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Child Life Specialist Impact on Family Stress Resilience: A Parent's Perspective

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Child Life Specialist Impact on Family Stress Resilience: A Parent's Perspective

An Honors College Project Thesis

Presented to

The Department of Psychology

Abilene Christian University

In Partial Fulfillment

of the Requirements for

Honors Scholar

By

Katie E. Bell

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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

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Dr. Jason Morris, Dean of the Honors College

Date

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Dr. Heidi Morris, Committee Chair

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ABSTRACT

This study aims to fill a void in current research on how parents believe child life specialists aid in stress resiliency, and how they aid the whole familial unit, rather than simply the child. The purpose of this qualitative study is to explore how parents perceive child life specialists impacting family stress resilience as they face medical stressors associated with their children. The phenomenological study is guided by the primary question: What impact do child life specialists have on family stress resilience, as told from the perspective of parents with children experiencing medical events? Through interviews of parents who have experienced child life services, this study will contribute to the limited research on the parents' perspective of the value of child life specialists, specifically related to strengthening family stress resilience; and promote rationale for hospital funding of child life programs through this study's evidence of the value child life specialists have in strengthening family stress resilience. This project is unique in that it records child life experiences from a parental perspective and combines research on benefits of child life and experiences of families. The evidence found in this research can be used by hospitals to advocate for child life funding. By this study seeking to provide additional evidence that child life specialists provide a service that parents value, hospitals can see the value in supporting and funding child life programs.

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INTRODUCTION

A child life specialist is an advocate for children and families in hospital settings. Their role is to utilize support and preparation to encourage developmental growth of hospitalized children. They also educate children and their families in order to bring the familial unit together as partners in the healthcare experience. These programs strive to promote patient- and family-centered care. This is not only used for hospitalized children, but can also be used to help children with ill siblings or parents. The need to better serve families has been addressed by child life, but now the need for research in this field has also occurred. Since the inception of the child life profession over the past 40-50 years, there has been a limited number of research studies focusing on the field. LeBlanc, Naugler, Morrison, Parker, and Chambers (2014) recently conducted a study on parental perceptions of child life specialists and found that 86.7% had no previous knowledge of child life specialists or their roles, but after the parents' experience with a child life specialist, 85-99% were highly satisfied with the interventions received. Based on research, child life specialists provide a great service to hospitalized children, but there is a need to further the work and increase awareness of their services. The work of child life specialists is rather unique and extraordinary. When children are faced with serious medical events, child life specialists can be utilized to help these children and their families better understand the medical event that is occurring, and cope with any challenges that may occur with medical events, such as surgery, hospitalization, and treatments. Some say that while the medical staff seeks to heal the child's physical condition, child life specialists work to heal emotional wounds surrounding medical events.

OBJECTIVE

The purpose of this qualitative study is to explore how parents perceive child life specialists impacting family stress resilience as they face medical stressors associated with their children. The primary question guiding this project is: What impact do child life specialists have on family stress resilience, as told from the perspective of parents with children experiencing medical events? The following ancillary questions also guide the study:

1. What types of stressors do families encounter when a child is experiencing a medical event?
2. How do child life specialists help families cope with stressors associated with a child's medical event?
3. What actions performed by child life specialists are perceived by parents as being beneficial in promoting family stress resilience?

The principal goals of this study are: (1) Contribute to the limited research on the parents' perspective of the value of child life specialists, specifically related to strengthening family stress resilience; and (2) promote rationale for hospital funding of child life programs through this study's evidence of the value child life specialists have in strengthening family stress resilience.

BACKGROUND

The Child Life Profession

In the 1920's a need was seen for a program in hospitals that helped promote emotional stability and healthy development of children. This began a movement to

introduce play, education and preparation programs. This program pioneered family-centered care and advocated for more parental involvement when children are in the hospital. The beginning of these programs was kick started by research in the early twentieth century that correlated young children's experience of the hospital with their familial contact during their hospitalization (Child Life Council, 2014). In the beginning, there was a bit of a learning curve as child life employees worked to adjust to the hospital environment and learn various procedures that caused distress. The hospital personnel also had to be taught the developmental needs of children by the child life employees. In 1965 there was a turning point in the profession when a group of women working in child life met in Boston to discuss the work they had done and the various challenges they faced (Child Life Council, 2014). These women, desiring to create an organization to create child and family friendly hospitals, joined the Association for the Care of Children in Hospitals. Within this association, the Child Life Study Section was created so that child life could develop its professional practices and policies. During the 1970's the child life profession grew as members of the study began to outline educational requirements, the theoretical basis for the profession, the need for such a program and necessary elements of the practice (Child Life Council, 2014). After all the hard work and research put into the profession, in 1982 the Child Life Council was created. After its creation, the council established an exam for certification to become a child life specialist. During a reduction in child life specialists due to a health care crisis in the 1990's, the Child Life Council restructured the profession with a Vision-to-Action plan. Now the profession exists in a wide variety of hospital settings like inpatient, outpatient and emergency room visits. The child life services have

also now extended beyond the hospital to dental offices, courtrooms, hospice programs and many other avenues.

