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Sarah Lawrence College

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CHRONICALLY ILL CHILDREN AND CHILD LIFE SPECIALISTS: AN INVESTIGATION
INTO HOW PLAY ACTS AS A FORM OF HEALING

Kortni Baughman

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of the requirements for the degree of
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ABSTRACT

A chronic illness diagnosis is a life altering event that induces stress and can greatly alter the way an individual lives. This is especially true for children as they do not have the cognitive capabilities to comprehend what is happening to and around them. This inability to comprehend is in addition to the emotional and psychological turmoil that a chronic illness causes. Child life specialists are trained professionals who specialize in aiding hospitalized children understand and cope with their conditions. These specialists aid children in preparing for upcoming medical procedures as well as debriefing with them after the procedures have been conducted. Child life specialists use a variety of techniques such as playing, reading books, and art to help hospitalized children cope. One form of therapy that has been proven to help children work through and better understand their emotional distress is child-centered play therapy (CCPT). This form of therapy allows the child to dictate the pace and content of the play that happens during a therapy session and, thus, provides the child with a sense of control over the situation. It is however, unclear from the literature whether the play that child life specialists engage their patients in is child-led. Through interviews, this study aims to find whether child life specialists working with chronically ill children conduct play therapy through a child-led model. Two practitioners were interviewed in this investigation and were asked a series of questions aimed to gain insight into the child life field and the process of formulating and administering treatment to hospitalized children. These interviews were recorded and analyzed for mentions of child-led versus adult directed play. The data was then further analyzed for the type of play that the children enjoyed participating in such as medical / dramatic play, sensory play, art, and literature. The analysis suggested that while child-led play was utilized and often encouraged, adult directed play was also needed due to the specific environment the play was taking place in. Due to the need for the

child life specialist to prepare the child for medical procedures in a timely fashion, the specialist needed to sometimes dictate the content of the play in order to do so. It was determined that some adult directed play was necessary for the hospital setting specifically. This study does suggest, however, that an additional session of child-led play therapy may be beneficial to hospitalized children. This additional session would provide these children with an outlet that is completely under their control and separate from their therapy which targets their medical conditions.

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INTRODUCTION

A chronic illness diagnosis is a life altering event. This diagnosis can be especially stressful for a child and their family. Not only is the child forced into a new way of living but their parents and siblings must also adapt to the affected child's new condition. It is imperative that the chronic illness be understood by the family as well as the child in a developmentally appropriate way. Education on the disease allows the child to be cared for properly and enables them to live in a healthy manner. It is also crucial that the child and the family learn to cope with this illness so as not to be completely overwhelmed by the change. It is critical that chronically ill children and their families receive this care and education so as to provide the best foundation and support for living with and managing their new diagnosis.

A chronic illness is set apart from other illnesses by the nature of their longevity and level of care it requires. The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) (2022) defines chronic diseases as “conditions that last 1 year or more and require ongoing medical attention or limit activities of daily life or both.” Chronic illnesses require constant care and thus become a constant concern and priority in one's life (Blackwell, Elliott, Herbstman, Forrest, & Camargo, 2019). This intense change in one's life can be intimidating and oftentimes frightening for the newly diagnosed child and their family. Thus it is important that a professional be present to aid the child and their family in learning about and coping with the inevitable and important changes that are required upon a chronic illness diagnosis. This is where the help of child life specialists come into play.

A child life specialist is a professional who works with children in a hospital setting and aids those children and their families in coping with their hospital stay and any procedures that occur during that time (Bandstra, Skinner, LeBlanc, Chambers, Hollon, Brennan, & Beaver,

2008; Turner & Fralic, 2009). These professionals offer support for children by helping them to understand what their new diagnosis is and what it will entail in a developmentally appropriate way as well as preparing them for any procedures that need to be done during their hospitalization. In addition to aiding other hospital personnel with educating the children on their newly diagnosed condition, they also help children learn coping skills. These specialists aim to provide children with an outlet for their feelings and emotions that accompany the hospital experience (Bandstra et al., 2008). By giving these children an opportunity to process these emotions, child life specialists are working towards adjusting these children into accepting their new diagnosis and preparing them to adapt to the necessary changes that their illness will require (Drayton, Waddups, & Walker, 2019). Child life specialists are trained in techniques that are age appropriate, which for young children, often includes playing out their experiences.

Playing is an important part of a child's life. While to an adult a child's play may seem trivial, play actually serves as a way for a child to express themselves and learn about where they find themselves in the world. Yogman et al. (2018) defines play as "... an activity that is intrinsically motivated, entails active engagement, and results in joyful discovery" (p. 2). Play serves as a natural avenue for children to find what they do and don't like as well as express their interests and make discoveries about themselves and their world in a way that matters and makes sense to them (Barnett, 1990). In an environment such as a hospital, where a child may be frustrated, confused, or scared, it is crucial that the hospital staff care for these children in a way that they are familiar and comfortable with. This is where child-centered play therapy (CCPT) may serve as a useful form of therapy for these children. CCPT is a form of therapy in which the child uses the medium of play in order to process and work through any obstacles or emotions they may be facing (Landreth, 2001). The goal of CCPT is for the child to naturally bring up

what is bothering or upsetting them when they are ready to divulge this information and enact it in some way through play. Using this method of therapy as a form of treatment for children in hospitals, especially those being diagnosed with a chronic illness, can aid the children in working through their emotions revolving around their new health condition and the procedures or medical care that they are required to go through (Jessee, Wilson, & Morgan., 2000). Through this method children are allowed to take control of how they choose to share what they are feeling and thus regain a sense of control in an potentially otherwise overwhelming environment.

