sample population. Frequencies were tabulated for (1) the primary health care needs identified by chronically ill adolescents and their parents and for (2) the resources used to meet specific primary health care needs. "Degree of agreement" between needs identified by adolescents and those identified by their parents were calculated by averaging the percent agreement obtained for each adolescent/parent pair using the following formula: Number of items answered identically by the adolescent and his/her parent / 60 . Chi-square was used to determine the presence of statistically significant ($p < .05$) differences in identified primary health care needs between early, middle, and late adolescents.

Chapter IV: Findings

Introduction

Documentation of the research findings will begin with a description of the sample characteristics. Data will then be presented within the framework of this study's research questions:

1. What are the primary health care needs identified by chronically ill adolescents who receive care at specialty clinics associated with a university medical center?
2. What are the parental perceptions of these needs?
3. What is the degree of agreement between the needs identified by these chronically ill adolescents and those identified by their parents?
4. What resources are used by chronically ill adolescents to meet identified primary health care needs?
5. What clusters of primary health care needs are identified by early, middle and late adolescents in the sample population?

Sample Characteristics

This section begins with a presentation of the demographic and chronic illness information given by the adolescents in this sample. It will be followed by parental demographics and descriptive data regarding parental perceptions of the adolescents' chronic illnesses. Finally, sample data will be summarized to provide guidance for the interpretation of PHCNA data.

The adolescent sample was composed of 14 females and 10 males with a mean age of 15.4 years (Table 1). They were predominantly white (67%) and most commonly Catholic (42%) in their religious affiliation. Over half were in the 10th

grade or higher (55%) and had been absent from school 3 weeks or less (63%) during the past year.

The chronic illnesses represented in the sample were asthma (5), end-stage renal disease (4), spina bifida (3), juvenile rheumatoid arthritis (3), diabetes (2), congenital heart disease (2), systemic lupus erythematosis (2), seizures (2), and dystonia (1) (Table 2). Adolescents stated the duration of the their illnesses in the range of 1 to 18 years with a mean of 9.7 years. They recalled being hospitalized on the average of 2 times in the past year (range 0-10).

The average age of the 22 mothers and two fathers who completed the parent questionnaire was 44.7 years (range 33- 64 years, median 44 years) (Table 3). They were predominantly white (75%), Catholic (50%), and married (63%). Nearly all had completed high school (91%) and the majority had completed at least 3 years of college (51%). Over half of the parental respondents had been working full-time (55%). Family incomes were $30,000 or more in nearly three-fourths of the families who documented income (n=18).

Parents most frequently rated the severity of the adolescents' chronic illnesses as moderate (33%) or severe (38%) (Table 4). They noted the duration of the adolescents' illnesses in the range of 2 to 18 years with a mean of 9.6 years. They recalled between one and two hospitalizations of their adolescent children in the past year (range 0-8). A majority of the parents (79%) stated that their adolescents had primary health care providers outside the specialty clinics and had made visits to this provider in the past year (67%).

To summarize, this sample represented a relatively high level of socioeconomic status based on median parental level of education and family income. Although a

Table 1

Adolescent Demographic Data

	Frequency	%	Mean / S.D.	Median
Age (in years)			15.4 / 2.5	15.5
Sex				
Female	14	58%		
Male	10	42%		
Grade				
5th	1	4%		
6th	2	8%		
7th	1	4%		
8th	2	8%		
9th	5	21%		10th
10th	2	8%		Grade
11th	3	13%		
12th	3	13%		
College	5	21%		
Absence from school				
Not at all		2	8%	
< 1 week		9	38%	
1 to 3 weeks		4	17%	
1 month		2	8%	
>1 month and <4 months		5	21%	
4 months or more		2	8%	

Table 1 (cont.)

	Frequency	Percent
Race		
White	16	67%
Hispanic	3	13%
Black	2	8%
Asian	1	4%
Filipino	1	4%
Don't know	1	4%
Religion		
Catholic	10	42%
Jewish	3	13%
Protestant	3	13%
Buddhist	2	8%
None	2	8%
Don't know	2	8%
Other	2	8%

Table 2

Adolescent Chronic Illness Data

	Frequency	Percent
Type of illness		
Asthma	5	21%
Kidney Disease	4	17%
Arthritis	3	13%
Spina Bifida	3	13%
Congenital Heart Disease	2	8%
Diabetes	2	8%
Lupus	2	8%
Seizures	2	8%
Dystonia	1	4%

	Range	Mean/S.D.	Median
Duration of illness[a]	1-18 yrs.	9.7 / 4.7	11
No. hospitalizations in the past year [a]	0-10	2.0 / 2.7	1.5

[a] Data on 23 adolescent subjects, data missing on 1 subject

Table 3

Demographic Data on Parental Respondents

	Range	Mean / S.D.	Median
Age [a]	33-64 yrs	44.7 / 8.0	44

	Frequency	Percent	Median
Sex			
Female	22	92%	
Male	2	8%	
Highest level of education completed [b]			
Grade school	2	9%	
High school	6	26%	
1 yr. college	1	4%	3 years of college
2 yr. college	2	9%	
3 yr. college	1	4%	
4 yr. college	7	31%	
Graduate school	4	17%	
Employment			
Not employed	5	20%	
Part-time	6	25%	
Full-time	13	55%	
Family income [c]			
$0-4999	2	11%	
$5000-9999	1	5.5%	
$10000-14999	0	0%	
$15000-19999	1	5.5%	$30,000 or more
$20000-29999	1	5.5%	
$30000 or more	13	72%	

[a] Data on 21 parental subjects, data missing on 3 subjects
[b] Data on 23 parental subjects, data missing on 1 subject
[c] Data on 18 parental subjects, data missing on 6 subjects

Table 3 (cont.)

	Frequency	Percent	Median
Race			
White	18	75%	
Black	3	13%	
Asian	1	4%	
Hispanic	1	4%	
Filipino	1	4%	
Religion			
Catholic	12	50%	
Protestant	6	25%	
Jewish	3	13%	
Buddhist	2	8%	
Other	1	4%	
Marital status			
Married	15	63%	
Divorced	7	29%	
Separated	1	4%	
Widowed	1	4%	

Table 4

Chronic Illness Data from Parental Respondents

	Frequency	Percent
Adolescent's illness severity		
No longer a problem	1	4%
Mild	6	25%
Moderate	8	33%
Severe	9	38%
Primary care provider outside specialty clinic		
Yes	19	79%
No	5	21%
Time since last visit		
0 to 1 year ago	16	67%
1 to 2 years ago	3	13%
Over 2 years ago	5	20%

	Range	Mean/S.D.	Median
Duration of illness	2-18 yrs.	9.6 / 4.6	12
No. Hospitalizations in the Past Year	0-8	1.6 / 2.0	1

variety of ethnic groups were represented, Caucasians predominated in this sample.

Primary Health Care Needs Identified by the Chronically Ill Adolescents

Twenty-six (43%) of the items on the Adolescent PHCNA were identified by at least one-third of the sample as primary health care needs. Only one item "concern about being to tall" was not identified by any subject. The instrument appears sensitive to the most common primary health care needs of chronically ill adolescents. A single subject used the space alotted to list other concerns and her's was "memory problems".

The frequencies with which adolescents identified specific primary health care needs are presented in Table 5. Concurrently, the frequency with which particular items were identified among the adolescents' "top 5" concerns is also shown (Table 5). While the former frequency alludes to the general prevalence of a particular primary health care need, the latter refers to its relative importance among all those who identified it as a need. Using only the frequency as a guide to what primary health care needs are priority needs for adolescents may be misleading, as illustrated by the following examples. Although having a "sore throat" in the past year was documented by 17 adolescents (71%), only 2 placed it among their "top 5" concerns. Conversely, while only 7 adolescents (29%) identified "problems getting along with their parents", four out of the seven listed it among their top-ranked concerns.

A table of those PHCNA items which were both prevalent in this population and top-ranked in importance by the subjects is used to focus on a more discriminant group of primary health care needs (Table 6). A criterion of 33% (overall frequency) was set by the researcher to identify the most prevalent primary health

Table 5

Primary Health Care Needs Identified by Chronically Ill Adolescents

PHCNA item	Number checking item as a primary health care need n=24	%	Frequency in "top 5" concerns
Bored a lot	17	71%	8
Sore throat	17	71%	2
Tired a lot	16	67%	3
Wondered how my _____ will affect me when I get older	15	63%	8
Acne	13	54%	4
Not able to do the things my friends do	13	54%	5
Worried about my health	12	50%	6
A lot of headaches	12	50%	5
Wondered if I will be able to have children when I get older	11	46%	4

Table 5 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Wanted to learn more about my ___	11	46%	3
Trouble explaining my ___ to my friends	11	46%	3
Hard time adjusting to school after being absent	10	42%	2
Been depressed	10	42%	4
Not doing well in school	10	42%	5
Worried about being overweight	10	42%	6
Breathing problems	9	38%	4
Skin rash	9	38%	2
What to expect when I am in the hospital	9	38%	1
Hard time explaining my ___ to people at school	9	38%	1

Table 5 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Needed help to decide about my future	8	33%	2
Wondered what makes my body go through these changes as a teenager	8	33%	2
Problems getting along with my teachers	8	33%	1
Diarrhea	8	33%	1
Wanted someone to listen to what bothers me	8	33%	2
Tooth ache	8	33%	0
Problems with my teeth	8	33%	1
Constipated	7	29%	1
Questions about sex	7	29%	0
Problems sleeping	7	29%	1

Table 5 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Concerned about being too short	7	29%	2
Problems getting along with my parents	7	29%	4
Hard time fitting my treatments into my regular schedule or routine	6	25%	2
Ear ache	6	25%	0
Hard time making friends	6	25%	3
Anxious a lot	6	25%	1
Had sex	6	25%	0
Not able to see very well	5	21%	3
Problems finding a job	5	21%	1
Nervous a lot	5	21%	0
Wanted to learn more about my medicines	5	21%	1

Table 5 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Not able to learn how to drive	5	21%	3
Concerned about being too thin	5	21%	2
Hard time fitting my medicines into my regular schedule or routine	4	17%	0
Wanted to learn more about my treatments	4	17%	0
Not known how far to go with sex	4	17%	2
Gotten drunk	4	17%	0
Concerned about VD (venereal disease)	3	13%	1
Concerned about being pregnant	3	13%	1
Hearing problems	3	13%	2
Questions about contraceptives	3	13%	0

Table 5 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Trouble getting along with my brothers and/or sisters	3	13%	1
Sprained ankle	2	8%	0
Problems from wetting the bed or my underwear	2	8%	1
Hard time explaining my ___ to my brothers and/or sisters	2	8%	1
Problems with my period (a lot of pain or bleeding)	2	8%	0
Problems urinating	2	8%	0
Smoked cigarettes	1	4%	0
Broken bone	1	4%	1
Used drugs	1	4%	0
Concerned about being too tall	0	0%	0

care needs of these chronically ill adolescents. An additional criterion was set to account for the relative importance of these items to the adolescents. Items were included in Table 6 when at least 33% of those identifying an item as a concern also place it in their "top 5" concerns. For example, being "bored a lot" was included in this refined list because it had a prevalence over 33% and it was a "top 5" concern for at least 33% of all those who identified it as a concern (8/17 = 47%). The resultant list includes needs which were top-ranked in importance by these adolescents: boredom, the effect of the illness with increasing age and in childbearing, worry about their health, not being able to do things their friends do, headaches, depression, overweight, not doing well in school, breathing problems, and needing help to decide about the future. Not only were boredom and a concern about future effects of the chronic illness listed as needs by most of the sample, they were also identified by one-third of the total sample as a "top 5" concern.

