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IMPACT OF CHILDREN'S CHRONIC DISEASES ON THE GLOBAL SELF-WORTH OF SIBLINGS

By

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ABSTRACT

IMPACT OF CHILDREN'S CHRONIC DISEASES ON THE GLOBAL SELF-WORTH OF SIBLINGS

By

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Advances in health care have led to an increased prevalence of chronic illness in children and longer life spans for chronically ill children. Chronic childhood health disorders are a significant threat to effective family functioning and the well-being of individual members. This study investigated the impact of chronic childhood illness on siblings. The study used global self-worth as one measure of children's global perception of their worth. Global self-worth is the extent to which the child likes him/herself as a person, is happy in the way he/she leads their life, and is generally happy with the way he/she is. Thus, global self-worth constitutes a judgement of one's worth as a person, rather than a domain specific item, such as scholastic or athletic competency. Self-worth was directly evaluated through specific questions rather than measuring indirectly by inferring information from an average or sum of other self descriptions.

The study compared global self-worth in siblings of children with chronic illness and siblings of healthy children. The results were encouraging in that no difference in global self-worth was found between siblings of a chronically ill child and siblings of a healthy child. In viewing chronic illness as a stressor the APN can utilize King's theory to assist siblings in adjustment through education, anticipatory guidance, consultation and community referrals. Further research is necessary to identify siblings' positive coping strategies to assist other siblings of chronically ill children.

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INTRODUCTION

Advances in health care have lead to an increased prevalence of chronic illness in children and longer life spans for chronically ill children. The actual number of children living with chronic diseases is not known. Gale (1989) estimated 7.5 million children have a chronic condition. Estimates from United States census data indicate more than three million children age one to nineteen are limited in activities of daily life by severe, chronic childhood illnesses. Their family members are also affected by chronic diseases (Fulton, 1995).

Chronic childhood health disorders are a significant threat to effective family functioning and the well-being of individual members. This study investigated the impact of chronic childhood illness on siblings. The study used global self-worth as one measure of children's perception of their worth. Global self-worth constitutes a judgement of one's worth as a person, rather than a domain specific items, such as scholastic or athletic competency.

The definition included direct evaluation of self-worth through specific questions rather than measuring indirectly by inferring information from an average or sum of other self descriptions.

RESEARCH QUESTION

Is there a difference in perception of global self-worth between siblings of chronically ill children and siblings of healthy children? The specific aim of the study was to identify whether there was a difference in global self-worth between the two groups of siblings. The hypothesis was that perception of global self-worth would be significantly lower in siblings of chronically ill children than in siblings of healthy children.

DEFINITIONS

Self perceptions are linked to people's mental well-being and motivational states. Harter (1990) clearly demonstrated that children with a low self-worth and a depressed affect or mood also had decreased motivation and decreased energy levels. Self-concept, self-esteem, and perceived competence have been examined as outcomes of overall sibling adjustment. *Self-concept* is defined as a person's self description of whom and what they are. Combs (1981) defined self concept as the thoughts that people have about themselves and the affect (values) that accompany the thoughts.

Self-esteem/self-worth (synonyms) is the person's evaluation of the good, or value inherent in his or her self description. This general evaluation of self-worth is based

on the parts of self-concept that one perceives as important. To understand self-esteem, it is necessary to determine what competency's one recognizes in oneself and the perceived social acceptance by people who are important to the person.

James (1890) emphasized competence and adequacy by stating self-esteem is determined by the ratio of one's "success" to one's "pretensions" He believed that people set standards for themselves and feel good about themselves if they meet or exceed those standards. If they fall short, they may have negative self feelings. James' formulation that self-esteem equals ones' successes divided by one's pretensions have been supported by others (Harter, 1985).

Harter (1985) described self-worth as more than a total sum of equally weighted components of the self-concept. Harter developed a differentiated model and suggested that people have a general sense of self, which is not a simple summation of self-concept elements. Rather, it is a result of assessment of the elements of one's self-concept in relation to the importance of those elements to the individual. Therefore, important elements contribute to self-esteem; unimportant ones do not. This differentiated view of self-esteem allows one to examine not only the effects of interventions, but also the relationship of various self-concept elements to each other and to one's

self-esteem.

Harter (1986) found that both perceived competence and social support were important predictors of global self-worth in children. Harter (1983) described a hierarchical structure to explain the development of self-worth. According to Harter, global self-worth is composed of four second-order domains; competence, power, moral worth and acceptance. Harter's (1985) model is hierarchical, but does not simply sum the domain scores to arrive at an estimate of global self-worth (Figure 1). Harter viewed self-worth as more than the sum of the parts.

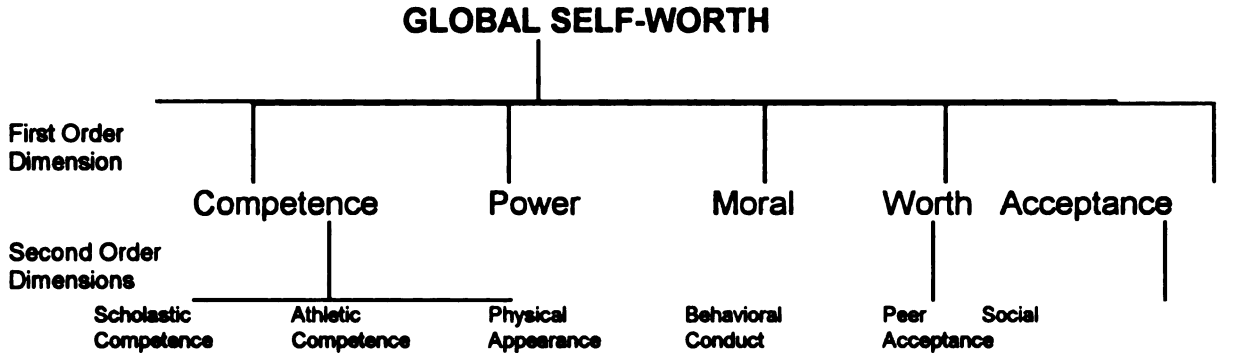

Figure 1. The dimension's of Harter's Self-Perception Profile for Children.

Harter's (1985) studies supported that both competency and social support contribute to general self-worth ratings. She found that competence and social support had no interaction effects, but both added independently to general self-worth. Children with the highest self-worth scores were those who had both high social support scores and low discrepancy scores between self-worth and competence/importance. Conversely, children with the lowest self-worth scores were those with low perceived social support and high discrepancy scores. Between these two extremes were the children who showed relatively low self-worth ratings if either their discrepancy scores were high or their perceived social support was low. Thus, both competence and social support appeared to contribute to self-esteem, with neither being able to fully compensate for deficiencies in the other (Mayberry, 1990).

To evaluate self-worth Harter uncovered several

important developmental themes for children. First, items measured needed to be graded according to the child's developmental level to ensure his or her activities are representative of their views. Second, the test items needed to be described in a manner appropriate for the level of the child. Third, children may overestimate their competency due to an age appropriate tendency to confuse desire to be competent with reality and receipt of positive feedback from significant others regarding accomplishments.

Harter (1989) noted young children's global self-worth as rated by others (parents or teachers) is not expected to be related to the child's perceived competence level, whereas children's perceptions of acceptance especially from parents are related to global self-worth. Harter found that the dimension of competence only begins to play an actual role in global self-worth during middle childhood (eight years and older).

Harter developed and validated scales to evaluate both physical and psychological domains which impact global self-worth (Whitehead, 1995). Harter's work demonstrated that subdomain perceptions were correlated with global perceptions of one's self-worth. She demonstrated the necessity to examine the importance that *individual's* attach to being competent/adequate in five subdomain areas. Harter showed that individuals have a self-serving tendency to protect their global self-worth by psychologically

discounting the importance of subdomains where they perceived incompetence or inadequacy. Harter demonstrated that if children were unable to discount the importance of subdomain perceptions of incompetence/inadequacy, their global self-worth scores would be lowered. This may be due to the high value placed on those aspects by significant others. The resulting low competence-high importance discrepancies were strongly predictive of lowered global self-worth. (Whitehead, 1995).

