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

Abstract

Background: This study examined how occupational therapists use play in their treatments when working with children with life-threatening conditions.

Methods: This narrative qualitative study used an interpretive phenomenological approach to data analysis. Three semi-structured interviews were conducted with each therapist; 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 use play.

Results: 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.

Conclusion: 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. In addition, therapists who incorporate play into treatment when working with children with life-threatening conditions face many challenges, including the limitations of insurance reimbursement and the confines of practicing in a hospital-based setting.

Comments

The authors report no conflicts of interest to disclose.

Keywords

play, children with life-threatening conditions (CWLC), underground therapy

Cover Page Footnote

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 and Kimberly Wilkinson for working with me through this process. I cannot 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 year.

Credentials Display and Country

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Through advances in modern medicine and the specialization of medical care, mortality rates in the United States have continued to drop and life expectancy has risen. However, the childhood mortality rate in 2015 was 24.9 per 100,000 for children 1 to 4 years of age and 13.2 per 100,000 for children 5 to 14 years of age (Centers for Disease Control and Prevention, 2017). Therefore, there is still a need to explore the care and quality of life provided to children facing the end of life and to examine the role of occupational therapists in working with these children.

Pediatric Palliative Care

Pediatric palliative care focuses on improving quality of life for children with serious illness and their families by providing holistic support to relieve pain and other physical symptomatology and to address psychosocial and spiritual issues while helping the child and family maintain normal activities (Kaye et al., 2015; Tester, 2006). While traditional palliative care has been associated with hospitalization, it has become increasingly available in community health centers, schools, and in the home (Kaye et al., 2015). Although a commonly held assumption is that pediatric palliative care is offered only when death is imminent, it has evolved to be appropriate at any stage of an illness, including diagnosis, and even when a cure is possible (Himmelstein et al., 2004). Occupational therapists may provide services at any point in this continuum as members of a formal pediatric palliative care team or as individuals who provide services in the community.

One of the main foci 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. 566). The American Occupational Therapy Association’s (AOTA) statement on the role of occupational therapy in end-of-life care indicates that occupational therapists help clients to find relief from pain and to improve their quality of life through meaningful and purposeful everyday occupations (Burkhardt et al., 2011). While much of this statement focuses on the needs of adults, the case of a 5-year-old boy in hospice care is included. The goal of occupational therapy for this child was to “maintain [the child’s] ability to play and engage socially with his family despite declining physical and cognitive abilities” through modifying activities and supporting posture to foster engagement (Burkhardt et al., 2011, p. S72). Children’s palliative care is aligned with occupation-centered practice, which focuses on occupation as the central element of practice and, therefore, considers the meaning of occupation for children and their families, as well as the importance of occupation on children’s health and well-being (Rodger, 2010). Tester (2006) wrote that in occupational therapy in pediatric palliative care, “Normality is maintained as far as possible for the child and family, encompassing activities of daily living, mobility, accessing the school curriculum, being able to play, whether early play or participating in sport, and social and leisure activities” (p. 108).

Occupational therapy’s unique perspective of promoting participation in meaningful occupations pairs itself well with the holistic nature of palliative care. Participation in individual occupations may be increasingly difficult for people dealing with life-threatening illnesses (Lyons, Orozovic, Davis, & Newman, 2002). Therapists use an interdisciplinary approach to treat clients with life-threatening illnesses to maintain their quality of life (AOTA, 2011). Occupational therapy intervention should focus on activities that are meaningful to the client, allow them to feel as independent as possible, and stress 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).

The importance of play for children. Play has long been considered a meaningful activity for children that is important for occupational therapists. As Alesandrini (1949) noted over 60 years ago,

“Play is a child’s way of learning and an outlet for his [or her] innate need of activity” (p. 9). Parham and Fazio (2008) wrote that “play is a significant and primary occupation of children” (p. 3). These authors characterize the play experience as including intrinsic motivation, process rather than product, free choice, enjoyment or pleasure, spontaneity, active engagement, and non-instrumental activity. Play is thought to give a child’s life meaning and a sense that it is worth living (Parham & Fazio, 2008).

