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The Effect of Caregiver Anxiety on Play in Children with Disabilities

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Abstract

Play is a major occupation that contributes to child development and quality of life. The purpose of this study was to examine how caregiver anxiety impacts play with children with disabilities. Using a qualitative phenomenological approach, researchers conducted interviews with four mothers of children with either Autism Spectrum Disorder or Down syndrome to gain information on their lived personal experiences regarding play with their child. All caregivers had scores at or above mild anxiety on the Generalized Anxiety Disorder-7 questionnaire. After analyzing transcripts of the interviews, researchers found three major themes: finding joy in play, causes of anxiety, and the impact of anxiety on play. Caregivers reported feelings of joy and happiness during play with their child when they created a unique bond and discovered satisfaction and empowerment in their play. However, common causes of anxiety were lack of time, delayed achievement of developmental milestones, and feelings of “playing wrong” with their child. Caregivers described the effects of their anxiety on play as difficulties with balancing play with personal responsibilities and making play seem purposeful or educational. Clinicians should emphasize interventions aimed at decreasing the anxiety of caregivers to improve overall experiences of play for both the caregiver and the child.

The Effect of Caregiver Anxiety on Play in Children with Disabilities

Play looks different to all who engage in it, thus play can be difficult to define. Occupational therapists Parham and Fazio (2007) define play as, “Any spontaneous or organized activity that provides enjoyment, entertainment, amusement, or diversion,” (p. 448). Play is essential for children to engage in because it impacts their cognitive, physical, social, and emotional development (Gagnon & Nagle, 2004; Ginsburg, 2007; Kelly-Vance & Ryalls, 2008). Play encourages creativity, which allows caregivers and children to interact together and build trust (Ginsburg, 2007). Children with disabilities may struggle in developing the essential skills needed for participating in play, impacting their overall development (Brodin, 1999). Therefore, it is important to consider the effect a disability may have when assessing play and development in children.

Children diagnosed with a disability may present additional demands on a family, increasing caregivers’ risk for anxiety, grief, and interruption to normal routines (Nabors et al., 2013). Recognizing the health of caregivers is important, as their health impacts their child’s development and well-being (Murphy, Christian, Caplin, & Young, 2007). Research indicates that the physical and emotional health of caregivers is more likely to decline with increased caregiving demands (Murphy et al., 2007). Occupational therapists are encouraged to help caregivers find sources of support and provide education on ways to care for a child and the caregiver by teaching strategies and skills to improve caregivers’ physical and mental health (Manee, Ateya & Rassafiani, 2016). Although the benefits and importance of play and child development are clear, little research has been conducted that indicates a connection between a caregiver’s level of anxiety and its possible effects on the way they participate in play with their child who has a disability.

Play of Children with Disabilities

Caregivers may have expectations for how their child should play. For a child with a disability, their style of play may look different, thus requiring the caregivers to adapt to the child's needs. Researchers found that children with intellectual and social disabilities need additional guidance with initiation of play and interaction with toys as these children have been found to be less motivated to play, have decreased self-esteem, and possess fewer social skills (Brodin, 1999; Holmes & Willoughby, 2005; Missiuna & Pollock, 1991). Children with intellectual and motor disabilities experience increased childhood stress, decreased availability of resources to assist with coping and improving their intellectual disability, fewer educational opportunities, and lessened opportunities to participate in certain activities (Floyd & Gallagher, 1997; Murphy et al., 2007; Paczkowski & Baker, 2007).

Specifically looking at children diagnosed with Autism Spectrum Disorder (ASD), play can look different when compared to typically developing children. Children with ASD have characteristics such as poor social participation, fixated interests, decreased flexibility, repetitive behaviors, and hypersensitivities to external stimuli, which can make play difficult (Lin, Tsai, Li, Huang, & Chen, 2017; Román-Oyola et al., 2018). Children with ASD typically desired more control during play to decide which activities they participated in (Román-Oyola et al., 2018). With the child in this role, caregivers were led to express more frustration and decreased understanding of how their child wants them to play (Román-Oyola et al., 2018). Children diagnosed with ASD have decreased abilities or interest for engaging in pretend play and sensorimotor play and are more likely to engage in rough and tumble play (Lin et al., 2017; Román-Oyola et al., 2018). Decreased engagement in pretend play can lead to lowered

opportunities to express creativity, apply attention skills, participate in fine motor skills, and monitor emotional regulation (Lin et al., 2017).

Higher success rates for children with ASD have been found when caregivers structure play around the child's preferences of play that are intrinsically motivating to the child (Román-Oyola et al., 2018). It was found that when caregivers force play patterns or have very structured play patterns and routines, children with ASD tend to avoid these types of play and demonstrate negative behaviors (Román-Oyola et al., 2018). Caregivers have reported increased competence and self-efficacy when they discover the ability to play and interact with their child, leading to a stronger caregiver-child bond (Román-Oyola et al., 2018). Mothers in particular placed greater emphasis on making progress towards skills and accomplishing tasks and on integrating play into daily activities (Román-Oyola et al., 2018).

