Educating the Severely Disabled Medically Complex Child:

A Case Study on Parent Perspectives

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ABSTRACT

This study examines the perspectives of parents who have children with severe and profound disabilities and medically complex conditions. Children have the right to a free and appropriate public education. However, when faced with extremely significant physical, cognitive, and medical deficits, quality of life plays a central role in determining the least restrictive environment for their education to take place. In this qualitative single case study research design, parent participants were interviewed to gain their perspective based on the conceptual framework that incorporates school options, barriers and resources, parent support, and quality of life. Data from interview transcripts were coded leveraging thematic analysis. Four major themes were found, and conclusions were developed by weaving evidence from the interviews and literature. Results revealed the importance of education, the importance of quality of life, giving the child what he or she needs, and finding the support needed to raise a child with severe and profound disabilities and medically complex conditions. These findings indicate that all stakeholders play a positive role in fostering more inclusive and equitable educational practices. This includes supporting educational programs, ensuring access to specialized schools or medical care, promoting social opportunities, advocating for vulnerable students, and acting with empathy, thereby shaping the policies and frameworks that guide special education.

PREFACE

Quality of life is so very important to me because of my sweet son, Jack. Jack was born with a rare brain malformation caused by a partial deletion on the short arm of chromosome 17. At four months old he was diagnosed with Epilepsy and then after genetic testing Lissencephaly Miller-Dieker's Syndrome. At that time my husband and I were so naive, and we were worried about questions such as "Will he walk? Will he talk?" that we did not even consider the elephant in the room, life expectancy. Children with Jack's diagnosis have a life expectancy of two years. We were so blessed to have him for almost eight and a half years. Jack passed away in our arms on November 7, 2020.

When I think about quality of life, I think about providing the best love, care, interaction, and experiences while the person still has time. Our initial thoughts about development quickly turned to quality of life as Jack became more and more medically complex. He was so fragile that we decided to keep him at home for school. Everyone came to him. This worked for us, and we feel this gave Jack the most quality of life. School was a very important part of Jack's quality of life. When I say school, I think of his teachers that devoted time outside of their work schedule for him. I think of his related service providers such as vision, speech, occupational therapy, and physical therapy. I think of his nurses that were committed to his care. All these factors provided Jack with so much more than we could have ever expected.

Understanding perspectives, where people come from, how they react, relationships they have built and the knowledge they have gained from situations is all telling. This is only touching the surface, but I hope the reader can see the love, care, and heartache that goes into something as significant as caring for a child with severe and profound disabilities and medically complex conditions.

DEDICATION

To my beloved son, Jack Clyde Grassmyer.

If it were not for you, I would not be me. I love you.

You are the reason.

Keep sending me the moon.

ACKNOWLEDGMENTS

Over the past three years I have received support, guidance, and encouragement from some very special individuals. I would like to thank my dissertation committee: Dr. Jessica Hall-Wirth, Dr. Toni Mild, and Dr. Julie Nagle. Your continual support, feedback, and encouragement has been invaluable. Your dedication to your respective professions is inspiring.

To the parent participants of this study, I would like to thank you for contributing your stories and giving your precious time to share your personal experiences and perspectives. I have learned so much from all of you and your beautiful children.

Dr. Stephanie Ivory, Dr. Jennifer Misura, Dr. Melissa Peppetti, and Mrs. Angela Boutiller have been my mentors, colleagues, and friends.

I would like to extend my heart and pride to my Slippery Rock Co-Hort 7 Besties, Amy, Angela, and Jess. I cherish our friendship and constant support of one another.

To my loving friends and family, especially my parents Steve and Nancy Thompson, I could not have done this without you. Mom and Dad, thank you for always believing in my dreams, bankrolling my ideas, and loving me unconditionally.

Finally, Steve and Nancy’s son-in-law, Cassie’s husband, Jack’s dad, Jimmy. My husband, Jim, has been my rock and my strength through all the ups and downs of our rollercoaster life. I’m never getting off this ride with you. I love you so much and I thank you for your endless support.

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CHAPTER 1 INTRODUCTION

Among all children with disabilities, children with low incidence disabilities make up less than 20%. Children with low incidence disabilities demonstrate significant needs that vary from physical to medical to intellectual deficits (Dodds & Rempel, 2016; Kuo & Houtrow, 2016; Yu et al., 2020). Sometimes these children have frequent and lengthy hospitalizations due to multiple specialists involved in their complex care (Black et al., 2022; Kuo & Houtrow, 2016; Yu et al., 2022). Their care may also involve life sustaining equipment, durable medical equipment, numerous medications, and many therapies.

Parents of these children become their caregivers and decision makers (Anderson, 2009). Being a parent caregiver can be very difficult and emotionally draining (Prieto, 2022). Parenting and caregiving cross paths and leave parents with a unique perspective on many aspects of life that are not thought of regularly by others. Parents of children with severe and profound disabilities and medically complex conditions worry if their child will have a seizure on the school bus, if their child will live through the next complex surgery, or if their child will catch the next common cold and end up in the pediatric intensive care unit. Homes turn into hospital rooms with life sustaining equipment. Family rooms become therapy rooms where durable medical equipment is utilized to make the most of the child’s abilities. Trips to doctors’ offices, hospitals, and emergency rooms requiring urgent procedures or transfers by helicopter life flight to specialized treatment centers have become second nature. These thoughts, these decisions, these everyday occurrences can make for a stressful but beautiful life. What constitutes a beautiful life?

Children with severe and profound disabilities and medically complex conditions are a very small percentage of children with disabilities. Since this low incidence classification has such a small population of children, studies are limited (Duc et al., 2017). Research efforts have shown information about one classification of severe and profound disabilities and a separate classification of children with medical complexities. The population being discussed in this research study is that of both children with severe and profound disabilities and medically complex conditions. These children present with numerous disabilities and diagnoses, leaving them often in a fragile state dependent on around the clock care, not being able to live independently, and a potential for a reduced quality of life. Most research happens in the medical field, not with educators (Mancini & Layton, 2014). Further research is warranted to explore school experiences of children with severe and profound disabilities and medically complex conditions through parents' perceptions of quality of life.

There is value in approaching quality of life of children with severe and profound disabilities and medically complex conditions from a sensitizing concept as it leaves the inquiry open for exploration (Patton, 2015). Quality of life is difficult to define as it means something different to everyone (Carr et al., 2001). Quality of life can embody a variety of factors, such as medical, physical, social, and emotional health. Talking about quality of life often includes discussing intense subjects of death and dying of loved ones. Quality of life is a vulnerable topic. When talking about the life and death of children, the inquiry is even more delicate.

Measuring quality of life is just as difficult as trying to define it. "Promising research suggests that while chronic illness represents a challenge, it does not prevent children from living fulfilling lives" (Black et al., 2022, p. 2). Complex medical conditions do not prevent children from living fulfilling and meaningful lives (Black et al. 2022). Even though these children living with severe and profound disabilities and medically complex conditions are known to have life limiting illnesses, medical advancements, pediatric palliative care coordination, and other high levels of clinical care have increased the chances of living longer (Kuo & Houtrow, 2016; Mancini & Layton, 2014; Yu et al., 2020; Yu et al., 2022). Environmental issues such as geographical location, availability of services, socioeconomic status, access to assistive technology, support, and relationships can impact the probability of insufficient educational resources and affect children with severe and profound disabilities (Black et al., 2022; Chien et al., 2017). Educational effects could include barriers to access, absenteeism, social and emotional well-being, and quality of life.

In his book about qualitative research, Patton (2015) speaks of the way that things are changing in our world and how things are happening to people and families. These interactions and implications need to be observed, recorded, and analyzed. Society can learn a great deal from sharing stories. Parents can describe what impacts their child's quality of life through telling their stories and sharing their journeys. Listening to how parents perceive education concerning the quality of life of their child with severe and profound disabilities and medically complex conditions transcends through storytelling to help find meaning. This storytelling can provide purpose to their lives, their ability to share and help others in similar situations and gain a sense of belonging among a community they surround themselves with. Children, no matter how disabled and medically fragile, still have the right to a free, appropriate, and public education. This study will focus on how quality of life and education are connected by investigating parent perceptions.

Statement of the Problem

It is not known how parents of children with severe and profound disabilities and medically complex conditions perceive educational experiences and options for schooling in comparison to quality of life. Children with severe and profound disabilities and medically complex conditions have a right to a free and appropriate public education (FAPE), as referenced in the Individuals with Disabilities Education Improvement Act of 2004. Children with complex needs in and outside of the home add a whole other level of complexity to providing FAPE. The setting of education, environment, and quality of care children with significant needs receive in schools is not explained in the mandates other than stating that these settings should be the least restrictive environment (Anderson, 2009).

School districts provide services and educational solutions to address the diverse needs of these children. Sometimes school districts can provide these services in general education classrooms and self-contained classrooms. Sometimes these school districts are not able to provide these services within their district. Therefore, children with severe and profound disabilities and medically complex conditions must attend a specialized school or receive instruction conducted in the home (Shaw et al., 2014). How do educational leaders, teachers, administrators, and parents know the right decision about placing a child in the least restrictive environment? Resources and barriers can affect the safety of the environment, requiring the provision of appropriate levels of support. Among those barriers are access to curriculum, assistive technology, and medical needs, including skilled nursing services and highly qualified teachers. These needs can be challenging to all involved in the child’s care.

The basis for conducting this study is to elucidate the following research questions:

Research Questions

1. How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?
2. How do communication, interaction, and sensory integration impact quality of life for children with severe and profound disabilities and medically complex conditions?

3. How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life?

Existing Research

To better understand the concept of educating students with severe and profound needs, a thorough literature review was conducted of topics surrounding medically complex children, severely disabled individuals, parent perspectives, quality of life, inclusion and the continuum of alternate placement, as well as resources and barriers to access. Dodds and Rempel (2016) made reference to the quality of life model, "while the child's own physical and intellectual functioning influence which activities and at what level of participation can take place, in this biopsychosocial framework, society (e.g., attitude, legalities, fear) and environment (e.g., lack of community provider/caregivers and transportation) constrain performance and participation in life rather than the child with medical complexity" (p.254). This means that even if a child cannot be "fixed" does not mean that they cannot be involved, educated, and loved all while being "respected for their uniqueness and individuality and are recognized as deserving the right to overcome difficulties and to develop capacity" (Dodds & Rempel, 2016, p. 254).

In a study by Kruithof et al. (2020), they explored parent knowledge of their child with severe and profound disabilities and medical complexities. The findings from that study suggest that "parents possess unique, experiential knowledge of their child" and that they use this knowledge to advocate and communicate their child's needs to professionals (Kruithof et al., 2020, p. 1146). Nieuwenhuijse et al. (2019) introduce their study by stating that "quality of life is often a key factor in the decision making process for those caring for people with complex care demands" (p. 261). Nieuwhenhuijse et al. (2019) and Johaningsmeir (2015) also discussed the importance of having a parent caregiver involved in the understanding of what constitutes quality of life for their child and the decision making processes whether they are medical or educational.

A study conducted by Black et al. (2022) revealed that more research is warranted on the connection of health and education of children with complex medical needs due to the understudied population. “Fundamental questions about the impact of learning on health and quality of life outcomes in the short and long-term, appropriate teacher training, educating healthcare professionals, best practices for delivering homebound services, and student performance and engagement in online and non-online environments need further exploration” (Black et al., 2022, p. 14).

The key concepts this study is investigating are related to how parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and complex medical conditions. School options, barriers and resources, quality of life, and the parents’ stories of caring for their children come together to form the assumptions that underpin this research study. The conceptual framework upon which this study is based comes from a perspective of increasing quality of life and understanding what brings happiness and joy to the lives of children with severe and profound disabilities and medically complex conditions. This study aims to provide multiple parent perspectives in relation to the mode in which their child is or was educated. School modalities could include instruction conducted in the home, specialized schools and or classrooms, and inclusion in regular education. These perspectives aim to facilitate reflection, increase knowledge and understanding, promote positive practice, inform other parents and families in similar situations, and potentially provide educational policy changes.

Rationale for Methodology

This study uses qualitative methodology to investigate how parents of children with severe and profound disabilities and medically complex conditions perceive their child's school experiences in comparison to quality of life. A qualitative case study is used to define the lived experiences of individuals, often occurring through narratives (Patton, 2015; Saldana, 2021; Yin, 2019). Interviews with the parent participant sampling are the focus of data collection for this study to explore their lived experiences. These participants have their own perceptions about how school impacts their child's quality of life. Semi structured interviews are the means of collecting the data.

The researcher takes the transcriptions of the interviews to become immersed in the data and create codes that have significance in relation to the themes and ideas that come out of the parent participant open ended interviews. The codes then develop and expand through analysis. Qualitative research may be considered highly subjective. Patton (2015) tells us that "operationalization involves translating an abstract construct into concrete measure for the purpose of gathering data on the construct" (p. 361). Reducing a concept like quality of life to an operation does not sit well with most empathetic minds, therefore qualitative methods were selected over quantitative.

Significance of Study

The purpose of this qualitative single case study is to consider the parents' perspectives on school experiences and the quality of life for children with severe and profound disabilities and medically complex conditions. These school experiences can occur in a variety of settings and under a number of pretenses. This study investigates explicitly the parent perspectives regarding these opportunities and how these opportunities impact their child's quality of life.

Children with severe and profound disabilities and medically complex conditions may have shortened life expectancies, according to Yu et al. (2022). Initial thoughts about development and hitting milestones can quickly turn to thoughts of quality of life. Parents may think of quality of life as providing the best love, care, interaction, and experiences while the child still has time. Parents are often advocates for their children and the ones that fights to bring meaning to their lives.

School is a very important part of childhood, and that is no different for children with complex and severe needs. Teachers devote time to ensuring students' various needs are being met at school, and related service providers such as vision, speech, occupational therapy, and physical therapy offer treatment plans that increase success in school and other environments. Depending on where the child with severe and profound disabilities and medically complex conditions lives depends on what school opportunities he or she may have and what access is available to services, equipment, training, and support (Mancini & Layton, 2014). Parents' perspectives of these situations and what is available to their child are vital to understanding the needs of children with severe and profound disabilities and medically complex conditions.

This study provides a unique outlook on factors that largely contribute to the health and well-being of these vulnerable children and their families. Inequities in education are one thing we can address for our most vulnerable population to ensure they are receiving everything they need in life. "Meeting the educational needs of these children to provide a foundation for their fulfillment and independence requires a robust support system, dedicated resources, and interprofessional collaboration" (Black et al., 2022, p. 2). Environmental restrictions for children with severe and profound disabilities and medically complex conditions suggest there is a need for resources to support the children, the families, and all that are involved in their care (Black et al., 2022; Chien et al., 2017). This study hopes to help support parents and stakeholders when it comes to making decisions for their children with severe and profound disabilities and medically complex conditions.

Delimitations

Delimitations refer to restrictions resulting from the intentional choices made by the researcher. There are methodological limitations in this qualitative study related to the researcher's lived experiences and preconceived ideas. Personal assumptions of the researcher, a bereaved parent of a child with severe and profound disabilities and medically complex conditions, may make it difficult to believe the study is free from bias. The participants of this study are parents of children with medically complex conditions and severe disabilities. These parents' perceptions are not the only ones that matter when investigating educational experiences. This study does not consider the perceptions of other stakeholders, such as teachers or special educators, nurses, medical staff, and school administrators; instead, it is delimited to parent perceptions.

The research of quality of life is a sensitive topic. Assessing the quality of life in children with severe and profound disabilities and medically complex conditions is a challenge that is left up to interpretation from the parent participants and the researcher (Nieuwenhuijse et al., 2019, p. 268). This research must be performed with empathy, not objectivity (Nieuwenhuijse et al., 2019; Patton, 2015).

There is also the possibility that readers may not feel that the amount of data collected from the interviews is sufficient in sample size. The participants come from a relatively small population, and the researcher has limited access to these participants based on geographical locations of Pennsylvania.

Definition of Terms

Assistive Technology (AT) – any device, high tech or low tech, that helps improve learning and daily life.

Augmentative and Alternative Communication (AAC) – AAC systems are created to help others with speech and verbal difficulties communicate in different ways for example, using sign language, speech generated devices, and eye gaze technology (Couper et al., 2014; LaRue et al., 2016; Lu et al. 2022).

Children with Medical Complexity (CMC) - are a medically fragile pediatric population that experience severe chronic illnesses resulting in significant health care needs, functional limitations, and health care utilization, and are at the highest risk for morbidity and mortality among all children (Yu et al., 2020)

Continuum of Alternate Placement (CAP) – IDEA 2004 mandates that school districts have a continuum of placements available so the IEP team can choose the placement (where the student receives supports and services) that is in the least restrictive environment (Kauffman, 2022).

Free appropriate public education (FAPE) - The obligation for public schools to provide free appropriate public education to all children in the least restrictive environment. (IDEA 2004)

Individual Education Program (IEP) – a plan for academic and functional programming

Individuals with Disabilities Education Act (IDEA 2004) – Individuals with Disabilities Education Improvement Act, U.S.C. § 1400 (2004). Mandates free and appropriate public education in the least restrictive environment for all children with disabilities.

Inclusion – The idea of providing an environment for that increases potential for all students to have a sense of belonging and acceptance when placed in the general education classroom.

Instruction Conducted in the Home – School services are provided by the school district to a child with disabilities in their home. Is considered the most restrictive environment because no other children are being educated at the same home (Lustig, 2018).

Least Restrictive Environment (LRE) – Educating children with disabilities with children that do not have disabilities in the same environment to the maximum extent possible (IDEA 2004).

Medically Fragile Children – Children that have medical needs that require expert clinical care from doctors and nurses beyond the typical child. These children may require the use of medical equipment to sustain life and are dependent on others for specialized care (Mancini & Layton, 2004; Rehm & Bradley, 2005).

Pediatric Palliative Care (PPC) – Provides end of life care for children with life-limiting or terminal illnesses and diseases which may improve quality of life (Yu et al., 2020).

Quality of Life – The definition of quality of life is subjective as it is defined by health and well-being (social and emotional) of individuals and the capacity to live a full life no matter how much time is granted in that life (Carr et al., 2001).

Related Services – Any supportive services that can be provided to the students such as speech and language, audiology services, occupational therapy, physical therapy, vision therapy, social work (Lustig, 2018).

Self-Contained Classrooms – full time special classrooms for children with disabilities.

Severe and Profound Disabilities – Children with extreme physical disabling conditions or overwhelming developmental or intellectual disabilities such as blindness, deafness, and sensory impairments, as well as disabilities in speech and intelligence (Lustig, 2018).

Specialized Schools - to provide students with individualized and specialized instruction; however, research has suggested that this type of instruction happens less often (McCabe et al., 2020).

Summary

The terms above suggest the nature of this research study and hope to guide the reader into a greater understanding of what is forthcoming. As literature suggests, there is a need for more research on the small population of children with severe and profound disabilities and medically complex conditions. These children are living longer due to medical advances, technology, and care, and they deserve to have the best quality of life, including education, during their time in this world. This case study seeks to tell the stories of parents' perceptions of their exceptional children who are living with extensive needs. Their stories will hopefully lay the foundation for best practices and bridge the gaps to accessible education for children with severe and profound disabilities and medically complex conditions.

Chapter 2 provides the reader with a careful review of the literature surrounding the population of children with complex medical needs as well as children with severe intellectual disabilities. The chapter begins with educational foundations for special education and progresses to school options for children with low incidence disabilities. Discussion of sensitive topics such as quality of life, medical treatments, and pediatric palliative care are explored across different perspectives of clinicians, researchers, and parents. Least restrictive environment (LRE), free and appropriate public education (FAPE), and barriers to access are examined within the literature.

CHAPTER 2 LITERATURE REVIEW

Chapter 2 provides a review of literature related to the quality of life, school experiences, and parent perspectives of children with severe and profound disabilities and medically complex conditions. This literature review will explore the opportunities these children experience with reference to least restrictive environment (LRE) and free appropriate public education (FAPE). Historically speaking, the literature and litigation will be reviewed starting with the Education for All Handicapped Children Act, U.S.C. § 1400 (1975), spanning through the Individuals with Disabilities Education Improvement Act, U.S.C. § 1400 (2004). Implications discussed will traverse from the least restrictive environment, full inclusion, to the most restrictive environment, no inclusion, and instruction conducted in the home.

In a study of children who are medically fragile, a subset of children with special health care needs, Rehm and Bradley (2006) identified approximately 12.8% of American children as being children with special health care needs, meaning they have chronic conditions that require help and support beyond the typical child. Medically fragile children “require ongoing skilled supportive care to survive and partake in daily life” (Rehm & Bradley, 2006, p. 299). Medically fragile children will often qualify for special education and fall under one of the disability categories due to their dependence on durable medical equipment and assistive technology such as wheelchairs, walkers, feeding tubes, ventilators, and communication devices. Rehm and Bradley (2006) indicate that “the important goals of education for all students include the following: to learn social skills (such as cooperation, negotiation, and mutual support), to develop the capacity for positive peer interactions, and to learn how to get along with both peers and adults” (p 300).

Purpose

The purpose of this literature review is to investigate school experiences for children with severe and profound disabilities and medically complex conditions specifically looking into the opportunities that these children have that affect their quality of life as well as their parents' perspectives regarding these opportunities. Parent perspectives play a vital role in the lives of children with medical complexities. As disclosed in 1989 Timothy W. v Rochester, New Hampshire School District, all school districts must provide special education to students in need regardless of severity of disability. Timothy's parents fought for his right to be included in education even though it was deemed that he was not capable of learning. Parents are their child's voice and advocate, especially for children who have communication barriers. In addition to keeping their children healthy by becoming the primary caregivers, it is also the responsibility of the parents to help break down those barriers to enhance their child's quality of life. This literature review will overview previous research and studies on topics related to quality of life, parent perspectives, school options, barriers and access to resources including teacher preparedness and other inequities.

Research Questions

1. How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?
2. How do communication, interaction, and sensory integration impact quality of life for children with severe and profound disabilities and medically complex conditions?
3. How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life?

Overview

The first section of this literature review focuses on the historical background of special education law and how special education has evolved since 1975. The second section identifies the gaps in the literature and the need for this study due to the lack of current research on the population of children with severe and profound disabilities and medically complex conditions. The third section focuses on the conceptual framework of this study. The fourth section of this literature review focuses on the literature by pulling major themes such as medically complex children and their parents, options for schooling, resources and barriers, and parent perspectives. Within those major themes, there are sub-themes including quality of life, instruction, education settings, assistive technology, supports, services, and teacher preparation.

The researcher used peer-reviewed articles, empirical studies, journal articles, and books to search for literature from the library catalog discovery search and the following databases: Education Resource Information Center (ERIC), Education Source, Educator's Reference Complete OneFile, Directory of Open Access Journals, MEDLINE, PubMed, Sage Premier, and the Teacher Reference Center. The researcher conducted searches using a variety of terms such as least restrictive environment, quality of life, medically fragile children, children with medical complexities, multiple disabilities, severe and profound disabilities, continuum of alternate placements, inclusion, specialized schools, instruction in the home, and parent perspectives.

Historical Background

The United States mandated school districts to provide the least restrictive environment to children with disabilities in 1975 under the Education for All Handicapped Children Act (Public Law 94-142), also known as the EHA. Least Restrictive Environment (LRE) means children with disabilities are with the regular education population as much as possible or as most appropriate based on the needs of the child. Prior to 1975, there were no such mandates about educational placements for children with severe and profound disabilities. Many children categorized under this population were institutionalized because of lack of resources, services, and supports. Schools were not equipped to provide appropriate environments, let alone meaningful instruction. In 1990, the Education for All Handicapped Children Act was reauthorized and renamed the Individuals with Disabilities Education Act or IDEA. IDEA has been reauthorized several times since its creation, with the most recent being in 2004.

According to Lustig (2018), in 1975, there were more than 8 million children (birth to 21) requiring special education services, "however, only 3.9 million of those children with disabilities were receiving an appropriate education; 2.5 million children with disabilities were receiving an inappropriate education; and 1.75 million children with disabilities were receiving no educational services at all to meet their individualized needs," (p. 260). Schools across the nation now provide many options for children to learn and grow based on their needs. When schools cannot provide these educational services, there are other options. One of these options is a specialized school that exists to support children from birth to age 22 in their development. These schools are typically in larger cities and affluent areas and are not always accessible to all children due to distance. When these specialized schools are not available and going to a brick and mortar school is not an option, another option to educate that child could be instruction conducted in the home.

The Education for All Handicapped Children Act of 1975 stated that ‘‘To the maximum extent appropriate, children with disabilities... [should be] educated with children who are not disabled, and that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily’’ (EHA, 1975, sec. 1412). These modalities and services have evolved to provide opportunities for children with severe and profound disabilities and medically complex conditions.

In 2004, the Individuals with Disabilities Act further explained LRE as ‘‘the education of children with disabilities can be made more effective by having high expectations for children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible’’ (IDEA, sec. 601). According to Lustig (2018), most students with disabilities are educated in regular school buildings. This could mean students with disabilities are fully included in regular education, partially included in regular education, in a self-contained classroom, or a combination of those choices. If students are not able to attend regular education, there are options for specialized schools through a continuum of alternate placements. “However, despite the success of the IDEA over the last 30 years, thousands of students with medical disabilities continue to be segregated from their peers, teachers, and even the normal school environment through the provision of homebound instructional services” (Lustig, 2018, p. 206).

In a study about LRE trends, Brock (2018) performed an analysis of the percentage of students with intellectual disabilities by educational placement, revealing in 2014 there were 16.9% of students that spent 80% or more of the day in general education, 26.3% spent 79-40% in general education, 49.2% spent less than 40% in general education, while 7.6% utilized separate schools or other placements (p. 311). Why is this important?

Need for the Study

Efficacy research is important to the improvement of quality of life for children with severe and profound disabilities and medically complex conditions, specifically looking into the educational opportunities that these children have, barriers they may face regarding LRE and the continuum of alternate placement, as well as the parent perspectives regarding these opportunities. Little research has been conducted for the students who fall into this category, potentially due to the relatively small populations of children with both life-limiting conditions and intellectual disabilities. Lustig (2018) agrees that a study of this nature is needed to promote positive practice and educational policy changes.

Identification of the Gap

Although the LRE should be considered full inclusion for all, there are still many schools that do not have the resources or supports needed to provide children with severe and profound disabilities and medically complex conditions what they need to be successful in an inclusive setting (Agran et al., 2020). When this occurs, educational teams consisting of parents, teachers, therapists, and administrators work together to plan for options that will best meet the needs of the child. Many will advocate for full inclusion but may not understand the diverse instructional needs of children who have severe and profound disabilities and may also be medically fragile (Kauffman et al., 2023). It does not always matter where the child's body is, but it does matter if the needs are being met through instruction and intervention, no matter where this takes place.

> The nature of instruction and the quality of teaching, not placement, were the overriding concerns in EAHCA. Yes, placement certainly played a role, but it clearly was "second fiddle" to the primary objective of providing FAPE based on individualization. Those who conflate academic benefit with place of instruction as the primary objective of law simply neglect or, worse, wish to subvert the purpose of the law and its primary FAPE requirement. The law requires full and careful consideration of LRE to achieve FAPE, (Kauffman et al., 2023, p. 66).

Is inclusion too much of a good thing? Kauffman (2023) explains that “a primary part of maximizing the quality of the LRE is increasing the capacity of general education to provide supplementary aids and services and increasing the capacity for special education to be offered in a variety of diverse places so that all children with disabilities receive FAPE,” (p. 69). Sometimes inclusion is just not enough of an appropriate educational placement for a child with medical complexities (Mooney & Lashewicz, 2015). Other options, wherever they may occur, need to be explored diligently on a case-by-case basis (Kauffman, 2023).

Identifying these problems is only one part of the bigger issue. Just because children with severe and profound disabilities and medically complex conditions should go to a specialized school does not always mean that it is an option. There are barriers such as resources, location as in geographical area, and access (Yu et al., 2020). Problems can also occur when it comes to teacher preparedness and IEP team knowledge due to the small population of children identified as severely and profoundly disabled or medically complex (Lehr, 2020; Mancini & Layton, 2004; McCabe et al., 2020; Mooney & Lashewicz, 2015; Nabors et al., 2008; Rehm & Bradley, 2006; Vandercook et al., 2020). Parent perspectives and wishes regarding quality of life and expectations of education also function in recognizing these problems. This is where examining the quality of life of children with severe and profound disabilities and medically complex conditions becomes equitable.

How Will This Study Help?

Inclusive education may not be the best option for all children. “While inclusive education can be seen as the ultimate goal for many families, what is most important is a high quality and effective education for the child” (Downing & Peckham-Hardin, 2007, p. 17). Cologon (2022) says investigating this concept of high quality education “requires engaging in dialogue with people who are directly impacted by the ethical and political dimensions of inclusive and segregated education" (p. 400). Pufpaff et al. (2015) agree with others who have reported, there is minimal research about children with complex medical needs and their care coordination in schools. It has been suggested that further research focus on the identification of evidence-based practices that lead to safe and successful educational outcomes for this vulnerable population of students as critical. It is the aim of this study to provide multiple parent perspectives on the quality of life of our most fragile children so that special educators and administrators can help guide IEP teams to meet these diverse needs, all while bringing joy and happiness to their lives through educational experiences.

Review of Literature

When exploring the impacts of education on children with severe and profound disabilities and medically complex conditions, one must look at the whole picture, including the child, the parent, and the school setting. Who are children with severe and profound disabilities and medically complex conditions? What is it like to parent a child with extensive needs? What constitutes quality of life? How does one measure quality of life? What brings joy to these children and their families? What barriers are in the way of providing these children with the provisions and supports they need? Why is school important to quality of life? These questions will be explored through an extensive literature review of empirical studies and peer reviewed journal articles. Themes that have emerged through the review of literature include medically complex children, severe and profound disabilities, parent perspectives, quality of life, options for schooling, resources, and barriers to access.

