

FAMILIES OF CHILDREN WITH CHRONIC ILLNESS: A REVIEW OF THE LITERATURE

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ABSTRACT: A significant number of children are born with some kind of serious chronic illness and increasing numbers of youth with chronic illness are admitted to the care system. Given the improvements in medical treatments, the life expectancy of these children is rapidly increasing. The consequence is that affected families will need to adapt to, and accommodate, the needs of these special children. This literature review provides an overview of key research in this area, paying special attention to investigations that have focused on parents and siblings. This review will be especially salient for those child and youth care professionals who support these children and their families in the care system.

KEY WORDS: Chronic illness; family functioning; children and youth.

INTRODUCTION

According to Perez (1997), between 10 and 20 percent of all children suffer from a chronic illness. "The management of chronic illness depends to a great extent on pain control (e.g., sickle cell disease) or the reduction of attacks (e.g., asthma), bleeding episodes (e.g., hemophilia), or seizures (e.g., epilepsy)" (Midence, 1994, p. 311). Differing from an acute illness, a chronic illness may develop slowly and will often last a lifetime. The cause may be due to an immune system deficiency or an organ failure. Although a chronic illness is rarely cured, diet, medication, and adequate exposure to education and resources may influence and help to control the illness and its effects (Wishnietsky & Wishnietsky, 1996). To this end, effective support from the care system is vital to support these children and their families.

The most common childhood illnesses include asthma, kidney disease, sickle cell disease, and congenital heart disease. According to Hoffman (1990), "congenital heart disease occurs in approximately 1 per cent of live-born children, but in a much higher percentage of those aborted spontaneously or stillborn" (p. 39). Congenital heart defects are one of the most serious and pervasive chronic illnesses in children (Davis, Brown, & Bakeman, 1995). Other illnesses such as childhood cancer and diabetes are not as common but frequently occur in children today.

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Infectious diseases that once claimed the lives of many children throughout history have been eliminated due to medical advances, proper sanitary practices and vaccines (Newacheck & Taylor, 1992). Some illnesses, such as polio and tuberculosis, have declined considerably over the past fifty years. "However, reductions in the prevalence of childhood chronic illness have not been nearly as dramatic" (Newacheck & Taylor, 1992, p. 364). With the advances in medical knowledge and treatments, many chronically ill children (who typically would have died), are now surviving into adulthood (Newacheck, & Taylor, 1992). "These changes have affected the types of care that families provide, and often the meaning of the illness for the child and family" (Kazak & Nachman, 1991, p. 2). These gains have led researchers to study the effects chronic illness have on the family system. Although "conducting family research is a challenging and relatively new field for psychologists" (Kazak & Nachman, 1991, p. 3), research does suggest that families are seriously affected by a child's illness.

EFFECTS ON FAMILIES

Research has addressed the importance and significance of relationships at various stages of the lifespan. It is understood that parent-child interactions change with the child's maturation and developmental stage. In early childhood, parents provide the context for learning and conceptual development. Throughout the later years, parents instill self-control in children, thereby facilitating their pursuit of independence (Lamb, Hwang, Ketterlinus, & Fracasso, 1999).

Family relationships provide the context for growth, development and support. According to Germain (1991), a family is considered to have many functions. Some of these include raising children, socializing all individuals into gender-specific roles that are viewed as being acceptable by society, and household maintenance such as domestic labour, authority, and decision making. In addition, Germain (1991) suggests that a family functions as a unit to produce effective, developed members who will make positive contributions to society throughout the course of their lives.

A child's chronic illness is known to have a serious impact on the family. "The care of a child with a severe and chronic physical disorder makes considerable emotional and practical demands on all family members" (Taylor, Fuggle, & Charman, 2001, p. 953). These then translate into increased demands on the care system. Everyone in the family is affected by the condition. Wong (1999) indicates that parents experience both emotional and physical challenges when caring for a child with a chronic illness.

