

Child Life Specialists' Facilitation of Family-Centered Care: The Importance of Sibling Support

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Abstract

Certified Child Life Specialists' understanding of family-centered care, and their beliefs and practices involving siblings of chronically/critically ill children were examined using an online survey. Participants were Certified Child Life Specialists recruited from the Child Life Council Forum. Relationships between utilization of certain words and support programs offered to siblings, were examined. Findings revealed a relationship in one area of coded language and support program for siblings, but not the other. Findings also revealed that all CCLS believe in the inclusion of siblings during the treatment process, however they are offered less support services than parents. Diverse results regarding multiple beliefs and practices of family-centered care and sibling inclusion raise further questions for future research.

Keywords: siblings, chronically/critically ill children, family-centered care, Child Life

Chapter 1

Introduction

Families dealing with a chronic/critical childhood illness are affected in many areas of their life since the severity of these forms of illness intrude on a families' daily functioning. When family functioning and daily dynamics are altered for a long period of time, siblings of the ill child begin showing negative effects as a result. The negative effects felt by siblings of chronically/critically ill children are explored throughout literature, describing specific outcomes related to age and gender, emotional effects, and family dynamics.

Researchers revealed outcomes regarding siblings' gender and age, in which both components seemed to play a role in the negative effects felt by siblings. Houtzager, Oort, Hoekstra-Weebers, Caron, Grootenhuis, & Last (2004) found sisters and older siblings experienced more anxiety than brothers and younger siblings. Vermas, Susante, van Bakel (2011) revealed older siblings have more mental health problems due to various expectations placed on them related to their age, and greater understanding of the severity of their ill sibling's illness. Although older siblings and females show a *larger* negative effect, siblings across age and gender groups show negative effects. Sharpe & Rossiter (2002) describe the unfortunate way siblings cope with the negative feelings they experience. Most siblings were found to internalize their feelings rather than externalize their feelings because they do not want to disturb their overburdened parents, or their sibling who is in a fragile state of health. These internalized feelings experienced by siblings often include: depression, anger, jealousy, loneliness, neglect, and guilt (Houtzager, et al., 2004; U.S. Department of Health and Human Services).

The toll of these negative effects on siblings require therapeutic support and attention. Family-centered care plays a significant role in the healing process of families affected by a childhood chronic/critical illness. The understanding of family-centered care has expanded over the past couple of decades creating a variety of professional beliefs and practices. Historically, family-centered care is defined as a partnership between parents and professionals, in which parental rights and a sense of control are established (King, King, Rosenbaum, & Goffin, 1999; Shelton, Jeppson, & Johnson, 1987). Siblings need to be regarded as a significant family member that need attention during family-centered care practices as well. Family needs are variable and constantly changing dependent upon each member in the family (Shelton et al., 1987). Thus, it is important for health professionals to be attentive to siblings based on their specific needs, such as negative outcomes previously discussed, and their cognitive understanding of illness.

Administering therapeutic care to siblings according to their cognitive understanding is critical, because concept of illness has proven to transform continually throughout a child's development. This development of understanding affects the way siblings views the causation and treatment of illness. Koopman, Baars, Chaplin and Zwinderman (2004) found that young children associate causation of illness with being disobedient and experience feelings of guilt and self-blame, because of their cognitive understanding. William & Binnie (2002) discovered that young children have a difficult time understanding the longevity of treatment and efficacy of medicine. Both of these findings also conclude that understanding improves continually with age as children's cognitive development progresses. Misconceptions such as viewing illness as a punishment, and all medicines will cure any illness quickly, are likely to intrude on a healthy sibling's emotional process during their ill sibling's treatment. Family-centered care practices

need to administer therapeutic treatment in accordance to their cognitive development to eradicate misunderstandings, and to provide information according to their cognitive understanding abilities.

Studies have revealed various interventions health professionals can utilize to improve knowledge and family adjustment to support siblings of chronically/critically ill children. Farmer, Marien, Clark, Sherman, & Selva, (2004) found that parents' primary needs are social support and information about services for their child to promote their child's health and development are the primary needs. If family-centered care practices meet parents' needs, they can better support the siblings, hopefully leading to decreased distress in parents and siblings. Lobato & Kao (2002) created an intervention stimulating discussions among siblings and parents. This allowed siblings and parents to foster a mutual understanding for their feelings, and provided parents a chance to personally support their healthy child. This intervention also created room for parents and siblings to better communicate with each other and seek out help when needed. William & Binnie (2002) revealed that peer-group directed discussions, rather than individual discussions, foster the most knowledge improvement among children. Siblings who receive individual support only have themselves to reason with after discussions with a health professional. On the other hand, siblings who discuss an illness topic with other children, problem-solve from multiple perspectives and support each other. This provides far more room for understanding, and feelings of connectedness with other siblings who can relate. These interventions can be used in the treatment place to establish healing, broaden understanding, and provide education and activities that can be utilized beyond the treatment center.

Certified Child Life Specialists are trained professionals with expertise in child development, coping skills and expressive therapy, and family systems and adjustment. CCLS could apply the interventions discussed to expand their utilization and understanding of family-centered care. As health professionals who help and support families through life's greatest health challenges and beyond (Child Life Council), I believed Certified Child Life Specialists were a fit population to study regarding pediatric treatment practices. Specifically, this project investigated Certified Child Life Specialists' understanding of family-centered care to see if it is including the siblings of the ill child in the treatment and healing process, and being utilized beyond the treatment place.

