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STRONG AND WEAK TIES: SOCIAL SUPPORT
FOR FAMILIES OF CHRONICALLY ILL CHILDREN

presented by

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has been accepted towards fulfillment
of the requirements for

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STRONG AND WEAK TIES: SOCIAL SUPPORT
FOR FAMILIES OF CHRONICALLY ILL CHILDREN

By

LilnaBeth Punsalan-Somera

A DISSERTATION

Submitted to
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ABSTRACT

STRONG AND WEAK TIES: SOCIAL SUPPORT FOR FAMILIES OF CHRONICALLY ILL CHILDREN

By

LilnaBeth Punsalan-Somera

Research on social support provision provides evidence for its influence on coping mechanisms or the management of stressful situations. "Strong ties" associated with kin and close friends are theorized to be the primary source of social support. "Weak ties" outside of the primary network, with the lack of emotional involvement and the lower level of reciprocity, may be used to compensate for the inadequacy of support from strong ties.

This dissertation study investigated the influence of social support on the extent to which families of chronically ill children are able to cope with the impact of chronic illness. The study sample was a group of 38 families who were receiving services from a network of weak ties developed in the local community, composed of a group of professionals which providing comprehensive, health-related support services. After the network had been in place for a year, parents were asked to evaluate its services and indicate their perceptions of its effect on the impact of chronic illness.

A model of the process of support provision in this context was developed, and assessments were made of the families' resources, the frequency and quality of communication in their networks of strong and weak ties, their

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perceptions of support availability, and the impact of chronic illness. The results of the study provide evidence for the dimensionality of social support, for both measures used - network support and perceptions of availability . Strong and weak ties provided differential levels of affective, cognitive and instrumental support. Affective support from strong ties was the strongest predictor of perceptions of affective, cognitive and instrumental support. It also correlated most highly with indicators of mastery or coping, indicating its importance to individuals dealing with stressful situations. Consistent with the "compensatory hypothesis", weak tie sources of support were only activated when families' resources were not adequate.

for my mother,
Lillian Ortigoza Punsalan

and the men in my life -
Rene and Lester Miguel

and

in loving memory of my father,
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Rene, my best friend and editor, for sharing the experience of life, parenthood, and graduate school, and for giving up Europe and the Ivy League for me -

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CHAPTER I

INTRODUCTION AND LITERATURE REVIEW

A substantial portion of the literature on social support has focused on the investigation of the nature of its influence on the level of stress individuals experience during crises and the extent to which they can cope with the demands of these situations. For most of the populations which have been studied, crises occur in transitory processes such as organizational change (Miller and Monge, 1985), socialization in organizations (Albrecht, Ireys and Mundy, 1981; Jablin, 1984), immigration (Inglis and Gudykunst, 1982; Yum, 1982; Shival, 1982), divorce (Kitson, Moir, and Mason, 1982; White and Mika, 1983), withdrawal from drugs or alcohol (Gitterman and Schulman, 1986), transition to college (Shaver, Furman, and Buhrmester, 1985), pregnancy (Brown, 1986), bereavement (Parkes and Weiss, 1983; Osterweiss, Solomon, and Green, 1984), or acute illness (Dunkel-Schetter, 1984).

However, for families of chronically ill children, the crises are constant, often progressive, without the possibility of eventual recovery (Hobbs, Perrin and Ireys, 1985). In contrast to acute diseases in which the crises may be intense and costs high for a short period, chronic illnesses have both periods of brief high

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costs and prolonged, never low, costs. Chronic illnesses create enormous financial and emotional demands on the entire family (Massie, 1985). In addition, the future course of all chronic illnesses is highly unpredictable, thus generating uncertainty and tremendous psychological problems for the child and his or her family (McKeever, 1983; Hobbs, Perrin, Ireys, Moynihan and Shayne, 1984; Drotar and Bush, 1985).

Aside from the psychological problems it may cause, chronic illness affects other aspects of the life of the child and the family. While the nature of care and the symptomatology may vary from one specific type of chronic condition to another, the presence of any type of chronic illness creates tremendous financial and emotional demands on the parents and siblings of the child. In effect, it does not strike individuals, it strikes the whole living unit of the family (Hobbs, Perrin and Ireys, 1985, p. 79, emphasis added; also Shapiro, 1983). Thus, the ability of the entire family to respond to the demands of the chronic illness can be the decisive element in working with and overcoming the effects of a chronic illness (Massie, 1985, p. 15). The manner by which family members choose to utilize available sources of support is crucial. In addition, the relationship of the source of support to the recipient is important, as well as the quality and type of support he or she may offer (Laumann, 1973; Hirsch, 1981).

Family theories generally postulate that the family constitutes the primary support network which tempers the impact of stress on psychological well-being (Eggert, 1987; Dunst, Trivette and Deal, 1988). Unfortunately, the impact of

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chronic illness is often such that the family's resources are not sufficient for the members to sustain themselves, much less each other (McCubbin, Cauble and Patterson, 1982; Stein and Riessman, 1985). Instead of the family mediating stress for its members, the prolonged stress of chronic illness may destroy the buffering role of the family (Shapiro, 1983, p. 921). The father of a child dying after years of illness describes the situation:

The problem was that each of us needed to draw the same consolation from each other... support comes in many subtle ways...but great as any love may be, it is never enough to turn the trick by itself... how could I turn for solace to my wife, the mother of my child, when she was the mother of the child dying, and going through the same thing as I, wanting the same thing? How do you give the very thing you need more of yourself? (Deford, 1983, p. 70).

As a result, family members may have no other choice but to draw upon sources outside of the family network to help them cope with the strain of illness (Chesler and Barbarin, 1984; Cohen and Syme, 1985; Gottlieb, 1985; Dunst, Trivette and Deal, 1988).

The extent to which individuals draw on and benefit from outside sources may be a function of their satisfaction with the support they have (or have not) received from the family. Outside sources of support may become relevant or activated only as compensatory mechanisms to make up for inadequate support from the family network. For instance, it has been suggested that people turn to mutual help groups only when they are unable to discuss their experiences with family members (Gitterman and Schulman, 1986). Individuals who join such groups may be those who are not receiving the amount or particular kind of

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support they need from their families (Taylor, Falke, Shoptaw and Lichtman, 1986). Similarly, individuals in stressful situations may utilize a wide range of community services only when relevant support is unavailable from within the family unit (Hobbs, Perrin and Ireys, 1985).

While a family network may have a greater potential for support, it may also, paradoxically, place greater constraints on members' behavior and be a source of stress (Hays and Oxley, 1986; Hammer, 1983). In other words, the reduction of stress and other benefits which may be derived from social support does not rest upon the sheer availability of social relationships, or the structure of one's social network, but rather, on the strength and character, as well as the satisfaction with, one's most significant ties (Gottlieb, 1985). As Howard (1980) puts it, "many people turn to their relatives as a haven from the marketplace, and turn to the marketplace as a haven from their kin". Cummins (1988) refers to this phenomenon as "negative buffering", that is, some efforts to diminish the impact of stress may in fact increase the individual's vulnerability to stressful events (p. 698, emphasis in original).

Wortman (1984) suggests that the ideological assumption that support is always beneficial may be erroneous; that is, many behaviors that are intended to be supportive may have negative or harmful effects (p. 2342). At inappropriate times, the most well-intentioned efforts can backfire (Wellman, 1981; Shinn, Lehmann and Wong, 1984; Dunkel-Schetter, 1984; Jacobson, 1986). Similarly, House (1981) argues that the assumption that social support improves adaptive

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competence "begs the major question for research and practice - how, when and for whom are supportive social relationships beneficial in adapting to stress" (in Wortman, 1984; p. 2342).

In the context of families with chronically ill children, the issue of whether social support from family and other sources has a significant influence on coping with the constant pressures of living with the illness needs to be addressed. Specifically, the relationship between support coming from strong or family ties and weak ties or outside sources deserves clarification. Specifically, are outside sources utilized to compensate for the absence of support from strong ties, or are they tapped by individuals in addition to the support they receive from strong ties? Finally, is there a difference in the function of strong and weak ties in the provision of specific kinds of support?

To clarify the nature of social support in the context of families with chronically ill children, the next section describes the characteristics of the context, its unique stressors, and its demands for support. The rest of the chapter will review various conceptualizations of social support, its functions and structure, and the relationship between stress and social support.

The Context of Chronic Illness

The family context is a complex system of transactional influence that provides the most critical source of support to the chronically ill child, as well as other family members. It also provides for the growth and well-being of its

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members (Burr, 1985). The presence of the chronically ill child exerts a profound influence on virtually all aspects of family life. It also affects parental self-esteem and the psychological well-being of each family member (Drotar and Bush, 1985).

Recent research has taken a broad perspective on families, viewing them not only as contributors to the child's physical and psychosocial health, but also as potential victims of the effects of illness (Burr, 1985, emphasis added; also Chesler and Barbarin, 1984). A family with a chronically ill child confronts challenges and bears burdens unknown to other families. These include

the shock of the initial diagnosis and the urgent compelling need for knowledge; the exhausting nature of constant care unpredictably punctuated by crisis; the many and persistent financial concerns; the continued witnessing of a child's pain; tensions with one's spouse that can be aggravated by the fatiguing chronicity of care; the worries about the well-being of other children; and the multitude of questions involving the fair distribution within the family of time, money and concern (Hobbs and Perrin, 1985; p. 80).

Despite all these problems, however, most families resolve their problems successfully, in spite of the obstacles raised by "an often perverse health care system, professionals who may be poorly informed, and insensitive communities (Hobbs, Perrin, and Ireys, 1985; p. 80). For instance, the divorce rate among families with chronically ill children is not very different from other families, indicating that marriages of parents of children with chronic illness are no more unstable than those of healthy children (Burr, 1985).

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In fact, families who triumph over the obstacles testify to the resiliency of family ties. Unfortunately, for the many families who lack this resilience, the emotional cost is severe (Hobbs et al., 1985; Burr, 1985). Thornton and Freedman (1983) point out that current changes in family patterns may threaten the family bonds that assist in the care of chronically ill children. These changes include divorce, which affects at least one million children every year, and the proportion of babies born to unmarried mothers which accounted for 18% of all babies born in the United States in 1980 alone. As of 1982, six million households were maintained by single mothers, partly as a result of divorce and out-of-wedlock births, representing 19% of all American households. The authors estimate that, if the current trend persists, 40-50% of all children in the United States will live in a fatherless family before the age of nineteen (p. 33). Finally, Thornton and Freedman reveal that, as of 1982, 49% of married mothers with children under six years of age were in the labor force. Fifty-one percent of married women were employed, up from 22% in 1948, largely because of financial need (p. 24).

For families with chronically ill children, these statistics have profound consequences (Hobbs et al., p. 81). The stress of divorce, the resulting loss of a second parent and potential caregiver for the child, and the diminished resources, compound the stressors associated with the illness itself. Some children may question whether their illness contributed to the divorce. If the parent has to

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work outside the home for financial reasons, the care of the child poses another problem.

There has been some speculation that the stress of chronic illness may strengthen family unity and adaptation and enhance family closeness (Drotar and Bush, 1985). However, no matter how strong the family unit is, its resources are not inexhaustible, and the need for outside support is vital if the family is to function at an adequate level.

Thus, the family needs many types of support. The long-term demands of coping with the illness require cognitive support so parents will have knowledge about the illness and the care of the child. At the same time, there is a tremendous need for affective support in dealing with the constant demands and the uncertainty of the future, which includes the possible premature death of the child (Hobbs et al., 1984). Finally, instrumental support is needed to meet the astronomical costs of medical treatment, special equipment, special schooling, and nursing care (Hobbs, et al., 1984). Aside from the medical costs, a parent may need to give up employment in order to care for the chronically ill child, thereby compounding the financial burden. Support is also needed in the maintenance of family functioning (Dunst, Trivette and Deal, 1988) particularly if other children, whose needs cannot be ignored, are involved.

The saliency of a particular type of support may be a matter of timing. For example, the appropriateness of communicating information about the diagnosis has to be matched with the parents' emotional readiness to understand

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its relevance. Stage theories of the stressors experienced by the families have attempted to understand the process of dealing with the illness and providing appropriate support. Typically, these theories postulate an initial period of shock and bewilderment, followed by a time of denial or a sense that the situation is unreal or a bad dream. The third stage includes a time of anger, sadness, and much worry as the demands of care continue unabated and limitations become more apparent. Final stages are usually represented by "some measure of adaptation, defined as a lessening of the intensity of feelings and a time of reorganization, in which parents are able to offer support to each other and to emphasize any positive aspects of the situation" (Hobbs et al., 1985; p. 83).

While stress can be depicted as a process and the corresponding support needed can be separated theoretically, it is not as easy to identify what stage the family is currently going through, with the unpredictable setbacks and flare-ups characteristic of various types of chronic illness. The problem of "timing" support so that it is beneficial is compounded by the fact that the stress of chronic illness is not only brought about by the presence of the condition, but by other issues which arise as a result of its very presence in the life of the family.

Considering what the family with the chronically ill child has to deal with, it becomes apparent that the entire unit should be considered in the process of treatment. Although Chesler and Barbarin (1984) were referring specifically to cancer, their suggestion that the illness be considered a "family disease" (p. 132) can very well be extended to all types of chronic illness. This perspective

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highlights the ways in which a family's social network may be affected, and consequently, how its members can extend support to the family unit.

The next section discusses in greater detail the conceptualization of the various forms in which support can be manifested.

Conceptualizations of Social Support

Arguments regarding what constitutes social support have raised several issues regarding its conceptualization and operationalization (O'Reilly, 1988; Sarason, Shearin, Pierce and Sarason, 1987; Orth-Gomér and Undén, 1987; Thoits, 1982; Hirsch, 1980). Gottlieb (1985) asserts that it can qualify as "social science's most polymorphous perverse locus designator" (p. 9). Obviously, the variety of conceptualizations has led to a plethora of ambiguous and confusing operationalizations, and to difficulty in cumulating findings across individual studies. O'Reilly (1988) suggests that it is necessary to clarify the essential elements of social support in order to make a distinction between behavioral (support) and structural (network) variables.

Recent reviews of the literature on social support (Cohen and Syme, 1985; Sarason, Shearin, Pierce and Sarason, 1987; Orth-Gomér and Undén, 1987; O'Reilly, 1988) have continued to emphasize the need to clarify the distinction among the various conceptualizations of the construct and their relationship with outcome variables. Typical conceptualizations of social support have focused either on (a) structural variables describing the basic morphological

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characteristics of a network and differentiating between supportive and nonsupportive networks, usually on the basis of size, density, or multiplexity of the network, (b) content variables describing the day-to-day quality of each of the linkages in the network, e.g., kin or friend, economic, economic, recreational, mutual aid, or service, (c) function, describing those linkages in which individuals serve some cognitive, emotional/affective or instrumental function for each other, and (d) subjective appraisals of perception and/or satisfaction with available support.

According to Gottlieb (1985), these various conceptualizations can be classified according to differences in the unit of analysis from which support arises, and the substance of support. At the macrolevel of analysis, social support is measured in terms of social integration or participation, and is tapped by "measures of people's involvement with the institutions, voluntary associations, and informal social life of their communities" (p. 10). Questions, if any, about primary group ties are limited to the sheer number and frequency of contact with family members and friends. At the mezzolevel of analysis, the focus is on the structure and supportive functions of social networks and the set of actors who are considered close peers and with whom there is regular interaction. Once the members of the network have been identified, one can examine certain dimensions of the individual's relationships with significant others in the network (properties of dyadic ties) and probe the network structure (properties of the aggregate). Finally, the microlevel approach is reflected in studies which

concentrate on intimate relationships. This approach is based on the belief that "social support essentially comes from the deep emotional nurturance which only a select few can provide" (p. 12). Thus, the research attends to the "quality or content" of social relationships rather than their quantity or structural organization.

Each approach to the study of social support appears to have its own virtues and limitations. At a general level, macrolevel studies lend support to the hypothesis that social support is capable of moderating stress, but they provide none of the details necessary to determine how social support can be mobilized, or what dimensions can be beneficial to people facing threatening life events or chronic burdens. Mezzolevel studies, on the other hand, reveal the advantages of the network approach in the study of social support. This level allows the examination of "the adaptive consequences arising from different structural configurations of people's networks, and accounts for the effect of interactions among them on individual well-being" (Gottlieb, 1985, p. 12, emphasis in original). Finally, the focus of the microlevel approach on the quality and content of social relationships has led to research probing such issues as the affective potency and emotional provisions of social relationships. These studies have concluded that the presence of at least one confidant, even in the face of reduced contact with others, is positively associated with better health and greater life satisfaction (Lowenthal and Haven, 1968; Cassel, 1976). However, such a relationship may be severely taxed by demands to furnish all

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supportive provisions. In addition, in situations in which all the individuals involved are affected by a stressor, they may not have enough energy to meet their own needs, as well as others'. This makes the need to marshal a wider network of supporters more apparent (Gottlieb, 1985).

Because no singular conceptualization of social support has been satisfactory, some attempts have been made to combine these various approaches into what researchers hope is a more holistic way of dealing with all the dimensions of social support. Caplan (1974), for instance, describes "support systems" as social aggregates which are best able to provide feedback, material assistance and cognitive guidance to their members in times of stress and thus help mobilize their psychological resources and master their emotional burdens. However, a systems approach towards support hardly seems realistic or functional; the behavior of social networks cannot be characterized as unconditionally positive and helpful. As Gottlieb (1985) describes it, "people do not participate in social orbits that communicate exclusively positive feedback" (p. 9). In other words, supportive ties are parts of a system which contains nonsupportive ties as well (Parks, Stan and Eggert, 1983).

In particular, the family or the primary network is not unconditionally positive and helpful in its behavior. However, weak ties outside the family network may prove valuable in the access they may provide to external sources of support, and may make up for deficiencies in the primary network. The failure to take this fact into consideration distorts both the content of

interactions and the structure of support systems by wrenching isolated ties out of the larger networks in which they are embedded (Jacobson, 1987).

Functions of Social Support

Another controversial issue related to the conceptualization of social support concerns what actions, interactions and effects should be considered relevant in the provision of social support. A "tripartite classification" (Jacobson, 1986) which is consistently mentioned in the literature includes three types of behaviors: cognitive, affective, and instrumental (Caplan, 1974; Schaefer, Coyne and Lazarus, 1981; Wilcox, 1981; Ganellen and Blaney, 1984; Israel, 1985; Taylor, et al., 1986; O'Reilly, 1988). Cognitive or informational (Ganellen and Blaney, 1985) support refers to information, knowledge and/or advice that help the individual understand the world, adjust to changes in it, find solutions for problems and get feedback about one's behavior. Affective or emotional support involves behavior that fosters feelings of comfort and leads an individual to believe that he or she is admired, respected and loved, and that others are available to provide caring and security (Jacobson, 1985, p. 252). In some schemes, it may also include venting, or simply the provision of opportunities to "verbalize personal concerns to clarify feelings" and eventually begin active problem- solving. (Wortman, 1984, p. 2343). Instrumental support (also referred to as material, tangible or practical support in some studies) involves the

provision of goods, services, or financial assistance that helps solve practical problems.