EFFECTS ON PARENTS

According to the Nemours Foundation (2002), taking care of a chronically ill child may be one of the most draining and difficult tasks parents can face. "Parents of chronically ill children face a demanding and often lonely ordeal" (Gordon, Hsia, & Kwok, 1996, p. 59). Gordon et al. suggest

that parents of ill children may also become overwhelmed with the challenges of raising a child who is ill. Parents are faced with the worries regarding the effects of the illness and have to accept the fact that their child is not going to have a typical childhood. They are required to assume numerous tasks and responsibilities in caring for their child, often before they have had a chance to mourn or grieve the loss of a normal child.

Gordon et al. (1996) also identify that, as a child with a chronic illness begins school, additional stressors arise. Parents are required to give control of the caregiving to teachers and other school personnel when, in many cases, the school has limited knowledge and expertise of how to care for the student. If the child is physically disfigured, that would also increase anxiety for the child as well as the parents. Caregiving can be a huge burden on parents as they are expected to know a great deal about their child's illness. They are expected to make decisions and educated judgments on the need for treatment and may feel enormous guilt if they make a mistake or misjudge their child's symptoms. Additionally, parents may believe that they have limited social support if they feel that no one understands what they must be going through. Parents are also faced with the financial constraints that a chronic illness creates. Maintaining health insurance, daily home care, hospitalization, and treatment are aspects of a chronic illness that can create enormous financial stress (Gordon et al., 1996). It is, therefore, clear that caring for a chronically ill child can take its toll on parents in a number of ways.

According to Streisand, Braniecki, Tercyak, and Kazak (2001), "parents caring for children with physical limitations are at risk to experience poor mental health outcomes" (p. 156). In this sense, both the child with chronic illness and his or her parents will require increased support from the care system. Health care professionals need to be prepared to understand and provide additional support where needed. Stress also affects an individual's ability to remember, process information, and learn. When parents are under a great deal of stress, they are prone to an inability to adequately comprehend a child's treatment and condition. A parents' level of stress may also create elevated levels of stress in the child (Streisand et al., 2001). Streisand et al. suggest that a parent's response to medical procedures, communication with family members and doctors, or their role as a caregiver may also have a substantial effect on their child's mood and emotional well-being.

Parents of repeatedly hospitalized children are under a great deal of stress and have a high potential for long-lasting problems. According to Burke, Harrison, Kauffman, and Wong (2001), hospitalizations may put chronically ill children at a greater risk of psychiatric and social problems compared to their healthy counterparts. Burke et al. suggest that a parent's distress and reaction to hospitalizations may consequently affect their ability to cope with their child's illness as well as the child's ability to accept and react to his/her illness. Burke et al. (2001) suggest that professionals must find strategies that will assist parents to work with their child throughout hospitalizations. The amount of stress on parents who

care for a chronically ill child varies among families. It can, however, also be expressed as a function of gender.

In a study by Knafl and Zoeller (2000), the authors reported the outcomes of a secondary analysis of a larger study that examined the experiences of families of chronically ill children. In the original study, the authors looked at the impact a chronic illness had on family life. "For the secondary analysis, the unit of analysis shifted from the family to mother-father pairs to determine the extent to which parents in the same family held shared or discrepant views of their situation" (p. 291). Data for the study were obtained from 43 couples and 7 wives whose husbands chose not to participate. Using purposive sampling techniques, the authors selected a sample of families in which a child between the ages of seven and fourteen years had a chronic illness that required daily monitoring and management. A variety of chronic illnesses, including asthma, diabetes, and rheumatoid arthritis, were the most common illnesses that affected the children.

In the Knafl and Zoeller (2000) study, parents were involved in individual qualitative interviews that addressed the impact of the illness, including how it was defined and managed. In addition, the parents completed the *Feetham Family Functioning Survey and the Profile of Mood States*. The findings of this study suggest that most fathers and mothers develop a shared view of their child's illness. In most cases, this view minimizes the impact on family life. However, some parents reported very individual experiences of their child's illness. The authors indicate that, because parental differences may contribute to child and family functioning, more support will be required from health care professionals to help parents adapt to the illness. In addition, the authors concluded that nurses and other professionals must provide appropriate assessments and interventions based on how each individual manages the child's illness.

