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Playing with a Child with Down Syndrome: The Anxious Mother's Experience

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Under the direction of the research advisor:

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A Research Project Entitled

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By

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Abstract

Background: Play is an essential occupation for children and has a role in facilitating proper child development. The demands related to caring for a child with a disability can be anxiety-inducing for some caregivers, which may impact how they play with their child.

Study Aim: The purpose of the study was to explore the anxious caregiver's experience of playing with their child with a disability.

Methods: A case study design was used to explore the unique experiences of two mothers with 5-year-old children with Down syndrome. Researchers used semi-structured interviews to gather information. An inductive analysis approach was used to derive themes from the data gathered.

Findings: Qualitative data from the caregiver interviews centered around three themes: the need to make play educational or purposeful, comparing themselves to other families of children with disabilities, and overall happiness during play with their child in spite of their anxiety.

Conclusion: When caring for a child with Down syndrome, anxiety may impact parent-child interactions during play. Play may feel more like a task and less like an enjoyable co-occupation. Caregiver anxiety is important to consider during occupational therapy intervention, as it may impact the caregiver's overall quality of life, in addition to their child's play.

Literature Review

Play is defined as “any spontaneous or organized activity that provides enjoyment, entertainment, amusement, or diversion” (Parham & Fazio, 1997, p. 252). For children, play is a critical occupation that can provide developmental benefits (Graham, Truman, & Holgate, 2014). Children who have disabilities may experience difficulties engaging in this fundamental activity, which often leads to the need for parental facilitation (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011). Another key difference regarding the play of children with disabilities is the unique forms of play that occur. Children with disabilities frequently participate in adaptive forms of play that may include play through communication, vicarious play, and therapy through play (Graham et al., 2014).

Caring for a child with a disability can be an extremely demanding role (Bourke-Taylor, Howie, & Law, 2010). Caregivers must work to balance a variety of issues related to their child, which may include behavioral problems, educational concerns, and medical services (Bourke-Taylor et al., 2010). Additionally, there may be challenges with the rest of their family and their home, such as financial problems (Bourke-Taylor et al., 2010). This combination of responsibilities placed on the caregiver frequently leads to mental health issues, such as anxiety and depression (Whaley, Pinto, & Sigman, 1999). Existing research provides data on how anxiety affects the caregivers themselves but lacks information on how it may affect interactions with their child, specifically related to play.

Play for a Child with Disabilities

The Americans with Disabilities Act (ADA) defines an individual with a disability as “a person who has a physical or mental impairment that substantially limits one or more major life activities” (Americans With Disabilities Act, 1991, Section 12102). Occupational therapists label

the ADA's phrase 'major life activities' as *occupations*, or "everyday activities that people do as individuals, in families, and with communities to occupy time and bring meaning and purpose to life" (American Occupational Therapy Association [AOTA], 2014). Occupations are unique for every individual, based on cultural, personal, temporal, and virtual contexts, as well as the individual's physical and social environments (AOTA, 2014). The occupation of play, which takes many unique forms, is considered to be one of the most important occupations for children. It is also the occupation that is most likely to be affected for a child with a disability (Ginsburg, 2007).

Developmental benefits. Play, which includes play exploration and play participation (AOTA, 2014), is an occupation that is essential to a child's development, providing benefits related to cognition, socialization, communication, and creativity (Fabrizi, Ito, & Winston, 2016; Missiuna & Pollock, 1991). Play helps children gain important skills such as working in groups, sharing, decision-making, and problem solving (Ginsburg, 2007; Missiuna & Pollock, 1991). Through play, children can discover and engage in activities related to their own unique passions, while also learning about the characteristics of objects in their environment (Ginsburg, 2007; Missiuna & Pollock, 1991). In addition, play can have benefits related to the academic environment, like enhancement of school readiness skills and the ability to learn (Ginsburg, 2007). Missiuna & Pollock (1991) also identified that children with physical disabilities may develop secondary disabilities if play deprivation occurs. These secondary disabilities include increased dependency on a caregiver, decreased intrinsic motivation, low self-esteem, and poor social skills (Missiuna & Pollock, 1991).

