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Parents' Perceptions of the Benefits of Practices Used by Child Life Specialists to
Improve the Hospitalization Experience:

A Phenomenological Approach

An Honors College Project Thesis

Presented to

The Department of Psychology

Abilene Christian University

In Partial Fulfillment

of the Requirements for

Honors Scholar

by

Annie Bailey

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This Project Thesis, directed and approved by the candidate's committee,
has been accepted by the Honors College of Abilene Christian University
in partial fulfillment of the requirements for the distinction

HONORS SCHOLAR

Dr. Jason Morris, Dean of the Honors College

Date

Advisory Committee

Dr. Dale Bertram, Committee Chair

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Abstract

This phenomenological study explores in-depth the descriptions of several families' lived experiences with Child Life Specialists (CLS). The researcher hoped that a picture would emerge about how families find holistic support for their needs from CLSs during their child's hospitalization. The in-depth interview method prompted specific stories about the participants' experiences with CLSs from a phenomenological method. From these stories, the researcher gathered and organized participant-specific open codes, and those fell into three broader categories called meta-themes. The selective code, *benefits families perceive from experiences with CLSs*, sums up the meta-themes and open codes gathered from the participants' interviews.

Keywords

Benefits of Child Life Specialist Practices, CLS, phenomenology, lived experience, spirituality, healthcare

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Introduction

Health professionals have known since the 1920s, and current research suggests that children need more stimulation and developmental encouragement during prolonged hospitalization than do other age groups (Child Life Council [CLC], 2015; Brewer, Gleditsch, Syblik, Tietjens, & Vacik, 2006). More sophisticated than play therapy and other entertaining activities, the Child Life Specialist (CLS) profession provides support for the family (Oers, Haverman, Limperg, Dijk-Lokkart, Maurice-Stam, & Grootenhuis, 2014) and prepares everyone involved for the processes they will go through during a prolonged hospitalization (CLC, 2015; LeBlanc, Naugler, Morrison, Parker, & Chambers 2014; Metzger, Mignogna, & Reilly, 2013). CLSs play an important role by “providing care designed to minimize stress, encourage normalization, enhance preparation, and promote children’s normal growth and development” (Turner & Fralic, 2009, p. 40).

Though the description of the CLS’s job sounds very positive, the extent of the potential benefits of CLSs are as of yet unknown, especially because this field is relatively new. More research and improvement is required in order to ensure that each family has the best hospital experience possible with the involvement of a CLS (Turner & Fralic, 2009).

CLSs come from many different fields of study and have extremely varied learning even before coming to the job. The website for the Child Life Council suggests that “Child Life Specialists have earned a minimum bachelor’s or master’s degree, with an educational emphasis on human growth and development, education, psychology, or a related field of study” (Professional Standards of Practice, 2016), which means there is no regulated education for a CLS, and basically any students can become one if they pass

the certification test. For instance, in their schooling, CLS students go through a variety of programs that may not highlight important, relevant topics in the curricula (Parvin & Dickinson, 2009). A recent study (Wilson-Vacik et al. 2001) suggests that research in the area of child life curriculum content and practical preparation is limited. Additionally, the literature related to the impact of caring for dying children is almost exclusively written from the nursing field, primarily from pediatric oncology nursing or pediatric palliative care (Ungureanu & Sandberg, 2008; Vacik, Nagy, & Jessee, 2001; Sutter & Reid, 2012; Oers et al., 2014; Brewer et al., 2006; Cole, Diener, Wright, & Gaynard, 2001), rather from research from CLSs, whose job it is to work with dying children and their families. It is, therefore, imperative to research the strategies and practices used by professional CLSs in order to determine whether they significantly improve hospitalization experiences for children and families, and what it is they incorporate that works best across the board for clients personally, so that students and teachers will know what is most important in the field application.

The majority of the findings from the literature suggested that the CLSs improved prolonged hospitalization (Sutter & Reid, 2012), parents understood the need for CLSs (LeBlanc et al., 2014), and the child life profession complimented the work the clinicians in the hospital were doing (Cole et al., 2001). Research conducted over the years has slowly helped in the improvement of the profession. Cole et al. (2001) sought to find “how health care professionals perceive child life specialists... [in order to clarify] possible misperceptions, and maximize the potential of child life specialists as pediatric team members.” (Cole, et al., 2001, p. 4). According to this study, the child life profession complimented the work of the clinicians in the hospital. Wilson (2006) states

that the services CLSs provide are an indispensable part of the experience hospitals provide to patients and their families.