A double jeopardy of "negative outcomes" might result for individuals who are low in perceived competence. If such individuals could successfully protect their global self-worth by discounting the importance of competence in a subarea, their motivation to take part in activities would be reduced. Alternatively, if the importance of competence in the area was stressed sufficiently to prevent those individuals from easily discounting it then theoretically their global self-worth would be suppressed (Whitehead, 1995).

MECHANISMS FOR ASSESS AND MAINTAINING SELF-ESTEEM

To understand self-esteem one must understand the mechanisms for its formation and modification. James (1890) described the ratio of success to pretension as a determinant of self-esteem. One can change self-esteem by either changing one's successes (i.e., becoming better in a

domain that is important) or changing one's pretensions (i.e., lowering one's expectations). Changing one's success may involve long term effort and may be impossible. Some things are beyond a person's ability to change. An examination of the feasibility of changing ones' pretension, therefore is important. Discounting is a mechanism that may be used to ensure that a person has an adequate level of self-esteem. Discounting described by Bem (1972) is a mechanism by which expectations might be changed. When people discover, they are not good in a domain they may choose to subsequently discount the importance of that domain thereby balancing the equation in order to maintain adequate self-esteem. Harter (1985) described evidence for discounting when it was noted that children with high self-worth tended to have importance ratings that were similar to their corresponding competence/adequacy ratings, where as children with lower self-esteem tended to have importance ratings that were much higher then their corresponding competence/adequacy scores (Harter 1982). Such findings could be explained by discounting. Harter's instrument evaluates the importance of the domain as the hypothetical child would evaluate it. The scale is from *"(1)-hardly important at all, (2)-not very important (3)-pretty important or (4)-still very important."* Harter's findings initially indicated that the children with low self-esteem actually discounted more than the children with medium or

high self-esteem (Appendix A and B).

SUMMARY OF DEFINITIONS

Chronic Illness. Illness characterized by long duration, need for specialized health care services, potentially limited life expectancy, and either no known cure or uncertain prognoses (Whitehead, 1995). In this study chronic illness was determined by family self-report, medical records and diagnosis by a pediatric sub-specialist physician that the child was diagnosed with asthma, cystic fibrosis, diabetes, or congenital cardiac disorders.

Global Self-worth. Global self-worth is the extent to which the child likes oneself as a person, is happy in the way they lead their life, and is generally happy with the way they are.

Perceived Self Competence. A feeling of being able to cope with problems and meet goals. A positive attitude of their ability to problem solve and be responsible for their own actions to achieve success. Overall, integration of self evaluation to form an overall sense of self-worth.

RELEVANCE TO NURSING PRACTICE

Childhood illness causes a variety of stressful situations. When the illness is chronic, additional stressors such as lifestyle changes, loss of developmental gains and failure to master anticipated social and developmental roles evolve. The number of people affected by chronic disease has increased due to advances in technology. Currently new treatment extends the life of individuals with previously fatal illnesses. Health care providers have also expanded expectations for the family to provide more technical in-home care for ill family members (Wheeler, 1993). The setting of care for chronically ill individuals has shifted from health care settings to home care by parents and family members.

Description of the impact of chronic childhood disease on siblings contributes to nursing's knowledge base which supports the role of the Advanced Practice Nurse (APN) for families. The impact of disease on all family members must be taken into consideration to provide holistic family nursing care. Brody, Stoneman & Mackinnon's (1986) evidence suggests that the family environment is a critical force in shaping a broad range of important social and emotional childhood behaviors.

The APN must understand the impact of chronic childhood illness on *all* family members to assess individual and family health care needs (Lubkin, 1986). The APN can educate and counsel parents about anticipated behavior in siblings and support development of positive parenting skills for their children. Ongoing counseling and education assist in stabilization of the family through developmental milestones and encourage development of problem-solving skills (Mays, 1988). The APN and family can develop goal-directed strategies to facilitate achievement and maintenance of health-oriented behaviors (Whall, 1993; Willoughby, 1996). The APN can direct the family to available community resources and develop needed resources to provide comprehensive health care. In the shift from episodic care to lifelong care, the APN's assessment of factors which influence self-perception are valuable to assist in the selection of positive coping strategies for people affected by chronic illness (Pless, 1994; Perrin, 1998). An understanding of factors which may influence global self-worth is important to provide anticipatory guidance for families as part of a comprehensive approach to health care. Such knowledge enable APN's to better assist families coping with the effects of chronic childhood illness.

Siblings can be encouraged to express their feelings about the effects of the illness on the family. They can be

counseled on the importance of open communication to share their concerns, to relieve feelings of isolation and aid siblings to adjust to the demands of a chronic childhood illness. Siblings have been identified as the most neglected of all family members during serious childhood illnesses. Siblings of children with chronic illness can experience great stress. Care providers have shifted from a protective approach to open communication APN's can support the entire family and encourage positive coping mechanisms among siblings (Harding, 1996).

CONCEPTUAL FRAMEWORK

Imogene King's nursing theory was chosen for the conceptual framework for this study. The foundation of King's theory, the nursing process, is conducted within three types of systems: personal, interpersonal and social. King stated before nurses can help maintain a person's health, nurses must *first* understand the person's interactions with the environment.

King viewed people as open unique systems which interact with the environment. Each person has permeable boundaries which permit an exchange of matter, energy, and information. All people develop perceptions of self which influence and are influenced by their personal, interpersonal and social systems (Figure 2).

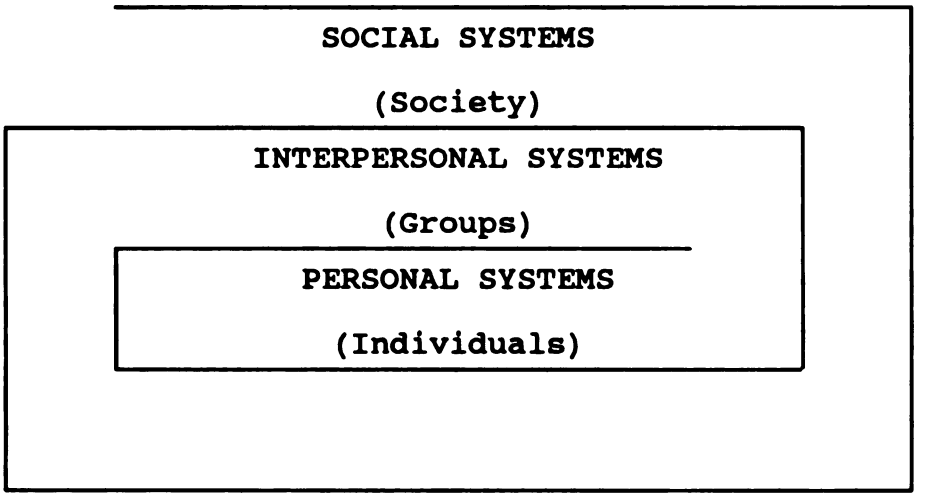

Figure 2. King's Interacting Systems Framework.

King's theory was applicable to siblings of chronically ill children because the framework included sibling interactions on the three levels. On the first level, the personal system or the siblings' perception of self image and in turn global self-worth is influenced by several factors. King describes concepts relevant to a person's self image as the individual's perception, body image, growth and development stages. The development of "self" is reflected in an individual's pattern of growth and development, knowledge of self, and body image. All are integral components of one's global self-worth. The child's self-worth influences how the child responds to people or events in life.