Other classifications of social support functions abound in the literature. For example, Dean and Lin (1977) suggest that these functions may be viewed as being organized around two systems: the instrumental system, which is geared toward the fulfillment of tasks, and the expressive system, which is geared to the satisfaction of individual needs and the maintenance of social solidarity. Albrecht, Adelman and Associates (1987) present another typology of functions based on the uncertainty reduction framework (Berger and Calabrese, 1975). They contend that "support providers directly reduce uncertainty and enhance control by reframing a recipient's cognitive perspective, improving the recipient's skill levels, offering tangible assistance, and expressing acceptance or reassurance" (p. 31).

Albrecht et al.'s definition is significant in its focus on the role of communication in the provision of social support. It takes into account the process of communication between recipients and providers, and how it "functions to enhance a perception of personal control in one's life experience" (p. 19). In the context of families with chronically ill children, the idea of control as the primary function of communication (Miller and Steinberg, 1975) is essential to the development of positive coping responses to the illness (Shapiro, 1983). To the extent that family members can identify, verbalize and seek the

action necessary to alleviate their situation, they will be able to tap coping resources which would otherwise remain in a quiescent state (p. 915).

From another perspective, Weiss' (1974) theory of the provision of social relationships describes the functions of social support in terms of the "provisions" that can be obtained from relationships with others. Weiss contends that the provisions are necessary for the perception of adequate support and the avoidance of loneliness. While each provision is most often obtained from specific relationships, multiple provisions may be obtained from the same individual. Weiss' six relational provisions include

(a) attachment, a sense of emotional closeness and security, usually provided by a spouse or lover; (b) social integration, a sense of belonging to a group of people who share common interests and recreational activities, usually obtained from friends; (c) reassurance of worth, acknowledgement of one's competence and skill, usually obtained from co-workers; (d) reliable alliance, the assurance that one can count on others for assistance under any circumstance, usually obtained from family members; (e) guidance, advice and information, usually obtained from teachers, mentors, or parent figures, and (f) opportunity for nurturance, a sense of responsibility for the well-being of another, usually obtained from one's children (Cutrona, 1986, p. 350).

The typologies of supportive behavior which have been developed are indeed numerous. The above examples are typical of what can be found in the literature. However, there is a certain degree of overlap in the typologies. A closer look shows that the general distinction among cognitive, affective and instrumental behaviors applies to all the typologies. As Orth-Gomér and Undén (1987) note, these behaviors are the most frequently covered components of the

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multidimensional concept of social support. Thus, this distinction appears to be the most useful classification of supportive behaviors.

Another school of thought, however, cautions against assuming the dimensionality of social support as a given. Sarason et al. (1987) report that the subdivision of social support into discrete functions does not add to the sensitivity of its indices. The authors suggest that social support represents a more global construct, "the extent to which an individual is accepted, loved, and involved in relationships in which communication is open" (p. 830).

Jacobson (1986) notes that much of the early work on social support treated it as a unitary concept; it was only later studies which argued that it was a complex phenomenon (p. 252). It appears that the precursor of the identification of social support as a multidimensional construct was Weiss' (1973) work on loneliness, in which he argues that compensatory roles are not interchangeable; that is, friends cannot take the place of a spouse and vice versa.

While the argument about the dimensionality of the social support has yet to be resolved, it appears useful to look at both approaches. An overall index of support, in addition to more specific functions, contributes useful information to the study of the construct.

Structure of Social Support

The study of networks of relational patterns, particularly for individuals under stress, focuses on the "infrastructure" of social support, the social

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architecture of an individual's environment (Albrecht et al., 1987). According to Gottlieb's (1985) mezzolevel of analysis, this approach allows the examination of social support at both individual and relational levels. At the individual level, a person's position relative to the other members of the network indicates how well he or she has access to sources of support. Characteristics such as centrality (the extent to which one is at the crossroads of information flow in the network; Farace, Monge and Russell, 1977), connectedness (the range of contact of an individual; Farace, et al., 1977) and density (the extent to which one's support contacts communicate with one another; Richards, 1975) affect the extent to which one can maximize the benefits from a support network.

At the dyadic level, distinctions about the multiplexity (the extent to which multiple message contents are exchanged in a supportive relationship; Rogers and Kincaid, 1981) and strength of ties (the frequency and rate of communication; Richards, 1975) may be critical to the perception of social support. Differentiations between support coming from strong ties (close, interpersonal relationships with one's primary group of kin/friends) and weak ties (direct or indirect links to individuals outside of one's primary support network; Granovetter, 1973) may also be made to assess the quality, as well as the type, of support coming from these sources.

It is generally assumed that strong, multiplex and therefore more supportive ties can be expected from members of an individual's primary network. However, Granovetter's (1973) theory on the strength of weak ties

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posits that weak ties often provide a wider, more diverse range of support mechanisms because they access a greater number and variety of social networks.

Weak ties is used to describe relationships which lack the intimacy and frequency of interaction characteristic of stronger ties to kin and close friends. They are theorized to be more useful in providing specific forms of support, such as information and advice. In the same vein, Laumann (1973) argues that loose-knit or "radial" networks are more flexible, and, consequently, more adaptive.

They also serve as more effective support systems because

as one's needs change, there will be a greater probability of finding individuals to satisfy one's changing requirements (and) if varied input can result in the formulation of superior coping strategies ... then having access to diverse role partners may enhance one's ability to cope with change. (Hirsch, 1979), p. 275.)

The presence of a "core" or intimate social network cannot in itself be assumed to be a source of effective support; in fact, it can even be a source of stress (Hays and Oxley, 1986; Hammer, 1983). Parks (1982) suggests that the bias towards intimate interpersonal relationships reflects a general "ideology of intimacy" which often discounts the significance of weaker, noninterpersonal relationships. Vaux and Harrison (1985) also point out that high density and low density networks can be beneficial under different circumstances. Low density networks may work best in facilitating change and adaptation to new situations, or providing cognitive support during transition; while high density networks may be more effective in situations in which the appropriate response includes retrenchment, recuperation and validation, or material and emotional support in

a deficit state. Since these are simultaneously occurring situations for families with chronically ill children, both high and low density networks are potentially valuable sources of support.

Stress and Social Support

Weiss (1976) originally described the three types of stressful situations mentioned above: (1) crisis, characterized as a situation of sudden onset and limited duration, severely threatening to one's well-being, and marked by emotional arousal; (2) transition, a period of personal and relational change that involves a shift in a person's assumptive world; and (3) deficit state, a situation in which an individual's life is defined by chronically excessive demands. These situations may be related temporally, occurring in the order of crisis, transition, and deficit state, or take place simultaneously. Families of children with chronic illnesses typically find themselves in a deficit state, accompanied by periodic crises. The onset of the chronic illness can be described as a transition, during which the families' world is permanently altered by the requirements of coping with the illness.

Jacobson (1986) suggests that different kinds of support may be called for at different times. For example, emotional support is most useful during crises, since it "provides a person reassurance that others are able and willing to help in the struggle to regain equilibrium" (p. 254) while cognitive support is beneficial in transitions, which helps the individual understand the changes which he or she

has experienced. On the other hand, material aid is most relevant to the deficit state, to enable the individual to remedy an imbalance between needs and tangible resources. Considering the dilemma of families with chronically ill children, seeking sources of various forms of support outside of the primary family network seems to be inevitable. Extrafamily sources of support have been documented to be a major source of assistance necessary for meeting individual and family needs (Cohen and Syme, 1985; Dunst, Trivette and Deal, 1988). In fact, Albrecht and Adelman (1984) note that the results indicating that weak ties are major sources of support make it prematurely "tempting to advocate low dense structures for maximum support" (p. 25).

While weak ties or extrafamily sources may be capable of rendering all kinds of cognitive, affective and instrumental support, it seems reasonable to suggest that individuals would differentiate among various sources of support. For instance, one would turn more naturally to a spouse or a close family member than an outsider for affective support. It is unfortunate that this assumption has been used as a basis for regarding the simple presence of a spouse, or the fact of living with others rather than living alone, as an indicator of social support (Shinn, Lehmann and Wong, 1984). While strong ties are typically regarded as main sources of affective support, other possibilities exist. This includes the possibility that strong ties could provide all the support that a person needs, or that weak ties may be better sources of cognitive support. In the case of instrumental support, the influence of the potential source of support

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is not very clear. Members of one's primary network may give a loan or provide transportation more readily. However, the pressure to provide reciprocal support may exceed the person's abilities to meet them, such that one might prefer to pay interest at a bank or avail of public transportation rather than impose undue strain on personal relationships.

Since primary family networks are virtual givens in an individual's life, the impact of the support one receives from them is essentially an issue of process, with the most relevant question being concerned with support mobilization, that is, "how potential supporters in a network become actual supporters, given a stressful situation" (Eckenrode and Gore, 1981, p. 53, emphasis in original). Communication is crucial to this process of mobilization since needs often cannot be perceived unless they are expressed in verbal, or sometimes nonverbal, ways. If support is not readily available from the primary network, it appears that the solution is for the individual to cultivate unconnected weak ties. As Albrecht and Adelman (1984) suggest, "it may be that whether the individual is freed and assisted in forming weak ties is largely determined by the assistance and encouragement provided by the primary network of kin or close friends" (p. 26).

The research shows that strong ties are the predominant source of support, while weak ties may be utilized to complement or make up for the deficiencies of strong ties. However, no definitive conclusions have been made about weak ties being used as compensatory mechanisms, or whether they have an additive function. Are their resources tapped simultaneously or in addition to

what the strong ties provide? Another concern is the possibility that weak ties may be preferred over strong ties for support provision, because of the lower level of reciprocity. Finally, the effect of the type of support needed on the choices that individuals make needs further clarification.

Summary

The preceding discussion has presented a review of key areas of research on the social support construct and its application to the context of families with chronically ill children. While the findings indicate that the area is robust; previous literature has not fully developed the role of communication networks in the process of social support provision in this specific context. The final section of this chapter identifies conceptual gaps which provided the basis for the research problem addressed in this dissertation.

Statement of the Problem

Research on social support provides evidence for its influence on coping mechanisms or the management of stressful situations. While the controversy regarding its direct or buffering effects continue, the evidence suggests that the role of social support in stress management, particularly in health situations, cannot be underestimated.

Some theoretical gaps in the conceptualization of social support need to be addressed, however. First, a distinction between the functions of support

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provided by strong ties coming from the individual's primary network and weak ties from other external sources needs to be made. Second, the relationship between the conceptualization of support as a perception of its availability versus what is reportedly provided by the extant strong and weak ties need to be clarified. Third, the role of social support from a communication perspective in the context of families with chronically ill children needs to be investigated.

Findings in the literature indicate that perceptions of support availability and characteristics of communication networks have differential effects on the impact of stress. This dissertation study investigates the role of social support on the impact of illness on families with chronically ill children. It assesses the resources of the families, the characteristics of their networks, their perceptions of support availability, and their corresponding impact on the extent to which the families cope with the presence of chronic illness in their lives. Chapter II describes the hypothesized model depicting the interrelationships of the variables involved in the process of social support provision in the chronic illness context, and the hypotheses which guide the study.

CHAPTER II

CONCEPTUAL FRAMEWORK AND HYPOTHESES

The purpose of the present study was to investigate the provision of social support in the chronic illness context. The review in Chapter I suggests the necessity of making a distinction among the various types of support, as well as their sources. Moreover, the investigation of social support in the context of families with chronically ill children needs to take into account its unique characteristics. Unlike most situations in which the need for social support exists only for a time or only until a certain situation has been overcome, families with chronically ill children have to contend with the virtually constant demands of the illness, shifting only between minor and major problems. Hence, there is often little opportunity for recovery before the next crisis begins.

However, the family's needs, whether they be for social support or other aspects of dealing with the illness, are largely determined by the family's initial resources. For instance, the family's financial situation, with its implications for medical insurance, the care of other children in the family, as well as all other expenses which insurance does not cover, is crucial to minimizing the impact of chronic illness. Furthermore, psychological resources such as esteem and morale

affect the family's ability to communicate needs, and contribute to their perception of control or mastery over the situation (McCubbin and Comeau, 1987; Hobbs, Perrin and Ireys, 1985).

Along with these family resources, it is expected that social support will contribute significantly to the reduction of the impact of chronic illness. This study considered the three functions of social support most frequently mentioned in the literature - affective or emotional support, cognitive or informational support, and instrumental or practical support. Furthermore, it took into consideration the possibility that social support may be a unitary concept (Sarason et al., 1987), which would eliminate the necessity of specifying specific functions.

Conceptual and operational distinctions were made between perceptions of support availability and network support. The first conceptualization focuses on the perceived readiness of significant others to come to the individual's assistance, given certain situations which require affective, cognitive and/or instrumental support. These are hypothetical situations, in which the individual is asked to project him or herself, and assess whether support would be forthcoming if he or she were in these situations. The second conceptualization concentrates on the actual support which has been provided by specific members of both networks of strong and weak ties. It requires the identification of specific individuals in the networks who have provided affective, cognitive and/or

instrumental support, and assessing how often each type of support has been provided.

The relationships among these two conceptualizations of social support, family resources and the impact of chronic illness on the family are summarized in a causal model which is presented in Figure 1.

Insert Figure 1 about here

The model suggests that family resources influence network support. That is, families with greater resources tend to have a wider range of strong ties from which they can draw affective, cognitive and instrumental support. A strong relationship between family resources and strong ties can be expected since the wider range allows more options within the network of strong ties. In contrast, a weak relationship between family resources and weak ties can be predicted, since the presence of strong ties reduces the need to look for additional sources of support outside the network of strong ties. Thus, we would hypothesize:

- H₁: The relationship between family resources and strong ties will be stronger than the relationship between family resources and weak ties.

In turn, it is expected that the availability of network support from both strong and weak ties will result in the perception that various forms of support are readily available when needed. Thus the hypothesis:

- H₂: Support from both networks of strong and weak ties will lead to perceptions of affective, cognitive and instrumental support.

That is, support from both networks will be positively related to perceptions of support. However, it is expected that the relationship between strong ties and perceptions of support will be stronger than the relationship between weak ties and perceptions of support. Therefore, we would hypothesize:

- H₃: The relationship between support from strong ties and perceptions of support will be stronger than the relationship between support from weak ties and perceptions of support.

While it is hypothesized that, overall, perceptions of support from strong ties will be significantly greater than perceptions of support from weak ties, some variability is expected in terms of the specific functions of social support.

Considering the emotional bonds with significant others in the network of strong ties, it should have more evidence for affective support than the network of weak ties. Thus, the fourth hypothesis:

- H₄: The relationship between strong network ties and perceptions of affective support will be stronger than the relationship between weak network ties and perceptions of affective support.

On the other hand, with the presence of caregivers and other health professionals in the network of weak ties, it is reasonable to expect that more

cognitive support would be evident in the network of weak ties. Therefore, the next hypothesis is proposed:

- H₃: The relationship between weak network ties and perceptions of cognitive support will be stronger than the relationship between strong network ties and perceptions of cognitive support.

These perceptions of the availability of the different types of support presumably lead to a heightened sense of control and increase the possibility that the family would be in the position to utilize their resources most effectively in coping with the presence of illness. In terms of the impact of chronic illness, Stein and Riessman (1985) have identified four dimensions which can be used as indicators of areas in family functioning which are affected: personal strain, financial burden, familial or social, and mastery or coping. The relationships between perceptions of social support and the dimensions of the impact of chronic illness are hypothesized as follows:

- H₄: Perceptions of affective, instrumental and cognitive support will be negatively related to personal strain.
- H₅: Perceptions of affective, instrumental and cognitive support will be positively related to mastery or coping with chronic illness.
- H₆: Perceptions of affective, instrumental and cognitive support will be related to positive financial impacts.
- H₇: Perceptions of affective, instrumental and cognitive support will be related to positive familial/social impacts.

The first nine hypotheses stated above are concerned with the relationships among the adjacent variables in the model proposed in Figure 1. To examine the relationships among the nonadjacent variables, the following hypotheses are formulated:

- H₁₀: When the effect of network support is controlled for, the relationship between family resources and perceptions of social support will not be significant.
- H₁₁: When the effect of perceptions of support is controlled for, the relationship between network support and impact of chronic illness will not be significant.

It is maintained that family resources and perceptions of social support are conceptually independent constructs, and should not be significantly correlated. Thus, it is expected that controlling for network support, the intervening variable in the model proposed in Figure 1, should account for this independence, and result in zero correlations. Similarly, no correlation is expected between network support and impact of chronic illness. Controlling for perceptions of support, the intervening variable in the model, should also produce zero correlations. This process of controlling for the influence of intervening variables accounts for the relationships among the nonadjacent variables in the model.

Consequently, the entire model represents the theoretical conceptualization of the process of social support provision and its influence on the impact of chronic illness. As the previous chapter has suggested, strong and

weak ties serve different functions in the provision of social support. Strong ties are considered to be the primary sources of support. On the other hand, weak ties are regarded either as compensatory mechanisms to make up for the absence of support from strong ties or additional sources of support. Therefore, positive links between family resources and strong ties and negative links with weak ties are predicted. These hypothesized relationships account for what has been referred to in the literature as the compensatory effect; that is, weak ties only become mobilized when the family resources do not provide the kind or quality of support that they are expected to via strong network ties.

In turn, the combined or overall support as well as cognitive, affective and instrumental support from the networks of both strong and weak ties are seen as predictors of perceptions of cognitive, affective and instrumental support. Since strong ties are considered the primary sources of support, the relationship between overall support coming from strong ties with perceptions of cognitive, affective and instrumental support are predicted to be stronger than those coming from weak ties. In terms of the distinction among cognitive, affective and instrumental support, the literature has consistently indicated that strong ties provide more affective support. There is also some indication that weak ties provide more cognitive support. However, there is no consensus in the literature concerning instrumental support. The hypothesized relationships between support from the networks of strong and weak ties and the perceptions of the specific types of support are presented in Table 1.

Insert Table 1 about here

Consequently, it is anticipated that perceptions of cognitive, affective and instrumental support would have some influence on the impact of chronic illness on the individual. Dimensions of this impact include the perception of financial burden, familial or social impact, personal strain and mastery or coping with the chronic illness. While financial burden and personal strain suggest negative impacts on the individual, the dimensions of familial or social impact and mastery or coping are posited to be positively linked with perceptions of support. These relationships are presented in detail in Table 2.

Insert Table 2 about here

In effect, the model suggests that individuals will be able to deal more effectively with the financial burden and overcome the personal strain associated with chronic illness if they perceive adequate affective, cognitive and instrumental support. The perceptions of support will also lead to positive familial or social impact and a sense of mastery over the situation. In addition, the perception of instrumental support is posited to have a more substantial negative effect on the impact of financial burden than the other types of support. Similarly, it is

suggested that the perception of affective support will have a greater influence on the reduction of personal distress and a significantly more positive effect on mastery.

In the following chapter, procedures used to test these hypotheses are presented.

CHAPTER III

METHODOLOGY

The procedures for testing the hypotheses stated in Chapter II are specified in this chapter. The research project is described, followed by a discussion of the data collection procedures. Finally, details about the instruments and the statistical procedures which were used in the study are presented.