Personal Interest and Goal of the Project

My personal interest in the care of children with chronic illnesses stems from my own experiences of being diagnosed with type 1 diabetes at the age of four. I did not have access to a child life specialist at the time of my diagnosis or any sort of similar intervention offered to me. I was educated only by the doctors and nurses and was not given the opportunity to work with someone dedicated to aiding me in coping with my emotions surrounding my newly diagnosed illness. As a four year old child needing to adapt to multiple insulin injections and finger pricks a day, it was a rough transition and my mother was challenged with helping me adapt to my altered way of life without any support. Having been thrust into my current lifestyle without the aid of a professional such as a child life specialist showed me firsthand how important it is to have people like these child life professionals in hospitals who can simultaneously comfort and prepare children for living with their newly diagnosed conditions.

This thesis project aims to find if and to what extent child-centered play therapy is utilized in the child life practice when interacting with chronically ill children. While various forms of play have been shown to be utilized by child life specialists the literature does not

express to what extent the play is truly child-led. A child life specialist may recognize the therapeutic benefits of play for children. However, having the specific goal of helping children cope and adapt to their chronic illness diagnosis appears to lead the child life specialist to direct the child's play toward medical play or play that incorporates coping / emotion-regulation practices. Through this project I am aiming to find how and if child life specialists follow the cues of their patients when engaging them in play. For this investigation two interviews were conducted, one with a child life specialist and a second interview with a pediatric palliative care social worker, in order to gain insight about how play might be utilized as a form of treatment for children hospitalized due to a chronic illness diagnosis. The goal of this project is to see to what extent a truly child-led play model is present in the hospital environment.

CHAPTER ONE: LITERATURE REVIEW

Chronic Illnesses and Their Effects

Chronic illnesses are prevalent among young children in the United States. The National Center for Health and Statistics found that about 1 in 5 children have a chronic illness that affects their daily life (as cited in Blackwell et al., 2019). Due to the nature of these illnesses needing constant medical attention and their effects on how one functions in daily life, chronic illnesses are life altering conditions.

These long lasting conditions serve as a source of stress for the diagnosed individuals as well as their families and loved ones (Morris, T., Moore, & Morris, F. A., 2011; Compas, Jaser, Dunn, & Rodriguez, 2012; Cousino and Hazen, 2012). This can be especially true for children and their caretakers. In many cases a constant sense of worry about their health can lead to an individual developing anxiety around their health. These conditions can also be incredibly frustrating and lead to a sense of hopelessness and depression in the affected individual (Pao, and Bosk, 2011; Lacomba-Trejo, Valero-Moreno, Montoya-Castilla, & Pérez-Marín, 2020). Learning to care for and cope with a chronic illness can be a daunting and overwhelming experience.

This transition can be especially hard for children who may not be at the developmental level to understand what is happening to them and how to process the emotions surrounding their health condition. LeBlanc, Goldsmith, & Patel (2003) state:

“The patient experiences lifestyle changes that include loss of social and physical activities, incorporation of complex medical procedures, and periodic, and often unpredictable, crisis events. These changes occur at a time when children and

adolescents are still attempting to master emotion regulation, develop identity and independent social relationships, and adjust to physical and hormonal changes” (p. 860-861)

In addition to the normal challenges of growing up, chronically ill children also need to contend with adapting to a new lifestyle which may be stressful, scary, even ostracizing.

The child may also feel frightened by the hospital environment. Salmela, Aronen, & Salanterä (2010) report that children’s fears regarding the hospital were centered around medical procedures and experiencing pain, being separated from their parents or being left alone, not understanding what is happening to them, and the medical equipment. Salmela et al. also found that these fears were associated with specific emotions such as sadness, anger, helplessness, and shame. Due to the nature of some chronic illnesses requiring long hospitalization periods, these children may be subjected to these fears and emotions for longer durations of time. Therefore, it is crucial that healthcare professionals find ways to help these children adjust and cope while in the hospital.

Play and Child-Centered Play Therapy

Playing is what children do. Landreth (2001) states, “Play is the singular central activity of childhood, occurring at all times and in all places...Children do not need to be taught how to play, nor must they be made to play.” (p. 3) Play has been shown to be a beneficial experience for children as it is how they learn to interact with the world and make meaning of their experiences. Barnett (1990) states, “One of the critical benefits of a child's play has long been thought to be its contribution to the child's thinking ability. Children have been shown to acquire knowledge most easily through play across a variety of contexts” (p. 139). Children learn to

navigate the world through play. Play can be used to help children navigate the major life shift that is a chronic illness diagnosis through a developmentally appropriate method that comes naturally to children.

Play therapy is an intervention method that aids the child in processing emotions through a channel that they can easily understand and engage with. In this approach, play is used as the child's primary form of communication and this sense of familiarity provides the child with the freedom to express themselves (Landreth, 2001, p. 3). By adapting play to be a therapeutic method, children will be naturally engaged. Play therapy allows the child to work through problems that they may not have been able to initially express in a way that does not require them to adapt to unfamiliar methods.

Child-centered play therapy (CCPT) is a form of play therapy that is led by the child. While a therapist is present to offer support and reassurance, the child takes the lead in deciding what play activities they engage in during the session and what information they disclose as they play. The methods of CCPT are based heavily on the eight basic principles presented by Virginia Axline (1974) which are as follows:

1. The therapist must establish a warm, friendly relationship with the child, in which good rapport is established as soon as possible.
2. The therapist accepts the child exactly as he is.
3. The therapist establishes a feeling of permissiveness in the relationship so that the child feels free to express his feelings completely.
4. The therapist is alert to recognize the feelings the child is expressing and reflects those feelings back to him in such a manner that he gains insight into his behavior.

5. The therapist maintains a deep respect for the child's ability to solve his own problems if given the opportunity to do so. The responsibility to make choices and to institute change is the child's.
6. The therapist does not attempt to direct the child's actions or conversation in any manner. The child leads the way; the therapist follows.
7. The therapist does not attempt to hurry the therapy along. It is a gradual process and is recognized as such by the therapist.
8. The therapist establishes only those limitations that are necessary to anchor the therapy to the world of reality and to make the child aware of his responsibility in the relationship.

