Understanding Therapists' Use of Play with Children with Life Threatening Conditions: A Qualitative Study

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UNDERSTANDING THERAPISTS’ USE OF PLAY WITH CHILDREN WITH LIFE THREATENING CONDITIONS: A QUALITATIVE STUDY

A Master’s Thesis presented to the Faculty of the Graduate Program in Occupational Therapy
Ithaca College

In partial fulfillment of the requirements for the degree
Master of Science

By
Rachel Bambrick
May 2015
Abstract

This study examined how occupational therapists use play in their treatments when working with children with life threatening conditions. The study followed a qualitative format, and all therapists were interviewed a total of three times using semi-structured interviews. The interviews were designed to gather an understanding of how these occupational therapists work with children with life threatening conditions and the ways in which they utilize play. Four major themes arose from the interviews along with two sub-themes. The four major themes were, play as a means, playful moments, condition dependent limitations, and reimbursement. The two sub-themes were, the importance of play and allowing for more play at end of life. Findings from this study suggest that while therapists value play as an occupation, they are typically using it as a means to another end in therapy with children with life threatening conditions. Additionally, therapists face many challenges to incorporating play into treatment when working with children with life threatening conditions such as, insurance reimbursement and the confines of practicing in a hospital-based setting.
Acknowledgements

I would like to thank the four therapists who agreed to participate in my study. Your help and willingness to participate was invaluable.

Thank you to Carole Dennis & Kim Wilkinson for working with me through this process. I can’t express how much I appreciate all of your hard work and dedication to helping me get this far.

I would also like to thank my family for supporting me in this journey and being willing to listen to me constantly tell them how overwhelmed I was!

Finally, thank you to my friends for being such a wonderful support system this whole year.
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Chapter One Introduction

Background

Through advances in modern medicine and specialization of medical care, mortality rates in the United States have continued to drop and life expectancy has risen. Despite this, there are still individuals of all ages facing life threatening conditions and death across the country. In 2011, the childhood mortality rate for children ages 1-4 years was 26.3 per 100,000 and 13.2 per 100,000 for children 5-14 years of age (CDC, 2011). Therefore there continues to be a need to explore care and quality of life for these children facing the end of life.

Occupational therapy plays an important role in end of life care for individuals (Burkhardt, et al., 2011). There is sufficient research supporting the need for occupational therapy for individuals with life threatening conditions. A significant focus for occupational therapists in any setting is to “provide skilled intervention to improve quality of life by facilitating engagement in daily life occupations throughout the entire life course” (Burkhardt, et al., 2011). The American Occupational Therapy Association’s statement paper on the role of occupational therapy in end of life care emphasized that occupational therapists help clients to find relief from pain and work to help clients improve their quality of life through the use of meaningful and purposeful everyday occupations (Burkhardt, et al., 2011).

Play is the primary occupation for children. Through play, a child can develop fine and gross motor skills, as well as psychosocial behaviors and interactions with peers. Play has been referred to as a natural human right every child should be allowed because it has such an impact on development (Brown & Patte, 2013). Play is one of the most meaningful occupations that children across the globe engage in. It has numerous implications for a child’s development, social interaction, and overall quality of life (Brown & Patte, 2013; Parham & Fazio, 2008;
Reilly, 1974). Through play, children are able to explore their worlds in non-threatening and less monotonous ways (Brown & Patte, 2013).

**Problem Statement**

Despite the literary understanding that play is one of the most important occupations for children, there is little literature about the importance of fostering play opportunities for children with life threatening conditions (CWLC). At the same time there is a great deal of research about the importance of allowing adults with life threatening conditions to engage in meaningful, purpose-driven occupations and leisure activities (Orozoic, Davis & Newman, 2008; Vrkljan & Miller-Polgar, 2001). If we are able to access the perspectives of occupational therapists who have worked with CWLC, and understand how they chose to foster play with these children, we will be able to better understand care and occupational therapy for CWLC.

**Purpose of Study**

The purpose of this study is to determine how and why occupational therapists used play when working with CWLC, and to gain a better understanding of their view of the importance of play for children who are dying. Through a qualitative study involving focused interviews with occupational therapists who have worked with CWLC, we can better understand what therapists find important when working with this population, and the steps they may have taken to allow for play during therapy and in the child’s life. This information will increase our knowledge of occupational therapy care and quality of life for CWLC, specifically from the perspectives of therapists.
Chapter Two Literature Review

The Importance of Play for Children

“These are the opening lines from an article written nearly 60 years ago by occupational therapist, Norma Alessandrini”:

Play is a child’s way of learning and an outlet for his innate need of activity. It is his business or his career. In it he engages himself with the same attitude and energy that we engage ourselves in our regular work. For each child it is a serious undertaking not to be confused with diversion or idle use of time. Play is not folly. It is purposeful activity (as cited in Parham & Fazio, 2008, p. 3).

Since this definition was written, many definitions of play have come about from a variety of different theories, but one thing remains the same… “play is a significant and primary occupation of children” (Parham & Fazio, 2008, p. 3). There are numerous characteristics that help to describe the play experience; intrinsic motivation, process rather than product, free choice, enjoyment or pleasure, spontaneity, active engagement, and non-instrumental. These characteristics allow the goal of play for children, to be playing for the sake of play (Parham & Fazio, 2008).

Play also holds a crucial role in development; children can “[play their] way gradually and safely towards the skillful mastery of [their] world” (Reilly, 1974, p.148). Play helps children to gain skills, abilities and interests in their world, and it helps children to understand rules of various objects, people, and ways of thinking within their environment (Parham & Fazio, 2008). Play behaviors then translate to school performance, and later to work experiences (Reilly, 1974). Play helps to develop a child’s fine and gross motor skills, psychosocial behavior, cognitive abilities, and socialization. If a child is unable to play, their development may be
compromised in many areas (Reilly, 1974). Play remains important despite the child’s length of life.

Children are constantly playing in various places and spaces and with a variety of playthings that allow them to express their feelings through play. Play is something that is intrinsically good for them, and by watching children play; you are able to better understand their lives (Ramsden & Vawda, 2007). Many adults do not realize the great importance play holds for child development, and the significance of engaging children in play so they may benefit from it. Adults must understand this importance and the developmental stages children progress through while using play as a primary occupation (Shevil, n.d.).

Play has also been described as meaningful for children; it is thought to give a person’s life meaning and a sense that it is worth living (Parham & Fazio, 2008). For all people, play provides their life with a feeling of meaning and allows them to realize their potential to engage in everyday occupations. It is a unique aspect of the occupational therapy profession that therapists are able to allow individuals to both play for the sake of playing and to use it as a valid intervention method (Parham & Fazio, 2008).

**Understanding Meaning in Occupations**

In Catherine Trombly’s 1995 Slagle lecture on purposefulness and meaningfulness in occupation, she spoke of the meaning in occupations as coming from the mind-body connection. The actions we carry out through occupations that are meaningful to us come from the meaning that is dedicated to them by the mind. In this sense, the client always individually creates meaning, and therapists need to be cautious to not implement their own values into treatment (Trombly, 1995). This personal sense of meaning and value in occupation is connected to well-being, particularly when the occupations a person chooses to engage in are intrinsically
motivating and unique to the individual. In recent years, it has been understood and recognized that engaging in occupations that are personally valued and motivating can contribute to overall well-being (Eakman, Carlson & Clark, 2010). Meaningful occupations cannot only improve people’s well-being, but also their life satisfaction. Particularly, it is the meaningfulness of occupations that creates greater well-being and quality of life for individuals. (Goldberg, Britnell & Godlberg, 2002).