Major Theme 1: Medically Complex Children and Their Parents

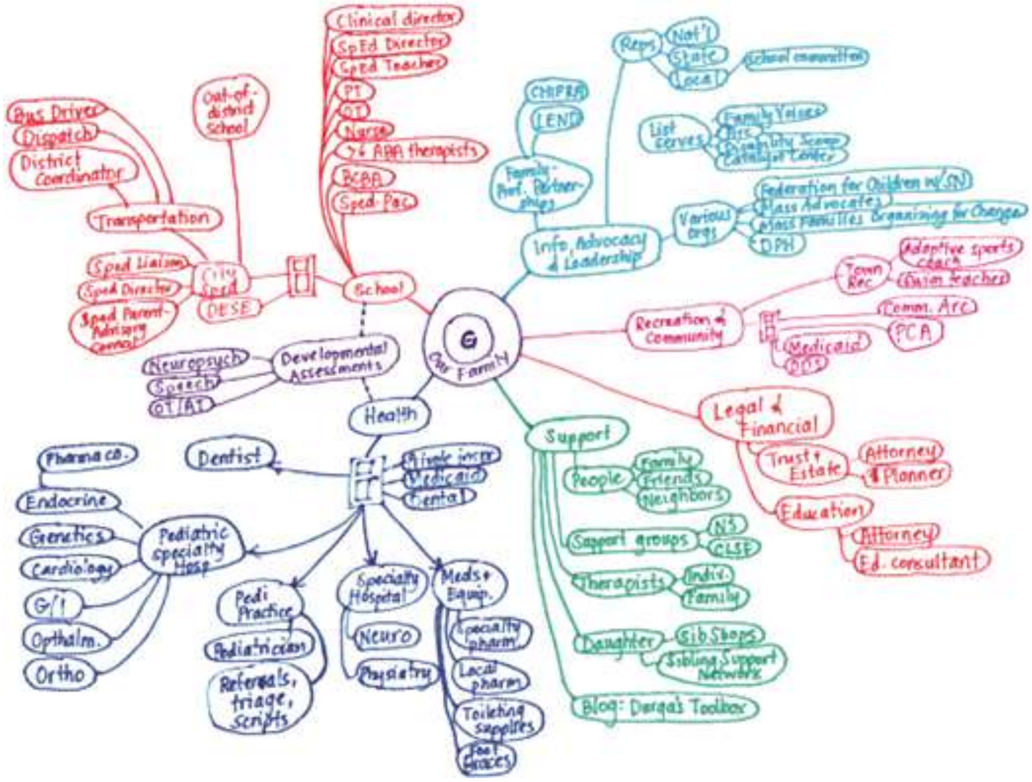
The population of children discussed in this literature review involves children who are dependent on others in many, if not all, aspects of life. These caregivers are often the child's voices but are also their decision makers for health, wellness, education, social interactions, recreation, etc. (Prieto, 2022). Duc et al. (2017) discuss the complex care of children with life-limiting conditions and intellectual disabilities. The goal of pediatric palliative care, "to help children live as well as possible, for as long as possible," involves an interdisciplinary approach. The audience of a literature study by Duc et al. (2017) is broad and includes clinicians, teachers, families, and therapists. The literature is focused on the child in a palliative care situation but also has an added layer of complexity with intellectual disabilities. This is where the terms come together as children with severe and profound disabilities and medically complex conditions.

Yu et al. (2022) describe children with medical complexity as having chronic and life limiting conditions needing around the clock care. Children with medical complexity typically have a limited life expectancy and high rates of poor outcomes regarding health and morbidity. Much of this care is often provided by family caregivers in the home. This takes a remarkable amount of support from medical specialists, additional doctors, nurses, related service providers, and therapists, as well as family and close friends (Coller et al., 2022; Ellzey et al., 2015; Kuo & Houtrow, 2016; Sobotka, 2022).

Children with complex medical needs are living longer due to medical advances in care and technology (Kuo & Houtrow, 2016; Rallison & Raffin-Bouchal, 2013; Sobotka, 2022). Rallison and Raffin-Bouchal (2013) inform us that medically complex children have a wide range of "often rare conditions including congenital abnormalities, genetic conditions, and neurodegenerative conditions" (p. 194). Children with neurodegenerative illness have a number of complexities and problems that require complete care. These children will experience a range of issues from mild to severe developmental delay, mobility issues, communication needs, feeding problems, respiratory complications, technology dependence, seizure disorders, autonomic dysfunction, and neuro irritability. A study by Duc et al. (2017) provide readers with a clear picture of the intricacies of caring for a child with medical complexities physically, psychologically, socially, educationally, and spiritually. The theme of their review was the benefits of early integration of palliative, also known as supportive care for children with intellectual disabilities and life-limiting conditions. Figure 2.1 outlines the thoughts of a parent of a child with severe and complex needs and the complexity that goes into taking care of that child.

Figure 2.1

The Complexity of Care



Note. Image retrieved from Kuo, D. Z. and Houtrow, A. J. (2016). Recognition and management of medical complexity. *American Academy of Pediatrics*, *138*(6). https://doi.org/10.1542/peds.2016-3021

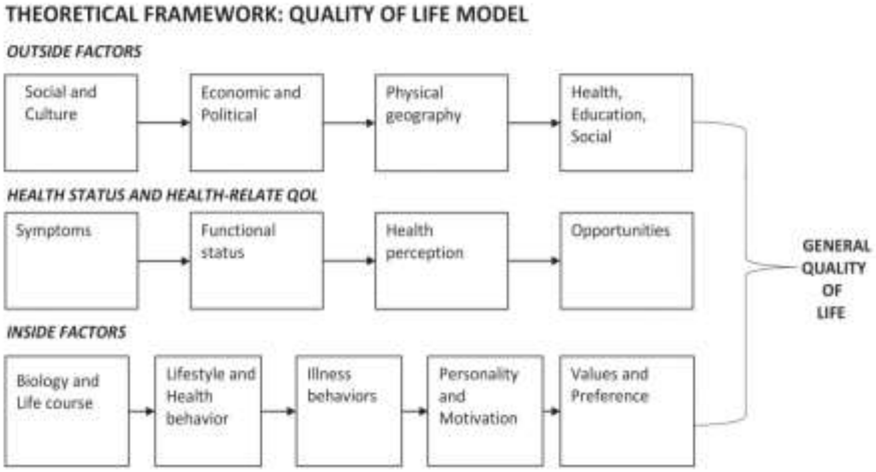
Rallison and Raffin-Bouchal (2013) reiterate that “there is very little research on the population of children and families requiring palliative care services where the child has a diagnosis other than cancer” (p. 195). This population of children has rare and extremely complex conditions requiring many specialized needs that are often hard to assess. Rallison and Raffin-Bouchal (2013) summarize a mother’s thoughts about her son’s total care by gathering that most children are going to gain independence over the years and require less and less care. However, for children with medical complexities, the care becomes increasingly difficult, requiring more and more with disease progression and child growth (Raffin-Bouchal, 2013). Caring for children with complex medical needs can be extremely overwhelming. Continuously supporting these children and families is very important to their quality of life.

Quality of Life. What is quality of life? How does one measure quality of life? These are difficult questions that cannot always be answered in the same way for everyone. Quality of life can and will vary from person to person and can be objective at times but is almost always subjective to the needs of the individual and what makes that life worthy (Carr et al., 2001; Petry et al., 2005). There is not one meaning of quality of life according to an article by Carr et al. (2001), “definitions range from those with a holistic emphasis on the social, emotional, and physical well-being of patients after treatment to those that describe the impact of a person's health on his or her ability to lead a fulfilling life” (p. 1240). Carr et al. (2001) aim to develop a way to explain how to evaluate quality of life as the discrepancy between expectations and experience.

There are multiple measures of pediatric quality of life through various protocols researched by Hullmann et al. (2011). Hullmann et al. (2011) provide a comprehensive overview of the following questionnaire used to survey children with or without chronic health conditions: Child Health Questionnaire (CHQ), DISABKIDS Chronic Generic Measure (DCGM), KINDL-R, Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales, and Quality of My Life Questionnaire (QoML). After exploring each of these protocols, it can be anticipated that they are meant for children who are able to answer questions using a Likert Scale in order to self-reflect on feelings based around health, feelings, social and emotional encounters, and even school experiences. Some of these protocols have a parent proxy form for parents and caregivers to complete if children are unable to do so independently. When referencing the specific population of children with severe and profound disabilities and medically complex conditions, these protocols are not effective and do not support the values of the parts of life that may be important to these children and their families. Figure 2.2 defines factors related to the quality of life model presented in a study by Dodds and Rempel (2016). Each child with severe and profound disabilities and medically complex conditions has his or her own meaning of quality of life, and so do the parents, caregivers, and educators supporting these individuals.

Figure 2.2

Theoretical Framework: Quality of life.



Note. Image retrieved from Dodds, C., & Rempel, G. (2016). A quality of life model promotes enablement for children with medical complexity. *Journal of Pediatric Rehabilitation Medicine, 9*(4), 253–255. https://doi.org/10.3233/PRM-160402

Children with severe and profound disabilities and medically complex conditions are often more vulnerable than typically developing children. They are at a higher risk for hospitalization from the common cold or other germs and viruses. “Indeed, children with CIMC are at a high risk for acute illnesses that require inpatient hospitalizations and frequent readmissions” (Bravo et al., 2020, p. 305). Sometimes taking the risk with germs to have social interaction is more valuable for the quality of life of certain children and their families, while others feel that social interaction is not worth the risk. It is fundamental to keep in mind that everyone will have different expectations and values based on those expectations while on different phases of their medical journeys. Despite the risks, parents, educators, nurses, doctors, and administrators feel that attending school is a positive opportunity to increase quality of life for a child with severe and profound disabilities and medically complex conditions (Anders, 2009; Rehm & Bradley, 2006). The question becomes, in what capacity can these children “attend” school, and how should they be educated to effectively meet their needs and provide a positive quality of life in their often shortened lives?

Education and Quality of Life. The importance of education for children with severe and profound disabilities and medically complex conditions is critical to quality of life. Often children with neurological disorders or neurodegenerative diseases have numerous comorbidities that inhibit independence. The population focused on for the purpose of this study are children who are non-ambulatory, nonverbal, and have multiple disabilities. These children have medical complexities that prohibit them from speaking and making choices on their own, and they are essentially trapped in their own bodies. They do not always have a way to express their wants, needs, or preferences. A child with severe and profound disabilities and medically complex conditions may not be able to communicate in a way that is easily understood by others. Caregivers and educators may need to develop innovative ways to communicate with these children to increase their quality of life. Rehm and Bradley (2006) agree that “children who are medically fragile and developmentally delayed (MF/DD) are often unable to initiate and encourage social encounters in the same manner as agemates of typical health and development because of their need for constant monitoring and assistance and the limits imposed by technology dependence, mobility impairments, sensory deficits, or cognitive ability” (p. 299). Communication and relationship building are two places to start through responsiveness.

Eliciting responsiveness from children with profound and complex disabilities and medically complex conditions is sometimes futile yet often remains a goal. Finding stimuli that will reinforce targeted behaviors through preference assessment can help determine the hierarchy of those preferences (Graff & Karsten, 2012). Carolyn W. Green et al. (1988, 1991) studied and evaluated preference assessment to identify reinforcers for individuals who were severely disabled. The individuals that Green et al. (1991) studied were completely dependent on caregivers due to being non-ambulatory and having multiple disabilities such as visual or sudatory impairment, seizures, spasticity, hypertonicity, or quadriplegia. This population is generally a challenging group to teach due to non-responsiveness. Green et al. (1991) wanted to determine stimulus preference and identify reinforcers for these children to assist in skills training programs. Since these children were not able to make choices in ways that typically developing children do, “approach was defined as the student making an apparent voluntary body movement toward the stimulus maintaining contact with the stimulus for at least 3 seconds, exhibiting a positive facial expression or making a positive vocalization within 5 seconds of the presentation of the stimulus” (Green et al., 1988, p. 32). After investigation, at least one of the preferred stimuli was accompanied by behavior change, resulting in a conclusion that systematic assessment procedures developed by Pace et al. (1985) can aid in the identification of preferences for children with severe and profound disabilities (Graff & Karsten, 2012; Green et al., 1988). These preferences are important because they bring joy and happiness to the lives of the children and families by directly influencing quality of life.

Continued research in the areas of preference assessment and reinforcer identification would help the population of severely disabled and medically complex children. Green et al. (1991) agree that “research seems warranted to explore further alternative treatment programs for persons with profound multiple handicaps and to determine objectively whether such programs do enhance quality of life” (p. 551). Preference assessments in children with severe and profound disabilities and medically complex conditions can prove to be beneficial and provide meaning to their lives. For example, a nonverbal child with vision impairment can show he prefers certain colors, objects, toys, television shows, or even people. Preferences bring pleasure, happiness, and even joy, making a positive impact on these children.

Children who are nonverbal and non-ambulatory might not be able to say what they want, point to what they want, or touch a picture or switch to say what they want. Making choices can be challenging. Parents, therapists, and educators can determine preferences by presenting two items or pictures to a child and see which way the child's eyes gaze. Presenting these items numerous times over the course of an assessment period would help collect data on the choices a child makes with his or her eyes. This is communication and relationship building for children with severe and profound disabilities and medically complex conditions.

After practice and continued exposure to making choices, children with complex needs may also benefit from AAC devices. Eye gaze technology is an incredibly amazing way to see children with severe disabilities increase independence, illicit communication, and continue to make choices with their eyes (Blackstone et al., 2021; Lui et al., 2022). With that in mind, research should extend to include electronic AAC devices that are eye tracking and speech generating in nature, such as tablets, iPads, eye gaze devices, Tobi Dynovox devices, etc., as mentioned in the LaRue et al. (2017) discussion.

Preference assessments have been applied to increase spontaneous communication (LaRue et al., 2017), improve behavior, and decrease frustration and unwanted behavior. One may wonder why any of this is important for children with such severe disabilities. Even if the stimuli do not have reinforcing value in training programs, knowing a child's preferences can certainly aid in their quality of life and "make the client's routine environment more pleasant" (Green et al., 1988, p. 42). Child preference is important and vital to learning and living. It is not just what the parent, caregiver, educator, or therapist wants or thinks best. Preference is never "one size fits all." What works for one child may or may not work for another. "The deficits in communication can be particularly problematic as they interfere with the ability to establish meaningful relationships with others and hinder skill acquisition" (LaRue et al., 2017, p. 32). The purpose of identifying preferences and reinforcers can help increase spontaneous communication. It can also reduce frustration in children (and adults) because positive reinforcement and desire encourage target behaviors. LaRue et al. (2017) agree that "not only could these systematic assessment procedures lead to more effective communication intervention, but they could help resolve disagreements and save time when selecting instructional targets for students" (p. 41). Preferences are meaningful for all children and their cognitive and emotional well-being. Quality of life is vital to these children and all who love and care for them.

Making choices and defining preferences is only one small part of educating children with severe and profound disabilities and medically complex conditions. When educating these children, focusing on participatory opportunities that foster positive engagement, interactions, physical movement, sensory input, play, and happiness can certainly add to their quality of life (Dodds & Rempel, 2016). According to Shikako-Thomas et al. (2012), being able to identify the factors associated with quality of life can help "guide program planning and the allocation of resources, thus optimizing the well-being of these children" (p. 2). With all the ways children can learn and be educated, one must consider the environment in which children learn. What are the options for schooling for students with severe and profound disabilities?

Major Theme 2: Options for Schooling

Regular School Setting (Inclusive). What are the implications of inclusion for students with severe disabilities and complex healthcare needs? Ballard and Dymond (2018) found that research demonstrates that inclusive educational practices promote social communication development, student engagement, and diversity awareness. Barriers include healthcare challenges, administrative issues, and teacher attitudes toward inclusivity. Themes that emerged from the research focused on the roles of personnel, including ensuring student safety, building trust, collaborating to balance healthcare needs, and advocating for inclusion.

Rehm and Bradley (2005) explored family challenges, including identification of the risks and advantages of school attendance for children with severe disabilities and complex healthcare needs. Ideally, parents and school support systems will work together to weigh the options and decide what is best for the child regarding safety, security, achievement, and enrichment. Rehm and Bradley (2005) identified important advantages of attending brick and mortar schools. These advantages include socialization with peers and other adults, as well as the opportunity for caregivers to have respite time. Respite time could be time away from caring for a child with special needs; it could also be time to participate in normal aspects of life such as working a job, cleaning the house, and taking care of other family matters (Rehm & Bradley, 2005; Suzuki & Kamibeppu, 2022). Rehm and Bradley (2005) aim to define "normalization in families raising children" with medical complexities (p. 811). What is normal? Going to school is typically viewed as normal in childhood. Schools provide programs and services for children with severe and profound disabilities and medically complex conditions in the least restrictive environment. Interviews by Rehm and Bradley (2005) found that "school allowed the regularization of family schedules, created opportunities for parents to concentrate on meeting the needs of other family members besides the child who was medically fragile and developmentally delayed, and provided brief respite from the intense demands of caregiving" (p. 815).

Children with severe and profound disabilities and medically complex conditions have challenged school systems. Lehr (2020) addresses the question of why these children are not being placed in general education classrooms. Data is limited on the number of students in schools with severe and profound disabilities and medically complex conditions due to the lack of a federal reporting category for this population of students as also outlined in Brock (2018). Court litigation has helped interpret the meaning of related services as complex healthcare needs for school districts. Consequently, they must provide the services. Consistent with other research, Lehr (2020) addresses the limited evidence and research based best practices for supporting students with severe and profound disabilities and medically complex conditions.

Vandercook et al.'s research "indicates that the use of systematic instructional strategies that have long been the hallmark of effective instruction for students with severe disabilities have been used effectively in general education classrooms to support academic learning and progress" (2020, p. 65). Using systematic instruction and high-leverage practices are ways to support positive outcomes that enhance development as well as social and emotional skills of children with severe and profound disabilities and medically complex conditions (Vandercook et al., 2020).

Zagona et al. (2020) completed a study to learn about how and to what extent students with complex support needs participated in the general education classroom, specifically in literacy activities, as well as the different types of supports that educators use to promote participation for them, and how educators learned these useful strategies. In this study, a child who has complex support needs "may receive special education and related services under the categories of intellectual disability, autism, and/or multiple disabilities" (Zagona et al., 2020, p. 2). After observations were completed, it was found that students "with complex support needs were participating in academic activities for over 75% of observations" (Zagona et al., 2020, p. 19). This was because many educators implemented prompts and directions throughout the lesson to help keep students on task. The types of prompts that were used included positive academic feedback, directions, and questions, and thoroughly explaining classroom expectations. The behavior supports that teachers used were "incentive systems, praise, offering breaks, and teaching the classroom expectations for the student" (Zagona et al., 2020, p. 13). The two most common ways that these teachers learned these strategies were through their colleagues and observing special educators, as well as simply learning through experience and determining what works best for students.

The Zagona et al. (2020) study is very useful for future and current educators because they can use these evidence-based practices within their own classrooms to better support students with complex support needs. Zagona et al. (2020) listed specific modifications they observed teachers using. For example, while all the students were handwriting whole words, the student with complex support needs was using an iPad to write and trace letters. Another accommodation mentioned was that while all the students were independently working on a writing activity, the student with complex support needs was being supported throughout the writing activity. There are so many other ways to support students with complex needs. Additional research would be helpful for educators working with students with complex support needs exploring the effectiveness of instructional literacy strategies that focus on supporting progress is essential to growth. Evidence-based practices, special supports such as assistive technology, and behavior interventions can be further investigated for future research.

Being fully included in the LRE is different for every child, especially children with severe and profound disabilities and medically complex conditions. Sometimes regular school settings where children are included as much as possible with their peers are not an appropriate placement, nor is it responsible inclusion (Mooney & Lashewicz, 2015). Kauffman and Badar (2016) defend that “the nature of the instruction students receive is far more important than the place where they receive it” (p. 58). Children with severe and profound disabilities and medically complex conditions require an extensive amount of care and attention. These children will often come to school with the mentioned assistive technology, durable medical equipment, a full time nurse, and a particularly vulnerability to regular brick and mortar school placements. In these cases, IEP teams must look at the continuum of alternate placement to make informed decisions.

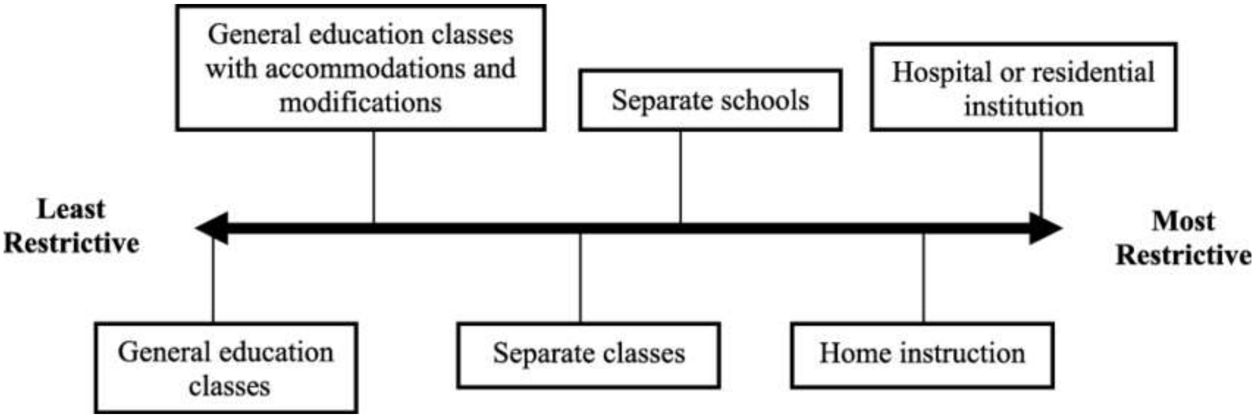
Specialized Schools and the Continuum of Alternate Placement. IDEA (2004) requires a continuum of alternative placements. The list of these alternative placements includes but is not limited to, instruction in regular classes, special classes, special schools, instruction in hospitals and institutions, and instruction conducted in the home (IDEA, 2004). McCabe et al. (2020) stated that in an examination of placement trends, children with severe and profound disabilities and medically complex conditions are usually placed in a more restrictive setting such as a self-contained classroom, specialized school, or other alternate placement. Alternative placements are not intended to replace school district responsibilities to the child. Instead, alternative placements are meant to help the school districts provide FAPE and overcome barriers preventing the child from being fully included.

Determining placement is based on how learning differences are affected by the identified disability through access to environment, curriculum, instruction, supports and services. Least restrictive environment for students with cognitive and intellectual disabilities pose barriers to educational attainment (Agran et al., 2020; Kauffman et al., 2023). Consider the continuum of alternative placement beginning with the local public school placement and moving towards a specialized or private school placement**.** Figure 2.3 provides visual representation of the LRE and CAP. Decisions about placements must be made individually for each child and with the support of the entire IEP team, including the parents.

> Special education appropriate for the individual child with disabilities was mandated, even if associated costs were more than the usual per-pupil expenditure or if providing FAPE necessitated a separate class or teacher or even a special school. Moreover, the law assumed that placement options ranging from general education to special schools and hospitals, as reflected in a CAP, should be considered in connection with the LRE for providing FAPE. Additional resources that sometimes involve different placements, such as teachers, training, materials, small teacher–pupil ratio, and assistive technology, are necessary to implement the right to FAPE for some students with disabilities. If the quality of placement and the material and economic aspects of the right to education are neglected, then the right to FAPE can only serve students with disabilities poorly (Kauffman et al., 2023, p. 66).

Figure 2.3

Least Restrictive Environment and the Continuum of Placement.



Note. Image retrieved from Rozalski, M., Stewart, A., Miller, J. (2010). How to determine the least restrictive environment for students with disabilities. *Exceptionality, 18*. 151-163. https://doi.org/10.1080/09362835.2010.491991.

The value of providing children with the appropriate education is what is most essential. There are advantages to specialized schools. McMahon (2014) discusses these benefits as having more meaningful opportunities, peers that are similar, environments and facilities that are appropriate and accessible, and specifically trained faculty and staff members that specialize in children with specific needs. Kauffman (2022) agrees that children with severe and profound disabilities and medically complex conditions should receive instruction in a specialized setting, especially when it “offers a more efficient, more effective, or more dignifying opportunity to learn” (p. 112). Instruction in specialized settings not only relies on procedures, routines, life skills and environments that contribute to educational progress, but also attributes to the health and well-being of children with complex medical conditions requiring around the clock care from clinicians or trained caregivers.

Nursing Services. Pufpaff et al. (2015) investigate the roles of the school nurse and special educator during the incidence of children with special healthcare needs and intellectual disabilities. Collaboration, coordination, preparedness, delegation and delivery of care are topics explored during this study. Pufpaff et al. (2015) conducted a survey of school nurses with both a quantitative and qualitative approach. Common themes presented were the complexities with collaboration that come with special healthcare needs and severe disabilities, the number of stakeholders involved in the education of students with special healthcare needs, and internal collaboration at the school personnel level, essentially between school nurses and special educators. Parents need to be included in this collaboration at the school as well. Parents are often the main caregivers maintaining care for their child’s specific needs for much of the day (Kuo & Houtrow, 2016; Prieto, 2022).

Ballard and Dymond (2019) completed another study to explore the importance of involving students in their own self-care to promote independence through qualitative inquiry. Students with severe disabilities are often looked at as patients, not learners. In the case study, the authors shared issues related to student involvement in specialized healthcare procedures within the school context. These specialized healthcare procedures include but are not limited to tube feedings, catheterization, insulin injection, and ostomy care. Ballard and Dymond (2019) broke down involvement into four themes: (a) partially participating, (b) interacting with adults, (c) engaging in risky behaviors, and (d) passively participating. The findings suggest a need for higher expectations for students with the most severe disabilities during self-care, including a need for a systematic approach, such as forward chaining, to teach these students independence and self-efficacy (Ballard & Dymond, 2019). Research is extremely limited on this topic, and most previous studies were completed in hospitals or outpatient settings, not schools. The authors conclude that more research should be done to examine an understanding of how schools address self-care vs. caretaking and why the gaps exist.

Nursing services are essential to children with severe and profound disabilities and medically complex conditions. Skilled nursing services are often used in the home as well as in the community, including school settings. Lustig (2018) considers the Garret F. case an access case where one-to-one continuous nursing services were considered a related service. Without the skilled nursing, Garret Fry would have been restricted to homebound instruction. Lustig (2018) shares that “the administrative law judge, whose decision was the subject of the Supreme

Court's review, recognized Garret's potential and had the foresight of similar related service and placement issues" (p. 265).

> Yet, it is possible that some ventilator dependent student, who like GF is bright, personable and creative, may come along someday who does not have, or does not qualify, for outside support for health care needs while at school. The only apparent alternative is a home-bound program. If the District refuses to provide health care and the family can't provide it, there is no middle ground. While the law anticipates that the appropriate program for some children will be an education program provided at home, that appears to be totally inappropriate for GF and any similar student. The lack of stimulation he now receives from a variety of teachers and peers would have a profound effect on the rest of his life. A home-bound program would certainly not be an education with nondisabled children to the "maximum extent appropriate. Clearly, GF receives much more benefit from his being in school than his being at home, his presence is not substantially disruptive to the school environment and his teacher's time is not unduly taken up working with him individually. Under Iowa statute, only when a child "cannot sufficiently profit from the work in the regular classroom" may he be removed (Lustig, 2018, pp. 296–297).

There are many stories like those of Garret Fry. Nursing is an essential component to providing children with severe and profound disabilities and medically complex conditions access to education in the least restrictive environment. Specialized schools make this easier having multiple skilled nurses available within the setting where it may be difficult for public schools to provide such services in part due to nursing shortages (Sobotka, 2022).

Specialized schools are an extremely beneficial alternative for children with severe and profound disabilities and medically complex conditions. One might say they are the best option. That is not always the case. There are still disadvantages of these specialized schools. One drawback and often a dealbreaker for parents is the distance to these specialized schools, in other words, the availability of these schools to all children in need of these specialized opportunities. Children will often need to travel long distances to attend specialized schools, resulting in residential opportunities, meaning these children would live at the school during the week away from their parents and other family members (McMahon, 2014). Many parents are uncomfortable with the thought of this situation and decide to keep their children at home. When an alternate placement or specialized school is not an option, there is the option for instruction conducted in the home as included in federal and state special education regulations.

Instruction Conducted in the Home. Instruction conducted in the home takes place when a certified teacher enters the student's home to provide individualized instruction to students who are unable to attend school due to illness or injury. According to the Pennsylvania Department of Education (2021),

> The use of Instruction Conducted in the Home is restricted to students whose needs require full-time special education services and programs outside the school setting for the entire day. Ordinarily, these will be students who, because of a severe medical condition or mobility impairment, are unable to leave home to attend school. Although a student placed by his or her IEP team on Instruction Conducted in the Home does not receive his or her program in the school setting, he or she remains entitled to a free appropriate public education (FAPE) equal to his or her non-disabled peers, unless this

amount of instruction would jeopardize the child's health or welfare (Pennsylvania Department of Education, 2005).

Shaw et al. (2014) focused on the topic of home instruction for students with chronic illness as a risk reducing practice for students in a non-traditional environment. The article begins with mention of early intervention and the Individualized Family Service Plan as a transition to school aged education. Services provided through early intervention in the home are part of this process until age five. At age five or sooner, children are evaluated for school age special education services. Instruction conducted in the home for students receiving special education services is considered the most restrictive environment in which special education services can be provided. Sometimes this is necessary and the most appropriate option for students, especially those with severe and profound disabilities and medically complex conditions (Petit & Patterson, 2014).

Lustig (2018), a professor at the University of Iowa, completed legal research that interprets and explains the law regarding home based instruction and least restrictive environment. It was clear that the author was in favor of inclusive practices and social interaction in a school setting being the least restrictive environment. Although, it was found through evaluation of legal research that home instruction is an appropriate and necessary option for placement, especially for students with complex medical health needs and for students with significant cognitive disabilities. Lustig (2018) concludes that home based instruction should only be used as a last resort. The student’s placement should be developed through a multidisciplinary evaluation providing a detailed individual education plan, developmentally appropriate programs, services, and multi-tiered systems of support.

Instruction conducted in the home falls under state regulations and defers to the school districts and ultimately, the IEP team. Students receiving instruction in the home receive a few hours per week of one-to-one teacher instruction. It is sometimes difficult to find a qualified teacher to commit to home based instruction as it is often an additional time commitment beyond the regular school day. According to Lustig (2018), there are no guidelines of the appropriate use of home placements. Lustig (2018) calls home instruction “a catch-22,” meaning it is wonderful for those students who need it and have no other options for instruction, but on the other hand, it can be implemented unduly for districts to take the easy way out and not provide inclusive opportunities for children with complex medical needs.

There are many implications for instruction conducted in the home. Families of children who are medically fragile worry about the child’s condition and intensity of care. Parents are typically the go-to caregivers while some children will also have skilled nursing services. Caregivers must be vigilant in caring for medically fragile children limited their abilities to modify routines and schedules (Kuo & Houtrow, 2016; Prieto, 2022; Rehm & Bradley, 2005; Yu et al. 2020, 2022). A common cold can turn into a lengthy intensive care stay at a pediatric hospital. This population of children is often dependent on life-sustaining technologies such as suctioning, enteral feeds or intravenous nutrition, breathing treatments, chest percussion treatments, positioning changes, dressing changes, and catheterizations. At times, it is just not feasible to transport the child to school daily, let alone to doctor appointments. In home treatments, services, and instructional support are sometimes the best and only option for children with severe and profound disabilities and medically complex conditions (Petit & Patterson, 2014).

Major Theme 3: Resources and Barriers

Many school districts lack resources, staffing, procedures, and even documented policies when it comes to making decisions about instruction in the home. Shaw et al. (2014) discusses barriers that can be addressed with the use of technology, communication, planning, and collaboration with families and medical professionals involved in the care of the student. The relationship between teachers, students, and their families is often the most effective approach to overcoming some of these barriers.

Barriers to Access. Chien et al. (2017) discussed the importance of participation in normal everyday life as well as environmental factors. Social, emotional, and physical well-being are factors of quality of life and are also greatly impacted by environmental factors (Chien et al., 2017; Milicevic, 2023). These environmental factors may pose barriers to access for children with severe and profound disabilities and medically complex conditions. Chien et al. (2017) extensively cover different categories of environmental factors in the research including "(1) Products and technology; (2) Natural environment and human-made changes to environment; (3) Support and relationships; (4) Attitudes; and (5) Services, systems, and policies" (p. 61).

An important barrier to address is the availability of specialized schools that provide specific services and supports for students with severe and profound disabilities and medically complex conditions. When IEP teams meet to discuss progress and placement, a specialized school is not always an option. Simply put, there are not a lot of specialized schools, especially in rural settings. Students would need to travel a long time to get to school in some circumstances. Transportation, social restrictions, and the amount of care needed could cause restrictions. Taheri et al. (2017) agree that children with severe and profound disabilities and medically complex conditions have a lower participation rate than typical children. Chien et al.

