SIBILITIES: A PROPOSED PROGRAM FOR SIBLINGS OF CHILDREN WITH A CHRONIC ILLNESS OR DISABILITY

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

in

Psychology:

Child Development

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by

Alisha Nicole Alanis-Ayala

September 2009

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ABSTRACT

Children living with a disability or illness experience life altering changes. There are also dramatic changes experienced by their parents and their healthy siblings. These children and their families endure stress and times of crisis that can result in short- and long-term negative emotional and behavioral effects. Evidence within the literature indicates the need for family centered care and psychosocial support for all family members during and after the treatment process. Due to the unique issues and individual personal needs of healthy siblings a support program for siblings is suggested. Although support services for this population currently exist, interventions are implemented through diverse approaches. A qualitative research design making the use of survey data collection is utilized to examine Child Life professionals' beliefs regarding the suggested sibling support program model. Study results illustrate the participants' perceptions regarding the potential effectiveness and feasibility of the proposed program and the likelihood that it will be beneficial in providing psychosocial support to siblings and their families. Participants responded the program positively and indicated that it is needed. They also noted that the program would meet its established goals if put into practice. Suggestions for potential improvement, design, and implementation were also highlighted. The two primary barriers to implementing the program that were identified by participants were funding and transportation for families. Further parental involvement was also suggested.

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CHAPTER ONE

RECOGNIZING THE PSYCHOSOCIAL NEEDS OF FAMILIES WITH AN ILL OR DISABLED CHILD

There is a growing awareness that the psychological needs of ill children and their families are an additional factor to be considered when providing medical treatment and services. Researchers agree that the whole family is affected when a child is diagnosed with an illness or disability. Several of these researchers have concluded that siblings in particular can undergo noteworthy emotional and behavioral changes. These responses in healthy siblings play a major role in the family dynamics and how each member adapts to the constraints of the illness or disability.

Statement of the Problem

Historically, a number of empirical investigations have been limited in design and have been conducted primarily on siblings of children with cancer. Data has also been largely gathered from sibling or parent report rather than soliciting professional opinions regarding program design and implementation. Researchers have identified barriers to providing sibling support. Data indicates that staffing shortages, lack of access to siblings, institutional constraints, and the lack of support for sibling support programs all contribute to the lack of services for families living with an ill or disabled child (Murray, 2002).

Researchers emphasize that supportive interventions can be instrumental in lessening the psychological impact siblings experience related to the stressors of having a sibling with a serious illness. Social support interventions can also assist healthy siblings adjust to the life events that correspond with the ill or disabled child’s care. Although advances have been made in identifying the needs of siblings of children with a chronic illness or disability, there is a lack of consistency to the variety of approaches that have been taken to provide supportive intervention to healthy siblings.

Purpose of the Study

Ongoing research and awareness is necessary in order to tailor interventions that best meet the needs of healthy siblings of children who face continual health care needs.

The purpose of this project is to develop a comprehensive sibling support program and survey Child Life Specialists regarding the design and potential implementation of the program. The support program will address not only the recreational needs of the siblings, but also the educational and emotional. Additionally, parental needs are addressed. While a logical next step, the proposed program will not be put into operation during the course of this project due to funding constraints. The major goal of this project is to learn more about Child Life professionals' perceptions and recommendations that would be instrumental in delivering a support program that addresses the unique needs of healthy children with an ill or disabled sibling.

Scope

The literature illustrates that there are numerous benefits from the differing programs that have been developed in response to concern for the needs of siblings of children with an illness or disability. The goal of the proposed program, SiBilities, is to provide emotional support and intervention to siblings in an effort to lessen the families' stress, increase sibling knowledge of the illness or disability, and help the sibling and family to develop and strengthen positive adaptive coping styles. In an effort to achieve this goal, SiBilities will offer school-age children a supportive environment where they can meet others like themselves. It is imperative that healthy siblings socialize with age-mate peers in a place where they can feel "normal", validated, and accepted.

SiBilities also aims to give siblings a place to have fun and express themselves. Healthy siblings have consistently reported their need for emotional care; therefore it is vital that these children have the opportunity to express their feelings and concerns (Murray, 2001). Although this program is not intended to be therapy or a formal manner of psychological intervention, it may have therapeutic effects on the sibling participants and their families.

Additionally, SiBilities hopes to aid parents as they support and comfort their children. Research has consistently indicated that parent reports are not consistent with child reports in regards to identifying the sibling of the chronically/terminally ill child's most important needs (Murray, 2001). Data has also indicated that parental coping with a chronic childhood illness is strongly and positively correlated with the emotional and instrumental support they receive from others (Murray, 2000). SiBilities will strive to promote parental awareness and understanding of siblings' questions, concerns, and unique needs.

The SiBilities program contains elements and activities that have been adapted from existing sibling support interventions (Meyer & Vadasy, 1994; Dyson, 1998; Houtzager, Grootenhuis, & Last, 2001; Barrera, Chung, Greenberg, & Fleming, 2002; Lobato & Kao, 2002; Gursky, 2007; Loma Linda University Medical Center (2007), Camp Good Grief). Although there are supportive interventions that currently exist, they are carried out through differing program designs and no two are exactly alike. These various interventions are widely spread across the country and provide services that are located in specific geographic areas.

Significance

There is no question that when a child is diagnosed with a disability or illness, the whole family is affected. Each family member is unique in their coping and may exhibit varying degrees of reaction. It seems evident that siblings of children with disabilities or an illness are a population that is in great need for support services. Sibling support groups are one means of providing services that address the psychosocial needs of families in addition to making strides in the direction of family-centered care.

Through support programs, professionals can focus on and address familial issues and relationships. This type of supportive intervention can increase the chances for positive adjustment in not only the healthy sibling, but the parents and patient, as well. Sibling support groups may also be a catalyst for many future changes in support services.

CHAPTER TWO

LITERATURE REVIEW

The Ill and Disabled Child and Their Family

It is estimated that nearly 12% of U.S. children have difficulty with performing one or more daily activities. These activities may include learning, communication, mobility, and daily living skills. Struggles may be attributed to biologically based developmental disabilities, communication disorders, mental retardation, or other forms of developmental delay (Lerner, Jacobs, & Wertlieb, 2005). Additionally, between 4 and 7 million children are afflicted with one or more chronic illnesses. These children, in comparison to their peers, are believed to be in greater jeopardy of developing emotional disorders, abnormal behavior symptoms, and adjustment problems in school (Sharpe & Rossiter, 2002).

Families living with an ill or disabled child have been known to depict their lives as a roller coaster ride. While on this ride they encounter an array of emotional reactions (Morison, Bromfield, & Cameron, 2003). Parents report that stress, uncertainty, anxiety, hopelessness, guilt, fear, and sorrow are emotions that they persistently experience (Hopia, Paavilainen, & Astedt-Kurki, 2005). One parent stated, "I had this picture of what being a new parent was, but I didn't know how I was meant to feel because he was broken" (Morison, Bromfield, & Cameron, p. 125, 2003).

Although previous research has illustrated a clear portrait of families living with an ill or disabled child, over the course of the last few decades there have been numerous advances in pediatric medicine. These advances have led to an increase in cure rates and medical successes. The long term medical, psychological, and family outcomes resulting from these cutting edge developments are presently unfolding (Kazak, 2006). It is possible that future research will show how family outcomes have changed due to progressive medical treatment options and ill children having a better prognosis.

Thompson (1985) (as cited in Solomon & Breton, 1999) depicted the burdensome effects a child's chronic illness has on parents. Thompson found that increased energy must be given to home care; leisure time is often very limited, family activities must be arranged according to the needs of the ill child, and amplified financial responsibilities are incurred. It was also found that parental coping is important in the overall psychosocial outcomes of other family members and the management of the ill child's health (Solomon & Breton, 1999).

It is evident that parents and other family members of children with an illness or disability are often enlisted as adjunct health care providers. In addition to managing routine home care, family members are asked to run medical machinery, give medications, and monitor the child's clinical status. In the mid-1990s the number of family members that were providing health care at home had reached alarming proportions. This was a result of the growing rate of national home health expenditures. It was estimated that as many as 25 million family members were being asked to provide health care at home. These family members spent an average of 18 hours per week caring for their ill or disabled loved one (Steinglass, 2006).

Moreover, besides concern for the ill or disabled child's health, the adjustment of healthy siblings in the family provides an added stress to parents (Taylor, Fuggle, & Charman, 2001). Parents often have negative and potentially frightening information to share with other family members regarding the ill or disabled child. They often are uncertain as to how to they should inform their healthy children about the ill child's condition (Gursky, 2007).

The family system as a whole is at risk for probable impact. There is the likelihood that the typical course of development of children and their families may be interrupted when a child is ill or injured. Families who are at risk for increased psychosocial problems are those with single-parent homes, families with minor parents, large families, those with limited social and/or financial support, parental psychopathology, or those with behavioral concerns related to other children in the family. Children in families who are at risk due to severe, chronic, and/or increasing problems are susceptible to lasting long-term impact (Kazak, 2006). According to children living with a chronic condition, the limitations due to their illness were their chief illness-related stressors. They also felt increased anxiety in everyday stressful situations versus illness situations (Murray, 2000). In addition to the child's normative development being affected, the marital, parenting, and sibling relationships are disturbed (Kazak, 2006).