Barriers to play and necessary adaptations. A child who has a disability may experience challenges related to play exploration and play participation. The impact of a

disability on a child's capacity to play can range from mild to severe, depending on the type of disability and the type of play that is desired (Missiuna & Pollock, 1991). Existing research indicates that children with physical disabilities may face barriers with regards to their play activities (Bult et al., 2011; Missiuna & Pollock, 1991). According to Bult et al. (2011), children with physical disabilities are less likely to engage in play or leisure activities than their physically healthy peers. Common barriers to play include limitations imposed by caregivers such as being too overprotective during play, and personal limitations of the child such as limited physical mobility or communication skills (Missiuna & Pollock, 1991).

Much of the existing body of research indicates that children with disabilities will require facilitation with their play activities (Bult et al., 2011; Graham et al., 2014; Missiuna & Pollock, 1991). These reasons may include lack of mobility, limited communication skills, impaired sensory abilities, and difficulty with motor skills, such as reaching and grasping (Missiuna & Pollock, 1991). There may also be intrinsic factors that can cause a child to need facilitation with play including lack of motivation and drive, withdrawal—due to frustration, and decreased concentration (Missiuna & Pollock, 1991). Environmental barriers such as not having a physically safe home or community can also limit the play activities of a child with a disability (Missiuna & Pollock, 1991).

The experience of play can be adapted so that participation is possible for a child with a disability. Ways of adapting play may include facilitation of play by an occupational therapist or the child's caregiver, or expanding the concept itself to include unconventional ways of playing. Occupational therapists have the knowledge and skills needed to help create and maximize opportunities for play among children with disabilities (Missiuna & Pollock, 1991). Unconventional ways of playing that are likely to be more successful for children with

disabilities include play through communication, vicarious play, and therapy in play (Graham et al., 2014). Play through communication refers to enjoyment and satisfaction gained from participating in playful conversations, while vicarious play is gaining the same enjoyment of play through watching and providing comments on the activity without physically participating (Graham et al., 2014). Therapy in play allows children to make their own choices in order to motivate them for therapy (Graham et al., 2014).

Play among children with Down syndrome. Children with different disabilities experience unique challenges engaging in play with their caregiver. In a study conducted by Bentenuto, de Falco, and Venuti (2016), researchers found that children with Autism Spectrum Disorder (ASD) participate in more exploratory play than typically developing children or children with Down syndrome. However, findings of another study indicate that children with Down syndrome engaged in significantly more exploratory play with their mothers as opposed to play by themselves. Additionally, children with mothers who displayed higher sensitivity to their child's specific needs during play engaged in more symbolic play compared to children with mothers who displayed lower sensitivity to the child's needs (Gokhale, Solanki, & Agarwal, 2014; Venuti, de Falco, Giusti, and Bornstein, 2008). Children with Down syndrome display less advanced exploratory play skills when compared to children of similar cognitive abilities, which can be attributed to their attention, visual, physical, and cognitive deficits (de Falco, Esposito, Venuti, & Bornstein, 2010). Because of these deficits, children with Down syndrome may require increased caregiver facilitation during play to promote growth in play exploration skills. It is important to understand the unique needs of children with different disabilities so that the occupation of play can be adapted for successful participation for all children.

Caring for a Child with Disabilities

Although caregivers recognize that play is very important for their child, it is sometimes forgotten amidst a wide array of other responsibilities related to their child's health and well-being. A child with a disability will most likely require some level of assistance with activities of daily living (Ma & Mak, 2016). Children with disabilities often have special medical, educational, and developmental needs that must be coordinated by the caregiver. It is important that occupational therapists and other health professionals collaborate with caregivers to ensure they are appropriately involved in a child's therapy (Wilkes-Gillan, Munro, Cordier, Cantrill, & Pearce, 2017). These responsibilities vary based on the age of the child and severity of the child's disability, and usually require substantial physical, emotional, social, and financial resources (Murphy, Christian, Caplin, Young, 2006). While most caregivers perceive caring for their child with a disability as a natural responsibility, the situation may eventually become burdensome if lifelong care is necessary (Ma & Mak, 2016).

Caregiver health concerns. The existing literature indicates that caregivers of children with disabilities are likely to experience declines in their own mental health and well-being. Because caregivers put in a significant amount of time, energy, and effort into another individual, they often are not able to care for themselves appropriately. The evidence suggests that caregivers of children with a disability, regardless of the differences in diagnosis, are at risk for both physical and mental illnesses, including chronic diseases, anxiety, depression, physical pain, sleep deprivation, and chronic fatigue (Murphy et al., 2006; Pedron-Giner, Calderon, Martinez, Garcia, and Gomez-Lopez, 2014).

