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RESEARCH ARTICLE

THE EFFECTS OF CHRONICALLY-ILL CHILDREN ON FAMILY SUBSYSTEMS

***[1]VictoriaAeby Gibbs, [2]Victor Aeby and [3]Tracy Carpenter-Aeby**

[1]Private Practice, East Carolina University
[2]Department of Health Education & Promotion, East Carolina University
[3]School of Social Work, East Carolina University

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ABSTRACT

All family members are impacted by the presence of a chronic condition within a family, particularly having a child with a treatable, but not curable disease. Medical advances, although positive, may result in children living longer, but who may also be faced with lifelong chronic health problems. Family resources, energy, and time are divided leaving siblings to navigate school alone. This paper examines the professional literature related to the family's relationships, dynamics, roles, and responsibilities that may be significantly impacted by the chronic illness through the experiential family therapy lens. Specifically, key theorists, such as Carl Whitaker and Virginia Satir, suggest that families with chronically ill children may need to recognize their own suffering and grief and find ways to express those feelings. Further, family engagement in the school is essential for academic and psychosocial achievements while maintaining a healthy quality of life. Findings of this investigation indicate that the family therapist performs an influential role in helping the family to understand the issues and meaning to having a child with a chronic condition and that families may need to be reengaged with the schools to ensure academic success for those students as well as their siblings.

Key words: Chronic illnesses, Children, Families, Satir.

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INTRODUCTION

Approximately 35.3 million Americans, young and old, are limited in their daily functioning because of their chronic mental or physical health conditions (Seaburn, 2001). Chronic illness is a major-life altering experience that can devastate families (Nichols, 2012). When people are diagnosed with chronic illnesses, the quality of life for the family, regardless of culture or religion, is substantially altered (Ellenwood & Jenkins, 2007). Chronic illnesses hijack families' lives, ravaging health, hope, and peace of mind (Nichols, 2012). As one researcher explained, it can be like a robber "who has appeared on the doorstep, barged inside the home and demanded everything the family has" (Steinglass & Horan, 1988, p.129). The onset of an illness in a family member can disrupt life cycles temporarily or permanently (Gladding, 2011). The quality of life experienced by the family prior to the onset of a chronic illness is difficult if not impossible to restore (Ellenwood & Jenkins, 2007). Because childhood chronic illness disrupts the family, therapists need to be aware of the significant effects that impinge the entire family system. In an effort to understand the effect of a child's chronic illness on family functioning there are a number of variables to be considered, including family constellation, genetics, socio-economic, and culture (Cloutier, Manion, Walker, & Johnson, 2002). This paper will examine the professional literature related to chronic illness and families and the potential impact on family's relationships, dynamics, roles, and responsibilities. The following research questions will guide the primary focus of this paper: "What are the effects of childhood chronic illnesses on family subsystems?" and "What are the appropriate treatment interventions using an experiential family therapy lens?" In an effort to address these important questions, the author identified the empirical literature in the last decade that addresses how childhood chronic illnesses affect family systems and recommends treatment and interventions using experiential family therapy. This review will provide current interventions that examine the impact on families using a systemic framework, with the intention of providing professionals greater insight and awareness when working with individuals and families with children who have chronic conditions. This next section of this paper will provide a brief overview of: (1) chronic illnesses including those with an onset in childhood; (2) effects of childhood chronic illness and family systems; and (3) evidence-based interventions for families with childhood chronic illness using experiential family therapy. Lastly, model application including conclusions and recommendations are provided specifically focusing on experiential family therapy.

Corresponding author: **VictoriaAeby Gibbs,**
Private Practice, East Carolina University