Using the chi-square test, there was no statistically significant difference ($p > .05$) between the responses of male and female subjects on all but one item of the PHCNA. Significantly more females than males were "concerned about being overweight" ($p < .02$). Statistical tests of the differences in primary health care need prevalence among the chronic illness groups were insignificant; however, the chance of finding significant differences which may have truly been present was greatly diminished by the small number of subjects in each chronic illness group (median number in each group= 2, range 1-5). Any differences between age groups will be addressed in a later section of this chapter.

In summary, a diverse group of chronically ill adolescents was able to identify primary health care needs which not only had a prevalence rate of at least 33% for

Table 6

Adolescent Primary Health Care Needs which were Prevalent and Top-Ranked in Importance

PHCNA item	Frequency (%) identifying item as a primary health care need	Frequency (%) identifying item as a "top 5" concern
Bored a lot	17 (71%)	8 (47%)
Wondered how my ____ will affect me when I get older	15 (62%)	8 (53%)
Not able to do the things my friends do	13 (54%)	5 (38%)
Worried about my health	12 (50%)	6 (50%)
A lot of headaches	12 (50%)	5 (41%)

This percentage = $\frac{\text{Number of adolescents placing the item in their "top 5"}}{\text{Total number of adolescents who checked it as being a need}}$

Ex. Bored a lot: 8/17 = 47%

Table 6 (cont.)

PHCNA item	Frequency (%) identifying item as a primary health care need	Frequency (%) identifying item as a "top 5" concern
Wondered if I will be able to have children when I get older	11 (46%)	4 (36%)
Been depressed	10 (42%)	4 (40%)
Not been doing well in school	10 (42%)	5 (50%)
Worried about being overweight	10 (42%)	6 (60%)
Breathing problems	9 (38%)	4 (44%)
Needed help to decide about my future	8 (33%)	3 (38%)

this population but also had relative importance to the adolescents at this point in time. The majority of primary health care needs which had the greatest prevalence and importance to these adolescents focused on behavioral adaptation (not doing well in school, boredom, effect of the chronic illness later in life) rather than on strictly medical or illness issues (headaches, breathing problems).

Primary Health Care Needs of Chronically Ill Adolescents Identified by their Parents

Twenty-three (38%) of the items on the Parent PHCNA were identified by at least one-third of the sample as primary health care needs. The items not identified by any parent were cigarette smoking, adolescent concerns with being pregnant or too tall, using drugs, and having had sex. The instrument appears sensitive to parental report of the most common primary health care needs of chronically ill adolescents. Three subjects used the space alotted to list other concerns: "explaining [his illness] to acquaintances and strangers," "she will not care for herself without constant prompting," and "not contributing to chores."

The frequencies with which parents identified specific primary health care needs of their adolescents are presented in Table 7. Concurrently, the frequency with which parents identified an item as one of their "top 5" concerns regarding the adolescent is shown. Those parent PHCNA items which were both perceived by parents as prevalent among their chronically ill adolescents and which were top-ranked in importance by the parents are presented in Table 8. The criteria for inclusion were (1) overall prevalence as a primary health care need of at least 33% and (2) listing of the item as a "top 5" concern for at least 33% of all parents identifying it as a need for their adolescents. The resultant list includes the following primary health care needs: boredom, the effect of the illness with

Table 7

Primary Health Care Needs Identified by Parents

PHCNA item	Number checking item as a primary health care need n=24	%	Frequency in "top 5" concerns
Not able to do the things his/her friends do	15	62%	8
Bored a lot	14	58%	5
Wanted someone to listen to what bothers him/her	14	58%	4
Sore throat	14	58%	0
Wondered how his/her ___ will affect him/her when he/she gets older	13	54%	9
A lot of headaches	12	50%	4
Tired a lot	12	50%	1
Wanted to learn more about his/her _____	12	50%	4

Table 7 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Been depressed	12	50%	6
Questions about sex	12	50%	2
Worried about his/her health	12	50%	7
Breathing problems	11	46%	6
Acne	10	42%	2
Not doing well in school	9	38%	7
Wondered what makes his/her body go through these changes as a teenager	9	38%	1
Problems getting along with his/her parents	8	33%	6
Constipated	8	33%	0
Wondered if he/she will be able to have children when he/she gets older	8	33%	3

Table 7 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Hard time fitting his/her treatments into his/her regular schedule or routine	8	33%	0
Hard time explaining his/her ____ to people at school	8	33%	2
Problems sleeping	8	33%	3
Nervous a lot	8	33%	0
Needed help to decide about his/her future	8	33%	2
Skin rash	7	29%	0
Trouble explaining his/her ____ to his/her friends	7	29%	1
Worried about being overweight	7	29%	4
Hard time making friends	7	29%	4
Concerned about being too short	7	29%	2

Table 7 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Hearing problems	6	25%	4
Problems getting along with his/her teachers	6	25%	2
Not been able to see very well	6	25%	3
Questions about contraceptives	6	25%	1
Tooth ache	5	21%	0
Concerned about being too thin	5	21%	1
Hard time adjusting to school after being absent	5	21%	2
What to expect when he/she is in the hospital	5	21%	2
Diarrhea	5	21%	0
Anxious a lot	5	21%	2
Wanted to learn more about his/her medicines	5	21%	1

Table 7 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Problems with his/her teeth	4	17%	0
Problems from wetting the bed or his/her underwear	4	17%	1
Hard time fitting his/her medicines into his/her regular schedule or routine	4	17%	0
Wanted to learn more about his/her treatments	4	17%	2
Problems with her period (a lot of pain or bleeding)	4	17%	1
Concerned about VD (venereal disease)	3	13%	0
Ear ache	3	13%	0
Gotten drunk	3	13%	1
Not been able to learn how to drive	3	13%	0

Table 7 (cont.)

PHCNA item	Frequency as primary health care need	%	Frequency in "top 5" concerns
Problems finding a job	2	8%	1
Problems urinating	2	8%	0
Not known how far to go with sex	2	8%	0
Sprained ankle	1	4%	0
Hard time explaining his/her to his/her brothers and/or sisters	1	4%	0
Broken bone	1	4%	0
Trouble getting along with his/her brothers and/or sisters	1	4%	0
Smoked cigarettes	0	0%	0
Concerned about being pregnant	0	0%	0
Used drugs	0	0%	0
Concerned about being too tall	0	0%	0
Had sex	0	0%	0

Table 8

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

PHCNA item	Frequency (%) identifying item as a primary health care need	Frequency (%) identifying item as a "top 5" concern
Not able to do the things his/her friends do	15 (62%)	8 (53%)
Bored a lot	14 (58%)	5 (36%)
Wondered how his/her____ will affect him/her when he/she gets older	13 (54%)	9 (69%)
A lot of headaches	12 (50%)	4 (33%)
Wanted to learn more about his/her ____	12 (50%)	4 (33%)
Worried about his/her health	12 (50%)	7 (58%)
Been depressed	12 (50%)	6 (50%)
Breathing problems	11 (46%)	6 (54%)
Not been doing well in school	9 (38%)	7 (78%)

Table 8 (cOnt.)

PHCNA item	Frequency (%) identifying item as a primary health care need	Frequency (%) identifying item as a "top 5" concern
Wondered if he/she will be able to have children when he/she gets older	8 (33%)	3 (38%)
Problems getting along with his/her parents	8 (33%)	6 (75%)
Problems sleeping	8 (33%)	3 (38%)

increasing age and in childbearing, headaches, depression, not doing well in school, breathing problems, not being able to do the things his/her friends do, wanting to know more about the chronic illness, worried about his/her health, problems getting along with his/her parents, and problems sleeping.

Using the chi-square test, there was no statistically significant difference ($p < .05$) between the PHCNA responses of parents of male and female adolescents. There was also no statistically significant difference between parental responses for any PHCNA item across different chronic illness groups.

In summary, parents of chronically ill adolescents were able to identify a body of particular primary health care needs which they felt were both prevalent among their adolescents and which were of importance to them as parents. Similarl to the adolescent sample, this body of primary health care needs is much more focused in the behavioral and adaptive realm than the pathophysiological realm.

Degree of Agreement Between Chronically Ill Adolescents and Their Parents Regarding Primary Health Care Needs

The degree of agreement between these chronically ill adolescents' perceptions of their primary health care needs and their parental perceptions of these needs will be discussed as it relates to the entire PHCNA and to the subset of prevalent and important primary health care needs identified by the adolescents. An analysis will also be presented by sex, age, and chronic illness grouping of the adolescents (Table 9). Whenever an average degree of agreement is noted in this section, it refers to an average of the degree of agreement between each adolescent-parent pair.

Out of sixty PHCNA items, the average number of items which were marked identically by adolescent-parent pairs was 46 (46/60= 76% agreement). When

considering those primary health care needs which were prevalent and important to the chronically ill adolescent sample (Table 6), the degree of agreement was 73% , e.g., on the average, 8 of the 11 items were marked identically by adolescents and their parents. The degree of agreement seems to be consistent despite the relative importance of a particular primary health care need to the adolescent.

Use of independent groups t-test demonstrated no statistically significance difference between the degree of female adolescent-parent agreement (75%) and male adolescent-parent agreement (78%). No test can accurately determine statistical significance between groups when at least one group has only a single subject in it (dystonia group). When the Kruskal-Wallis test was attempted, despite the limitation noted above, no statistically significant difference was found among the groups; however, the degree of agreement within these groups ranged from 67% (lupus) to 90% (diabetes). Hence, an accurate evaluation of the interaction of particular chronic illnesses in determining the degree of adolescent-parent agreement could not be performed. Appropriate use of the Kruskal-Wallis test found no statistically significant difference in the degree of agreement among early (78%), middle (80%), and late (72%) adolescent groups.

In summary, the degree of agreement between chronically ill adolescents and their parents regarding items on the PHCNA appears to remain fairly constant at 76% and relatively unaffected by adolescent sex, age, and chronic illness grouping. It is worthy to note that, in a comparison of Tables 6 and 8, the subgroup of items which were perceived as the most prevalent and important by parents contained 9 out of the 11 items that adolescents themselves identified as the most prevalent and important to them.

Table 9

Degree of Agreement on PHCNA Items
Among Different Sample Subgroups

Group	N	Degree of agreement
Overall		
For all 60 items	24	76%
For 11 prevalent and top-ranked items	24	73%
Sex		
Males	10	78%
Females	14	75%
Age group		
Early adolescents	6	78%
Middle adolescents	9	80%
Late adolescents	9	71%
Chronic Illness Group		
Systemic Lupus	2	67%
Spina Bifida	3	67%
Asthma	5	75%
Dystonia	1	78%
Congenital Heart	2	78%
Arthritis	3	78%
Kidney Disease	4	78%
Seizures	2	83%
Diabetes	2	90%

Resources Used to Meet Chronically Ill Adolescents' Primary Health Care Needs

The PHCNA allowed subjects to identify as many resources as were actually used to meet their identified primary health care needs (Table 10). Of particular interest in the data are those needs which have been met by no one. The researcher has used descriptive statistics alone to highlight areas of interest. This current section will commence with a presentation of how resources were used to meet the adolescents' primary health care needs which were most prevalent and top-ranked in importance. It will be followed by attention to other needs which frequently have been met by no one. A general comparison of the different resource groups will then be made. Finally, parents perceptions of the resources used by their adolescents will be compared with adolescent reports.