**Occupational Therapy and the Importance of Meaningful Occupational Engagement for Individuals Who Are Dying**

Occupational therapy’s unique perspective of promoting participation in meaningful occupations pairs itself very well with the holistic nature of palliative care. Therapists use an interdisciplinary approach to treat clients with life threatening illnesses in order to maintain their quality of life (AOTA, 2011). Occupational therapy intervention should focus on activities that are meaningful and valuable to the client to allow them to feel as independent as possible and stresses the use of leisure and community based activities that clients find to be valuable, despite a change in occupational roles for the client (AOTA, 2011).

Researchers have found that individuals in hospice care often identified feelings of hopelessness and helplessness in the face of their illness. It is therefore crucial to examine how engagement in meaningful occupations can still be achieved in the face of illness (Lyons, et al., 2008). In the study done by Lyons, et al. (2008), the experiences of 13 male and 10 female day hospice participants were examined using focus groups, interviews, and observation. The researchers interpreted using constant comparison, coding, and theme building. They used Wilcock’s occupational model of becoming through doing and being in order to frame the coding of their data. Wilcock’s occupational model is based around the idea that individuals are
continuously changing and never stop becoming who they are. Occupation is viewed by Wilcock as part of a dynamic and ever-changing relationship between what people do, who they are, and who they are becoming as occupational beings (Wilcock, 2006). The researchers found that participants expressed regret surrounding having to give up activities that had previously given them a sense of independence or pleasure. When the researchers asked the participants about their feelings towards the activities provided by the hospice, the responses demonstrated just how integral engagement in the hospice activities was to the becoming of the participants in the face of their life-threatening illness. They also found that engagement in occupation while dealing with a life-threatening illness helped participants maintain their well-being. The researchers in this study found important implications for occupation and doing while facing death, and were able to show the importance of occupational engagement to health and well-being for individuals at the end of life (Lyons, et al., 2008).

In 2001, Vrkljan & Miller-Polgar completed a qualitative study to explore occupational engagement and what it means to individuals after receiving a life threatening diagnosis. They used semi-structured interviews with three women diagnosed with breast cancer and explored common themes that arose from the interviews. The researchers noted that crises such as receiving a life-threatening diagnosis can negatively impact the ability of an individual to engage in meaningful occupations. Through the interviews done with the three women, the main theme that the researchers found was the idea that doing equals living and that engagement in meaningful occupations had a strong connection to an individual’s perception of their health and capabilities. The researchers found that the women they interviewed often spoke of feeling determined to keep their life as normal as possible and not let their diagnosis take over. The women found that meaningful engagement in occupations helped them to feel like they could
still maintain their roles and daily routines even in the face of a life-threatening diagnosis (Vrkljan & Miller-Polgar, 2001). Continued engagement in meaningful occupations, particularly when facing a life-threatening illness has been proven to be very important in maintaining that individual’s sense of well-being, their roles, and their daily routines.

**The Role of Occupational Therapy with Individuals with Life-Threatening Illnesses**

In the American Occupational Therapy Association (AOTA)’s Fact Sheet (2011) on the role of occupational therapy in palliative care, it was noted that occupational therapy’s unique focus on the promotion of occupations that are meaningful to the client ties in well with the focus of palliative care which is based around a holistic and client-centred approach working to make an individual’s life as independent as possible at the end of life. Occupational therapists should use meaningful intervention with clients at the end of life that enables them to maintain their independence and feelings of accomplishment. It should also be noted that occupational therapists have a role in intervention in working on play, leisure, and social participation for individuals receiving palliative care.

Occupational therapists also have a role in modifying occupations for individuals so they can still be performed despite developments in their illness, because practitioners value the fact that continued engagement in occupations across the lifespan contributes to an individual’s ability to successfully live their life (Burkhardt, et al., 2011). The authors also noted that engagement in meaningful occupations can have multiple positive impacts on an individual with a life-threatening illness including improvements in quality of life and in symptom management. These positive impacts can take a client’s mind off of the physical pain or symptoms they may be experiencing (Burkhardt, et al., 2011). While much of this statement paper focused on adults,
AOTA did include one case example involving a child. The case described Peter, a 5-year-old boy in hospice care as follows:

Occupational therapy was included in the hospice plan of care to maintain Peter’s ability to play and engage socially with his family despite declining physical and cognitive abilities … interventions … included modifications for current games and activities that Peter enjoyed and appropriate positioning strategies to support participation…[this allowed] Peter … to successfully maintain his ability to engage in play and family interaction even as his condition deteriorated (Burkhardt, et al., 2011, p.72).

Occupational therapy’s role when working with individuals with life threatening illnesses is to provide individuals with opportunities to continue to engage in meaningful occupations, which in turn can improve their quality of life. While most literature focuses on occupational therapy’s role when working with adults with life threatening illnesses, AOTA has acknowledged that occupational therapy also has a role to play when working with children with life threatening conditions.

Medical Care of CWLC

While the specialization of the health care system has contributed to increased survival rates across the country, it has also created an overall depersonalization of care. Kane & Primomo (2001) describe how many medical professionals have a tendency to not view the child as a whole being, but rather focus on the individual body systems that need care or are causing the child pain. Kane & Primomo (2001) indicate that this can lead to medical professionals’ ignoring the whole child and the lived experiences at the end of life. While the disease can have the potential to impact all areas of the child’s life, the fragmentation of medical care often neglects to realize this all-encompassing aspect of disease. This type of care may interfere with
the child’s ability to engage in daily occupations such as play and may not consider the child’s overall well-being and independence. (Kane & Primomo, 2001). If this holistic view of the child is missed, then care can be incomplete (Kane & Primomo, 2001). A holistic view should include a palliative care plan that goes beyond the medical care of the child. It provides opportunities for play, education, interactions with others, and opportunities to engage in activities that are developmentally appropriate for the child (Canadian Hospice Palliative Care Association, 2006). Children receiving palliative care also have the basic right and need to be given the opportunity just to be a child and engage in developmentally appropriate play. They need to be given as much freedom and choice in play as their condition allows, as it can give them a sense of control while living under the restrictions of their illness (Boucher, Downing & Shemilt, 2014). This research coincides well with the role of pediatric occupational therapy, where practitioners are focused on engaging children in activities that include activities of daily living (ADLs), play, and education. Pediatric occupational therapists can support the medical care of CWLC by assisting children at the end of life to continue to engage in both purposeful and meaningful activities (Cantu, 2005).

**Shortcomings of Previous Research**

Though this paper has only explored the relevant highlights, there is an abundance of research on the importance of play for children (Parham & Fazio, 2008; Kuhaneck, Tanta, Coombs, & Pannone, 2013; Reilly, 1974; Shevil, n.d.), and on the importance of allowing individuals with life threatening conditions to engage in meaningful activities (Burkhardt, et al., 2011; Lyons, et al., 2008; Vrkljan & Miller-Polgar, 2001). However, there is no research that specifically explores how medical professionals support CWLC to engage in play. Play is a central occupation in the lives of children, and one that gives them intrinsic joy, meaning, and
purpose. While there is so much literature addressing the importance of engaging in meaningful, purposeful, and intrinsically motivating activities for adults with life threatening conditions, the importance of these types of activities including play for children with these conditions is rarely touched upon. There is currently very little research looking at whether play is something that is fostered when working with this population, or on therapists’ perceptions of the importance of play for this population.