Anxious caregivers and their children. The caregiver-child relationship can have both positive and negative influences on the child. Caregiver anxiety may have an impact on the

psychological health of the children for whom they are providing care (Whaley et al., 1999). Childhood is a critical time for rapid development, so children are especially vulnerable for developmental delay if their caregivers have a psychological disorder, such as anxiety or depression (Nicol-Harper, Harvey, & Stein, 2007). Studies show that anxious caregivers engage with their child less effectively (Nicol-Harper et al., 2007; Whaley et al., 1999). Anxious caregivers displayed less positivity and warmth when interacting with their children (He et al., 2014; Nicol-Harper et al., 2007; Whaley et al., 1999). These studies also found that children of anxious caregivers are at a higher risk of developing anxiety themselves (He et al., 2014; Nicol-Harper et al., 2007; Whaley et al., 1999).

Research has shown that a positive caregiver-child relationship leads to better engagement in play (Wilkes-Gillan et al., 2014). One study reported that caregivers who are more sensitive and responsive to their child's needs would be more likely to search for play opportunities for their child (Fabrizi et al., 2016). The formation of this healthy relationship is important, regardless of the type of disability, in order to promote positive engagement in play.

Study Aim

The present study explored the anxious caregiver's experience of playing with their child who has a disability. Previous studies indicated that a caregiver's anxiety can affect performance in other activities of daily living, but there is limited data showing how a caregiver's anxiety can impact their engagement with their child in play. There is strong existing evidence on the importance of play and the use of play-based interventions in therapy for children with disabilities. It is also clear that mental health issues, such as anxiety, are prominent among those who care for children with disabilities.

Methods

Theoretical Approach

This study originally utilized a phenomenological approach in exploring the potential effects of a caregiver's anxiety on their child's play. The purpose of phenomenology is to investigate the experience of individuals regarding a phenomenon of interest to the researcher (Daly, 2007). When exploring a potential link between caregiver anxiety and their child's play, one must first investigate how anxious caregivers play with their child and obtain data on this lived experience. Because no link has yet been made between caregiver anxiety and play with their child, the purpose of this study was to learn about the experiences of anxious caregivers in playing with their children. Due to a low participant response rate, the researchers gathered data utilizing a phenomenological approach but analyzed and present the data through a case study approach. The two participants had similarities in demographic information for both themselves and the children for whom they provided care.

Instruments

The Generalized Anxiety Disorder 7-item scale (GAD-7) was utilized as a screening tool for acceptance into the study. Participants completed it electronically through Qualtrics(R), an online survey software. This screening tool measures how severe the caregiver's anxiety is, based off of their responses to each of the seven questions (Spitzer, Kroenke, Williams, & Löwe, 2006). Each item receives a score of 0-3. A score of 0 means the caregiver did not report anxiety about the listed item, and a score of 3 means the caregiver reported anxiety about the listed item nearly every day (Spitzer et al., 2006). An overall score of 0-4 indicates minimal anxiety, 5-9 indicates mild anxiety, 10-14 indicates moderate anxiety, and a score of 15-21 indicates severe anxiety (Spitzer et al., 2006). The GAD-7 is a valid and reliable screening tool for assessing the

severity of generalized anxiety disorder (Spitzer et al., 2006). When comparing an individual's self-reported scores from the GAD-7 to a professional's diagnosis, Spitzer et al. (2006) found that individual self-reported scores from the GAD-7 indicated a level of anxiety similar to a mental health professional's diagnosis. The GAD-7 has strong criterion validity to support its use in identifying GAD cases (Spitzer et al., 2006).

Participants

Participants in this study had to be 18 years of age or older and care for a child with a disability under the age of 5 years and 11 months. Individuals also were required to understand and speak English fluently. Finally, participants had to score a 5 or above on the GAD-7, indicating that they have mild or greater anxiety. Recruitment methods included hanging flyers within the communal spaces of fourteen local pediatric outpatient therapy clinics, emailing members of the University of Indianapolis Community Patient Resource Group (CPRG), and posting on social media sites in order to target a wide variety of organizations and individuals to gather information from a diverse population. Twelve individuals completed the GAD-7. Of those, eight qualified for the study, and four participants provided an email address to be contacted about participation in an interview. Only two individuals scheduled an interview, and researchers conducted these interviews with two mothers who both had a 5-year-old child with Down syndrome.