While there is less research regarding the play of children with Down syndrome (DS), these children are also likely to experience differences in the developmental progression of play compared to typically developing children (Venuti, de Falco, Esposito, & Bornstein, 2009). Children with DS were shown to have lowered attention span during sustained play and tended to repeat play schemes (Venuti et al., 2009). Typically, children with DS tend to have fewer skills in exploratory play, resulting from lowered cognitive skills and less structure in their daily routines (de Falco, Esposito, Venuti, & Bornstein, 2008; Venuti et al., 2009).

Venuti, de Falco, Giusti, and Bornstein (2008) found that children with DS showed increased play skills when they were in sight of their mothers as opposed to playing by themselves, indicating that parental involvement in play is impactful for the development of a child's play skills. An additional study indicated that a child's exploratory and collaborative play increases with maternal involvement, as a result, serving as an increased motivator for children

to participate in play (Venuti et al., 2009). Similar to children with other intellectual disabilities, children with DS greatly benefit from positive caregiver involvement (de Falco et al., 2008). Caregivers who possess a positive affect, demonstrate greater sensitivity to their child's development and diagnosis concerns, and engage in play with their children have an increased chance for healthy development and decreased medical complications (de Falco et al., 2008). When parents demonstrate over-protectiveness or over-bearing attitudes, they can have an overall harmful effect on children's play (de Falco et al., 2008). Parental involvement has been supported to have positive effects on a child's development and play patterns.

Children with motor disabilities are found to be at risk for behavioral problems, decreased coordination, poor concentration levels, and poor academic performance, which all impact play (Smyth & Anderson, 2000). Play participation has shown to lower self-efficacy of the mother and the child with motor impairments (Smyth & Anderson, 2000). Similar to children with intellectual disabilities, without access to early intervention and proper adaptations, these problems have the potential to persist into adolescence (Smyth & Anderson, 2000; Soref et al., 2012).

Impact of Caregiver Health on Children with Disabilities

When looking at factors that impact the way a caregiver plays with his or her child with a disability, it is important to understand the impact on caregivers' health when caring for a child with a disability. Caregivers of children with disabilities reported increased anxiety levels, depression, chronic health problems, grief, interruption to normal routines, and additional demands (Brehaut et al., 2011; Manee et al., 2016; Murphy et al., 2007; Nabors et al., 2013). Caregivers of children with ASD were found to experience higher levels of stress related to a lack of professional support, concerns regarding the diagnosis affecting their child's current

life and future, and disapproval from others about behaviors demonstrated by the child as well as feelings of incompetence, emotional dysregulation, depression, and feelings of hopelessness (Román-Oyola et al., 2018; Sharpley, Bitsika, & Efredmidis, 1997). Caregivers of children with DS and other intellectual disabilities were more likely to experience parental stress and lower self-efficacy levels (de Falco et al., 2008). Children with disabilities tend to require increased care and attention, causing caregivers to place more emphasis on their child's health than their own (Murphy et al., 2007). Furthermore, poor caregiver health correlated with more hospitalized children and created the need for placing the child outside of the home (Murphy et al., 2007).

Numerous factors can increase stress when caring for a child with a disability. Stress may negatively affect the child's education, play, language, and communication (Murphy et al., 2007). Caregivers' stress may increase due to impaired sleep, lack of a support system, increased caregiving demands, lack of time, and negative child behaviors (Murphy et al., 2007; Plant & Sanders, 2007). Impairments in caregivers' psychosocial health may occur due to low income levels, lack of job opportunities, decreased support from a significant other, young age, additional dependents in the household, caregiver's own disability, and/or a high school degree or lower education (Klassen et al., 2004; Lewis et al., 2015). Caregivers reported feelings of frustration and discouragement when they were unable to perform childcare responsibilities due to their personal disability, lack of resources and adaptation tools, barriers inside or outside the home, and/or limited ability to interact and bond with their child (Wint, Smith, & Iezzoni, 2016). Caregivers also reported that being away from home, misunderstanding their child's diagnosis, emotional stress, and siblings and other immediate family members not coping well with the diagnosis exacerbate stressful circumstances (Nabors et al., 2013). A more relaxed and emotionally well-adjusted caregiver played more freely with their child and reported less anxiety

when they had opportunities to take breaks and had a strong support system (Murphy et al., 2007).

The health effects that caregivers experienced, especially anxiety relating to stress about their child's medical diagnosis, had a negative impact on the interactions they had with their child (Kenneson & Bobo, 2010). Employed mothers who cared for their children had a higher level of social support but increased anxiety because of separation from their child while at work, leading to less opportunities for play (Kenneson & Bobo, 2010). Studies have found that depression caused mothers to be less engaged and less responsive to their child's needs (Lefkovich et al., 2014). In regards to play, the child lost confidence and became shy, as they did not want to socially interact with other individuals (Wood et al., 2003). Overall, quality interaction is vital for a child's development (Morrissey & Brown, 2009). It is crucial to understand the causes of a caregiver's decreased engagement with their child, as play is important for development and children need their caregivers to model what play should look like.

