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KEEPING UP WITH FRIENDS: A GROUNDED THEORY OF
FRIENDSHIP AND WELL-BEING IN CHILDREN
WITH JUVENILE RHEUMATOID ARTHRITIS

by
Nancy Ann Steinke

A Dissertation Submitted to the Faculty of the
COLLEGE OF NURSING
In Partial Fulfillment of the Requirements
For the Degree of
DOCTOR OF PHILOSOPHY
In the Graduate College
THE UNIVERSITY OF ARIZONA

1999
As members of the Final Examination Committee, we certify that we have read the dissertation prepared by Nancy Ann Steinke entitled Keeping Up With Friends: A Grounded Theory Of Friendship And Well-Being In Children With Juvenile Rheumatoid Arthritis and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy.

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Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copy of the dissertation to the Graduate College.

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SIGNED: Nancy A. Steinke
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DEDICATION

This work is dedicated to my fantastic family and friends. To my mother, Charlene Medenwald, R.N., M.S., for her love of nursing, and her many trips to Tucson to let me study. To my father, Robert Medenwald, for sending her every time I asked. To my children: Charlie, Julia, and James, with the hope that they will always find good friends to share their lives with. To my husband's parents: Rosy Steinke, for her courage in living with Parkinsonism, and her wonderful example of mothering, and John Steinke, for always being there for her. To a very special friend who listened so well, Debbie Thorpe, R.N. Most of all to my husband, David Steinke, for his loving support and help all these years.

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ABSTRACT

Children with Juvenile Rheumatoid Arthritis (JRA) often describe themselves as lonely. This grounded theory investigation documented ways that friends aid children with JRA. In depth, open ended interviews with three children with JRA, their best friends, and mothers of each were done. Observations at Arthritis Camp supplemented the interview data. In this document only the data from the children with JRA were reported. A substantive range nursing theory was generated to specify the process by which friendships influence the child with JRA's well-being.

The basic social psychological process of Keeping Up, the child with JRA's ability to maintain acceptable play interactions, was identified as the core category in the grounded theory Keeping Up With Friends. Three stages of friendships were identified: Making Friends, Being Friends, and Losing Friends. The process of Keeping Up took place in the stage of Being Friends. Categories that positively related to the child with JRA's sense of well-being were: Keeping Up, Maintaining Acceptable Play Interactions, Companionship, Help from Friends, and Strategies to Manage Denigrating Social Responses. Categories that decreased the child's well-being included Problems with Having JRA and Missing Out. Well-being was defined by the children with JRA as feeling good, happy, strong, and as normal as possible.
Being Visibly Different from friends and Barriers to Friendships were found to negatively affect the child with JRA's ability to Keep Up. Among several implications for nursing practice and research was the importance of the children learning to pace themselves as they participated in social activities as well as their sensitivity to unwanted attention in social situations. Clinically this model could be used "as is" when working with girls with JRA who are lonely, being teased or left out of social activities.
CHAPTER ONE

FRIENDSHIPS OF CHILDREN WITH JUVENILE RHEUMATOID ARTHRITIS

Chapter One introduces the background for this study of friendships of children with Juvenile Rheumatoid Arthritis. Juvenile Rheumatoid Arthritis (JRA) is a chronic childhood illness that can be life threatening when severe. Similar to adult arthritis, JRA is an inflammatory, auto-immune disease involving the connective tissues in the joints of children (Fife, 1993; Hughes & Ambrosia, 1993). The exact etiology and pathogenesis of JRA remains unknown. The prognosis can vary from child to child. Some have a relatively benign experience, while others progress into destructive arthritis, and severe disability. It is difficult to tell which child will progress, and therefore who needs the most aggressive treatment at onset (Tucker, 1993). Outcome studies with adults indicate arthritis takes a profound toll on people's livelihood and quality of life (Makisara & Makisara, 1982; Scott et al., 1987). There are about 200,000 children in the United States with some form of arthritis, of which about 71,000 have JRA ("Arthritis Children", 1996).

For parents the unpredictability of painful symptoms, the uncertainty of the disease progression, and the limited effectiveness of current medical treatments make the disease experience a constant source of stress, anxiety, and worry. Fear of their child's permanent disablement are realistic in
the sense that any joint damage suffered in childhood usually continue into adulthood.

To the child with JRA, the issues of developing and maintaining friendships may be of greater concern than the actual illness, treatment, or long-term prognosis. To adults these concerns may seem minor. Yet, the reality in childhood, that is often forgotten by adults, is of a social world that has both positive and negative aspects. On the positive side, good friends often provide a haven of predictability and acceptance. Friends have been found to be the best indicator of a child's long-term psychosocial adjustment or well-being (Parker & Asher, 1987). "Friends are important sources of companionship, and recreation, share advice and valued possessions, serve as trusted confidants and critics, act as loyal allies and provide stability in times of stress or transition" (Asher, 1990, p. 3). On the negative side teasing and ridicule by other school age children may be a painful daily experience for any child with visible health problems and/or disabilities (Arizona Daily Star, December 18, 1993; Bustamante, 1994; Whyte, 1992).

Natural supports, such as close friends, can participate in a chronically ill child's daily care, and make the child's illness experience more understandable and less frightening. Examples of this are found in newspaper
reports of how entire classes may visit an ill child in the hospital or at home. One class chose to shave their heads in a show of support for a child on chemotherapy (Arizona Daily Star, March 19, 1994). Elementary students with asthma reported enjoying an "Open the Airways" program designed to teach about asthma in school. One mother was concerned about her child being singled out, but felt afterward the program was valuable because it taught other children how to help when her daughter had trouble breathing. Friends continued to play with her daughter. They were more considerate of her condition, and willingly modified their games to accommodate her limitations. Her friends also found the school nurse if she had trouble breathing (Tucson Citizen, January 29, 1998).

In summary, friendships in childhood are essential for the child's mental health and personal development. Yet parents of children with chronic illness often struggle with decisions about the importance of their children's social life in the face of multiple demands on their time as caregivers, limited financial resources, and a child's actual health status. For children with chronic illness, friends may provide some assistance during exacerbations of the disease as well as companionship during routine health maintenance tasks such as exercise or rest periods. Miller (1993), however, has documented that children with both mild
and severe levels of JRA have consistently reported taking part in fewer activities and having fewer friends than siblings or healthy children. He suggests that all measures to increase the child's mobility be seriously considered, as the limitation of the child's social activities may be more a result of parental or health professional concerns than actual pain or disability and may contribute to depression and the impact of external stressors.

The exact nature of the social support needed for a child's well-being or happiness is poorly understood. For example, in Steinke's (1987) ethnographic work with well children, "Being There" or "Presence of Friends" was as an important domain to the children as "Things Friends Say" or "Things Friends Do Together." The physical presence or companionship of a friend may be more important to a child than any information, tangible help, or verbal encouragement the friend actually provides (Reid, Landesman, Treder & Jaccard, 1989; Steinke, 1987). More qualitative work is needed to describe from the chronically ill child's perspective how friendships, the physical presence and companionship of friends, influence an ill child's well-being. There are many unknowns: how the type of support needed varies with the severity of illness; the "costs" the child incurs to obtain needed support from a friend; and by
what processes social support is obtained in the culture of childhood.

A variety of construct level sociological and psychological theories are available under which friendship processes may be considered: social exchange theory, social learning theory, social comparison theory (downward), self efficacy and personal control theories, and self esteem theories (Wills, 1985). None of these are derived from research on the perspective of a chronically ill child. In addition, grand theories can be difficult to apply directly in clinical practice because of difficulty identifying key operational variables for specific populations. If a nurse wanted to use social learning theory as a model for friendship behavior for children with JRA, certain social cues and reinforcers would need to be identified, which may or may not differ from those of healthy children. To deal with these limitations Walker and Avant (1988) suggest the use of specific research strategies such as grounded theory, to generate limited, but clinically useful, middle-range nursing theories applicable to certain patient populations. This study focused on generating such a theory with applicability to children with JRA.

Purpose of Study

The purpose of this study was to explore the world of the child with juvenile rheumatoid arthritis to clarify the
processes and issues involved in creating and maintaining friendships. The structure, function, and nature of friendships in childhood was examined from the child's point of view. A grounded theory was developed that describes the process by which support from their friends contributes to the development of a sense of well-being in the children.

Research Questions

The focal question of this research study was: By what processes do friendships influence a school age child's sense of well-being when that child has JRA? School age children were defined as children between the ages of five and twelve.

Additional heuristic questions that provided an initial framework for the study were from the perspective of the child, parent, best friend, and best friend's parent. These were: 1) What is the friendship network like? 2) What are functions of supportive friendships for children with JRA? 3) What is the nature of supportive friendships for children with JRA? 4) How do illness specific factors such as onset, symptom course, prognosis, and mobility impact on a child with JRA friendships and the process by which well-being is maintained?

Background and Significance

Broadly defined, this study focused on friendships as a source of social support in childhood. Research on social
support has proceeded extremely rapidly since the Cobb (1976) and Cassel (1976) landmark studies that provided convincing evidence of the existence of social support and its beneficial buffering effect on health. Literally thousands of studies involving social support have been done over the last 30 years, yet there is still no agreement over the definition of social support. Separate research traditions and languages have developed around the various definitions of social support and social networks (Sarason, Sarason, & Pierce, 1990). This section addresses studies of social support in childhood, functions of social support in childhood, the effect of JRA on social support from friends, and the rationale for studying the child's point of view.

Studies of Social Support and Children

When researchers take a developmental perspective, most cite Sullivan's (1953) Theory of Interpersonal Psychiatry, which described how an individual's personality could be shaped by social relationships including peers and chums. Bowbly's (1969, 1973, 1988) work on attachment influenced child development researchers to view social support as a personality variable with its source in early parenting relationships instead of as a situational variable. Weiss (1973) is another researcher who is frequently quoted in the childhood literature, even though his qualitative work was with young adults experiencing loneliness. From these
interviews he described six provisions of social relationships: attachment, social integration, reassurance of worth, opportunity for nurturance, sense of reliable alliance, and obtaining guidance. These provisions of social relationships are still used as a comparison for most definitions of social support (Table A1.1). Attachment, reassurance of worth and guidance are included in all the definitions. Weiss does not specify tangible aid or material support, as do all the definitions of social support listed. His concept of social integration is reflected in 6 out of the 10 definitions, with more emphasis on friendship functions in the definitions over time.

In the early to mid 1980's nurses began to consider assessing the social support of families with a chronically ill school age child. Initial studies were based on definitions of social support found in the adult literature. For example, Brandt (1984) suggested that nurse researchers use the Norbeck Social Support Questionnaire (NSSQ) or the Personal Resource Questionnaire (PRQ) to assess adolescents once the psychometric testing was completed. The NSSQ was based on Kahn and Antonucci's definition of social support and the PRQ was based on Weiss's six provisions of social relationships. The PRQ85 was later validated for use by adolescents by Yarcheski, Mahon, and Yarcheski (1992) using a sample of 365 adolescents aged 12 to 21. In contrast,
Ellison's (1983) development of the Family Peer Relationship Questionnaire was developed from in-depth separate interviews from mothers, fathers and a school age child in 30 families, which focused on their day-to-day experiences and behavior. The instrument was designed to measure the quality of the child's relationships with parents and peers. From these interviews parent support was seen as including concepts of parental availability, parental companionship, parental nurturance and the parent as a mediator. Initial test results showed the new scales to be internally consistent at acceptable levels. Mothers consistently overestimated the amount of parental support given to girls and boys, indicating a need to include children's perspectives when assessing family support.

In 1985 Cohen and Wills's landmark review of social support literature identified four types of social support typically described in the adult social support literature: esteem, informational, instrumental, and social companionship. Esteem support is "information that a person is esteemed and accepted" (p. 313). Informational support is "help in defining, understanding and coping with problematic events" (p. 313). Social companionship refers to "spending time with others in leisure and recreational activities" (p. 313). And Instrumental support is "the provision of financial aid, material resources and needed services" (p.
Cohen and Wills reviewed 56 social support studies to determine how much evidence there was for viewing social support as having a main effect on well-being or acting as a buffer in highly stressful situations. The studies were sorted by whether a measure assesses support structure or function, and the degree of globality of the scale. Structure referred to the existence of relationships and function to the extent the interpersonal relationships provide particular resources. Fourteen articles contained specific measures of confidant relationships. This is important because the literature on intimacy and close adult relationships that was also rapidly developing in the early 1980's indicated that having just one confidant could significantly buffer stress. Cohen and Wills (1985) considered these studies functional in nature and assumed that esteem support and informational support would be offered by confidants, whether spouses or close friends. These types of support were thought to lead to increased self-efficacy in the person experiencing stress. Cohen and Wills (1985) also noted that confidants are a more important source for women than men, as the content of their activities concerned talking about feelings, problems and people.

Friends can also serve as companions in recreational or leisure activities. Social companionship seems to fulfill a
need for contact with others, provide distraction, and be a source of positive affect. Social companionship is also referred to as belongingness or diffuse support. The content of men's activities showed a preference for companionship activities and instrumental tasks. Cohen and Wills (1985) note that the main effect for social integration may in fact apply only to men.

During the 1980's an interest in the development of children's friendships was increased when the presence or absence of friends in childhood was found to predict psychosocial adjustment. Work on peer rejection and childhood loneliness (Asher, Hymel & Renshaw, 1984; Asher, 1990) focused on the child's peer relationships. In an effort to link child social support to the adult literature, Reid, Landesman, Treder and Jaccard (1989) developed an instrument to measure social support in childhood entitled "My Family, My Friends" based on Cohen and Wills (1985) typology of social support. Reid, Landesman, Treder, and Jaccard (1989) identified companionship as the primary support function provided by children's friends. The quality of friendships was explored as a link between peer group acceptance and loneliness in childhood (Parker & Asher, 1993).

Berndt's (1989) review of the childhood friendship literature suggested that children's friendships were
comparable to supportive relationships of adults, although the childhood friendship literature's base is more qualitative in nature. For example, the childhood friendship literature asked "How can you tell someone is your best friend?" and then grouped responses into categories. The dimensions of adult social support and the categories of childhood friendship literature are comparable although different terms are used. He found that esteem support, which refers to statements or actions that convince people of their worth or value" (p. 311), and emotional support, which refers to friend's "aim ... to make a person feel better about themselves or their life situation" (p. 310), both terms that are used in the adult social support literature, are referred to as self-esteem enhancement by Berndt and Perry (1986) in the child friendship literature. However, often these categories included liking and attachment items as well. Informational support, which is defined in the adult social support literature as "advice or guidance that is helpful in coping with problems" (p. 311), is called intimacy by most childhood friendship researchers. It may also be labeled frankness, spontaneity, or intimate self disclosure. Instrumental or tangible support referring to "the provision of resources necessary for solving practical problems" (p. 311) in the adult social support literature, is often called prosocial behavior, or taking
and imposing, sharing, or helping in the childhood friendship literature. Companionship support, or belonging support, which in the adult social support literature refers to "the simple opportunity to share activities with another person" (p. 312) is called play, association, contact, common activities or interaction frequency in childhood friendship literature. Other features of social support that children refer directly to in the friendship literature are liking or affection for friends (love) and faithfulness of friends (reliable alliance).

Results in the adult social support literature and child friendship literature are difficult to compare and summarize because of the different definitions, terminology, and methodological approaches. One way of dealing with these difficulties is suggested by Stewart (1993). Reflecting on the difficulty of integrating social support theory and concepts into the nursing literature, Stewart (1993) suggests focusing on three basic aspects of social support: structure, function, and nature. Structure refers to the social network in which children live. Specific variables of interest include network size, number of friends, range, density, reachability, content, intensity, directedness, and frequency. Function refers to what the people in the network actually do and the type of social support actually available to the focal person. Emotional support,
informational support, instrumental support, and companionship are all types of support. Finally, the nature of social support refers to the quality of the relationships or characteristic types of messages, including the existence of conflict. For children's relationships, the child development literature suggests consideration of cooperation and competition are important as well.

This study followed Stewart's suggestion to broadly describe the current state of knowledge in terms of structure, function, and nature of social support. This study focused primarily on the function and nature of social support provided by friends and on the processes by which well-being is promoted through friendships.

Structure and Function of Social Support in Childhood

Any relationship a child has may be a possible source of support to the child. From Reid, Landesman, Treder, and Jaccardet's (1989) development and testing of the scale "My Family, My Friends" on school age children (six to twelve years old) it was apparent that different providers gave different types of support. Parents, especially mothers, were usually the best support generalists in a child's network. Friends were the best providers of companionship, and were second only to mothers in offering emotional support. Friends were rated higher in emotional support than informational or instrumental support. In contrast, teachers
were rated high on informational support but were not considered good sources of emotional support or companionship. Fathers were also seen as excellent sources of informational support, but less available for direct help than mothers. These results are generally consistent with the child friendship literature. Furman and Buhrmester (1985) found friends were the greatest source of companionship for preadolescents, and that friends rated highest in intimacy (emotional support), with mothers and fathers following. As Sullivan (1953) predicted, intimacy with friends increases with age.

Friendships are a special source of social support that differ from other relationships because they are "chosen" whereas siblings or parents are not. Friendships are also characterized by a relatively equal balance of power between people in the relationship, with either having the ability to end the relationship. Children may consider people, animals, objects, and "ideas" to be friends and socially relate to all of them (Neale, 1984). For purposes of this study only human friends who were considered by the child with JRA to be good or best friends were interviewed. Although a child may consider siblings to be friends and they may be a very important source of companionship to an ill child, sibling relationships are affected by the presence of the chronic illness in the family. Dunn and
McGuire (1987) suggest sibling relationships be considered separately. Therefore only non-sibling friends were studied.

Models of Social Support and Well-being

Two theoretical positions explain the effect of social support: the main effect model and the buffering hypothesis. The main effect model of social support indicates that social support has an overall beneficial effect on a person's well-being. Initial studies of the main effect model examined how social ties were related to the distribution of disease in certain communities or the general population. From a socioepidemiology perspective social ties were shown to be a factor in reducing illness (Cassel, 1976; Cobb, 1976). Social ties have also been shown in prospective longitudinal studies to be related to better physical health and reduced mortality (Berkman & Syme, 1979; Wills, 1991). However, adult social support research has not linked lack of social support to specific physical diseases very well. Also little research has been done on the daily effects of social integration on the chronic, low stress, frustrations of everyday life. Rather researchers focused on dramatic life events, e.g., death of a spouse, divorce, moves (Lazarus & Folkman, 1984). In a phenomenological study of healthy middle class 9-11 year old children, Jacobson (1994) found that feelings of loss, feelings of threat to self and feelings of being hassled were the three dimensions
of meaning in regard to stressful life experiences of children, with the first two categories being more traumatic.

The buffering hypothesis suggests a process by which social support reduces (or buffers) the impact of negative life events on well-being, so that social support would be mainly beneficial for people experiencing high levels of life stress. When subjects are divided by level of support, the group with high support should show significantly less symptoms than people with the same stressful experience receiving low support. Buffering effects of social relationships have been observed in adolescents (Wills, 1986) as well as in adults with JRA (Fitzpatrick et al., 1988).

The main effect and buffering model are not exclusive. Social support may operate through both pathways at the same time. These models demonstrate the existence of social support at a construct level, although what is being measured as social support may be social competence or a general sociability factor. In addition, it's not clear if either of these models applies to children or how it works in a child's world. Cohen and Wills (1985, p.353) suggested that social support transactions themselves be studied, in terms of how and where they occur, what aspects of the social environment are seen as supportive, and how support
receiving experiences are involved with the general process of coping with stress.

**Effect of JRA on Social Support**

During the 1980's chronically ill children were viewed as at high risk clinically for psychosocial problems because of changes in body image, poor self-esteem, limited access to friends and opportunities to practice social skills (frequent hospitalizations), over or under-protective parents, and the possibility of early death. Research findings in support of these assumptions were mixed in the 1980's for children with JRA. King and Hanson (1986) noted in their review of this literature, that the better the study, the closer to normal the children with JRA appeared to be. Reasons for this included small sample sizes, limited ranges of disease severity in some samples, instrumentation problems, and pooling results from children across various age groups. With these problems in mind, Ungerer, Horgan, Chaitow, and Champion (1988) studied 363 Australian children with JRA. Scores on the Piers-Harris Self-Concept scale of the primary group, age 7 through 13, were similar to a small normative sample of healthy Australian children. Similarly, Miller (1993) found children with JRA did as well psychosocially on the Piers-Harris when compared to healthy American children, or siblings.

Results from Ungerer, Horgan, Chaitow, and Champion
(1988) study seemed to indicate that children in the primary group with low self-concept scores were lacking in close friendships. Ungerer, Horgan, Chaitow, and Champion (1988) found that children with low scores on the Piers-Harris were more likely to spend leisure time alone, although they were similar to the high self-concept group regarding structural variables: number of close friends, having a best friend, frequency of contact with friends during the week, weekends and holidays, and club memberships. One premise of Cohen and Wills (1985) review is that "structural measures only provide a very indirect measure of the availability of support functions" (p. 315) with correlations between the number of social connections and functional support usually ranging from 0.20 to 0.30. Multiple superficial relationships may not provide adequate functional support the way one very good relationship could. Children in the lowest self-concept group felt lonely more often, reported being teased more about having arthritis, and having less interesting things to do during their leisure time. Also these children were less likely to report liking most of the people in their class at school. These psychologic differences may indicate a lack of companionship and esteem support from close friends.

Other disease specific factors that may influence a child's well-being include the severity of the JRA, the lack
of mobility, chronic pain and fatigue. Disease specific factors are discussed separately below.

**Severity of Illness**

Higher levels of disability scores were associated with lower self concept scores in the primary and high school groups but not with young adults. Ungerer, Horgan, Chaitow, and Champion (1988) note that "disease severity may be more significant in younger ages because it increases the extent to which ill children appear and behave differently from their healthy peers during a time when peer pressure for conformity is most strong" (p. 102).

However, there is some evidence indicating that the severity of JRA is not the only factor influencing these children's friendships. In Miller's (1993) ongoing longitudinal study of families with a child attending the Rheumatic Disease clinic at Stanford, a larger study (N=200) of children with various rheumatoid diseases, including JRA, and their siblings, found differences on the Piers-Harris subscale measuring self-appreciation of appearance and physical attributes. At T1 only the children with severe disabilities scored significantly lower, but one year later (T2), children in the mild and severe groups scored lower on self appreciation of appearance and physical attributes, as well as in popularity. In addition, children with both mild and severe disabilities reported taking part in fewer
activities with friends than siblings and also having fewer very good friends than sibling on at both T1 and T2.

Mobility

The lack of mobility experienced by children with arthritis may result in activity restrictions during gym or wheelchair use at school. Both of these may be experienced negatively by children with JRA as it could make them feel different from other children (Steinke, 1989). Steinke (1989) found that sometimes friends accompanied immobile children to special rest-periods during recess. Sometimes the wheelchair bound child befriended other disabled children during rest periods.

Chronic Pain

Children with JRA experience chronic pain in the affected joints. Ross, Lavigne, Hayford and Berry (1993) found three variables related to higher reported pain: the child's emotional distress, the mother's emotional distress, and family harmony. The family harmony result was unexpected, perhaps indicating an environment that positively reinforces pain behaviors and reports. No studies of the impact of children's friendships on reported pain were found.

Fatigue

In the Steinke (1989) study one girl with JRA mentioned that she did not want to interact with her friends during a
flare, not even to talk to them on the phone, as she felt so exhausted. By flare she meant a period of acute, painful, exacerbation of the JRA requiring intensive medical attention and rest. Loneliness was a problem with extended flares. In addition, this child often spent time resting with other disabled children, instead of playing with classmates at recess and lunch. Although rest enabled her to make it through the school day, this resulted in some social isolation as well.

Social isolation as a result of having a chronic illness such as JRA can result from many factors. For example: friend's or relative's reactions to the chronically ill child, family embarrassment of visible deformities, limited mobility of the ill child, unavailable child care, fear of exposure to illness or conditions that might exacerbate the illness (especially when the child is on immunosuppressants), and strained family relationships. Pain and fatigue also limit social activities. Periodic flares of the JRA can restrict a child to bed rest. Contact with friends may be minimal, as they drop off homework, or are not able to come at all (Steinke, 1989).

Rationale for Studying the Child's Point of View

Parents and children may not always agree on the impact of arthritis on their lives or on the members of their
family. Ennet, Devellis, Earp, Kredich, Warren, and Wilhelm (1991) did a small study in North Carolina of 38 children and their mothers. Each participant individually assessed the child's psychosocial adjustment to JRA. Results indicated modest correlations between mother's and children's scores (r = 0.39), between children's and mother's assessments of perceived competence (r = 0.39), and for perceived disease experience (r = 0.44). Mothers rated athletic competence and social acceptance items more negatively than the children did on the Harter Scale and family burden items more negatively than children on the disease experience scale. Children rated day-to-day experience items significantly more negatively than mothers. Their perceptions of the day-to-day experience and of being different from other children were related to their feelings of social acceptance.

Children's perceptions of their illness and its effects differ from adults because they essentially live in a different social culture. Rom Harr (1976), a cultural anthropologist wrote that the world of school aged children is a precursor world to adulthood, complete in itself. He cited the qualitative work done by Oppie and Oppie (1959) as evidence that the schoolchild's child world differs only in content from the normal adult's adult world. The schoolchild's world can be described in terms of social
ceremonies, personal styles, and the ways children manage common types of social problems.

For example, a standard solution to the common adult social problem of meeting someone new can be described as a social ceremony or handshake ritual. This ritual is usually present in the adult world, but is not standard in the school age world. School age children might say "Hi, I'm Julie. Do you want to play?" instead of offering to shake hands. Parents are very aware of the need to teach social skills, e.g., please, thank you, acknowledging another child's greeting. Creative nonstandard solutions are developed by adults and children when experience is not available.

Children learn to recognize the standard social scenes of their culture and what actions are appropriate. Adult processes may or may not apply in a child-child world. In the child's world, business is conducted by the power of words alone, a ritual declaration, with a child's word being his/her bond.

Harr (1974) believed that social support processes can only be learned at a certain level of cognitive development. Social maturation into the adult world is described as not "confirming the ability to treat one's experiences objectively, but in being able to read them for the meanings they do contain or even more important, could contain" (p.
Harr (1974) suggested that new social skills are needed and learned in the world of childhood that differ from both the autonomous world of the infant and the adult social world. Therefore the school age world should not be thought of as a primitive adult world, but rather as an independent social world.

By studying the world from the child's point of view, adults gain insight into the child's behaviors. Rather than assuming friends help a child with chronic illness purely out of affection, social rituals may be identified that help children with chronic illness maintain their social world during periods of emotional flux. By understanding the social world in which a child with a chronic illness lives, the nurse can identify and predict which intervention strategies may be successful. For example, when a child is teased, it may be more appropriate to teach them how to tease back then to advise them to "ignore it".

The Significance of the Study for Nursing

In 1980 the American Nurses Association defined nursing broadly as the "diagnosis and treatment of human responses to actual or potential health problems" (p. 9). The human responses include "the reactions of individuals and groups to actual health problems (health restoring responses) such as the impact of illness effects upon the self and family, and related self care needs" (p. 9). Clearly friends fall
into this category when they interact with the child with JRA. However the art of nursing is sometimes ahead of the research knowledge base, as in the case of social support in childhood. Current knowledge of the school age child's social world outside the family is limited in the sense that very little is known from the child's point of view, nor are the processes clear that describe how social support "works" in childhood.

This study contributes to nursing theory development by increasing understanding of how friendship processes function in promoting a chronically ill child's sense of well-being. With the development of substantive theory from the children's perspective, nurses will be able to understand the meaning of friends to the child with JRA as well as the process that goes on between them that supports a sense of well-being in the child. Nurses may be able to use this information when interacting directly with a child with JRA or in planning programs for them. By understanding the nature of friendships from a child's point of view, specific nursing interventions may be more accurately conceived, implemented, and evaluated by clinicians. This information is also of use to nurse scientists in developing and evaluating measures of social support in childhood. Finally the development of substantive theory linking friendships in childhood and a sense of well-being in a
child with a chronic illness provides a framework to guide practice and research on children's adjustment to chronic illnesses like JRA.

Conceptual Orientation

The theory generated by this study was influenced by concepts drawn from the symbolic interactionism literature as well as my own personal experiences with children and JRA. Since grounded theory methodology has its roots in symbolic interactionism, critical concepts relative to symbolic interactionism which may be applicable to analyzing childhood cultural interactions are presented. This includes a brief description of McCall and Simmons' (1978) model of role identity, which illustrates how symbolic interactionism can be applied. The advantages of using a grounded theory approach are then considered. This is followed by a brief outline of my personal perspective.

Symbolic interaction refers to "the process by which individuals relate to their own minds or the minds of others; the process in which individuals take account of their own or their fellows motives, needs, desires, means, ends, knowledge, and the like" (Swanson, 1968, p. 441; Blumer, 1937). Denzin (1989) describes three basic assumptions of symbolic interactionism. First, social reality as it is understood is a social production between individuals interacting to define their own definitions of
situations. Second, humans are capable of engaging in self-reflexive behavior so that they can shape and guide each other's behavior. Third, humans interact in ways that are emergent, negotiated, and unpredictable. Interaction is symbolic because words, meanings, and symbols are manipulated. The meaning of objects in the world depends on the actions human beings take towards them. Humans learn basic symbols, their conceptions of self, and definitions they attach to social objects through interaction with others. Each person carries on simultaneous conversations with him/herself and others. Behavior can be observed at the symbolic and interactional level. Human interactions are the basic source of data.

The Role Identity Model

In McCall and Simmons' (1978) Role Identity Model interactions are described as any situation where there is evidence of mutual influence between people, where the actions of one person are dependent on the action of the second or vice versa. Friendships are an example of everyday human interaction that can be considered in this model. Humans are viewed as active agents in their own environment, having multiple projects and plans which they pursue. Anything encountered in their environment, especially other people, take on meaning in relation a person's plan of action. Plans may change as new meanings are discovered.
Each person in the situation must answer the basic question "Who am I in this situation?" so that a social consensus can be reached about the meaning of the scene, in order for everyone's various plans of action to be smoothly carried out.

In McCall and Simmon's (1978) model Mead's (1934) description of the inner forum is used to describe the silent internal conversation a human is capable of having with him or herself. The forum is made up of all the perspectives on oneself that have been learned from others, which listen to what the "I" of a person is actively planning, to evaluate and critique it. This continuous self appraisal process is the basis for intelligent, controlled, social behavior.

Role identities provide a frame of reference for appraising a person's thoughts and actions. They provide for plans of action and systems of classification of objects encountered in the social scene. Each person has many roles and different roles may be more salient in different scenes. Role performance serves to legitimize the role identity, as individuals try to act in ways to confirm one's identity. Identity is always dependent on the amount of role support given by other people. As in social exchange theory, role support is seen as a limited commodity. However, McCall and Simmons stress that it is a key reinforcer and the subject
of much negotiation. Extrinsic factors such as money or social status, and intrinsic factors such as relief of discomfort or a sense of self-efficacy also reinforce social behavior. Actual behavior is determined by the prominence of the role identity, the person's need or desire for kinds and amounts of support in the role, intrinsic and extrinsic gratifications, and the perceived degree of opportunity for it's profitable enactment in the present circumstances. In essence, a calculus is done to determine the cost/benefit ratio, and if not thought to be beneficial, alternatives are proposed.

People often perceive a gap between their ideal image and their actual performance in a role and feel pain if they fail in an important role identity. Friends may play a role in over-evaluating one's performance and reciprocal trade agreements are often set up in relationships. A major function of an "in group" is maintenance and reinforcement of self conceptions. When one finds a person who shares the right vocabulary for a role identity it may be experienced as "sheer delight" (McCall et al., 1978, p.99). The lonelier a person is, the more people will be acceptable in providing role support and even minimally adequate role support will be treasured.

McCall and Simmons (1978) suggest that people establish interpersonal relationships to develop dependable sources of
role support, with both extrinsic and intrinsic rewards. Social ties are described as the psychological glue that cement individuals into social units. In addition to reward dependability, reasons for ties to develop include ascription, for example kinship or teacher-student relationships; commitment; investment, that is respect for another's investment of work, money, or time; and attachment.

Specific people may be built into a role identity and become crucial to legitimation and enactment. Close relationships can make one vulnerable to others' decisions and be a source of grief, but the benefit of collective action is an important consideration. While people in groups may be replaceable, people in a dyadic situation are more uniquely connected and are not easily replaced. In general relationships may change if identities change, making the relationship less attractive. Otherwise it's difficult to really stop a relationship and the actual break may be made by the person who is offended by a sign of alienation by the other.

Advantages of Grounded Theory

Grounded theory is a useful method in describing basic social processes in specific clinical situations (Glaser, 1978; Glaser & Strauss, 1967). There are four main advantages to using a grounded theory approach to this
problem. First, grounded theory provides an emic (insider) description of how children with JRA present themselves to the world and their friends (Stern, Allen, & Moxley, 1982). Secondly, this approach can give ill children a voice in the process of theory development so their world can be understood by health care providers who interact with and have power over them. Third, grounded theory can provide data from the child's viewpoint that can help assess the fit of logico-deductive theories of social support derived from work with adults, as well as confirmation of work begun with well children. Fourth, from a substantive theory, clinically applicable in one situation, it may be possible to develop a more formal theory in the future. The grounded theory approach has been shown to be helpful in situations where variables are known, but poorly defined, or the relationships between variables are unknown, as in this case.

**Personal Perspective**

When using a grounded theory approach to data collection and analysis, the researcher acts as a sensitive instrument that allows the theory to develop and guide the research. Glaser (1978) describes how "Within the analyst, as the research continues, is a long term biographical and conceptual buildup that makes him quite 'wise' about the data-- how to detail it's main problems and processes and
how to interpret and explain them theoretically" (p. 2). The following perspective provides the reader insight into some of my early experiences as a nurse caring for children with JRA.

My first experience with a child with arthritis was in Butte, Montana. I was teaching a small class of senior undergraduate nursing students about chronic illness in childhood. This was rather difficult for me, as my Master's work had emphasized well children.

The public health nurse provided me with the name of a 10 year old girl with severe JRA. I remember looking everything up I could about JRA before I went to meet her so that I could do an appropriate nursing assessment. I was rather proud of my effort! At first, she was very quick to answer my questions. She seemed so small for her age and lay on the couch for most of my visit. Finally, we reached the end of my list of medical questions and I asked her about pain, from the arthritis and also the gold injections she received once a week. She said that she could handle all the pain, even the gold shots, herself. I was really very worried at this point, wondering what my student could ever do to help this sad little girl. I finally just asked her what the problem really was then. She said "The problem is that there's really no one to play with, I don't have any friends." It turned out that the only time she left her
small apartment, which she shared with her mother, was to go to the doctors. They didn't have a car so this was difficult. A teacher provided lessons in home. Her mother carried her to the bathroom. She was very lonely and isolated every single day. I wish I could write here that we were wildly successful but I have little memory of what we did. I remember thinking that I was so used to looking at children in bed, as a hospital nurse without children of my own, that her lack of mobility hardly registered.

Most social support research has focused on the effect of social support for people experiencing high levels of stress, rather than exploring the everyday effects during a long illness. When I started to study friendship, I started with six well-children (Steinke, 1987), using an ethnographic approach to learn about school age children and their friends. From this study it was apparent that often just the physical presence of another child was fun for them, even if they weren't really playing, but just hanging out. This study sensitized me to some of the "realities" of the children's world from their point of view, including the unpredictability and nature of roughhousing. Children tended to classify friendships into Best friends, Good friends, School friends, Neighborhood friends, Church friends, Half-enemies and Enemies. Siblings could be like best friends or half enemies, depending on if the child believed they wanted
to hurt or be nice to her/him.

When I compared these findings to the social support literature, I became aware for the first time of the confusing nature of the many definitions of social support in use. Friendships were viewed as a source of social support which could provide emotional support, appraisal support, instrumental support and informational support (House, 1981). The importance of physical presence was not emphasized in the adult literature. The study of children's friendships was just beginning. As researchers began to focus on the development of close relationships and intimacy in the 1980's there was some mention of social companionship (Wills, 1985) and belonging support (Cohen, Mermelstein, Kamark, & Hoberman, 1985).

When I was presenting this finding of this initial study at a poster session at the University of Arizona College of Nursing 1987 Fall Research Conference, an older woman came up and read my poster. She asked me what I was going to study next. I said I wasn't sure if I should continue. She said she thought friendships were really important to her daughter with JRA. She did not go into detail at the point but I was left with the impression that children with JRA would be an important population to study. Years later I was fortunate to meet that woman's daughter when she agreed to review the grounded theory that emerged
from this project. The daughter shared with me some of her childhood memories. As a teenager with JRA she had been homebound for a considerable period of time and her experiences of being isolated from her schoolmates and friends were still painful later in her life.