Study Design and Procedure

This study received exempt approval from the University of Indianapolis Human Research Protections Administrator in the fall of 2017. The study was advertised actively for approximately six months. Following the completion of the GAD-7, those who met the inclusion criteria and provided an email address were contacted to determine their interest in participation.

Those who scored a 4 or below on the GAD-7 were thanked for their interest in the study but informed that they did not meet the criteria to continue through the remaining portion of the study. The semi-structured interviews were led by the primary investigator, an occupational therapy faculty member with experience in pediatrics and qualitative research, and an occupational therapy student. Researchers began the interview by asking simple background questions to better understand the child's behavior and the caregiver's anxiety. Questions were designed to learn more about the caregiver's experience when playing with their child. Additional probing questions were asked as appropriate to each interview. Questions can be found in Figure 1.

Interview Questions:

1. Tell me a little more about your child.
2. What does a typical daily routine look like for you and your child?
3. How does your child spend his/her time? (How would you describe play for your child?)
4. What does it look like when your child plays alone?
5. What does it look like when your child plays with other children?
6. When you play with your child, what does it look like?
7. How does your current play with your child look different from your expectations of play?
 - a. **Follow-Up Question:** Based on the online questionnaire you took, your score indicated that you have at least a level of mild anxiety. Would you say that is accurate?
 - b. **Follow-Up Question:** How do you feel that your anxiety impacts your play with your child?
8. If you could change anything about how you play with your child, what would you change?
9. How do you feel when you play with your child?
10. What is your favorite part about playing with your child?

Figure 1. Interview questions. This figure includes the questions asked during the interviews conducted by the researchers.

Each interview lasted approximately 30-45 minutes. Each interview was audio-recorded and transcribed by the student researchers. In order to ensure safety and protection of the information gathered, transcripts were stored behind password-protected software that was only accessible by the research team.

Data Analysis

Qualitative data gathered during the interviews were analyzed using an inductive analysis approach, which provides a less restrictive environment to allow themes to emerge (Thomas, 2006). Researchers followed guidelines by Thomas (2006) to identify common themes from the two interviews. The goal of this research study aligns with the goal of inductive reasoning to describe an experience supported with emerging themes from the collected data (Thomas, 2006).

The recorded interviews from this study were transcribed verbatim. Researchers independently read the transcripts and coded the data from each interview. After all independent coding was completed, the researchers discussed their findings as a group and agreed on 3 common themes; these themes are explored in greater detail below.

Findings

Case Study 1: “Amy”

Amy (pseudonyms are used throughout), the mother of a five-year-old girl with Down syndrome, stated her child was “a miracle” because Amy had tried for a long time to become pregnant. Amy described her child as “the light of her life,” one who was very social and loved being around other people. Her daughter attended kindergarten, where she spent two-thirds of her day in a regular classroom and the last part of the day receiving one-on-one special education services.

Amy described her child's daily routine and explained that she typically liked to play before and after school. Her daughter's primary play activity was playing with different dolls through pretend play. She explained that she noticed that her daughter had an increased interest in interactive play with others since starting kindergarten. Amy noted that the family had a playroom at home with a toy kitchen, and that her daughter thoroughly enjoyed cooking and preparing pretend meals.

Amy explained to the researchers some of the difficulties that her child experienced related to play. Her daughter struggled with speech, specifically expressive language. Amy explained that this made play more difficult because her daughter could not express to others how she would like to play. She stated that her child did well with receptive language when the instructions were kept short and concise. Her daughter's difficulties with communication typically resulted in her mimicking and following the play of other children. She explained that when her daughter played with other children, she took the lead if the peer had a more passive personality, but she followed the leader if the peer wanted to dominate. Amy said that her daughter played well with others, especially her older stepsister.

Amy enjoyed playing with her daughter and stated that she made play as educational as possible. She encouraged communication during play, but said that was difficult for her at times. When the topic of anxiety was directly addressed within the interview, Amy stated she felt like her anxiety came from constantly wondering if she was doing enough while playing with her child. She wished she did not have to worry about constantly making play educational. Amy stated, "...I feel like there are a lot of times that I would probably rather just be playing with her to have fun and I have that constant feeling of, 'Am I doing enough?'" In terms of the educational play, Amy tried to address communication, turn-taking, and understanding patterns.