REVIEW OF THE LITERATURE

An Overview of Chronic Illnesses: There are challenges in defining chronic illness in children and adolescents. Adult definitions and measures are not accurate or sufficient means to evaluate children's illness and conditions (Barlow & Ellard, 2005). In an effort to combat the distinction between adult and childhood chronic illness, numerous definitions of chronic illness have been created for research purposes (Stein, Westbrook, & Bauman, 1997). The following definitions for chronic illness were found in this review: (1) "Chronic illness or medical condition is a health problem that lasts three months or more, affects a child's normal activities, and requires frequent hospitalizations, home health care, and/or extensive medical care" (Compas, Jaser, Dunn, & Rodriguez, 2012, p. 457); (2) "A chronic disease is a non-communicable illness that is prolonged in duration, does not resolve spontaneously, and is rarely cured completely" (Checton *et al.*, 2012, p. 114); (3) "A chronic illness or medical condition is a health problem that lasts three months or more, often for life, and cannot be cured" (Midence, 1994, p. 311). For the purpose of this paper, chronic illness, chronic disease, health condition, and chronic health condition are used interchangeably. In these definitions, chronic illnesses are characterized by the following characteristics: they are prolonged in their duration (Checton *et al.*, 2012), they do not resolve spontaneously (Checton *et al.*, 2012), and they are rarely curable (Checton *et al.*, 2012; Midence, 1994). There are many other characteristics one could focus on such as affecting life activities; however, the family and the subsystems are directly and indirectly affected whenever there is a member with a chronic illness.

Childhood chronic illnesses: In the United States, about 10.3 million children live with one or more chronic illnesses (Nobors & Lehmkuhl, 2004; Sharpe & Rossiter, 2002). These chronic illnesses and medical conditions include asthma, metabolic disorders, type 1- and type 2-diabetes, cystic fibrosis, sickle cell disease, cancer, and chronic pain (Compas *et al.*, 2012; Evans, 2004; Nobors & Lehmkuhl, 2004). These illnesses and their treatment present children, adolescents, and their parents with significant sources of chaos and stress contributing, but not limited to emotional and behavioral problems (Compas *et al.*, 2012). Family systems are impacted by each other especially when there is a child who has a chronic illness. A number of the chronic diseases that were once considered terminal are now treatable, and children are surviving at much higher rates today than 20 to 30 years ago, (Compas *et al.*, 2012). However, it is estimated that approximately 15%-18% of children in the United States are living with a chronic illness or disability, such as cerebral palsy, spina bifida, and cystic fibrosis (Holm, Patterson, Rueter, & Wamboldt, 2008; Lubkin & Larsen, 2006; McDaniel *et al.*, 1992). All family members are impacted by the presence of a chronic condition within a family, especially having a child with a sometimes treatable, but not curable disease. The end result of all the medical advances is that children are living longer but faced with lifelong chronic health problems.

Effects of Childhood Chronic Illness on Family Subsystems: Family members influence one another because the family is a whole, which is more than the sum of its parts (Bertalanffy, 1973). Combining ecological and developmental perspectives, the family is viewed as a transactional system that functions in relation to its broader sociocultural context and evolves over the mutigenerational family life cycle (McGoldrick, Carter, & Garcia-Preto, 2011; Walsh, 2012). Families attempt to balance change and stability; hence, a change in one family member affects all of the family members (Smith-Acuna, 2011). Likewise, stressful events, environmental conditions, and problems of an individual member affect the whole family as a functional unit, with reverberations for all members and their relationships (Walsh, 2012). Therefore, the family processes, in relating and handling problems, contribute to individual and relational dysfunction.

Family systems therapy: Family systems therapy is a "psychotherapeutic endeavor that explicitly focuses on altering the interactions between or among family members and seeks to improve the functioning of the family as a unit, or its subsystems, and/or the functioning of the individual members of the family" (Cottrell & Boston, 2002, p. 573). Chronic illness affects all members in a family; researchers have proposed that family therapy be a part of treatment for chronic illness (Sayger, Bowersox, & Steinberg, 1996). A chronic illness affects family functioning in a manner consistent with family systems theory, and chronic illness tends to organize families in some of these ways. Chronic illnesses affect not only the individual, but also the relationships within the family (Ellenwood & Jenkins, 2007). In a study conducted by Murray, Kelley-Soderholm, and Murray (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 were facing additional crises (Williams et. al, 1999). The struggles faced by families during a child's serious illness encompass not only the stress of the illness, but also the stress of the role changes, absent members, and the loss of normative family functioning (Murray *et al.*, 2007). Families with a childhood chronic illness have more adjustment problems and relationship difficulties. When a member of the family suffers from a chronic illness, the family dynamics may drastically change. A chronic illness has an influence not only on the development of the individual suffering from it, but also on the individual's family members and relationships. The impact of the chronic illness is best understood as a "family problem" that affects spouses and children alike (Stiell, Naaman, & Lee, 2007). The family may be understood in terms of its subsystems and the ways in which they interact.