As children grow and develop, their experiences change

and their self perception and their concept of self is affected by their experiences. Each person's perceptions are based on their interactions with people. Perception is a process of organizing, interpreting and transforming information which represents one's image of reality and guide's behavior. In King's framework each person's perception of interaction impact the personal system and in turn the development of self-worth.

Interpersonal systems, the second level, consist of two or more people interacting in situations. Each person brings knowledge, needs, goals, expectations, perceptions, and experiences that influence interactions. King defines nursing as "a process of human interaction between nurse and client whereby each perceives the other and the situation and through communication set mutual goals" to improve the client's health. The goal of nursing is to help individuals maintain their health so they can function in their roles. Health is defined as dynamic life experiences in which there is continuous adjustment to stressors in the internal and external environments. Nursing interventions are actions which take place in the interpersonal system between the nurse and client or between the nurse and the family.

The nurse and client meet in a situation, perceive each other, judgements are made, and they react to their perceptions. The interpersonal interactions guide each person's action toward goal attainment behaviors. One of

the assumptions of King's theory is that behavior is reciprocal and contingent on the behavior of the other person in the interpersonal relationship (Figure 3). The nurse and sibling then implement action toward their goals. Since each behavior is contingent on the other, the nurse and sibling's interpersonal systems continuously affect each other's behaviors.

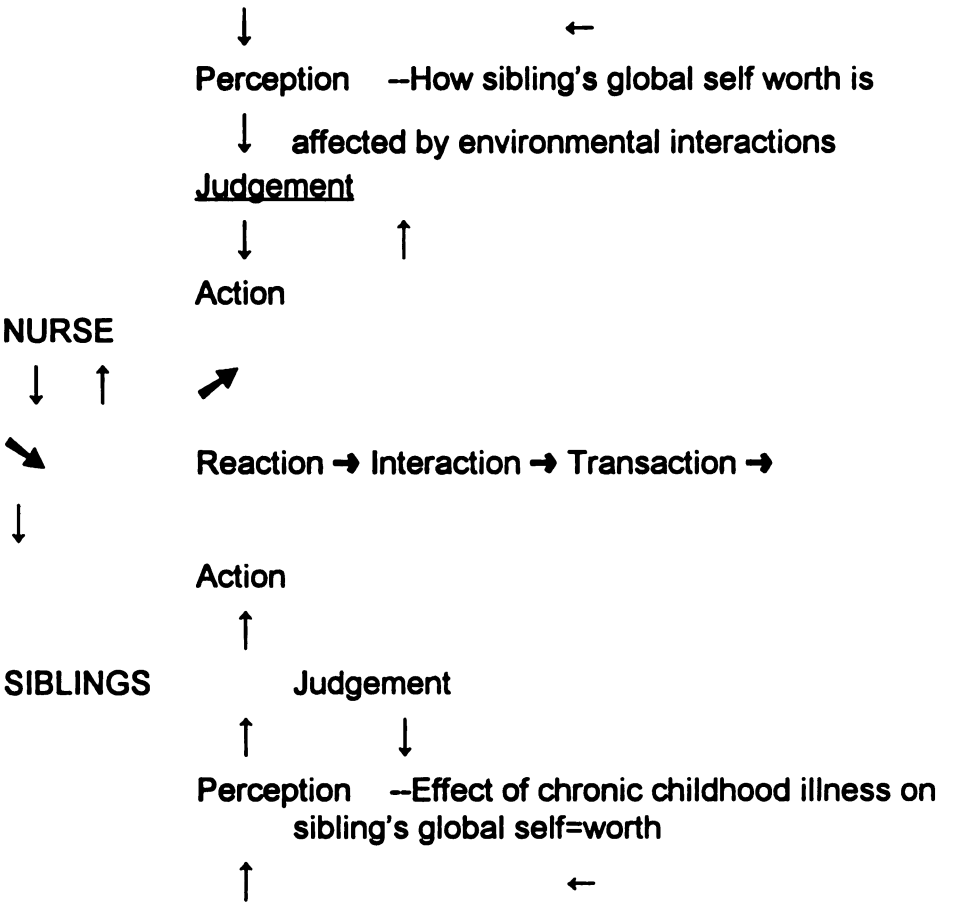

Figure 3. Process of Human Interactions Adapted from King (1981).

On the third level the nurse interacts with the sibling of a chronically ill child in social systems as well. Social systems are created when groups with common interests and goals come together within a community or society. The family is a complex social system. Sibling bonds are complex relationships which include many facets such as love, cooperation, friendship along with competition, jealousy and other feelings. As parent's focus on the needs of an ill child the needs of the healthy sibling may be unmet. The sibling's response to the episode depends on many factors such as family structure, dynamics and communication patterns, ages of the ill child and sibling, individual perception of the situation, relationship between siblings, cognitive and developmental levels. Social systems are important to incorporate information and support groups for individuals and families coping with chronic disease.

In summary, King's framework is helpful in describing responses of siblings of a chronically ill child. The sibling's personal system is influenced by the sibling's perception of the environment. Factors such as lack of family communication, lack of understanding of the nature of the illness, and rationale for deviations from the normal routine change the family environment. The sibling's perception of the changes may lead to changes within the sibling's personal system. The child's perception of the

situation impacts the sibling's perception of themselves and in turn their global self-worth.

Nursing's ultimate goal is to promote health, to prevent premature illness and to improve the quality of life (Lubkin, 1986). Chronic illness and its effect on families present a demanding challenge to this goal. The application of King's framework to siblings of chronically ill children guides APN's actions. The APN can gather and organize assessment data to formulate appropriate interventions to maximize the sibling's coping abilities and positively support development of the sibling's self-worth. Knowledge of the complexity of interpersonal and social systems which impact self-worth of siblings assist APN's to counsel siblings and parents. Siblings may need assistance to meet the demands their role and to provide for individual growth and development which are integral to the development of self-worth.

LITERATURE REVIEW

A fundamental nursing belief is the family is an entity greater than the sum of its individual members. A change that affects one member of the family, affects all members. The future course of a chronic disease for an individual is unpredictable. However, the influence of chronic illness causing disruption of family life and development is well documented. Adaptation to chronic illness brings significant changes in family role patterns and expectations (Canam, 1993; Meyerowitz, 1967). Gayton (1977) noted reduction in overall satisfaction with communication levels of families after the onset of chronic childhood illness. For example, healthy siblings had increased responsibilities such as household maintenance tasks, child care, and support for parents, while expectations of the ill child tended to be drastically reduced (Klien, 1976; Sourkes, 1980; Hartman, 1992). To adapt to chronic childhood illness families restructured communication patterns to accommodate new roles and demands (Meyerowitz, 1967). As a result, siblings reported decreased involvement in family decision making and communication. The family's overall satisfaction with affectionate and emotion-satisfying behaviors decreased.

This placed healthy siblings at risk for problems in individual adjustment due to disruptions of the family's support systems and integrative communication patterns (Crain, 1966; Graliker, 1962). During illness parents must make difficult decisions about the distribution of the family's emotional and material resources. This often places the good of all family members against the needs of one member.

Sibling relationships are characterized by intensity, complexity, and ambiguity. They span a longer period of time than most relationships and include involvement in which children spends hours, days and years together. Siblings have a powerful influence shaping each other's identity. Siblings serve many roles for each other including mentor, supporter, comforter, protector, and socializer (Lavigne, 1979). The sibling subsystem is affected by an ill child.