To summarize, understanding how play differs in children with disabilities compared to typically developing children is beneficial when exploring ways to enhance a child's participation in the occupation of play. Due to increased responsibilities caring for a child with a disability, caregivers' stress and anxiety impacts their personal health and the interaction with their child. When caregivers valued their child's play and became aware of the most effective play techniques for their child and their unique abilities, they reduced their child's anxiety and negative behaviors (Swan & Ray, 2014). Although research has suggested that the health of the caregiver affects the child's play, no research currently exists on if or how caregiver anxiety impacts play in children with disabilities.

Methods

Study Design

The research design for this study was a qualitative phenomenological approach in which researchers investigated the lived experience of caregivers to better understand the participant's own experiences and attitudes as a caregiver. The phenomenological approach was used by collecting data through interview questions to explore caregivers' attitudes and personal experiences with their child with a disability relating to their anxiety levels experienced during play. Interested participants completed an online screening tool, the Generalized Anxiety Disorder-7 (GAD-7) questionnaire. Once the GAD-7 was completed, the participant was informed whether he or she qualified to participate in the study, requiring a score indicating at least mild anxiety. If they did not have a score that indicated at least mild anxiety, they were directed to a screen thanking them for their participation and informing them that they did not qualify for our study. If they did qualify for the study, they had the option to provide contact information for the primary investigator, who then attempted to schedule a 30-60 minute semi-structured interview.

Participants

Caregivers were recruited from various facilities through flyers, social media, email, and newsletters. Inclusion criteria for participants consisted of caregivers of a child with a disability between the ages of birth to five years and eleven months old. Caregivers had to be 18 years of age or older in order to participate.

Instruments

The instrument utilized for screening was the GAD-7, a self-reporting measure of anxiety (Spitzer, Kroenke, Williams, & Löwe, 2006). The GAD-7 measures the reported level of anxiety

in caregivers and gives a score based on their responses to seven questions. The GAD-7 takes less than five minutes to complete. The highest score that can be given is twenty-one (Spitzer et al., 2006). Scores between zero and four did not qualify participants for our study, but any score above four indicates mild anxiety (scores between five and nine), moderate anxiety (scores between ten and fourteen), or severe anxiety (scores above fifteen) and qualified participants for our study. For those whose scores qualified them to participate in the study, they were offered an opportunity to provide a method of contact for the primary investigator to schedule an interview.

Researchers found that the GAD-7 exhibits excellent internal consistency along with good construct and factorial validity, therefore, making it a reliable and valid tool to evaluate the existence and severity of generalized anxiety disorder (Spitzer, et al., 2006). In a previous study examining the social, psychological, and financial burden on caregivers of children with chronic illnesses, the GAD-7 was used to screen for depressive and anxious symptoms (Khanna, Prabhakaran, Patel, Ganjiwale & Nimbalkar, 2015). Researchers found significant psychological distress, financial, and social burden experienced by the caregivers (Khanna et al., 2015).

Interview Process

Once the participant qualified for the study, an interview was scheduled at the University of Indianapolis. Participants had the option to be interviewed virtually if they were unable to have an in-person interview. Interviews included the participant, the principal investigator, and an occupational therapy student co-investigator from the University of Indianapolis. Interviews lasted approximately 30-60 minutes and were audio recorded. Participants received an informed consent, providing the option to stop the interview at any time. Recordings were transcribed verbatim by investigators. If the participants accidentally provided identifiable information, the data was redacted from the transcripts. Caregivers and children were provided with pseudonyms

to protect their anonymity for the purpose of this manuscript and these pseudonyms are provided in Table 1. Specific questions were asked during each interview, as well as any probing questions deemed appropriate by the primary investigator. A list of interview questions is shown in Figure 1, which served as a guide to gather information during the interview.

Table 1

Participant Pseudonym Information

Mother	Child	Age	Diagnosis
Amy	Allie	5 years old	Down Syndrome
Beth	Ben	5 ½ years old	Down Syndrome
Carissa	Cody	3 years old	Autism Spectrum Disorder
Denise	Dylan	4 years old	Autism Spectrum Disorder

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?

Data Analysis

Three researchers were assigned to each interview to transcribe the recordings, which were checked for accuracy by another team member. Qualitative data was analyzed using a general inductive analysis approach as described by Thomas (2006); he refers to general inductive analysis as making interpretations from raw data to discover themes that contribute to research. A general inductive approach is an efficient and convenient way to analyze qualitative data (Thomas, 2006). The major goals of inductive analysis include summarizing raw data into themes, detailing correlations found in the study that link to the research objectives, and creating a model or theory about the data determined from the study (Thomas, 2006). The research team members independently reviewed the transcripts to reduce bias and to develop initial impressions of the data. The PI led a group discussion, where each member shared their initial interpretations of the findings. After a period of a discussion, the data were reduced to broad categories, and a set of three themes were developed. Trustworthiness of these findings was enhanced by use of multiple analyst triangulation, the use of verbatim transcripts, and maintenance of an audit trail.