There are various potential traumatic events that are experienced by children and their families during the course of treatment for an illness or injury (Kazak, 2006). In recent years traumatic stress has been recognized as a potential effect amongst diverse populations. Those afflicted with prolonged illnesses are included. Traumatic stress can be of concern for the individual who is ill or for those caring for a loved one with a severe illness, particularly a child. Most families are not identified as experiencing clinical Post Traumatic Stress Disorder (PTSD), but they may encounter times of crisis which have the potential to have a traumatic impact on them (Morison, Bromfield, & Cameron, 2003).

Generally, health care teams have contact with a select few members of an ill or disabled child's family. Often times it is only the mother that doctors see. This makes it difficult for health care providers to properly assess and understand the family's social ecological status and functioning. Without a thorough understanding, there is a greater chance for risk in errors in recognizing psychopathology or in minimizing the reaction of other family members (Kazak, 2006). This evidence contributes further support for the need of a collaborative approach when treating patients and providing psychosocial support to their families.

While families run the risk of experiencing negative effects, there are many instances where families have positive outcomes. Resilience has been identified in families who have faced prolonged, intense, life-threatening diagnoses and treatment (Kazak, 2006). Although families of ill and disabled individuals are at jeopardy for maladjustment and psychopathology, the majority of them are robust and develop tactics in order to cope during times of crisis (Morison, Bromfield, & Cameron, 2003). Creating a workable and balanced lifestyle may require families to make permanent changes or ongoing adjustments in the family's structure and function. The challenge for health care professionals is to develop an approach to ill or disabled children and their family that aims to provide ample support and reduce the effects of the stresses they face (Kazak, 2006).

Healthy Siblings: The Other Children

The most immediate network that a child encounters is the family. The child becomes socialized and learns the rules of family membership early on. Siblings are particularly important within the context of the family because they provide social models for each other and develop simultaneous attachments. Siblings also share objects, experiences, and people during the early part of their childhood. It is not uncommon for siblings to protect and help one another (Lewis, 2005). Developmentalists concur that these relationships are an important foundation in a child's development of functional peer and adult interactions (Benson, Gross, & Kellum, 1999).

Due to the nature of sibling relationships and the family system, an alteration of the sibling relationship may be observed in a family with an ill or disabled child. Siblings of children with a disability may have fewer opportunities to imitate and identify with their brother or sister when acquiring behaviors. Healthy siblings might also begin to recognize that their sibling is progressing slower through development or that they are surpassing their older sibling. This may be more evident with children who have a sibling with a visible impairment of deformity, such as Down syndrome, craniofacial anomalies, or dwarfism (Benson, Gross, & Kellum, 1999).

Additionally, siblings of children with an illness or disability may experience different expectations from their parents. There are times when parents inadvertently expect healthy siblings to compensate for the lost potential of their child who is ill. Parents may impose greater school performance standards and peer expectations on their well children (Benson, Gross, & Kellum, 1999).

Well siblings have unique psychological issues and individual personal needs (Dyson, 1998). It has been noted that healthy siblings show great concern over the ill child's care, are more likely to blame themselves for the illness, and may exhibit psychosomatic symptoms (Hopia, Paavilainen, & Astedt-Kurki, 2005). Siblings of children with an illness or disability may also play a distinctive role within their family unit and have unique experiences from their peers. Some of these experiences may include extra caregiver duties, differential treatment, and an imbalance of family resources. Healthy siblings possibly will have limited information regarding their sibling's condition, have negative peer reactions, and disruption in their extracurricular activities (Lobato & Kao, 2002).

As a result of the probable changes within the family, healthy siblings can often have an array of emotional responses. Several siblings have expressed feeling guilty, lonely, and incompetent (Dyson, 1998). Other significant emotional outcomes that might be observed in siblings are the feeling of being displaced, confusion and isolation, and the siblings’ concern for their own health. During times when the ill or disabled child is hospitalized, well siblings may have difficulty sleeping, eating or concentrating, feel more nervous, and want to spend more time with parents (Gursky, 2007).

Additionally, researchers have discovered that siblings of children with chronic illnesses and developmental disabilities have an increased likelihood versus their peers of having psychological adjustment problems (Lobato & Kao, 2002). It is estimated that 25% of siblings of children with life-threatening diseases are at risk for poor adjustment (Taylor, Fuggle, & Charman, 2001). Maladjustment may be due in part to the presence of chronic stress, social stigma, and the responsibilities associated with caring for an ill brother or sister (Lerner, Jacobs, & Wertlieb, 2005). Further data supports the hypothesis that siblings of children with disabilities assume greater caregiving or are at greater risk for psychopathology (Lerner, Jacobs, & Wertlieb, p. 383, 2005). Whether or not the child has a more or less severe illness does not seem to affect the functioning of the healthy sibling. However, it is the siblings of children who need more intense daily assistance that are more negatively affected (Sharpe & Rossiter, 2002).

By taking on a caregiver role, healthy siblings may temporarily act as a quasi-parent (Sharpe & Rossiter, 2002). As the disabled child gets older and he or she has less adaptive and self-help skills, sibling caregiving responsibilities tend to increase (Stoneman, 2001). One might speculate that in response to this new role, siblings may internalize their behaviors via anxiety and depression rather than engaging in externalizing behaviors such as aggression. The frustration that results from decreased attention from parents or imposed caretaking responsibilities may be difficult for the healthy sibling to express outwardly given the health status of their ill brother or sister (Sharpe & Rossiter, 2002).

Guite, Lobato, Kao, & Plante (2004) highlighted that the research supporting siblings' increased risk for internalizing behaviors, adjustment problems, and difficulties with peers has been primarily generated from parent reports. The parent participants who have characteristically contributed information about children's' emotional and behavioral health were primarily mothers. Data collected from child reports suggests that siblings perceive their psychological functioning and symptoms to be different from that of the reports of their parents. This inconsistency is possibly attributed to the parent's emotional state. If the parent is experiencing greater stress and depression, then it may impair their ability to accurately rate the sibling's functioning. As a result, the parent may minimize or overrate their child's symptoms (Guite, Lobato, Kao, & Plante, 2004).

Guite, Lobato, Kao, & Plante (2004) also indicated that based on reports provided by parents and siblings, there was a significant finding associated with sibling and family characteristics. Siblings who reported having a more negative adjustment than their parents reported were more likely to be younger and male. This age effect is consistent with prior research. It is probable that younger siblings need more time to age and develop coping skills in order to deal with the stress associated with the ill or disabled sibling's diagnosis and treatment. Also, as children grow older, their focus shifts from the family to peers and their social network. This shift can lead to the sibling concealing their concerns about their ill or disabled sibling from their parents. With regards to the gender effect, female children may be more prone to be responsible for the household and child care responsibilities. As a result of these responsibilities, parents and healthy female siblings have more opportunities to discuss the ill or disabled child. Consequently, there is an increase in parental awareness of the healthy sibling's questions and concerns (Guite, Lobato, Kao, & Plante, 2004).

Additional data has been generated from a sizeable amount of sibling research that has been conducted on siblings of children with cancer. With the practice of new medical advances, many childhood cancers are not as fatal as in previous times and childhood cancer is now likened to chronic illnesses (Murray, 2000). Packman et al. (2004) noted that the whole family is met with high levels of distress and healthy siblings are subjected to an increased psychological risk. Further research revealed that other family members' emotional needs were met at a significantly higher level than those of the siblings (Murray, 2000). Among the controversial findings regarding the psychological welfare of siblings of children with cancer, it was estimated that 63% of siblings experience some degree of brief psychological adjustment difficulties (Barrera, Chung, Greenberg, & Fleming, 2002). Healthy siblings were found to experience low self-esteem, have school and social problems, and were susceptible to developing a range of emotional and somatic symptoms (Packman et al., 2004).

Similar to siblings of those with a disability or illness, siblings of cancer patients may become overwhelmed with fears, guilt, frustration, isolation, jealousy, and anger. At the time of a diagnosis, healthy siblings are suddenly presented with the idea that their sibling is ill, there is often a dramatic decrease in attention from their parents, and the roles within the family unit are altered (Houtzager, Grootenhuis, & Last, 2001). In order to cope, siblings may exhibit wishful thinking, attention-seeking behaviors, engage in solitary play, and talk to others (Murray, 2002). Findings suggest that there is a gap in communication between parents and healthy siblings. This lack of communication can exacerbate feelings of anxiety. It is speculated that this gap could be due to the sibling protecting themselves or their parents by masking their emotions (Houtzager, Grootenhuis, & Last, 2001).

In cases where the disabled or ill sibling dies, the surviving sibling is at additional risk for adjustment difficulties. The sibling may experience feelings of isolation, sorrow, and loss of parental accessibility. Surviving siblings can have enuresis, headaches, fear, poor school performance, separation anxiety, and feel rejected. Lastly, he or she may also feel guilt, depression, withdrawal, become accident prone, and exhibit externalizing behaviors in direct relation to the grief (Murray, 2002).