The majority of literature in occupational therapy on the role of occupational therapy in palliative care or end of life contexts focuses on the adult population (Orozoyic, Davis & Newman, 2008; Vrkljan & Miller-Polgar, 2001). Currently we lack literature on the role of occupational therapy when working with CWLC. In addition, while there is an abundance of literature on how pediatric occupational therapists use play when working with children and the importance of play to children, (Reilly, 1974; Clark, 2003; Parham & Fazio, 2008; Brown, 2013) there is no literature on how occupational therapists use play when working with CWLC.
Chapter Three Methodology

Design and Procedure

In this study I used a qualitative, narrative approach to collect and analyze data on therapists’ use of play when working with CWLC. I chose this format in order to use the stories of the therapists interviewed to explore the use of play with CWLC in occupational therapy. I focused on collecting the lived stories of therapists’ daily lives when working with CWLC, told from the perspectives of occupational therapists using semi-structured interviews. The narrative approach was important to this study because this format allowed the therapists’ stories to guide the data collection process, and through using this format rather than non-narrative interviews, individuals often tell stories that are more meaningful and important to them. The Ithaca College Review Board for Human Subjects Research approved the study (Appendix C), and all research participants gave informed consent. Each participant received a $25 gift card at the completion of the study.

Participants

I sent a recruitment statement to local clinic supervisors or rehabilitation directors in the northeastern United States. These individuals forwarded the statement to therapists they believed met the criteria for the study. The clinic supervisors or rehabilitation directors first confirmed that these therapists would be willing to participate, and then gave the names and contact information of these therapists to me. I then contacted therapists via email, and four licensed occupational therapists that had worked with CWLC in the past agreed to participate in the study. Inclusion criteria for the therapists in this study were as follows: worked as a registered occupational therapist, had worked with children with life threatening conditions between the
approximate ages of 3 and 8 years, and were willing to discuss their time working with these children.

**Data Collection and Measures**

I interviewed each therapist a total of three times, with the first two interviews taking place over the phone or video chat on the computer, and the final interview taking place either over the phone, video chat, or in-person. One final interview took place over the phone, two therapists participated in a video-chat focus group for the final interview and another participated in an in-person final interview. I conducted the focus group due to convenience of location and to allow the therapists to create an open dialogue and bounce ideas and stories off of one another. All interviews were audio recorded. Interviews lasted between 15 min to 60 min, with the first interviews being the shortest and the last interviews lasting the longest. I designed the first interview to acquire knowledge about the therapists’ background and experience working with this population. In the second interview, I asked the therapist to focus on and describe one or two CWLC that stood out to them for a particular reason. In the final interview, I asked the therapist to delve into the specific details of one treatment session with a child and tell an in-depth story of that particular session.

**Data Analysis**

Interview data was manually transcribed and analyzed using a method based on interpretive phenomenology and narrative theory. Interviews were transcribed and read after each interview allowing for an initial pass of data analysis and development of questions for the following interview. After all interviews were completed, transcripts were read multiple times and similarities and differences that occurred across cases (between different therapists) and within cases (between different interviews with one therapist) were noted. Conceptual categories
were created based upon the themes discovered and an initial large list of themes based on these
codes was created and modified based upon a second in-depth reading of the transcripts. In the
second read through, fewer codes and themes were identified. Themes that emerged from both
analyses were then compared and consolidated into four major themes that appeared in the
interviews. These are: the use of play in therapy, playful moments, condition dependent
limitations, and reimbursement. It is important to note that within some of these major themes,
minor related themes were identified as well. Analysis continued until a point of saturation was
reached, where the major themes had been identified and no new information was needed to
support or add to these themes (Creswell, 2008).

Three methods were used to validate findings and ensure accuracy and credibility in this
study (Creswell, 2008). The first was external auditing. A faculty member who is a therapist
familiar with pediatric practice and the relevant literature reviewed all themes identified to
ensure that they were appropriate and logical (Creswell, 2008). In addition, at the beginning of
the second and third interviews with each therapist, the information from the previous interviews
was reviewed and they were asked to confirm that initial interpretations of the previous
interviews agreed with their perception of what had been said. Corrections were made if needed,
though the therapists did not have any corrections to note. This process, known as member
checking helps to ensure that the findings are accurate and credible (Creswell, 2008).

Throughout the interview process, I kept a journal of thoughts and biases to ensure continual
awareness of these throughout the research process.
References


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Introduction

Through advances in modern medicine and specialization of medical care, mortality rates in the United States have continued to drop and the life expectancy has risen. Despite this, there are still individuals facing life threatening conditions and death across the country, including children. In 2011, the childhood mortality rate for children ages 1-4 years was 26.3 per 100,000 and 13.2 per 100,000 for children 5-14 years of age (CDC, 2011). Therefore there continues to be a need to explore care and quality of life for these children facing the end of life.

Occupational therapy plays an important role in end of life care for individuals. There is ample research supporting the need for occupational therapy for individuals with life threatening conditions. One of the main focuses of occupational therapists in any setting is to “provide skilled intervention to improve quality of life by facilitating engagement in daily life occupations throughout the entire life course” (Burkhardt, et al., 2011, p. 66). The American Occupational Therapy Association’s statement paper on the role of occupational therapy in end of life care stated that occupational therapists help clients to find relief from pain and to improve the client’s quality of life through the use of meaningful and purposeful everyday occupations (Burkhardt, et al., 2011). While much of this statement paper focused on adults, AOTA did include one case example involving a child. The case described Peter, a 5-year-old boy in hospice care. In this case,

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Play is the primary occupation for children. Through play, a child can develop fine and gross motor skills, as well as psychosocial behaviors and interactions with peers, and it is often referred to as a natural human right every child should be allowed because it has such an impact on development (Brown & Patte, 2013). Play is one of the most meaningful occupations that children across the globe engage in. It has numerous implications for a child’s development, social interaction, and overall quality of life. Play holds a crucial piece to development, children can “[play their] way gradually and safely towards the skillful mastery of [their] world” (Reilly, 1974, p.148). Play helps children to gain skills, abilities and interests in their world. It helps children to understand rules of various objects, people, and ways of thinking within their environment (Parham & Fazio, 2008). Play behaviors first translate to school performance, and then to work experiences (Reilly, 1974). It is a unique aspect of the occupational therapy profession that therapists are able to allow individuals to both play for the sake of playing and to use it as a valid intervention method (Parham & Fazio, 2008).
Despite the amount of research on both the importance of engaging in meaningful activities through the end of life and the role occupational therapy can play in this, and on the importance of play as a meaningful and important occupation for children, there is little research addressing the importance of facilitating play opportunities for children with life threatening conditions (CWLC) and the role that occupational therapy can play.

The majority of literature in occupational therapy on the role of occupational therapy in palliative care or end of life contexts focuses on the adult population (Orozoyic, Davis & Newman, 2008; Vrkljan & Miller-Polgar, 2001). Currently we lack literature on the role occupational therapy plays when working with CWLC. In addition, while there is an abundance of literature on how pediatric occupational therapists use play when working with children and the importance of play to children, (Reilly, 1974; Clark, 2003; Parham & Fazio, 2008; Brown & Patte, 2013) there is no literature on how occupational therapists use play when working with CWLC. Based on the gaps found in the literature, the purpose of this study is to determine how and why occupational therapists used play when working with CWLC, and to gain a better understanding of their view of the importance of play for children who are dying.
Methods

Design and Procedure

This qualitative study used semi-structured narrative interviews to explore the stories of four occupational therapists about the use of play with CWLC in occupational therapy. It focuses on a collection of the lived stories of therapists’ daily lives when working with CWLC, told from the perspectives of occupational therapists. The narrative approach was important to this study because this format allowed the therapists’ stories to guide the data collection process, and through using this format rather than non-narrative interviews, individuals often tell stories that are more meaningful and important to them. The Ithaca College Review Board for Human Subjects Research approved the study, and all research participants gave informed consent. Each participant received a $25 gift card at the completion of the study.