Two consistent themes from the literature prompted particular interview questions for this study. The researcher hoped to find out whether the findings of this study are consistent with the findings found in the previous literature. Literature suggested that CLSs reduce pain without the use of medical practices. Bandstra et al. (2008) state that helping children with pain management using strategies other than pharmacological ones is a goal of CLSs. The study found that CLSs used the most effective strategies, such as “providing information, positive reinforcement, behavioral distraction, and therapeutic play” most often (Bandstra, et al., 2008, pg. 327). The literature also suggests that a role of the CLSs is to “reduce anxiety” and “minimize stress” for scary life events such as a chronic illness, intensive procedures, and prolonged hospitalization (LeBlanc, et al., 2014, p. 254; Turner & Fralic, 2009, p. 40).

Much of the literature is conducted through scales using quantitative data collection methods. Additionally, a topic that creates a gap in the literature about CLSs is the spiritual aspect the clients can experience while going through a hospitalization with a sick child. Though it is not specified in the job description for the CLS to encourage the spiritual faith of the child and the family, some of the CLSs will go out of their way to do so.

Currently, CLSs in training only need a bachelor’s degree in order to “become eligible for the certification examination” (Smith, Desai, Sira, Engelke, 2014, p. 347), though they act as both a counselor and a medical worker. With a minimum of a 480-hour internship and only 10 career-specific courses (Smith et al., 2014), the requirements

for becoming a CLS seem lenient, especially considering that they work closely with members of a vulnerable population as hospitalized children.

According to the Association of Child Life Professionals, new requirements have been implemented for students hoping to become CLSs after January 1, 2019 (ACLP, 2017). In order to be eligible to take the CLS certification exam, “candidates must either graduate from an ACLP-endorsed degree program or successfully complete 10 college courses...” which focus on topics such as child development and skills a CLS will need in the field such as play and loss/bereavement (ACLP, 2017). These additional requirements should help the students hoping to be future Child Life Specialists be more prepared for the situations they will face while interacting with children and their families in the hospital.

Phenomenon of Interest

CLS programs are a significant factor to patients’ healing, reduction of stress, and establishment of expectations. They also tend to improve general outlook on hospitalization for child patients and their families. In this study, parents gave their own perspectives of how the CLSs were able to positively influence the course of their child’s hospitalization.

Purpose

The purpose of this qualitative study was to learn through an inductive approach, by gathering the insights of the parents, whether the participants and their families found CLSs beneficial to the hospitalization experience, and if so, how. Families revealed the phenomena which they observed, and from their responses, the researcher discovered

salient categories which emerged from the data. The study focused on the features of the lived experiences mentioned by the participants, with an eye toward discovering a theory of how working with CLS's benefits patients and families "in practice". The goal of this paper is to fill in the gap in the current literature on this topic of the lived experiences of participants in situ. In sharing this research project, the researcher hopes professionals in the CLS field will gain a better understanding of the perceptions of families they serve.

Method

Participants

The participants in this study consisted of eight families. The target sample included families of children who have been hospitalized between the ages of 0 and 13, all of whom have belonged to a faith community in a mid-sized southwestern city, prior to or during an illness. The goal of the participant search was to identify children and their families who have worked with a CLS during one or more trips to the hospital. All participants are parents of children who have been hospitalized. The families were selected as a unit, rather than exclusively focusing on the patients, so as to capture the lived experiences of the entire family. We perceive hospitalization and the experience with a CLS to impact the entire family. The researcher was acquainted with the initial family who was willing to interview for this study. The remaining participants to be interviewed were recommended from prior participants, thus the study employed a snowballing strategy in order to find willing participants rather than to request participation. This study was approved by the institutional review board of the author's university. This was an important step since the families involved minor children, who are considered to be in a vulnerable population. Informed consent was obtained prior to

interviews with each set of participants.