Although many of the negative effects have been highlighted, typically developing siblings can also exhibit positive effects due to living with their brother or sister's illness or disability. Healthy siblings may display more prosocial behaviors, increased maturity, patience, and be more tolerant of individual differences (Lerner, Jacobs, & Wertlieb, 2005). Depending on the disabled child's play abilities, sibling relationships involving a child who is disabled may be depicted as more positive due to the prosocial, warm, and nurturing interactions (Stoneman, 2001). Adolescent and adult siblings have expressed that their experience of living with a mentally retarded sibling has helped them to foster empathy and appreciation of familial relationships (Lerner, Jacobs, & Wertlieb, 2005).

The adjustment of healthy siblings can be influenced by various factors. Some factors that have been identified are the behavioral, psychological, and health problems related to the sibling's disability, the severity of the disability, and the healthy sibling's temperament. For instance, when the disabled child displays behavioral difficulties, parents often spend more time and resources caring for that child. This results in differential treatment of the siblings. Any perceived differences in parental attention can result in conflict between the siblings (Lerner, Jacobs, & Wertlieb, 2005). Furthermore, Taylor, Fuggle, & Charman (2001) recognized parental awareness of the siblings' perceptions and attitudes towards the experience of having a physically disabled child in the family as a resilience factor. Researchers have also noted that an additional way to promote resilience and improve the psychosocial adaptation of siblings is through social-support interventions (Murray, 2000).

The Benefits of Supporting Siblings

There is substantial evidence that social support is beneficial to health outcomes. It has been positively linked to social functioning and adjustment to the illness. Social support has also been identified as an aspect that affects parents' ability to cope with their child's illness (Murray, 2000).

Williams et al. (2002) reported that a number of additional variables that were identified as being interrelated and influencing the behavior of the well siblings were the well siblings' knowledge of their brother or sister's illness, attitude towards the illness, self-esteem, and feelings of social support. Sibling mood and the support felt by the sibling also have an effect on their self-esteem (Williams et al., 2002). Although some support interventions may be aimed at meeting the emotional needs of the healthy sibling, they do address not the instrumental needs siblings express as being important to them (Murray, 2001). Instrumental support may consist of the sibling having access to someone who can aid him or her with day-to-day tasks and help them maintain a routine as much as possible (Murray, 2002).

Research also suggests that siblings want to increase their understanding of their brother or sister's disability as well. Studies indicate that healthy siblings desire to have support and group discussions to aid them in coping with their feelings and understanding of their sibling's disability (Dyson, 1998). In a study by Graff (2001), as cited in Williams et al. (2002), nearly 30% of the inconsistencies in sibling attitude were attributed to the level of the well sibling's knowledge about the illness.

Illness related education for siblings is a significant intervention. Research has shown that siblings' knowledge has a direct effect on their attitude toward the illness and influences their own self-esteem (Williams et al, 2002). Increased knowledge can lessen confusion, anxiety, and adverse emotional and behavioral effects. Siblings who are not provided with information about the ill or disabled child are likely to formulate their own explanations for the unknown. This can lead to misconceptions and increased fears (Gursky, 2007). Sibling knowledge is also affected by the nature of the ill child's diagnosis and the age of the healthy sibling. Older well siblings are typically better equipped to cognitively grasp more complex information (Williams et al., 2002).

Lastly, several siblings of children with an illness or disorder have commented on their benefit from having other adults available for them to talk to and seek out support. These relationships with extended family members and friends may compensate for their parents' decreased physical presence and emotional availability. Siblings of chronically ill children appear to benefit from a consistent and supportive relationship with any adult. These relationships may become a protective mechanism during times of traumatic crisis (Taylor, Fuggle, & Charman, 2001).

The aforementioned research shows that specific variables and types of interventions have been identified as being beneficial in aiding healthy siblings cope. Social support, educational opportunities, and positive relationships with adults seem to be the primary type of interventions that generate a positive effect in sibling outcomes. Although these factors have been identified, they can be carried out in a range of approaches. It is vital that various programs be examined to see what best addresses the unique needs of children with an ill or disabled sibling.

Existing Support Program Models and Their Effects

A variety of programs have been developed to provide support to siblings of children with cancer, disabilities, and chronic illnesses. During the 1980s and 1990s, Donald

Meyer and his colleagues developed the concept of Sibshops. Sibshops gives school-aged children who have a brother or sister with special health or developmental needs a chance to meet others while being supported and educated in a recreational context. The Sibshops model combines information and discussion activities along with games and cooking activities. Sibshops are not therapy, group or otherwise (Meyer & Vadasy, 1994).

The Sibshops curriculum is used throughout the United States, Canada, England, Ireland, Iceland, Japan, New Zealand, Guatemala, Mexico, and Argentina. Sibshops can be modified for slightly younger and/or older children. It has also been adapted for brothers and sisters of children with specific needs, including cancer, hearing impairments, epilepsy, emotional disturbances, and HIV-positive status (Meyer & Vadasy, 1994).

Sibshops has provided a model for supporting siblings. Similar to other programs, Sibshops serves as a basis for the formation of a range of support interventions. Models like Sibshops can be easily tailored to the populations being served. The various interventions and programs illustrated below differ in the ways services are administered, for example, inpatient sibling visitation, camp, support groups, and integrated sibling-parent support intervention.

One modality of sibling support is educational intervention. Child Life Specialists provide developmentally appropriate education for siblings of ill or disabled hospitalized children. Research has indicated that after visiting the hospital and being provided with education regarding their brother or sister, healthy siblings appear to have decreased anxiety levels. Data also suggests that the siblings effectively processed the educational information provided and were able to exhibit positive coping responses (Gursky, 2007).

The literature also demonstrates that support programs are beneficial in reducing anxiety in siblings of pediatric cancer patients (Packman, et al., 2004). Group support programs for siblings of cancer patients have not only been found to reduce anxiety and depressive symptoms, but also aid with behavior problems, attitude, and mood (Gursky, p. 393, 2007). One example of a support program for siblings of pediatric oncology patients is Camp Okizu. Camp Okizu is a summer camp specifically designed to focus on building siblings' self-esteem, foster peer socialization and validation, and address emotional troubles. Participants are given the opportunity to meet and communicate with other siblings who share common experiences. They are also given positive feedback, reinforcement, and recognition from supportive counselors (Packman, et al., 2004).

Packman et al. employed standardized measures to gauge posttraumatic stress, anxiety, quality of life, and the self-esteem of participants pre- and three months post camp attendance. The total number of siblings who were assessed was 77 and they ranged in age from 6-17 years old. Researchers found a significant decrease in siblings' symptoms of posttraumatic stress (PTSD) and anxiety after they attended camp. There was also a significant enhancement in the siblings' quality of life and self-esteem. While all sibling participants' PTSD scores dropped, the higher benefit seemed to be for first time campers. The researchers suggested that the camp experience might be normalizing for healthy siblings in families where their normality has been disturbed by the diagnosis of the illness (Packman et al., 2004).

The findings above seem to be consistent with additional research. Barrera, Chung, Greenberg, & Fleming (2002) demonstrated that positive psychological changes in well siblings were reported after an 8-week group intervention for siblings of cancer patients. The group focused on addressing the emotional and behavioral problems of the healthy siblings. Seventeen siblings were evaluated pre- and post group participation. Results illustrated a decline in siblings' anxiety and depressive symptoms. Behavior scores also suggested a movement in the same direction. Sibling self-reports implied that the group participants had a reduction in their fear of cancer and an improvement in intrapersonal factors related to cancer. Lastly, parental reports indicated that communication within the family regarding cancer had improved. Previous data had implied that under normal circumstances parents may have trouble gauging their children's beliefs, worries, and feelings when they are not clearly expressed (Barrera, Chung, Greenberg, & Fleming, 2002).

Further research with siblings of pediatric oncology patients also showed a decrease in anxiety post participation in a 5-week psychosocial support group. The program aimed to foster feelings of control in the siblings, which would then hypothetically result in a reduction in their feelings of anxiety. Facilitators emphasized improving communication about the cancer and enhancing siblings' confidence in medical caregivers.

Findings illustrated that the ill siblings' diagnosis appeared to have an effect on the group participants' reduction in anxiety. Healthy siblings of children with a brain or solid tumor exhibited the least amount of anxiety reduction. Researchers hypothesized that this could be due in part to the poorer prognosis for brain tumor patients versus the more promising diagnosis of leukemia or lymphoma. A number of siblings stated that they felt reassured when interacting with other children who had similar experiences (Houtzager, Grootenhuis, & Last, 2001).

Although there is substantial evidence that the adjustment of the well sibling and their parents seem to be interrelated, parents have not been routinely incorporated into sibling support groups. A study by Lobato and Kao (2002) was conducted on an integrated support group for siblings and parents of children with a chronic illness and/or developmental disability. The sibling and parent groups met separately for six sessions. Session topics focused on sibling knowledge, family information exchange, identifying and managing sibling emotions, problem solving in challenging situations, and on balancing individual sibling needs. During a portion of four of the session meetings siblings and parents met in order to engage in interactive activities and exercises. Data was collected from the fifty-four sibling participants who were between 8-and 13-years old. Researchers measured sibling knowledge, sibling adjustment to the disorder, sibling connectedness, and sibling global behavioral functioning (Lobato & Kao, 2002).