The LINC Project

The model of social support in the context of chronic illness presented in the previous chapter was tested with data from parents or primary caregivers of chronically ill children who are participating in Local Individualized Networks of Care (LINC¹), a current research project at the Department of Pediatrics and Human Development at Michigan State University. The LINC project was developed on the assumption that "a rural, community-based, coordinated, comprehensive network of health-related support services can be established,

¹LINC, Barbara Desguin, M.D., Principal Investigator, is supported in part by project MCJ#256009 from the Maternal and Child Health Program (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

using existing community resources" (Desguin, 1986). The project's main objective is to develop a network of professionals which will provide case management, advocacy training, social work and counselling services to a group of children and their families. In effect, it seeks to cultivate weak ties to meet the various needs of these children and their families.

Before LINC, health care for these children was provided by local physicians and specialty medical clinics which tend to be located in larger urban areas. With the medical focus, little attention was paid to the psychosocial effects of the illness on the child and the family. Furthermore, since intervention plans were formulated by the health professionals, the role of the family was reduced to simple compliance. The disregard for family autonomy and other aspects of family functioning resulted in poor communication, frustration, misunderstanding, and dissatisfaction for all concerned (Desguin, 1986).

To address these concerns, the LINC project established a network of professionals in a rural community in Central Michigan to provide coordinated support for a group of families with chronically ill children. The group of professionals was developed first, and included two case managers, public health nurses from the community's health department, who took charge of recruiting 50 families qualified to join the project. Eventually, the group included a local pediatrician, a health educator, a nutritionist, the special education director of the local school district, a hearing impaired specialist, and a school psychologist. Within the last two years, some professionals have left the LINC network for a

variety of reasons. However, an effort has been made to maintain the balance of its membership.

Families who joined the LINC project were identified by local health practitioners, the Community Health Department, and self-referral. Information about the project was also published in the community newspaper to bring the project to the attention of families with chronically ill children who might be interested.

During the enrolment period in 1987 and the early part of 1988, 50 families agreed to participate in LINC. After the families were introduced to the LINC network, their needs for information, counselling, special therapies, financial support, educational planning and other support were considered. Needs were identified at bi-weekly meetings among the professionals and during individual contacts with the case managers and other network members.

To monitor the effectiveness of the network and determine if it has brought about any changes in the attitudes of the families, the amount and costs of health services, management of care, and the well-being of the child and other family members, evaluations have been conducted every six months. The data for this dissertation study were taken from the second evaluation conducted from October - December, 1989.

Data Collection Procedures

Parents or guardians who served as the children's primary caregivers were asked to come in at a pre-arranged time and fill out the questionnaires. With the high incidence of cancellations during the first evaluation (not surprising considering the unexpected crises which could occur in chronic illness situations), arrangements for individual appointments or mailing out the questionnaires were made on a case-to-case basis. In a few cases, the case manager had to conduct a home visit and ask the parent, usually the mother, to fill out the questionnaire in their home.

Instrumentation

The proposed model of chronic illness and social support required the measurement of family resources, the network support coming from strong and weak ties, perceptions of affective, cognitive and instrumental support, and the impact of chronic illness. Since these constructs essentially involve internal, psychological reactions, self-report measures were used. In addition, network data was obtained to identify the composition of networks of strong and weak ties.

As an indicator of the resources available from the primary family network, family resources was assessed with the Family Inventory of Resources for Management (FIRM, Appendix A) by McCubbin and Comeau (1987). This instrument was developed on the premise that families possessing a larger

repertoire of resources will manage more effectively and will be able to adapt better to stressful situations (McCubbin and Comeau, 1987, p. 145). The measure is composed of four subscales purporting to tap family strengths I (esteem and communication), which represents a combination of resources in family esteem, communication, mutual assistance, optimism, problem solving ability and encouragement of autonomy among family members; family strengths II (mastery and health), which reflects a sense of mastery over family events and outcomes, family mutuality, and physical and emotional health; extended family social support, which indicates mutual help and support given to and received from relatives; and financial well-being, which taps into the family's perceived financial efficacy (pp. 145-146). Overall reliability of the FIRM (Cronbach's α) is .88, while those of the four subscales range from .62 to .85 (McCubbin and Comeau, 1987).

An instrument to elicit network data was developed for this study to assess the network support provided by strong and weak ties (Appendix B). The format was adapted from Orritt, Paul and Behrman (1985). Subjects were asked to identify the members of their primary and secondary networks from whom they receive various forms of support. The extent to which they receive affective, cognitive and instrumental support was indicated on a five-point scale ranging from "none of the time" to "all the time". In addition, frequency of communication was assessed by asking subjects to indicate how often they communicated with each individual they identify. Responses ranged from

"several times a day" to "every month". This is probably the easiest format for subjects to use (Richards, 1975) since it does not require an estimate of precise numbers, such as minutes or hours. It was deemed most appropriate for this sample, considering the range of the subjects' educational backgrounds. The various forms of support were treated as subscales, whose scores were summed across to obtain a measure of overall network support from strong and weak ties.

For each type of support, the number of links identified were summed. The strength of ties was also obtained by summing across the responses for each type of support. Thus, there were two indicators of each type of support for both strong and weak ties.

Perceptions of affective, cognitive and instrumental support were assessed by means of Russell, Altmaier and VanVelzen's (1984) Social Provisions Scale, and Wilcox' (1981) Social Support Index (Appendix C). The Social Provisions Scale was developed to assess the six relational provisions as identified by Weiss (1974). It asks subjects to rate the degree to which their social relationships are currently supplying each of the provisions. Subjects indicated on a five-point scale ranging from "Disagree Strongly" to "Agree Strongly" the extent to which each statement describes their current social relationships. Internal consistency (based on Cronbach's α) for the scale has been reportedly high, ranging from .85 to .92 across several populations (Cutrona, 1986).

To measure perceptions of affective support, the attachment and reliable alliance subscales of the Social Provisions Scale were used. Perceptions of cognitive support were assessed with the guidance subscale from the Social Provisions Scale, along with five items from the Social Support Index. Finally, six items from the Social Support Index were used to evaluate perceptions of instrumental support.

The Social Support Index (Wilcox, 1981) is an eighteen-item measure which has been developed to tap three dimensions of social support: emotional, tangible, and social support. A test-retest correlation of .89 has been reported (Orth-Gomér and Undén, 1987), along with an internal consistency of .92, based on Cronbach's α . The original instrument asks for "true" or "false" responses. For the sake of consistency with the other measures in this study, subjects were asked to indicate how much the statements applied to their situation on a five-point scale ranging from "not at all" to "always".

The impact of chronic illness on the family was measured with the Impact on the Family scale developed by Stein and Riessman (1985, 1980; Appendix D). Composed of twenty-six items, the scale taps four dimensions of the construct: financial burden, the extent to which the illness alters the family's economic status; social/familial impact, the nature of interactions with those outside the immediate household as well as within the family unit; personal distress, the strain experienced by the primary caregiver that is directly related to the demands of the illness; and mastery, coping with the stress of the illness (Stein

and Riessman, 1980). Reliability analysis using Cronbach's α resulted in a coefficient of .88 for the total score and a range from .56 to .83 for the four subscales (Stein and Jessop, 1985).

Analyses

Before testing the model and the hypotheses in Chapter II, confirmatory factor analysis was conducted to assess the unidimensionality of the instruments used. The confirmatory factor analysis (CFA) subroutine in PACKAGE (Hunter and Lim, 1986) was used to assess the measurement models using the three criteria for evaluating the unidimensionality of hypothesized scales: homogeneity and content validity, internal consistency, and parallelism with outside factors (Hunter, 1977, 1980).

The statistical tests were broken down into four steps (Hunter, 1977). First, an empirical clustering of the variables was specified. Since previously developed instruments were used in this study, the clusters identified by their respective authors were used in the initial clustering. Second, the parameters of the model were estimated by performing a confirmatory factor analysis with communalities in the diagonal, thereby correcting for attenuation. These estimates constitute the matrix of "observed" correlations. Third, the internal consistency theorem was applied to the correlation matrix to generate another matrix which one would predict if the observed matrix were internally consistent. The matrix of predicted correlation coefficients make up the matrix of "expected"

correlations. The evaluation of the magnitude of departures from internal consistency was based on the difference between the "observed" and "expected" matrices. These departures from internal consistency constitute the "deviation" matrix. Finally, parallelism with outside factors is determined by comparing the correlation of each item in the cluster to the outside factors (the other scales) with the mean correlation of the cluster. Items beyond the tenable range established by the confidence interval drawn around the correlation coefficients were removed from the cluster. The procedure was repeated several times until internally consistent and parallel clusters were obtained. Only the items in these final clusters were used in subsequent analyses.

To test the hypotheses stated in Chapter II, correlational analysis using the Statistical Package for the Social Sciences (SPSS-PC) was used. Confidence intervals were drawn around each coefficient to estimate confidence limits ($p \leq .05$) as well as provide a basis for comparing relationships, such as those between strong and weak ties. Indirect relationships suggested in Hypotheses 10 and 11 were tested by partial correlation procedures, while controlling for the effect of the intervening variables in the hypothesized model. This routine is not available on the SPSS-PC, so the analysis was conducted on the mainframe computer using SPSS-X.

The results of the confirmatory factor analyses are presented in the next section.

Confirmatory Factor Analyses

To evaluate the unidimensionality of the instruments used in this study, confirmatory factor analyses (CFA) was conducted. An examination of the items in each of the scales indicated that they were satisfactorily homogeneous in content. That is, they appeared to be conceptually related to the construct they purported to measure. Therefore, all the items were included in the initial analyses. Because of limitations concerning the number of variables which could be included in each PACKAGE routine, parallelism tests were conducted in two sets. The first set allowed for comparisons among the subscales in the measure of family resources, the Family Inventory of Resources for Management (FIRM). A second routine conducted parallelism tests for the subscales in the measures for perceptions of social support and the impact of chronic illness.

The means, standard deviations and factor loadings of the items which were retained in the final clusters are found in Appendix E. In addition, Appendix E also presents the means and standard deviations for the various types of network support and subscales of the various instruments. Strong tie network support mean scores are greater than the means for weak tie support, for both strength of ties and number of links. However, the differences are minimal.

The analyses for the individual scales are discussed in the next section.

Family Resources

FIRM is composed of four subscales which purport to measure two types of family strengths - esteem and communication, mastery and health - as well as extended family social support and financial well-being.

The 15 items in the original esteem and communication scale formed a cluster which was highly intercorrelated (average $r=.94$, $SE=.02$) with Cronbach's α at .99. The number of deviations from internal consistency was well below what might be expected due to sampling error. While some of the deviations from parallelism were larger than what would be expected from sampling error alone ($p \leq .05$), the 15 items were retained because succeeding tests indicated that the removal of any one particular item would not improve the cluster. Observed correlations, expected correlations, and deviations for this scale are presented in Table 3, along with the results of the test for parallelism with other factors.

Insert Table 3 about here

The second FIRM subscale, mastery and health, originally had 16 items. While all the items were conceptually homogeneous, only 12 items ($\alpha=.99$) met the requirements for internal consistency. The average correlation among the items was .91 ($SE=.03$), with one significant deviation. The parallelism test also

resulted in one significant deviation. Results for the final cluster are presented in Table 4.

Insert Table 4 about here

Four items comprised the extended family social support subscale and formed an internally significant cluster without a single significant deviation. The test for parallelism resulted in a single significant deviation. With Cronbach's α at .98, none of the four items were removed from the cluster, as shown in Table 5.

Insert Table 5 about here

Finally, the cluster representing financial well-being was tested. Two of the 16 original items in the subscale were eliminated, as they resulted in more significant deviations than what might be attributed to sampling error. The final cluster of 14 items, which appears in Table 6 below, contained one significant deviation, with an average correlation of .82 ($SE=.05$) and Cronbach's α at .99. The parallelism test resulted in no significant deviations.

Insert Table 6 about here

The average correlations among the items in the four FIRM clusters and the corresponding Cronbach's α are extremely high. There are two possible explanations. First, the population is more homogeneous than the normal population in terms of their family resources. Second, social desirability may have had some influence on the responses to the instrument. An examination of the contents of some items, particularly those related to financial resources, suggests a possible concern for social desirability. Conveniently, FIRM includes a social desirability subscale, which is not part of the factor structure, but is simply intended to provide additional information. In this case, the correlation of the social desirability subscale with the FIRM subscale ranged from .83 to .89, which is high enough to be of some concern. Because of this finding, some caution needs to be exercised in the interpretation of the FIRM results.

Perceptions of Social Support

The measure of perceptions of social support were taken from several extant instruments. The affective support subscale was taken from the attachment and reliable alliance subscales of the Social Provisions scale developed by Russell, Altmaier and VanVelzen (1984), which was based on Weiss' (1976) framework. Items in the cognitive support subscale were taken from the cognitive support subscale of Social Support Index (Wilcox, 1981) and the guidance subscale of Russell et al.'s (1984) Social Provisions Scale. Finally,

the instrumental support subscale items were taken from Wilcox's (1981) Social Support Index's instrumental support subscale.

Insert Table 7 about here

Table 7 presents the results of the CFA for the perception of affective support subscale. The final scale which met the standards for internal consistency ($\alpha=.98$) consists of eight items which essentially reflect the presence of strong relationships and emotional bonds in the individual's life, the availability of someone who can be trusted, who one can talk to or turn to in different circumstances. Negatively-worded items formed a different cluster, and were eliminated from the scale. The final scale has an average correlation of .86 ($SE=.04$) and has one significant deviation from sampling error. The parallelism test yielded two significant deviations. However, these were not very large, so the items were retained.

Insert Table 8 about here

Table 8 presents the cluster of internally consistent items which tap perceptions of cognitive support. The scale ($\alpha=.90$) consists of two items from Russell et al.'s (1984) guidance subscale and two items from Wilcox's (1981) Social Support Index. All the items are negatively-worded and required reverse-

coding. They indicate the absence of a person who could give "advice" or "guidance" about matters such as hiring a lawyer or surgeon and personal or family problems. The correlations among the four items form a fairly flat matrix with an average correlation of .69 (SE=.09), with no significant deviations. The parallelism test indicates that the correlation of all four items with the other factors are within sampling error.

Insert Table 9 about here

Five of the six items from Wilcox's (1981) instrumental support subscale formed an internally consistent and parallel cluster, with Cronbach's α at .95, as shown in Table 9. These items indicate the availability of someone in situations which require specific assistance, such as bail, a loan, help with moving to a new home, or the use of a car. The items form a flat matrix with an average correlation of .79 (SE=.06). There were no significant deviations. In the parallelism test, there were two significant deviations. However, these were small and distributed across items, and the removal of any item would not have improved the cluster significantly.

Impact of Chronic Illness

Stein and Riessman's (1985) measure of the impact of chronic illness on the family has four dimensions: financial burden, familial/social, personal strain,

and mastery or coping. Tests of the subscales' unidimensionality are presented in the next four tables.

Insert Table 10 about here

Table 10 presents the items in the financial burden subscale. The four items in the original scale formed an internally consistent scale ($\alpha=.81$) which taps various forms of financial burden resulting from the presence of illness. The correlations among the items form a flat matrix with an average correlation of .51 (SE=.12). None of the deviations were significant. Similarly, there were no significant deviations in the correlations with other factors in the parallelism test.

The original familial/social impact subscale had nine items. Five items formed an internally consistent cluster ($\alpha=.85$) as shown in Table 11.

Insert Table 11 about here

These five items reflect changes in social activities resulting from the presence of chronic illness. Correlations among the items form a flat matrix with an average correlation of .53 (SE=.12), without a single significant deviation for either internal consistency or parallelism.

Insert Table 12 about here

Table 12 presents results of the CFA for the personal strain subscale. One item was dropped from the six in the original cluster. The items reflect personal consequences of chronic illness for the caregiver. Correlations among the items form a flat matrix with an average correlation of .38 (SE=.14) and Cronbach's α at .75. There were no significant deviations from internal consistency. On the other hand, the parallelism test resulted in three significant deviations. However, these were spread across items, and subsequent attempts to remove any one item did not improve the cluster significantly.

There were five items in the original mastery subscale. Three items form an internally consistent subscale (α =.64) with an average correlation of .37 (SE=.14). These are presented in Table 13.

Insert Table 13 about here

These items indicate various successful strategies and resources in dealing with the presence of chronic illness. The test for parallelism did not result in any significant deviations.

After the unidimensionality of the various instruments was established, the resulting items were used to test the proposed hypotheses. These results are presented in the next chapter.

CHAPTER IV

RESULTS

This chapter presents a summary of the results of the analyses. The first part of the chapter describes demographic characteristics of the respondents. The second part reports the tests and evaluations for the hypotheses presented in Chapter II.

Demographics

Families in the LINC Network

When the LINC project began its initial enrolment of families with children with chronic illness, 50 families agreed to participate in the project. Baseline information was gathered at the time of enrolment, and periodic six-month evaluations were conducted to monitor changes, if any, in attitudes, child behavior and functioning, and the impact of chronic illness on the family. The data for the present study were collected as part of the second six-month evaluation conducted from October to December, 1989. At that point, some significant attrition had taken place, resulting in a sample of 38 families. Two of the children had died, the others had either moved away, withdrawn from the

project for a variety of reasons, or were too heavily burdened with other concerns to participate in the evaluation.

The Children

Fifty-three percent of the children in the sample were male, 47% were female. The children's ages ranged from two to 17, with the mean age at 8.03 (s.d.= 3.72). Of the children who were in school, 50% are in regular classes, while the other 50% are in special education programs. The mean number of absences which these children had during the previous school year (1988-1989) was 17.6 days (s.d.=31.46), with the number ranging from 2 to 126 days. This is 9.4% of the total number of days (180) for the school year, slightly higher than the findings of other studies of other chronic illness samples (e.g., Burr, 1985), and significantly higher than absence rates of healthy children.

Insert Figure 2 about here

Figure 2 shows the distribution of chronic conditions among the children in the sample. Twenty-six percent of the children had asthma, 18% had cerebral palsy, while 13% had otitis media or chronic ear infections. The children with allergies made up 11% of the sample, while those with a seizure disorder made up another 11%. Chronic conditions which were common to one or two children

constituted 78% of the sample. Some children had more than one chronic condition.

Parents

For all but one of the children in the sample, the mother was identified as the primary caregiver. The mean age of the fathers was 33.5 (s.d.=9.08), while the mean age for the mothers was 30.9 (s.d.=4.69). Seventy-five percent of the children's parents were married, 11% were single parents, while 14% were either divorced or separated. The rate of divorce in this group was not significantly different from families with healthy children (Burr, 1985). Twenty-one percent of the mothers had not finished high school. Forty-two percent did finish high school, while 6% went to trade school and 21% had some college education. Only 5% were college graduates, and another 5% went to graduate school. For the fathers, 39% finished high school while 28% did not. Fourteen percent went to college, but only 8% obtained a college degree. Another 11% went to graduate school.