These incidents in my past were important in helping me realize the limitations of relying on my adult perspective and the medical model for nursing children. My observations alone were not enough to sensitize me to what these children needed. I became interested in looking for research techniques that would allow me to explore the child's world from a child's point of view. As Glaser (1978) said, each state of generating theory relies on "the social psychology of the analyst; that is, his skill, fatigue, maturity, cycling of motivation, life cycle interest, insights into and ideation from the data" (p. 2).

Summary of Chapter One

JRA is a serious chronic condition that effects children's ability to grow and interact with family and friends. Children with JRA may experience daily pain, stiffness, and lifelong limitations of mobility and growth. Close relationships such as friendships can be an important source of companionship and emotional support for these children. Loneliness can be a problem as these children may have difficulty maintaining their friendships as the illness
worsens. Parent's and children's perspectives of the illness effects can differ since they essentially belong to different social worlds. Understanding of the child's social world is limited and needs explicating in terms of how their friendship processes work to maintain the child's sense of well-being in spite of the illness. Grounded theory helps conceptualize behavior in complex situations. A grounded theory approach, based on symbolic interactionism, was used to examine how childhood interactions with friends aid children with JRA in the process of maintaining their sense of well-being. By its nature a grounded theory has "grab" and can be employed directly by individuals using the theory. However, its main purpose is to generate not a complete description of a culture, but a basic pattern of social life. From this substantive theory describing how friendship processes function in promoting a child with JRA's sense of well-being, nurses can identify appropriate ways to intervene when needed.
CHAPTER TWO
REVIEW OF LITERATURE

The review of literature is presented in four parts. Part One, Childhood Friendships as a Source of Social Support, begins with a brief discussion of close relationships and theories of childhood friendship development. This is followed by a review of the childhood friendship literature, describing the structure, function, and nature of childhood friendships. Summaries are included with each of these sections. Finally, an in depth look at the social support function of companionship is taken. Part Two, Loneliness, begins with definitions and types of loneliness in adults, and then focuses on factors that contribute to childhood loneliness. These factors may be situational, age related, cognitive, or a result of peer rejection. Part Three, Well-being, focuses on the development of the concept of Well-being in the psychology literature and from a nursing perspective. Finally Part Four, Childhood Friendships in the Context of Chronic Illness, is concerned about what is known about childhood friendships in five illness populations. These include children with either mental illness, cancer, diabetes, asthma, or juvenile rheumatoid arthritis (JRA).
Part One: Childhood Friendships
as a Source of Social Support

In 1986 Coyne and Delongis called for a broader psychosocial inquiry into social support. Noting the profound connections between good relationships (complex, reciprocal, and contingent) and well-being they described a need to focus on "how people find, build, maintain and end relationships; how they are constrained by their personal characteristics, their circumstances, and the pool of people available; and the benefits and costs they incur" (p. 458). In short they suggested a shift in focus from viewing social support as a cognitive process to viewing support as an individual experience of the interpersonal dynamics of close relationships. This shift has methodological implications as well, creating a need for studies using in depth interviews regarding the nature of supportive relationships and support processes as they unfold over time.

Close Relationships

Friendships, by definition, are close relationships. A close relationship is one in which two people have a great amount of mutual impact on each other, or there is high interdependence. A high degree of interdependence is characterized by four properties: 1) the individuals have frequent impact on each other, 2) the degree of impact per occurrence is strong, 3) the impact involves diverse kinds
of activities for each person and 4) all these properties characterize the interconnected activity for long durations of time. Close relationships need not involve exchanges of intimate information or produce regular intense positive feelings - rather they reflect the notion of people closely connected or physically close in time or space and may be destructive or constructive in nature (Kelley et al., 1983). Relationships can be divided into two types: attachment relationships such as between a parent and child or close friends, and community relationships such as relationships with a school friend, neighborhood friends, or co-members of support groups (Weiss, 1991). Attachment relationships are characterized by strong affectional bonds. Ainsworth (1991) described an affectional bonds as "a relatively long enduring tie in which the partner is important as a unique individual ... there is a desire to maintain closeness to the partner .... and often joy upon reunion" (p. 38). First, childhood friendships will be discussed, and then the role of parents in childhood socialization.

**Children's Friendships**

Children's friendships may vary from "best friends" whose loss precipitates extensive grief, to good friends, school friends, or neighborhood friends who are less deeply missed. These more superficial friendships may be characterized as community relationships. Figure 2.1 shows a
typology of children's friendships (Steinke, 1987). Youniss (1980) found that close friendships may be lasting at any age, with partners able to pick up the threads after long absences. Friends depend on each other for understanding, reassurance, and help. Also some siblings (close in age) may be playmates and some become best friends, with cooperative, reciprocal, and mutually trusting relationships.

Figure 2.1: Example of a relationship typology for family and friends based on preliminary studies of well children and children with JRA, intact families.

Although people have widely differing notions of friendship, depending on their age, all people seem to refer "to nonfamilial relationships which are likely to foster a
sense of belonging and a sense of identity" (Rubin, 1980, p. 32). Rubin (1980) suggested that friendship is really what a child makes it out to be and researchers need to try and understand it in the child's own terms. For example, children may consider pets, inanimate objects, cartoon characters and imaginary people as friends.

A stepladder progression of four stages of friendships that children go through in the development of social awareness was identified by Selman (1980, Figure 2.2). In stage 0, the young child, about age three to five, views friends as momentary playmates; that is, whoever the child is playing with at the time. When questioned they reflect more on the physical attributes and activities of the playmates rather than personal interests or traits. In stage 1, most characteristic of 6 to 8 year children, the child conceives of friendship as one-way assistance. A friend, is seen as an individual who does things to please the child. At this stage, friends must be aware of each others' likes and dislikes. In stage two, about age 9 to 12, the notion of reciprocity develops, with friendships seen as being more of a two way street. These friendships are limited to specific incidents. By stage 3, about age 12-14, children can reflect on the nature of friendship and it's development over time. The emphasis is on intimacy and mutual sharing.
**Figure 2.2. Stages of Friendship Development.**

Selman (1980)

<table>
<thead>
<tr>
<th>Age 3-5</th>
<th>Age 6-8</th>
<th>Age 9-11</th>
<th>Age 12-14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friends are who ever you are playing with at the time.</td>
<td>Friends are someone who does things to help you.</td>
<td>Friends are someone who helps you and you help them. (Reciprocity)</td>
<td>Friendships involve intimacy, mutual sharing, reflection over time.</td>
</tr>
<tr>
<td></td>
<td>Friends have likes and dislikes.</td>
<td>Friendships limited to specific instances.</td>
<td></td>
</tr>
</tbody>
</table>

Youniss (1980)

<table>
<thead>
<tr>
<th>Age 6-8</th>
<th>Age 9-11</th>
<th>Age 12-14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friendships focus on playmate relations, sharing.</td>
<td>Reciprocity Present Friends are someone you can depend on for help or companionship.</td>
<td>Cooperative Reciprocal Trusting Reveals Negotiates differences. Reveals feelings. Negotiates differences. Understands you. Has similar interests.</td>
</tr>
</tbody>
</table>

The progression through these stages is not that the lower stages are discarded but that they are built upon and remain available for future use, even into adulthood. This model is based on Piaget's model of cognitive development.
and reflects the child's cognitive shifts from concrete to abstract thought. It also reflects Sullivan's (1953) approach that emphasizes that children learn to appreciate other's capabilities, desires, and values as they attempt to cooperate with each other. During the school age years peers are thought to play causal roles in building the framework for the child's gradual understanding of social rules for cooperation and competition and social roles such as deference and dominance. In the next stage, preadolescence, Sullivan suggested that "chumships" fostered development in conceptualization of equality, mutuality, and reciprocity as central, defining characteristics of intimate relationships" (p. 218). There is no inevitable relation between a child's age and interpersonal understanding. In fact there is almost always a discrepancy between how children answer questions about friendships and how children relate to their friends in practice, their actual friendship skills being more advanced than their ability to describe them. Piaget (1973) emphasized that thought always lags behind actions and a child's personal experience with friendship processes is critical to more advanced understandings of the social world.

In summary, friendships may be categorized as close relationships when there is a great amount of mutual impact on each other. For children a friend may be defined as any
voluntary relationship outside the family that helps the child feel a sense of belonging and identity. Friendship characteristics vary with age. Children age 6 through 8 view friendship as a one-way process, where friends do things to help you, including playing together and sharing their things. They become aware of their friends likes and dislikes. By ages 9 through 11, the concept of reciprocity develops, so that friendships become more of a two-way street. Friendships are often confined to specific instances like camp or school. Friends are depended on for help and companionship, and a dim view is taken at a friend's failure to be there when needed.

A developmental framework is valuable because it gives one an idea of how children's friendships change over time, as intimacy develops. There is still a gap between how a child verbally describes friendship processes and what the child actually is capable of doing to maintain them, with the latter being more advanced. This makes prolonged observations of the children helpful in determining how their social world works.

Parental Roles in Childhood Socialization

Parents play a critical role in supporting a child's efforts to socialize and develop friendships by: providing access to friends, acting as social role models, coaching and monitoring children and their friends for appropriate
social behavior, selecting the neighborhood, school and people where the children will interact, and arranging organized educational and sports activities (Rubin & Sloman, 1984). Parents are in a position to monitor their children's expressions of loneliness and general well-being on a daily basis. For these reasons parents of the children with JRA were included in this study, as they may directly and indirectly impact on the child's peer relationships.

Cochran and Bassard (1979) described how personal social networks of parents influence children. The personal social network of either a parent or a child was defined as: "people outside the household who engage in activities and exchanges of affective and/or material nature with members of the immediate family" (p. 601). Transmission of network influence to a child could be indirect through network-parent interactions, and direct by the child seeing other adults as role models, providing cognitive stimulation, providing direct aid to parents which then helps the children, and providing opportunities for active participation. Network influences on parents included access to emotional and material assistance, provision of role models and child rearing controls. Positive development outcomes for a child were described in terms of cognitive development and social attachment, including less stranger anxiety, more independent behavior on part of the child, and
improved self concept through positive interactions with others.

Little work has been done in determining what role parents play in the origins of their children's social status among peers. The general parent-child literature provides evidence that: parent's personal characteristics, parenting styles, disciplinary techniques, and quality of attachment to their infants, all influence the social behavior of children. Second, some degree of gentle parental control relates positively to peer competence. Third, parent's sensitivity, responsiveness, and involvement with their children positively influences peer relations. Fourth, the use of a democratic and inductive reasoning approach by parents has favorable influence in developing a child's socialization skills (Putallaz & Heflin, 1990). Often the higher status children in a group are more skilled at generating solutions, explaining the rules, encouraging cooperation, and comforting and helping peers (Newcomb et al., 1993).

A literature based, but untested, model of how parents influence a child's sociometric status was proposed by Putallaz and Heflin (1990). This model is useful in visualizing how parental influence might work. They suggested parents both directly and indirectly influence the child's social motivation, social behavior/skills and
cognitive control of interactions. Parents may indirectly influence social development by designating the social scene and by the frequency of parent-child interactions.

Four direct pathways of parental influence were specified in the model (Putallaz & Heflin, 1990). First, the parent's use of classical conditioning with warmth and responsiveness and the quality of parent-child attachment was predicted to directly impact the child's social motivation, that is the tendency to approach or avoid social interaction, and the child's sense of security and self confidence. Second, the parents modeling of social interactions to children was predicted to directly effect the child's social motivation, social behavior, and skills. Third, the parents use of operant conditioning reinforcement or punishment/ignoring techniques evokes certain responses in social situations. Operant conditioning also affects social skills. Fourth, parental coaching by discussing emotions and social interaction strategies was predicted to directly effect the child's thinking patterns about their social world, that is their capacity to regulate an interaction, their ability to recognize certain effects in themselves and others, and the knowledge of possible strategies for interacting with others. This theory helps to illustrate the complicated role of parents in childhood socialization processes.
Summary of Parent's Roles

Parents play an important role in their child's social development. They influence the child's social motivation, teach social skills, and how to interpret social cues and responses. Parents provide access to certain friends, select the neighborhood a child will live in, and arrange for organized activities with other children. Little research has been done on the parent's role in childhood socialization. Two theories were presented to demonstrate how parents influence children through their own social network (Cochran & Bassact, 1979) and how parental interactions may effect a child's later social status (Putallaz & Heflin, 1990). For these reasons, it was important to include parents in this study.

Childhood Friendship Literature

In children's friendship literature a provider-function model of social support is often studied, based on Weiss's (1974) suggestion that different types of relationships offer different provisions. For example, attachment relationships provide a sense of security and place. In their absence there may be feelings of restlessness and loneliness. Other relationships in a social network may provide companionship, a sense of worth or competence, a sense of being needed or a sense of reliable alliance.
Social relationship networks may be described in terms of their structure, function and nature (Stewart, 1993). Structure refers to the network system that provides specific types of support under certain conditions, to the persons, family, or culture under study. Function refers to the types of support offered, e.g., emotional, appraisal, or tangible. Nature of support refers to the content or quality of the relationship in terms of affection, intimacy, conflict, power, satisfaction, and importance. Social relationship networks vary with children's age, in terms of their structure, functions, and nature. The following sections focus on describing what is currently known about school-age children's social networks.

The Structure of Children's Friendship Networks

In 1989 Furman wrote that even a young child's social network defies easy categorization. He distinguished four levels of children's networks: global, group, dyadic and interactional network level. The global network level includes the entire set of relationships. All the levels are interrelated. Lower levels could be influenced by higher levels as well. For example, in high density networks fewer individuals were known and became increasingly connected over time, so new friendships were less likely to develop with outsiders. The high density relationships could be more stable and multiplex in nature (serve more functions) with
criteria for defining friendships becoming more stringent over time (Milardo, 1986).

The second level was the group level. Groups provide coherent sets of relationships. They are also more than the simple sum of specific relationships. For example, some children had several supportive friendships but did not feel accepted by the peer group as a whole (Furman, 1989).

The third level, dyadic relationships, or ongoing relationship phenomena between two individuals, could be described by children. For example, a child might note which interactions he had with his father were supportive (interaction level), but felt his relationship with his father was not very supportive overall because he didn't see his father very often (dyadic relationship level).

Relationships can also be considered to continue in the absence of interactions, as when a child's parent dies, or they may develop without any interactions occurring, such as with movie idols (Furman, 1989).

The fourth interactional level involved face-to-face encounters and has been less frequently studied. Most of the children's friendship research pertains to the first three levels.

Furman's (1989) description of social networks focuses on the structure, function, and nature of childhood social support. Furman's (1989) levels are useful in organizing
results from a variety of children's friendship studies to provide a view on what is quantitatively known about children's social worlds.

**Global level.**

Social networks increase in size as the child ages. Fiering and Lewis (1989) found under three years of age the mean size of social networks was 22, excluding the immediate family. By age 6 through 9, the mean was 39 people, with the biggest increase associated with school entry. Children sorted the memberships in their network by adult versus peers, by gender, and by kin versus non-kin. All children had more adults than peers in their networks through age 9 (Fiering & Lewis, 1989).

There are some gender differences present even though boys and girl's networks are similar overall. Belle (1989) found boys tended to have larger circles of friends (team sports) and interact more with adults than girls did. Boys also saw their network members more frequently than girls. The gender differences in network membership started early, at about 33 months. Boys played well in groups of three or more. Girls liked one-to-one interactions, used self-disclosure more and sought help more. Girls spent more time with their family, boys spent more time with friends. These differences may reflect American cultural patterns, not innate differences.
Kahn and Antonucci's (1980) model of social convoys was used by Levitt, Guacci-Franco and Levitt (1993), to study 333 elementary school age children. The convoy is viewed as a network of relationships that moves with a person throughout the lifetime. They found that family relationships remained significantly important across all ethnic and age groups. The increased involvement with the extended family in middle childhood was somewhat supplanted by peers in adolescence.

To understand the type and nature of social support provided at the network level, Furman (1989) gave the Global Network Inventory to 300 fourth, seventh and tenth graders. He found that reliable alliance, that is the expectation of help, despite lack of mutual affection or reciprocation for past help, decreased with age. Intimacy, involving self disclosure, increased with age for girls, while punishment and conflict decreased by tenth grade for all children and adolescents.

**Group level.**

The nature of the peer group at the elementary level has not been described well. Parker and Gottman (1989) found in qualitative work in middle childhood, peer groups became segregated on the basis on gender, and race to a lesser extent, and reflected popularity and power hierarchies. Small cliques formed. Children considered the attitudes and
reactions of peers as important as their parents in terms of their self-definition and esteem. There was a strong desire for belonging and social acceptance. Children became skilled in self presentation and more knowledgeable about social forces.

Gossip made up the bulk of conversational content of school aged children and was mainly negative. Information exchange, humor, self disclosure occurred almost always in the context of gossip. Gossip served to reaffirm membership in important same sex peer groups, and affirmed the norms and values of the groups.

School age children tried to abstract display and feeling rules from peer reactions to emotional displays. Open sentimentality was avoided, and children attempted to maintain the impression of "being cool". Situations of embarrassment were common topics of self disclosures at this age. Concrete thoughtfulness showed in their extreme devotion to logic, integration of ideas and plans, and a fascination with rules.

The concepts of peer group acceptance and dyadic friendships that are satisfying and supportive are sometimes confounded in the friendship literature. This is because some best friend sociometric measures do not compare classmates nominations, so that a popular child may be listed by many children as a best friend, while in fact that
child acknowledges only one or two classmates as best friends. For this reason Parker and Asher (1993) suggested reciprocal friendships nominations be used to assess friendships, and roster rating scales be used to gauge overall peer acceptance. Children are usually described as fitting into one of four sociometric status categories in their class: popular, average, neglected and rejected (Coie & Dodge, 1983; Coie et al., 1990). Often children in the neglected group will have friends outside of school. Most of the research has focused on peer-rejected children. This will be discussed in more detail in relation to literature on loneliness.

**Dyadic level.**

Friendship measures need to include at least two elements. First there must be mutual acknowledgement of the friendship, as measured by using reciprocal friendship nomination. The second element is the quality of the child's best friendship, in terms of the degree of companionship provided, supportiveness and level of conflict. Berndt and Perry (1986) found conflicts common among children and their friends. However close friends were able to resolve them quickly and amicably (Gottman & Parkhurst, 1980).

Close friends are an important buffer for peer group problems in early adolescence. Furman and Buhrmester (1985) found that although the peer group itself was less
supportive in early adolescence, dyadic relationships were supportive and provided some shelter in the "adolescent popularity wars." They gave 550 fourth, seventh, and tenth graders the Network Relationship Inventory describing relationships with parents, siblings, grandparents, teachers, friends, boyfriends, or girlfriends. For each relationship the students rated 11 characteristics: attachment, social integration, reassurance of worth, opportunity for nurturance, guidance, reliable alliance, intimacy, conflict, power, punishment, and satisfaction. Correlations among the relationships were positive, which supports the idea they are interrelated, but decreased with age, showing relationships became more specialized. Over time parents were perceived as less supportive, with the largest change between fourth to seventh grade.

Peer relationship support scores were consistent with Sullivan's (1953) description of chumships which are usually close friends of the same sex. From fourth to seventh grade there was an increase in affection and intimacy. The decreases from tenth to twelfth grade were specifically related to companionship and nurturance provisions. Attachment, reassurance or worth, and guidance remained stable. Reliable alliance increased. As students aged they described their romantic relationships as increasingly supportive, and spent less time with their friends.
Children's relationships with their pets was also examined by Furman (1989) because children repeatedly asserted pets were important "people" in their lives. Fourth grade children turned repeatedly to pets for companionship, alliance, intimacy, and opportunities to provide nurturance. In fact they gave more nurturance to pets than anyone else in their network. Marked developmental decreases were found between fourth to seventh grade.

Interactional level.

Furman (1989) notes that social scientists usually study interactions with particular people or groups, and do not often work at the interactional level. However, over the course of development a relationship quality may be expressed differently in the child's interactions. For example, an infant may seek proximity by physical contact with the parent and as a toddler may be able to rely on visual contact.

Summary.

Furman's approach is useful in trying to organize information about children's networks at three levels: global, peer group, and dyadic interactions, including close friendships. The Global level refers to the entire set of a child's relationships. Changes in network size, gender differences, and functions of the peer group are apparent as children age. By middle childhood there was an increased
involvement with the extended family and friends, although family relationships remained primary (Levitt et al., 1993).

The peer group includes children of the same age, in the child's network. The peer group in elementary school has not been studied as extensively as adolescents, although gender specific cliques may begin forming as early as fourth grade, usually gender specific.

Friendship relationships are studied at the dyadic level. Furman (1987) found that strong friendships helped early adolescents survive the struggles with peer groups. Parents were perceived as less supportive between 4th and 7th grades, as chumships or close friendships developed. This is the point where it is helpful to turn to Stewart's overall model and look at the functions and nature of childhood friendships.

The Functions of Children's Friendships

The features of close friendships in later childhood are similar to adults, that is childhood friendships also provide emotional, informational, instrumental, and companionship support (Berndt, 1989). Emotional support is similar to esteem support as described by Cohen and Wills (1985), that includes feeling accepted.

Informational support includes receiving helpful suggestions and guidance in coping with a personal problems. Berndt (1989) notes intimacy increases with age, so that the
emergence of intimate self disclosure is a hallmark of development, with children under fifth and sixth grade rarely disclosing. Parker and Gottman (1989) suggested that younger children develop close relationships through extensive cooperative or fantasy play.

Instrumental support was defined as tangible aid, provision of resources and pro-social behavior such as helping and sharing. Berndt, Hawkins, and Hoyle (1986) found elementary school age children less likely to share when in a contest situation where they might lose by sharing. Junior high age students were more likely to share with close friends. Adolescents preferred sharing over competition with their friends.

Companionship support was described as the simple opportunity to share activities with another person. Observational studies suggested interactions with peers increase with age. Furman and Burhmester (1985) in a study with 199 fifth and sixth graders found companionship to be greater between friends than between children and their parents, but reliable alliance was judged greater between parent-child than friends. Companionship support from friends was found to be preferred over all other providers, by Reid, Landsman, Treder and Jaccard's (1989) study of a childhood social support measure called "My Family, My Friends".
Berndt (1989) discussed two other features of friendship that were not covered in Cohen and Will's four categories: 1) "liking" or affection for ones friends and 2) faithfulness of friends. Berndt notes that "liking" or attachment items often present a measurement problem if they are included on a scale measuring emotional support, as the mean scores may not change significantly over time. Faithfulness is valued when friends pick each other for partners and never leave them for someone else. This speaks to the value of commitment and is similar to Weiss's reliable alliance. Berndt concludes features of close friendships are similar between children and adults. He concludes friendships are not equally supportive at all ages, especially as a desire for intimacy increases with age.

As mentioned above, Reid, Landesman, Treder, and Jaccard (1989) developed an instrument titled "My Family My Friends" that assessed both supportive and problematic aspects of relationships. Twelve dialogues were created to evaluate the social network using a provider/function model (based on Cohen & Wills, 1985), the perceived availability of support and the child's satisfaction with the quality of support in a group of 250 children ages 5 through 14. Ninety three percent of the children said they had at least one friend.
Children's social support functions provided by each type of relationship were described. Friends were found to be the main source of companionship support, followed by mothers then fathers. Friends were found to provide emotional support, but followed parents in this category. Friends provided some informational and instrumental support as well.

Cauce, Reid, Landesman, and Gonzales (1990) continued to use "My Family My Friends" and found friends showed a dramatic increase in emotional and companionship support with age, while informational and instrumental support was stable. Siblings were low providers of support throughout the elementary school years (sibling rivalry) but provided more support in middle school. Support generalists are core network members, such as parents, who provide many types of support. Support specialists such as friends, siblings and teachers offer more limited types of support. Friends may become support generalists with age. This instrument provides an excellent way to track changes in children's social support systems with age.

Summary.

Children's friendships can provide types of social support that are similar to adults, however they are usually specialized into fewer categories. Types of social support provided by children include: companionship, emotional, or
esteem support, informational, instrumental, and reliable alliance. Friendships increase in support with age, as self disclosure and intimacy increase after fifth to sixth grade. Friends are the best source of companionship for children (Furman & Burmester, 1985; Reid et al., 1989).

The Nature of Children's Friendship Relationships

The nature of childhood friendships can be described by four general facets of childhood relationships: "1) the degree of warmth or support in the interaction, relationship, or group; 2) the degree of conflict; 3) the distribution of power and status; and 4) the relative nature or status of the relationship or group in the participants networks" (Furman, 1989, p. 153). Furman notes that in friendships no power factor is found, and the fourth factor, status, may reflect things like rivalry in sibling relationships, exclusivity in friendships, and protectiveness in parent-child relationships. Conflict is a normal part of all close relationships (Kelley et al., 1983) and needs to be assessed to give a more complete picture of the costs and benefits of the relationship.

Usually studies combine provider, function and nature to provide a more complete description of the child's social world. For example, Furman and Buhrmester (1985) Network Relationship Inventory uses four categories pertaining to function: reliable alliance, enhancement of worth,
instrumental help, and companionship. The next six qualities pertain to the nature of the relationships: affection, intimacy (disclosure), power of child and other, conflict, satisfaction, and importance of the relationship. With a sample of 199 fifth and sixth graders, results showed that parents were rated highest on affection, reliable alliance, enhancement of worth and aid. Mothers were rated higher on companionship and satisfaction than fathers. Friends were rated highest on companionship. Friends rated equally in terms of intimacy to children's mothers. Girls relied on their best friend more than boys for intimacy, affection, and enhancement of worth. Boy's relationships were more extensive with many peers. Siblings relationships were paradoxical as they were important sources of companionship and conflict. Older siblings were a source of aid. This study found that preadolescents could not only differentiate between relationships based on these functions but that functional relationships overlap.

The Friendship Quality Questionnaire (FQQ) was developed by Parker and Asher (1993) to measure qualitative features of best friendships of school age children. The FQQ includes six subscales: validation and caring, conflict resolution, companionship and recreation, help and guidance, intimate exchange, and conflict and betrayal. Children were asked how true a particular relationship quality was with
regard to their best friend on a five point scale of forty items. All subscales had adequate internal consistency. Test-retest data were not available.

This cross correlational study included 881 children from third through fifth grade. Five measures were used: a roster and rating sociometric procedure to determine peer group acceptance (poor, average, or high accepted), the FQQ, two items to measure friendship satisfaction, and Asher and Wheelers (1985) Loneliness and Social Dissatisfaction Scale. Since so many items overlapped with the FQQ, a three item "pure" loneliness scale was constructed. Best Friends were determined by mutual reciprocity across children for any of their three best friend nominations. A computer put the name of their best friend in each item.

Results indicated that 77.6% had at least one friend and 54.9% had very best friends. One third of children who were highly accepted by peers did not have their best friend include them on their list of friends. Better accepted children were more likely to be involved in specific dyadic friendships. Many children who fell into the low acceptance by peer category did have friends, however their best friendships were more problematic. Children without best friends were more lonely than children with best friends, no matter how accepted they were by peers. Friendship quality and peer acceptance contributed about equally to the
prediction of loneliness. Three sources of loneliness were reported: poor peer acceptance, lacking a friend, and having friendships that failed to meet important relationship needs.

The FQQ scale represents an excellent advance in measuring the quality of children's friendships. However when partner's data were compared, correlations ranged from 0.64 for companionship items to 0.21 for conflict resolution items, indicating important differences between children's perspectives. In conclusion, the nature of the friendship relationship can be described in terms of the degree of affection, intimacy, and conflict between the friends, as well as the distribution of power and status. However, friends' reports of the same relationship may significantly differ. That, in itself, is the reason for including the best friend and family interviews in this study. Also public acknowledgment of the friendship contributes to the credibility of the results. Problems with the relationship, of which one child may be unaware, may then be apparent. This will help portray the interactional nature of the friendship process.

Summary of Childhood Friendship Literature

Social relationships can be described in terms of their structure, or network providers; their functions, such as esteem support, companionship, informational, and
instrumental; and their overall nature, such as the degree of affection, intimacy, level of conflict, distribution of power, and status. Friendships can be studied at the global, or network level, the peer group level, the dyadic level and the interactional level. Instruments are available to measure childhood support in a large group setting or on an individual basis. Initial instrumentation studies suggested that friends are an important source of emotional support and companionship to school age children. The processes involved in children's friendships have not yet been specified in relation to a child's well-being.

This study focus is on the dyadic level, or the relationship between the child with JRA and their best friend. Friendships developed in the school age years provide an important source of emotional support and companionship, and when continued into early adolescence can provide a shielding effect from negative peer group interactions. This study developed a model of how the friendship processes work to influence a child's well-being in the illness context of JRA.

A Closer Look at Companionship

Studies show that companionship is the primary function of children's friendships (Furman & Buhrmester, 1985; Reid et al., 1989). However, companionship may need to be studied separately from other friendship functions. Reasons include:
1) the basic motivation of companionship is to engage in pleasurable interactions rather than obtaining assistance with personal problems; 2) the context of companionship is daily life, not just periods of stress; and 3) the impact on psychological well-being differs, as companionship can increase one's level of contentment whereas social support seems to restore a person to equilibrium (Rook, 1990). Cohen and Wills (1985) noted that people with more social companionship probably have more access to instrumental and esteem support because shared activities lead to more reciprocity and closer friendships. They expected that social companionship, instrumental support, and esteem support would correlate somewhat, but still make independent contributions to well-being.

Some empirical evidence supporting conceptual distinctiveness of companionship is available (Hays, 1985; Rook, 1987). For example, in gerontological research Rook (1987) found in a representative community sample of adults that companionship had a main effect on psychological well-being and a buffering effect on minor life stresses, whereas social support had a buffering effect on major life stresses. Also in three other studies Rook (1990) reported companionship was associated with more satisfaction with friends and decreased loneliness than emotional support or instrumental support. This supports the distinctiveness of
the concepts.

Although Weiss (1973) described the need for companionship as universal, the need for companionship seems to vary in the context of illness. For example, one child with JRA stated she did not want to see friends when experiencing severe flares (Steinke, 1989). Different companionship processes may occur in childhood. Cohen and Wills (1985) discuss motivational support as a separate form of support where friends may encourage a child to persist, that things will work out, or that better things are ahead. This may not be true from an adult point of view, but denial may be an important form of coping for children with JRA (Miller, 1993).

In conclusion, companionship is very important to healthy school age children, however conceptually it differs from other concepts of social support and is often not included in adult studies of social support. In addition the desire to see friends may vary with the severity of a child's illness. Although companionship has been linked to well-being in adults, the processes involved remain unspecified.

Part Two: Loneliness in Childhood

Childhood loneliness, often due to the absence of a companion or rejection by peers, has been studied since the 1980's. As the social sciences began to recognize that
social relationships were essential to personal health and happiness, researchers developed three independent traditions of study: social support, loneliness, and social isolation. At the same time work on loneliness was proceeding in the 1980's, attention was being given by developmental and clinical psychologists to the consequences of poor peer relations, processes that create and maintain peer rejection, and the results of interventions with children rejected by peers. This section briefly discusses the definition of loneliness and general types of loneliness, followed by a more in depth look at childhood loneliness. Factors influencing childhood loneliness and predictors of loneliness are described.

The Definition of Loneliness

Loneliness is "the unpleasant experience that occurs when a person's network of social relationships is significantly deficient in either quality or quantity" (Perlman & Peplau, 1982, p. 15). After reviewing many definitions, Peplau (1983) concluded that there were three common points of agreement regarding loneliness. First, loneliness is a personal subjective experience of being alone so that a person can feel lonely even in a crowd. Objective social isolation or physical isolation from others may be experienced as either solitude, the glory of being alone, or loneliness. Second, loneliness results from a
deficiency in a person's social relationships where basic human needs for intimacy are not met. There may be a mismatch between a person's needs or desires for social contact and the person's actual social relations. Third, loneliness is an aversive experience associated with depression, emptiness, anxiety, boredom, helplessness, and desperation.

Types of Loneliness

An interactionalist view of loneliness includes both personal vulnerabilities and situational constraints. Weiss (1973) described the differences between the loneliness of social isolation and the loneliness of emotional isolation for a group of young adults. Emotional loneliness is the result of the absence of intimate attachment figure such as a parent or spouse. Social loneliness is where a person lacks a sense of social connectedness or community that might be provided by friends or associates at work or school. Weiss (1973) noted that emotional loneliness appeared to be the most severe and said people need a network of social relationships. He identified six basic provisions of social relationships that a network of people could provide: attachment, social integration, opportunity for nurturance, reassurance of worth, reliable alliance, and guidance.
Childhood Loneliness

Studies of loneliness in childhood appeared slowly in the literature and paralleled the adult literature closely. Asher, Hymel, and Renshaw (1984) developed a reliable self-report scale for children's feelings of loneliness and social dissatisfaction. The 24 item questionnaire was developed with 16 primary items focused on children's feelings of loneliness, social adequacy, and subjective estimates of peer status. Eight items were included about hobbies and preferred activities to help children feel more relaxed. The five point scale was read aloud item by item to 506 children in third through sixth grades. Two weeks later two sociometric measures were given: a positive nomination measure of three best friends, and a rating scale measure of how much they each would like to play with each classmate. Results indicated over 10% of the children reported feelings of considerable social dissatisfaction. There was a significant negative relationship between loneliness and friendship nominations and similarly with play ratings. Loneliness scores increased as the number of friends decreased. Some variability remained as high loneliness was experienced by 6% of the "unpopular" group with up to one best friend, and 5% of the "popular" group with greater than four best friends.
Some qualitative work has been done concerning children's definitions of loneliness. Asher (1990) cites Hayden's (1988) qualitative interviews with third through eighth grade children. He found three dimensions of loneliness: 1) affective/emotional, 2) cognitive, and 3) situational. Affective feelings included: sadness, boredom, feeling unneeded, left out, like no one likes you, like an outsider, in a corner, in the dark. The Cognitive dimension included the lack of: companionship (no one to play with, talk to, do things with), a sense of belonging to a group, emotional support (no one to share private thoughts with), of affection (love), of reliable alliances, of trust and continued availability of contact, of enhancement of a sense of worth, of opportunities for nurturance. Traumatic situations included: loss of an important other, moves, separations, conflict, rejection, broken loyalties, exclusion or being ignored. Again these data are very similar to Weiss description of adult loneliness.

Factors Influencing Childhood Loneliness

Childhood loneliness is influenced by several factors: the child's home situation, the child's age, the degree of peer group acceptance of the child, and the cognitive thought processes of the child relating to social activities.
Situational

Children's situations vary in the opportunity they provide for social contact with others. Children are considered high risk for loneliness if they have recently moved, parents have recently separated or divorced, they suffer an illness that requires frequent hospitalizations, or they are "latch key" children (Berman, Winkleby, Chesterman & Boyce, 1989; Peplau & Goldston, 1982). No specific studies on loneliness and children with JRA were found when reviewing the literature even though Miller (1993) identified loneliness as the children's main complaint (p. 39) in his study of children with JRA.

Age Related

Peplau (1983) believed loneliness is precipitated not only by changes in a person's actual social relationships, but also by changes in a person's social needs and/or desires. Social needs may change with age. For example, as school age children mature into adolescents they may desire more intimate relationships, allowing more self-disclosure, than their chumships formed during their school age years. Clique formation which can begin as early as fourth grade, about age 9 to 10, can result in excluded children feeling lonely, if only temporarily. Cassidy and Asher (1992) demonstrated that 10% of children as young as kindergarten and first grade experience loneliness.
Sociometric Status: Peer Group Acceptance

Sociometry is defined as "the measurement of attitudes of social acceptance or rejection through the expressed preferences among members of a social grouping" (Stein, 1975, p. 1248). Children may fall into status categories labeled popular, average, controversial, neglected, and rejected based on classmate nominations of friends. Asher (1990) reported about 10% of the elementary school children were not named as a best friend by anyone in their class. These children fell into the peer rejection category. This percentage may be higher if the criteria of reciprocal nomination is used, or if special subgroups of children are considered, such as those with mild mental retardation, hyperactivity, or learning disorders. Peer relationship problems exist in every group, even high achievers.

Sociometric rating scales can be used to distinguish "rejected" children from "neglected" children. In general "rejected" children are overtly disliked by their peers while "neglected" are reasonably well liked although they lack friends in their class. Coie and Dodge (1983) found 30 to 50% of rejected children remain rejected over a five year period, so there is some evidence rejected status is stable over time. Asher and Wheeler (1985) found rejected children are more likely to report loneliness, depression, and to express an interest in getting help with their social
relationships. Asher asked a group of third through sixth graders if they would like help in learning how to get along better with other children. Forty eight percent of the rejected children said yes, while only 16% of the neglected said yes. It is important to note that neglected children may have sources of best friends other than the classroom, which are unmeasured in these studies. Also neglected children move more easily into the average group when placed in a new group of peers (Coie et al., 1990).