Findings

Researchers completed interviews with four caregivers of children with disabilities, including two caregivers of children with Down syndrome and two caregivers of children with Autism Spectrum Disorder between August of 2017 and November of 2018. In total, 28 individuals completed the GAD-7, with 18 receiving qualifying scores. Nine caregivers provided methods of contact, and four interviews were successfully completed. The following themes were derived from the data depicting the caregivers' experiences: causes of anxiety, anxiety's impact on play, and finding joy in play.

Causes of Anxiety

Researchers found a wide variety of causes leading to caregiver anxiety that were expressed during interviews. Major subthemes found included caregivers' lack of time to balance caregiving and life demands; caregivers' desire to make play purposeful; caregivers' feelings of inadequacy; delayed achievement of developmental milestones; and child portraying negative behaviors.

Difficulty Balancing Schedules and Times

All four caregivers expressed their concern of lack of time and difficulty balancing busy schedules, leading to increased feelings of anxiety. Caregivers expressed struggling to find a balance between play, work, household management, therapy sessions, driving extended distances for school and therapies and they voiced how it can be hard to find motivation to play after long days. For example, Amy 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 you know...I feel like she could be doing a lot more, and we could make so much more progress if I was able to just spend my time with her playing. But...we have to cook dinner and get ready for bed and I've gotta go to work and...there's so many responsibilities that if somebody could take those away I feel like...I could handle the play stuff.

Other caregivers also indicated if they could have fewer responsibilities and more energy, they would have more time to play with her child.

Desire to Make Play Purposeful

All four caregivers expressed the need to make play purposeful, successful, or educational with their child. Play was found to bring anxiety to caregivers if they felt they could not achieve a successful level of play or if they felt like they were not playing the “right” way. Carissa stated that her anxiety increased when she chose educational play versus fun play with her child, “He goes at his own pace... my anxiety does not do well with that...the more anxious I am the more likely I am to pull out the therapy toys instead of the fun toys.” Denise expressed her view of successful play as taking more time and energy and this increased her anxiety level and impacted her feelings of self-efficacy.

I would say at that point you’re just stressed out or you feel like you’re doing everything wrong so then you just shut down as a person...I feel like...a person...who is narrating what’s going on to get...language...matching up with actions...like you need to be on it to have...a successful play I feel like so it just takes more energy; it just takes more time. The desire from all caregivers to make play purposeful, successful, and educational increased anxiety levels, affecting overall mental health.

Feelings of Inadequacy

Caregivers expressed increased anxiety when they were evaluating if there was anything additional that they should or could be doing with their child in order to promote healthy development. Increased guilt was experienced when caregivers felt that they were not doing enough to enhance their child’s abilities. Amy stated,

Am I working with her enough? Is she keeping up? Should I be spending more time doing this? Like she’s not in this therapy, maybe I should be doing extra PT (physical therapy) stuff or extra OT (occupational therapy) type stuff with her since she’s not doing

therapies outside of the school. Or how can I make this play more productive so that she is getting something out of it?

Another cause of caregivers' anxiety was feeling like they were not playing the right way with their child and not meeting their child's expectations, affecting the child's mood and increasing caregiver's frustration. Caregivers also had previous expectations about what play should look like and when their child with a disability did not play in ways that met their expectations, it caused the caregivers to feel frustrated, anxious, or inadequate. Denise stated her view on feeling frustrated when her child made her feel as though she was not playing right, "I would say...with...the frustration and stuff...you just feel like you're not playing right, you're not doing it the right way. So you just kind of have to learn to let him take lead."

Additionally, all four mothers agreed that play with their child was different than what they expected it to be when they thought about play with a typically developing child. Beth said, "I thought it was going to be...snuggling in bed and reading books together or being able to just go to museums or go to the zoo and it just be...fun...I would be looked to as someone fun and...I'd be able to take them to fun places...or at least I thought that's what it was going to be like...but yeah it's a lot different."

Researchers found that caregivers experienced elevated anxiety and feelings of inadequacy when they compared themselves and their parenting styles to other caregivers. Amy said, "I think there's this constant comparison...that's 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." Beth similarly stated, "You see on Facebook what everyone else is doing and then you...know that...guilt or that anxiety can...increase. It's like oh maybe he should be doing that...and this."

Delayed Achievement of Developmental Milestones

Caregivers noted various areas of concern with their child not meeting developmental milestones, which increased anxiety levels. For the children with DS in the study, commonly reported unmet skills and inappropriate behaviors included deficits in expressive language, possessing selective attention, demonstrating sensory-seeking behaviors, and decreased fine motor skills. Both caregivers of children with DS expressed their children's strengths in pretend play. On the other hand, caregivers of children with ASD expressed concerns about deficits in skills and inappropriate behaviors in effective communication skills, expressive thoughts, non-established preferences to people or toys, decreased engagement in play, self-stimulating behaviors (specific abnormal body movements, repetitive behaviors, or fixations), unpredictability during play, and sensory-seeking behaviors. Carissa discussed when she started noticing her child not meeting milestones and how that impacted her anxiety.