Special attention was given to the subgroup of those primary health care needs which were found most frequently among the adolescent subjects and which were relatively important to them in comparison with other identified needs (Table 11). Five of the 13 adolescents who had identified "not being able to do the things that their friends do" as a concern did not use anyone to help them deal with this problem. It is also noteworthy that one-third of the adolescents who were concerned about "whether they would be able to have children when they got older" went to no one for help with this concern. Nearly one-third of those who were concerned about being overweight also did not seek assistance from anyone. Data on the number of subjects who received help from no one for the more prevalent primary health care needs are listed in Table 11.

Some less frequently identified primary health care needs are worthy of mention as resources have been used infrequently to meet these needs (Table 10).

Out of 13 adolescents with acne, 4 sought help from no one for this problem which may have been more effectively managed by a health care provider. A very similar pattern is seen with the complaint of being "tired a lot" and not using health care providers as resources to deal with what may likely be a manageable psychological or physiological problem. Trouble explaining the adolescent's chronic illness to friends was a problem for 11 adolescents, 5 of whom did not seek help from anyone with this problem. A smaller proportion of the sample identified "fitting treatments into their regular routine" (n=6) and "being anxious a lot" (n=6) as identified needs; however, one half of the adolescents did not use any resource for assistance with these problems.

This chronically ill adolescent sample most frequently used physicians and parents as resources to meet identified needs. Parent and physicians were used nearly equally except in some of the strictly medical problem areas such as skin rashes, medicines, ear aches, and vision problems. Nurses were not utilized as a primary resource for any identified primary health care need. The total number of times friends were used as resources nearly equaled the total number of times no resource was used. Teachers and social workers were infrequently utilized as resources.

In comparing adolescent reports with parental perceptions of what resources were used to meet identified primary health care needs, several patterns emerged (Table 12). First, parents view themselves as being, by far, the most frequently utilized resource by their adolescents. Secondly, they underestimated the utilization of friends (48 vs. 83) and overestimated the utilization of social workers (30 vs. 2) as resources used to meet primary health care needs. Lastly, parents

Table 10

Resources Identified by Chronically Ill Adolescents as Meeting their Primary Health Care Needs

Freq (%) as primary health care need	PHCNA item	Resources used						
		Doctor	Nurse	Parent	Friend	Teacher	SW[a]	No one	Other
17 (71%)	Bored a lot	1	1	8	8	1	3	2
17 (71%)	Sore throat	6		8			5	
16 (67%)	Tired a lot	6	1	8	4	1	5	
15 (63%)	Wondered how my __ will affect me when older	9	1	5	1		2	
13 (54%)	Not able to do the things friends do	1		1	1		5	
13 (54%)	Acne	5		5			4	
12 (50%)	Worried about my health	10	1	4	3		1	
12 (50%)	A lot of headaches	6	1	7	1		1	

[a] SW = Social Worker

Table 10 (cont.)

Freq (%) as primary health care need		PHCNA item	Resources used							
			Doctor	Nurse	Parent	Friend	Teacher	SW	No one	Other
11	(46%)	Wondered if I will be able to have children when older	5		5				4	
11	(46%)	Trouble explaining my ___ to friends	1	1	3	3			5	
11	(46%)	Wanted to learn more about my ___	8	2	6	1			1	
10	(42%)	Worried about being overweight	1	1	6	3	1		3	1
10	(42%)	Not doing well in school	1		5	2	5		1	2
10	(42%)	Been depressed	1		7	3	1		1	2
10	(42%)	Hard time adjusting to school after absence	2	1	4	4	7		1	1
9	(38%)	Breathing problems	7	1	3				2	
9	(38%)	Skin rash	6	2	4	1			1	

Table 10 (cont.)

Freq (%) as primary health care need		PHCNA item	Resources used						
			Doctor	Nurse	Parent	Friend	Teacher	SW	Other / No one
9	(38%)	What to expect when in the hospital	9	3	3				
9	(38%)	Hard time explaining my ___ to people at school	1		4	2	1		2
8	(33%)	Needed help to decide about my future			3	2	2	1	2 1
8	(33%)	Wanted someone to listen to what bothers me	1	2	5	5		1	2
8	(33%)	Wondered what makes my body go through these changes as a teenager	5	2	5	1	1		1
8	(33%)	Problems getting along with teachers			2	2	2		1 2
8	(33%)	Problems with my teeth	4		4	1			2
8	(33%)	Diarrhea	4	4					1

Table 10 (cont.)

Freq (%) as primary health care need		PHCNA item	Resources used							
			Doctor	Nurse	Parent	Friend	Teacher	SW	No one	Other
8	(33%)	Toothache	1		1				3	3
7	(29%)	Problems getting along with parents			1	3			1	3
7	(29%)	Concerned about being too short	3	1	4	3			2	
7	(29%)	Problems sleeping	4		3				2	
7	(29%)	Constipated	4		3				1	
7	(29%)	Questions about sex	1		4	1	1		1	1
6	(25%)	Hard time making friends			4	1	1		1	
6	(25%)	Hard time fitting treatments into my regular schedule	2		1	1			3	
6	(25%)	Anxious a lot	1		2	3			3	
6	(25%)	Had sex (intercourse)	1		1	3			2	1

Table 10 (cont.)

Freq (%) as primary health care need		PHCNA item	Resources used							
			Doctor	Nurse	Parent	Friend	Teacher	SW	No one	Other
6	(25%)	Ear ache	5	1	2				1	
5	(21%)	Not able to see well	4	1	1	1				
5	(21%)	Not able to learn how to drive			1	1	2		1	
5	(21%)	Concerned about being too thin	2		4	1			1	
5	(21%)	Problems finding a job			3	4	2			
5	(21%)	Wanted to learn more about my medicines	5	3						
5	(21%)	Nervous a lot	2		2	1		1	1	
4	(17%)	Not known how far to go with sex			3				1	1
4	(17%)	Hard time fitting my medicine into my regular schedule	2		1	1			1	

Table 10 (cont.)

Freq (%) as primary health care need	PHCNA item	Resources used						
		Doctor	Nurse	Parent	Friend	Teacher	SW	Other / No one
4 (17%)	Gotten drunk	1		1	3		1	
4 (17%)	Wanted to learn more about my treatments	3	2	1				
3 (13%)	Hearing problems	1	1	1	1		1	
3 (13%)	Concerned about being pregnant	2	1	1	1			1
3 (13%)	Concerned about VD	1		1			1	
3 (13%)	Trouble getting along with brothers/sisters			2			1	
3 (13%)	Questions about contraceptives	1		1	1			1
2 (8%)	Hard time explaining my ___ to brothers/sisters	1		1				
2 (8%)	Problems from wetting the bed or underwear	1		1				

Table 10 (cont.)

Freq (%) as primary health care need	PHCNA item	Resources used							
		Doctor	Nurse	Parent	Friend	Teacher	SW	No one	Other
2 (8%)	Problems urinating	2							
2 (8%)	Problems with my period (a lot of pain/bleeding)	2	1	1					
2 (8%)	Sprained ankle			1					1
1 (4%)	Broken bone	1			1				1
1 (4%)	Smoked cigarettes							1	
1 (4%)	Used drugs	1		1	1				
0 (0%)	Concerned about being too tall								
Total number of times a resource was used to meet a primary health care need		155	32	175	83	28	2	81	29

Table 11

Prevalent and Top-Ranked Adolescent PHCNA Items Met by "No one"

PHCNA item	Frequency of item identification as primary health care need	No. of adolescents identifying "No one" used as a resource
Bored a lot	17	3
Wondered how my ____ will affect me when I get older	15	2
Not able to do the things my friends do	13	5
Worried about my health	12	1
A lot of headaches	12	1
Wondered if I will be able to have children when I get older	11	4
Been depressed	10	1
Not been doing well in school	10	1

Table 11 (cont.)

PHCNA item	Frequency of item identification as primary health care need	No. of adolescents identifying "No one" used as a resource
Worried about being overweight	10	3
Breathing problems	9	2
Needed help to decide about my future	8	2

Table 12

Resources Used to Meet the Primary Health Care Needs of Chronically Ill Adolescents

Resource	Frequency of resource use to meet identified needs (Percent of total needs identified)	
	Adolescent Identified Needs (n= 416)	Parent Report of Adolescent Needs (n= 381)
Parent	175 (42%)	260 (68%)
Physician	155 (37%)	146 (38%)
Friends	83 (20%)	48 (13%)
No one	81 (19%)	25 (7%)
Nurse	32 (8%)	29 (8%)
Teacher	28 (7%)	35 (9%)
Other	29 (7%)	51 (13%)
Social worker	2 (.5%)	30 (8%)
Don't know	------	7 (2%)

NOTE More than one resource could have been chosen by a subject to meet an identified need

acknowledged far fewer times when primary health care needs were addressed by "no one" than did their adolescents (25 vs. 81).

In summary, this sample of chronically ill adolescents often did not utilize any resource to meet their most common and top-ranked primary health care needs. Parents did not have an accurate perception of the resources that were used by their adolescents. According to the adolescents, physicians and parents played equal roles in meeting most primary health care needs.

Clusters of Primary Health Care Needs Common to Early, Middle, and Late Adolescents

This final section of research findings will attempt to extract those primary health care needs which were uniquely prevalent within early, middle, and late adolescent samples and those which were common to all groups. Finally, an initial analysis to detect trends over the stages of adolescent development will be presented. An overall note of caution must be used when interpreting the data in this section: males were most prevalent in the early adolescent group and females were highest in number in the middle and late adolescent groups (Table 13). As was previously stated, however, there had been a statistically significant difference on the frequency of only one primary health care need when males and females were compared using the chi square test.

Due to the relatively small numbers of subjects in each group, a criterion level of 50% was set by the researcher to extract the most frequently identified primary health care needs of the adolescent age subgroups. The early adolescent sample's most frequently identified primary health care needs are listed in Table 14. At least half of the adolescents who identified boredom, acne, headaches, and trouble

Table 13

Demographic Characteristics of Adolescent Age Subgroups

	Adolescent subgroup		
	Early n=6	Middle n=9	Late n=9
Sex			
Male	4	3	3
Female	2	6	6
Chronic Illness			
Systemic Lupus	0	0	2
Spina Bifida	2	0	1
Asthma	1	3	1
Dystonia	0	1	0
Congenital Heart	0	2	0
Arthritis	1	0	2
Kidney Disease	1	1	2
Seizures	1	0	1
Diabetes	0	2	0

explaining their illness to friends also identified them among their top-ranked concerns. They share many of the concerns expressed by middle adolescents as well. Body image issues surrounding acne are of note given the previous finding that many of the adolescents had not sought any intervention for this problem. Surprisingly, other body image concerns had not been frequently noted by this subgroup (overweight, too thin, too short). They were, however, able to identify difficulties in their peer relationships that may have been precipitated by the often traumatic transition to junior high school that occurs at this age. Issues such as skin rashes, dental problems, and diarrhea may have been artifact given the small sample size.

Middle adolescents continued to identify boredom as both a prevalent concern and as a relatively important (Table 15). In addition, concern regarding how a particular chronic illness will affect the adolescent when he or she gets older first appeared in this age group as did poor school performance. The predominance and relative importance assigned to the former concern is noteworthy in that it shows the beginnings of future planning, a hallmark of progressive adolescent development. The list of primary health care needs presented here are shared by either the early or late adolescent subgroups.

