
Parents' Understanding of Play for Children With Cerebral Palsy

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MeSH TERMS

- cerebral palsy
- comprehension
- parents
- play and playthings
- play therapy

OBJECTIVE. To present the findings of an exploratory study regarding the experience of play as an everyday occupation for children with severe cerebral palsy from their parents' perspective.

METHOD. We took a qualitative methodology and interpretive descriptive approach. After ethical approval, 7 participants were recruited and completed an interview and contextual information sheet.

RESULTS. The interview data led to the exploration of four themes: typical play, burden of play, expanding the concept of play, and therapy and play. These components were interlinked and contributed to parents' understanding of play.

CONCLUSION. Occupational therapy practitioners can aim to further understand the importance of affirming typical play, recognizing the burden of play, explaining expanded play, and explaining the importance of play for play's sake.

Graham, N. E., Truman, J., & Holgate, H. (2015). Parents' understanding of play for children with cerebral palsy. *American Journal of Occupational Therapy, 69*, 6903220050. <http://dx.doi.org/10.5014/ajot.2015.015263>

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Play is a concept that has been widely debated and is often hard to define (Sheridan, Howard, & Alderson, 2011). Seminal work and play theory originally defined play within concrete stages of development (Piaget, 1951). Since Piaget, theory has expanded to incorporate a more dynamic and flowing definition of play. A widely recognized definition is that *play* is an activity incorporating freedom, choice, and control (Sheridan et al., 2011). Skard and Bundy (2008) have explained a child's playfulness as a balance of these three components; the closer these components are on a continuum toward free play, intrinsic motivation, and internal control, the closer the balance tips toward play. In this study, we aimed to understand the concept of play for a particular population; therefore, we did not explore children's playfulness in terms of the extent to which play is experienced.

Play is a dominating component of a child's everyday life (Chiarello, Huntington, & Bundy, 2006), and all children have a right to play, according to Article 31 of the United Nations Convention on the Rights of the Child (UNICEF, 1989). Because occupational therapy practitioners are concerned with everyday occupations and activities, play is an important consideration for those working with children. The seminal work of Mary Reilly (1974) highlighted the importance of play as a primary occupation and premise for learning. Despite the recognition of play as an everyday occupation, however, research has suggested that children with disabilities often experience limitations in the extent to which they can participate in typical play activities (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011) yet has not indicated ways in which children with disabilities can play.

Cerebral palsy (CP) is defined as a group of disorders of motor function resulting from a nonprogressive lesion or abnormality of the developing brain (Surveillance of Cerebral Palsy in Europe [SCPE], 2011). It is a long-term condition

affecting between 1.5 and 2 children per 1,000 live births (SCPE, 2011). This study links together an expanded concept of play for parents of children with severe CP (Graham, Truman, & Holgate, 2014), the burden of play, how parents understand their children's play, and how this understanding links to parents' engagement in the therapy process.

Literature Review

Play has been found to enhance children's development and learning (McInnes, Howard, Miles, & Croley, 2009). The *International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY*; World Health Organization [WHO], 2007) suggested that play is an important component of children's lives. Play as a concept is therefore important to explore.

Play as a Concept

Within the literature, the concept of play has been widely debated; it has been defined by its educational components (Ginsburg, 2007) and, conversely, by its freely chosen components (Goodley & Runswick-Cole, 2010). Play has been reported as children's primary occupation (Rigby & Gaik, 2007), and unstructured play has been found to improve children's self-efficacy (Starling, 2011). Childress (2011) suggested that facilitated and educational play can aid learning and development, and McInnes et al. (2009) suggested the same for free play. Goodley and Runswick-Cole (2010) argued that activities focusing on education cannot be seen as true play. Much debate exists as to what constitutes play; further research needs to ascertain whether true play can involve education or purely consists of play for play's sake.