Play 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 and abilities; to develop interest in their world; and to understand the rules governing various objects, people, and ways of thinking in 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. In addition, play also yields pleasure and enjoyment and is believed to be necessary for social-emotional and mental well-being (Alexander, Frohlich, & Fusco, 2014; Milteer & Ginsburg, 2012). Child advocates view play as a natural human right for every child (Brown & Patte, 2013).

Play for children with life-threatening conditions. 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 and Primomo (2001) describe how many medical professionals have a tendency not to view the child as a whole being but rather to focus on the individual body systems that need care or cause the child pain. These authors indicate that this fragmentation of care can lead to medical professionals ignoring the whole child and the lived experiences at the end of life. In addition, medical 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). 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 to and need of the opportunity to be a child and to 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; Koukourikos, Tzehe, Pantelidou, & Tsaloglidou, 2015).

A child life-and-play therapist frequently uses play in hospital settings to familiarize children with medical procedures, provide a distraction, and foster communication with hospitalized children to reduce and improve the child’s reaction to medical care (Burns-Nader & Hernandez-Reif, 2016). Two recent systematic reviews found inconclusive results for the use of play to reduce anxiety and negative behaviors in perioperative conditions and invasive procedures, noting that the studies that have been done often lack sufficient rigor (da Silva, Austregésilo, Ithamar, & de Lima, 2017; He, Zhu, Chan, Klainin-Yobas, & Wang, 2015). In response, Li, Chung, Ho, and Kwok (2016) examined the effects of intervention through play to help children to deal with the general stress of hospitalization using a quasiexperimental design to compare usual medical care to play-based intervention for hospitalized children. The play-based intervention used a standardized protocol that allowed children some choice in play activities. The results indicated that children in the play group exhibited fewer negative emotions and had lower levels of anxiety than children who received usual care.

Occupational therapists have linked playfulness to a child’s ability to cope with adversity (Hess

& Bundy, 2003; Saunders, Sayer, & Goodale, 1999). One study supervised by occupational therapists examined the impact of self-selected play on hospitalized children's stress (Potaszi, Varela, Carvalho, Prado, & Prado, 2013). Hospitalized children were randomly assigned to a no-play condition and a play condition where children's spontaneous play was supported but not directed in a play environment. Children assigned the play condition demonstrated greater stress reduction overall than children assigned to the no-play condition.

This preliminary evidence suggests that occupational therapists can have an important role in normalizing the hospital experience for children though providing opportunities to participate in typical activities that may or may not be directly related to their medical needs.

Occupational Therapy Research for Individuals with Life-Threatening Conditions.

Researchers have examined occupational participation among adults facing life-threatening illnesses. Lyons, Orozovic, Davis, and Newman (2002) examined the experiences of day hospice participants using focus groups, interviews, and observations. The researchers found that participants expressed regret about having to give up activities that had previously given them a sense of independence or pleasure. The researchers also found that engagement in occupation helped participants maintain their well-being. Vrkljan and Miller-Polgar (2001) examined the importance of occupation in a qualitative study of three women diagnosed with breast cancer. They reported that doing equalled living for the participants, and that engagement in meaningful occupations had a strong connection to the women's perceptions of their health and capabilities. The women found that meaningful engagement in occupations helped them to feel that they could still maintain their roles and daily routines even in the face of a life-threatening diagnosis. Jacques and Hasselkus (2004) reported that participants in their qualitative study of hospice residents chose to engage in occupations that were important to them and appeared to appreciate ordinary daily activities. Lala and Kinsella (2011) examined the nature of occupation at the end of life through interviews with eight individuals who were facing dying and death; seven of the interviewees lived at home while one lived in a long-term care facility. Participants spoke of sadness and depression around difficulties completing even simple daily activities, such as chewing and eating. Occupations involving social relationships were particularly important to many participants.