Instead of focusing on what negative effects are experienced by siblings, this project examined what leads up to these negative effects, and interventions that have proven to benefit siblings who may be experiencing these negative effects. This created a basis for my methods of study. Certified Child Life Specialists were sent an online survey through the Child Life Council Forum. This survey investigated a CCLS's understanding of family-centered care, how they view siblings in the treatment process, if they are promoting the utilization of family-centered care beyond the treatment center, and what programs they offer to support and encourage parents and siblings of a chronically/critically ill child.

This study differs from past research because it examined Certified Child Life Specialists' understanding of family-centered care, and if this understanding affected the programs offered to parents and siblings of the ill child. It was hypothesized that CCLS understandings of family-centered care would be related to the support programs offered to

siblings. It was also hypothesized that CCLS would provide more support programs for parents than siblings. Various components of these hypotheses were proven and rejected.

Relations between family-centered care understandings and programs offered to parents and siblings were statistically analyzed. Various other result frequencies were also analyzed. CCLS had various understanding of family-centered care, and few understood that family-centered care should encompass “family-specific” needs *and* “all-inclusive” family practices. It was encouraging to see that all CCLS described a uniform belief in the importance of supporting siblings and including them in the treatment process. Support programs provided for parents and siblings turned out to be an interesting finding when compared to literature. Results also implicated that Certified Child Life Specialists are aware of siblings and their needs for support. However, family-centered care understandings described and programs available display a gap in understanding of specific family needs, and interventions that provide all-inclusive family support at the treatment place and beyond.

This study allows health professionals to explore their own professional practice and understanding of family-centered care. Treatment centers can utilize findings from this project to provide more support services specifically tailored to families, to specifically enhance the support of siblings. It is my hope that this reflection on childhood illness’s effect on siblings and the utilization of family-centered care will broaden understandings, and motivate development of new interventions to emotionally support siblings at the treatment place and beyond.

Chapter 2

Review of Literature

Expansive research has been performed on the traumatic effects of chronic/critical illness on pediatric patients. However, other significant family members who are important bystanders during a pediatric patients' treatment process are often forgotten. Thankfully, sufficient medical treatment is available and provided to pediatric patients, but there is a lack of practical support for families coping with childhood chronic/critical illness (Willis, 2003). Recent research has begun to investigate the importance of supporting the entire family, specifically parents and siblings. Parents experience a great deal of distress and fatigue, and they are in need of support. As a repercussion, the siblings are sometimes lost in the tornado of change, sadness, and anger, with only their tired and distressed parents to turn to for support. This review of literature examines the effects of childhood chronic/critical illness on siblings, therapeutic support available, children's understanding of illness, and possible interventions to improve knowledge and adjustment. It will also examine possible ways to expand the utilization of family-centered care to support the *entire* family beyond the treatment place.

Chronic illness is defined by Williams (1997) as a "medically diagnosed ailment with a duration of six months or longer which shows little change or slow progression" (Sharpe & Rossiter, 2002, p. 799). Chronic illnesses such as cancer, diabetes, anemia, and bowel disease tend to have stronger negative effects on a family than a surgery or incidental major life event (Vermaas, Susante, & van Bakel, 2011). Illnesses of this magnitude that intrude on a family's daily functioning have also shown, throughout literature reviewed below, to negatively affect siblings' psychological functioning. The comparison of psychological functioning of siblings of

children with chronic/critical health conditions compared to the sibling of a healthy children, has revealed outcomes that vary based on numerous factors such as age, gender, emotions, and family dynamics.

Sibling Outcomes

Age and Gender Mediate Sibling Outcomes

Houtzager, Oort, Hoekstra-Weebers, Caron, Grootenhuis, & Last (2004) studied families of children with chronic/critical illness by examining the anxiety, quality of life, behavior-emotional problems, uncertainty, loneliness, emotional involvement, and positive emotions in siblings through interviews and questionnaires. Houtzager et al. (2004) found that sisters and older siblings experienced more anxiety than brothers and younger siblings. Vermas et al. (2011) conducted a met-analysis to further understand how chronic childhood health conditions could negatively and/or positively affect siblings. They found older siblings were more at risk for mental health problems than younger siblings. According to Vermas et al. (2011), older siblings' higher risk for mental health problems may be due to their parents' expectations of them. For instance, more may be expected from older siblings than younger siblings, such as domestic responsibilities, emotional control, and self-sufficiency. Many older siblings are also expected to support and take care of their other healthy siblings, if present. With an increased amount of parental expectations, paired with a flood of emotions in regards to their sibling's illness, it is not surprising that older siblings exhibit a greater amount of mental health problems, compared to younger siblings.

Emotional Effects

Although siblings of different ages and genders are diversely affected by their sibling's chronic illness, all groups have displayed negative emotional outcomes. Sharpe & Rossiter (2002) performed a meta-analysis on fifty research studies examining siblings of children with chronic illnesses to explore what is underlying their negative emotional experiences.

Investigators found that siblings often internalize problems rather than externalize them, perhaps because they do not want to bother their already overburdened parents. In addition, many siblings may experience feelings of helplessness, because they are rarely directly or actively involved in their sibling's treatment (Sharpe & Rossiter, 2002). "They may feel like powerless bystanders of the medical-care process" (Verma et al., 2011, p. 167). This could lead to feelings of anxiety, depression, anger, and jealousy (Houtzager et al., 2004). The U.S. Department of Health and Human Services recognizes these potential outcomes and articulates that siblings of children with cancer may experience a variety of negative emotions such as: fear, guilt, anger, neglect, loneliness, embarrassment, and jealousy. Internalizing these types of emotions is associated with even larger negative effects on healthy siblings than if these feelings were being externalized (Verma et al., 2011). Siblings, however, may feel an inability to exhibit external coping behaviors, such as aggression, due to the fragile health status of their chronically ill sibling (Sharpe & Rossiter, 2002).