Late adolescents identified a more extensive list of primary health care needs than did either previous group (Table 16). Nearly half of all those identifying boredom, needing help to decide about the future, and a desire to learn more about their chronic illness also identified these items as top-ranked concerns. The frequency with which items relating to friends and school are noted may be related to the transition to college life and a recognition that once again their life plans may be

Table 14

Primary Health Care Needs Prevalent among the Early Adolescent Group

PHCNA Item	Frequency (%) checking the item as a concern		Identification by over 50% of middle (M) or late (L) adols	
Sore throat	5	(83%)	M	
Bored lot	4	(67%)	M	L
Acne	4	(67%)	M	
Not able to do the things my friends do	3	(50%)	M	
Tired a lot	3	(50%)	M	L
A lot of headaches	3	(50%)	M	
Trouble explaining my __ to my friends	3	(50%)		L
Skin rash	3	(50%)		L
Problems with my teeth	3	(50%)		
Diarrhea	3	(50%)		

Table 15

Primary Health Care Needs Prevalent among the Middle Adolescent Group

PHCNA Item	Frequency (%) checking the item as a concern		Identification by over 50% of early (E) or late (L) adols	
Sore throat	8	(89%)	E	
Not able to do the things my friends do	6	(67%)	E	
Bored a lot	6	(67%)	E	L
Not doing well in school	6	(67%)		
Tired a lot	5	(56%)	E	L
Wondered how my __ will affect me when I get older	5	(56%)		L
Acne	5	(56%)	E	

Table 16

Primary Health Care Needs Prevalent among the Late Adolescent Group

PHCNA Item	Frequency (%) checking the item as a concern		Identification by over 50% of early (E) middle (M) adols	
Wondered how my ____ will affect me when I get older	8	(89%)		M
Tired a lot	8	(89%)	E	M
Bored a lot	7	(78%)	E	M
Needed help to decide about my future	7	(78%)		
Been depressed	7	(78%)		
Worried about my health	7	(78%)		
Wanted to learn more about my ____	7	(78%)		
Wondered if I will be able to have children when I get older	6	(67%)		

Table 16 (cont.)

PHCNA Item	Frequency (%) checking the item as a concern		Identification by over 50% of early (E) middle (M) adols
A lot of headaches	6	(67%)	E
Skin rash	5	(56%)	E
Trouble explaining my ____ to my friends	5	(56%)	E
Hard time adjusting to school after being absent	5	(56%)	
Questions about what to expect when I am in the hospital	5	(56%)	
Hard time explaining my ____ to people at school	5	(56%)	
Problems sleeping	5	(56%)	

significantly different from those of their "healthy" friends. In general, there are many more concerns related to worry about health and future plans, adjustment, and depression in this group than there were in either the early or middle adolescent samples. Late adolescents accounted for 7 of the 10 instances in which depression was identified as a primary health care need by the entire sample.

Boredom and being tired a lot are primary health care needs which are prevalent across the early, middle, and late adolescent samples. The chi-square test was used to identify differences in the frequency of identified needs among early, middle, and late adolescents. Significant differences among the groups were found for "wanting to learn more about the chronic illness" ($p < .05$), "being depressed" ($p < .02$), and "needing help to decide about the future" ($p < .001$). Additional post hoc testing was done to determine if there were any correlations between the frequency with which a primary health care need was identified and progressive devleopment from early to late adolescence. Kendall's tau was the statistic used to determine the correlations between ratio (frequency) and ordinal (adolescent age subgroups) data. The resultant analyses are presented in Table 17.

Three main themes emerge from this analysis of the primary health care needs of early, middle, and late adolescents. First, the concerns which are prevalent across these adolescent age subgroups are boredom and being tired a lot. These particular items are of concern as they may be equivalents of depression, especially when they appear together. Boredom may reflect the restrictive nature of the adolescents' chronic illnesses or parental overprotectiveness. Second, the sharp rise in the number of prevalent primary health care needs in the late adolescent subgroup points to an increased awareness of and ability to identify concerns. Their frequent

Table 17

Changes in Primary Health Care Need Prevalence Across Early, Middle, and Late Adolecent Groups

PHCNA item	Frequency (%) checking item as a primary health care need						
	Early n=6		Middle n=9		Late n=9		
Needed help to decide about my future	2	(33%)	2	(22%)	7	(78%)	***
Been depressed	1	(17%)	2	(22%)	7	(78%)	**
Problems sleeping	0	(0%)	2	(22%)	5	(56%)	*
Wondered how my _____ will affect me when I get older	2	(33%)	5	(56%)	8	(89%)	*
Trouble getting along with my brothers and/or sisters	0	(0%)	0	(0%)	3	(33%)	*
Wanted to learn more about my ____	2	(33%)	2	(22%)	7	(78%)	*

* p< .05 ** p< .01 *** p<.001

identification of depression is also notable. Third, behavioral and adjustment issues predominate among the primary health care needs expressed by the early, middle, and late adolescent samples.

Chapter V: Discussion

Introduction

This final chapter will commence with a summary of study conclusions and a description of significant research findings within the theoretical framework used for this study. A presentation of the study's limitations, as they apply to generalizations from the findings, will follow. Implications for theory and practice will then be discussed. Finally, future directions for research will be explored.

Conclusions

The conclusions of this study may be summarized as follows:

1. Psychosocial issues and those related to adjustment to chronic illness are the most common primary health care needs of chronically ill adolescents.
2. Lack of parental awareness of significant adolescent self-identified primary health care needs necessitates direct assessment of adolescent clients.
3. Chronically ill adolescents are frequently unaware of concerns which could be readily managed in a primary health care setting (i.e., acne and weight problems).
4. The culmination of adjustment issues related to chronic illness seems to occur in late adolescence in conjunction with an increase in the prevalence of "being depressed."

Significance of Research Findings

Several theories were used in this study to validate the need for a direct assessment of chronically ill adolescents' perceived primary health care needs, to specifiy the scope of such an assessment, and to place the assessment within a

developmental perspective. This section will discuss the most prominent findings from this study as they relate to the frameworks of symbolic interactionism, Lamberton's model of health and illness, and developmental theory. The findings will be compared with those of similar research studies and possible competing explanations will be discussed.

Rankings of primary health care needs allowed the adolescents to place relative values on their specific needs. Within "definition of the situation theory," the greater the value attached to a situation, the greater will be its effect in social interactions. One would assume that adolescents expect primary health care providers to address top-ranked concerns such as childbearing ability and future effects of the chronic illness. Another proposition of symbolic interactionism states that if a situation is definied as real by a person, the consequences of the situation are also real. Boredom was both prevalent and top-ranked in importance by the adolescents. Many people might consider this a trivial concern when compared with the physiological effects of a chronic illness; however, because these adolescents placed such importance on the issue of boredom, it must be taken seriously in practice. For example, one could look at its relationship to depression or an increase in risk-taking behavior to alleviate boredom.

Chronically Ill Adolescents' Perceived Primary Health Care Needs

Symbolic interactionism identifies the need to understand the meanings an individual assigns to events or objects, or as was the case in this study -- primary health care needs. Knowledge of these individually assigned meanings is needed for effective communication. After the meanings attached to primary health care needs by chronically ill adolescents in this study are discussed, a comparison will be

made with the meanings assigned to similar needs in earlier research studies. The unique life experiences of different adolescent samples can affect the way needs are described and the relative importance of certain needs to adolescents at that point in time.

Needs Common to the Current Sample. Use of Lamberton's model of health and illness was beneficial for the development of a needs assessment which did not focus solely on physiological and illness related issues but incorporated developmentally appropriate health concerns. Lamberton's health continuum more frequently encompassed the primary health care needs of greatest concern to this population than did the illness continuum. The chronically ill adolescents focused on psychosocial issues and those related to adjustment to the chronic illness, i.e., boredom, feeling depressed, school difficulties, and questions about the future effects of the chronic illness. These concerns parallel the "new morbidity" discussed by Haggerty, Roghmann, and Pless (1975). School functioning and adjustment to adolescence are examples of the psychosocial issues which come to the forefront once the initial medical crisis is resolved. The interaction of development with both the health and illness continua will be discussed in a later section.

It is striking that many of the prime concerns of these adolescents could be seen as sequelae of their chronic illnesses : worries about their health, school difficulties, depression, an inability to participate in the peer activities, and concern about childbearing capability. This study, however, cannot exclude other factors which may have been responsible for these concerns. For example, depression may have been the result of parental divorce and school difficulties may have been the result of

a previous learning disability. Possible competing explanations for the prevalence of these particular concerns do not negate the implications of their frequent appearance within this population.

Comparison with a Previous Study of Chronically Ill Adolescents. As previously noted in the review of the literature, there is a dearth of studies with which the results of this study can be compared. Carroll et al. (1983) were the only researchers to study an entirely chronically ill adolescent population (14 to 18 years) with regard to their primary health care needs. The overall prevalence for items similarly assessed by both studies was approximately 20 percentage points higher in the current study (Table 18), especially for the most prevalent concerns. The only exceptions were the frequency of anxiety, menstrual difficulties, and problems finding a job. The number of adolescents who cited "being anxious a lot" may have been less than in the Carroll sample because there were additional items which allowed subjects to identify a specific reason for the anxiety, i.e., "wondered if I will be able to have children when I get older" and "concerned about being pregnant." The smaller number who identified menstrual difficulties may be due to the inclusion of adolescents from age 11 and a mean age of menarche which may have been greater than in the Carroll sample. "Actual or expected difficulties finding a job" were assessed in a single question by the earlier study whereas the current study asked specifically about "problems finding a job" currently. Future concern about jobs may have been accounted for by response to the item "wondered how my illness will affect me when I get older." Despite the differences in actual prevalence of particular primary health care needs, the most frequently identified concerns in Carroll's study tend to parallel those of the current study.