Rejected children differ from neglected children in characteristic thought patterns and behavior. In general, aggression and disruptiveness are major causes of peer rejection throughout childhood and adolescence (Asher, 1990; Cassidy & Asher, 1992).

Shy and withdrawn children may also experience peer rejection. Hymel, Rubin, Rowden, and LeMare (1990) used data from a longitudinal study of 155 second grade children who were followed into the fifth grade (n=87). Children were observed playing in groups of 4, with peers of the same age and sex. Peer rating of social acceptance were obtained as well as teacher ratings. Results showed a pattern similar to previous research in that popularity was negatively related to aggressive behavior and sensitive-isolated behavior at second and fifth grades. By fifth grade negative social self perceptions were more clearly linked to social isolation and
shyness-anxiety than they were to aggression and acting out. One cost of early social withdrawal may be the failure to develop social skills which leads to further withdrawal and lower self regard.

Cooperativeness and prosocial behavior (helpfulness, rule conformity, friendliness) are the major correlates of positive status at each age (Coie, Dodge, & Kupersmidt, 1990). The nature of children's aggression changes with age. At younger ages negative status is associated more with hitting, name calling, and highly visible misbehavior. By adolescence aggression is indirect. Hypersensitivity to teasing or criticism is also associated with negative status.

Gender differences in peer rejection have been found. Boys reject children who are very aggressive or demonstrate help seeking behavior. Girls base rejection status on cooperativeness and social participation (Coie et al., 1990). In general rejected children were off task more often; engaged in fewer positive interactions with classmates, and more negative interactions; were aggressive and argumentative; they engaged in negative interactions with the teachers at high rates. Rejected boys frequently engaged in rough and tumble play, which can easily lead to misunderstanding and conflict. Rejected girls were engaged in more parallel play (Coie et al., 1990).
In a series of weekly observations where six children of each sociometric status were brought together to play, Coie, Dodge, and Kupersmidt (1990) found social withdrawal of the rejected children after the second week. Popular boys engaged in more norm setting, reminded others of the rules, and gave directions in ambiguous situations. Neglected boys could change status with ease in these new groups.

Outcomes of peer rejection have been described in terms of criminal behavior, mental health (schizophrenia and depression), perceived health status, and early withdrawal from school. Many methodological problems are involved with sorting through this literature. Coie, Dodge, and Kupersmidt (1990) noted three major issues: 1) overall design of predictive studies - those that follow randomly selected groups forward in time are stronger than retrospective studies on groups of people with specific problems; 2) operational definitions of poor peer relations vary greatly (sociometric peer nominations, adult/teacher ratings, behavioral descriptions); and 3) the wide range of negative outcomes involved.

Much of the evidence of these negative outcomes is archival and there is little empirical data to assess causality. Several hypotheses are possible. First that peer rejection is a marker variable indicating risk has accrued from a more basic problem, i.e. social skills deficit.
Secondly the experience of being accepted by peers may moderate or buffer a child from psychopathology by enhancing self esteem and coping abilities. A third point is that social rejection is directly causally linked to psychopathology, for example by being deprived of early play experiences that develop adaptive capacities, or by leading to reactions of loneliness, anger, and resentment or feelings of inadequacy which then gives rise to maladaptive behavior. The children most at risk are those continuously rejected throughout childhood.

Social Cognitive Processes Related to Loneliness

Cognitive factors in adult loneliness include both personal standards and causality (Peplau, 1983). Personal standards refereed to the person's own subjective assessment of the quality and quantity of their friendships. Very high standards might limit selection of friends which may result in a greater chance of loneliness. By causality Peplau refereed to the psychological process by which the person placed the blame for the loneliness. The blame could be placed internally, on the self, or externally on another. A second aspect of causality is the stability of the cause, whether the person views the cause as changeable or unchangeable. For example, depression is associated with an internal, unchangeable attribution of causality. Understanding cognitive factors is an important aspect in
the treatment of loneliness.

A scale to measure children's attributions about social outcomes was developed by Crick and Ladd (1993). This was correlated to Asher and Wheeler's (1985) loneliness inventory and Frank and Hymel's (1984) social anxiety and social avoidance scale, as well as sociometric rating procedures. The sample included 175 third graders and 164 fifth graders. Results showed that controversial children, or children who were well liked by some peers but equally disliked by other peers, as a group were not more socially distressed than other children. Likewise members of the neglected group were not greatly distressed by their relative lack of relationships. However, rejected children suffered high levels of social distress and loneliness. The attribution scale showed that rejected children were more likely to view peers as the cause of their social difficulties. Significant variation was evident within each group. For example 16% of popular children showed high distress and 56% rejected children showed low distress.

Two attribution patterns were exhibited. The first pattern was a self-protective bias, where external attributions were made for any social failures and credit was taken for any social successes. This was found to be associated with low social distress. This pattern is normally seen in adults and helps maintain self-esteem. The
second pattern was a non-self serving bias, where internal attributions were made for any social failures and they failed to give themselves credit for any social success. The internal attribution pattern, where children blamed themselves for social failures was associated with high social distress in the popular, average, and controversial groups of children. Even being well liked by peers was not always sufficient for emotional well being for children in these groups. For these children more of an external attributional style is needed.

In contrast, rejected children with high social distress, exhibited the self-protective bias, describing other children as "mean" and blaming others for negative relational events. This pattern may develop over time with numerous and painful social failures. This effort to maintain self-esteem makes it difficult for these children to acknowledge their own role in social interactions. Neglected children showed a combination of both attribution patterns.

In addition to personal standards and attributional styles, the task of defining a situation is part of social cognition itself, the child must organize an array of social cues into a meaningful set. The same cues may represent different situations to different children. Dodge and Feldman (1990) suggested critical situations be analyzed to
generate relevant taxonomies of situations relevant to certain populations. The five most problematic situations are: responding to threats, teasing, or insults; responding to actual provocation; being excluded from play; initiating friendships; and fulfilling peer group norms such as helping.

A one year longitudinal study to determine predictors of loneliness in middle childhood was conducted in Australia by Renshaw and Brown (1993). One hundred and twenty eight children were given Asher and Wheeler's (1985) loneliness and social dissatisfaction scale, an eight item behavioral rating scale completed by teachers on the children's withdrawal or aggressive tendencies; sociometric indices including a five point classmate play preference rating scale by Singleton and Asher (1977); friendship nominations (name 3 best friends) and vignettes by Goetz and Dweck (1980) to determine attributional indices of social functioning. Children were tested three times: at third and sixth grade, again 10 weeks later, and finally at fourth and seventh grade a year later. Results supported an additive model of loneliness. That is: withdrawn social behavior plus lower peer acceptance plus few or no friendships plus an internal attribution style predicted higher levels of concurrent and future loneliness. The results supported Asher's (1990) claim that one reciprocated friendship may be
of adaptive value and prevent extreme loneliness because children with no friends were significantly more lonely than children with one or more friends.

Summary of Loneliness in Childhood

Loneliness is an unpleasant, aversive subjective experience for children and adults. Loneliness results from a deficiency in a person's social relationships where needs for intimacy or companionship are not met. This deficiency can be either due to a lack of quality or quantity of relationships (Peplau, 1983; Perlman & Peplau, 1982).

Social loneliness has been documented in children as young as kindergarten (Cassidy & Asher, 1992). Affective feelings related to loneliness include: sadness, boredom, and feeling hurt and left out. Cognitive patterns related to loneliness involved the lack of others to play with, or talk to; there was a lack of various types of social support. Situations that can result in loneliness for children include: moves, divorces, illness, being ignored, and peer rejection (Hayden, et.al. 1988). Loneliness is a frequent complaint of children with active JRA (Miller, 1993).

Peer rejection is experienced by about 10% of children. This may extend for several years (Asher, 1990). Younger school age children tend to reject peers that are noisy, aggressive, and disruptive. Older children tend to reject shy and withdrawn children, or children who react strongly
to teasing or criticism. This may relate to the early formation of cliques in classrooms. Gender differences are present, with rejected boys engaging in more rough and tumble play, and rejected girls in more parallel play (Coie et al., 1990). Rejected children with high social distress also tended to have an external attribution pattern, where they tend to blame others for their problems, making them somewhat difficult to coach (Crick & Ladd, 1993).

Studies show that loneliness is found in all sociometric groups of children. The best predictors of future loneliness for 8 to 12 year children include: withdrawn social behavior, low peer acceptance, few or no friendships, and an internal attribution style (self-blame) (Renshaw & Brown, 1993). Even one reciprocated friendship may be of great value in preventing extreme loneliness (Asher, 1990). Loneliness was experienced by children with JRA, both during flares and times when activities were limited by JRA, for example when forced to rest instead of going to recess (Steinke, 1989). The grounded theory process, followed in this study, allowed exploration of both the times with friends and the times without them, during which loneliness was a factor. By focusing on how friendships help a child maintain their sense of well-being, this study described a process by which these children cope
with feelings of loneliness through their play interactions and support from good friends.

Part Three: Well-Being

Well-being is a useful outcome variable in studying chronically ill children. Early Greeks referred to Well-being as "eudemonism, or happiness" (Bradburn, 1969, p. 6). Nursing theorists have incorporated this concept into models of health, linking well-being to self realization (Smith, 1981). The goal of nursing interventions under this model would be to promote a child with JRA's happiness and self-actualization to the maximum. The nurse would work to help improve the child's capacity to reach the child's highest aspirations, physically, emotionally, spiritually, and socially, despite illness conditions and limitations.

Well-being or happiness in childhood is just beginning to be studied. Key variables from the world of childhood need to be identified and compared to key variables of the well-being concept for adults. Part 3 of this chapter will first look at the historical development of the adult concept of well-being, including nursing perspectives, followed by the concept of well-being as it applies to children.

**Historical Development of Concept**

Bradburn's (1969) work was undertaken to understand the psychological reactions of normal individuals to the
stresses and strains of everyday life. He was able to demonstrate that reliable and valid self report measures of well-being or happiness could be constructed, at a time when many psychologists distrusted self reports. Campbell (1981) then expanded on Bradburn's foundation and studied subjective well-being and life satisfaction. Together this work has provided a foundation for nursing theorists in their efforts to define health.

In 1969, Bradburn developed an empirically based model of psychological well-being from a large, randomized panel study consisting of four waves of interviews (1963-1964) with the same adults, selected from six communities that were likely to experience some major change. His correlational results indicated that a person's psychological well-being was a result of the person's position on two independent dimensions, one of positive affect and one of negative affect. The best predictor of psychological well-being was the discrepancy between the two scores, e.g., a person high in psychological well-being has an excess of positive affect over negative affect.

Positive affect "concerns the degree to which an individual is involved in the environment around him, social contact, and active interest in the world. These factors include such things as degree of social participation, which is reflected in organizational membership, number of
friends, frequency of sociability and companionship with one's spouse; and exposures to life situations that introduce a degree of variability into one's life experiences" (p. 13). Positive Affect was measured by subjects reporting feeling excited or interested in something, proud, pleased about an accomplishment, "on top of the world", or that "things are going your way" in the last few weeks.

Negative affect was measured by feelings of restlessness, loneliness, boredom, depressed, very unhappy, or upset by someone's criticism in the last few weeks. From these definitions it is clear that well-being is more than just the affective feeling of happiness, but rather the balance of a variety of feelings. The argument could be made that happiness specified by Bradburn is associated with variables tapping "social well being", providing evidence of the link between friendship and psychological well-being, but leaving causal mechanisms unspecified.

The positive and negative affective states were found to be essentially independent of each other. In a given week people may experience many different emotions, both positive and negative, but not necessarily in relation to each other. People also differ on the number of feelings they report. Both the group with high numbers of reported feelings and
the group who reported low numbers of feelings, have similar distributions of self reports on happiness.

Several factors were associated with greater happiness or increased positive affect: income, status, education and novelty. These relationships were stronger with positive affect than for negative affect, indicating "money may enable one to increase his joys, but cannot decrease his sorrows" (Bradburn, 1969, p. 227). A consistent empirical finding in sociology is a positive correlation between socioeconomic status (SES) and social participation. Again those with money or higher education would be more likely to travel, do different things, and have a chance to meet new people. This would facilitate the kinds of experiences associated with higher positive affect. Bradburn went on to discuss the possible importance of novelty in generating positive affect, especially for people in poverty, where restricted and hostile social environments cannot be avoided because of marginal incomes. He was careful to point out that causality may work equally well in the opposite direction, as his results didn't show concomitant variation between positive affect and social participation over time. For example, items that showed the highest correlation with positive affect were: made new friends, met new people, and traveled farther distance, suggesting the novelty of experience is important. Items reflecting sociability
(getting together with friends, chatting on telephone, being in touch with relatives) had a lower correlation with positive affect.

Another possible explanation for the failure to find a larger increase of positive affect with an increase in social participation is suggested by the close relationship literature. While this may be true during initial phases of friendship formation, after six weeks or so ambivalence and conflict appear (Hays, 1985). The costs and benefits of continuing the relationship are then more apparent.

Factors associated with negative affect included poor health and anxiety. A worry index was used to determine what different areas people had worried about in the last few weeks and the intensity of these worries in general. Physical symptoms experienced in the last few weeks were measured along with psychological anxiety (nervousness, trouble sleeping, not having enough energy to do projects). A fifth general indicator of past psychological problems was the "Have you ever felt you were going to have a nervous breakdown in life?". Each of these indicators showed a strong positive association with negative affect and essentially zero association with positive affect. Data also indicated one consequence of long term mental problems is that there is a relatively high degree of negative affect experienced for a considerable time.
Physical health was a prime source of worry. People who reported long standing illness which required them to restrict their activities, had moderate associations with high and fairly stable levels of negative affect, and nearly zero associations with positive affect. Anxiety and physical symptoms related to reports of negative affect regardless of whether the subject was ill or not, being in fact stronger among the healthy. Bradburn's formulations were important in the process of defining mental health as more than just the absence of physical symptoms.

In 1981 Campbell reported the results of a national survey between 1957 and 1978 measuring happiness and life satisfaction. First, Campbell asked individuals in four large national probability samples: "Taking all things together, how would you say things are these days - would you say you are happy, pretty happy, or not too happy?" This question measured subjective well-being. He also gathered information on objective indicators of well-being as he looked at the conditions people live in. He measured subjects' satisfaction with the following domains of life: marriage, family and friends, standard of living, work, community (neighborhood, nation, and housing) health, education, the self as a person.

Like Bradburn (1969), Campbell (1981) measured affect in terms of positive and negative feeling states that may
fluctuate from day to day. Satisfaction was described as a more stable quality of experience, an act of judgment, a comparison of what people have to what they feel they deserve. If the discrepancy was small they were satisfied. Campbell considered strain to be an aspect of negative affect and what people experienced when confronting problems of daily life. Strain was measured by symptoms of anxiety, feelings of being tied down, feeling that life is hard, worry about money, or fear of having a nervous breakdown.

Scores of affect, satisfaction and strain were kept separate to give a better picture of how people describe their lives.

Campbell (1981) assumed life satisfaction could be measured with a simple additive process, the more domains a person felt positive about, the stronger the sense of life satisfaction. Domains varied in value with age. For example older people valued health to a greater extent than the young. Domains tended to cluster: satisfaction with family life was associated with satisfaction with marriage and friendships. Satisfaction with health was not related to any other clusters. Satisfaction with self, standard of living, family life, marriage, friends and work had the greatest influence on level of satisfaction in general.

He concluded that well-being is a complex experience containing affective feelings of happiness and misery,
strain and cognitive impressions of satisfaction and dissatisfaction.

The greatest difference in degree of well-being was not between people of different income, education, or occupational status, but between patterns of social relationships. He noted pockets of people in the general population who were predisposed to unusual heights or depths of well-being. For example groups reporting high levels of well-being included young married women without children and men living in the "empty nest". The groups reporting the lowest well-being included those who were: unemployed, separated, divorced, unmarried mothers, socially isolated, physically disabled, or low income African Americans (all reported low positive affect, low satisfaction with life, high strain). With the possible exception of low income African Americans, these results support the notion that social support, including friendships, is important in maintaining a positive sense of well-being.

Nursing Perspectives of Well-Being

The construct of well-being is not clearly defined in nursing literature. Concepts of health, health promotion, wellness, well-being, quality of life, health related quality of life, and life satisfaction are often used interchangeably. Nursing theorists have struggled with a
variety of definitions of health, as health is a metaparadigm concept in nursing.

An attempt to resolve these multiple views of health was made by Smith (1981) who found four models of health used in nursing: (1) eudemonistic, (2) adaptive, (3) role performance, and (4) clinical. The eudemonistic model is the only model to link "the idea of health to general well-being and self realization." (p. 44). In this model, health is viewed as the condition of actualization, the ideal of persons to measure up to their wisest and best aspirations. Illness is seen as a condition that impedes self actualization. Extreme end points on this continuum model of health include "exuberant well-being" versus "languishing debility" (p. 45). This description portrays health as sort of a static point on a line. Nurse theorists have since been moving in a direction of describing health as a process including patterns and rhythms in human interactions.

In conclusion, one of the general goals of nursing research is to identify and study variables concerned with the human response to illness (ANA, 1980). Thus it is of great importance to identify variables that enable children to maintain a positive sense of well-being despite illness conditions. The grounded theory process is useful in doing this.
Definitions of well-being as developed by Bradburn (1969) and Campbell (1981) are helpful to nurses trying to model the link between the concepts of social support and health. One major difficulty is trying to keep variables conceptually and operationally distinct. For example the World Health Organization (WHO) defines health "as a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (WHO, 1948,). Social well-being may refer to the person's social or economic environment, or social interaction and integration (Patrick & Erickson, 1993). Therefore the presence of supportive friends may be viewed as an indicator of health as well as an indicator of social support. In this study subjective psychological well-being or happiness of the child was studied as an outcome variable.

Children's Well-Being

Children's well-being is just beginning to be studied. No studies were found involving school age children and well-being at this time. One study was available concerning predictors of emotional well-being in adolescents, with and without chronic illness. This was a large study by Wolman, Resnick, Harris, and Blum (1994), where chronically ill adolescents were found to have significantly lower emotional Well-being scores than healthy adolescents. Using the Adolescent Health Survey, 1683 students (grades 7 through
with a variety of chronic conditions (including C.P. or M.S., \( n = 90 \); arthritis, \( n = 129 \); scoliosis, \( n = 134 \); diabetes, \( n = 188 \); asthma, \( n = 789 \); and seizure disorders, \( n = 291 \)) were compared with 1650 students without chronic conditions with regard to emotional well-being, worries and concerns, and body image.

Results indicated that adolescents with chronic illnesses had lower emotional well-being scores, worried more about dying soon, school, future work, peer relationships, and had poor body images. The best predictors of emotional well-being were body image (\( R^2 = 0.18 \)), family connectedness (\( R^2 \) change = 0.10), concern about school and future work (\( R^2 \) change = 0.04), chronic condition (\( R^2 \) change = 0.02), and worry about peer relationships (\( R^2 \) change = 0.01). The final model accounted for 36% of the variance in emotional well-being of adolescents with and without chronic conditions.

A higher percentage of adolescents with chronic illness perceived their family connectedness as low. Students who perceived their family connectedness as high obtained significantly higher emotional well-being scores. There were no significant differences between students with visible (\( n = 371 \)) and invisible (\( n = 1312 \)) conditions, the visibility scale used may need revision.
Although teens with chronic illness did less well on these psychological outcomes (emotional well being, worries and concerns, and body image), it should be noted that a chronic condition was fourth in the list of variables in predicting emotional well being. More important predictors were body image, family connectedness, and concern about future school and work. This research also found adolescents with a chronic illness to be more concerned with peer relationships than healthy teens. These factors may or may not apply to school age children.

Activity may be a key variable for the development of subjective well-being in school age children. Activity can be defined as "the pattern of movement in relation to time and space, characterized by change, energy, and purpose" (Redecker & Mason, 1994, p. 283). Activity theories suggested that happiness is a by-product of certain human activities, including social interaction, exercise, and hobbies (Diener, 1984). Flow theory (Csikszentimihalyi, 1975) suggested activities are pleasurable when matched to a person's skill level. For example, if an activity is too easy, a person becomes bored. If the activity is too difficult, feelings of anxiety result. However if the activity demands intense concentration and the person's skills and task difficulty is roughly equal, then the person experiences a pleasurable flow or happiness. For children,
play activity with close friends may be a major mechanism by which well-being is influenced.

Gail Kieckhefer's (1988) study of 9, 10, and 11 year old children with asthma suggested the importance of activity in understanding how school age children view health. A sample of 71 children were briefly interviewed about their views of health. Forty-six percent of the responses described health as the ability to be more active than usual, that is being able to run, jump, and play better than usual. Twenty seven percent of responses described feeling good, happy or joyful. Only nine percent of responses discussed health in terms of the absence of asthmatic signs and symptoms, and five percent of the responses discussed health in terms of absence of general illness symptoms. Common categories used by children to determine health included the presence of: physical/functional ability (99%), affective attributes (84%), normalcy (25%), uncertainty (10%), social affirmation (1%), and appearance (0%). Health was also determined by the absence of: physical/functional limitations (8%), affective attributes (18%), asthma specific symptoms (40%), and general symptoms (20%). Categories used to determine non-health were the presence of: physical/functional limitations (82%), affective attributes (76%), asthma symptoms (53%), general symptoms (50%), difference (11%), social affirmation
(6%), and uncertainty (6%). Non-health was also determined by the absence of: physical/functional abilities (47%) and affective attributes (3%). These data clearly show the importance of physical activity, affective feelings and normalcy to children with chronic illness. Although the absence of asthmatic symptoms was incorporated, the presence of positive qualities predominated. Kieckhefer suggested that the ability to be active may be "a universal reflection of health regardless of culture or illness" (p. 331). If happiness is taken as an indicator of well-being this data also suggested that activity be an important element in life satisfaction.

The importance of activity to children is also documented in the studies on children coping with stress. Atkins (1991) reviewed 14 studies conducted between 1979-1989 concerning 8 to 12 year old children's perspectives of stress and coping. The most common stressors were fear of negative evaluations (adult or peer), parental conflict or loss, or conflict with an adult. The most common coping mechanisms included "social support", physical activities and avoidance.

Loss of activity or immobility, has major consequences for people of any age. In general, "Inability to move can result in decrease self esteem, decreased sense of well-being and powerlessness" (Redeker & Mason, 1994, p. 285).
Florence Blake (1969) used her own observations and psychoanalytic theory to explain the initial impact of immobility upon hospitalized school aged children and adolescents. She described children suddenly immobilized as feeling frustrated with the immobilization sometimes perceived as a punishment. School age children with concrete thinking styles generally focused on their current needs for pleasure and growing up. Since they often used motor activity rather than verbal activity to express their feelings, the effort to maintain control over their angry feelings was difficult. Without understanding from the hospital staff, children would fall back on energy consuming defenses such as prolonged regression, denial, and depression. When anger was released by acting out or verbal outbursts, a loss of self-esteem could result. The importance of being free to play was stressed by Blake (1969), as a safe way for children cope with strong feelings.

In some cases the absence of friends while hospitalized added to their frustration of not being able to master natural developmental tasks and obtain the kind of stimulation they needed to prevent boredom. Conversely it was also difficult to obtain needed solitude in the hospital, especially when a child experienced changes in body image. Feeling of helplessness, fear of bodily injury,
grief, guilt, despair, hopelessness, and unworthiness of pleasure have also been observed (Blake, 1969).

Children's well-being may be thought of as similar to adults, in the sense that they experience happiness when they are active and healthy. Chronic illness has been shown to reduce adolescents' emotional well-being. Several factors have been identified that effect well-being for adolescents: body image, family connectedness, concern about future school or work, chronic condition, and worry about peer relationships (Wolman et al., 1994). Whether these same factors predict well-being in a school age population remains to be tested. The importance of being physically active is suggested as a possible factor for well-being with younger children.

Summary of Well-Being

Well-being is defined from work with adults, as a complex experience containing affective feeling of happiness and misery, strain, and cognitive impressions of satisfaction and dissatisfaction with important domains of life. For adults these domains include: close relationships (marriage, family, friends), standard of living, work, community, health, education and self as a person (Campbell, 1981). Key affective experiences of well-being for school aged might include feeling good, happy, and joyful. Important domains of life related to a child's ability
include: family and friend relationships, home and neighborhoods, health - especially in terms of the ability to be active and to experience novelty, school, and self as a person. Negative affective experiences of well-being for school aged children include illness symptoms, changes in body image, feeling of worry, boredom, loneliness, depression, rejection, and fears of early death. Socioeconomic status of the family is an important background variable to consider. Higher income parents would have more resources to help in meeting a child's social needs. For school aged the social support of companionship, the being together and playing with good friends, may be critical to their development of a positive sense of well-being.

This study was designed to develop a model that describes how friends help children with JRA feel happy. JRA is a chronic, yet unpredictable disease that can immobilize children slowly as more and more joints are damaged, or suddenly with the onset of a flare. The concepts that were important to the children in the process of maintaining their sense of well-being were identified in this grounded theory. This study provides a qualitative look at how social support in the form of friendship is important to children's well-being.
Part Four: Childhood Friendships in the Context of Chronic Illness

This chapter so far has discussed concepts of childhood friendships, loneliness, and well-being from a very academic perspective. Much of the data were quantitative in nature, and clues to the process by which childhood friendships work to maintain well-being remain elusive. This section of Chapter Two focuses on available qualitative data that may aid in the identification of friendship processes at work. Friendships were important to children with mental health problems, cancer, diabetes, asthma, and JRA. Companionship was frequently mentioned as an important function of the social support they provided. These illnesses provide a range of visibility. This is appropriate because visibility of childhood JRA symptomatology varies as well.

Mental Health

Goodyer (1990) makes the case that events need not be bizarre or catastrophic to be of etiological importance in psychopathology. Whether an event is "good" or "bad" depends on the social context of the event and personal characteristics of the child. Goodyer (1990) describes how friendships may buffer or protect children against stressful events.

Goodyer (1990) suggested that good peer relationships are necessary for healthy mental development by increasing
self esteem, instrumental skills, and emotional ties with older children. When he studied 100 children at a mental health clinic and matched controls in the community, he was able to confirm a significant association in school age children between emotional disorder and presence of poor to moderate friendships prior to the onset of the disorder. Friendships were rated on a three point scale concerning availability, adequacy, and intimacy by mothers and children aged 8 through 16. Agreement between mother and child was good. Poor friendships were extremely uncommon in the community control group, 2%, versus 14% of the children with diagnosed mental health problems. Moderate friendships were found for only 14% of the control group and 25% of the diagnosed children. However friendship deficits do not occur in all emotional disorders. Fifty two percent of the diagnosed children did not report them.

Cancer

The psychosocial adjustment of children with cancer and those surviving cancer has also been the focus of nurses concern since the mid 1980's. Although a cancer diagnosis is considered more life threatening than JRA, these qualitative studies also demonstrate the importance of friends in the life of a child with chronic illness.

Aamodt (1988) completed an ethnographic study involving 15 children aged 4 through 17 with cancer. In this study 28
domains of meaning emerged, in which "friends were ever present" (p. 120). "Friends will pull you through" was the title of one domain identified under Self Care Strategies. Friends act as cheerleaders especially in times of relapse. Friends help children persevere with chemotherapy and keep them from giving up. Friends invite you over, come over, and know what to expect in terms of the effect of treatment on a child. Friends would talk about being afraid of dying and would convince each other "it's ok" to die and that "it would be better" than living in a world "full of danger and no more treatments".

Children with cancer watched friends go through remissions, relapses and death, sometimes losing several friends (p. 129). These were some of the most intense moments of the children's lives. They smiled and had parties to celebrate their remissions. They cried and were angry to find their friends relapsing and to see the people die who had helped them. They wondered "Will this happen to me too?" Children reported continuing to talk to their friends who had died. One child reported it was helpful to follow a counselor's suggestion and pretend to talk with a friend who had died so suddenly they didn't have time to say goodbye.

Haase (1994) conducted a phenomenological study concerning seven children aged 5 to 17 who survived cancer. Six major theme categories were identified in the data that
described the process the children went through when their cancer treatment was completed. First there was a gradual realization of completion. All of the children were able to share with the researcher a story about "finding out" when their treatment was ending, although some were not told until the last treatment was over. They usually shared the news with family and friends, and usually had some sort of celebration.

Secondly, the children experienced hierarchial and cyclical recurring fears, not of dying from the cancer, but of having to go through the treatment again with its terrible side effects. Children made deliberate decisions about when to worry and when to block discussions about reoccurrence. They were reluctant to talk about these fears with their school friends. Talking about cancer returning was associated with the possibility it might come true (magical thinking).

The third theme was that completion was embedded within the entire cancer experience. Like war veterans, they experienced "triggers" that reminded them of their ordeal, and they could recount vivid details of their treatment processes. Triggers might be catheter scars, stomach aches or "treats" if used during therapy. They described an increase in vigilance, being afraid to be exposed to sick people even when their blood counts were okay. They
described the social effects of the cancer experience in terms of being separated from other children as lost time that could never be replaced as well as boredom from missing friends.

Friends also played a role as the child began to seek signs of normalcy, as part of the fourth theme: seeking a new normal. During this time friends could come over again. Children generally looked forward to returning to school. They were nervous in terms of how the children at school would react. Peer acceptance was critical. Friends helped the child redefine a new normal by accepting limitations the child had. For example a boy with an above the knee amputation said "my friends just treat me like I was my old self, but they know I can't do certain things like run" (p. 12). The school kept his classmates constantly apprised of his condition and bused the class to see him at home after the amputation. This made his return to school somewhat easier.

The fifth theme, modifying relationships, included changes in the children's friendships when treatment ended. For example they found out who their good friends were, whether pre-illness friends or new friends who had cancer as well. Good friends knew all about the treatments and cancer experience. They avoided cruel comments and came to the rescue when others teased. Good friends had a broad non-
illness perspective and adjusted their own activities to meet the child's needs. Again these children experienced grief if their friend did not respond to treatments and died.

The final theme category, resolution and moving on, was marked by the children feeling a sense of hope and a "Transcendence of their situation that allowed them to extend themselves personally and to others" (p. 15). They were able to make plans again for their future and decide how they were going to help others.

Diabetes

LaGreca (1992) found in her interview with 74 teenagers with diabetes, that although most support came from family members over three aspects of care (insulin shots, glucose testing, meals), friends were equally important as family members in encouraging exercise by providing companionship during activities. Friends were also more effective than family members in providing support for "feeling good about having diabetes" (p. 779). Friends provided important emotional support by accepting special health needs and being sensitive to them. For example friends would avoid tempting them with "forbidden foods", help adjust peer activities around the timing of meals, or selecting "fast foods" that fit the diabetic meal plan. Friends also provided limited tangible support, mainly in reminders to
take insulin, or helping treat reactions. LaGrecca (1992) suggested that children with limited friendships could be missing a significant source of support for diabetes care, and that friendships could promote adjustment to chronic illness and quality of life.

Asthma

Kintner (1994) studied six adolescents with asthma to identify the essential structure of the process of coming to accept asthma as an ongoing part of life. Friends played important roles in helping the children feel connected to the illness, family, friends, and others with similar experiences, rather than feeling different and alone. Best friends were accepting and understanding. They asked questions and recognized symptoms. They suggested strategies to maintain optimal control over the asthma effects. Friends also stayed with them when they couldn't breathe. Participants were interested in reaching out to other children with asthma, and talking to them about what they knew.

Preliminary Studies of JRA

An ethnographic pilot study was conducted to provide insight into the world of the child with JRA from the child's point of view (Steinke, 1989). Special attention was paid to their friendships, and these data regarding their friendships were compared with previously collected
ethnographic data from a group of healthy school age children. Spradley's (1979) method of ethnographic research was used to analyze the content of the series of two to three one hour taped interviews. Three children aged 10 to 12 with varying degrees of JRA participated.

The three children interviewed (Mary, Ruthie, and John) varied in the severity of the arthritis they suffered. For the girls, the arthritis was in all the joints, and for John, it was mainly in the knees, ankles, back, right thumb, and neck. Ruthie was so active that she was able to play competitive soccer on a winning team. Mary was confined to a wheelchair most of the day, but could walk with braces. John was not allowed by his doctor to participate in competitive team sport activities but could play sports at school and home. The children reported the arthritis symptoms were worse in the Fall, Winter, at nighttime, and when their friends weren't there to distract them. All were on daily medication involving aspirin therapy, usually three times a day, at breakfast, after school, and bedtime. Ruthie described being "programmed" to take her medicine as "beep, beep, into my brain". In general children liked taking higher dosages so they could avoid going to the school nurse which was a hassle because hall permits were needed and it was not something required of the other children. Only Mary was also on methotrexate and prednisone, and relied on her
mother to administer these medications at home. In general, mothers were depended on for reminders to take medicines and to bring medicines along during exacting events such as the Arthritis Awareness Day workshop.

All the children could describe specific things they did for arthritis pain, including using electric blankets at night, massage, watching TV while resting in bed, hot showers, heating pads, dressing warmly in winter, and going to the school nurse for a note to sit out gym class. Mary reported going with a friend of hers to the physically handicapped classroom at lunch and stretching out on a bean bag while she helped a fellow student with cerebral palsy write.

Flares are a period of time when the arthritis is very painful and active. Joints are swollen. Children may be completely immobilized. Medications are increased. Fever is present and the children tend to sleep a lot. During flares Mary usually missed one to two months of school and her mother stayed home full time to care for her. She described a flare as a time when "in the beginning it hurts really bad. I don't want to move or do, sometimes it gets very bad, I don't even want to eat". For Mary, a flare was a time she didn't necessarily want to see friends and didn't expect them to do things for her.
In contrast, Ruthie reported missing about two weeks of school because of the flu. She didn't experience any arthritis pain, even though she had to stop taking the aspirin because of nausea and vomiting. She reported her friends calling every day to talk about what happened in school and to give homework assignments.

One issue that was important to children with arthritis involved what to tell other children about the arthritis. Ruth described the first day of kindergarten as being critical in her development of friendships. "I was so small and skinny and they just didn't like me. But the most popular girl in kindergarten came up to me and said 'Hi' and I'm like 'Oh my gosh!'. And that's Sally and she's been my friend ever since. And I said 'I have juvenile rheumatoid arthritis'. And she says 'I don't care what you have' and so that's how it started".

All of the children felt their friends were able to understand about arthritis from their brief explanations. John reported an encounter where other children thought he was lucky because he had a special chair. "I don't think I am. I said 'You wouldn't like it either if you had this disease.'" An important characteristic of a friend was that they "just treat you like a normal person." As a consequence it was important that once they were told about JRA, they were given opportunities to forget it. However, all the
children were able to identify specific things their friends did for them when they couldn't do something because of the arthritis. For example, John described his friends as deliberately not doing things that he shouldn't be doing. And if his knees started to hurt, his better friends would offer to go in the house and play video games, draw, or watch movies so he could rest. Mary described her best friend helping her by pushing her around in the wheelchair. This didn't impress me as being important until I saw Mary being pushed by her friends at Arthritis Awareness Day. They pushed her at high speeds so she could keep up with the group of children roaming through the exhibits. She was laughing and smiling in the center of the group.

Two themes that related to friends were found in this study: "Treat Me Normal" and "Missing Out". The desire to be treated and seen as normal was very strong in this group of children. During the interviews this was illustrated in several ways. First the children never complained about having arthritis. If they hadn't been asked directly about it, the subject wouldn't have come up! Parents were evidently familiar with the nature of this thinking. One mother commented after my first interview she was surprised her son even mentioned arthritis. This was as her son and a friend were having a mock sword fight in their socks outside
after just finishing talking to me about his arthritis. She was trying to get them to come in as it was damp and cold.

The children had mixed reactions to being with other kids with arthritis. None of the children, even ones involved with the arthritis support group or camp, mentioned other children with arthritis as friends during the first interview. Only direct questions prompted mentions of encounters with other children with JRA. They never actually talked with each other about having arthritis, but made judgments upon how active and self confident each other were. They watched how much they "tried to be normal", that is, how hard they try to walk or swim. They expressed disappointment when a child with JRA chose to use a wheelchair instead of braces. Children stated meeting a person who was wheelchair bound could make you feel "lucky if you weren't". The children who were less acutely ill did not desire to talk with another child with more severe arthritis who would understand what they were going through.