Virginia Axline set these guidelines so as to educate play therapists on how to best allow children to bring what they wish to the therapy sessions. These principles of child-centered play therapy allow the child to be in complete control and not be pushed to do or share anything that they are unwilling to. According to Axline, the hallmark of this type of therapy is meeting and accepting the child where they are and allowing them the control to dictate the pace and content to the therapy sessions.

This method of play therapy is especially useful in traumatic experiences, such as a chronic illness diagnosis and hospitalization, because a child who has experienced some form of trauma may feel out of control and afraid in their circumstances (Ray, Bratton, Rhine, & Jones 2001). Play therapy serves as a remedy for this feeling of disconnect. CCPT, by nature, puts the child in control of what transpires in their therapy sessions and thus allows them a reprieve from the uncertainty that comes with experiencing a traumatic event. In the case of a hospitalized child it may provide them with an opportunity to gain some control of their hospital experience.

Medical Play

Medical play is a subcategory of dramatic play. In medical play children are encouraged to pretend to be a part of a medical setting such as being the doctor, nurse, or patient. Oftentimes dolls may also be used in these play scenarios as those who need to be “treated” so that the child can pretend to be the doctor or nurse in the scenario. Jesse et al. (2012) explain that medical play provides children an opportunity to gain an understanding of what is happening to them as well as to become familiar with medical equipment and procedures. This type of play allows children to play out their experiences while working out their emotions revolving around their medical procedures. They are able to “perform” these medical procedures themselves which allows them to process the necessity of the situation while simultaneously expressing their emotions about having to experience it themselves.

Medical play is also a very useful tool to prepare children for upcoming medical procedures. Medical professionals are able to use toy medical supplies and dolls to show the child what is going to happen during the medical procedure they are about to undergo. This provides the child with the information that they need in order to feel informed about what is going to happen to their body. With this information the child will not be kept in the dark and they won't have such intense feelings of uncertainty upon beginning their medical procedures (Bolig, Yolton, & Nissen 1991). Medical play provides children with reassurance about what is happening and assures them that they will be safe and cared for during their treatment. They understand that, although it may be scary, the treatment they are receiving is to help them and to keep them healthy.

Child Life Specialists. Are they Child-Led?

Play has been established as a beneficial approach to helping chronically ill children cope with their hospitalization. But who is providing this type of therapy? Child life professionals are certified to provide treatment for children in hospital settings. They help children understand what is happening with their body during their stay in the hospital and aid them in coping with whatever their health concerns may be (Bandstra et al., 2008). Child life professionals are trained to provide developmentally appropriate methods of treatment that help children understand and cope with their diagnosis as well as prepare them to undergo medical procedures during their hospital stay.

Another key component that child life specialists incorporate into their treatment plans for their patients is ensuring that they have a way to express themselves and their emotions. Being hospitalized comes with many complicated and overwhelming emotions. Young children are at a place developmentally where they are trying to make sense of their experience in the world (Barnett, 1990). When they are then placed into a circumstance that is unfamiliar and possibly frightening they need to learn to readjust their perceptions and make new understandings for themselves. This can all be a challenging process, especially as they may not feel well and can't fully comprehend what is happening to them. A child life specialist helps children with these transitions and emotions (Drayton et al., 2019). These professionals are tasked with providing children support and opportunities to express these strong and confusing emotions through activities that are approachable for a child.

Purpose of this Project

There is plenty of literature that elaborates on the nature of chronic illnesses and how they affect children and their families. These illnesses are an all-encompassing diagnosis and take over the lives of these children as well as their parents, caretakers, siblings, and other loved ones. Chronic illnesses require constant treatment which can serve as a major learning curve and a source of immense stress. Child life specialists are trained to educate these children on what is happening to them and why they are hospitalized. They provide these children with opportunities to express their emotions and fears as well as teaching them coping mechanisms that will help these children work through their feelings throughout their medical procedures.

One way that child life specialists treat children is through therapeutic play scenarios. These play scenarios serve as an opportunity for children to play through their experiences in the hospital and how they feel about their time there. However, what is unclear from the literature surrounding this topic is whether or not these play experiences are child-led. This project aims to gain information directly from child life specialists and people who work directly with children in a hospital setting about how they conduct their therapy and how they decide on their treatment plans. Through interviews with two professionals, this study hopes to find how prevalent CCPT is in the treatment of chronically ill children and how much agency these children have over the play scenarios that they partake in.

CHAPTER TWO: METHOD

Participants

The participants involved in this study were two individuals who worked as child life specialists. The focus was to conduct interviews with these professionals to gain insight into what is involved in the child life profession and what their work entails. In order to be able to gain knowledge about what methods these professionals use when treating chronically ill children it was determined that interviewing child life specialists directly was the best way to obtain the information desired.

It should be noted, however, that one participant (Participant B) does not work as a certified child life professional. Participant B works as a Pediatric Palliative Care Social Worker. Although Participant B does not fit the criteria originally set to be interviewed for this project they were deemed acceptable to participate as they work directly with and provide care for children who are chronically ill. Due to their position that requires them to have direct interactions with children in a hospital setting they were allowed to participate as it was determined that they could provide insight into the hospital experience of a child who is dealing with a chronic illness diagnosis.

Recruitment

All participants involved in this study were put in contact with the researcher through connection to Sarah Lawrence College. Thesis advisors aided in helping find participants that fit the criteria of the project and, upon confirming interest in participating in the study, were introduced to the researcher via email. The researcher then followed up by sending a recruitment

email that explained the intent of the study being conducted and informed the participants that they would be asked to be interviewed about their experience serving as a child life professional. Upon confirmation that they were willing to be interviewed a date and time were established for the interview to be conducted via zoom.