(2017) “found that environmental restrictions at home were the least restrictive to children’s participation, a finding that is consistent with that of a previous study” (p. 70). With that being said, where are children learning best? What factors are considered barriers at the school level and at the family level? (Chien et al., 2017; Taheri et al., 2017).

Developing environments that are accessible to people, places, things, and resources influence quality of life (Taheri et al., 2017). Having access to community recreation such as parks, playgrounds, and other environments can be barriers for children with complex medical needs. For example, if a playground is not accessible, a child in a wheelchair may not be able to access an adaptive swing. If a child is going to see a show about their favorite character on television and the theatre is not handicap accessible, the child and family would not be able to attend without a struggle. If a child cannot access the stairs to get to his or her bedroom, the whole environment of the family home might need to change. Positive experiences in the school, in the community, and in the home are important contributing factors of quality of life. “School experiences are an important part of everyday life for children and families, and the quality of this experience may also be an important determinant” (Taheri et al., 2017, p. 1153).

Assistive Technology. Along with physical and environmental barriers, there are barriers to providing modifications and assistive technology that are individualized, meaningful, and relevant (Downing & Peckham-Hardin, 2007). Assistive Technology (AT) is any device, high tech or low tech, that helps improve learning and daily life for someone who requires support. Augmentative and Alternative Communication (AAC) is a topic that needs to be explored for students with complex needs. AAC systems are created to help others with speech and verbal difficulties communicate in different ways for example, using sign language, speech generated devices, and eye gaze technology (Couper et al., 2014; LaRue et al., 2016; Lu et al., 2022).

Presuming competence of individuals with complex needs is essential, and it should be believed that students can learn, can communicate, and can participate in daily life activities. Norburn et al. (2016) reference the quality of life of individuals with complex needs due to feeling isolated because of lack of social interactions and opportunities to communicate with peers, family, and friends (p. 290). Using AAC is apparent and is not only about communication.

Norburn et al. (2016) reinforce the fact that students with severe and complex needs will often need someone to support them with using AAC. It is up to these individuals to help gain access for these students, whether it be visual, communicative, or physical. This study highlights the importance of communication in terms of expressing views, needs, wants, and responding to others. The study also addresses the barriers students face. The research by Norburn et al. (2016) analyzes the experiences of staff working with students with these severe needs, what services they provide and their needs for further education and professional development. According to Norburn et al. (2016), 69 out of 72 participants (staff) used some form of AAC regularly. "Considering that 57% of participants supported students with PMLD and 56% supported students with autism, two of the populations most likely to need an AAC, one would expect there to be a higher incidence of children using AAC to express themselves. This frequency of use has significant implications on the children who are dependent on those around them to interpret their communication attempts" (Norburn et al., 2016, p. 300). Inconsistency of use and knowledge across the participants was presented in the data. Continued professional development and training would allow staff to get more comfortable with using AAC. "Adequate, regular training is important, not just for communication partners, but also for professionals who are working with children who have complex needs" (Norburn et al., 2016, p.

301). AAC is essential to the quality of life of children with complex needs and needs to be used frequently to be effective.

Providing resources such as AAC or other assistive technology is a barrier to access for some school districts in the United States. Obtaining this type of equipment and people with expertise in using the functional and instructional tools are two hurdles to jump. Blackstone et al. (2021) created a study to gather information from school-based professionals who work with children with cortical visual impairment who use AAC. These professionals included speech-language pathologists, teachers of the visually impaired, special education teachers, assistive technology specialists, occupational therapists, orientation and mobility specialists, and “other.” The second goal of Blackstone et al. (2021) was to gather the perspective of parents of children with cortical visual impairment. This included types of services, the level of use of AAC, accommodations the child has, and any barriers to access.

Blackstone et al. (2021) explained that cortical vision impairment is a disability that most people are not familiar with. Cortical visual impairment is considered an underreported, underdiagnosed, and undertreated condition. Many children with severe and profound disabilities and medically complex conditions will often have a visual impairment. Blackstone et al. (2021) found that many students with cortical visual impairment are not receiving the support and services they need to be successful. There were many barriers and gaps that school-based professionals disclosed. The first thing was the lack of training and knowledge of students with cortical vision impairment and AAC. Access to resources and materials was also ranked as a significant barrier. Lack of knowledge about cortical visual impairment was a barrier for 35% of the participants. Lack of knowledge about AAC was a barrier for 30% of participants. Another concern was the lack of time school-based professionals have to collaborate and plan for students with complex conditions and needs. 52% of participants ranked time limitations as a significant barrier. Most school-based participants, about 75%, agreed that planning is a challenge. (Blackstone, et al., 2021).

Parents expressed concern about how their child lacked access to symbolic language because AAC has so many visual components and their child relied heavily on body movements to communicate. Only 33 out of 63 parents selected personal photos as language symbols that can be understood and used by their children (Blackstone, et al., 2021). To reiterate, using AAC for communication and expression is just one small part of teaching children with severe and profound intellectual disabilities.

A major strength of Blackstone et al. (2021) was that it presents people with valuable, current, information regarding children with cortical visual impairment who use AAC. As educators and providers, it allows stakeholders to better understand the barriers students with cortical visual impairment face. With the findings from this study, there needs to be more training on cortical visual impairment and accommodations to help. There is a lack of services provided to students with cortical visual impairment and this needs to be addressed immediately. The parent surveys were valuable because they are the sole providers and know their children the best and can bring valuable insight. The study can suggest valuable information for providers and educators. With this study it can be concluded that school-based professionals need to develop reliable and valid information about both cortical visual impairment and AAC. They need to determine “what types of AAC approaches support the development of language and communication skills for children with cortical vision impairment is essential” (Blackstone et al., 2021, p. 612). It is hopeful that with the information provided through Blackstone et al. (2021), stakeholders will be more aware of the limitations and barriers children face when diagnosed with cortical vision impairment as well as other neurodegenerative diseases and how AAC use is essential to development and quality of life.

Teacher Preparedness. Nabors et al. (2008), researchers from the University of Cincinnati and Walden University, assessed 247 regular and special education teachers' perceptions of their knowledge about and confidence in meeting the academic and social needs of children with chronic medical conditions through a survey. The survey results showed that the teachers did know about the chronic medical conditions, but they lacked confidence in the areas of educational and social needs of children with chronic illnesses. This study and others like it are important because more children with complex healthcare needs are being included in regular education settings as the least restrictive environment. According to Nabors et al. (2008), due to advances in medical and assistive care along with medications, it is indicated that nearly every teacher will have interactions with a student with a medical condition during their teaching tenure. Lack of teacher preparedness and comfortability in educating this population of students is suspected (Nabors et al., 2008).

There is a need for teacher preparation programs to address teaching low incidence disabilities to receive the necessary training to support inclusivity at all levels. In a study by Downing and Peckham-Hardin (2007), teachers discussed the need for more support especially when expected to modify curriculum to meet diverse needs. Teachers are looking for ways to increase positive learning through factors such as collaboration, instructional strategies, systematic instruction, and the support of highly qualified teams (Downing & Peckham-Hardin, 2007).

There are supplementary researched based resources available now, but there is still a need for more, easy to access, reliable information for providers and parents. Perkins eLearning, Paths to Literacy, Lesson Pix, and PrAACtically Speaking, among others, are valuable resources as they offer diverse tools, strategies, and materials to enhance teaching and support learning for students. Perkins eLearning provides professional development for teachers working students with visual impairments and other specific needs, while Paths to Literacy focuses on literacy skills. Lesson Pix and PrAACtically speaking support the use of communication through lesson planning, strategies, and resources to aid in creating engaging and inclusive learning opportunities for students. There is a critical need to target preparation programs in education, occupational therapy, speech and language pathology, etc. since CVI and AAC is content relevant across multiple disciplines (Blackstone et al., 2021).

Vandercook et al. (2020) addressed the mindset of teachers by saying, “the mindset, attitudes, and behaviors of each teacher, whether trained as a general or special educator, was that they shared responsibility for each student who walked or wheeled in the front door of the school, they could join their unique skill sets to work together to more effectively support the learning of each student,” (p. 66). Building relationships with students is very important in the part of the teacher, but so are building relationships with colleagues and having a climate of collaborative teamwork.

Supports and Services (OT, PT, Speech, Vision). Schools also serve as a place for children with severe and profound disabilities and medically complex conditions to participate in related educational service such as occupational therapy, sensory integration, physical therapy, speech therapy, vision therapy, and social services (Vestel et al., 2023). These related services are critical to the health and well-being of these children. It is concerning when children do not receive hands on, in person, supports and services through educational programs. This affects not only the child’s quality of life, but also the family’s structure (Vestel et al., 2023). Without therapies provided, parents and caregivers of children with severe and profound disabilities and medically complex conditions take on those additional roles. Vestel et al. (2023) reference this disparity during the COVID-19 pandemic and the struggle with virtual related services.

The magnitude of related services within education programs makes a huge difference in the lives of children with severe and profound disabilities and medically complex conditions. In a study to better understand quality of life of children with Cerebral Palsy, Milicevic (2023) presented valuable data regarding “the planning of disability-related services and policies” (p. 69). When children require related services due to deficits in development, consistency and practice can become an issue. Limited sessions of these therapies are never enough, meaning teachers, parents, and other caretakers will need to continue to implement strategies learned during these sessions to help improve the quality of life of the child (Downing & Peckham-Hardin, 2007; Milicevic, 2023).

Major Theme 4: Parent Perspectives (what is it like to be a parent to a child with severe and profound disabilities and medically complex conditions?)

“Children with medical complexity (CMC) are characterized by chronic and deVere health conditions, significant health service needs, major functional limitations, and high health care utilization” (Yu et al., 2020, p. 1117). Children with severe and profound disabilities and medically complex conditions typically have a limited life expectancy and high rates of poor outcomes regarding health and morbidity. To help these children, and in response to the patient-centered medical home, strategies for improving quality of life of children with severe and profound disabilities and medically complex conditions and caregiver quality of life have been a recent focus of the pediatric medical field (Kou & Houtrow, 2016). According to Yu et al. (2020), the majority of children with severe and profound disabilities and medically complex conditions live at home with family caregivers being responsible for providing 24/7 medical care that is often complex with little support. These family caregivers are often not medically trained professionals, instead they are moms and dads who love their children and are willing to learn how to turn their home into a hospital/make-shift intensive care unit (Kou & Houtrow, 2016; Sobotka et al., 2022; Yu et al., 2020).

Due to the amount of stress family caregivers are under, the researchers found it important to evaluate the family caregivers' health and quality of life quantitatively. "Improved understanding is needed to properly guide CMC health care providers in attending to family caregivers' needs" (Yu et al., 2020, p. 1116). Yu et al. (2020) assess the relationship between children with severe and profound disabilities and medically complex conditions and family caregivers' health-related quality of life (HR-QOL) and experiences with care coordination. Yu et al. (2020) "hypothesized higher quality experiences of care coordination would be significantly associated with higher caregiver HR-QOL, with greater positive association with caregiver mental health relative to physical health" (p. 1117). Most of the children in this study had neurologic/neuromuscular (91.9%), gastrointestinal (87.5%), and respiratory (66.2%) issues and required medical technology assistance (Yu et al., 2020).

Yu et al. (2020) found that caregivers' mental health was significantly connected with specific aspects of care coordination. It was reported that there were significantly fewer mentally unhealthy, depressed, and anxious days for the caregivers having supportive and knowledgeable care coordination and feeling that their child with severe and profound disabilities and medically complex conditions are having their needs being met and advocated for. These caregivers are under a tremendous amount of pressure and have stressful responsibilities caring for their child with medical complexities and making care decisions with little support (Johaningsmeir, 2015;

Kou & Houtrow, 2016; Sobotka et al., 2022; Yu et al., 2020). This research is a priority for families of children with severe and profound disabilities and medically complex conditions. Caregiver health is so very important to the quality of life of the caregiver and the child being cared for. The focus on caregiver quality of life can have a meaningful impact on child health outcomes.

In a qualitative study, Rehm and Bradley (2005) focus on normalization in families facing the range of demands essential in raising a child who is both medically fragile and developmentally delayed or disabled. Most previous research evaluated normalization for children with serious physical conditions causing medical fragility, not both medically fragile and developmentally delayed children. The authors used parent interviews for this study to learn how families cared for their children who were both medically fragile and developmentally delayed. They also explored how these parents worked with schools, nurses, case managers and other community supports in identifying the risks and advantages of school placement. The response to the interview questions recognized that family goals and priorities vary greatly, and that normalization does not necessarily equate to a desirable clinical strategy to cope with chronic complex conditions (Rehm & Bradley, 2005). Reading Rehm and Bradley’s (2005) study about parent perspectives and how they struggle to relate to the normalcy lens was different from other research conducted. These families needed to vigilantly prioritize the care of their child and could not place the child’s condition in the background for extended periods. Their lives were centered around the care of their medically fragile developmentally delayed child, often being the one consistent factor keeping the child alive with life sustaining treatments.

Continuity of care and accessibility are other themes that arise in studies of children with medical complexities (Kou & Houtrow, 2016; Sobotka et al., 2022; Yu et al., 2020). Continuity of care means the clinician is available and makes sure the caregivers know how to contact them at any point in time (Yu et al., 2022). The value of having a “quarterback,” one clinician in charge who understands all the child’s health issues is very important to caregivers (Yu et al., 2022). This allows one clinician to become the care coordinator for the child with medical complexities, working directly with other clinicians and specialists on the child’s team keeping everyone informed and on the same page with the care plan. This “quarterback” is a trusted voice, one that parents and caregivers can lean on.

Complex care clinicians become personally invested. Yu et al. (2022) share that the parents and caregivers feel that the clinicians did not treat their child like a typical patient. These clinicians approach the children and caregivers differently going “above and beyond”. They show compassion and talk to the patient despite a non-verbal variable. There is a sense of partnership between the clinician and the parent caregiver. Parents felt that clinicians truly listened to their questions and concerns. This equates to relationship building. Caregivers felt comfortable enough to ask questions and clinicians would take the time at appointments, never rushing. Finally, this is a longitudinal relationship thorough knowledge of a child’s entire clinical picture (Altman et al., 2018; Kou & Houtrow, 2016; Yu et al., 2022). Relationships were built on compassionate communication and commitment to the child with complex medical needs.

Commitment to the child with severe and profound disabilities and complex medical conditions goes beyond the clinical lens. Parents are not only worried about the medical concerns of their children, but they are also worried about the commitment to providing their children with an appropriate education. When faced with a life limiting diagnosis for their child, one might think school would not be a priority. In some circumstances, this is true, while in other cases, parents have a variety of reasons for focusing on the importance of educating their child with severe and profound disabilities and medically complex conditions.

Parents rely on school for a number of reasons including the structure, consistency, routines provided to their children, access to related services such as occupational therapy and physical therapy consistently, the one on one attention provided by teachers and paraprofessionals, and the skills and new knowledge that help their children learn, (Downing & Peckham-Hardin, 2007). Decisions about their child's education can be difficult. Each family's story is unique from diagnosis to prognosis, and education falls on the continuum of importance in different places for everyone (Anders, 2009; Kou & Houtrow, 2016; Vandesande et al., 2023; Yu et al., 2020). Vandesande et al (2023) in an attempt to get an overview of parent perspectives and their relationships with their children, a tool called the Attachment Strengths and Needs Interview was studies. The study helped uncover the factors that might be important to individual situations, hence the family's story. There is a need for more information on how decisions are made by various stakeholders' perceptions to improve the lives of children with severe and profound disabilities and medically complex conditions.

Summary

The review of literature suggests that education is an important factor in the lives of children with severe and profound disabilities and medically complex conditions. In the 1970's when the rights of these children were not considered and many were institutionalized, policymakers and litigation guided the way to what is now the Individuals with Disabilities Education Improvement Act of 2004 (IDEA). Kauffman et al. (2023) suggest that "many who promote inclusion and disability rights have argued for decades that IDEA does not go far enough…" (p. 61). Least restrictive environment promotes inclusion, but deciding what is best for the child is more complex than that. These are the decisions that parents and other IEP team members evaluate when deciding on a place. It is important to remember that special education is not a place. Brick and mortar buildings, public schools, specialized schools, private schools, and even the home are places to educate children with severe and profound disabilities and medically complex conditions. Special education is the support and service provided to these children to improve their quality of life.

The literature points to school supports and services (educational and medical) improving quality of life. Attending school in some capacity provides children with severe and profound disabilities and medically complex conditions the opportunity to participate, be a part of something, stay engaged, interact with others, express who they are as they socialize, and find contentment in new environmental factors. When a child can simply express themselves, it is a powerful thing, not only for the child but for everyone involved in the child's life (Lui et al., 2022).

The role school plays in the quality of life for these children is particularly important from the perspective of parents. This research study will explore these perceptions through the parent lens along with their experiences, expectations, needs and even their fears. "Previous research identifies that concerns regarding inadequate support in 'regular' settings are commonly raised as a barrier to inclusive education, with a need to address the financial and practical concerns regarding providing appropriate supports across education settings" (Cologon, 2022, p. 411). Parents have a need for their children to be kept safe. Resources and barriers can affect the safety of the environments requiring provision of appropriate levels of support. Among those barriers are access to curriculum, assistive technology, and medical needs, including skilled nursing services and highly qualified teachers.

When looking for literature involving children with medical complexities, it is limited, especially when looking at topics surrounding quality of life, therefore, further research within the children with severe and profound disabilities and medically complex conditions population is needed. Rallison (2013) summarizes that due to the limited population of children and families described in the studies, there is minimal research. Rallison (2013) also mentions the challenges and "the many variables involved with research of vulnerable children, the difficulty of assessing children with communication problems, and the ethical dilemmas concerning research with this population" (p. 195).

The goal of this research study is to explore the stories of children with severe and profound disabilities and medically complex conditions through parent perspectives. The researcher will use qualitative research to interview parents in a case study format, collecting the data through semi-structured interviews, and analyzing the data looking for themes and trends pulling out similarities and highlighting differences in the stories told. Chapter 3 expands on the methodology and research design used in this study.

CHAPTER 3 METHODOLOGY

This chapter provides an overview of the methodology used in this study beginning with the rationale for the use of qualitative research, specifically case study research and the conceptual framework built upon the foundation of the literature reviewed. This chapter will also include information about attaining participant sampling, methods used for developing interview questions, as well as an explanation of data collection and analysis procedures.

Research Questions

The goal of this research study is to explore the stories of children with severe and profound disabilities and medically complex conditions from the parent perspective specifically looking at the role school plays in their child's quality of life.

1. How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?
2. How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions?
3. How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life?

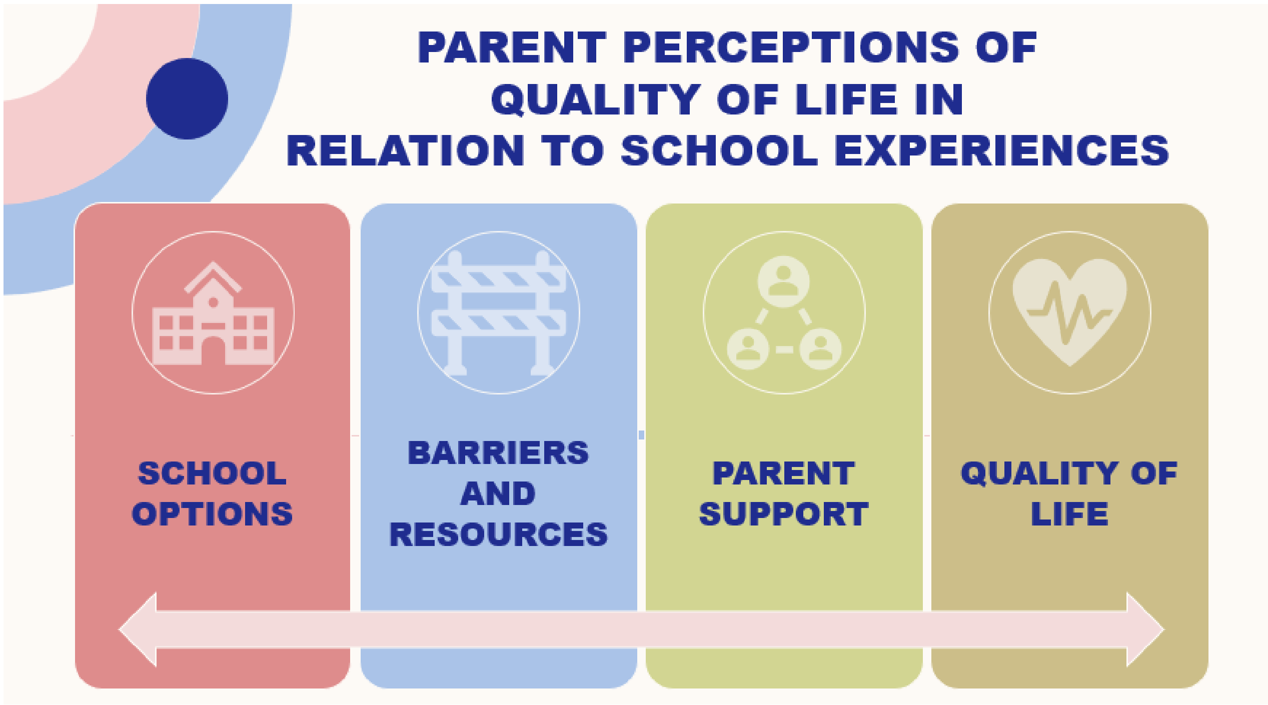
Conceptual Framework

When exploring ideas for conceptual frameworks, a worldview focus comes to mind where "people who share a common experience or perspective" can share those stories (Patton, 2015, p. 261). Doing so creates a conceptual framework to guide this study. The key concepts this study is investigating are related to how parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and complex medical conditions. School options, barriers and resources, quality of life, and the parents' stories of caring for their children come together to form the assumptions that underpin this research study.

The following Figure 3.1 describes the conceptual framework for this study.

Figure 3.1

Conceptual Framework



Research is valuable to improving quality of life for children with severe and profound disabilities and medically complex conditions. Limited research has been conducted when looking into the educational opportunities that this small population of children have, barriers they may face regarding LRE and the continuum of alternate placement, as well as the parent perspectives regarding these opportunities. It is the aim of this study to provide multiple parent perspectives on the quality of life of our most fragile children. In doing so, special educators, related service coordinators, therapists, and administrators can help guide IEP teams by promoting positive practice and potentially educational policy changes. The needs of these children are very diverse, but this study will show how important quality educational experiences can help improve quality of life and bring happiness and joy to their lives.

Qualitative Research Methodology

The nature of qualitative research is essentially useful for telling stories of individuals' lived experiences to help better understand and explain phenomena, or observable events that happen in society. Patton (2015) emphasizes the significance of storytelling allowing researchers to capture prolific accounts of people's experiences and perspectives. Storytelling enhances our understanding of human experiences and contributes to more holistic qualitative research (Patton, 2015). This study seeks to understand the lived experiences of parents with severe and profound disabilities and medically complex conditions. The overarching question of this research study is: How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions? To answer this question, the research will examine the complex phenomenon of educating children with severe and profound disabilities and medically complex conditions from the parents' perspective through the application of qualitative case study design.

Case Study Design

According to Bloomberg (2023), a "case study is an in-depth exploration from multiple perspectives" (p.83). Bloomberg (2023) goes on to explain case study research purpose as a way to inform practice, provide action, or develop policies within community and social situations. A goal of this research study is to deeply understand the perspective of parents and the importance of school and the role it plays in quality of life of this small population of students living through the unimaginable.

Yin (2018) explains that “rationale for a single-case study arises when the case represents an extreme case or an unusual case, deviating from theoretical norms or even everyday occurrences” (p. 50). Such cases can occur in educational situations where special education populations of students may offer unique or unusual perspectives about the field. For example, these findings may reveal insights about procedural efforts to educate students with severe and profound disabilities and medically complex conditions. “From this perspective, the prime meaning of a case study is the case, not the methods by which the case is created” (Patton, 2015, p. 259). Understanding the case is critical to describing the lived experiences of those being studied.

Little is known about the population of children with severe and profound disabilities and medically complex conditions. This warrants an approach consistent with qualitative research to gain perspectives from individuals who care for these children and an opportunity to tell their stories. Patton (2015) tells us that “stories are more memorable and better support learning and understanding than nonstory narratives” (p. 219).

Case study researchers may break down case study design and methodology more specifically; they focus on the different types of qualitative research. This study intertwines a few of those methods in the research design. Ethnography simply stated is writing about people. Ethnography combines research with way of life and “learning about what it is like to be a member of the group from the perspectives of the members themselves” (Bloomberg, 2023, p. 86). Parents of medically complex children are in a group of their own. Unless part of that group, it is hard to imagine their lived experiences. Ethnographical research can help a researcher immerse themselves into the culture of being a parent of a child with severe and profound disabilities and medically complex conditions. Why are their lives so different, and what defines them? How can they relate to others?

Phenomenology aims to investigate the meaning of the lived experience of people by “studying individuals to better understand the essence of their experiences” (Bloomberg, 2023, p. 88). These individuals being studied have already lived the experience or are currently living the experience. Parents of children with severe and profound disabilities and medically complex conditions have been thrust into a world that is often outside of their wheelhouse. This is a world they are not necessarily prepared for, nonetheless, it is a world that they are living and experiencing. These experiences are what is being studied. There is a commonality between phenomenology and ethnography (Bloomberg, 2023). That commonality is the participants while intrinsically researching to gain a better understanding of a case and trying to find what participants have in common.

Depending on research design choices, a researcher will trade off between depth or breadth. Qualitative case studies with a narrative research design increases understanding focusing on storytelling (Patton, 2015; Bloomberg, 2023). Patton tells us that “the practical side of qualitative inquiry is skillfully asking open-ended questions of people and observing matters of interest in real-world settings to solve problems, improve programs, or develop policies” (2015, p. 154).

Bloomberg (2023) defines the underpinnings as “interpretive constructivist philosophy with the goal of describing and explaining how everyday practices in specific places are connected to larger constructs and processes” (p. 84). The hope is that through interviews, narrative case studies will illustrate the complexity of understanding quality of life while raising a child with severe and profound disabilities and medically complex conditions by pulling out themes and highlighting differences in the cases. The value of this case study design can be connected to the larger group, well beyond those suffering (Yin, 2018).

Population and Sample Selection

Patton (2015) explains that “qualitative methods typically produce a wealth of detailed data about a much smaller number of people and cases” (p. 257). This study investigates the experiences of parents with children with severe and profound disabilities and medically complex conditions through their perceptions of quality of life and the importance of education. Since this population is very specific, stratified purposeful sampling was used to select participants. The combination of criterion sampling and networking sampling was utilized since the participants must meet certain criteria to be a part of the study (Bloomberg, 2023; Patton, 2015; Yin, 2018). Due to the small population of participants in the geographical area of Pennsylvania, the researcher needed to network with others to select an appropriate sample size. “Since the goal of qualitative research is not to generalize to a larger population, but rather develop a deep understanding of a specific phenomenon, the qualitative research intentionally selects specific individuals and sites in order to understand the phenomenon” (Bloomberg, 2023, p. 269).

Participants are the parents of school aged children with severe and profound disabilities and medically complex conditions from Pennsylvania. The goal of the research was to acquire six to eight participants through recruitment efforts. Recruitment occurred through the use of networking via the Pediatric Palliative Care Coalition, email, and additional clarification to further explain the study. The researcher began by emailing members of the parent advisory council of the non-profit organization Pediatric Palliative Care Coalition (PPCC) for interest in the study by sharing a flyer as well as networking opportunities.

Specifically, participants in this study had to be over the age of 18 and a parent to a severely and profoundly disabled child between the ages of 5-24 with medical complexities. Eight potential participants showed interest by contacting the researcher by email. Six of those participants signed and returned consent to participate in the research study after being emailed the participant email outlining the study and interview process.

Data Collection

The sources of data collection in this study on how parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions were collected through interviews, verification of transcripts, and any other documents the participants wanted to share with the researcher. Qualitative research requires a certain amount of triangulation since generalizability is not an option.

In a previous study on the normalization of families with children with severe and profound disabilities and medically complex conditions, Rehm and Bradley (2006), elaborated on the importance of interview questions based on “such topics as the child’s care, family routines, activities, and social lives” including interactions of families and schools as well as “their definitions of normal family life and how their own families fit with that definition” (p. 812).

Interviews

The researcher used qualitative research methods to interview parents in a case study format collecting the data through semi-structured interviews. According to Patton (2015), we interview people “to find out from them those things we cannot directly observe and to understand what we have observed” (p. 426). Acquiring insight and information about feelings, lived experiences, complex situations, and relationships is not something that researchers always gain through observation. Instead of observation, researchers can interview people and ask those people who share a common experience to share their perspectives.

“Interviews are commonly found in case studies” (Yin, 2018, p. 118). The guided interviews were scheduled in advance coordinating schedules of the participants and the researcher. The interviews lasted approximately 30-60 minutes. The open-ended interview questions focused on caring for children with severe and profound disabilities and medically complex conditions, quality of life, education, and schooling options, as well as barriers to access and resources. The interview protocol is included in Appendix D.

The interviews occurred via recorded Zoom sessions with parents of children with severe and profound disabilities and medically complex conditions. During these interviews, the researcher asked semi-structured questions to guide the interview in an open format. The semi-structured interview guide ensured that the researcher had carefully determined how to best use the time available (Patton, 2015). Open ended questions allow the participant to tell their story through guided conversations that are fluid more than structured questions that are ridged while using their own words to express their own personal perspectives (Patton, 2015; Yin, 2018).

With participant consent, the interviews were recorded using Zoom as the platform the researcher uses to record interviews. The researcher also kept a field work journal to take notes and observations during the interview process. Transcriptions of the recorded interview sessions were completed by the researcher. Patton (2015) discusses the importance of researchers having the opportunity to be immersed in data by completing his or her own transcription. Member checks were completed to allow participants to review the transcriptions and check for accuracy as well as triangulation through the form of literature review.

Documents

The researcher asked for documents from the parent participants. Helpful documents may include their child's individual education program (IEP) or doctor notes that help further explain their story. If the parent(s) consent to sharing their child's IEP, the researcher asked to make a copy of the document to be kept confidentially electronically within the password protected Microsoft 365 One Drive. If the parents were not comfortable with the researcher making a copy, the researcher would ask to view it and make notes on certain sections such as present levels, measurable annual outcomes, related services, and progress reporting notes. If the parent participant was not comfortable sharing any parts of the IEP document, the researcher did not use it as a data collection source.

Children with medically complex conditions will often have doctors' notes to document related services, and information about the child's specific needs in the classroom or alternative setting. Doctors' notes can be used as evidence of the need for accommodations or modifications required to meet the needs of the child. Environmental, instructional, medical, and social needs may be addressed in doctors' notes. These documents may be very important to school districts to help support the child with severe and profound disabilities and medically complex conditions. If the parent participant feels that any of these doctors' notes would help the researcher or answer any questions pertaining to this study, the participant would be asked if they would be willing to share the notes for review. The researcher assured participants that there is no pressure to share these documents and under no circumstances will it affect the study negatively, rather just add to the study. During the interview process or thereafter, documents could be shared with the researcher.

Data Analysis

The goal of this qualitative single case study is to explore the experiences of parents with children with severe and profound disabilities and medically complex conditions through their perceptions of quality of life and the importance of education. The data collected through interviews guided the analysis in answering the research questions.