Therapists' Perspectives on Play in Therapy

Play has been used as an assessment tool to show the skills children use in play (Bundy, 2010); play is also useful in other aspects of therapy. A study carried out at the Bobath Centre (London), which uses play during therapy, found significant improvements in function and self-care skills after 6 wk of therapy (Knox & Evans, 2002). Play appears likely to have a positive contribution to skill acquisition, and research has suggested that free choice and leisure activities increase children's motivation to participate in therapy and build rapport with the therapist (Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2010).

Parents' Perspectives on Play in Therapy

It is possible that parents' view of play differs from that of therapists. Despite play being an everyday occupation for

children, research has found that parents' priorities for therapy are often based on physical development with little regard to play (Knox, 2008). Parents' understanding of play may be affected by their child's functioning; children with a high level of physical disability play and interact in a very different manner from those who are physically able.

Parents are responsible for facilitating their children's home programs, which allow them to practice the skills they have learned in therapy and bring them into their everyday life (Novak, 2011). Time constraints often restrict parents' ability to carry out home programs (Piggot, Hocking, & Paterson, 2003). Home programs focused on play, an everyday activity, may be easier for parents to implement.

Study Aims

Play is an everyday occupation for all children and has been demonstrated as such by the literature and by frameworks such as the *ICF-CY* (WHO, 2007). As an everyday occupation, play is important for development, health, and quality of life for children (Chiarello et al., 2006). Currently, research exploring play for children with severe CP is lacking, and further research is necessary to understand play as a concept for children with CP. In this study, we therefore aimed to explore parents' understandings of play for their children with severe CP. Within this aim, we had two specific objectives:

1. To explore parents' understandings of how their child with severe CP plays
2. To explore parents' understandings of how play is used as a therapeutic tool within therapy and home programs.

Method

We used a qualitative methodology and interpretivist paradigm from a constructionist perspective for this study. The interpretive descriptive approach allows the investigation of a phenomenon within the context of practice (Thorne, 2008). This approach aims to explore each participant's view from the perspective that each individual will have a different interpretation of the concept of play; meaning is constructed through interactions between participants' views and the researcher's perspective (Bunniss & Kelly, 2010). The Southampton University ethics committee approved the study's design.

Participants

A convenience sample of 7 parents was selected for this study. Participants were recruited by referral from the Bobath Centre (2010), a British charity providing occupational, physical, and speech therapy for children with CP. The inclusion criteria were as follows:

1. Children with severe CP, or Gross Motor Function Classification System (GMFCS) Level 4 or 5 as assessed by Bobath Centre therapists. (The GMFCS is used to measure the level of physical functioning a child has. Levels range from 1 to 5; children at Level 1 are able to walk and run, and children at Level 5 need support for sitting; Knox, 2008.)
2. Children between ages 3 mo and 9 yr
3. Parents living in Buckinghamshire, Hampshire, Hertfordshire, Greater London, Oxfordshire, Surrey, or Sussex (enabling the researcher to travel for interviews). Parents of children without a diagnosis of CP and parents who were unable to speak English fluently were excluded.

The primary researcher (Naomi E. Graham) undertaking the interviews was based at Southampton University and neither knew the families nor had therapy interaction with them. All participants were given details of a national charity, Scope (London), which can support parents of children with disabilities and could discuss the study with the primary researcher or clinical supervisor if parents felt distressed.

Data Collection Tools

We used a contextual information sheet to collect brief demographic details about the parent and child with CP, the level of functioning of the child, and the number of other children in the family, thus avoiding beginning the interview with closed questions. In-depth, semistructured interviews were carried out in the participants' homes. An interview schedule was used that provided key topics and prompts to guide the researcher. The interview schedule included questions such as "Can you think of and describe a play experience your child has had within the past week?" and "Has your child ever engaged in play in a way you didn't expect? Can you describe this?" Supplementary questions allowed the researcher to ask parents to

expand on their answers. Parents were asked to recall and discuss a recent play experience, other typical play, unexpected play experiences, therapist play, home programs, and play in their child's home program.