Wong (1999) describes similar gender differences. According to Wong, fathers of children with special needs struggle with issues that are quite different from those faced by mothers. It is further indicated that, historically, men were not expected to share their feelings. This may still be the case for some men today. Thus, they are often left without the emotional support required to help them cope. The father's self-esteem may also be compromised as he may feel unable to protect the family or manage the increasing financial burdens (Wong, 1999).

As a result, the needs of both parents must be addressed in order to promote adequate family functioning. However, it is also important to acknowledge the effects and experiences that a child with chronic illness has, not only on the parents, but also on other family members such as siblings.

EFFECTS ON SIBLINGS

According to Labato, Faust, and Spirito (1988) "sibling relationships are among the most important precursors to peer and later adult relationships" (p. 389). Stoneman and Brody (1993) indicate that the sibling relationship

can be characterized as one of the longest-lasting human relationships. "In a very real sense, children encounter most of the significant social experiences to be faced as they progress through life in the microcosm of sibling relationships" (McKeever, 1983, p. 210).

Stoneman and Brody (1993) indicate that little is known about the factors that influence the relationship between individuals with chronic illness and their healthy brothers and sisters. Kazak and Nachman (1991) suggest that "concerns about the effects of illness on siblings are frequently raised by parents, yet siblings are rarely included in systematic research" (p. 4). Siblings, as a population, have been greatly overlooked as most family research has focused on the mother-child dyad (McKeever, 1983). In many investigations, siblings have rarely spoken for themselves as data have been derived from parental observations and interpretations (McKeever, 1983).

Sibling relationships are vital to the socialization and education of each individual. They provide the context for sharing and negotiations as well as for emotional experience and development (Lobato et al., 1988). Given the significant influence siblings have on each other, it would appear that the illness of one would certainly affect his or her healthy siblings to some degree (McKeever, 1983).

The National Resource Center for Respite and Crisis Care Services (NRCRCCS, 2002) suggests that the concerns of individuals with a chronically ill sibling include feelings of loss and isolation as much of the parent's time and attention is consumed by the disability or illness. Healthy siblings often have less knowledge about the illness and ways they can help as resources and information are not usually created for young readers. Having a chronically ill brother or sister may leave the healthy siblings feeling concerned, worried and angry (NRCRCCS, 2002). Children may fear they have their sibling's illness or may catch it, which creates anxiety and stress in an already stressful situation. Berkobien (2002) also indicates that children may begin to feel guilty that they do not have the disability or that they are to blame for their sibling's condition. If the sibling is physically affected by an illness, the children without the condition may feel embarrassed and may refuse to invite friends over or be seen with their sibling (Berkobien, 2002). According to Berkobien, when parents are consumed with their child's illness, siblings may react with jealousy and anger, often resulting in resentment towards the brother or sister. Tritt and Esses (1988) further indicate that such resentment towards a sibling may be a result of the healthy child's worry and "their sense of exclusion and loss" (p. 217). Healthy children may also feel the pressure to excel in sports or school in order to make up for the chronically ill sibling's inability to do so (Berkobien, 2002).

However, according to Wong (1999), many studies to date have shown inconsistent findings regarding the experiences of siblings. Some confirm that siblings are at higher risk for maladjustment; others report no significant differences between siblings of chronically ill children and siblings of healthy children; and still others illustrate beneficial aspects of having an ill sibling.