The second theme, "Missing Out", that appeared in the data concerned the fear of being left out of things because of having JRA. This came up under several domains: things friends do that make you angry, things that are bad about having arthritis, and things teachers do that make you angry. For example, children felt it was better to stay in the gym and watch the rest of the team than be sent to the
nurse's office to rest. One of the reasons given for having other friends with arthritis was not that they would understood the physical pain, but they understood what it is like to miss out on things. Friends played an important role here by "being there" and "sticking up" for the child with JRA. For example one day John told about being in gym class and "we were doing races and I go 'Aw shucks, I didn't win that one.' and he goes 'You'll never win. You're so slow, you have arthritis.' And all the kids who were racing, I don't know, stuck up for me about it ... yeah, that made me feel good."

One painful experience for Mary was missing out on horseback riding at camp. Instead she was sent to run errands in with the camp director. Although she understood the reason for being left out because she had "arthritis in my neck and it's sort of bad if you go over big bumps", she did not want to go back to camp next year.

Summary

Friends were important in all five of these chronic illness populations. In the case of children with mental health problems, a significant association was found between the presence of poor to moderate friendships before the onset of the disorder and the emotional disorder itself, when a friendship deficit was reported (Goodyer, 1990).
For children suffering with cancer, close friends were an important source of emotional support, especially by supporting each other in the grief process for themselves and others. The emotional costs of having a friend with cancer die were especially heavy (Aamodt, 1988), as the children wondered if they would die next. Friends helped cancer survivors celebrate their recovery, but couldn't reassure them about their fears of reoccurrence. This may have been due to the children's fear of bringing the topic up, as the cancer might then return. Also as they tried to seek normalcy, discussions of illness with school friends would have been limited.

Good friends of children with cancer, diabetes, asthma, and JRA knew all about the specific illness experience. They provided companionship and emotional support. They were able to defend the child from negative peer comments, and were about to adjust their own activities to meet the child's needs (Haase, 1994; Kintner, 1994; LaGrecca, 1992; Steinke, 1989). Sometimes they provide tangible support in terms of specific treatments like diabetic reactions.

The desire to be "treated as normal" as possible was seen in the children with cancer, diabetes, and JRA. The fear of "missing out" was described in the cancer studies as well as the JRA.
These studies provide valuable insight into the ways friends help children with chronic illness. These findings related to friendship suggested that the process by which friendships aid a child is not illness specific. However it is not clear if all the key variables are identified and how they relate. By limiting the study to one chronic illness population, a first step taken in developing a midrange nursing theory that may be more broadly applicable.

Summary of Chapter Two

Chapter Two provides a broad look at literature that may relate to children who are experiencing JRA and their friends. In Part 1, much evidence is presented that suggests that close friendships are an important source of social support in childhood. The structure, function and nature of these friendships are explored with the primary function being companionship. Parents play an important role as well, especially in teaching social skills and providing access to friends. Part 2 reviews the loneliness literature as this is often a problem experienced by children with JRA. The lack of companionship may be temporary, or more serious if the child is rejected by peers. The concept of well-being was discussed in Part 3, as this variable seemed to closely match the school age children's definitions of health. Here the probable importance of activity and novelty as factors influencing childhood well-being was noted. Finally in Part
friendship information from specific illness populations was explored. In the qualitative work support was found for the helpfulness of good friends, and the desire of the child to as normal as possible.

What is clearly missing in Chapter Two are definitions of social support and well-being from the child's point of view. What elements of social support are perceived as important by children? What do childhood friendships provide that really matters to children with a chronic illness? To address these points a qualitative approach was taken to let the children guide the interviews allowing prolonged observation.

Secondly, a theory is missing that suggests how friendship processes might aid children in maintaining their sense of well-being, despite having a chronic illness. The grounded theory process was selected because it is useful in identifying key variables and their relationships.
CHAPTER THREE
METHOD

Chapter Three describes the method for the study, in two sections. The first section, Introduction to Grounded Theory, includes the definition and usefulness of grounded theory, as well as an overview of the grounded theory process. The second section, Procedures, includes discussions of theoretical sensitivity, the role of the researcher, the ongoing literature review, sampling, data collection, data analysis and the evaluation of the trustworthiness of the data.

Background on Grounded Theory

Grounded theory is a systematic inductive research strategy that can be used to generate explanatory theory directly from data concerning a social and psychological phenomenon, usually one which is relatively unexplored from specific cultural perspectives (Glaser & Strauss, 1967). For example, for nurses to understand how friends help children with JRA maintain their sense of well being, grounded theory can help identify core variables important to these children and the steps or stages of the process involved.

Usefulness of Grounded Theory Method

A qualitative approach is often used in areas of theory development where relationships between key variables are unknown, or the variables themselves are poorly defined. In
this case grounded theory would be appropriate as little work is available to nurses about how children experiencing illness define social support from friends or a sense of well-being. Very little specific information is available from the point of view of a child with arthritis. The Friendship processes used by children with JRA as they attempt to elicit social support and enhance their sense of well-being is a new area of investigation. Specific questions asked in this study are as follows: How do children with JRA create and maintain supportive friendships? How do children with JRA describe supportive behaviors of peers? How does being a child with JRA change the process of eliciting support from friends? How do children with JRA describe their sense of well-being? And finally how do children see their friends helping them maintain their sense of well-being? In order to answer such questions this investigator attempted to discover, identify, and describe the psychological and social processes used by children with JRA and their friends to maintain their sense of well-being.

The Grounded Theory Process

Grounded theory can be used to discover processes and patterns of social phenomena, such as how a child's interactions with friends help maintain the child's sense of well-being. The specific method involves a process of
comparative data analysis by which qualitative interviews are fragmented into data bits and labeled with all possible categorical names. Respective properties of each category are developed from the data, which offer information on the nature of each category. As category names are refined, the categories are assembled in an order that represents the child's picture of reality. Sometimes categories are referred to as a "slice of data" (Glaser & Strauss, 1967, p. 193).

Core categories emerge as central variables in the process under study. They tend to recur frequently in the data, and take more time to saturate because they are related to so many other categories. Glaser (1978) notes they have such "grab" that the researcher tends to see the core category in all relationships. Core categories can be a process, a condition, a consequence or a dimension. They are usually completely variable as to degree, dimensions and type, and account for the major variation in a pattern of behavior (Glaser, 1978).

When a basic social process (BSP) is discovered, it is usually processed out into stages that occur over time. The idea of change is built in, so that over time new conditions, stages and transitions may need to be added. Glaser (1978) describes two types of basic social processes: basic social psychological processes (BSPP) and basic social
structural processes (BSSP). A basic social structural process usually represents growth (or deterioration) and is often helpful in explaining why a researcher may be interested in studying the BSPP involved. For example, an increase in formal support groups for children with various chronic illnesses (BSPP) might facilitate the basic social psychological process of maintaining well-being.

Procedures

Glaser, Strauss and Corbin offer insight into the qualitative nature of grounded theory by describing the method as both systematic and flexible. The theory emerges from the data, and categories reflect the data and are not preconceived. The strategy is adaptive and creative. Since it is data driven it is important to understand that data bits, not individuals, are sampled. Data may come from a variety of sources including the ongoing literature review, newspaper, TV, books, and who ever is available in the situation to be observed, talked with, overheard and surveyed in order to gain multiple perspectives on the phenomenon. However, explicit coding and analytic procedures are followed, so that although one cannot guarantee two analysts would get the same result, the theory generated is clear enough to be tested quantitatively if desired (Glaser & Strauss, 1967). The grounded theory that emerges depends on the researcher's skill, fatigue, maturity, motivation,
and insight, or what Glaser (1978) describes as theoretical sensitivity. Strauss and Corbin (1990, p. 41) define theoretical sensitivity as the personal awareness of the researcher as to the subtleties of meaning in the data. A researcher can come to a situation with varying degrees of sensitivity depending on previous reading, work or life experience. Theoretical sensitivity refers to the researcher's capacity to give meaning to the data, to sort out pertinent data from that which isn't so that the theory produced is well grounded, conceptually dense and well integrated. The first step is to be open minded and to attempt to bracket previously held ideas, using several procedures. Finally the method of data collection and analysis, called the constant comparative method, allows for analyzing data sentence by sentence or fragment by fragment until all data is conceptualized into categories and is integrated into the theory. The process is really a set of double-back steps to insure the theory actually reflects the data.

The grounded theory process for this study is described in Table 3.1. The study was done in two phases, a preliminary phase, and the actual study phase which resulted in the grounded theory. During the preliminary phase, two small ethnographic studies were conducted, the first involved six well children and their friends, and the second
involved three children with JRA, two girls and one boy, who were in elementary school at the time. Outcomes of the preliminary study with well children noted the types of friends described by children, including best friends, good friends, neighborhood friends, church friends, half enemies, and enemies. Half enemies were children or siblings who could not be relied on to always be nice, and at times would hurt them intentionally. The physical presence of friends was very important to well school age children. The outcomes of the ethnographic study of children with JRA are discussed in Chapter Two.

Table 3.1 Timeline of Study

<table>
<thead>
<tr>
<th>Date</th>
<th>Preliminary Phase</th>
<th>Method</th>
<th>Setting</th>
<th>Key Findings</th>
</tr>
</thead>
</table>
| 1987 | Well children and their friendships (n=6) | Ethnographic | Homes | - Types of friends  
- Nurses are 1/2 enemy  
- Physical presence of friends very important |
| 1989 | Pilot of children with JRA and friends (n=3) | Ethnographic | Homes | - Friends important except during flares  
- "Treat me normal"  
- "Missing out"  
- "Friends can help" |
Table 3.1 Timeline of Study (continued)

<table>
<thead>
<tr>
<th>Date</th>
<th>Study Phase</th>
<th>Method</th>
<th>Purpose</th>
<th>Outcome</th>
</tr>
</thead>
</table>
2. Evaluate camp setting for in depth interviews.  
3. Observe friendships in natural setting.  
4. Identify key informants. | 1. Met all children.  
2. Too hot, noisy and busy. Hard to concentrate outside.  
3. Field notes and descriptions of camp life and interactions.  
Selected 3 school-age girls with JRA and their families. No boy available in that age group. |
| Fall 1995  | In depth home visits (n=12) | Open ended interviews and observations | 1. To conduct in depth interviews about childhood friendships with child, best friend.  
2. Observe child in family setting.  
3. Identify preliminary concepts. | 1. Data gathered.  
2. Some observations of friendship (B.F) interactions.  
3. Preliminary concepts identified. |
2. To observe group discussions.  
3. To identify adults for validation.  
4. Develop theory. | 1. Field notes--friendships.  
2. Pacing, blending reactions to JRA.  
3. Two adults volunteer who have JRA since childhood. Basic Social Psychological Process of Keeping Up identified |
| Summer 1996 | Data analysis after camp continues | | |
| Fall 1998 | Validation visits (n=9) | Present theory/discussion to children and families in study | 1. Report findings to children and families.  
2. Elicit feedback on theory.  
3. Follow up on child friendships | 1. Closure of study.  
2. Validation, feedback obtained.  
3. 2 of 3 friendships continue. |
| Winter 1998 | Validation using adults who had JRA (n=2) | Present theory and discuss results with 2 adults who have grown up with JRA | 1. Present theory to adults with JRA.  
2. Elicit feedback. | 1. Validation by adults with JRA.  
2. Feedback obtained. |
There were five steps of data collection in the study phase, with data analysis following each step. The first step involved semistructured interviews with the children at Arthritis Camp (1995), which were followed later in step 2, with in-depth open interviews with three children with JRA, their best friends, and the mothers of both. This step is referred to as the Home interviews. In step 3, field observations of the children were again made at Arthritis Camp (1996). During this Summer the BSPP of Keeping Up was identified. Step 4, in Winter 1998, involved returning to the nine study informants for validation visits. The theory was presented and discussed with each. Finally in step 5, also in the Winter of 1998, validation visits were conducted with two adults who had experienced JRA. The validation interviews provided additional information as to credibility of the grounded theory.

**Theoretical Sensitivity**

Theoretical sensitivity, the personal awareness of the researcher to subtleties of meaning in the data (Strauss & Corbin, 1990) can also be thought of as an issue of reactivity in qualitative research (Paterson, 1994). Reactivity can be defined "as the response to the researcher and the research participants to each other during the research process" (p. 302). This definition stresses the interactional nature of the process. Qualitative researchers
have to be willing and able to reflect about their own beliefs and values, attitudes, behavior, and past experience in order to identify how the researcher's subjectivity has influenced the study. A variety of methods is available, with grounded theorists using a memoing process to document their reactions, thoughts, and feelings for later review. Paterson (1994) suggests a framework of five central themes to begin to identify sources of reactivity in qualitative research. These include: emotional valence, or the feeling tone of the interaction; distribution of power among participants; the goal of the interaction; the importance of the interaction; and cultural standards of the participants involved.

**Emotional Valence**

The first theme is emotional valence or the feeling tone of the interaction. This usually depends on the level of trust established between the researcher and participant. This trust in a stranger develops over time.

To increase the participants and families sense of trust I met the parents before the children left for camp at the arthritis foundation. I spoke to each set individually and explained the study. All families gave permission for their children to participate if they so desired. I then went to camp myself for two summers where I observed the children and helped out the adults as "an extra set of
hands". Then, during the first summer I interviewed all the children at camp except those who did not wish to participate. Children who chose not to participate were the camp nurse's daughter, although her mother tried to encourage her, and another girl who didn't want to miss out on camp activities. Because of concern for the children missing out on camp activities, the second year I did not interview at camp. Instead, the camp interviews from Summer I were followed with home interviews after Summer II. Three of the most verbal and friendly girls appeared comfortable and happy to meet with me again. It was harder during the first interview for their best friends who did not know me. For the second phase of interviews, I always talked to the parent and child together first to explain the study and have the children decide where the interview would take place. The children primarily chose their room for the setting, and the mother's interviews were primarily done in the living room or kitchen. One family wished to do the interviews at the child's grade school as the mother worked there as well.

The interviews were audio-taped and the tape recorder was somewhat intimidating for some of the participants. We solved this by covering it with a piece of paper or moving it to a less obvious location. At times it was turned off
and we just talked. This was usually at the end of the interview and I made notes later.

Distribution of Power

The distribution of power is the second theme Paterson considers, noting for adults power distribution is usually associated with roles. People in less powerful positions may desire to earn the researcher's approval. Clearly children may realistically consider themselves less powerful than an adult researcher and may alter their initial behavior and responses. This is usually short lived in qualitative research because of the prolonged engagement at the site. Participants may consider one an insider or an outsider - clearly children may see an adult as an outsider to their social world. This was most clearly evident at camp. After lunch the children would rest in their rooms for an hour or so and play quietly. I felt that I was kind of inhibiting the interaction when I tried to watch or be with them. After a while I only went to their rooms if someone invited me. Another problem the adult researcher may experience is feeling like an "insider" because of having experienced childhood already. This is also referred to as adult ethnocentrism by Spradley (1979) and can lead the researcher to overlook certain data, or impose one's own definitions on the child. Fine (1988) suggests taking on the role of a
friend to the participants. This seemed to be helpful in small play groups.

Goal of the Interaction

The goal of the interaction may not be clear at times for either or both of the participants. Sometimes research and therapeutic goals are confused and participants may view the researcher as a counselor, giving comfort and guidance. For children this is certainly an ethical issue, with children relying on the adult researcher for role clarification. I tried to be empathetic, but at times it was difficult not to intervene. Usually I just gave an experience from my own childhood. These disclosures seemed to improve rapport.

Keeping the focus on friendships meant not asking questions about family relationships. This sometimes was confusing as children would often view a sibling as a best friend if they played a lot together. Sometimes siblings shared best friends with the subject and they played together as a group. One mother wondered why I didn't ask her daughter about her relationship with herself, as they did so much together that at times the mother thought of herself as her daughter's best friend.

Importance of Interaction

Importance of the interaction is the fourth theme Paterson considers. Clearly when a researcher is fatigued,
bored, or ill, one may convey this disinterest to the child. Children themselves have limited attentions spans, and all interviews should be kept short (less than 1 hour). Special strategies such as going to a private place to talk can help. This was very difficult at camp. Often we talked outside where it was difficult to be comfortable because of the heat.

The camp interviews were difficult to arrange so that the child would not miss out on any key camp activity. I did most of the interviews during the quiet period after lunch, but this really was valuable time for the children to play and make friends in a relatively unsupervised situation where only teenage counselors were present.

**Cultural Standards**

Normative or cultural standards of behavior are directed toward the persons involved in the data collection. The researcher's sensitivity towards a child's comfort level with questions is important. For example, most of the children found it easy to talk about what they liked about their friends, and much more difficult to discuss the bad times.

Using Paterson's framework to evaluate possible sources of reactivity in memos can be a first step in documentation. Keeping a daily personal journal of each encounter is an important second step. The researcher is really asking
herself how each of these themes influenced the data collection. The results may indicate the need for another sample to check out the researcher's analysis or change data collection practices (Morse, 1991).

The Role of the Researcher

In qualitative inquiry the researcher can be viewed as the instrument of data collection, an adaptive, sensitive human data gathering device (Rew, Bechtel & Brown, 1993). However unlike a real machine, the human machine cannot fulfill the research objectives without incorporating previous experiences and tacit knowledge. Secondly unlike a machine, human researchers require careful self pacing to maintain their creativity and productivity (Glaser & Strauss, 1967).

Researcher's Background

In reference to this study, the researcher's background includes both experience in child health nursing and personal knowledge about children. At the beginning of data collection my children were in first grade, kindergarten, and a toddler. Classroom and play group observations of my children helped sensitize me to the responses of informants. For example, questions could be formulated in relation to the normal routines in school. An ethnographic study with well children was very helpful in learning how older school age children view their friends. The pilot study with
children with JRA was helpful in identifying friendship issues of concern to the ill children, however the pilot study was limited in scope. For example I had not talked with a child who was actively experiencing a flare, or to the parents of children with JRA. Doing so helped expand my understanding of the effects of JRA, as I am not a parent of a child with JRA, nor have I had arthritis as a child.

Self Pacing

In terms of self pacing, Glaser (1978) recommends doing other work or projects and deliberately planning time for recreation. He suggests collecting data, coding and analyzing for 2 to 4 hours a day, with the goal of writing all memos before theoretical ideas are forgotten or lost by talking with others. Again each researcher has to work out his or her "recipe". Glaser notes that it is helpful if the research is focused on issues relating to life cycle interests of the researcher, so that an interest level can be maintained. For myself, I found that going to summer school full time allowed me to focus on the study, while hiring a full time person to replace me at home. During the year my own children's health needs and school demands make it difficult to obtain regular blocks of time. I also kept field notes of camp experiences on a daily basis. These were somewhat limited by my inability to take notes during group discussions. I thought the children would be upset by the
intrusiveness of it. I found the week at camp both fun and exhausting, as I drove back and forth (140 mile round trip every day). Also, the first year the entire camp was held outside, with no air conditioning. On one of the last days my own family came to the parent dinner, and the camp children were able to meet and play with them. This was fun for my children who were wondering where I was going everyday, and seemed to give some credibility to the camp children, that I was a mother of young children like them.

Ongoing Literature Review

Glaser (1978) suggests data be collected and the theory generated before turning to the literature in the same field during the saturation phase. This is one way to limit preconceived ideas from entering the theory generation stage. In this case it was necessary to review the theoretical context of the study from the beginning. This does result in increased awareness of the theoretical context of the study in the researcher. However it was difficult to sort through so much literature in the related areas of social support, friendship, loneliness, intimacy, chronic illness for children. One basic reason for doing grounded theory was to identify the salient variables to the children in this specific situation. Also much of the work has been empirical rather than theoretical in nature. Finally the notion of "bracketing" adapted from
phenomenology, or partitioning off previous theoretical knowledge can be useful while the basic theory is being generated. Once fairly established from the data, the specific research literature may be integrated into the study findings. There may be certain literature that should be considered data from the beginning. This would include writings by children with arthritis and stories or novels about them. In terms of more formal theory development it may also be helpful to consider other data from other qualitative work that elicited information on children with a chronic illness and their friends (Aamodt, 1988).

Sampling

Purposeful theoretical sampling is done to discover categories and their properties and to suggest the interrelationships in the theory (Glaser & Strauss, 1967). Sampling decisions are not preconceived, but are based on the researcher's efforts to saturate the categories, properties, and interrelationships. First, informants are selected who are articulate and have typical experiences with the phenomenon under study. Secondly, the researcher selects people with atypical experiences in order to obtain data on a complete range of phenomena (Morse, 1991).

In regards to this study a volunteer sample was obtained from the local arthritis foundation. An effort was be made to find English speaking children aged 6 through 12,
who had a range of experiences with arthritis. Parents were first contacted by the researcher in person the morning the children were dropped off for camp at the Arthritis Foundation. The study was briefly described and consent forms were signed by interested families. This allowed the researcher to interview 12 children at Arthritis Camp. From this group the researcher was able to get to know the children in terms of their willingness to talk about their experiences with JRA and their friendships. After camp three families were contacted by phone in order to determine their interest in participating in home interviews. If the mother and child expressed interest the initial home interview was scheduled.

At the home, interviews were done with parents to explain the study further and to assess the health of the child. Questions included the length of time since diagnosis, the type of JRA, the medications the child was on, school attendance and grade level, and level of activity (ambulatory, wheelchair, bed). Parents also discussed the impact of JRA on the family.

Permission was sought to speak with the best friend of the child with JRA because friendships are interactional and are often not viewed identically. This was only attempted if the child with JRA initially identified a best friend and felt it would not negatively impact on their relationship.
Parents were asked to contact the parents of the best friend to see if they would be interested in being in the study. This worked well because the families involved knew each other fairly well, and the children saw each other frequently. The mother of the child with JRA then called me to let me know the best friend's phone number. Both the mother and daughter of the best friend were interviewed after the interviews with the children with JRA were completed.

Permission was also sought to attend arthritis camp for two consecutive summers in order to observe the children and their interactions with camp friends.

Data Collection

Data collection took place among sixteen children who live in southern Arizona and attended Arthritis Camp 1995. Parents were given a brief description of the study as the children were dropped off at the Arthritis Foundation to be taken to camp. Parents signed consent forms at this time. Children signed assent forms at the time of the camp interview. The researcher read the form to the younger children. Sample copies of the forms are located in Appendix B.

Of the initial group, only five girls were school age, between six and twelve years of age, with JRA (See Table 3.2). Twelve of the original sixteen children were
interviewed at camp (See Table 3.3). Four refused for a variety of reasons (See Table 3.4). One was later dropped from the study because her parent did not return a consent form. The camp interviews took place where ever the child felt comfortable and it was quiet. These interviews were guided (semistructured) in nature and provided a way to assess the children's ability and willingness to communicate their thoughts. Sample questions are listed in Appendix C. By talking with the teenagers the researcher was able to identify a range of issues that may be of concern to the school age children in the future, as well as gain a basic understanding of what effects mobility restrictions have on boys.
<table>
<thead>
<tr>
<th>Subject</th>
<th>Sex</th>
<th>Age</th>
<th>Grade</th>
<th>Dx</th>
<th>Family</th>
<th>Number of Siblings</th>
<th>Family Income</th>
<th>Ethnic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dave</td>
<td>M</td>
<td>13</td>
<td>8</td>
<td>JRA</td>
<td>Yes</td>
<td>3</td>
<td>20-30</td>
<td>W</td>
</tr>
<tr>
<td>Bridget</td>
<td>F</td>
<td>11</td>
<td>5</td>
<td>JRA</td>
<td>Yes</td>
<td>1</td>
<td>50-60</td>
<td>W</td>
</tr>
<tr>
<td>Alice</td>
<td>F</td>
<td>8</td>
<td>3</td>
<td>JRA</td>
<td>Yes</td>
<td>1</td>
<td>30-40</td>
<td>A</td>
</tr>
<tr>
<td>Juanita</td>
<td>F</td>
<td>13</td>
<td>9</td>
<td>JRA</td>
<td></td>
<td></td>
<td></td>
<td>H</td>
</tr>
<tr>
<td>Tom</td>
<td>M</td>
<td>10</td>
<td>5</td>
<td>EDS</td>
<td>Yes</td>
<td>2</td>
<td>50-60</td>
<td>W</td>
</tr>
<tr>
<td>Roberto</td>
<td>M</td>
<td>9</td>
<td>4</td>
<td>Lupus</td>
<td>Yes</td>
<td>2</td>
<td>10-20</td>
<td>H</td>
</tr>
<tr>
<td>Peter</td>
<td>M</td>
<td>8</td>
<td>3</td>
<td>EDS</td>
<td>Yes</td>
<td>2</td>
<td>50-60</td>
<td>W</td>
</tr>
<tr>
<td>Sue</td>
<td>F</td>
<td>6</td>
<td>2</td>
<td>JRA</td>
<td></td>
<td></td>
<td></td>
<td>W</td>
</tr>
<tr>
<td>Kestrel</td>
<td>F</td>
<td>11</td>
<td>6</td>
<td>JRA</td>
<td>Yes</td>
<td>2</td>
<td>20-30</td>
<td>W</td>
</tr>
<tr>
<td>Mary</td>
<td>F</td>
<td>11</td>
<td>6</td>
<td>JRA</td>
<td>Yes</td>
<td>4</td>
<td>70+</td>
<td>W</td>
</tr>
<tr>
<td>Karl</td>
<td>M</td>
<td>13</td>
<td>7</td>
<td>JRA</td>
<td>Yes</td>
<td>5</td>
<td></td>
<td>NA</td>
</tr>
</tbody>
</table>

Best Friends:

<table>
<thead>
<tr>
<th>Subject</th>
<th>Sex</th>
<th>Age</th>
<th>Grade</th>
<th>Dx</th>
<th>Number of Siblings</th>
<th>Family Income</th>
<th>Ethnic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annie</td>
<td>F</td>
<td>11</td>
<td>5</td>
<td>Yes</td>
<td>4</td>
<td>70+</td>
<td>W</td>
</tr>
<tr>
<td>Beth</td>
<td>F</td>
<td>6</td>
<td>1</td>
<td>Yes</td>
<td>1</td>
<td></td>
<td>W</td>
</tr>
<tr>
<td>Lilly</td>
<td>F</td>
<td>12</td>
<td>7</td>
<td>Yes</td>
<td>1</td>
<td></td>
<td>W</td>
</tr>
</tbody>
</table>
Table 3.3. Interviews Completed by Study Participants in Fall 1995.

<table>
<thead>
<tr>
<th>Name</th>
<th>Camp S-95</th>
<th>Home F-95</th>
<th>Mother F-95</th>
<th>Explanation of the model Spring-98</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dave</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bridget</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Alice</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Juanita</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tom</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Roberto</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peter</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sue</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kestrel</td>
<td>X</td>
<td>XX</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Mary</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Karl</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annie</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Beth</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lilly</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Table 3.4. Description of Families/Children who Refused Participate in the Study.

<table>
<thead>
<tr>
<th>Parental Permission Obtained</th>
<th>Child Permission Obtained</th>
<th>Reason for Refusal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anita</td>
<td>X</td>
<td>Child's camp interview excluded as parent did not return permission form.</td>
</tr>
<tr>
<td>Amy</td>
<td>X</td>
<td>Very shy during interview, age 6, didn't want to continue.</td>
</tr>
<tr>
<td>Cathy</td>
<td>X</td>
<td>Wants her mom to be present during interview. Can recontact at home.</td>
</tr>
<tr>
<td>Lucy</td>
<td>X</td>
<td>More interested in doing interview at home. Wants to go to arts and crafts.</td>
</tr>
<tr>
<td>Jill</td>
<td>X</td>
<td>Refused, no reason given.</td>
</tr>
</tbody>
</table>

At the onset of the interviews, informants were asked for permission to audiotape the interviews. This allowed the interviewer to attend to non-verbal cues such as fatigue and adjust the interview appropriately. Most children were familiar with tape recorders and some even wanted to help operate it.

Tapes were then transcribed in a specific format and the transcript read by the researcher while listening to the
tape to double check accuracy. After the transcripts were proof read, and corrected, all audio tapes were destroyed. The participants were coded by numbers and letters. For example, interview one of child two would be S2.1. Interview one with the mother, or best friend of child two would be labeled S2M.1, or S2BF.1 as appropriate. Children picked their own pseudonyms if desired.

**Participant Demographics**

Of the 12 children initially interviewed at camp, three school age girls with JRA were selected for follow up interviews in the home. Their mothers, their best friend, and the mother of the best friend were also interviewed. The sample for this report consists of data from 7 interviews with the three girls. The volume of the data precludes inclusion of best friends or mothers in this report. One girl was age 8 of Japanese/American descent, and two were age 10 of caucasian descent. All were from intact families and all had at least one sibling. The children were selected for followup based on ability to verbalize and willingness to participate. Audio taped interviews ranged from 45 to 60 minutes in length. One interview had to be repeated as the tape recorder was not on during the last half. The interviews were conducted in a private spot in the child's home with a parent present in another room.
Arthritis Camp

Going to camp was a very interesting and exhausting experience. The camp was held at Rex Ranch, a beautiful resort, about 50 miles from Tucson, Arizona. The children stayed for a week as guests, using the pool and horseback riding facilities. In 1995 the staff had to do all the cooking for the children (about 16). Mealtime, arts, and crafts were done in the open at tables under a tree. Temperatures ranged in the 90's to the 100's during the midday. I did not stay overnight but arrived about 9 AM and stayed until 4:30 or 5, except on family night which ran until 10 PM. The camp activities included horseback riding and arts and crafts in the AM, a health education group discussion after lunch and swimming in the afternoon. Evenings included campfires, movies, and magic shows. In 1996 an air conditioned room was available for arts and crafts, and meals were served by ranch staff in air conditioned dining rooms.

Camp was important to all the children, and they did not want to miss out on any fun! Even though the camp director was very supportive, it was difficult the first year to find times for the initial interviews. This was one reason I did not conduct interviews during the Camp in 1996.

Camp Interviews

The camp interviews were done using an interview guide
(Appendix C) based on the pilot study and review of literature. Questions were open ended, but because there were so many of them, it was fairly intimidating to everyone involved. For younger children questions were shortened or deleted, and drawing was done during the interview to increase the child's comfort. The 7 year old children were very apprehensive. Two managed to complete the interviews, one 6 year old was overcome by shyness, and we stopped after about five minutes.

Home Interviews

The key questions were sent to the family ahead of time in a letter, confirming the interview time and place. They were:

1. Tell me all about your arthritis.

2. Tell me about your friendships and your relationships with your friends, the good times and bad times.

3. Tell me a story about how your friendships influenced your arthritis and/or how arthritis influenced your friendships.

This strategy was only partially successful. No child really understood these questions or had prepared an answer. After consulting with Dr. Haase, I usually started by asking how they were feeling. Then the questions were rephrased in terms of the good and bad times they've had with friends,
making or losing friends, about how arthritis changes friendships and how friendships change arthritis, times they wished they had a friend with them, and times when friends notice their pain. The goal of the interviews was to encourage the children to talk as much as possible and to minimize my input. After the initial camp 95 interviews, the children asked if they would be "paid" or rewarded. So approval was sought from Human Subjects to give each child doing home interviews a set of $7.00 movie passes in recognition for their effort. As a result more children volunteered for home interviews after Camp 95. Three sets of children, best friends, and mothers were actually contacted and followed up with.

Description of the Study Participants

Alice.

Alice was age 8, in third grade. Her family lived on an Air Force base. She was of Japanese-American descent, with English as her primary language. She became ill with arthritis about age four while the family was in Japan. She had a severe flare while in Japan, but had not experienced one since living in Tucson. She was very active and had a circle of neighborhood friends to play with everyday, including her sister, age 6. She was not on medication.

Bridget.

Bridget was age 11, in 5th grade. Her family lived on a
horse farm in the rural area of Tucson. She was of caucasian
descent, with English as her primary language. She had a 14
year old sister. She became ill with JRA as an infant at
about 9 months old and was diagnosed at 14 months. She had
flares every year, but they were not as severe as when the
family lived in the Midwest. She was outgoing and popular at
school, with a large close group of friends. She had a
service dog and used a wheelchair for long distances. She
had known her best friend since grade 3. She was on many
medications and received methotrexate injections weekly.

Kestrel.

Kestrel was age 11 in 6th grade. She was of caucasian
descent with English being the primary language. Her family
lived in a guest house at her grandparent's rural home. She
had two sisters, ages 8 and 10, who were her main playmates.
She had a severe flare in second grade that resulted in her
missing the last part of the year. The flare lasted four
months during which she was confined to bed and used a
wheelchair. Afterward she was active, able to run and jump
rope. She reported having only one school friend, and saw
her best friend at church. She was not on medications.

Data Analysis

Data analysis was not always able to be done
concurrently with data collection as is usual for grounded
theory research. The camp interviews were done in only one
week, so it was not possible to transcribe them immediately. However, the camp interviews were transcribed and reviewed before the home interviews were conducted. The formal data analysis began with the home interviews, as I decided to practice interviewing using a more open ended interview process. I felt these interviews were of a better quality, then the initial, more guided camp interviews. The home interviews were analyzed first, generating categories, and later the decision to add the camp interview data were made. The constant comparative method is used in data analysis to generate theory in a systematic manner from the data. Preliminary data analysis helped drive the theoretical sampling as the researcher attempted to make comparisons between children with different experiences. For example, after talking to Bridget who had severe JRA, I was able to interview Kestrel with a milder case, in that she was on no medication, and had less contact with her doctor at this point.

Stages of Analysis

Glaser and Strauss (1967) describe four stages in the constant comparative method:

1. Comparing incidents with categories.
2. Integrating categories and properties.
3. Delimiting the theory.
4. Writing the theory.
These stages are integrated throughout the analysis process. Grounded theory suggests (but doesn't test) many categories, properties, and hypotheses about general social problems and although these categories are saturated, not all available data are used.

Comparing Incidents with Categories.

The first stage of analysis involved comparing incidents applicable to each category. At first, incidents were coded into as many categories as possible.

There were many data bits that fell into the general category of Problems with Having JRA, which is defined as: Physical problems the child with JRA reports due to the symptomatology of JRA. This category was then sorted into six subcategories: immobility, pain, medication reactions, small size, weight loss, and fatigue. Each of these was defined. For example, immobility was defined as: the degree to which the child with JRA experiences stiffness, decreased motion in the joints. Then the data bits relating to immobility were further sorted into three groups: non-flare, flare, and visibility.

The non-flare group was defined as "the degree of immobility experienced on a daily basis by a child with JRA." This included data bits like "Well every morning my back gets stiff and my hands get stiff." (Alice).
The flare group was defined as: "A higher degree of immobility experienced during a period of disease exacerbation by a child with JRA." This included data bits by Bridget such as "you don't do anything, I watch T.V. I could move a little bit and I could read sometimes." Or later Bridget added "Well it was painful, I guess. I missed a few days of school. I just couldn't get out of bed sometimes in the morning, or anything, so it was pretty hard." Kestrel described "being in her wheelchair" or "all curled up in bed".

The visibility group was first defined as "the degree to which the immobility is perceived by others" and included statements such as "He said I walked funny." (Bridget). This was later combined with a subcategory named "infamity" which had been part of the category "Being Different". Being different was defined as "the feeling held by the child, with JRA that she is not normal.". Infamity referred to "a child with JRA experiencing a negative feeling of self consciousness." Things that caused this included: having to explain JRA, TV interviews, all children in the school knowing your name, splints, using a computer in class, a walking cane, a service dog, and being small (pixie like). Later Being Different was combined into Well-being, and infamity combined with Immobility/Visibility. This combined group was then relabeled "Visible Differences" in the final
theory and defined as: "Any symptom of illness or deviation in behavior from the peer group as a result of accommodating the illness, that is observable by others, and leads to a negative feeling of self consciousness in the child with JRA.

This example shows how categories can be reorganized to reflect properties such as "visibility". Then memos are written to describe the full range of each category, the dimensions, conditions where it is maximized or minimized, major consequences, and how it relates to other categories.

Incidents were compared with previous incidents in each category, so that theoretical properties of each category were identified. For example, the researcher is trying to determine: the full range of each category, it's dimensions, conditions where it is maximized or minimized, major consequences and how it related to other categories. As the researcher formulates his/her theoretical ideas, a memo is written to document the researcher's conclusions which can be used as a first step in writing up the major themes of the theory.

Integrating Categories and Properties.

The second stage involves integrating categories and their properties. Now incidents in each category are compared with the properties known about the category from stage 1. The researcher is looking for reasons the
properties are related. As the comparisons continue the properties themselves integrate.

A memo from 7/16/96 provides an example of how categories and properties are integrated. Properties of flares from a child's point of view were described in Tables 3.5 and 3.6 comparing active and passive play, or Friends Present or Absent, versus times of flare, or non-flare.

Table 3.5. Example of Reduction Typology, based on the Acuity of Illness and Type of Play.