Schler (1994) reported siblings of childhood cancer patients were vulnerable to psychosocial problems. Before diagnosis, the prevalence of psychosocial problems among siblings is similar to the general population, but after diagnosis, siblings experience significantly more emotional and behavioral distress than controls (Murray, 1995; Ross-Alaolmolki, 1995). Problems frequently noticed by parents are feelings of jealousy and guilt, academic under-achievement, somatic problems and acting out behavior. It

has been found that during treatment there were striking similarities in the emotional distress between siblings and pediatric cancer patients, including anxiety, social isolation, vulnerability to illness and feelings of low self esteem (Bendor, 1990; Havermans, 1994). The major theme in the discussion of siblings' concerns was the disruption they experience in interpersonal relationships especially with their parents. Siblings of chronically ill children felt a lack of a close relationship with their parents more frequently than the ill child felt there was a lack of a close relationship with their parents (Carpenter, 1994). It has been shown that within the family, the needs of the sibling are met least of all. Simultaneously, they felt isolated from supportive systems outside the family. As a result siblings were labeled as "the forgotten children."

A question arose of what the long-term consequences were for healthy siblings after being exposed to prolonged periods of family disequilibrium (Van Dongen-Melman, 1995). When parents stay at the hospital, healthy siblings may be cared for at home by relatives or friends. Siblings were often separated from their parents and from knowledge of the ill child's prognosis (Walker, 1993). Disturbed sibling reactions to chronic illness may include guilt, distorted concepts of illness or death, disturbed attitudes toward physicians, hospitals, and religion, death phobias, disturbances in cognitive functioning. Walker, (1993) found

in families with a child with cancer, one or more previously well siblings showed significant behavior problems, indicating difficulty in coping with the illness. Siblings displayed a variety of physical symptoms including enuresis, headaches, abdominal pains, and symptoms of emotional disturbance including poor school performance, school phobia, depression, separation anxiety, feelings of guilt and fear that they might die. Coleman and Coleman (1985) identified areas of concern in helping siblings' cope with death and dying and illustrated these issues with clinical vignettes. They stressed that all health care providers who worked with ill children "need only an open ear and they will hear about the siblings." In several studies when siblings were compared with an ill child, siblings were in more distress than the patient (Cairns, Clark, Smith & Lansky, 1979). Their analysis of responses focused on three areas:

a) individual reactions (feelings of guilt, sadness, anger and loneliness),

b) family reactions, (failure to talk to each member about the illness)

c) societal responses (friends, neighbors and teachers conveyed either a message of "be strong for your parents" or pointed silence was experienced by siblings which in turn neglects their feelings and needs) (Walker, 1993).

Kleiber (1995) described the sibling's perceptions and feelings about information needs during the ill child's admission to a hospital. Parents reported siblings had numerous questions about the reasons for hospitalization and expectations for the future of the family. The findings indicate that parents may either be unaware of the effects of the hospitalization experience on the siblings, or not have the knowledge and skill to assist them. Parents may need counseling to increase their awareness of the siblings' need for information and teaching to increase skill in providing the information (Broughton, 1995).

Having a brother or sister with a chronic illness, may affect the sibling relationship in many ways (Copeland, 1993). The healthy child may feel guilty when engaging in normal sibling teasing or rough play. Family expectations may not allow for normal sibling rivalry and the well child may be expected to act mature and responsible even though he or she may not be developmentally ready for this responsibility. The healthy child may experience conflicting feelings of jealousy, hatred, and love toward the ill child. The feelings may act as a barrier in their relationship (Thibodeau, 1988). Siblings may feel they are not included in decision making. "Protecting" siblings from information and excluding them from full participation in family problems increased their feelings of loneliness and anxiety (McKeever, 1983; Siemon, 1984). Sargent et al

(1995) found that siblings reported distress about family separations and disruption, lack of attention, focus of the family on the ill child, negative feelings in themselves and family members, medical treatments and their effects, and fear of death.

Siblings also reported positive experiences such as becoming more compassionate, families becoming closer, and having experiences they otherwise would not have had (Craft, 1993). Positive effects of having a chronically ill sibling were also described as sensitivity, ability to see events from another's point of view, maturity, responsibility, compassion, altruism, empathy for their parents, appreciation of family bonds, their own good health and feelings of family pride and loyalty (McKeever, 1983; Simeon, 1984). Long & Moore (1979) reported siblings of epileptic children were found to be significantly more self-directed and had higher self-esteem than the epileptic children. Sibling interviews also revealed higher levels of empathy for parental needs, cognitive understanding, self-esteem, and respect for the ill sibling (Eiser, 1993; Faux, 1993).

When siblings of children with cancer were compared with healthy siblings on measures of adjustment, pro-social behavior, and family cohesion and adaptability, no significant differences were found on major behavioral and social problems between the two groups which was consistent

with published norms for the measures (Horwitz & Kazak 1990). The siblings of oncology patients were studied by using content analysis on sibling and parent interview data. Siblings with lower self-concept scores and a sense of "not being enough" were found to also believe that the parents favored the ill child in some ways. In contrast, siblings with higher self-concept scores perceived that they had grown and matured from the experience, and that their parents were proud of them and valued them as individuals.

Zeltzer (1990) found siblings were moderately healthy, although siblings reported significant problems with sleeping and eating. Health care utilization was reduced for siblings. More important, the parents of these siblings are less likely to seek medical attention for a variety of conditions for which parents of control children would bring their children to a provider. A pattern was identified that parents under reported sibling health variables when compared to what the sibling's themselves reported. When the relationship between health outcomes and the siblings adaptation to their sick siblings illness was examined, the resilient and dysfunctional groups significantly differed from each other. It appeared that health outcomes were related to siblings' adaptation to the changes brought by the ill child's chronic illness diagnosis (Gage, 1994). Overall the focus of care in these families was limited to the child with the chronic illness.

Chronic diseases in children lead to changes in sibling relationships which effect feelings and behaviors (Craft, 1986; Craft & Craft 1989; Craft & Wyatt, 1986; McKeener 1983). Researchers have reported positive effects on siblings such as maturity of attitudes and behavior (Druger 1980; Iles 1979; Simeonsson 1986). Negative effects such as losses in relationships with the affected child, difficulty with the presence of parent substitutes, (Iles, 1979) decreased family communication, family role changes and increasing expectations (McKeever, 1983) were also reported.

Global self-worth may also be influenced by the siblings age and gender. Noll (1995) reported age and gender differences in responses indicate distinctive perceptions of vulnerability to the chronic illness experience. Older siblings were far more likely to report positive effects than younger siblings, suggesting that level of maturity can moderate the stress of an ill child within the family (Noll, 1995). Findings suggest that if siblings of chronically ill children have difficulties with peers or other people. The problems may be the result of factors other than presence of a chronically ill child in the family.

Overall, siblings of chronically ill children have received limited attention in the literature. They have been utilized as comparison groups for the chronically ill children more than as the focus of research. Research on siblings of chronically ill children has focused on

maladjustment. Siblings were viewed to be at risk for role strain and role shifts which place them at risk for maladjustment. Earlier studies describe relatively high levels of psychosomatic, emotional, behavioral, and academic problems among the siblings of children with chronic illness or disability. Frequently noted sibling responses were jealousy, resentment (Anderson, 1982; Binger, 1969), increased anxiety (Cain, 1964; San Martino, 1974) acting out behaviors such as decreased school performance (Binger, 1969; Blinder, 1972; Cain, 1964), increased fighting or aggressiveness (Blinder, 1972) and social withdrawal (Cain, 1964; Blinder, 1972; Wold, 1969).

The majority of research utilizes maternal reports rather than sibling self-reports. Maternal ratings reveal negative perspectives of sibling functioning compared to studies using sibling self-reporting and other sources, such as teachers (Lobato, Faust, & Spirito, 1988). Siblings were rated by their mothers as significantly higher on social withdrawal and irritability scales than were healthy controls (Lavigne 1979). Tritte & Esses (1988) found no significant differences in self-esteem and self-appraisal between siblings of chronically ill children and those of healthy children. Conversely, the parents of chronically ill children perceived the siblings as having significantly more behavior problems of a personality nature such as shyness and withdrawal than siblings of healthy children

(Williams, 1993).