Procedures

Both participants that had agreed to be interviewed were sent the informed consent form via email ahead of the interview and were asked to read it over and sign the form where indicated. The researcher informed the participants that any questions they might have about the informed consent form or the interview process could be answered through email or over Zoom before the start of the interview. Both participants signed the informed consent form and returned it via email to the researcher.

The data found for this study was collected via interview. This interview was conducted in a semi-structured style. This interview style includes the use of questions that guide the interview but allows the interviewer some flexibility in how they are asked and in which order. This also allows the interviewee to answer with more freedom in sharing information (Merriam, 2009). Their answers can be elaborated on and they can share information that relates to the question without being held to strict exact questions. This method was used in order to provide a more free-flowing interview process and allow the opportunity for information that would not be included by a highly structured interview style to be shared and taken note of.

Interview Questions

The questions asked all pertained to the child life profession. The questions were designed to elicit responses that allowed the participants to elaborate on their work as child life specialists and what their work involved. The goal of the questions was to see if the participants mentioned play as a treatment method that they used with the chronically ill children that they worked with. The questions asked during the interview are listed below:

1. How did you get into the child life field?
2. What does a typical work day look like for you?
3. How would you describe the child life profession?
4. What type of children do you work with?
5. Can you share a child's story or case that really stands out to you?
 - a. Can you tell me what the treatment looked like or what you did?
6. Are there specific types of play that are utilized during the treatment process?
7. If time and funding wasn't a problem what type of services would you like to provide as treatment options?
8. How do you establish a treatment plan?
9. Do / what extent do the child life professionals in your hospital use dramatic play?
Sensory play? Or any other types?
10. Can you reflect on a case where play really worked?

The beginning questions aimed to set up the interview by asking the participant to reflect on themselves as a child life specialist and their career (questions 1-3). These questions were asked in order to get insight into how a child life professional views their work and how they would

describe it. These initial questions are followed by a series of questions that allow the participants to share specific cases and experiences that they have had while working with chronically ill children (questions 4-8). These questions allow the participant to provide specific examples of the children that they work with and the types of treatments / methods that they use with their patients. These questions are asked to get insight into what one might observe if they were to shadow a child life specialist as they work. There is also a special interest in what these specialists wish they had better access to. Finally the interview ends with asking the participants more targeted questions about the use of play in their treatment plans (questions 9-10). These questions were included to draw out any instance that may have happened that included play as a part of a child's treatment plan. Dramatic and sensory play were mentioned in question 9 as examples of types of play. However, when asked the question this was asked to elaborate on any other types of play that may have been used as well.

It is important to note that the questions do not directly ask the participants if the play is child-led or if it is directed play. This is due to an attempt to steer away from biased or suggestive questions. The use of more open ended questions were used to have the participants explain how they decide on treatment options. Through these questions the participant has an opportunity to highlight what types of play, if any, are used and who initiates the play scenario. This form of questioning allows the participant to naturally answer the questions without being prompted to include the child being involved in the process to appease the researcher.

Conducting the Interview

Both interviews involved in this project were conducted on Zoom. Once a time and date were scheduled, the interviewer was responsible for creating and sending the participants a Zoom

link. This was done in order to ensure that the researcher would be able to allow access to the Zoom meeting to the participant so as to maintain confidentiality. The Zoom meeting had a waiting room so the researcher had the ability to see who was requesting access to the zoom meeting. The Zoom meeting was also password protected so that only the participants who were sent the invitation, which included the needed password, could gain access to the zoom meeting.

Participants were asked verbally at the beginning of the meeting if they gave their consent for their interview to be recorded. In addition to being asked verbally before the interview began, they were also asked to provide their consent to being recorded by signing their agreement on the Informed Consent Form. Once they provided their verbal consent the researcher began to record the zoom interview. These recordings were then transcribed into a written format.

Analysis

The interviews were analyzed by taking note of any instance where the participants mentioned play as a form of treatment used in their practice. The goal of the interviews were to see if the participants used play to help children understand what was happening with their bodies as well as to aid them in expressing their emotions regarding their hospital experience. Thus, any mention of play during the interviews was flagged and added to the set of data collected that pointed toward the confirmation of play as a treatment method used in the child life profession.

Any mention of child-led play was also flagged. Therefore, the data that was collected that showed the use of play as a form of treatment was further categorized as either directed or child-led. These two sub-categories served as another point of comparison. Since child-centered

play therapy focuses on the child as the one to initiate play and bring in certain themes of their own volition it was important to separate the data collected in this way so as to showcase the frequency of child-led versus adult guided play. In this study, child-led play is defined by the child initiating the play and being in charge. In contrast, directed play is defined by the child life specialist being the one to introduce the play scenario and to dictate what is done during the play session (Kottman (1997). This differentiation was made when analyzing data because this study aims to find the nature of the play conducted in hospital settings when interacting with child life specialists.

The absence of play was also taken into account. When discussing the treatment plans that the participants described in their interviews, special note was also taken when play was not used as a treatment option. As mentioned previously, the questions were created so as to not prompt particular answers from the participants. Therefore, it was important to note if play was not mentioned as being a part of the child's treatment. Creating a category of "no play" provided an opportunity to point out a gap in the treatment methods that could be utilized when working with chronically ill children. This category was crucial in providing a full picture of the methods that child life professionals use when helping children cope and adapt and whether the child's natural inclination to play was being tapped into as a potential therapeutic method.

Once the data were categorized into the previously mentioned groups they were also categorized by the type of play. The four categories were (1) medical play / dramatic play, (2) sensory play, (3) art, and (4) literature. These categories were used to further analyze specifically what types of play are common in the hospital. The four categories highlighted what types of play child life specialists find particularly helpful as well as what children in the hospital gravitate towards.

CHAPTER THREE: RESULTS

Participant A

Participant A is a child life specialist who works in a Pediatric Cardiac Intensive Care Unit (ICU). She began her career as a nursing student and found that she wanted to have more time to spend with her patients. This led to her discovering the child life profession through volunteer work she had done in hospital settings. Thus, she decided to pursue becoming a child life specialist.