Breslau, Weitzman, and Messenger (1981) examined the psychological adjustment of normal siblings of children who were disabled. The majority of the children used in the study experienced a variety of illnesses including cystic fibrosis, cerebral palsy, myelodysplasia, and various other multiple disabilities that required the child to receive clinical care. The sample consisted of 239 families with normal siblings between the ages of six and eighteen years. The siblings' psychological functioning was measured using the *Psychiatric Screening Inventory* which assesses psychiatric impairment in children. Impairment in this inventory was defined according to how well a child functions in a context with parents, teachers, siblings and peers. The *Psychiatric Screening Inventory* "was constructed by a factor analytic method using a large pool of descriptive items covering extensively the domain of child behaviour" (p. 346). The premise behind their research is that normal siblings tend to be neglected because the majority of parental attention and care is given to the sick child. This can have everlasting effects on the emotional well-being of the healthy siblings. These children may act out, feel jealous and angry, and may, at times, assume roles and responsibilities like those of the parents in order to help care for the child.

The findings of Breslau et al. (1981) indicate that the siblings of chronically ill children did not manifest higher rates of psychological impairment when compared to control subjects. However, these children did score higher on scales measuring interpersonal aggression with peers and within the school. The gender and birth order of the healthy child did appear to be related to psychological functioning. Male siblings that were younger than the ill child were psychologically worse off than their female counterparts. The authors conclude that, overall, siblings were not worse off than those in their control groups. However, they do suggest that future investigations examine other factors apart from parental attention that may contribute to higher levels of aggression in healthy siblings of chronically ill children.

A positive self-concept in healthy siblings appears to affect the self-concept in the child with a disability. When a child has an illness or disability, there may be a general sense of empathy for the child by a healthy sibling. This can have a positive effect on the unhealthy brother or sister. For example, Janus and Goldberg (1995) investigated the relationship of healthy siblings' empathy to the psychosocial adjustment of children with a congenital heart disease (CHD). They suggested that siblings with a chronically ill brother or sister are more capable of empathy, sensitivity, and an awareness of others' suffering. Prior to the study, the authors anticipated that children with CHD would have fewer behaviour problems if their siblings had higher empathy than if their siblings had lower empathy. They also suggested that sibling empathy is positively related to sibling behaviour towards the child with CHD.

The participants in Janus and Goldberg's (1995) study consisted of 28 sibling pairs, between the ages of three and eleven years, in which one

child had CHD. Mothers were interviewed by phone and completed the *Child Behaviour Checklist (CBCL)* for both children. Each child completed one empathy task and, along with the mother, rated the healthy sibling's behaviour using the *Sibling Inventory of Behaviour*. Two empathy tasks were chosen due to the age range of the subjects. The *Bryant Empathy Task* was chosen for siblings above five years of age and a modified procedure based on Borke (1971) and Lewis (1993) was used for siblings under five years of age.

The findings of the Janus and Goldberg (1995) study indicate that sibling empathy was not related to behaviour problems of chronically ill children. However, the study does illustrate that siblings who express higher degrees of empathy toward their ill brother or sister are perceived as more positive in their interactions toward their ill sibling. In addition, "maternal perceptions of siblings' behaviour, though consistent with other maternal ratings (*CBCL*), were not highly concordant with the ratings by the child with the illness and generally not related to the siblings' empathy. However, mothers judged siblings in the high empathy group to be more resentful of the child with CHD" (p. 328). Although the study did not illustrate that the healthy sibling's behaviour was a mediating factor for the chronically ill child's maladjustment, it did indicate a connection between a child's empathetic abilities and the chronically ill sibling's perception of the healthy child's behaviour toward him or her.

Dyson (1996) further examined this phenomenon in a study that addressed the self-concept of siblings in families where one child had a learning disability. The sample in this investigation consisted of 19 families in which there was one child with a learning disability and one child without, both between the ages of seven and fourteen years. Sixteen questionnaires were completed by the mother, one was completed by the father, and two were completed by both parents. In order to meet the criteria of the study, one sibling in each family must have been diagnosed as having severe difficulties. The comparison sample was drawn from previous work by Dyson and consisted of 55 normally achieving children. Parents are faced with worries regarding the effects of the illness and have to accept the fact that their child is not going to have a typical childhood. In addition, they are required to assume numerous tasks and responsibilities in caring for their child, often before they have had a chance to mourn or grieve the loss of a normal child.