Red flags for it started around six months of age...some days it seems like he has a milder form and you kinda think 'oh yeah, he'll grow out of it,' then there are other days like, 'whoa, it's gonna be a long ride'...So the anxiety is pretty high currently because we've kinda hit this...stopping point in his program where he needs to make that next jump (developmentally). We can't do anything until he does.

Caregivers' anxiety levels were found to increase during play when they were unable to understand their child's attempts at communication, which reportedly led to overall frustration from the child as well as the caregiver, thus impacting overall play engagement. Amy mentioned how her daughter struggled with speech and how her impaired speech impacted play, "I think her biggest struggle right now is probably with...expressive language...It makes play really hard because she's got certain things she wants us to do and she can't tell us."

Child Negative Behaviors

Lastly, caregivers also talked about how negative behaviors portrayed by their child increased anxiety. They explained that their child would get accustomed to certain activities or environments and did not adapt well to change. Some of the caregivers also discussed their anxiety toward going out in public with their child due to safety concerns.

Overall, a variety of factors can have an influence on caregivers' levels of anxiety. Caregivers voiced concerns with the difficulty of balancing caregiver demands and responsibilities with life demands, which influenced caregivers' attention and attitudes expressed during play. Caregivers voiced concerns with making play purposeful and whether they were playing the "right" way with their child, increasing feelings of inadequacy during play. Developmental concerns in the child increased anxiety levels of caregivers, therefore, decreasing positivity displayed during play from caregivers. Knowing the causes of anxiety will provide further insight on the impact that caregiver anxiety has on play in a child with a disability.

Impact of Anxiety on Play

The impact of anxiety on play is complex and manifested by a host of interrelated factors. These include negative child behaviors and developmental deficits, increased difficulty in balancing play and responsibilities, and the pressure caregivers experience to make play purposeful and educational. Together, these influences can contribute to increased caregiver anxiety and have negative impacts on the occupation of play.

Child Characteristics

One major deficit noted by all four caregivers was communication, specifically expressive language and listening skills. Denise mentioned, "Communication, that's where he struggles... communicating clearly, and speaking clearly of what he wants but then also

receptively understanding what is being asked of him.” Other caregivers echoed this statement; they described a lack of eye contact from the child and at times a lack of response at all. Amy said, “She picks and chooses what she listens to...we definitely have to keep instructions shorter and more concise.” Attention was also a factor as the caregivers noted their child’s “short attention spans.” These communication skills deficits were found to affect play because the child did not consistently respond or demonstrate awareness of their peers or family members.

Another deficit noted was the type of play children engaged in. Amy and Beth talked about their children with DS engaging in more parallel and pretend play, while Carissa and Denise said their children with ASD were not as interested in collaborative play and would rather play alone. Denise mentioned her child, “...Won’t insert himself, or he might watch other kids play at a playground.” Deficits in fine motor skills and delayed development were found to affect the way the children played as well. Beth commented to explain the activities she sees her child has deficits in, “...Like handwriting, scissors, dressing, undressing, those types of things.” These mentioned deficits were found to increase the time required for completing fine motor activities. Carissa said her son, “Goes at his own pace...my anxiety does not do well with that.” Increased time demands can cause anxiety for the mothers because as discussed below, the caregivers feel like the time they have to play with their child is limited.

All four caregivers also described how their child preferred to be in control of their play, making it difficult to structure. Denise stated, “he controls it all,” while Carissa said she tries “to follow his lead.” This presents challenges for the caregiver to play with the child because they feel like they are not playing right or in the correct ways, leading to increased frustration from them. Denise stated,

I've tried looking on Pinterest and coming up with ideas and getting it all ready and thinking okay we're just going to do this one thing I already have it to like three fourths of the way done I just need him to help with like one little thing. It just never works out. So you kind of just, you can never really plan anything. You just have to be very flexible because you just never know what will set him off.

Negative child behaviors also made play more challenging. Amy mentioned, "she's incredibly stubborn...she's got a horrible attitude sometimes when she...spits at us." Carissa said her child is "starting to get a little aggressive, a lot of stimming going on." In addition, Denise stated, "you never know what will set him off." These behaviors led to increased anxiety and decreased positive mood for the caregivers in regard to playing with their child. Carissa elaborated,

...because he's knocked into you so hard you, I'll snap and I'll get angry...and he...doesn't understand what it means to hurt somebody. So he's just confused and then when he starts crying...everything else kind of falls to pot...it affects play and sometimes I'll just not do it at all.

Balance of Play and Responsibilities

Another factor that was similar among all the caregivers and increased anxiety during play was establishing consistent routines that were structured and incorporated into play. Carissa said, "It is pretty structured throughout the week...we have such a good established routine, I'm a very routine person." With that being said, the children were often resistant to change in the routines as Amy mentioned her daughter "eats the same exact thing every day." All the caregivers mentioned the responsibilities as part of their routines that limit the time they have to play with their children. Amy stated, "It's a time constraint you know trying to balance

everything and fit it all in and figure out what's the most important thing." Carissa said balancing everything "feels like the biggest obligation in the world." Because of this, caregivers' attention is frequently divided, mentioning they were often unable to devote enough time, attention, and effort to play.