Parental subsystems: Adults in families may belong to multiple subsystems and may function as part of both parenting and spousal subsystems. Empirical studies indicated that families with a childhood chronic illness have more marital dissatisfaction, depressive symptoms, more stress, and distress that may be understood in terms of the specific roles or subsystems with which it is associated (Berge, Patterson, & Rueter, 2006; Campbell, 2003; Cohen, 1999). Parents have difficulties in understanding their child's condition and may be unsure how to relate to their child with a chronic health condition. Chronic illness may present a crisis for the family, and a family's response to this crisis may result in new or more frequent dysfunctional communication (Sayger *et al.*, 1996).
Family structures are challenged by the introduction of chronic illness into the family system. If a child is chronically ill, "coalitions may form between the primary caretaker and child, leaving the other family members feeling neglected" (Sayger *et al.*, 1996, p. 13). As a result, a parent finds it difficult deciding and knowing how a child with a chronic condition fits into their family, a situation referred to as "boundary ambiguity"

(Berge & Holm, 2007). Berge and Holm (2007) defined boundary ambiguity as “a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system” (p. 123). Role ambiguity occurs when parents have difficulty determining what their parental role is vis-à-vis the ill child. Additionally, parents of children with chronic illnesses are at risk for symptoms of psychological distress. Empirical studies and review articles indicate that caring for a child with a chronic illness affects the couples (Berge *et al*., 2006; Cohen, 1999). Research specifically indicates that parents of children with chronic health conditions are at increased risk for a variety of psychological distress, caregiving burdens, increased parental stresses and strains, as well as increasing their vulnerability to depression and marital dysfunction (Berge & Holm, 2007; Cohen, 1999; Ellenwood & Jenkins, 2007). Beyond the psychosocial impacts that a child’s illness brings to the family, the financial impact and for many families unemployment issues create a sense of identity loss (Knapp, Madden, Curtis, Sloyer, & Shenkman, 2010).

Sibling subsystems: A growing body of research indicates childhood illness impacts the sibling subsystem. The healthy siblings are referred to as the “forgotten ones” or “lost ones” (Madan-Swain, Sexson, Brown, & Ragab, 1993). In one study,Foster *et al*., (2001) found that siblings can be both directly and indirectly affected by living with a sibling who has a chronic illness. Research comparing sibling relationships and child adjustment in families with a chronically ill child versus families without a child with a disability or chronic illness revealed two patterns. First, dyads with a chronically ill sibling consistently displayed more warmth and positive affect than typical-only dyads (Stoneman, 2001). Second, typical siblings of disabled or ill children had a slightly elevated risk of adjustment problems (Sharpe & Rossiter, 2002). This research implies that atypical sibling may make for greater variability in children’s adjustment and that conditions under which children adjust in more positive or negative ways are an important target for research (McHale, Updegraff, & Whiteman, 2012). Thus, having a brother or sister with a chronic illness is a risk factor for adjustment problems. In a frequently cited quantitative study focusing at coping and family adaptations in siblings with a chronic illness, Madan-Swain *et al*. (1993) found that older children adjust better to their siblings’ chronic illness. This may be a result of blurred boundaries in the parent-child relationship and the healthy sibling is under pressure to decrease the demands on the family. Thus, the older sibling may withdrawal emotionally in order to return a sense of balance and normalcy to the family system (Madan-Swain *et al*., 1993). The issues surrounding sibling relationships change over time as children develop and the family responds to illness-related and other life experiences (Lobato & Kao, 2005).

The sibling influences on youth development and adjustment are unique in the sense that evidence of sibling influences emerges even after the effects of other significant relationships are considered. As Sharpe and Rositer (2002) emphasized in their meta-analysis, healthcare providers must be aware that siblings of children with a chronic illness are at risk for negative psychological outcomes, and consequently, that intervention programs should be developed for patients and siblings alike. Furthermore, the literature suggests that siblings may be at risk of adjustment and emotional problems with increased difficulties in peer interactions (Giallo & Payne, 2006; Laboto & Kao, 2005; O’Brien, Duffy, & Nichols, 2009). Specifically, research strongly suggests that individual, family, and extra-familial forces shape sibling relationships.