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Data Collection and Measures

Each therapist was interviewed a total of three times, with the first two interviews taking place over the phone or a video chat on the computer. For the final interview, one took place over the phone, two therapists participated in a video-chat focus group interview together and the fourth participated in an in-person final interview. The focus group was conducted due to convenience of location and to allow the therapists to create an open dialogue and bounce ideas and stories off of one another. All interviews were audio recorded. Interviews lasted between 15 min to 60 min, with the first interviews being the shortest and the last interviews lasting the longest. The first interview was designed to acquire knowledge about the therapists’ background and experience working with this population. The second interview asked the therapist to focus on one or two CWLC that stood out to them for a particular reason. The final interview asked the therapist to delve into the specifics of one treatment session with a child and tell an in-depth story of that particular session.

Data Analysis

Interview data was manually transcribed and analyzed using a method based on interpretive phenomenology and narrative theory. Interviews were transcribed and read after each interview allowing for an initial pass of data analysis and development of questions for the following interview. After all interviews were completed, transcripts were read multiple times and similarities and differences that occurred across cases (between different therapists) and within cases (between different interviews with one therapist) were noted. Conceptual categories were created based upon the themes discovered and an initial large list of themes based on these codes was created and modified based upon a second in-depth reading of the transcripts. In the second read through, fewer codes and themes were identified. Themes that emerged from both
analyses were then compared and consolidated into four major themes that appeared in the interviews. These are: the use of play in therapy, playful moments, condition dependent limitations, and reimbursement. It is important to note that within some of these major themes, minor related themes were identified as well. Analysis continued until a point of saturation was reached, where the major themes had been identified and no new information was needed to support or add to these themes (Creswell, 2008).

Three methods were used to validate findings and ensure accuracy and credibility in this study (Creswell, 2008). The first was external auditing. A faculty member who is a therapist familiar with pediatric practice and the relevant literature reviewed all themes identified to ensure that they were appropriate and logical (Creswell, 2008). In addition, at the beginning of the second and third interviews with each therapist, the information from the previous interviews was reviewed and they were asked to confirm that initial interpretations of the previous interviews agreed with their perception of what had been said. Corrections were made if needed, though the therapists did not have any corrections to note. This process, known as member checking helps to ensure that the findings are accurate and credible (Creswell, 2008).

Throughout the interview process, the primary researcher kept a journal of thoughts and biases to ensure continual awareness of these throughout the research process.

Results

Participant Characteristics

The therapists interviewed were all female, with a mean age of 30.75 years of age. The mean number of years of practice was 3.25 years; the mean number of years of practice at their current place of work was 2.63 years. The low level of experience may be due to the fact that the therapists who wanted to participate were recently out of school and could relate to and
remember the process of trying to find research participants when completing their own graduate research. *Table 1* presents an overview of the therapists’ participant characteristics. In the narrative below, all therapists’ responses are recorded either within the text or within boxed quotes.

**Table 1. Participant Characteristics**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age, yr</th>
<th>Years Practicing</th>
<th>Settings Worked</th>
<th>Years at Current Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann*</td>
<td>28</td>
<td>5.5</td>
<td>Pediatric outpatient, pediatric acute care, pediatric inpatient rehab</td>
<td>4</td>
</tr>
<tr>
<td>Claire*</td>
<td>32</td>
<td>4</td>
<td>Pediatric outpatient, adult rehab, adult acute care, pediatric acute care</td>
<td>3</td>
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<tr>
<td>Tanya*</td>
<td>29</td>
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<td>Pediatric inpatient rehab</td>
<td>2.5</td>
</tr>
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<td>Samantha*</td>
<td>34</td>
<td>1</td>
<td>School-based</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note. *Names have been changed to protect privacy

*The Use of Play in Therapy*

All therapists spoke of using play in therapy with CWLC and finding ways to make sessions fun for the children they worked with. In describing how play was used in a session, all of the therapists described its use as often being a motivator for children or a means to reach another end or goal. Tanya described a therapy session in which the use of a child’s favorite toy, a doll, was used to get the child to enter the pool, a stepping stone toward getting her comfortable with participating in an important self-care activity, bathing:

I knew what activity she liked, she liked to play with dolls umm so I kind of stood in the middle of the water and had the doll and said, she’s hungry, come feed her you know and like slowly she was able to get into the water, and you know by the end of the session she was sitting in the pool. Now, that didn’t completely correlate back to the bath, we had to do a few more pool
sessions and bath sessions where we had paint and all of that but just to see her kind of switch that, turn, turn a page and kind of be ready to like get in the water, and wasn’t fearful of it you know and I was able to engage in an activity that she really enjoyed, so I think that the real motivating factor.

In the session described, the toy was the motivating factor to get the child to participate in a pre-bathing activity in the pool. The child had previously resisted being in the water, but with this playful interaction with the doll being used as a motivational tool, the therapist was able to get the child to engage.

Therapists spoke of situations where play was used to motivate a child to “do what they [the therapist] wanted to do” and these were often activities of daily living (ADLs) such as dressing, bathing or toileting. The therapists tried to make these ADLs more fun and motivating through the use of play. Claire spoke of working with a child who had previously resisted toilet training while in the hospital:

I downgraded it to just like she didn’t have to sit on the potty, but just like near the potty and we played games and stuff like that, listen to music in the potty, whatever and then we’d put her on and then she’d come back off but after I would say those two weeks the screaming definitely decreased, her acceptance got more, she could, she at least started understanding like I have to sit quietly on the potty for 2 min before I could get whatever game or food we used as a motivator too umm and I’m pretty sure, if my memory’s correct that our last session, she did go to the bathroom on the potty and it was just like this big, you know party in the potty.

When asked directly if they typically used play as a means or end in therapy almost every therapist responded by saying they used it as a means. For instance, Ann said that, “It’s definitely a combination. But it’s usually a means. It’s typically a means, but you want them to enjoy themselves too.” When Tanya was asked, she quickly replied with, “I would say a means.”
Play is not only used in therapy as a motivator to get a child to engage in a non-preferred activity such as toileting or bathing, but it is also used to facilitate other skills the child may be having difficult with. For instance, the therapists found ways to work on dressing through the use of a game. Ann spoke about how she finds she is able to do so within a session:

“Oh yeah, oh yeah. I mean we incorporate that into our treatment sessions, because it’s the only way to get kids to do things or to keep up their strength or endurance, is to get them to play. So we incorporate that a lot. We link it to other functions. So you know, them reaching their feet to pick up something off the floor, like a toy, so we’re simulating lower body dressing, you know, so that’s how you do that with kids.

The therapists recognized that the ability to work on goal areas through something fun and playful that is motivating to the child is essential to being a pediatric therapist. Claire found it to be the main way that occupational therapists are able to get children to engage while still addressing other goal areas:

“You don’t need to make your session doing buttons every time or doing dressing every time. You know, you can play and work on postural strength and coordination and that kind of stuff and document that appropriately and truthfully but you are addressing their ADLs without making them take on and off their shirt a million times. I think play’s important especially if you’re going to keep the child engaged in an hour session.

For Samantha, it was picking games and activities that she knew the child liked but that also worked on the skills they needed to develop at the same time:

“Then we did a balloon, a balloon toss back and forth and really get his motor planning in there and some bilateral stuff, umm and also that visual motor again so we did a, just a balloon toss back and forth and I mean, all his motor planning kinda just came into play and he did really awesome.”
For all therapists, play is the main tool they used throughout therapeutic intervention. Its role seems to be one of a motivator or means to working on another skill or occupation. The therapists identified two ways in which they used play as a means. The first was as a motivational tool, as demonstrated in Tanya’s example of using the doll to get the child into the water to ready herself for bathing, and the second was as a way to work on other skills needed for occupations, as demonstrated in Samantha’s example of using a balloon toss game to work on visual motor and motor planning skills to aid the child in other occupations.