Data in this study was coded using inductive and deductive coding and evaluated with thematic analysis. Data from each transcript was coded separately using a combination of descriptive, in vivo, initial, emotion, and concept coding in relation to the research questions and then combined into categories and subcategories (Saldana, 2021). The figure below represents the coding scheme leveraged while analyzing the data.

Figure 3.2

Coding Scheme

Thematic analysis is a method for pulling patterns and themes out of given data to help in analyzing and discovering those themes (Saldana, 2021). The researcher began analyzing the codes by looking for themes and trends, pulling out similarities, and highlighting differences in the stories told. Thematic analysis is important in this study because identifying themes among parent perspectives is necessary to address the research questions through patterns, categories, and concepts presented.

Coding Interview Data

Interviews were recorded using audio/video technology such as Zoom. Zoom will also be the platform the researcher uses to record interviews. Zoom creates transcriptions of recordings when saved to the cloud. The researcher read the transcriptions carefully while listening to the recording of the interviews. The researcher used Microsoft Word to complete the final transcriptions of the interview before sending to the participants for their review.

After transcriptions were complete, the researcher prepared for manual coding. The Microsoft Word document was divided into three sections: section one was the transcription of the interview, section two was the code, and section three contained any notes the researcher took during coding. These ideas of "data layout" were employed after reading The Coding Manual for Qualitative Researchers by Johnny Saldana (2021).

The first cycle of coding consisted of reading and rereading the transcribed interviews. Provisional coding included predetermined codes including the following: Quality of Life, Parent Perspectives, Children with Severe and Profound Disabilities and Medically Complex Conditions, Importance of Education, School Options, Barriers and Resources, Inclusion, Exclusion, Teacher Preparedness, Assistive Technology, Communication, Related Services, Medical Information, Nursing, Caregiving. While reading the transcriptions, the researcher used the provisional codes and created new codes utilizing the following methods of coding: descriptive, in vivo, initial, emotion, and concept coding. During the first cycle of coding, the researcher also used analytic memos to reflect upon and make connections to the participants responses.

Saldana (2021) outlines tips for coding that include these recommendations: "Code only the most essential parts of your data corpus. Code as a 'lumper' not a 'splitter'. Use selected codes repeatedly. Subsume codes into broader codes or categories as you continue coding. Let analytic memoing do some if not most of the work for you" (p. 36). After the first cycle of coding is complete, the researcher recoded and recategorized the data using the same methods before moving into the second cycle of coding to refine, synthesize, and conceptualize data further (Saldana, 2021).

The researcher also collected data from email communications about transcriptions and documents provided by the participants. Documents might have included Individual Education Plans (IEPs) of the participants' child, medical documentation, doctor notes, and related service reports or evaluations from therapists. The researcher would analyze these documents and communications in a similar manner to coding the interview transcriptions. The sources of data were recorded in one column and a second column was used for analytic memos or notes about those data. If coding was appropriate, the researcher would apply codes to the data collected. If coding was not appropriate, the researcher would pull contingent similarities to create themes among the documents from the participants leveraging a relativist approach to analyze these sources of data. No additional documents were collected during this study.

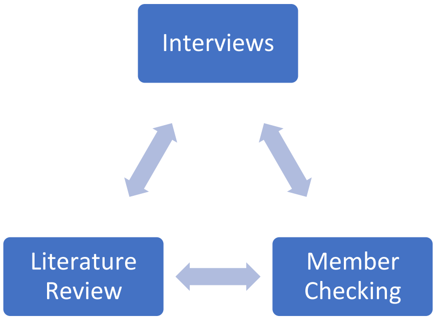
Validity and Reliability

Patton (2015) justifies triangulation as being ideal by combing methods or data. Data triangulation will strengthen a study. Patton explains triangulation by discussing the triangle, "the world's strongest shape" (2015, p. 316). The study is a point on the triangle and the data are two other points. "You can take bearing in two directions and locate yourself at their intersection" (Patton, 2015, p. 316). While interviews alone may limit the ability to triangulate data, one can still employ a form of triangulation within the interviews themselves by interviewing multiple participants and asking questions to cross-validate the information gathered. Additionally, the researcher compared interview data with existing literature to strengthen the credibility of the findings. Furthermore, the researcher employed member checking, to verify transcripts with participants to ensure accuracy.

Triangulation helps test for consistencies between data sources while also finding the inconsistencies across the data to provide the depth of comprehension into the case being studied (Patton, 2015; Yin, 2018). Data triangulation strengthens case study validity through the "convergence of evidence" (Yin, 2018, p. 129) as findings are explained in Figure 3.3.

Figure 3.3

Convergence of Evidence Through Data Triangulation.



Note. The flow chart visualized the data (interviews, member checking, and literature review) working together to strengthen validity of the study.

The case study protocol found in Appendix A, B, and C determines external validity, while the rules outlined in the protocol and the materials collected in the case study database provided reliability of the case study. The researcher maintained a chain of evidence to increase build validity (Patton, 2015; Yin 2018). Through thematic analysis and coding schemes, the researcher constructed validity and reliability of the study.

Presentation of Results

Bloomberg (2023) defines the presentation of findings as a "detailed analysis of themes and overall lessons learned from the bounded case or cases…" (p. 171). The presentation of this case study is in narrative form including descriptive case study samples from the interviews of the parents of children with severe and profound disabilities and medically complex conditions.

The researcher tells the stories of the participants through sharing their responses and addressing the research questions from a thematic view.

The findings and results are presented within this dissertation and included in a case study database through Microsoft OneNote, where data collected, and researchers reports, and field notes are kept. This also helps increase the reliability of the study in hopes that the study will be able to be replicated in the future using the same protocols. The researcher plans to publish this study in the future, which may include articles, podcasts, presentations, and webinars. The information and findings in this study will help parents, families, educators, service providers, medical clinicians, and anyone else who has the opportunity to engage with children that have severe and profound disabilities and medically complex conditions.

Ethical Considerations

The researcher brought insights from the Collaborative Institution Training Initiative (CITI) course taken at Slippery Rock University to safeguard the ethical considerations related to this qualitative single case study. According to the Belmont Report of 1979, the following standards in research be warranted, “respect of persons, beneficence, and justice” (p. 4). This population of participants are sensitive to the issues being addressed such as quality of life, medical complexity, severe and profound disabilities, palliative care, as well as caregiving and medical decision making. The researcher is well aware of these issues through lived experience and will contribute to the sensitivity of the research through moral and ethical decision-making skills. The researcher is committed to conducting interviews within an atmosphere of empathy and care for the participant to ensure no harm (Belmont Report, 1979; Patton, 2015).

To conduct research ethically in accordance with the Institutional Review Board, the researcher took every precaution to assure confidentiality and protect the privacy of participants.

The researcher developed a formal consent for participants to be involved in the study as well as permission to record audio or video data. The researcher aims to do everything possible to ensure no harm by conducting the interviews with respect and protecting confidentiality, carefully storing data collected, password protecting and coding any identifiable information.

Member checking was employed to improve the trustworthiness of the study. Participants were offered the opportunity to review transcription of the interviews. The researcher also kept a case study database to include all data collected, documents, transcripts, personal information, and notes. This database is kept confidential and under lock and key on a password protected computer and Microsoft 365 secure One Drive. The participants were reminded that they could withdraw from the study at any time.

Limitations

Patton (2015) discusses the application of exploratory research to develop inquiry via qualitative methods. Qualitative studies may get a lackluster reputation because they are often hard to measure or quantify by numbers. Remember that depth vs. breadth plays a role in the elucidating of research methods and design. All research studies have inequities based on different limitations. Possible limitations related to this study on parent perspectives of children with severe and profound disabilities and medically complex conditions include personal assumptions of the researcher, participant familiarity with the researcher, and research design.

Researcher bias

The researcher has a special interest in this topic because she is a bereaved mother of a child with severe and profound disabilities and medically complex conditions. The researcher has a known passion for the small population of children considered medically fragile and severely disabled often categorized as having low incidence disabilities. The researcher has her own perceptions of the questions being asked but is putting those thoughts and feelings aside to investigate the lived experiences of other parents. The researcher has lived similar experiences, but she is concerned about how others are living and how society can help these families improve their quality of life. Although these children have life limiting diseases or disabilities, they deserve the best chance at living a quality life.

Looking through the lens of empathic neutrality, this limitation does not mean that this is researcher bias (Patton, 2015). Instead, this allows the researcher to better identify with the participants and have a mutual understanding of that lived experience of being a parent caregiver. The researcher wants to ensure that this study has a strong foundation to support these parents, children and their families going through difficult situations in hopes to improve quality of life. To help avoid bias critical colleagues will offer feedback, alternative explanations, and suggestions (Yin, 2018).

Participants

The participants may be familiar with the researcher. The researcher used purposeful criterion-based sampling to select participants. Due to the nature of the study and the research on children with severe and profound disabilities and medically complex conditions, there are a limited number of qualified identifiable participants. The researcher had to rely on prior knowledge and networking connections to find parent participants through snowballing sampling.

Patton (2015) claims that interviews are interventions that affect people through feelings, knowledge, and experiences (p. 495). With that being said, these interviews are intended to gather data, but there may be a lot of feeling and emotion attached to the data being gathered. The researcher and the participants may have old wounds that are reopened and potentially painful. Sharing experiences can also bring healing and joy. There is a risk in being vulnerable and brave.

Participants may not be “equally cooperative, articulate, and perceptive” (Bloomberg, 2023, p. 282). Participants may not want to answer all the questions posed or their answers might not maintain the depth of the expectations of the researcher. Participants who experience oppression because of life situations share different perspectives. Demographic information might be helpful such as age range, geographical location, years of schooling, occupation, etc. In a study by Cologon (2022), the goal of the researcher is defined as listening, drawing meaning, and “accurately reflecting diversity of the family experiences” (p. 400).

Research Design

Qualitative studies tend to be criticized because of the inability to generalize and reproduce while also adding the bias of the researcher. Qualitative studies are subjective in nature and are “limited by research subjectivity” (Bloomberg, 2023, p. 312). One may wonder why the researcher did not choose a survey that would lead to more quantitative data collection results. An open-ended interview is certainly more qualitative in nature, but it is also more personal. When trying to understand lived experiences, quantitative data does not add up.

Another limitation in research design is the fact that the researcher is a novice. Interviews require skills that this researcher may not possess as a beginner. Since the researcher is the interviewer, the data gathered may not seem neutral as they are the result of interactions, conversations, and settings (Bloomberg, 2023).

Delimitations

The delimitations that follow will help set boundaries for this study on the parent perspectives of quality of life of their children with severe and profound disabilities and medically complex conditions. This study is limited to a criterion-based sample of parents that live in Pennsylvania having a child with severe and medically complicated diagnosis. The parents of these children have difficult decisions to make regarding education and how that will impact their quality of life. The scope of this study is to investigate how parents perceive themes such as quality of life, caregiving, education, inclusion, resources, and barriers. These children may also receive medical care from the same children's specialty hospital which consciously could contribute to data collected and themes analyzed. "Small samples that are truly in-depth have provided many of the most important breakthroughs in our understanding of the phenomenon under study" (Patton, 2015, pp. 312-313).

Bloomberg (2023) discusses the choices researchers make in research study design to "intentionally and purposively limit a study" (p. 313). The researcher has intentionally limited the study to parents who live within the geographic area of Pennsylvania. This is due in part to several reasons including the states having control over education, the relation to where parents live to where the researcher lives, and the familiarity of both of those aspects of the study.

From the researcher's perspective, "selecting such cases requires prior knowledge of the outcomes" (Yin, 2018, p. 59). The researcher has an extensive personal background with the population of children who have severe and profound disabilities and medically complex conditions. The researcher was a parent of a child with those complex needs for the better part of eight years. The researcher has lived the experiences that these families have also lived and is able to listen, make connections to issues and, ask good questions while paying attention to ethical standards, documenting results, and applying the empathetic neutrality needed for a proper qualitative case study (Patton, 2015; Yin, 2018).

Summary

The rationale for conducting this study is to illustrate and portray (a) How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions? (b) How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions? and (c) How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life? To truly understand these questions, it is necessary to go right to the source, the parents. Parent perception is what drives this study. The goal of this is to irradiate parent perceptions of delicate subjects such as quality of life, palliative care, instruction in the home or in specialized schools in hopes of shedding light on the small often unresearched population of children with severe and profound disabilities and medically complex conditions.

Through qualitative research methods and single case study design, semi-structured interviews of parent participants guide the data collection process through transcribed interviews. The interview questions provide purposeful data to answer the research questions within the study along with member checking and literature review. This data was coded using the thematic analysis approach to determine patterns and themes.

The researcher received IRB approval from Slippery Rock University and the research was conducted. Chapter 4 will report the findings of the research based on the analysis of data collected in the study. The chapter will focus on the interview transcripts from the semi-structured interviews with parent participants there were gathered then coded. Chapter 4 will emphasize the coding process and the analysis of the findings with the outlining of the results providing the answers to research questions.

CHAPTER 4: RESULTS AND FINDINGS

Chapter 4 presents a detailed explanation of the findings of this qualitative single case study exploring the perspectives of parents of children with severe and profound disabilities and medically complex conditions. There is a lack of research on this low incidence population of children who are not only intellectually disabled but that are also critically ill or medically complicated. This study provided valuable insight into the perspectives of parents who love and care for their children on a daily basis.

The purpose of this study is to investigate the perspectives of parents with children with severe and profound disabilities and medically complex conditions in relation to education and quality of life. This study specifically investigates the parent perspectives of the experiences their children have with school and how these opportunities impact their child’s quality of life. This chapter outlines findings completed through qualitative single case study methodology. The data analysis of participant interviews through the process of coding and thematic analysis results in the finding of the research gathered to answer the research questions.

Research Questions

The research questions that guided this qualitative single case study were intended to explore the stories of children with severe and profound disabilities and medically complex conditions from the parent perspective, specifically looking at the role school plays in their child’s quality of life. This study included the research questions below, where question one specified the overarching research question and questions two and three support that question.

1. How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?

2. How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions?
3. How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life?

This study's methods are a qualitative case study design. Consequently, information about participants is pertinent to understanding the data found through the results of the semi-structured interview process. Case study research aims to tell the story of the participants and their lived experiences.

Participant Profiles

Data in this study were gathered from parents with experience raising children with severe and profound disabilities and medically complex conditions. Parents were over the age of 18 and had a child identified with severe and profound disabilities and medically complex conditions between the ages of 5-24. The researcher gathered participant profiles in order to contextualize their perspectives, and more importantly, share their stories. This section outlines participant profiles by briefly summarizing their story to get a glimpse into their life.

Participant 1 (P1)

P1 is a mother of four biological children and has been fostering children with medical complexities for over 32 years. Her family lives in a suburban area in Eastern Pennsylvania. At the time of the interview P1 was caring for four children that were either hers through adoption or in foster care. These children had a wide range of needs. P1 and her husband along with nurses take care of these children twenty-four hours a day, seven days a week. The children attend school and receive services through a local school district and intermediate unit. The child we focused on during the interview had a stroke in utero, has seizures, and received a kidney transplant. P1 is employed as a social worker and is active in children and youth services.

Participant 2 (P2)

P2 is a mother of four boys, two being affected by Spinal Muscular Atrophy (SMA). SMA is a neuromuscular disease. SMA presents similarly to lung disease or Lou Gehrig's Disease (ALS), but it occurs in infants affecting motor function, movement, breathing, swallowing, and eating. Babies are born perfectly normal but progressively lose motor function quickly. Her first born, T, with SMA passed away before the birth of her second son, C, with SMA. Her 15 year old son, C, attends school at home. He receives instruction in the home from his school district after issues with staffing nurses and placement when he used to attend a multiple disabilities classroom within his local school district. School has been a struggle for the family. P2 lives in the rural suburban area outside Allentown, Pennsylvania and is a Registered Nurse, BSN. P2 stays home with her son to care for him around the clock and she is paid through a nursing agency to be his nurse. P2 is also supported by nurses to help with his care.

Participant 3 (P3)

P3 is a mother of two boys, ages ten and three, from Pittsburgh, PA. Her ten-year-old son, J, was diagnosed with a rare genetic disorder called Lissencephaly, which basically means smooth brain. He is limited in what he can do. In addition to Lissencephaly, he has Cortical Vision Impairment, Cerebral Palsy, intractable epilepsy with a Vagus Nerve Stimulator (VNS), severe developmental delays, a feeding tube, and inability to swallow requiring suctioning. P3 works full time for a health insurance network. Her son attends Child's Way, a medical daycare, in Pittsburgh and the Western Pennsylvania School for Blind Children. Western Pennsylvania

School for Blind Children is a private school chartered by the Commonwealth of Pennsylvania that educates and provides services to visually impaired students with a variety of needs. P3s urban home school district approves and funds this placement. P3 is supported by skilled nurses to help with her son's care overnight so she and her husband can sleep knowing he is being monitored.

Participant 4 (P4)

P4 is a mother to two girls ages 14 and 11. Her youngest daughter, A, was born with Trisomy 17. She is currently the only known case in the world with her exact chromosome duplication. Her rare diseases affect her in many ways. She's non-ambulatory, has a feeding tube, and spent her first few years fighting for her life in and out of Children's Hospital of Pittsburgh. P4 lives outside of Pittsburgh in somewhat rural Butler, Pennsylvania, works part time, and is supported by skilled nursing care for her daughter while she and her husband work and while they sleep. Her daughter receives instruction conducted in the home. She used to attend a private special education school, The Watson Institute, about an hour from home in Sewickley, PA, but since the COVID-19 Pandemic, she has remained home to reduce the risk of getting sick due to her medical fragility.

Participant 5 (P5)

P5 is a mother of four from the Shippensburg area of Pennsylvania. Three of her daughters were born with a rare genetic disease. All three have passed away. Her youngest, K, passed away in January of 2024 at the age of 13. Canavan disease is a rare neurological disorder that causes loss of white matter in the brain and severe damage to nerve cells caused by a mutation in the ASPA gene. Essentially the brain deteriorates due to the lack of the enzymes the gene produces. K was trach vent dependent and required suctioning and a feeding tube. She was non-ambulatory and needed 24 hour care. She was very susceptible to illnesses. P5 was a stay at home mother and nurse to her daughter. Her three affected children did not attend school or participate in instruction in the home. Medical doctors wrote letters to exempt K from compulsory school attendance requirements. Since K's passing, P5 works as an LPN taking care of children, like her daughters, in their homes as a skilled nurse. She is working on her Bachelor of Science in Nursing degree.

Participant 6 (P6)

P6 is a mother of three. Her second child. O, was born with a very large Parietal Encephalocele. Encephaloceles are rare neural tube defects, but O's was extremely rare being so large (one of the largest most doctors have seen) and located on the top of his head including 20-25% of his brain and a large volume of cerebral spinal fluid. O was not expected to survive birth, let alone 10 years. His brain is very disorganized. O has a shunt, is non-ambulatory, suffers from seizures and severe developmental delay, and has a feeding tube for nutrition. O attends the Western Pennsylvania School for Blind Children. P6 works in accounting for a school district in the Pittsburgh area. P6 and her husband moved to Pittsburgh because of employment opportunities, but mostly because of their son so they could be closer to Children's Hospital of Pittsburgh.

Findings

This presentation of the findings is organized by research question. Major themes emerged to answer each research question. The discussion of each theme includes evidence for the findings in the form of direct quotations from the data as well as comparisons between participants' experiences**.** The following three research questions were used to guide this study: (1). How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions? (2). How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions? (3). How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child’s quality of life? The remainder of the chapter will focus on responding to each research question based on the data in the form of themes.

Research Question 1: How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?

Research Question 1 examined parent perspectives on school and how important school was for their child with severe and profound disabilities and medically complex conditions. Interview questions addressed information about school placement, educational expectations, risk factors involved in school setting, and quality of life.

Theme 1: Importance of School

There are a number of reasons parents with children that have severe and profound disabilities and medically complex conditions rely on school including the structure, consistency, routines provided to their children, access to related services such as occupational therapy and physical therapy consistently, the one on one attention provided by teachers and paraprofessionals, and the skills and new knowledge that help their children learn, (Downing & Peckham-Hardin, 2007). Five out of six participants considered school to be very important for their child with severe and profound disabilities and medically complex conditions ranking high on the continuum next to health and safety. During P1’s interview she was very adamant about the importance of school.

> We try really hard to make sure these kids get what they need, especially educationally, because that seems to be the last thing that people think about with our kids. They’re medical kids. Well, no, they're kids.

Conversely, P5’s perspective on the importance of school for her medically fragile daughters was very different.

> For the girls it [school] wasn't. It wasn't important at all. They didn't have any use for it. They were always going to be dependent. There was no chance that they would be able to do anything functional on their own, just because of the nature of the disease, and for us it was more of a risk sending them to all the germs than it was of a benefit.

Rehm and Bradley (2005) explored family challenges including identification of the risks and advantages of school attendance for children with severe disabilities and complex health care needs. P5 identified that the risks far outweighed the benefits for her children attending school.

For other parents, school attendance was so important that lives were uprooted to provide the best opportunities for their children. P3 and P6 both made big moves by selling homes, changing jobs, and moving closer to Pittsburgh so their sons could attend the Western Pennsylvania School for Blind Children. Where they lived previously, the specialized school would have been more than an hour drive. They both relocated to make it work because school is such a vital resources for them to keep their boys going.

For most participants school was important but health, medical needs, and safety will always be the priority. Quality of life is essential to all the participants and their children. P3 explains the importance of quality of life for her son.

> We focus on quality of life. That's the biggest thing for us. Even in the IEP last week I kept saying to them, I know his going to school has dwindled the past couple of months because he's been sick or he has seizures going on and things like that, but we're constantly thinking about is it still worth him going to school? Is he still getting as much out of it as he can? And those are the questions I'm posing to his teachers. Is he still awake for a good portion of the day? Is he still involved? And as long as I'm getting a yes, he's still involved, and yes, he's still awake, and yes, he's still engaged. We will support as much as we can, but we know when those kind of metrics change, we're going to have to have a harder conversation with our palliative care team about is it worth continuing to do what we're doing because school is such an important factor in who J is.

School is important for not only the child, but for the parent as well in bringing some sort of normalcy to their ever-complicated lives. Parents yearn for normalcy and sending a child to school is a normal part of childhood and parenthood. P3 talks about the importance of sending her son to school regarding her career and personal life.

> I didn't want to give up my job because I felt like I would have lost myself as a person like I already lose myself to some extent. So, I knew the importance of keeping some balance between myself and my husband being able to do what we were doing before we had J was important. I knew staying home was just not an option for us. Plus, the complexities of trying to figure out nursing during the day. It's a lot harder to have those

> kind of services 24 hours a day. I have a hard enough time keeping nurses at night. That was just always ruled out. But then, after that I think from an early stage, we thought J had some kind of potential. We always hope that he would be the anomaly that you know as you're seeing kids on Facebook. And you're like, oh, that kid's really disabled, but J's gonna be different. We always thought he had some potential and I would say once we got into the school system, we really saw what the potential could be. That really drove us to decide that we needed to do something educationally for him. I didn't want him to just sit around and not be stimulated and not grow to whatever length he could grow. He may not be a rocket scientist, but he definitely is not just a kid that needs to sit there and stare at a TV screen. So, that's what school was for us. It provided some kind of quality and growth for him.

Sub-Theme: School Options. Parents, educators, nurses, doctors, and administrators feel that attending school is a positive opportunity to increase quality of life for a child with severe and profound disabilities and medically complex conditions (Rehm & Bradley, 2006). The question becomes in what capacity can these children “attend” school and how should they be educated to effectively meet their needs and provide positive quality of life in their often shorten lives.

Participants were asked about their child’s school placement. Among the participants, there was a vast continuum of alternate placement based on their children’s diverse needs physically, cognitively, and medically. Table 4. 1 outlines the participants and where their child goes to school.

Table 4.1

Continuum of Alternate Placement

Participant	School District	Specialized School	Instruction in the Home	Waived Instruction
P1	X			
P2			X	
P3		X		
P4			X	
P5				X
P6		X		

When P1 first started fostering medically complex children she had to advocate for inclusion. She felt that it was important to find a classroom that challenges her children all the while ensuring they are happy and well taken care of.

> I am very blessed because we live in a supportive school district. It took me a long time to get there. I think that I was one of the first. And again, I've been doing this for 30 plus years, so I had to really push for inclusion of my children into the school districts, because when my first children were coming, they wanted to send them to alternative schools. And I'm like, no, no, no. We can make a classroom. There's gotta be more than just my children that need this. And they did. And there were a couple of parents that we advocated with. They have become a school district that's very pro inclusion.

Some participants have also tried multiple school settings for their child to ensure that they are making the correct decision and to provide the least restrictive environment. P2 shared that her struggles with the local school district have been ongoing. She wished she had done her research first because they ultimately placed her son in a multiple disabilities classroom. P2 felt that it was not the right placement for him. They tried this for a long time and pushed to be more included with his peers. Ultimately staffing of nurses, illnesses, and safety issues got in the way of this and P2 decided to pull her son out of school and agreed to instruction in the home.

> If I had done my research I never would have accepted going into multiple disability classroom. I would have said, No, thank you. He was to go into a normal classroom with an aid, and that was my mistake way back when. When C was born there wasn't any treatment, and his life expectancy was too short and he was so unstable that my focus was on his medical stability as opposed was educational needs. So we are now going years later. He's now officially a tenth grader but maybe academically, first to third grade, especially since they've not really done much with him through the years.

Another participant shared her experiences in multiple school settings, a specialized school and then instruction conducted in the home.

> We are homebound now, ever since COVID happened, we switched to homebound. She used to go to Watson, and that was fabulous. They're such a great school, and it was nice that A got to be with her peers and do fun things that she doesn't normally get to do. But we did deal with sickness after sickness, because she's like a magnet for every possible virus out there. It was the good with the bad kind of thing. But then, once COVID hit and we pulled her out, obviously she did do some virtual stuff, but she absolutely hated it, and would cry as soon as the teacher came on the screen. That didn't go great. We finished off the year like that, but then we went home bound, and we've been doing that since.

Others have decided to put their children into specialized schools that truly meet all their needs. These specialized schools are few and far between in the state of Pennsylvania and are typically in the private sector which requires school district approval for placement in these very important facilities. Two of the participants live in the Pittsburgh area and were lucky enough to learn about the Western Pennsylvania School for Blind Children when their boys turned school aged. Western Pennsylvania School for Blind Children is a full day school that gives children with visual impairment the opportunity to attend school, participate in activities that are developmentally appropriate and adapted to meet their needs, have their therapies, socialization, and nursing care. They have small class sizes and operate in teams with a teacher, related service providers, nurses, and instructional aides as well as assistive technology. P3 talked about her son having swimming class, adapted physical education, and even playing soccer. These are things she never thought he would be able to do. “They've adapted everything to fit him. So, it's very important to us, because I feel like he's getting all the simulation that he wouldn't get at home” P6 agrees that the Western Pennsylvania School for Blind Children is essential for her child.

> They are truly amazing, I mean what they do. And they just love the kids. He gets physical therapy there and he gets occupational therapy. There he gets vision therapy. O has cortical vision impairment. His brain is disorganized. That's why we chose that school, and I would never pull him out of there. He’s been going there since he’s been three . . . He has a really good nurse. I mean, we rely heavily on this, because we don't know how his day goes. He can't tell us. They send a note home every day on the Remind app. The nurses will reach out on Remind to tell me that she is sending us Onfi [seizure med] home for refill, or you know, whatever medicine. They're phenomenal, I mean, they truly are.

Some parents choose to keep their children home and have the support of skilled nurses for home health care. P2 and P4 both agree that instruction conducted in the home is the least restrictive environment for their child. Instruction conducted in the home is when a teacher visits the home to educate the child. Often this happens two to five days a week for a total of five hours a week of direct instruction in most cases.

> I think it's very important. It's just nice that she gets to do what a typical child gets to do in that sense of attending school, even if it is at home. She gets to do activities like coloring and craft stuff like that. Your typical kid gets to go to school and bring you home things. But she gets to do that while she's at home and makes her pretty pictures and all that. She's learning stuff like math and all that, you know, not like she loves that. But you know, it's something that typical kid gets to do. It's nice that she gets to do that kind of stuff, too.

Instruction conducted in the home is often paired with related services. The participants all spoke of the therapies their children receive whether in school or outside of school. When children have instruction conducted in the home, everyone comes to them. Physical, occupational, speech and language, vision, and music therapy are related services outlined within the child's IEP that help with physical, cognitive, and emotional quality of life.

Just because children with severe and profound disabilities and medically complex conditions should go to a specialized school does not always mean that it is an option. There are barriers such as resources, location as in geographical area, and access (Yu et al. 2020). Problems can also occur when it comes to teacher preparedness and IEP team knowledge due to the small population of children identified as severe and profoundly disabled or medically complex (Lehr, 2020; Mancini & Layton, 2004; McCabe et al., 2020; Nabors et al., 2008; Rehm & Bradley, 2006; Vandercook et al. 2020). Parent perspectives and wishes regarding quality of life and expectations of education also function in recognizing these problems. This is where examining the quality of life of children with severe and profound disabilities and medically complex conditions becomes equitable.

Sub-Theme: Safety Considerations and Risks. Children with severe and profound disabilities and medically complex conditions are more vulnerable than typically developing children. They are at a higher risk for hospitalization and intensive care stays from the common cold or other germs and viruses (Bravo et al., 2020). It is fundamental to keep in mind that everyone will have different expectations when considering safety and risk while on different phases of their medical journeys.

When raising a child with severe and profound disabilities and medically complex conditions, there are so many factors to consider when keeping the child safe whether physical or medical. Caregivers [parents, nurses, and schools] must ensure that all their medical needs are being met and that they are safe going to school. There must be an appropriate transportation plan. There must be an appropriate nurse or aide on the bus. Some children with severe and profound disabilities and medically complex conditions are on a bus for an hour or more to get to their school or specialized school. P1 shared:

> They have to be safe first, and that to me is paramount. Making sure that they have the supports needed to succeed in school. Including an appropriate teacher that knows what the child needs in case the nurse is in the bathroom. I mean, I think it needs to be a team.

Sometimes school is just not possible even with the best of teams. P1 described a situation she deals with every year.

> And again, I am not one that pushes a child into inclusion when they shouldn't be there. It's what's best for that specific child and I have a child right now that has severe temperatures, instability, and I can't send her as much as I want to send her [to school]. It's not in her best interest to be in the cold classroom. Her body temperature drops into the low nineties, and her heart rate goes into the thirties and everybody's calling the

> ambulance. I kind of push the envelope a little hard on that because they're calling the ambulance all the time. Then they would get to the hospital, and they were like she's fine. We'll send her home and warm her up. I needed as a parent to realize that this was not about me. This was about her needs, and that I needed to understand that this wasn't in her best interest to send her to school. So now in the winter she stays home, and they come into the home to read to her and to do her therapies. After Easter, she'll go back because the temperatures are better.

P5 discussed not sending any of her medically complex children to school because they got sick frequently and it just was not worth the risk. Even instruction conducted in the home was not the least restrictive environment for P5's daughter due to the nature of her disease. Bringing a teacher into the home meant bringing germs into the home.

> Because we didn't do school, I had her doctor write a note, and she was excused from compulsory attendance. The school district didn't have to provide anything. Her insurance provided physical therapy for a number of years, and then about two years before she passed they decided that I could do that myself. So, she didn't have any therapies or anything coming into the home. It was just what we could provide. So she was put on hospice, and then she got massage therapy and music therapy.

