

How Chronic Illness Affects Family Relationships

and the Individual

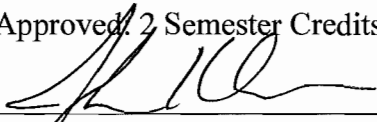
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ABSTRACT

This research project reviewed the current literature on how chronic illness affects an individual and the relationships within a family. The research demonstrates that chronic illness can have dramatic effects not only on the individual, but also on the relationships and psychological selves of a chronically ill person's family members. In addition, the research suggests that a person's culture may impact how an individual views his/her chronic illness. More research needs to be conducted to better illustrate how a chronic illness impacts the family relationships, function, and structure, as well as give a more comprehensive understanding of how different cultural factors directly impact chronic illness.

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Chapter I: Introduction

A chronic illness impacts nearly every aspect of an individual's life and leaves a devastating imprint on the lives of everyone involved. Boice (1998) found that 10% of children in the United States suffer from a chronic illness. Furthermore, chronic illness in children and adolescents has easily become one of the most serious issues in pediatric medicine to date (Boice, 1998). In the past, children with these illnesses never lived long enough to become adolescents. However, because of current research and treatments, this is no longer the case. Unfortunately, even with the new research and treatments available the specialized and time consuming care needed to cope with a chronic illness can be emotionally and physically exhausting for the family of a person who is chronically ill (Gravelle, 1997). Furthermore, a child's chronic illness will have both direct and indirect effects on family members and their relationships (Murray, Kelley-Soderholdm, & Murray, 2007). Once diagnosed with a chronic illness, it is not unusual for an individual's family members to feel anger, denial, self blame, fear, shock, confusion, and helplessness (Ellenwood & Jenkins, 2007). Since chronic illnesses are usually not curable, it is necessary to understand how chronic illness affects not only the individual, but also the relationships within the family (Ellenwood & Jenkins, 2007).

Statement of the Problem

When a member of the family suffers from a chronic illness, the family dynamic may drastically change. A chronic illness has a monumental impact not only on the development of the individual suffering from it, but also on the individual's family members and relationships. Based on this fact, it is imperative for people working in the helping profession to gain a more comprehensive understanding of how a chronic illness continuously affects the individual and the family structure as a whole.

Purpose of the Study

The purpose of this study is to present a comprehensive overview of the current research regarding chronic illness so that individuals in the helping professions can gain awareness about the effects of chronic illness on the individual and its impact on the family. In addition, this review will provide an outline of current treatment options and examine how culture influences the manner in which a family deals with chronic illness.

Definition of Terms

There are five terms which must be more clearly defined to provide the reader with optimal understanding of this literature review. They are:

Chronic Illness. “An illness that can last for an extended period, at least three months, often for life, and cannot be cured” (Midence, 1994, p. 311).

Disability. “Identified as disabled by two or more (up to five measures)... (1) the existence of a chronic condition; (2) the existence of a functional limitation; (3) not being able to work; (4) 31 or more days spent in bed due to a disability; and (5) receiving SSI (social security insurance), SSDI (social security disability insurance), or a pension due to a disability” (Pfeiffer, 1999, p. 392).

Emotionally Focused Therapy. “Emphasizes the present and the specific...Emotionally Focused Therapy derives from its emotional (rather than cognitive or behavioural) approach to counselling, and from its emphasis on wholeness in the context of interpersonal relationships” (Benson, 2006, p. 1).

Holistic Approach. “It's a wellness approach that addresses the body, mind and spirit or the physical, emotional and spiritual aspects of an individual” (Perkins, 2007, p.1).

Psychosomatic Symptoms. “Psychosomatic symptoms refer to a mind (psych) and physical body (soma) relationship. Illnesses of psychosomatic nature are caused by mental processes of the sufferer rather than physiological causes” (Serendip, 2008, p. 1).

Assumptions and Limitations

It is assumed that there will be enough quality research on the impact of chronic illness on the individual, their siblings and family relationships. Furthermore, it is also assumed that previous research has been conducted on cultural differences in the perceptions of chronic illness and possible treatment options. A possible limitation of this review is the lack of pertinent information in the above areas to complete a comprehensive literature review.

Chapter II: Literature Review

This chapter will begin with a comprehensive overview of how chronic illness impacts the individual. Next will be a discussion of how chronic illness affects the family and parental relationships. This chapter will then examine how sibling relationships are altered by the illness and how culture influences the effects of chronic illness on family relationships. Finally, the chapter will conclude with a discussion on relevant intervention and treatment options.