The Recognized Importance of Play

In addition to recognizing that all of these therapists who work with CWLC used play in their therapy sessions, each also spoke of the overall importance of play for a child. When asked what a child’s most important occupation was, with or without a life threatening illness, Samantha said:

For children I definitely think it’s play. I mean I think it’s how they learn best and I think it’s how and it gives them their ability to get to their level but also gives them the opportunity to make mistakes and learn from their mistakes in a nonthreatening way. And they need that nonthreatening way, you know when they’re in the classroom and stuff they have to do it right. And when they’re doing it through play it’s their rules, their directions, and it’s safe. And kids are just kids they still need to play, they still need to run, they still need to get those sensory experiences through play. And so I think that’s what they need the most as their number one occupation, play in a nonthreatening way.

All therapists recognized the importance of play to childhood learning and development, and its use in just allowing a child to have fun. Tanya recognized its importance by responding to the question of if it was important to facilitate play with CWLC by saying, “Yes because I think kids learn through play, so I think it’s important. So, I think they should be able to enjoy their
time.” Overall, therapists agreed that play is constantly used in therapy with children and that play is an important piece of a child’s life. Additionally, Samantha tied both the importance of play for development and play for fun by saying:

> Kids benefit a lot more from play and, and they really do, they I mean, when they’re into it, they learn. And, and there’s a lot of evidence, a lot, a lotta evidence that kids learn best through play and that that’s what they need in order to learn because especially because it’s a self exploratory kind of thing and, and it’s just fun and it’s fun for us too. And instead of having to just sit there and do the same, kinda like a rote routine, play is spontaneous umm and that’s what makes it the most fun, it’s just that spontaneoussness of it, and when a kid can be laughing and goofy and you can get up and dance around.

To all therapists interviewed, play had an important role in their pediatric practice. It was identified as having purpose both in terms of childhood development and in fostering playful, fun moments.

*Playful Moments*

While play was recognized as often being used as a means or motivational tool in therapy, in talking to the therapists there were many instances where descriptions of purely playful moments occurred. Therapists spoke of moments where therapy began to no longer feel like therapy. Throughout these descriptions, words like “playful” “fun” and “laughing” came out in many of the stories therapists told. Ann spoke of working with a child who was in the midst of treatment and experiencing drastic mood swings. The nurses were unsure of whether or not she could tolerate a visit from the occupational therapy, but the child’s father agreed to let Ann try:

> I approached her the same way I always did and you know just like really slow and really fun and umm just bringing up like different things that we can do so I remember I brought in bubbles, because she loved bubbles, that was always like a good way to get her to just like start playing with me umm so we did bubbles while she was just like sitting in the bed and then
ummm I put a mat down on the ground … and we got her down to the mat and she like sat on the mat then and we did more bubbles and then umm I remember we just started singing then … sometimes you forget to just use simple things, and you always just think that you need a toy and you need to be you know working on having a fine motor, having a fine motor activity you know plan. So, we just started singing and she got so into it and umm then she wanted to stand up and do the hokey pokey and so she stood up and that was like huge because she hadn't for like the past few days, being up in the ICU and so she stood up and we were doing that and she was just laughing and having a blast.

When asked to reflect upon a moment in therapy where it felt like she was the one having fun, Ann quickly replied by laughing and saying, “Oh my gosh. Stop. Umm oh I always do.”

Additionally, she reflected on an experience working with a CWLC and a student she was supervising:

I had a student for some of that time umm with, with the 2 year old … and you know that was like more fun for me because I didn't have the pressure of coming up with activities and I got to play, I was just like the aide that umm was there to play, while she facilitated, kneeling and standing and different things like that, so I just got to play. So that was super fun.

She really valued the experience of being able to just play for the sake of play with this child. When these purely playful moments occurred, many therapists recognized that they often saw unexpected gains or that their sessions ended up being more therapeutic. For instance, when Ann spoke of doing the Hokey Pokey with the child she was working with, she noted that the child stood up for the first time in days. This wasn’t a skill that she had planned on targeting or even addressing in the session, but through the use of play for the sake of play, the child stood on her own. Additionally, when asked the same question about moments in therapy when it felt like she was the one having fun, Samantha responded by saying:
Well, a lot of them are like that. I mean sometimes you’re just playing so much and it doesn’t, it doesn’t quite, like that session I described, it’s just kind of fun, fun stuff, and a game of balloon toss, when you don’t have, when it’s kind of just balloon toss and you don’t have to really cue him to do anything and you’re just goofing around and it just really feels like you’re just goofing around and it’s really, really therapeutic ... to me it’s just play and to him it’s just play and at the same time and a lot of the times it’s just fun and it doesn’t feel like therapy and that’s one of the things I love the most about doing it. It’s that you can just goof.

She recognized the therapeutic value of just being able to have fun and goof around with a child during a therapy session. When Claire was asked to think of moments in therapy when it no longer felt like therapy anymore, she even looked at comparing occupational therapy with other disciplines:

I’ll just be like nurses, aren’t you jealous, don’t you wish you were an [occupational therapist]? I think working with pediatrics, because we get to play so much umm it it ends up being fun and you know umm you always have to bring yourself back like how could I make this more challenging? Is it too fun? I’m always questioning myself, uhh, is this too fun?

To all of the therapists, their core value when working in pediatrics is fun and playfulness with the children they work with. As they shared their stories of sessions, the ones that all stood out as being memorable and “favorite sessions” all involved play and usually play just for the sake of playing.

Condition Dependent Limitations

CWLC are a very unique population, with an array of medical complications, physical restrictions, and setting-based restrictions. The therapists who work with these children are presented with the unique challenge of finding ways to make fun and to make play occur while
faced with a variety of barriers. The therapists spoke about what they try to do in face of these challenges, but many remarked that sometimes the complications and barriers they face when working with this population could be too much and simply prevent play from occurring. Tanya articulated this challenge by describing how the situation can feel very defeating at times:

You know you’re kind of like wanting to show that all of your hard work and all of the interventions that you’re trying are working, but you’re not seeing the gains and from a medical standpoint, they’re unable to participate in therapy. And I think that’s probably the hardest part with life threatening conditions, that they’re out of your control.

In working with these children, the therapists recognized that often their conditions would drastically vary from day to day. They would think that they knew a child one day and then see a completely different personality the next. This challenge made creating rapport difficult, carrying on with sessions difficult, and creating playful opportunities difficult. Ann often described the CWLC that she worked with as “waxing and waning” as the children’s states either improved or deteriorated. In thinking about a young girl she had worked with she said, “You know she’d [be] on and off each day, you didn’t know what you were walking into for her, you know.” Tanya also stated that, “you never know what you’re going to get out of a session.”

With the child’s condition constantly being in limbo, it makes it difficult as a therapist to choose if the child should receive therapy on a given day. Tanya reflected on the guilt she felt when she pushed a child who simply was just not up to therapy that day:

We do our best to ensure that they are getting their therapy for the day so that being said, you know having some of these patients in kind of their last weeks of radiation, they’re really feeling horrible, they don’t want to play, they don’t want to participate, all they want to do is lay in bed umm so I’d have to say, and I feel like this has happened more than once where I’ll go in and I’ll you know say nope, we have to do therapy, let’s go umm and
then bring them down to the gym and then having it be a horrible session where either the patient does not participate or umm they’re just not even doing their best umm and it’s obvious so maybe they’re having more instances of loss of balance or you know maybe they’re not even visually attending to the task and then I’ve even had a lot of kids umm get sick and actually throw up and it was like was this worse? Was it worth it to force this patient to participate when they’re feeling horrible?