Table 18

Comparison of Primary Health Care Need Prevalence in the Current Study with Those in Previous Studies of Chronically Ill and "Healthy" Adolescents

PHCNA Item	Percent of the sample identifying the item as a concern						
	Current Study (1988) n = 24 11-19 y.o. Chronic illness	Carroll et al. (1983) n= 61 14-18 y.o. Chronic illness	Sternlieb (1972) n= 1346 15-20 y.o. Healthy	Parcel et al. (1977) n= 3255 9-12 grade Healthy	Hodgson et al. (1986) n= 730 12-20 y.o. Healthy	Smith & Turner (1987) n= 149 12-15 y.o. Healthy
Tired a lot	67			16		
Wondered how my ____ will affect me when I get older	63					58
Not able to do the things my friends do	54	34				
Acne	54	37	18	30	47	39
Worried about my health	50	30	9	22		
A lot of headaches	50	27	9	13		
Worried about being overweight	42	40	6	23	26	25
Not been doing well in school	42	14				
Been depressed	42	23				
Problems getting along with with my teachers	33					35
Problems with my teeth	33		27	22	26	46
Problems getting along with my parents	29	10		23		
Concerned about being too short	29	36			9	
Hard time making friends	25	7		16		

NOTE Blank entries indicate that the specific item was not assessed in that study

PHCNA Item	Percent of the sample identifying the item as a concern					
	Current Study (1988) n = 24 11-19 y.o. Chronic illness	Carroll et al. (1983) n= 61 14-18 y.o. Chronic illness	Sternlieb (1972) n= 1346 15-20 y.o. Healthy	Parcel et al. (1977) n= 3255 9-12 grade Healthy	Hodgson et al. (1986) n= 730 12-20 y.o. Healthy	Smith & Turner (1987) n= 149 12-15 y.o. Healthy
Anxious a lot	25	50				
Not able to see very well	21				22	45
Concerned about being too thin	21			13	7	
Problems finding a job	21	46				
Nervous a lot	21		29	20	26	17
Not known how far to go with sex	21			29		
Gotten drunk	17			12	1	
Concerned about being pregnant	13			22		
Concerned about VD	13		1	23	1	
Trouble getting along with my brothers and/or sisters	13	5				
Questions about contraceptives	13			27	9	
Problems from wetting the bed or my underwear	8	2				
Problems urinating	8			3		
Problems with my period (bleeding, pain)	8	70	10	7	31	
Used drugs	4			12	2	
Concerned about being too tall	0				3	

Comparision with Studies of "Healthy" Adolescents. When comparing the responses of the current sample with those of "healthy" adolescents assessed in previous studies (Sternlieb & Munan, 1972; Parcel, et al., 1977; Hodgson, et.al., 1986; Smith, et al., 1987) (Table 18), similarities and differences emerge. The overall prevalence of similarly assessed primary health care needs was higher in the current sample of chronically ill adolescents than in the comparison samples. Only Smith, Turner, and Jacobsen's (1987) nursing study assessed healthy adolescents' concern about the future and concurrently found that this was a concern for 58% of their sample. This compares closely with the 63% prevalence regarding concern about the future effects of an adolescent's chronic illness found in the current study. Other major areas of concern in the present study were not assessed in the "healthy" samples, i.e., boredom, depression, and fatigue. Thus, comparisons cannot be made. The prevalence of pregnancy, contraceptive, and venereal disease concerns was as high as 23% among "healthy" adolescents (Parcel, et al., 1977). These areas of concern were the only ones in which the prevalence for the chronically ill sample was notably lower, although 25% were sexually active.

Summary. Many of the most prevalent and important primary health care needs of this chronically ill adolescent population were within the range of health concerns and adaptation to the chronic illness. Lamberton's model of health and illness was helpful in placing adolescent primary health care needs in a framework which addressed issues related to maximal health attainment as well as illness management. At this time, it is not possible to determine if many of the primary health care needs that are common to this sample of chronically ill adolescents are as prevalent among "healthy" adolescents.

Comparison of Adolescent and Parental Perceptions of the Chronically Ill Adolescents' Primary Health Care Needs

The theory of symbolic interactionism supported the comparison of how chronically ill adolescents and their parents perceived the adolescents' primary health care needs. Their differing spheres of social interaction predispose them to differences in perceptions. The fairly good average degree of adolescent-parent agreement at 76% may reflect the relatively high level of parental education or a closeness which has developed between the pair as a result of family coping with the chronic illness.

The similarities found here should not, however, reinforce the previous research practice of neglecting the direct assessment of adolescent clients. It must be remembered that an "average" degree of agreement is just that and it represents a wide range of individual adolescent-parent pairs. It is noteworthy that the parents in this sample were relatively unaware of the risk-taking behaviors of their adolescents. This was evident in the differences in reported prevalence for sexual activity and alcohol use.

A Developmental Perspective on Chronically Ill Adolescents' Perceived Primary Health Care Needs

Adolescent development interacts with health and illness issues among chronically ill adolescents. Two primary health care needs were highly prevalent across the early, middle, and late adolescent groups -- being "bored a lot" and "tired a lot." These concerns, in isolation, have significance for this sample but they have even greater meaning when they are viewed from a developmental perspective.

Boredom may be a manifestation of a lack of drive or purpose in the adolescent's life. Boredom at school may be the result of work that is too easy for the adolescent or work that is so difficult that the adolescent feels defeated and loses interest. Lack of goals for the future could result in an inability to apply oneself to current endeavors. Having a chronic illness may involve a true need for restricted activities or activities may be the result of parental overprotectiveness of a once fragile child. The effects of boredom can include a lack of productiveness which leads to a self-perpetuating cycle of lowered self esteem. Without a sense of purpose, many adolescents may participate in risk taking behaviors which they feel may decrease the boredom they are experiencing.

Frequent fatigue may be the manifestation of physiological (anemia) or psychological (depression) disorders. Although this study did not assess activity level more specifically, the concurrence of fatigue and boredom raise a greater suspicion of depression. In the early and middle adolescent sample, depression is not expressly identified by the adolescents as a concern. This may be the result of an inability to attribute a specific word to their feelings. It is very striking that "being depressed" was both a prevalent (78%) and top-ranked concern among late adolescents. They also identified other symptomatology associated with depression -- fatigue, boredom, and sleep disturbance. These late adolescents identified a greater number of common primary health care needs than did the other two groups. The vast majority of these needs related to future effects of the chronic illness and current adjustment within peer groups and school.

The culmination of adjustment issues related to chronic illness seems to have occurred in the oldest adolescent subgroup in this sample. The concurrence of these

issues in addition to the depressive equivalents mentioned earlier gives credence to the increased self-identified depression in this group. In late adolescence, individuals begin to make future plans, emancipate from their parents, and develop intimate relationships. Late adolescents with chronic illnesses may be unsure of the long-term effects of their illness on career, ability to emancipate from parents, and ability to bear children. It is not difficult to see how these issues could precipitate depression.

In summary, the prevalence of boredom and frequent fatigue in the early and middle adolescent sample raises the suspicion that they may be early depressive equivalents which are more expicitly identified in late adolescence. The majority of the late adolescents' most prevalent concerns were explicitly related to the impact of their chronic illnesses on daily living and future plans.

The Use of Resources to Meet the Adolescents' Identified Primary Health Care Needs

The chronically ill adolescents assessed in this study were able to specify a variety of resources in their environment which they had utilized to meet many of their identified needs. There was, however, insufficient use of resources for some problems which are often well managed with the assistance of health care professionals, i.e., acne, overweight, fatigue, difficulty fitting treatments into the adolescent's routine, and difficulty explaining the chronic illness to others. There was a marked lack of health care personnel involvement in the issues of depression, boredom, and school adjustment. Within a specialty clinic setting the focus is often on the specifics of illness management. The time or interest may not be present to look beyond immediate concerns to the broader effects of the illness on the

adolescent's psyche. Primary health care providers who regularly attend to these concerns were not utilized at all by 21% of the adolescents and an additional 16% had not made a visit to such a provider in over two years.

Physicians and parents were utilized fairly equally by the adolescents to meet their primary health care needs. Although physicians were used primarily for physical concerns, parents were the only resources used by some adolescents for physical ailments. Health care providers may have been sought out only after parents felt they could not provide the needed assistance. Friends were used as resources less frequently than expected, especially for those needs requiring emotional support. This may be due to the difference in life experiences between these adolescents and their "healthy" peers. Developmentally appropriate concerns about the future may be complicated by aspects of the chronic illness that peers could not understand.

The utilization of nurses as resources for primary health care needs fell far behind the use of parents, physicians, friends, and "no one." Although five of the eight specialty clinics represented had nurses working as part of the health care team, many of the adolescents did not know that this individual was a nurse. The two nurse practitioners associated with two individual clinics did not have contact with all of the adolescents seen there. The relatively lower use of nurses in the management of primary health care needs may be falsely low. Nurses were noticeably absent from representation among resources used to assist school adjustment, communication with parents and peers, and questions about the adolescents' development.

In summary, the chronically ill adolescents in this study have not used available resources in their environment to sufficiently address their primary health care needs. They do not seem to be aware of the concerns which can be readily managed in a primary health care setting and many do not have exposure to a provider who would regularly assess these needs. There is also a marked lack of nursing presence among the regular providers for primary health care needs which are well within the scope of nursing practice.

Limitations of the Study

Due to the descriptive nature of this study, inferences cannot be made based on the results. The major limitation of the study is its small sample size. The resultant cell sizes among the chronic illness groupings made it unrealistic to find statistical differences between the groups even if these differences were present. The early, middle, and late adolescent groups were of unequal size and unequally represented by adolescent sex. The combined effect may have been an factor in the developmental differences found in the prevalence of some primary health care needs.

Use of a nonprobability sampling technique predisposed the study results to bias from a potentially unrepresentative sample. The predominance of Caucasians and relatively high parental education and family income in this sample limit the generalizability of the results to other groups of chronically ill adolescents outside the specific geographic region in which the study was conducted. It was not possible to determine how the primary health care needs of these chronically ill adolescents compared with those of "healthy" adolescents due to the lack of a control group.

Implications for Nursing Practice

The results of this study have implications for the practice of pediatric nurse practitioners (PNP) in both primary health care and chronic illness specialty settings. Specific recommendations will be given for the assessment of chronically ill adolescents in each setting. Additionally, recommendations for particular interventions will be made.

Pediatirc nurse practitioners in primary health care settings should maintain close contact with chronically ill adolescents and their families. As the primary provider, the PNP has the responsibility of coordinating the adolescent's care and ensuring continuity and comprehensiveness of services. Before any assessment is made, the PNP should identify him or herself as the primary provider and should also define the role of a PNP to both the adolescent and his or her parent(s).

Assessment is then used to determine the specific primary health care needs of these adolescents. It is of the utmost importance that adolescents be assessed directly and with confidentiality regarding their self- identified needs. A checklist of primary health care needs can be very helpful in quickly identifying those concerns which need clarification or indepth assessment. This assessment should take place at every well visit, preferably every year (Marks & Fisher, 1987). The PNP should be aware of the health and illness concerns common to these adolescents -- boredom, depression, fatigue, school difficulties, the future effects of the chronic illness, overweight, and headaches. Efforts should be made to assess for depression throughout adolescence by investigating self-concept, future goals or ideals, sleep and appetite patterns, and availabilty of supportive persons at home or

in the peer group. Late adolescents will be able to identify more concerns about the future and living with the chronic illness.

Adolescence is an ideal time to make individuals aware that they are the PNP's primary client and to educate them as good health care consumers. This involves being aware of the services that the PNP offers and knowing how to gain access them. An additional role of the PNP is communication with the chronic illness specialist regarding particular primary health care issues which may affect the plan for illness management.

The pediatric nurse practitioner who works in the chronic illness specialty clinic should also begin his or her interaction with adolescents and their families by explaining the role of the PNP and the services he or she provides. Every effort should be made to refer the adolescent back to his or her primary health care provider for the management of primary health care concerns which are not part of the standard practice for that specialty clinic, i.e., weight control, headaches, acne. If the adolescent does not have a primary health care provider and is not likely to seek care elsewhere, the PNP in the specialty clinic can assess the adolescent's needs more fully and provide care based on available protocols and referral. Coordination remains an integral part of this PNP's role with regard to illness management. The comprehensive plan of care should be shared with the primary provider and communication should occur on a regular basis to ensure that the adolescent is receiving comprehensive care.

Assessment of those primary health care needs result ing from an adolescent's chronic illness is needed within the chronic illness specialty clinic. The PNP should be aware of common adolescent concerns which may be related to the chronic

illness -- future effects of the illness, depression, boredom, difficulty explaining the illness to friends, difficulty fitting treatments into the adolescent's "normal" routine.

