

ABSTRACT

A Qualitative Study of Individuals with Special Needs and Their Families

Xana A. Toth

Director: Lindsey Camp, M.S.

The research on individuals with special needs and their families lacks the eclectic voices of the family. This study presents a qualitative questionnaire to individuals with special needs and their family members to understand what each has experienced from their unique point of view within their family: parent, sibling, and self. In the responses collected from four participants through a snowball sampling method via Facebook, four themes were found: communication, closeness, advice, and advocacy. The four themes were present in each family member's experiences and had impact on their perception of their family. Further, the findings have larger implications on society.

APPROVED BY DIRECTOR OF HONORS THESIS

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APPROVED BY THE HONORS PROGRAM

Dr. Elizabeth Corey, Director

DATE: _____

A QUALITATIVE STUDY OF INDIVIDUALS WITH SPECIAL NEEDS
AND THEIR FAMILIES

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By
Xana A. Toth

Waco, Texas

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DEDICATION

For my uncle

CHAPTER ONE

Introduction

Individuals with special needs and their families have long sought to be fully understood by others. Research has been conducted to understand their individual life experiences, only focusing on singular perspectives—parent, sibling, and self—not how these perspectives interact with each other. Family systems theory posits that the whole is greater than the sum of its parts. Thus, this study recognizes that family members have a bidirectional influence on one another and, in result, the family as a whole (Hardmen, Drew, & Egan, 2014).

This study began because of a class project conducted by the principal investigator in the spring of 2021. In that project, four interviews were conducted. The interviewees were an individual with special needs, their mother, their father, and their sister. In each interview, the principal investigator noticed a similar account of the disability, but differing perceptions of the family's lifestyle. Building upon this research, the current study further investigates how their different experiences impact their unique perception of the family.

Statement of the Problem

This study had two primary goals. First, it aimed to investigate the interpersonal relationships and functions of families with children with special needs. To do so, the principal investigator heard directly from individuals themselves, rather than a third party. Second, the study sought to raise awareness of social misconceptions about

individuals with special needs and their families. The goals were achieved by hearing the voices of four participants: (1) a parent to an individual diagnosed with spina bifida, (2) an individual with special needs who is also a sibling to an individual diagnosed with having seizures, (3) an individual with special needs, and (4) an individual diagnosed with epilepsy. They will be referred to later as B, C, L, and R, respectively.

For this study, responses were collected from participants to answer the question: What are the experiences of individuals with special needs and their families? The participants provided their own insight by responding to survey questions. The answer was given in a unique way because rather than only a parent or a sibling or the self, the voices overlapped for the reader to hear the perceptions of their experiences. One participant responded, “I cannot even speak for the other members of my family. They may see the world profoundly different than I do.” The family is complex and should not be categorized by one familial association type. The participants in this study seemed to understand this as well.

This study includes a literature review of previous research, followed by the method for this qualitative study. The results and discussion follow. Finally, the conclusion addresses the implications of the research, including how the findings impact both society and individuals with special needs and their families.

Operational Definitions

- Awareness
 - Perception or knowledge of something. Accurate reportability of something perceived or known is widely used as a behavioral index of conscious awareness. However, it is possible to be aware of something

without being explicitly conscious of it (American Psychological Association, *dictionary.apa.org* 2022)

- Disability
 - Used interchangeably with the term “special needs”
 - A condition resulting from a loss of physical functioning; or, difficulties in learning and social adjustment that significantly interfere with normal growth and development (Hardmen, Drew, & Egan, 2014)
- Family
 - Limited to adult individuals with special needs, adult parents of an individual with special needs, adult siblings of an individual with special needs, and adult children of individuals with special needs
- Perception
 - The process or result of becoming aware of objects, relationships, and events by means of the senses, which includes such activities as recognizing, observing, and discriminating. These activities enable organisms to organize and interpret the stimuli received into meaningful knowledge and to act in a coordinated manner (American Psychological Association, *dictionary.apa.org* 2022)

CHAPTER TWO

Literature Review

Current literature on individuals with special needs and their families is abounding, however the focus tends to be on one familial association type at a time. In the research by Strohm (2005) and Moyson & Roeyers (2012), only the sibling perspective is presented. Bernstein (2007) presented only the parent perspective. Lambert et al. (2014) presented the apprehension of an individual to tell others of their disability. The findings of Caldwell et al. (2018) indicated that the positive relationships between individuals with special needs and their family members impact the whole family's resilience and functioning. Therefore, providing one perspective at a time is insufficient to provide a complete picture of the family. With this in mind, this study included the voices of multiple perspectives within the family.

Meyer (1997) presented the voices of siblings of individuals with special needs. Meyer (1997) received personal stories from siblings of individuals with special needs. Meyer (1997) included a list of prompting questions, similar to this study's method, to request for the siblings to describe their sibling with special needs and their own experiences. Meyer (1997) received letters from 45 siblings of individuals with varying types of special needs between the ages of 4 and 18 years old. The work did not alter the message from the siblings; the letters were put in the work as they were written. Meyer (1997) added to the end of the book a glossary of the types of special needs mentioned by the siblings who had participated in his research.

