Impact Of Developmentally Disabled Child On Family Dynamic

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Background of the Problem

It’s a beautiful feeling to have the title of parent. To have your child’s first words be “mama” or “dada.”To watch your children take their first steps. To see who they grew up to be. However, this title brings greater implications and there’s a shift in a parent’s focus when they have a developmentally disabled child. Their questions move towards when exactly their child will reach their milestones. We saw the need for families to speak out about their marital experiences raising a child D.D., which is why we conducted this study. With marriage being difficult, we wanted to know if having a child with D.D will bring added stressors. Does their family unit get stronger or break down? It’s important for other families crossing through this path to understand they are not alone, to gain insight on what other families do. The term caretaker burnout is twofold. A caretaker is someone who is responsible for one’s daily care and decision making(Fung, et al., 2011). Burnout comes when the caretaker begins to feel overwhelmed and stressed with the amount of time and work that goes into taking care of the individual.

Purpose of the Study

This study focuses on the impact a child with developmental disabilities has on a family dynamic. This study takes a qualitative approach. Twenty families were interviewed in New York City. Ten families had children with D.D and the other ten had adults with D.D. All answers are based on their childhood experiences. When we say children, we are referring to early to late childhood; ages 3-10. And adult’s from the ages of 21-40. In addition, when we refer to a child/adult categorized as developmentally disabled it means they have a “physical, learning, language or behavioral impairment"(Park & Kim, 2019). We defined family as one group of members where a father and mother are present and have been married for at least 2 years, before the birth of the child. We began the study by handing out flyers throughout three hospitals around the city where children with developmental disabilities were treated. We wanted to take a different approach and not only interview families that currently have children with D.D but also families with older adults with D.D that have gone through the childhood face. This gives us a better insight. This study was done with the hopes of broadening research by holistically looking at the family dynamic.

Literature Review

It's every parent's dream to have a happy and healthy baby. They'll do anything in their power, to protect them. Anything to make sure their child, the one they brought to this earth, won't suffer. However, what happens when you receive the news that your child has a developmental disability? What goes through a parents mind when the first words they hear from the doctors are, " I'm sorry but.." That once perfect dream of a healthy baby now feels so far away. When doctors begin saying things like " your baby will never walk on their own, your baby will require around the clock assistance, your baby won't be like the others" it does something to you. Your mind starts to wander and the first questions that'll pop into your mind are " how will we do this and what will our life look like?" For everyone it's different but one thing is for sure, caring for a person with a disability takes a toll on one's finances, relationships, and even marriage itself (Rothwell, Gariepy, Elgar & Lach, 2019). The goal of this paper is to shed light on what life is like for the caretakers of someone with a developmental disability. We will be looking at the family as a unit and how their spiritual, financial, and personal life is impacted.

Developmental Disability

By definition, someone who is categorized as having a developmental disability has either a “physical, learning, language or behavioral impairment”(Park & Kim, 2019). They can live a long life with impediments to their basic functioning. In other words, individuals with developmental disabilities are able to survive up to adulthood but may need assistance with moving around, reading, getting dressed, or some sort of support (Namkung, Song, Greenberg, Mailick & Floyd, 2015). According to the CDC, 1 in 6 children has some sort of developmental disabilities. Some of the diagnoses involved are cerebral palsy, autism, down syndrome, and intellectual disabilities(Kim & Dababnah, 2019).

Stressors

Kim & Dababnah in 2020 presented a qualitative study where they brought together 20 Korean American immigrant parents of developmentally disabled children. Families were found through organizations and support groups and given a $30 gift card for their participation. The criteria were Korean American immigrant families, with a child who has a developmental disability. Using the contextual model of family stress as a framework they focused on 4 themes, “sources of difficulties, sources of support, perceptions of developmental progress and personal transformations”(Kim & Dababnah, 2020). Within the sources of difficulties mothers of children with ASD mentioned how their child’s behavior was hard to handle. Behaviors included tantrums, self-injury and even running away from the caretaker. Mothers of down syndrome children expressed physical health problems as a stressor. After reading the mother’s scenarios, you can see that the overall stressor is seeing their children hurting. They would see their children hurt themselves. They would see the effects depression has on them, from not eating for days or sleeping to saying things like “ I hate me.” To see their child hurting so deeply, any parent would do anything to take away this pain, even carrying that pain themselves. It takes a toll on them. The author changes its focus to spousal support. Mothers saw the need to share responsibilities within each other and expressed that the Korean fathers only provided financial as opposed to American fathers who they saw as doing a “mother's job.” Since the people in this study were immigrants, it meant they left behind a family; the family that could have served as extra support. This caused a need for respite care. When thinking about their child's developmental progress, this causes more pain. This article did a good job of detailing the parents' concern for their child's future and the implications set out for what they will lead to within the marriage. Some limitations included the ratio from fathers to mothers being 5:15 and the specific ethnicity they used. It’s a study that can be generalized to the public because of this.