The Work and Function of a Child Life Specialist

According to the Mayo Clinic, a child life specialist steps in as an advocate for hospitalized children and their families. The child life specialist's role is to provide developmental and procedural support by utilizing play, education and preparation. They also serve the purpose of educating children and their families in order to bring all members of the family together as partners in the healthcare experience. These specialists utilize psychological studies and theories in order to assess children and provide personalized coping mechanisms unique to each situation. Child life specialists can use different types of developmentally appropriate interventions to help prepare children for tests, procedures or drastic changes they may face. These programs strive to promote patient- and family-centered care. This is not only used for hospitalized children, but can also be used to help children with ill siblings or parents (Mayo Clinic, 2014).

Familial Stress Resilience Research

In order to contextualize the field of child life and this specific study examining the parental perspective of the impact that child life specialists have on family stress resilience, it is important to connect this study to the larger framework of research surrounding family medical stress and family stress resilience in the wake of medical events. Streisand, Kazak, and Tercyak (2003) conducted a study that examined the association between pediatric parenting stress and family functioning outcomes in parents with children who were engaging in medical treatment for different types of cancer. The results of their study revealed a significant relationship between pediatric parenting stress and family

functioning in children treated for cancer. Such findings provide implications for the field of child life, and according to Streisand et al. (2003):

Future examination of these constructs [pediatric parenting stress and family functioning] in both clinical and research settings, and with populations of parents of children affected by other medical illnesses, will help us to better understand a family's unique psychological concerns. These works will undoubtedly result in focused behavioral interventions to promote stress resilience in families during times of medical crisis.

Based on research such as that conducted by Streisand et al. (2003), there is evidence to support the ongoing investigation of how the work of child life specialists can positively contribute to family resiliency as they face stressors associated with a child's medical event. Medical crises can create stress for a family, making them potentially vulnerable to negative impacts. As Walsh (1998) states, "Stressful life events are more likely to affect functioning adversely when they are unexpected, when a condition is severe or persistent, or when multiple stressors generate cumulative effects". This highlights the necessity for services helping families encountering stressful life events such as having an ill or hospitalized child. Walsh is recognized for research in the area of resilience and holds the position that the family unit and its members are affected by how a family responds to disruptive life events. Walsh's (1998) words expose the need for family-centered care during times of stress, specifically, for the purpose of this project, in the hospital setting.

METHODOLOGY

Research Design

This project is using a research method called phenomenological research which has been influenced by the works of Edmund Husserl and Alfred Schutz. This approach to research is unique in that it focuses on life events as told from the person's perspective (Taylor & Bogdan, 1998). Connected to the Weberian tradition, phenomenological research highly regards the importance of verstehen, "the interpretative understanding of human interaction" and seeks to understand the lives of everyday people in a particular situation and as a result, attempts to analyze the meanings of events and interactions (Bogdan and Biklen, 1992). As the researcher seeks to obtain the subjective meaning of the participant's lives, he/she must restrain from obstructing the investigation with his or her own opinions regarding the phenomena being researched (Merriam, 1998).

In using this phenomenological qualitative research method, the questions asked are used to glean information and insight concerning the parental perspective of parents who have experienced medical events in relation to their child, and the impact they observed the child life specialist has had on their family stress resilience. By obtaining these first-hand accounts from parents' stories, the phenomenological research method allows the researcher to better understand the lived experience of the familial unit and the meaning parents place on their experiences, specifically their experiences with child life services and how these services enabled the familial unit to endure medical events. To obtain this parental perspective, the researchers use qualitative methods to intentionally create a framework within which parents can express themselves in a way that accurately and thoroughly portrays their real life experiences as they see it (Patton, 1990).