Shortcomings of previous research. Researchers have discussed the importance of occupational therapists addressing engagement in meaningful activities through the end of life (Jacques & Hasselkus, 2004; Lala and Kinsella, 2011; Lyons et al., 2002; Vrkljan & Miller-Polgar, 2001). In addition, authors have focused on the importance of play as a meaningful and important occupation for children (Kuhaneck, Tanta, Coombs, & Pannone, 2013; Parham & Fazio, 2008; Reilly, 1974) and for children who are hospitalized (Potaszi et al., 2013). However, there is no research that has specifically examined the use of play by occupational therapists working with children with life-threatening conditions (CWLC). The purpose of this study was to describe how and why some occupational therapists use play when working with CWLC and to gain a better understanding of their view of the importance of play for children who are dying.

Method

Design and Procedure

This study used a combination of narrative techniques and interpretive phenomenological analysis to collect and analyze data. Both narrative approaches to collecting and interpreting qualitative data and interpretive phenomenology align well with research in occupational therapy because they

focus on accessing the meaning found in people's day-to-day lived experiences (Bruner, 1986; Kleinman, 1988; Polkinghorne, 1988; Smith & Osborn, 2015). Therapists make clinical decisions based on the meaning they assign to activity and the particulars about patients and populations. Using interviewing techniques that encourage participants to tell specific stories about the topic of interest creates a window into how these therapists are assigning meaning. As each participant makes decisions about how to describe events, he or she interprets the experience for the interviewer. Analysis of these narrative decisions allow the researcher to develop an understanding of the meaning that these events hold for the therapist being interviewed. Asking therapists to narrate this level of specificity can also provide access to the day-to-day meaning-making decisions that occur in the lived world of daily practice (Mattingly, 1998; Mattingly & Fleming, 1994). Interpretive phenomenology seeks to explore meaning making, both at the level of the participant who is making sense of his or her own world and trying to express that meaning, and for the researcher who is attempting to understand the meanings lived by the participant (Smith & Osborn, 2015).

This study focused on a collection of stories told by occupational therapists who work with CWLC. To elicit these stories, semi-structured interviews were designed by the primary researcher and a faculty member with experience using narrative interviewing techniques. 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.

Participants

A recruitment statement was sent 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 the lead author. Therapists were then contacted via email, and four licensed occupational therapists who had worked with CWLC in the past agreed to participate in the study. Inclusion criteria for the therapists in this study were: (a) worked as a registered occupational therapist, (b) had worked with children with life-threatening conditions between the approximate ages of 3 to 8 years, and (c) were willing to discuss their time working with these children

Data Collection and Measures

Each therapist was interviewed three times by the first author. The first interviews were conducted over the phone or via a video chat on the computer, and the second interview was conducted either over the phone or in-person. One final interview took place over the phone. Two therapists participated in an interview with a faculty advisor present via video-chat and the lead author participating by video-chat, and the last therapist participated in an in-person final interview. All interviews were audio recorded. The interviews lasted a mean average of 20 min, with the first interviews being the shortest and the last interviews lasting the longest. Though many narrative and phenomenological interviews are longer, the short format for the interviews was designed to minimize disruption to the therapists' work days. Each of the series of three interviews had specific aims for developing an understanding of the therapists' lived experiences in treating CWLC. 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 tell stories about specific CWLC they had worked with, and 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 session. To help ensure accuracy and credibility,

member checking was performed (Creswell, 2008). Following each interview, the first author spoke briefly with the participant and shared initial thoughts about themes and interpretation of the data shared. Any corrections to interpretation were noted in field notes and were considered in on-going analysis. The first author conducted all interviews and kept a journal log of thoughts and possible biases during data collection and analysis.

Data Analysis

Interview recordings were manually transcribed and analyzed using an interpretive phenomenological analysis model. Transcripts were initially read by the first author and cross-case (between different therapists) and within-case (between different interviews with one therapist) themes were noted. After the initial interviews were completed, all authors read the transcripts, reviewed the initial themes, and identified directions for the following interviews. Once all of the interviews were completed, they were re-read by the first author to create a master list of themes. These themes were then refined through additional reading and discussion among the authors and were eventually narrowed down to four major theme categories. Analysis continued until the first author decided that no new information was needed to support or add to these themes and therefore saturation had been established (Creswell, 2008).