Mentions of Play in Interview

Upon analysis of participant A's interview, there were seven play scenarios mentioned. In the data collected from participant A, both directed and child-led play are present (Table A). Additionally, three out of the four sub-categories were mentioned during the interview which were medical play, sensory play, and literature (Table B).

Child-Led Play Scenarios

There were mentions of child-led play in participant A's interview. All of these scenarios are characterized by the child being in charge of what is done during the play session as well as by the child not being prompted to play about specific circumstances or emotions. The scenarios described are as follows:

Tapping into the Parents to Know what the Child Likes

In this scenario Participant A describes speaking with the parents of the child upon hospitalization. This is done to get an idea of what the child is like and what interests them when they are in a normal environment (not the hospital). Knowing what the child likes when they are in a comfortable environment allows Participant A to bring similar toys, when permissible, into the hospital when working with the child. This provides the child with a sense of familiarity when in an unfamiliar and stressful environment. Important to note in this scenario is that although Participant A is not actually playing with the child they are still taking their cues from the child. The parents are providing valuable information as to what the child would choose for themselves and thus Participant A is allowing the play to be led by the child by bringing materials that they would normally enjoy. This is a starting point that allows Participant A to break the ice with their new patient.

The Case of “J”

During the interview, Participant A shared the story of J, a child she had worked with in their Pediatric Cardiac ICU. J was a 10 year old boy with autism who was hospitalized due to a virus that had traveled to his heart. Through this account of working with J, Participant A provided four examples of play being used as a treatment method.

Sensory Play with J

Participant A described a scenario with J that showcased an example of child-led sensory play. While working with J, Participant A found that J enjoyed specific tactile stimulation and certain sensations would calm him down during his medical procedures. Participant A stated:

“I really needed to step back and understand his needs as an autistic child, you know, in terms of his sensory needs...and figuring out what would keep him calm. You know those sensory beads? I finally figured out that for whatever reason he loves those. So, during all his procedures I would have these buckets around. He’d have his hands in them and his feet in them trying to keep him calm.”

Participant A describes a scenario in which the child made his needs known. Participant A adapted a sensory play activity to aid in maintaining a level of calm during his needed medical treatment. Participant A provided the material that J had indicated liking and thus allowed him to lead the form of treatment that he received during his hospital experiences.

Medical Play

Instances of child-led medical play were also presented by Participant A. She recounted that a popular choice amongst the children in her ICU unit was playing out the medical procedures they were going to have or had already gone through. Participant A stated:

“We just went to town with whatever baby or doll and say ‘Oh my baby isn’t feeling well. Can you help me?’ and ‘What do you think she needs?’ and sort of like let them lead the play....sort of let them play it out. We would do this alot before procedures and after procedures as well because kids needed to process. Sometimes I would need to leave and come back. They didn’t want anything to do with it at that point.”

Participant A describes here that although the medical play was prompted due to an upcoming or previously done procedure the child was in charge of what the play looked like and how they “treated” the doll. Participant A stressed that allowing the child to play at the rate they wish to is crucial. She mentions in the above paragraph that if the child was not ready to play she would

leave them and come back at a later time. If the child was not ready to engage in play they were not pushed to do so.

Directed Play Scenarios

Throughout the interview, Participant A provided five scenarios of directed play scenarios. These scenarios were categorized by the nature of the play being introduced by the child life specialist and dictating what transpired in the scenario.

Encouraging J Through the Song

Participant A described how she would start each morning by singing a good morning song with J. This was a song that she introduced to J and began to sing it every morning as a part of his routine. J would not sing this song along with Participant A but was comforted by the routine of the song being sung.

This song is classified as directed as the child does not spontaneously engage in this song on their own. It was introduced by Participant A in an attempt to find a routine that worked for J but was not initiated by him. J did not participate in the song and seemed to enjoy the song as it offered a sense of stability and consistency in his day. However, due to the song being a technique that Participant A used to start J's day it is a directed activity and not child-led.

Medical Play with J

Participant A shared that J really loved bringing Elmo dolls into the hospital with him. He would constantly have Elmo dolls around him and had one doll in particular that he would take with him everywhere. Participant A would use this favorite toy of J during instructive

medical play where she would explain to J what medical procedures he would be having done that day.

One such instance was when J needed to have an ultrasound on his heart. J was not a fan of the jelly substance that medical personnel are required to use when conducting ultrasounds and so it was important for J to be aware of the components of the procedure before going into it. Participant A would use J's favorite Elmo doll as the "patient" in need of an ultrasound. Participant A would show J how the ultrasound would be done on him by doing the procedures on the Elmo doll. They would squeeze the Jelly onto the Elmo doll and then Participant A would run the ultrasound wand over the Elmo doll's chest to replicate what would happen during J's procedure.

This experience is a directed play scenario as Participant A was in charge of the play the entire time. They brought in the pretend ultrasound machine and the ultrasound jelly and walked J through the procedure step by step. Though it was conducted on the toy that J chose, the actual play experience was directed and progressed by the adult in the scenario.

Literature With J

Participant A also used picture books with J to explain his medical procedures. This was a technique present in every instance when J would have an ultrasound. Participant A explained that ultrasounds were a major stressor for J. Thus every time he was scheduled to have one she brought in an ultrasound book that showed pictures of ultrasound machines and what would happen throughout the procedure. This book allowed Participant A to give J information about what was going to happen to him that day and prepared him to deal with the components of the ultrasound that J did not like.

Again, we see an example of an adult directed activity. Although the book may have brought J comfort, it was not initiated by J. He did not ask Participant A to read the book and he did not get the choice of how he was informed about the procedure. Participant A found that this book calmed J and so it was included in his care when an ultrasound was necessary. However, it is not considered child-led because it was a technique determined to be used by the child life specialist.