Marriage and Family

Another stressor comes when the family dynamic is jeopardized. In America, there’s a 50% divorce rate with reasons stemming from infidelity to financial strain. Having a child with a disability becomes an added stressor in a marriage. Like any other couple, life gets in the way, the difference is, now a special needs child is put into that equation. This means double the stress, double the finances, double the anxiety. There is no such thing as a “day off”. It's around the clock care. In 2015 a 50-year longitudinal study was done, where its purpose was to research whether there was a higher chance of divorce within families of developmentally disabled. It interviewed 190 families with a developmental disability. child and 7,251 without a developmentally disabled child(Namkung, Song, Greenberg, Mailick & Floyd, 2015). The results showed that in contrast with their hypothesis, there actually isn't much difference in divorce rate between both groups. This study showed that only 22% of the parents with children with developmental disabilities, divorced, as opposed to 20%. Although these numbers aren't high, a study done by Caicedo in 2014 showed problems families face as a unit. She described it as problems with "communication, stress within the family, a conflict between family members, difficulty making decisions, and difficulty solving problems as a family"(Caicedo, 2014). The highest being communication at 45%.

Caretaker Burnout

There is a term that is famous all around caretakers of people with disabilities, and that is caretaker burnout. According to Caicedo, 2014, this refers to when a caregiver basically gives their heart, sweat, and tears to take care of that person that needs it. Usually, family members are the first to feel this. In this study, 81% of parents said they felt this because they took the time off work to care for their loved ones. This included "bathing, feeding, dressing, grooming, and toileting; mobility; administering medications; monitoring; and providing treatments"(Caicedo, 2014). These are duties that are considered a full-time job.

Financial Stability

With a developmental disability comes many doctors' appointments and with that comes bills. A longitudinal study was done to examine the economic course taken from families took with members with disabilities and without. This is data that has been collected over a span of 25 years. The researchers concluded that special needs children were more likely to be born to a low-income family. Their finances seemed to suffer more when the child hit 5 years of age, showing that at this age “caregiving responsibilities and expenses were perhaps most demanding” (Rothwell, Gariepy, Elgar & Lach, 2019). This showed that families with children with special needs are at a higher risk to be economically unstable than the other way around. Some of the costs that parents are looking at, range from prescription medicine, home health care, medical equipment, therapies, and the list goes on. Sometimes the insurance does not pay and families are left to fend for themselves. Taking into account what we said earlier about their SES, you can imagine how hard this can be. According to the article, families with special needs children spend more than $1000 out of pocket(Donley, King, Nyathi, Okafor & Mbizo, 2018).

Health and Life Satisfaction

According to Caicedo, 2014, the physical, emotional, psychological, and social health of families with developmentally disabled children is compromised. This longitudinal study showed that 82% of parents expressed feeling frustrated, 66% expressed feeling anxious, 63% said they were sad, 44% said they were hopeless or helpless. These statistics show what impact having a developmentally disabled child can have on parents’ mental health. Parents admitted to not wanting to talk about their child’s health, not having the energy to go out on social activities. Nevertheless, the greatest percentage was when it got to talking about parents worrying about their children's future, 86% of parents thought of that(Caicedo, 2014). According to Park & Kim, 2019, the most common health care problem for parents of these children was depression, especially in mothers. These are moms that will care for their kids until their adulthood. In this study, a survey was given to test life satisfaction, caregiving time, and severity of behavioral problems. This study showed that the more time you cared for and the more severe behavior problems, the more depressed a mother would feel, which would cause her life satisfaction to decrease.

Conclusion

In conclusion, all these articles showed us the impact a child with developmental disabilities has on a family dynamic. First, we saw the stressors involved. Things like caretaker burnout strain on a family unit, financial struggles. We also saw how this can take a toll on a parent’s marriage and even on their health. We see mothers have a greater chance of suffering from mental problems like depression. They explained the fear parents have in talking to others about their child's diagnosis. The majority of the articles were longitudinal studies and gathered information from over 25 years back. Going forward I would like to look more on the impact this has on the child with the developmental disability itself. I found it weird that no article spoke on that concept. It is something interesting to dive into.

Method

Past research has only focused on the individual with a developmental disability and how they have navigated through life but left out a vital piece of information, the family component. Fung, et al.,(2011) states that the child and family need to adapt to the disability together. In a family dynamic when one individual suffers, it’s as if everyone is collaboratively going through that suffering. A child with a developmental disability affects everyone in the family, all in different ways. We wanted to get a better understanding of what kind of impact a child with a developmental disability has on the family. Using a qualitative approach we answered this question.

Participants

For this study, we interviewed about 20 families who currently reside in the city of New York. For this study, a family was composed of a mother, father, and either a child or an adult with a developmental disability. They all had to live together in the household. We searched for ten families with an adult with D.D and ten families with a child with D.D. We weren't looking for a specific race, we were open to different nationalities. Participants were recruited through flyers. These flyers were handed out by our research assistants in three different hospitals in New York City- Hospital for Special Surgery, Hassenfeld Children's Hospital at NYU Langone**,** and Premier HealthCare & YAI Center for Specialty Therapy. For this study, the participants will receive respite care. We choose this as a reward for parents to enjoy themselves while knowing their child is in good hands.