Applying an Experiential Family Therapy Lens

The experiential approach to family therapy evolved from existential-humanistic psychotherapy (Brown & Christensen, 1999). Individual members are encouraged to share personal experiences with each other. Experiential family therapy focuses on the expression of feelings, conscious, or preconscious fantasies, intrafamilial transference reactions, and the therapist’s use of his or her experience in the family to expand the feelings range of the family (Sholevar, 2003). The key theorists of this model are Carl Whitaker and Virginia Satir. Carl Whitaker, the originator of Symbolic-Experiential Family Therapy (Whitaker & Keith, 1981), used a provocative and sometimes-outrageous style to decrease pretense so that a client would “become more of who he or she is” (Whitaker & Keith, 1981, p. 200). Virginia Satir, with her Human Validation Process Model (Satir & Baldwin, 1983), embraced an almost evangelical belief in the power of compassion and genuineness to heal all human problems. However, the model decreased in popularity when Satir and Whitaker died. Experiential family therapy is founded on the premise that the root cause of family problems is emotional suppression (Gladding, 2011). This approach helps family members begin to feel, to experience each other as real people, and to directly attack the emotional sterility that has enveloped in the family (Piercy, Sprenkle, & Wetchler, 1996). Experiential family therapists use their own personal experience to join with and identify possible solutions for their clients. In addition, experiential therapists use the immediacy of the therapeutic encounter with family members to help catalyze the family’s natural drive toward growth and fulfillment of individual members’ potential (Goldenberg & Goldenberg, 2008). A defining feature of this form of family therapy is the attention to the moment-by-moment emotional experience. For the purposes of this paper, the author is going to focus on experiential family therapy from the Satir Model (Satir, Banmen, Gerber, & Gomori, 1991), which is also known as Satir Communications Approach (Gehart & Tuttle, 2003), Human Validation Model (Satir & Baldwin, 1983), and Conjoint Family Therapy (Satir, 1983). These are all different components of Virginia Satir’s practice of family therapy.

Experiential/Satir Model Application

The Satir model is a dynamic, organic, humanistic approach to growth (Banmen, 2002) and is based on general systems theory (Bertalanffy, 1973). Satir’s chief goal of family therapy was to help the family members have more self-esteem (Satir *et al*., 1991). Satir viewed self-esteem and its enhancement as one of the most important family functions, if not the most important one. Satir believed in inherent goodness and growth potential of the individual and maintained that all humans carry within themselves the resources needed to grow (Satir *et al*., 1991). Family relationships and roles change due to childhood chronic conditions especially family members perceptions of their self, others, and the overall family functioning. A therapist assesses each member’s survival stance and level of self-esteem. In conjunction with self-esteem, the therapist observes the homeostatic function of the presenting problem, focusing on what the symptom helps communicate. Satir’s purpose is to help people gain a sense of wholeness and potential and a

commitment to individual awareness and expression, self-fulfillment, and individual growth, which is central to Satir's approach. Satir's philosophy and focus is the concept that families must respond to each other in ways that enhance each other's self-esteem. Banmen (2002) describes self-esteem as "one's own judgment, or experience, of one's own value" (p. 11). Essentially, self-esteem represents the feelings and ideas that one has about oneself. According to Satir *et al*. (1991), "self-esteem is learned, especially through the primary triad: mother, father, and child" (p. 19). A chronic illness has an immense impact not only on the development of the child suffering from it, but also on the individual family members and relationships. In an effort to enhance the family's development of self-esteem, Satir would complete an assessment that would involve an exploration of the family's congruent/incongruent communication patterns and each person's survival stance. A complete assessment of these issues provides a detailed and intimate glance into the perception and reality of each individual and the family as a whole (Gehart & Tuttle, 2003). According to this approach, communication and self-worth are the foundation of the family system. Communication is the means by which people measure each other's feelings of self-worth (Banmen, 1986; Satir, 1983). The family may come into therapy with a low self-worth because the family's communication, especially in the context childhood chronic illness, has decreased due to the negative impact of the illness.