Family Dynamics

Although the focus of most research on siblings of chronically ill children has been on adjustment outcomes rather than the process that leads to the negative outcome, Houtzager et al., (2004) found that coping and family functioning are significant predictors of anxiety and distress

reactions in siblings. Reduced quality of life, behavioral-emotional problems, insecurity, and loneliness were all found to be associated with high family adaptability. "Family adaptability is defined as the tendency of a family system to change its power structure, role relations, and relationship rules in reaction to distress" (Houtzager et al., 2004, p. 600). Family adaptability may be beneficial during transition to illness, but when such flexibility is ongoing and new family structures are continuously forming, it can be detrimental to siblings. Long-term flexibility lacks stability and support resulting in emotional distress. A cohesive family structure that balances both stability and change seems to be the most functional longterm (Houtzager et al., 2004).

Parental distress has also proven to be associated with family functioning. Expectedly, the more distressed a parent became, the more emotionally distressed the siblings became (Houtzager et al., 2004). Possible explanations for this could include a chaotic and stressful atmosphere, and the emotional burden of an absent parent. Vermas et al. (2011) found siblings of chronically ill children had significantly fewer positive self-attributes than siblings of healthy children. This finding was similar to other studies of children bereaving a parent. "Self-attributes (i.e., self-esteem) mediate the relationship between stressful life events and internalizing mental health problems. Haine and colleagues theorize that parentally bereaved children have lower self-esteem, because the available parent is unable to provide contingent responsive environment which causes these children to devalue their own needs for attention, thus inducing feelings of helplessness and incompetence" (Vermas et al., 2011, p. 172). The intrusion of distress from family dynamic changes due to the ill child's treatment, therefore, negatively affects a sibling's

self esteem as if they had lost a parent or parental figure, because a distressed parent feels like an absent parent. One sibling describes--

“When my dad comes home from being with my sister at the hospital all day, he is so grumpy. One day I just asked him why he always seemed so mad at me. He got quiet and said he’s so worried and stressed that even little things set him off... and that being on edge isn’t fair to me and my other sister. Hearing what was going on inside my dad’s head made me realize how tough this whole situation is for him, too. It made me feel a lot closer to him, instead of so alone and mad” (U.S. Department of Health and Human Services, 2013, p. 13).

Parents need to feel a sense of control and freedom of expression to ease their own emotional distress, so they can support their other children. Family-centered care attempts to promote this.

Therapeutic Support

Family-Centered Care

Health professionals need to recognize the family as the constant in the ill child’s life (Shelton, Jeppson, & Johnson, 1987). Partnership between parents and professionals is critical during the utilization of family-centered care. One approach is to engage in family-centered care.” Family-centered care ensures that parents have primary control over decision making, they are being treated respectfully and supportively, and that parents are provided with all information involving their child’s treatment (King, King, Rosenbaum & Goffin, 1999). This form of collaboration between health professionals and parents can allow the parents to individually tailor care plans to both the child’s and family’s strengths and needs (Shelton et al., 1987). King et al. (1999) performed a study on 175 mothers of three to five year old children in a rehabilitation center to examine the effects of family-centered care. They discovered that family-centered care, with social support, lowered stress levels and burden, and created better emotional well-being for parents. This decrease in parental distress would also predictably decrease sibling

distress, in accordance to Houtzager et al., (2004) study. Providing support to parents through family-centered care can extrapolate to providing support to other family members.

Implementing professional recommendations and treatment options while balancing individual family priorities is difficult. It may not always be possible to reduce the demands faced by families dealing with a chronic/critical childhood illness, but family-centered care can provide resources that support existing family strengths and the balancing of these demands (Shelton et al., 1987). Family needs are variable and constantly changing throughout the treatment of a chronic/critical illness. All individuals process information differently, especially depending on the cognitive and perceptual development of children. Sharing information with siblings in doses and providing time for follow up conversation is an important component of family-centered care. Especially during a child's charged emotional state, ensuring each sibling is attended to accordingly and compassionately, will maximize understanding and support (Shelton et al., 1987). Therefore, family-centered care will likely be most effective when used by health professionals who are knowledgeable in child development, such as Child Life Specialists

Child Life Specialists

Willis (2003) recognizes the importance of including siblings of the child in treatment, but also emphasizes that siblings need support in their normal development removed from their difficult circumstance. An important principle of family-centered care includes empowering each child and family member to discover their own strengths. Understanding that the family is each child's primary source of strength allows family-centered care to stay grounded in collaboration among health professionals and families (Committee on Hospital Care, 2003). Health professionals who primarily work with families during the treatment of an ill child, are titled

Child Life Specialists. Committee on Hospital Care (2003) measured emotional distress, coping during procedures, and adjustment during hospitalization, the post hospital period, and recovery among families. They found families who received care from Child Life Specialists did significantly better than other families who did not receive care from a Child Life Specialist. Child Life Specialists are more knowledgeable in child development and family functioning in comparison to other health professionals in the medical setting. Family-centered care can be utilized well by Child Life Specialists if they actively consider how they can incorporate all aspects of family-centered care into their practice at the treatment place and beyond. Tailoring this care to a child's conceptual understandings of illness will increase family-centered care's impact and goal of support.