<table>
<thead>
<tr>
<th></th>
<th>Active Play (jump rope)</th>
<th>Passive Play (TV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flare</td>
<td>too painful, must slow down, can't play</td>
<td>feel lonely, bored at times</td>
</tr>
<tr>
<td>Non-Flare</td>
<td>feel good, Keeping Up</td>
<td>resting, conserving energy</td>
</tr>
</tbody>
</table>

Table 3.6. Example of Reduction Typology based on Acuity of Illness and Presence or Absence of Friends.

<table>
<thead>
<tr>
<th></th>
<th>Friends Present</th>
<th>Friends Absent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flare</td>
<td>visitors fun, distraction, can't play hard, watch movies</td>
<td>lonely, bored, missing out</td>
</tr>
<tr>
<td>Non-Flare</td>
<td>feel good, Keeping Up</td>
<td>feel left out</td>
</tr>
</tbody>
</table>

These demonstrated that one property of flares or reduced mobility, is that it alters properties of play. It also shows how Keeping Up is related to increased mobility and feeling good. Missing Out was related to reduced
mobility, and feeling left out occurred during periods of normal mobility.

**Delimiting the Theory.**

In stage 3, the theory itself is delimited and solidifies. This involves a process of reduction as categories are clarified, perhaps collapsed into higher order concepts. With reduction of terminology the theory may be generalized to a wider population. The two major objectives of this stage are parsimony of variables and enlarging the scope while keeping a close correspondence to the data. As this process proceeds categories become theoretically saturated.

In this case the grounded theory has emerged from a process of specification of categories as described above, and a process of combining categories with similar properties to make the theory more parsimonious. At this point not all the categories are saturated, but are included in the model as they related to the core variable of Keeping Up. This is discussed in more detail in Chapter Four. Also the camp interview data were added in to further saturate the categories.

**Writing the Theory.**

The final theory writing stage involves the researcher processing the data, a series of memos and the theory. A good way to start is by summarizing the major themes in the
memos. For example, the major theme of this study is that a child with JRA, being able to Keep Up with one's friends is critical to their sense of well-being. This was demonstrated by describing Keeping Up in relation to play activities, subcategories of play, and properties of play. To move a substantive theory to a more formal level, articles and materials from other studies can be included.

Substantive versus Theoretical Coding

Glaser (1978) discussed data analysis in terms of two types of codes: substantive and theoretical. A substantive code conceptualizes "the empirical substance of the area of research" while a theoretical code conceptualizes "how substantive codes may relate to each other as hypotheses to be integrated into the theory". For example, three substantive codes for children with JRA were Accepted by Peers, Keeping Up, and Well-being. These were theoretically coded into a series of hypothesis which stated: the more a child with JRA was accepted by peers, the more the child would be able to maintain acceptable play interactions, or Keep Up. The more the child was able to Keep Up, the greater the child's sense of well-being. The double arrows indicate that at times the flow may be reversed.

Open Coding.

Open coding refers to "running the data open" (Glaser, 1978, p. 56) so that as many relevant categories and their
properties as possible are generated, in order to determine categories that fit, work and are relevant to the emerging theory. This is one way to reduce the effects of the researcher's previous training. It's the opposite of using a preconceived code that is substantive (legitimizing) or theoretical (looking for consequences) that preconceives core processes. Open coding helps drive the theoretical sampling decisions before the researcher begins the focus on a certain problem. By the time the core category is identified, the researcher is sure the categories are relevant. This also means that all data were coded initially, so that the theory that emerges does fit the data, for if later data cannot be coded, the theory must be modified until it is. Open coding and memoing are processes that aid the researcher in obtaining some distance from the data and be able to transcend his/her empirical view.

Memos help the researcher or auditors follow the trial of the theory's development step by step. Tapes were transcribed double spaced on the left side of each page, leaving the right hand side available for memos as the researcher reviewed the data. Later after initial categories are formed more complex theoretical memos may be generated. Coding was interrupted to memo ideas that otherwise might have been be lost.
Fracturing the data refers to taking a line-by-line approach to the analysis. Data were divided first into manageable categories and then again as needed into data bits. Significant phrases were put onto coded index which indicated the data source. To maintain organization a code book was kept of all categories and data sources. The data were then sorted and grouped by the investigator into related piles and named. By looking at the data line by line, a richer, denser theory is produced as categories are verified and saturated.

**Selective Coding.**

Selective coding refers to the time when the researcher decides to stop open coding and to just code for the core variables (often basic social process) of the theory. In other words the researcher focuses on the conditions and consequences that relate to the core process. Selective coding is the process used to develop a dense, rich, parsimonious theory. The goal of grounded theory is based on multi-indicator concepts, so that the theory can be transferred if desired by looking for indicators in substantive areas that produce the same categories. This is how a formal theory would be generated. In this study all the data were used as the number of subjects was small.

**Theoretical Coding.**

Theoretical coding helps transcend the empirical nature
of the data. The coding analysis begins with substantive codes and progresses to how the substantive codes or categories relate to each other as hypotheses that are integrated into the theory. Theoretical codes must earn their way into the theory, not just be selected based on the researcher's familiarity. Glaser (1978) gives an excellent summary of 18 possible theoretical (p. 74-81) codes. For example, a process must have at least two stages and refer to something happening over time. The process if Keeping UP involves three stages of friendships: Making Friends, Being Friends, and Losing Friends.

Theoretical coding can help identify the core categories of the grounded theory. First of all the analyst must constantly look for the main theme. It takes time to verify that a category is a core variable through saturation, relevance and workability. Core categories are central in that they are related to as many other categories and properties as possible and more than other possible core variables. They reoccur frequently in the data and take more time to saturate than other categories. A core category relates meaningfully and easily to other categories, and has clear implications for formal theory. The core category is completely variable in degree, dimension and type. Different conditions vary easily. For example, Problems with Having JRA varies with Keeping Up. The greater the Problems with
Having JRA are the less the child is able to keep up. the more the child works to keep up, the more the problems with having JRA increase. Usually the core category is also a dimension of the problem, somewhat explaining itself. Core categories have so much "grab" that the analyst begins to see if in all relations. This must be guarded against.

Basic Social Processes are just one type of core category, as core categories can be any type of theoretical code. Basic social processes have two or more clear stages. They give the feeling of process, change and movement over time. Often they are labeled by a "gerund" (ing) such as connecting or becoming. They are hard to contain and rather easily over generalized. Stages can act as theoretical units in themselves with conditions, consequences, and properties. Transitions may involve specific turning points such as being accepted as a friend, or be gradual and blurry. People experience the same process in many different ways.

Theoretical Memos.

Glaser (1978, p. 85) described theoretical memos as the bedrock of theory generation. As previously mentioned they document the thought the researcher has regarding the categories, properties and their relationships. The four basic goals in memoing are to freely develop ideas (codes) into a memo fund which is highly sortable and can be used at a later date. A memo's basic aim is to raise descriptive
data to a theoretical level. All memos are titled with the category or property or hypothesis the memo is about. The original is duplicated so that a copy can be easily cut up if need be. Memos can be color coded to be distinctive from the raw data.

Theoretical Sorting.

At this stage the field research is about complete and most coding is almost saturated. Many memos are developed, but must be sorted conceptually to put the fractured data back together to write the theory. The sorting of memos forces a complex integration of the theory as the focus is on the connections between categories and properties (not just writing up the data). The data and ideas are theoretically ordered so that the researcher understands the direction and what to write next. Generally all categories and properties are sorted if they relate to the BSP or core variables under consideration. All ideas must fit somewhere within the outline. Sorting continues level by level, i.e. first chapters, then sections. Sorting forces theoretical completeness, that is the theorist explains with the fewest possible concepts and the greatest possible scope the variation in the behavior and problem under study.

Member Checks.

"Member checks" refers to informants being asked to review the emerging theory at various points during the
study. Those informants who are classified as expert informants by the researcher are asked to provide feedback on the logic and fit of the theory. The categorization of an "expert" informant implies being thoroughly enculturated and being willing and able to verbalize one's thoughts, feelings, and cultural knowledge. The children with JRA were the "experts" as well as parents by virtue of their close association with their children with JRA (Morse, 1991). During member checks existing categories were confirmed and incomplete categories filled out. The confirmation of categories began with the second interview as the researcher began to verify her understanding of what the child or parent said and meant.

**Analytic Diary.**

I kept a journal to record personal reactions to the research process as it impacted on theoretical sensitivity (fatigue, etc.), thinking about the emergent theory, and the decision making process as to the investigation. Each reference was listed, along with the data from it. This diary was useful in determining the trustworthiness of the study, and storing memos when the computer program became unreliable.

**Trustworthiness**

Qualitative research is based on a naturalistic paradigm as opposed to the more traditional logical positive
scientific paradigm. Since there are critical differences in the ontology, epistemology and methodology between the two paradigms they can not be evaluated by the same criteria (Guba & Lincoln, 1989). For example in the logical positivist paradigm there is a belief in a single reality, where things follow natural laws that can be predicted and eventually controlled. In comparison the naturalistic paradigm, also called constructionist by Guba and Lincoln, denies a single objective reality and suggests there are multiple socially constructed realities devised by people as they try to make sense of their interactive experiences in the world. In this case truth is not isomorphic with objective reality, but rather the most informed and sophisticated construction on which there is consensus by individuals the most qualified to evaluate it. Multiple constructions can stand side-by-side. Epistemologic differences suggest that the observer detachment that is seen as mandatory in the traditional model of science is impossible to believe from a naturalistic view point, which suggests an interlocking relationship between the "inquirer" and "inquired into", so that any findings are a literal creation of the inquiry process. Individual's beliefs and values are recognized as major factors in the process.

Finally methological differences prevail. Interventionist methodology attempts to eliminate
confounding variables physically or statistically in order to lead to a capacity to predict and control causal mechanisms. Hermeneutic methodology involves ongoing dialog between involved parties to create a joint construction of the case. These philosophic differences between the paradigms help explain why the criteria developed for the logical positivist tradition can not be applied "as is" to the naturalistic paradigm. For example the concept of a study's internal validity, which is designed to evaluate the trustworthiness of the study or the degree of isomorphism between a study's findings and the "real" world, has little meaning if the world is viewed as having "multiple" realities. Similarly generalizability or external validity has little meaning if realities always differ. Reliability in terms of stability and instruments is difficult to assess when a phenomenon constantly changes it's very nature. Guba and Lincoln (1989) suggest a useful set of four research criteria for a naturalistic paradigm, based on the constructionist assumptions, that can be used to establish the trustworthiness of qualitative data.

Credibility

Guba and Lincoln (1989) define credibility as "the isomorphism between the constructed realities of the respondents and the reconstructions attributed to them" by the researcher (p. 237). In other words the focus, as in
internal validity, is on the match between the informants reality and those represented by the researcher and attributed to them. In order to increase the probability of a qualitative data and interpretations being found credible, Guba and Lincoln (1989) suggested the following strategies: prolonged engagement at the site, persistent observation, peer debriefing, negative case analysis, progressive subjectivity, and member checks. Before briefly discussing each of these it is important to note that procedures discussed under collecting, coding and analyzing the data used in constant comparative analysis are designed to promote credibility and structural coherence. Every datum is tested against all others so that contradictions and negative cases in the data are identified and explained. Also the mixture of data sources in the grounded theory process is a way of reducing bias (triangulation of source).

**Prolonged Engagement**

"Prolonged engagement" at the site is the time taken to learn about the phenomena of interest. The time spent with informants allowed me to build rapport and trust with the children as well as to identify the scope of the recurrent features in the life experiences of children with JRA. This strategy permitted me time to detect and take into account the distortions that may occur in the data. In this study time was spent individually with each child during
interviews as well as in group situations. By obtaining permission from parents first (Fine & Sandstrom, 1988) and interviewing the child privately at home with a parent available, the child may feel more relaxed and secure. Taking time to do a drawing of the child and their friends may be a helpful way to begin (Faux et al., 1989) as well as giving the child a choice over the use of the tape recorder, length of the interview and involvement of their friends.

Persistent Observation

"Persistent Observation" is needed to identify characteristics and elements in the situation most relevant to the problem. By observing the children in their home environment, school environment and at support group meetings over a several month period, irrelevant data can be sorted through. For example in my pilot study of children with JRA, one child told the researcher her friends helped her at support group meetings by pushing her in her wheelchair. I did not think very much about this until attending the next meeting I observed her laughing and being pushed at high speed in the middle of a running pack of children. The importance of their "help" was then clarified. Another reason for persistent observation is that school age children seem to do best at interviews that are focused on the present (Faux et al., 1989). By being in their cultural scene, I can direct questions towards issues of the moment.
Also friends change with different environments for the school age children, i.e., school friends, neighborhood friends.

Peer Debriefing

"Peer debriefing" is a strategy suggested by Guba and Lincoln (1989) to test out "finding" with a disinterested peer of the researcher. This process is helpful in making explicit any tacit information the researcher might possess. This is a chance to develop questions and test out working hypothesis, and is helpful in reducing psychological stress of the researcher. My summer class with Dr. L. Phillips and periodic meetings with Dr. Haase were very helpful.

Negative Case Analysis

"Negative case analysis" involves revising and reworking hypothesis until all cases are accounted for. The processes of reduction and substruction of typologies as described in Glaser (1978).

Progressive Subjectivity

The issue of "progressive subjectivity" has been discussed as well, with the idea of the researcher keeping a daily analytic journal. However Guba and Lincoln stress the importance of taking time to record at the beginning the researcher's idea of what she will find and then again at periodic intervals. In this case the theoretical models remain in the analytic journal, so one can see the
development of the theory. This issue is discussed further in Chapter Four.

**Member Checks**

"Member checks" have also been discussed. In general these allowed the child or parent a chance to correct errors in interpretation by the researcher and also serves as an opportunity to get more information. This also gave the child and parent the chance to be aware of the accuracy of the interview and the seriousness of the researcher in trying to understand his/her viewpoint. In this framework the parent's information is not expected to verify the child's information, however there will be a great deal of overlap. Faux, Walsh and Deatrick (1989) describe children as competent observers of their world.

Member checks were done as part of the interview process and more formally when the model was presented to the children and families in the fall of 1998. Their reactions and comments were noted. I also presented the model to two adults who had grown up with JRA.

**Transferability**

Transferability refers to the ability to determine the extent to which findings of one study have applicability in other contexts or with other subjects. Guba and Lincoln (1989) point out that in the naturalistic paradigm the burden of proof in on the reader to determine how much
salient conditions overlap. Thick rich description of the
time, place, context and culture in which the working
hypotheses of the study hold is needed for the reader to
make this evaluation. A second important step is to obtain a
representative sample in terms of varying geographic
locations and socioeconomic backgrounds, so that it may be
reasonable to apply this theory of the process of friends
helping a child with JRA maintain a sense of well being to
other school age children with JRA in similar circumstances
and settings. Clearly this sample is limited, as only middle
class girls with JRA from intact families have been
included.

Dependability

Dependability, like reliability, refers to the
stability of the data over time. However, unlike the
experimental environment, the naturalistic setting has many
extraneous and uncontrolled variables. The goal of grounded
theorists is to learn from informants, not to control them
per se, so that variation in addition to patterns of
repetition is sought and incorporated into study findings.

Glaser and Strauss (1967) stress the importance of
documenting the events in the grounded theory process that
affect sampling decisions, data collection, and the analysis
process. Guba and Lincoln (1989) recommend a dependability
audit be left so that an outside person could follow an
audit trail left by the investigator that provides a
description of procedures used and decisions made, so that
process of events and logic of the study conceptualizations
could be reconstructed (Miles & Huberman, 1984). This
information was kept in Nudist, a computer program, and in
notebooks demonstrating the data analysis phases.

Confirmability

Confirmability refers to the neutrality of the researcher in assuring the reader that the data,
interpretations and outcomes are rooted in the data, not the researcher's mind. In a confirmability audit the data is tracked through the process of conceptualization into theory, back to the original raw data by an outside person. Again documentation using the data and memos of the Nudist program is provided.

Guba and Lincoln (1989) recognize the interactive nature of the qualitative research process, so that the goal becomes one of the researcher being aware of how her own thoughts and feelings are influencing the grounded theory process and her responses towards informants. Again processes used in demonstrating credibility such as peer debriefing may help to bring these value issues to the surface so adjustments in data collection can be made. The goal is not for the researcher to maintain an objective, isolated stance from the child, but to react as a person the
child can come to know and admit briefly into their life. Fine and Sandstrom (1988) recommend taking on the role of a "friend" to the child and avoiding roles of authority over them. While treating children with respect the adult researcher is free to ask certain "ignorant" questions. Positive affective feedback allows the researcher to be less threatening than a person in a strict observer role.

Usefulness

The goal of nursing research is to generate a midrange substantive theory explaining how the interactions of a child with JRA and his/her friends help maintain the child's sense of well being. To be useful to nurses the theory generated must demonstrate six characteristics described by Glaser (1967). First of all the theory must fit the data well in the substantive area where it will be used, not be forced into preconceived categories. Emergent fit refers to categories that do exist in the literature that are thoroughly supported by data. The theory must work in the sense it is general enough to apply to lots of daily situations by identifying controllable variables and ways to access them (Glaser & Strauss, 1967). The theory should explain what happened, interpret what is happening, and predict what will happen in the substantive area of inquiry (Glaser, 1978). The theory must be relevant in that it is based on core problems and processes that emerge. Basic
social processes help integrate core categories into the theory. The theory must continue to be modifiable as social life changes. Finally the theory must be of a transcending nature, so it provides a succinct way to remember and view the data for potential users.

Summary of Chapter Three

This chapter described the grounded theory method as a process that can generate useful substantive midrange nursing theories. An introduction to the method was presented as well as descriptions of maintaining theoretical sensitivity, sampling, data collection and analysis. Finally methods for establishing the trustworthiness of a qualitative study were discussed. Criteria for assessing grounded theory in terms of usefulness were identified.
CHAPTER FOUR
RESULTS

This chapter presents the results of the data from the camp and home interviews of the children with JRA. These interviews concerned how friends help children with JRA maintain their sense of well-being. The first section: the explanation of the grounded theory, follows the diagram in Figure 4.2. Each stage and variable of the grounded theory are defined, followed by examples given from the data. Figure 4.1 is included to show how the categories developed from the data. The core category identified in the grounded theory is the process of Keeping Up, or the child with JRA's ability to maintain acceptable play interactions with friends. All the categories in the model are related to the core category of Keeping Up. Because of the volume of data from the children with JRA, the data from the best friends and parents was not integrated into the model for the dissertation.

The second section of Chapter Four summarizes the results of presenting the grounded theory to the children and families involved in the study. Also the grounded theory was presented to two adults who have both experienced JRA since childhood. A summary and the need for further analysis end the second section.
Figure 4.1 Grounded Theory: Keeping Up with Friends, Substantive Category Names

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making Friends</td>
<td>Being Friends</td>
<td>Losing Friends</td>
</tr>
</tbody>
</table>

- Feeling different
- We are friends
- We are not friends
- Reasons we can't be with friends
- Problems with having JRA
- Things to do when kids are mean
- Missing out
- Feeling good, strong as normal as possible
- Keeping up during play
- Things friends do to help
- Just hanging with friends
- Feeling left out by friends
- Stay away from some kids (enemies)
- Problems with having JRA
- Missing out
- Feeling good, strong as normal as possible
- Keeping up during play
- Things friends do to help
- Just hanging with friends
- Feeling left out by friends
- Stay away from some kids (enemies)
- Problems with having JRA
- Missing out
- Feeling good, strong as normal as possible
- Keeping up during play
- Things friends do to help
- Just hanging with friends
- Feeling left out by friends
- Stay away from some kids (enemies)
Figure 4.2 Grounded Theory: Keeping Up with Friends, Theoretical Category Names

<table>
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<tr>
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- Making Friends
  - Visible Differences
  - Accepted by Peers
  - Peer Rejection

- Being Friends
  - Companionship
  - Help from Friends
  - Keeping up: Maintaining Acceptable Play Interactions
  - Problems with Having JRA
  - Missing Out
  - Strategies to Manage Denigrating Social Responses

- Losing Friends
  - Well-Being of Child with JRA
  - Barriers to Friendship
  - Peer Avoidance
  - Left Out by Friends
  - Missing Out

Signs:
- + Positive relationship
- - Negative relationship
Explanation of the Grounded Theory

Figure 4.1 depicts the friendship processes of children with JRA. There are three general stages of children's friendships identified by the grounded theory: Making Friends, Being Friends, and Losing Friends. The model is discussed in relation to these phases in childhood friendships.

Stage One: Making Friends

In relation to time, Making Friends, the friendship formation stage, can be extremely short for children. This short phase can be thought of as containing two parts: a brief observation period where the children become aware of each other, and a decision making period, where the children decide whether or not to become friends. For example, Alice at age 8 described the steps of making a new friend as: introducing herself, asking if they want to play, and if the answer is "yes", starting to play with old friends joining in. Now they are friends.

The friendship formation sequence described above may be elaborated when visible signs of being different from each other are present during the first contact. Examples of visible differences might include a swollen joint, the child's small size, or difficulty walking. The child with JRA may then include a warning statement after the introduction, such as "My name is Alice and I have JRA." She
then might go on to include a description of JRA in terms of the definition (JRA means juvenile rheumatoid arthritis), the physical damage (scars in my joints), the things she can't do (cart wheels, make a fist), because of its location (neck, back, hands, or all over). If the new friend looks taken aback, the child with JRA points out it's not contagious. The warning offered by the child with JRA also serves to delimitate the social contract and modify the usual expectations of childhood friends, so that the new friend will be gentle and careful during play. For example:

Alice:

The first day I was at school, she kind of wanted to be my friend, and I just letted her know that I have arthritis, so (then she) kind of said, "Oh", and she said "Where?", and I said "all over my body". Because I used to have it all over my body.... She said,"oh, I won't, I won't do anything to you. I won't hurt you or anything like that."

Visible Differences

During the first contact the children look for similarities and differences between them. Visible differences may be addressed directly, as Bridget describes happened to her once:

Bridget:

Well I've never really been teased... well once but that was no big deal. He's a friend of mine now, ... but he said that I walked funny in like third grade or something.... (it was) kind of hard but he found out that I had Arthritis and he said he was sorry, and it was like no big deal. But then somebody would always say, "Why do you get to be on the computer? That's not
fair" or "break your arm?" or something like that ... Because I wear splints in the day. Yeah. I'm not wearing them now but I do. Something like that and then they're, you know, (Pauses, 2 deep breathe, makes a face).

Other visible differences include: any physical sign of having JRA, such as being small, evidence of not being able to keep up with peers such as use of the computer during school while other children write answers out, unusual attention by teachers, and unusual attention from school mates. For example, having the principal talk to you during lunch, or the other children helping you can set one apart. Being teased by other children can be a threat to friendship development and maintenance. Being popular and having other friends is also observed by a new child to the social scene and may influence the decision to enter into a friendship.

Accepted by Peers

Friendships involve unwritten "social contracts" between the children. Once the decision is reached to be friends, the other child is expected to be nice, gentle, careful, understanding, willing to play, willing to spend time together, willing to look for shared interests, and willing to overlook the problems associated with having JRA. Over time friends may learn to explain JRA to others and act as social buffers when new children are encountered, by answering question about visible differences. This allows the child with JRA a chance to continue interaction, and to
avoid having to be self-conscious about differences. Also, over time friends are tested in their willingness to stick up for the child with JRA, leading to their selection as "good" or "best" friends.

Being accepted by a friend means the child is believed, unquestioned, approved, and chosen. Friends show acceptance by their tolerance, patience, sympathy and understanding. Conflicts are minimized and avoided.

Peer Rejection

When no friendship is established, children with JRA may experience denigrating social responses. Denigrating social responses are defined as social indicators to the child that the child is different, such as teasing, negative personal comments, or rude actions. These result in the child with JRA feeling put down, belittled, or hurt. Children with JRA may be teased about their small size, wearing glasses, hanging out with their younger siblings and their friends, wearing old clothes or their appearance.

Strategies to Manage Denigrating Social Responses

Strategies to manage denigrating social responses are developed over time. The child may be coached by a parent about what to say or do in these difficult situations. These include: walking away, ignoring. The more strategies that are developed, the greater the child with JRA's sense of well-being is predicted to be. For example, Bridget
describes her feelings about negative comments from other children when she wears her splints or uses a computer in class.

Bridget:

*It makes you, it kind of puts you down at first but you learn to, I don't get much of it so.*

The theory also predicts that the fewer strategies that are developed, the more the child with JRA may avoid peer interactions. This was described by Kestrel in her initial reaction to a new school. She was teased about her small size, playing with her younger sister's friends, wearing glasses, and stringy hair. Kestrel's habit of wearing the same socks everyday may be thought of as a strategy to divert their attention from other aspects of the illness. As a second strategy she used wrist splints hoping the children would understand or remember about the arthritis.

Kestrel:

*Most times, until they really wanted to pick on me, and then they'd poke me and stuff. And then that way I'd, and then I'd just, I'd would get really mad and tell them to stop it, and, I wouldn't tattle, I'd just tell them to stop it .... They usually didn't. Sometimes they ran away laughing, and sometimes they just kept poking at me and sometimes they backed away.*

Stage Two: Being Friends

Being friends or the stage of maintaining a friendship requires thought, energy, and reciprocity on the part of both children.
Barriers to Friendship

Two types of barriers to friendship were specified: structural and parental. Both may interact to slow down or stop the child's ability to keep up, and maintain acceptable play interactions. Both must be overcome in order to keep up, that is to maintain acceptable play interactions.

**Structural barriers.**

Structural barriers are defined as physical obstacles to children playing together. For example, Kestrel lives in a rural area, where houses are far apart, few children her own age living nearby, no sidewalks, and lots of open desert. Alice lives on a military base where there are many children close in age, houses are close together, sidewalks are present, there are grass front yards and many unfenced back yards.

**Parental barriers.**

Parental barriers is defined as parent's decision to encourage or not to encourage a close friendship between the two children. For example, Kestrel's best friend was a church friend who lived at least 15 miles away. Kestrel's mother had her daughter's best friend's family over for dinner after church and also gave her daughter permission to stay overnight at her best friend's house. Without this parental support the children's play opportunities would be limited to Sunday mornings at church. Note: In the child
data all examples of parental support were of a positive nature, but clearly there are times when parents may decide to withhold support for a child's friendship. Parental concerns were discussed with the mothers of both the child with JRA and their best friend, and for this reason the lack of parental support is seen as inhibiting the process of "keeping up". When the mother interviews are analyzed the relationship between parental support and the long term well-being of the child may be clarified.

**Keeping Up**

The process of Keeping Up centers around maintaining acceptable play interactions between the child with JRA and their friends. Acceptable play interactions would involve: the selection of activities that are fun for both and allow the child with JRA to blend in to the group; the maintenance of an adequate frequency and pace of play between friends, and both children being open to trying new and exciting things.

**A definition of play.**

Play is broadly defined as activities in which children with JRA and their friends participate for fun, in which there is no intention to harm anyone. If there is an intent to do harm, then the interaction was not considered play. For example a group of children hurting a animal would not
be a play interaction, whereas a group of children enjoying "saving" animals from a swimming pool would be.

**Play activities.**

In general play activities vary by age and the severity of the JRA. For example a 8 year old was interested in jumping rope, hoola hoops and basketball. She was able to participate in Physical Education and loved to run. Chasing neighborhood boys with her friends was a favorite pastime. However she was not able to do so when her arthritis acted up. For the older girls, talking with their friends was a major interest, along with a shared interest in horses.

**Subcategories of play.**

Subcategories of play include: group, dyadic, and solitary play. Group play is defined as when three or more children interact together for fun. Note that solitary play may occur simultaneously during the group activity. Halloween parties are a good example. Dyadic play interactions describe situations where pairs of children interact together to have fun. These might include talking with a best friend, making a video, and practicing dancing. Solitary play includes activities the child engages in alone. These might include reading or playing with computers.

**Properties of play.**

There are several properties of play that help describe
play interactions. These include: activity level, pacing, blending, novelty/excitement, and frequency. These are individually described below. There may be more properties that remain to be identified.

1. **Activity level**

The level of energy output required for play varies with the type of play (Table 4.1). Some games (tag, basketball) require a lot of physical endurance for running, chasing, or jumping. Other games such as "murder" played at camp involve sitting as quietly in a circle as possible and watching for someone to wink at another person in the circle. The person winked at falls over and screams. Everyone tries to figure out who did it! At camp the children often chose to go horseback riding every A.M. despite the fact they would be sore later.

<table>
<thead>
<tr>
<th>Type of Play</th>
<th>Play Activity Level (physical endurance required)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
</tr>
<tr>
<td>Watch TV</td>
<td>Run</td>
</tr>
<tr>
<td>Computer</td>
<td>Basketball</td>
</tr>
<tr>
<td>Robots</td>
<td>Chase</td>
</tr>
<tr>
<td>Arts and crafts</td>
<td>Jump rope</td>
</tr>
<tr>
<td></td>
<td>Swim</td>
</tr>
<tr>
<td></td>
<td>Horseback riding</td>
</tr>
</tbody>
</table>
2. "Pacing"

Pacing is a property of play that describes the ratio of hard or physically active play activities to restful, physically inactive play activities. Children seem to do this naturally, in cycles, however for the child with JRA who "over does it", certain consequences are experienced the next day in terms of increased illness symptoms such as pain, swelling, and stiffness, and fatigue. Often these symptoms result in missing out of school the next day. Adequate pacing may moderate the relationship between Keeping up and Problems with having JRA, which is why the positive feedback loop from Keeping Up to Problems with having JRA is only a dotted line. Best friends learn to alternate physically demanding activities with quiet ones.

The pace of play interaction can also influence the feeling of the children involved (Table 4.2). For example, if the pace of the child with JRA matches the pace of her friend, a good feeling develops. If the pace of the friend's play is too fast, the child with JRA may feel excluded or left out. If the pace of the friend is too slow, the child with JRA may feel bored, unexcited. If the pace of the child with JRA becomes too fast, a sense of danger is experienced.
Table 4.2. The relation of the Pace of Play to Feelings of the Child with JRA

<table>
<thead>
<tr>
<th>Best Friend</th>
<th>Child With JRA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fast Pace</td>
<td>Feel Good</td>
</tr>
<tr>
<td>Slow Pace</td>
<td>Bored, Unexcited</td>
</tr>
</tbody>
</table>

3. "Blending"
This property refers to the ability of the play activity to conceal any differences of the JRA child from normal children, or to enable the child with JRA to look as normal as possible while participating in the activity (Table 4.3).

Table 4.3: The relation between Type of Play and Blending Level.

<table>
<thead>
<tr>
<th>Play Blending Level</th>
<th>Type of Play</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Basketball</td>
</tr>
<tr>
<td></td>
<td>Fine motor things -</td>
</tr>
<tr>
<td></td>
<td>painting jars</td>
</tr>
<tr>
<td></td>
<td>Cutting small pieces</td>
</tr>
<tr>
<td></td>
<td>Dancing (with group of</td>
</tr>
<tr>
<td></td>
<td>normal teens)</td>
</tr>
</tbody>
</table>

Swimming was enjoyed because:

Bridget:

_It's something you can do and you don't feel like, I don't know, kind of different._ (laughs)
Horseback riding was extremely popular for several reasons. First, the size differences between children are minimized, as all children look small next to a horse. Secondly, problems with keeping up were minimized as the horse kept the pace. The third reason, novelty, is discussed below.

In contrast to the above examples, the invitation to line dance with a group of performing teenage girls, was accepted by less than half the camp children. Some children who did not participate were angry this activity had been chosen.

4. Novelty/excitement of activity

Activities also vary in how exciting or novel they are to a child. For example, horseback riding was described as:

Bridget:

You kind of get a sense of freedom, I guess, when you are riding a horse, you feel like, it's just a different feeling. I only get to do it once a year anyway, so it's something to look forward to, you know, something that is pretty exciting.... well I guess it's not real safe, it's safe, but I mean anybody can fall off a horse and hurt themselves.

She goes on to describe how just the challenge makes it worth it: Bridget:

So with jolting it's kind of hard on you after a long ride, you have to spread your legs so far. It hurts. But I think that if people really want to do it, then they're going to do it.... Yeah, it's just being there, you know.

Problems with having JRA and Blending may interact to affect the choice of activity. For example in Bridget's discussion
of horseback riding she mentioned that she wouldn't want to wear a (neck) collar while she was riding, even though she has arthritis in the neck:

Bridget:

*It's fun. I like it, but.... I think you should but I really wouldn't want to wear, like a collar, if you have severe arthritis in your neck, because when the horses run they jolt and stuff.*

5. Frequency

Frequency of play interactions is the number of times the children are together and able to play. The less they see each other, the harder it is to maintain the relationship, and their sense of well-being. They experience loneliness. Kestrel described how much she missed her camp friends. Her best friend was from church. She did not have any close school friends. She even invited them to her birthday party. Still a year was a long time to wait. Unfortunately during the time period of the study there was not a children's support group meeting.

Help from Friends

Help from friends is defined as: things friends do and say that aid the children with JRA in maintaining their ability to play, or enhance their sense of well-being. These data can be compared to Will's (1985) definition of social support in childhood. This includes all the tasks undertaken by a friend in order to provide: tangible aid, esteem
support, information support, motivational support, or social companionship. Examples of each type of support follow. Companionship is treated as a separate category because it was more important to the children than any specific helping.

**Tangible aid.**

Tangible aid includes things like bringing a chair for a friend with arthritis to sit on during auditorium events at school (without being asked), staying close to a friend and being willing to confront/fight any child teasing your friend. There are contradictions in the data about whether or not school friends notice or help with the pain or fatigue a child with JRA experiences. Kestrel did not report any help with physical problems. Bridget reported friends noticing she was having pain:

Bridget:

*They just, they sit down, or they stop what they're doing, they just stop walking or something.*

Notice this has a lot to do with pacing. These friends realize they may have done too much, that the child with JRA can't keep up. They slow down in order to give her time to recover.

Also friends helped push Bridget's wheelchair at Halloween:

Bridget:
Yeah, they both helped me, I mean, the mom, she would push me sometimes, in my wheelchair, when I needed it, and then the other friend, it was kind of hard though, because they would want to run ahead. But I, I did ok.

Again notice that the help is positively related to well-being. In the above example "it was hard", refers to the threat to Bridget's well-being and feelings of sadness, when the friends got too far ahead to "be with" her. She was aware that her friends had to deliberately slow down, so she tried to keep up with their mother helping her, otherwise she would have missed out on the fun. Having the friends "help" her provided a way to ensure their presence and companionship.

One explanation for the discrepancy between friends willingness to help is the degree of closeness between the school friends. Bridget had known her school friends since 1st grade. Also her mother had spoken to the class about arthritis several years in a row (1st - 3rd). Kestrel was just making new school friends who knew she had arthritis (she told everyone) but her new friends did not know what to watch for and how to help her.

Esteem support.

Esteem support is provided by the other child accepting the child with JRA as a friend, listening to her problems, calling during flares, talking together, playing together, distracting the child with JRA, and never leaving
the child with JRA alone in social (peer group) situations. The child with JRA feels valued, well-liked, part of the group, and safe.

Motivational support.

Motivational support was described by Wills (1985) as often overlapping with esteem support, but occurring in situations that are chronic in nature that require persistence and endurance before they can be overcome. Friends may play an important role by providing everyday encouragement that better things will come, that their efforts will be successful. One example might be clipping out newspaper ads of horses for sale and sending them to a child with JRA who wanted to get a horse (Note: this incident occurred between camp friends, both having JRA, sharing a love of horses). Motivational support is also provided by the social comparison processes that occur at camp when children see counselors coping with their own arthritis or other children with JRA being as active as possible. Struggling to keep from being wheelchair dependent is encouraged by counselors. At this point the children who are friends at camp do not see each other on a routine basis during the year which might enable more motivational support with regard to having arthritis. The best friends interviewed did not provide verbal encouragement, as much as companionship.
**Informational support.**

Informational support is defined as filling the child in on what's happening in the social scene, not information about having JRA or treatment. Good friends might call or bring over schoolwork if the child with JRA was absent that day.

**Companionship**

Companionship is defined as: the child with JRA "being with" or a friend's "being there", either in a dyadic or group situation. This has to do with the idea that the physical presence of a friend has a beneficial effect on the JRA child's sense of well-being. The time spent with friends is important to the child, even if the friend is not doing or saying anything in particular. Companionship is characterized by a peaceful, easy time of being together. Wills (1985) considers this part of his definition of social support for children. It is not included in most adult definitions of social support. Examples from the data are: being together, watching TV, hanging out, talking, eating lunch at school together, sitting on a bench together.

Examples of comments about companionship include:

Bridget:

*And we just hang out, just talk.*

Bridget:
Just being with my friends is a good time, you know, all the time.