Procedure

A separate pilot interview was undertaken to refine the interview schedule and analysis process. The study interviews were arranged through the primary researcher's supervisor. The primary researcher conducted all interviews and analysis. An opportunity for questions was allowed before completion of the consent form, contextual information sheet, and audio-recorded interview. Each interview lasted between 1 and 1.5 hr.

The data were transcribed verbatim; pseudonyms were used to protect participants' confidentiality. The primary researcher demonstrated reflexivity and trustworthiness by recording thoughts and observations in a research diary throughout the research process. The interpretivist perspective suggests that every person will have a different view of play; consequently, data saturation was neither aimed for nor reached (Caelli, Ray, & Mill, 2003).

Analysis

Data analysis followed the four-stage interpretive descriptive approach: (1) understanding the data through reading and rereading transcripts; (2) coding and synthesizing meaning by asking questions about the data, such as "What does this mean?"; (3) finding relationships among the data by comparing the transcripts; and (4) recontextualizing the data by applying the findings to occupational therapy practice (Thorne, 2008). This process is exemplified in Table 1. The primary researcher undertook the analysis but discussed it with two supervisors; the analysis process began after the first interview

Table 1. Example of Data Analysis Process

Stage	Example	Notes on Analysis
1. Gaining an understanding of the data	"Which is awful, isn't it, because I have to play with him, and I don't want to." (Jane)	Transcribing, reading, and rereading the data helped with familiarization.
2. Coding and synthesizing meaning	Quote from Jane coded as "Burden of play—Burden on parent"	Asking "Why is this here?" led to thinking about why play is a burden and why parents feel guilty when not playing. Is this worse for Jane as a single parent?
3. Finding relationships among the data	"But everything, everything takes more work—feeding, playing, everything." (Peter)	Comparison between transcripts; Peter's quote explains a bit more why facilitation of play can be a burden—because it can feel like it takes more work.
4. Recontextualizing the data	Play taking more work and being difficult for parents to facilitate was linked to the child's level of disability and led to comparing this level to GMFCS levels (Knox, 2008).	Application to practice in terms of how play is facilitated according to disability—how therapists encourage and enable facilitation.

Note. GMFCS = Gross Motor Function Classification System.

and continued until all participant data were analyzed. Throughout the analysis, the primary researcher referred to each participant's contextual information sheet.

Findings

The 7 parents ranged in age from 29 to 42 yr and were from a variety of socioeconomic backgrounds. Participant contextual information can be found in Table 2. Analysis of the data led to the development of four themes: *typical play*, *burden of play*, *expanding the concept of play*, and *therapy and play*.

Typical Play

Within the theme of typical play, parents focused on three subthemes: playtimes, play as a primary occupation, and play as any other child. Playtimes involved specific times of the day at which children were likely to play. All the parents in this study referred to elements of their child's routine that involved play. Parents most commonly reported playtimes occurring at bath time, as part of the morning routine, and at school. Parents often referred to the opportunity to play after school: "You've picked him up after after-school club and work, and he just comes in through the door, 'Play!'" (Jane).

Frequent mention of playtimes illustrated that in each parent's eyes, play was their child's primary occupation. Even the parents of children with severe disabilities who could not typically participate as much in play referred to their children as playing all the time. This view was often referred to as play being at the forefront of every child's mind:

At the moment, whatever age he's at, the only thing on his mind is playing, in each and every sense. . . . Even if it's studying, even if I ask him to write something, first he'll be doing drawings. (Sanna)

Finally, parents considered each child's play typical in that they spoke of their children playing as would any other child. In addition to mentioning the time spent playing, parents made references to age-appropriate and gender-specific types of play and toys. Although parents often commented on how their child's play was similar

Table 2. Summary of Participant Contextual Information

Child Characteristic	Parent Pseudonym						
	Jane	Peter	Sanna	Emma	Genna	Anna	Sarah
Pseudonym	Jack	Harry	Tom	Harry	George	Laura	Eve
Age	6 yr	17 mo	6 yr	17 mo	3 yr	5 yr	5 yr
GMFCS	4	5	4	5	4	5	4

Note. GMFCS = Gross Motor Function Classification System.

to that of other children, they simultaneously admitted this play occurred within their child's limitations: "He does painting and all sorts of things . . . so he does a lot of things that normal children do but at his level" (Peter). These elements of typical play discussed by the parents in this study suggested that they needed to see their child as similar to typically developing children.