Overview of Chronic Illness

Midence (1994) defined a chronic illness as, “An illness that can last for an extended period, at least three months, often for life, and cannot be cured” (p. 311). In a qualitative study focusing on the strengths, challenges, and relationship processes in families of children with congenital upper limb differences, Murray et al. (2007), categorize a chronic illness using five characteristics, “type of onset (acute or gradual), course (progressive, constant, or episodic), outcome (fatal or nonfatal), incapacitation or the degree of impairment (cognitive, sensation movement, stamina, disfigurement, and social stigma), and uncertainty (the degree of predictability of the condition)” (p.277). Additionally, Boice (1998) describes chronic illness as living with a condition which drastically alters an individual’s daily activities for more than three months out of the year, or requires hospitalization for the same time period. Some of the specific illnesses that fall within the category of a chronic illness include: sensory and nervous system disorders, lupus, diabetes, cystic fibrosis, cancer, multiple sclerosis, and cardiovascular disease (Boice, 1998).

Looking through current literature, it is apparent that many researchers group a disability and chronic illness together due to the similar, yet devastating effects they can have on individuals. Livneh (2001) stated that the causes of chronic illnesses and disabilities include, “genetic or hereditary dispositions, birth traumas and other conditions

present at birth, accidents and injuries, diseases and illnesses, and conditions associated with the aging process” (p. 152). Additionally, Livneh (2001) identified variables that are linked to a disabling condition such as: severity of symptoms, body parts that are affected, functional limitations that the individual experiences, the course of the condition, presence of pain, the duration of the condition, side effects from necessary medications, the impact on an individual’s appearance, and the effectiveness of treatment.

In another study discussing the domains of psychosocial adaptation to chronic illness and disabilities, Livneh and Antonak (2005) found that the degree of functional limitation, ability to perform daily activities and roles, course of medical treatment, uncertain prognosis, impact on family and friends, financial loss, and psychosocial stress associated with the trauma or disease hold the most profound impact on an individual who has a chronic illness or disability. Further, Livneh and Antonak (2005) identified three domains of psychosocial adaptation to chronic illness and disability. These include: basic concepts, chronic illness and disability triggered reactions, and chronic illness related coping strategies. Included under the heading basic concepts are the concepts of: stress, crisis, loss and grief, body image, self-concepts, stigma, uncertainty and unpredictability, and quality of life. Similarly, feelings such as shock, anxiety, denial, depression, anger/hostility, and adjustment were all categorized under chronic illness and disability triggered reactions. Finally, Livneh and Antonak (2005) identified useful chronic illness associated coping strategies such as disengagement coping strategies and engagement coping strategies.

In a different study, Sandstrom (2007) implemented a study to compare the lived experiences of 22 individuals with cerebral palsy. This study utilized the five-level Gross Motor Function Classification System and included people with functional levels ranging from II-IV. In this study, Sandstrom (2007) found that like people with a chronic illness, individuals with a disability felt different from others when they were unable to do

certain activities or keep up with the high paced tempo set by others. In addition, this same study found that other people's attitudes towards disabilities greatly affected disabled individuals. Having positive and supportive friends and family were viewed as important for bringing about a sense of normalcy and belief in ones self. Another similarity was that individuals with disabilities tend to hide in an attempt to avoid situations where they feel they may receive negative reactions from others (Sandstrom, 2007).

Midence (1994) found that how a child responds to her/his chronic illness can be influenced by the characteristics of the child, the illness, and the family and social environment, and also the effectiveness of the medical, social, and environmental support. Gregory (2005) notes that while people with a chronic illness desire to live without the constraints of constant medical assistance or care, sometimes the limitations are unavoidable and the individual is forced to adapt in this way of life.

Chronic Illness and the Individual

According to Boice (1998) chronic illnesses can magnify developmental issues, increase the desire to be socially accepted, and cause children and adolescents with a chronic illness to spend significantly more time in isolation than their peers. Children with a chronic illness may also miss school more often and experience difficulties with concentration and mental functioning due to certain medications and stress related to their illness. Additionally, he found that chronically ill children experience more stress, depressive symptoms, rejection, and feelings of incompetence due to their illness, peers, and family members (Boice, 1998). One study also found that people with a chronic illness were shown to experience financial burden, sibling resentment, frequent hospitalizations, and grief (Manion & Cloutier, 1996). Adolescents also worry about their ability to reproduce and the probability that they could pass on the disease to their offspring (Boice, 1998).

Children may have a difficult time conceptualizing their disease because during Piaget's concrete operation stage, children believe that they do not have good health because they have a chronic illness (Boice, 1998). This view changes during adolescence. Boice (1998) notes that during adolescence, individuals understand that there are physical, social, and psychological consequences of being chronically ill. Huebner and Thomas (1995) also found that children with a chronic illness are at increased risk for neurotic disorders, social maladjustment, conduct disorders, various psychiatric disorders and attention disorders. According to Boice (1998), the limits put on the chronically ill child by family and society may contribute to higher levels of depression. It was found that less than 20% of chronically ill adolescents receive the support of social or mental health services (Boice, 1998).