Children's Understanding of Illness

Perrin & Gerrity (1981) randomly selected children from kindergarten through eighth grade to answer a series of standardized questions regarding illness. Their responses revealed a naive concept of illness in young children due to their level of cognitive development. Researchers found the conceptual differences to be significant through every age level. Conceptual understandings are compared to Piaget's theoretical framework of cognitive development. These conceptual differences are significant among adjacent grade levels, except between fourth and sixth grade. It was also discovered that once a child reaches eighth grade, presumably reaching the formal operations stage, a greater understanding of the complexity of illness is grasped. Responses also displayed most children understood the function of hospitalization, but had a difficult time understanding the cause or treatment of illness.

Koopman, Baars, Chaplin, and Zwinderman (2004) also investigated children's understanding of illness. They performed a study on 158 children, half of participants had diabetes mellitus and the other half investigated were their healthy classmates. Researchers interviewed all of the children on different types of illnesses and illness related concepts. They found that most children attribute the causation of illness to being disobedient, and experience feelings of punishment, guilt, and self-blame. This negative concept of illness causation decreases with age. As children's concept of illness continues to progress, biological causes of illness are also increasingly understood as body processes, and various forms of causes are comprehended. The developing child's basis for understanding shifts with age from reliance on external cues to reliance on internal body cues (Koopman et al., 2004). This finding could explain the greater amount of mental health disorders in older siblings from Vermas et al. (2011) meta-analysis. Younger siblings naive concept of illness may protect them from a threatening situation because they do not cognitively understand it. Older siblings are given more extensive information with the capacity to understand the severity of their sibling's illness (Vermas et al., 2011).

William & Binnie (2002) presented preschoolers and elementary level children with a series of vignettes about contagious illness and non-contagious illnesses or injuries. They examined children's beliefs about cause of illness, treatment time, and recovery factors. Obeying rules and complying with the external world to cure illness was a common misconception found in two to seven year olds. It was also concluded that children's poor understanding of body processes intrudes on their understanding of the slow healing process of a serious illness as opposed to an injury. Misunderstanding treatment longevity could negatively affect siblings of

chronically/critically ill children being treated for a long period of time. Raman & Gelman (2007) examined developmental trends in children's recognition of time in the cause and treatment of illness. Interestingly, they discovered that children have a better understanding of treatment than cause. Until adult years, participants appeared to not appreciate the time lag between contact and symptoms, however, most participants were aware of the time lag between treatment and cure. Findings also revealed that children believed that medicine would be effective all the time, but older participants judged medicine to be less effective than younger participants. Trends throughout all of these studies seem to portray that children have some sort of disease conception (regarding germs, contagion, and the necessity of medicine/hospitalization), however, dependent upon cognitive development, children appear to miss important pieces of the causation and treatment process of illness.

Misconceptions are likely to intrude on a sibling's emotional process during their ill sibling's treatment. A naive concept of illness could negatively affect younger siblings of chronically/critically ill children if the illnesses longevity or severity is misunderstood. They may blame themselves or their sibling for the illness because they do not cognitively understand otherwise. This lack of complete (external vs. internal) conceptual awareness could hinder a sibling's coping style, adjustment, and balance of internalization of emotions. Therefore, it is critical for health professionals to utilize terminology according to a child's cognitive developmental level to irradiate any misconceptions and emotional burdens. Interventions designed to improve sibling knowledge and overall family adjustment are critical in the utilization of family-centered care.

Improving Knowledge and Family Adjustment

Identifying and predicting unmet family needs can decrease some of the stressors that increase emotional burden in families dealing with chronic/critical childhood illness. Farmer, Marien, Clark, Sherman, & Selva (2004) distributed a family needs survey among children with chronic health conditions and their parents. They discovered the most prominent need for families was information about services for their child, and ways to promote their child's health and development. They also discovered social support was a significant predictor of information needs and balanced family functioning. This further supports the importance and necessity of family-centered care. It is important that health professionals realize the necessity to apply these findings to *all* children in the family. Siblings' development, especially life outside of their difficult circumstance, is important to be attentive to and support. Parallel to this, health professionals must adapt their services and support to specific family needs. An individualistic approach towards family-centered care improves service delivery to support the family unit as a whole, therefore, optimizing overall family functioning and healing (Farmer et al., 2004).

Individually helping families according to their specific needs, includes individually educating children according to their developmental level. Research has already proven that young children have a capacity to understand illness, they just need assistance in furthering the development of this understanding. With increased experience of illness and support during treatment, children become more aware of the physiological and biological processes involved. (Perrin & Gerrity, 1981; Raman & Gelman, 2007; William & Binnie, 2002). This further developed concept of illness, through the support of health professionals, can ease a child's emotional burden, and promote healing and growth.

Lobato & Kao (2002) created an intervention called SibLink, which consisted of group sessions to improve sibling knowledge and family information exchange, identifying and managing sibling emotions and coping mechanism, and balancing siblings' individual needs. Siblings and parents were evaluated before and after this intervention. Compared to baseline, siblings' knowledge about illness increased, sibling connectedness to other children in similar circumstances increased significantly, and internalizing and externalizing behavior decreased for boys and girls across all types of chronic illness conditions of their sibling. Promoting conversation and collaboration with parents allows family-centered care to be utilized beyond the treatment place. Bringing home coping techniques and positive family functioning tools will create a safe atmosphere for the entire family's feelings to be heard and understood.