There was an emphasis on the reality of a sibling's life, the good and the bad. While it is important to hear the sibling point of view, this research was lacking because the only voice represented was the voice of the sibling. To understand an individual with special needs and their family, one needs to engage and hear from each member because a family is made up of many unique people. With each unique person comes a unique perspective. This work also only gave the letters, and it did not provide an analysis of the letters. More work could be done in the analysis of the letters to understand what it is that siblings of individuals with special needs have to say.

This work by Meyer (1997) aided in the formation of this study. The principal investigator used the interview questions intended for the siblings as a model to the qualitative survey used in this study. This work also added to the current topic because it gave insight on the sibling perspective and experience. It aided in the understanding that siblings of individuals with special needs also have a voice that have the right to be heard.

Klein (2001) reported the perspective of parents of individuals with special needs. His work was made up of personal stories from parents of individuals with special needs with the intention they would be read by new parents of individuals with special needs. It included stories from over 60 parents, and it included a list of resources for new parents at the end of the book.

The parent stories had an emphasis on the initial reaction to finding out their child has a disability. The grief and joy experienced are shared and extended to the new parents, as well as other comforting words for the reality of the life the parents had. While it is important to hear the parent point-of-view, this research was lacking because the only

voice represented was the parent. To understand an individual with special needs and their family, one needs to engage and hear from each member of a family unit. This work also only gave the narratives from the parents with no further analysis. There could have been more work done to understand what it is that parents of individuals with special needs want and have to say.

This work by Klein (2001) contributed to this study because it provided a clear guide for how to gain awareness: to read from those who live what it is you are becoming more aware of. It also provided a source of support and understanding for other individuals with special needs and their families through personal stories. This contributed to this study because it is focused on hearing personal stories.

Schachter (2007) provided the individual with special needs perspective. This work was a part of a series of research called *Brainstorm*. Each work in the series provided a different point of view regarding their experience with epilepsy.

This work focused on the voice of the individual who was diagnosed with epilepsy. It focused on the shared and unique experiences of those who have epilepsy. This work highlighted the variability in the way disability looks and impacts life. It highlighted individual view of disability itself and the person who has a disability. There was description of individual experiences of seizures. While it is important to hear the individual point of view, this research was lacking because the only voice represented is the individual. To understand an individual with special needs and their family, one needs to engage and hear from each member. With an analysis of the responses, more work could be done to understand what it is that individuals of individuals with special needs have to say.

The research by Schachter (2007) is important to this study because it emphasized on the individual and epilepsy. In this study, two participants remarked on an individual within their family being diagnosed with epilepsy. This also aided to the present study because it gave perspective on how to gain awareness about epilepsy: to listen to those who experience it. This is presented by the personal narratives by individuals diagnosed with epilepsy throughout the book. Each person explained their experience with their diagnosis and how the same diagnosis looked different from person to person.

While the previously mentioned studies focused on one perspective, Solomon (2012) showcased multiple perspectives. The book *Far from the Tree* was published in 2012, and it was later filmed as a documentary in 2017. The documentary showed clips of Solomon (2012) speaking himself, and it had contributions from individuals, parents, and spouses in special needs families.

Solomon (2012) began this work to tell how he struggled with his identity growing up due to the social pressures and limits put on him because he was gay. He created a space for others who felt this way to share their life story. There was a focus on hearing from individuals themselves about their life experiences with a disability. It highlighted the differences and similarities of life between individuals with special needs and without. There was insight on what is considered special needs, as this could be different depending on who is answering. There was a focus on what it means to be human. The individuals explained their lives and how they are made out to be so vastly different from others, when in fact many aspects are the same.

While this work is different from the others because it included the multiple perspectives from an individual with special needs and their family, it was lacking the

analysis of the voices put together. This work also took a stance on how to represent individuals with special needs in mass media types. It demonstrated multiple perspectives in one work, which is what this study has an intention to do. It showcased those multiple perspectives are present, and special need impacts the whole family unit.

Puig (2021) combined the parent and grandparent perspectives to provide aid to teachers. This provided a better understanding of how to care for and educate children with special needs.

This work focused on giving multiple individuals with special needs and their families a place to tell personal stories to their teachers to better educate them on how to care for the children and the family itself. The work also gained perspectives from medical professionals and leaders of advocacy groups and programs. While this work had multiple perspectives included with an aim for awareness to teachers, it was lacking because it did not provide the perspective of the individual with special needs.

The work by Puig (2021) was important to this study because it had multiple perspectives in one work with intention to bring awareness to a greater audience. The structure of this work also had influence on the structure of this study. This work conducted in-person interviews, and this study conducted one in-person interview. While the rest of the participants participated via emailed response, their statements are presented the same in this study. This work is also impactful because it provided a thematic analysis of the interviews with personal thoughts from the researcher. This is a similar format to this study.

Other research on the societal view and awareness of disability has been conducted, such as by Buelow et. al (2015). The researchers analyzed awareness campaigns from

2001 to 2013 for epilepsy by examining their content, their presentation to the public, and the channel used to present the campaign.

Epilepsy Foundation conducted yearly campaigns for broad and targeted populations through traditional media, social media, community opinion leaders, and celebrity spokespersons. The article was made because an apparent stigma resulted from a lack of education by public. There was also shown to be a lack of education by individuals diagnosed with epilepsy. The researchers had a belief that proper and right education of epilepsy would reduce the stigma and gain overall awareness. The study found that there was a change in how campaigns presented to the public, such as social media gained major ground in the later years of the study with the invention of new technologies.