A study conducted by Millen and Walker (2000) found that society still views individual's with a chronic illness as a burden on society due to their incurable disease. Not only does an person diagnosed with a chronic illness need to adapt to the negative views of others, but also the loss of self esteem which may emerge from social isolation, and the loss of privacy over personal bodily functions. In addition, the individual suffering from the chronic illness must adjust to the stress of treatment, the symptoms of the disease, finical burden of their illness, changes in family structure, and feelings of vulnerability and loss of control (Millen & Walker, 2000). The initial impact of being diagnosed with a chronic illness can result in denial, shock, feelings of loss and grief, and anxiety and depression. However, it has been shown in recent studies that if a person allows these feelings to continue on for too long, they can have a negative impact on the illness. A chronic illness is viewed as a crisis because it serves has a turning point which results in an individual making adjustments in their social, emotional, physical, and possibly their vocational selves (Millen & Walker, 2000).

Effects of Chronic Illness on the Family and Parental Relationships

Families and individuals alike may be affected by the stigmas surrounding chronic illness. Murray et al. (2007) found that not only will children with visible differences contend with some level of external or internal stigma, but their families may as well. To expand on this, these researchers highlight a paradox known as the spread phenomenon in which people further stigmatize a person's physical differences by assuming that along with the physical differences, there are also some cognitive disabilities (Murray et al., 2007).

Even with the variety of community services available today, family members are often the primary caregivers for people with a chronic illness (Smith, Greenberg, & Mallick Seltzer, 2007). Some common challenges of this role include: tension in family relations, time managements struggles, disrupted family activities, disconnection from social networks, high medical costs, and difficulties interacting with the children's schools (Murray et al., 2007). Many areas of family life can be affected by a chronic illness such as: daily routines, financial decisions, careers, developmental transitions, friendships, school performance, parenting strategies, and sibling relationships. If the family views the stressors as unmanageable, or they are unable to attain supportive resources, family relationships may weaken and the negative effects of stress can accumulate (Murray et al., 2007).

Another area of chronic illness is a parent's perception of a child's behavior. Parents may become more overprotective and concerned about their ill child's health and skew their perception of discipline problems (Zahr, Khoury, & Saoud, 1994). Research has also shown that the more stressed the chronically ill child's mother is, the more she will perceive the child's behavior as deviant (Boice, 1998). According to Zahr et al. (1994), chronic illness impacts all members of a family, and some parents may also experience periods of anxiety or depression. In addition, Boice (1998) established that

fathers experience more difficulty forming attachment with their chronically ill child, especially if this child is male. Ellenwood and Jenkins (2007) note that mothers of chronically ill children may become neurotic, introverted, and lack self confidence, whereas fathers of chronically ill children may form long-term personality changes (Ellenwood & Jenkins, 2007). One study also found that children with a chronic illness are more likely to have adjustment problems and behavioral disorders than healthy children (Zahr et al., 1994).

In a study conducted by Murray et al. (2007), findings indicated that families often develop a set of rules to cope with their child's chronic illness. Distress levels tend to be higher in families who have poor cohesion, have limited access to resources, and are facing additional crises (Williams et al., 1999). If families utilize available resources to cope with and negotiate a stressor that is perceived as manageable, they are more likely to become adaptive and confident. Since the family was able to cope effectively, Murray et al. (1997) state that the family will view the demands of dealing with a child's chronic illness as more manageable and will, "develop a coherent, adaptable meaning system related to the health condition and its related challenges"(p 278).

Family relationships can be greatly affected as a result of a child's chronic illness. For example, one study demonstrated that parents felt stronger emotional responses toward the challenges their children with a chronic illness faced and did not have the same emotional response to their other children (Murray et al., 2007). Similarly, as a result of the many struggles encountered, some parents noticed that they had disconnected from their partner (Murray et al., 2007).

McDaniel, Hepworth, and Doherty (1997) note that in some cases, the child with the chronic illness holds the family together and acts as a diversion for the family so it can avoid other issues. In addition, extended family member relationships are strongly affected by the challenges faced when a child has a chronic illness. Family members may

question the child's condition and search for explanations, whereas healthy children express great curiosity towards the chronic condition and concerns about the cause of the chronic illness (Murray et al., 2007; Madan-Swain, Sexson, Brown, & Ragab, 1993). In another study, Fisman, Wolf, Ellison, and Freeman (2000) found that when stress is produced as a result of a child's chronic condition, this stress can impact parental and marital functioning, and lead to behavioral and chronic emotional problems in healthy children. Likewise, family members may experience ongoing conflicts and somatic illnesses (Ellenwood & Jenkins, 2007).

Williams et al. (1999) said that families caring for chronically ill children may experience more strains and burdens on their emotional, physical, and emotional resources. Other research indicates that, these families may become more resilient and have more advanced problem solving skills (Williams et al., 1999). In addition, Murray et al., (2007) have shown that family relationships may strengthen as a result of the child's chronic condition. Many families see the illness as an opportunity for increased communication among family members (Murray et al., 2007).

Studies have shown that since the family is the first community to which a person belongs, a child's birth order gives the child characteristics associated with her/his place in the family (Kids Development, 2008). Also, this sense of belonging gives children a sense of community and self confidence (Kids Development, 2008). When the birth order is changed due to a chronic illness, children may feel lost, suffer from low self-esteem, and have increased anxiety (Buckley, 1998). Still, children may automatically adopt different roles in order to fit into the new family system. As previously noted, this can have a negative impact on the child's development (Buckley, 1998).