Burden of Play

Each parent discussed the burden of play, which included burden on parents, a tag team of support, and each child's physical disability. The burden on parents was clear throughout all the interviews, and it included the time and energy parents needed to play with their child, the need to facilitate their child's play, the burden of incorporating therapy into play, and the need for more than one person to facilitate therapeutic play. Some parents discussed feelings of guilt and jealousy resulting from being unable to leave their child to play:

It isn't the easiest thing in the world to do, having a social situation, you know, sort of "mums' coffee mornings," because you don't feel that you can leave him to play on his own, really. . . . I feel that if he's in his bouncy chair and I'm talking to people, then that's at the expense of his playing. So it tends to be more that I would sit on the floor with him and engage with him and then go back to chatting. (Emma)

The difficulty with leaving children on their own appeared to be linked to each child's physical disability. Parents discussed limitations with children being unable to physically manipulate or access toys.

That wondering, Is she really quite content, or bored just sitting there? The idea of just leaving her and knowing that she can't instigate, pick up a toy, or amuse herself. (Anna)

The parents in this study did, however, have a strategy to help overcome the burden of play: All the parents discussed a team of people and resources that allowed them to carry out other household and care tasks while their child played. These people included spouses, grandparents, school staff, volunteers, paid caregivers, the child's friends and siblings, and technology: "My Mum and Dad come up regularly, and yeah, they're very good with her. . . . [Caregiver] comes on a Saturday, and she plays with her regularly" (Sarah).

Expanding the Concept of Play

Although parents discussed play similar to that of typically developing children, the parents also expanded the concept

of play. This expanded view of play included vicarious play, play through communication, and therapy in play. This aspect of the study is reported more fully in Graham et al. (2014).

The idea of children experiencing play without being able to physically participate in the activity emerged as a result of the interviews:

They don't tend to interact and play, the three of them, but she loves watching them play and will be encouraging them by saying, "Oh, look what they're doing" or "[Cousin] is being naughty and doing this" or "Everybody jump in the tent." . . . So she can comment on the activity and at the moment doesn't seem to have a problem with the fact that she's not physically participating. It seems to me that she thinks she's fully joining in by commenting and watching. (Sarah)

Communication was reported as an element of play in two different ways. For the children with significant cognitive impairment, it seemed that participating in playful conversation was a means of playing. For other children who were cognitively able and could communicate their thoughts but had physical impairments, communication skills featured predominantly in their play.

The parents were divided in their opinion of play and therapy. Some parents expanded their concept of play to include therapy, and others saw play and therapy as very separate entities (Graham et al. 2014).

Therapy and Play

The theme of therapy and play particularly focused on how parents carried out their child's play and therapy, which involved automatic thinking, play with no focus on therapy, and play as a motivation or reward. *Automatic thinking* was an expression used by one of the parents to describe the process by which they incorporated therapy into their child's play. Throughout the interviews, all the parents mentioned to some extent how they would automatically remind their child to, for example, use their affected limbs. One mother summarized her thinking process:

The first thing that comes into your head would be his posture. Whatever you're trying to do, you would just be thinking, what posture should he be in, not be in? Now, if you're trying to play something, you're going to be thinking how you should be doing it, how you should not be doing it. And then third thing you'd be moving onto, you would be thinking, What am I going to achieve out of it, what can I do more so he's getting that good stretch, good posture, good in the moment in every way in his body? Then once that's settled, then you think, OK, so he should be getting more out of it; how can I make it more fun, exciting for

him? So it's a step-by-step process that happens automatically with each and every thing. (Sanna)

Despite this automatic thinking, all parents also referred to times at which they chose to allow their child to play with no focus on therapy. This kind of play seemed important to parents because it allowed their children to have fun and experience free play without any restrictions: "Some things are not good for him, and you feel like he shouldn't be doing this, but you can see that he's enjoying it so much and you're thinking, let's forget about it, let him enjoy" (Sanna).