All caregivers consistently reported that the amount of responsibilities and trying to find a balance among all life's demands made the caregivers feel anxious. Amy stated, "There's so many responsibilities...and I am just tired." Beth would like to be "a little bit more relaxed and not so worried." Carissa confessed, "I'm shorter on temper...I don't always want to play with my children...I would change my patience level." Denise feels like "there's no break for me...it just takes more energy it takes more time...I wish that I could replicate myself." The increased schedule demands the caregivers experienced had a negative impact on sleep. Carissa discussed how having a rough day or lack of sleep increased the likelihood of decreased play performance with her child.

If I've had a particularly bad night of sleep, which is usually driven by the anxiety...I'm shorter on temper in the morning too, or I may choose not to sit on the floor and play with him. I'll still get out the bucket of toys but...he wants to play with me but I'll choose to sit on the couch and growl while I'm cuddling my coffee, and...it's not my proudest moment but I...don't always want to play with my children.

Making Play Purposeful

All caregivers felt the need to engage in purposeful and educational play, considering play to be a learning opportunity. Instead of allowing play to run freely and be directed by their child, caregivers admitted to possessing some desire to maintain structure. Amy stated, "I try and make my play with her as educational as possible and encourage communication through play."

When asked if there were intentions and goals during play, Beth responded that she approaches play as a form of learning. Beth said, “If we’re playing, it’s going to be educational. So, some sort of purpose.” Fostering an educational and purposeful play time was highly important to the caregivers and the weight of this responsibility was described as exhausting. Denise admits, “You need to be on it to have a successful play...it just takes more energy and it just takes more time.”

In comparison to their children without a disability, the play is not centered around fun, but rather an emphasis is placed on making it educational and purposeful. Amy stated, “I’m putting a lot more work into it than I would if Allie didn’t have Down syndrome...if she didn’t, we would actually just be playing for fun rather than trying to learn things.” Beth compared feeling relaxed when playing with her neurotypical daughter to wanting to make play with Ben purposeful for him by saying,

If we were just all sitting in her room and like just doing creative play and I could kind of follow her lead and elaborate on it...with Ben...this is going to have like a purpose and a goal and like I’m not gonna let you slip and just run the car back and forth.

The pressure for purposeful play with their child created a difference in how caregivers play with their typically developing children. Facilitating play that is done “right” caused the caregivers to question their self-efficacy and abilities to meet their child’s play expectations while preserving purposeful play.

The anxiety involved in creating productive play is evident from the interviews and the impact is observed in the behaviors of both caregiver and child. All four caregivers used the word “anxiety” in reference to play with their child during the interview. Findings represent very close similarities between causes of anxiety and caregivers’ anxiety and the effects that their

anxiety has on play with their children. Caregivers expressed how lack of time and difficulties with balancing caregiving and life demands impacts negatively their willingness to play with their child due to their lowered energy and patience levels. Caregivers also expressed their concerns with their child's negative behaviors and impaired communication skills and how this impacted their willingness to engage in play with them. The anxiety the caregivers experienced from attempting to make play productive, purposeful, and educational impacted the kinds of toys they choose to play with, as well as how much time they spent playing with their child. Caregivers also voiced how their anxiety was impacted by comparing themselves to other caregivers and play with other neurotypical children.

Finding Joy in Play

Despite the difficulties and anxiety that were found to come along with play, all four caregivers stated that they found joy while playing with their child. Each caregiver's joy was discovered to be experienced in unique ways and most of the caregivers lit up when describing what they enjoyed most about playing with their child. All caregivers reported that they felt happy seeing their child laughing and enjoying themselves during play. Amy stated,

I think my favorite part of playing with Allie is just seeing her little personality starting to come through...she's so bossy and just so fun loving and it...it just makes my heart feel like it's going to explode when we do things when we play together and she's talking gibberish or bossing me around telling me what to do or we're dancing just it just makes me happy to see her happy and engaged.

Beth also mentioned enjoying the playful side of her child. She stated,

He's just the funniest kid I've ever met in the whole entire world, and he likes to do funny things like he like tries to play jokes on you or make you laugh instead, so I mean I just love that. He's just so funny. He cracks me up.