If support groups are set up for chronically ill adolescents, the previously noted primary health care needs may be meaningful topics for discussion. A group including adolescents with a variety of chronic illnesses may be most effective because the most prevalent concerns appear to span diagnostic groupings. Separate groups may be set up, however, for late adolescents (17 years and older) because their needs tend to be focused on future concerns that may not be grasped cognitively by younger adolescents.

In summary, the pediatric nurse practitioner should demonstrate to chronically ill adolescents and their families the specific services he or she can provide to meet the full range of adolescent primary health care needs. A developmentally appropriate assessment will help to ensure the comprehensiveness of this care throughout adolescence. Inquiry into the adolescents' perceived primary health care needs will help to maintain effective communication between the primary health care provider and the adolescent client.

Directions for Future Research

Directions for future research arising from the current study are focused in the areas of methodological issues and additional research questions. Future studies should consider methodologies which utilize a noncategorical approach to chronic illness. This approach maximizes resources and the application of results and also appears to produce valid results. A larger sample size would enhance the generalizability of results as would matching for sex across early, middle, and late

adolescent groups. An additional assessment of adolescent physical development by Tanner staging would ascertain whether physical development has a greater effect on the common clusters of primary health care needs than chronological age. The use of a sex and age matched "healthy" adolescent control group would give more information regarding primary health care needs which may be uniquely prevalent among chronically ill adolescents. More indepth information could be obtained by progressing to a methodology using open interviews to investigate the primary health care needs of chronically ill adolescents illuminated in the current study.

The findings from this study have stimulated additional research questions pertinent to the study of the primary health care needs of chronically ill adolescents. What is the prevalence of the correlates of depression (sleep and appetite disturbance, low energy level, lack of goals or ideals, sense of futility, poor self concept) among chronically ill adolescents? What are chronically ill adolescents' specific concerns related to the future effects of their illnesses? What are the etiological factors involved in boredom among chronically ill adolescents? How do the primary health care needs of chronically ill adolescents compare with those of "healthy" adolescents? How do adolescents view the role of the pediatric nurse practitioner?

In conclusion, symbolic interactionism provided the overall framework in this study for the need to assess the adolescent client directly. A comprehensive and developmentally appropriate needs assessment resulted in a description of what chronically ill adolescents and their parents identified as the adolescents' primary health care needs. This study has stimulated methodological recommendations and

additional questions for future research with regard to the primary health care needs of chronically ill adolescents.

References

Aten, M., & McAnarney, E. (1981). A behavioral approach to the care of adolescents. St. Louis: C.V. Mosby.

Battle, C. (1972). The role of the pediatrician as ombudsman in the health care of the young handicapped child. Pediatrics, 50, 916.

Blumer, H. (1969). Symbolic interactionism: Perspective and method. Englewood Cliffs, NJ: Prentice-Hall.

Burns, C., & Thompson, M. (1984). Developing a nursing diagnosis classification system for PNP's. Pediatric Nursing, 10, 411-414.

Burr, W., Leigh, G., Day, R., & Constantine, J. (1979). Symbolic interaction and the family. In Burr, W., Hill, R., Nye, F., & Reiss, I. (Eds.), Contemporary theories about the family: Vol. II (p. 41-111). New York: Free Press.

Carroll, G. et al. (1983). Adolescents with chronic disease: Are they recieving comprehenisve health care. Journal of Adolescent Health Care, 4, 261-65.

Chow, M., Durand, B., Feldman, M., & Mills, M. (1984). Handbook of pediatric primary care (2nd ed.). New York: John Wiley.

Coupey, S., & Cohen, M. (1984). Special considerations for the health care of adolescents with chronic illness. Pediatric Clinics of North America, 31 (1), 211-219.

Elkind, D. (1967). Egocentrism in adolescence. Child Development, 38, 1025-1034.

Elkind, D., & Weiner, I. (1978). Development of the child. New York: John Wiley.

Erikson, E. (1968). Identity, youth and crisis. New York: W.W. Norton.

Featherstone, H., & Petersdorf, R. (1978). The medical specialist as a primary care provider. The Mount Sinai Journal of Medicine, 45, 620-627.

Gortmaker, S., & Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. Pediatric Clinics of North America, 31, 3-18.

Haggerty, R., Roghmann, K., & Pless, I. (1975). Child health in the community. New York: John Wiley.

Hansen, M. (1970). An educational program for primary care: Definitions and hypotheses. Journal of Medical Education, 45, 1001-1006.

Hodgson, C., Feldman, W., Corber, S., & Quinn, A. (1986). Adolescent health needs II: Utlization of health care by adolescents. Adolescence, 21 (82), 383-390.

Hymovich, D. (1985). Nursing services. In N. Hobbs & J. Perrin (Eds.), Issues in the care of children with chronic illness. San Francisco: Jossey-Bass.

Institute of Medicine. (1977). Primary care in medicine: A definition. Washington, D.C.: National Academy of Sciences.

Ireys, H. (1981). Health care for chronically disabled children and their families. In The Select Panel on the Promotion of Child Health, Better Health for Our Children: A National Strategy (pp. 321-353). Washington, D.C.: U.S. Government Printing Office.

Irwin, C. (1982). Developmental stages of adolescence. In A. Rudolph (Ed.), Pediatrics (11th ed.) (p. 39). Norwalk, CT: Appleton-Century Crofts.

Kanthor, H., Pless, B., Satterwhite, B., & Myers, G. (1974). Areas of responsibility in the health care of multiply handicapped children. Pediatrics, 54, 779-784.

Klerman, L. (1985). Interprofessional issues in delivering services to chronically ill children and their families. In N. Hobbs & J. Perrin (Eds.), Issues in the care of children with chronic illness. San Francisco: Jossey-Bass.

Korsch, B., Gozzi, E., & Francis, V. (1968). Gaps in doctor-patient communication: 1. Doctor-patient interaction and patient satisfaction. Pediatrics, 42, 855-871.

Lamberton, M. (1983). Health and illness: A co-existence hypothesis. Nurse Practitioner, 8 (2), 47, 50, 52.

Lau, R., Williams, S. Williams, L., Ware, J., & Brook, R. (1982). Psychosocial problems in chronically ill children: Physician concern, parent satisfaction, and the validity of medical records. Journal of Community Health, 7, 250-261.

Levy, J., Bonanno, R., Schwartz, C., & Sanofsky, P. (1979). Primary care: Patterns of use of pediatric medical facilities. Medical Care, 17, 881-893.

Marks, A., & Fisher, M. (1987). Health assessment and screening during adolescence. Pediatrics, 80 (1), s135-s158.

Mattson, A. (1972). Long-term physical illness in childhood: A challenge to psychosocial adaptation. Pediatrics, 50, 801-811.

Molde, S., & Diers, D. (1985). Nurse practitioner research: Selected literature review and research agenda. Nursing Research, 34, 362-367.

Orr, D., Hoffmans, M., & Bennetts, G. (1984). Adolescents with cancer report their psychosocial needs. Journal of Psychosocial Oncology, 2 (2), 47-59.

Palfrey, J., Levy, J., & Gilbert, K. (1980). Use of primary care facilities by patients attending specialty clinics. Pediatrics, 65, 567-572.

Parcel, G., Nader, P., & Meyer, M. (1977). Adolescent health concerns, problems, and patterns of utilzation in a triethnic urban population. Pediatrics, 60, 157-164.

Passo-Coffman, S. (1983). Parents' perceptions of needs for themselves and their children in a cerebral palsy clinic. Issues in Comprehensive Pediatric Nursing, 6, 67-77.

Perrin, J. (1985). Introduction. In N. Hobbs & J. Perrin (Eds.), Issues in the care of children with chronic illness. San Francisco: Jossey-Bass.

Pless, B., & Pinkerton, P. (1975). Chronic childhood disorder: Promoting patterns of adjustment. Chicago: Yearbook Medical.

Pless, B., Satterwhite, B., & Van Vechten, D. (1976). Chronic illness in childhood: A regional survey of care. Pediatrics, 58, 37-46.

Pless, B., Satterwhite, B., & Van Vechten, D. (1978). Division, duplication and neglect: Patterns of care for children with chronic disorders. Child: Care, Health, and Development, 4, 9-19

Polit, D., & Hungler, B. (1983). Nursing research: Principles and methods (2nd ed.). Philadelphia: J.B. Lippincott.

Ryberg, J., & Merrifield, E. (1984). What parents want to know. Nurse Practitioner, 9 (6), 24-32.

Schade, J., & Passo, S. (1981). Needs assessment of parents in pediatric ambulatory care. Journal of Ambulatory Care Management, 4, 23-32.

Smith, K., Turner, J., & Jacobsen, R. (1987). Health concerns of adolescents. Pediatric Nursing, 13, 311-315.

Starfield, B. (1980). Psychosocial and psychosomatic diagnoses in primary care of children. Pediatrics, 66, 159-166.

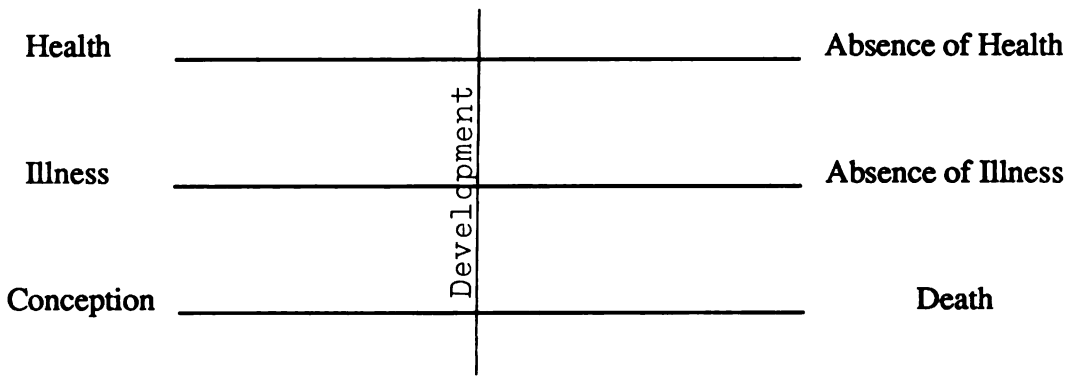
Stein, R., & Jessop, D. (1982). A noncategorical approach to chronic childhood illness. Public Health Reports, 97, 354-362.

Sternlieb, J., & Munan, L. (1972). A survey of health problems, practices, and needs of youth. Pediatrics, 49 (2), 177-186.

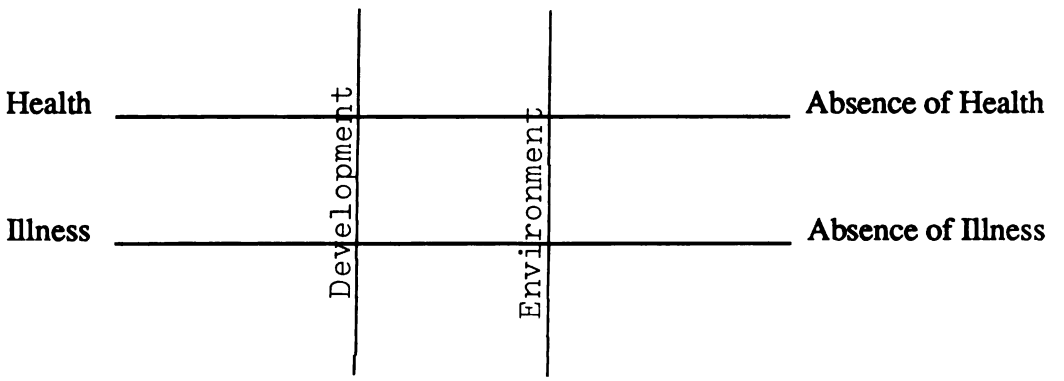
World Health Organization. (1978). Primary health care: A joint report by the director-general of the World Health Organization and the executive director of the United Nations Children's Fund. New York: World Health Organization.