Finally, all the parents also used play as a motivation or reward; it appeared to encourage children to participate in therapeutic activities that they might otherwise find difficult: "I guess you're subtly incorporating things that will help her, but making it fun so she's motivated to do it" (Sarah).

As concepts, parents' construction of play and therapy appeared to influence the frequency with which they facilitated their child's play or therapy. Parents who felt that play and therapy were intertwined concepts appeared to frequently facilitate their child's play; parents viewing play and therapy as separate discussed specific but less regular occurrences in which they facilitated their child's therapy.

Discussion

Typical Play

A number of core components of play are the same for parents of both typically developing children and those with CP; this includes play routines (Harkness et al., 2011) and play as a primary occupation (Chiarello et al., 2006). Rehm and Bradley (2005) suggested that a sense of normality and a view of their child as typical enables parents to cope with their child's disability. MacDonald and Gibson (2010) disagreed, suggesting that in normalizing the daily activities of a child with disabilities, parents may hinder their ability to cope. It may be that recognizing the differences in their child's play allows parents to better cope and adjust to their child's CP.

Burden of Play

All children require opportunities to play; adults need to physically facilitate this play for children with severe disabilities (Chiarello et al., 2006), which places a burden on parents who already experience burden because of the responsibilities they have caring for their child (Woodgate, Edwards, & Ripat, 2012). Drawing on a tag team who provides support enables parents to share their burden, thus reducing their stress and leading to better outcomes for their child and their own well-being (Bourke-Taylor,

Howie, & Law, 2010). In addition to the burden of play for play's sake, parents reported feelings of guilt for not incorporating therapy into their child's play; this guilt has been reflected in the literature (Novak, 2011).

Expanding the Concept of Play

Parents expanded the concept of play to involve play that may not be defined as play for typically developing children. Child development theory can be used to explain experiences such as vicarious play and play through communication. Piaget (1951) described *practice play* as the first stage of play based in the sensory-motor stage of development. At this stage of development, children carry out play through their senses and imitate or respond through the use of their body. Children with CP may remain at a sensory-motor level of development; thus, therapists can expect their play to be vicarious and through communication.

The incorporation of therapy into everyday activities is widely promoted by therapists (Piggot et al., 2003). However, Goodley and Runswick-Cole (2010) have argued that true play cannot be experienced when activities focus on therapy components. This study's findings would suggest that parents saw their children as experiencing play during therapy. It is possible that children with severe disabilities may be enabled to experience play to a fuller extent when it incorporates therapy (Graham et al., 2014).

Therapy and Play

The ability to automatically think about therapy and play at once could be attributed to parents becoming experts in their child's therapy. The idea of parents as experts has been increasingly seen in the literature (Novak, 2011) and could be likened to the journey from novice to expert practitioner; as parents practice their therapy skills, they begin to think automatically. An expert practitioner has been seen as someone who is a master in his or her field and can respond to practice situations automatically (King, Jackson, Gallagher, Wainwright, & Lindsay, 2009).

Carrying out play with no focus on therapy can be clearly linked to the occupational engagement literature. Participation and engagement in an activity can occur purely through sensorimotor experience (Polatajko et al., 2007). Play even without a focus on therapy has developmental benefits for all children (Fisher, Hirsh-Pasek, Golinkoff, & Gryfe, 2008); therefore, parents should not feel guilty for allowing free-choice play. Play experiences in themselves can be seen as therapeutic; occupational therapy practitioners could encourage parents in enabling their children to play for play's sake.