Structured group work and discussion between peers has also proven to be a productive way to foster conceptual growth. William & Binnie (2002) performed research on preschool and elementary level students and their understanding of illness. Peer group discussion was facilitated with a story book, illness information, and prompts to initiate dialogue among the children. Along with their conclusion that children have varying levels of understanding illness according to cognitive development, post-test results revealed that all children participating in structured group work and peer discussion, had significantly greater concept of illness than those who did not participate in peer group discussion. This same technique could be used beyond education of illness to building coping skills and social support among peers. It is an open question whether sibling support groups with facilitated peer discussion and activities would produce a similar result in regards to a significantly higher feeling of emotional support and decreased distress.

Interventions like these provide siblings and families with great opportunities to learn from each other, relate to one another, and share support with one another. As seen throughout literature, siblings' overall negative effects from chronic/critical illness suggest that this population deserves significant attention in pediatric care. Knowledge of the effects of chronic/critical childhood illness on siblings has seen significant growth throughout literature over the past few decades, however, mental health problems in siblings have gotten worse (Verma et al., 2011). More interventions and research are needed to identify specific family needs and siblings at risk. All health professionals need to be aware of siblings' risk when working with families of children with a chronic/critical childhood illness, who are adapting to stress and anxiety demands. According to Wamboldt & Wamboldt (1998) information sessions and support groups have proven to "enhance children's psychological state, their knowledge of disabilities, and their understanding of the family situation" (Sharpe & Rossiter, 2002, p. 707). Providing support groups and other specific interventions tailored to siblings, educating parents on the importance of family-centered care beyond the treatment center, and acknowledging chronic/critical childhood illness as an experience the *entire* family endures, will strengthen family-centered care ideals and positively impact families who need this support most.

The goal of this project was to explain the necessity to include siblings in family-centered care during the treatment of a childhood chronic/critical illness. Review of literature provided an overview of how siblings and families are affected by childhood chronic/critical illness, and what is currently being done to reduce negative effects. A survey was developed to assess Certified Child Life Specialists' understanding of family-centered care, and their professional beliefs and practices involving siblings. The end goal of this project was to better understand the diverse

perspectives of family-centered care among CCLS, their understanding of sibling importance, and support programs currently provided to parents and siblings. Reflection on these results were intended to discover room for improvement in the professional practice of CCLS regarding family-centered care beliefs and practices, develop family-centered care to attend to specific family needs, including siblings, and to provide tools and education for parents to utilize family-centered care beyond the treatment center.

Chapter 3

Methodology

Participants

Twenty seven Certified Child Life Specialists participated in this study. All of the Certified Child Life Specialists were members of the Child Life Council, a professional organization for the education, communication, and expansion of Child Life. The large majority of participants (96%) reported they were female. In addition, all participants (100%) declared that they use family-centered care in their professional practice. Most of the participants began their practice after 2003 (68%), and currently practice in the Southern region of the United States (42%). The mean age of CCLS who participated in this study were approximately 34.5 years. Participants did not receive any compensation for participation.

Measure

The questionnaire sent out through the Child Life Council forum was a voluntary self-report questionnaire that sought information regarding participant demographics and their specific views of professional practice regarding family-centered care and sibling consideration. Some of the questions used a Likert scale or multiple choice options. These required answers to various demographic questions, and various questions soliciting level of participant agreement with a variety of statements. Additional questions were open-ended and provided participants with an essay box within which they could enter their own responses. These questions measured participants' understanding of family-centered care, support programs offered to parents and siblings, and personal research or interventions. See Appendix A for the full survey.

Procedure

After obtaining IRB approval for this study, the questionnaire was sent to the Child Life Council online forum. The survey was open for two weeks. Once the survey was closed, a coding scheme was developed to code open-ended responses.

Coding. One of the open-ended questions asked: "Please define family-centered care." These family-centered care definition responses were coded based upon their use of "family-specific" language, "all-inclusive" language, both or neither of these. "Family-specific" language included descriptions pertaining to culture, individual needs, family-specific needs, etc. "All-inclusive" language included descriptions of the *whole* or *entire* family during the treatment process. Another open-ended question asked: "Please describe the programs you offer to support and encourage parents during the treatment process." This question was repeated regarding siblings. CCLS descriptions of their parent and sibling programs were coded into five categories. These categories were not mutually exclusive; each participant's response could contain more than one category if listed. These categories included: support groups, independent support, beyond the treatment place support, medical support, and family support. "Support groups" include programs where siblings could meet with other siblings, and parents could meet with other parents. "Independent" responses included one-on-one social support, individual therapy, crafts/activities, gift programs, etc. "Beyond the treatment place support" included educating parents about how to use family-centered care at home, how parents can talk to and support their children, in-home services, etc. "Medical support" included pain management, medical terminology, educational books, etc. "Family support" included programs that involve the *entire* family. All other questions in the survey were scored quantitatively.