Lobato and Kao's (2002) findings concluded that siblings of children with autism spectrum disorders, psychiatric disorders, and mental retardation were less able to accurately describe the disorders. The post group participation evaluation showed that this particular cluster of siblings' accuracy improved when compared to siblings of children with physical illnesses or disabilities. Lobato and Kao also discovered that girls in general were more accurate than boys in naming their sibling's illness or disorder. Data illustrated that the male participants' accuracy increased from pre- to post-group participation. Finally, post evaluation indicated a reduction in negative adjustment symptoms, an increase in sibling connectedness, and a significant reduction in global behavior problems (Lobato & Kao, 2002).

It is evident that each support intervention reviewed above has its own unique attributes. Each program has predetermined goals and tailors its approach to support its objectives. For example, Camp Okizu aims to build self-esteem, promote peer socialization, and address siblings' emotional troubles. Whereas, the integrated parent-sibling support group session topics focused on sibling knowledge, family information exchange, identifying and managing sibling emotions, problem solving in challenging situations, and on balancing individual sibling needs.

Although not one intervention is exactly alike, they all seem to have a positive and therapeutic effect on their participants. The findings from each program's evaluation are consistent in demonstrating that healthy siblings of ill or disabled children benefit from supportive intervention. Siblings were found to exhibit a decrease in anxiety levels, depression, fears, and PTSD symptoms. Post intervention results also indicated that siblings were able to demonstrate positive coping skills, felt reassured by interacting with children who share similar experiences, and exhibited an increase in self-esteem.

The findings also suggest that the programs positively impact the whole family unit. As a result of participating in the support groups, an improvement in family communication was noted along with an increase in sibling connectedness. Based on these results researchers can conclude that these types of interventions display a family centered care approach.

Overall, the above findings lend further backing for the provision of sibling support interventions. Although the primary focus of the family is on the ill or disabled child, siblings exhibit a range of psychological and behavioral reactions. It is crucial that this population receives adequate attention and appropriate support.

Sibling Support Groups in Southern California

Although the program models described above are beneficial for siblings and families, they are found in specific locations. A survey of 15 California hospitals within the Inland Empire area was conducted. The researcher explored each hospital's website in order to locate which hospitals had any type of support groups. A majority of the support groups that were identified focused on adults with diabetes, cancer, cardiac issues, bereavement, and welcoming a new baby. One out of the 15 hospitals offered a support group for children. This support group serves children between the ages of 7-17 years old who have a parent or loved one with cancer.

The researcher also came across a listing of registered Sibshops in California. Eight Sibshops were identified. Of the eight programs, half of them were located in the northern California region. The remaining four was found in southern California. The locations of nearby Sibshops were in neighboring counties and ranged from 58 to 90 miles away from the current study participants' hospital.

In addition to searching nearby hospitals, the researcher surveyed local area resources for support opportunities. Various programs were identified. Similar to the location of Sibshops, these programs ranged from 43 to 87 miles away from the current study participants' hospital. The first program that was identified was a yearly camp for families who have a child under the age of 6 with a significant medical, cognitive, developmental or mental health disability. During the camp session parents have the opportunity to attend workshops while networking with other parents and the speakers. A staff of doctors and nurses are available during the presentations and workshops in order to provide specialized child care if needed. Siblings participate in supervised activities at designated times, such as arts and crafts and swimming.

Additionally, a weekend camp for families of a child (ages 5-19) with epilepsy was discovered. The weekend camp is designed to offer the children fun activities in a safe and accepting environment, while their parents attend educational seminars. Camp activities include a family night, carnival, arts and crafts, campfire talent show, derby race, teen scene, and a parent's bistro.

Lastly, a support group held specifically for siblings was discovered. This particular group serves children ages 7-16 who have a brother or sister with a developmental disability. The program intends to provide siblings an opportunity to meet, establish peer support, obtain education, and engage in recreational activities.

Other identified programs included a Spanish-speaking brain tumor support group for siblings, social group for children of all abilities, and a family support group. Additionally, a parent and sibling group offers support for families who have a child who is autistic. The sibling group meets while the parents meet for their support group.

The above programs appear to offer much needed support, but are dispersed across southern California. Due to the large geographic area, many families may be limited in accessing these programs. Therefore, it is beneficial to obtain useful information as a means to establishing a sibling support program in an area that currently lacks one. Offering support to siblings and families would greatly impact the local communities and continually provide family-centered care.

CHAPTER THREE

METHODOLOGY

Participants

The target participant population for the evaluation of the proposed program was Child Life Specialists. Participants were identified from pediatric units at a large children's hospital in southern California. Currently, there is no sibling support program offered by the hospital or within the nearby geographical area. The participants ranged in years of experience from zero to twenty plus years at the time of data collection. This particular participant group was selected because they work directly with children who are ill and/or disabled and have knowledge about the unique needs and issues of families living with a child who is ill or disabled.

Procedure

Participants were asked to read and provide feedback regarding the proposed intervention, a 6-week sibling support program that addresses the psychosocial needs of the healthy sibling and their family. A detailed written description of the proposed intervention, informed consent, and an evaluation form were distributed to 19 potential participants. Of the Child Life Specialists that were asked to participate, ten were employed full-time, two were part-time, and seven were *per diem*. Participants were instructed to read the program description and provide honest feedback regarding the program by answering the brief questionnaire.

The primary objective of the evaluation of the proposed intervention program was to determine whether or not the program is clearly designed, seems feasible, and is likely to be beneficial in providing support to siblings and their families. The data collected from the questionnaire permitted the investigator to analyze, record, and illustrate the participant's feedback regarding the proposed program. Although the development of this type of support program is in its fundamental phase, it is important to recognize the need and future direction for this type of support intervention.

The participants' anonymity was maintained and their responses were kept private. All completed questionnaires were kept in a secure site away from the participants' place of employment. Only the researcher has entry access to the locked location. At the conclusion of the data collection, the number of completed and returned questionnaires was nine (47%). A description of the SiBilities program can be found in Appendix A. Additionally, the informed consent can be located in Appendix B.

Questionnaire

The exploratory questionnaire used to elicit information from the participants consisted of eight short, open-ended questions. The questions were written text in a survey format with space allowed for the participants' response. The data obtained through these questions also consisted of written responses. In the questionnaire, participants were asked to explain whether or not the proposed program communicated and supported its goals clearly. Additionally, participants were requested to speak to the program's feasibility, any limitations to its design, and whether it would meet all its goals. Lastly, participants were asked to indicate what they found beneficial about the program, describe any barriers to its implementation, and list any areas for improvement. A version of the program evaluation questionnaire can be found in Appendix C.

Analysis of Data

The participant responses to the questionnaire were analyzed for patterns and themes that emerge regarding the proposed program. Particular attention was given to respondents' perceptions regarding potential effectiveness and feasibility of the proposed program. Suggestions for potential improvement and implementation were also explored.

CHAPTER FOUR

RESULTS AND PRESENTATION OF THE FINDINGS

Communication and Support of Program Goals

According to every participant, the goals of the program were communicated clearly. Participants also indicated that the program supported its goals. It was reported that the support group encourages expression, education, and offers siblings tools to cope with stress. For example, one participant said, "Activities support sibs to learn knowledge about illness, etc. and gives sibs tools to cope with stress, learn to express feelings, etc." Other participants stated that each weekly topic is clearly connected to the program's goals and that it is logical to achieve the goals indicated. Lastly, one participant felt that there is the possibility that the coping tools may be difficult for younger children (8-9 y/o) to understand, but otherwise the activities support the program goals.

Program Feasibility

Each participant indicated that the program appears to be feasible. One Child Life Specialist stated, "Sessions like this can be held at a low cost with support from foundation involvement. Also with hospital staff support, participants can be easily obtained". Another participant pointed out that parents of disabled or chronically ill children are often looking for assistance.

An area of concern that was expressed by one participant was that the program would only be feasible for families living in close proximity to the hospital. Due to the large geographical area that the hospital serves, families may have to travel far in order to attend. The participant noted that, "The time might be too early depending on how far the family might need to travel".

A second area of importance that was indicated by participants was funding for the program. Three (33%) respondents stated that procuring funds could be difficult. One participant said, "Economy being the way it is, the foundation may not be as willing to provide ongoing funds for a sib group". The same participant also commented that space for the program to be held in may also be hard to guarantee. Another participant added that the program might need to be facilitated by at least one full-time employee if events and sessions were to be held year round. This participant noted that securing approval and funds for the facilitator's position might be the greater challenge.

Limitations of Program Design

Of the nine participants, four (44%) found the program to have no limitations. On the other hand, one participant disclosed that in their experience with running support groups, parents might not be as motivated to bring siblings if they do not have a meeting to attend at the same time. The participant went on to say, "Having a parent group meet at the same time might encourage participation".

Other limitations reported were the time of day that sessions were held and snack options. Due to many children having food allergies, being diabetic, etc., it was suggested by one participant that facilitators provide additional selections in order to meet everyone's dietary needs. Lastly, as indicated in earlier feedback, one participant stated that a number of the younger sibling group members might not grasp certain concepts. The participant also asked the researcher, "What do you do if families want to participate again? What if you have worked with all possible siblings? How can the program be "taken to the next level?".