Sixty-nine percent of the fathers worked full time, while 11% were employed on a part time or seasonal basis. Another 20% were either laid off, unemployed by choice, or unable to find a job. Only 21% of the mothers worked full time. Eleven percent worked part time, and 5% would have liked to work full time, but worked part time because of the child's illness. Of the 40% of the mothers who were unemployed, 18% indicated that they were unemployed

because of the child's illness. As expected, the mothers carried more of the burden of caring for the child, with 23% of the group either working part time or unemployed because of the child's illness. In addition, it appears that the category "unemployed by choice" may have been interpreted in a variety of ways. In some instances, the "choice" to remain unemployed was influenced directly by the child's illness. Thus, the 23% of mothers whose decision about employment was affected by the child's illness may be an underestimate. Other studies report that as high as 50% of mothers who were employed at the time of the diagnosis of their child's illness left their jobs to stay at home with the child (Burr, 1985).

Within the six-month period prior to the evaluation, 10% of the families spent less than \$100 for the child's illness. (This refers to out-of-pocket expenditure not covered by insurance). Sixty percent of the families spent between \$100 to \$999, while 11% spent between \$1000 to \$4999.

Almost half (40%) of the children were on MEDICAID, while 11% received some financial assistance from Supplemental Security Income (SSI), a government program which provides assistance to children with specific diagnoses (Drebushenko, personal communication, June 18, 1990). Only 50% of the children were covered by private insurance.

Considering the parents' educational background and work history, the presence of chronic illness appeared to be a threat to the equitable allocation of resources to family members' needs. The lack of insurance, coupled with the need to shoulder out-of-pocket expenses compounds the problem for families

with a child who needs a disproportionate part of their resources, leaving less for other family members. In this sense, this study population is not representative of the general population. However, it is typical of the estimated 10-15% of the children and their families in the state of Michigan (Desguin, 1989) and the country (Hobbs et al., 1984; Hobbs et al., 1985) who deal with the presence of chronic illness in their lives.

Tests of the hypothesized relationships among the factors which impact on the influence of chronic illness in this sample are presented in the next section.

Hypotheses

- H₁: The relationship between family resources and strong ties will be stronger than the relationship between family resources and weak ties.

To test this hypothesis, correlations between family resources, as measured by the Family Inventory of Resources for Management (FIRM), and network support, as measured by the number of links and the strength of ties, were computed. The results for the test using the number of links are presented in Table 14.

Insert Table 14 about here

Table 14 shows that two out of the four types of family resources - esteem and communication, and financial well-being - are significantly related ($p \leq .05$) to affective, cognitive, and instrumental network support from both strong and weak ties, based on the number of links. Extended family support is significantly related to network support from strong ties, but not to weak ties. Mastery and health is not significantly related to any type of network support from both strong and weak ties. Total resources, the sum of all four types, is significantly related to all types of network support, as well as to overall network support, the sum of all three types of support.

A comparison of the relationships between family resources and network support from strong and weak ties indicates that the correlations between family resources and strong ties are larger than those between family resources and weak ties. While the overlap in the confidence intervals indicates that the difference is not significant, a definite trend can be observed. In particular, correlations of network support from strong ties with extended family support, are almost twice the size of the correlations with network support from weak ties.

Insert Table 15 about here

Table 15 shows that the relationship between family resources and network support, as measured by the strength of ties, indicates a different

pattern. All types of family resources are significantly related to strong tie affective support. However, as in the case of network support based on the number of links, only esteem and communication and financial well-being are significantly related to weak tie affective network support. The relationships between family resources and cognitive network support are similar for both strength of ties and number of links measures - only significant relationships were observed with esteem and communication and financial well-being. In the case of instrumental support, the relationship between strong tie network support and esteem and communication was significant; weak tie instrumental network support and esteem and communication were not significantly related. However, both strong and weak ties instrumental support were related to financial well-being.

Generally, the correlations between family resources and network support indicate stronger relationships with strong ties, particularly with affective support. Correlations between mastery and health and extended support and affective network support from strong ties are significant; those with weak ties are not. The same case is true with esteem and communication and instrumental support, although the magnitude of difference is not as large.

H₂: Support from both networks of strong and weak ties lead to perceptions of affective, cognitive and instrumental support.

The expectation of this hypothesis is that perceptions of support will be related to network support from both weak and strong ties. Tables 16 and 17 present the results of tests of this hypothesis using the two measures of network support - number of links and strength of ties.

Insert Table 16 about here

Table 16 shows that none of the correlations between network support, as indicated by the number of links, and perceptions of support were significant, with the exception of those between strong tie network support and the perception of cognitive support. Apparently, the sheer availability of links in the network of strong ties leads to perceptions of cognitive support.

Insert Table 17 about here

On the other hand, Table 17 indicates that using the strength of ties as the measure of network support produces different patterns of relationships between network support and perceptions of social support. In this case, affective network support from strong ties was significantly related to perceptions of affective, cognitive and instrumental support. The relationships between perceptions of support and cognitive and instrumental network support were not significant.

- H₃: The relationship between support from strong ties and perceptions of support will be stronger than the relationship between support from weak ties and perceptions of support.

A comparison of the correlations between perceptions of support and network support from strong and weak ties in Tables 16 and 17 indicate a general trend for stronger relationships between the variables in the network of strong ties. This finding is consistent for both two indicators of network support, number of links and strength of ties. However, the difference in the size of the coefficients is most prominent between network support and perceptions of cognitive support when number of links are considered; and between affective network support and perceptions of support, when strength of ties are taken into account.

- H₄: The relationship between strong tie network support and perceptions of affective support will be stronger than the relationship between weak tie network support and perceptions of affective support.

The test of this hypothesis is presented in Table 17, which shows that the correlations between strong tie affective network support and perceptions of affective, cognitive and instrumental support are all significant. Surprisingly, however, the strongest relationship is between affective network support and the perception of cognitive support, and not with the perception of affective support, as suggested in Table 1. This is consistent with the finding, shown in Table 16,

that the perception of cognitive support is related to network support, as measured by the number of links. Consequently, the perception of cognitive support was also significantly related to overall network support. This is again contrary to what was hypothesized in Table 1, that the perception of affective support would have the strongest relationship with overall network support.

H₃: The relationship between weak tie network support and perceptions of cognitive support will be stronger than the relationship between strong tie network support and perceptions of cognitive support.

No support for this hypothesis was found, for either measure of network support. As Tables 16 and 17 show, correlations between perceptions of support and network support from weak ties are all nonsignificant. However, as mentioned earlier, perceptions of cognitive support were significantly related with network support from strong ties, as measured by the number of links. This finding may be a function of the item content in the instrument used to tap cognitive support. As a result of the confirmatory factor analysis, the items which formed an internally consistent cluster (see Appendix E) were essentially concerned with "guidance" or "advice" (e.g., "There is no one I can turn to for guidance in times of stress;" "There is no one I feel comfortable going to for advice about personal or family problems"). Thus, members of the personal network may have been seen as more accessible sources of cognitive support for these types of items, considering that the network of strong ties is mainly composed of health professionals and caregivers.

The next four hypotheses are concerned with the relationship between perceptions of social support and the impact of chronic illness on the family.

- H₆: Perceptions of affective, instrumental and cognitive support will be negatively related to personal strain.
- H₇: Perceptions of affective, instrumental and cognitive support will be positively related to mastery or coping with chronic illness.
- H₈: Perceptions of affective, instrumental and cognitive support will be related to positive financial impacts.
- H₉: Perceptions of affective, instrumental and cognitive support will be related to positive familial/social impacts.

Tests for these hypotheses are presented in Table 18.

Insert Table 18 about here

The data on the impact of chronic illness were reverse-coded. Therefore, the positive correlation coefficients in Table 18 indicate that perceptions of high levels of social support resulted in lower levels of the impact of chronic illness. The table shows that cognitive, instrumental and overall support are significantly correlated with personal distress ($p \leq .05$), with cognitive support having the strongest relationship ($r = .64$; $p \leq .01$). Surprisingly, the perception of affective support was not significantly related to the impact of personal distress.

In terms of the three other impacts of chronic illness, the data in Table 18 reveal that only cognitive support had a significant relationship with the

financial impact of chronic illness ($r=.62$; $p\leq.01$). Again, considering the item content in the cognitive support measure, it is logical to assume that the availability of guidance and/or advice could lead to the identification of various resources which could provide financial assistance, or the provision of services which would eliminate some expenditure.

Perceptions of support had very low nonsignificant correlations with familial or social impact, ranging from .07 to .12. On the other hand, perceptions of support had the strongest positive relationships with mastery or coping, with correlations from .59 to .82 ($p\leq.01$). Of the three types of support, cognitive support had the greatest influence on mastery or coping.

The first nine hypotheses are concerned with relationships between adjacent variables in the model of social support in the chronic illness context presented in Figure 1. The last two hypotheses are concerned with relationships between the nonadjacent variables in the model.

H₁₀: When the effect of network support is controlled for, the relationship between family resources and perceptions of social support will not be significant.

To test the tenth hypothesis, partial correlations between family resources and perceptions of social support were computed, while controlling for the effect of network support.

Insert Table 19 about here

Table 19 reveals that, after controlling for the influence of weak ties, there are still significant relationships between family resources and perceptions of support. With the exception of correlations with esteem and communication, all other family resources are correlated with at least two types of support. This is consistent for both indicators of weak tie network support - number of links and strength of ties - and suggests that the contribution of network support from weak ties to the overall model may not be treated independently of its relationship with family resources and perceptions of support. That is, this finding can be taken as an evidence of the compensatory effect of weak tie support, particularly in the light of the results of controlling for the effect of strong ties presented in Table 20.

Insert Table 20 about here

Table 20 demonstrates that controlling for network support from strong ties has a consequential effect on the relationship between family resources and perceptions of support. When the number of links are considered, only the correlations between extended family support and affective, instrumental and overall support remain significant ($p \leq .05$). On the hand, when the strength of

ties are taken into account, mastery and health is significantly correlated with cognitive support; extended family support with instrumental and overall support. This suggests that, apart from their relationship with network support, family resources and perceptions of social support do not greatly influence subsequent variables in the social support model.

H₁₁: When the effect of perceptions of support is controlled for, the relationship between network support and impact of chronic illness will not be significant.

This final hypothesis is concerned with the relationship between the two other nonadjacent variables in the model - network support and the impact of chronic illness. Separate analyses considering the two measures of network support, number of links and strength of ties, were taken into account. The results involving the number of links are presented in Table 21.

Insert Table 21 about here

Table 21 provides a basis for accepting the hypothesis - all correlations between the dimensions of impact of chronic illness and types of network support are nonsignificant, and are either approaching zero or negative. Similarly, when network support based on the strength of ties is taken into account, the pattern of correlations is very comparable. This is shown below in Table 22.

Insert Table 22 about here

These data demonstrate that, regardless of the measure of network support used, controlling for effect of perceptions of support results in no correlation between network support and the impact of chronic illness. As far as the overall model is concerned, these findings indicate that the unique contributions of network support and impact of chronic illness can be considered apart from the influence of perceptions of support.

This chapter has presented results of analyses of the study population and the hypotheses. Chapter V provides a discussion of the results, and implications of the study.

CHAPTER V

SUMMARY AND RECOMMENDED RESEARCH

The purpose of this study was to develop a model of the process of social support provision in the chronic illness context and investigate the role of communication networks and social support on the impact of chronic illness. This chapter provides a summary of the study and its (1) conclusions, (2) major limitations, and (3) implications for future research.

The literature review revealed a need to examine the dimensionality of social support and its impact on the population of families with chronically ill children. This unique population has been characterized as being in a constant state of stress; functioning in a deficit state, punctuated by periodic crises. While members of the family unit, particularly the primary caregiver, are expected to provide support to the child and the rest of the family, they also need to draw upon sources of support for themselves. When the resources within the family are inadequate or depleted, the need to turn to external sources becomes imperative. The process of support provision within the network of "strong ties" and among "weak ties" was a key aspect in this study.

Social support comes in various forms, and it has been conceptualized both as a unidimensional and multidimensional construct. The distinction between network support and perceptions of support in this study, as well as the tripartite classification of the affective, cognitive, and instrumental functions, reflects the dimensionality of the construct. At the same time, the overall indicator of social support takes into account the unidimensional point of view. These distinctions were most useful to this study's operationalization of network support and perceptions of support. On the other hand, network level classifications did not prove relevant to the study.

Conclusions

Several conclusions can be drawn from the findings of this study. At the conceptual level, the results provide some evidence for the dimensionality of the social support construct. Perceptions of affective, cognitive and instrumental support, as well as overall support or the summation of the three dimensions, relate differently to outside variables, indicating that each makes a unique, if not entirely independent, contribution to the model proposed in this study. In addition, network support from strong and weak ties are distinct from perceptions of support. They are moderately correlated, and relate to other variables at different levels. In addition, various types of network support - affective, cognitive, and instrumental - relate differentially to other variables. Contrary to Sarason et al.'s (1987) contention that the perception of support is a

unidimensional construct which "generally assesses the extent to which an individual as accepted, loved, and involved in relationships in which communication is open" (p. 813), the results indicate that affective, cognitive and instrumental support have different effects on the impact of chronic illness.

The significance of affective support is specifically highlighted through this study. The results show that affective support from the strong ties in one's network leads to perceptions of affective, cognitive, and instrumental support. Based on the strength of links, which can be taken as an indicator of the quality of these relationships, this finding is consistent with previous research which has constantly emphasized the influence of affective support and the value of emotional attachments in coping with stressful situations. Apparently, the presence of affective network support contributes significantly to the general perception that other forms of support are available, or could be called upon when necessary. Furthermore, affective support correlates most highly with mastery or coping, which provides a sense of its importance to individuals dealing with stress. In other words, it enables the individual to heighten self-esteem, overcome the stress of the illness, and work towards normalizing family life (Stein and Riessman, 1980). Conversely, its low correlation with familial or social impact indicates that the nature of the interactions with those outside the immediate household as well as within the family unit are not perceived to be supportive in nature.

This low correlation may also be relevant to the finding that, in terms of the number of links, network support is not significantly related to perceptions of support, with the exception of cognitive support. It appears that the sheer magnitude of the number of individuals in the network who provide various forms of support leads to the perception that these individuals can provide guidance or advice when needed, regardless of the nature of interactions with these individuals or their capacity to actually render appropriate cognitive support.

In turn, these perceptions of support lead to positive outcomes in coping with the impact of chronic illness. The strong relationship between affective support and mastery or coping has already been emphasized. Cognitive support, on the other hand, leads to a reduction in financial impact, possibly through the provision of information which leads to the identification of sources of services and various forms of financial assistance. Consequently, it also lessens personal distress and facilitates mastery or coping.

The perception of instrumental support leads to a lower level of personal distress as well as to a higher level of mastery or coping. Practical assistance may provide respite to families burned out from the continuous strain, provide them with occasional opportunities for relaxation, and give them renewed physical and psychological strength to deal with the presence of illness in their lives.

The varying relationships of affective, cognitive, and instrumental support with other variables demonstrate that they represent separate dimensions of social support. Therefore, they cannot be combined into a single indicator of social support or regarded as substitutes for each other. The distinction between network support and perceptions of support provides additional evidence for this conclusion.

Another major conclusion is concerned with the role of strong versus weak ties in the provision of support. The results of this study support previous findings (e.g., McCubbin, Cauble and Patterson, 1982; Eggert, 1987; Dunst, Trivette, and Deal, 1988) that strong ties, not weak ties, are the primary source of social support and its consequent effect on the impact of stressors. The distinction between strong ties representing members of the primary network, and weak ties composed of the members of the LINC network developed in the research project, health professionals, and the other families in the LINC network, demonstrates that strong ties have a more significant effect on decreasing the personal strain and financial impact brought about by the illness and improving the sense of mastery or coping (Drotar and Bush, 1985; McCubbin, 1987).

However, this does not imply that "weak ties" have no function in social support provision. The significant relationship with family resources indicates that the mobilization of weak ties is a function of the level of family resources. When the family resources are considered adequate, support from weak ties is

not activated or utilized. This finding is consistent with the literature on the "compensatory hypothesis". When the resources are not enough or do not meet the individual's particular needs, the likelihood that support from weak ties will be sought out increases.

Since perceptions of support from strong ties are fairly independent of family resources, they are more likely to be mobilized than weak ties. Nevertheless, in the event that family resources are not sufficient, weak ties are necessary to compensate for their inadequacy. Since the possibility that family resources would be exhausted at some point is practically inevitable in the chronic illness context, the role of weak ties is very important. Therefore, the cultivation of networks of weak ties or the development of networks which could provide support outside of the network of strong ties is an important consideration. Weak ties should be ready to provide support if and when family resources are exhausted.

However, this conclusion should take into account the concern regarding the manner in which weak ties were operationalized in this study. Since cognitive support was conceptualized as "guidance or advice" in a broad sense, the type of information which could be provided by particular weak ties, such as health care professionals, may not have been associated with the perception of cognitive support. Therefore, a more context-specific indicator of network support may provide clearer support for the "strength" in these weak ties.

Finally, the results of the study have several pragmatic implications. The model proposed in this study provides a framework for looking at the provision of social support in the context of chronic illness. It clarifies the contribution of strong and weak ties to the perception of various dimensions of social support, and the influence of social support on the extent to which families are able to cope successfully with the strain of chronic illness.

The findings are also useful in the design of intervention strategies for families with chronically ill children. The demonstrated importance of strong ties suggests the need to assess the existing resources families have before the cultivation of weak ties. This assessment can lead to the identification of "high risk" families; that is, those whose strong ties are not providing adequate support. Consequently, the provision of support from weak ties can be prioritized, and more effort and resources can be directed to families who need it most.

In the light of these conclusions, rigorous work in the area remains worthy of interest by both researchers and practitioners.

Limitations of the Study

The major weakness of the study reported here was the relatively small sample size. Although there were 50 children in the LINC project when it first began, the sample size had gone down to 38 by the time the data for this study were collected. While it was considered essential to wait at least until the second six-month evaluation to give the network intervention some time to have

an effect on the participants, it was difficult to prevent attrition due to numerous illness-related concerns. Needless to say, the sample size had a profound impact on estimations of sampling error, confidence intervals and the results of significance tests. Furthermore, the sample size limits the generalizability of the findings to a certain extent. However, it must be recognized that losing statistical power as a result of mortality and other realities in this particular context may often be a necessary compromise to access to this unique population.

The conceptualization of support from weak ties may have restricted the range of possible sources of support for this particular sample. In the measure of network support designed for this study, the participants were asked to indicate who among the LINC network members, the health professionals who were involved in their child's care, and the other families in the LINC network, have provided them with affective, cognitive and/or instrumental support. These groups may not have been perceived as the most relevant sources of guidance or advice, as described in the items tapping perceptions of cognitive support. The inclusion of items directed more specifically towards health care information may have demonstrated more clearly the nature of the interactions between the families and these particular "weak ties".

Future Research

The results of this study have implications for future research, both conceptually and operationally.

First of all, considering the major limitation of this study, a replication with a larger sample would be most useful. This will allow for comparisons, for instance, among families of children classified according to severity of illness, duration of involvement in an intervention program, or socio-economic factors. In addition, a larger sample will certainly boost the statistical rigor of the findings.

Further investigation of two measures used in the study needs to be made. In the case of the Family Inventory of Resources for Management (FIRM), the subscales turned out to be very highly correlated. Whether this was due to an extremely homogeneous sample or to social desirability is not clear; this needs to be tested in other populations.