Participant Characteristics

The participants were all female with a mean age of 30.75 years. The mean number of years of practice was 3.25; the mean number of years of practice at their current place of work was 2.63. The low level of experience may be because 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 participant characteristics.

Table 1

Participant Characteristics

Participant	Age, year	Years practicing	Settings worked	Years at current setting
Ann*	28	5.5	Pediatric outpatient, pediatric acute care, pediatric inpatient rehab	4
Claire*	32	4	Pediatric outpatient, adult rehab, adult acute care, pediatric acute care	3
Tanya*	29	2.5	Pediatric inpatient rehab	2.5
Samantha*	34	1	School-based	1

Note. *Names have been changed to protect privacy.

Results

Themes Derived from the Interviews

The use of play in therapy. All of the therapists spoke about using play in therapy with CWLC and finding ways to make the sessions fun for the children. When describing how play was used in a session, all of the therapists described play as being a motivator for the 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, encouraged 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, 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 [was] the real motivating factor.

In the session, the toy was the motivating factor to get the child to participate in a prebathing activity in the pool. The child had previously resisted being in the water, but with this playful interaction with the doll, the therapist was able to get the child to engage.

The 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 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, listened 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 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 that they use it as a means. For instance, Ann said, "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 used in therapy not only as a motivator to get a child to engage in a non-preferred activity, such as toileting or bathing, but also to facilitate other skills with which the child may be having difficulty. For instance, the therapists found ways to work on dressing by playing a game. Ann spoke about how she achieves this in 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 working on goal areas through something fun and playful that motivates the child is essential to being a pediatric therapist. Claire found play to be the main way that occupational therapists 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 is important, especially if you're going to keep the child engaged in an hour session.

Samantha selected games and activities that she knew the child liked but that also worked on the skills they needed to develop:

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 these therapists, play was the main tool they used throughout therapeutic intervention, whether they used it as motivator or as a means to work on another skill or occupation.

The recognized importance of play. In addition to discussing how they used play with CWLC in their therapy sessions, each therapist 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 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 of the therapists recognized the importance of play to childhood learning and development and its use in allowing a child to have fun. In response to the question about whether it is important to facilitate play with CWLC, Tanya said, "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, the therapists agreed that play is constantly used in therapy with children and that play is an important piece of a child's life. In addition, Samantha connected 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 lot of evidence that kids learn best through play and that that's what they need in order to learn 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 [spontaneity] of it, and when a kid can be laughing and goofy and you can get up and dance around.

For all of the 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 being used often as a means or motivational tool in therapy, the therapists stated that there were many instances when purely playful moments occurred. The therapists spoke of moments when therapy began to no longer "feel like therapy." Throughout their descriptions of these moments, words like "playful," "fun," and "laughing" came out in many of the stories. Ann spoke of working with a child who was in the middle of treatment and experiencing drastic mood swings. The nurses were unsure of whether she could tolerate a visit from the occupational therapist, 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, umm, 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 on a moment in therapy when 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.” In addition, 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 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, several of the 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 noted that the child stood up for the first time in days. This was not a skill that she had planned on targeting or even addressing in the session, but through play for the sake of play, the child stood on her own. In addition, when asked the same question about moments in therapy when it felt like she was the one having fun, Samantha responded:

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, 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.” For all of the therapists, their core value when working in pediatrics is fun and playfulness with the children. As they shared their stories of sessions, the ones that 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 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 play occur while faced with a variety of barriers. The therapists spoke about how they face 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 these children's 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 a rapport, carrying on sessions, 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." Due to the complexities involved in most life-threatening conditions, the therapists often had to make difficult decisions about whether a child should receive therapy on a given day. Tanya reflected on the guilt she felt when she pushed a child who simply was not up to the challenges of 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?"