Design

This study used a qualitative design. We used a semi-structured interviewing process where we arrived with a set of questions but went dug deeper with questions like, " can you tell me more about that.'' Since this study has a lot to do with experiences, we went with a phenomenological approach.

Procedure

We will begin this study by creating a flyer that has a clear description of what the study was about. We will send out three research assistants to each hospital. One will hand out the flyers to families in Hospital for Special Surgery, another hands out flyers to families in

Hassenfeld Children's Hospital at NYU Langone**,** and the last assistant hands out flyers in Premier HealthCare & YAI Center for Specialty Therapy. The assistants will go daily for one week between the hours of 10 am to 3 pm. When potential participants call in, we will ask if they are a family with a mother, father, and developmentally disabled child or adult, living under one roof. If they answer yes, we will ask if they are open to being interviewed and sharing their life experiences. If they say yes, we set up a date to meet and sign consent forms.

To allow for the participants to be more open and feel comfortable, the interviews will be held in their homes and proctored daily per family. Each family member will be interviewed separately and then together as a focus group. We want to get their individual perspective and allow them to open up without fear of who's around. Coming together is also therapeutic and allows the rest of the members to hear what others are feeling. The questions for the parents are as follows.

1. Tell me about yourself.
2. What did you imagine your life would look like before you had (child/adult with D.D name).
3. In a few words describe how your marriage is going.
4. What are some stressors in your marriage?
    a. What do you usually do when this happens?
5. What is one thing you wish your partner would help you more in?
6. "Describe a typical day with your family"(Heppner et al.,2016, pg.371).
7. What's difficult about being a parent with a D.D child/adult?
8. What's rewarding about being a parent with a D.D child/adult?

9. What are your experiences being a parent with a D.D. child/adult?
10. What impact has a child/adult with D.D had on your marriage and family?

Once the family was interviewed, we gathered them up. These were the questions for the focus group.

1. If you can describe your family dynamic in one word, what would it be and why?
2. From what we spoke about earlier, what’s one thing you shared with me but never have with you the family.

Discussion

This study fills the gap and allows you to see what marriages are like when they have a developmentally disbaled child. One limitation to this study is the timing the flyers were handed out. Maybe because of school, many children would not be at the hospital. Also, since flyers were handed out as opposed to being put up, we aren't sure if there were any bias in who gets the flyer and who doesn't. This study can also be done as a mixed methods design and include questionnaires apart from interviews. Since this study was geared towards marriages, other members of the family were taken into account. A follow up study can be done and revolve around other members of the family and their perspective on this situation. This study was open with race but a follow up study can look into different races and how that variable fits into the equation. Ultimately, the purpose of this study was to see what kind of impact someone with D.D has on the family. We wanted to gain some insight so other families in the same situation can be helped.

Appendices

Appendix A

Informed Consent

I,________________________ volunteer to participate in a research study conducted by Jeanette Farias from Nyack College.

I understand the purpose and objectives of this study.

I understand that the results and findings of this study will be shared among others without using my name.

I understand that I will be interviewed by Ms.Farias, in my home along with other members of my family.

I understand that for this study to be as thorough as possible, I have to be honest.

Finally, I have read and understood what has been said to me.

I have received a copy of this consent.

______________________________ ______________________________

Researcher Participant

____

Date

Appendix B

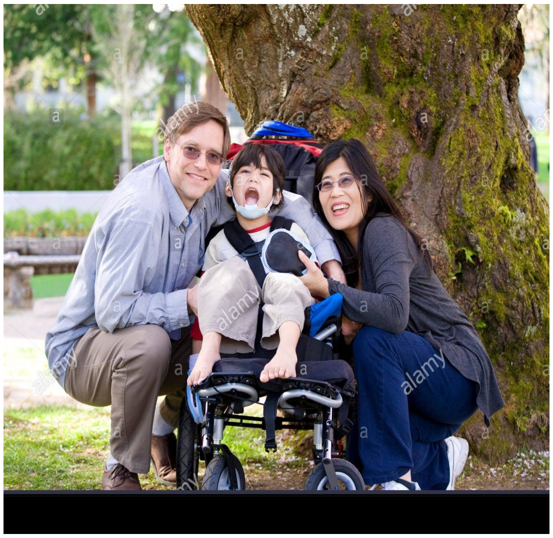
Recruitment Flyer

Are you a family with a developmentally disabled child or adult?

If you are a family with a mother, father and developmentally disabled child or adult, you may be eligible to participate in our research study.

Every child is put on this earth with a purpose, especially someone with a developmental disability. They bring joy, laughter, and love.

We know it isn't easy and can cause a strain on the family dynamic, especially marriages. The purpose of this study is to see the impact a child with a developmental disability has/had in the family. We are looking for 20 families that feel comfortable sharing their experiences.



Participants will receive:

- **Respite care**

Location

- **Interviews will be done in the comfort of your home.**

Are you eligible?

- **Father, mother and developmentally disabled child or adult living at home**
- **Comfortable being interviewed**

If you are interested in volunteering ot if you're unsure you meet the requirements, call or email a member of the study team:

Jeanette Farias

(BA psychology)

Email:

jfarias@nyack.edu

Phone number:

347.319.6453

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