The measure of perceptions of cognitive support can also be improved to include other types of information which potential weak ties may provide. The present measure is limited to general "advice or guidance" about issues which individuals typically seek from their strong ties. The inclusion of information more relevant to the context may clarify the contribution of certain types of weak ties to the provision of support.

The effect of the three exogenous variables in the model leading to impact of chronic illness -- family resources, network support, and perceptions of support -- can also be tested in other contexts in which other types of stressors are undermining individual coping resources. The chronic illness context is unique in the type of stress it brings on families; examining the effects of the

variables in other contexts which have varying stressful situations would cast more light on the process of social support provision and its role in managing stressful situations.

One issue in the review of literature that was not addressed in this study is the notion of timing (Jacobson, 1986). Purportedly, if the type of stressful situation the individual finds himself or herself in can be identified, the appropriateness of support can be assessed more accurately. However, this type of information is difficult to obtain by means of survey data. Qualitative information from interviews about what types of support were most beneficial at certain times would enhance the data needed to address this research problem.

Considering the dynamic nature of the process of social support provision, determining what type of support will be beneficial at a particular stage is problematic. From the practitioner's viewpoint, the assessment of existing resources, the identification of appropriate intervention, and timely provision must be synchronized. The researcher, on the other hand, has to consider carefully what constitutes effective support provision. For example, in terms of network support, does increased interaction indicate the availability of more supportive others, or more reasons to seek help? Conversely, less interaction may mean that the individual's network size is relatively small or that fewer people are involved because the individual's resources are sufficient.

Finally, the composition of strong and weak tie networks may undergo periodic changes. As a result, perceptions of support may change in the process.

In effect, support provision is not constant. Providers of emotional support may undergo burnout, providers of cognitive support may not be able to render appropriate advice constantly, and givers of instrumental support may simply not be available. When this takes place, weak ties may become more salient to the process of social support provision. Nevertheless, the findings of this study highlight the importance of strong ties in this process, particularly in the context of chronic illness, and the study of how their contribution to individual and family well-being can be enhanced continues to be a research challenge.

Figure 1

A Model of Social Support in the
Chronic Illness Context

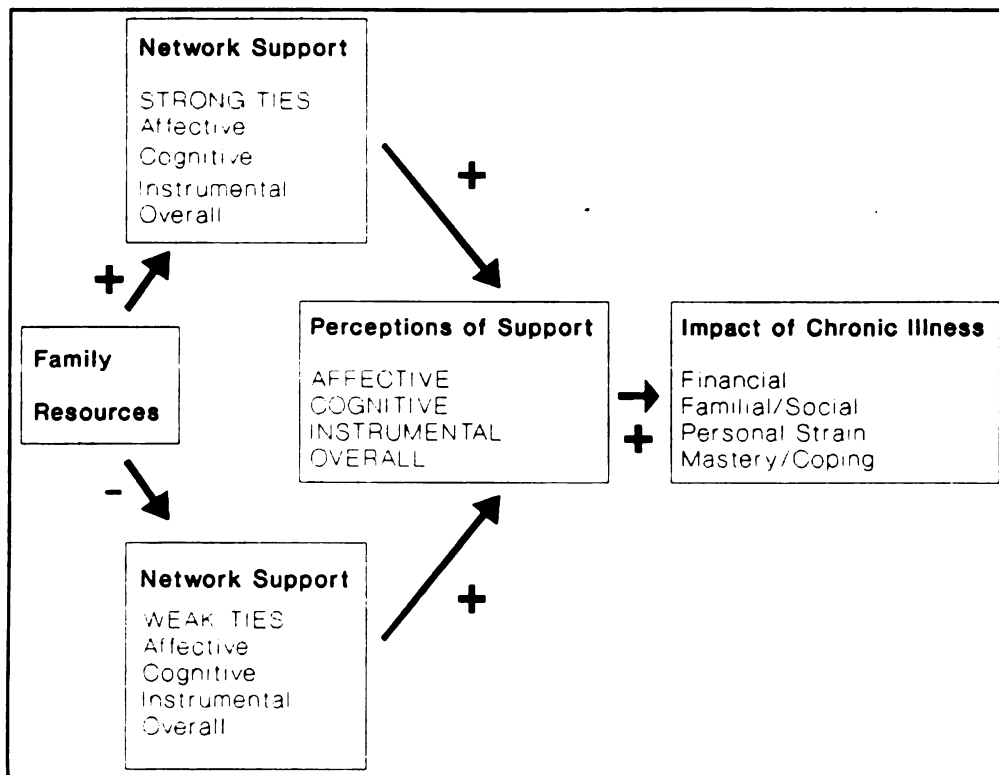
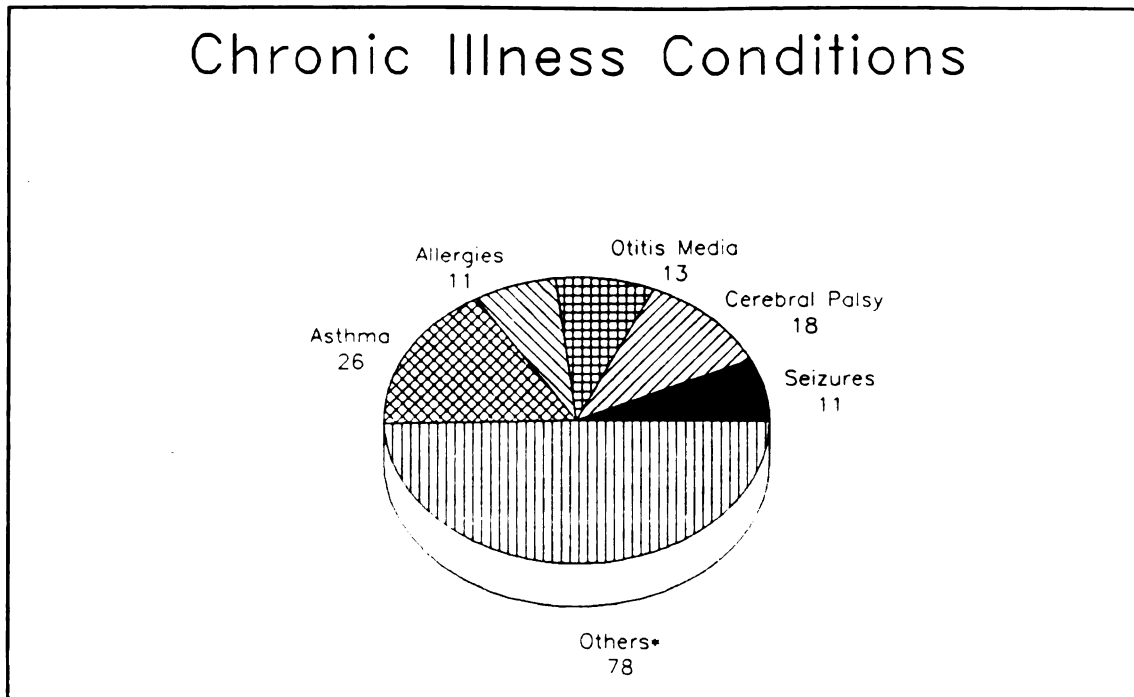


Figure 2



*OTHER CHRONIC CONDITIONS

	<u>N</u>	<u>%</u>		<u>N</u>	<u>%</u>
GASTROENTEROLOGY			SENSORY/COMMUNICATION/ INTELLECTUAL FUNCTION		
Intestinal Malrotation	1	3	Mental Retardation	1	3
RESPIRATORY			Down Syndrome	1	3
Cystic Fibrosis	1	3	OTOLARYNGOLOGY		
Recurrent Upper Respiratory Infections	1	3	Chronic Sinusitis	1	3
CARDIOLOGY			Hearing Loss	1	3
Truncus Arteriosus	1	3	Chronic Tympanic Membrane Perforation	1	3
Congenital Heart Disease	1	3	Recurrent Epitaxis	1	3
ENDOCRINOLOGY/METABOLIC			IMMUNOLOGY/INFECTIOUS DISEASE		
Diabetes Mellitus	1	3	Asplenia	1	3
Phenylketonuria (PKU)	2	5	Immune Deficiency	1	3
Hypoglycemia	1	3	DEVELOPMENTAL		
NEUROLOGY			Developmental Delay	1	3
Microcephaly	2	5	HEMATOLOGY		
MUSCULAR/SKELETAL			Leukemia	1	3
Cleft Palate	2	5	OPHTHALMOLOGY		
Missing Limb/s	1	3	Estropia	1	3
Spinal Injury	1	3			
Legg-Calve-Perthes Disease	1	3			

Table 1

Hypothesized Relationships Between Network Support and
Perceptions of Support

NETWORK SUPPORT				
<u>STRONG TIES</u>				
	Affective	Cognitive	Instrumental	OVERALL
PERCEPTIONS OF SUPPORT				
Affective	++	+	+	++
Cognitive	+	+	+	+
Instrumental	+	+	+	+
Overall	+	+	+	+

<u>WEAK TIES</u>				
	Affective	Cognitive	Instrumental	OVERALL
PERCEPTIONS OF SUPPORT				
Affective	+	+	+	+
Cognitive	+	++	+	+
Instrumental	+	+	+	+
Overall	+	+	+	+

Table 2
Hypothesized Relationships Between Perceptions of Support
and Impact of Chronic Illness

	PERCEPTIONS OF SUPPORT			
	Affective	Cognitive	Instrumental	Overall
IMPACT OF CHRONIC ILLNESS				
Financial Burden	-	-	--	-
Familial/Social	+	+	+	+
Personal Distress	-	-	-	-
Mastery/Coping	+	+	+	+

Table 3a

Matrices of observed and expected correlations
among the items in the ESTEEM AND COMMUNICATION (FIRM) scale
and deviations from correlations predicted by factor loadings

	44	53	62	55	38	50	58	46	65	52	36	39	67	68	60
44	.96														
53	.95	.92													
62	.97	.96	.99												
55	.95	.91	.96	.93											
38	.93	.92	.97	.94	.95										
50	.99	.97	.99	.95	.95	.98									
58	.98	.98	.98	.94	.94	.99	.97								
46	.97	.95	.98	.97	.97	.96	.97	.96							
65	.98	.98	.98	.97	.96	.99	.98	.98	.97						
52	.91	.85	.90	.89	.89	.91	.88	.88	.90	.86					
36	.92	.90	.96	.93	.95	.94	.94	.94	.93	.91	.93				
39	.93	.91	.96	.91	.97	.95	.94	.93	.93	.93	.99	.94			
67	.95	.96	.96	.92	.95	.97	.96	.94	.97	.93	.96	.96	.96		
68	.94	.91	.92	.90	.90	.94	.93	.90	.93	.96	.94	.94	.97	.90	
60	.91	.91	.96	.94	.96	.93	.95	.95	.94	.86	.94	.94	.91	.86	.91

	44	53	62	55	38	50	58	46	65	52	36	39	67	68	60
44	.96														
53	.94	.92													
62	.97	.95	.99												
55	.94	.92	.96	.93											
38	.95	.93	.97	.94	.95										
50	.97	.95	.98	.95	.96	.98									
58	.96	.94	.98	.95	.96	.97	.97								
46	.96	.94	.97	.94	.95	.97	.96	.96							
65	.97	.95	.98	.95	.96	.98	.97	.97	.97						
52	.90	.89	.92	.89	.90	.92	.91	.91	.91	.85					
36	.95	.93	.96	.93	.94	.96	.95	.95	.95	.89	.93				
39	.95	.93	.96	.93	.94	.96	.95	.95	.96	.90	.94	.94			
67	.96	.94	.97	.94	.95	.97	.96	.96	.97	.91	.95	.95	.96		
68	.93	.91	.94	.91	.92	.94	.93	.93	.94	.88	.92	.92	.93	.90	
60	.93	.91	.95	.92	.93	.94	.94	.93	.94	.88	.92	.92	.93	.90	.91

Table 3a (con't.)

	44	53	62	55	38	50	58	46	65	52	36	39	67	68	60
44	.00														
53	.01	.00													
62	.00	.01	.00												
55	.01	-.02	.01	.00											
38	-.02	-.01	.01	.00	.00										
50	.02	.02	.01	.00	-.01	.00									
58	.01	.03	.00	-.01	-.01	.01	.00								
46	.01	.01	.00	.03	.01	-.01	.00	.00							
65	.01	.03	.00	.02	.00	.01	.00	.01	.00						
52	.01	-.04	-.02	.00	-.01	-.01	-.03	-.02	-.02	.00					
36	-.03	-.03	.00	.00	.01	-.02	-.01	.00	-.03	.02	.00				
39	-.02	-.02	.00	-.03	.03	-.01	-.01	-.02	-.03	.03	.02	.00			
67	-.01	.02	-.01	-.02	-.01	.00	-.01	-.02	.00	.02	.01	.01	.00		
68	.01	-.01	-.02	-.02	-.03	.00	-.01	-.03	-.01	.08**	.02	.02	.04*	.00	
60	-.02	-.01	.01	.02	.04	-.01	.01	.02	.00	-.02	.02	.01	-.03	-.04*	.00

Average correlation = 0.94

Standard error = 0.02

$\alpha = .99$

Table 3b

Parallelism test for the ESTEEM AND COMMUNICATION (501) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS						
			44	53	62	55	38	50	
502 :	.94	.02	.91	.90*	.96	.93	.97	.93	
503 :	.97	.01	.96	.96	.98	.94**	.97	.98	
504 :	.95	.02	.91	.91	.94	.93	.95	.92	
			58	46	65	52	36	39	67
502 :		.94	.95	.94	.91	.98*	.96	.94	.92
503 :		.98	.95	.98	.93**	.97	.98	.99	.97
504 :		.95	.96	.94	.88*	.94	.93	.93	.90

* significantly deviates from sampling error at $p \leq .05$

** significantly deviates from sampling error at $p \leq .01$

Table 4a

Matrices of observed and expected correlations
among the items in the MASTERY AND HEALTH (FIRM) scale
and deviations from correlations predicted by factor loadings

	13	22	27	23	14	26	11	20	17	29	32	15
13	.93											
22	.97	.94										
27	.94	.96	.97									
23	.90	.94	.94	.89								
14	.95	.95	.95	.94	.97							
26	.86	.88	.94	.91	.93	.89						
11	.88	.86	.94	.85	.90	.93	.88					
20	.91	.94	.96	.90	.93	.96	.91	.92				
17	.95	.91	.89	.83	.92	.82	.88	.86	.86			
29	.93	.93	.94	.88	.92	.90	.93	.92	.89	.91		
32	.90	.88	.92	.87	.89	.83	.88	.86	.87	.90	.84	
15	.91	.90	.90	.91	.99	.91	.85	.88	.85	.86	.85	.88

	13	22	27	23	14	26	11	20	17	29	32	15
13	.93											
22	.93	.94										
27	.95	.95	.97									
23	.91	.91	.93	.89								
14	.95	.95	.97	.92	.97							
26	.91	.91	.93	.89	.92	.89						
11	.90	.91	.92	.88	.92	.88	.88					
20	.93	.93	.94	.90	.94	.90	.90	.92				
17	.89	.90	.91	.87	.91	.87	.87	.89	.86			
29	.92	.92	.94	.90	.94	.90	.89	.91	.82	.91		
32	.89	.89	.90	.86	.90	.86	.86	.88	.85	.88	.84	
15	.91	.91	.92	.88	.92	.88	.88	.90	.87	.90	.86	.88

Table 4a (con't.)

	13	22	27	23	14	26	11	20	17	29	32	15
13	.00											
22	.03	.00										
27	-.01	.01	.00									
23	-.01	.03	.01	.00								
14	.00	.00	-.02	.01	.00							
26	-.05	-.03	.01	.02	.00	.00						
11	-.02	-.05	.02	-.03	-.02	.05	.00					
20	-.02	.01	.02	.00	-.02	.06	.01	.00				
17	.05	.01	-.02	-.04	.02	-.05	.02	-.03	.00			
29	.01	.00	.00	-.02	-.02	.00	.03	.00	.00	.00		
32	.01	-.01	.01	.00	-.01	-.04	.02	-.02	.02	.03	.00	
15	.00	-.01	-.03	.03	.06*	.02	-.03	-.02	.02	-.04	-.02	.00

Average correlation = 0.91

Standard error = 0.03

$\alpha = .99$

Table 4b

Parallelism test for the MASTERY AND HEALTH (502) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS					
			13	22	27	23	14	26
501 :	.92	.02	.92	.92	.96	.93	.95	.92
503 :	.93	.02	.92	.91	.98*	.92	.95	.94
504 :	.94	.02	.91	.91	.94	.94	.95	.94
			11	20	17	29	32	15
501 :			.89	.94	.90	.89	.92	.92
503 :			.94	.94	.92	.92	.93	.92
504 :			.89	.94	.92	.93	.90	.97

* significantly deviates from sampling error at $p \leq .05$

Table 5a

Matrices of observed and expected correlations
among the items in the EXTENDED FAMILY SOCIAL SUPPORT scale
and deviations from correlations predicted by factor loadings

	56	66	48	41
56	.93			
66	.99	.96		
48	.91	.91	.92	
41	.88	.91	.94	.89

	56	66	48	41
56	.93			
66	.94	.96		
48	.92	.94	.92	
41	.91	.92	.90	.89

	56	66	48	41
56	.00			
66	.05	.00		
48	-.01	-.03	.01	
41	-.03	-.01	.04	.00

Average correlation = 0.92
Standard error = 0.02

$\alpha = .98$

Table 5b

Parallelism test for the EXTENDED FAMILY SOCIAL SUPPORT (503) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS			
			1	2	3	4
501 :	.66	.09	.77	.60	.61	.66
502 :	.11	.11	.84*	.54	.39	.46
504 :	.33	.15	.51	.16	.22	.41

*significantly deviates from sampling error at $p \leq .05$

Table 6a

Matrices of observed and expected correlations
among the items in the FINANCIAL WELL-BEING (FIRM) scale
and deviations from correlations predicted by factor loadings

	43	35	47	57	69	51	40	42	63	45	59	61	49	64
43	.90													
35	.83	.76												
47	.87	.73	.84											
57	.88	.80	.87	.88										
69	.96	.81	.87	.89	.89									
51	.94	.80	.84	.88	.92	.87								
40	.87	.85	.94	.85	.48	.87	.87							
42	.82	.72	.73	.79	.77	.80	.73	.71						
63	.87	.85	.81	.85	.84	.85	.87	.80	.87					
45	.89	.80	.84	.81	.93	.83	.76	.70	.78	.76				
59	.74	.79	.82	.76	.73	.79	.88	.77	.87	.68	.74			
61	.79	.76	.87	.89	.81	.79	.87	.76	.83	.72	.84	.81		
49	.79	.75	.80	.92	.81	.76	.79	.83	.82	.72	.69	.85	.76	
64	.90	.84	.81	.85	.90	.92	.86	.80	.93	.84	.84	.87	.80	.90

	43	35	47	57	69	51	40	42	63	45	59	61	49	64
43	.90													
35	.83	.76												
47	.87	.80	.84											
57	.89	.82	.86	.88										
69	.89	.82	.86	.88	.89									
51	.88	.82	.85	.87	.88	.87								
40	.88	.81	.85	.87	.88	.87	.87							
42	.80	.74	.77	.79	.79	.79	.79	.71						
63	.88	.81	.85	.87	.88	.87	.87	.79	.87					
45	.83	.76	.80	.82	.82	.81	.81	.74	.81	.76				
59	.81	.75	.79	.80	.81	.80	.80	.73	.80	.75	.74			
61	.85	.79	.82	.84	.85	.84	.84	.76	.84	.78	.77	.81		
49	.83	.76	.80	.82	.82	.82	.81	.74	.81	.76	.75	.79	.76	
64	.90	.83	.87	.89	.89	.89	.88	.80	.88	.83	.82	.85	.83	.90

Table 6a (con't.)