While this study is beneficial, it was lacking because it did not include personal stories. It would have benefitted more by hearing from individuals diagnosed with epilepsy and their beliefs on the campaigns. It also did not give what should be included in a campaign, rather just what has been in the campaigns, their reach, and effectiveness. Despite this, this work was important to this study because mass media plays a large role in how information is spread in the present day. Participants in this study also commented on how society views them and their disability. One participant remarked specifically about the lack of accurate information being spread through mass media about disabilities.

In the above literature, each is beneficial yet each is lacking. This study has been designed to fill what is lacking in each of the previous studies. While the current literature is beneficial to understanding the experiences of individuals with special needs and their families, this study is important because it hears the voices from many members

in a family, providing a “more” complete picture of a family. A thematic analysis was also conducted in this study to provide a deeper understanding of what an individual with special needs and their family wants to say and has to say.

CHAPTER THREE

Method

Research Question

In a class project in the spring of 2021, the principal investigator conducted four interviews with an individual with special needs, their mother, their father, and their sister. Each interview had similar levels of awareness of the disability, but each interview had different perceptions of the family's lifestyle and function. To further this research, the principal investigator developed the current study to ask individuals with special needs and their families of their different life experiences and how that impacted their perception of their family. The overarching research question was "What are the experiences of individuals with special needs and their families?"

Participants

The target subject population for this study was individuals with special needs and their families. In this study, the term family was limited to adult individuals with special needs, adult parents of an individual with special needs, adult siblings of an individual with special needs, and adult children of individuals with special needs. Throughout the study, the term "special needs" was used interchangeable with the term "disability." In this study, disability was defined as "a condition resulting from a loss of physical functioning; or, difficulties in learning and social adjustment that significantly interfere with normal growth and development," (Hardmen, Drew, & Egan, 2014). In total, there

were 17 inquiries on participating in the study that qualified for this study. Four out of the seventeen inquiries returned the questionnaire survey to the principal investigator. Each the four participants were in a special needs family as defined by the study, and their responses were deemed valid for this study.

The four participants who responded are referred to as B, C, L, and R throughout this study. In the submitted response, B stated they are a parent to a child who was diagnosed with spina bifida at birth. In the submitted response, C did not state their diagnosis, but it was inferred they were diagnosed with hearing impairment. C stated they are the sibling to an individual diagnosed with having seizures in his teens. In the submitted response, L did not state their diagnosis, but it was inferred they received a diagnosis of a disability that happened recently in their life. In the submitted response, R stated that they were diagnosed with epilepsy at a young age. No adult children of individuals with special needs completed the questionnaire. This was all of the demographic information that was collected.

Procedure

This study had a family systems theory framework and a qualitative research methodology. The instrument in the current qualitative study was the principal investigator. This study was modeled and adapted from the research conducted by Donald Meyer (1997). Since his research was conducted before wide usage of the internet and social media, changes were made to the platform of recruitment of participants and collection of responses to have a broader reach. Changes were also made to the survey questions to focus more on the family as a whole, rather than only focusing on siblings. This study received exempt approval from Baylor IRB on November 2, 2021.

To recruit participants for the study, a snowball sampling method was conducted via Facebook by the principal investigator. Facebook was used as the main recruitment platform because of its ability to reach mass numbers of people within a short amount of time, and many people use this social media site. The principal investigator posted the following public post on Facebook on November 8, 2021, at 2:40pm:

Hi, my name is Xana Toth! I am a senior University Scholar at Baylor University concentrating in Psychology and Child & Family Studies. As a part of my requirements in the honors program, I have the opportunity to write a thesis. This is where you come in!

My thesis research revolves around answering this question: what is awareness, particularly to individuals with special needs and their families? Awareness is typically seen as ad campaigns on television, books, social media, etc. Last semester, I was involved in a project where I conducted multiple interviews amongst family members within a special needs family. I gained amazing insight on what it means to be in a special family. In doing this, I also became interested in the interpersonal relationships of this particular type of family. My thesis seeks to understand the awareness of other family members within a special needs family. To do this, I need your help! My goal is to not tell your story for you, rather I want to create an outlet for you to tell your own story.

If you are interested in participating in this study and are over the age of 18 years old, please message me on Facebook or email xana_toth1@baylor.edu to receive more information.

Following the principal investigator's initial post, the post was then shared by others on Facebook. Once potential participants requested more information of the study, the principal investigator emailed the consent form and questionnaire to the participants. Seventeen people emailed the principal investigator for more information.

The consent form contained an overview of the research. The document informed the potential participant of the research purpose, study activities, risks and benefits, and confidentiality measures. A copy of this full document can be found in appendix A.

Participants were led to read a list of questions curated by the principal investigator and her advisor. The questionnaire contained eleven questions that encouraged the participant to think on the interworkings of their family. The questions are provided below:

1. How do you describe your family?
2. What are major strengths of your family?
3. How has your family maintained relationships since the diagnosis of yourself/ your family member?
4. What have you learned about yourself through being a member of your family?
5. What would it take for others to be truly aware of your family life?
6. What would your ideal support look like for you and your family?
7. When it comes to your family, what do you now know that you wish you had known sooner?
8. How does your family communicate about major events in your family life?
9. What are circumstances that make it tough to be in your family? What are circumstances when you like being in your family?
10. What would you like others to look at your family and see?
11. Do you have any further insights after having written this response?