Chapter 4

Results

Analyses focused on participants' responses to an online survey containing fifteen questions. All participating Certified Child Life Specialists analyzed stated that they use family-centered care in their professional practice. However, only about 81% of CCLS stated that they received education on the importance of family-centered care. When defining family-centered care, approximately 35% of responses included "family-specific" language, and approximately 27% of responses included "all-inclusive" language in their family-centered care definition. Approximately 11.5% of participants included both "family-specific" and "all-inclusive" language in their understanding of family-centered care, and 27% of participants included neither forms of language. This data set includes large amount of various results, so a few important components of results' frequencies were calculated to display Certified Child Life Specialists' understanding of family-centered care, understanding of sibling importance and inclusion, and support programs offered to parents and siblings of chronically/critically ill children. Distributions of responses regarding family-centered care understanding, lead to the conclusion that CCLS have diverse views of family-centered care. It also seems that CCLS find importance in one aspect of family-centered care, either "family specific" or "all inclusive," rather than both parts as mutually importance.

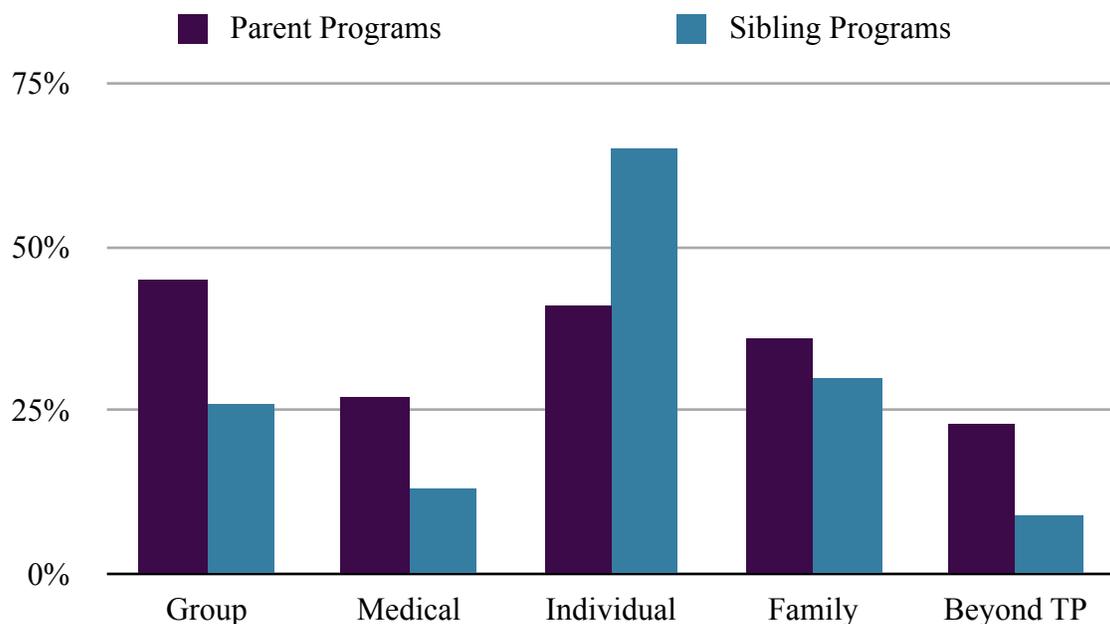
In order to explore the relationship between the utilization of "all-inclusive" language in family-centered care understanding responses and "family support" services offered to siblings, a chi-square test was performed. The relation between these variables was significant, $X^2(1, N = 23) = 4.41, p < .01$ (See Appendix D.). A chi-square test was also performed to asses a possible

relationship between “family specific” language in family-centered care understanding responses and “individual support” services offered to siblings. The relation between these variables was insignificant, $X^2(1, N = 23) = 0.61, p < .01$ (See Appendix E.).

Differences in support services provided can also be seen between parents and siblings. Participating CCLS provide slightly more support programs to parents ($M = 1.8, sd = 0.95$) than siblings ($M = 1.4, sd = 0.95$). Table 1 displays the frequencies of parent and sibling support programs offered according to participating CCLS. As displayed by Table 1, parents are offered more support programs than siblings in all areas, except individual support. According to participating CCLS, siblings are offered 24% more individual programs. It is important to take note that participating CCLS state that they offer at least one program to parents, but 17% of CCLS stated that they do not provide support programs to siblings.

Table 1

Parent and Sibling Support Programs



Although support programs for siblings may be concerning at face value, *all* participating CCLS stated that they believe siblings are important to include in the treatment process. Of these responses, about 85% said that they believe siblings are *very* important to include in the treatment process. Parallel to this belief, *all* participating Certified Child Life Specialists said they do include siblings in the treatment process, varying from sometimes to always. *All* participating CCLS also stated that they educate parents about siblings. On the other hand, it is interesting that about 31% of participants said they do not educate parents on the importance of family-centered care. Another 42% of participating CCLS said they do educate parents on the importance of family-centered care in both the home and treatment place.

Chapter 5

Discussion

As discussed previously, there were different approaches to family-centered care and how Certified Child Life Specialists utilize family-centered care in their professional practice. It was hypothesized that a Certified Child Life Specialist's definition of family-centered care would determine the programs available to siblings of chronically/critically ill children. It was also hypothesized that CCLS provided more support programs for parents than siblings. Results proved to support and reject various aspects of these hypotheses.

Family-Centered Care Understanding

Results showed variability in responses regarding family-centered care definitions. Although 35% of participants utilized only "family-specific" language in their definition, and over a quarter of participants used only "all-inclusive" language in their definition, only 11.5% of participants used *both* forms of language in their definition responses, and over a quarter did not use any forms of these descriptions. Earlier discussions explained the importance of incorporating family-specific needs *and* the involvement of all family members, specifically siblings in the treatment process (Farmer, et al., 2004; Houtzager et al., 2004; Lobato & Kao, 2002; Vermas et al., 2011). As a result, the current finding is concerning in that it indicates the possible relationship between family-centered care understanding and support programs offered to siblings.