Outside of health safety there is physical safety. P2 discussed her son's first school placement in a multiple disabilities and life skills classroom. This particular classroom had children with autism spectrum disorder and some children with volatile behaviors.

> You have a student who, now we're getting into 18 to 22 year olds, have behavioral problems, losing control and start throwing things around. I have a quadriplegic son who cannot defend himself, can't even put his hands up to protect his face if something's

> thrown. If that person should decide just to take his frustrations out of my son he is a sitting target, and that's another reason why I do not send him in.

Theme 1 Summary. Kauffman and Badar (2016) defend that “the nature of the instruction students receive is far more important than the place where they receive it” (p. 58). School options are a lot to consider for parents when they look at the risks and benefits from sending their children with severe and profound disabilities and medically complex conditions to school. Many factors come into play, but ultimately parents look at what is best for their child and what is best for their family. Quality of life is critical to these families while keeping their children safe, happy, and fulfilled for as long as possible.

Theme 2: Importance of Quality of Life

Quality of life can and will vary from person to person and can be objective at times but is almost always subjective to the needs of the individual and what makes that life worthy (Carr et al., 2001). There is not one meaning of quality of life. According to an article by Carr et al. (2001) “definitions range from those with a holistic emphasis on the social, emotional, and physical wellbeing of patients after treatment to those that describe the impact of a person's health on his or her ability to lead a fulfilling life” (p. 1240). During this study, specific areas of inquiry during the participants’ interview included personal definition of quality of life and how to measure quality of life for their child with severe and profound disabilities and medically complex conditions, what fears they have when it come to their child, and how their child finds joy.

In Table 4.2 the participants were asked to define quality of life.

Table 4.2

Defining Quality of Life

Participant	Definition of Quality of Life
P1	“Quality of Life is to me is getting the most out of life that you possibly can and being comfortable and enjoying what it is that you can do.”
P2	"Basics is symptom management. You don't want to be in pain. You want him breathing comfortably. So ABC's, you know, airway breathing circulation. So those basic things come priority. Next is basic physical needs. . . Then we get to the higher needs, and that is, you know, love and affection. And he has that with Bruce and I and his brother Josh when he comes and his sister-in-law and nieces, and Matthew when he comes home from college. That basic family.”
P3	“That he has some level of purpose that is not just like I don't wanna say he's a vegetable, but like if he is sedated all day, and he isn't stimulated in some way, or he's not talking to us, and he's just like out cold. That is not a quality of life that we would define. I want him to feel like he's getting something, whether he gives me a smile or he vocalizes. Or he just goes to school and he smiles, cause they sing his good morning song. That's good enough for me. But if he's at the point where he's not being able to stay awake, or his seizures so hard on his body. That is not a quality of life that I would want for him.”
P4	“We always said we would let God show us a way, cause, you know, in the beginning they said that we should have aborted, she didn't have a chance at life. I was like, Hmm, no like to each their own. But we're gonna give A whatever chance she got. So obviously she fought really hard for the first few years there. But like I always said, whatever happens, happens. It's all God's plan. But here we are.”
P5	“I would define quality of life as minimal pain still being able to find joy in everyday things and just feeling love from every direction.”
P6	“So when O was born he wasn't expected to live, and most of the doctors wanted us to terminate the pregnancy, and I just couldn't. I couldn't do it. I remember one conversation with my husband. He went like we're Catholic so abortion is out of the picture, and my husband set up a meeting with one of our priest friends that tell us like, it's okay. And I remember walking with my husband that night. And I was like, if I don't fight for him, who's going to? He was like, Okay, that's it. So like not knowing what was gonna happen. We didn't know what his quality of life was gonna be but I wasn't making that choice. So that's where I am. God has made him. Here he is. He is happy, he's loved, he's yep, our family is better off with him. That's it.”

Quality of life is not just limited to health for children with severe and profound disabilities and medically complex conditions. Evidence from the interviews with participants shows that school is part of the quality of life conversation. Participants talked about school providing consistency, interactions, socialization, and a sense of normalcy. P3 shared the following:

> But I would say school has been the consistency that J has needed. They've done a great job of keeping him with the same teachers for a couple of years, because I don’t want to say my son is a special snowflake, but he is a snowflake that, you have to know what it's like to treat him and what is normal for him and what's not. We've been very lucky with the help of the school and all that it provides.

P3 and P6 would agree that their boys are well taken care of during the day because of what school provides. P6 shared the following:

> O’s brain is disorganized so it's hard to like. I don't know if he's learning, but I know he's getting his therapies. I'm really not concerned with obviously his learning. I'm concerned with his therapies. So I know he's getting those there, and he's being well cared for while I'm working.

Sub-Theme: Measuring Quality of Life. Measuring quality of life involves assessing various dimensions that contribute to overall well-being. There are indices and tool that can be used to measure quality of life such as the Human Development Index or the Quality of Life Index, but perceptions on health and well-being, social relationships, family and community support, living conditions, education, and safety and security are all very specific to the person (Hullmann et al., 2011). Participants were asked during the interview process to not only define quality of life but to explain how they measure quality of life for their child with severe and profound disabilities and medically complex conditions. P1 said,

> If my children are happy and they're not stressed. I just want them to be happy. And if they are successful at whatever they can be successful at whether it be sitting up, that's success. Whether it be smiling at a friend when they're talked to, that's success. I don't measure by ABC's with my medical kids. I measure by happiness and contentment

> and the ability to move forward, if possible, or, if not possible, to be happy with who they are.

P4 expressed the following about measuring quality of life for her daughter:

> We try and make as many memories as possible, and taking lots of pictures. We always said you never know, even if it was her worst day, we still took pictures because we didn't know if that would be the last picture. We just try to make every day the best that we can because we get it. We know that every second counts in this journey. Good days, bad days, no matter what we still figure out how to count our blessings. And I always say it could be worse. It could be worse like that's always been my thing, and well, we know what the worst is [death]. We just definitely just try to make every memory possible, so we have something to always remember.

Simply put, P5 states,

> I measured that by smiles and giggles and communication. We had ways to communicate. And you know, just using their eyes. Speak volumes. You can tell just by looking in their eyes if they were happy. If they were contented. Or if they were unhappy, or in pain, or were just tired and finished.

Conversations about quality of life can be very difficult depending on where the child with severe and profound disabilities and medically complex conditions is on his or her journey. Some children’s hospitals in the state of Pennsylvania have entertained the idea of Pediatric Palliative Care while other hospitals have not yet jumped on the bandwagon. Table 4.3 shows the participants that are involved with Pediatric Palliative Care and those that are not.

Table 4.3

Participant Involvement with Pediatric Palliative Care (PPC)

Participant	**Involved with PPC**	**Not Involved with PCC**	**PPC is not an option at their hospital**
P1	X		
P2		X	X
P3	X		
P4		X	
P5	X		
P6		X	

When seeing or hearing the words “palliative care” one most likely thinks of hospice and end of life care. This is not the case. Pediatric Palliative Care is aimed at improving quality of life for children with serious life limiting diseases. This is a holistic approach that is not just medical in nature. Pediatric Palliative Care addresses the physical, emotional, social, and spiritual needs of the child and the family. P3 shared,

> I would say that we've had a very good relationship with the Supportive Care Team at Children's Hospital. We've had a lot of frank conversations with them about what we want and what we don't want. So, to be totally blunt, we've eliminated a ton of the specialist he sees, because it was just creating extra grief for me. It was taking his time away from school, and it wasn't really like prolonging his life in the quality way we would think about it. Eliminating a lot of the rehab doctors and eliminating a lot of the pulmonologists and things that we could skip, to concentrate down to like palliative care or complex care. Complex and Supportive care are doing all my prescribing now, so I don't have to go to 15 different clinics.

Sub-Theme: Fear. Parents of children with severe and profound disabilities and medically complex conditions do have realistic fears. When constantly considering a child’s life expectancy, quality of life, and all of the many responsibilities that come with that, fears emerge. Participants were asked “What are your fears?” during the interview session. The obvious surfaced. Many participants fear the inevitable death of their child. P3 openly shared her plan for their son.

> We have a DNR for him, so I've had to have the blunt conversation that if his nurse is called to his classroom and he doesn't have a pulse, I need someone to just sit there and hold his hand. I don't need them to be like doing CPR. That's the risk for me, or that's the scariest point for me. Is that something's going to happen, and someone else is going to be there when he's dying and it's not gonna be me. So sending him to school and placing my trust in those people to be that person if I can't be there is the hardest part.

Future fears and not being able to care for their child is something else that emerged during interviews. A few participants discussed their children getting bigger and not being able to carry them or even care for them. They talked about home renovations because of this and then ultimately what happens if something happens to them. Who would take care of their child? P4 shared her fears.

> Well, obviously, there's the worst one [death]. But you know we're gonna stay positive here. But you know, her getting bigger is definitely something that you know is gonna happen. But as she's getting bigger, I'm only getting older and it's like one of those fears of. Oh, my God! What if I can't lift her eventually? And I don't have my husband around to help me. You just worry about every little thing . . . I don't have no one else that can take care of her. I just have all those worries of the future. I guess the future can be a very scary thing to think about.

Other fears participants discussed included being worried about someone taking advantage of their child in one way or another while not in their care. P1 explained,

> The fear of them passing away isn't even a fear to me anymore. It's just part of life, and if I've given them all I can, that’s all I can do. My fears are that someone will take advantage of them, and you know and harm them, or hurt them physically, and I can't watch them 24 hours a day, and I need to sleep, and I don't know what they're doing at night when I'm not there, and that is a huge fear of mine.

The not knowing and the limitations of the child are concerning as well. P2 shared,

> Another scary thing is you don't know if someone's abusing them. They can't express if someone was mean to them. The teachers get frustrated, and you see horrible stories of children recording teachers, belittling name, calling, even smacking disabled children around. My son would come home, and I would never know unless they left a mark. Like I said, if it was physical. There was any other nature I wouldn't know and that that terrifies me.

Specifically, P1 discussed a fear about school.

> Educationally, you know, I don't want the kids to be made fun of. I don't want them to be laughed at. That's a huge fear for me. I want them to be there [at school] and kids to enjoy them and understand who they are. That's probably my biggest fear.

Sub-Theme: Joy. Participants’ responses indicated that having a profound sense of happiness that comes from meaningful experiences in one’s life is considered joy. It was evident that for children with severe and profound disabilities and complex medical conditions, joy is present through all the hardships. Participants articulated that this joy can have a lasting impact on quality of life. During the interview, participants were asked “What brings your child joy?” Responses are recorded in Table 4.4.

Table 4.4

What Brings Your Child Joy?

Participant	**What brings your child joy?**
P1	“I think, just knowing that they're loved for who they are. They don't have to be the best or the smartest of the fastest. They just are, and we love them for that, and we relish that they can do what they do, and I think they feel included and loved. And what more is there to life than that? Yeah. And it brings up joy.”
P2	“C's very happy doing what he likes. So if he's watching television listening to music, playing on the computer, playing Xbox, being in his familiar surroundings. He's very happy with his room. He gets very anxious if you move something in his room or you just clean something. And we were just cleaning his windows last weekend, and I took things off the windowsill to clean and stink eye I was getting, I said. I'm just cleaning up a bit. I’ll put it back. He's very happy and that's good. Then I doing my job with that and as a mom, and you know, when your kids are happy. I'm happy. That's it. I’m fine as long as everyone else is happy and cared for. Then I'm doing my job. That's all I need.”
P3	“J gets joy from like the sun roof in the car, and talking like yelling at his brother, listening to his brother cry. He really enjoys that like it's like the small random things his app on the phone that the giggle gang he loves that or the xylophone, or watching Encanto . We've learned what things make him excited, and he just gets a ton of that. Keep him engaged and excited. There's a lot of random things like that.”
P4	“Just being together. And like, you know, you look into their eyes, and you know they can't say I love you, but as she's crying. But you know you could feel that love and you know, just cuddling and filling that love through that, and playing and just being together. There's nothing better than that. Yeah, that's joy.”
P5	“We just enjoyed spending time together. She was mama's girl. She didn't like it when I did things independent of her and she let you know it, too. So I think we brought each other joy and just being and spending time with our family. You know she enjoyed her brother. She had a hamster. She enjoyed her hamster. She enjoyed just sitting on the beach listening to the ocean or being outside and listening to the birds.”
P6	“He is happiest is when he is cuddled up and just on someone's lap. And there's times where he doesn't want to be held, and I get it. But you can tell when he's happy, and his sounds. He can't speak, but his sounds are different. He has a yell that he's yelling, and then he has a like a higher pitch tone sometimes when he's super happy. He has a sitting position that it's like he's lounged over, and

	he's just comfortable like he's just nothing's gonna bother him. So you can tell in his body posture. He really, in a sense, he likes to be included. I mean, he knows when he's alone in a room like he wants to be held. He wants to be cuddled. He likes music. As much as I think he hates being in the cold like he likes to be outside. I think he likes to hear the sounds."

When the days are long and the nights are even tougher, focusing on the joy that their children bring them makes it all worthwhile. P3 discusses her relationship with her son.

> What brings me joy is seeing him have good days. So like, I said, I have a weird relationship with the good and bad of J. I can tell you. It happens at like 1:50pm every day. I get that note from school that tells me how his day was. So when I read he had a great day, like today was a great one, I take a screen capture, and I send it to my husband. And he responds with "he was a rock star today." That makes us happy. It's like we're seeing that he's getting something out of life. It's not just like a waste. That brings us a severe amount of joy.

Going on vacation or taking trips are other things that bring the participants and their children joy. P5 talked about taking her daughter to beach or to the park.

> We just did things. We took her to the beach. We took her outside when we were doing yard work, or whatever. I took her in her wheelchair for walks outside. We live right near the rail trail. We would meet friends at the park, and she would just enjoy listening to the other kids play. Just things like that, just trying to keep things as normal as we could for our situation.

P3 shared the many vacations they have taken J on. As a family they have been to Florida, Disney World, Las Vegas, Arizona, and even on a cruise ship. P4 shared her camping experiences with her family.

> We've done a lot of camping trips. We ended up getting a camper. So we do different camping trips throughout the year. Couple of years ago, we went out West and took the camper, and we were out there for like 3 and a half weeks. We just did Wyoming, Idaho, Montana. It was like a bucket list for all of us. It was one of those things where she was turning 10 while we were on vacation. And you know, being told that we wouldn't see that day we were like, “Double digits! Here we are!” We said we're gonna make this big trip and show everyone that we can do this. So, we made it work. It was a lot of work too. Pack her and all her equipment and supplies and everything, her meds. Make sure we had everything good to go. But yeah, we did it. And it was nice to be able to accomplish something that big.

Theme 2 Summary. Participants agree that quality of life is probably the most important thing to consider while raising their children. Yu et al. (2022) describes children with medical complexity as having life limiting conditions being completely dependent on others for around the clock care. The participants’ children are the children that need around the clock care. The participants are often the ones giving that care. Limited life expectancy is a reality. P4 spoke of this when she said, “The reality of things weighs heavily like a dark cloud over our head that you know, these things [death] will most likely happen to our children eventually.” Providing the best care, the best education, the best of everything for their children with severe and profound disabilities and medically complex conditions is the top priority.

Research Question 2: How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions?

Research Question 2 focuses on the parent perspectives of the impact of communication, interaction, sensory integration, and inclusion on quality of life for their children with severe and profound disabilities and medically complex conditions. Interview questions addressed parents' thoughts and feelings about inclusion of and interaction with their child. Access to resources, barriers they have faced when trying to be included, or getting what they need were also discussed. A major theme emerged from the data and will be explained in the following section.

Theme 3: Giving the Child What He or She Needs

Quality of life for children with severe and profound disabilities and medically complex conditions is significantly dependent on others. These children suffer from medical complexities and physical disabilities that limit how they can communicate and act independent of oneself. The participants interviewed for this case study all have children that are non-verbal and non-ambulatory, meaning they cannot talk, and they cannot walk. All of the children were also provided nutrition through a feeding tube and some were on ventilators to help them breath. These significant needs are all being fulfilled by an outside factor, most often the parent, a nurse, a teacher, or a doctor. The children are completely dependent on others to live. Therefore, the theme of "giving the child what he or she needs" emerged from the data.

When reading about children with severe and profound disabilities and medically complex conditions on paper, sadly they might not look like they can do or be anything. This becomes difficult when attending IEP meetings or even medical appointments. P1 expressed her feelings by saying, "They look at them on paper, but they don't see who they are." Inclusion becomes a subtheme in answering this research questions, because for most participants, it is important to them. They want their children to learn, grow, be stimulated, and have social interactions. Inclusion, school placement options, and resources availability are all factors that impact giving the child what he or she needs.

Each participant has a discrete view on the definition of inclusion and its importance for their child on varying levels. Inclusion was not particularly important to P5 as she stated that her and her husband provided her girls with everything they needed on their own. "I think that we did that ourselves for the girls and it gave us more control over the situation. You know who they're having contact with. I mean we were the people that wore masks and everything out before COVID." P6 discussed the possibility of placing her son in a multiple disabilities classroom and she hesitated by saying:

> I immediately go with the seizures, and then I immediately go to his feeding tube. I just don't know if he would always be safe. I don't want him to be ignored if he's yelling. I want someone to go to him. And I want someone to be able to pick him up and hold him. Not that saying that wouldn't happen. I mean, he'd probably have an aide, I would assume, and I don't know, I guess you'd have to have a nurse full time.

Other participants felt that inclusion was a very important part of who their child is. P1 shared,

> There's different levels of disabilities or needs, and my children are pretty involved. They don't have a lot of peers and friends that they can socialize with, or that understand who they are, or aren't even frightened of them. Some of their peers are frightened of them. So to me, getting them out into the world and letting them see. Letting the other children see who they are is so very important. Because no one's afraid of my children anymore. They ask to push them at the playground. They ask to read to them. They fight over who is gonna wipe their chins off when they drool. So, they've [her kids] taught them. Not only is it good for my kids, but it's good for the whole world to see that these kids can

> learn. And when you can see the other kids go, “Oh, she lifted her arm up!” It's something so minuscule, but it gives such joy to everybody that sees the tiny little accomplishments in these kids.

Looking at the whole child and investigating who they are and what they need become the first step in meeting their needs, whether medical, physical, or educational. Communication, interaction, sensory integration, and inclusion are crucial for enhancing quality of life for children with severe and profound disabilities and medically complex conditions.

Sub-Theme: Looking at the Whole Child. Not having a comprehensive understanding of the needs of a child with severe and profound disabilities and medically complex conditions can lead to gaps in development, medical care, attention, and overall quality of life. These needs may include medical, physical health, emotional, social development, cognitive, communication, interaction and sensory. Having a holistic view of the child and their needs is paramount.

Physical health and well-being are often a challenge for children that have medical complexities. Yu et al. (2022) describes children with medical complexity as having chronic and life limiting conditions needing care 24 hours a day seven days a week. Children with medical complexity typically have a limited life expectancy and high rates of poor outcomes regarding health and morbidity. Medical requirements such as managing medications, monitoring health conditions such as pulse oximetry or seizures, and physical accessibility must be integrated into educational plans. P1 explains her child’s need for safety while being transported to school:

> She's 5. She has all kinds of medical issues. She has a nurse. That's a huge barrier for her to be able to get to school and be in a good place to learn. I mean, she's been sitting on a bus, you know, for almost an hour. She's one of those that soaks through her diaper. It

> takes them 25 min to get her in a good place once she gets to school, and it's not fair. It's not right.

A comfortable environment is important to quality of life. Along with long bus or van rides, classrooms do not often lend themselves to being comfortable with desks. A classroom might need places for children with severe and profound disabilities and medically complex conditions to lay down, stretch out and participate in therapies that help support their overall growth and development. There needs to be room for equipment such as wheelchairs, standers, walkers, therapy benches, and soft mats or cushions. This helps support sensory accommodations. P3 talks about what the Western Pennsylvania School for Blind Children does in her son’s classroom to create an environment that meets his needs.

> They’re [the school] embedding therapy in what they're doing. They'll do circle time like a normal first or second grader would have. But he's doing it on a therapy bench seat where they're doing supportive sitting or he's spending a lot of time in his Rifton Chair. That's giving him different angles and sitting closer to the floor so he can play with kids that are more normal because they’re crawling around and playing. So, he's at their level. It's giving them a variety of learning opportunities.

Engagement in play and educational activities tailored to the child's abilities enhances learning and developmental outcomes. P6 shares details about what goals they work on with her son, O, in the classroom.

> They’ve assessed him to say that he's latent on one side of his eye, his face, when he looks with his right eye. They focus his goals around those kind of activities like adapting toys with mylar and sound. And you can see the progression of how he was before, where he was very heavily dependent on sound. And now he can have complex colors and see a

> lot of things . . . So I think that's probably the greatest thing they provide to us is that they give him the opportunity to succeed as much as he can, and when he can't surpass that they change up the goal to kind of continue to meet what he needs.

Regulation and comfort comes from proper sensory integration therapies that can help children process sensory information more effectively, reducing anxiety and discomfort from overstimulation or sensory overload. P6's example of her son's use of mylar paper to see is a great example of how sensory integration supports development, in this case visual development. When educating these children, focusing on participatory opportunities that foster positive engagement, interactions, physical movement, sensory input, play and happiness can certainly add to quality of life (Dodds & Rempel, 2016). Tailored sensory environments and interventions make it easier for children to engage in and enjoy various experiences, leading to a richer and more fulfilling life.

Cognitive and communication skills are often addressed though individualized education plans that are tailored to the strengths of the child and ensure that the child's development is supported. Challenging, realistic goals are encouraged to cater to the child's needs, presuming competence first. Setting unrealistic goals can be frustrating. COVID-19 also presented barriers to in person learning for children with intellectual and development disabilities (Vestal et. al, 2023). P3 shares her frustrations of virtual learning during the COVID-19 Pandemic for her son.

> I think about the times of COVID. When he was home for that full year, we saw a tremendous amount of regression because he wasn't able to go to school. Being on a screen and working remotely is just not beneficial to him. Considering the kind of work they would do, like bench sitting, and all his speech therapies and the different textural

> things he plays with. They have a lot more that stimulates him to see progress over the past 5 years.

The use of Augmentative and Alternative Communication (AAC) devices can help children with severe and profound disabilities and medically complex conditions express needs, preferences, and emotions and engage with others. This leads to better satisfaction and reduced frustration. Consistent communication strategies help children in their environment and with daily routines, contributing to a sense of security and predictability. Children with severe and profound disabilities and medically complex conditions are no different. Even though communication might not be verbal, they are able to share preferences and feelings by using body language and facial expressions. The more time spent with these children the more one recognizes their cues and communication efforts.

There are devices such as eye gaze technologies that allow children that are non-verbal and have limited mobility to be able to use their eyes to communicate. P4 discusses her daughter's speech therapy and tablet that they use as an AAC device.

> She does get speech every week for a half hour. She has the tablet that we got from Variety. She taps on it which sometimes she's just tapping just you know, because of a chaos kind of thing. But sometimes she actually does what she's supposed to do. And I'm like, Hmm! Wonder if you actually did that?

P2 is anxious for her son to receive his eye gaze device stating "I can't wait to hear what he has to say."

AAC does not always have to be high tech. There are low tech interventions that can help bring meaning to a child's life that has severe and profound disabilities and medically complex conditions. P3 describes a time when her son's teacher was able to provide her son with a voice.

> She's like, “I think he's trying to talk, and he's mad that like he's not getting his voice heard.” So she went out and bought a microphone for his like tray. Then he would be standing in a stander, and he'd be vocalizing into the microphone because it would project his voice. He thought that was the coolest thing! Just giving him a different opportunity to be engaged kept him a little bit more interested than if he would just have to sit there and listen. He would just go to sleep. So instead, she gave him a voice.

Encouraging social interactions can foster peer relationships that can help children with severe and profound disabilities and medically complex conditions have a sense of belonging. P3 shared,

> Some of the coolest things J gets to do is like they have a holiday program at the school for blind children. So, they dress them up, and they sing with the people. I'm sure he doesn't want to be dressed up like a snowman, but he is and you know, it's amazing the kind of stuff they include him in like trying to make it as normal as possible of a school experience. They have prom for the kids that are in the older ages. So like things that are normal behaviors for kids, their age, they're getting it. They're being included in those activities, but having it adapted to their specific needs.

Having these experiences clearly is impacting quality of life for children with severe and profound disabilities and medically complex conditions and it is also impacting the quality of life of the parents. P3 describes her son’s participation in Miracle League. Miracle League provides children who suffer from physical or mental disabilities an opportunity to play baseball in an adapted program. She says “It still feels like me, as a parent, is still getting to see him play. My kid runs the bases at a baseball game. Like that's cool!”

Keeping in mind long term outcomes are important to quality of life for parents of children with severe and profound disabilities and medically complex conditions. Looking at the whole child is essential in educating children with severe and profound disabilities and medically complex conditions because it ensures that all of their needs are met in a comprehensive and coordinated manner. It supports not only the children but their families and those that educate them.

Sub-Theme: Inclusion. Inclusion can be defined as the idea of providing an environment that increases potential for all students to have a sense of belonging and acceptance when placed in the general education classroom. Inclusion promotes acceptance and understanding, reducing stigma and discrimination. Inclusion is important for everyone, especially children with severe and profound disabilities and medically complex conditions. Inclusion will look different for everyone based on their specific needs and comfortability with being included. Participants in this study were interviewed and asked to define "inclusion" in their own words. Table 4.5 outlines their responses.

Table 4.5

Defining Inclusion

Participant	**Definition of Inclusion**
P1	"To me inclusion looks like what is in the best interest of everyone. I want my child to be included and appreciated and respected, but I also do not want it to pull away from the children that are in the classroom."
P2	"I would define inclusion that any child of any ability or disability are all in the same classroom and you have the resources that they need to be able to succeed in that classroom."
P3	"Allowing people to have their differences, but still trying to adapt some things to include them in the general way of life. I think of like how B looks at J right now. He knows J's different, but he still talks about him that he loves his brother, and he is part of the family, like there's just a general like ease, an inclusion when you're looking at a child."

P4	“We're trying to let A live as normal as a life as possible. So, including her in as much as possible. But it's hard doing certain things, and certain people like not including her. I don't know. It's hard.”
P5	“Well, I guess it would be to me just including the special needs child with the typical kids and giving them some kind of experience with that and with a normal population”
P6	“Just because of working in school like regular Ed kids intertwined with special Ed kids and I think O’s school does a fantastic job of that. They bring in their teachers that have children. They'll have days where, like they come in to like help with the classroom, and I think it's amazing that they do that I love when they send pictures out and like I don't know. It just warmed your heart because it's like inclusion.”

Being included gives one the sense of belonging. Inclusion impacts social emotional well-being. Building new relationships and fostering existing relationships can be challenging as a parent of a child with severe and profound disabilities and medically complex conditions. P5 talks about how her family always invited them to things even though they knew she would probably not come. “Our family always tried to involve us in anything. You know, we always got invited even if they knew that we wouldn't come. You know, we still got the invitation, and like I said for us It was just having control.” Having control over the situation was important to her as a parent. P4 discusses her friend’s family always trying to include them.

> My best friend's family is always like, “Oh, bring A over,” and you know, obviously, I usually don't. It's nice that they invite us over for holidays or parties and stuff. They always say, “make sure you bring A,” or “you know you could park up close to the house.” It's nice that they include us bringing her. But there's times that I can't leave the house because I do have A, and people want to go out and do stuff. I'm like, “Sorry I can’t, but you guys can come over and sit with me and hang out with A and watch a movie.” But obviously no one wants to do that, because they wanna go out.

Being part of a community can reduce those feelings of isolation and loneliness that parents of children with severe and profound disabilities and medically complex conditions may face on a regular basis. Having a sense of belonging and being part of something contributes to better social and emotional health.

Sometimes being included turns into being excluded. P2 explains that “It's not the world's fault. It's just not geared for wheelchairs, so we can't even get to most of our family and friends' homes. We're not even invited to people's houses because we just can't physically get him in.” She went on to share a story about going to a birthday party at her brother’s house. He told her that it would be accessible for her to take her son. It ended up not being accessible at all.

> C had to just lay on the couch while the kids are downstairs for the magic show, which I couldn’t get him down the steps, and the kids are in their pool, which I also couldn't get him in. So it was, it was just very disheartening, especially for someone that should know better. I mean, just tell me you know what it won't work, and we wouldn't show up, and that that'd be fine. I’d rather the honesty than put me in that position which was very awkward.

With every disheartening story of feeling excluded, there is a story of remarkable community presence and innocence of young children being naturally accepting of others. P6 told us a story about her typically developing daughter attending a Special Olympics event that her husband was involved with.

> My husband helps out with Special Olympics and they were at his school. I told my daughter that they were going to play basketball and we were going to cheer on people with disabilities . . . So, we spent all day there, and we got in the car. And she's like Mom, I mean, she was probably 3 or 4 years old, She's like, “Mom, I thought, we're gonna see people with disabilities.” And I was like “We …,” and I stopped myself.

> I was like oh my God, that whole day she never looked at anybody differently and that to me was like, so eye opening because it's the adults that look at people differently.

Theme 3 Summary. Looking at the whole child can help answer how do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions? When we look at a child with severe and profound disabilities and complex medical conditions, they are like no one else in this world. No two children are alike. This means their needs are individualistic. What is comfortable to one child might be uncomfortable to another. A seizure plan for one child might be complete opposite of what another child with epilepsy needs. It is critical to look at the whole child when addressing quality of life. Providing a comfortable environment, cognitive and communications skills, along with the use of assistive technology can offer children with severe and profound disabilities and medically complex conditions a sense of belonging, inclusion in the community.

Research Question 3: How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child’s quality of life?

Research Question 3 focuses on the support of parents of children with severe and profound disabilities and medically complex conditions. To answer this question, participants were asked questions about their support systems during the semi-structured interview. They were also asked about their current life/work situations, family dynamics, resources they use and barriers they may have faced during their journey raising a child with complex conditions. Finding the support needed to raise a child with severe and profound disabilities and medically complex conditions emerged from the data reviewed.

Theme 4: Finding the Support Needed to Raise a Child with Severe and Profound Disabilities and Medically Complex Conditions.

"It takes a village" is what many parents will say when asked how they take care of their child with severe and profound disabilities and medically complex conditions. This sort of care requires a system of support that involves various stakeholders working together to meet the very diverse needs of the child and the family. In a 2020 study conducted by Yu et al., it was found that there were significantly fewer mentally unhealthy, depressed, and anxious days for the caregivers having supportive and knowledgeable care coordination and feeling that their child with severe and profound disabilities and medically complex conditions is having their needs being met and advocated for. Caregiver's mental health was significantly connected with specific aspects of feeling supported. In this theme we will talk about "the village" while addressing who those key stakeholders are and what role they play.

Sub-Theme: Reliance on Support Systems. Most parents of children with severe and profound disabilities and medically complex conditions begin their journey not knowing anyone that has a child similar to or like their child. They might know someone that has a child with special needs, but most do not have the complexity of the children we are discussing in this study. Parent participants talked about using the resource they had immediate access to, Google. The parents yearn for support, to find someone else that understands. Google, Facebook, and networking allow the research to take place and the beginning of the support system evolves. Once they stumble on one resource, they usually stumble on another, then another.