Childhood Chronic Illness and Experiential Family Therapy

Branstetter, Domian, Williams, Graff, and Piamjariyakul (2008) explain, "the family's ability to alter its power structure, roles, relationships, and communication patterns in response to change is critical to managing the demands of childhood chronic illnesses"(p. 173). In particular, the communication barriers and the distressed family's communication reflect the excessive stress and burden caused by chronic conditions. The child's behavior or the symptomatic child is best understood in the context of the family. Ultimately, the family system becomes unable to cope and can become chaotic. Satir views family problems an inability to cope (Satir *et al*., 1991). The childhood chronic illness is not the problem, but the family's inability to cope is the problem. Moreover, coping is the outcome of self-worth, rules of family systems, and links to the outside world. In essence, symptom relief is secondary to personal integrity. A therapist can help transform individual and family rules into guidelines by altering language. Thus, making a change in the family's rules, they are influencing their self-esteem and communication for the better. A healthy family is considered to be one who expresses feelings and is open to experiences with each other (Smith, 2002). According to the Satir's model, dysfunctional families are ones who resist taking affective risks and are rigid in their interactions (Satir *et al*., 1991). Children in dysfunctional families grow-up repressed and unable to express their feelings in healthy ways. Overall the goal of the experiential model is to help individuals become more honest emotionally and as they get in touch with their true feelings, they can then have more open communication and healthier family relationships (Banman, 2002; Satir *et al*., 1991). In an effort to help the family become healthy, a therapist's goal is to support and strengthen each individual's sense of uniqueness and self-esteem. The therapist uses the parts party technique and variations to help family see how their parts interact with each other. This will help the family increase their congruent communication especially related to the change in family dynamics from the chronic illness in the family. Struggling for normalcy is culminated in a shared understanding of what it meant to communicate within the context of a childhood chronic illness. Only when problems emerge do the family members communicate; otherwise, they are going different directions and no time for one and another. Change requires a step backwards or temporary loss in functioning. Thus, change may be followed by a stage of chaos, as families become vulnerable to sensing and expressing potentially threatening feelings (i.e., "connected to their guts" (Griffin & Greene, 1999). Satir's model recognizes the presence of dysfunction in one family member is symptomatic of dysfunction in other family members or the larger family system (Banmen, 2002). The concept of a family's style of coping reflects feelings of self-worth of its members are especially relevant to families with childhood chronic illnesses in multiple ways. One example is the child's low self-worth is associated with the chronic illness. Thus, the child's is symptomatic of the dysfunction in the other family members. Satir emphasizes that coping is the problem, and coping is the outcome of self-worth.

Techniques

Family therapy focuses on prevention efforts, which include behavioral family therapy and behavioral parent training to optimize family coping, social support expressiveness, while ameliorating family conflict (Gold, Treadwell, Weissman, & Vichinsky, 2008). Family therapists can help the family acknowledge and accept the family member's disease as well as aid in the treatment planning with other external factors. Moreover, the current findings support a family-centered paradigm for both assessment and treatment (Sharpe & Rositer, 2002; Sperry, 2009). Understanding the impact that childhood chronic conditions have on families offers an opportunity to design interventions to enhance communication, cohesion, and adaptation, and to support development in these families. With a systems framework, Virginia Satir used the concept of family homeostasis to demonstrate how individual behavior and relationships within the family function to maintain a sense of balance. For example, when a child is diagnosed with a chronic illness, the family system must readjust. The mother and father must attend to the new activity of caretaking and must cope with the experience of being less available to one another. There may be considerable, temporary conflict within the relationship. Satir would ask questions to uncover major triadic relationships in the system. Thus, Satir uncovers the roles, rules, and communication processes in the family, examines the relational messages (especially Metacommunication), and examines the content of communication with the family. The experiential therapist's role is that of a facilitator of healthy communications within the family; a role model to the family for good communications; a mediator to help families with communication impasses; and a teacher and educator to help the family see new solutions for old problems and view new ways of coping with problems (Satir & Baldwin, 1983). This model also uses a very creative approach and draws from Gestalt, psychodrama, client-centered therapy, and group movements. Emphasis is on here-and-now, affective expression, spontaneity, action, encounter, and process-oriented (Gehart and Tuttle, 2003). Satir's approach to families combined her early interest in clarifying communication

"discrepancies" or incongruences between family members with *humanistically* oriented efforts to build self-esteem and self-worth in all members (Goldberg & Goldberg, 2008; Satir *et al*., 1991).