Appendix A

Lamberton's Model of Health and Illness (Original)



Adapted Form of Lamberton's Model of Health and Illness



ID NO._____(A) PRIMARY HEALTH CARE NEEDS ASSESSMENT

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

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

For example:
If you had a tooth ache in the last year, put a check mark in the space next to "had a tooth ache".

(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, 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.

the past year, I have ..

(1) _____ had a tooth ache.

(2) _____ had breathing problems.

(3) _____ had a sprained ankle.

(4) _____ smoked cigarettes.

(5) _____ been concerned about being too thin.

(6) _____ not been able to do the things my friends 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.

For each item that you checked, put another check mark in the column that shows who you went to when that happened. You can mark more than one person for each thing that happened to you. If the person you went to is not on the list, please write who they are in the column for "Other". If you didn't go to anyone put a check mark in the column for "No one". There are no right or wrong answers.

For example:
If you wanted to learn more about your medicines in the past year, you would put a check mark in the column that shows who you went to to learn more about your medicines. You may have gone to the doctor, the nurse, your parents, or maybe you didn't go to anyone.

	Doctor	Nurse	Parents	Friends	Teacher	Social Worker	No one	Other
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								
13								
14								
15								
16								

(3 _____ had questions about sex.

(4 _____ been worried about my health.

(4 _____ been concerned about being too tall.

(4 _____ wondered how my _____ will affect me when I get older.

(4 _____ had questions about contraceptives.

(4 _____ had diarrhea.

(4 _____ wanted someone to listen to what bothers me.

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

(4 _____ had acne (pimples, zits).

(4 _____ had a hard time making friends.

(49) _____ had problems sleeping.

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

(5 _____ been nervous a lot.

(5 _____ needed help to decide about my future.

(5 _____ had problems urinating (pee).

(5 _____ been concerned about being too short.

(5 _____ been anxious a lot.

(5 _____ not known how far to go with sex.

(5 _____ wanted to learn more about my medicines.

(5 _____ had sex (sexual intercourse).

(5 _____ gotten drunk.

(6 _____ not been able to learn how to drive.

If I have any other concerns please write them on these lines.

Next to each one write who you went to for help.

	Doctor	Nurse	Parents	Friends	Teacher	Social Worker	No one	Other
39								
40								
41								
42								
43								
44								
45								
46								
47								
48								
49								
50								
51								
52								
53								
54								
55								
56								
57								
58								
59								
60								

(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 medicines into my regular schedule or routine.

(29 _____ had a broken bone.

(30 _____ had an ear ache.

(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.

	Doctor	Nurse	Parents	Friends	Teacher	Social Worker	No one	Other
17								
18								
19								
20								
21								
22								
23								
24								
25								
26								
27								
28								
29								
30								
31								
32								
33								
34								
35								
36								
37								
38								

ID NO. _____ (P) PRIMARY HEALTH CARE NEEDS ASSESSMENT

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

(1) Read each item listed below. Place a check mark 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 tooth ache in the last year, put a check mark in the space next to "had a tooth ache".

(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 tooth ache.

(2) _____ had breathing problems.

(3) _____ had a sprained ankle.

(4) _____ smoked cigarettes.

(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.

For each item that you checked, put another check mark in the column that shows who your son/daughter went to when that happened. You can mark more than one person for each item. If the person that your son/daughter went to is not on the list, please write who they are in the column for "Other". If they didn't go to anyone put a check mark in the column for "No one". If you are not sure put a check under "I don't know". There are no right or wrong answers.

For example:
If your son/daughter wanted to learn more about his or her medicines in the past year, you would put a check mark in the column that shows who they went to to learn more about their medicines. They may have gone to the doctor, the nurse, parents, or they may have gone to no one.

	Doctor	Nurse	Parents	Friends	Teacher	Social Worker	No one	Other	I don't know
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									
11									
12									
13									
14									
15									
16									

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 ear ache.

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.

	Doctor	Nurse	Parents	Friends	Teacher	Social Worker	No one	Other	I don't know
17									
18									
19									
20									
21									
22									
23									
24									
25									
26									
27									
28									
29									
30									
31									
32									
33									
34									
35									
36									
37									
38									

(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 him/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.

(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 medicines.

(58) _____ had sex (sexual intercourse).

(59) _____ gotten drunk.

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

you have any other concerns please write them on these lines.

:t to each one write who you went to for help.

	Doctor	Nurse	Parents	Friends	Teacher	Social Worker	No one	Other	I don't know
39									
40									
41									
42									
43									
44									
45									
46									
47									
48									
49									
50									
51									
52									
53									
54									
55									
56									
57									
58									
59									
60									

Appendix D

Primary Health Care Needs Assessment:Item Documentation

Documentation for each item appears on the line next to it as a numbered reference or series of numbered references. At this stage, only previous research employing needs assessments of adolescents and parents were used. Texts and personal experience were used to substantiate those items not found in current studies. If an item is not referenced on the parent questionnaire, it did not appear in any primary care needs assessments designed for parents of well or chronically ill adolescents. If an item is not referenced on the adolescent questionnaire, it did not appear in any needs assessments concerning the primary care of well or chronically ill adolescents.

The following are the references used and their code numbers (please see previously attached PHCNA forms with item documentation appearing in blue ink):

1- (Carroll et al., 1983)
2- (Lau et al., 1982)
3- (Orr et al., 1984)
4- (Palfrey et al., 1980)
5- (Parcel et al., 1977)
6- (Pless et al., 1978)
7- (Ryberg & Merrifield, 1984)
8- (Schade & Passo, 1981)
9- (Starfield et al., 1980)

When the items on both instruments are considered the following were not referenced by any research articles:

(3) sprained ankle -included as a common injury
(4) smokes cigarettes- not specifically mentioned in other instruments but considered a component of adolescent health assessment
(17) bored a lot- based on experience with chronically ill adolescents who may be homebound or have few friends
(21) hard time explaining illness to brother and/or sisters- based on references to parental difficulty explaining the adolescent's illness to siblings and included here to determine any effect on the ill adolescent
(27) hard time fitting treatments into regular schedule- based on experience with this population
(28) hard time fitting medicines onto regular routine- same as above

(29) broken bone- included as an injury seen in adolescence
(45) wanting someone to listen to what bothers him/her- not specifically referenced but general adolescent desire based on experience
(55) anxious a lot- included to check reliability of item concerning being "nervous a lot", this specific term not mentionned in the literature surveyed
(60) not being able to learn to drive- included as a rite of passage that may be of concern to adolescents who are prevented from doing so because of their illness

ADOLESCENT PRIMARY HEALTH CARE NEEDS ASSESSMENT

(1)	5	had a tooth ache.
(2)	4	had breathing problems.
(3)		had a sprained ankle.
(4)		smoked cigarettes.
(5)	1,5,8	been concerned about being too thin.
(6)	1,3	not been able to do the things my friends do.
(7)	5	been concerned about VD (venereal disease).
(8)	4	had a sore throat.
(9)	8	wondered what makes my body go through these changes as a teenager.
(10)	1,4,5,9	had a lot of headaches.
(11)	1,3,5,8	had problems getting along with my parents.
(12)	8	had a skin rash.
(13)	5	had problems with my teeth.
(14)	4,8,9	been constipated.
(15)	1,4,8,9	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)	5,9	been concerned about being pregnant.
(19)	4	had hearing problems.
(20)	5	had problems getting along with my teachers.
(21)		had a hard time explaining my____ to my brothers and/ or sisters.
(22)	5	been tired a lot.
(23)		had a hard time adjusting to school after being absent.
(24)	4	not been able to see very well.
(25)	8	wanted to learn more about my __.
(26)	5	been depressed.
(27)		had a hard time fitting my treatments into my regular schedule or routine.
(28)		had a hard time fitting medicines into my regular schedule or routine.
(29)		had a broken bone.
(30)		had an ear ache.
(31)	8	wanted to learn more about my treatments.

(32)	3	had trouble explaining my ____ to my friends.
(33)	5	used drugs.
(34)	8	had questions about what to expect when I am in the hospital.
(35)	1,4,8,5,9	not been doing well in school.
(36)	1	had problems finding a job.
(37)	1,5,8	been worried about being overweight.
(38)	3	had a hard time explaining my ___ to people at school.
(39)	5,8	had questions about sex.
(40)	1,5	been worried about my health.
(41)	1	been concerned about being too tall.
(42)	6	wondered how my _____ will affect me when I get older.
(43)	5,8,9	had questions about contraceptives.
(44)	4,8	had diarrhea.
(45)		wanted someone to listen to what bothers me.
(46)	1,5,8	had trouble getting along with my brothers and/or sisters.
(47)	1,4,5,8	had acne (pimples, zits).
(48)	1,5,8	had a hard time making friends.
(49)	8	had problems sleeping.
(50)	1,4,5,8,9	had problems with my period (a lot of pain or bleeding).
(51)	4,5	been nervous a lot.
(52)		needed help to decide about my future.
(53)	5,8	had problems urinating (pee).
(54)	1	been concerned about being too short.
(55)		been anxious a lot.
(56)	5	not known how far to go with sex.
(57)	8	wanted to learn more about my medicines.
(58)	5	had sex (sexual intercourse).
(59)	5	gotten drunk.
(60)		not been able to learn how to drive.

PARENT PRIMARY HEALTH CARE NEEDS ASSESSMENT

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

(1)	_____	had a tooth ache.
(2)	_____	had breathing problems.
(3)	_____	had a sprained ankle.
(4)	_____	smoked cigarettes.
(5)	1,6,8	been concerned about being too thin.
(6)	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)	6,8	wondered what makes his/her body go through the changes of being a teenager.
(10)	1,9	had a lot of headaches.
(11)	2,8	had problems getting along with his/her parents.
(12)	8	had a skin rash.
(13)	_____	had problems with his/her teeth.
(14)	8,9	been constipated.
(15)	_____	had problems from wetting the bed or his/her underwear.
(16)	6	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)	9	had hearing problems.
(20)	_____	had problems getting along with his/her teachers.
(21)	_____	had a hard time explaining his/her ____ brothers and/or sisters.
(22)	_____	been tired a lot.
(23)	2	had a hard time adjusting to school after being absent.
(24)	_____	not been able to see very well.
(25)	8	wanted to learn more about his/her _____.
(26)	_____	been depressed.
(27)	_____	had a hard time fitting treatments into his/her regular schedule or routine.
(28)	_____	had a hard time fitting medicines into his/her regular schedule or routine.