Where do these resources come from? Sometimes it is obtained at a pediatrician's office or at the hospital after diagnosis. Sometimes it is acquired by word of mouth. Often it is by making connections and building relationships with those around that can offer and provide help and support. Support comes in many forms while caring for a child with severe and profound disabilities and medically complex conditions including nursing, family, friends, schools, and coordination of care. We will explore each support in the sections that follow.

Nursing. Families that have children with complex medical needs in the state of Pennsylvania may qualify for skilled nursing services through medical assistance offered by the state. Primary insurance agencies do not often cover these skilled nursing services, but medical assistance does. Children with severe and profound disabilities and medically complex conditions often qualify for state funded medical assistance through a loophole that is not based on income, however, based on diagnosis. Medical assistance provides these children with the extra medical support they need for healthcare, assistive technology, durable medical equipment, and even nutrition.

Of the participants interviewed, four out of six have nursing services in the home to assist with the complex care of their child. Table 4.6 outlines the participants and whether they have nursing support at home.

Table 4.6

Nursing Services in the Home

Participant	Has nursing support at home.	Does not have nursing support at home.
P1	YES	
P2	YES	
P3	YES	
P4	YES	
P5		NO
P6		NO

P1 talks to us about her village of nurses that help care and support her four special children that she has adopted or fostered.

> We have four nurses that come right now to care for our four special kids, to take them where they go during the day. So they all show up. It's still packing the lunches and making sure that they have appropriate clothes on for color day. I mean, they're still regular kids. I want to ensure that they go to school, doing what their peers do. So we still do all those crazy spirit day things, and the feeding tubes, and the pumps, and the ventilators...if the nurses show up. If they don't show up, then we have to replan the day because there's somebody who doesn't have a place to go.

It's critical that these nurses work with P1’s children. If the daylight nurses do not show up, the children cannot go to school and P1 must make other arrangements. If the night nurses do not show up, P1 has to stay up and care for the child without a nurse through the night monitoring and doing all of the nursing tasks required. The next morning this leaves P1 exhausted and having to do it all over again. Parents of children with severe and profound disabilities and medically complex conditions rely heavily on nurses to support their children. It’s fundamental for P3 to have nurses as she explains here:

> We wouldn't be surviving if we did not have them. I think between my husband and I, we'd probably be divorced, or of killed each other. I remember when J was first diagnosed. We were a week out and my husband was like “you're gonna have to quit your job,” and I was like this is our life. You're gonna have to do this. And that's when we found Child's Way, and that's when we heard about nursing. We started working with our main nurse. And she told me it was okay and that you can figure out a way to balance your life. J can do more things and just be sitting there. So, we would be in a very

> different place if we didn't have the support system and the infrastructure we have around us.

P4 discusses how having nurses has given her some sort of normalcy back in her life. She can run errands, go to work, and even socialize with friends.

> Having nurses gives us some normal life. We can actually go out and get groceries and go to work and maybe go get coffee with a friend and not have to worry about everything, especially lugging A in public and risking the germs, and you know, taking all her stuff with her. So, it's just nice to have some normalcy.

Families that have nursing services will often qualify for nursing hours when the parents are at work, are sleeping, or are at school (the parent or the child). There are many agencies across the state that provide pediatric nurses that are LPNs or RNs. These nurses are trained specifically for the children they are placed with. In more critical situations, comparable to some of the study's participants' children, nurses basically run a mini intensive care unit in the home overnight watching stats and machines, such as ventilators, heart and oxygen monitors. They also monitor seizure activity, provide suctioning, breathing treatments, diaper changes, repositioning, and medications. If a nurse is not there, it is the parent's job to step into that nurse/doctor role. P3 spoke about her baptism by fire.

> I pretend I'm a nurse or a doctor most days. That's why I'm in healthcare. I have an accounting and marketing degree, so I do not have nursing background. But from 10 years of doing this I feel as though I know more than most of the residents [doctors] at this point.

P3 discussed how the nurses that they have in their homes daily or nightly have become part of her family.

> Our nurses have steadily become part of our family, so I don't worry about them being here. Our one nurse has been with J since he was 7 weeks old. She knows him. She knows him probably better than I do in some ways.

P4 agreed that her daughter’s nurses are a part of their family.

> Having nursing, you know, we actually have a great team right now, which can be hard to actually find the right nurses. It's an off and on thing. But right now we have a great group and they have become not just friends, they're definitely family.

P4 goes on to say that her and her two daughters were in one of the nurse’s wedding a few years ago. That is how important nursing is to these families.

Family and Friends. Nurses are important, but most families do not get nursing coverage 24 hours a day, consequently, parents also need family and friends to support them. P3’s support system includes her sister, mother, aunts, and nurses as she explains below.

> I have a very close sister. My mother is heavily involved. My mom is actually a retired nurse, but she used to do geriatric nursing. But now she's decided to help with pediatrics. So, when J's nurses call off or can't make it in because they're sick, my mom is picking up shifts and actually getting paid through Interim [nursing agency] to be his caregiver on certain nights . . .We have an extended family, like this weekend when we were away, it was my mom, our main nurse, and then the overnight nurses were here, and then my aunt, and, like just everybody, seems to love J, and they're more than happy to help us do that kind of stuff.

P4 is also heavily supported by her mother so she can work and spend time with her teenage daughter running to activities when her husband works out of town.

> My mom helps out she actually just went part time at work so that she's able to help out more cause B started doing volleyball and archery and stuff. So she comes down. She lives right up the road, so it's nice that she can just pop on down here and sit with A for an hour or 2, so that I can take B to do her activities.

Sometimes families choose not to have nursing help at home. P6 is not supported by nurses, except when her son is at school, so they have a lot of family assistance.

> We have a lot of family help. So that's amazing. My husband’s family. His parents come down here and live with us throughout the week to help. Oh, my God, they are amazing! I mean really, truly. They come down pretty much every Sunday, and they'll leave Friday sometime Saturday and come back. It's harder because my husband coaches football and my kids are getting into sports. We're running every which way. As O is getting older, it's getting harder to put him in the car, get him out like, and then run them everywhere which way? So, if they're running around, it's just easier for my in-law’s to say “I'll just sit with O.” My mother-in-law's notorious for saying “O doesn't really wanna go.” Like how do you know, grandma?

P6 is interested in nursing coverage, but also thinks it would be difficult to get her son’s case covered. Since she has her in-law’s support for now, she is not worried about finding nursing services right now. P5 did not have any nursing support, just her husband and mother-in-law to help her. She said, “My husband was pretty good as long as everything was written down, and my mother-in- law is an RN so, she was our backup. Most of the time I just powered through it.” Family support is often a safety net helping to provide respite care and various medical tasks.

Unfortunately, not everyone has an extended family that can fill in. P2 lost her parents years ago. After her parents’ death, P2 and her family made moved from New York to

Pennsylvania. Her husband’s family is all located in New York, and she has no extended family that lives near where they are living now.

> We are basically homebound. I do get out when there's nursing staff here. Monday through Friday 7 to 3. So that's my time to get out. So, it's difficult to have a support system, because to develop relationships you have to give and take. I just don't have much to give outside of C and my other children when I was raising them, and my husband that I just have not been able to establish too many friends in the area.

P2 also mentioned the disadvantage of not having time or energy to develop relationships outside of the home. In addition to family, friends are often another safety net when family is not available. Building relationships with others takes time and commitment. Friends become key factors in helping raise a child with severe and profound disabilities and medically complex conditions. Friends can provide companionship for parents and provide socialization by bringing their own children around.

Old friends are sometimes hard to keep. Participants mentioned this during their interviews. Sometimes it is hard to relate to others that are not in similar situations. Many parents talked about Facebook and being able to find other parents through online support groups that are going through a rare and difficult journey. P4 talks about making friends with other special needs moms locally through Facebook connections.

> Making friends with other special needs moms it definitely helps. You know, we all have different journeys, but there's a lot of similarities and the fights that we have to go through and everything. So, it's definitely the biggest thing that we've had to do was find other people that “get it.” That's the most important thing I think, in this journey was just finding someone that got it.

P6 said it best when she said, “I think the best resources are other parents with special needs kids, I mean, truly, that is that's the most helpful to me.” She goes on to explain when she was first pregnant with her son. She had to use the internet to learn about his diagnosis and hoped to find others that had the same diagnosis. There was a mother in Wisconsin that put her in contact with the surgeons in Boston that ended up saving her son’s life. She found this mom on Facebook. Nurses, family, and friends become dedicated villagers ensuring quality of life to these children and their parents.

Coordination of Care. Coordination of care is needed to help care for and support parents of children with severe and profound disabilities and medically complex conditions. Increased understanding from healthcare providers is necessary to address primary family caregivers’ needs. (Coller et al., 2022; Ellzey et al., 2015; Johaningsmeir, 2015; Yu et al., 2020). Yu et al. (2020) assess the relationship between children with severe and profound disabilities and medically complex conditions and family caregivers’ health-related quality of life (HR-QOL) and experiences with care coordination. Yu et al. (2020) “hypothesized higher quality experiences of care coordination would be significantly associated with higher caregiver HR-QOL, with greater positive association with caregiver mental health relative to physical health” (p. 1117). Children with severe and profound disabilities and medically complex conditions are dependent on others and those others need to be supported.

When P5’s first daughter was born with a rare disease there was not as much support available to her by way of resources and via medical coordination of care. Her two younger daughters both received help through the Palliative Care Team at Children’s Hospital in Hershey, PA. P5 shared that “A and K both were part of that program, and they provided a lot of resources for us. If I needed something. That's who I called first.”

P3 is highly supported by care coordination through the Children's Hospital of Pittsburgh. Her son sees the Complex Care Team and the Supportive Care Team, and they take care of all the other medical specialties for them. It saves the family time, gives them an opportunity to be present at work or at school, and provides consistent medical care all while adding to their quality of life.

Sub-Theme: Educational Support. School districts may not feel that they are part of the village that supports parents of children with severe and profound disabilities and medically complex conditions, but they most certainly are. When a child with severe and profound disabilities and medically complex conditions becomes school-aged, the school district will take over the management of their IEP. Educational options will be talked about for the continuum of alternate placement based on the least restrictive environment. This should be a collaborative approach leveraging interdisciplinary teams to have clear and open communication between the school and the parent, and any other stakeholders.

School options are discussed. Depending on where the family lives options are explored to either stay within the school district, seek specialized school, or have instruction conducted in the home (Mancini & Layton, 2014). No matter the choice, it is the home school district's responsibility to provide services for the child. P2 argued that she wished she would have been provided and education advocate to help in understanding IEPs.

> I wish we had an education advocate because I'm sure you understand IEPs far better than I do. They are 42 pages of nonsense in my head. It'd be like you reading a medical journal or a surgical journal. It's comparable. It just the jargon is not understandable for the everyday person. And you know I'm not an idiot, but it's just, it's horrible. They have these algorithms and these numbers and these things. And I'm like I hate it, I hate it.

> I don't understand it, and it's hard to advocate when you don't understand the IEP to begin with. So, I wish there was someone to explain it better.

Most of the participants agreed that their home school districts were supportive in education options, markedly of specialized placements. P3 referenced her son’s home school district as a part of her support system.

> Plum has been fine since we've moved in. They have no issues. They've never fought it. They've been at the IEP before. They've never had an issue with it even when you see how much it costs to go to the Western Pennsylvania School for Blind Children. I think like the last report I saw it was like $93,000 a year for my child to go to that school. The fact that they're doing it without putting up a stink. It is amazing that the school district is willing to support that.

P6’s son also attends the Western Pennsylvania School for Blind Children and say that they are “the extension of the support system that we have. There’s always people we can go to when we have those kind of questions.” She also said that her school district did not fight to have her son go to school there, and that “they've been super supportive, and I know it's not cheap. So yeah, they've been great, truly.”

It is wonderful when school districts can support families far beyond the brick-and-mortar walls. Providing the low incidence population of children with severe and profound disabilities and medically complex conditions what they need physically, mentally, and even medically is not always easy. Using systematic instruction and high leverage practices are ways to support positive outcomes that enhance development as well as social and emotional skills of children with severe and profound disabilities and medically complex conditions (Vandercook et al., 2020). Several issues came to light while interviewing the six participants in this case study. Transportation, staff issues, and access to resources will be analyzed.

Transportation Issues. Children with severe and profound disabilities and medically complex conditions are hard to transport by car. Getting a child that has low tone or spasticity into a car seat to travel is challenging. If there is a wheelchair accessible vehicle and proper wheelchair with tie does, transportation can be easier. There are many factors to consider while transporting a child with these complexities. Are they safely positioned? Do they have head control? Are they comfortable? Do they need to be monitored by a nurse during the trip for suctioning or seizure activity? How long will their ride be? P1's child must go almost an hour on a bus to get to school. P4's child's first school placement was also an hour drive from home.

> The only other thing [besides germs] with her going to Watson was the drive because it was almost her being in the bus for a couple of hours. So, by the time they picked up all the other kids, cause it's like an hour from here, we are talking a couple of hours almost in the van or the bus. She actually did really good most of the time on the bus but if she had a cold, or soiled diaper or something, and had to sit in it that long she would obviously be upset and annoyed. She did have a nurse that rode the bus with her, which was great.

P3 and P6 moved closer to the city so their children could have access to a specialized school. Even while living closer to the school the bus still makes P3 nervous. P3 shares "I'm nervous every day about him being on a bus because right now he's just on a bus with a bus driver and an aide, so there's no nurse with him. I'm constantly worried about seizure activity."

Staff Issues. Other barriers to educating children with severe and profound disabilities and medically complex conditions are staffing of the appropriate personnel to teach or take care of them while they are at school. If there is no staff to take the children to school, they cannot go. If a nurse calls off, they cannot go to school. This makes it difficult for parents often having to be flexible if they are working full time and have contingency plans for when this sort of issue arises.

Sometimes teachers and paraprofessionals are not always prepared to handle a child with severe and profound disabilities and medically complex conditions, to no fault of their own. This child is part of a very low incidence population, so educators might not know what to do with him or her. In a study by Nabors et al. (2008), survey results showed that the teachers did know about the chronic medical conditions, but they lacked confidence in the areas of educational and social needs of children with chronic illnesses. In an ideal world there would be specialized training for educators when having to teach children with severe and complex needs. This can be a scary thing for a teacher. P1 recognizes the fear that staff might feel.

> There's so much that goes into making sure your kids get what they need. I absolutely know it would be so much easier to have them home, because, you know, they're safe. You know they're being watched. You know that they're not too cold, not too hot, their meds are given. But it's not in the child's best interest, and we have to figure out a way to get these barriers out of the way, so that families feel good about sending their kids [to school], and the kids feel great about being there, and the staff feels good about them being there, because they're scared of them, too. I mean, every time she beeps they're like, is she alright? Should she go to the hospital? Should we call an ambulance? No, she's fine. But yeah, we have to find a way to educate people.

Educating people about a child that has a complex medical history and severe development needs is something that could best come from the parent. Parents know their children best. The findings from a study by Kruithof et al. (2020) suggest “that parents possess unique, experiential knowledge of their child” and they use this knowledge to advocate and communicate their child’s needs to professionals (p. 1146). Everyone else cannot possibly know every child they work with as well as the parents. P1 discussed the importance of parent and teacher communication.

> I think they get lost in the muck of the traditional kids and maybe my kids. And there's so much more they can do. But how do teachers? How do you hone in on the educational piece to know that? I think parent input could improve a lot. They don't really reach out to parents and say “we're struggling with this” because they're the professionals. They think that they can read in a book how to fix this issue. You can’t find our kids in a book. If they would include the parents I think it would be so helpful. But I don't think they reach out to us.

Schools can work together with parents to overcome the barriers of staff issues by providing open communication, flexibility, and a sense of understanding.

Assistive Technology Issues. Assistive technology is anything that can enhance the functional capabilities of an individual with disabilities. There are so many low tech options that are easy to use and are relatively inexpensive. There are also high tech assistive technologies designed to help people perform tasks that might otherwise be difficult or impossible due to some limitation. Assistive technology can range from communication devices, computers, wheelchairs, standers, and other durable medical equipment. Some of this technology can be difficult to use if unfamiliar with the software or have never seen or used the technology before. Lack of knowledge and time to commit to learning to use these devices becomes an issue (Norburn et al., 2016). Students need to be supported and challenged with assistive technology.

P2 is discouraged with the lack of ability from her son’s teachers when it comes to his high tech equipment due to not taking the time for the communication devices.

> They don't have the technology ability. A lot of these teachers. They still, you know, want to stack blocks or push coins in front of them. It really for Christopher, because of his disability, has to be highly technologically based and they're just not there. The teachers aren't there.

These barriers to access that might happen at school are just that, barriers. How can educational support help overcome those barriers so that children with severe and profound disabilities and medically complex conditions can have access to the people, places, and things they need in life?

Sub-Theme: Advocacy. When a parent has a child that is newly diagnosed with a severe and profound disability and a medically complex condition, they can go into survival mode. Just trying to learn about the diagnosis is overwhelming. There is grief that also comes with the diagnosis. Everyone grieves differently. When a parent gets to the point where they are ready to learn about what will be best for their child, they may need support. During the journey the parent will learn to advocate for their child. Advocacy brings a sense of empowerment to parents because they have a passion for their child, and they have a passion for making things better for their child.

Some people struggle with finding a voice for themselves, but if their child is involved, they want and deserve respect. P1 shares her experiences as a social worker and a mom.

> What I've learned [as a social worker] carries over to how I present myself. But I'm telling you these are my kids, so I become more of the mama bear. Then the social worker kind of flies out. These are my kids, and I want them treated the way I would like them to be treated. I think it’s how you present things when you can get the most for your

> child. If you don't advocate, they don't get what they need. And if you over advocate and become a thorn in everyone's side, then you get shut down as well. So, it's all about the approach, and that's where the social work aspect, I think, comes into play.

P2 is also a mama bear that describes herself as the squeaky wheel when she is trying to advocate for something for her son.

> Well, luckily my husband and I have both been in the medical field for so long, so we kind of know how to navigate it far better than the average parents, especially a new parent and a young parent. So those are definitely our strengths. I definitely know how to navigate. My personality is also a strength. I will be persistent, and I will research, and I will be the squeaky wheel. I will call you 10 times a day until you call me back because I'm gonna be home, anyway, so I might as well annoy the crap out of you.

Advocacy is crucial for parents of children with severe and profound disabilities and medically complex conditions. It helps ensure the child receives everything they need medically, physically, mentally, emotionally, and educationally. Parents are navigating the medical field while trying to advocate for healthcare access. Here are a few examples of medical advocacy from the parent participants. P3 places quality of life above all else for her son.

> I'm not going to put rods in his back. We are not going to go through that kind of surgery, so is it worth me seeing a rehab doctor, or are they just gonna tell me that I have to have surgery? We had a frank conversation about that is not the quality of life we want for J. We're not going to put him through those kind of surgeries . . . Those are the kind of supportive conversations we're having with those clinicians outside of school to make sure we have the wishes for J addressed.

P4’s daughter spent the beginning years of her life in and out of the hospital in critical condition due to aspiration pneumonia.

> She used to get aspiration pneumonia all the time, and pulmonology wouldn't agree with me that she needed a chest vest. So, I contacted the company myself and talked to them about how I could go about it. They gave me all their advice, and so I went above pulmonology, and I contacted other doctors and her PCP. I had a whole bunch of doctors write letters and we were able to finally get the chest vest. When we got it, she didn't get aspiration pneumonia again, and I made sure I told pulmonology that they messed that one up.

P4 goes on to reiterate that even though the “doctors are smart, sometimes we know better than them, so just don’t give up your fight, because you know exactly what your kid needs.” Being able to communicate the needs of a child is empowering. Having open lines of communication with all stakeholders is empowering. P3 shared how she conveyed concerns with her son’s teams.

> I think we have a good dialogue with the teams that support him like when I have concerns. I'm very vocal about them. There was a time where he was very sedated, and he would get the stander and immediately go to sleep. It became a behavior thing for him. I knew it wasn't like him just falling asleep. He was doing it as a way to tune out and get out of the stander because it’s hard work. He would do that, so I brought it up to school, and we immediately started working with a behavioral therapist at the school to change up his behavior so he would stay engaged in the school day. I feel like they were very reactive to any concern I bring up. So, I don't think that's really a problem that we've had many barriers with. Everybody has been very supportive.

Sometimes advocating is the difference between life and death. P6’s son was not expected to survive after birth. They spent time in a Neonatal Intensive Care Unit in Pittsburgh before advocating to go to Children’s Hospital in Boston. P6 shared,

> Well, you know how they travel with teams. I mean, we had neurology there. Neurosurgery was there. Carol's Supportive Care Team was there, and the NICU staff. They're all like “there's really nothing we can do. If we take his encephalocele off his head, it's just going to fill back up with fluid. Half of his brain was in the encephalic seal. So there's really nothing we can do.” I remember this vividly. I can smell the smells. He was on my lap, and I looked at the neurosurgeon, the head neurosurgeon at Children's Hospital, and I asked him, “what would you do if this was your kid?” And he said, “I wouldn't have brought him to term.” So obviously 10 years later he’s still here.

If P6 had not advocated for her son to go to a different hospital for complex neurosurgery, he likely would not have survived. Instead, she was empowered to stand up for her son and make sure did everything she could to keep him alive.

Theme 4 Summary: When parents are empowered by the support they receive it can create a network of support that improves the quality of life for their children with severe and profound disabilities and medically complex conditions. Sometimes the decisions parents must make are life and death. Doing any of this can be extremely stressful if not supported by others. P3 summarizes research question 3 well when she explains how important her support system is.

> The resources around us, the support system I have, whether it's people that did know me before J or the people that didn't know me before J have made a tremendous impact on our lives, and they're the reason why J is. I'm part of the reason. But the whole amount of people there, everybody is part of the reason J has come as far as he has. That's why we

> do what we're doing. Because everybody sees it, you know. J's nurse will say you just look in his eyes and you see something special. You know there's something else there that it's not just a kid with epilepsy. So yeah, it's the people that make it worthwhile doing what we do.

These children are special. These parents are special. The nurses, doctors, teachers, therapists, administrators, family, and friends are special. Together they make the village that supports parents during their best days and their worst days. Finding the support needed to raise a child with severe and profound disabilities and medically complex children is essential when trying to provide the best quality of life (Kuo & Houtrow, 2016; Sobotka, 2022).

Summary

Chapter four presented the results of the data analysis in narrative form from transcribed interviews in this qualitative case study. Differences between parent perspectives on topics including the importance of school, the importance of quality of life, the reliance on support systems, as well as barriers to access, and advocacy efforts were evaluated through the weaving of literature and participant responses. These responses were arranged into themes and sub themes written in narrative form relying heavily on direct quotes.

With the growing number of children with severe and profound disabilities and complex medical conditions, the need to analyze parent perspectives on the impact of education and quality of life is necessary. Additional findings included participants’ views on personal factors that would influence their educational decisions for their children as well as their perspectives on quality of life, inclusion, support, etc. The next and final chapter, Chapter 5, is a discussion of the practical implications of these findings as well as the limitations, recommendations for future research, and conclusions drawn from the results of the study.

CHAPTER 5 CONCLUSIONS

Introduction

Literature suggests that education is an important factor in the lives of children with severe and profound disabilities and medically complex conditions. Attending school in any capacity on the continuum of alternate placement (CAP) provides these children the opportunity to participate, be a part of something, stay engaged, interact with others, express who they are as they socialize, and find contentment (Rehm & Bradley, 2006). When children can freely express themselves, it is a remarkable experience not only for the child but for everyone involved in their life (Lui et al., 2022). However, educating the child with severe and profound disabilities and medically complex conditions can be challenging for all stakeholders involved.

Least Restrictive Environment (LRE) suggests that children with disabilities should be with the regular education population as much as possible or as most appropriate based on the needs of the child (IDEA, 2004, sec. 601). According to Lustig (2018), thousands of children with medical disabilities are not in appropriate school placements and continue to be separated from their peers. Many will advocate for full inclusion but may not understand the diverse instructional needs of children who have severe and profound disabilities and medically complex conditions (Kauffman et al., 2023). It does not always matter where the child’s body is, but it does matter if the child’s physical and cognitive needs are being met through instruction and intervention, no matter where this occurs. Special education is not a place. Sometimes, inclusion is not an appropriate educational placement for a child with intellectual and medical complexities, and other options must be explored on a case-by-case basis to give the child what he or she needs (Kauffman, 2023).

There is equity when addressing the challenges this study is grounded on. Yu et al. (2020) discussed additional barriers to LRE, such as resources, geographic location, and access.

Problems can also occur when it comes to teacher preparedness and interdisciplinary team knowledge due to the small population of children identified with severe and profound disabilities and medically complex conditions (Mancini & Layton, 2004; Rehm & Bradley, 2006; Nabors et al., 2008; Lehr, 2020; McCabe et al., 2020; Vandercook et al., 2020). Parents' wishes regarding quality of life and educational expectations also function in recognizing these issues.

The purpose of this qualitative single case study was to investigate the perspectives of parents of children with severe and profound disabilities and medically complex conditions to explore their thoughts on how education impacts the quality of life for their children by looking into the opportunities their children have experienced. Cologon (2022) says investigating high quality education "requires engaging in dialogue with people who are directly impacted by the ethical and political dimensions of inclusive and segregated education," (p. 400). Efficacy research is important to the improvement of the quality of life for these children by investigating educational opportunities, barriers they face regarding the LRE and the CAP, and the parents' perspectives regarding these factors.

Children with severe and profound disabilities and medically complex conditions have chronic life limiting conditions needing continuous support and around the clock care to live (Yu et al., 2022; Rehm & Bradley, 2006). Children with severe and profound disabilities and medically complex conditions often have limited life expectancy and high rates of poor health due to neurological disorders or neurodegenerative diseases partnered with numerous comorbidities that inhibit independence, requiring a tremendous amount of critical care. This care comes from parents and caregivers in the home while also requiring a remarkable amount of support from medical specialists, nurses, related service providers and therapists, as well as family and close friends (Kuo & Houtrow, 2016; Sobotka, 2022). Children with medical complexities will often qualify for special education under one of the disability categories due to their dependence on durable medical equipment and assistive technology such as wheelchairs, standers, walkers, enteral feeding tubes, ventilators, and communication devices. Educators and administrators become part of the interdisciplinary team that cares for the child with severe and profound disabilities and medically complex conditions.

Rallison and Raffin-Bouchal (2013) discuss the gap in research on the populations of families and children with severe and profound disabilities and medically complex conditions. To fill the gap in the literature regarding this extremely small population of children, this qualitative single case study was imperative and contributed to the existing body of knowledge regarding parent perspectives of children with severe and profound disabilities and medically complex conditions. This study provides multiple parent perspectives on the quality of life of our most fragile children so educators, practitioners, and other parents can help guide interdisciplinary teams to meet their diverse needs, all while focusing on bringing joy and happiness to their lives through their educational experiences. Duc et al. (2017) focus on an interdisciplinary approach to the complex care of children with life-limiting conditions and intellectual disabilities with the goal of helping children live as well as possible for as long as possible.

This study addressed the problem statement that it was not known how parents of children with severe and profound disabilities and medically complex conditions perceived their child’s education in relation to the importance of quality of life. To address this problem of the study, it was necessary to consider parents’ perspectives and perceptions. Parents play a vital role in the lives of their children, especially if they have severe and profound disabilities and medically complex conditions. Parents are their child’s voice; they advocate for their needs and keep their child healthy by becoming primary caregivers. Therefore, they were the most qualified to contribute valuable insight into the questions being asked. Three research questions guided this study:

1. How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?
2. How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions?
3. How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life?

Information provided in Chapter 1, the introduction, included the history and background of the study, problem statement, need for the study, as well as the study's purpose. The rationale for the methodology, research design, and the definition of terms were outlined. Chapter 1 also addressed the limitations and delimitations significant to the study. Chapter 2 offered a careful review of the literature surrounding core themes of quality of life, education, inclusion, least restrictive environment, the continuum of alternate placement, barriers to access, and resources. The researcher developed a conceptual framework for this study, which is defined in Chapter 3. Chapter 3 described the methodology and research design used to conduct the study along with ethical considerations. This chapter also detailed the procedures for the case study protocol including data collection through semi structured interviews, transcription of those interviews, coding, and recoding of the data sets, and analyzing themes. Chapter 3 discussed limitations of the study such as researcher bias and validity of the data.

Chapter 4 provided a detailed explanation of the findings of this qualitative single case study leveraging thematic analysis. Chapter 4 provides a concise summary of the results of the interviews through narrative analysis categorized by the research questions and the themes that emerged from the data. Chapter 5 focuses on synthesizing the findings and drawing conclusions for interpretation and implications for further research. Chapter 5 concludes the research study.

Summary of the Study

Children with severe and profound disabilities and medically complex conditions typically have limited life expectancy and high rates of vulnerability. Children with severe and profound disabilities and medically complex conditions require an extensive amount of care and attention. To help these children, and in response to the patient centered medical home, strategies for improving quality of life have been a recent focus of the medical field (Kou & Houtrow, 2016). Commitment to the child with severe and profound disabilities and medically complex conditions goes beyond the clinical lens, and parents are not only worried about the medical concerns of their children, but they are also worried about the commitment to providing their children with an appropriate education. These children will often come to school with a nurse, durable medical equipment such as a wheelchair and a stander, and medical equipment such as feeding tubes, oxygen, medications, ventilators, and a particularly exposed vulnerability to germs. Interdisciplinary teams examine the Continuum of Alternate Placement (CAP) to make informed decisions. Least Restrictive Environment (LRE) for children with severe and profound disabilities and medically complex conditions pose barriers to educational attainment (Kauffman et al., 2023). There is value in providing these children with appropriate education.

The literature suggests that education is an important factor in the lives of children with severe and profound disabilities and medically complex conditions. Kauffman et al. (2023)

suggests that “many who promote inclusion and disability rights have argued for decades the Individuals with Disabilities and Education Improvement Act of 2004 (IDEA) does not go far enough . . .” (p. 61). Least Restrictive Environment promotes inclusion, but deciding what is best for a child is more complex than that. According to Pufpaff et al. (2015), there needs to be more research about children with complex medical needs and their care coordination in schools.

This study used a qualitative single case study methodology to investigate parent perspectives of children with severe and profound disabilities and medically complex conditions. Parents are often the primary caregivers sustaining care for their child’s critical needs for much of the day (Kuo & Houtrow, 2016; Prieto, 2022). Their perceptions were critical to answering the following research questions: (1) How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions? (2) How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions? and (3) How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child’s quality of life? These questions helped to investigate, understand, and explain participants’ lived experiences of raising children with severe and profound disabilities and medically complex conditions.

Participants were recruited through networking and snowball sampling strategies. Six parents over the age of 18 of children with severe and profound disabilities and medically complex conditions between the ages of 5-24 participated in the qualitative case study. This small sample size made it easier to narrow the focus of this study. Their participation included agreeing to participate in a semi-structured interview session via Zoom to share their stories of raising children with complex needs. IRB approval was received to ensure the protection of participants' human rights. After signed consents were collected, interviews were scheduled using Zoom. To ensure confidentiality, the participants were assigned study codes P1-P6 and were referenced as such throughout the study. Interviews were recorded and transcribed, each lasting between 30-60 minutes. The researcher utilized member checking to validate the accuracy of the transcripts with the participants.

Data was collected, coded, and categorized into themes based on the research questions. The researcher began analyzing the codes by looking for themes and trends, pulling out similarities and highlighting differences in the stories told (Saldana, 2021). Thematic analysis is important in this study because identifying themes among parent perspectives is necessary to address the research questions through patterns, categories, and concepts presented. Themes emerged in relation to the study's research questions. The researcher used direct quotes from the participants and connections to the literature to state the facts uncovered from the thematic analysis of the data. The remainder of Chapter 5 will outline the key findings, draw conclusions through interpretation of the findings, and offer implications for future research.