It can be difficult to decide because as she had said, “You never know what you’re going to get out of a session” but how do you know when you should be pushing a child to participate or choosing to cancel the session that day? This also relates back to the child’s condition impacting their ability to participate in play. As noted previously, many occupational therapy sessions are play-based and fun, but when a child cannot participate due to their condition, they can be deprived of the play they need and want to engage in. Claire also remarked that many CWLC have either gross motor impairments or restrictions that can limit their ability to play, even if their motivation to do so is there:

A lot of them also will have like other like the gross motor impairments too so like they like can’t be running around and stuff like that so then that limits them, and there’s just like so much stuff to think about sometimes like it can get a little overwhelming.

Additionally, many therapists also reflected back on the hospital environment where many CWLC spend a lot of their time as being a barrier to play. Many children are often hooked up to a variety of different machines, which can be complicated to work with to even get the child out of bed. Ann described a session where she was able to take a child outside for a walk, but only because for whatever reason that day, “she wasn’t hooked up to anything because her line pulled out or something and she wasn’t getting another one for a little while.” Additionally, as many CWLC have undergone transplants and other complicated procedures, hospitals have
standards of cleanliness that they must uphold to protect the health of these children. These standards are creating a barrier to play as well, because as Ann stated:

[The children] are like confined to their rooms or just the one unit and can’t go anywhere like there’s a playroom you know that they can go into and be by themselves but all the toys are like super clean and not many are out, it’s just not very conducive.

Allowing More Play at End of Life

Many therapists noted that a CWLC’s state varies day to day, making it difficult to decide what to do in therapy that day or even to have a session at all. As is the reality when working with CWLC, some ultimately pass away. These therapists have the unique experience of working with these children at the end of their life. What does therapy look like at this point? Many therapists noted that when they realize a child may be at the end of their life or they are not expecting the child to get better, that this is where they can allow for purely playful moments or play for the sake of play. The therapists stressed the importance of allowing the child to do what they want to do at this point. Tanya said:

I think when they have a life threatening illness we’ll do a lot more play and also comfort, that sort of thing as opposed to someone that we know is going to go home ... maybe they have a week to live, they might be able to do more just play.

Ann agreed by saying:

You know you try to include it [play] as much as possible but again with these kids that you know ultimately you know could potentially pass away, you know, in a week, any day, you know umm, you do stuff like focus on them and what they want to do.
There seems to be a sense that when working with a CWLC who is nearing the end of life, goals no longer become as important to the therapists, and a focus on making the child happy through the use of play for play’s sake takes over.

Reimbursement

In addition to facing condition and hospital-based barriers to facilitating play with CWLC, many therapists spoke of the influence of insurance companies and reimbursement for services on their sessions. Documentation of services and tailoring treatment sessions to meet the goals for the child in order to get reimbursement from insurance companies was always on the therapists’ minds. If their services cannot be paid for, they cannot continue to deliver them.

Tanya stated:

The thing is you always have to make it come back to your goals, because at the end of the day insurance is paying for those goals and for your progress towards those goals. It’s something that’s always in the back of our heads.

Insurance companies will often reimburse for functional, measurable goals such as being able to dress oneself or increasing arm strength. Claire spoke about the balance between knowing as a clinician that children are motivated by play and need to play, but also needing to document services so they are reimbursable. “I definitely think that’s where it takes that skill set as a clinician to you know the appropriate ways to document so you’re tying everything together.”

In reflecting on a very playful, fun session with a child, Claire also remarked that at the end of the session, “his mom went back to like, ‘Well did you do any grabbing with his hand?’ and I was like ‘Aww man, like we just had so much fun.’” There seems to be a balance between making their sessions fun and purely playful, but needing to also get their services reimbursed.
Claire also spoke about this line between reimbursement and playfulness in sessions, by remarking that often times therapists cannot even talk about their use of play in sessions because it will not be billed for.

*I think that one of the reasons that we don’t talk about it a lot is because you’re not gonna get billed for it or you’re not going to be able to get billing through an insurance company saying we played with the Wii, we played baseball, he demonstrated great shoulder stability dah dah dah dah, it’s usually you just say what we did like he played you know he did weight bearing, cause you know everyone knows that weight bearing’s important and he showed active range of motion to this height and this many reps you know for strengthening or you know umm kind of umm muscle reeducation like muscle reeducation umm but you can’t really mention all the play stuff that you do so it’s kind of like I think forgotten.  

Despite being something that all the therapists noted was important for children to engage in, Claire stated that play ends up being forgotten because insurance companies may not easily pay for it. Additionally, she spoke about the challenges this brings about when substituting for the child’s regular therapist.

*Unfortunately I don’t think we can talk about it that much or that openly even to have ideas cause like when we read each other’s documentation I don’t really know what the activity was that she did to get him to perform so well so then when I go in to try to replicate that session like say I’m covering her or something, odds are I’m probably not going to do that great of a job cause I don’t know the kid and we can’t speak openly about what got that child engaged umm we typically will leave like notes outside of umm our billing for each other so we have a little bit of an idea.

The emphasis insurance places on the delivery of services as being functional and measurable is impacting the quality of care that Claire feels she is able to give. Documenting play and its benefits is challenging, and it is difficult for her to replicate sessions and understand
how to “get to” the child through play, because other therapists cannot document it for fear of not having their services billed for. This complication has created an “underground therapy” of sorts, where therapists are secretly communicating with each other about how they use play with these children because they cannot speak openly about it.

Tanya noted that in working in inpatient rehab she feels she has a little more flexibility to write goals and document sessions that have to do with play, but that the play goals are never their primary goals for the children, despite the fact that for some children play skills may what they should be working on.

I think in rehab we’ll still make developmental play goals, will engage in developmental play at times for so and so minutes umm but by no means would that be like our primary goal that’s just something that we add in on there umm but I’ve seen several kids and that’s like their biggest challenge is that they can’t engage in play so how are they supposed to develop these fine motor skills if they don’t engage in play where are they supposed to learn them if they’re just you know walking around and they don’t really like sit down and engage in anything.

The therapists’ narratives paint a picture of how occupational therapy services are delivered when working with CWLC. They illustrate how play is used in therapy and the challenges the therapists all faced to incorporate play. All of the therapists noted that play is something that they use frequently in therapy, typically as a motivator or means, but also purely for play. While play is a tool readily used, there are complications specific to working with this population that can create a barrier to play. The overarching emphasis that has been placed on reimbursement and billable services often appears to stand in the way of allowing for play with this population.
Discussion

The findings from this study describe how and why occupational therapists are incorporating play into therapy sessions when working with CWLC, and the various barriers they face when trying to do so. While all of the therapists had a variety of stories to share, the therapists in this study all shared stories of play. Pediatric occupational therapy practitioners are taught to use play in therapy, however typically they are taught to use play as a means to getting a child to engage or to achieve another goal (Parham & Fazio, 2008; Kuhaneck, Tanta, Coombs, & Pannone, 2013; Reilly, 1974; Shevil, n.d.). This use of play was reflected in the stories told by the therapists, as they often told stories of using play to motivate a child to achieve another goal in therapy such as upper body dressing, rather than just using play for the sake of play and allowing children to be natural players.