She felt like she put a lot of work into play with her child and might not have felt that pressure if her daughter did not have Down syndrome. Amy stated that play with her child who has Down syndrome looked very different from play with her typically-developing stepdaughter. She said her daughter struggled with fine motor play and often needed assistance with things like dressing dolls or cooking in her play kitchen.

Researchers asked Amy what she would change about playing with her daughter, if anything, and she stated she felt it was hard to prioritize play. She said, "...I think if I could change anything about how I get to play with her it would be...I would want people to come in and do all my mom work, so I could just play with her..." She said her daughter enjoyed playing by herself, but there were times when she wanted to play with Amy or her husband, and if they were in the middle of a certain task it became difficult.

Amy described how comparisons to other families caused anxiety as well. She said, "...one of my personal biggest struggles is comparing myself to other moms of children with Down syndrome and . . . look at all the things they're doing and I'm not doing that." She discussed that she thought many families may feel this way, and she felt that social media made the problem even worse. Amy stated how people shared so much on the internet, which sometimes was perceived as judgmental if parenting styles were different.

The researchers concluded the interview by asking Amy about her favorite part of playing with her child. When she described her feelings during play with her child, Amy stated that she felt very happy. She said, "...it makes me feel fulfilled and I think part of that comes from the fact that . . . I didn't even know if I was gonna be able to have a child, you know." Amy stated that she often reminded herself of this time when she became frustrated, and it helped her. She also described that she loved seeing her daughter's personality come through during play,

and said “she is very fun-loving.” Amy said, “It just makes me happy to see her happy and engaged.”

Case Study 2: “Beth”

Beth was the mother of a five-year-old boy with Down syndrome. He was the oldest of three children. Beth provided some medical history on her son, which included multiple heart surgeries and a six-month neonatal intensive care unit (NICU) stay followed by intensive therapies that he still received. Beth’s son attended preschool with a group of typically developing peers, where he also received school-based therapy services. She stated that her son was very social and felt that her son’s gross motor abilities were his strength.

Beth shared with the researchers what her family’s daily routine looked like. Her son typically woke up very early and got ready for the day. He often played whenever he had free time, including after he completed his morning routine and before he left for school. When she described her son’s play, Beth stated that he engaged in emerging imaginative and creative play with cars, kitchen, and food toys. She stated that his favorite game was hide-and-seek, and he enjoyed playing any game that involved a ball. When she compared her son’s individual play to group play with his siblings, she stated, “...I have to imagine it’s pretty much the same, I mean sometimes it’s...a little bit of parallel play...[where] they might be doing the same activity but just right next to each other.” In terms of directing play, Beth described her child’s ability to stand up for himself and converse with his siblings about how play should be done. When asked to describe her child’s play with his typically developing peers, Beth stated that she recently observed him take a leadership role, while other times he followed his peers and jumped into the activity or game. Beth’s child also had the opportunity to play with other children with Down syndrome through a local organization for children with Down syndrome. She stated, “we are

there pretty often and... that's his happy place for sure." Beth stated she does not notice any differences in her son's play with other children with Down syndrome compared to his play with typically developing children.

When asked about her play with her son, she stated that their play was intentional and educational. She often focused on having him "use his own words" and advocating for himself during social interaction; for example, when one of his siblings was taking his toys. She also stated that this was the type of play that she engaged in with her other children. Beth discussed how she let her other children lead the imaginative play, but with her son with Down syndrome, she tended to lead play more and pushed him to do more than "just run the car back and forth." She also added that she felt like she pushed him in play because she felt that play was a strength of his, but she backed off when he became frustrated. She felt she could read her son well and adjust to his needs.

When the topic of anxiety was directly addressed within the interview, Beth stated that she was not surprised by the results. She discussed how she felt hypervigilant with her son's behaviors. An example that she shared was when her son started to fidget, she immediately corrected him to encourage him to sit still, but when her typically-developing daughter fidgeted and twirled her hair, she was not alarmed by it in the same way. She also attributed this to the anxiety that she experienced when she noticed her son's potential development of a self-stimulating behavior. She added that "you don't want to lose a moment to grow."

Beth shared that some of her anxiety also came from her family's busy schedule that was largely filled with many opportunities for enrichment for her child with Down syndrome, as well as extracurricular activities for her other children. Beth sought out a specific school that more fully met her child's needs; however, it required a longer drive that took more time out of her

day. She opted to remove her son from a developmental preschool where he had an Individualized Education Plan (IEP) and was receiving therapy services to go to a different school that she felt was a better fit for him.