	43	35	47	57	69	51	40	42	63	45	59	61	49	64
43	.00													
35	.00	.00												
47	.00	-.07	.00											
57	-.01	-.02	.01	.00										
69	.06	-.01	.01	.01	.00									
51	.06	-.02	-.02	.01	.04	.00								
40	-.01	.03	.08	-.02	-.04	.00	.00							
42	.02	-.02	-.05	.00	-.02	.01	-.06	.00						
63	-.01	.04	-.04	-.03	-.04	-.02	.00	.01	.00					
45	.07	.04	.05	-.01	.11*	.02	-.05	-.03	-.03	.00				
59	-.08	.04	.03	-.05	-.08	-.01	.08	.04	.07	-.07	.00			
61	-.07	-.03	.05	.04	-.04	-.05	.03	.00	.00	-.07	.06	.00		
49	-.04	-.01	.00	.10	-.01	-.05	-.02	.10	.01	-.04	-.07	.06	.00	
64	.00	.01	-.06	-.04	.01	.03	-.03	.00	.04	.01	.03	.01	-.03	.00

Average correlation = 0.82

Standard error = 0.05

$\alpha = .99$

Table 6b

Parallelism test for the FINANCIAL WELL-BEING (504) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS							
			43	35	47	57	69	51		
501 :	.89	.04	.88	.84	.91	.90	.88	.86		
502 :	.90	.03	.90	.84	.92	.95	.91	.90		
503 :	.88	.04	.88	.82	.89	.89	.88	.87		
			40	42	63	45	59	61	49	64
501 :		.91	.86	.93	.83	.91	.93	.86	.90	
503 :		.93	.80**	.92	.86	.86	.92	.90	.93	
504 :		.93	.80*	.94	.85	.90	.93	.85	.94	

* significantly deviates from sampling error at $p \leq .05$

Table 7a

Matrices of observed and expected correlations
among the items in the PERCEPTION OF AFFECTIVE SUPPORT scale
and deviations from correlations predicted by factor loadings

	25	30	26	27	32	33	42	46
25	.84							
30	.87	.84						
26	.89	.85	.91					
27	.89	.83	.95	.89				
32	.91	.92	.94	.93	.97			
33	.88	.89	.92	.89	.96	.93		
42	.74	.76	.81	.81	.84	.84	.74	
46	.76	.83	.80	.81	.85	.84	.85	.77

	25	30	26	27	32	33	42	46
25	.84							
30	.84	.84						
26	.87	.88	.91					
27	.86	.87	.90	.89				
32	.90	.90	.94	.93	.97			
33	.88	.88	.92	.91	.95	.93		
42	.79	.79	.82	.81	.85	.83	.74	
46	.80	.81	.84	.83	.87	.85	.76	.77

	25	30	26	27	32	33	42	46
25	.00							
30	.03	.00						
26	.02	-.02	.00					
27	.03	-.03	.05	.00				
32	.01	.02	.00	.00	.00			
33	.00	.01	.00	-.02	.01	.00		
42	-.05	-.03	-.01	.00	-.01	.01	.00	
46	-.04	.02	-.04	-.02	-.02	-.01	.09*	.00

Average correlation = 0.86

Standard error = 0.04

$\alpha = .98$

Table 7b (con't.)

Parallelism test for the PERCEPTION OF AFFECTIVE SUPPORT (505) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS					
			25	30	26	27	32	33
501 :	.32	.15	.45	.24	.31	.29	.31	.34
502 :	.29	.15	.37	.22	.34	.33	.29	.25
503 :	.25	.15	.40	.14	.24	.18	.25	.31
504 :	.44	.13	.59	.35	.46	.42	.49	.56
506 :	.31	.15	.19	.40	.35	.35	.30	.21
507 :	.93	.02	.88*	.92	.95	.93	.98*	.97
					42	46		
501 :					.32	.30		
502 :					.24	.27		
503 :					.29	.22		
504 :					.40	.26		
506 :					.26	.41		
507 :					.89	.91		

*significantly deviates from sampling error at $p \leq .05$

Table 8a

Matrices of observed and expected correlations
among the items in the PERCEPTION OF COGNITIVE SUPPORT scale
and deviations from correlations predicted by factor loadings

	36	41	28	37
36	.65			
41	.73	.84		
28	.59	.58	.46	
37	.71	.92	.62	.86

	36	41	28	37
36	.65			
41	.74	.85		
28	.54	.62	.45	
37	.75	.86	.63	.87

	36	41	28	37
36	.00			
41	-.01	.00		
28	.05	-.04	.00	
37	-.04	.06	-.01	.00

Average correlation = 0.69
Standard error = 0.09

$\alpha = .90$

Table 8b

Parallelism test for the PERCEPTION OF COGNITIVE SUPPORT (506) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS			
			36	41	28	37
501 :	-.17	.16	-.14	-.26	-.04	-.24
502 :	.11	.16	.16	.08	.16	.05
503 :	-.44	.13	-.39	-.54	-.29	-.53
504 :	.58	.11	.55	.58	.50	.69
505 :	.28	.15	.23	.28	.35	.26
507 :	.28	.15	.20	.31	.34	.25

*significantly deviates from sampling error at $p \leq .05$

Table 9a

Matrices of observed and expected correlations
among the items in the PERCEPTION OF INSTRUMENTAL SUPPORT scale
and deviations from correlations predicted by factor loadings

	29	34	45	47	31
29	.78				
34	.76	.78			
45	.73	.64	.60		
47	.79	.85	.76	.89	
31	.86	.90	.70	.91	.94
29	.77				
34	.78	.78			
45	.68	.68	.60		
47	.83	.84	.73	.89	
31	.85	.86	.75	.92	.94
29	.00				
34	-.02	.00			
45	.05	-.04	.00		
47	-.04	.01	.03	.00	
31	.01	.04	-.05	-.01	.00

Average correlation = 0.79

Standard error = 0.06

$\alpha = .95$

Table 9b

Parallelism test for the PERCEPTION OF INSTRUMENTAL SUPPORT (507) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS				
			29	34	45	47	31
501 :	.30	.15	.27	.39	.22	.30	.29
502 :	.30	.15	.31	.30	.28	.30	.28
503 :	.27	.15	.20	.33	.22	.35	.28
504 :	.40	.14	.35	.60	.20	.43	.44
505 :	.89	.03	.87	.94	.76**	.93	.96*
506 :	.30	.15	.27	.21	.38	.30	.32

*significantly deviates from sampling error at $p \leq .05$

Table 10a

Matrices of observed and expected correlations
among the items in the FINANCIAL IMPACT scale
and deviations from correlations predicted by factor loadings

	1	2	3	4
1	.64			
2	.49	.57		
3	.56	.55	.41	
4	.59	.55	.30	.44

	1	2	3	4
1	.64			
2	.60	.57		
3	.51	.48	.41	
4	.53	.50	.42	.44

	1	2	3	4
1	-.00			
2	-.11	.00		
3	.05	.07	.01	
4	.07	.05	-.12	.00

Average correlation = 0.51
Standard error = 0.12

$\alpha = .81$

Table 10b

Parallelism test for the FINANCIAL IMPACT (501) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS			
			1	2	3	4
502 :	.66	.09	.77	.60	.61	.66
503 :	.11	.11	.84*	.54	.39	.46
504 :	.33	.15	.51	.16	.22	.41
505 :	.25	.15	.48	.03	.25	.24
506 :	-.15	.16	-.16	-.19	-.03	-.19
507 :	.25	.15	.46	.06	.20	.23

*significantly deviates from sampling error at $p \leq .05$

Table 11a

Matrices of observed and expected correlations
among the items in the FAMILIAL/SOCIAL IMPACT scale
and deviations from correlations predicted by factor loadings

	5	6	7	9	10
5	.59				
6	.51	.38			
7	.60	.49	.57		
9	.42	.44	.47	.43	
10	.68	.43	.61	.63	.69

	5	6	7	9	10
5	.59				
6	.48	.38			
7	.58	.46	.57		
9	.51	.41	.49	.43	
10	.64	.52	.63	.55	.70

	5	6	7	9	10
5	.00				
6	.03	.00			
7	.02	.03	.00		
9	-.09	.03	-.02	.00	
10	.04	-.09	-.02	.08	-.00

Average correlation = 0.53
Standard error = 0.12

$\alpha = .85$

Table 11b

Parallelism test for the FAMILIAL/SOCIAL IMPACT (502) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS				
			5	6	7	9	10
501 :	.67	.09	.62	.64	.66	.67	.78
503 :	.45	.13	.45	.20	.41	.54	.62
504 :	.10	.16	.05	.19	.16	.14	.36
505 :	.23	.16	.30	.23	.28	.13	.20
506 :	.10	.16	.20	.24	.11	.00	-.05
507 :	.24	.15	.34	.23	.27	.12	.24

*significantly deviates from sampling error at $p \leq .05$

Table 12a

Matrices of observed and expected correlations
among the items in the PERSONAL IMPACT scale
and deviations from correlations predicted by factor loadings

8 19 22 21 24

8 .30
19 .41 .55
22 .26 .52 .39
21 .32 .61 .54 .56
24 .41 .21 .22 .29 .18

8 19 22 21 24

8 .30
19 .41 .55
22 .34 .46 .39
21 .41 .56 .47 .56
24 .23 .31 .26 .32 .18

8 19 22 21 24

8 .00
19 .00 .00
22 -.08 .06 .00
21 -.09 .05 .07 .00
24 .18 -.10 -.04 -.03 .00

Average correlation = 0.38
Standard error = 0.14

$\alpha = .75$

Table 12b

Parallelism test for the PERSONAL IMPACT (503) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS				
			8	19	22	21	24
S01 :	.48	.13	.70	.42	.21*	.34	.75*
S02 :	.38	.14	.74*	.23	.15	.13	.65
S04 :	.51	.12	.39	.57	.55	.66	.36
S05 :	.17	.16	.40	-.02	.07	.06	.34
S06 :	-.32	.15	-.10	.49	.47	-.49	-.08
S07 :	.19	.16	.42	-.03	.11	.12	.34

*significantly deviates from sampling error at $p \leq .05$

Table 13a

Matrices of observed and expected correlations
among the items in the MASTERY/COPING scale
and deviations from correlations predicted by factor loadings

	11	13	15
11	.16		
13	.30	.59	
15	.25	.56	.49

	11	13	15
11	.15		
13	.30	.61	
15	.27	.54	.49

	11	13	15
11	.01		
13	.00	-.01	
15	-.02	.02	.00

Average correlation = 0.37
Standard error = 0.14

$\alpha = .64$

Table 13b

Parallelism test for the MASTERY/COPING (504) scale

	Mean Correlation	Standard Error	ITEM-FACTOR CORRELATIONS		
			11	13	15
S01 :	.28	.15	.58	.14	.14
S02 :	.09	.16	.33	.08	.14
S03 :	.51	.12	.48	.53	.53
S05 :	-.30	.15	-.25	-.37	-.27
S06 :	.43	.13	.40	.38	.53
S07 :	-.28	.15	-.18	-.38	-.28

*significantly deviates from sampling error at $p \leq .05$

Table 14

Correlation Between Family Resources and Network Support

	NETWORK SUPPORT			
	<u>Strong Ties</u>			
	(number of links)			
	Affective	Cognitive	Instrumental	Overall
FAMILY RESOURCES (FIRM)				
Esteem and Communication	.59* (.13) .34 ~ .84	.55* (.13) .30 ~ .80	.59** (.13) .34 ~ .84	.58** (.13) .33 ~ .83
Mastery and Health	.41 (.16) .10 ~ .72	.38 (.16) .07 ~ .69	.41 (.16) .10 ~ .72	.40 (.16) .09 ~ .71
Extended Family Support	.49* (.14) .33 ~ .76	.44* (.16) .13 ~ .75	.49* (.14) .33 ~ .76	.48* (.15) .19 ~ .77
Financial Well-being	.69** (.10) .49 ~ .89	.64** (.12) .44 ~ .84	.69** (.10) .49 ~ .89	.68** (.10) .48 ~ .88
TOTAL	.65** (.10) .45 ~ .85	.61** (.12) .37 ~ .85	.65** (.10) .45 ~ .85	.64** (.10) .44 ~ .84
<u>Weak Ties</u>				
(number of links)				
	Affective	Cognitive	Instrumental	Overall
FAMILY RESOURCES (FIRM)				
Esteem and Communication	.52* (.14) .25 ~ .79	.53* (.14) .26 ~ .80	.44* (.16) .13 ~ .75	.51* (.14) .24 ~ .78
Mastery and Health	.16 (.18) -.19 ~ .51	.17 (.18) -.18 ~ .52	.18 (.18) -.17 ~ .53	.17 (.18) -.18 ~ .52
Extended Family Support	.29 (.17) -.04 ~ .65	.30 (.17) -.03 ~ .66	.22 (.18) -.13 ~ .57	.27 (.18) -.08 ~ .62
Financial Well-being	.58** (.13) .33 ~ .83	.58** (.13) .33 ~ .83	.53** (.14) .26 ~ .80	.58** (.13) .33 ~ .83
TOTAL	.48* (.15) .19 ~ .77	.49* (.14) .22 ~ .76	.48* (.15) .19 ~ .77	.48* (.15) .19 ~ .77

* $p \leq .05$ ** $p \leq .01$

standard error appears in parenthesis before confidence intervals

Table 15

Correlation Between Family Resources and Network Support

FAMILY RESOURCES (FIRM)	NETWORK SUPPORT			
	<u>Strong Ties</u>			
	(strength of links)			
	Affective	Cognitive	Instrumental	Overall
Esteem and Communication	.66** (.11) .48 ~ .88	.44* (.15) .15 ~ .73	.51* (.14) .24 ~ .78	.56** (.13) .31 ~ .81
Mastery and Health	.53* (.14) .26 ~ .80	.22 (.18) -.13 ~ .57	.25 (.18) -.10 ~ .60	.35 (.17) .02 ~ .68
Extended Family Support	.67** (.10) .47 ~ .87	.25 (.18) -.10 ~ .60	.30 (.17) -.03 ~ .63	.42 (.16) .11 ~ .73
Financial Well-being	.66** (.11) .48 ~ .88	.57** (.13) .32 ~ .82	.57** (.13) .32 ~ .82	.63** (.11) .41 ~ .85
TOTAL	.73** (.09) .55 ~ .91	.47* (.15) .18 ~ .76	.50 (.14) .23 ~ .77	.60** (.12) .36 ~ .84
FAMILY RESOURCES (FIRM)	<u>Weak Ties</u>			
	(strength of links)			
	Affective	Cognitive	Instrumental	Overall
	Affective	Cognitive	Instrumental	Overall
Esteem and Communication	.53* (.14) .26 ~ .80	.50* (.14) .23 ~ .77	.42 (.16) .11 ~ .73	.50* (.14) .23 ~ .77
Mastery and Health	.18 (.18) -.17 ~ .53	.10 (.19) -.27 ~ .47	.10 (.19) -.27 ~ .47	.13 (.19) -.24 ~ .50
Extended Family Support	.31 (.17) -.02 ~ .64	.27 (.18) -.08 ~ .62	.20 (.18) -.15 ~ .55	.27 (.18) -.08 ~ .62
Financial Well-being	.61** (.12) .37 ~ .85	.53* (.14) .36 ~ .80	.48* (.15) .19 ~ .77	.56** (.13) .31 ~ .81
TOTAL	.50* (.14) .23 ~ .77	.43* (.15) .14 ~ .72	.38 (.16) .07 ~ .69	.45* (.15) .16 ~ .74

* $p \leq .05$ ** $p \leq .01$

standard error appears in parenthesis before confidence intervals

Table 16

Correlation Between Perceptions of Support and Network Support

PERCEPTIONS OF SUPPORT	NETWORK SUPPORT			
	<u>Strong Ties</u>			
	(number of links)			
	Affective	Cognitive	Instrumental	Overall
Affective	.30 (.17) -.03 ~ .63	.26 (.17) -.10 ~ .54	.30 (.13) -.03 ~ .63	.29 (.17) -.07 ~ .51
Cognitive	.51* (.14) .24 ~ .78	.49* (.14) .22 ~ .76	.51* (.14) .24 ~ .78	.51* (.14) .24 ~ .78
Instrumental	.32 (.16) -.01 ~ .63	.30 (.17) -.03 ~ .63	.32 (.16) -.01 ~ .63	.32 (.16) -.01 ~ .63
TOTAL	.39 (.15) .10 ~ .68	.36 (.16) .05 ~ .67	.39 (.15) .10 ~ .68	.38 (.16) .07 ~ .69

PERCEPTIONS OF SUPPORT	<u>Weak Ties</u>			
	(number of links)			
	Affective	Cognitive	Instrumental	Overall
	Affective	Cognitive	Instrumental	Overall
Affective	.23 (.18) -.12 ~ .58	.21 (.18) -.14 ~ .56	.18 (.18) -.17 ~ .53	.21 (.18) -.14 ~ .56
Cognitive	.22 (.18) -.13 ~ .57	.21 (.18) -.14 ~ .56	.14 (.18) -.21 ~ .49	.19 (.18) -.16 ~ .54
Instrumental	.18 (.18) -.17 ~ .53	.17 (.18) -.18 ~ .52	.12 (.18) -.23 ~ .47	.16 (.18) .19 ~ .51
TOTAL	.23 (.17) -.10 ~ .56	.21 (.18) -.14 ~ .56	.16 (.18) -.19 ~ .51	.21 (.18) -.14 ~ .56