A copy of the full questionnaire can be found in appendix B. After receiving the study information, participants were asked to share, to their comfort level, their responses to the questionnaire, their relation to the individual with special needs, and the individual's diagnosis. Responses were received from November 8, 2021, through December 11, 2021. Participants were informed they could withdraw from the study at any time. Out of the seventeen inquiries on the study, four continued through the process of submitting a response.

Data Collection

To receive information for the study, potential participants directly requested information from the principal investigator via email. After receiving the information, those who decided to participate in the study submitted a typed response, a maximum of three pages, to the principal investigator via email. Each participant submitted a typed response, with the exception of one. This participant requested to give their response verbally. The participant was interviewed face-to-face in a restaurant of the participant's choice, and the interview lasted four hours. The interview was recorded by iPhone voice recording. The principal investigator read the consent form and questionnaire as written

to the participant. The participant verbally gave their response. Later, the recorded response was directly transcribed by the principal investigator into a written response, and this is what was used throughout this study.

As responses were received, the principal investigator transferred them to a flash drive for confidentiality purposes. The responses were then sorted by family membership to the individual with special needs (self, sibling, parent).

Data Analysis

After the four responses were received, the principal investigator conducted a thematic analysis (Braun and Clarke, 2006). Initially, the principal investigator read and re-read the responses to identify potential themes. In the analysis, the principal investigator found four themes: communication, closeness, advice, and advocacy. In the next step, the principal investigator forwarded the responses to the thesis mentor to review the themes. The principal investigator and thesis mentor agreed the themes were congruent to this study's overarching question. Once the themes were finalized, the principal investigator began writing the report. After conducting the thematic analysis, the principal investigator and thesis mentor decided to change the study title to better fit the findings of the study.

CHAPTER FOUR

Results

The thematic analysis produced four themes: communication, closeness, advice, and advocacy. Each of the themes took place in certain settings: both within the immediate family and outside of the immediate family. As this study's intended question sought to understand the interpersonal relationships between an individual with special needs and their family, the distinction between the two contexts will be made through the discussion of the themes.

Communication

In their accounts, most participants gave insight on how their family communicates on a daily basis.

B: We talk to each other daily about things coming up, especially within our family. We pray together. Even with my daughter who is now married with her own child, we speak daily.

C: I remember a sharp shift in the dynamic of my relationship with the older two, because suddenly I felt like the glue holding everyone together. I was the middle man telling them what was going on at home and telling my parents how they were handling it. And since my parents both still kept busy with full-time jobs and busy lives outside of work, I felt like the middle man between my brother and my parents.

L: Usually, we have 'family meetings' where we sit down together and talk about major events. My parents will often lead the discussion, but my sister and I's input is always valued. As us children have gotten older, our opinions held more weight.

All participants highlighted how the individual with the disability communicated their wants and needs to the rest of the family. These varied from not having to say what was needed and it be given to not knowing what they needed until later.

B: My wife and I created a foundation for kids with special needs after our first son began to ask, "When would he get to play?"

C: In my family home, there was an unspoken seating adjustment in every room that allowed me to hear everyone else. There was an understood tolerance for higher volumes coming from the radio, the tv, and the yelling siblings. When things weren't the way I needed them to be, somebody usually caught on before I even had to ask for accommodations or changes.

L: Since my diagnosis, my family has generally maintained our relationships in a similar way prior to my diagnosis. However, at the beginning of my disability journey, I would often wish that my family would acknowledge the hardships we were going through. With well-intent, they wanted our life to go back to 'normal' as quickly as possible; however, I was struggling as my life was never going back to 'normal' and admitting that feeling felt like I was burdening them.

R: I would like to tell the other families to push your kids, even if you're a sister or brother. Tell them "You can do it. Don't let this hold you back because you're a person too." If I would've known that more, I probably would've had more effort in me to do it, but at least I feel like I didn't have to be pushed ever.

One participant remarked on the open communication in their marriage with their spouse.

R: When we were beginning dating and I told her about my seizures, she was scared and worried. She told me after the fact that we got married that she thought about not talking to me because it is a burden and you don't know much about seizures and they say they are an epileptic. You would be their main provider, and that puts a ton on your back. I thank her all the time for doing all the stuff she has to do that I can't do.

Each participant remarked on the aspect of perception within communication.

Perception is important to analyze in the communication section because how one perceives and interprets impacts how they react. The accounts of perception in the

responses mostly wrote of the want of a different perception from those outside of their immediate family.

C: But I'll say this: when others look at my family, I hope we are a reflection. I hope we are seen as we honestly are: as perfectly imperfect, beautifully broken people who were created to share life with each other as we fulfill our purposes in this life. I hope they see that in all of my family members, with or without disabilities. And I hope the unabashed display of imperfection will encourage people to look elsewhere for a picture of perfection. For me, that's God: the one who holds all things and all people together, the giver of purpose and joy, who is given glory in everything we are and everything we have, and in everything we are not and everything we lack.

C: I would like to see the notion of 'special needs' go away, and in its place I would like to see accommodation of needs become so commonplace we will wonder how those needs were ever perceived as 'special.'

C: Being in my family, seeing these two distinct timelines for me and my brother learning to live with a disability, I have learned something I wish I would have known a long time ago: at its core, life with disability is not so different from life without it.