The significant dependency found between "all-inclusive" family-centered care understandings and "family support" services offered to siblings, implies that a participant's understanding that family-centered care should include the *entire* family also affects their

likelihood to provide programs to siblings that involve the *entire* family. This is critical for health care professionals to consider as previous discussions have explained the importance of family support, especially for siblings. Beneficial family support opportunities discussed earlier include educating families about adaptability and stability (Houtzager, et al., 2004), providing siblings with time with their parents which is important for their positive self attributes (Verma, et al., 2011), and providing education and support activities to facilitate communication between parents and siblings (Lobato & Kao, 2002). To put thought into action, CCLS understandings of family-centered care need to be broadened, so all families have the opportunity to heal together as a family unit through family support services.

The same significance was not found for “family-specific” family-centered care understandings and “individual support” programs for parents and siblings. This raises the question of what understanding could be influencing the individual programs offered, especially when the other form of family-centered care understanding seemed to affect family support programs offered. A possible explanation for this could be that family-centered care and “individual support” services are viewed as separate forms of practices. Both practices could be misunderstood as separate entities, however, they are both significantly intertwined together in the professional practice of family-centered care.

Educating Parents

Results also revealed diversity in participant responses regarding how Certified Child Life Specialists educate parents on the importance of family-centered care. Over a quarter of participating CCLS stated that they do not educate parents on the importance of family-centered care, whereas, close to half of participants stated they educate parents about the importance of

family-centered care in the treatment place *and* home. This suggests an undiscovered gap in understanding and practice of Certified Child Life Specialists. Perhaps, specific trainings or work environments (ICU, Out-patient, ER, NICU, etc.) can affect the approaches that CCLS use in the education of family-centered care. This is an important finding to further study, so more parents can learn the skills and importance of family-centered care beyond the treatment center.

Sibling Importance

Although the belief in educating parents about family-centered care differs amongst participating CCLS, sibling importance is a uniform belief among all participating CCLS. It is encouraging to see that *all* CCLS responses displayed their understanding of sibling importance during the treatment process of the ill child. Even more encouraging, a large majority of these respondents emphasized that siblings are *very* important. All participating CCLS also revealed they educate parents about siblings. It is great to hear participating CCLS are aware of the risks siblings encounter during the stressful treatment of a chronic/critical illness. Certified Child Life Specialists display an understanding of the necessity to include siblings and to be attentive to their needs, however, there seems to be a lack of actual support according to program responses.

Support Programs for Parents and Siblings

The variability of services offered to support and encourage parents and siblings was surprising. It is concerning to see that siblings are offered fewer services than parents in all areas except individual support. This observation is very significant and should be utilized as a motivational tool for treatment centers and CCLS to provide more services to siblings. Another concerning aspect of this finding was that siblings were offered more individual support than parents. Previous discussions stated the importance of social support for parents (Farmer et al.,

2004) and the benefits for family functioning this individual support provides. Individual support for siblings is very important, but as discussed previously, it did not seem to be the most important. Support groups, such as structured peer groups discussed by William & Binnie (2002), and family support, such as SibLink discussed by Lobato & Kao (2002), have provided evidence of the value of peer-based and parent-child support for siblings. Therefore, it is interesting that treatment centers are providing more individual support for siblings, when in fact, parents are in need of more individual support, and siblings are in more need of family and peer support and interaction.

Limitations

Although many findings discovered through this research are significant or thought-provoking, various limitations could have altered results. The participants included only Certified Child Life Specialists, whom work primarily with families of pediatric patients. Broadening the survey to include other health professionals' responses (such as pediatric nurses, pediatricians) could change results. The participant sample size was also small, including 27 CCLS. A larger sample size would have provided a more representative population of Certified Child Life Specialists. Another important limitation includes how written response information was coded. All written responses were self-coded, therefore there is room for error or misinterpretation. Obtaining inter-reliability would be necessary before further interpreting these data. Reliance on open-ended written response sections could also be a limitation because a participant may have certain professional practice beliefs that they forgot to include, or did not have time to include, in the few sentences they chose to write. Lastly, all survey responses were self-reported by participants providing the possibility for error and personal bias.

Conclusion

The importance of prior research on family-centered care and sibling inclusion, combined with the findings reported from this study, are critical for other Certified Child Life Specialists and other health professionals to ponder. Many health professionals and treatment facilities are aware of the support and encouragement families and children need when dealing with chronic/critical illness. However, they may not be sufficiently educated about the *types* of support specific family members need. Family-centered care that encompasses the entire family, and provides support for family-specific needs, is important for health professionals to understand and utilize in their professional practice. Utilizing this broader understanding of family-centered care to include education beyond the treatment place, specific family member support, and all-inclusive family programs, could benefit so many siblings and families in the future. Siblings are a part of the family unit, and although they may not be directly undergoing medical treatment, they are undergoing the emotional and mental burden of many changes. All family members are in need of support and specific programs through family-centered care to provide healing for siblings and the entire family.