Being together results in feeling normal, right, good, and together:

Bridget:

It's just normal. Feels right, you know, just.... (pause) It feels good. Together.

The children feel connected to their friends by spending time with them.

Problems with Having JRA

Problems with having JRA is defined as: Physical signs and symptoms of illness which are perceived as difficulties by the child with JRA. For these children problems with having JRA included the following subcategories: Immobility, Pain, Medication reactions, Small size, Fatigue, and Weight Loss during flares. All these subcategories may vary in severity and visibility to friends.

Immobility.

Immobility is defined as the degree to which the child with JRA experiences stiffness or decreased motion in the joints. Many or few joints may be involved at one time. One property of immobility is that it varies with "flares" or periods of disease exacerbation. Immobility/Nonflare is defined as the degree of immobility experienced by a child on a daily basis. For example Alice experiences a stiff back and hands every morning.
Immobility/Flare is defined as the degree of immobility experienced during acute disease exacerbation. Examples of immobility include not being able to get out of bed, not being able to walk, curling up in bend (fetal position), using a wheelchair, or having to be carried from place to place by an adult. Each child is at a different point of severity of illness, and during a flare, these symptoms worsen. Generally some limitation of mobility is always present.

A second property of immobility is that it varies in visibility to uninformed children. Visibility is defined as the degree to which impairment of mobility is perceived by others. Swollen joints may not be noticed by another child, however the use of wrist splints, wheelchair, or a "funny walk" is. Visible signs of immobility create awareness of Being Different for both the child with JRA and their friends.

Pain.

Pain is defined as the degree of personal discomfort described by the child, usually in relation to joint movement, but may include side effects of treatments as well such as a burning sensation at the injection site. Pain/Low subcategory is defined as the end of the range of pain that reflects a steady, continuous, low grade sensation of
discomfort. Children can sometimes block out pain with
distraction from friends. Pain/High subcategory is defined
as the extreme end of the individual's range of pain that
can be described as "hurting too much to walk", "intense".
It is hard to distract the child from this kind of pain.

**Medication reactions.**
Medication reactions can be a problem for children with
JRA. Medication reactions are defined as: types of side
effects of drug therapies used in the treatment of JRA.
Methotrexate leads to nausea and vomiting several hours
after injection. When given I.M., there is also a burning
sensation at the injection site. Penicillin tastes bad. Gold
injections burn. Note: these three subjects did not report
the possible side effects of high dosage of salicitates such
as severe gastritis and severe diarrhea.

**Fatigue.**
Fatigue is defined as the degree of exhaustion the
child with JRA experiences from trying to maintain a normal
pace of activity in the presence of JRA. One property of
fatigue is that is increases with the child's activity
level.

**Small size.**
Small size is defined as the height of the child with
JRA being perceived by the child as below average for her
age, usually due to growth retardation or metabolic changes
associated with JRA. JRA children are described as "pixie like" by parents.

**Weight loss.**

Weight loss is defined as a negative difference in body weight over time, usually due to loss of appetite during flares or metabolism changes associated with JRA.

Problems with having JRA can be described as a tension variable or a variable that drives the system. The tension variable usually cycles and would have a feedback loop coming back to it. This model broadly indicates that the greater the problems the child is with having JRA, the less the child with JRA can keep up and engage in play interactions with friends. The feedback loop indicates that the effect of too much play may be an increase in problems with having JRA, such as fatigue or soreness. Parents were very aware of this trade off, but allowed the children to socialize anyway, especially on holidays.

**Flares.**

Flares are the time of disease exacerbation that essentially stop the process of Keeping Up. They may last from weeks to months. Kestrel, for example, reported missing a year of school. Flares have two phases: an acute phase when the child is the sickest, and a recovery phase when the child has more energy. During the acute phase activities are very passive and involve little movement (reading, watching
TV). In addition, the child sleeps a lot. As the child recovers, interaction with siblings increased and more active play was engaged in. Friends might go to a movie together.

One characteristic of flares is that they are unpredictable. Some subjects reported more problems with JRA during the Fall, or periods of high humidity. Living in Arizona's dry climate was seen as beneficial by all subjects. Ways children monitor their progress include: watching medication dosages decrease (and feeling bad when they flare and medications increase to previous or higher levels), watching faces of people around them, watching the weather, and assessing the pain in certain joints.

**Missing Out**

As problems with having JRA increase, there is a likelihood the child with JRA will begin to miss out on activities as her need for rest increases. Missing Out was defined as a sad, lonely or boring time when a child was not able to participate in activities friends were participating in, and which she would be included in, if present. Some examples include: missing school, missing Physical Education, and missing a good time with friends because of my camp interviews.

Being able to keep up during play decreases the child's self awareness of being different, as do successful
strategies to manage denigrating social responses such as teasing or unwanted personal questions. Not being able to keep up, missing out, and peer rejection all contribute to feeling different, and a diminished sense of well-being.

Well-Being

Well-being is simply defined as the degree to which the child feels good, strong emotionally and physically and as normal as possible. However, the data indicated that the children with JRA were always aware of being different, no matter how good they felt. Being different was somehow incorporated into their self-concept. For example:

Bridget:

*When you're feeling good, it's like nothing can stand in your way, it's like you're normal. You know you're not normal, you know that, when you look at yourself in the mirror walking, you know you don't walk normal.*

Self-awareness of being different or the child's perception that she/he is not normal or at least average is associated with feeling bad about one's self. Self-consciousness about being different directly negatively effects the well-being of the child with JRA. For example:

Bridget:

*But, the worst thing, not actually the pain, it's the, it's the not be able to do things, not be able to be like everybody else.*
Maintaining a high pace of play activities with friends is associated with well-being as described by Alice at age 6:

Alice:

When, [I'm well] it's ok, I kind of feel good, I run around, going on rides and stuff like that. I go to Girl Scouts.

Help from friends is positively linked to a sense of well-being because help from friends increases self-confidence in the child's ability to handle certain situations. For example:

Kestrel:

Well, sometimes I would ... get really hurt by the things people would say. And I wasn't really defending myself all that much when people said that, but after I was defending her, she started defending me, and It just kind of helped me out. I realized I can do something about it sometimes. I don't always have to hide in a corner or go get a grownup all the time. I can take care of it myself. Or I can just ignore them and not get emotional about it.

Companionship, or just being together with friends can positively influence well-being, as Bridget described:

Bridget:

Well I think that it takes my mind off it a little bit, you know when you have your friends you don't sit there and grieve about your arthritis or anything, you know you have somebody to talk to. There's always somebody there that, [Bridget's best friend] she's a real good friend and you can just lean on your friends, you know when you have something to say you just say it, and it's always good to have somebody you can let your feelings out to like that. I think that helps a lot with my arthritis.
Well-being is the final output variable in this model. The evidence for well-being is limited. At this time no feedback loops are identified linking well-being back into the model. Possibly a greater sense of well-being may connect positively with their openness to making new friends.

**Stage Three: Losing Friends**

Losing friends, or the ways friendships end, makes up the third stage of friendship relationships in the grounded theory Keeping Up. Friendships ended for the children with JRA for a variety of reasons: they changed schools, a friend moved away, old friends are placed in a different class at school, and sometimes because of conflicts over the time and effort a friend wanted from the relationship. When the children with JRA discussed losing a friend, they reported having a hard time, feeling sad and hurt, but with time they got used to it and begin to forget after new friends were made. The length of time associated with losing a friend might be long or short, but usually the child who felt "left out" at a certain point decided the friendship was over.

**Being Left Out**

Being left out by friends is defined as an incident where the child with JRA is deliberately excluded from a group. One reason often given was they were not able to keep up. Being left out causes the child to feel angry and
intensely hurt. This differed from "missing out", in that Being Left Out was very personal. One painful example of being left out involved being left out by a girl's scouting troop. No scout offered to stay behind, to be with the child with JRA while the rest left on the hike, an activity she could not keep up with. This was understandable from the other child's point of view. Going on the hike was a highly valued, fun activity that permitted the children to earn badges. Eventually the child with JRA left the troop concluding she had no friends there. The scouts kept breaking their friendship contract. Being left out is a social cue that the friendship is over.

Peer Avoidance

Peer Avoidance was defined as a conscious decision on the part of the child with JRA to stay away from specific children who have engaged in teasing or bullying the child with JRA in the past. Physically walking away from the social encounter serves as a social cue that no relationship is desired with the inappropriate child. This is done without tattling to adults if possible, as that just makes the situation worse in the future. Peer Avoidance is not desirable as often the child's ability to avoid unfriendly children is limited. Peer Avoidance could be considered a special strategy in Managing Denigrating Social Responses, however it differs from the rest of the strategies as it was
not used in the context of Being Friends. This category is unsaturated. Only Kestrel reported having no friends at school. She noted, "I try to avoid everybody at school!". By the fall home interview she reported having one friend at middle school to talk to at lunch and a good friend at church who was helpful in managing other children's teasing.

Summary

Keeping Up with friends is important to maintain the child's sense of well-being. The model addresses the worst thing about having arthritis for these subjects:

Kestrel:

[the worst thing is] my friends at school. I never really had any really good friends. The only good friends I have now are the ones at Arthritis camp.

Bridget:

The, the pain ... [the worst this is] not actual the pain, it's the, it's the not be able to do things, not be able to be like everybody else. I can't, can't do PE. Can't run. Can't walk very fast. You just kind of get, you just kind of, you know, you're not really in all that stuff. Well, just, I think that's the worst thing.

By showing the wide range of impact JRA has socially on a child, and the importance of play activities, the model suggests variables that may be key to developing nursing interventions to improve the well-being of these children. This model represents a first step in the data analysis of the children with JRA. Keeping Up is the central process of
concern for children with arthritis in maintaining their friendships.

Member Checks

Member checks were done to assess the credibility and trustworthiness of the grounded theory Keeping Up with Friends.

Comments by Children and Families in the Study

The validation meetings took place in the spring 1998, almost three years after the children had started the study. First, the grounded theory was briefly presented to the family members and children. Then they discussed their impressions. Only Kestrel and Bridget were able to review the model. Alice's family was moving at the time. All three best friends and two of their mothers were able to review the theory. Lilly's mother was unable to meet.

There were changes in the friendships over time. Kestrel and Lilly were still best friends, and their families continued to socialize together at church. Kestrel's mother invited Lilly to stay overnight, so both girls were together at the validation interviews. Kestrel told of having a good time last summer at camp. She was able to room together with her three best camp friends. She had also made a new neighborhood friend to play with. She planned to go back to camp as a counselor.

Alice and Beth were still at the same school, but
Beth's mother had divorced Beth's father. Alice's family was in the process of moving and was not available to interview at that time. Bridget and Annie attended the same middle school, and shared classes, but at this point had ended their friendship. They were interviewed with their mothers at separate times. Bridget had a new best friend who was new to Tucson. She was present as an observer at the validation interview after school, and for this reason the conflict with Annie was not discussed.

In general, the children seemed to understand the theory as it was explained to them. Bridget thought the model would still apply to her today. Also Bridget's (former) best friend Annie thought the model would still apply to her today. Annie said she would like to continue her friendship with Bridget.

The theory was useful in showing what could happen if social cues were misinterpreted or unintentionally given leading to one friend feeling left out. The theory was also useful in discussing the decision to attempt to restore relationships. Annie also thought the theory would apply to her cousin with diabetes, noting "anything that makes her feel different, makes her feel bad." Also Beth's mother, the best friend of Alice, thought that aspects of the model might apply to Beth who has diabetes.
Visible Differences

Bridget had a cast on one arm after a recent surgery. She discussed how when she wore a wrist splint, which was better for her wrist, the teachers expected her to take it off to write. No one questioned the cast, but her mother noted this puts her at high risk for losing her ability to write. She now needs a wrist operation on the other wrist because of overuse. Bridget also had a spinal fusion last year and is supposed to wear a neck brace all day. She found it was "hot and uncomfortable" and now only wears it on the bus to school. Her mother gives her a ride home. Another visible difference at school is that she is able to leave class early to avoid the crowd rushing to the next class.

Kestrel told a story about meeting a girl with brain cancer at church who was thrilled to meet her because they were both in wheel chairs.

Barriers to Friendship

As mentioned above, Beth moved but still saw Alice at school. When Alice's family moves, Alice may change schools. The effects of the divorce on the two families' relationships was not discussed, other than to say they were still friends. The girls might be able to continue their friendship since they could be on the same side of town.

Keeping Up

Bridget discussed with some difficulty (tears) how
difficult it was for her to always be slow, or last at things. "It really annoys me ... even eating, and writing." These were especially difficult with the cast on.

Bridget's mother noticed that Bridget seemed to have a lot of fun planning activities, sometimes more than the actually doing them: she could plan at her own pace, she could sit down, it's a thoughtful time. Bridget has joined the student council and found a social niche that she really enjoys. Band did not work out as her instrument was too heavy.

Kestrel also reported finding a new social niche in guiding children through the wildlife museum, as part of her school's honor program. She sets the pace for the group because she is in charge. She also identifies now with the bright students at her school and feels she has caught up in her school work.

Companionship

Bridget continued to emphasize the importance of her friends "staying with" her. She thought this was most important in the model, not the help the best friend provided. She described her last Halloween as being very fun because her new best friend stayed close by ("possibly because her costume was coming off!") but the mother noted the girls had a good time "giggling and talking" while the other children she didn't know as well went ahead. Her
mother thought it was "almost like her better friends go at her pace, with their relationships being deeper with all the talking."

Help from Friends

Bridget told of her friends sharing class notes with her, as she can't write fast enough in class. Kestrel emphasized that she felt help from friends was equally important to companionship in the theory. She felt help from friends seemed to remind other children to be gentle with her and quiet down (acting as social cue).

Problems with Having JRA

Kestrel was doing well at this point, not on any medication, and very active.

Bridget continues having methotrexate shots once a week, that make her sick for 24 hours. She attends school anyway. Her mother noted she would be ill two to three days after being awake for hours at a slumber party.

Missing Out

Bridget's mother described how the increased homework load in 6th grade, taking her 20 to 30 minutes per class for eight classes, really limited her ability to get with friends, even on Sunday evenings. Also, all her days off were taken up with doctor appointments. She was missing out of many social activities.
Left Out by Friends

Bridget described another time with scouting where she felt really left out. They were in a cemetery tracing names, and at one point the other girls all ran off leaving her alone. She was scared.

Annie thought one reason her friendship with Bridget had ended was because she did some things with other children and Bridget may have felt left out. She was unsure because the girls had not discussed it. This was very hard for her to talk about, as she still felt bad.

Summary

The girls and mothers seemed to understand and like the theory. There was some disagreement over the importance of the variables Companionship and Help from Friends. There were several suggestions that it might be relevant for children with diabetes. The friendships that survived seemed to have strong parental support, and involvement at a family level. There was further support for some of the variables, and the feedback loop from Keeping Up to Problems with Having JRA continued to be a problem.

Comments by Adults with Rheumatoid Arthritis since Childhood.

One way to validate a grounded theory is to ask experts in the area of study to evaluate it. In this case two adults who have fairly severe Rheumatoid Arthritis volunteered to
discuss the model with the researcher. Meetings were scheduled with each adult, in a quiet place, where the theory could be laid out and discussed. The model was first explained and then a discussion followed. With their verbal consents, the meetings were audio taped for the researcher's convenience and the tapes were returned to each volunteer at the end of the study. Each volunteer was given an opportunity to read and edit what the researcher wrote before their personal communications were published. Their names have been changed to protect their privacy.

The first volunteer, Mr. Kelly (personal communication, Feb. 9, 1998), had JRA since 6-7 years of age. He can still remember his life before his first flare. He remembered some incidents from his childhood vividly and was able to provide many examples that fit the model from his school-age years. In general he seemed very positive about the study results, as play had been so important to him as a child. He still was in contact with some of his early childhood friends, and visited them on trips home.

The second volunteer, Ms. Morgan (personal communication, Feb. 16, 1998), did not have her first flare until age 15. Although unable to give specific examples from her school age years, she was able to use the theory to describe her adolescent experiences with JRA. For this reason I have included some of her comments in this section.
The comments by both volunteers are presented by theory variables. They do know each other somewhat through their work at the local Arthritis Foundation. Both have attended Arthritis Camp as adult role models and helpers. Both have attended the university. Ms. Morgan was employed full time at the time of the meeting and Mr. Kelly was at home, doing some consulting and volunteer work. Both came from strong, intact families that were very supportive of their efforts to achieve independence as adults.

**Visible Differences**

Mr. Kelly reported having braces on both legs in his early grades of school. He was not in a wheelchair, but by high school he "could not have gotten up if he had fallen down". Ms. Morgan described feeling "freakish" in High School because she had so much difficulty just walking down the hall. She would have to slowly shuffle and it was very painful.

**Accepted by Peers**

Mr. Kelly felt he had a "pretty good acceptance factor" among the children at his school. He grew up in the mid 1950's, outside a small town in the Northeast, where his father was the school superintendent. He was mainstreamed, long before mainstreaming became the standard, and was the only disabled child at his school. No physical accommodations were made for him at school, such as ramps or
lifts, which made it difficult to get around. He thought that a few children may have resented his father's position as superintendent, but in general he was ignored by children he was not in class with and was friends with the children in his class.

Ms. Morgan had a very strong support group of friends as she was growing up. Unfortunately her family moved just prior to the onset of the arthritis, when she was starting High School. Her frequent absences made it difficult to make friends, although one girl did bring her homework assignments.

Peer Rejection

A second reason it was so difficult to make friends for Ms. Morgan during the initial phase of her illness, was that her diagnosis remained uncertain for about a year. Initially she was told she had Rheumatic Fever. She described a painful encounter with a classmate in her chorus class. This girl had noticed her many absences and asked her what was the problem. Ms. Morgan replied "I have Rheumatic Fever." To this her classmate sarcastically replied, "You don't have a fever!" Ms. Morgan described her reaction as not knowing what to say or how to describe what was wrong, and not even knowing what Rheumatic Fever meant. She remembered thinking, "I'm not going to tell anybody again."

Also Ms. Morgan remained isolated from her peers by the
physician's prescription of bed rest, although necessary at the time. She ate alone in the cafeteria a lot the first year of High School. She felt lonely, there was no one that she knew that she could say to "Hey, I've been different, this isn't really me."

**Strategies to Manage Denigrating Social Responses**

Mr. Kelly noted he had a certain amount of peer avoidance, but not a lot. He was in several fights with other boys. He only remembered being teased once as a ten year old. He went directly to the boy's parents and complained. They called his parents and apologized, the boys became friends. Mr. Kelly pointed out the need for a positive feedback loop between Strategies to Manage Denigrating Social Responses and Accepted by Peers.

**Barriers to Friendship**

Mr. Kelly mentioned that even as a small child he felt anger at times because of the physical barriers all around him. He saw himself as fairly normal, but he had a huge problem in that people without disabilities controlled and set up the world.

Childhood hospitalizations separated Mr. Kelly from his family and friends. His family was only allowed to visit one hour on Sundays. One close friend of his father was very inventive. He made a traction devise so Mr. Kelly could come home from the hospital several weeks early.
Both volunteers experienced some difficulty in attending the University because of the physical requirements of attending class. Ms. Morgan had a lot of trouble walking on a large campus. In fact her physician suggested she rest her joints at least two years before attempting college. The thought of more social isolation from peers, (her family had just moved again), was so painful at this point, that she decided to live at home and attend classes part-time. This decision resulted in some friction with her family, although they highly valued education. Despite invitations from her new classmates, she was often too exhausted to attempt to walk to the student union for a cup of coffee.

**Keeping Up**

Mr. Kelly described play as central to his life as a child. He said he would do almost anything he could in order to stay in the center box (Keeping Up). Mr. Kelly felt he kept up pretty well through 6th grade. He started feeling left behind in 7th grade as children began to pair up although he did participate in school dances. He described himself as always "pushing himself hard." He felt he could do anything he wanted to. In High School he realized he couldn't do sports the way his father had and began to "let go", however he continued to push himself hard socially.

He spent more time in High School, being in clubs and
organizations than in doing academic work, and his grades suffered for it. But he had to be with: the sports teams, the band, the choirs, the debate team, the newspaper staff, the photo club, and the projectionist club. This was a lot more fun than studying Latin and Algebra. Part of it was being seen as capable. It was more fun to get a request from the driver education instructor, to get out of a study hall period and go run the projector for his driver education classes. He was "king of the heap". He was in charge. At this time he had pretty bad arthritis. If he had fallen down, he couldn't get himself back up. With Marching Band he would push himself right to the point of exhaustion. After a parade or a football game he was "wiped".

Mr. Kelly was not taught pacing as a child. In High School Mr. Kelly often slept through his fifth period class, after taking his aspirin and eating lunch. Although his teachers noticed, no arrangements were made for him to rest. He thought his efforts to keep up may have contributed to some joint damage. In his twenties he had several joints replaced, and this is when he realized he consciously had to pace himself. Mr. Kelly noted that even as an adult, his pacing needs can be a source of stress at times in his marriage. He finds it difficult to keep a fair balance, often his wife feels she has to accommodate his pacing needs more than he does hers. He thought in relation to the theory
that "it is good that kids are wrestling with this issue now, as it might help later."

Similarity to Ms. Morgan, there was no question in Mr. Kelly's mind that he was going to drive and attend college. His success at both were important milestones for him. Although he was very small, he passed his driver's test. However the state trooper refused to give him his license. He waited over four months until he was able to get approval to drive. He handled the entire situation himself, an important step towards independence.

Ms. Morgan also reported problems with pacing in High School. She noted "I remember in High School that I would do things that would cause me to flare real badly and I just decided it was worth it." For example, she decided to participate in the senior play. It was after school, so she would have to make it all the way through the day and evening without a break. But you couldn't go to the rehearsal at all if you didn't go to school that day. Since she knew that this was going to cost her a lot to go to the rehearsal, she decided that she would not go to school the next day if she was really bad. Her parents supported this decision, because they wanted her to do something social in her senior year. She remembers missing tests, because she had to skip the next day due to going to this rehearsal. She felt guilty sometimes she had done that, because she took
makeup tests and had more time to study than the others. However her peers had no idea what she was coping with in between. She did have an English teacher that said it was okay, and that she was glad she was in the play.

Both Mr. Kelly and Ms. Morgan saw Keeping Up as the center of the model. They felt that Problems with Having JRA limited their ability to keep up, and the description of the exhaustion they experienced in trying to keep up, supports the negative feedback loop, increasing the Problems with Having JRA.

Problems with Having JRA

Ms. Morgan gave a good description of what it was like to be so severely sick including the high fevers, painfully swollen joints, the fatigue, the injections in her hands, wrists and shoulders. Also she experienced great uncertainty and anxiety as what was wrong with her during her initial flares.

Mr. Kelly did not mention his physical problems, other than in relation to Keeping Up.

Help from Friends

Mr. Kelly recalled several specific incidents of help from his friends. In his early grades (1-3) his friends would give him piggy back rides so he could keep up on the playground. One friend could pick him up and put him into the branches so he could climb with them. When a boy came up
and pushed him down, his friends came around and told him "that's not how it's done." He had a lot of friends that were physically a lot bigger than him. One good friend from before the arthritis struck was very strong, but gentle, and was able to "rough house" with him, without hurting him. He really enjoyed this rough and tumble play. As an older child he learned to "accept help". He learned that once he took the first step, there were always a lot of people willing to help him take the second.

Mr. Kelly described his friends in adulthood continuing to act as "social buffers" for him under their own initiative. Friends would offer explanations of his illness to decrease another adult's perceived uncertainty and discomfort, even when he did not in any way ask it, seek it, or indicate he needed this help. He described it as "if they had crossed a barrier", so on the basis of their friendship they are often very eager to help other people get past the barriers too.

Companionship

Companionship was very important to Mr. Kelly as a child. As previously mentioned he had several close friends, one across the street, whom he played with every day. He also attended Boy Scout Camp and Crippled Children's Camp. In the Shriner's Hospital he made friends with a boy with Polio, whom he saw two summers after that at camp. He
described himself as seeking out companionship: "I would do anything that was required in terms of putting out physical energies." As a teenager he spent time with his friends at the local pizza parlor, just hanging out. And he mentioned "I've forgotten how powerful that was until I hear kids say it: 'What do you want to do? ... I don't know ... Let's just hang.'"

In contrast, Ms. Morgan experienced a lot of loneliness during her High School years, especially after her illness began. She had lost her close friends, including her best friend, with her family's move and was unable to replace them in High School because of her illness.

Well-Being

Mr. Kelly described himself even as a child with JRA as having "fairly good sense of well-being". He had the sense that he was very capable, very able, and very normal. But he was really frustrated by a lot of physical barriers that made things difficult. This feeling of being basically "normal" he credited as giving him the confidence to look for social niches where he could excel in High School. For example he mentioned that when he was going into Junior High school, he became aware of a boy who was "nerdy", but kept the statistics books for the football team. After the football game, everybody crowded around this boy, as he crunched out the numbers, saying "this was the number of
passes, this was the average pass". Mr. Kelly thought to himself: this guy is as wonderful and important as the hero who has caught the touchdown football! In the end, when everybody wanted to know what really had happened, everybody came to this guy. So he thought: "That's what I want to be." There's a normal guy doing that and I can do that too."

Mr. Kelly credited his sense of well-being as giving him enough confidence to obtain his driver's on his own, at age 16, even though he weighed only about 90 pounds. He said it was from his sense of well-being that he could go in to confront the state trooper. He wouldn't let his parents go in with him. He said "It was me one-on-one, talking to the 6 foot 2 inch trooper with the smokey bear hat and the 38 revolver on the hip. And so all of that came out of play for me, from going to the crippled children's camp, and going to boy scout camp, and being in band, and also to have enough gall to ask a woman to let me be her husband. I mean it all comes out of play."

In contrast, Ms. Morgan felt very different from her peers through her high school years. She wondered what was wrong with her, she felt so bad. She wasn't any better after a year of treatment, in fact was getting worse and worse, her joints were swelling, and she was having a lot of trouble walking. It was painful just to take steps down the
hall. So she thought of herself in terms of "being a freak" she felt so different.

The medical system also contributed to her sense of being "real freakish". Her family practitioner seemed uncertain as to what was wrong and what to do for her. His many consultations with other doctors before deciding on a treatment increased her anxiety that she was outside the norm. When she was referred to the rheumatologist after her first year of illness, the rheumatologist would call in the other physicians to see her. She thought "Okay, I have gone to the person who sees a lot of this and he's amazed! So I said 'Whoa' this is really horrible."

**Missing Out**

Ms. Morgan described missing out of chorus which was more of a social class. She missed the social interaction. She would try to keep up, but felt "out of it". She could not go to Physical Education, a class that had been one of her favorites before the illness.

As a small child Mr. Kelly described missing out on playground fun. He remembered not being able to do a lot of playground activities. He did an "awful lot of watching". He couldn't go up the ladder and down the slide anymore. He couldn't get going like a maniac on the swing and jump off yelling 'whee' like his friends could. These are both
examples of missing out of social events and play opportunities due to problems with the JRA.

Summary

Both adults were able to respond to the Grounded Theory of Keeping Up, in terms of their own childhood and teenage experiences with JRA. They viewed their families as major sources of support during their experience with JRA. Both were from intact, well educated families, that were able to foster their child's independence and growth. Both were able to identify ways in which families directly supported their efforts to develop friends.

In general, their responses to the theory were positive. Mr. Kelly commented that he was impressed by the definitions and depth of descriptions. He felt strongly that Keeping Up was central to his childhood experience. He suggested an additional feedback loop from Strategies to Manage Denigrating Social Responses to Accepted by Peers. He differed from the school age girls as he did get in several physical fights, but felt they were good experience.

Ms. Morgan's teenage experiences seem to work well with the model, except we did not discuss play interactions as such. She spoke of her efforts to keep up with her peers, to participate in school activities as a senior in High School, and how difficult having JRA made this. Interestingly the last half of our discussion centered on her difficulties as
an adult in keeping up in the work force. She stressed how important work was to her sense of well-being and how good it made her feel. She was able to identify many barriers to her efforts to work. She felt the model would apply to her current adult friendships as well.

The discussion of the grounded theory with adults with JRA provided information that contributes to the overall trustworthiness of the study. Their information suggests the theory developed from school age girls may be useful with school age boys, teenage girls experiencing JRA and possibly adults. This transferability cannot be assumed, but was indicated by these discussions.

The usefulness of the theory was addressed by both adults. Ms. Morgan hoped that a theory directly developed from children with JRA would help medical professionals understand some of the friendship issues that are important to them. In this way professionals might help guide parents in what to expect regarding children's reactions to treatments and any needed restrictions of activity. Mr. Kelly thought that it was important to talk about pacing at an early age with children especially to prevent further joint damage. The theory may provide one way to do that. Both adults were strong advocates of the Arthritis Camp experience for the children's development of a sense of
well-being. They saw camp friendships as an important step in this process.

Summary of Chapter Four

In Chapter Four a three stage grounded theory of Keeping Up: maintaining acceptable play interactions was presented. The grounded theory's credibility was addressed through member checks, with the children and mothers involved in the study. The theories trustworthiness and transferability was assessed when presenting the theory to two adults who had grown up with JRA. In general, the responses of everyone was positive. The children seemed to understand and be able to use the theory in describing friendships. The adults with Rheumatoid Arthritis also felt the theory was applicable to their own experiences. There is reason to believe the theory is trustworthy, credible, transferable, and could be useful.
CHAPTER FIVE

DISCUSSION

Methodological Issues

The grounded theory methodology was helpful as the Basic Social Psychological Process (BSPP) of "Keeping Up" was identified directly from the data. Three stages and thirteen variables were identified as relevant to the theory, all relating to the core category of Keeping Up.

Usefulness

This theory is useful from a research perspective because it offers a solid foundation for theory building in the future. The categories are quantifiable in the sense that scales may be developed to measure them from the data. The role of social support is specified in the model as companionship and helping with less emphasis on verbal support. Social Support Instruments are available to measure these aspects in childhood. Finally the theory is useful because it suggests the correspondence between the pediatric literature and adult literature is close in terms of definitions of social support and well-being.

From a practice perspective the theory is useful in several ways. Since the theory is from the child's point of view, "Keeping Up" is a useful way of talking about concepts of pacing and well-being to children. Second, the importance of play in the child's world is acknowledged, making the
theory useful as a point of discussion with children and parents. Third, the theory provides a way of discussing friendship interactions and the inherent conflicts therein.

The theory also reminds medical professionals of the importance of Keeping Up in the child's world, so that anticipated feelings of frustration and anger with the limitations children encounter may be discussed with them in advance. The importance of friends in maintaining a child's well-being is documented, offering one piece of support for clinicians involved in camp and support group activities for the children with JRA. By returning to camp year after year, the children may develop close friendships. These findings suggest the importance of offering support group meetings for the children throughout the year, which would allow children to continue to deepen their camp friendships.

The Grounded Theory Process

The grounded theory process was followed for this study. The Review of Literature was useful to discern the breadth of the problem, with the exception that the Review of Literature was conducted prior to the data collection and analysis. If the Review of Literature was conducted concurrently, I would have been overwhelmed with all the information. When additional categories were identified in the data analysis that were not included in the original
literature review, additional literature was sought which is included in Chapter Four, the Discussion of the Findings.

Data Collection

The data collection was done in two stages, first at camp and then in more depth at children's homes or schools (Table 3.1). These data were transcribed for accuracy but not analyzed until the home interviews were completed. This enabled the original categories to emerge from the home interview data first. This was important because the Home interviews were of better quality and were more open ended in nature. The camp interview data were added later.

Camp interviews.

The camp interviews were useful in many ways. I was able to observe the children in normal play interactions by just being at camp. I became more sensitive to their problems with mobility, fine motor skills, fatigue, and pain, than I would have been otherwise. Before the camp interview were started I read the child assent forms to each child. During this process I learned that the consent forms were too long and involved. It would have been more efficient to take care of all the paperwork before we left for camp, but this was not possible. The camp interview sites were selected by the child. Some proved noisy, most were hot, and generally we sat hunched over the tape recorder, as I was not sure how much it could pick up. The
camp interviews were semi-structured in nature. There were too many questions, so the interviews were either shortened or sometimes completed over two days. Camp interviews were fun for the children to a point, as long as the interviews were not in sight of other children playing. Unfortunately the interviews were usually conducted at "rest time" after lunch, the children's only free time. The camp staff had every other daytime hour planned with fun activities and group discussion sessions. The camp interviews were valuable because they allowed rapport to develop and gave me a chance to assess the children's willingness to participate and communicate. The youngest children had the hardest time, but by the next year's camp were willing to participate. I would not try to interview six year old children outside of the home setting in the future. The children needed parental support unless the researcher was already known to them.

Home interviews.

I found practicing the open ended style of the grounded theory interviews very helpful. I was nervous at first, doing too much talking myself, interrupting the flow of thoughts. When doing the home interviews it was helpful to talk with the mothers first, as this seemed to help the children feel more at ease. Focusing on just three or four open ended questions at the child's level was very beneficial. Dr. Haase was extremely helpful to me in
simplifying the questions. I found it difficult to know what language to use to discuss social support in concrete terms the children would understand. I decided to use the word "help". Also, visiting the children's homes provided ways to personalize the interview process. Sometimes it was difficult to relax when the interviews were done after school. Everyone was tired and these interviews tended to have a much more formal feel.

One disappointing incident took place when I forgot to turn on the tape recorder for the second half of an interview. As a result I made a second trip out to redo this part, but the spontaneity and descriptiveness of the incidents was not regained. In this case my original field notes were just as helpful, if not more.

Field notes were also helpful with describing key points from validation meetings with families and adults. Some information from camp field notes and home visit observations was categorized into the theoretical variables. These observations included ways friends helped each other at camp or observations from the child and best friend interaction in their home environments. For example, when I visited Kestrel her best friend (who lived far away) was invited also and I was able to watch the girls play together briefly before and after the interviews. I saw Lilly pick up Kestrel, who was a lot smaller, and swing her around. They
had a lot of fun with this rough and tumble play, but Lilly was always careful not to drop her.

Data Analysis

The data were analyzed during the summer of 1996 after all the tapes were transcribed and double checked. First, the data were divided into categories by hand, and then the initial categories were placed into the Nudist computer program. Each time this was done, a printout was generated, and I kept a notebook of the printouts each time the data were passed through. The categorization of the data was reviewed by Dr. L. Phillips as the theory developed.

I used the Nudist program for data management and found it helpful because it allowed the data to be printed out by category, with definitions and memos at the same node. Unfortunately, Nudist would not allow shifting categories around without deleting the definitions and memos stored at the same node. This became necessary after the fourth pass through of the data, when reduction and combination of categories was necessary. Also, at this point Nudist was very unforgiving of mistakes, and entire memos would be deleted if the wrong key was hit. As a result, I began to store memos in my study notebook instead of relying on the computer. After each pass through the data printouts were obtained, indicating the progress of the theory development.
Models of the theory drawn by hand were included at the end of each pass.

The development of the categories from data bits was fairly straightforward, in that each piece was grouped by similar content or meaning until all the data were accounted for. Each time data were passed through, categories were refined and specified (Table 5.1).

Table 5.1. Data Analysis Strategies

<table>
<thead>
<tr>
<th>Pass</th>
<th>Data Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st</td>
<td>Opening coding of Fall 95 home interviews.</td>
</tr>
<tr>
<td>2nd</td>
<td>Data matrix (subject by category) completed data grouped into 20 categories.</td>
</tr>
<tr>
<td>3rd</td>
<td>Data entered in Nudist. Categories refined. Definitions developed. Models developed of possible relationships between categories. Identified core category: &quot;Keeping Up&quot;</td>
</tr>
<tr>
<td>4th</td>
<td>Camp data added for S2, S3, S10 into Nudist. Data in 31 categories. Subcategories developed, defined. Properties identified, defined. BSP model developed - uses 13 categories.</td>
</tr>
<tr>
<td>5th  (future)</td>
<td>Consider adding Sue's and Mary's camp data into study. Both are school age girls with JRA, however home interviews were not conducted.</td>
</tr>
</tbody>
</table>

The actual theory development was not as straightforward. The theory started out developing in relation to play. Most of the variables important to the children in relation to their friends seemed to center around play. I
was having difficulties defining the "core variable". I was thinking about the data in relation to things the children with JRA's best friends had said, some of which was about the conflict within the relationships. I realized that one recurrent "complaint" had been the need to slow down and wait or miss out of things because of the staying behind with the child with JRA. From this negative case analysis, I asked myself what was the major conflict from the child with JRA's view? I realized the children with JRA focused their efforts on Keeping Up with their friends. From this step, I was able to put the categories into the theory as the data suggested.

Limitations of Study

There are still many areas where this model needs to be refined.

1. More data are needed to support the relationships between visible signs of being different and acceptance by friends and peer rejection.