When asked how she would change play with her son if she could change anything, Beth responded by saying that she wished it could be more relaxed and laid back. However, when she let herself do this from time to time, she then reported feeling guilty, and felt as though she should be doing more, especially when it came to language and communication. Play was described almost as work, or therapy: “We should be working on this and maybe somehow we should fit in... fine motor goal into this play or...It is hard to look at it as play.” When she described her play with her son, Beth said she felt good, as well as relaxed. She aimed to make play funny and silly but stated that getting to this relaxed and silly point took a couple of years. Beth stated that she “had to make this conscious choice to...not lead such a stressful life and give yourself grace and kind of bring down that anxiety level so that you can best be there for your child.” Having had her child enrolled in school and many other programs also decreased Beth’s reported anxiety because she felt as though her son was learning a lot from these opportunities. She said that the team of people and influences in his life took some of the stress off of her. Beth stressed the importance of social support from the community but also said it can “backfire,” especially when she saw things on social media that other families were doing for their kids. When Beth compared herself to these other families on social media, she often acquired feelings of guilt and anxiety for not doing enough for her son to help him meet certain milestones. In the end, Beth described her favorite part of playing with her son as hearing his laughter and seeing his sense of humor.

Themes

After inductive analysis of the interviews, the researchers derived three themes from the data based upon the responses of Amy and Beth. The three themes identified included: play with a purpose, causes of increased anxiety, and caregiver happiness during play. These themes are utilized to guide discussion of the case studies further below.

Discussion

Play with a Purpose

After analyzing interview transcripts, researchers concluded that the two mothers had similar thoughts and experiences when playing with their child with Down syndrome. Both Amy and Beth discussed trying to make play with their child educational and purposeful, noting that this pressure surrounding play could be contributing to their anxiety. Amy felt her anxiety derived from concern regarding if she was doing enough for her child to progress developmentally. Therefore, she has less time to play with her child leisurely because of the pressure she feels to make play educational and purposeful. She stated, "I want it to be fun too, so trying to find that balance between making it productive play that's getting something and her just being able to have a good time." Both Amy and Beth mentioned that their children struggled with expressive language and fine motor skills during play. Both mothers discussed their tendency to put a greater emphasis on improving communication skills when they facilitate play with their child. This is congruent with the findings of Graham et al. (2014), who reported that some parents of children with a disability saw their child's play and therapy as one component, in that it combined the educational aspects of therapy into their child's play. Additionally, parents reported that they had to consciously make time for free play for their child (Graham, Truman, & Holgate, 2015).

While both participants were highly involved mothers of 5-year-old children with Down syndrome, some differences were noted. The first notable difference was related to the mothers' styles of facilitating play. Amy reported that she lets her daughter be more of a leader during play, while Beth likes to provide more guidance for her son's play. Although both mothers feel the need to make play educational and purposeful, Beth described taking more control when playing with her son, whereas Amy encouraged educational play tailored to her child's interests. When it comes to the participants' feelings of anxiety, both mothers agreed that these feelings could be related to play; however, there were additional factors present.

Causes of Increased Anxiety

A contributor of anxiety that was discussed by both mothers was their tendency to constantly compare themselves and their family to other families of children with disabilities. Beth stated, "...you see on Facebook what everyone else is doing and then you know that...guilt or that anxiety can, like, increase." In comparison to other families, the mothers felt they may not be providing enough play opportunities and different treatment strategies for their children.

In addition to the commonality of making comparisons with other families, Amy and Beth described additional factors that contributed to their anxiety. Amy stated specifically that her anxiety stems from feeling like she does not have enough time to play with her child due to the time required to complete other parenting tasks. Existing research shows that these tasks, such as assisting with toileting, hygiene, and other healthcare needs, may get in the way of time for personal or leisure activity (McCann, Bull, & Winzenberg, 2016). Beth discussed two additional factors contributing to her anxiety: keeping up with her busy schedule and family demands and seeing her child participate in self-stimulatory behaviors. Sanders and Morgan (1997) found that parents of children who exhibited extreme behavioral problems such as self-

stimulatory behaviors were found to have higher levels of stress. Beth appeared more anxious than Amy, which could be due to her child demonstrating self-stimulatory behaviors, having multiple children to care for, or constantly feeling the need to make play purposeful. Another notable difference between the two participants was that Beth described more qualities of her child's negative behaviors, which could potentially be contributing to her anxiety as well.