Meeting of Program Goals

Participants were asked to indicate how the program would meet all of its goals. A majority of responses (55%) point out that the program provides a place where communication is established. Others support that the program provides a safe place for siblings to develop friendships, communicate with others, and participate in activities. One participant indicated that the program "is developmentally appropriate and easy to apply for the intended purpose". Two participants stated that meeting every week and having a 2-hr time period to spend with the children while concentrating on one goal weekly, was sufficient time to accomplish the established goals.

In response to each specific program goal, participants provided additional reactions. A number of Child Life Specialists (33%) felt that the siblings' emotional needs would be met through group discussion with others who share similar experiences. Emotional support would also be provided in the form of empathy expressed by the group members and the facilitators.

Participants also suggested that the siblings' educational needs would be met through open discussion and by providing developmentally appropriate teaching.

Increasing sibling knowledge would also be achieved by giving siblings the opportunity to share and ask questions. One participant pointed out that, "Education can alleviate any misconceptions the sibling may have about the illness or disability". One issue of concern that was highlighted by one participant was that providing education for siblings might be a challenge if there are many different disabilities or illnesses represented.

With respect to strengthening siblings coping skills, participants believed that this goal could be achieved by providing group members with ways to cope through group activities and discussion. It was noted that by participating in the support program, siblings would have the "opportunity to develop positive coping behaviors" in response to their daily challenges. On a final note, one participant stated, "The focus on feelings and future dreams would also provide encouragement to healthy communication and thought processes".

Lastly, participants addressed the program's aim to aid parents. Two participants indicated that they felt the parent "Tip of the Week" was helpful. Although helpful, one participant suggested that a parent support group would provide an opportunity for 2-way communication. One Child

Life Specialist also pointed out that family stress could decrease when fears are diminished through discussing the reality of their child's disability or illness. Furthermore, participants in general, stated that by providing a much-needed resource would decrease family stress.

Program Benefits

Participants listed a range of reasons why they felt the support program would be beneficial if implemented. The first reason noted was that the support program fills a need and services a population that is underserved (44%). One participant stated, "It would meet the need of a much neglected population." Another commented, "This would be an important and much needed program for any pediatric hospital". Participants (44%) also mentioned that the program allows for a group of children to come together under common circumstances. One participant said, "It would help these siblings recognize that they are not alone with their unique challenges that come with being a sibling to a brother or sister with a chronic illness or disability". Another Child Life Specialist stated, "It would get a group of kids together that might not otherwise meet - allowing them to normalize their struggles, gain empathy, and feel equipped to give feedback when they are ready while being supported". Additionally, the program was felt to be an outlet for siblings who tend to feel neglected and overlooked. One Child Life Specialist said, "It would provide siblings with an opportunity to get some healthy attention from their parents and hospital staff".

In conjunction with the aforementioned reasons, 33% of the participants noted that the program provides for family-centered care. One participant stated, "It would promote a family's comfort and trust with the hospital caring for the needs of the 'whole' family". Another participant said, "Siblings are the ones that typically get left behind/out of things with hospitalized children. This is family-centered care!". That same participant went on to say that participating siblings will increase their knowledge and may gain a better understanding of what the patient is dealing with. As a result, the participant felt that the sibling might be able to teach the ill brother or sister some positive coping skills. Lastly, another participant stated, "Concentrating on the family as a whole, brings the family together during a difficult and stressful time for the support and benefit of the patient and family combined. This would be an important and much needed program for any pediatric hospital".

On a final note, one participant highlighted that if the program followed its original design and was carried out in 6-week sessions, more people could be reached. The participant went on to say, "Due to the designated time allotted for the program sessions, facilitators could keep it exciting and not get lackluster while meeting with the same children continuously". The participant also commented that the briefness of the sessions could aid in preventing burnout in the facilitators and children alike.

Barriers for Implementation

When asked to describe any barriers to carrying out the proposed program, seven participants provided feedback. A majority of the participants indicated that funding (57%) and families' access to transportation (71%) to be the main barriers. Other barriers that were mentioned were securing a physical spot for the group to meet, getting parents "on board", families' schedules, and facilitator recruitment. One participant suggested that another means of connecting siblings who could not physically come to the session meetings would be via Internet, etc.

Areas for Improvement

Suggestions for improvement were made by three of the participants. One participant stated that any improvements would be best made after the implementation of the program. This would allow for feedback from parents and the siblings. On a similar note, one participant indicated that because feedback would be gathered from the group participants and their parents at the conclusion of the 6-week program, a chance for communication and reflection would occur. As a result, adaptation of the program would ensue if needed. One Child Life Specialist suggested allowing older siblings or close cousins to participate or get involved. Lastly, a participant proposed that the siblings would also benefit by receiving attention regarding what makes them special and valuable (strengths, talents, abilities) unrelated to their sibling. This would help siblings recognize their own gifts.

Additional Responses

Overall, the participants responded positively to the support program and considered it to be essential. One participant particularly expressed fondness for the "graffiti wall" activity. In order to secure funds and stay with budget funds, it was also suggested that the facilitators present a projected cost for everything needed to run the group.

CHAPTER FIVE

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary

Overall, all the participants positively received the support program. Based on the participants' response, it appears that the support program model communicates its goals clearly and seems feasible. Participants also provided the researcher with suggestions for enhancing the program prior to its implementation. In addition, participants indicated that the program goals were clearly met through sibling participation, group discussion, developmentally appropriate activities and education, peer interaction, and the availability of empathy and emotional support.

Two recurring themes that were highlighted by the participants were the concern for program funding and family access to transportation. The Child Life Specialists indicated that securing funding was the chief barrier to implementing the program. Secondly, a number of participants noted that it might be difficult for families to have a consistent means of transportation or travel far distances to attend the group.

Conclusions

On the whole, participants revealed that they liked the program and felt it would be beneficial in various ways. The responses from the participants seemed to reflect the opinion that siblings of ill or disabled children benefit from being around others who share common experiences. Their reactions support the notion that by providing an opportunity for siblings to gather in a safe place, there is the likelihood that connections and friendships can be made. Through these supportive relationships, open and honest lines of communication can be established. The Child Life Specialists also seemed to convey the idea that by being with these peers, it would allow them to normalize their feelings and recognize that they are not alone in their experiences.

The feedback from the Child Life Specialists also reflected the sentiment that siblings of ill or disabled children are a population that is underserved. Their responses echoed the feeling that siblings of ill or disabled children are often forgotten or feel left out. Due to parents attending to the ill child's needs, there is often limited time and energy given to the healthy sibling. The Child Life Specialists implied that a sibling support program is an opportunity for parents to stay involved with the healthy sibling and offer them attention.

Finally, the participants seemed to believe that the support program would serve as a means to providing family-centered care. The Child Life Specialists indicated that the program offers support that not only benefits the sibling, but the patient and parents, as well. They noted that siblings would be able to increase their knowledge and understanding of what the patient is dealing with. Parents would also gain insight to the healthy sibling's unique needs while increasing their trust and comfort in the hospital staff. On the whole, the feedback from the Child Life Specialists appeared to suggest that a support program would promote positive coping and adaptation along with lessening the family stress level.

Recommendations

As mentioned, the study participants provided various recommendations for improving the program's design and implementation. The primary concern that was expressed was regarding funding. It would be beneficial for the researcher to devise a projected budget prior to petitioning the hospital's foundation for funds.

Additionally, by having a projected budget, facilitators would be aware of specific costs and better prepared to stay within their allotted yearly budget.

Additional suggestions for improvement concerned the incorporation of other closely related children into the program, ideas for snacks, and a simultaneous parent support group. With regards to involving other close relatives, many homes include extended family members like aunts, uncles, cousins, etc. The program could offer an invitation for cousins and young aunts or uncles to participate. Although these children may not be biological siblings, they are the ill or disabled child's peers and may experience similar reactions to those of the biological siblings.

The second item of concern was the possibility that any of the support group participants may have a food allergy and not be able to partake in the snacks offered. It would be crucial for facilitators to request from parents any special information about the participating sibling e.g. food allergies, special diet, etc. This information would be helpful in providing alternative options and accommodating any specific needs.

Additionally, the participants highlighted that parents may not be as prone to have their child participate in the program if they do not have a group to attend at the same time. If parents are not "on board", there is the probability that facilitators may have difficulty enrolling siblings who will consistently attend. It would be beneficial for the researcher to explore how to carry out an integrated sibling-parent support group.

While research indicates that sibling and parent adjustment are interrelated, group interventions have not typically incorporated parents with siblings simultaneously (Lobato & Kao, 2002).The benefits of developing an integrated sibling-parent support group program would be twofold. Initially, parents would have increased motivation to bring their child if they knew they also had a group to attend. This would increase the rate of participation for siblings and parents. Secondly, parents will have the opportunity to access social support and address their own needs. Providing that there is the availability of funding, a meeting place, etc., it would significantly improve the proposed sibling support program if parents were more actively involved. On a final note, an integrated parent-sibling support group would further enhance the care provided for the "whole" family.