C: My younger brother and I had the reference point of being a sibling with a disability, and one might think that would have given us greater comfort in knowing we were different—that we had to do things differently and ask for things other people take for granted.

R: We get pushed aside, and we shouldn't get pushed aside because we ain't any different in God's eyes. The only difference is the person right across from me and what they see. If they see it as a piece of trash, they are going to throw it away. If they see it as a piece of gold, they are going to keep it and treat it equal. We are not trash.

Participants also commented on the topic of perception by normalizing their family, that they are like any other family.

B: We have our problems just like any other family, but we have learned to overcome them as a team.

C: My family is, at first glance, about as typical and uninteresting as it gets. Just a mom, a dad, three boys and a girl living it up in Middle America.

C: It is my philosophy and my experience that among people who recognize that humans are intrinsically imperfect, perception of my family and other families that include people with disabilities is not really different from perception of families consisting only of typically-abled people. We may need extra time or extra grace, and we may not have extra spending money, but that can be true for any family.

Participants also reacted to how current perceptions from society are not accurate to what living with a disability actually looks like.

L: There is quite a bit of stigma surrounding my disability and people often assume that our life is not impacted by my disability. Further, they often blame our lifestyle choices for my disability, which is untrue, and results in apathy.

R: I'd rather see movies not portray it like life or death. Show to be beside him and don't make such a huge deal about it. It's someone having a seizure. It's going to be okay. It's just going to take a little bit of time, and he will be fine. They give seizures a bad rap in tv shows. This is what people think they need to do, and it makes me feel like if I have a seizure people will look at me like "stay away."

Closeness

When asked about family bond, each participant remarked on the closeness of their family.

B: We have our problems just like any other family, but we have learned to overcome them as a team.

C: I often took it upon myself to make sure my younger brother got all the attention and guidance he wanted and needed. This dynamic further emphasized my own disability as not-all-that disabling. So when he suddenly started having severe seizures when he was 15, there wasn't a script flip. Whatever my brother needed, I was determined to fill that need.

L: My family consists of my mother, father, younger sister, and me. We are not particularly close with our extended family so we are incredibly close.

R: I describe my family as close, very tight, loving, caring, kind, just love. That's about it. Major strengths of my family are how close we are, how much of a bond we have, how much we would do anything for each other, what I would do for them and them for me, how far they would go to help me with stuff.

All participants highlighted their family's faith and how this element has brought their family closer together.

B: Circumstances that I like are when we as a family are all together. This can be a game night or serving together through our foundation. Going to mass together every week.

C: My brothers and I grew up with a strong parent and community influence in our lives propelling us to put God first, our neighbors second, and ourselves last. We've all wavered from that in a number of ways, but I would say the biggest strength of my family is unconditional love for one another—and lots and lots of grace.

L: We are a Christian centered family who loves to tell stories and spend quality time together.

Participants gave insight on the sacrifices made for their family, by themselves and by others.

B: Circumstances that make things tough are when doing more for others seem to overshadow what we do for ourselves. It's tough when you don't get any me time or that individual attention from your spouse because there is a greater need.

C: My own personal life took a backseat while I watched over him—I couldn't leave him alone, I couldn't let him drive or swim; there were nights I would wake up and check on him just to make sure nothing went wrong while he slept. No one asked me to take on this role; it was just the way my family had always been.

L: The major strengths of my family are loyalty, our ability to laugh, and our willingness to make sacrifices for each other.

R: That is one of the reasons our family is so close. Me and Mom are close because when I was on homebound in 4th grade... That's why Momma had to stay home instead of start working.

R: It brought me and [my wife] closer. People just don't know how loving she is when it comes to it. She would give so much for me. Because of me, there is a lot on her plate that people don't know about. Being a wife of an epileptic puts a burden.

R: And I will always cherish it until the day I die because I love my family that much. Because of what they have been through and given up because of me. Not get because we had to go to hospital after hospital and money had to be spent. They didn't get what they wanted. It just gets to me, it's because of me.

One participant remarked of his family's closeness to other individuals with special needs and their families.

B: My family has always put their time into our year-round program because we see how much other families like ours appreciate it.

Another participant mentioned the importance of the closeness of a family.

R: Because family doesn't just mean three kids, a husband, and a wife. Family means what you would do for them. Family means how much you love them. It means that it's like a bond that never goes away, even in the bad. You don't leave because it is tough. Family is caring, loving, cherishing each other.

R: I would like others to look at my family and see how close we are because if a family ain't close with the person who has epilepsy, then something is wrong with that family because the person who has epilepsy needs that extra support and needs to know they have their back. If not, that person is going to get lost.

Other participants remarked on the closeness of society, such as the need for society to get close enough to know about these families' lives.

B: My wife and I lost many of our friendships from our college years after the birth of our first son. Since then we have rekindled most of those relationships and created new ones with families like our own.

L: To be aware of my family life, others would have to actually ask questions about the hardships of my disability and the impact it has on my family.

R: I would tell others to not be afraid. Don't look at me like I'm a dead dog on the side of the road. Like I'm worthless. Don't be afraid. Don't run off. Be caring, be kind, be helpful, be supportive.

Participants also commented on the closeness and support from those outside of their immediate family. Following a story about their brother-in-law taking them to the hospital, R stated, "Through this stuff, we have gotten close. He is aware of seizures a lot more."