The findings of the current study differ from the findings of a study completed by Dabrowska and Pisula (2010), who reported that parents of children with Down syndrome did not differ from parents of typically developing children. While Amy and Beth both demonstrated some levels of stress and anxiety related to caring for their children with Down syndrome, the results from Dabrowska and Pisula (2010) indicate that this may be atypical. This difference in findings may be due to the current study participants' unique caregiving experiences, which could not be accounted for in the previously mentioned study.

In contrast to Beth's family demands and concerns with self-stimulatory behaviors, Amy was more anxious about her role as a mother and if she was doing enough for her child during play. Beth seemed slightly more confident in the opportunities she has provided for her child, mentioning that she did research on preschools in the area and that her son is now enrolled in a very specific preschool that she felt would best meet his needs. This is something that Amy did not mention and can be assumed that this is because she is satisfied with the school in which her child is currently enrolled. The mothers also differed in their choices to employ others to help care for their child; Beth employs a nanny, while Amy chooses not to do so.

Overall Happiness During Play

Despite the anxiety felt when comparing self to others, making play educational, and demanding schedules, both mothers still felt joy when they played with their children. Both

participants were asked to explain their thoughts on how playing with their child makes them feel. They stated that playing with their child makes them happy. Beth described happiness during play with her child as, “You can’t help but smile when you look at his smile and hear his laugh. His smile is definitely contagious. Definitely.” Amy stated that she enjoys being able to see her daughter happy when playing. She stated, “How do I feel when I play with her? Good, like it always makes me so so happy and even those times that ... I don’t wanna get out of this chair, I don’t wanna do another puzzle, or I don’t wanna play blocks, ...[but] once I’m doing it, I feel very happy.” Both mothers reported and demonstrated happiness when thinking about their child and the play that they experience together. Research shows that when mothers play with their child with a disability, they find enjoyment both in playing and seeing their child enjoy play (Buchanan & Johnson, 2009). Stainton and Besser (1998) also found that parents of a child with an intellectual disability felt that their child gave purpose to their family, and simply being in the presence of their child brought the parents great joy.

Limitations

The present study is limited in its generalizability due to the small, homogenous sample of participants. Both mothers had 5-year-old children with Down syndrome. The mothers were highly involved in the lives of their children, were very attuned to their child’s needs, and expressed concerns relating to the type of play completed with their child. They both compared themselves to other parents of children with Down syndrome and had demanding schedules. While the small size and homogeneity of the sample helped researchers to make the decision to use a case study approach, it is seen as a limitation because it may not be representative of a broader population of caregivers of children with Down syndrome. This makes it difficult to generalize the results.

Future research should include a larger sample size of parents with children who have a variety of diagnoses, as well as a more diverse sample with varying ages of children. In addition, future studies should observe play interactions between parents and children to obtain more quantitative results regarding anxious play experiences. It may also be beneficial to compare the findings of this study to play interactions among parents with children who are typically developing.

Implications for Future Research

The themes developed from these interviews demonstrate the importance of the role of the occupational therapist in providing services to caregivers and their children with Down syndrome. Occupational therapy offers a holistic approach to care, including psychosocial support for mental health of the caregiver, as well as interventions aimed at improving physical and cognitive limitations in a child's occupations, often with a focus on play. Occupational therapists can use their skills and knowledge to adapt play to make it developmentally beneficial for the child, as well as providing suggestions on improving mental health of caregivers.

Occupational therapists must be aware of the potential for stress and anxiety among mothers of children with disabilities and take appropriate measures to screen these mothers utilizing methods such as interview or standardized assessments. Based on this data, occupational therapists can refer mothers to professional and community resources such as a clinical psychologists or caregiver support groups. By providing this support, occupational therapists can help mothers provide better care for their children with disabilities.

Conclusion

Caring for a child with Down syndrome can lead to many sources of anxiety that may impact parent-child interactions, specifically during play. Participants mentioned that they

constantly felt the need to make play a learning experience, which may take away from the leisure aspect of play. In addition, managing a demanding schedule leaves less time to interact in play with their children. Participants also found themselves comparing their lifestyles to other families of children with a disability, which was believed to be a source of anxiety. It is important that occupational therapists consider the caregiver's anxiety when treating children with disabilities as it has the potential to substantially impact the child's play, a crucial occupation for development.

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