Limitations of Study Design and Procedures

Although the information derived from the data collection in this project is valuable in the future implementation of sibling support programs, these results must be regarded as a prelude to the development and implementation of support interventions. The study design has a few limitations to consider. First, Child Life Specialists were the only healthcare professionals surveyed. Although Child Life Specialists are knowledgeable in addressing the psychosocial and developmental needs of patients and their families, this project did not gather information from multidisciplinary team members. Responses from multidisciplinary team members may present valuable information not yet offered to the researcher. Second, the study participants were employed at the same institution; therefore, they are likely to share common workplace mission, vision, and values. Given the religious orientation of the hospital, this shared perspective may be intensified. The attitudes and opinions of the group sample may perhaps be biased and therefore limits the generalizability of the study results to other hospitals and Child Life programs. Lastly, the data was solely collected and analyzed by the researcher. The author recognizes the limitation of researcher bias when analyzing results.

Implementation and Discussion of SiBilities

The importance of sibling support and family centered care is gradually being recognized. Unfortunately sibling support programs and services that assist families are not widely spread. As mentioned earlier, support programs for children are very limited in the southern California area. The existing programs primarily focus on one illness and do not encompass a larger population of children who are underserved.

The current study and its results are twofold. First, if the proposed program was implemented it would support children and their families in an area that does not currently have this type of intervention. Current data would be beneficial in helping others within the community to recognize that family members of children with an illness or disability, specifically siblings, are in need of support. As awareness grows, resources and funding may be more easily accessible. These efforts allow facilitators to be one step closer to implementing the proposed program.

Secondly, the information collected from the current study's participants is valuable. In previous research, investigators have utilized parent or child reports when gathering data. That data has been used as a measure of the benefits and outcomes of existing programs. The current study chose to examine professional opinion prior to implementing the proposed program. The data collected provides the researcher with applicable information so that the program can be modified and tailored to the community it will serve.

In efforts to provide a beneficial and effective source of support for siblings and their parents, it would be advantageous to take into account the ideas recommended by the current study participants. The researcher should integrate practicable modifications to the program's design and plan of execution. Following any program revisions, the researcher should seek funding in order for the program to be carried out. Once funds are secured, facilitators should be recruited and the program implemented.

As noted by one of the study participants, any program improvements would also be best made after sessions meet. Feedback should be gathered from the siblings and their parents after the program is implemented. For example, siblings should be given the opportunity to share with the facilitators what they liked best, if the meeting times were convenient, and what they would like to see change in the future. Any forthcoming responses will be instrumental in making program adjustments and taking it to the "next level".

In order to fully evaluate the benefits of the sibling support program, facilitators should collaborate with researchers and gather informative data. It would be beneficial to examine sibling and parent stress levels pre- and post- group participation. Additionally, a study that addresses the level of sibling knowledge prior to and after group attendance would allow professionals to help support siblings' informational needs. By assessing sibling knowledge, facilitators can gain insight as to whether or not having a "general" support group that represents multiple illnesses is successful versus providing illness specific groups. Further research with larger samples could consider a range of variables and their effect on the sibling's and family adaptation to the illness or disability. For example, Guite, Lobato, Kao, & Plante (2004) pointed out that there is a gender effect with female children being more prone to caring for the ill child and taking on household responsibilities. In turn, there is an increased opportunity for parent-child communication and parental awareness of the healthy child's concerns. Additional data that examines variables like the above mentioned would reveal a more accurate depiction of how families are adjusting to an illness or disability. This data can also assist healthcare professionals and facilitators in adapting support interventions that best suit the individual needs of siblings.

As well as examining the specific benefits of the proposed support program, future directions and promising areas for program development might be to expand support opportunities, increase involvement of former participants and their parents, and educate others in the community about the unique needs of families with children who have an illness or disability. Program expansion can be accomplished through teen sibling support groups, adult sibling support groups, sibling camp, and family camp. An additional area for advancement is to facilitate disability and/or illness specific sibling support groups, for example, autism, sickle cell, kidney disease, asthma, and the like. Former sibling support group participants who are teens or young adults might be incorporated as "Junior" facilitators to enhance the support provided during the session meetings. Parents of children who have previously been in the program can also act as mentors to subsequent participating parents. Lastly, community education in the way of half or full day workshops on families and siblings living with a child who has an illness or disability can be beneficial in informing nurses, doctors, students, and others about the patients' unique needs and issues. The knowledge gained from support group participants and their families can be used to design the workshops and training packets for those working with this population.

As a final note, an area that has not been met with equal attention is the meeting of the instrumental needs of siblings. Research indicates that healthy siblings rate the need for meeting their instrumental needs as one of the most helpful (Murray, 2001). Future program designs may consider incorporating strategies to meet those needs. Some possible instrumental needs of well siblings that need attention are transportation to school, activities, and support group meetings, as well as, homework help.

The review of literature and the current study results illustrate the growing need to provide support programs for siblings of children who have an illness or disability. As healthcare professionals become more aware of the need to not only treat the patient, but to also assess the social support resources available to the whole family, it will be more common for medical teams to refer families to supportive intervention. By developing and implementing programs in conjunction with research efforts, the gap in providing effective family centered care can be minimized.

APPENDIX A

SIBILITIES PROGRAM DESCRIPTION

Group Members

The target population for this intervention program will be siblings of pediatric patients who have a chronic illness or disability. For the purpose of the program, a chronic illness is defined as an illness or condition that is recurring or persists over a long period of time. The illness can bring about long-term physical or developmental changes and/or require ongoing treatment. Disability is identified as an unusual or delayed development and/or a condition that limits one's ability to perform some or all adaptive skills such as communication, self care, social skills, or daily living.

Group members will be identified as siblings of patients from pediatric units at a university children's hospital in southern California. Referrals for members will also be gathered from the hospital's affiliated pediatric specialty team clinics. Any multidisciplinary personnel can refer the sibling and their family to the support program. These staff may be social workers, child life specialists, nurses, chaplains, or doctors. Children from families in the surrounding communities not directly receiving care from the hospital or its associated clinics may also be referred to the program. Siblings may range in age from 8-13-years-old. The age and diagnosis of the ill or disabled sibling will have no bearing on the sibling's inclusion in the group. Research supports the notion that there are generalized aspects of all illnesses, which allow for facilitators to provide effective support to a diverse group of participants (Morison, Bromfield, & Cameron, 2003).

Program Design

Facilitators who are knowledgeable in working with children who have a disability or an illness will lead SiBilities. These leaders will be sensitive to helping the child and family adjust to the illness and treatment, encourage normative development of the healthy sibling, and aim to decrease any psychological trauma. Facilitators will be provided with training and a manual that guides the course of the session meetings. While facilitating, group leaders will be open to being available to discuss the participants' concerns or allow for expression of feelings. They will also provide emotional support by exhibiting empathy, encouragement, understanding, care, and love, while providing a trusting environment. In order to be available to the participating siblings with adequate attention and support, the facilitator-to-participant ratio will be 1:4. Facilitators will be comprised of qualified service providers such as child life specialists, social workers, therapists, nurses, and the like.

The program will be sponsored and funded by donations generated by the hospital's Foundation department. All monies will cover costs for the facilitators, materials, food, facility, and additional miscellaneous expenses, for example, postage, photocopying, brochures, etc. Enrolling in the program will be free of charge to all families. The program facilitators will be accountable for registering siblings and managing the program budget. Facilitators are also responsible for publicizing the program via brochures and multidisciplinary referrals.

Throughout each calendar year, SiBilities will conduct sessions that will meet once a week for two hours for six consecutive weeks. There will be one six-week session per quarter. Facilitators will hold each meeting at a suitable meeting area provided by the hospital. The time in between each six-week session will be utilized to evaluate the program, plan for future sessions, and follow up with families.

In addition to the standard session meetings, SiBilities will host ongoing special events for siblings and families throughout the year. Events and activities may be in the form of family picnics, movie nights, holiday parties, and the like. First time SiBilities members and former members are welcome to attend these events and opportunities. Every year a special annual celebration will be held to recognize siblings on National Sibling Day, April 10th. These events provide siblings and families an occasion to make contact with a community that shares similar dynamics in a nonjudgmental environment, access ongoing support, and socialize.

Prior to the start of each 6-week session, facilitators will hold an informative meeting for parents who are interested in the program. During this time parents will hear about the program and how it may be beneficial for their child(ren) to participate. Later, facilitators will contact each incoming family and conduct a brief phone interview if an in person interview is not feasible. Through this discussion with the parent or guardian, the facilitator will obtain information on the family's social situation, the ill or disabled child's condition, and the participating sibling(s).

While siblings are the primary consumers of support within the SiBilities program, their parents are influential in their ability to adapt and cope positively. Facilitators will offer parents supplemental information about how to recognize and deal with the unique needs of the sibling. Each meeting will have a parent "Tip of the week". Parents will also be provided with helpful printed informational resources in conjunction with supportive listening by the facilitators. This allows for facilitators to have an opportunity to be able to identify those in need of further referrals and offer appraisal support. Through supportive listening, facilitators can aid parents by helping them to identify their support network, such as family, friends, neighbors or others that can help them meet the needs of their healthy children. Some of those needs may be transportation, homework help, and continuing their child's routine schedule that involves sports, activities, and hobbies.