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Appendix

A. This is a copy of the survey that was sent to Certified Child Life Specialists.

1. What is your gender?

- Male
- Female

Other (Please Specify)

2. What is your age?

3. What year did you begin your practice as a CCLS?

4. Where are you from?

- Outside of the USA
- Western USA
- North Eastern USA
- Southern USA
- Midwest USA

5. Was the importance of family-centered care described or taught to you during your certification?

- Yes
- No
- Not Sure

6. Please describe how you would define family-centered care.

7. Do you use family-centered care in your professional practice?

*If your answer to this question is "No," please skip to questions 14 and 15.

- Yes
- No
- Not Sure

8. To what extent do you agree or disagree with the following statement:

It is important to include siblings in family-centered care.

1-strongly disagree 2-disagree 3-neutral 4-agree 5-strongly agree

1	2	3	4	5
strongly disagree				strongly agree

9. How do you educate parents on the importance of family-centered care?

- I explain the importance of family-centered care to the entire family. I educate parents on how to utilize family-centered care at home as well.
- I explain the importance of family-centered care at the treatment place, but I do not educate parents of its importance at home as well.
- I do not educate parents on the importance of family-centered care.

Other (Please Specify)

10. Does your utilization of family-centered care include the siblings of chronically/critically ill pediatric patients?

- Yes
- No
- Sometimes

11. Do you educate parents on the importance of supporting the siblings during the treatment process?

- Yes
- No
- Sometimes

12. Please describe the programs you offer to parents to support and encourage them during the treatment process.

13. Please describe the programs you offer to siblings to support and encourage them during the treatment process.

14. Are you currently conducting research to help families with a child with a chronic/critical health condition?

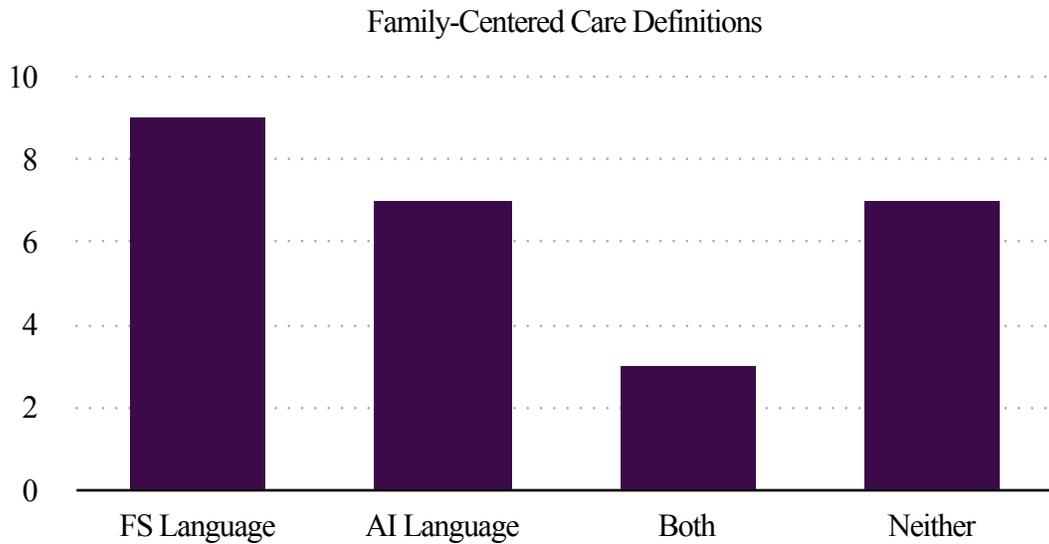
- Yes
- No

15. Has reflecting on family-centered care during this survey created any goals for future professional trainings or strategies?

B. This is a frequency table displaying utilization of “all-inclusive” and “family-specific” language in family-centered care understanding definitions.

	N	# of participants who used the language	Percent
All-inclusive Language	26	9	35%
Family-Specific Language	26	7	27%
Both Forms of Language	26	3	11.5%
Neither Forms of Language	26	7	27%

C. This is a bar graph displaying the distribution of family-centered care definition responses.



D. A chi-square test was performed on the utilization of “all-inclusive” language and “family support” services provided to siblings.

	Family Support I	Family Support 0	Marginal Row Totals
All-Inclusive I	5 (2.74) [1.87]	4 (6.26) [0.82]	9
All-Inclusive 0	2 (4.26) [1.2]	12 (9.74) [0.52]	14
Marginal Column Totals	7	16	23 (Grand Total)

E. A chi-square test was performed on the utilization of “family-specific” language and “individual support” services provided to siblings.

	Individual Support I	Individual Support 0	Marginal Row Totals
Family Specific I	5 (5.87) [0.13]	4 (3.13) [0.24]	9
Family Specific 0	10 (9.13) [0.08]	4 (4.87) [0.16]	14
Marginal Column Totals	15	8	23 (Grand Total)

F. This is a frequency table displaying the amount of parent and sibling programs offered at each participant’s place of practice.

	N	Mean	Std. Dev.
Parent Programs	22	1.8	0.87
Sibling Programs	23	1.4	0.95

G. This is a frequency table displaying the variety of support programs offered to parents and siblings.

	Support Groups	Medical Support	Individual Support	Familial Support	Beyond Treatment Center Support	No Support
Parent Programs	9	5	9	8	5	0
Sibling Programs	6	3	14	7	2	4

H. This is a frequency table displaying the variety of ways CCLS educate parents about Family-centered care.

	N	# of participants who agreed	percentage of participants who agreed
Treatment Place	26	7	27%
Both (T.P. and home)	26	11	42%
Do not educate	26	8	31%