Gallo (1993) described concerns mothers of chronically ill children identified about siblings. The mothers identified both positive and negative aspects of behavior. Specific behaviors that concerned them were attention getting behaviors, school problems and withdrawal behaviors. Siblings also showed positive behaviors such as showing empathy and concern toward the ill child, and an understanding of the limitations that the illness placed on the ill child. Many mothers reported little effect on the siblings and at times mothers attributed behavior to the well siblings' temperament rather than the presence of a chronically ill child. Overall, Gallo showed that the mother's perceptions of the extent to which they can control the illness may affect adjustment of healthy siblings in childhood chronic illness. It was not clear to what extent the relationship between siblings' behavioral adjustment and control of illness was causal, rather it may have been that the mothers were overwhelmed by the illness and perceived the well sibling's behavior as troublesome, regardless of the siblings' actual behavior. These findings support studies that focus on multiple factors and need to measure more than mother's perception (Gallo, 1993).

Quittner reported potential differential parental treatment of siblings (material, time, affection, or discipline) in normal and high-risk families. Quittner

(1994) found mothers spent more individual time with younger, chronically ill children for play and mealtime activities than mothers spent with their older, healthy siblings. Mothers of children with chronic illness rated time spent with older children as significantly more negative than time spent with younger children.

Craft and Craft (1988) showed a large discrepancy in reported perceptions of sibling behavior between parents and siblings. The differences between parent and siblings are not completely understood, but may be related to parental preoccupation with the ill child, parental stress and separation of parents and sibling (Craft & et al 1989). The documented gap in parent and sibling perception demonstrates the need to assess siblings' perceptions directly. Hogan and Balk (1990) compared adolescent siblings of chronically ill children with perceptions of the mother and father. Surprisingly, self-concept scores reported by the mothers were significantly different from those of the teenagers, but there was no significant difference between the score of the fathers and teenagers. The investigators concluded that family dynamics surrounding a child's illness need to be studied further.

Leda (1992) documented a positive correlation between life events and cognitive competence. Leder concluded the more stressful their life events, the higher the children were rated in cognitive competence. A negative correlation

was found between life events and physical competence. Noll's (1993) findings suggest that if siblings of children with sickle cell disease have difficulties with peers, these problems may result from factors other than presence of a chronically ill child in the family.

Van Dogenet et al (1995) described 60 siblings of children who had been treated for cancer at least three to five years prior to the interview. They found no significant difference in psychosocial functioning between siblings of children with cancer and children in the comparison groups. On all emotional and behavioral problems and competencies the total group of siblings fared the same or better than those with whom they were compared. They showed siblings and parent reports coincided. There were no serious psychosocial sequelae for the sibling of the cancer survivors and in fact found the siblings showed significantly fewer problems than the cancer survivors. Overall, Van Dogenet showed no difference in psychosocial functioning between siblings of cancer survivors and controls suggesting that childhood cancer does not heighten the risk of psychological disturbances after treatment of siblings.

Overall, siblings serve an important function for each other in self-appraisal, support, forming alliances, and socialization (Lavigne 1981). Much of the research available is based on anecdotal, impressionistic data, small

sample sizes, and tools of uncertain reliability and validity. Typically, siblings are either ignored or described solely through parent reports; rarely are they allowed to speak for themselves. Using maternal ratings, behavior problems and social withdrawal have been documented. The many studies of siblings of ill children support good psychosocial function and self concept when compared to siblings of healthy children. The majority of siblings of chronically ill children appear able to adapt within their families and some studies report positive effects of their experience. Although siblings of chronically ill children are at risk for psychosocial problems, most do not appear to develop them (Lavigne 1981). The siblings' self-esteem and psychosocial functioning which were built through the crises positively contribute to family resources (Janus & Goldberg, 1992).

Researchers have begun to move away from describing the pathology to identifying the developmental, environmental, and individual psychosocial attributes (self-concept) that impact the siblings. Research methodology has moved from predominately case studies, and retrospective descriptive studies to prospective descriptive studies to prospective exploratory descriptive studies using objective measures and a few studies testing interventions. In most studies, larger samples and more rigorous methods were employed.

Several decades of study of siblings' adjustment to

chronic illness have yielded few consistent findings (Gallo, 1993). Researchers have begun to describe the relationships between sibling adjustment and parental or family functioning. The family is considered a major influence on a sibling's overall adaptation and adjustment to a child illness (Drotar, 1981). Because parents of children with chronic illness need to manage or help the ill child manage the illness for an extended period of time, the family as a whole must adapt to these demands. When parents are under stress, they may have less capacity for supportive, sensitive, and involved parenting for their healthy children. Additionally, they are more likely not to be able to serve as a buffer for the stress of the illness within the family (Johnson, 1985).

STUDY DESIGN

The current quasi-experimental study used secondary data to describe the global self-worth of siblings of children with and without chronic illness, using the Harter Self Perception Profiles for Children and Adolescents.

The primary study (Spence, 1992) described several aspects of adaptation through examination of the adaptation of families with chronically ill children compared to families with healthy children. The primary study utilized established non-invasive questionnaires (Appendix C).

HYPOTHESIS

Perception of global self-worth scores as measured by Harter's Self Perception Profile, will be significantly lower in siblings of chronically ill children than in siblings of healthy children.

DEFINITIONS

Adolescent was defined as a child age thirteen to eighteen years of age.

School age child was defined as a child age eight through

twelve years of age.

Family was defined as parents(s) (biological, adoptive or stepparents), target child and siblings (biological or step-siblings) eight years of age or older, who currently lived in the home.

Health status was defined as either having a chronic illness or the absence of chronic illness or developmental disabilities.

Chronic Illness was defined as family self-report, medical records and diagnosis by a pediatric sub-specialist physician that the child was diagnosed with asthma, cystic fibrosis, diabetes, or congenital cardiac disorders.

Global Self-Worth was measured by the Harter Self Perception Profiles. The children's scale questions were item numbers 6, 12, 18, 24, 30, and 36, and item numbers 5, 11, 17, 23, 29 and 35 for the adolescent scale.

METHODOLOGY

All procedures were the same for the families with chronically ill children and comparison families. Target families were recruited for the primary study through pediatric subspecialty clinic at a university medical center. Comparison families were recruited through university, neighborhood, and community agency announcement. To be included in the study, children must have been at

least eight years old. The criterion was selected to avoid the cognitive transitional period that occurs between five and seven years of age and thus facilitate the children's ability to understand and respond to the instruments used in the study. It is during this time that the child is acquiring knowledge and skills that allow self-direction, make judgements about their competence in different domains and have constructed a view of their general self-worth as a person.

Families meeting the criteria received a letter explaining the study and inviting their participation. A follow-up phone call was made to establish a home visit. During the visit the study was explained to the entire family, questions answered, and informed consent obtained. Each family member was asked to complete appropriate instruments in the natural setting of their home. The investigator assisted the younger children with completion of the instruments. In the original study data was collected using several instruments during two visits. The self-perception data for the current study was collected during the first visit.

SAMPLING PROCEDURES

Data is from a non-probability convenience sample. Families were matched for age, gender, and birth order of the target child, number of parents in the home, approximate

family size, and income. Birth order of the target child was matched on oldest, middle or youngest. Family size was matched for 1-2, 3-5, or six or more children. Income was matched for <$20,000, $20,000-34,999, $35,000 to 49,999, $50,000 - 74 999 and > $75,000. Thirteen of the comparison families were able to be matched to the randomly selected chronic illness families. The other four comparison families were matched to four non-randomly selected chronic illness families that were evenly distributed across the diagnostic categories.