How Chronic Illness Affects the Sibling Relationship

Healthy siblings have commonly been referred to as "the forgotten ones" (Madan-Swain et al., 1993). Foster et al. (2000) found that siblings can be both directly and

indirectly affected by living with a sibling who has a chronic illness. In many cases, this may cause resentment between the siblings. Based on the physical and emotional demands placed on parents as a result of the chronic illness, differential treatment of siblings is not uncommon. Parents have been shown to be more tolerant of children with a chronic condition and these children receive more parental attention than healthy siblings (Foster et al., 2000). In addition, in a cross-sectional study looking at the impact of chronic illness on children, healthy siblings, and mothers, Foster et al. (2000) found the expectations of good behavior are raised for healthy siblings and parental tolerance for misbehavior is lowered.

Similar to the findings of Foster et al., a study conducted by Weiss, Schiaffino, and Ilowite (2001) looked at how sibling relationships develop under the strain of a chronic illness. These researchers found that sibling relationships are essential because they are foundational to how a child will develop and maintain other close relationships later in life. A child who has a solid support network of family and friends surrounding her/him may also have a more positive view of herself/himself (Weiss et al., 2001). However, when a child suffers a chronic illness, sibling relationships may be altered or strained because a chronically ill child is perceived as needing more protection and attention in order to survive. Findings from this same study also showed that other risk and resistance factors found to be associated with sibling involvement include: age, birth order, functional loss, parental distress, and dysfunction, family social support, child perceptions of competence, cohesion, coping, and gender (Weiss et al., 2001). In addition, Hollidge (2001) found that the psychological growth of the healthy sibling may be affected if a chronic illness brings stress to the sibling relationship. Ellenwood and Jenkins (2007) note that healthy siblings may feel abandoned by their parent, become resentful, and pick fights with peers and/or other siblings.

To illustrate how a chronic illness can affect a healthy sibling, Hollidge (2001) used a semi-structured interview evaluating factors such as emotional isolation, resentment toward the chronically ill sibling, exaggerated sibling rivalry, and a strong sense of responsibility. Results indicate that the healthy sibling is at a higher risk to develop depression, anxiety, and a low self-esteem. Healthy siblings are more likely to experience psychosomatic symptoms such as: difficulties with social isolation, poor communication with parents, and a sense of responsibility and resentment toward their ill sibling (Hollidge, 2001). These are similar to the results of Williams et al. (1999) who found that siblings of chronically ill children can feel neglected, may withdraw, and are at higher risk for developing adjustment problems. Buckley (1998) noted that children who have a sibling with a chronic illness experience more stress and are at higher risk for developing behavioral problems and psychopathology. Further, sibling relationships in which one sibling has a chronic illness are more complex and tend to be affected by many variables such as: age, socioeconomic status, severity of illness, birth order, and care-taking responsibilities (Buckley, 1998).

Hollidge (2001) conducted a study which looked at the psychological adjustment of healthy siblings living in the same house as a chronically ill child. In this study, it was found that healthy siblings actually hold the greatest amount of stress in the family due to a sibling's chronic illness. The author of this study asserted that this greater level of stress is due to the fact that the healthy child's demands and needs for parental attention and affection are not being met. Hollidge (2001) found that in an attempt to gain this valuable attention, parents reported that healthy children may feign an illness, ask for medication, and engage in disruptive behaviors as a means to receive some parental attention. Additionally, while taking a closer look at healthy children, Hollidge (2001) found that these children appear highly capable and competent in the external world; however, their emotional health may be unstable. Hollidge (2001) also found that many healthy children

suffer from high amounts of anxiety which stems from worry, guilt, shame, and competitive feelings with their chronically ill siblings. These feelings of guilt and shame originate from the negative feelings that a healthy child may feel toward the chronically ill sibling. Upon further examination, Hollidge (2001) indicated that the healthy participants stated that they were unable to share these negative, and often aggressive, actions and fantasize with their friends or family. Moreover, the study also revealed that healthy siblings internalize their difficulties and worries and are unable to share these worries with others. Likewise, the healthy siblings also reported feelings of unhappiness and jealousy in relation to their sick sibling (Hollidge, 2001).

In another study, siblings responded not only to the chronically ill child, but also to the parent's preoccupation and distress over the needs of the ill child (Carter & McGoldrick, 1999). Frequently, siblings have been found to become distressed when parents ask them to treat a chronically ill sibling as normal when they are expected to care for their ill siblings needs. Nevertheless, caring for their ill siblings has also been shown to increase maturity but may cause siblings to feel disconnected from their peers (Carter & McGoldrick, 1999).

In another study, researchers discovered that siblings could identify and describe one or more personal strengths that developed as a result of coping with the challenges of having a sibling with a chronic illness (Smith et al., 2007). Many of these strengths included: enhanced coping skills, increased personal competence, greater appreciation of the sibling's life and well-being, and a strengthening of family bonds. Further, the healthy sibling became more sensitive to people with disabilities, made new friends, and had a greater appreciation for a person's inner strengths (Smith et al., 2007).