Data Collection

Data for this study is collected through the use of interviews conducted through Webex with parents who have a child who has previously experienced, or is currently experiencing a medical event that involved interaction with a child life specialist. This qualitative study seeks to collect first-hand accounts from 10 parental units, so as to provide thick, rich account of responses. Up to this point, first-hand accounts have been obtained from 3 parental units and a total of 8 parental units have been contacted. Prospective parents are identified through a snowball technique where the researchers independently contacted a parent who is believed to meet the study criteria, and then ask that parent for additional referral names of other possible parent participants. Once a parent is identified as a possible participant, he/she is contacted via email to inquire of interest in participating. Once interest is confirmed, the parent was emailed a participation disclosure and consent form. The consent form is attached in Appendix A. When written permission is given, researchers schedule an interview through the Webex platform (Webex is online platform that allows for secure, real-time web interactions). These interviews are guided by an interview protocol of questions and each interview is recorded securely through Webex to allow for storage and retrieval of data. The interview protocol of questions is listed in Appendix B. Data from the interviews is then transcribed and an in-depth analysis of data occurs through the use of a qualitative software package, where thick-rich descriptions will be examined for themes and meaning.

ANALYSIS

Due to the continuing nature of this project, a basic analysis has been conducted to observe themes and important statements within the three completed interviews. One theme that has been present in two of the three interviews conducted is that the familial unit was strengthened by the stressors encountered. All three parental units expressed appreciation of child life services and demonstrated a strong understanding of all services child life provides. Statements proving the efficacy of child life to family stress resilience include, but are not limited to:

- “Coming from [a hospital] where they didn’t have a children’s floor or child life or anything, I thought it was wonderful that they could come and help not only the kids, but even help the parents out.”
- “I think [child life] is a huge value. [My daughter] is old enough now where she kind of understands and knows what is going on; she knows the whole routine. But when you’re talking about a younger kid, like maybe a toddler or elementary school age, the first time they’ve ever been in the hospital, everything is new, everything is scary. I think that they can help bring a little peace to the family while they’re there and give them stuff to do and help them through it.”

Stressors mentioned by parental units in addition to having a hospitalized or ill child include, but are not limited to:

- Financial burdens
- Marital stress
- Moving to a new town
- Separation from other family members

- Unknowns related to child's illness
- Any medical requirements related to child's illness

As parental units described services provided by child life, they demonstrated a rich appreciation for the services and explained the benefits of child life services provided to their family. As previously suggested, familial stress makes the family unit more susceptible to negative impacts. At a base analysis, because two out of three families mentioned strengthening of the family unit throughout the many stressors encountered and noting that both of these families had experiences with child life specialists, it could be inferred that services provided by child life programs contributed to the strengthening of the family unit through providing support and aiding in the development of coping strategies. Although there could be other contributing factors such as coping skills adapted independently within the family unit and/or parental involvement, once a more in-depth analysis is conducted, the evidence could be indicative of the child life specialist impact on family stress resilience.

LIMITATIONS

Valuable information is being collected as a result of this project contributing to knowledge of parental perceptions of child life, specifically relating to the child life specialist's impact on family stress resilience. The snowball technique can introduce a limitation of a homogenous sample due to parents forming relationships with others whose children have a similar diagnosis. While this does not make the information collected any less valuable, it does present the need for a variety of diagnoses to adequately represent the efficacy of child life across the healthcare continuum. As with any research project that

utilizes any form of technology, limitations with the functioning of these technologies can hinder the integrity of the project. On one occasion, the audio features on the WebEx technology were not functioning correctly, so the audio portion of this interview was conducted via telephone and collected using a voice recording device. This does not affect the data collected but it simply deviates from the procedure outlined for this project. Another instance where technology provided limitations was when the internet connection affected the recording abilities of the WebEx technology. This was a face-to-face interview, but in order to record the data, the interviewer utilized a voice recording device. The limitation provided in this situation is the inability to return to the data and analyze body language and facial expressions that often provide insightful information in addition to the words spoken.

IMPLICATIONS

One of the values listed by the Child Life Council is for child life specialists to form therapeutic relationships in order to help children and their families develop resiliency (Child Life Council, 2014). Although this is mentioned in the values, limited research has been conducted that gathers information from the parents. This project is unique in that it records child life experiences from a parental perspective. The parents' perspective of the quality of care has been recorded and the benefits of child life have been recorded, but by combining the two, this study provides additional backing for how important child life services are to families. When seeking to understand the benefits of these services, it is necessary to recognize the parental perspective. Since child life seeks to encourage family centered care, this study provides unique insight by bringing together the parents' experience and their perception of child life specialists' impact on family stress resilience.

The evidence found in this research can be used by hospitals to advocate for child life funding. By this study seeking to provide additional evidence demonstrating that child life specialists provide a service parents value, hospitals can see the value in supporting and funding child life programs.