Phenomenology

This qualitative research study utilized a phenomenological methodology to find themes in the responses participants provided during the interview process.

Phenomenology is a qualitative research design used to attempt to understand participants' perceptions, perspectives and interpretations of a situation through which they lived. The data collection focuses on gaining an understanding of the lived experiences of participants throughout one or more hospital visits, during which a CLS worked with them. This study examined the perceptions families of hospitalized children had of the effectiveness of CLSs. The researcher interviewed 8 families. Creswell (2012) notes that sample sizes in phenomenological research are often smaller because the researcher wants to gather extensive, content-rich data. Dahl & Boss (2005) note that small sample sizes in phenomenology allow for "in-depth description of the experiences of each participant." (p. 71). However, since the researcher was most interested in the lived experiences of the families, a phenomenological approach was selected because it focuses on the meanings of the lived experiences of participants (Merleau-Ponty, 1962; van Manen, 1990).

Procedures

The researcher invited families to tell the stories of their experience by answering a series of questions in a semi-structured interview with specific stories from their experiences. Participants chose the location in which they would prefer to have the interview. Locations included participants' homes, churches, restaurants, or by telephone.

Interviews were recorded with the permission of each participant while the researcher simultaneously took memoing notes.

Once all interviews were conducted, the researcher began coding the data with three steps of coding. The first step, open-coding, allowed for the researcher to highlight recurring words or phrases found throughout the interviews, which became the key themes in the study. This step included segmenting data into single words or phrases relevant to the development of the theory. The open codes provided a foundation from which the axial codes and meta themes could be extracted. The next step was axial coding, which helped group the open codes into three major, meta-themes. In this step, the researcher identified relationships and connections between the open codes and from there, established category headings, or meta themes, which summarized those groups. After establishing the meta themes, the researcher began the third step, selective-coding, to identify which three core categories were most important, broad, and essential themes to the phenomenon of interest, and established one selective code which encompassed them all. The selective coding step incorporated a process in which meaning units from each of the axial categories were extracted, examining key quotes and the context around these quotes. (See Table 1 on page 13 for details about the codes). The meaning units, which are key quotes and contexts, were pulled from the interviews and sorted based on which open code they fit into (see Table 2 on pages 14-15 for details about the meaning units).

Questions

The interview protocol consisted of meeting with the families to ask questions that would serve as prompts for them to tell their stories of working with CLSs. This was

an important step in the research to establish good questions because of the sensitive nature of the illnesses that children in these families experienced, including chronic and terminal illness (three families had lost children to terminal illness). The questions served as a vehicle for allowing families to tell their stories with as much ease as possible.

It was decided to begin the interviews with dual grand tour questions, rather than just one. This decision was informed by wanting to know their lived experiences of working with CLSs and also their thoughts and attitudes about the practices of CLSs. The two grand tour questions follow:

Grand tour questions:

1. Tell me about your experiences of Child Life Specialists from the beginning until now.
2. What are your thoughts and attitudes about practices you saw Child Life Specialists use throughout your experiences?

There were other questions in our protocol which allowed for obtaining a more textured view of their experiences. The additional questions were asked in sequential order, unless the question had been addressed when the family answered it in a previous question. The additional questions were:

1. What practice did you find most beneficial to your child?
2. What practice did you find least beneficial? (not as positive for child)
3. Did you notice a change in your child's outlook (experience) over time about their hospitalization as a result of working with a Child Life Specialist?

4. Did your outlook on your child's hospitalization change because of working with a Child Life Specialist?
5. Was there anything that could have improved your child's experience working with a Child Life Specialist?
6. What could have improved you (or your family's) experience with a Child Life Specialist?
7. Did the experience of working with a Child Life Specialist have an impact on your faith?
8. Were Child Life Specialists able to reduce pain without the use of medications?
If yes, how?
9. Were Child Life Specialists able to reduce stress? If yes, how?
10. Did the Child Life Specialist address needs of the sibling? If so, how?
11. How did the sibling react to working with the Child Life Specialist?