* $p \leq .05$ ** $p \leq .01$

standard error appears in parenthesis before confidence intervals

Table 17

Correlation Between Perceptions of Support and Network Support

		NETWORK SUPPORT			
		<u>Strong Ties</u>			
		(strength of links)			
PERCEPTIONS OF SUPPORT		Affective	Cognitive	Instrumental	Overall
Affective		.45* (.15) .16 ~ .74	.10 (.18) -.35 ~ .45	.15 (.18) -.20 ~ .50	.24 (.17) -.09 ~ .57
Cognitive		.61** (.11) .39 ~ .83	.35 (.16) .04 ~ .66	.40 (.15) .11 ~ .69	.46* (.14) .19 ~ .73
Instrumental		.46* (.14) .19 ~ .73	.14 (.18) -.21 ~ .49	.20 (.18) -.15 ~ .55	.27 (.17) -.06 ~ .60
TOTAL		.53** (.13) .28 ~ .78	.19 (.18) -.16 ~ .54	.26 (.17) -.08 ~ .58	.33 (.16) .02 ~ .64
		<u>Weak Ties</u>			
		(strength of links)			
PERCEPTIONS OF SUPPORT		Affective	Cognitive	Instrumental	Overall
Affective		.25 (.17) -.11 ~ .55	.16 (.18) -.19 ~ .51	.14 (.18) -.17 ~ .49	.19 (.18) -.16 ~ .54
Cognitive		.26 (.17) -.10 ~ .56	.13 (.18) -.22 ~ .48	.10 (.18) -.25 ~ .45	.17 (.18) -.18 ~ .52
Instrumental		.19 (.18) -.16 ~ .54	.09 (.18) -.26 ~ .44	.06 (.18) -.28 ~ .41	.12 (.18) -.22 ~ .47
TOTAL		.25 (.17) -.11 ~ .55	.15 (.18) -.20 ~ .50	.11 (.18) -.24 ~ .46	.17 (.13) -.18 ~ .52

* $p \leq .05$ ** $p \leq .01$

standard error appears in parenthesis before confidence intervals

Table 18

Correlation Between Impact on Family and Perception of Support

	PERCEPTION OF SUPPORT			
	Affective	Cognitive	Instrumental	Overall
IMPACT ON FAMILY				
Financial	.41 (.16) .10 ~ .72	.62** (.12) .38 ~ .86	.35 (.15) .06 ~ .64	.50* (.14) .36 ~ .74
Familial/Social	.07 (.19) -.12 ~ .26	.11 (.19) -.26 ~ .48	.12 (.19) -.25 ~ .49	.11 (.19) -.26 ~ .48
Personal Distress	.42 (.16) .11 ~ .73	.64** (.11) .42 ~ .86	.44* (.15) .15 ~ .73	.54* (.13) .29 ~ .79
Mastery/Coping	.74** (.09) .56 ~ .92	.82** (.06) .70 ~ .94	.59** (.12) .47 ~ .71	.79** (.07) .65 ~ .93

* $p \leq .05$ ** $p \leq .01$

standard error appears in parenthesis before confidence intervals

Table 19

Partial Correlations Between Family Resources
and Perceptions of Support
Controlling for the Effect of Weak Ties

FAMILY RESOURCES (FIRM)	PERCEPTIONS OF SUPPORT (controlling for strength of ties)			
	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Esteem and Communication	.33 (.18) -.02 ~ .68	.39 (.17) .06 ~ .72	.37 (.17) .04 ~ .70	.40 (.17) .07 ~ .73
Mastery	.39 (.17) .06 ~ .72	.52* (.15) .23 ~ .81	.36 (.17) .03 ~ .69	.45* (.16) .14 ~ .76
Extended Family Support	.47* (.16) .16 ~ .78	.48* (.15) .19 ~ .77	.52* (.15) .23 ~ .81	.53* (.14) .26 ~ .80
Financial Well-Being	.44* (.16) .13 ~ .75	.40 (.17) .07 ~ .73	.41 (.17) .08 ~ .74	.46* (.16) .15 ~ .77
TOTAL	.44* (.16) .13 ~ .75	.48* (.15) .19 ~ .77	.43* (.16) .12 ~ .74	.49* (.15) .18 ~ .80

FAMILY RESOURCES (FIRM)	PERCEPTIONS OF SUPPORT (controlling for number of links)			
	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Esteem and Communication	.34 (.18) -.01 ~ .69	.35 (.18) .00 ~ .70	.35 (.18) .00 ~ .70	.38 (.17) .07 ~ .71
Mastery	.40 (.17) .07 ~ .73	.50* (.15) .31 ~ .79	.35 (.18) .00 ~ .70	.44* (.16) .33 ~ .75
Extended Family Support	.47* (.16) .36 ~ .78	.46* (.16) .35 ~ .77	.52* (.15) .33 ~ .81	.52* (.15) .33 ~ .81
Financial Well-Being	.45* (.16) .34 ~ .76	.35 (.18) .00 ~ .70	.39 (.17) .06 ~ .72	.44* (.16) .33 ~ .75
TOTAL	.44* (.16) .33 ~ .75	.45* (.16) .34 ~ .76	.42 (.16) .31 ~ .73	.48* (.15) .19 ~ .77

^acontrolling for affective network support

^bcontrolling for cognitive network support

^ccontrolling for instrumental network support

^dcontrolling for overall network support

*p ≤ .05

**p ≤ .01

standard error appears in parenthesis before confidence intervals

Table 20

**Partial Correlations Between Family Resources
and Perceptions of Support
Controlling for the Effect of Strong Ties**

FAMILY RESOURCES (FIRM)	PERCEPTIONS OF SUPPORT (controlling for strength of ties)			
	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Esteem and Communication	.20 (.19) -.17 ~ .57	.29 (.18) -.06 ~ .64	.32 (.18) -.03 ~ .67	.31 (.18) -.04 ~ .66
Mastery	.26 (.19) -.11 ~ .63	.46* (.16) .05 ~ .77	.32 (.18) -.03 ~ .67	.39 (.17) .09 ~ .72
Extended Family Support	.33 (.18) -.02 ~ .68	.41 (.17) .08 ~ .74	.50* (.15) .31 ~ .78	.47* (.16) .06 ~ .78
Financial Well-Being	.29 (.18) -.06 ~ .64	.26 (.19) -.11 ~ .63	.33 (.18) -.02 ~ .68	.35 (.18) .00 ~ .70
TOTAL	.29 (.18) -.06 ~ .64	.38 (.17) .05 ~ .71	.38 (.17) .05 ~ .71	.41 (.17) .08 ~ .74

FAMILY RESOURCES (FIRM)	PERCEPTIONS OF SUPPORT (controlling for number of links)			
	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Esteem and Communication	.31 (.18) -.04 ~ .66	.19 (.19) -.18 ~ .56	.24 (.19) -.13 ~ .61	.28 (.18) -.07 ~ .65
Mastery	.36 (.17) .06 ~ .69	.39 (.17) .06 ~ .72	.25 (.19) -.12 ~ .62	.37 (.16) .04 ~ .70
Extended Family Support	.44* (.16) .13 ~ .75	.32 (.18) -.03 ~ .67	.44* (.16) .13 ~ .75	.45* (.16) .14 ~ .76
Financial Well-Being	.40 (.17) .07 ~ .73	.14 (.20) -.25 ~ .43	.24 (.19) -.13 ~ .61	.31 (.18) -.04 ~ .66
TOTAL	.41 (.17) .08 ~ .74	.28 (.18) -.07 ~ .63	.30 (.18) -.05 ~ .65	.37 (.17) .04 ~ .70

^acontrolling for affective network support^bcontrolling for cognitive network support^ccontrolling for instrumental network support^dcontrolling for overall network support

*p ≤ .05

**p ≤ .01

standard error appears in parenthesis before confidence intervals

Table 21

Partial Correlations Between Impact on Family and Network Support
(based on the number of links)
Controlling for the Effect of Perceptions of Support

NETWORK SUPPORT				
<u>Strong Ties</u>				
IMPACT ON FAMILY	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Financial	.16 (.15) -.21 ~ .53	-.06 (.20) -.45 ~ .33	.17 (.19) -.20 ~ .54	.09 (.16) -.48 ~ .30
Familial/Social	.03 (.20) -.36 ~ .42	-.01 (.20) -.40 ~ .38	.01 (.20) -.38 ~ .40	.01 (.20) -.38 ~ .40
Personal Distress	.04 (.20) -.35 ~ .43	-.24 (.19) -.13 ~ .61	.02 (.20) -.37 ~ .41	-.07 (.20) -.46 ~ .32
Mastery/Coping	.26 (.19) -.11 ~ .63	-.12 (.20) -.51 ~ .27	.26 (.19) -.11 ~ .63	.11 (.20) -.28 ~ .50
<u>Weak Ties</u>				
IMPACT ON FAMILY	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Financial	-.14 (.20) -.53 ~ .25	-.18 (.20) -.57 ~ .21	.02 (.20) -.41 ~ .37	-.12 (.20) -.51 ~ .27
Familial/Social	.04 (.20) -.35 ~ .43	.04 (.17) -.35 ~ .43	.18 (.19) -.19 ~ .55	.08 (.20) -.31 ~ .47
Personal Distress	-.05 (.20) -.44 ~ .34	-.10 (.20) -.49 ~ .29	.03 (.20) -.36 ~ .42	-.06 (.20) -.45 ~ .33
Mastery/Coping	.13 (.20) -.26 ~ .52	.15 (.20) -.24 ~ .54	.26 (.19) -.11 ~ .63	.17 (.19) -.20 ~ .54

^acontrolling for perception of affective support

^bcontrolling for perception of cognitive support

^ccontrolling for perception of instrumental support

^dcontrolling for overall perception of support

* $p \leq .05$

** $p \leq .01$

standard error appears in parenthesis before confidence intervals

Table 22

Partial Correlations Between Impact on Family and Network Support
(based on the strength of ties)
Controlling for the Effect of Perceptions of Support

IMPACT ON FAMILY	NETWORK SUPPORT			
	<u>Strong Ties</u>			
	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Financial	.21 (.19) -.16 ~ .58	.13 (.20) -.26 ~ .52	.03 (.20) -.36 ~ .42	.03 (.20) -.36 ~ .42
Familial/Social	.11 (.20) -.28 ~ .50	-.07 (.20) -.46 ~ .32	-.11 (.20) -.50 ~ .28	-.04 (.20) -.43 ~ .35
Personal Distress	.09 (.20) -.30 ~ .48	-.27 (.19) -.64 ~ .10	-.07 (.20) -.46 ~ .32	-.10 (.20) -.49 ~ .29
Mastery/Coping	.26 (.19) -.11 ~ .63	-.12 (.20) -.51 ~ .27	.14 (.20) -.25 ~ .53	.08 (.20) -.31 ~ .47
IMPACT ON FAMILY	<u>Weak Ties</u>			
	Affective ^a	Cognitive ^b	Instrumental ^c	Overall ^d
Financial	-.05 (.20) -.44 ~ .34	-.18 (.19) -.55 ~ .19	.04 (.20) -.43 ~ .51	-.10 (.20) -.49 ~ .29
Familial/Social	.05 (.20) -.34 ~ .44	.03 (.20) -.36 ~ .42	.15 (.20) -.24 ~ .54	.07 (.20) -.32 ~ .46
Personal Distress	-.02 (.20) -.41 ~ .37	-.14 (.20) -.53 ~ .25	-.02 (.20) -.41 ~ .37	-.08 (.20) -.47 ~ .31
Mastery/Coping	.18 (.19) -.19 ~ .55	.20 (.19) -.17 ~ .57	.25 (.19) -.12 ~ .62	.20 (.19) -.17 ~ .57

^acontrolling for perception of affective support

^bcontrolling for perception of cognitive support

^ccontrolling for perception of instrumental support

^dcontrolling for overall perception of support

* $p \leq .05$

** $p \leq .01$

standard error appears in parenthesis before confidence intervals

APPENDICES

APPENDIX A

Family Inventory of Resources for Management (FIRM)

(McCubbin, Comeau, and Harkins, 1981)



FAMILY STRESS COPING AND HEALTH PROJECT
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

Family Health Program
FORM 8
1981
© H. McCubbin

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

Hamilton I. McCubbin Joan K. Comeau Jo A. Harkins

PURPOSE

FIRM—Family Inventory of Resources for Management was developed to record what social, psychological, community and financial resources families believe they have available to them in the management of family life.

DIRECTIONS

To complete this inventory you are asked to read the list of "Family Statements" one at a time. In each statement, "family" means your immediate family (mother and/or father and children).

Then ask yourself: "HOW WELL DOES THE STATEMENT DESCRIBE OUR FAMILY SITUATION?"

Then make your decision by circling one of the following:

- ① = *Not At All* — This statement does not describe our family situation. This does not happen in our family.
- ② = *Minimally* — This statement describes our family situation only slightly. Our family may be like this once in a while.
- ③ = *Moderately* — This statement describes our family situation fairly well. Our family is like this some of the time.
- ④ = *Very Well* — This statement describes our family very accurately. Our family is like this most of the time.

PLEASE BEGIN—Please read and record your decision for EACH and EVERY statement below.

COMPUTER CODES: IID ☐☐☐☐ GID ☐☐☐ FAMID ☐☐☐☐₁₁

Describes Our Family:

FAMILY STATEMENTS		Describes Our Family:				For Computer Use		
		Not at all	Minimally	Moderately	Very Well	SFS	RS	SD
1	We have money coming in from our investments (such as rental property, stocks, bonds, etc.)	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
2	Being physically tired much of the time is a problem in our family	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
3	We have to nag each other to get things done	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
4	We do not plan too far ahead because many things turn out to be a matter of good or bad luck anyway	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
5	Our family is as well adjusted as any family in this world can be	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
6	Having only one person in the family earning money is (or would be) a problem in our family	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
7	It seems that members of our family take each other for granted	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
8	Sometimes we feel we don't have enough control over the direction our lives are taking	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
9	Certain members of our family do all the giving, while others do all the taking	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
10	We depend almost entirely upon financial support from welfare or other public assistance programs	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
11	We seem to put off making decisions	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
12	Family members understand each other completely	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
13	Our family is under a lot of emotional stress	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
14	Many things seem to interfere with family members being able to share concerns	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
15	Most of the money decisions are made by only one person in our family	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
16	There are times when family members do things that make other members unhappy	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
17	It seems that we have more illness (colds, flu, etc.) in our family than other people do	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
18	In our family some members have many responsibilities while others don't have enough	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
19	No one could be happier than our family when we are together	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
20	It is upsetting to our family when things don't work out as planned	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
21	We depend almost entirely on income from alimony and/or child support	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
22	Being sad or "down" is a problem in our family	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
23	It is hard to get family members to cooperate with each other	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
24	If our family has any faults, we are not aware of them	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
25	We depend almost entirely on social security retirement income	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
26	Many times we feel we have little influence over the things that happen to us	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
27	We have the same problems over and over—we don't seem to learn from past mistakes	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
28	One or more working members of our family are presently unemployed	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
29	There are things at home we need to do that we don't seem to get done	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
30	We feel our family is a perfect success	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
31	We own land or property besides our place of residence	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
32	We seem to be so involved with work and/or school activities that we don't spend enough time together as a family	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
33	We own (are buying) a home (single family, condominium, townhouse, etc.)	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	
34	There are times when we do not feel a great deal of love and affection for each other	0	1	2	3	<input type="checkbox"/>	<input type="checkbox"/>	

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SFS RS SD

FAMILY STATEMENTS		Describes Our Family:				For Computer Use		
		Not at all	Minimally	Moderately	Very Well	FS	FWS	SS
35	If a close relative were having financial problems we feel we could afford to help them out	0	1	2	3		<input type="checkbox"/>	<input type="radio"/>
36	Friends seem to enjoy coming to our house for visits	0	1	2	3	<input type="checkbox"/>		<input type="radio"/>
37	We feel we have a good retirement income program	0	1	2	3	<input type="radio"/>	<input type="checkbox"/>	
38	When we make plans we are almost certain we can make them work	0	1	2	3	<input type="checkbox"/>		<input type="radio"/>
39	In our family we understand what help we can expect from each other	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
40	We seem to have little or no problem paying our bills on time	0	1	2	3	<input type="radio"/>	<input type="checkbox"/>	
41	Our relatives seem to take from us, but give little in return	0	1	2	3		<input type="radio"/>	<input type="checkbox"/>
42	We would have no problem getting a loan at a bank if we wanted one	0	1	2	3	<input type="radio"/>	<input type="checkbox"/>	
43	We feel we have enough money on hand to cover small unexpected expenses (under \$100)	0	1	2	3		<input type="checkbox"/>	<input type="radio"/>
44	When we face a problem, we look at the good and bad of each possible solution	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
45	The member(s) who earn our family income seem to have good employee benefits (such as paid insurance, stocks, car, education, etc.)	0	1	2	3	<input type="radio"/>	<input type="checkbox"/>	
46	No matter what happens to us, we try to look at the bright side of things	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
47	We feel we are able to go out to eat occasionally without hurting our budget	0	1	2	3		<input type="checkbox"/>	<input type="radio"/>
48	We try to keep in touch with our relatives as much as possible	0	1	2	3		<input type="radio"/>	<input type="checkbox"/>
49	It seems that we need more life insurance than we have	0	1	2	3		<input type="checkbox"/>	<input type="radio"/>
50	In our family it is "okay" for members to show our positive feelings about each other	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
51	We feel we are able to make financial contributions to a good cause (needy people, church, etc.)	0	1	2	3		<input type="checkbox"/>	<input type="radio"/>
52	We seem to be happier with our lives than many families we know	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
53	It is "okay" for family members to express sadness by crying, even in front of others	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
54	When we need something that can't be postponed, we have money in savings to cover it	0	1	2	3	<input type="radio"/>	<input type="checkbox"/>	
55	We discuss our decisions with other family members before carrying them out	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
56	Our relative(s) are willing to listen to our problems	0	1	2	3		<input type="radio"/>	<input type="checkbox"/>
57	We worry about how we would cover a large unexpected bill (for home, auto repairs, etc. for about \$100)	0	1	2	3		<input type="radio"/>	<input type="checkbox"/>
58	We get great satisfaction when we can help one another in our family	0	1	2	3	<input type="checkbox"/>		<input type="radio"/>
59	In our family we feel it is important to save for the future	0	1	2	3		<input type="checkbox"/>	<input type="radio"/>
60	The working members of our family seem to be respected by their co-workers	0	1	2	3	<input type="checkbox"/>		<input type="radio"/>
61	We have written checks knowing there wasn't enough money in the account to cover it	0	1	2	3		<input type="radio"/>	<input type="checkbox"/>
62	The members of our family respect one another	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
63	We save our extra spending money for special things	0	1	2	3	<input type="radio"/>	<input type="checkbox"/>	
64	We feel confident that if our main breadwinner lost his/her job, (s)he could find another one	0	1	2	3	<input type="radio"/>	<input type="checkbox"/>	
65	Members of our family are encouraged to have their own interests and abilities	0	1	2	3	<input type="checkbox"/>		<input type="radio"/>
66	Our relatives do and say things to make us feel appreciated	0	1	2	3	<input type="radio"/>		<input type="checkbox"/>
67	The members of our family are known to be good citizens and neighbors	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
68	We make an effort to help our relatives when we can	0	1	2	3	<input type="checkbox"/>	<input type="radio"/>	
69	We feel we are financially better off now than we were 5 years ago	0	1	2	3		<input type="checkbox"/>	<input type="radio"/>

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

FS FWS SS

PLEASE Check all 69 items to be sure you have circled a number for each one. THIS IS IMPORTANT

C-2247

APPENDIX B

Network Analysis Questionnaire

NETWORK ANALYSIS QUESTIONNAIRE

This questionnaire attempts to get information about your experiences with the people who help you with your child's illness. Help from other people is defined as:

EMOTIONAL

- allowing you to "let off steam," relax, or joke around
- willingness to listen, accepting you for what you are
- showing affection and/or concern

INFORMATIONAL

- providing advice or information about coping with your child's illness
- helping to find answers to "where", "what to do", "how to" questions about your child's illness

PRACTICAL

- material goods (e.g., money, medicine)
- practical assistance (e.g., baby-sitting, rides, errands)

For each of the persons listed below, check the appropriate box to indicate:

- A) How often in a usual month you communicate with the person (face to face, on the phone, in writing) using the following scale:
 1 - Several times a day 2 - Every day 3 - Every week 4 - Every two weeks 5 - Every month
- B) How much emotional, informational, or practical help you receive from the person using the following scale:
 1 - Much less than you need 2 - Not as much as you need 3 - About right 4 - More than you need 5 - Much more than you need

If you do not communicate with a person at all, leave the space blank and move on to the next. Use the blank spaces in the "other" category if you get support from other family members, friends, co-workers and/or other people (e.g., day care provider, school teacher, etc.). Please indicate your relationship with them in the space provided.

