RESEARCH PROSPECTUS

FAMILY AND ILLNESS:

Introduction

In recent years, the family has come under scrutiny as a possible focal point in health care delivery (Pattison & Anderson, 1978; Potash & Migenes, 1978). Numerous studies have pointed up the relationship between health, disease, and the family unit (Kaplan et al, 1977). Interaction between family and disease has been examined for several varieties of severe or chronic illness (Vigliano et al, 1964; Robertson & Suinn, 1968; Minde et al, 1972; Litman, 1964; Bruhn, 1977); genetic diseases and congenital abnormalities (Turk, 1964; Lawler et al, 1966; Mattson & Agle, 1972; Mattson & Gross, 1966; Gardner, 1968; Block, 1969; Golden & Davis, 1977); and lifethreatening illness (Friedman et al, 1971; Knudson & Natterson, 1969; Chodoff et al, 1964; Verwoerdt, 1966; Vollman et al, 1971; Parkes, 1975). In exploring the etiology and treatment of diseases such as asthma, diabetes mellitus, anorexia nervosa, the concept of the psychosomatogenic family has gained increased acceptance (Dubo et al, 1961; Minuchin, 1974; Minuchin et al, 1978).

Several models of family response to severe and chronic illness have been proposed (Burr, 1978; Mattson, 1977), although none has been validated empirically. A few articles focus on how the physician can facilitate optimal family response to illness (Grant, 1978; Dayringer, 1972; Epstein & Bishop, 1973) but again, the discussion is theoretical and descriptive, rather than empirical. Thus, despite increasing clinical interest in the impact of disease on the family and in the family's response to disease, little systematic, behavioral investigation

has thus far been attempted. Clearly a more empirical, less impressionistic analysis of family response and family coping styles is needed. In addition, minor illness, a heretofore largely neglected category of disease which is nevertheless a commonplace experience in every family (Shrand, 1965; Mattson & Weisberg, 1970), needs to be examined.

The rationale for the proposed line of investigation is twofold:
1) Currently, much attention in health care has been devoted to improving the doctor-patient relationship (Little, 1973; Bogdonoff et al, 1965; Rittelmeyer, 1971; Balint, 1979; Adler and Hammett, 1973). However, it may be argued that the exclusive focus on the doctor-patient dyad is inappropriate, and ignores a critical enviornomental context within which that dyad functions - namely, the family. One effect of the proposed studies will be to emphasize and clearly delineate the relationship between family and disease, which may ultimately alter the thrust of health care delivery in this country. The family is an appropriate unit both for descriptive and intervention studies, as it is the unit primarily responsible for shaping and influencing an individual's attitudes and beliefs, as well as behaviors, vis-a-vis wellness and illness. Also, despite recent fragmentation and diminution of the importance of the nuclear family, the family is still the primary caretaking and supportive unit in the event of illness.

2) Much attention and money have been directed toward improved intervention with life-threatening and crippling diseases. Yet the average family physician spends a good deal of his or her time treating the common cold, upper respiratory infections, and otitis media. One hypothesis is that it is at this most basic level that the physician needs to begin to intervene with the family, to develop patterns of functioning and coping which will later stand the family in good stead in the event of

the development of more long-standing serious illness. The various stages and coping strategies that occur in a family dealing with major illness can also be observed, albeit on a small scale, in families dealing with minor illness. It is possible that families develop their response patterns for coping with catastrophic illnesses early in their family careers (Carey & Sebinga, 1972). Thus, families may lock into either minimally functional or dysfunctional coping styles, which they may be able to get by with when confronted by a minor illness, but which lead to total family decompensation and disorganization in the face of major illness.

Although the majority of families cope well enough with minor illness, anecdotal evidence identifies a significant minority of families whose response does not appear to be justified by the relative lack of severity of the illness at hand. These families tend to demand overmedication from their physician, and waste their time and the physician's time in unnecessary office visits. It would be of benefit to develop predictive factors to be used in identifying such families, so that preventive measures could be taken to minimize their nonadaptive coping responses. Thus certain families are at risk in the face of relatively minor illness in one family member. It is hypothesized that such families may include single parent families, working parent families, and new parent families.

It is hypothesized that an optimal response pattern to illness can be identified and reduced to its component parts. Significant aspects of such a response pattern might include: 1) open and mutual communication about the illness 2) information seeking behaviors 3) access to resources (monetary, social, familial) 4) ability to utilize resources 5) willingness to discuss feelings about

illness etc. Once a set of optimal behavioral responses is identified, it can be used in a preventive medicine, patient education capacity, particularly with high risk families.

It is hypothesized that generally well-functioning families will cope well with the onset of a minor illness and that generally poorer-functioning families will cope less well. If this hypothesis is supported, it will provide ways for the physician to identify at risk families and initiate preventive measures.

The overall goal of this line of investigation is to turn over more responsibility to the family unit in coping with minor illness, and to give poorer-coping families specific skills to implement appropriate response patterns. The end result will be fewer office visits, fewer prescribed medications and possibly fewer illnesses during a given time period.

Because of the multiplicity of unanswered questions in the area of family and illness, this line of investigation has been conceptualized as a series of studies, to allow for better control of the dependent variables.