Though families mentioned that the questions caused them to think about their experience in new ways, the families typically answered the questions with ease because the researcher prepared them prior to the interview with the goal of the study and requested that they answer the questions with specific stories about their experiences. Question numbers five and six were the most challenging for participants to answer, and most could not think of a way their experiences with the CLSs could have been improved. The final four questions were included in the interviews to check up on claims from literature. Participants' answers to the final four questions confirmed the claims from the literature.

Results

These interview questions helped gather contextually relevant information about the effectiveness of CLSs, as well as the practices they use with families who have experienced hospitalization of a child. This information gathered from the interviews was organized based on the descriptions of the lived experiences of the families who were interviewed. The researcher followed several steps in order to conduct an analysis of this information.

Following a robust review of each interview, open coding emerged from each of the eight interviews. This was followed by axial coding in which three meta-themes emerged under which each open code was categorized. The axial coding was done in two forms, which helped shape the ultimate decision for the axial coding categories. It was first done in a traditional format in which the coding was organized on a Google Sheet. See Appendix for image.

This was followed by another way of selecting the axial codes in which each open code was placed in descending order on a piece of butcher paper and the researcher then reorganized the codes to fit under larger themes. Through doing the axial coding in these two separate ways, it helped to identify the specific meta-themes more specifically, which were CLS Strategies, CLS and Family Interaction, and CLS and Patient Interaction. This was followed by a very lengthy analysis of the data to capture the selective code from the interviews. The selective code was: Benefits families perceive from experiences with CLSs. It appears that the overarching theme across all families interviewed was that families benefitted in multiple ways from their interaction with CLSs.

The diagram below visually captures the relationship between the selective code, meta-themes, and the open codes:

Selective-Code: Benefits families perceive from experiences with CLSs

Meta-themes	Open Codes
CLS Strategies	Consistency, able to reduce pain, flexibility, holistic treatment, modelling for procedures, liaison between hospital and family, stayed positive, provided solutions and knew patient options
CLS and Family Interactions	Gave family breaks, established expectations, asked about family expectations and preferences, included siblings, gave a sense of peace
CLS and Patient Interactions	Made holidays special, individualized distractions, age-specific language, CLS became friends, made patient feel normal, remembered patient's likes, love for patient

Table 1: Selective-code augmented open codes organized by meta theme.

The final step in the coding process was to identify meaning units from the families' interviews which amplified the families' stories of working with CLSs came through the identification of meaning units from each family's story. These meaning units were linked to an open code and axial code. Several of those meaning units which were most poignant to the research are captured in the diagram below.

Meaning Units Diagram

Meta-Themes	Open Codes	Quote 1 from open codes	Quote 2 from open codes
CLS & Patient interactions	Age-Appropriate Language	“Usually children want to know more than parents want to tell them, so the CLS was able to tell [patient], in a not-threatening way, exactly what was going to happen”	“[CLSs] talked with the girls... in age-appropriate language... about what was happening, and help them understand so it wasn’t so scary.”
CLS & Patient interaction	Love for Patient	“I think feeling love from someone, is what we said at [patient’s] funeral, was how we felt God’s love. Our CLS was more helpful and encouraging than our chaplain.”	“It was very obvious how much they loved [patient] and cared about the kids as individuals.”
CLS & Family Interactions	Gave Family Breaks	“If we had to go anywhere...get something... take a shower, they were more than willing to hang out with [patient] to give us 20 minutes.”	“[CLS] would say ‘I’ll stay with [patient] so you can leave’ so we could go outside, take a walk, get some coffee, and have a break, because my husband and I would spend 12 hours at the hospital. I would stay all day and he would stay all night.”

CLS & Family Interaction	Established Expectations	“Knowing what was about to happen, that would reduce pain.”	“Just to have the procedure explained to [patient] so she understood before she woke up with machines hooked up to her.”
CLS Strategies	Modelling with Dolls	“They did a great job talking to [patient and sibling]. They had dolls that had a port like [patient] did, and they would explain to both about what the port did.”	“Anytime there was some kind of a procedure, they would come in and explain the procedure to [patient], on his level, usually utilizing dolls.”
CLS Strategies	Individualized Distractions	Rover Sunshine Kids/ Teen Council Bake lemon pie Made holidays special- Easter egg hunt Service dog Remembered patient likes <i>Casting Crowns</i>	

Table 2: Meaning units organized by meta themes and open codes.