EXAMPLES:

Example #1: You see your sister "Jane" once a week. She's too busy to help you with the children, but you can share your worries about your child with her. She often takes you to a movie or shopping so you can get your mind off things.

Example #2: Your child's day care provider, Mary Smith, often keeps her for an extra hour while you take your child with the chronic illness to the clinic.

	FREQUENCY OF COMMUNICATION					EMOTIONAL					INFORMATIONAL					PRACTICAL				
	Every month	Every two weeks	Every week	Every day	Several times a day	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time
Family Member: <u>SISTER</u>	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Other: <u>day care provider</u>	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

	FREQUENCY OF COMMUNICATION					EMOTIONAL					INFORMATIONAL					PRACTICAL									
	Every month	Every two weeks	Every week	Every day	Several times a day	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time					
Spouse or Partner	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Family Member:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Neighbor or Friend	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Co-worker	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Religious Leader	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Other:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Other:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Other:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

Other:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Other:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Other:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Other:	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

NOW, PLEASE DO THE SAME THING FOR THE MEMBERS THE LINC NETWORK YOU'VE HAD CONTACT WITH.

	FREQUENCY OF COMMUNICATION					EMOTIONAL					INFORMATIONAL					PRACTICAL				
	Every month	Every two weeks	Every week	Every day	Several times a day	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time
WILLIAM CAUL Sedation	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
ANNE MARIE COLLINS Health Dept. Nurse	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
KAREN DONLEY Health Dept. Nurse	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

	FREQUENCY OF COMMUNICATION					EMOTIONAL					INFORMATIONAL					PRACTICAL				
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	Every month	Every two weeks	Every week	Every day	Several times a day	None of the time	Almost always	Usually	Sometimes	All the time	None of the time	Almost always	Usually	Sometimes	All the time	None of the time	Almost always	Usually	Sometimes	All the time
ELIZABETH DREBUSHENKO Health Dept. Nurse	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
JOHN FRISCH Health Education	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
KATHE HELMS Health Education	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
JULIE KLINKENBERG Nutritionist	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
MARTHA NACY Community Mental Health	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

ON THE NEXT PAGE, WRITE DOWN THE TYPES OF PROFESSIONALS (e.g., pediatrician, physical therapist, social worker, dentist, etc.) YOU'VE CONTACTED IN THE LAST SIX MONTHS OR SO ABOUT YOUR CHILD'S ILLNESS.

IN A TYPICAL MONTH, HOW OFTEN DID YOU CONTACT THESE PERSONS AND RECEIVE ANY KIND OF HELP FROM THEM?

PROFESSIONAL	FREQUENCY OF COMMUNICATION					EMOTIONAL					INFORMATIONAL					PRACTICAL									
	Every month	Every two weeks	Every week	Every day	Several times a day	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time					
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

Do you know any of the other families who are members of the LINC Network? ____ NO ____ YES

If you answered NO, STOP RIGHT HERE. If you answered YES, PLEASE PROCEED.

WRITE THE FAMILIES' NAMES BELOW AND INDICATE HOW OFTEN YOU COMMUNICATE AND THE TYPE OF SUPPORT YOU RECEIVE FROM THEM. If you met them before you joined LINC, please put a star (*) after their names.

NAME	FREQUENCY OF COMMUNICATION					EMOTIONAL					INFORMATIONAL					PRACTICAL									
	Every month	Every two weeks	Every week	Every day	Several times a day	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time	None of the time	Sometimes	Usually	Almost always	All the time					
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

APPENDIX C

Perceptions of Support Items

Social Support Index (Wilcox, 1981)

**Social Provisions Scale
(Russell, Altmaier and VanVelzen, 1984)**

PERCEPTIONS OF SOCIAL SUPPORT MEASURES

Affective Support

- Subscales from the Social Provisions Scale
(Russell, D., Altmaier, E. and VanVelzen, D., 1984)

Attachment

1. I have strong relationships that provide me with a sense of emotional security and well-being.
2. I have a strong emotional bond with at least one person.
3. I feel that I do not have close relationships with other people.
4. I lack a feeling of intimacy with another person.

Reliable Alliance

1. There are people I can depend on to help me if I really need it.
2. There are people I can count on in an emergency.
3. If something went wrong, no one would come to my assistance.
4. There is no one I can depend on for aid if I really need it.

Cognitive Support

- Subscale from the Social Provisions Scale
(Russell, D., Altmaier, E. and VanVelzen, D., 1984)

Guidance

1. There is someone I could talk to about important decisions in my life.
2. There is a trustworthy person I could turn to for advice if I were having problems.
3. There is no one I could turn to for guidance in times of stress.
4. There is no one I feel comfortable talking about my problems with.

- Items from the Social Support Index (Wilcox, B., 1981))

1. I wouldn't know who to ask for advice about hiring a lawyer or finding a good surgeon.
2. If I needed straight talk about how to deal with a family problem, there is someone I can turn to.
3. There is no one I feel comfortable going to for advice about personal or family problems.
4. When I need suggestions for how to deal with a personal problem, I know someone I can turn to.
5. There is at least one person I know whose advice I really trust.

Instrumental Support

- Items from the Social Support Index (Wilcox, B., 1981)

1. If for some reason I were put in jail, there is someone I could call who would come bail me out.
2. If I had to go out of town for a few weeks, someone I know would look after my house (the plants, pets, yard, etc.).
3. If I were sick and needed someone to drive me to the doctor, I would have trouble finding someone.
4. There is no one I could call on if I needed to borrow a car for a few hours.
5. If I needed a quick emergency loan of \$100, there is someone I could get it from.
6. If I needed some help in moving to a new home, there is someone I could depend on for help.

APPENDIX D

Impact of Chronic Illness on the Family Questionnaire

(Stein and Riessman, 1980, 1985)

IMPACT ON FAMILY (ENGLISH)

40. I am going to read some statements that people have made about living with an ill child. For each statement I read, please tell me whether at the present time you would strongly agree, agree, disagree, or strongly disagree with the statement.

	<u>Strongly</u> <u>Agree</u>	<u>Agree</u>	<u>Disagree</u>	<u>Strongly</u> <u>Disagree</u>	
a. The illness is causing financial problems for the family	1	2	3	4	50/
b. Time is lost from work because of hospital appointments	1	2	3	4	51/
c. I am cutting down the hours I work to care for my child	1	2	3	4	52/
d. Additional income is needed in order to cover medical expenses	1	2	3	4	53/
e. I stopped working because of my child's illness	1	2	3	4	54/
f. Because of the illness, we are not able to travel out of the city	1	2	3	4	55/
g. People in the neighborhood treat us specially because of my child's illness	1	2	3	4	56/
h. We have little desire to go out because of my child's illness	1	2	3	4	57/
i. It is hard to find a reliable person to take care of my child	1	2	3	4	58/
j. Sometimes we have to change plans about going out at the last minute because of my child's state	1	2	3	4	59/
k. We see family and friends less because of the illness	1	2	3	4	60/
l. Because of what we have shared we are a closer family	1	2	3	4	61/

	Strongly Agree	Agree	Disagree	Strongly Disagree	
m. Sometimes I wonder whether my child should be treated "specially" or the same as a normal child	1	2	3	4	62/
n. My relatives have been understanding and helpful with my child	1	2	3	4	63/
o. I think about not having more children because of the illness	1	2	3	4	64/
p. My partner and I discuss my child's problems together	1	2	3	4	65/
q. We try to treat my child as if he/she were a normal child	1	2	3	4	66/
r. I don't have much time left over for other family members after caring for my child	1	2	3	4	67/
s. Relatives interfere and think they know what's best for my child	1	2	3	4	68/
t. Our family gives up things because of my child's illness	1	2	3	4	69/
u. Fatigue is a problem for me because of my child's illness	1	2	3	4	70/
v. I live from day to day and don't plan for the future	1	2	3	4	71/
w. Nobody understands the burden I carry	1	2	3	4	72/
x. Traveling to the hospital is a strain on me	1	2	3	4	73/
y. Learning to manage my child's illness has made me feel better about myself	1	2	3	4	74/
z. I worry about what will happen to my child in the future (when he/she grows up, when I am not around)	1	2	3	4	75/
aa. Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable	1	2	3	4	76/

☐ SKIP TO NEXT PAGE IF CHECKED

ASK IF SIBLING(S) IN HOUSEHOLD

	Strongly Agree	Agree	Disagree	Strongly Disagree	
bb. It is hard to give much attention to the other children because of the needs of my child	1	2	3	4	77/
cc. Having a child with an illness makes me worry about my other children's health	1	2	3	4	78/

☐ SKIP TO NEXT PAGE IF CHECKED

79-80/05

ASK IF SIBLING(S) ARE 4 YEARS OR OLDER:

dd. There is fighting between the children because of my child's special needs	1	2	3	4	6/
ee. My other children are frightened by his/her illness	1	2	3	4	7/
ff. My other children seem to have more illnesses, aches and pains than most children their age	1	2	3	4	8/
gg. The school grades of my other children suffer because of my child's illness	1	2	3	4	9/

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APPENDIX E

Descriptive Statistics

Appendix E

Means, Standard Deviations and Factor Loadings
of the Items in the Various Instruments

		Means	Standard Deviations	Factor Loadings
<u>FAMILY RESOURCES</u>				
<u>A. Esteem and Communication</u>				
44.	When we face a problem, we look at the good and bad of each possible solution	2.33	1.27	.98
53.	It is okay for family members to express sadness by crying, even in front of others	2.59	.76	.96
62.	The members of our family respect one another	2.70	.53	.99
55.	We discuss our decisions with other family members before carrying them out	1.97	.98	.96
38.	When we make our plans we are almost certain we can make them work	1.76	.90	.97
50.	In our family it is okay for members to show positive feelings about each other	2.70	.59	.99
58.	We get great satisfaction when we can help out one another in our family	2.61	.61	.98
46.	No matter what happens to us we try to look at the bright side of things	2.36	.74	.98
65.	Members of our family are encouraged to have their own interests and abilities	2.36	.86	.99
52.	We seem to be happier with our lives than many families we know	1.97	1.02	.92
36.	Friends seem to enjoy coming to our house for visits	2.15	.97	.97
39.	In our family we understand what help we can expect from each other	2.30	.88	.97
67.	The members of our family are known to be good citizens and neighbors	2.52	.80	.98
68.	We make an effort to help our relatives when we can	2.21	.89	.95
60.	The working members of our family seem to be respected by their co-workers	2.06	1.14	.95

Appendix E (con't.)

	Means	Standard Deviations	Factor Loadings
B. <u>Mastery and Health</u>			
13. Our family is under a lot of emotional stress (R)	1.36	.93	.97
22. Being sad or down is a problem in our family (R)	.88	.82	.97
27. We have the same problems over and over - we don't seem to learn from past mistakes (R)	.49	.62	.98
23. It is hard to get family members to cooperate with each other (R)	1.09	.93	.94
14. Many things seem to interfere with family members being able to share concerns (R)	.85	.94	.98
26. Many times we feel we have little influence over the things that happen to us (R)	1 .00	.83	.94
11. We seem to put off making decisions (R)	.91	.88	.94
20. It is upsetting to our family when things don't work out as planned (R)	1.56	.84	.96
17. It seems that we have more illness in our family than other people do (R)	1.03	1.05	.93
29. There are things at home we need to do that we don't seem to get done (R)	1.61	.93	.96
32. We seem to be so involved with work and/or school activities that we don't spend enough time together as a family (R)	.88	.96	.92
15. Most of the family decisions are made by only one person in our family (R)	.97	1.13	.94
C. <u>Extended Family Social Support</u>			
56. Our relatives are willing to listen to our problems	1.82	1.10	.97
66. Our relatives do and say things to make us feel appreciated	2.06	1.00	.98
48. We try to keep in touch with our relatives as much as possible	2.36	.82	.96
41. Our relatives seem to take from us, but give little in return (R)	.12	.42	.94

Appendix E (con't.)

		Means	Standard Deviations	Factor Loadings
D. <u>Financial Well-being</u>				
43.	We feel we have enough money on hand to cover small, unexpected expenses (under \$100) (R)	1.42	1.26	.95
35.	If a close relative were having financial problems we feel we could afford to help them out	.49	.67	.87
47.	We feel we are able to go out to eat occasionally without hurting our budget	1.34	.90	.91
57.	We worry about how we would cover a large, unexpected bill (for home, auto repairs, etc.) (R)	1.91	.95	.94
69.	We feel we are financially better off now than we were five years ago	1.52	1.23	.94
51.	We feel we are able to make financial contributions to a good cause (needy people, church, etc.)	.85	.94	.93
40.	We seem to have little or no problem paying our bills on time	1.55	.97	.93
42.	We would have no problem getting a loan at a bank if we wanted one	1.55	1.30	.84
63.	We save our extra spending money for special things	1.52	.97	.93
45.	The members(s) who earn our family income seem to have good employee benefits (paid insurance, stocks, education, etc.)	.97	1.28	.87
59.	In our family we feel it is important to save for the future	2.12	.89	.86
61.	We have written checks knowing there wasn't enough money in the account to cover it (R)	.61	.90	.90
49.	It seems we need more life insurance than we have (R)	1.24	1.23	.87
64.	We feel confident that if our main breadwinner lost his/her job, he/she could find another one	1.70	1.13	.95

PERCEPTIONS OF SOCIAL SUPPORT**A. Affective Support**

25.	I have strong relationships that provide me with a sense of emotional security and well-being	3.88	1.29	.91
30.	I have a strong emotional bond with at least one person	4.31	1.06	.92

Appendix E (con't.)

	Means	Standard Deviations	Factor Loadings
26. There are people I can depend on to help me if I really needed it	4.22	1.04	.95
27. There is someone I could talk to about important decisions in life	4.22	1.13	.94
32. There is a trustworthy person I could turn to for advice if I were having problems	4.16	1.14	.99
33. If I needed straight talk about how to deal with a family problem, there is someone I can turn to	4.03	1.18	.96
42. When I need suggestions about how to deal with a personal problem, I know someone I can turn to	3.72	1.37	.86
46. There is at least one person I know whose advice I really trust	4.09	1.00	.88
B. <u>Cognitive/Informational Support</u>			
36. There is no one I could turn to for guidance in times of stress (R)	2.22	1.31	.80
41. There is no one I feel comfortable talking about my problems with (R)	2.19	1.26	.92
28. I wouldn't know who to ask for advice about hiring a lawyer or finding a good surgeon (R)	2.75	1.44	.67
37. There is no one I feel comfortable going to for advice about personal or family problems (R)	2.19	1.26	.93
C. <u>Instrumental/Practical Support</u>			
29. If for some reason I were put in jail, there is someone I could call who would bail me out	3.97	1.25	.88
34. If I had to go out of town for a few weeks, someone I know would look after my house	3.88	1.21	.88
45. If I needed a quick emergency loan of \$100, there is someone I could get it from	3.34	1.47	.77
47. If I needed some help in moving to a new home, there is someone I could depend on for help	4.00	1.22	.94
31. There are people I can count on in an emergency	4.25	1.11	.97

Appendix E (con't.)

	Means	Standard Deviations	Factor Loadings
IMPACT ON FAMILY SCALE			
A. <u>Financial</u>			
1. The illness is causing financial problems for the family	2.38	.83	.80
2. Time is lost from work because of hospital appointments	2.70	.85	.75
3. I am cutting down the number of hours I work to care for my child	2.97	.73	.64
4. Additional income is needed in order to cover medical expenses	2.54	.84	.66
B. <u>Familial/Social</u>			
5. I stopped working because of my child's illness	3.03	.82	.77
6. People in the neighborhood treat us specially because of my child's illness	3.23	.60	.62
7. We have little desire to go out because of my child's illness	3.08	.68	.75
9. Sometimes we have to change plans about going out at the last minute because of my child's state	2.61	.87	.66
10. We see family and friends less because of the illness	2.87	.79	.83
C. <u>Personal Strain</u>			
8. It is hard to find a reliable person to take care of my child	2.70	.91	.50
19. Fatigue is a problem with me because of my child's illness	2.71	.73	.77
22. Travelling to the hospital is a strain to me	2.62	.83	.36
21. Nobody understands the burden I carry	2.74	.80	.70
24. Sometimes I feel like we live on a roller coaster; in crisis when my child is acutely ill, OK when things are stable	2.35	.86	.36
D. <u>Mastery/Coping</u>			
11. Because of what we have shared we are a closer family (R)	2.05	.80	.79
13. My relatives have been understanding and helpful with my child (R)	2.05	.66	.62
15. My partner and I discuss my child's problems together (R)	2.30	.94	.62

Appendix E (con't.)

Means and Standard Deviations
of the Strength and Number of Links
in the Networks of Strong and Weak Ties

	<u>Means</u>	<u>Standard Deviations</u>
<u>STRENGTH OF LINKS</u>		
A. <u>Strong Ties</u>		
1. Affective Support	9.82	7.09
2. Cognitive Support	11.47	7.89
3. Instrumental Support	11.21	7.31
4. Total	32.50	21.67
B. <u>Weak Ties</u>		
1. Affective Support	9.58	6.87
2. Cognitive Support	10.18	8.00
3. Instrumental Support	9.47	7.20
4. Total	29.24	21.50
<u>NUMBER OF LINKS</u>		
A. <u>Strong Ties</u>		
1. Affective Support	3.47	2.33
2. Cognitive Support	3.42	2.32
3. Instrumental Support	3.47	2.33
4. Total	10.37	6.97
B. <u>Weak Ties</u>		
1. Affective Support	3.24	2.43
2. Cognitive Support	3.26	2.42
3. Instrumental Support	3.03	2.28
4. Total	9.53	7.04

Appendix E (con't.)

Scale Scores

	<u>Means</u>	<u>Standard Deviations</u>
IMPACT ON FAMILY		
Financial	10.60	2.35
Familial/Social	14.89	2.65
Personal Distress	13.03	3.12
Mastery/Coping	8.60	1.86
PERCEPTION OF SOCIAL SUPPORT		
Affective	32.63	7.36
Cognitive/Informational	14.66	4.12
Instrumental/Practical	19.61	4.77
Overall	67.39	14.85
FAMILY RESOURCES (FIRM)		
Esteem and Communication	49.41	7.42
Mastery and Health	35.26	7.29
Extended Family Support	13.12	2.38
Financial Well-being	34.25	7.59
Total	131.93	21.74

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