Assessments

Satir identified three areas of assessment that create a foundation for conceptualizing the family system. This communication approach involves the assessment of (a) "the family system's symptomatic behavior", (b) "communication patterns and stances", and (c) "the influence and exploration of family of origin issues" (Banmen, 1986; Gehart & Tuttle, p. 109). Through the assessment process, an isolated and "closed" family can begin to shift into a more open, connected, and flexible family unit.

The Goals and Structure of Therapy

Congruence, high self-esteem, and personal growth are major goals in the Satir approach (Satir *et al*., 1991). These three goals assist in the process of improving communication and growth within the family system, while contributing to high self-esteem and self-worth in the individuals. Within families, members often experience role reversals, a shift in balance of power among family members (particularly children and parents), and problems with maintenance of cultural issues (Ellenwood & Jenkins, 2007). The stages of change can usually be identified in any single session that Satir conducted, but the purpose is to promote healthy, growth, communication, and change.

Stage I—Status quo: Stage one is whatever it is that draws attention to the need to move from the status quo. This is the beginning stage when people have an awareness of a need for change, but the pull to stay with the familiar is stronger than the pull to change. In this stage, the family members operate in a manner that reflects their patterns and beliefs and can be referred to homeostasis or "status quo" (Satir *et al*., 1991, p. 99). As the therapist beings to "make contact" and emotionally connect with the family, the family's homeostatic pattern begins to be disrupted, thus creating a space for change (Banmen, 1986; Gehart & Tuttle, 2003). For families with children with chronic conditions, this represents "life as it was" preceding the instant that the onset or diagnosis of the illness occurred. For most families, this is the shift from the idyllic and idealized past, as compared to what lies ahead. The therapist attempts to make an emotional connection with the family by establishing warm, supportive environment where the family feels comfortable discussing the medical diagnosis or the problem. At this time, allowing the family's voices to be heard and addressing the meaning of the chronic illness to this family is an important to "making contact" with them. The onset of illness triggers a crisis for which individuals seek relief through medical diagnoses and treatment, and family therapy help.

Stage II—Introduction of a foreign element: Stage two is when an event or person such as a therapist enters the system, unbalancing the established dynamics. During stage two, the family initiates contact with a "foreign element" (or therapist) to assist in the process of change (Banmen, 1986). The first interview involves the establishment of rapport and hope, while determining treatment focus and goals (Satir *et al*., 1991; Gehart & Tuttle, 2003). If resistance is apparent, it is addressed and reframed using the coping stances. Now the system has to respond to the introduction of a new component. Thus, the status quo is cracking; a new rearrangement has to take place.
Therapy can help the family acknowledge and accept the family member's disease as well as the treatment plan and prognosis. In reaction to a diagnosis of a chronic illness, the family undergoes stages of adjustment just as the child does. Often the individuals become traumatized and report becoming confused and estranged for themselves as well as their family members. Ellenwood and Jenkins (2007) stated, "both extended and immediate family members, particularly the parents, will experience the following emotional reactions: shock, confusion, numbness, denial, anger, anxiety, guilt, self-blame, fear, hopelessness, depression, as well as inner resentment toward the sick person, spouse, and other children," (p. 266). With such pain or unbalance, a wish for change might be articulated by one or another part. Often, one member of the family is more willing to let go of the status quo and change. In therapy terms, this is when a family member picks up the telephone and calls for an appointment. Stage two, then, introduces a foreign element or the therapist in to the family system. During this process, the expectations and barriers are explored such as the treatment locations and time. There is empirical evidence to indicate the families with chronically ill members are less likely to receive family therapy (Ellenwood & Jenkins, 2007; Malone *et al*., 1997), which may be attributed to inaccessible treatment locations. Families with chronically ill members are often unable to adjust to a session that is 50-60 minutes initial interview and yet, they are experiencing significant dysfunctional relationships and are in dire need of family therapy interventions.