Gordon et al. (1996) also identify that, as a child with a chronic illness begins school, additional stressors arise. Parents are required to give control of caregiving to teachers and other school personnel; in many cases, the school has limited knowledge and expertise on how to care for the student. If the child is physically disfigured, that would also create anxiety for the child as well as the parents. Caregiving can be a huge burden on parents as they are expected to know a great deal about their child's illness. They are expected to make decisions and educated judgments on the need for treatment and may feel enormous guilt if they make a mistake or misjudge

their child's symptoms. Additionally, parents may believe that they have limited social support if they feel that no one understands what they must be going through. Parents are also faced with the financial constraints that a chronic illness creates. Maintaining health insurance, daily home care, hospitalization, and treatment are aspects of a chronic illness that can create enormous financial stress (Gordon et al., 1996). It is, therefore, clear that caring for a chronically ill child can take its toll on parents in a number of ways.

Using the *Questionnaire on Resources and Stress—Short Form*, the *Family Environment Scale—Form R*, and the *Piers-Harris Children's Self-Concept Scale: The Way I Feel About Myself*, the author examined parental stress, family functioning, and sibling self-concept. The data were then analyzed using the constant comparison method.

The findings of the Dyson (1996) study illustrated that almost half of the families indicated having no problems with the siblings at home. However, more families suggested problems for the family and even more reported problems with the school. Relationships between siblings were generally positive and most parents reported the sibling who was not disabled to be understanding and patient with the sibling with the disability. However, a significant problem reported by the parents was feelings of guilt due to having to spend so much more time with the child with the disability than with their other children. In addition, Dyson indicates that the self-concept of the non-disabled siblings may be related to their sibling with a disability. Although the study calls for further investigation of siblings of children with disabilities, it does illustrate the fact that a child's perception of other's attitudes may be a significant contributing factor towards their self-concept and that families of children with learning disabilities do have needs that must be supported.

As a result, it is clear that, when helping a family cope and adjust to a child's chronic illness, siblings must be included, and their needs must be addressed as they are part of the family unit. "Variables such as the nature and the extent of the illness, the age and the gender of the sibling, and the resources available to the family all play a role in shaping the healthy sibling's response to the situation" (Gordon et al., 1996, p. 62). Health professionals play a part in accommodating the needs of all family members. Information regarding the needs of siblings will aid in the provision of adequate material and care for these individuals.

The extant literature does indicate that brothers and sisters of children with chronic illness are, at least to some degree, affected by their sibling's condition. Continued research in this area is required in order to develop a more comprehensive knowledge base regarding the experiences of healthy siblings. These children need to be considered and have their needs identified and met in order to promote a better quality of life, optimum development, and adequate adjustment to the effects of their brother or sister's chronic illness. McKeever (1983) further states that:

The fact that many siblings of chronically ill children do not develop symptoms that dictate professional intervention may reflect their capacity to function under stress. This does not, however, absolve health professionals from their clear responsibility to include siblings in both their practice and research endeavours. (p. 217)

THE NEED FOR FUTURE RESEARCH

According to Kazak and Nachman (1991), "conducting good family research is difficult, and many of the theoretical and methodological issues involved are exceedingly complex" (p. 11). Despite the challenges, family research has made considerable gains over the years. However, siblings have remained an overlooked population in family investigations. Very little research has addressed the needs of siblings as they have had little opportunity to speak for themselves (McKeever, 1983). Given the lack of conclusive research, it is strongly suggested that siblings of chronically ill children are a population at risk and must be considered in future research (McKeever, 1983). Information is required about the daily stressors and challenges these healthy children face and the effects their chronically ill siblings have on their development. In addition, it is vital for health professionals to hear from the healthy siblings themselves in order to implement programs that address the needs of these children and their families (McKeever, 1983). This research will greatly inform the practice of child and youth care professionals who support these children and families in the care system.

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