SAMPLE

The primary sample consisted of 160 subjects (45 families). The 28 target families had a school age child diagnosed with a chronic illness for at least one year. This group included 47 parents (28 mothers, 19 fathers) 28 target children, and 27 siblings (17 children, 10 adolescents). There were eight children with asthma, six with congenital heart disease, eight with cystic fibrosis, six with insulin dependent diabetes mellitus. The 17 comparison families had healthy children without known physical abnormalities or developmental deficits. This group included 28 parents (17 mothers, 11 fathers), 17 target children, and 12 siblings (four children, eight adolescents) (Spence, 1992) and (Ward, 1994). The target

population of interest for the present study is siblings of school-age children with chronic illnesses.

FAMILY MEMBER CHARACTERISTICS

The original analysis revealed no significant differences between the families with a chronically ill child and comparison families. Specific information is in Table 1.

There was no significant difference in children's characteristics such as age, gender, and birth order. There were no significant differences in parent characteristics such as fathers', education, occupations and full or part time work status. There was little variation in fathers employment status or annual household income. All (100%) of the twelve fathers in the healthy group worked full time. Twenty-one of the fathers (91%) of the chronically ill group worked full time with one father working part-time (Spence, 1994).

According to the primary study (Spence, 1992) there was a slight variation in the mothers' employment status. This may suggest mothers of chronically ill children may not be able to be employed due to the necessity to care for their children. Mothers in comparison families had significantly more education and were significantly more likely to work outside of the home and in graduate professional positions than mothers in the chronic illness families.

Significantly, more mothers in the comparison group worked full time outside of the home (Spence, 1992).

The family income was well matched for the groups. Fifty percent of the healthy children had a family income of $30,000 or less per year and fifty-three percent of the chronically ill children had a family income of $30,000 or less per year (Spence, 1994).

TABLE 1

FAMILY CHARACTERISTICS

Variable	Chronically Ill			Comparison		
	N	%	Mean	N	%	Mean
Number of Families	28			17		
Number of Parents			2			2
one parent	4	14		5	29	
two parents	22	79		12	71	
one parent plus sign. other	2	7		0	0	
mothers	27	96		17	100	
fathers	19	68		11	65	
Number of Children			2			2
one child	5	18		4	23.5	
two children	14	50		8	47	
three children		3	11		4	23.5
four children		3	11		1	6
five children		2	7		0	0
six children	1	3		0	0	
Income			$35,000-44,999	45,000-54,999		
under $12,000		5	18		0	0
$12,000-24,999	5	18		4	23	
$25,000-34,999	5	18		3	18	
$35,000-44,999	3	10.7		1	6	
$45,000-54,999	3	10.7		1	6	
$55,000-64,999	4	14		1	6	
$65,000-74,999	1	3.6		5	29	
over $75,000	2	7		2	12	
Age of Ill Child			9.93 years		10.45 years	
Sex of Ill Child						
Female	13	46		8	47	
Male	15	54		9	53	
Ill Child Birth Order						
Youngest	8	29		7	41	
Middle	4	14		2	12	
Oldest	11	39		4	23.5	
MOTHER						
Education		some college		college		
Less than high school	1	4		0	0	
high school	6	22		0	0	
business, trade, jr. college	5	18		2	13	
some college	10	37		1	6	
college	4	15		9	56	
postgraduate	1	4		4	25	
Occupation		trade, clerical technical	graduate		professional	
no work outside home	9	33		2	12	
unskilled labor	2	7		0	0	
trade, clerical technical	7	26		4	23	
sales	3	11		0	0	
management	1	4		0	0	
graduate professional	5	19		11	65	

Amount of work		full time			full time	
no work outside home	9	33			2	12
full time	8	30			12	70
part time	10	37			3	18

Variable		Chronically Ill			Comparison		
	N	%	Mean		N	%	Mean
FATHER							
Education		some college			college		
Less than high school	1	4		0	0		
high school	5	22			0	0	
business, trade, jr. college	4	17.4			2	18	
some college	5	22			1	9	
college	4	17.5			3	27	
postgraduate	4	17.4			5	46	
Occupation		trade, clerical technical	graduate			professional	
no work outside home	1	4			2	12	
unskilled labor	3	13			0	0	
trade, clerical technical	7	30			6	50	
sales	5	22			0	0	
management	2	9			10	8.30	
graduate professional	5	22			4	33.365	
postgraduate prof	0	0			1	8.3	
Amount of work		full time			full time		
no work outside home	1	4.3			0	0	
full time	21	91.3			12	100	
part time	1	4.3			0	0	

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INSTRUMENTS

The **"Harter Self Perception Profiles"** for Children (eight years of age or in third grade to thirteen years of age) and for Adolescents (age thirteen and older) were used. These tools were developed to measure children's domain-specific judgements of their competence as well as a global perception of their worth or esteem as a person. Children received specific standardized instructions as described in Appendix A. The questions are in a structured alternative format which allows four potential choices. The child is asked to decide which kind of child is most like themselves and then asked whether this is only sort of true or really true for him or her. The question format is effective because children choose answers based on how they view themselves. The influences of social desirability and defensiveness on children's self-esteem ratings can be considered in the maintenance of self-esteem. Social desirability involves the tendency to respond as one should, regardless of what one actually thinks or feels. Children have a natural tendency to provide socially desirable responses when provided with "yes or no" alternatives in self-report instruments. To combat this tendency Harter developed the format for the "Self Perception Profiles" to give children permission to choose the half of a two-part item that was most like them and then to rate whether their choice was just "sort of true" for them or "really true'"

for them. Harter's competency/adequacy scales, social support scales, and importance rating forms all followed the same format allowing a score from one to four for each item.

In general the means fluctuate around the value of 3.0, which is above the midpoint of the scale. However, there are differences associated with both gender and grade level for certain subscales, and some sample variation. The majority of standard deviations fall between 0.50 and 0.85 indicating considerable variation among individuals.

Harter (1985) demonstrated the precision of the tool as a measurement instrument in previous studies. The internal consistency was demonstrated for all subscales (Table 2).

TABLE 2

INTERNAL CONSISTENCY SELF PERCEPTION PROFILES

SCHOOL AGE CHILDREN	
Global Self-Worth	0.78-0.84
Scholastic Competence	0.80-0.85
Social Acceptance	0.75-0.80
Athletic Competence	0.80-0.86
Physical Appearance	0.76-0.82
Behavioral Conduct	0.71-0.77
ADOLESCENCE	
Global Self-Worth	0.80-0.89
Physical Appearance	0.84-0.89
Social Acceptance	0.77-0.90
Scholastic Competence	0.77-0.91
Athletic Competence	0.86-0.92
Close Friendship	0.79-0.85
Behavioral Conduct	0.58-0.78
Romantic Appeal	0.75-.85
Job Competence	0.55-0.93

The reliability tests were based on Cronbach's Alpha and were considered acceptable. This tool has been utilized in numerous studies and face and construct validity demonstrated.

HUMAN SUBJECTS

The primary study received human subjects approval by the Michigan State University Committee on Research Involving Human Subjects (UCRIHS) (Appendix D). The data for the secondary data analysis was transferred on a computer disc. To maintain confidentiality and anonymity subjects were described only by code number; no identifying information was available on the computer disc. The present study was also approved by UCRIHS (Appendix D).

DATA ANALYSIS

Data analysis included T-Test for global self-worth scores of the Harter Self Perception Profile for siblings to determine if there was a significant between groups difference.

LIMITATIONS

Several limitations occur due to utilization of existing data for this study design. The present study is a cross sectional analysis of all family members. A longitudinal study would be helpful to assess self-worth incorporating more information gathered over a longer period of time. Self-worth and adaptation at one point in time could differ at a second point. The study did not measure

self-worth as an ongoing process, the impact of development transitions, or the effect of the family's or individual's coping strategies on global self-worth.