Stage III—Chaos: The opening of the system introduces stage three. The system is in a state of flux. The therapeutic process proceeds by exploring expectations, patterns, and dynamics and results in a state that the family experiences as "chaos" (Gehart & Tuttle, 2003, p. 108). During this process, the therapist explores conflict, normalizes associated feelings, examines family of origin and family rules, and attempts to uncover unexpressed feelings and thoughts. The family knows that their old ways are not working like when they were given medication to reduce their anxiety. Unfortunately, in doing so, the family members would move back to the "good old days," the dysfunctional status quo of the past (Banmen, 1986, p. 484). The therapist can help the child and family focus on the acceptance of his or her illness and treatment compliance. The stressors faced by children, adolescents, and parents dealing with childhood chronic illness are multifaceted and can include stress related to daily role functioning, stress related to treatment, and stress related to uncertainty of what caused the condition (Compass *et al*., 2012). The diagnosis, treatment, and ongoing management of chronic illness are stressful for children and families, and the onset and course of chronic illness may be affected by other sources of stress. During this phase, Sayger and colleagues (1996) stated, "Therapy can aid the family in developing active coping styles and decrease the occurrence of maladaptive family patterns such as enmeshment, triangulation, rigidity, and overprotectiveness" (p. 16). The temperature reading is an experiential intervention that a therapist can use to help open up communication and encourage support by members in the family (Satir *et al*., 1991). The technique was developed by Satir, in which family members set aside a specific time each day to get in touch with each other (Piercy *et al*., 1996). This intervention can also be used during the therapy session by having the child or family

share specific information on expressing their appreciation of each other, complaints and recommendations, questions, hopes, and wishes (Gehart & Tuttle, 2003). The temperature reading essentially explores thoughts and feelings while improving communication and self-worth. This intervention would be especially important when exploring the concerns of the new information regarding a childhood chronic illness within the family.

Stage IV—New possibilities and integration: This is the conscious period when the person still feels awkward. Satir and colleagues (1991) describe stage four as a process of "developing new possibilities using dormant resources, integrating our parts, and reevaluating past and present expectations" (p. 114). The client consciously chooses the new comfort over familiarity. This process uncovers the possibilities for change and more adaptive ways of communication. For example, the family begins to accept the child's pre-illness self will not return and adjust expectations for the child. The child reconsiders or develops new friendships and other resources. With a new set of predictions, the old automatic reactions are no longer in place. The child needs to grieve the loss of pre-illness self but so does the family. The awareness and options help develop a new self and meaningful philosophy of life and spirituality. The new perceptions, connections, and skills help to create a more fully functioning system that promotes and experience high self-esteem.

Stage V—Practice and implementation: Stage five is considered the "implementation" or "practice" stage (Gehart & Tuttle, 2003, p. 109). This stage involves the family system experiencing the changes and exploring feelings and thoughts concerning the shift in communication and self. Furthermore, stage five allows the therapist and family system to explore the increased awareness regarding change within self and the system (Banmen, 1986; Gehart & Tuttle, 2003). The focus is on helping the child to forge a new sense of self as a whole person who happens to have a chronic medical condition. This is especially important that the family restructures to focus on changing the structure of the family and adjust to having a child with a chronic medical condition. The therapist or other external help can assist in the adjustment of the family to the child's new friends and medical team. Since human beings often would rather stay with the familiar instead of moving to a place of comfort, the therapist needs to assume that the family has ample opportunity to practice and experience the new level of growth (Satir *et al*., 1991). Satir has developed many exercises for change in the family system. Family reconstruction is Satir's system of three-generational transformation of dysfunctional coping to an open, healthy functional system (Banmen, 1986). A technique of Virginia Satir (Satir & Baldwin, 1983), family reconstruction utilizes psychodrama to help individuals experience the key triads in their families of origin. Children or family members can select individuals to act out the roles of members of the primary triads in their families of origin. In the process, a child with a chronic illness can have members of his family reenact some previous experiences or parts of his life before the onset of his illness. As a result, the child and family are reconstructing perceptions from new information, which results in different perceptions and feelings about one's self. While acting out key family situations, clients gain new insights into their family and their own lives (Piercy *et al*., 1996). Through this intervention, the child has an opportunity to make sense of all the relational parts of one's experience. A strong emphasis in family reconstruction is to bring to the surface family rules, family themes, and family myths. Often these rules, themes, and myths limit the individual and family to reactions from their past and do not provide them ample freedom of choice based on the present. Freeing the child from the negative impacts of these becomes an important therapeutic intervention in the Satir model. This can promote self-awareness and increase one's level of self-esteem. This stage reflects a new status quo, a sense of equality, wholeness, and openness to possibilities (Gehart & Tuttle, 2003) because the changes helped create successful attainment of the therapeutic goals. A family terminates with the therapist once an aura of hope and a willingness to do things in a different way has been created. The mother of a child with a chronic illness was much better at expressing herself and seemed to become more engaged with the children—especially the child with the chronic illness. Having families express and apply new understandings through experiences in the session create new behaviors outside of the therapy session. It remains important that families maintain an open system and feel comfortable sharing with each other in an honest and genuine manner. It is a positive sign when members can argue, disagree, and make choices by taking responsibility for outcomes (Gladding, 2011). The sending and receiving of clear communication is further indicator that the family is ready to end treatment (Satir *et al*., 1991). If family members can tell each other that they would rather go somewhere different for their clinic visit than back to the same clinic they visited last year, progress has been made. This is especially important with children with a chronic condition. One of the important aspects of the child's self-worth is knowing their parents are listening and hearing what the child is saying especially about medical decisions and caretaking.