R: Like when I was in the hospital, [siblings] stayed with different families.

R: I've had a lot of support in my life from family: aunts, uncles, grandmothers, grandfathers. They really cared and supported me through thick and thin.

Advice

The participants gave advice for those within their immediate family, such as how to gain understanding and acknowledging their way of life.

B: We had to accept the situation first to help others understand.

B: All of us have problems at one time or another but over the years we stress much less over them.

L: However, at the beginning of my disability journey, I often wish that my family would acknowledge the hardships we were going through.

The participants gave advice for the individual with special needs within the family.

L: I wish I had known that my disability did not ruin my family's life.

Participants gave insight on how they view life from his or her viewpoint.

C: Thus, I don't try to hide my perfections or the imperfections of my family; I hold our imperfections in one hand and my faith in the other, and they are reconciled in the truth of God's love, sovereignty, and goodness.

One participant gave advice on how the special family should view and treat the individual with special needs.

R: That's one thing I hope in the future that other families do with their kids even though they have seizures, don't let it stop them. Push them to achieve still...

As well as giving advice to members within the immediate family, the participants had a wealth of advice for those outside of the immediate family.

B: People should ask what we need or what they should say instead of staying quiet and keeping to themselves. Especially from other extended family members.

C: We may need extra time or extra grace, and we may not have extra spending money, but that can be true for any family. I wish more people would learn to think this way.

L: To be aware of my family life, others would have to actually ask questions about the hardships of my disability and the impact it has on my family. There is quite a bit of stigma surrounding my disability and people often assume that our life is not impacted by my disability. Further, they often blame our lifestyle choices for my disability, which is untrue, and results in apathy.

R: Awareness. Just like letting people know what goes on in families who have epilepsy. This would look like talking to people and letting them know what you can do for the person that has seizures.

R: I would tell others not to be afraid. Don't look at me like I'm a dead dog on the side of the road. Like I'm worthless. Don't be afraid. Don't run off. Be caring, be kind, be helpful, be supportive.

The participants gave insight on how to view each other as human first, not disability first.

B: I'd like them to see just our family, not that family with the kid in the wheelchair. I'd like them to see us...to see beyond the wheels.

C: We may need extra time or extra grace, and we may not have extra spending money, but that can be true for any family. I wish more people would learn to think this way.

C: What if we stopped defining ourselves as people with and without disabilities, and just defend ourselves as people. My family is probably more like yours than you might assume. Maybe someday we can move past those assumptions and start from a place of understanding.

L: When others look at my family, I would like them to see a family who loves Christ and loves one another. Additionally, I would like them to see a family with a disabled member that is by no means perfect, but has a wonderful, fulfilled life.

R: I want to be looked at like a person, a normal person.

In their accounts, the participants gave advice on how to view life from any viewpoint.

C: The world is full of challenges and hindrances to all different kinds of people. The quality of our experience in this life isn't dictated by the abilities we do or don't have; it's dictated by how we face the harshness of the world.

The participants highlighted how support could and should be given to special families.

L: Ideal support would look like acknowledging the hardships of our lives without judgement and offering to walk through our struggles with us. We do not need pity but actions and words that convey the message of “I see you. I love you. I want to do life with you.” Would be incredibly appreciated.

L: Disability impacts family members almost as much as the person with disabilities. A diagnosis is not exclusive to an individual but encompasses a whole family. When offering support for people with disabilities, their loved ones need to be at the forefront of people’s minds.

R: I would tell others not to be afraid. Don’t look at me like I’m a dead dog on the side of the road. Like I’m worthless. Don’t be afraid. Don’t run off. Be caring, be kind, be helpful, be supportive.

R: Push them, doesn’t matter how old they are. Push them and tell them they can do it.

R: Push them to read, learn, read the Bible. If you don’t, they won’t know much and feel worthless. Like you don’t know what other people know.

Advocacy

The act of sending a response and each quote above serves as advocacy. In each, the participants are speaking towards a subject, in this is their lives, and they are being heard. This theme overlaps heavily with all the previous themes because it is the underlying basis of this overall project.

The participants stated how they have advocated for themselves and their loved ones. R relayed a story in which the newspaper refused to put his name in it for making honor roll because they said the special education honor roll was not the same. R’s father threatened to sue the newspaper if his son’s name was not in the paper. R’s father

advocated for him to be treated with the same respect and dignity as the others who made honor roll.

B: My wife and I created a foundation for kids with special needs after our first son began to ask, "When would he get to play."

Participants stated how advocacy is needed for the entire family, not just one person within the family.

L: Disability impacts family members almost as much as the person with disabilities. A diagnosis is not exclusive to an individual but encompasses a whole family. When offering support for people with disabilities, their loved ones need to be at the forefront of people's minds.

Participants highlighted the importance of self-advocacy within their lives.

C: I never realized that the greatest strength I have in conjunction with my disability—self-advocacy—is a byproduct of the home and family I grew up in.

Participants advocated for a change: change of their family and change in societal view of humanity.

C: But in taking the four of us together, it's easy to see that we have all navigated the same essential struggle: the world is big and filled with people who seem to have it easier than we do. But at the end of the day, that simply isn't true.