The sample size is limited to the small number of families in the primary study. The primary study was a convenience sample and does not address whether the subjects were representative of the overall population of families with chronically ill children. It would be ideal to have a larger number of comparison families so that the matching can be accomplished without any significant differences between the groups.

Another serious shortcoming related to the small sample size is the need to have a large variance to identify a significant difference in global self-worth between the two groups. A small variance in the scores may make a significant difference undetectable. To accommodate for the individual variation a larger sample size would be suggested.

The study design does not account for historical experiences which may have occurred and affected global self-worth. A limitation of using questionnaires is an individual may not accurately recall information and may answer question inaccurately. The force field questions allow only closed ended questions which may produce "biased" information because they don't allow subjects to respond in their own words.

The style of medical management was purposely controlled by recruiting from the same site. Styles of management include variables such as the amount of information, input and decision-making power given to the chronically ill child and his family. Factors that may address siblings needs were not addressed in the primary study. The medical facilities routinely included siblings in visits.

Overall, the study design allowed examination of differences in global self-worth between siblings of children with chronic illness and siblings of healthy children. However, due to the limited sample and generalizability of the data further study would be necessary. This study can be used as a beginning research project to identify if a difference exists. Further studies can be developed to demonstrate the difference utilizing more subjects.

RESULTS

The results of the study showed that there was no significant difference in global self-worth between siblings of chronically ill children and siblings in the comparison group with healthy children. The Analysis of Variance for global self-worth showed no significant difference for global self-worth in siblings by health status. There were

28 siblings of chronically ill children. The mean for global self worth was 2.5238, and the standard deviation was 0.519. There were 12 siblings of healthy children. The mean for global self worth was 2.8056 and the standard deviation 0.639.

TABLE 3

T-Test for Global Self-Worth

VARIABLE	NUMBER OF CASES	MEAN	STANDARD DEVIATION	STANDARD ERROR OF MEAN
SIBLINGS				
Chronically Ill Children	28	2.5238	0.519	0.098
Healthy Children	12	2.8056	0.639	0.184

Mean Difference = 0.1190
Levene's Test for Equality of Variances: F= 0.352 P= 0.556

DISCUSSION OF FINDINGS

The results of the study showed the global self-worth of the siblings of chronically ill children was comparable to siblings of healthy children. This study supports that having a sibling with a chronic illness does not necessarily lower a child's global self-worth.

The results did not support previous literature which included reports that high-risk siblings who were judged as competent by outside observers (mothers, teachers, or peers)

may have experienced distress that was not visible such as excessive sadness or anxiety or low self-worth. Additional factors may influence sibling's self-worth. Previous reports of low global self-worth may be due to mothers who felt overwhelmed by the illness and perceived the well sibling's behavior as troublesome, regardless of the sibling's actual behavior. It is conceivable that parental difficulties associated with having a child with a chronic condition may be apparent in the expectations of the sibling, but that sibling self perception of global self-worth was not effected.

It is also important to acknowledge the importance of identification of specific domains which are important to the individual sibling. In Harter's model, the assessment of global self-worth is based on assessment of the elements of self-worth in relation to the importance of those elements to the individual. Therefore, important elements contribute to global self-worth; unimportant ones do not. If assessment of a sibling revealed the sibling values a specific domain such as athletic competence, the APN can enhance communication and guide interventions to include activities the sibling values and are appropriate for the age and developmental level of the sibling. For example, if a sibling wanted to participate in a sport, the family may be better able to consider the multiple time demands if the family understood the importance of athletic competence to the sibling and the impact on the sibling's global self-worth. The family may be able to

arrange community resources to allow participation in specific activities.

IMPLICATIONS FOR NURSING PRACTICE

King's framework guides nursing interventions for interventions for siblings of chronically ill children. As the siblings grow and develop their experience's change their self perception and self-worth is effected. All perceptions of self are affected by the sibling's interactions with their personal, interpersonal and social systems. A siblings' response to a child's chronic illness may be influenced by the family and how the sibling individually and family collectively cope and relate to one another and the circumstances of their daily lives (Wright, 1994). The findings show siblings have adapted and have no measurable difference in global self-worth.

The APN has a unique opportunity to assess and identify sibling and family needs and provide education, anticipatory guidance, consultation and community referrals. Viewing chronic illness as a stressor in the framework integrates family strengths, coping, competence, resilience, self-regulation and well being. The APN can utilize King's theory to maintain family members health by assisting with their adjustment to life experiences. The study supports siblings of chronically ill children can adjust without a decrease in global self worth. Therefore, study supports the use of

nursing interactions to assist siblings and the family as a unit to cope with stressors of chronic disease and to decrease the risk to self worth.

Although no difference in sibling's global self worth were found in this study the APN's can utilize the knowledge to assist families in coping with illness to reduce the impact of disease. Brett (1988) identified coping strategies to assist families in living with chronic illness. The APN can assist with normalization of the children within the family to strengthen patterns of family interaction and with mastery of living demands which allow siblings to increase their self confidence. The APN can also assist the family to enhance open communication, provide opportunities to discuss age appropriate questions and explore the meaning of the illness for the family.

The study supports APN interventions for families which address social, psychological, physical and spiritual needs for the entire family. Education of family members that the chronic illness had no effect on sibling's global self-worth may be helpful to motivate families to participate in anticipatory guidance to improve overall family functioning. The APN can encourage parents to spend time with siblings, provide honest responses to their questions, and allow siblings to express their feelings. Parents can be encouraged to bring siblings to office visits or hospitals to better understand the ill child's experience. The APN can encourage

the family to balance life so that the ill child is not the continual focus of the family.

APN's must look at the parent's reaction to the illness and its effects on siblings when parents are unable to attend to the needs of siblings and the siblings have a functional loss of the parents. APN's must help families recognize and accept that each individual family member copes and reacts distinctively.

IMPLICATIONS FOR NURSING EDUCATION

Nursing education can incorporate the importance of the inclusion of siblings in treatments and goal planning for the ill child and the family in the curriculum. Siblings may wish to be involved with care and need direction and support to assist the ill child. The nurse will need to know how to facilitate this effectively. The APN can also assist the family in adaption to chronic childhood illness through education and anticipatory guidance about the needs of the sibling. To cope with chronic childhood illness the family must restructure communication patterns and family decision making. During illness parents must make difficult decisions about the distribution of the family's emotional and material resources. This often places the good of all family members against the needs of one member. It is important that APN guide families to include siblings in family discussions and

decision making processes. APN students would benefit from both theory and supervised clinical experience in how to facilitate the family and sibling adaptation to chronic illness. With support children are resilient and can adjust to chronic illness with positive effects for the family and siblings relationships.

IMPLICATIONS FOR FUTURE RESEARCH

Literature clearly demonstrates chronic childhood illness is a family stressor that may increase risk for sibling psychosocial maladaption (Murray, 1995; Ross-Alaolmolki, 1995; Schler, 1994). This study did not find a difference in global self-worth of siblings of children with chronic illness. Further research would be necessary to identify siblings' positive coping strategies to assist other siblings of chronically ill children.

Studies to identify factors which contribute to positive outcomes for siblings would be beneficial to cost effectively manage family interventions. The APN can coordinate sibling sessions for discussion of problems living with chronic childhood disease. Support groups aimed at increasing siblings' confidence in coping with chronic illness or controlling associated problems may be helpful.

CONCLUSIONS

The study was encouraging in that no difference in global self-worth was found between siblings of chronically ill children and siblings of healthy children. The APN can support the family and individual members in their positive adaptation to chronic illness. The APN can utilize King's conceptual framework as a foundation for interpersonal interactions with families and siblings of chronically ill children.