However, in the therapists’ stories, moments of play for reasons other than a means to another end arose. Therapists began to speak of times in therapy where play was used just for the sake of play; the sessions became silly or goofy, and they started to no longer feel like therapy. The therapists found these moments to be very meaningful when working with these children, and some even found unexpected therapeutic gains arose from these moments of play for play’s sake. Despite the meaning the therapists attributed to these sessions, there is little literature supporting occupational therapy’s role in fostering these purely playful opportunities. Often when the literature discusses play as being purely playful, it focuses on its overall importance to children, and not as much on occupational therapy’s role in facilitating play (Parham & Fazio, 2008). Anita Bundy is one of the few therapists who has written and advocated for promoting playfulness in children and making play a valid occupational therapy goal (Bundy, 1992).
Despite her work, there is still far more literature discussing the role of therapists in using play as a means (Reilly, 1974; Parham & Fazio, 2008; Shevil, n.d.).

This study’s findings also draw attention to the barriers that therapists face when working to facilitate play with CWLC. Children living with life threatening conditions often spend a large amount of time in hospital settings. The protocols and standards that hospitals must abide by to prevent infection and transmission of diseases can create a less than ideal play environment for a child. Therapists expressed difficulties incorporating toys into sessions because everything had to be properly sterilized first. It was also difficult moving a child from their bed due to the medical equipment they were hooked up to. Literature suggests that for all medical professionals, working in a specialized setting can cause many barriers to optimal care (Boucher, Downing & Shemilt, 2014; Kane & Primomo, 2008; Affleck, Lieberman, Polon & Rohrkemper, 1986), and there may be an innate tension in facilitating occupation in a biomedical setting (Keesing & Rosenwax, 2011; Wilding & Whiteford, 2007). Additionally, while CWLC are in the hospital, they are often there for a variety of other procedures and treatments, not just occupational therapy. The therapists reflected on the difficulties of working with children in the midst of radiation treatment or different medications that could alter their mood. They noted that some days complications from their conditions and treatments simply became too much and the child could not or did not want to engage in play.

This study also demonstrates additional barriers to the therapists’ ability to use play in therapy. Therapists often referred to always needing treatment sessions to tie into reimbursable goals. There was emphasis placed upon meeting the goals that insurance companies would reimburse for, which often were ADL or biomechanical (strengthening, range of motion) goals. Insurance companies often will not reimburse for play based goals or interventions, and therefore
therapists will not document these moments. In Claire’s story she described instances of covering for another therapist and not being able to give the child optimal care, because she did not know the games that the child liked or that engaged him, due to the fact that it was not documented. The therapists reported that they will leave sticky notes for one another outside of the child’s chart in order to help other therapists understand what to do to engage the child in play. This type of dilemma is referred to in literature as underground practice (Pierre, 2001; Mattingly & Fleming, 1994). Therapists are faced with a problem in which they need to engage the client and build rapport, and often the way to do so with children is through play, but therapists also adhere to and document the biomechanical goals and treatments that insurance companies will reimburse (Aiken, Fourt, Cheng & Polatajko, 2011; Wilding & Whiteford, 2007; Pierre, 2001; Mattingly & Fleming, 1994). It is a predicament that the therapists found themselves in: the challenge of documenting and reporting on the benefits of play for children.

Play is recognized by pediatric occupational therapists as one of a child’s most important occupations, as it provides meaning and value to the child as well as opportunities for learning and development (Parham & Fazio, 2008; Reilly, 1974; Shevil, n.d.). Despite this recognition, play is primarily used in therapy as a means or motivational tool (Kuhaneck, Tanta, Coombs, & Pannone, 2013). While playful moments do naturally arise in therapy, therapists in this study did not report independently fostering these moments for their own sake and did not document or acknowledge them, causing purely playful moments in therapy to become an underground, secretive part of practice that therapists know about but are unable to document and write about.

**Limitations and Future Directions**

This was a small-scale study with a small sample size. The length of interviews for a qualitative study were also relatively short. In addition, all therapists interviewed were female
and with no more than 5 years of practice experience. Further research with a more diverse sample could examine a wider range of perspectives on this topic. Further research could also examine how and why therapists chose to work with CWLC, to better understand how they work with this population. Additionally, a large-scale mixed methods study could be done in order to determine how the findings from this study translate to a larger population size and in order to continue research in an under-researched practice area.

**Implications for Occupational Therapy**

Play is acknowledged as being an integral part of pediatric occupational therapy practice, but not much work has been done in exploring its use as an ends in practice particularly with CWLC. Research has shown that there is a role for occupational therapy in end of life care in providing ways to engage in meaningful occupations, but all of these studies focus on the adult population (AOTA, 2011; Burkhardt, et al., 2011; Lyons, et al., 2008; Vrkljan & Miller-Polgar, 2001). Yet, despite this, many occupational therapists working in an adult palliative care setting also face numerous barriers to providing occupation-based services (Keesing & Rosenwax, 2011). Additionally, there is currently no other research on occupational therapy’s role with a pediatric population or CWLC. This study leaves the reader with the following questions for occupational therapy practitioners:

- What is the balance between allowing play for the sake of play to allow CWLC to still feel like children and occupational therapy being a skilled and billable service that needs to be reimbursed for?
- What is our role as skilled clinicians in fostering purely playful moments when working with children and their families in life threatening and end of life situations?
• Is there a need for education on what an occupational therapist’s scope of practice is when working with this population and how to facilitate play and meaningful occupations when working with children at end of life? (Hammil, Bye, & Cook, 2014).

• Do we as occupational therapists need to advocate for broader reimbursement of play-based interventions and for our role in providing playful opportunities for CWLC?
References


Shevil, S. (nd). *The Importance of Play In The Healing of Traumatised/Abused Children*. Adapted from Children’s Rights Centre Publications.

Appendix A

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ALL-COLLEGE REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH

PROPOSAL

1. General Information:
   a. Funding: Funding from the Ithaca College Occupational Therapy Department
   b. Location: Homes, workplaces, or other sites to be determined by the occupational therapists
   c. Time Period: October 2014-March 2015
   d. Expected Outcomes: I anticipate sharing the results of this research at the Occupational Therapy Department’s Graduate Research Colloquium. I expect that these findings will be of use to occupational therapists, particularly in their treatment of children with life threatening conditions. I may also share results in a professional presentation or publication.

2. Related Experience of Researchers:
   Rachel Bambrick is a graduate student at Ithaca College. Rachel completed her bachelor’s degree in occupational science, and is now completing her final year of study for the master’s degree in occupational therapy. She has completed related coursework that has helped prepare her to be involved in this research study. She has taken a statistics course in which she learned how to properly use and assess statistics regarding research, a research methods course in which she reviewed basic methods and designs used in research, and a research seminar, which built on research methods and expanded her understanding of research studies. She has written a research paper that included a development of a problem statement and research questions suitable for thesis research. She has completed both her Level I and Level II pediatric fieldwork experiences. Work with children with HIV and research on the disease’s impact on a child’s play while abroad in South Africa was the foundation for beginning this research project.

   Dr. Carole Dennis is an associate professor in the Occupational Therapy Program. Dr. Dennis has advanced training in treatment approaches used for children with developmental disabilities, including Neurodevelopmental Treatment and Sensory Integration. Dr. Dennis has collaborated with students and colleagues in research studies related to a variety of issues for children with disabilities. Dr. Dennis has clinical experience working with children with life threatening conditions, and has experience advising occupational therapy students on their theses.

3. Benefits of the Study:
   This work will help occupational therapists better understand their role while working with children with life threatening conditions. It will highlight the importance of play for these children, and allow the profession as a whole to better understand the role of occupational therapy. The participants in the study will benefit from being able to reflect on their experiences
while working with children with life threatening conditions, and understand their perceived importance of play in this population.