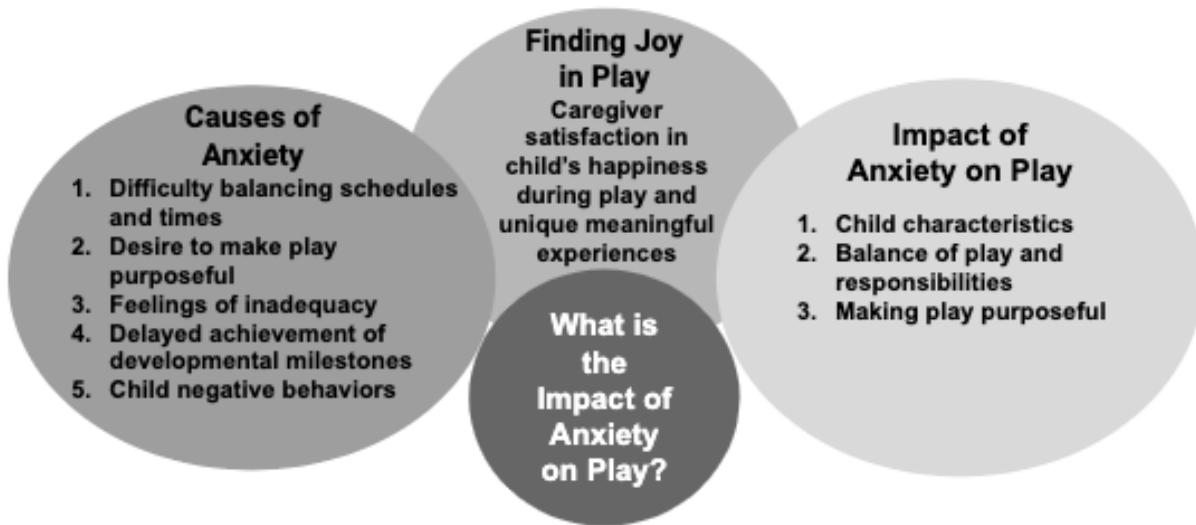
Carissa reported that, "most days it makes me feel pretty darn good because he's so giggly and happy and like 'oh you're going to spend some time with me' that's great." Denise stated how she finds joy in play through physical affection with her child,

I would say...with Dylan it's more of the cuddling...He wants to be touched and things like that...Dylan is just...smoochin' like crazy and I'm like alright take a break. But he just will lay on ya and just let you do whatever with him like, that's what I really love with him. That's his like, just me and him time.

Denise also reported finding fulfillment and joy when her child's play was successful, as shown through developing a new skill or doing an activity that the child has never completed before. Denise said,

A lot of times you just have to realize...what he's trying to do and then you can kinda figure out. And if I can figure out what he's talking about, he's almost even happy too cause I'm understanding what he's saying. Like that's when it's successful is when we're both on the same page.

Amy provides a great strategy for coping as she said, "I desperately wanted it so I try even in those moments that I do start to get frustrated to think back and remember those times and it really does make a huge difference." It is important for caregivers to feel empowered to find joy in playing with their children in order to increase the well-being and confidence of both caregivers and children.

Figure 2*Summary of Themes from Transcripts*

Discussion

Causes of Anxiety

Dabrowska & Pisula (2010) found that the additional responsibilities of caring for a child with a disability impacted the caregiver's stress significantly. The caregivers from our study reported feeling like they did not have enough time to play with their child because their time was being consumed with other responsibilities, such as work, appointments, and increased caregiver demands. Similar to this, Murphy et al. (2007) found that caring for a child with a disability was stressful because the caregivers had little time to complete tasks and had increased anxiety because of additional demands.

Similar to findings from Dabrowska and Pisula (2010), caregivers of children with ASD experienced stress that stemmed from their child's social deficits and communication barriers.

Missiuna and Pollock (1991) found that play is impacted in a child with a disability for a variety of reasons, including the lack of age-appropriate communication; this is similar to the communication barrier that our caregivers discussed having with their child. Additionally, Lecavalier, Leone, and Wiltz (2006) found that mothers associated greater stress with behavioral problems, similar to what the caregivers in our study reported about how negative behaviors caused them to have anxiety.

Our study found that parental anxiety increased due to feelings of not playing correctly or not meeting their child's expectations of play, preferred style of play, and needing to play "right." Román-Oyola et al. (2018) found that caregivers placed more emphasis on making progress toward skills and on integrating play into daily activities with their child. This is consistent with Brodin's (1999) findings that play and learning are linked closely together and that children with disabilities have a large opportunity to learn through play.

How Play is Impacted

Due to causes of anxiety such as time constraints, child developmental delays and negative behaviors, and playing "incorrectly," caregivers described how their play was impacted with their child. The caregivers from our study reported feeling like they did not have enough time to play with their child. Due to time restraints and other responsibilities, play was postponed or shortened; for example, extended mealtimes interrupted time for play with the child. Findings from our study also suggested that routines were very structured for these children and flexibility of adapting schedules may have led to decreased playtime or cause unwanted behaviors.

The caregivers in our study consistently reported choosing educational play over pretend play or the need to make play purposeful, successful, or educational, due to the caregiver's anxiety about their child's progress towards meeting developmental milestones. Caregivers

consistently questioned whether they should allow free play or use play as an opportunity to make progress toward developmental milestones. This is similar to several of the parents in Graham, Truman, and Holgate's (2014) study, who frequently reported that they incorporated therapy into play opportunities with their children. However, Goodley and Runswick-Cole (2010) felt as though combining therapy into play at home took away free choice of the child. In our study, caregivers reported that their child preferred to be in control of play, which was consistent with findings that play was centered around activities that the child enjoyed and was motivated to engage in, which elicited the most positive responses from the child (Román-Oyola et al., 2018). Finally, Bentenuto, Falco, & Venuti (2016) found that when mothers played with their children with ASD or DS, they reinforced the play skills that their child excelled in, trying to match their child's style of play. This supports our findings that mothers tend to let their child control play and take the lead.