R: Like don't panic, sometimes it will be okay if you only hold them, depending on the seizure type. There is some who just stare. Know the different types of seizures. Sometimes don't call 911. Maybe 20-30 seconds later everything will be okay because with me 20 seconds later and I'm fine, back to normal. Don't just rush to call 911. A lot of people don't know what to do or they panic and run. I've seen people not know what to do and basically ran off. I don't know if they got scared or what.

Participants advocated for the need for change in society for how individuals with special needs and their families are viewed and treated.

C: We have the social and systemic support we need to accommodate for our disabilities. Unfortunately, that's not true for every family. I long to see the day when that changes.

R: They give seizures a bad rap in tv shows. This is what people think they need to do, and it makes me feel like, if I have a seizure people will look at me like “stay away.” This type of thing isolates you.

A participant highlighted why there is a need for continued advocacy. R told a story about a teacher who pushed him in school, even when others gave him a pass because of his disability. He noted how this pushing him to do his best made him “feel loved in school.” When looking back on others in his life who did not push him as hard, gave him a pass, or did not know about epilepsy, he stated:

It’s like they are discriminating against you. It’s painful. That’s another word you can use. Throughout my life, because they don’t know and didn’t care to help, they just discriminate because of the looks they would give and do.

Ultimately, the participants seek more people to know and want to know more about their lives rather than assuming and acting out of fear. In reflecting on the importance of his words, R stated:

There is a lot that people don’t know that they need to know and I hope this helps them, that this is not just rambling.

The words spoken here have meaning, and they are more than printed letters on a page. Reading this, sharing this, and opening oneself up to acknowledge others in this way has an impact on many lives that is more than just one’s own.

CHAPTER FIVE

Discussion and Conclusion

Interpretation

The overarching question of this study was “What are the experiences of individuals with special needs and their families?” The collected responses indicated that perceptions regarding disability support need to be expanded to include support for the individual with special needs, for individual family members, and for the family as a whole.

L: Disability impacts family members almost as much as the person with disabilities. A diagnosis is not exclusive to an individual but encompasses a whole family. When offering support for people with disabilities, their loved ones need to be at the forefront of people’s minds.

The participants in this study answered that their experiences are most impacted by communication, closeness, advice, and advocacy. Open and clear communication between family members had an immense impact on the closeness of the family. The way disabilities were communicated to society through social media and other mass media impacted the societal view of disability. Many participants mentioned that misconstrued communication on disabilities is portrayed through social media and mass media. R mentioned that the way media has communicated disability has made society afraid of him and causes others to react to him with fear. The participants communicated that awareness from society is unattainable with this type of media portrayal. Since proper awareness is unattainable, proper perceptions of disability is unattainable. Since proper

perception is unattainable, proper interaction with individuals with special needs and their families is unattainable.

Regarding closeness, each participant agreed that a close family is a necessity. The family closeness is fostered by their experiencing of the same unique lifestyle. Participants also suggested that to be aware of their family, others outside of their family must become closer both physically and emotionally to them. The families need society to care enough to be present with them in the good and in the bad.

In their responses, participants gave advice to individuals with special needs, their family members, and general society. The advice was communicated in different ways. Advice was given to individuals with special needs on the importance of self-advocacy and maintaining open communication to others. Advice was given to family members on the importance of communicating the overall family well-being. Advice was given to general society on the importance of recognizing others as humans first, not disability first.

Overall, using good communication, getting physically and emotionally close, and adhering to the advice, others can advocate for disabilities. It is in these ways that others in the family and general society will truly gain awareness and correct their perceptions of individuals with special needs and their families.

Implication

The results of this study matter because this is real people. The United States population as of 2020 was 329.5 million people (Bureau, *Census.gov* 2022). Of this number, approximately 61 million adults live with a disability (Centers for Disease Control and Prevention, *Cdc.gov* 2020). If these words are deemed unimportant, then

roughly 19% of the United States population is deemed unimportant. This percentage is larger if it were to include the family members of these individuals as well. Their words are supported by their lived experience. A life they live on this earth just as every person does. Hearing what they have to say matters because what each has to say matters, out of respect of each being human.

Regarding the initial purpose of this study, the results matter because it is made up of the voices of the whole family. There is value in hearing the combined perspectives presented here from self, parent, and sibling at one time.

Limitation

This study has limitations in many ways. One limitation is that it does not give an example of what communication and closeness would look like; it only gives what is desired from the families. This study is also limited because only three disabilities, at minimum, are represented. The participants are also not from the same family. The participants have different perspectives and lifestyles because they are from different families and are associated with different disabilities. There is also a small sample size of four participants. This sample size may also be biased because of the methods used by the principal investigator of recruiting through Facebook.

Recommendation

In continuing this research, it is encouraged to conduct more studies to hear from more members within a special needs family. It would also be beneficial to hear from children. This study had a restricted timeline, and it did not have enough time to get the approval needed to include children's perspectives. It is also recommended to conduct research with more focused questions. This study asked questions that referred to many

areas. Asking questions that better relate to one or two areas would create a clearer answer to the study's question.

Appendices

APPENDIX A

Copy of Consent for Research

Baylor University

Child and Family Studies

Consent Form for Research

PROTOCOL TITLE: A Qualitative Study of Individuals with Special Needs and Their Families

PRINCIPAL INVESTIGATOR: Xana Toth

Invitation to be Part of a Research Study

You are invited to be part of a research study. This consent form will help you choose whether or not to participate in the study. Feel free to ask if anything is not clear in this consent form.