Weiss et al. (2001) found that in some cases, chronic illness may cause siblings to grow closer as they tend to be more isolated from the community and care for each other. Even so, the reverse may also happen where they have little in common and identify less

with each other because of a decreased sense of closeness (Weiss et al., 2001). Carter and McGoldrick (1999) also pointed out some gender differences in how siblings cope with a chronic illness. Males tend to spend more time away from home and may disengage from the ill sibling later in life. Females, on the other hand, tend to adopt a great sense of responsibility in later life and may feel closer to the ill child. However, if the chronically ill sibling is also a female who is close in age, sibling rivalry and competition may develop between the two sisters instead of affection (Carter & McGoldrick, 1999). In a meta-analytic review of randomized studies, Martire, Lustig, Schulz, Miller, and Helgeson (2004) uncovered some of the negative side effects that may occur due to a sibling's chronic illness. These include: poorer physical health and psychological well-being, caregiver burden, and a decreased relationship quality with the sibling. Cuskelly and Gunn (2006) also found that it is common for parents to disregard the healthy child's efforts and attempt to contribute to the family operation. When this occurs, the child may become resentful and aggressive. According to Cuskelly and Gunn (2006), male siblings are more likely to avoid a chronically ill female child. It also appeared that male siblings had lower self concept scores, high anxiety, and extreme feelings of guilt which could result from an elevated sense of hostility and aggression toward the sibling with a chronic illness (Hollidge, 2001).

In a quantitative study looking at coping and family adaptations in siblings with a chronic illness, Madan-Swain et al. (1993) also found that males were more likely to exhibit depressive symptoms and experience increased isolation versus healthy females. In addition, this study showed that older children adjust better to their sibling's chronic illness. This may be because boundaries in the parent-child relationship are blurred and the healthy sibling is under pressure to decrease the demands on the family, causing the sibling to withdraw emotionally in order to return a sense of balance and normalcy to the family system (Madan-Swain et al., 1993).

Younger children have a harder time putting the situation into perspective and adopting a leadership role (Carter & McGoldrick, 1999). Healthy preschool-aged siblings display a lower self concept, increased sensitivity, and seem to experience a greater sense of distance from their parents. Healthy adolescent siblings also experience this sense of distance. However, they suffer from a decreased feeling of cohesion and an increased sense of conflict (Madan-Swain et al., 1993). Madan-Swain, Sexson, Brown, and Ragab (1993) noted that some common coping strategies among healthy siblings include: expressing emotions, wishful thinking, and talking to someone. Other coping strategies are social isolation and blame particularly in males and in older siblings (Madan-Swain et al., 1993).

Overall, there are many questions that arise in terms of sibling relationship and future sibling involvement. Smith et al. (2007) pointed out that there are a number of factors that go into predicting how siblings will respond to one another later in life. For instance, healthy siblings may be socialized to help care for their chronically ill sibling if they are living at home when their sibling is first diagnosed. In addition, the nature of the sibling relationship determines how involved siblings will be with each other. If the sibling relationship has equal amounts of giving, receiving, and support, a healthy sibling will be more inclined to be actively involved with their chronically ill sibling. Similarly, siblings who are younger in age and married were found to be more likely to provide help and support in areas such as, daily living tasks, transportation, and household chores. Additionally, multiple factors have been identified as possibly limiting sibling involvement such as: severity of the illness, geographic distance, family and work demands, and personal health problems (Smith et al., 2007). It is important to note that sibling relationships are extremely complex and can be affected by any number of variables, not only health (Weiss et al., 2001). However, no matter which way one looks at it, sibling relationships play a crucial role in one's development.

Cultural Viewpoint

Ellenwood and Jenkins (2007) note that culture-specific behaviors and religious attitudes greatly influence a family's response to a chronic illness. Boice (1998) stated, "culture affects relationships inside and outside the family, including interactions with the medical profession...and social class may determine the level and quality of care received, and ethnicity may influence the approach to treatment" (p. 933). Becker (2001) took a more in-depth look at the relationship between chronic illness and ethnic minorities. This qualitative study examined interview data and the responses of insured and uninsured African Americans, Latino Americans, and Filipino Americans. Becker (2001) also took a closer look at ethnic minorities and various issues regarding the management of chronic illnesses. Findings of this study indicate that uninsured ethnic minorities with a chronic illness received less information regarding their illness, had fewer tools to manage their illness, and had less control over their chronic illness (Becker, 2001).

In Latino cultures, the lives of siblings are intertwined which creates a positive influence on the sibling relationship (Lobato, Kao, & Plante, 2005). The act of caretaking and companionship are routine which leads to elevated levels of satisfaction, intimacy, and companionship. However, Lobato et al. (2005) found that children from America have greater levels of companionship with their friends rather than their siblings. It was noted that even the most highly acculturated Hispanics are more family oriented than Americans. Furthermore, studies show that Latino children that have a chronic illness display elevated anxiety levels, internalizing symptoms, and higher rates of depression in both clinical and educational settings compared to European American children (Lobato et al., 2005).