4. Description of Participants
   a. Number of participants: 4-5 occupational therapists who have worked with children with life threatening conditions
   b. Salient Characteristics: Occupational therapists will have worked with children with life threatening conditions within the last five years. They will have worked with children between the ages of 3-12 years.

5. Description of Participation
Participants will be asked to meet with Rachel Bambrick either at their homes or another predetermined meeting location. They will be asked to meet for interviews on at least two occasions to allow for richness and depth in data and to give the interviewee time to think over their responses and to give the interviewer time to formulate more questions based on previous answers. Interview sessions are anticipated to last from 45 minutes to 1 hour, but time will be flexible depending on what the interviewee wants to share. In order to prevent biases from the therapists, the first round of interviews will focus on the therapists' perceived roles when working with the population and the second round of interviews will then focus on play and how it was or was not facilitated. The interviews will be audio recorded and then analyzed using annotation software. The transcriptions will then be analyzed to look for common themes between the different interviews. Please refer to Appendix C for guiding interview questions.

6. Ethical Issues:
   a) Risks of Participation:
      Risks of participation are minimal. Due to the fact that this is a sensitive subject matter, during the interview process there may be psychological risks for the interviewees if they have to bring up painful memories of working with a child who has passed away. Ithaca College’s Center for Counseling and Psychological Services will be available to all participants if needed. Their phone number is: 607-274-3136.
   
   b) Have you attached an Informed Consent Form or Tear-Off Cover Sheet for anonymous surveys?
      Informed consent forms are attached.

7. Recruitment:
   a) Procedures
      I will recruit participants through phone calls and emails sent to county early Intervention directors and supervisors and recruitment information via email to therapists they work with who might meet the criteria for participation, and be willing to do so. Please refer to Appendix A for the recruitment statement.
   
   b) Inducement to Participate/Extra Credit
      Participants will be given a $25 gift card for their participation in this study.

8. Confidentiality/Anonymity:
The identity of all participants will be protected. No identifying information of the occupational therapists or children will be used in any reports or publications that arise from this work. A pseudonym will be used to protect the identity of the participants. A separate key will be maintained that links the pseudonyms with the identifying information of the participants. Research records and audiotaped materials will be maintained securely in the Occupational Therapy Department, in Carole Dennis’ locked office. All data will be maintained for five years. All audiotaped materials will be destroyed in September of 2018.

9. Debriefing:
Not applicable.

10. Compensatory Follow-up:
Not applicable.

Proposed Date of Implementation:
November 2014.

Signature of Principal Investigator:

Electronically submitted protocols must be sent from an Ithaca College e-mail account. Original signatures are not required. Ithaca College e-mail IDs have been deemed by the College to constitute a legal signature.
Announcement for Clinic Directors

Can you help me make a difference?

I am conducting a study about the role of occupational therapy for children between the ages of 3 years and 12 years of age with life threatening conditions. I would like to interview therapists who have had the experience or working such a child in the past five years. These occupational therapists can help me in my work to better understand the need for and role of occupational therapy for this population.

Occupational therapists will be asked to participate in at least 2 semi-structured interviews that are anticipated to range from 45 to 60 minutes per session, and that will take place either at their homes, places of work, or predetermined meeting locations. Participants will receive a $25 gift card. Would you please share this information with occupational therapists who meet my criteria?

If you are interested in learning more about this research study, please contact me!

Rachel Bambrick, OTS
Ithaca College
Phone: 508-542-4007
Email: rbambri1@ithaca.edu
INFORMED CONSENT FORM FOR OCCUPATIONAL THERAPISTS

Children with Life Threatening Conditions: A Qualitative Study

Investigators: Rachel Bambrick, OT graduate student & Carole Dennis, ScD, OTR

1. Purpose of the Study
   The purpose of this study is to understand how occupational therapists frame their treatment of children with life threatening conditions, and to gain a better understanding of the perceived roles of occupational therapists working with this population. Through a qualitative study involving focused interviews with occupational therapists who have worked with children with life threatening conditions, we can get a better understanding of what therapists find important when working with this population. This will allow us to better understand occupational therapy care and quality of life for children with life threatening conditions, specifically from the perspectives of therapists.

2. Benefits of the Study
   This work will help me to understand how occupational therapists perceive their role in working with children with life threatening conditions. The participants in the study may benefit from the opportunity to reflect on their experiences while working with children with life threatening conditions, and to better understand the roles they played while working as a therapist with this population.

3. What You Will Be Asked to Do
   Participants will be asked to meet with me either at their homes, workplaces, or another predetermined meeting location. They will be asked to meet for interviews on at least two occasions to allow for richness and depth in data and to give the interviewee time to think over their responses and to give the interviewer time to formulate more questions based on previous answers. Interview sessions will last between 45 minutes and 1 hour, but time will be flexible depending on what the interviewee wants to share. The interviews will be audio recorded, and the audio recordings will be analyzed using annotation software, to look for common conceptual themes and categories.

   _____________________________
   Participant’s Initials

4. Risks
   Risks of participation are minimal. Due to the fact that this is a sensitive subject matter, during the interview process there may be psychological risks for the interviewees if they have to bring up painful memories of working with a child who has passed away. Ithaca College’s Center for Counseling and Psychological Services will be available to all participants if needed. Their phone number is: 607-274-3136.

5. Compensation for Injury
   If you suffer an injury that requires any treatment or hospitalization as a direct result of this study, the cost for such care will be charged to you. If you have insurance, you may bill your
insurance company. You will be responsible to pay all costs not covered by your insurance. Ithaca College will not pay for any care, lost wages, or provide other financial compensation.

6. **If You Would Like More Information about the Study**
   If you would like more information about the study at any time, please contact Rachel Bambrick (telephone: 508-542-4007; email address: rbambri1@ithaca.edu)

7. **Withdraw from the Study**
   You may refrain from answering any questions that you are asked if they make you feel uncomfortable. You may elect to discontinue participation at any time.

8. **How the Data will be Maintained in Confidence**
   The identity of all participants who participate in this study will be protected. No identifying information will be used in any reports or publications that arise from this work. A pseudonym will be used to protect the identity of the participants. A separate key will be maintained that links the pseudonyms with the identifying information of the participants. Audio recordings will be maintained by Rachel Bambrick on a flash drive that will be locked in the Occupational Therapy Department, in Carole Dennis’ locked office. All data will be maintained for five years. All audio recordings will be destroyed by September 2018.

I have read the above and I understand its contents. I agree to participate in the study.

_____________________________________________________
Print or Type Name

_____________________________________________________
Signature Date

I give my permission to be audiotaped.

_____________________________________________________
Signature Date
Appendix B

Interview Questions:

1. What setting did you work in while working with a child with a life threatening illness?
2. How long was the typical treatment period for a child with a life threatening illness?
3. What occupational therapy frames of reference did you use while working with children with life threatening conditions?
4. What were the goal areas that you typically worked on while working with children with life threatening conditions?
5. What are goal areas that you typically work on with children without life threatening conditions?
6. What types of occupations did you feel were important for children with life threatening conditions to engage in?
7. Do you feel that it is important to facilitate play with children with life threatening conditions? Please explain why or why not.
8. If you did facilitate play with children with life threatening conditions, please explain how you did so.
9. Did you use play as a means or an ends in therapy while working with children with life threatening conditions?
10. Have you ever worked with adults with life threatening conditions?
11. What were the goal areas that you typically worked on while working with adults with life threatening conditions?
12. What types occupations did you feel were important for adults with life threatening conditions to engage in?
13. What do you feel is the most important occupation for children to engage in?