Illustrating the Linked Concepts

The findings suggest that the way parents of children with CP understand play has several components. Four themes, each with three connecting subthemes, can be linked to demonstrate this understanding, as shown in Figure 1. Gears were chosen to illustrate each component; when one gear turns, it leads to another turning. This analogy demonstrates the close relationship between each element of parents' understanding of their child's play. Links between these components were seen throughout the interviews, as demonstrated in the following quote, in which Jane recognizes the importance of typical play with other children, discusses the burden of the need to facilitate play, demonstrates how Jack plays through watching, and recognizes that play for play's sake is important yet describes facilitation within play:

I have to play with him, and I don't want to, which is a terrible thing to say, but I don't, I don't want to, and I get very, very envious when I see my friends' kids. I went round to somebody's house for lunch the other day, and we were in the garden for 2 hours, and I think the kids came up maybe twice to just ask for something—"Can I have an ice lolly?" or something. And they just spent that on the trampoline and just running around the garden and talking to each other and playing. I just thought, Wow, it's so, so different, you know. I would have been there, he would have wanted to be on the trampoline, and I would have been there on the trampoline with him. . . .

So when [friend] came round—that's his best friend from school—and we did, we were building the marble run, so Jack really likes the marble run. And that was kind of me and [friend] building it and Jack kind of watching and telling him where bits were and thinking, Jack is quite good at thinking through, you know, "try and turn that round" or something, and he can communicate that. I think he can see what's happening, so he does that. (Jane)

Implications for Occupational Therapy Practice

The implications for occupational therapy practice resulting from each theme are also presented in Figure 1. Occupational therapy practitioners can aid parents in their normalization process; recognize that because play is an everyday occupation, the facilitation of play can place a burden on parents; enable parents to understand an expanded concept of play; and recognize the importance of play for play's sake. By explaining child development theory, practitioners may enable parents to better understand that their child's play is normal but that their child's progression through the developmental stages is