In a quantitative study, Lobato et al. (2005), point out a disparity between Latino and American cultures in dealing with children and chronic illness. Siblings will respond

drastically different to a chronic illness in a culture where the sibling relationship is secondary to friendships. Likewise, Lobato et al. (2005) found that internalizing behavior was also found to be more prevalent in Latino children since a sibling's chronic illness can disrupt opportunities for sibling companionship and intimacy which plays a large role in Latino children's emotional adjustment. Further psychological adjustment problems may develop in healthy children due to the lack of information they may receive from their parents regarding their sibling's condition. In their study, Lobato et al.'s (2005) study found that due to potential language and/or literacy barriers, parents may lack knowledge and understanding regarding their child's illness and have decreased access to valuable information and services that could potentially assist the family and help alleviate stress.

Within the African American culture, individuals with a chronic illness usually receive a tremendous amount of support from not only the immediate and extended family, but also from the surrounding community (Boice, 1998). Traditionally, women are viewed as the primary caregivers; they may feel overburdened and overwhelmed by their caretaking responsibilities (Boice, 1998). "Historically, African American women have been seen as resilient in the face of all odds and have been viewed as the caregivers of the family and community at the expense of their own needs and well-being" (Murry, Owens, Brody, Black, Willert, and Brown, 2003, p.170).

Murry et al. (2003) looked at how personal and social stressors affected the psychological and physical functioning of African American women with a chronic illness. These researchers noted that African American women will utilize exaggerated coping behaviors in an attempt to prove their competence which in turn may prevent her from seeking help when it is needed. Some examples of these coping behaviors included relentless nurturing, caring, and giving for the wellbeing of the family, and a drive to take on multiple roles, as well as an overstated performance of her role within the family. As a

result, these behaviors are likely to have a negative impact on this person's health, functioning, and chronic illness because of the amount of time and energy needed to sustain these additional roles and behaviors (Murry et al., 2003).

Middle Eastern families believe that children with a chronic illness impose a heavy burden on their families where as American families feel differently (Zahr et al., 1994). In a quantitative study which utilized the Impact-on-Family scale, Zahr et al. (1994) claim that, "This finding may be due to the fact that Middle Eastern people tend to dramatize and exaggerate their sufferings..." (p. 400). In fact, Lebanese mothers thought that children with a chronic illness were perceived to be more difficult and less adaptable than healthy children. The same is also true of mothers in Egypt where children with a chronic illness are said to be more temperamental than healthy children. Zahr et al. (1994) reasoned that because of their own stress, mothers may view their chronically ill child as more temperamental and, therefore, be less tolerant of her/his behavior. Also, due to the value placed on males in the Middle East, more distress is noted if the chronically ill child is a male versus a female (Zahr et al., 1994).

From a cultural and beliefs standpoint, McDaniel et al. (1997) note that strong spiritual beliefs are instrumental in helping families cope with a chronic illness. Carl Rogers also points to religious experience as an integral aspect of the treatment process (Zimring, 1999). Nevertheless, Zimring (1999) also notes that Rogers endorses strong beliefs in the actions of the therapist implementing treatment. Rogers believes that the therapist does not necessarily have to understand the client's personality or problem. However, the therapist does have to be genuine and unconditionally accepting while maintaining empathy throughout treatment (Zimring, 1999).

Effective Treatments Options

Researchers have noted that interventions which focused on the chronically ill child and their family members appeared to be the most effective in reducing depression

among both people with a chronic illness and family members (Martire et al., 2004). Huebner and Thomas (1995) defend that the use of psychopathology is three times more likely in children with a chronic illness. It is also imperative that the siblings are a part of the treatment program (Madan-Swain et al. , 1993). According to Foster et al. (2000), “siblings should be told why treatment is necessary and what the parent needs to be involved...parents may try and protect patients and siblings by not talking to them about certain aspects of the illness and treatment” (p362). However, if teachers, parents, siblings, and classmates offer support and encouragement to a chronically ill child, the child is less likely to become depressed due to their illness (Timko, Stovel, Baumgartner, & Moos, 1995). Also, some additional ideas for helping chronically ill children and their families cope with the illness are introspective coping strategies and arming them with the appropriate problem-solving tools (Madan-Swain et al., 1993).

In another study conducted by Nims (2007), which examined the positive effects of integrating play therapy techniques into solution-focused brief therapy, it was found that children are more resilient and flexible than adults. Even though solution-focused therapy has been shown to be highly effective in adult populations, it was also shown to help children in difficult situations form a more positive outlook on life. Solution-focused therapy empowers children and families to use their own knowledge and strengths to find solutions that would help facilitate the desired change (Nims, 2007). In a similar study conducted by Harvard (2006), findings indicate that solution focused therapy helps highlight the positives in any situation. This has been shown to be extremely helpful when working with clients who suffer from a chronic illness. The solution-focused therapist can help the client focus on her/his strengths rather than her/his perceived weaknesses (Harvard, 2006).