Descriptive Studies

Study 1 focuses on family and physician perceptions of two dependent variables: 1) effect of minor illness on the family 2) coping styles of the family in response to minor illness. Minor illness will be operationalized in this study to include upper respiratory tract infections and otitis media, both febrile and afebrile conditions in which the parent has sought medical assistance for the child. This study will arbitrarily investigate both white and Mexican-American families with two or more children, at least one of whom is in the

vulnerable age range of 0-6, when families are most plagued by the occurrence of acute minor illness. A questionnaire will be administered to 50 mothers bringing children for treatment. The same questionnaire will also be sent home for completion by the father. Questionnaires will focus on parents' perception of behavioral and attitudinal effects of illness on the identified patient (in this study, arbitrarily designated to be the child), on siblings, on parents, and on family function as a whole. An instrument evaluating level of family functioning will also be administered (Family APGAR). In this way, comparisons of mother's and father's perception of impact of illness and coping styles in the family can be made. Also, based on the relationship between questionnaire responses and assessment of healthy family function, effective coping styles can be identified. In an effort to establish concensual validity for parental observations, a questionnaire will also be administered to the family physician. The physician will evaluate the family's ability to cope with the illness, and will also rate the family's compliance with medical regimen, capacity for engaging in health-maintaining behaviors etc. On a selected sub-sample of families, intensive interviews will be conducted to gather more information about coping styles and strategies. These interviews will focus on families at both extremes of the effective-ineffective coping continuum and will include children as well as parents in the discussions.

The variables to be identified in this study are as follows. Independent variables include age of identified patient, sex of identified patient; level of education of mother and father, occupation of mother and father; number of illnesses this year so far. Dependent variables include behavioral and attitudinal response of mother, of patient, of father, of siblings; coping

styles employed by family members; generalized level of family functioning and physician perception of family coping with illness.

The purpose of this initial study are several: 1) To gather more detailed and in-depth information about a) effects of illness: on the patient in relationship to various family members (mother, father, siblings); and on the interactions of various family members with each other (mother-father, mother-siblings, sibling-siblings, father-siblings); and about b) responses to illness: i.e., the coping styles of individual family members, and of the family as a whole when illness occurs in the identified patient. In addition, other factors, such as the family's view of the illness and their concept of the role of treatment, will be examined in light of their relationship to family coping styles. From the families themselves, information will be gathered about what they feel to be effective and maladaptive ways of coping with their child's illness. 2) This information will then be compared with a measure of family function to establish whether families with a generalized effective functioning style indeed perceive themselves and are perceived by their physicians to respond more effectively to the crisis of illness. An additional comparison will investigate whether poorer functioning families are effected more calamitously by the introduction of illness into the family system. 3) Finally, the physician's perception of effect of illness and family response will be measured, to obtain some consensual validity of family perceptions. In cases where there is agreement between physician and family about high functioning, we will have further justification to begin to develop an ad hoc analysis of effective coping styles.

Study 2:

There are several methodological problems with the above study as described: 1) its reliance on parental retrospective comparisons of family functioning during illness compared to family functioning under illness-free conditions, 2) its subjective rather than behavioral emphasis, 3) its emphasis on maternal rather than paternal perceptions. The next study proposes to remedy these deficits and examine at a more behavioral level changes and responses in the family system when illness is introduced into that system. This study, prospective and longitudinal in nature, will follow 50 families over the course of 2 years. Family members will be required to monitor certain behavioral and attitudinal variables at regular intervals. In this way, families will serve as their own controls. In addition, periodically observers will provide ratings of family function as well. The physician will also be involved in evaluating effective family coping in response to specific illnesses which occur in the family during the time of the study. This study will lend increased reliability to the self-reports of the earlier study, and based on that earlier information, will focus on specific areas of concern. This study will also provide more concrete information about how coping is manifested in specific illness situations.

Additional studies:

It will be critically important to investigate several permutations of these original studies. In the original set of studies, the identified patient is the child. Certainly the population selected has wide generalizability. However, much could be learned from varying the independent variables. For example, does

the effect of illness and the family coping patterns remain the same when the identified patient is a parent rather than a child? Do families with different ethnic and cultural backgrounds (for example, black and Mexican-American) evidence different, perhaps more adaptive coping styles? Have families in which serious or chronic illness is already present developed additional effective coping mechanisms for surviving the day-to-day crises of minor illness?

Additionally, the hypothesis of a relationship between coping styles in minor and major illnesses needs to be tested. Similarly, we need to see to what extent the family's initial experiences with illness determine subsequent attitudes and responses toward illness.

Intervention Studies:

Phase one of the investigation involves a series of descriptive studies, whose purpose is to gather information and clarify relationships between variables. Phase two focuses on the development of interventions and training programs: its primary emphasis is preventive and rehabilitative based on findings of original set of studies. The long-term aim of this investigation is to provide the family physician with improved tools to employ in patient care. Specifically, the development of educational interventions will emphasize the treatment of the family as a whole, as well as specific techniques for doing so. The second purpose of these intervention studies will be to train physicians to teach families under their care effective coping mechanisms for responding to illness. A controlled series of studies will be employed to determine the effectiveness of these interventions, and assess whether families thus trained

differ significantly on a variety of variables, such as satisfaction with health care; compliance to medical regimen; decreased contact with physician; decreased duration and frequency of illnesses. In this phase a wide variety of behavioral techniques will be employed, combined with physicians' clinical observations and information gathered from earlier studies. In subsequent studies, various components of this intervention package will be systematically tested to determine their contribution to the variance existing between experimental and control populations.

Thus the purpose of the line of investigation delineated above is first to gain specific and generalizable information about how the family unit copes with acute minor illness; what are adaptive and maladaptive coping strategies; and secondly, how the family physician can educate families under his or her care to more effective ways of coping with the occurrence of illness. It is proposed that the unit of health care expand from individual to the family, and that the responsibility for the training of coping skills for the implementation of health care, is so far as possible, disseminated by the physician to the family.