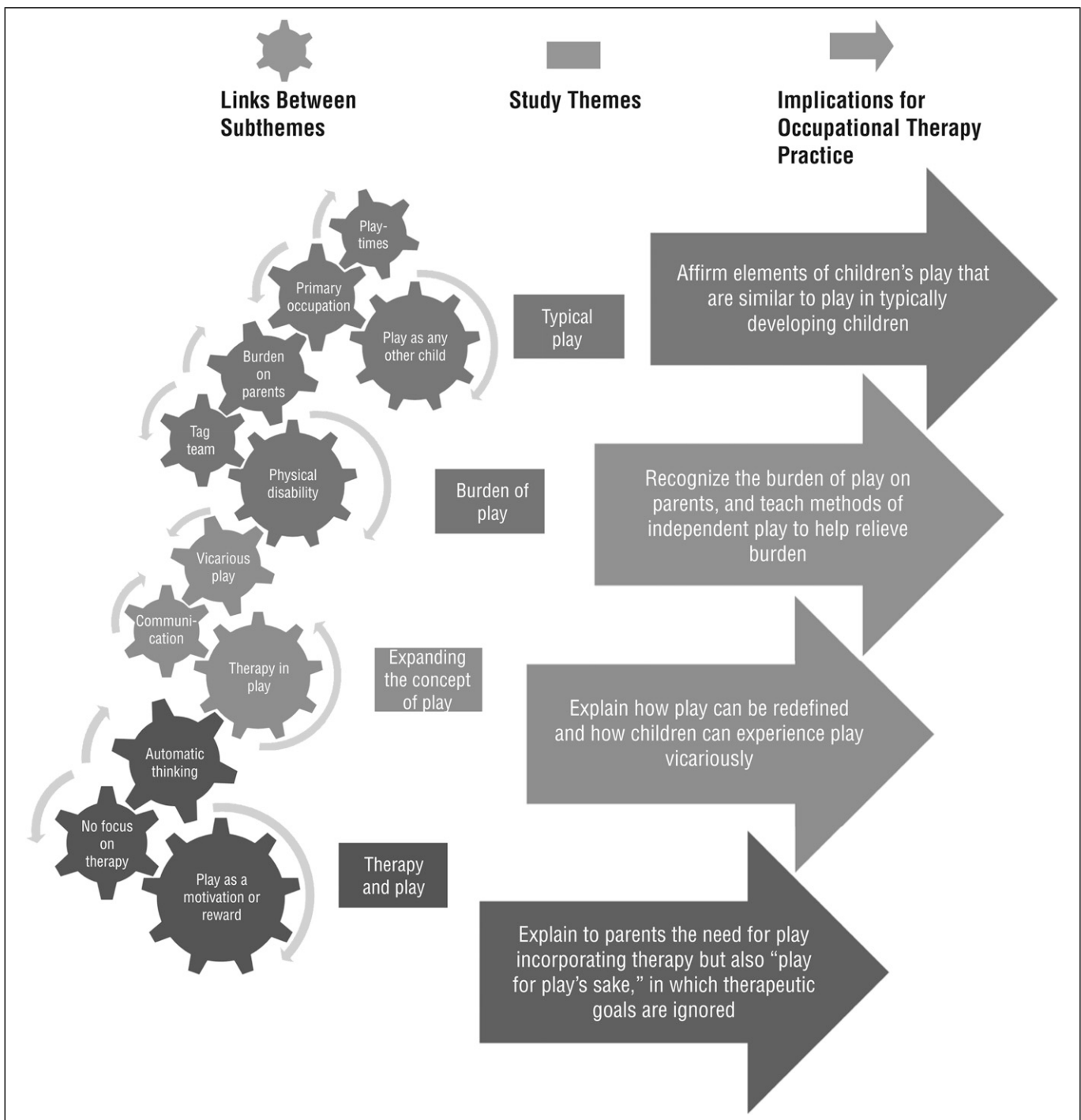


Figure 1. Illustration of parents' understanding of play for their children with cerebral palsy and implications for occupational therapy practice.

slower than that of a typically developing child. Practitioners may be able to help reduce the need for parents to facilitate play by teaching children independent play skills that allow parents the opportunity to carry out other household tasks. The implications of this study for occupational therapy practice are summarized as follows:

- A multifaceted understanding of play is needed for children with severe CP.
- Play is an everyday occupation that often needs to be facilitated for children with severe disabilities. Helping

parents with play facilitation may be an important role for occupational therapy.

Limitations and Future Research

This study used a small convenience sample from a population of parents whose children all had similar therapy experiences, which could reduce the transferability of the study findings. Parents were aware of the study aims, which may have skewed their reporting of their participation in therapy programs.

Further research could explore in more detail the nature of vicarious play, play through communication, and therapy in play for children with CP and other disabilities, including practitioners' use of this play in practice. The burden of play for parents is not discussed in the literature; further research could address the impact of the amount of time parents spend facilitating their child's play. Finally, researching independent play opportunities for children with severe disabilities may enable practitioners to teach play strategies that help reduce the burden of play on parents.

Conclusion

Our findings show that parents of children with CP have a multifaceted understanding of play and its use in therapy. Although the findings are specific to the study sample, occupational therapy practitioners can use them to develop their understanding of different parents' perspectives on play. By recognizing parents' understandings of play in this population, practitioners can better understand and champion play as an everyday occupation for children with severe CP. ▲

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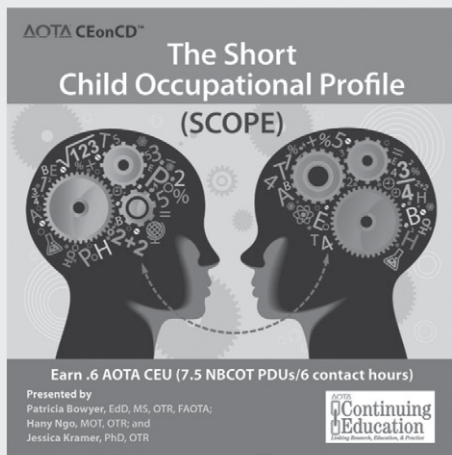
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