Participant B

Participant B worked in a children's hospital as a Palliative Care Social Worker for five years. She would work directly with children and their families and participated in determining the best course of treatment for these patients. She helped determine which interventions were needed for the child such as physiological care but also any psychological treatment that may be needed.

*As previously noted, Participant B is not a child life specialist, however, she was deemed fit to participate in this study as she works directly with chronically ill children in a hospital setting and oversaw the intervention treatments that these children received.

Mentions of Play

Throughout the interview, Participant B mentioned seven instances of play as treatment. These instances consisted of both directed and child-led play scenarios (Table A). Additionally, three of the four subcategories of play were mentioned by Participant B (Table B).

Child-Led Play Scenarios

There were four instances of child-led play scenarios mentioned by Participant B. These scenarios are characterized by the children involved being able to choose their play activity and dictate what transpires in these scenarios.

Art Used for Coping

Participant B described a popular form of play present among the children she worked with in her palliative care group was art. The most common form of art expression was drawing and writing. Participant B explained that art expression allowed the children to express themselves and provided a way for their voices to be heard. Participant B recounts:

“I really enjoyed working with young adults. For many of our young adults my work would be meeting with them individually to talk about both their experience of life of living with their serious illness and also who they are as a person outside of their serious illness. I think that's what palliative care does really well. The first thing we ask when we meet someone is tell me who you are as a person. ‘Outside of these walls, what makes a good day? What makes a not good day? What do you do you enjoy? What are your hobbies? What are your passions? What are your hopes for the future?’ I have worked with young adults connected to things like art, or dance, or writing expression. I figure out a way for their voice to be heard....”

Participant B describes a scenario in which the patients she works with are allowed to choose the medium through which they express themselves. This type of art expression is a type of play for older children. They are allowed to create or do anything they want and the outcome is meant for them, and them alone to resonate with.

Participant B also provided an example of art being utilized by younger children. She explains that in her work, Participant B works closely with siblings as well as the chronically ill child themselves. She would run bereavement groups for the siblings of the children in palliative care and provide an opportunity for them to express their emotions revolving around their siblings' diagnosis. In these groups there would be a designated time for the children to participate in play activities of their choice. Participant B explains that often, young children would gravitate towards drawing as a way to express their feelings and put their experiences into their art. This activity was for them to choose and the children would not be prompted to participate in or encouraged toward any one activity. This was child-led as the children were given the freedom to choose and were not prompted by the social workers to disclose any information they were unwilling to share.

Pretend Play as Coping

Pretend play was also present in the previously mentioned bereavement group settings. Children were provided the opportunity to play with dolls during these sessions as well. Participant B explains that many young children would use the dolls to play out things they had seen and experienced throughout their siblings' life with a chronic illness. This child-led play scenario allowed the children to play out their experiences and emotions in a setting that revolves around them. These children were given the choice to use these dolls however they saw fit and expressed hard and scary emotions at their own pace while in a controlled and monitored environment.

Literature with Children

Participant B explained that books would be used with children if it resonated with them.

Participant B states:

“We’ll bring a book, or two, or three, depending on that family and who they are and where they are in their treatment. Either I’ll read the book at bedside or help the parent in reading the book. Or the parent might look at it and I’ll come back another day and read it together. They might read it to their kiddo, if it is a kid for whom books really resonate.”

Books can be a very useful tool in communicating with children if it is a child that finds books fun and engaging. In this instance reading these books is a child-led activity as the parents and Participant B are taking their cues from the child. Participant B explains that her job was to help the family unit function and communicate when she or other medical professionals aren’t around. In order to do this they need to find an activity of the child’s choosing or that interests them and provide the support or materials to open that line of communication and connection between parent and child. This is an example of a child-led activity as it is up to the child to determine which techniques are used in their treatment.

Directed Play Therapy

In Participant B’s interview there were 2 mentions of directed play scenarios. These scenarios are defined as being directed due to an adult introducing the play and directing the play toward a specific goal.

Encouraging Dramatic Play

Participant B explained that during the previously mentioned bereavement groups hosted for siblings, there would sometimes be play stations set up for the younger children to participate in. While sometimes the child could choose what activities they participated in and what transpired during this play time, other times the playstations were set up with a particular goal in mind. She explains that when these stations are used, they aim to help the children cope with grief and provide them with tools to handle the loss of a sibling. This is an example of directed play therapy as it uses play to help these children cope, but the adult is in charge of what end the play is supposed to meet. They are guiding the children in a direction that serves a predetermined purpose.

Use of Bibliotherapy

Participant B also further explains the potential use of books in helping children understand grief. In the bereavement groups Participant B would help run, she mentioned that they would use books to explain the loss of a sibling to younger children. Participant B states:

“There is a book that we particularly love called ‘The Invisible String’ and it's about connectivity with people, whether they are physically with you or not.... The book will be read aloud. There will be a developmentally appropriate discussion based on that book and then, depending on your developmental age, you would go off and do an activity.” *Activity previously mentioned above.

This approach to a structured sit down story time followed by a discussion and activity is classified as a directed play therapy. The social workers running the group have predetermined what book they are going to read and the activities that are to follow. The discussion is led by

the adult. While the children contribute what they want to say to the conversation, the adult is still in charge of steering the discussion toward the goal that was already set before the story was read.