Making the decision about when to push a child to participate involves difficult clinical reasoning tasks. This also relates back to the child's condition impacting his or her 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 his or her condition, they can be deprived of the play they need and even want. Claire noted 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.

In addition, many therapists also reflected on the hospital environment where many CWLC spend a lot of their time as a barrier to play. Many children are often hooked up to a variety of different machines, which can make working with the children and even getting the child out of bed complicated. Ann

described a session where she took a child outside for a walk, but only because of an unusual situation where “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.” In addition, as many CWLC have undergone transplants and other complicated procedures, hospitals have standards of cleanliness that they must uphold to protect these children’s health. These standards create 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.

Throughout the interviews, the therapists described the limitations that the children’s conditions created. It was evident in their stories that they did important work to attempt to overcome these barriers by using flexibility and creativity to help these children participate in the important occupations of childhood.

Allowing more play at end of life. As noted above, many of the therapists noted that a CWLC’s state varies from day to day, making it difficult to decide what to do in therapy on any give day or even whether to have a session at all. In addition, all of the therapists were aware of the reality that when working with CWLC, some children would ultimately pass away. These therapists have the unique experience of working with these children at the end of their lives. The therapists noted that when they realize a child may be at the end of his or her life or when they are not expecting the child to get better, they could allow for purely playful moments, or play for the sake of play. The therapists stressed the importance of allowing the child to do what he or she wants 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:

You know you try to include [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 child 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 play for play’s sake takes over.

Reimbursement. In addition to facing condition-dependent limitations 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 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 the 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 get their services reimbursed.

Claire also spoke about this line between reimbursement and playfulness in sessions by remarking that often therapists cannot even talk about their use of play in sessions because it could not be billed to the insurance company.

I think that one of the reasons that we don’t talk about it a lot is because you’re not ... 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, [be]cause you know everyone knows that weight bearing [is] 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, 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.

Although all of the therapists noted that play was important for children, Claire stated that play ends up being forgotten because insurance companies may not easily pay for it. In addition, she spoke about the challenges that arise 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 [be]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 [for] her or something, odds are I’m probably not going to do that great of a job [be]cause I don’t know the kid and we can’t speak openly about what got that child engaged. 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 reimbursed. This complication has created an “underground practice” of sorts, where therapists are secretly communicating with each other about how they use play with these children because they believe they cannot speak about it openly. Pierre (2001) noted that this discrepancy between what is occurring in therapy sessions and what is documented occurs frequently in professional written communication in the profession, even when the therapist expressed a high value for the undocumented work.

Tanya noted that in working in inpatient rehabilitation, she feels she has a little more flexibility to write goals and document sessions that incorporate play, but that the play goals are never their primary goals for the children, even though for some children she feels that play skills may be what they should be working on.

I think in rehab we’ll still make developmental play goals, [like] “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? These 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 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 these occupational therapists are incorporating play into therapy sessions when working with CWLC and what barriers they face when trying to do so. While all of the therapists had a variety of stories to share, play was repeatedly central to their stories. Pediatric occupational therapists are taught to use play in therapy, however, typically they are taught to use play as a means of getting a child to engage in or achieve another goal (Kuhaneck et al., 2013; Parham & Fazio, 2008; Reilly, 1974). Kuhaneck, Tanta, Coombs, and Pannone (2013) surveyed occupational therapists about their use of play with children. Results indicated that few therapists developed goals for play or addressed play as a therapy outcome, despite the profession's view of the importance of play as an occupation. Although three of the four therapists interviewed for this study stated that play is the most important occupation for children, they often told stories of using play to motivate a child to achieve another goal in therapy, such as upper body dressing, rather than using play for the sake of play and allowing children to be natural players.

In the therapists' stories, however, moments of play for reasons other than a means to an end arose. The therapists began to speak of times in therapy when 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 meaningful when working with these children, and some even found unexpected therapeutic gains arise from these moments of play for play's sake. Despite the meaning the therapists attributed to these sessions, there is only a small amount of literature supporting occupational therapy's role in fostering these purely playful opportunities (Bundy, 1993; Bundy et al., 2008). 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).