In a qualitative study to look at how families respond to treatment, Ellenwood and Jenkins (2007) found it helpful to redistribute the roles and responsibilities of all family

members since there is a high-risk for adjustment difficulties. Therapists should try to find a balance for the family structure and try to understand not only the reality of the chronic illness, but also the impact of the illness. Another factor that Ellenwood and Jenkins (2007) point out is that, while working with a family who has a chronically ill child, therapists should be open to traveling to a different location such as the client's home or even hospital room in order to provide services. Although families may be very interested in seeking counseling, the treatment location may be seen as inaccessible and, therefore, not utilized (Ellenwood & Jenkins, 2007).

In addition to the suggestion made by the Ellenwood and Jenkins (2007) study, it would be important for the therapist needs to keep in mind adaptive strategies which, with a little modification, may be useful during a chronic or crisis phase of treatment (Madan-Swain et al., 1993). Some siblings develop considerable adjustment difficulties; thus, it is vital that the therapist continually evaluate the alliance, roles, and boundaries within the family system (Madan-Swain et al., 1993).

It is vital that people with a chronic illness follow the health care regimen established by their physician. It is also important to remember that what works for one person may not work for another. Also, as a chronically ill child grows into an adult, coping strategies will need to change along with the individual (Boice, 1998). New research has shown that by combining a more holistic approach to treatment and also concentrating on the physical and psychological well being, assessing the sources and causes of excess stress, and involving the entire family, the outcome is more successful (Boice, 1998). Murray et al. (2007) also found that the way the family responds to stressors will determine if the unit will grow stronger or weaker over time due to the child's health condition. Interestingly, Boice (1998) also noted that it is more beneficial for the child with a chronic illness and the child's parents to have a job and participate in activities outside of the home. This may cause chronically ill children to feel more

competent because s/he feels as though there are fewer parental restrictions and that the child is contributing to the family life. Since families of chronically ill children also feel socially isolated, parents may benefit from the additional social contacts, personal interests, and work outside of the home (Boice, 1998).

In addition, Emotionally Focused Therapy (EFT) has shown promising results and could be very effective for people with a chronic illness to use with their partners or even for the parents of someone with a chronic illness (Manion & Cloutier, 1996). The therapy focuses primarily on attachment needs and affective processes which assist partners that may fear a possible death of a child or the loss of a normal life. Manion and Cloutier (1996) found that EFT may be useful in helping partners deal with emotions such as grief and anger. In fact, EFT is known to establish secure attachment and intimacy and assist couples and individuals in dealing with ongoing stress and the negative effects this may have on their relationship (Manion & Cloutier, 1996).

In recent studies, psychological interventions have been shown to be the most promising and popular approaches. Martire et al. (2004) state that such interventions can include, “support groups, patient education, and cognitive-behavioral skills training...” (p. 600). These interventions have been found to have positive effects on the health status and psychological functioning of individuals with chronic illness, in particular, people suffering from cancer, heart disease, or arthritis. Martire et al. (2004) compared family interventions and medical care through randomized, controlled studies and found that utilizing a behavioral approach combined with medical care produces great results. These studies established that interventions have a strong, positive effect on family members’ attitudes and behaviors. Interventions which also focused on relational issues between the family and the chronically ill child left family members less anxious, burdened, and depressed (Martire et al., 2004).

Parents can play a critical role in the therapeutic process. They may reinforce negative perceptions and responses or act as a buffer (Pless et al., 1994). Timko et al. (1995) point out that chronically ill children, their siblings, and their parents, may try to form and maintain supportive relationships and good communication with others due to constant concerns about managing the illness. Zengerle-Levy (2006) found that nurses may spend more time with hospitalized chronically-ill children than the child's parents who may need to be at home to take care of other family members. Nurses have the most human contact with hospitalized chronically-ill children than any other health care professional (Zengerle-Levy, 2006).

Walker and Markos (2002) believe that chronic illnesses may have prolonged effects which could affect a person on many levels. Because a chronic illness is as unique as the person suffering from it, treatment options vary, and may require the intervention of medical specialists. For anyone who suffers from a chronic illness, adjustments must be made so that s/he can continue to form relations and impact the community in which s/he lives. In addition, Huebner and Thomas (1995) found that psychopathology is more likely to develop in children with an insecure attachment. Without this secure attachment, children are less likely to develop trust, reach social competence, develop a strong sense of self, and be more resilient against stress (Huebner and Thomas, 1995).

Conclusion

Medical advances have made diagnosing chronic illnesses easier and people who have these illnesses are living longer lives with their families. It has been shown that chronic illness has a monumental impact on not only the family, sibling, and parental relationship, and on how people within a person's own culture will begin to view him/her, but also on the psychological development of the individuals themselves suffering from the chronic illness.