Table A: Child-Led vs. Directed Play in Treatment for Chronically Ill Children

Type of Play	Interview A	Interview B
Child-Led Play	<p>Talking with the parents to see what the child likes and which toys / activities they enjoy.</p> <p>Taking their cues from what the child normally likes outside the hospital</p>	<p>Art used as a medium for self expression.</p> <p>The young adults and children (patients and siblings) were able to choose art and writing as a means of expressing their emotions and frustrations.</p>
	<p>Use of water beads to keep J calm during his medical procedures.</p> <p>Participant A found that these water beads kept him calm and thus utilized them in J's treatment.</p>	<p>Use of dolls to reenact life experiences.</p> <p>Young siblings of chronically ill children chose to use dolls to act out their experience of having an ill sibling as a means of coping.</p>
	<p>Use of medical play to prepare for or reflect on medical procedures.</p> <p>The child was never forced to play and they controlled the pace of the play.</p>	<p>The use of books to help chronically ill children and their families communicate.</p> <p>If the child showed interest in literature the child life specialist would bring in a book related to the situation and read it to the patient or help the parent do so.</p>
Directed Play	<p>Singing of a "Good Morning" song by Participant A.</p> <p>The song was introduced by the therapist and was not brought into the treatment by the child.</p>	<p>Dramatic play used in bereavement groups for siblings of chronically ill children.</p> <p>Play stations were presented to the child to participate in but a predetermined goal was set by the social worker.</p>
	<p>Use of instructive medical play to prepare J for upcoming medical procedures.</p> <p>J participated and chose the doll used in the play but the pace and content was set by the child life specialist.</p>	<p>Use of literature and post-reading discussion to aid siblings in coping.</p> <p>The goal of the bereavement session was predetermined by the social worker. The discussion is led by the social worker and thus the children are prompted to think about / express certain emotions.</p>
	<p>Use of picture books to prepare J for ultrasounds.</p> <p>The child life specialist brought in the book to explain the procedure but J had not requested it.</p>	

Table B: Play Categories Present in Treatment of Chronically Ill Children

Play Category	Interview A	Interview B
Medical / Dramatic Play	Use of dolls as “patients” when playing out medical procedures these children will / had endured.	Young siblings using dolls to reenact their lived experiences revolving around their chronically ill sibling.
	Child life specialist prompting specific medical play in preparation of medical procedures.	Dramatic play presented as an option for siblings during bereavement groups with an intended goal of helping the child understand grief.
Sensory Play	Use of water beads to keep J calm during medical procedures.	None mentioned
Art	Singing of the “Good Morning” song to J.	Use of drawing and writing as a means for self expression by both patients and siblings.
Literature	Use of a picture book to explain ultrasounds to J.	Books being used with a child interested in literature as an avenue of communication.
		Bereavement groups utilizing books to encourage a discussion led by the social worker about loss.

CHAPTER FOUR: DISCUSSION

This study showcases the importance of children being provided with developmentally appropriate interventions during times of extreme stress and traumatic circumstances. The research done for this project suggests that play can serve an appropriate approach for children hospitalized due to a chronic illness diagnosis. A chronic illness diagnosis can serve as a source of stress and uncertainty for the diagnosed child and as well as their families and loved ones. However, this stress can be managed for the child through intervention approaches. This study data suggested child-centered play therapy can be particularly beneficial for children diagnosed with chronic illnesses.

The interviews conducted showed that when a child is presented with an opportunity to play they will take advantage of the situation and use it to manage their experiences and feelings surrounding things happening in their life. Play can serve as a valuable resource for these hospitalized children to play through their experiences with overwhelming feelings and frightening medical procedures. Play in this case, served as a way to calm down and be comforted by familiar toys and activities.

The above interviews also suggested the importance of play as a teaching tool. Child life specialists can use a child's favorite activity and play style to teach their patients about what is happening with their body and what the doctors and nurses that are around them are doing and why these procedures are necessary. Giving the child an opportunity to see what is going to happen to them in a developmentally appropriate manner with toys and materials that are non-intimidating and familiar to them provides them with a sense of understanding without scaring or confusing them. Children need to feel as though they have a sense of control and

bodily autonomy. Allowing them to see and play out what has and will happen to them while in the hospital gives them the opportunity to work through the feelings of lost control and no control over what happens to them physically during needed medical procedures.

Directed vs. Child-Led Approaches in the Hospital

Through the data collected in the interviews conducted it was suggested that a typical play therapy scenario needed to be adapted by child life professionals in order to help their patients cope with the stress and fear associated with longer hospitalization periods. The examples provided show that child-led play was used when possible. Each participant stressed the importance of meeting the child where they are and not forcing them to participate in play scenarios when they did not want to. It was crucial to their treatment that the professional working with them respected their boundaries and recognized when they were not in a place to process what was currently happening to them. They emphasized the need to listen to the child in these instances and give them the space to process their emotions quietly before they share.

Included in the data collected was the notion of listening to the child's preferences and supplying types of play or activities that met their needs. This could be seen in the case of J who needed tactile sensory stimulation in order to remain calm during his procedures. It was also pointed out when J needed other forms of play such as medical play and bibliotherapy. In addition it was seen in the case of the children in palliative care with Participant B when books would be provided to parents to read to their children to help them understand and cope with concepts about their treatment. Using the specific types of play that the child gravitates toward engages the child and makes the play meaningful for them. When a child is engaged with the play, they will participate in a way that makes sense for them and get more out of the treatment.

Although it could be seen that child life professionals preferred to use child-led approaches during their interaction with the children they were treating, it became necessary for them to take control of the play in certain ways. This was especially evident in the medical play that was presented in the interviews. For instance, in the examples provided by Participant A, medical play was used frequently to explain medical procedures and how they worked. Here we see the adult in the situation interfering and guiding the play so that a goal is met. The child life professional needs to prepare the child for the upcoming procedures for that day and thus need to take control of the play scenario so that the child has an understanding of what is about to happen to them. The medical play will turn into an information session of sorts so that the child is aware of what is going to transpire during their medical care. Due to the need for them to see exactly what is going to happen the play is no longer child-led. The child is involved and participates in the play but the adult directs it so that the exact medical procedure is played out.

These examples show that although the importance of letting the child be the one to dictate the course of their therapy treatments is acknowledged, it is necessary to have adult directed play present in a hospital setting. Child-centered play therapy is not absent from the field of Child Life but it is not the sole means of play therapy used in these circumstances. Instead Child Life Professionals use a hybrid of child-led play and adult directed play to best meet the needs of the unique population of children that they serve.