2. A possible negative link between peer rejection and accepted by peers was not supported by these data although one danger of teasing is that your friends might believe what is said, and decide not to continue the friendship.

3. More data are needed to support the double arrow between maintaining an acceptable pace of play and the well-
being of the child with JRA. If the child is feeling
good and very excited, she may keep going no matter
what problems with JRA are experienced.

4. More data are needed in relation to being left out.
Possibly the less able the child with JRA is to maintain the pace, the more likely she/he is to be left out. Being left out may be a special case of peer rejection.

5. Help from friends is under-specified in the sense that some help directly enables the child to keep up, and some contributes to well-being. This could be divided into subcategories. More data are needed about different types of support.

6. Reciprocity is not portrayed in this model. A joint model including both the child with JRA and friends is needed to understand reciprocity.

Credibility Issues

Peer Debriefing

Although I attempted to validate this grounded theory, there were many issues raised in the process. For example, was it adequate peer debriefing to speak with Dr. L. Phillips and Dr. J. Haase? There were several reasons it was successful. First, Dr. L. Phillips has a great understanding of the grounded theory process. She was "neutral" in the sense that she was not a children's nurse per se, but worked
extensively with adults including the elderly, who are also a special population. She has a wide knowledge of sociology and theory building. I felt that she added an enormous amount to my ability to understand the data by asking questions, helping me to clarify and define the variables, their definitions and relationships. She was able to read the raw interview transcripts and follow the model development.

Dr. J. Haase was helpful in an entirely different way. She monitored my progress in terms of study's effect on me personally. She did not try to influence the development of the model, but to understand it from the children's point of view. Her experience in child-family nursing was extremely helpful in phrasing the research questions, and keeping the study focused on children's well-being. Her strong background in qualitative research made her sensitive to sampling decisions and interview techniques.

Theoretical Saturation

Another issue relating to credibility is the theoretical saturation of particular categories. In the Keeping Up with Friends model some categories are not fully saturated, such as Peer Rejection, Strategies for Managing Denigrating Social Responses and Peer Avoidance. If this study was continued with an additional group of children with JRA, more examples of the negative aspects of peer
relationships would be obtained. Two of the three children were socially accepted by peer groups at school at the time of this study. The peer rejection categories could also be considered a negative case analysis mainly describing one child's experiences. Although not saturated, these variables related to Keeping Up, so they are included in the theoretical model to make a more complete picture of the children with JRA's social world.

**Member Checks**

The member checks with the adults raised several issues. For example: Should the adults have signed Human Subject forms? Since they were not subjects, and had agreed voluntarily to discuss the findings, I felt that consent to participate would not be necessary. I did not anticipate their enthusiastic response and their willingness to self disclose so much information. I had planned to publish any comments as personal communications from them; but, because of the personal nature of some of their comments, I have withheld their names. In retrospect it might have been more appropriate to obtain Human Subjects Committee approval for the adult participation, although this is not a common practice when validating qualitative work.

A second issue is the selection of these volunteers. First, they were known to me from Arthritis Camp. I did not prescreen the volunteers by asking specific questions about
themselves (When did you get arthritis?), or by their gender, for several reasons. First, I did not know what kind of "informants" they would be in terms of willingness and ability to discuss the model. Second, because of my pilot work I thought that gender differences were minimal between boys and girls and their reactions to JRA and the value they placed on friendships. Third, I thought it was useful they knew about the children's camp experiences, to understand some of the examples better. Finally, it seemed better to match the volunteers with the informants in terms of their positive feelings about arthritis camp so that this study's biases could be clarified.

The use of adults with JRA to add credibility the BSPP of Keeping Up was a strength for several reasons. First, the adults with JRA were able to remember their own childhood experiences so clearly. Neither was a parent at the time. Although the adults with JRA may have forgotten some details, the incidents they did remember were verbally described in detail in regard to their emotions at the time. Their greater understanding of the way the model could work, based on their own childhood experiences, enabled them to judge it's usefulness.

Presenting the model to a new group of school age girls with JRA would be of great interest, but perhaps results would be limited by their lack of rapport and trust in the
researcher. I noticed the friends of the children with JRA were much more relaxed and open during the second (validation) visit. I also think there would be value in talking to some of the "best camp friends" after camp was over, as well as a group of children with JRA who did not attend camp.

Bracketing

The notion of "Bracketing" previous knowledge is somewhat misleading. While absorbed in the enormous quantities of data it was possible to focus only on the emergence of categories and to ignore previously reviewed literature. When the process came to working with data relating to social support, I tended to sort it into two basic types, "being with friends" and "things friends do for me". I could see all the types of social support identified in the literature by adults, but these didn't seem as relevant. If I had talked to more children, the types of social support subcategories may have been more saturated. The actual naming of categories reflects two levels of thought, the children's description and the literature.

As the theoretical specification continued, looking at the relationship/properties between the categories, I was unable to bracket my experiences with social learning theory and previous knowledge of theory construction. I say this because I was immersed in the retroductive social learning
approach as a student and when confronted with a sea of variables I tend to look for social cues, behaviors, reinforcers, and tension variables. This is akin to what Glaser and Strauss (1978) referred to as theoretical coding and can be considered another way to code. This does not dilute the value of the theory, it just reframes it so the categories' relationships can be better understood.

The credibility of the theory will be enhanced if supported, when the simultaneous data from best friends and parents are analyzed. As previously described, one issue the friends have mentioned in relation to the child with JRA's need to "keep up", was the friends efforts to "slow down" to maintain the friendship. The cost of Slowing Down was sometimes very high, and resulted in conflict in the friendship. Part of the close relationship process seemed to be learning to assess and judge these costs. Interestingly, no data from the children with arthritis dealt with this issue. Their lack of concern may not result from complete unawareness, but rather from the inability to verbally describe all their actions and feelings. For example, the children with JRA were aware when friends were bored in the play situation and then changed activities. An alternative perspective is that the children may have "healthy denial" that they are different (Miller, 1993).
The fact that the friends' data were gathered simultaneously should allow for comparison between the groups and help identify specific variables where the groups interact. Possibly the friends' theory would evolve to help explain the keeping up process further. The parents' reaction to the children's efforts to keep up would be important to describe, and their strategies to control it would be important. Also, as the adult validators indicated, it may be that as children develop, and if the disease progresses, the "Keeping Up" process would be balanced by a process of "Letting Go".

Transferability

One purpose of providing thick, rich descriptions of the study write-up is to improve the reader's ability to judge the applicability of the setting to other groups of children. This study is limited to school age girls with JRA who attended Arthritis Camp, a very small population. The problem comes with the powerful nature of the basic social process of Keeping Up. As Glaser and Strauss (1978) note, there is a tendency to see the BSPP of Keeping Up everywhere. Further work is needed to evaluate if the theory could apply to boys with JRA, to children with other chronic illnesses, or to other age groups and ethnic groups. Differences will probably be found as populations shift. For example, boys may not be as interested in receiving "help"
from their friends, or view it as positively as girls did. In my field notes there was a subgroup of camp participants who choose not to tell their friends about the arthritis. An adult with JRA who led the discussion chose not to reveal his arthritis when he was a teenage boy. A current camper, a teenage Native American boy, also did not discuss his arthritis with others. This is not to say these boys didn't have friends, companionship, and a sense of well-being developing from their play together. However, it may have been possible to "hide" the problems at this stage in the disease process. Choosing not to tell friends about arthritis may not reflect some type of "denial", so much as a realistic notion of other boys responses. The choice of revealing arthritis needs further exploration because the effort to Keep Up and reach for normalcy may continue into later years, affecting career choices that may be difficult to continue as the disease progresses.

Discussion of Findings by Category in Relation to the Literature

Chapter Two is a broad overview of childhood social support, friendship, well-being, and literature. There are sections on loneliness and peer rejection in relation to the absence of friends and qualitative descriptions of the importance of friends to children experiencing a variety of chronic illnesses. At the time Chapter Two was written there
were no middle range theoretical models available of how friendships worked to provide social support to chronically ill children. In fact, most of the work on childhood social support was developed deductively. Wills' (1985) definition that included companionship was influenced by his work with teenagers and seemed closest to school age viewpoints (Steinke, 1987). In the following section each variable will be discussed first in relation to the Review of Literature in Chapter Two and then in relation to other literature that emerged as pertinent to the findings.

Visible Differences

The category of Visible Differences found in the BSPP of Keeping Up is closely related to the literature on body image. Wolman, Resnick, Harris, and Blum (1994) found that body image was significantly related to emotional well-being for teenagers with a variety of chronic illnesses, including JRA.

Visible differences could be thought of as an indicator of severity of illness. Increased severity of illness does not automatically imply more psychosocial problems, although less severity of illness (invisible differences) has been found to be significantly associated with poor school adjustment, negative self comments, and personal adjustment (McAnarney, Pless, & Satterwhite, 1974; Daltroy et al., 1992). When the illness severity (visible differences) are
less, the peer group may have expected normal behavior from the child with JRA. The findings of this study support this notion, with the example of Kestrel wanting to wear her wrist splints as a reminder to school classmates and teachers that she was "sick". In effect, the wrist splints acted as a "social cue" in her elementary school. It is interesting to note that in the follow-up visits with Bridget, teachers expected her to take off her wrist splints to write in middle school. By wearing a cast instead of a splint, she was able to elicit the teacher's response of allowing her to not write and use other children's notes.

A second finding that related to body image was the concern the children felt about their small size. Concern about size seemed to be compensated for by Kestrel by selecting a best friend that was bigger than she was, which made her feel safer among her Sunday School peer group. Kestrel and Alice both played with younger children a lot, their younger sister's friends were about the children with JRA's size.

The category of visible differences also included perceived behavioral differences of adult's around children with JRA. For example, the children with JRA were made to feel different through actions such as the teacher allowing Bridget to use a computer to write with in class, or the principal ignoring a group of children while greeting the
child with JRA by name. Other children were quick to question these differences, and the differences could become a source of conflict. School age children are somewhat preoccupied with the notion of rules and fairness. Again these findings support the idea of visible differences functioning as social cues. When accepted as a friend, these visible differences seem to be important in eliciting helping behaviors from friends.

Finally the stigma literature supports the importance of the visible differences category. Goffman (1963) defines stigma as an attribute that is deeply discrediting to a person's virtual social identity, a characterization built on assumptions and societal norms. Goffman (1963) identified three basic type of stigma: physical deformities, character deformities, and tribal stigma, that is due to race, nation, or religion. At camp and in the interviews the children did not refer to themselves as crippled at any time. The children were aware of the difficulties each other had in walking and moving and watched each others efforts to keep up. At camp in 1995, adults with arthritis showed the children special assistive devises which could help them in the future. The children seemed uninterested.

Goffman (1963) suggests that the families create a protective "bubble" around the children as does the camp staff, so that these issues of acceptance may be of more
concern as the children with JRA reach teenage years and adulthood. A sense of shame may develop as the person with physical differences perceives he is not accepted. Acceptance becomes the central feature of the children with JRA's lives. However in this study, shame was not expressed by the children with JRA. Rather they seemed to experience a negative feeling of self-consciousness. Acceptance as a friend was just one step in the friendship process. The children with JRA did not dwell on it.

Goffman (1963) describes a range of responses by the disabled, from trying to cover up the defect at all costs to using it for secondary gains to escape from competition, social responsibilities, or to identify the limitations of normals. The camp discussions sometimes touched on the idea of the children using their illness to get out of doing something they wanted to avoid. Most of the children admitted using their illness for gain. Efforts to cover up the arthritis were discussed by the adults at camp but not actively encouraged. One of the purposes of camp was to help the children begin to plan for possible future outcomes of the arthritis by accepting the existence of the JRA as a long term problem.

Essentially the children with JRA seemed to view themselves as normal children with a health problem. Their families seemed to encourage this view as much as possible.
Complementary to the literature on stigma are writings on the concept of normalization or normalcy (Deatrick, Kuafl, & Murphy-Morse, 1999; May, 1997). Although conceptual development has been based on work with adults or parents of children who had low birth weight or chronic conditions, the theme of "trying to be normal" is relevant for analyzing children's view of Keeping Up.

The children with JRA viewed Keeping Up with friends as an important physical demonstration to other children of their ability to be part of the social world of childhood. The byproduct of these efforts was an increased sense of well-being, as they were able to feel as normal as possible. The BSPP of Keeping UP is similar to the "subjective experience of normality" (Deatrick et al., 1999). The children were cognitively learning from parents and camp counselors to define themselves as normal. That is, all normal people have problems, which in the children's case is JRA. At the same time they were learning behavioral strategies useful in maintaining their sense of well-being and normalcy.

Robinson (1993) suggests that parental practices of: covering up, including pushing, pacing, controlling information; doing normal things, such as maintaining a routine, letting children go, letting others fill in; desensitization of the child to negative social
interactions; and making tradeoffs all contribute to maintaining the family story of normalization. While parent data from this study not been fully analyzed, there was discussion in parent interviews of pushing the children in terms of self care, teaching pacing, controlling information (especially about possible future outcomes of JRA), maintaining normal routines, and "letting go" of the children in terms of the decision to send the child to Arthritis Camp. Tradeoffs were made in terms of the parent's decision to let the child participate socially, knowing the child's fatigue and pain might increase significantly the next day.

It is important to recognize that the child's efforts to blend in, control the pace of play, to watch playmates for boredom, to select novel and fun activities, and to participate as much as possible in normal social activities, are beginning strategies in their own efforts to normalize. Their dislike of talking about the arthritis is part of their effort to be normal and not evidence of denial. These findings support Robinson's (1993) description of similar strategies used to control visual and verbal information. Later, in adolescence, strategies such as pushing oneself to keep up or deciding who to tell about the arthritis, seem to come into play as evidenced by camp observations and the adult validators' experiences.
Friends play an important part in the child and family's decision to employ the normalization lens. Robinson (1993) had likened the family's decision to focus on normal events to a camera lens. "It permits one to see part of the scene while rendering other parts invisible or blurry" (p. 12). In the face of visible evidence to the contrary, friends are asked to accept the family story that the child is essentially normal and work around it. Good friends are willing to do so and may redefine "normal" to mean psychological health, overlooking physical problems. Friends help maintain the child's focus on how normal they are by including them in important social activities, acknowledging them as a friend and helping them keep up physically. When the best friend data is analyzed the costs of maintaining the story may be clarified. The study findings support and complement the normalization literature.

One difficult situation Goffman (1963) described was when a normal person and a stigmatized person meet. Stigmatized people may be uncertain of their reception, and self-conscious about the impression they are making. Their minor accomplishments may be overrated, their minor failures interpreted to be a result of their illness. When there is a visible deformity other children may stare, or strangers may talk to the person inappropriately. The "normal" person feels uncertain as well, afraid to make demands, or offer
too much sympathy. In these mixed contact situations the anxiety levels of both people can remain high. Goffman (1963) notes a child may want to avoid other children, and may vacillate between hostile bravado and cowering. Over time, the person who is stigmatized may learn to manage these mixed contact situations. Goffman (1963) describes "good adjustment" on the part of stigmatized people being when disabled people cheerfully accept themselves as essentially the same as normals, but keep themselves out of situations where normals find it difficult to accept them. For example, the adults with JRA at camp believed it was good for the children with JRA to have time away from normal children.

Being at Arthritis Camp limited problems in Keeping Up with healthy campers. Also, Goffman (1963) suggested that by sheltering the normals from the unfairness and pain helps normals remain "uncontaminated" by close contact. This definition of good adjustment was not completely supported by the adults with arthritis at camp. As was evident by their mixed reactions to the children being prepared to meet with some TV reporters, the adults with JRA were uncomfortable with the need to coach young children to smile to be "poster children", but very aware of the need to elicit funds for camp. The camp staff wanted the children with JRA to be able to be themselves and express themselves.
As a researcher at camp, I was in some ways exactly in the mixed contact situation described above. The younger children were not aware of the reactions as described by Goffman (1963) and they were more willing to accept me once they were over their initial shyness. Yet, the discomfort remained in some of my relationships with the teenagers and adults with arthritis. As a person without arthritis, I was not part of the group, but rather the minority. I was only accepted as a courtesy member after explaining my personal experiences with arthritis, on a one-by-one basis, and this was not always possible.

Accepted by Peers

The Accepted by Peers category reflects the establishment of the friendship, the social contract between two children, at the dyadic level (Furman, 1989). There was mutual recognition of the friendship by both children verbally, and the families confirmed it. This grounded theory of Keeping Up with Friends suggests that once a child is accepted as a friend by another, the children will attempt to play together, if certain barriers are surmounted. This category also reflects the quality of the friendships. For example, when the explanation of JRA is included, the acceptance as a friend implies understanding the need for gentleness, and that there are certain things the child cannot do. Tolerance and patience might be needed.
In general the Accepted by Peers/Peer Rejection categories of the model simply reflect the decision to become friends. Accepted by Peers indicates the formation of the social contract between friends. Elements relating to social support are generated as part of the friendship interactions in Being Friends.

There are some data suggesting that Help from Friends may positively feedback to acceptance as a friend. For example, often Bridget's friends would explain the arthritis problem to newcomers, which was helpful to her because it allowed her to Keep Up with what she was doing and increased their acceptance as a friend before she ever spoke to the possible new friends herself. She did not ask her best friend to do this, so I didn't list this under strategies to manage socially denigrating social responses.

Barriers to Friendship

Two types of barriers to friendships were identified in the Barriers to Friendship category. The subcategories were: structural or physical obstacles in the environment, and parental barriers. Structural barriers, such as distance between friends referred to in the adult social network literature as the "reachability" of friends in the network (Mitchell, 1969). In this study the children who lived rurally could not walk to the homes of friends. This was accepted as a normal condition. Anger, frustration, and
sadness were expressed more when a child felt left out because of physical barriers, such as when Bridget was left behind on scouting hikes or in Physical Education. Another consideration in the children's "lack of concern" with physical barriers, may be due to the tremendous support provided by these families and taken as normal. Mothers often drove the children to visit friends or carried the children when the child with JRA couldn't walk.

Parental Barriers reflected actions the parents might take as a result of their decision to promote or discourage the children's friendship, that may or may not be known to the child. For example, Kestrel's mother often arranged play dates after church, or activities after church where the two families could get together. The great distance between the families and work schedules prevented daily contact. In this way a parent's decision to support the friendship could influence a child's ability to maintain a friendship. Also parent's decisions as to whether to visit the school and explain JRA to the class are another example of how parents may act to try to increase the acceptance rate by peers. As noted in Chapter Two the role of the parents in promoting friendships has not been well studied. Cochran and Bassard (1979) have suggested that as the families interact as part of a social network, the children's relationships will benefit, along with the child's level of independence and
self concept. While some parental decisions were known to the children in the study, children may be unaware of other factors such as the financial cost, or compatibility of the families that parents may need to consider. This perspective may be enhanced when the parent interviews are analyzed.

Although parent's interviews have not been analyzed yet, it was interesting to note that in the two sets of families where the friendship survived, both children in the friendship had some long term difficulty, such as a learning disorder and diabetes. This may indicate a common "bond" between mothers as well as children. The mothers may have encouraged the children's friendship for a variety of reasons.

In the future, Barriers to Friendship could be further specified in the grounded theory into parental barriers and physical barriers. A more complete model may be more useful in a teaching situation with families, especially when parental support strategies are included.

Keeping Up: Maintaining Acceptable Play Interactions

In the findings, the idea of "acceptable" play interactions reflected the child's satisfaction with play interactions in terms of their overall positive nature of the play, despite normal conflicts between the children. Maintaining the frequency of play interactions was important to the relationship's development. Also, the child's current
ratio of dyadic to group activities may influence the child's choice of play experiences. To illustrate, the need to participate in a Birthday Party or Halloween trick or treating may be calculated by the child. Suddenly the alternative activity to the party becomes less appealing. More research is needed to clarify the child's cognitive decision making in relation to Keeping Up.

Play interactions have not been extensively studied. Play has been used in therapeutic contexts to help children work through difficult feelings and lower stress (Axline, 1969). Research in the area of creativity showed that good early play skills predicted the ability to generate alternative solutions to everyday problems and higher quality solutions (Russ, Robins, & Cristiano, 1999, p. 137).

Studies in the literature suggest play activity is a key variable for the development of subjective well-being in children (Caplan & Caplan, 1974; Diener, 1984; Kieckhefer, 1988) and as a way to cope with stress (Atkins, 1991). Play is a voluntary act, involving one child or many, which is a happy activity, "that begins in delight and ends in wisdom" (Caplan & Caplan, 1974, p. 12). Physical activity is the foremost aspect of play (Caplan & Caplan, 1974, p. 1). Children learn about their social world through play. They are free to learn about roles (adult, animal) in real or imagined situations. They learn through trial and error,
without the fear of failing, and usually without adult interference. Fantasy play allows "social rules" to be suspended, allowing the release of feelings of aggression, and disapproval of authority to be expressed.

Play activities may result in a feeling of strength in children and a relief from the powerlessness that all children may experience as minor members of an adult society (Caplan & Caplan, 1974). Note that feeling strong was an important finding in relation to the children with JRA's definition of well-being. Caplan and Caplan (1974) explain that "play gives children a chance to lay plans, judge what is best in each play situation, and to create and control the sequence of event." (p. 7). In this way play may provide a sense of autonomy (mastery) and competency.

Play may be more important to children whose mobility is restricted. Caplan and Caplan (1979) describe play as vitalizing, as it is a diversion from routines and transcends ordinary behavior. These study findings support the idea that play is a way of diverting a child from symptoms of JRA, including pain, which then increases the child with JRA's sense of well-being. Also the findings of this study suggest that novelty is an important aspect of play situations. Novelty keeps the friends engaged in the play for longer periods of time, with the intense focus on
the play, serving to block uncomfortable sensations related to JRA.

It is sometimes said that play is the child's work (Eriksons, 1963). In this sense, play interactions could be thought of as children's role behavior. In her study of adults with arthritis, Braden (1990) found maintenance of adult role behaviors directly influenced quality of life and this relationship was stronger \( r=0.75 \) for the more disabled. The relationship was weaker \( r=0.5 \) for the less disabled, who may have had more ways available to them to define their quality of life. These findings suggest that interventions for the more disabled adults need to focus on other ways to increase well-being. Identifying alternatives to work might be an useful approach. One mother of a child with JRA suggested in the validation discussion of the BSPP of Keeping Up that the active involvement of her daughter in planning student council activities benefiting others might be one approach to promoting her daughter's well-being, even if it was difficult for her to participate in the activities herself.

The properties of play that were identified also have some support in recent nursing literature. For example, in a qualitative study (Leidy & Haase, 1999) of 12 adults with Chronic Obstructive Pulmonary Disease (COPD), pacing was found to be an important way to conserve energy to maintain
their sense of effectiveness or of being able. "Being Able", "Effectiveness", "Being With" and "Connectedness" were important components of the participant's personal integrity or wholeness. Pacing was defined as "a self regulated rate of performance that permitted the accomplishment of a task or tasks with minimal or no symptoms or discomforting effects" (Leidy & Haase, 1996, p. 85). When these adults prioritized, planned, and paced themselves, past successes and failures and previous methods of expressing effectiveness were often recalled. The illness brought on a search for "alternative, less physically taxing" outlets that enabled them to continue to feel effective and able (Leidy & Haase, 1999, p. 72). The notion of pacing being a self-regulating behavior in adults is somewhat different to pacing in relation to the BSPP of Keeping Up. In this study pacing is seen as a natural ebb and flow of activity between two friends. There was no plan to accomplish a task, but symptoms did suggest to the child with JRA that the pace be slowed. This may be an earlier stage in the development of pacing.

The property of blending somewhat relates to Goffman's (1963) description of "covering", in the sense that he describes covering as: things people do that enable and make normal people more comfortable (like the blind wearing dark glasses), not in an attempt to hide the disablement, but
just to minimize their distraction by it. Another example would be a blind child being taught to "look" at the person speaking to them, rather than having their eyes wander. However, blending differs from covering because it allows the child with arthritis (not others) to feel more normal, able to keep up with the group and be part of it. Activities that promote blending, such as horseback riding and free swim, are preferred over any activity that emphasize the arthritis's effects. In this way, as with adults with COPD (Leidy & Haase, 1999), the children's effectiveness or ability is not brought into question, they are able to keep up.

The novelty/excitement level of the activity was an important property of play in the BSPP of Keeping Up that the children monitored in terms of their own and their friends reaction to what they were playing. When they detected feelings of boredom, more experienced playmates found new activities to keep the play going. Research on creativity in play with 5th and 6th graders suggests that the ability to find creative solutions in play carries into adulthood (Russ et al., 1999).

In the BSPP of Keeping Up, the frequency of the play activities was important to the children in both maintaining the relationship and increasing their ability to play. They learn to be good playmates over time. They learn strategies
to minimize conflicts so that the play session continues. If the play becomes too difficult to maintain, the friendship declines.

Help from Friends

The Help from Friends category supports concepts found in the social support literature: tangible aid, esteem support, motivational support, and informational support (Wills, 1985) and in that sense confirms the general approach in measuring children's social support in use today. This "help" was defined as things children do and say that aid the children with JRA in maintaining their ability to play, including participation in group activities. The literature on help seeking was not reviewed for this study, but a gender difference in willingness to seek help was apparent in the pilot study, with the boys less willing to ask friends to do things (Steinke, 1989).

One issue that came up was whether or not to include emotional support under the Help from Friends category or Companionship. In general it makes sense that a child receives Help from Friend when the child is upset, and a friend provides reassurance so play can resume. There was evidence in the data that friends give emotional support by talking about the arthritis and allowing the children with JRA to express their feelings. Sometimes talking served more as a distraction from the discomfort and other problems with
having arthritis. As friends spent time together there were more opportunities for talk, or emotional support to be given. The reason for the direct link to well-being is because of their repeated statements that talking with their friends made them feel good. However, the literature suggests that most emotional support at this age comes from parents (Reid et al., 1989). More research needs to be done to determine whether it is what the children actually say to each other that influences their well-being or the being together while they are talking. The confounding of emotional support with companionship is also reflected in the social support literature (Wills, 1985).

Companionship

Companionship in this study was defined as the child with JRA "being with" a friend or the friend's "being there". The physical presence of the friend was found to be important to the development of a sense of well-being of well school age children (Steinke, 1987). The findings of this study of children with JRA supported this original work. Children with JRA also missed their friends and were glad to get back to school. They liked being with a group of friends, such as when Bridget's group crowded together on the bench. They may have felt a sense of belonging. Thus companionship or "hanging" became the context for their play interactions. The physical presence of friends then served
as a visual cue to other children of Bridget's acceptance by peers.

The phenomenological study by Leidy and Haase (1999) provides evidence that personal integrity, or a sense of "being whole" was affected by illness. In a sample of adults with COPD, the illness could impair the adults ability to feel effective or able, and to feel connected with others, or the world outside themselves. If applied to children these findings suggest that "being able" to play and feeling connected or a sense of companionship during play may increase a child's feeling of "being whole" or well-being. This model of personal wholeness in chronically ill adults seems to correspond well with the grounded theory of Keeping Up.

Connectedness is defined as "a sense of significant, shared, and meaningful relationship with other people, a spiritual being, nature or aspects of one's inner self (Haase et al., 1992). Connectedness entailed familiarity, comfort, shared experiences, understanding, and trustworthiness. Again the actual physical presence of a friend may not have been so critical for the adults as they were able to recall shared experiences.

The adults ill with COPD desired a sense of familiarity and comfort, which seemed to motivate their social behavior. They would stay home more or only shop at familiar stores.
They felt socially disconnected in unfamiliar places. There were data indicating that visible differences such as nasal oxygen cannulas made them feel conspicuous in public places. Their interactions with both family and friends declined. This gives some support to the impact of visible differences in even an adult population, on their ability to maintain social relationships. They were reacting to being "looked at", as described by Goffman (1963).

The adults experienced enhanced connectedness through life long relationships including friendships. These were close relationships that could not be easily replaced and were grieved for when disrupted. Having understanding and trustworthiness of others was important for the adults to feel connected. These overlap with the social support literature in terms of emotional support and reliable alliance, although the definition of connectedness is more extensive than social support, which is usually limited to human interactions that are reciprocal in nature.

Problems with Having JRA

Problems with Having JRA include a list of symptoms associated with JRA that is well documented in the medical literature (Tucker, 1993). These include: immobility due to swollen and or damaged joints, pain in the involved joints, fever, fatigue, weight loss, and small stature. Reactions to medications have been documented as well (Siegel & Baum,
1993). Flares are usually associated with systemic JRA and all three girls experienced at least one major flare of the illness.

In general, the more problems or symptoms the girls experienced with JRA, the more medications they took, and the more reactions to medications were experienced. Both parents and the adults with JRA validated the existence of a "payback" mechanism in the theory, that is the more energy the children expended to maintain an "acceptable" pace of play, the more problems they experienced with the JRA in the next few days. This payback mechanism was not described in the medical literature. However, the medical literature reports that the actual joint damage occurring in childhood is permanent, although the inflammatory episodes may decline. Increased joint damage is associated with reduced ability to function in activities of daily living. Wallace and Levinson (1991), in a review of ten studies, found that the number of children in Steinbock's functional classes III and IV increased from 12% at 3 to 7 years after onset to 48% at 16 or more years after onset. This may indicate overuse of certain joints with age increases damage.

The payback mechanism was described by Weiner (1975) in relation to her grounded theory study of adults with rheumatoid arthritis attempting to normalize in the face of uncertainty. Keeping Up with normal activities (preparing
meals, working a job) was undertaken despite the risk of increased pain and fatigue because the feedback loop was not always inevitable. Sometimes efforts to Keep Up were made to maintain one's self image, despite the seemingly irrational nature. Some adults managed to raise their pain threshold so much that they were slow to read the signs of other types of bodily dysfunction. A final problem occurred when adults engaged in supernormalizing activity or excessive Keeping Up. Sometimes this was to prove their capacity, other times to regain a former identity. On pain free days they might try to "catch up", which may or may not result in increased symptoms the next day. The intermittent nature of the payback loop added to their uncertainty. It did not seem to do so for the children in this study. In fact parents would try in increase the children's cognitive awareness of symptomatology in order to teach self-pacing.

The BSPP of Keeping Up theory does not directly link the illness symptoms with well-being, because from the children's point of view, the key factor to well-being was their ability to keep up during play activities. The problems with JRA could often be surmounted with help from friends or family. The JRA symptomatology was just one factor in the children's overall well-being. However, these data were collected when the children were not acutely ill, so they were actively involved in their friendships and less
focused on the illness. Some literature describes such activity as "healthy denial" of the illness in children with JRA (Miller, 1993). However, parents were concerned about their children's fatigue levels, and the possible long-term joint damage. Parents were aware of the "costs" of play interactions, and sometimes intervened to limit damage.

Braden (1990) also suggests that for adults with arthritis severity of illness symptoms do not directly impact their quality of life. Braden (1990) developed a quantitatively tested five stage self-help model for adults with chronic illness such as arthritis. In this model severity of illness was not directly linked with life quality, but rather indirectly affected self-help. Self-help was defined in terms of adult role behavior, which estimated the degree to which adults were "instrumentally involved in sex roles, leisure time roles, social activity roles, family roles and self-care roles" (p. 31). Life quality was measured by the Index of Well-being (Campbell, Converse & Rogers, 1976). Results from a survey of a convenience sample of 288 adults with arthritis showed that Severity of Illness significantly influenced uncertainty to a greater degree than dependency, which together in turn influenced the adults enabling skills, self help, and finally quality of life. These results suggest that as illness symptoms increase, uncertainty and dependency would then increase as
well. These would be important issues to explore when the children are acutely ill.

Well-Being

Well-being was defined in the BSPP of Keeping Up as the degree to which the child feels good, strong emotionally and physically, and as normal as possible. The children were always aware they were "different" because of having arthritis, and anything that increased their sense of differences diminished their sense of well-being.

In the study analysis the decision was made to consider the "being different" category as part of the negative aspects of well-being such as feeling bad, weak, or slow. The feeling of being different never went away. These findings suggest affective well-being could be calculated as a difference formula, supporting Campbell's (1981) interpretation. Satisfaction with life could be measured in terms of the child with JRA's life experiences with Campbell's (1981) domains of family and friends relationships, home and neighborhoods, health (especially in terms of being able to play), school, and self as a person. Strain could possibly be measured by the children reporting symptoms of anxiety they experience, however this revision of Campbells' instrument calls for additional retesting of the validity and reliability.
Missing Out

The Missing Out category was identified as a theme in the ethnographic study of children with JRA (Steinke, 1989) and was supported in this study. Although the methodology changed, the children in both studies missed out of activities because of the problems with JRA, resulting in a negative impact on Well-being. The children felt "angry" and "bad" as a result of Missing Out, although they were not angry with their friends. They knew their friends wanted them to be there.

Missing Out was referred to only indirectly in the medical literature as part of a woman's personal description of growing up with JRA. Hall (1990) writes that as a child "My friends accepted my limitations and included me in everything as much as possible" (p. 643), although the JRA progressively worsened from age 7 to 13. Hall did not mention her specific feelings in regard to missing out as a child, but encourages the reader to maintain a positive attitude. She writes "No one likes a complainer, and it only makes you have a negative attitude about yourself. It is much easier to get up every morning if you do it with the attitude that you will feel better as the day goes on...and I feel good about myself for not giving in" (p. 644). Although she is speaking as an adult at this point, she indicates that missing out of normal daily activities has a
connection with her well-being. She goes on to say that "you don't have to give up all your activities, just learn to slow down a little and pay attention to the signals your body gives you when it starts to tire" (p. 644). She ends by saying "I just do my best to take each day as it comes, and keep a positive attitude about myself. I pay attention to the signs my body gives me and don't push myself beyond my limits. But most of all I rely on the love and encouragement of my husband, my daughter, and my parents to keep me going and to know that I can make it no matter what comes my way" (p. 644). She acknowledges the important role of social support from her family in her ability to keep up.

In addition, Miller (1993) found children with mild and severe levels of JRA reported participating in significantly fewer activities than siblings or healthy children, in a longitudinal study of children with JRA.

**Left Out by Friends**

In the findings of this study, when a child felt "left out" by a friend, the entire relationship was threatened. Left Out by Friends was interpreted by the children as a social cue that the friendship was in the termination phase. McCall and Simmons (1978) describe how difficult it can be to end a relationship, however easy it was to form. The loss of Bridget's and Annie's friendship was still painful to both girls, although the loss may be mediated as new
friendships develop.

The category Left Out by Friends was not fully integrated into the model. For example, no data from the children indicated that the more the child missed out, the more the child was left out. However, this may be the case, as indicated in the validation process by Ms. Morgan. The year she missed so much school, she ate alone in the cafeteria a lot. This category needs further exploration, and its relationship to the model clarified.

Peer Rejection, Strategies to Manage Denigrating Social Responses and Peer Avoidance

Although these three categories were not as saturated as the others, the findings support their inclusion in the model. The importance of these categories seem to depend on the stage of children's current friendship, and the life situations that children found themselves in. As supported by Goffman's (1963) work, every new person on the social scene caused uncertainty for the children and required some kind of social response.

Peer rejection was frequently found in the literature, but strategies for managing cruel actions and remarks by peers were not. Cruel actions and remarks are a significant problem, as results from recent (1999) annual Parents Resource Institute for Drug Education (PRIDE) survey indicate. In the data from the 1997-1998 summary of 6th
through 12th graders, specific questions related to name calling and teasing were not included, but 39.9% of the children admitted threatening to hurt their peers, and 39.4% had been threatened of being hit, slapped, or kicked by another student. 17.6% had been actually hurt, hit, slapped, or kicked, and 30.9% said they had actually hit, slapped, or kicked another student. In general, these results indicate that bullying behavior is fairly common at the middle through high school grades. It is reasonable to assume it's fairly common at grade school as well.

The need for a feedback loop from Strategies to Manage Denigrating Social Responses to Accepted by Peers was suggested by an experience reported by an adult validator, Mr. Kelly (see Chapter Four, Comments by Adults with JRA Since Childhood). Also when the findings were reviewed there was an incident where Bridget reported becoming "friends" with a new boy that commented about her funny walk. Since her friends had intervened for her by explaining her JRA, leading to his acceptance, this incident was considered under ways friends help. Kestrel also had difficulties with being teased, but her strategies worked only to divert the focus of the teasing from her illness and she mainly avoided these children. The presence of a direct feedback loop from Strategies to Manage Denigrating Social Responses to Accepted by Peers needs more study.
An article in the local newspaper described a program that could combat cruel actions. The program "Circle of Friends" was developed to promote friendship between disabled children and their more able classmates. The program indirectly supports the grounded theory of Keeping Up in that it was based on the idea that just having classmates "help" the disabled student was not enough to form friendships, but the children needed to "hang out together" (Cook, 1995). The program involved letting the children play games, eat pizza, share songs, and talk about friendship together. Anecdotal responses were positive from the faculty and children involved. Although the children did not understand the disabilities completely, they understood they could be friends with a disabled child.