During SiBilities meetings, participating siblings will get the opportunity to engage in various activities within a core curriculum. Each session will focus on a predetermined theme with specific goals and objectives in mind. The siblings will also have the opportunity to engage in informal activities. Activities include, but are not limited to, group discussion, journaling, discovering coping "tools", and group games. A guest speaker such as a nurse, doctor, or adult sibling of an ill or disabled individual may also be invited to candidly talk with the group participants and answer their questions. It is desired that through these activities and exercises siblings will feel safe sharing their experiences and feelings while developing a social network.

Although the themes of each meeting are predetermined, siblings' issues and concerns will be addressed as they arise. All information shared within the sibling group meetings or during one-to-one follow up with parents will be kept confidential. Should the siblings or their parents exhibit serious signs of mental health symptoms at any time the proper referrals will be made to the appropriate agencies.

Each SiBilities group meeting will generally open with an activity as the children enter. This will give them the opportunity to occupy themselves and socialize while waiting for others to arrive. Dyson (1998) points out that half of the siblings sampled from a sibling support group program indicated that they liked the activities the most.

Once all the siblings have arrived, the facilitators will conduct a "Welcome" period. During this time, siblings can share about the happenings of their last week and any new or exciting things about themselves. Proceeding the "Welcome" period, facilitators will lead a discussion and activity focusing on the week's theme. Siblings will also be given a coping "tool" at each meeting that corresponds to the week's theme. This tool will be something tangible that the sibling can use, for example, a journal book, picture frame, stress ball, and the like. Lastly, a snack will be provided during the meeting. At the conclusion of each meeting, the group will re-cap what was discussed and be given important information or reminders.

Session Meetings

Week 1

During the first meeting, facilitators will introduce themselves and the program. Siblings will collaboratively develop rules for the group, learn about the goals of the program, and get to know each other through "ice breaker" activities. They also have the opportunity to share something about their families and their ill or disabled sibling. Prior to the first meeting siblings will have been encouraged to bring in photos or mementos they would like to share during this discussion.

Week 2

In order to address the healthy siblings' informational needs, during the second meeting siblings will learn more about the types of illnesses and disabilities that affect people. They will also be provided with developmentally appropriate information about their brother or sister's specific illness. Research suggests that by providing accurate and realistic information, children will have fewer chances for developing misconceptions (Gursky, 2007). Informational support has also been found to aid coping responses by encouraging cognitive and behavioral techniques. As a result, individuals may be able to accommodate increased stress levels and redirect negative coping actions (Murray, 2002). Facilitators will provide advice, direction, and information on the illness experience.

Week 3

"Changes" is the theme of the third meeting. Siblings will discuss the different types of physical or developmental changes that are a result of their brother or sister's illness. Additional changes to the family structure and operation may result from the care and attention needed by their brother or sister. These changes, big or small, may bring about gains and/or losses. Siblings will be provided with strategies on how to deal with these changes and how to enhance their sibling relationship.

Week 4

Meeting four will focus on the array of emotions that siblings may experience. Their feelings can range from fear and anger to guilt and sadness. Siblings are given the opportunity to vent and share their emotions while learning how to identify and deal with them. Emotions can also evoke a range of physical and behavioral reactions. Siblings will brainstorm acceptable and unacceptable ways of dealing with their feelings. Facilitators will encourage siblings to use adaptive coping skills such as eating healthy and exercising, finding support from others, having fun, expressing their feelings, and asking for help when needed.

Week 5

The theme of meeting five is nurturing hope and building on the positives. Much research has focused on the negative outcomes of families with an ill or disabled child. On the contrary, many siblings and their families have become resilient despite times of crisis. Siblings will discuss their future dreams and aspirations. Additionally, facilitators will talk about the positives of having a brother or sister with an illness or disability such as warm, nurturing relationships and their transformation of maturity and patience. The development of tolerance, empathy, and compassion along with appreciation of familial relationships will be highlighted.

Week 6

Lastly, week six will have a "graduation" ceremony for all the siblings who participated in the session. The siblings' families will be invited to join in the celebration. Families will participate in an activity together and have snacks. At the conclusion of the last meeting, parents are invited for a brief time to learn from the facilitators and children what was learned throughout the 6-week session meetings. Lastly, the group participants and their parents will be asked to provide feedback and evaluate the program via a brief questionnaire. The information gathered will be used to enhance future support group sessions and aid in identifying potential areas for growth.

Week 1 - Introductions

3:30 pm	
Arrival Activity	Make your own nametag. Materials needed: Stick-on nametags, markers, stickers, etc.
	Facilitators will introduce themselves.
Develop rules of the group	Siblings will collaboratively develop rules for the group.
"Welcome" period	Participants will learn about the goals of the program.
Discussion of the week	Siblings will share something about their families and ill or disabled sibling. Prior to the first meeting siblings are encouraged to bring in photos or mementos they would like to share during this discussion.
Snack	Juice/water. Microwave s'mores & apples. Ingredients: Juice/water, graham crackers, marshmallows, chocolate bars, apples, plates/cups/napkins. On a plate, place 1 cracker square. Top with chocolate and a marshmallow. Microwave on high until marshmallow puffs (Approx 8 secs.). Remove from oven and cover with another cracker square. Eat like a sandwich.
Activity	M&M "Ice breaker" activity Materials needed: M&M candies, bowl. Pour M&Ms into bowl. Have the siblings grab a handful from the bowl. Make sure that no one eats his or her candy right away. For each piece of M&M candy each person took, they will have to answer a question, depending on its color: Red candy: favorite hobbies/things to do Green candy: favorite foods Yellow candy: favorite movies Orange candy: favorite places to go or travel Brown candy: most memorable or embarrassing moments Blue candy: wild cards (they can share anything about themselves) The facilitator will then call out the color topic and everyone will go around the room sharing 1 answer per M&M. For example: if someone chooses two red pieces of candy, they will have to name two of their favorite hobbies. After the individual has shared that color with the group, he/she may then eat their candy. Continue to go around the room until each color topic has been shared.
Coping tool	Mini photo album: Encourage the group to preserve memories through photo sharing.
5:30 pm	
Re-cap, reminders, and goodbye	Ask siblings to come up with questions about their brother or sister's illness/disability to address next time. Parent "Tip of the Week": Keep the lines of communication open. An open and honest relationship builds trust and support with your child.

Week 2 – "What is an illness or disability?"

3:30 pm	
Arrival Activity	Make your own nametag. Introduce the "Graffiti wall" Materials needed: Butcher paper, markers, crayons, etc. The "graffiti wall" will be a large section of paper posted to the wall where siblings can "leave their mark" on a weekly basis.
Review rules of the group	Siblings and facilitators will briefly review the established rules of the group.
"Welcome" period	Siblings will have the chance to share any happenings about their last week or any new exciting things about themselves.
Discussion of the week	In order to address the healthy siblings' informational needs, siblings will learn more about the types of illnesses and disabilities that affect people. They will also be provided with developmentally appropriate information about their brother or sister's specific illness. Facilitators will address siblings' concerns and provide advice, direction, and information on the illness experience. *Ask siblings to save a question or two for the activity later.
Snack	Juice/water. Chex mix & grapes. Ingredients: Chex mix, juice/water, grapes, plates/cups/napkins
Activity	Question Web Materials needed: Ball of string or yarn Ask the group to think of the questions they brainstormed about their sibling or illnesses and stand in a circle (arm's length from each other). One person is given the ball of yarn and finds the end of it. They will toss the ball of yarn to anyone within the circle while they are still holding the end of the ball of yarn. As each person tosses the yarn, a "web" that connects everyone will be created. This web will represent the group's questions and concerns. Now ask the group to reverse the tossing of the yarn, but this time as each person tosses the yarn, they are to ask their question so that it can be answered. As the "web" of questions disappears, the group can see that by getting answers they are better able to clearly understand what is happening with their sibling.
Coping tool	Small notebook: Encourage the group to write down their questions and answers or journal their thoughts.
5:30 pm	
Re-cap, reminders, and goodbye	Parent "Tip of the Week": Allow your child to ask questions or express concerns about their brother or sister. Helping them to understand can lessen their worries, clarify misconceptions, and deal with fears of the unknown.