Conclusion

Typically, experiential family therapists treat dysfunctional behavior as the result of interference with personal growth. From a theoretical perspective, Satir would claim that family problems result from the lack of awareness of feelings, lack of ability to express feelings, rigidity in responding to problems, and denial of impulses (Tuttle, 1998). For families to grow, communication between family members and self-expression of individuals must be open, while appreciating the uniqueness and differences between family members. The focus of the therapeutic experience is growth at the individual and systemic levels based on assumption that growth will result in symptom reduction (Gehart & Tuttle, 2003). Using Satir's model, the family therapists need to identify the family's spoken and unspoken suffering, the established symbiotic relationships, sources for hope, unhealthy belief systems, myths, and identify sources to help reconnect the family to the outside world. With this approach, untimed sessions can be conducted where family therapist's role focuses on the assessment of the family's emotional needs, which stem from the chronically ill child's neurological or physical functioning. In contrast, the primary goal of work with families of chronically ill children, should be to enhance the family's support system by increasing their contacts beyond the immediate family (Ellenwood & Jenkins, 2007). Furthermore, the therapist needs to challenge the homeostatic pattern or status quo that the family has developed. The family needs to be encouraged to take risks and activate resources that were present in their life prior to the

family member's illness. Mutual collaboration is a key component for many family therapists working through a family systems lens. Some family systems theories focus on the dysfunction within the family, rather than on the disease or illness like experiential family therapy (Banmen, 2002).

As a result, an experiential therapist does not provide a lot of education about the illness. The problem is in the context of the family, which eliminates a symptomatic client or patient.
One of the most compelling aspects of childhood chronic illness is the multifaceted nature of the psychological impact of the illness on children and their families. A chronic illness can affect the individual child's psychological adjustment as well as his or her activities and level of functioning in a wide range of important settings, such as healthcare, school, and with peers. In addition, the impact of a childhood chronic illness transcends the individual child and includes his or her family members (Drotar, Witherspoon, Zebracki & Peterson, 2006). Thus, treatment must address the family's context, including the social demographic characteristics and attitudes about illnesses" (McDaniel, 1995). Research has found that the meaning an individual places on a situation or event can have a significant influence on their functioning (Boss, 2002). Including a measure of perception would add a valuable layer to understanding to a complex situation such as having a child with a chronic condition (Berge *et al*., 2006). Therapists could have an influential role in facilitating discussions about the issues and meanings related to having a child with a chronic condition. This would target the potential problems suggested earlier which indicate that parental subsystems are impacted especially at risk for increased levels of marital dissatisfaction when they do not communicate about the negative impact of the child's condition on their relationships. Also, research indicates that sibling subsystems are impacted especially when they lose their "voice" and become "forgotten" (Madan-Swain *et al*., 1993). Satir believes that one can help the child and family find meaning through creativity, family relationships, and resources.

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