FUTURE DIRECTION

As this research continues, there will be seven more interviews conducted in order to obtain a varied sample of parental perspectives. The snowball technique will continue to be used to obtain at least two more contacts for interviews as contact has been made with only eight total parental units. Once all of the data has been received from ten interviews of ten distinct parental units, the researchers will conduct an in-depth analysis using a qualitative software package. After this project is completed, it may be beneficial to present this research to child life departments and hospitals who have not yet adopted child life programs. To further the research, it would be advantageous to supplement this project with a more qualitative study in order to have raw data and a larger sample of participants. It may also prove valuable to include data from families who did not have the opportunity to encounter child life in order to provide a control variable that can be compared with other data from familial units who encountered child life services.

APPENDIX A

INFORMED CONSENT for a Research Study entitled:

“Child Life Specialist Impact on Family Stress Resilience: A Parent’s Perspective”

You are invited to participate in a research study to examine child life specialists’ impact on family stress resilience, as described from the parent’s point of view. The study is being conducted by Katie Bell; Heidi Morris, Ph.D.; Dale Bertram, Ph.D.; and Julia Prior from the Abilene Christian University Department of Marriage and Family Studies. You were selected as a possible participant because you are a parent of a child who underwent a medical event and was served by a child life specialist at some point during the medical event. You are also age 19 or older.

What will be involved if you participate? If you decide to participate in this research study, you will be asked to conduct an interview with one or more of the researchers. Your total time commitment will be approximately 1 hour.

Are there any risks or discomforts? The risks associated with participating in this study are minimal. The possible risk that could exist is that in the process of being interviewed about your first-hand experience with a child life specialist in the course of your child’s medical event, the retelling of those experiences could bring out emotion. To minimize these risks, we will send you the interview questions prior to the interview, so that you are knowledgeable about the questions being asked. Finally, if you become personally bothered through the interview process, the interviewer will ask you if you wish to continue or stop participating. Your request will be respected and followed at that point. If the interviewer detects any emotional difficulties in you, he/she will also provide you with counseling referral information. ACU has no plan to compensate you for medical costs associated with participating in this research project.

Are there any benefits to yourself or others? If you participate in this study, you can expect to further the growing research in the field of child life, so as to better inform professionals as how to best serve families. We/I cannot promise you that you will receive any or all of the benefits described.

Will you receive compensation for participating? There will be no compensation for participating in this study. The researchers, however, thank you for your willingness to participate and sharing your experiences for this study.

Are there any costs? If you decide to participate, you will not incur any financial costs.

If you change your mind about participating, you can withdraw at any time during the study. Your participation is completely voluntary. If you choose to withdraw, your data can be withdrawn as long as it is identifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Abilene

Christian University, the Department of Marriage and Family Studies, or any of the named researchers.

Participant's initials _____

Your privacy will be protected. Any information obtained in connection with this study will remain anonymous (or confidential). Information obtained through your participation will be used to fulfill a grant requirement at Abilene Christian University, could be published in a professional journal, and could be presented at a professional conference.

If you have questions about this study, *please ask them now or* contact Heidi Morris at 325-674-6964 or email her at heidi.morris@acu.edu. A copy of this document will be given to you to keep.

If you have questions about your rights as a research participant, you may contact the Abilene Christian University Office of Research and Sponsored Programs by phone 325-674-2885 or e-mail at orsp@acu.edu.

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER OR NOT YOU WISH TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES YOUR WILLINGNESS TO PARTICIPATE.

Participant's signature Date

Investigator obtaining consent Date

Printed Name

Printed Name

Co-Investigator Date

Printed Name

APPENDIX B

1. Describe the medical event causing your child's hospitalization or hospital visit.
2. What was the level of stress you experienced surrounding this medical event?
3. What was the level of stress your child experienced surrounding this medical event?
4. Describe your first encounter with a child life specialist.
 - a. Why was the child life specialist called to work with your child/family?
 - b. How were the services introduced?
 - c. What intervention(s) was/were performed?
5. What was your perception of child life specialists before being introduced to your child's child life specialist?
6. Describe your perception of child life specialists during interactions that your child or you had with your child's child life specialist.
7. Describe your perception of child life specialists as you reflect back on your personal experiences with your child's child life specialist.
8. Describe your impression of the services provided by the child life professional.
9. What, if anything, did the child life specialist do that was helpful to your child?
10. What, if anything, did the child life specialist do that was helpful to you as a parent?
11. How, if at all, did the child life specialist help your child handle stress surrounding your child's medical event?
12. How, if at all, did the child life specialist help you handle stress surrounding your child's medical event?
13. What difference did having a child life specialist have on how your family handled any stress associated with this medical event?
14. If you were to describe to someone what child life specialists do for children and families, what would you say?
15. What, if any, value is there in hospitals providing a child life program?

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