Chapter III: Discussion

This chapter will begin with a summary of the main points emphasized in this literature review. The chapter will then provide a critical analysis of what previous research has found regarding the effects of chronic illness on the individual and family, as well as discuss the strengths and weaknesses of various treatment options. Finally, a discussion of future research will conclude the chapter.

Summary of Key Points

This literature review provides a comprehensive definition of chronic illness and the effects a chronic illness can have on family and parental relationships, the individual, and sibling relationships. Additionally, a brief look into how various cultures respond to chronic illness and effective treatments and intervention strategies that counselors can utilize when working with a client or family struggling with a chronic illness is also examined.

In most cases, once an individual is diagnosed with a chronic illness, her/his life changes drastically. Not only are daily living activities altered, but a chronic illness can affect a person's emotional, physical, and psychological development. As was previously stated, individuals with a chronic illness are at an increased risk for many mental health issues such as anxiety and depression. Also, it has been found that many chronically ill people spend more time in isolation thus impacting the individual's relationships with her/his friends and family. In addition, many adolescents suffering from a chronic illness have increased anxiety regarding common adolescent concerns such as body weight, acne, and sexual relationships than healthy adolescents (Boice, 1998).

Family and parental relationships are also directly impacted by a child's chronic illness. Financial decisions, daily schedules, and relationships with a person's peers and other family members are directly affected due to medical costs and time spent caring for the chronically ill child (Murray et al., 2007). Even so, if families are able to identify and

access useful resources within the community, some of the devastating stressors can be alleviated and the family may learn to cope effectively with the situation.

A chronic illness can cause resentment and jealousy to occur between siblings. These feelings are likely to result because the chronically ill child may receive more attention from others within the family and community. Thus, the healthy child may become resentful, feel abandoned, and have difficulty forming healthy relationships with others (Hollidge, 2001). Further, healthy siblings have been shown to develop adjustment problems and display more aggressive behaviors in an attempt to obtain more parental attention. On the other hand, some healthy siblings could develop enhanced coping skills and have an increased sense of family due to growing up with a chronically ill sibling (Weiss et al., 2001).

A person's culture can directly impact how an individual, family, and others within the community view chronic illness and respond to a person's treatment. In Latino and African American cultures, when a child is chronically ill, the child's family and friends tend to share the caretaking responsibilities (Lobato et al., 2005). More specifically, within the Latino culture, children may internalize symptoms and have increased rates of depression and anxiety due to the effects of living with a chronic illness. In the African American culture, if a woman is chronically ill, she may ignore her illness and symptoms to care for others within her family and outside in the community, consequently jeopardizing her health (Murray et. al, 2003). In Egypt, chronically ill children were found to over dramatize their symptoms and be more temperamental and behaviorally difficult than healthy children (Zahr et al., 1994).

In regards to counseling individuals with a chronic illness, all family members should be part of the therapeutic process. Counselors need to understand the roles that individuals play in assisting the family and be prepared to redistribute these roles to alleviate some of the stress and tension that may have developed. It is critical that the

therapist help find balance for the shaky family structure. Further, counselors should look into incorporating therapeutic techniques that help decrease anxiety and depression and assist the family in identifying healthy coping strategies. It is also beneficial for the counselor to take on a more holistic approach to treatment and be well acquainted with the medical model so that s/he is able to address all facets of the individual, the illness, and the family. In addition, research has shown that EFT can be very effective in helping individuals and families in treatment deal with the consequences of a chronic illness. This form of therapy has been shown to help people deal directly with the negative emotions, such as anger and grief, and help to establish a secure attachment between family members. Other therapies and strategies that have been helpful include Cognitive Behavioral Therapy, psychological interventions, patient education, and knowledge about helpful resources within the community.

Information is drastically lacking regarding how chronic illness effects culturally diverse populations. More research is needed to provide professionals with better resources to help meet the needs of the client and her/his family. Thus, research could provide professionals with a more thorough understanding of how the various relationships, roles, and family structures are impacted and altered because of the devastating effects of a chronic illness. More comprehensive research allow counselors to provide clients with a safer, more secure and culturally appropriate therapeutic environment.

Implications for Future Research

Future studies about how chronic illness affects the sibling relationships and the individual with the chronic illness may be helpful in gaining a more comprehensive understanding of the impact of illness on the family function, relationships, and structure. Currently, there is limited information available regarding chronic illness and various cultural factors, the role of gender, age, and culture in the outcome of family

relationships. In addition, future research must evaluate the effectiveness of other service models when working with this population. Another area that needs attention is how the children with a chronic illness and the healthy sibling are coping with the illness. Many of the survey forms that are filled out addressing these issues are completed by the children's parents and are, therefore, a perception of how the child may be feeling. It is vital to obtain a self report from the ill and healthy siblings themselves in order to obtain accurate information. In addition, further research on specific disease populations and the efficacy of interventions involving family members and the patient would be beneficial for not only counselors, but medical professionals as well. Likewise, it appears advantageous to test family interventions involving illnesses that have received little or no attention thus far. Finally, future research should examine the availability and accessibility of various resources available to families.

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