Findings and Conclusions

This case study seeks to tell the stories of parents' perceptions of their exceptional children living with extensive needs. Their stories lay the foundation for best practices and bridge the gaps to accessible education for children with severe and profound disabilities and medically complex conditions. This section explains the overall results associated with the research questions that guided this study. The perspectives of the six participants are explored, and a discussion of the potential implications of these findings on research, policy, practice, and stakeholders is reported. Recommendations for future research within this field of study are provided to address this important need for improvement of the quality of life of children with severe and profound disabilities and medically complex conditions and their parents. After careful review and analysis of the data collected in the study, four major themes emerged that addressed the research questions of the study. Table 5.1 defines the themes and corresponding research questions.

Table 5.1

Major Themes and Research Questions

Major Themes	Research Questions
Importance of School	How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?
Importance of Quality of Life	How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?
Giving the Child What He or She Needs	How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions?
Finding the Support Needed to Raise a Child with Severe and Profound Disabilities and Medically Complex Conditions.	How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child’s quality of life?

Research Question 1

The first research question of this study was: How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions? This research question was the guiding question of the research study and was necessary to explore the perspectives of the participants and their thoughts on the importance of school for their children. The data revealed two major themes: the importance of school and the importance of quality of life.

Theme 1: Importance of School. This emerged theme related to the need of providing children with severe and profound disabilities and medically complex conditions an appropriate education along the continuum of alternate placement. The results of this study indicated that five out of six participants shared the view that school is essential to their child’s quality of life. During review of participant data several subthemes emerged from the main theme, importance of school. The subthemes included school options and safety considerations and risks. There are a number of reasons parents who have severe and profound disabilities and medically complex conditions rely on school including the structure, consistency, routines provided to their children, access to related services such as occupational therapy and physical therapy consistently, the one on one attention provided by teachers and paraprofessionals, and the skills and new knowledge that help their children learn, (Downing & Peckham-Hardin, 2007).

In previous research, Rehm and Bradley (2005) discussed the advantages of sending children with severe and profound disabilities and medically complex conditions to school including socialization with peers and other adults, the opportunity for parents to have some respite time. During the interviews, participants spoke of the opportunities their children have being with other children and adults during school. They spoke about the connections with teachers, nurses, and therapists as well as the relationships built with other children that got to spend time with their children. Participants expressed that it’s important for their children to be able to socialize with peers and other adults, but it is just as important for those other children and adults to be around their children. Children with severe and profound disabilities and medically complex conditions can be great teachers of acceptance and the importance of inclusion.

McMahon (2014) discusses the benefits of specialized schools as having more meaningful opportunities, peers that are similar, environments and facilities that are appropriate, accessible, and safe as well as specifically training faculty and staff members that specialize in children with specific needs. Participants agreed that educational and therapeutic opportunities were crucial to the well-being of their children. Specifically, P3 shared the following:

> We always thought he had some potential and I would say once we got into the school system, we really saw what the potential could be. That really drove us to decide that we needed to do something educationally for him. I didn't want him to just sit around and not be stimulated and not grow to whatever length he could grow. He may not be a rocket scientist, but he definitely is not just a kid that needs to sit there and stare at a TV screen. So, that's what school was for us. It provided some kind of quality and growth for him.

Participants of this study agreed that it is very meaningful to have their child engaged in educational activities and therapies that will help sustain their development. Routines, consistency, quality care, stimulation, and interaction are factors that impact the well-being of their children. P3 talked about her son having swimming class, adapted physical education, and even playing soccer. These are things she never thought he would be able to do. “They've adapted everything to fit him. So, it's very important to us, because I feel like he's getting all the simulation that he wouldn't get at home” P6 also agrees that her son’s school is “truly amazing”.

> They are truly amazing; I mean what they do. And they just love the kids. He gets physical therapy there and he gets occupational therapy. There he gets vision therapy. O has cortical vision impairment. His brain is disorganized. That's why we chose that school, and I would never pull him out of there. He’s been going there since he’s been three . . .

Instruction in specialized settings attributes to the health and well-being of children with complex medical conditions requiring around the clock care from clinicians and trained caregivers or nurses. Specialized schools make nursing easier by having a number of skilled nurses available within the setting where it might be more difficult for public schools to provide such services in part due to nursing shortages (Sobotka, 2022). Participants were comforted knowing that their child was being well taken care of while at school.

Kauffman (2022) agrees that children with severe and profound disabilities and medically complex conditions should received instruction in a specialized setting, especially when it "offers a more efficient, more effective, or more dignifying opportunity to learn" (p. 112). Just because children with severe and profound disabilities and medically complex conditions should go to a specialized school does not always mean that it is an option. There are barriers such as resources, location as in geographical area, and access (Yu et al. 2020). Safety becomes an issue due to distance or rural settings. Some participants spoke of their children riding a van or a bus over an hour to get to school. P1 explains that "They have to be safe first, and that to me is paramount. Making sure that they have the supports needed to succeed in school." P3 and P6 moved closer to the city so their children would have access to a specialized school. These two participants felt the need so significant that they physically moved their families into new homes.

School is important, but for 100% of the participants, the health of their child came first. Health completely outweighed school for one of the participants. Her daughter did not attend school nor did she have instruction in the home, because it was considered too much of a risk medically. P5 discussed not sending any of her medically complex children to school because they got sick frequently and it just was not worth the risk. Even instruction conducted in the home was not the least restrictive environment for P5's daughter due to the nature of her disease. Bringing a teacher into the home meant bringing germs into the home.

Other participants agreed that their child’s medical needs will always come first and the ability to be flexible when it comes to those needs is what makes school work. P4 shared their struggle with health related restrictions with school.

> We are homebound now, ever since COVID happened, we switched to homebound [instruction in the home]. She used to go to Watson, and that was fabulous. They're such a great school, and it was nice that A got to be with her peers and do fun things that she doesn't normally get to do. But we did deal with sickness after sickness, because she's like a magnet for every possible virus out there.

Instruction conducted in the home falls under state regulations and defers to the school districts and ultimately IEP team. Students receiving instruction in the home receive a few hours per week of one to one teacher instruction. It is sometimes difficult to find a qualified teacher to commit to instruction conducted in the home as it is often an additional time commitment beyond the regular school day. P2 and P4 both agree that instruction conducted in the home is the least restrictive environment for their child. Instruction conducted in the home is when a teacher visits the home to educate the child daily or multiple times a week for approximately 5 hours a week in most cases. According to Lustig (2018) there are no guidelines of the appropriate use of home placements but that it is wonderful for those students that need it and have no other option for instruction, but it can also be a double edged sword for school districts to take the easy way out and not provide inclusive opportunities for children with complex needs.

In this study, most participants identified the need for school to be very important for several reasons including having their child stimulated and well taken care of. School is also crucial when parents are trying to function during their day to day lives. School brings some sense of normalcy to the lives of the parents and gives them the opportunity to go to work, to go to school, or even have a coffee with friends. P3 shared “I didn't want to give up my job because I felt like I would have lost myself as a person. Like, I already lose myself to some extent.” School provides that respite many parents need when caring for a child that needs medical attention 24 hours a day. Some parents choose to keep their children at home and have the support of skilled nurses for home health care. Previous research from Rehm and Bradley (2005) and Suzuki and Kamibeppu (2022) explain respite time as time away from caring for the child, it could also be time to participate in normal aspects of life such as working a job, cleaning the house, and taking care of other family matters. Rehm and Bradley (2005) aim to define “normalization in families raising children” with medical complexities (p. 811). All participants spoke of “normalcy” in their lives. While normalcy is not easy to define, it is something that participants wish to feel. P4 shared, “I think it's very important. It's just nice that she gets to do what a typical child gets to do in that sense of attending school, even if it is at home.” Having their children participate in school, being able to work or run errands, attend family functions, and even going on vacation are all things that make the participants feel normal.

“School experiences are an important part of everyday life for children and families, and the quality of these experiences may also be an important determinant” (Taheri et al., 2017, p. 1153). The analysis of data from the interviews of the six participants showed that school experiences are important to the quality of life for children with severe and profound disabilities and medically complex conditions, but this does depend on what is best for the needs of the child when considering the placement. Sometimes the importance of quality outweighs the risks of school.

Theme 2: Importance of Quality of Life. This emerged theme related to how important quality of life is to the parents of children with severe and profound disabilities and medically complex conditions. The literature reviewed in this study suggested that there is not one meaning of quality of life. According to an article by Carr et al. (2001) “definitions range from those with a holistic emphasis on the social, emotional, and physical wellbeing of patients after treatment to those that describe the impact of a person's health on his or her ability to lead a fulfilling life” (p. 1240). A strong consensus among the participants is that quality of life comes first for their children.

Participants in this study seemed to agree that quality of life had something to do with exceeding expectations by living each day to the fullest while being happy and comfortable. P4 explained it well when she spoke of what her family does.

> We try and make as many memories as possible, and taking lots of pictures. We always said you never know, even if it was her worst day, we still took pictures because we didn't know if that would be the last picture. We just try to make every day the best that we can because we get it. We know that every second counts in this journey. Good days, bad days, no matter what we still figure out how to count our blessings.

Participants talked about quality of life including doing normal things, like going on vacations to the beach, camping, or even going on cruise. Providing meaningful experiences and making memories that will last a lifetime become very important to parents raising children with life limiting diseases.

Fears become real when discussions of quality of life occur. Limited life expectancy is a reality for the children of the participants. P4 spoke of this when she said, “The reality of things weighs heavily like a dark cloud over our head that you know, these things [death] will most likely happen to our children eventually.” Providing the best care, the best education, the best of everything for their children with severe and profound disabilities and medically complex conditions is the top priority. “Indeed, children with CMC are at a high risk for acute illnesses that require inpatient hospitalization and frequent readmissions” (Bravo et al., 2020, p. 305). According to participants, sometimes taking the risk with germs to have social interaction is more valuable for quality of life for certain children and their families while others feel that social interaction is not worth the risk. P1 and P2 feel that socialization is important for their children where P4 and P5 disagree and feel that it is not worth the risk. It is fundamental to keep in mind that everyone will have different expectations and values of those expectations while on different phases of their medical journeys.

Despite the risks many stakeholders feel that attending school is a positive opportunity to increase quality of life for a child with severe and profound disabilities and medically complex conditions (Rehm & Bradley, 2006). The question goes back to the findings in Theme 1, in what capacity can these children “attend” school and how should they be educated to effectively meet their needs and provide positive quality of life in their often shortened lives? Decisions about their child’s education can be difficult. Each Family’s story is unique from diagnosis to prognosis and education falls on the continuum of importance in different places for everyone (Kou & Houtrow, 2016; Vandesande et al., 2023; Yu et al., 2020).

Research Question 2

The second research question of this study was: How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions? Unpacking that question revealed one major theme: giving the child what he or she needs.

Theme 3: Giving the Child What He or She Needs. This emerged theme related to providing the child with whatever he or she needs medically, physically, or cognitively involves looking at the whole child and how things like inclusion, communication, interaction, and sensory integration affect their quality of life. The population focused on for the purpose of this study are children that are non-ambulatory, nonverbal and have multiple disabilities and complex medical needs including durable medical equipment and life sustaining medical equipment. Those needs are intense.

These children that have medical complexities that prohibit them from speaking and making choices on their own are essentially trapped in their own bodies, being very dependent of other to meet their basic needs. They do not always have a way to express their wants and needs or even show preferences. A child with severe and profound disabilities and medically complex conditions may not be able to communicate in a way that is easily understood by others. (Rehm & Bradley, 2006). Caregivers and educators may need to develop innovative ways to communicate with these children to increase their quality of life. P3 describes a time when her son's teacher was able to provide her son with a voice.

> She's like, "I think he's trying to talk, and he's mad that like he's not getting his voice heard." So she went out and bought a microphone for his like tray. Then he would be standing in a stander, and he'd be vocalizing into the microphone because it would project his voice. He thought that was the coolest thing! Just giving him a different opportunity to be engaged kept him a little bit more interested than if he would just have to sit there and listen. He would just go to sleep. So instead, she gave him a voice.

Preferences for certain colors, objects, toys, television shows, or people bring pleasure, happiness, and even joy making a positive impact on lived experiences. Identifying preferences can help increase spontaneous communication and reduce frustration. Systematic assessment procedures could lead to more effective communication and help when setting instructional goals

(LaRue et al., 2017). All participants agreed that there were certain objects or things that their children preferred. P6 discussed a seated position her son loved. P2 talk about her son’s cat that sleeps with him. P1’s daughter needs to be warm at all times because she has trouble regulating temperature. P4’s daughter loves snuggles and cuddles. P3’s son enjoys the color red and the sound of mylar paper. P5’s daughter adored having her mother near and knew when she wasn’t. Discovering preferences contributes to quality of life.

According to Shikako-Thomas et al. (2012), being able to identify the factors associated with quality of life can help “guide program planning and the allocation of resources, thus optimizing the well-being of these children” (p. 2). Sometimes those allocations of resources include assistive technology. Eye gaze technology is an incredibly amazing way to see children with severe disabilities increase independence, illicit communication and make choices with their eyes (Blackstone et al., 2021; Lui et al., 2022). Children with severe disabilities and medically complex conditions may benefit from AAC devices. P4 talks about her daughter’s use of AAC during speech therapy.

> She does get speech every week for a half hour. She has the tablet that we got from Variety. She taps on it which sometimes she's just tapping just you know, because of a chaos kind of thing. But sometimes she actually does what she's supposed to do. And I'm like, Hmm! Wonder if you actually did that?

Limited sessions of therapies are never enough, meaning teachers, parents, and other caretakers will need to continue to implement strategies learned during these sessions to help improve the quality of life of the child (Downing & Peckham-Hardin, 2007; Milicevic, 2023).

Focusing on participatory opportunities that foster positive engagement, interactions, physical movement, sensory input, play and happiness can certainly add to quality of life (Dodds

& Rempel, 2016). Participants in this study shared that stimulation and interaction provides a substantial benefit for their children with severe and profound disabilities and medically complex conditions. For the participants that have children going to school, they appreciate the attempts made to include their children in things like holiday productions, playing on the playground, interacting with peers their own age, and participating in adapted and modified sports. For the participants that have their children at home for school, they also agreed that positive interactions with family and sometimes friends along with sensory stimulation provides their children with contentment and joy.

There are always barriers when getting children with severe and profound disabilities and medically complex conditions what they need. Barriers could include transportation, medical attention, access to resources or equipment that would make life easier or better. Participants discussed talking to insurance companies to advocate for needs. They talked about not being able to get certain medical equipment. They talked about people not always understanding the needs of their children. There is a lack of training and knowledge of students with disabilities (Blackstone et al., 2021). P1 discussed teachers and other staff struggling to provide these children with what they need simply because “they don’t know what they don’t know”. P2 discussed the lack of use of assistive technology during school sessions for her son based on the limited amount of time the teacher had to train or learn the technology in addition to creating materials for using it.

Developing environments that are accessible to people, places, things, and resources influence quality of life (Taheri et al., 2017). Having access to community recreation such as a park or playground or having access to a handicap bathroom or a one-story living space in the home can affect a child’s quality of life. Home modifications were consistently discussed among participants. If a child cannot access the stairs to get to his or her bedroom, the whole environment of the family home might need to change. Many of the participants have moved homes and uprooted lives to ensure their child has what he or she needs in the form of an accessible home. Others have made modifications and renovations such as building additional living spaces for their child, installing fully accessible bathrooms, or moving their own beds down into the family room so they can care for their child without having to worry about physical barriers such as walls or steps.

When we look at a child with severe and profound disabilities and complex medical conditions, they are like no one else in this world. No two children are alike. This means their needs are individualistic. It is critical to look at the whole child when addressing quality of life. Providing a comfortable environment, cognitive and communications skills, along with the use of assistive technology can offer children with severe and profound disabilities and medically complex conditions a sense of belonging and inclusion in the community.

These findings all come down to learning how to advocate. Advocacy is crucial for parents of children with severe and profound disabilities and medically complex conditions. It helps ensure the child receives everything they need medically, physically, mentally, emotionally, and educationally and this directly relates to the theme of finding the support needed to raise a child with severe and profound disabilities and medically complex conditions. Participants all shared stories about how they have advocated for the needs of their children and often that meant leaning on support systems to assist in advocacy.

Research Question 3

The third research question of this study was: How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child’s quality of life? The data revealed one major theme: finding the support needed to raise a child with severe and profound disabilities and medically complex conditions.

Theme 4: Finding the Support Needed to Raise a Child with Severe and Profound Disabilities and Medically Complex Conditions. This emerged theme related to the reliance on support systems, or as some may refer to “the village”. These support systems can be but are not limited to nursing, family and friends, coordination of care, and educational support. When finding the support needed, the issues and barriers seemed to also arise. Issues included those of transportation, staffing nurses and teacher preparedness, and assistive technology issues which lead to advocacy.

Caring for children with severe and profound disabilities and medically complex conditions takes a remarkable amount of support from medical specialists, doctors, nurse, related service providers and therapists as well as family and close friends (Kuo & Houtrow, 2016; Sobotka, 2022). Parents are often not medically trained professionals, instead they are moms and dads that love their children and are willing to learn how to turn their home into a hospital/make-shift intensive care unit (Kou & Houtrow, 2016; Sobotka et al., 2022; Yu et al., 2020). These families vigilantly prioritize the care of their child. Lives are centered around care of their child with severe and profound disabilities and medically complex conditions, often being the only consistent factor keeping the child alive with life sustaining treatments. Participants in this study indicated that they would be lost without their support systems.

Of the participants interviewed, four out of six have nursing services in the home to assist with the complex care of their child. P1 talks to us about her village of nurses that help care and support her four special children that she has adopted or fostered. “We have four nurses that come right now to care for our four special kids, to take them where they go during the day . . . If they don't show up, then we have to replan the day because there's somebody who doesn't have a place to go.” Parents of children with severe and profound disabilities and medically complex conditions rely heavily on nurses to support their children. It’s fundamental for P3 to have nurses as she explains, “We wouldn't be surviving if we did not have them. I think between my husband and I, we'd probably be divorced, or of killed each other.”

Family and friends are just as important as nurses. Children with severe and profound disabilities and medically complex conditions typically do qualify for nursing support, but it is not 24 hour coverage. Sometimes family and friends need to step in to support parents and their children. Over half of the participants rely heavily on the support of their family members when caring for their child with severe and profound disabilities and medically complex conditions. In other research conducted in 2013, Rallison and Raffin-Bouchal summarize a mother’s thoughts about her son’s total care by gathering that most children are going to gain independence over the years and require less and less care, but for children with medical complexities, the care becomes increasingly difficult requiring more and more with disease progression and child growth. Participants all feared the inability to be able to care for their child if he or she got too big or if something happened where they were not physically able to care for their child anymore. This is where coordination of care can come into play.

Coordination of care is often done by medical professionals. Three out of six of the participants are involved in their children’s hospital pediatric palliative care program. P3 is highly supported by care coordination through the Children’s Hospital of Pittsburgh. Her son sees the Complex Care Team and the Supportive Care Team, and they take care of all the other medical specialties for them. It saves the family time, gives them an opportunity to be present at work or at school, and provides consistent medical care all while adding to their quality of life. Duc et al.’s (2017) study provide readers with a clear picture of the intricacies of caring for a child with medical complexities while reviewing the benefits of early integration of palliative care for children with intellectual disabilities and life-limiting conditions. Four out of six parent participants agreed that palliative care teams provide support to their children and families often becoming their first call when in need. One of the participants does not have access to pediatric palliative care in her area. She feels as though her son would benefit from this care tremendously and she has become a fierce advocate in her local hospital community.

Educational Support is also part of the coordination of care and the village that supports parents raising children with severe and profound disabilities and medically complex conditions. Depending on where the family lives, school options are explored to either stay within the school district, seek specialized school, or have instruction conducted in the home (Mancini & Layton, 2014). No matter the choice, it is the home school district’s responsibility to provide services for the child. P2 argued that she wished she would have been provided and education advocate to help in understanding IEPs. As an educated woman she compared her son’s 42 page IEP to a medical-surgical journal.

Collaboration, coordination, preparedness, and delegation and delivery of care are topics explored in a study by Pufpaff et al. (2015). Collaboration is key with these interdisciplinary teams with the parent being the main caregiver and knowing the child best. Previous research conducted by Downing and Peckham-Hardin (2007) discussed the reliance on school for a number of reasons including structure, consistency, routines provided for their children, access to related services, the one on one attention provided by teachers and paraprofessionals, and the skills and new knowledge that help their children learn.

Summary. Children with severe and profound disabilities and medically complex conditions are living longer due to advances in medicine and this means that educational systems must continue to adapt to provide more appropriate and inclusive education among the continuum of alternate placements. Medical advances not only extend lifespans but can also improve the quality of life of these children through better symptom management, treatments, therapies, and advancements in assistive technology to enhance well-being and daily functions. Limited research exists when exploring these issues in educating the child with severe and profound disabilities and medically complex conditions. Attending school in any capacity on the continuum of alternate placement (CAP) provides these children the opportunity to participate, be a part of something, stay engaged, interact with others, express who they are as they socialize, and find contentment (Rehm & Bradley, 2006). The purpose of this qualitative single case study was to explore the perspectives of parents of children with severe and profound disabilities and medically complex conditions, focusing on their views regarding how education influences their children’s quality of life by examining the opportunities their children have encountered.

In addressing Research Question 1, how do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions, two major themes importance of school and importance of quality of life, emerged proving insights into how parents feel about school and quality of life for their children with severe and profound disabilities and medically complex conditions. The combined responses from participants established that school is crucial to the development and quality of life for children with severe and profound disabilities and medically complex conditions. Participants indicated that school options, opportunities for education and therapy, quality of care from teachers, nurses, and paraprofessionals, as well as knowing their child would be safe and comfortable were crucial when making decisions about where to send their children to school if at all. In regard to the importance of quality of life, consolidated responses from participants indicated that providing meaningful opportunities for their children with severe and profound disabilities and medically complex conditions ensuring happiness, contentment, comfortability, and safety were necessary to increase quality of life. The findings of the two themes importance of school and importance of quality of life supported the findings and conclusions in earlier research regarding school settings, quality of life, and least restrictive environment (Bravo et al., 2020; Carr et al., 2001; Downing & Peckham-Hardin, 2007; Kauffman, 2022; Kou & Houtrow, 2016; Lustig, 2018; McMahon, 2014; Rehm & Bradley, 2005, 2006; Sobotka, 2022; Taheri et al., 2017; Vandesande et al., 2023; Yu et al. 2020).

In addressing Research Question 2, how do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions, the data presented one major theme giving the child what he or she needs, appeared to stand out while analyzing the data. Children with severe and profound disabilities and medically complex conditions come with very diverse needs medically, physically, and cognitively. Participants shared complexities of their child’s day to day life including their care. The data from interviews indicated that all participants felt that stimulation, interaction, and engagement was essential to the quality of life of their children. Knowing their child’s needs is not often easy to figure out, but each participant reflected on the preferences of their children. This leads to the idea of parents knowing their children best. Participants indicated that there are barriers to accessing what their children need in relation to home, schools, assistive technology, medical equipment, nursing services, and continuity of care. Looking at the whole child while addressing their individual needs is an expectation participants found to be most valuable when trying to give the child access to everything that could potentially increase their quality of life. Advocacy is key. The findings of the theme giving the child what he or she needs supported findings in earlier research on the needs of children with severe and profound disabilities and medically complex conditions (Blackstone et al., 2021; Dodds & Rempel, 2016; Downing & Peckham-Hardin, 2007; LaRue et al., 2017; Lui et al., 2022; Milicevic, 2023; Rehm & Bradley, 2005, 2006; Shikako-Thomas et al., 2012; Taheri et al., 2017).

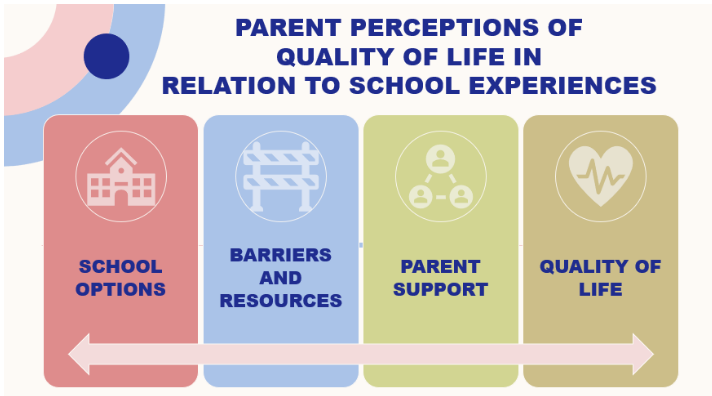
In addressing Research Question 3, how can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life, one major theme, finding the support needed to raise a child with severe and profound disabilities and medically complex conditions, revealed itself from the data gathered in this study. It takes a village to care for children referenced in this study. All participants spoke of the importance of their support systems, whether that be family members, nurses, medical professionals, school personnel. Participants indicated that they rely heavily on these support systems to get through day to day life. In finding the support needed to raise a child with severe and profound disabilities and medically complex conditions, participants indicated the magnitude of advocating for their child in regards to issues and barriers that arise. The data from the interviews show that parents' lived experiences with advocacy brings a sense of empowerment as they have such a passion for making things better for their child. Utilizing support systems, advocating for needs, and breaking down issues related to safety, care, and technologies that will improve the quality of life is all part of raising a child with severe and profound disabilities and medically complex conditions. The results of the theme finding the support needed to raise a child with severe and profound disabilities and medically complex conditions supported conclusions in earlier research on the support systems of nurses, friends and family, doctors, and schools, as well as the importance advocacy (Duc et al., 2017; Kou & Houtrow, 2016; Mancini & Layton, 2014; Pufpaff et al., 2015; Rallison and Raffin-Bouchal, 2013; Rehm & Bradley, 2006; Sobotka et al., 2022; Yu et al., 2020).

Implications

The purpose of this qualitative single case study was to explore the perspectives of parents raising children with severe and profound disabilities and medically complex conditions regarding their feelings on the importance of education in comparison to quality of life for their children. To address the purpose of this study, the researcher explored the perspectives of the parents related to their lived experiences. To conduct this study, the researcher used a qualitative methodology and a single case study design (Yin, 2018). Case study design allowed for the examination of the parent's personal accounts of their experiences pertaining to the conceptual framework of the study including school options, barriers and resources, parent support and quality of life. Figure 5.1 illustrates the conceptual framework used for this study.

Figure 5.1

Conceptual Framework



The findings of this study advanced the body of knowledge and understanding of the parent perspectives likely to help when considering the education of children with severe and profound disabilities and medically complex conditions. Furthermore, the findings of this study likely increased awareness of this low incidence population of children providing a glimpse into their lives through the stories told by the participants. This section explains practical and future implications of the study.

Conceptual Implications

The concepts in the conceptual framework that this study is built upon show that school options, barriers and resources, parent support, and quality of life are all very much intertwined among each other. One cannot talk about one without talking about the other. Essentially answering questions about one concept led to answering about another. Through the interviewing process, participants reflected on each of these concepts while answering questions about their experiences raising children with severe and profound disabilities and medically complex conditions.

The first concept of school options addressed where their child went to school. School placement was dependent upon what the local school district had to offer. Often barriers to access of specialized schools occurred causing considerations of safety outweighing the risks based on the importance of how quality of life would be affected by attending school in whatever placement was considered. The second concept of barriers and resources addressed the many factors that influenced why parents did what they did with their children. Barriers to school locations, access to specialized health care, nursing services and durable medical equipment were discussed among all six participants. The resources provided supported the children and their parents providing improved quality of life. The third concept of parent support overlaps with both the first and second concept through decision making based on those barriers and resources offered to their children. Parents need to be supported by the educational system, by family and friends and by the medical field. Being properly supported by all stakeholders increases quality of life. The fourth concept of quality of life embodies everything that is important to a person. The research study explored the impact of education, barriers to access, and supporting parents concerning quality of life for children with severe and profound disabilities and medically complex conditions.

Little research has been conducted for the children that fall into this category potentially due to the relatively small populations of children with both life-limiting conditions and intellectual disabilities. Lustig (2018) agrees that a study of this nature is needed to promote positive practice and educational policy changes. This study offered an important first step in addressing the concerns regarding educating the severely disabled and medically complex child.

Practical Implications

The results of this study confirmed that school is important to enhancing the quality of life of children with severe and profound disabilities and medically complex conditions. More significantly, the results clearly demonstrated that schools, medical professionals, and parents could benefit from the findings discussed in this study. Practitioners can learn to help support parents and families while providing what the child needs in school, at home, and in medical facilities.

Schools. School districts play a very important role in educating children with severe and profound disabilities and medically complex conditions. It becomes difficult for parents when making decisions about school placements due to what the school district can provide. Sometimes the school district cannot meet the needs of the specific child and specialized schools can be considered. As discussed before, special education is not a place. No matter where the child is being educated, whether it be in an inclusive environment in a school district building, a specialized school, or even at home, school districts assume the responsibility of that child's education.

Vandercook et al.'s research "indicates that the use of systematic instructional strategies that have long been the hallmark of effective instruction for students with severe disabilities have been used effectively in general education classrooms to support academic learning and progress" (2020, p. 65). Using systematic instructional and high leverage practices are ways to support positive outcomes that enhance development as well as social and emotional skills of children with severe and profound disabilities and medically complex conditions (Vandercook et. al., 2020). The practical implication of this finding is that the use of instructional strategies and best practices can assist in giving the child what he or she needs at school.

There are many ways to support students with complex needs. The practical implication of this finding is that school district personnel, educators, and related service providers could consider the individual needs of the child by looking at the whole child while considering their quality of life. Teachers learn through their colleagues, observing practices, and learning through experiences in determining what works best for each student. Ballard and Dymond (2018) found that research demonstrates that inclusive educational practices promote social communication development, student engagement, and diversity awareness.

Lack of teacher preparedness and comfortability in educating children with severe and profound disabilities and medically complex conditions is suspected according to Nabors et al. (2008). Eliciting responsiveness from children with severe and profound disabilities and medically complex conditions is a way to make connections and build relationships between the teacher and the child. Finding stimuli that will engage the child through preference assessment can help determine hierarchy of those preferences (Green et al., 1988, 1991). These preferences are important because they contribute to the quality of life of these children. When teachers leverage preferences during instruction and while learning about the child, comfortability can increase. Parents can also attribute sharing knowledge with teachers to help in understanding the complexities of their children. Teachers should seek out parents if they do not willingly share information.

How teachers teach and learn is currently a subject of debate. Educators can learn how to best support students through competency-based practices. Policies in education can guide action with established goals. There is a need for teacher preparation programs to address teaching low incidence disabilities to receive necessary training to support inclusivity at all levels. Downing and Peckham-Hardin (2007) discussed the need for more support, especially when expected to modify curriculum to meet diverse needs. Participants in this study agreed that not all teachers are prepared to teach their children with severe and profound disabilities and medically complex conditions to no fault of their own. Teachers are looking for ways to increase positive learning through factors such as collaboration, instructional strategies, systematic instruction, and the support of highly qualified teams (Downing & Peckham-Hardin, 2007). This could be addressed through teacher preparation programs at the university level, professional learning opportunities at the school district level, and talking with parents of the children with severe and profound disabilities and medically complex conditions at the individual level.