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APPENDICES

APPENDIX A

APPENDIX A

Harter' Self Perception Profile for Children

Administration and Instructions

The scale may be administered in groups as well as individually. After filling out the information at the top of the scale, children are instructed as to how to answer the questions, given below. We have found it best to read the items outloud for 3rd and 4th graders, whereas for 5th graders and older, they can read the items for themselves, after you explain the sample item. Typically, we introduce the scale as a survey and, if time, ask the children to give examples of what a survey is. They usually generate examples involving two kinds of toothpaste, peanut butter, cereal, etc, to which you can respond that in a survey, there are no right or wrong answers, its just what you think, you opinion.

In explaining the question format, it is essential that you make clear that for any given item they only check one box on either side of the sentence. They do not check both sides. (Invariable there will be one or two children who will check both sides initially and thus you will want to have someone monitor each child's sheet at the onset to make certain that they understand that they are only to check one box per item.)

INSTRUCTIONS TO THE CHILD

We have some sentences here and, as you an see from the top of your sheet where it says "what I am like," we are interested in what each of you is like, what kind of a person you are like. This is a survey, not a test. There are no right or wrong answers. Since kids are very different from one another, each of you will be putting down something different.

First, let me explain how these questions work. There is a sample

question at the top, marked (a). I'll read it outloud and you follow along with me. (Examiner reads sample question.) This questions talks about two kinds of kids, and we want to know which kids are most like you.

(1) So, what I want you to decide first is whether you are more like the kids on the left side who would rather play outdoors, or whether you are more like the kids on the right side who would rather watch T.V. Don't mark anything yet, but first decide which kind of kid is most like you, and go to that side of the sentence.

(2) Now, the second thing I want you to think about, now that you have decided which kind of kids are most like you, is to decide whether that is only sort of true for you, or really true for you. If it's only sort of true, then put an X in the box under sort of true; if it's really true for you, then put an X in that box, under really true.

(3) For each sentence you only check <u>one</u> box. Sometimes will be on one side of the page, another time it will be on the other side of the page, but you an only check one box for each sentence. You don't check both sides, just the one side most like you.

(4) OK, that one was just for practice. Now we have some more sentences which i'm going to read out loud. For each one, just check one box, the one that goes with what is true for you, what you are most like.

APPENDIX B

Appendix B

Harter's Self Perception Instrument

Harter's Self Perception Instrument

SELF-PERCEPTION PROFILE FOR CHILDREN
(Revision of the Perceived Competence Scale for Children

Susan Harter, Ph.D., University of Denver, 1985

1.	4	3	Some kids feel that they are very *good* at their school work	BUT	Other kids *worry* about whether they can do the school work assigned to them.	2	1
2.	1	2	Some kids find it *hard* to make friends	BUT	Other kids find it's pretty *easy* to make friends.	3	4
3.	4	3	Some kids do very *well* at all kinds of sports	BUT	Other kids *don't* feel that they are very good when it comes to sports.	2	1
4.	4	3	Some kids are *happy* with the way they look	BUT	Other kids are *not* happy with the way they look.	2	1
5.	1	2	Some kids often do *not* like the way they *behave*	BUT	Other kids usually *like* the way they behave.	3	4
6.	1	2	Some kids are often *unhappy* with themselves	BUT	Other kids are pretty *pleased* with themselves.	3	4

From: Harter, S. (1985). Manual for the Self-Perception Profile for Children. Denver: University of Denver.

APPENDIX C

APPENDIX C

PRIMARY STUDY PROCEDURES:

The primary study described several factors of adaptation through observation of chronic childhood illness and adaptation of families compared to families with healthy children. The primary study utilized established non-invasive questionnaires.

Target families were recruited for the primary study through a pediatric subspecialty clinic. Comparison families were recruited through university, neighborhood, and community agency announcement. To be included in the study criteria, children must have been at least eight years old and in third grade and under thirteen years of age. The criterion was selected to avoid the cognitive transitional period that occurs between five and seven years of age and would facilitate children's ability to understand and respond to the instruments used in the study.

Families meeting the criteria received a letter explaining study and inviting their participation. A follow-up phone call was made to establish a home visit. During the visit the study was explained to the entire family, questions answered, and informed consent obtained. Each family member was asked to complete appropriate instruments in the natural setting of their home. The original study collected data using several instruments during two visits. The self-perception data for the current study was collected during the first visit. The investigator answered questions and assisted the younger children with completion of the instruments.

Total and subscale scores as appropriate for each instrument were calculated for each person. The internal consistencies of scores for all instruments were calculated using coefficient alphas to determine composite family and individual scores. Individual scores were used to analyze family members' relationships. Families were matched for age, gender, and birth order of the target child, number of parents in the home, approximate

family size, and income. Thirteen of the comparison families were able to be matched to the randomly selected chronic illness families. The other four comparison families were matched to four non-randomly selected chronic illness families that were evenly distributed across the diagnostic categories.

CONSENT PROCEDURES

Target families were recruited for the primary study through a pediatric subspecialty clinic. Comparison families were recruited through university, neighborhood, and community agency announcement.

Families meeting the criteria received a letter explaining study and inviting their participation. A follow-up phone call was made to establish a home visit. During the visit the study was explained to the entire family and questions answered. Informed consent obtained from the parents to participant in the study and to allow children to participate in the study.

The primary study consent included explanation of the study, the family's specific involvement, and confidentiality of information. It informed subjects there were questions about alcohol and drug use. Subjects had been given opportunity to ask questions and understood they may ask questions at any time during the study. The subjects gave permission for the researchers to obtain information from medical records for the chronically ill child. The consent informed the subjects that participation in the study did not affect the care the family would receive. The consent stated the subjects voluntary participated in the study and could withdraw at any time without retribution.

PRIMARY STUDY CONSENT FORM

We are currently conducting a research project on situations that may influence family functioning. Our purpose is to develop ways for health care providers to work more effectively with families who have chronically ill members. We are, therefore, studying families both with and without chronically ill children.

1. I freely consented to have my family participate in a scientific study on situations that may influence family functioning being conducted by Carla L. Barnes, PhD, ACSW, Linda J. Spence, MS, RN, and Patricia L. Peek, MS, RN, Professors in the College of Nursing at Michigan State University.

2. I understand that I may contact the researchers (phone 355-6526) at any time about the research project, my rights as a subject, or in the event of a research related injury.

3. The study has been explained tome and I understand the explanation that has been given and what my family's participation will involves. I understand that we will be asked to complete two packets of questionnaires over a six month period and that one of the researchers will make two home visits per packet.

4. I understand that the answers to the questionnaires are confidential and will not be shared with anyone, including family members, and that there are five questions about the use of drugs and alcohol.

5. I have been given the opportunity to ask questions and I understand that I may ask questions at any time during the study.

6. I understand that the researchers will be obtaining information from the medical record of my child.

7. I understand that this study will not affect the care my family is now receiving.

8. I understand that the anonymity of my family is assured and that the results of the study will be treated in strict confidence. Within these restrictions, results of the study will be made available to me at my request, however, findings will not be available until the completion of the study.

9. I understand that my family's participation in this study is voluntary and that we may withdraw from the study without penalty. There are no anticipated circumstances under which the researchers will terminate our participation before the project is completed.

10. I understand that our participation in this study does not guarantee any beneficial results to my family.

Signatures:

_____	_____
Mother/Guardian Signature	Father/Guardian Signature
Date_____	Date_____

APPENDIX D

APPENDIX D

MICHIGAN STATE
UNIVERSITY

November 25, 1996

TO: Linda Spence
A230 Life Sciences

RE: IRB#: **96-732**
TITLE: IMPACT OF CHRONIC CHILDHOOD DISEASES ON THE GLOBAL SELF WORTH OF SIBLINGS
REVISION REQUESTED: N/A
CATEGORY: 1-B
APPROVAL DATE: 11/24/96

The University Committee on Research Involving Human Subjects'(UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Loynes Diana

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