Despite allowing children to have control, negative behaviors may present in play, such as aggression, spitting, and stubborn attitudes. Caregivers in our study indicated that when their child demonstrated some of these negative behaviors, they were less likely to engage in play with their child. Baker, Blacher, Crnic, and Edelbrock (2002) examined behavior problems exhibited during play by assessing 225 children with and without delays and the effects their behaviors had on the caregivers. According to the assessments used, the children with developmental delays showed more externalizing behavior and aggression and less emotional regulation (Baker et al., 2002). The researchers also discussed information about the correlation between the child's behaviors and the increase in stress for the family, which was similar to the testimonies of the caregivers in our study. Children with fewer demonstrated ASD behaviors were shown to have

an increased likelihood for stronger verbal communication and comprehension skills, leading to increased pretend play performance (Lin et al., 2017).

Finding Joy in Play

All four caregivers found joy and satisfaction while playing with their child; this is consistent with the findings from Román-Oyola et al. (2018), who found that mothers and fathers reported overall satisfaction when sharing about play with their child. These parents noted feelings of happiness when watching their child engage in play in meaningful ways (Román-Oyola et al., 2018). Generally, the mothers of children with DS included in our study reported more silly play in comparison to the mothers of children with ASD, which increased the joy they found during play. Mothers of children with ASD reported play with more sensory components, including deep pressure through hugs and snuggling. This element of physical affection increased joy.

The caregiver-child bond was a result of play that affected the mood of the participants and brought joy to them. Román-Oyola et al. (2018) found that when parents figured out how to play with their child, the parent-child bond was enhanced. Our findings are consistent with findings of Román-Oyola et al. (2018) because the caregivers discussed following their child's play patterns led to increased happiness when playing with their child. Ginsburg (2007) discussed how strong bonds between caregivers and their children are developed through play and caregivers are able to experience a deep sense of connection with their child as they can begin to understand and appreciate the ways that their child views the world. This caregiver-child interaction relates to the satisfaction of the caregivers in our study. It should be emphasized that there can be benefit to having a solid play pattern and routine, as well as being able to articulate to caregivers how positive play experiences can be of value to both them and their

child. Having satisfaction in play can motivate caregivers to continue to enhance play experiences and see the positive results that can come from the strong connection they have with their child during play.

Limitations

Researchers in this study only interviewed the caregivers of four children between the ages of birth to five years and 11 months with Autism Spectrum Disorder and Down syndrome. Including a wider age range of children with a greater variety of diagnoses would allow for research to be more transferrable to caregiver anxiety and its impact on play in children with disabilities. Additionally, it would be beneficial to interview fathers of children with varying disabilities in order to see similarities and differences of how anxiety levels in mothers and fathers affect the way they play with their child. Furthermore, research could focus on incorporating families with additional siblings in order to learn more about if family dynamics and anxiety levels are associated with children with disabilities. We encountered some challenges when recruiting participants for this study. The small number of caregivers interviewed limited the transferrable results of our study's topic. Although multiple means for recruitment were utilized (social media, clinics, and email), only twenty-nine individuals completed the GAD-7 screening tool, nine offered a means of contact for an interview, and four committed to participating in the interview.

Future Research

Future research should include additional caregivers of children with varying diagnoses, including motor disabilities, to encompass a greater variety of conditions in order to draw conclusions to contribute to this important topic in literature. Involving a greater spectrum of pediatric diagnoses to assess caregiver anxiety will provide further evidence of how children's

play can be impacted by increased anxiety levels in caregivers. Children's play contributes greatly to child development, thus future research should support the effectiveness of engaging parents and children in play in order to contribute positively to development. Future research should explore the effectiveness of interventions aimed at decreasing the anxiety of caregivers of children with disabilities to improve overall experiences of play for both the caregiver and the child. Caregiver anxiety and children's play are both within the occupational therapy scope of practice. Mental health is important to client factors and play is an ADL that children need to participate in to grow and learn to contribute positively to healthy child development and achieving developmental milestones.

Conclusion

Caregivers experienced anxiety when trying to make play purposeful and encountered increased caregiving demands associated with having a child with a disability. The level of caregiver anxiety was affected by feelings of not playing with their child in ways the child desired, experiencing pressure of adding educational components into their child's play to make play purposeful, and feeling overwhelmed with the additional caregiving demands and finding balance among their daily lives. However, caregivers still find joy in seeing their child succeed in play or progressing developmentally through play. The caregiver-child play bond is to be cherished and recognized as a key component of development. Joy found in play will motivate caregivers to continue to participate in play experiences with their child, leading to positive outcomes and a strong connection between caregiver and child during play.

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