Discussion

Through these interviews, a description emerged about how families perceived personal benefits from working with CLSs in terms of the CLS and patient interaction,

CLS and family interaction, and CLS strategies.

Age-appropriate language. One of the most important benefits of CLSs is the different ways they interact with the patients. When participants were asked directly which CLS practice was most beneficial to their child, most talked about the ways CLSs explained what the patient could expect using personal, age-appropriate language the patient could understand, in a way that was not scary, intimidating, or technical and detached. As mentioned in the first quote, one mother asked that no one provide her sick daughter with too much information because she was nervous that the doctors and nurses would stress her daughter and scare her away from any painful procedure that would ultimately help to heal her. The mother told the researcher that she and her daughter were relieved to hear the information from a CLS who knew the right words to explain what would happen and what they could expect. The CLSs are able to explain the same procedure in different ways, adjusting the terms they use to fit the children to whom they are explaining the procedures. The mother who said the second quote wanted both of her daughters to be educated about what was going to happen with her sick daughter, and expressed her relief that the CLS was able to explain the sickness and the procedures to both of them, in ways a three-year-old and a six-year-old could understand. Because the CLS used age-appropriate language, the family was more at ease and felt prepared to start the procedures that would heal their child.

Love for patient. CLSs work closely with the patients as they strive to provide holistic treatment. One family mentioned that their sick child became close friends with several CLSs who visited him regularly, and the family began to associate CLSs with love and genuine care. The family expressed to the researcher that though it is not the job

of the CLS to impact the families' faith, they found that they experienced God-like love from the CLSs far more than they did from other staff in the hospital. The family still keeps in touch with CLSs and takes any opportunity to talk about the benefits of having a CLS during hospitalization. One family mentioned how they were conscious of their child being known for the illness they had, and one family pointed out how grateful they were that the CLSs in the hospital made it a point to know the patients as individuals, rather than identifying them by their disease. The love, care, and support CLSs provide to the patients allow the parents to feel less anxious and stressed about their child's hospital stay.

Gave family breaks. The majority of the families expressed how they valued the flexibility and perceptiveness of the CLSs when the families needed a break from staying beside their sick child in the hospital. One father mentioned how he appreciated the breaks the CLSs offered the family when they needed to get away from the hospital for a little while. He told the researcher throughout his interview that they were comforted knowing that CLSs had flexible schedules and could show up to keep his sick child entertained, distracted, and in good hands. Another mom recalled how both she and her husband would work, and then they would switch off staying 12 hours at a time with their sick child in the hospital, so one of them was beside her around the clock for months at a time while she received treatments. The mother said that one factor that improved her own outlook on the hospitalization was that the CLSs were looking out for not just the child, but also the family unit, and sought to make the experience easier for everyone in whatever ways they could, so they would offer to spell the parents to give them a break.

Established expectations. To the question about whether or not the CLSs were

able to reduce the patient's pain, one mother answered with a resounding yes that the CLSs were able to reduce pain by establishing expectations for the course of the illness, and every procedure. Knowing the effectiveness of CLSs to reduce pain calms and relieves the stress the parents and family feels about the hospitalization. When talking to the families about procedures the patient will undergo, CLSs will often describe how other children the patient's age reacted to a certain procedure, so the family felt more prepared knowing what to expect and how to help the patient go through the procedures. She appreciated how the patient was not surprised at any step of the process because the CLSs were there to establish expectations. Another mother expressed her anxiety about how her sick daughter would react to a long, tedious procedure that the doctors had explained, prior to an interaction with a CLS. However, after hearing the way the CLS explained the procedure to the patient and what she could expect, the family was assured that she was prepared and could make it through the procedure bravely.