Data is limited on the number of students in schools with severe and profound disabilities and medically complex conditions due to the lack of federal reporting category for this population of students as outlined in Brock (2018). Court litigation has helped interpret the meaning of related services as complex health care needs for school districts, consequently they must provide the services. Consistent with other research, Lehr (2020) addresses the limited evidence and research based best practices for supporting students with severe and profound disabilities and medically complex conditions. A practical implication of this study would suggest policy change on category reporting.

Medical Professionals. This qualitative case study addressed the perspectives of parents raising children with severe and profound disabilities and medically complex conditions. Medical professionals support parents of these children, therefore it is imperative that they understand the parents’ perspectives. Participants in this study identified medical professionals such as nurses, doctors, specialists, and palliative care teams as being a vital part of their support system. A practical implication relates to the approach in which these medical professionals support the parents. Participants indicated that, at some point, they all needed to advocate for their child regarding certain medical issues.

When a child is diagnosed with a life limiting disease, support from medical providers should be imminent. A practical implication of this study would suggest that pediatric palliative care teams should be more prevalent and available to all children and parents that need them. Duc et al (2017) reviewed the benefits of early integration of palliative care for children with intellectual disabilities and life-limiting conditions. Participants in this study that were involved with pediatric palliative care indicated the importance of their support, especially regarding quality of life. Pediatric palliative care teams can equip parents and families with the necessary resources and support to enhance their child’s quality of life. There needs to be a focus on an interdisciplinary approach to the complex care of children with life-limiting conditions and intellectual disabilities with the goal of helping children live as well as possible for as long as possible (Duc et al., 2017; Yu et al., 2020).

Other Parents. Parents of children with severe and profound disabilities and medically complex conditions rely heavily on other parents in similar situations. Research of this nature could help other parents. A practical implication is that parents can support parents. P4 discussed the importance of having support from other parents during the initial diagnosis.

> Whenever you start your journey you're so lost. You have no idea who to reach out to or where to begin. And it's a slow process of finding people and finding groups and all that. So having something like that, finding different ways of where to begin, and who to reach out to, and who can be there for you to help you through everything. I know I was so lost in the beginning, and even back then, there was no Facebook groups for her diagnosis, and you know we were on our own for a while, just winging it. So you know, maybe this could be something that people can find helpful and bring awareness.

P3 went on to share that giving parents the knowledge of resources around them is empowering.

> Letting parents know that there are opportunities for their children to learn, and that they don't just have to sit at home with the nurse all day if they don't want to. There are opportunities for anybody that has any kind of ability. Even if your child does sleep all day, it's worthwhile to send them to a school because they could have physical therapy that's working with them for range of motion and doing things. There's always opportunity. I think this should help maybe guide parents to know that there are resources that they can have, and this could help them a lot sooner than what happened to me where I was struggling for a few weeks and months before I figured out what we were gonna do for J. The sooner those people get those resources and know that there's opportunities the better.

Social media, support groups, and community connections allow for networking of parents with severe and profound disabilities and medically complex conditions. Building relationships and making connections should be encouraged from the moment of diagnosis. Having someone that truly understands can bridge the gap in support systems.

Implications for Future Research

This study addressed the perceptions parents have about the education and quality of life of their children with severe and profound disabilities and medically complex conditions. This qualitative single case study demonstrated that exploring the lived experiences of parents and learning about what it is like to be a parent of child with intellectual and medical complexities could benefit many other stakeholders. The researcher used a qualitative methodology and a single case study design to conduct this study (Bloomberg, 2023; Patton, 2015; Yin, 2018). This allowed for the examination of the parents' personal accounts of their experiences, which were critical to answering the research questions that guided the study. The research had a goal of recruiting a minimum of three parent participants and a maximum of ten parent participants to validate the study. The Pediatric Palliative Care Coalition, located in Pennsylvania, assisted with recruitment by sharing a flyer that the researcher created about the study with potential participants. Through networking and snowball sampling, a total of 10 participants reached out to researcher via email and ultimately six consented to be participants. This smaller sample size could have reduced the generalizability of the study's results. A future study replicating this research and utilizing the interview semi-structured protocol (Appendix D) could include a much larger sample size from this low incidence population of children with severe and profound disabilities and medically complex conditions. A study such as this could substantiate the findings in this study.

This study applied a case study design rooted in qualitative research methods and was limited to a small number of parent participants located in the state of Pennsylvania. A possible future study could consider more parent participants from across the nation or even world to truly explore parent perspectives from different geographical locations. While this study did not consider gender as a variable, all the participants were women, more specifically, mothers. There is no evidence to indicate that this limitation had any impact on the results of the research, but including men, or fathers, in a future study could open up the perspectives and experiences shared. Fathers' voices in future studies could expand the data set.

To further triangulate data, researchers may want to consider developing a survey that is quantitative in nature. Quantitative research could strengthen and support this qualitative research single case study. Quantitative data could provide a broader context by providing statistical information about a larger sample size to make the findings generalizable. Using both quantitative and qualitative methods allows for triangulation, which can enhance the trustworthiness and validity of the findings.

This study adds to the very limited number of research studies associated with educating the child with severe and profound disabilities and medically complex conditions. There are so many ways to support students with complex needs. Additional research would be helpful for educators working with students with complex supports needs by exploring the effectiveness of strategies. Evidence based practices, special supports such as assistive technology, and interventions should be further investigated to learn more about supporting the needs of the whole child.

Research should also be conducted in program development for children**.** Future researchers could consider integrating the findings in this study to develop a resource or a tool for parents, teachers, or practitioners providing them with knowledge when working with a child with severe and profound disabilities and medically complex conditions. Pufpaff et al. (2015) agree with others that have reported, there is minimal research about children with complex medical needs and their care coordination in schools.

It has been suggested that further research focus on the identification of evidenced-based practices that lead to safe and successful education outcomes for this vulnerable population of students is critical. Evidence-based practices could also pertain to medical outcomes. Children are living longer and there has been a focus on quality of life in the medical field. (Kuo & Houtrow, 2016; Yu et al., 2020). Further research on parent perspectives of quality of life could contribute to medical advancement.

Summary

Commitment to a child with severe and profound disabilities and complex medical conditions extends beyond the clinical perspective. All six parent participants from this study are concerned not only with medical issues but also with ensuring their child has a meaningful quality of life. When confronted with a life-limiting diagnosis for their child, some may assume that education is not a priority. While this is true in some cases, many parents recognize the importance of educating their child and have various reasons for focusing on this aspect despite the challenges.

Exploring the concept of high quality education necessitates engaging in dialogue with individuals directly affected by the aspects of inclusive education (Cologon, 2022). The case study approach the researcher employed enabled parent participants to convey their individual perspectives of the experiences their children have had with education and how that relates to quality of life. Data in this study was gathered through semi-structured interviews recorded via

Zoom. To triangulate the interviews, the interview data was analyzed against literature reviewed, transcriptions were member checked, and critical colleagues were employed. The findings in this study were supported as such to increase the trustworthiness of the conclusions made with alignment of the qualitative single case study design of research (Bloomberg, 2023; Patton, 2015; Yin, 2018).

The findings and conclusions of this study significantly reflect the perceptions of the parent participants. When applying thematic analysis of the interview data, the researcher was able to group data into categories and themes, but while doing so found that one theme impacted the other. The conceptual framework on which this study was built is completely intertwined into each research question. The research questions do not stand alone. They are answered by each other and by the themes and conclusions presented in this study. What does that say about the relationship between the research and the participants? The lived experiences of the participants guided the findings and conclusions by comparing their stories to those who have also lived similar experiences. Sharing these stories contributed to a deeper understanding and richer context for the research, emphasizing the importance of participant narratives in shaping the study’s findings and conclusions (Bloomberg, 2023; Yin, 2018). This approach highlights the collaborative nature of the research, where participants are not merely subjects, but active contributors, whose insights are integral to the development of meaningful and authentic implications.

Deeply rooted in history, the implications of the 1975 Education for All Handicapped Children Act, U.S.C. § 1400 later reauthorized as the 2004 Individuals with Disabilities Education Improvement Act, U.S.C. § 1400, continue to significantly influence today’s educational landscape ensuring that children with disabilities have access to free and appropriate education (FAPE) in the least restricted environment (LRE). Parents have a significant role in the educational planning process for their children. Due to stumbling blocks, barriers, and unknowns this remains difficult for parents and other stakeholders to make decisions about their child's education and the importance of it related to quality of life.

How does this get easier for families? The themes of this research study imply just that. All stakeholders should recognize that school is important, that quality of life is vital, that meeting a child's physical, medical, and cognitive needs are essential, and that parents need to be supported while navigating life with their child that has severe and profound disabilities and medically complex conditions. It should be easier for parents of children with severe and profound disabilities and medically complex conditions to get what they need and what they should have because legally they are required to receive a free and appropriate public education. The hope is that research of this nature can lay the foundation for more inclusive and equitable educational practices promoting the rights and opportunities of students with severe and profound disabilities and medically complex conditions while shaping the policies and frameworks that continue to guide special education today.

Chapter 5 concludes this research study. The findings revealed four themes: (1). The importance of school, (2). The importance of quality of life, (3). Giving the child what he or she needs, (4). Finding the support needed to raise a child with severe and profound disabilities and medically complex conditions. Recommendations invite all stakeholders to contribute positively to the lives of children with severe and profound disabilities and medically complex conditions by fostering a supportive and inclusive environment. This may include advocating for educational programs, safeguarding access to specialized schools or medical care, promoting social opportunities, and encouraging advocacy. By working together, stakeholders can help create a network of support that addresses the unique needs of these children, enhancing their quality of life and promoting their overall well-being.

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APPENDIX A: RECRUTIMENT FLYER

ATTENTION

PARENTS (18+) OF CHILDREN WITH MEDICAL COMPLEXITIES

CHILDREN AGES 5-24 YEARS

WANT TO SHARE YOUR STORY?

ZOOM INTERVIEW OPPORTUNITY!

RESEARCH STUDY:

THE PURPOSE OF THE STUDY IS TO EXPLORE THE STORIES OF CHILDREN WITH SEVERE AND PROFOUND DISABILITIES AND MEDICALLY COMPLEX CONDITIONS THROUGH THE PARENT PERSPECTIVE SPECIFICALLY LOOKING AT THE ROLE SCHOOL PLAYS IN THEIR CHILD'S QUALITY OF LIFE.

EMAIL IF INTERESTED IN PARTICIPATING

CASSIE GRASSMYER
CMG1037@SRU.EDU

DR. JESSICA HALL-WIRTH
JESSICA.HALL-WIRTH@SRU.EDU

SCAN ME

APPENDIX B: EMAIL TO PARTICIPANTS

Email to Participants

Hello all. My name is Cassie Grassmyer, and I am a co-investigator conducting a research study for a doctorate program. I am looking for parents 18 years of age or older of children ages 5-24 with severe and profound disabilities and medically complex conditions to complete a one-to-one interview.

Things you should know:

- The purpose of the study is to share the stories of the lived experiences of parents caring for children with severe disabilities and medical complexities, paying close attention to quality of life and the importance of education in the lives of these families. There is limited research on this population of children and many others will benefit from the information shared.
- All people who choose to voluntarily participate in this study will be asked to provide contact information to the co-investigator.
- The interview will take approximately 1 hour.
- This interview will take place virtually via Zoom for accessibility purposes.
- The risks involved in this study are very minimal. The identity of the interviewees will be kept confidential by assigning a number as an identifier rather than a name. In addition, each participant will have the opportunity to consent at the time of the interview and will be allowed to withdraw from the interview process at any time without repercussion.
- This study will seek to understand the lived experiences of these families. Although the participants may not directly benefit from the study, many stakeholders may benefit including teachers, special educators, administration, supervisors, related service providers, therapists, social workers, nurses, doctors, and other medical professionals as well as parents, families, and children with severe disabilities and medical complexities.
- This study is completely voluntary.

If you are interested, please read the attached Consent to Participate and respond to the co-investigator via email.

Thank you for your help and support!

Cassie Grassmyer (co-investigator)
cmg1037@sru.edu

Dr. Jessica Hall-Wirth (principal investigator)
jessica.hall-wirth@sru.edu

APPENDIX C: CONSENT TO PARTICIPATE IN RESEARCH

SlipperyRock University

Approved
2/23/2024
Slippery Rock University
Institutional Review Board

College of Education
Departments of:
Counseling and Development
Elementary Education/Early Childhood
Physical and Health Education
Secondary Education/Foundations of Education
Special Education

CONSENT TO PARTICPATE IN RESEARCH

Educating the Severely Disabled Medically Complex Child: A Case Study on Parent Perspectives

Cassie Grassmyer – Co-Investigator
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Dr. Jessica Hall-Wirth – Principal Investigator
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Invitation to be Part of a Research Study

You are invited to participate in a research study. In order to participate, you must be a parent age 18 or older of a school-aged child (ages 5-24) with severe and profound disabilities and medically complex conditions. Taking part in this research project is voluntary.

Important Information about the Research Study

Things you should know:

- The purpose of the study is to explore the stories of children with severe and profound disabilities and medically complex conditions through the parent perspective specifically looking at the role school plays in their child's quality of life.
- If you choose to participate, you will be asked to partake in a recorded interview via Zoom that will take approximately 1 hour.
- Risks or discomforts from this research include emotional conversations about caring for your child. These conversations may open up old wounds. In general, the risks to this study are very minimal. All information and data collected will be kept confidential.
- The study will not have any direct benefits, but participants may indirectly benefit from the conversations had during the interview process.
- Taking part in this research project is voluntary. You do not have to participate, and you can stop at any time.

Please take time to read this entire form and ask questions before deciding whether to take part in this research project.

What is the Study About and Why are We Doing it?

The purpose of the study is to share the lived experiences of parents caring for children with severe and profound disabilities and medically complex conditions. This study aims investigate school experiences for children with severe and profound disabilities and medically complex conditions specifically looking into the opportunities that these children have that effect quality of life from the perspectives of parents. Parent perspectives play a vital role in the lives of children with medical complexities. As disclosed in 1989 Timothy W. v Rochester, New Hampshire School District, all school districts must provide special education to students in need regardless of severity of disability. Timothy's parents fought for his right to be included in education even though it was deemed that he was not capable of learning. Parents are their child's voice and advocate especially for children that have communication barriers. In addition to keeping their children healthy by becoming the primary caregivers, it is also the responsibility of the parents to help break down those barriers to enhance their child's quality of life. Little research has been conducted for the children that fall into this category potentially due to the relatively small populations of children with both life-limiting conditions and intellectual disabilities.

What Will Happen if You Take Part in This Study?

If you agree to take part in this study, you will be asked to complete a letter of consent and participate in an interview with the co-investigator. The interview will take approximately 1 hour via Zoom. The interview will be recorded and transcribed by the co-investigator. The transcriptions will be shared with you for review via email.

The co-investigator may also ask if you have any documents you are willing to share about your child, such as an IEP, doctor notes, or evaluations from related service providers. This is completely voluntary and if you are not comfortable sharing documents, do not feel pressured to do so. There may also be follow up emails between the co-investigator and participant that could be useful in the study.

Some of the interview questions might be triggers for emotions that you have endured or may encounter in the future. You may be asked to share the story of your child's diagnosis, discuss quality of life, and educational barriers your child may face. Research will be shared with all participants at the end of the study.

How Could You Benefit From This Study?

Although you will not directly benefit from being in this study, others might benefit because sharing your lived experience through case study research. There is little research on children with severe and profound disabilities and medically complex conditions. There is even less research on how school impacts quality of life for this population of children. Sharing your stories will help stakeholders such as teachers, principals, administrators, therapists, doctors, nurses, and other parents in similar situations.

What Risks Might Result From Being in This Study?

You might experience some risks from being in this study. The risks are minimal but might include some feelings of emotions causing you to remember things that make you sad or angry while sharing your (and your child's) story during the interview conversations. The co-investigator is a bereaved mother of a child with severe and profound disabilities and medically complex conditions. She will act with empathy and respect all things related to this study, your family, and your child(ren). Any discomfort you feel will hopefully be minimized with this prior knowledge. If needed, you will be provided with contact information for counseling resources.

For informational risks (e.g., those involving breach of confidentiality), the co-investigator will protect the data before, during, and after collection. The data will be stored on a password protected computer or in a lock box in the co-investigator's home office.

How Will We Protect Your Information?

We plan to publish the results of this study. To protect your privacy, we will not include information that could directly identify you unless you choose to be named in the research. We will protect the confidentiality of your research records by giving you a participant code name. Your name and any other information that can directly identify you will be stored separately from the data collected as part of the project. Only the co-investigator and you the participant will know the participant code name.

The results of this study may be published or presented at a conference. The researcher(s) will ask for separate written permission to include your name, or pictures, recordings, or other information that could identify you. If you wish to be identified in a publication or presentation, including photographs, audio or video recordings please indicate that on the consent form. This decision can be made at a later date and can be changed at any point in time during the study. Deciding to share or include your identity in the research will have no effect on the study. It is important to realize that this is completely optional.

If you are not comfortable with revealing your identity, we will only use the participant code and no other pictures or audio/video recordings that could identify you as the participant.

What Will Happen to the Information We Collect About You After the Study is Over?

We will not keep your research data to use for future research or other purposes. Your name and other information that can directly identify you will be kept secure and stored separately from the research data collected as part of the project when possible. Your name and other information that can directly identify you will be deleted from the research data as part of the project completion.

How Will We Compensate You for Being Part of the Study?

There will be no compensation for being part of this study.

Your Participation in this Research is Voluntary

It is totally up to you to decide to be in this research study. Participating in this study is voluntary. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer. If you decide to withdraw before this study is completed, any data provided will be destroyed.

Contact Information for the Study Team and Questions about the Research

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

Cassie Grassmyer – Co-investigator at cmg1037@sru..edu or by phone at (814)312-4377 or
Dr. Jessica Hall-Wirth – Investigator at jessica.hall-wirth@sru.edu or by phone at (724)738-2856

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:

Institutional Review Board
Slippery Rock University
104 Maltby, Suite 302
Slippery Rock, PA 16057
Phone: (724)738-4846
Email: irb@sru.edu

Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. 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 understand that I can withdraw at any time. A copy of this signed Consent Form has been given to me.

______________________________	______________________________	________
Printed Participant Name	Signature of Participant	Date

By signing below, I indicate that the participant has read and to the best of my knowledge understands the details contained in this document and have been given a copy.

______________________________	______________________________	________
Printed Name of Co-Investigator	Signature of Co-Investigator	Date

Photo Audio/Video Recording Release Form:

We request the use of photographic, audio, and video recorded material of you as part of our study. We specifically ask your consent to use this material, as we deem proper, specifically, for news releases, professional publications, websites and pictorial exhibits related to our study. We also emphasize that the appearance of these materials on certain media (websites, professional publication, news releases) may require transfer of copyright of the images. This means that other individuals may use your image. Regarding the use of your likeness in photographs, audio and video recording, please check one of the following boxes below:

☐ **I do** give unconditional permission for the investigators to utilize photographic and audio/video recordings of me.

☐ **I do not** give unconditional permission for the investigators to utilize photographic and audio/video recordings of me.

______________________________	______________________________	________________
Print Name	**Participant Signature**	**Date**

PLEASE NOTE: Should you choose not to allow your image or voice to be used, we can still benefit from your inclusion as a research study participant.

APPENDIX D: INTERVIEW PROTOCOL

Interview Questions: (Semi-Structured Open-Ended Questions)

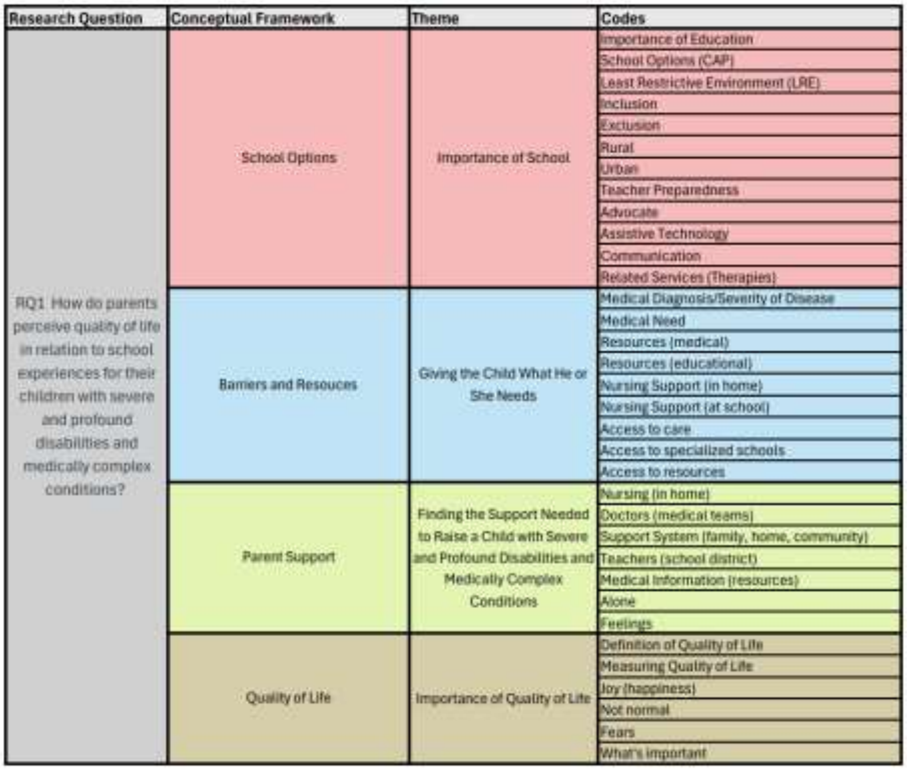
Research Questions	Interview Questions
4. RQ 1 How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions? **5. RQ 2 How do communication, interaction, sensory integration and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions?** ○ **RQ3 How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision-making process affecting their child's quality of life?**	**Everyday life situations – day to day.** • Tell me about yourself. • Tell me about your child. • Can you describe what a typical day looks like for you? • What is your current work/life situation? What does your support system look like? • What happens if your support does not show up? • What resources have you found to help you manage life with a child with medical complexities and how were they (the resources) made available to you? **School** • How important is school to you (as parent)? • Where does your child go to school? • What are your expectations for your child's education? • What brought you to the decision to either send your child to school or keep your child at home? • What risks are involved in attending school for your child (whether that be in a school setting or in the home)? **Inclusion** • How would you define inclusion/exclusion? • Is inclusion important to you and your family? Why/Why not?

	• Can you describe an experience of inclusion and how it impacted your child or family? • Can you describe an experience of exclusion and how it impacted your child or family? • What barriers have you run into when trying to access education and support for your child? • What did you do to overcome those barriers? • What would have helped you most when exploring resources for your child? • What would you hope to be available that might improve this overall process? • Do you feel supported within your school community? **Quality of life** • How do you define quality of life? • How do you measure quality of life? • How do you maintain and improve quality of life? • What is important to you regarding the quality of life of your child? • How does your quality of life differ from your peers? • What are your fears? • What brings you (and your child) joy? • How can research of this nature help you or parents in similar situations?

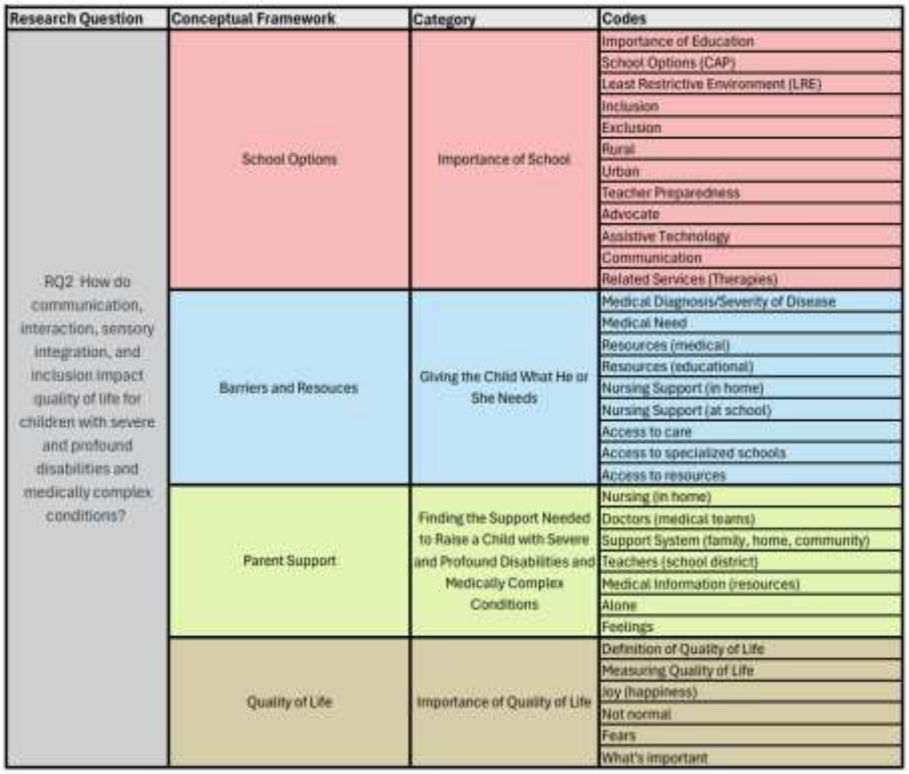
Other Data Collection:

- Interviews will be audio/video recorded using the application Zoom.
- Documents such as individual education programs (IEPs), doctors notes, or medical documentation that participants are willing to share will be collected via email.
- Email correspondence with participants will be documented.
- A fieldwork journal will be used to take notes.

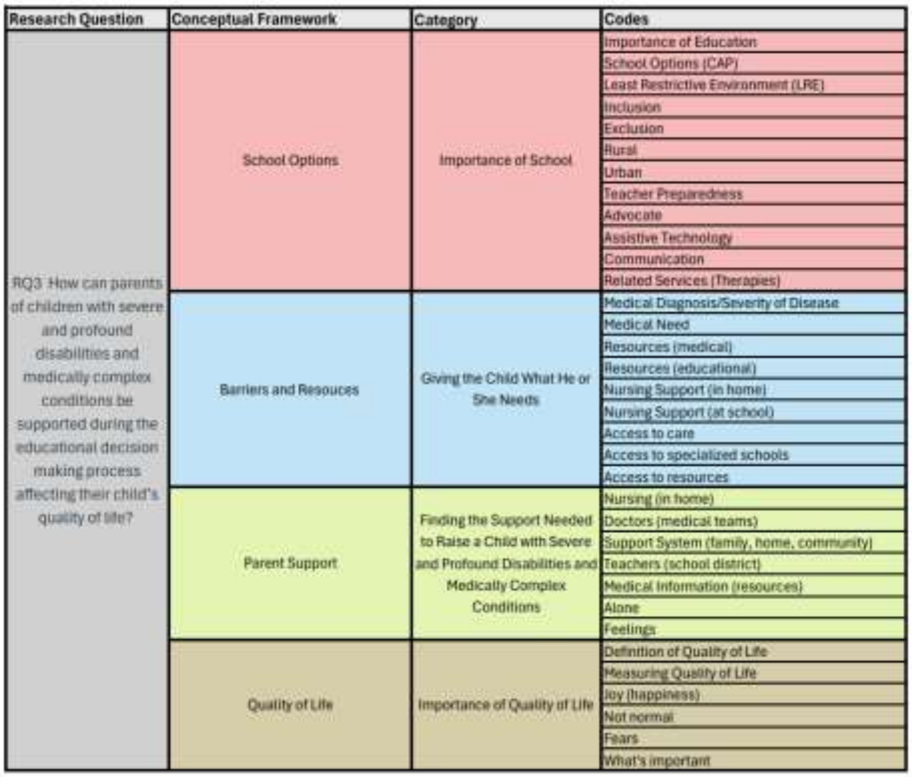
APPENDIX E: DATA ANALYSIS SPREADSHEETS



Research Question	Conceptual Framework	Theme	Codes
RQ1 How do parents perceive quality of life in relation to school experiences for their children with severe and profound disabilities and medically complex conditions?	School Options	Importance of School	Importance of Education
			School Options (CAP)
			Least Restrictive Environment (LRE)
			Inclusion
			Exclusion
			Rural
			Urban
			Teacher Preparedness
			Advocate
			Assistive Technology
			Communication
			Related Services (Therapies)
	Barriers and Resouces	Giving the Child What He or She Needs	Medical Diagnosis/Severity of Disease
			Medical Need
			Resources (medical)
			Resources (educational)
			Nursing Support (in home)
			Nursing Support (at school)
			Access to care
			Access to specialized schools
			Access to resources
	Parent Support	Finding the Support Needed to Raise a Child with Severe and Profound Disabilities and Medically Complex Conditions	Nursing (in home)
			Doctors (medical teams)
			Support System (family, home, community)
			Teachers (school district)
			Medical Information (resources)
			Alone
			Feelings
	Quality of Life	Importance of Quality of Life	Definition of Quality of Life
			Measuring Quality of Life
			Joy (happiness)
			Not normal
			Fears
			What's important



Research Question	Conceptual Framework	Category	Codes
RQ2 How do communication, interaction, sensory integration, and inclusion impact quality of life for children with severe and profound disabilities and medically complex conditions?	School Options	Importance of School	Importance of Education
			School Options (CAP)
			Least Restrictive Environment (LRE)
			Inclusion
			Exclusion
			Rural
			Urban
			Teacher Preparedness
			Advocate
			Assistive Technology
			Communication
			Related Services (Therapies)
	Barriers and Resouces	Giving the Child What He or She Needs	Medical Diagnosis/Severity of Disease
			Medical Need
			Resources (medical)
			Resources (educational)
			Nursing Support (in home)
			Nursing Support (at school)
			Access to care
			Access to specialized schools
			Access to resources
	Parent Support	Finding the Support Needed to Raise a Child with Severe and Profound Disabilities and Medically Complex Conditions	Nursing (in home)
			Doctors (medical teams)
			Support System (family, home, community)
			Teachers (school district)
			Medical Information (resources)
			Alone
			Feelings
	Quality of Life	Importance of Quality of Life	Definition of Quality of Life
			Measuring Quality of Life
			Joy (happiness)
			Not normal
			Fears
			What's important



Research Question	Conceptual Framework	Category	Codes
RQ3 How can parents of children with severe and profound disabilities and medically complex conditions be supported during the educational decision making process affecting their child's quality of life?	School Options	Importance of School	Importance of Education
			School Options (CAP)
			Least Restrictive Environment (LRE)
			Inclusion
			Exclusion
			Rural
			Urban
			Teacher Preparedness
			Advocate
			Assistive Technology
			Communication
			Related Services (Therapies)
	Barriers and Resouces	Giving the Child What He or She Needs	Medical Diagnosis/Severity of Disease
			Medical Need
			Resources (medical)
			Resources (educational)
			Nursing Support (in home)
			Nursing Support (at school)
			Access to care
			Access to specialized schools
			Access to resources
	Parent Support	Finding the Support Needed to Raise a Child with Severe and Profound Disabilities and Medically Complex Conditions	Nursing (in home)
			Doctors (medical teams)
			Support System (family, home, community)
			Teachers (school district)
			Medical Information (resources)
			Alone
			Feelings
	Quality of Life	Importance of Quality of Life	Definition of Quality of Life
			Measuring Quality of Life
			Joy (happiness)
			Not normal
			Fears
			What's important