(29)	_____	had a broken bone.
(30)	6	had an ear ache.
(31)	8	wanted to learn more about his/her treatments.
(32)	_____	had trouble explaining his/her _____ to friends.
(33)	_____	used drugs.
(34)	8	had questions about what to expect when he/she is in the hospital.
(35)	1,2,8,9	not been doing well in school.
(36)	6	had problems finding a job.
(37)	1,8	been worried about being overweight.
(38)	_____	had a hard time explaining his/her _____ to people at school.
(39)	5,6,8	had questions about sex.
(40)	_____	been worried about his/her health.
(41)	1,6	been concerned about being too tall.
(42)	_____	wondered how his/her _____ will affect him/her when he/she gets older.
(43)	8,9	had questions about contraceptives.
(44)	8	had diarrhea.
(45)	_____	wanted someone to listen to what bothers him/her.
(46)	2,8	had trouble getting along with his/her brothers and/or sisters.
(47)	1,8	had acne (pimples).
(48)	1,2,8	had a hard time making friends.
(49)	8	had problems sleeping.
(50)	8,9	had problems with her period (a lot of pain or bleeding).
(51)	_____	been nervous a lot.
(52)	6	needed help to decide about his/her future.
(53)	8	had problems urinating.
(54)	1,6	been concerned about being too short.
(55)	_____	been anxious a lot.
(56)	_____	not known how far to go with sex.
(57)	8	wanted to learn more about his/her medicines.
(58)	_____	had sex (sexual intercourse).
(59)	_____	gotten drunk.
(60)	_____	not been able to learn to drive.

Appendix E

Adolescent Demographic Data Form

(1) Age _____

(2) Birthday _____

(3) Sex [ ] Male [ ] Female

(4) Grade that you will be in next September

[ ] 4th [ ] 9th
[ ] 5th [ ] 10th
[ ] 6th [ ] 11th
[ ] 7th [ ] 12th
[ ] 8th [ ] College

(5) In the school year that just finished, how long were you absent from school?

[ ] Not at all
[ ] Less than 1 week
[ ] 1 to 3 weeks
[ ] 1 month
[ ] More than 1 month but less than 4 months
[ ] 4 months or more
[ ] The entire year

(6) What ethnic group or race do you belong to?

[ ] Asian [ ] Black
[ ] Hispanic [ ] Phillipino
[ ] White [ ] I don't know
[ ] Other (write it on the line) _____

(7) What religion do you belong to?

[ ] Catholic [ ] Jewish
[ ] Protestant [ ] Hindu
[ ] Buddhist [ ] None
[ ] Episcopalian [ ] I don't know
[ ] Other (write it on the line)

_____

(8) Do you have any jobs that help you to earn money?

[ ] Yes, (write what you do on the line) _____
[ ] No

(9) How long have you had _____?

_____ (You can write your answer in months or in years)

(10) How many times have you been in the hospital this year?

_____ times

Appendix F

Parent Demographic Data Form

		Mother	Father
(1)	Age	_____	_____
(2)	Highest level of school completed	[ ] No formal education [ ] Grade school [ ] High school [ ] College (Number of years _____) [ ] Graduate School	[ ] No formal educ. [ ] Grade school [ ] High school [ ] College (number of years _____) [ ] Graduate school
(3)	Type of job (write it on the line)	[ ] Part-time _____ [ ] Full-time _____ [ ] Not employed	[ ] Part-time _____ [ ] Full-time _____ [ ] Not employed
(4)	Ethnic Background or Race	[ ] Asian [ ] Black [ ] Hispanic [ ] White [ ] Phillipino [ ] Other _____ (write it on the line) [ ] I don't know	[ ] Asian [ ] Black [ ] Hispanic [ ] White [ ] Phillipino [ ] Other _____ (write it on the line) [ ] I don't know
(5)	Religion	[ ] Catholic [ ] Protestant [ ] Jewish [ ] Buddhist [ ] Hindu [ ] I don't know [ ] None [ ] Other _____ (write it on the line)	[ ] Catholic [ ] Protestant [ ] Jewish [ ] Buddhist [ ] Hindu [ ] I don't know [ ] None [ ] Other _____ (write it on the line)

(6)	Marital status	[ ] Married [ ] Separated [ ] Divorced [ ] Widow [ ] Single	[ ] Married [ ] Separated [ ] Divorced [ ] Widower [ ] Single
(7)	Family income per year	[ ] 0- $4999 [ ] $5000- $9,999 [ ] $10,000- 14,999 [ ] $15,000- $19,999 [ ] $20,000- $29,999 [ ] $30,000 or more	

(8) This form has been filled out by the adolescent's
[ ] Mother
[ ] Father
[ ] Other _____
(relationship to adolescent)

(9) How long has he/she had _____?

_____ (You can give it in months or years)

(10) How many times has he/she been hospitalized in the past year?

_____ times

(11) How would you describe your son/daughter's chronic health problem?
[ ] Mild
[ ] Moderate
[ ] Severe

(12) Does he/she see a pediatrician or nurse practitioner outside of the clinic here?
[ ] No
[ ] Yes
If yes, when was the last time that your son/daughter made a visit to this pediatrician or nurse practitioner?
[ ] In the past one year
[ ] 2 years ago
[ ] More than 2 years ago

Appendix G
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEPARTMENT OF FAMILY HEALTH CARE NURSING

Dear ,

My name is Mary Alice Dragone, RN, and I am a graduate student in nursing at the University of California, San Francisco. I would first like to thank you for taking the time to read this letter. I received permission to contact you from the clinic where your son/daughter is seen for their to inform you that a study is being done to learn more about the primary health care needs identified by both adolescents with ongoing health problems and their parents. You and your son or daughter are being asked to take part in this study to help doctors and nurse practitioners understand the full range of needs and concerns common to adolescents with ongoing health problems. The only requirements are that he/she has had this ongoing health problem for at least 3 months, is between 11 and 19 years of age (inclusive), and that both of you speak and read English fluently.

If you do no wish to take part in this study, please fill out your name and address on the enclosed postcard and return it within 7 days of the letter's postmarked date. Refusal to participate will in no way affect the care your son or daughter receives at the University of California, San Francisco.

If you would like to participate or would like more information before deciding, do not send the enclosed postcard. I will contact you at home within 10 to 14 days of the letter's postmark to answer your questions and to give more information. At this time you may tentatively agree or refuse to participate in the study. Of course you may withdraw from participation at any time. Should you decide to participate, I would set up a time and place to meet with you and your son/daughter. I will meet both of you at your child's scheduled clinic appointment or at your home, whichever is more convenient for you.

After this first phone call, you can expect to meet with me in person to
- complete consent forms (your son/daughter's permission is also needed for participation in this study) and
- a questionnaire that includes items that relate to health and illness concerns common to young poeople with ongoing health problems.

This should take about 20 minutes of your time.

There is a possibility that both of you would be contacted a second time by phone two weeks after you have completed the questionnaire. This would take no more than 5 minutes of time for each of you and would consist of answering 6 of the items from the questionnaire.

Thank you so much for your time. I have great hopes that the information that is gained from this study will help doctors and nurse practitioners like myself to better meet the needs of both young people with ongoing health problems and their parents.

Sincerely,

Mary Alice Dragone

Mary Alice Dragone, R.N., B.S.N.

Appendix H

Return Refusal Postcard

Mary Alice Dragone
1999 Beach Park Blvd. #9
Foster City, CA 94404

I do not wish to be contacted by Ms. Dragone regarding her study with young people having ongoing health problems.

Parent's name _____

Address _____

_____

Appendix I
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEPARTMENT OF FAMILY HEALTH CARE NURSING

Consent to Be a Research Subject

A study is being done by Mary Alice Dragone, a graduate student in nursing at the University of California, San Francisco, to learn more about the primary health care needs identified by both young people with ongoing health problems and their parents. When a young person has a condition that requires fairly frequent medical attention, their "health" concerns may be overlooked. My son/daughter and I have been asked to take part in this study in order to help doctors and nurse practitioners to understand the full range of needs and concerns common to young people with ongoing health problems.

PROCEDURES: If I agree to be in this study, I will have one and possibly two additional contacts with Ms. Dragone after signing this form.
- The first will occur immediately following signing this form at my child's scheduled clinic appointment or at my home, whichever is more convenient for us. It will consist of completing a questionnaire that includes items that relate to health and illness concerns common to young people with ongoing health problems. This will take approximately 20 minutes of my time. When I have finished, Ms. Dragone will ask for my comments about the questionnaire and any other information I wish to give her. I will be asked to complete the questionnaire without conferring with my son/daughter who will be completing a similar form. My son/daughter's permission is also necesssary for participation in this study.
- There is a possibility of a second contact with Ms. Dragone within two weeks after we fill out the questionnaires. This would take no more than 5 minutes of our time and would consist of answering 6 items from the questionnaire.

RISKS/DISCOMFORTS: As a result of answering this questionnaire there is a possible loss of my privacy. Ms. Dragone will separate names from responses and will keep names coded and the code locked. My confidentiality will be protected as much as is possible within the law. We have the right to refuse to answer any questions at any time. There is also a chance that answering the questionnaire will be stressful to my son/daughter and I.

BENEFITS: There will be no direct benefit to me or my son/daughter as a result of being in this study. However, the information may help future adolescents with ongoing health problems to have primary care which addresses the full range of their concerns.

REIMBURSEMENT: There will be no reimbursement to me or my son/daughter for taking part in this study.

QUESTIONS: I have talked with Ms. Dragone and have had all of my questions answered. If I have any further questions, I may contact her at (415) 341-4982.

CONSENT: I have been given a copy of this form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN THE STUDY IS VOLUNTARY: I have the right to refuse to participate or withdraw from the study at any time without any effect on the care my child currently receives.

_____ _____

Date Subject's signature

6/22/87 CHR Approval No. 944906-01* ID. NO. _____

Appendix J
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
DEPARTMENT OF FAMILY HEALTH CARE NURSING

Assent to Be a Research Subject

A study is being done by Mary Alice Dragone, a graduate nursing student at the University of California, San Francisco, to learn more about the concerns that young people with ongoing health problems may have. When an young person has a condition that often needs medical attention, his or her "health" concerns may be overlooked. I have been asked to take part in this study in order to help doctors and nurses understand the things that happen to and concern young people like myself.

PROCEDURES: If I agree to be in this study, I will have one and possibly two additional contacts with Ms. Dragone after signing this form.
- The first will occur immediately following signing this form at my clinic appointment or at my home, whichever is more convenient for me and my parent. It will consist of completing a questionnaire that includes items that relate to health and illness concerns common to young people with ongoing health problems. This will take approximately 20 minutes of my time. When I have finished, Ms. Dragone will ask for my comments about the questionnaire and any other information I wish to give her. I will be asked to complete the questionnaire without asking my parent any questions.
- There is a possibility of a second contact with Ms. Dragone within two weeks after I fill out the questionnaires. This would take no more than 5 minutes of my time and would consist of answering 6 items from the questionnaire.

RISKS/DISCOMFORTS: As a result of answering this questionnaire there is a possible loss of my privacy. Ms. Dragone will separate names from responses and will keep names coded and the code locked. My confidentiality will be protected as much as is possible within the law. I may refuse to answer any questions at any time.

BENEFITS: There will be no direct benefit to me as a result of being in this study. However, the information may help future young people with ongoing health problems.

REIMBURSEMENT: There will be no reimbursement to me for taking part in this study.

QUESTIONS: I have talked with Ms. Dragone and have had all of my questions answered. If I have any further questions, I may contact her at (415) 341-4982.

ASSENT: I have been given a copy of this form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN THE STUDY IS VOLUNTARY: I have the right to refuse to participate without any effect on the care that I receive.

_____ _____

Date Subject's signature

6/22/87 CHR Approval No. 944906-01* ID. NO. _____


UC
San Francisco
LIBRARY
UNIVERSITY OF CALIFORNIA · UNIVERSITY OF CALIFORNIA