Modelling with dolls. According to the majority of the patients, one of the main, beneficial strategies CLSs employ is to use dolls to show patients what doctors will do and the tools they will use during procedures in order to make them better. During her interview, one mother told the researcher how she was grateful for the way CLS paired age-appropriate language and doll modelling to give her daughters a visual idea about what kinds of things the doctors would do during a procedure. The girls were educated about how one's cells got sick, and what it would take for her to get better, all with a visual that she could relate to. Another father mentioned that though they had a nurse in the family, he was glad that the CLS taught the patient about procedures without using technical medical terms, and in a way which was non-threatening, by using a doll to

model different ways the doctors would be working on him. Because he had a visual of what to expect, the patient was easy-going throughout the time he was at the hospital.

Individualized distractions. The list at the bottom of the diagram represents a few of the unique examples families mentioned the CLSs came up with or made possible because there was a request or they saw a need for them. By listening to and remembering the patients' likes and requests, the CLSs customize the hospitalization experience to each individual. The individualized distractions make each patient's time in the hospital different, and shows the patients and the families that they are cared for as individuals, and the CLSs are on their side, and they will work to make their experience in the hospital as positive as they can.

Limitations and Future Research

Over the course of the research, several limitations arose. All participants who chose to interview were parents, and the perspective of the patients was absent in the data. Another limitation was the small sample size, because participants came from one town in one state, so the data cannot necessarily be generalized to the entire population. However, this study can provide guidance in how future quantitative studies might be developed to create generalizable data.

The next step for further research would be to interview patients directly. This next research project will focus upon the patient's experience, rather than the experience of the entire family or the families' perceptions of the patient's experience. Families obviously have their lives disrupted by hospitalizations related to severe and chronic illness, whereas patients have a different vantage point from which they can tell the story

of having been worked with directly by the CLS. The next study will provide additional data which will contribute to the understanding of the impact of the work of CLSs with families and patients. Eventually, this qualitative data will be used to inform the questions in a quantitative research project.

Implications

With the results of this research and other projects like it, patients and their families, who could be classified as a double-vulnerable population, can receive better, more effective care to fit their needs. Many of the participants mentioned that they jump at the chance to help others who are in a similar situation, and they appreciate getting to tell the stories of their lived experience in a significant way. By talking about families' lived experiences in the hospital with CLSs, the researcher hopes to increase awareness in the field about the importance of understanding the specific benefits families perceive from their experiences with CLSs.

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Appendix A

Open Codes for Participant Responses

Participants	Open Codes	Prevalence in cases	Suggested improvements	Reduced Pain?	Reduced Stress?	Perceived faith?			
Participant 1	Consistency- Trust & Repetition	1,2,4,7	Checking in with parents mo	NA	NA	Love, showed they cared			
	Respectful of family preferences	1,5							
	**Creative distractions	1,2,3,4,7,8							
	Able to reduce pain	1,2,3,4,5,7							
Participant 2	**Love for patient	1,3,4,7,8							
	Remembered likes	2	Distracted	Didn't always wo	No				
Participant 3	**Gave family breaks	1,2,3,5,6,8							
	Made patient feel normal	3	not enough CLSs on weeke	Calmed	Calmed	Loved, genuine care, more encouragement			
	Flexibility	3,6,8							
	Made holidays special	1,3							
	**Established expectations	1,2,3,5,7,8							
Participant 4	CLS were friends	1,3,6							
	Wholistic treatment	3							
	**Modelling for Procedures	1,2,4,6	She couldn't know when her	Yes	YES	Everything they do is an answer to a prayer			
	Teaching Coping skills	4							
Participant 5	Liaison for child and family (go be	5,7	Needed CLS for radiation flc	Yes	yes	Not a factor			
	Asked about family expectation/ p	5							
	Stayed positive	1,5,8							
Participant 6	**Age-specific Language	1,2,5,6							
	**Included siblings	1,3,4,5,6,8	few CLSs during weekends	No	Yes bc education	Didn't have an impact because of strong outside support			
Participant 7	Gave siblings attention	6							
	Listened	7	needed an advocate (earlier	Yes, with distract	Reduced anxiety f	Compassion & care			
Participant 8	Provided solutions & knew patien	7							
	Gave a sense of peace	8	Didn't see different CLSs, w	distractio	Yes	Gave hope, love, their job is a ministry, they're the acting and doing people			
KEY:									
** - Axial codes									
Meta Themes:									
CLS & family interactions 7									
CLS strategies 11									
CLS & patient interactions 6									