Why is this study being done?

The purpose of this study is to answer the question, “What is awareness?” through the lens of special needs families. This study seeks to understand the unique experiences of family members of individuals with special needs as it relates to their overall family story and family functioning. The rationale behind this study is to hear from families directly. Adult individuals and adult family members (parent, sibling, and children) over the age of 18 years are invited to take part in this study.

What will happen if I take part in this research study?

If you agree to take part in this study, you will be asked to submit a written response, maximum of 3 pages in length, to the principal investigator via email by December 11, 2021. You will also be asked to provide your relation to the individual with special needs and diagnosis. Below you will see a list of questions. These would be used only as a prompt. You can write about things on this list or not on this list, each to your comfort level. You do not need to feel pressure to answer each question.

1. How do you describe your family?
2. What are major strengths of your family?
3. How has your family maintained relationships since the diagnosis of yourself/ your family member?
4. What have you learned about yourself through being a member of your family?
5. What would it take for others to be truly aware of your family life?
6. What would your ideal support look like for you and your family?
7. When it comes to your family, what do you now know that you wish you had known sooner?
8. How does your family communicate about major events in your family life?
9. What are circumstances that make it tough to be in your family? What are circumstances when you like being in your family?
10. What would you like others to look at your family and see?
11. Do you have any further insights after having written this response?

How long will I be in this study and how many people will be in the study?

The written responses will be collected from participants until December 11, 2021.

However, participants are able to withdraw their response until March 15, 2021. About 40 individuals will take part in this research study.

What are the risks of taking part in this research study?

There are some risks you might experience from being in this study. There can be discomfort in sharing personal information regarding family life and personal story. To reduce this potential discomfort, participants are asked to share only to their comfort level and able to withdraw at any time prior to study completion.

Are there any benefits from being in this research study?

You might benefit from being in this study because it creates an outlet to share your story. It also may prompt new conversations you have with your family. It has the potential to gain more awareness of yourself and your relationships with your family member.

How Will You Protect my Information?

A risk of taking part in this study is the possibility of a loss of confidentiality. Loss of confidentiality includes having your personal information shared with someone who is not on the study team and was not supposed to see or know about your information. The researcher plans to protect your confidentiality.

We will keep the records of this study confidential by immediately transferring responses from email to a flash drive obtained by the principal investigator. This flash drive will be held for at least three years following the completion of the study. Subject names (first name, last name) will not be used throughout the project. Instead, the first initial of their first name will be used. We will make every effort to keep your records confidential. However, there are times when federal or state law requires the disclosure of your records.

The following people or groups may review your study records for purposes such as quality control or safety:

- Representatives of Baylor University and the BU Institutional Review Board
- Federal and state agencies that oversee or review research (such as the HHS Office of Human Research Protection or the Food and Drug Administration)

The results of this study may also be used for teaching, publications, or presentations at professional meetings. If your individual results are discussed, your identity will be protected by using a code number or pseudonym rather than your name or other identifying information.

Will information and/or biospecimens you collect about me be used for future research studies?

Information and/or biospecimens collected from you as part of this research may be shared with the research community at large to advance science and health. We will remove or code any personal information that could identify you before the information and/or biospecimens are shared with other researchers to ensure that, by current scientific standards and known methods, no one will be able to identify you from what is shared. The results of this project will be published in the Baylor University Library.

Will I be compensated for being part of the study?

You will not be paid for taking part in this study.

Your Participation in this Study is Voluntary

Taking part in this study is your choice. You are free not to take part or to withdraw at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled. If you decide to withdraw from this study, the information that you have already provided will be kept confidential. You cannot withdraw information collected prior to your withdrawal.

If you are a Baylor student or faculty/staff member, you may choose not to be in the study or to stop being in the study before it is over at any time. This will not affect your

grades or job status at Baylor University. You will not be offered or receive any special consideration if you take part in this research study.

Contact Information for the Study Team and Questions about the Research

If you have any questions about this research, you may contact:

Xana Toth

Email: xana_toth1@baylor.edu

Or

Lindsey Camp

Email: lindsey_swaithes@baylor.edu

Contact Information for Questions about Your Rights as a Research Participant

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

Baylor University Institutional Review Board

Office of the Vice Provost for Research

Phone: 254-710-3708

Email: irb@baylor.edu

Your Consent

SIGNATURE OF SUBJECT:

By clicking “I Agree”, you are agreeing to be in this study. We will give you a copy of this document for your records. We will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I understand what the study is about and my questions so far have been answered. I agree to take part in this study.

I Agree

I Do Not Agree

APPENDIX B

Copy of Questionnaire for Research

Questionnaire for Research

PROTOCOL TITLE: A Qualitative Study of Individuals with Special Needs and Their Families

PRINCIPAL INVESTIGATOR: Xana Toth

Below you will see a list of questions. These would be used only as a prompt. You can write about things on this list or not on this list, each to your comfort level. You do not need to feel pressure to answer each question.

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2. What are major strengths of your family?
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5. What would it take for others to be truly aware of your family life?
6. What would your ideal support look like for you and your family?
7. When it comes to your family, what do you now know that you wish you had known sooner?
8. How does your family communicate about major events in your family life?
9. What are circumstances that make it tough to be in your family? What are circumstances when you like being in your family?
10. What would you like others to look at your family and see?
11. Do you have any further insights after having written this response

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