Week 3 - Changes

3:30 pm Arrival Activity	Make your own nametag. Add to the "Graffiti wall".
Review rules of the group	Siblings and facilitators will briefly review the established rules of the group.
"Welcome" period	Siblings will have the chance to share any happenings about their last week or any new exciting things about themselves.
Discussion of the week	Siblings will discuss the different types of physical or developmental changes that are a result of their brother or sister's illness. Additional changes that will be addressed may occur within the family structure or routines and may result from the care and attention needed by their brother or sister. These changes, big or small, may bring about gains and/or losses. Siblings will be provided with strategies on how to deal with these changes and how to enhance their sibling relationship.
Snack	Juice/water. Banana dippers. Ingredients: Bananas, chocolate chips, miscellaneous dipping ingredients e.g. crushed cookies/graham crackers, sprinkles, etc., juice/water, plates/cups/napkins. Peel the bananas and slice into several pieces. Place chocolate chips in a microwave safe bowl and cook on high until melted/smooth. Dip the banana slices in the chocolate. Roll them in other ingredients as desired.
Activity	Say what?! Ask the group to sit in a circle and pick one person at random. That person will be asked to make up a message and not tell the rest of the group. Once signaled to start, that person will whisper the message to the person next to them. The next person will whisper the message to their neighbor - and so on. The last person to receive the message will tell the group the message they received. This allows for the group to see how things can "change".
Coping tool	Silly putty: Remind siblings that just like the putty can change and morph, life will bring about numerous changes. Encourage them to use the putty as a stress releaser.
5:30 pm Re-cap, reminders, and goodbye	Remind siblings that they cannot change the things that happen around them or how others behave. But that it is them that have the ability to change what they do and how they handle those changes. Parent "Tip of the Week": Maintain a consistent routine when possible. Consistency is predictable, allows for children to feel safe, helps to set boundaries and limits, and can aid children in handling change when they know what to expect.

Week 4 - Feelings

3:30 pm Arrival Activity	Make nametag. Add to the "graffiti wall"
Review rules of the group	Siblings and facilitators will briefly review the established rules of the group.
"Welcome" period	Siblings will have the chance to share any happenings about their last week or any new exciting things about themselves.
Discussion of the week	Participants are given the opportunity to vent and share their emotions while learning how to identify and deal with them. Siblings will brainstorm acceptable and unacceptable ways of dealing with their feelings. Facilitators will encourage siblings to use adaptive coping skills such as eating healthy and exercising, finding support from others, having fun, expressing their feelings, and asking for help when needed.
Snack	Juice/water. Trail mix & apples. Ingredients: Trail mix, juice/water, apples, plates/cups/napkins
Activity	Jumpin' Coin Materials needed: Bowl of cold water, glass soda bottle (with a small opening/mouth), coin (bigger than the mouth of the bottle). Fill bowl with cold water. Place the bottle neck and coin in the bowl of water to chill. This will help make an airtight seal when you place the coin on the top of the bottle. Remove the bottle and coin from the bowl. Place the coin on the bottle opening. Randomly select someone from the group to wrap their hands around the bottle and wait several seconds to see what happens. Ask them to remove their hands and wait. When the bottle is held, the air inside heats up and forces the coin to "jump". When their hands are removed the air cools down and then the coin stops "jumping". The hot air can be compared to the siblings' feelings and what happens when emotions are bottled up.
Coping tool	Stress ball and tissue pack: Remind siblings that all feelings are allowed. Encourage siblings to express their feelings positively through talking, writing, crying, stress ball, etc.
5:30 pm Re-cap, reminders, and goodbye	Parent "Tip of the Week": All feelings are OK. Actively listen to your child's feelings and acknowledge their perception. Help them to identify and put a name to how they feel. This gives them the message that you understand.

Week 5 – Finding hope

3:30 pm Arrival Activity	Make your own nametag. Add to the "Graffiti wall".
Review rules of the group	Siblings and facilitators will briefly review the established rules of the group.
"Welcome" period	Siblings will have the chance to share any happenings about their last week or any new exciting things about themselves.
Discussion of the week	The theme of meeting five is nurturing hope and building on the positives. Siblings will discuss their own future dreams and aspirations. Additionally, facilitators will talk about the positives of having a brother or sister with an illness or disability such as warm, nurturing relationships and their transformation of maturity and patience. The development of tolerance, empathy, and compassion along with appreciation of familial relationships will be highlighted.
Snack	Juice/water. Fruit kabobs. Ingredients: Misc. fruit (chunk size), marshmallows, wooden skewers, juice/water, plates/cups/napkins. Thread fruit and marshmallows onto skewers.
Activity	What are MY hopes and dreams? Materials needed: butcher paper, markers, crayons, miscellaneous craft materials e.g. stickers, glue, etc. The purpose of this activity is for the participants to express their dreams and wishes for themselves, their sibling, and/or their family. Each participant is given a piece of butcher paper approximately 2 feet wide. Allow for each sibling to find their own spot within the room to work. Ask the group to take a minute and think about their dreams and wishes. Explain to the group that they are able to express those dreams and wishes in a different way through art. Have the group use the various materials to create a story or picture that reflects their dreams/hopes. At the end ask the participants to share their stories and pictures with the rest of the group.
Coping tool	Dreamcatcher: Siblings are reminded that it is OK to have their own personal hopes and future aspirations.
5:30 pm Re-cap, reminders, and goodbye	Parent "Tip of the Week": Recognize your child's uniqueness. Siblings have their own hopes and dreams. Sometimes siblings assume the "third parent" role. Be aware and sensitive to the number of adult responsibilities these children are taking on. Allow siblings to get involved in hobbies or activities that they are interested in whenever possible.

Week 6 - Graduation

3:30 pm	
Arrival Activity	Make your own nametag. The siblings' families will also be invited to join in the celebration of the final meeting.
"Welcome" period	Facilitators will welcome all parents and siblings.
Discussion of the week	Parents and siblings are invited for a brief time to learn from the facilitators and participating children what was learned throughout the 6-week session meetings.
Snack	Grapes, cheese, & crackers. Juice/water. Cake. Ingredients: Grapes, cheese, crackers, juice/water, cake, plates/cups/napkins, decorations
Family Activity	Chew It Materials needed: Clean garden gloves, packs of gum Invite parents and children to participate. Set up teams of five. Each team will receive one pair of new garden gloves and a pack of gum (5 pieces per pack). Once signaled to start, the first person in each team is to put on the garden gloves, open the package of gum, pull out a piece, unwrap it, chew it, remove the gloves, and then pass the gloves to the next person. The first team to complete the task wins. *You can choose to have two packs of gum per team so that they would have to go around twice.
"Graduation"	The facilitators will honor the participating children by giving them a certificate of participation and a personalized award medal.
5:30 pm	
Re-cap, reminders, and goodbye	The group participants and their parents will be asked to provide feedback and evaluate the program via a brief questionnaire. The information gathered will be used to enhance future support group sessions and aid in identifying potential areas for growth.

Example of Sibling Questionnaire

1. What was the thing you liked most about SiBilities?

2. Did the meeting times work well for you? If not, can you suggest a better day or time?

3. What kind of activities did you like the best? Example: crafts, talking with others, learning about brothers and sisters, etc.

4. What did you learn from coming to SiBilities?

5. If someone asked you about SiBilities, what would you tell them?

6. Is there anything you would change about SiBilities?

7. What else would you like us to know?

APPENDIX B

INFORMED CONSENT FORM

INFORMED CONSENT

The study in which you are being asked to participate is designed to investigate a proposed support group for siblings of children who have a chronic illness or disability. Alisha Alanis-Ayala, graduate student in Child Development, is conducting this study under the supervision of Professor David Chavez, Professor of Psychology, California State University, San Bernardino (CSUSB). The Institutional Review Board, CSUSB has approved this study.

The primary objective of this research is to evaluate a proposed intervention program for siblings of ill or disabled children. The survey will examine the design, feasibility, and potential effectiveness of the proposed sibling support group. You will be asked to read about the program and give feedback. This study, qualitative in nature, will explore the data collected from questionnaire responses.

A survey and consent form will be distributed to all potential participants. Those agreeing to participate in the research will return the completed questionnaire in a self-addressed envelope to the researcher. All responses will be anonymous. At no time will your name or identifiable information be requested during your participation. Data collected will be kept confidential in a locked location off-site.

Surveys should take approximately 30 minutes to complete. Upon the return of the distributed questionnaire, participants will not be contacted for additional information or time.

Participation in this study is voluntary. Choosing to refuse to participate will not affect employment or result in penalty. Subjects may discontinue participation at any time without penalty.

The potential risks occurring during this research are minimal. The primary risk for participants is the maintenance of anonymity. However, this is minimized by the procedure in which you would take the materials home and return them at your own convenience. The expected benefits of this study will include the evaluation of the proposed support program and an understanding of professional beliefs regarding the design and implementation of an intervention program. These benefits provide for movement towards implementing effective support for siblings and their families dealing with chronic illness and disabilities.

If you have any questions regarding this research, subjects' rights, or any related information about the study, please feel free to contact Alisha Alanis-Ayala or Professor David Chavez at (909) 537-5572. If you would like to obtain a copy of the results of this study, please contact Professor David Chavez at the end of Summer Quarter of 2009.

I have read the above and understand that all information will be kept anonymous. By placing an "X" in the designated area below I am agreeing to participate in the stated research.

________________________ Date: __________________

Place an "X" above indicating

your agreement

APPENDIX C

PROGRAM EVALUATION QUESTIONNAIRE

Does the program communicate and support its goals clearly? Please explain.

Do you think this program is feasible? Why or why not?

Please list any limitations to the program's design.

If the support program were facilitated as stated, please indicate how it would meet all the goals indicated?

Would you find this program beneficial? If so, how?

Describe any barriers to carrying out the proposed program?

Can you indicate any areas for improvement?

Additional Comments?

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