This study's findings also draw attention to the barriers that therapists face when working to facilitate play with CWLC. These children often spend a large amount of time in hospital settings. The protocols and standards that hospitals must abide by to prevent infection and the 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 to move a child from his or her bed because of the medical equipment to which they were hooked up. Literature suggests that for all medical professionals, working in a specialized setting can cause many barriers to optimal care (Affleck, Lieberman, Polon, & Rohrkemper, 1986; Boucher et al., 2014; Kane & Primomo, 2001), and there may be an innate tension in facilitating occupation in a biomedical setting (Keesing & Rosenwax, 2011; Wilding & Whiteford, 2007). In addition, while CWLC are in the hospital, they are often there for a variety of other procedures and treatments, not just occupational therapy. The therapists in this study reflected on the difficulties of working with children

undergoing radiation treatment or receiving medications that could alter their mood. They noted that on 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 practical barriers to the therapists' use of play in therapy. The therapists often referred to always needing treatment sessions to tie into reimbursable goals. There was emphasis placed on meeting the goals that insurance companies would reimburse, which often were ADLs 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 being unable to give the child optimal care because she did not know the games that the child liked or that engaged him because it was not documented. The therapists reported that they will leave sticky notes for one another outside of the child's chart to help other therapists understand how to engage the child in play. This type of dilemma is referred to in the literature as underground practice (Mattingly & Fleming, 1994; Pierre, 2001). 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 they also need to adhere to and document the biomechanical goals and treatments that insurance companies will reimburse (Aiken, Fourn, Cheng, & Polatajko, 2011; Mattingly & Fleming, 1994; Pierre, 2001; Wilding & Whiteford, 2007). 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). Despite this recognition, play is primarily used in therapy as a means or motivational tool (Kuhaneck et al., 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.

Limitations and Future Directions

This was a small-scale study with a small sample. All of the therapists interviewed were female and had 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. In addition, a large-scale mixed methods study could be done to determine how the findings from this study translate to a larger population size in order to continue research in an under-researched practice area. This study explored therapists' reports of the use of play with CWLC and did not investigate the importance of play for families or for the children who may be facing death and dying. Weaver et al. (2016) emphasize the importance of considering the voices of the children themselves in pediatric palliative care and of including siblings and grandparents as integral to the family unit. It would be helpful for future studies to consider the family perspective and to consider the importance of play to the family. Cheung and Li (2008) posit that one's cultural background may impact his or her views on health maintenance and on play. In addition, it is possible that when caring for CWLC, the play may be viewed as less important than the myriad other tasks to which families must attend. As Smith, Cheater,

and Bekker (2015) indicate, parents may exert tremendous energy to maintain normalcy in their families when caring for a child with a significant medical condition.

Implications for Occupational Therapy

Because of the lack of literature addressing this topic, this study aimed to begin the discussion of how occupational therapists are working with CWLC. The therapists interviewed described the importance of play in working with this population along with the barriers to its inclusion in daily practice and documentation. Play is acknowledged as being an integral part of pediatric occupational therapy practice, but research that explores its use as an end in practice is limited. 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., 2002; Vrkljan & Miller-Polgar, 2001) where similar findings about the numerous barriers to providing occupation-based services are noted (Keesing & Rosenwax, 2011). This study suggests that there is an important role for occupational therapists in working with CWLC. As such, it is important to continue to define how play can be used as both an ends and a means in such pediatric practice and to work to overcome the barriers to play inherent in the children's conditions, the hospital environment, and the practical realities of insurance reimbursement. In addition, we propose that the scope of practice for occupational therapists working with children and families facing life-threatening conditions needs to be more clearly defined and described so that education about how and when to facilitate play and participation in meaningful occupations can be addressed, and we can advocate for broader reimbursement of play-based interventions with this population.

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