Future Research

The above discussion has outlined many ways in which this grounded theory could be further specified and validated. New samples could be found of children with arthritis including boys, or children who did not attend camp. In either case it would be best to finish the analysis of best friends and parent data before that decision was made. After the analysis was completed, possibly a more interactional theory could be developed that would be used clinically with both parents and children. Parents have a good deal of knowledge about strategies they use to help
stop the children with JRA from damaging themselves, yet maintaining the child's well-being. The findings that efforts by the children with JRA to Keep Up lead to increased fatigue, stiffness, and possible joint damage suggests that nurses focus on helping children learn to pace themselves during play. Further study of the concept of pacing in childhood illnesses would be useful.

From a research perspective it is important to develop a more formal theory, so that the role of the good friend in promoting well-being in children with arthritis could be illustrated as well as the effectiveness of nursing intervention programs tested. Working to define and measure children's well-being would be important in itself, as it could be used as an outcome variable in many nursing studies. One challenge to the researcher is to avoid confounding Well-being with Problems with Having JRA, as both definitions refer to aspects of physical health. Problems with Having JRA needs more specification at a formal level.

Specific questions to be answered to help clarify the BSPP of Keeping Up include:

1) What cognitive processes influence the child with JRA's (and their family's) decisions to keep up with their friends?

2) What strategies are most effective with children with JRA in managing denigrating social responses?
3) What strategies are helpful to children with JRA when they are "left out" by friends?

4) What strategies are used by parents and friends to promote the child with JRA ability to self-pace or to slow down when needed?

5) By what process does pacing develop and influence the child with JRA's play interactions with friends?

6) How does the BSPP of Keeping Up change with the child's maturation into adolescence?

7) How is the BSPP of Keeping Up influenced by the gender or ethnic background of a child with chronic illness?

8) How is the BSPP of Keeping Up influenced by the type of chronic illness the child experiences?

In the relation to Question 6, it might be important to talk with adults with arthritis about their selection of careers and their ability to keep up in the work world. The recollections and experiences of adults with arthritis would provide a wealth of data for younger children and adolescents. They may be able to help create intervention programs that would help the adolescents bridge into the work world without jeopardizing their health.

Clinical Implications

Friends become important in managing the unpredictable
social world of childhood, where it may be difficult for a child with JRA to keep up. Our general society's pace is accelerating. How will children with chronic disabilities manage? Nurses are concerned with children's psychological responses to their illnesses, and could play a role in educating children and families about the value of friendship to children, the effects of arthritis on friendships, the children's desire to keep up, the strategies for parents to support their children's friendships, and strategies to teach the children to reduce the negative physical effects of keeping up, by planning, prioritizing, pacing, and using special equipment.

There are several ways the grounded theory of Keeping Up can be used by nurses in practice. First the model can be used "as is" to help a child with JRA, or their friends, understand their social world. In one validation interview with a best friend of the child with JRA, using the model of Keeping Up seemed to help clarify her reactions to the loss of a friendship as well as her understanding of the child with JRA's possible reactions. The model made it possible to talk about the best friend's attempts to repair the relationship and her feelings about it. In this sense the theory also can be used as a clinical intervention by nurses to help children with JRA understand their social world and
in effect raise their level of social awareness so that play interactions can be maintained.

The grounded theory of Keeping Up also is helpful in reminding adults working with children with JRA, of their need to be treated the same as other children. The findings suggest that children with visible differences associated with JRA are very sensitive to "unwanted attention". Each child with JRA may vary in the control they desire over how much information is revealed to school mates. Just having to "go to the nurse" sets them apart from their peers. The children with JRA's sensitivity to unwanted attention seems to correspond with the theme "who knows and who doesn't" in the qualitative study of children with cancer (Haase, 1987).

Nurses can make note of successful strategies to manage social denigrating responses that their clients have used. Some children may need to be taught to be more assertive in these situations, others to avoid escalating the conflict. The model may be useful in helping children visualize the choices they are making, and the effect of certain choices on their feeling of well-being.

Play is at the center of the grounded theory of Keeping Up. Nurses may want to encourage best friends to visit at the hospital or spend a day at Arthritis Camp. Nurses may need to coach children on how to explain JRA to their friends. In either setting best friends could meet other
friends of the child with JRA, and broaden their understanding of the illness. The nurse may have an opportunity to point out the natural pacing going on.

The grounded theory of Keeping Up looks simple and straightforward, but nurses using it are in a position to remind children of how chaotic the social world can be. Many things can happen by chance that a child may misinterpret, for example, being left out may not always be a social cue of rejection.

The grounded theory of Keeping Up may aid nurses in helping parents understand children's "deliberate disobedience" to certain therapy restrictions, as the social values of certain courses of action may outweigh treatment advice in the child's mind. The nurses can take a more holistic approach, not just focusing on the reduction of symptoms, but viewing their decisions to participate in the social world as a form of self-care.

Finally the role of the parents has only begun to be specified in this model. Nurses need to be aware of important parental decisions made in regard to the child with JRA's social world. The nurse may encourage parent's efforts to increase young classmates understanding of JRA, of their efforts to help the children find social groups of niches to belong to. The parents in this study were concerned about their children's social experiences, and
went out of their way to provide them. Parents need recognition for their efforts to promote social well-being.

Conclusion

The larger question of this study was "How do friendships influence a child's well-being in the face of a chronic illness?" This question has begun to be answered by the development of the grounded theory of Keeping Up that is specific to school age girls with JRA. The BSPP of Keeping Up indicates the complexity of the child's social world and the importance of maintaining play interactions as the prime way to influence the well-being of a child with JRA. The theory identifies points in the friendship process where nursing intervention may help improve the Well-being of children with JRA. The theory shows how difficult it can be for children with JRA to keep up with their friends, and how every gain has a price. The data from best friends and parents needs to be analyzed further to find out what cues parents and friends respond to in the same social scene, as well as to indicate their cognitive and social responses to the BSPP of Keeping Up.

The BSPP of Keeping Up suggests that certain aspects of social support are important to a chronically ill child's well-being. These include companionship and help from friends, as well as parental support, especially in reducing barriers to friendship. The findings support the main effect
model of social support, in that social support influenced the children with JRA's Well-being on an everyday basis. For school age girls with JRA, the social integration into specific groups was not quite as important as integration into their classroom settings, and the development of a best friend relationship. This could have been because the children with JRA had so much difficulty in getting to meetings, and keeping up with the group activities.

Although intimacy seems to develop in adults through verbal communication, in childhood it seems to develop through extended play interactions with friends. This theory suggests that children's ability to keep up in play with friends is central to their development of a sense of well-being. Just being together with other children, and receiving help from them, is not enough to maintain a sense of well-being. Through many play interactions close friendships develop.

Illness itself directly impacted on the children with JRA's ability to Keep Up in play interactions, but from the children with JRA's view only indirectly impacted on Well-Being. Children with JRA describe one aspect of Well-Being as "feeling strong", so that it would be important to assess their satisfaction with their overall health as a measure of their Well-Being. Well-Being should also be assessed by the
children's overall satisfaction with their friendships in terms of social support and play at school and home.

There are negative aspects to well-being for the children with JRA, reflected in how much the child "feels different" or "not normal". Physical barriers in homes and at school may increase the child with JRA's difficulty in Keeping Up with peers, increase feelings of loneliness, anger, and frustration, and decrease their sense of well-being. The model does show a role for "coping" strategies as well. Perhaps maintaining friendships is a strategy in itself, but managing negative social reactions and peer avoidance are forms of coping as well. In general the theory indicates a child's coping ability positively affects well-being.

The BSPP of Keeping Up is limited in it's generalizability at this point, but works in that it reflects only the school age girls with JRA's views of their social world. The theory identifies key categories that promote the sense of well-being in these girls: the ability to keep up in play interactions, companionship and help from friends, and strategies to manage social denigrating responses. The model shows that ability to play is central in the child with JRA's world, as with healthy children, and that illness symptoms are viewed as indirectly affecting the child with JRA's overall well-being.
The findings of the study have implications for policy decisions at local and federal levels. For example, federal funding or tax credits may be sought to support programs to encourage friendships for children with visible differences. These programs might encourage socializing with friends with similar health problems away from the school setting, such as Arthritis Camp, or programs may be funded that encourage social interaction and friendship formation in the school setting. Federal funding of education is needed to develop faculty skills in working with children with disabilities, in both academic and extracurricular activities. Schools may consider at a local level adopting policies that allow all children a flexible graduation schedule, based on mastery of content. Forming mixed age homerooms would allow all children to experience schoolmates graduating at various time as normal, and allow children with disabilities the time to participate in extracurricular activities of interest to them. These type of policy decisions could help support the development of social well-being in children with disabilities, as well as provide a source of social support in the school setting.
APPENDIX A:

ADULT SOCIAL SUPPORT LITERATURE
Adult Social Support Literature

Most social support research has been done with adults. This section will describe several definitions of social support developed from adults, problematic assumptions in adult social support research, and defining characteristics of close relationships of adults and children. Attachment theory is included as it specifically applies to children's close relationships. Children's friendships are then discussed as an example of one type of close relationship in childhood.

**Definitions of Social Support**

Four kinds of support were described by Cobb (1979). The first type he called social support or communicated caring. Social support was informational in nature leading a subject to believe he/she was cared for and loved, esteemed and valued, and that he/she belonged to a group or network of communication and mutual obligation. The second form was instrumental support or counseling to guide people toward positive coping. The third form was active support or mothering. The fourth form was material support or goods and services. Cobb described social support as being the most important type. Over the years many definitions of social support have been offered, but there has been little systematic analysis of them. What Cobb described as "social" support is now usually called emotional support and is still
thought to be the most important type. Social support has been described in terms of verbal and nonverbal information (Cobb, 1979; Gottlieb, 1978), interpersonal transactions (Kahn, 1979), social resources (Wills, 1985), and as a byproduct of social interaction (Stewart, 1993, p.7). Table 1 shows the support functions of social support as identified by various authors. This table is an expansion and modification of a table developed by Cutrona and Russell (1990). Information in the table is arranged by date of publication.

Table A1.1 shows: 1) the initial discrepancies in definitions of social network structure and social support functions (see Cobb's network support), 2) the overlap in definitions of various support functions, 3) the initial focus on emotional support until mid 1980's, 4) the inattention to social integration or social companionship, 5) the decision to include tangible aid, 6) recent inclusion of the reliability of kin or health professionals, and 7) the confusion between providing emotional support and active caregiving. Currently Cohen & Wills' (1985) approach is used primarily in the child development literature, as it includes the notions of social companionship which is so important to children. Research instruments designed to measure social support generally reflect whatever functional
definition of social support is selected. As a result, it is difficult to compare findings across programs of study.

The multiple definitions in use in the social support literature have created widely varying views of the phenomena. Some researchers view "social support" as a general rubric for social interaction. Other researchers continue to view social support as a complex multidimensional phenomenon, in which various interpersonal behaviors by members of a person's social network may help a person successfully deal with adverse life events and circumstances (Cutrona and Russell, 1990).

Problems in the study of Social Support

Most studies of social support have been done with adults. Coyne and Bolger (1990) presented evidence that questioned four basic assumptions that were critical to concepts of social support. The first assumption is that social support is something that is provided in specific observable transactions and marshalled in times of stress. When social support seeking (Coyne, Aldwin, & Lazarus, 1981) and received social support (Barrera, 1981) were measured directly, they were negatively related to adaptational outcomes. Measures of the occurrence of supportive transactions in the past (received support) confounded support and neediness. For example, people who were failing to cope sought and elicited more support during stressful
times when their usual meanings and routines became inadequate. This means when received support was measured, the absence of a supportive exchange may indicate the presence of a strong support system, in which a person rarely has to ask for help, rather than a lack of available support. For this reason Perceived Support, or a person's belief that supportive transactions will occur, is usually measured.

Enacted support refers to the supportive action of others, which is measured by asking the other person to identify what they gave to the focal person. When compared with received support, as described by the focal person, there was only a 50-60% agreement rate among adults (Antonucci & Israel, 1986; Shulman, 1976). The agreement among children is unknown.

The second assumption commonly made in the social support literature is that the informants' perception of support is the most accurate predictor of an individual's benefit. Since researchers failed to link the occurrence of supportive transactions to the effectiveness of support provided (received support) there was a shift towards measuring an individual's perceived sense of support. Perceived social support was found to be the best predictor of health outcomes (Sarason, Sarason, & Pierce, 1990). Coyne & Delongis (1986) noted that social support came to be
regarded as a personal experience, with the emphasis on individual cognitive appraisal and coping processes, locus of control, and mastery. Self-report measures of social support were heavily used, generally in cross sectional correlational designs. Other members of the family or friends were considered "sources" of social support, but not active members in the process of generating support, with needs and desires of their own. The grounded theory approach allows friends to be active members in the process of generating support if supported by the data.

A third assumption in the social support literature is that social support is a unipolar construct, so that low support indicates a respondent has less of something and those with high support have more of it (Coyne & Bolger, 1990). There is evidence in the literature that respondents may be influenced by the negative as well as positive aspects of their interpersonal relationships. Sarason, Sarason, & Pierce (1988) note adolescents may list family members as sources of support, but be reluctant to ask them for help. Feelings of guilt or dependence are too high of a cost.

The costs and benefits of social support are just beginning to be explored. On many support measures where cost is not measured directly, the responses may be viewed as summary responses of positive and negative perceptions.
Satisfaction with the network and well-being were more strongly associated with the negative features of the relationships than with positive aspects, indicating that when people report satisfaction with their network, they may mean they have few problems with it, rather than that it's very supportive (Coyne & Bolger, 1990).

A second indication that costs are involved with social support is the wide divergence between social support literature and the family therapy literature (Coyne and Delongis, 1986). Family therapists saw families functioning best at moderate levels of involvement, with over and under-involvement in close relationships perpetuating other problems. In children with asthma or diabetes, over-protective, intrusive, indulgent and self-sacrificing parents discouraged a child's development of autonomy (Coyne, Wortman, Lehman & Turnbull, 1985). Children themselves may need different levels of parental involvement at varying ages.

The fourth questionable assumption identified by Coyne and Bolger (1990) is that most persons doing badly in stressful situations need an increase in social support. People low in social support are a very heterogenous group, not just social isolates. People may be involved in conflictual, insecure relationships in which the cost of involvement may be more troubling than being alone. There
may be much to be gained by not having to contend with a close relationship with someone who is upsetting or with whom talking is not possible. Thus, what one needs to do in recovering from an illness may differ in context of a good relationship or a bad relationship. For adults long lasting close relationships may be characterized by interdependence and a sense of shared fate and mutual responsibility. Attending to one's own coping tasks is another way of helping besides trying to provide "direct support" to another person. This argument is similar to assumption 3, in that the costs and benefits of relationships need to be weighed and that one can't assume relationships are always supportive. Again it is unknown how school age children access the costs and benefits of close relationships.

A fifth assumption often made by adults when working with children, is that social relationships have the same function and nature and processes in childhood as adulthood. However, the mechanisms of how social support works in childhood are just beginning to be studied. For example, intimacy develops during late childhood and adolescence. Self-disclosure seems to be a critical variable to the development of intimate relationships. Self-disclosure is not common in school age children's conversations so by what mechanism do they develop close relationships? For school aged children, close relationships may occur through
extensive cooperative or fantasy play (Parker & Gottman, 1989).

In 1986 Coyne and Delongis called for a broader psycho-social inquiry into social support. Noting the profound connections between good relationships (complex, reciprocal, and contingent) and well-being they described a need to focus on "how people find, build, maintain and end relationships, how relationships are constrained by the personal characteristics of the people involved, the pool of people available, the circumstances of the people involved and the costs and benefits to all parties." (p. 458). In short they suggested a shift in focus from viewing social support as a cognitive process to viewing support as an individual experience of the interpersonal dynamics of close relationships. This shift has methodological implications as well, creating a need for studies using in depth interviews regarding the nature of supportive relationships and support processes as they unfold over time.

**Structure of Adult Social Support**

In 1954 Barnes, an anthropologist, defined the concept of social network when doing a study of a Norwegian Island Parrish. "Each person is, as it were, in touch with a number of people, some who are directly in touch with each other and some of whom are not .... I find it convenient to talk of a social field of this kind as a network. The image I
have is of a set of points, some which are joined by lines. The points of the image are people, or sometimes groups, and the lines indicate which of the people interact with each other. We can, of course, think of the whole of social life generating a network of this kind." (Barnes, 1954, p. 43).

Mitchell (1969), a cultural anthropologist, defined components of social support networks still in use today. A social network is defined as "a specific set of linkages among a defined set of individuals used to understand the behavior of persons involved" (p. xx). Two aspects of the network included: 1) the structural characteristics or patterns of the links, and 2) the interactional or relational characteristics of the links. Structural characteristic patterns of linkages are described in terms of anchorage, range, density, and reachability.

Anchorage refers to the individual whose behavior the observer wishes to interpret. Range refers to the number of people included in the network. Reachability refers to how close people are geographically. Density refers to how connected the network is, does everyone in it know everyone else, or is it more loose, in that many people are strangers to each other. Density has been shown to impact help seeking from professionals so that in dense networks, help is quickly obtained and there is limited access to professional help.
The relational characteristics of the linkages or ties between the people vary in content, intensity, directedness, and frequency. Content "refers to the meaning which people in a network attribute to their relationships" or often the purpose for which they were established (kinship, friendship, professional help). Content can also refer to their function e.g. support, advice, feedback. Multiplex relationships are believed to be more influential on the focal person because they cover more than one content area (Pfouts & Safier, 1981). In terms of intensity, ties may be strong or weak depending on people's commitment and/or intimacy with each other. Intensity refers to the strength of the link or extent to which the individual feels obligations and/or freedom to exercise "the rights" implied in their relationship. Ties may be directed or asymmetrical if one person has more power in the relationship or relatively symmetrical as in friendships. Frequency refers to the number of contacts among people within a network. Some minimal criterion of frequency is often useful in determining the size of the network. Objective measures of frequency or continuity might include the weekly contact time with a friend, or the length of time one has known a friend (Brandt, 1984; Pfouts & Safier, 1981; Stewart, 1993).

The network analysis approach is helpful in clarifying the structure of social support, however the process by
which support given and received is not adequately described or emphasized in this type of framework. Although the emotional nature is alluded to in the mention of intensity and symmetry of relationships, level of conflict in relationships is not mentioned, nor is cognitive nature of social support mentioned.
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<tbody>
<tr>
<td><strong>Attachment</strong></td>
<td>Non-interchangeable social bonds, provide a sense of security &amp; place, involve caregiving</td>
<td>Refuge for stability and comfort</td>
<td>Emotional Support</td>
<td>Affect</td>
<td>Admiration, respect, or love</td>
</tr>
<tr>
<td><strong>Social Integration</strong></td>
<td></td>
<td>Network Support Defined position in network of communication and mutual obligation</td>
<td>Convoy: a person can be thought of as moving through life surrounded by a set of significant other people to whom that person is related to by the giving or receiving of social support</td>
<td>Environmental Action Support</td>
<td>Social advocacy</td>
</tr>
<tr>
<td><strong>Reassurance of Worth</strong></td>
<td>Help mobilizing psychologic resources &amp; mastering emotional burdens</td>
<td>Esteem Support</td>
<td>Feel valued and esteemed</td>
<td>Affirmation Agreement with another's behaviors or perception</td>
<td>(see emotionally sustaining behaviors)</td>
</tr>
<tr>
<td><strong>Opportunity for Nurturance</strong></td>
<td>Provision of material supplies and skill, help with tasks</td>
<td>Material Support</td>
<td>Goods and services</td>
<td>Aid</td>
<td>Symbolic, material, money, time, information</td>
</tr>
<tr>
<td><strong>Guidance</strong></td>
<td>Information, guidance, and feedback, cognitive guidance</td>
<td>Instrumental Support Counseling to improve coping</td>
<td>(see aid)</td>
<td>Problem solving Behaviors</td>
<td>New information or new perspectives</td>
</tr>
<tr>
<td><strong>Reliable Alliance</strong></td>
<td>Expect help from Kin despite lack of mutual affection or reciprocation for past help</td>
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Table A1.1 Functions Identified in Social Support Literature Compared to Weiss's Provisions of Social Relationships
Table A1.1 Continued

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<tr>
<td><strong>Emotional Support</strong></td>
<td>Intimate Interaction Non-directive interactions that allow for expression of feelings, concerns, mastering emotional distress</td>
<td>Esteem Support Feel accepted and valued</td>
<td>Esteem Support</td>
<td>Esteem Support</td>
</tr>
<tr>
<td><strong>Social Participation</strong></td>
<td>Social Companionship</td>
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<tr>
<td><strong>Appraisal Support</strong></td>
<td>Positive Feedback</td>
<td>Motivational Support</td>
<td>Appraisal Support Objective feedback, advice, problem solving</td>
<td></td>
</tr>
<tr>
<td><strong>Instrumental Support</strong></td>
<td>Physical Assistance Material Aid</td>
<td>Instrumental, Tangible or Material Aid</td>
<td>Tangible Support Aid</td>
<td></td>
</tr>
<tr>
<td><strong>Informational Support</strong></td>
<td>Advice</td>
<td>Informational Support (see appraisal support)</td>
<td>Information</td>
<td>Reliable Alliance</td>
</tr>
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Status Support
APPENDIX B:

HUMAN SUBJECTS CONSENT FORMS
PARENTAL CONSENT FORM

The Influence of Friendships on the Well-being of Children with Arthritis

I AM BEING ASKED TO READ THE FOLLOWING MATERIAL TO ENSURE THAT I AM INFORMED OF THE NATURE OF THIS RESEARCH STUDY AND OF HOW MY CHILD AND I WILL PARTICIPATE IN IT, IF WE CONSENT TO DO SO. SIGNING THIS FORM WILL INDICATE THAT WE HAVE BEEN SO INFORMED AND THAT WE GIVE OUT CONSENT. FEDERAL REGULATIONS REQUIRE WRITTEN INFORMED CONSENT PRIOR TO PARTICIPATION IN THIS RESEARCH STUDY SO THAT WE CAN KNOW THE NATURE OF THE RISKS OF OUR PARTICIPATION AND CAN DECIDE TO PARTICIPATE OR NOT PARTICIPATE IN A FREE AND INFORMED MANNER.

PURPOSE

My child and I are being invited to participate voluntarily in the above-titled research project. The purpose of this project is to study how children's friendships influence the well-being of children with Juvenile Rheumatoid Arthritis (JRA).

SELECTION CRITERIA

My child is selected to participate in this study because he/she has arthritis or is the best friend of a child with arthritis, and is under the age of 18. Five to ten children with arthritis, their parent, the child's best friend, and best friend's parent will be enrolled.

Procedure

If we agree to participate, one interview with the mother or father will be done to assess the physical status of the child. Questions include the type of JRA, the length of time since diagnosis, medications the child is on, school attendance, level of activity, frequency of flares, as well as the parent's impression of the child's friendships and the parent's role in maintaining them. A further interview may be needed during the course of the study.

Approximately 2 to 4 interviews will be done with each child at a convenient quiet place in the child's home, when one parent is present, or at arthritis camp. The interviews would be 30 to 60 minutes in length. These interviews will
focus on the child's experience with arthritis, friendships, and things friends do and say that help the child feel good.

At the end of the child's interviews, the child will be asked for permission to speak with his/her best friend. If permission is given, the parent of the child with arthritis will be requested to contact the best friend's parents to ask if the researcher could contact them. Approximately 2 to 4 interviews will be done with my child's best friend and their parent.

All the interviews will be audiotaped with permission of my child at the beginning of each session. This will allow the interviewer to attend to non-verbal cues such as fatigue and to shorten the interview if needed. All tapes will be transcribed, checked for accuracy, and then be stored in a safe, locked place.

Finally permission will be sought from the local arthritis foundation to attend community arthritis related activities, support group meetings, and summer camp in order to observe participating children's interactions with friends.

RISK

There is no known risk involved in this research other than possible fatigue from the interviews. Also there is a possibility the interview process may change the relationship between the child and his/her best friend.

BENEFITS

The benefit of this study is that more information may be gained as to the importance of friends in the lives of chronically ill children and how it influences their well being.

CONFIDENTIALITY

All information associated with this study will be held in confidence and only Nancy Steinke, R.N., M.S.N., and members of her dissertation committee will have access to the information. My child will be assigned a number and that number will be on all documents rather than his/her name. Only Nancy Steinke, R.N., M.S.N. will know the identity of my child.
PARTICIPATION COSTS AND SUBJECT COMPENSATION

I understand the only cost to me or my child will be that of the time involved in completing the interviews to which I am agreeing. I understand my child will receive a movie pass of about $7.00 value for his/her time.

I can obtain further information from Nancy Steinke, R.N., M.S.N., at 749-1621. If I have questions concerning my rights as a research subject, I may all the Human Subjects Committee office at 626-6721.

AUTHORIZATION

BEFORE GIVING MY CONSENT BY SIGNING THIS FORM, THE METHODS, INCONVENIENCES, RISKS AND BENEFITS HAVE BEEN EXPLAINED TO ME AND MY QUESTIONS HAVE BEEN ANSWERED. I UNDERSTAND THAT I MAY ASK QUESTIONS AT ANY TIME AND THAT I AM FREE TO WITHDRAW MY CHILD FROM THE PROJECT AT ANY TIME WITHOUT CAUSING BAD FEELINGS. MY CHILD'S PARTICIPATION IN THIS PROJECT MAY BE ENDED BY THE INVESTIGATOR. NEW INFORMATION DEVELOPED DURING THE COURSE OF THIS STUDY WHICH MAY AFFECT MY WILLINGNESS TO CONTINUE IN THIS RESEARCH PROJECT WILL BE GIVEN ME AS IT BECOMES AVAILABLE. I UNDERSTAND THAT THIS CONSENT FORM WILL BE FILED IN AN AREA DESIGNED BY THE HUMAN SUBJECTS COMMITTEE WITH ACCESS RESTRICTED TO THE PRINCIPAL INVESTIGATOR, NANCY STEINKE, R.N., M.S.N., OR AUTHORIZED REPRESENTATIVE OF THE COLLEGE OF NURSING. I UNDERSTAND THAT I DO NOT GIVE UP ANY OF MY LEGAL RIGHTS BY SIGNING THIS FORM. A COPY OF THIS SIGNED CONSENT FORM WILL BE GIVEN TO ME.

______________________________      ________________
Parent/Legal Guardian                Date

______________________________
Phone Number

______________________________
Child's Name

INVESTIGATOR'S AFFIDAVIT
I have carefully explained to the subject and the parent/legal guardian the nature of the above project. I hereby certify that to the best of my knowledge the person who is signing this consent form understands clearly the nature, demands, benefits, and risks involved in his/her participation and his/her signature is legally valid. A medical problem or language or educational barrier has not precluded this understanding.

Signature of Investigator ____________________________ Date _____________
Demographics

Child's Age _____

Grade in School _____

Primary Language Spoken at Home ________________

Ethnic Background

<table>
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<tr>
<th>Hispanic</th>
<th>Native American</th>
<th>Asian</th>
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<table>
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<tr>
<th>African American</th>
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<tr>
<th>Caucasian</th>
<th>Asian</th>
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Members of Family and Ages (Please circle who lives at home with the child)

Siblings: ________________ ________________ ________________

Step Children: ________________ ________________ ________________

Parents' Marital Status (current)

Married _____

Single _____

Step Parent _____

Parents' Education

Parent #1 __________

Parent #2 __________

Parents' Occupation

Parent #1 __________________

Parent #2 __________________

Parents' Income

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<tbody>
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<td>$0-10,000</td>
<td>$10,000-20,000</td>
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<td>$20,000-30,000</td>
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Parent's Address ________________________________
CHILDREN'S ASSENT FORM

The Influence of Friendships on the Well-being of Children with Arthritis

I am requesting your help with this research study about how children think and feel about their friends, and how friends help children when they have arthritis. I am asking children between 6 and 18 years to help me with this study. I will want to talk to you 2 to 4 times in a place that is private and comfortable for you, probably in your own home, with your parents around or during some quiet time at arthritis camp.

I will ask you to talk directly with me about how you feel about your friends. I will tape record your words so that I will not forget what you have to say. I think what you have to say about all this may help us to understand some of the things children with arthritis have to deal with as they grow up.

Please decide for yourself whether or not you wish to be a part of the study. However you decide will be all right. There is no reason I know of that any of this will hurt you. You may ask me any questions you wish about the study and I will answer them. You may stop talking with me anytime you like. You will not have to answer any questions you do not wish and you will not have to explain why. At the end of our interviews I will ask you if it is all right to talk with your best friend. I will do so only if it is all right with you, your parents, your best friend's parents, and your best friend. If you feel in any way this might hurt your friendship, I will not contact any of your friends. This really will be your decision.

When you finish talking I will write about what you have said, but I will not tell anyone your name. This means there will be no way for others to know what you have said. I will use what your have told me to write papers and to share with others what children like you think and feel about growing up with arthritis. I will keep the tapes in a safe place so others cannot hear them. In appreciation for all your time and effort, you will receive a movie pass worth about $7.00 at the end of the study.
I want you to remember that anytime you do not want to answer a question or anytime you do not want to be a part of the study, all you have to do is tell me. You will not have to explain why and it will not affect your relationship with me.

I want you to keep a copy of this form so you will remember what I have said to you. I am asking you to sign it. When you sign it, it means that you understand what I have said.
I understand what has been written in this assent. What it means had been explained to me and my parent(s). I know that I may ask questions and I may stop helping with this project any time I choose, and this will not make a difference in my relationship with the researcher. I understand that this consent will be kept in a safe place and that only the research people can look at it.

______________________________    _________________________
Subject's Signature                  Date

______________________________    _________________________
Principal Investigator              Date
ADDENDUM TO PARENTAL CONSENT FORM

The Influence of Friendships on the Well-being of Children with Arthritis

PARTICIPATION COSTS AND SUBJECT COMPENSATION

I understand the only cost to me or my child will be that of the time involved in completing the interviews to which I am agreeing. I understand my child will receive a movie pass of about $7.00 value for his/her time.

_________________________________________        ______________
Parent/Legal Guardian                                  Date

_________________________________________
Child's Name

_________________________________________        ______________
Signature of Investigator                                 Date
ADDENDUM TO CHILDREN'S ASSENT FORM

The Influence of Friendships on the Well-being of Children with Arthritis

In appreciation for all your time and effort, you will receive a movie pass worth about $7.00 at the end of the study.

Subject's Signature  Date

Signature of Investigator  Date
APPENDIX C:

SAMPLE SEMI-STRUCTURED INTERVIEW QUESTIONS
Sample questions for parents.

1) Would you tell me about when you first found out about your child's arthritis?
   - How old was the child (position in family)?
   - What happened?
   - Parents thoughts, feelings.
   - Early treatment - Prognosis given by doctors.
   - Any hospitalizations.
   - Family history of arthritis.
   - Who is main care provider - affect on them?

2) What type of JRA was diagnosed? What is this like for your child (S&S).

3) How extensive is the JRA?
   - level of activity
   - flares? - season, duration, pain
   - what bothers your son or daughter the most?
   - child's reaction to illness symptoms (loneliness, sadness, boredom)

4) What treatments have been prescribed?
   - medications, reactions
   - exercise programs
   - expenses

5) What kind of pain does your child experience?
   - medications
   - other behavioral/cognitive strategies
6) How is your child doing with the arthritis?
   - school attendance, grades, teacher support?
   - sports
   - camp attendance
   - support groups? / arthritis foundation activities
   - lonely periods

7) Do you think having arthritis has made a difference for your child in terms of his/her friendships?
   - does he/she have a best friend?
   - lots of friends/few friends
   - distance to friends? overnight? phone contact?
   - what kinds of things do you do as a parent to encourage/discourage his/her friendships
   - what about relationships with siblings

8) How do you think your child's friends influence his/her well-being or happiness?
   - examples
   - before/after play periods

9) What kinds of help do your child's friends give (emotional, tangible, infer, esteem)
   - at home
   - at school
   - at camp

10) What kinds of things does your son/daughter do with his/her friends? (play, spend time together).
11) Are there times when you are concerned about the effect his/her friends are having on your child's well-being? 
   - examples/how they handled it.

12) Is there anything that you would tell other parents of children with arthritis in relation to your thoughts or concerns about your child's friendships?

13) How would you describe your child's sense of well-being? What does he/she seem to base it on? What do you look for?
Sample questions for children.

Arthritis

1) Would you tell me about your arthritis? What is it like for you?
   - in day time, at home/school
   - at night
   - summer/winter
   - flare ups?
   - where does it usually hurt? (Can other people tell?)
   - what do you do if it hurts?
   - what medicines do you take? (what, when, who reminds them, purpose, reactions to medicines)
   - what exercises

2) How did you first find out about it? thoughts? feelings? what did you do?

3) What do you think caused it to start?

4) How long do you think it will last? thoughts? feelings?

5) What are the worst things about having arthritis? the best things?

6) What is it like to deal with arthritis on an everyday basis? (at home, at school)

7) What does your family do to help you with the arthritis?

Friendships

1) What kinds of friends do you have?
   - Best friend
- good friend
- school friend
- neighborhood friend
- teammates
- camp
- support group friends

2) How did you meet them?

3) What do you like to do together?

4) What kinds of things do you talk about?

5) Have your friends noticed the arthritis?

6) How did you explain "having arthritis" to your friends?

7) What are some things your friends do for you that helps you feel good?
   - about having arthritis?
   - when the arthritis really hurts?

8) What kinds of things do you do for your friends?

9) How do your good friends know when you need them to do something because of the arthritis? What do you do then? How do you feel if you ask them to help you?

10) Is it easier to ask some friends for help than others?

11) What is it like at school having arthritis?
    - gym
    - recess
    - lunch
    - teachers
12) How have your friends helped you at school?
13) Has anything embarrassing happened with your friends because of the arthritis?
14) Are you having any trouble with bullies, half enemies or enemies these days?
   - examples
   - what do your friends do?
15) Are there certain times you don't want to be with your friends? (flares)
16) Could you tell me about how just being together with your friends make you feel?
17) Even best friends argue or get mad at each other sometimes. Has this ever happened to you? How did you work things out?

Loneliness
18) How often do you get lonely?
   - What do you do when you are lonely?
   - How do you feel?
   - What do you think about?
   - How does being together with your friends help?

Well-being
19) What is it like when you feel your best? On top of the world?
Sample Questions for Best Friends

Friends

1) Would you tell me about how you first met (child's name)?
   (Are you best friends? Good friends? School friends or
   neighbor? Part of a group? Teammates?)

2) When do you usually see each other?
   - daily? weekly?
   - in school? after school?
   - summer/camp?

3) How do you arrange to get together?
   - phone calls

4) What kinds of things do you like to do together?

5) What kinds of things do you usually talk about together?

Arthritis

6) Would you tell me about when you learned (child's name) had arthritis? (how did you figure it out)
   - what were your thoughts?
   - feelings?

7) Let's talk a little about arthritis.
   - What do you think arthritis is?
   - How do children get it?
   - What is the best way to explain arthritis to another friend of yours?

8) Arthritis can be pretty painful sometimes. Can you tell if (child's name) is having pain from the arthritis?
What do you do for them?

9) What kinds of problems does (child's name) have with arthritis at home?
   - the park? (playground)
   - school?
   - camp?

10) What kinds of things do you do that helps?

11) How do you feel about help (child's name)? Are some kinds of help easier than others? What kinds of things does (child's name) do to help you?

12) What things do you worry about in terms of the arthritis and (child's name)?

13) Is there anything fun about having a friend with arthritis?

14) What's difficult (hard) about having a friend with arthritis?

15) Have you met any other children with arthritis? What was that like? What would you say to them?

Friends

16) What do you think is best about just being together with (child's name)?

17) Even best friends argue or get mad at each other sometimes. Has this ever happened to you? How do you usually work things out?

18) Sometimes other kids may not understand as much about
(child's name)'s arthritis as you do. Has anything happened with other kids that caused (child's name) or you to feel bad? (be embarrassed) What did you do?

19) Are there certain time you don't want to be with friends? With (child's name)? Just alone?

Loneliness

20) How often do you get lonely?

  - What do you do when you are lonely?
  - How do you feel?
  - What do you think about?
  - How does being together with your friends help?

Well-being

21) How can you tell when (child's name) is feeling really good? (On top of the world?)
REFERENCES


Paterson, B. L. (1994). A framework to identify reactivity in qualitative research. WJNR, 16 (3), 301-316.