It is also important to note that the original intent of this investigation was to conduct additional interviews with other child life specialists as well. Having a larger group of participants would have provided the study with more data to analyze and, thus, a deeper look into the child life profession and the use of CCPT in a hospital setting. However, despite efforts to increase participants, only two agreed to be interviewed and, thus, are the only interviews in

this analysis. Due to the small sample size, this study is not meant to be a generalization of the child life field as a whole or to represent how all child life specialists interact with chronically ill children. Rather, this investigation provides an in-depth look at the practice of two practitioners and how they interact with the children in their care.

Ideas for Further Research

Although the need for play therapy is met for the children described through the interviews conducted, a true child-led program was not used by these specialists in the hospital. Based on the research presented it would appear that complete freedom in a play setting is not met. It is important to acknowledge that the population being treated is unique in that they are enduring traumatic experiences everyday. This translates into the need for a stronger, more immediate and more directive form of intervention to help them cope and understand the circumstances they are in. However, research suggests that providing children an environment that provides them complete control over their play can be beneficial to socio-emotional and cognitive development (Barnett, 1990). To this end, I believe it would be beneficial to have a designated time in the child's schedule to experience and partake in a completely child-centered play therapy session. In this session the child would not be directed toward any particular type of play and would simply enter a playroom environment, or have material brought to them if needed, where they are told they can play however they want to.

During the current play that takes place with a child life professional, most of the time children are allowed to choose what they wish to do and the child life professional follows their lead. However, the child life specialist has the job of adjusting the child to the environment they are in and the medical treatments they must endure. This leaves little room for complete

autonomy during the play experience. Therefore, I am suggesting that an additional play session be provided that follows the child-centered play therapy approach where the child would be given the opportunity to have complete control over their play. This extra play session would allow children to experience the autonomy and freedom of choice that is not present in their day to day life in the hospital.

It is important to note that this additional play session would not replace the work that child life specialists are currently engaging their patients in. Instead it would only serve as a supplemental therapy session for the child to be able to play with no intent or pre-determined purpose. If, by the child's own volition, medical play or their hospital experience were to come up during play that would be fine. There should be no concept, emotion, or type of play that is off limits to the child during these play sessions (within the limits of what is appropriate for their illness). However, the difference between their chronic illness being brought up in this scenario is that the child has decided to bring these concepts and ideas up and not the child life specialist. In addition, if it is brought up, the child life specialist, or other therapist that may be assigned to this work with the child, should not attempt to guide the play. They should only be present to serve as a support for the child and to help them play out these scenarios in a safe environment. The therapist should engage in a reflective manner but not attempt to ask any guiding questions or perform any guiding behavior that would influence the child's play (Axline, 1974).

Contribution to the Child Life Field

This work can be used for reference as to how play therapy is particularly beneficial to children diagnosed with a chronic illness and who are subjected to long hospital stays. Children need an outlet for their emotions as well as a developmentally appropriate way to process and

work through their experiences. Play therapy can provide children with an opportunity to do this at their own pace and without the expectations that surround them in their daily lives including the responsibilities of their diagnosis. This paper provides descriptive explanations for how play therapy can be specifically applicable to chronically ill children who are hospitalized due to their condition.

This paper could also be helpful to child life specialists who would like to add more approaches to their work. If there is an instance where the child could be the one to instigate play and dictate the content of that play it would be beneficial for them to do so. It allows them to have the feeling of being in control and expressing themselves exactly as they wish to. If a child life professional has not been trained in the CCPT approach this paper can serve as a starting point for how they may be able to incorporate some of the ideas or prevailing thoughts and principles of play therapy specifically into their work with hospitalized children. This approach would also provide the child life specialist with a window into what the child is really struggling with. This would provide the child life specialist with a specific issue to target during the child's treatment, thus making treatment more meaningful for the child. CCPT could allow the child to tell the child life specialist what they need and, thus, the child life specialist can curate a treatment plan specifically directed toward the child's needs.

Additionally this paper provides insight into the daily routines of two practicing child life professionals as well as their thoughts and feelings on the best approach to working with chronically ill children. This is important data to have access to when thinking about treatment plans and methods for this population of children. Being able to see and hear about what other practitioners do in their work may spark conversation and interaction amongst people of different backgrounds which has the potential to find a best practice in different fields. Shared ideas lead

to more informed decision making and thus the possibility of bettering the fields in which an individual works.

This paper also provides a look at how play therapy and the methods used by child life professionals can be combined to create a comprehensive treatment plan for chronically ill children. Understanding that play is, in fact, therapeutic for children can open so many doors for professionals searching for ways to offer therapy to children. This paper serves as an example of how play can be incorporated into various environments. Children will play wherever they are allowed to (Landreth, 2001). It is natural for them to want to participate in play scenarios. Thus, we can see how including the child's natural inclination to participate in these play scenarios can make therapy engaging for children. Allowing children to make sense of things in their own way makes the therapeutic process more meaningful and provides the child with a sense of control over their current situation.

This paper presents research that suggests play should be involved in all aspects of a child's life. Play is what children engage in naturally and thus, child life specialists and other mental health professionals should incorporate play into their practice in some fashion. Importantly, play that allows children freedom and room to explore unrestricted should be leaned into. This allows children to make their own unique discoveries about the world and how they fit into it. Additionally, child-led play provides a special opportunity for children who have had their freedom and autonomy stripped, such as those diagnosed with a chronic illness, a chance to regain the lost control in their life and feel empowered and confident. This is where CCPT and child life can cross paths. Children can be provided the much needed coping skills and understanding that interactions with a child life specialist provides while still maintaining the child's freedom of choice through play therapy techniques. Ensuring that child life specialists

incorporate child-led play into the treatment of their patients is providing an experience of freedom and expression that is stripped away from chronically ill children.

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