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Caregivers' Experiences Supporting the Transition to Adulthood of Adolescents with Acquired Intellectual Disability

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Abstract

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BA, Clark Atlanta University, 1991

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Transitioning to adulthood can be challenging for adolescents with acquired intellectual disability (caused through an accident, brain injury, neglect, or health condition) and their caregivers. The purpose of this study was to examine lived experiences of caregivers who cared for adolescents with acquired intellectual disability during their transition into adulthood. This study used the phenomenological qualitative design guided by the social support theory. Three research questions were asked: what do caregivers of an adolescent with acquired intellectual disability experience as they support the adolescent's transition to adulthood, how do caregivers of an adolescent with acquired intellectual disability experience social support for their caregiving role in the adolescent's transition process to adulthood, and how do caregivers of an adolescent with acquired intellectual disability experience the development and implementation of the adolescent's transition plan. Eleven caregivers were recruited using criterion sampling from online caregiver support groups. Interviews were conducted with participants. NVivo was used to manage and analyze data. Three themes were identified: knowledge and meaning of caregiving, transition plan development and implementation experience, and social support systems. Caregivers expressed the need to receive support for their roles. They appreciated informal support from family and friends and they wanted more formal support from school and medical staff. Primarily, they desired communication throughout the transition process. This research will contribute to positive social change by highlighting what this subset of caregivers' needs are for their support roles and development of targeted interventions based on those needs.

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Dedication

This dissertation is dedicated to my loved ones and friends who have poured into my life over the years and especially throughout this process. To my mother Barbara J. Brooks, you have been my biggest supporter and my greatest champion. When you were scared, you pushed me to be fearless and unafraid. When you cried, you encouraged me to laugh. When you were doubtful, you taught me to be assured. When you felt you had no voice, you insisted that I sing. When you were in a dark place, you placed me in the light. Yet, when I was weak, you were strong. You say that I have done things that you have never thought of. I say I have done these things because you dreamed big dreams for me. I love you, Mom!

To my aunt Alice Daniels, God made you for me. You have chastised me when I needed it. You have given me your shoulder to cry on. You have listened to me and been the keeper of many secrets. You have provided a safe space to share free of judgement. I admire your spirit and I hope you are proud of me.

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Dr. Jeanne Connors, what can I say? A resounding THANK YOU for getting me across the finish line!

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Chapter 1: Introduction to the Study

Intellectual disability, formerly known as mental retardation, is one of several developmental disabilities (Zablotsky et al., 2020). Intellectual disability affects approximately 2% of the population (Hotez, 2021). Diagnoses can range from mild, moderate, and severe to pervasive. It can also be considered unspecified. Eighty-five percent of people with intellectual disability are in the mild range, and males are diagnosed more often (Melvin et al., 2022). Intellectual disability is characterized by having low intellectual functioning as indicated by an intelligent quotient (IQ) of less than 75 as well as problematic adaptive behavior such as limited social skills that is diagnosed prior to the age of 18 (Tassé & Grover, 2021). Acquired intellectual disability is acquired after birth. It can be caused through an accident, brain injury, neglect, or health condition (Patel et al., 2020). Epilepsy and meningitis are specific examples of health conditions that have been related to acquired intellectual disability (Bekiesinska-Figatowska et al., 2020; Perez et al., 2023).

There is little information about caregivers supporting adolescents with acquired intellectual disability through the transition process. These caregivers need to be given the opportunity to explicitly share and describe their experiences. Supporting a child with a disability at this stage of life is complex and may introduce obstacles that are not easily addressed without support (Boehm, 2021; Sanderson et al., 2020; Sharma & Subedi, 2022).

Raising a child with a disability is more demanding than parenting a child without a disability (Auriemma et al., 2021; Rafferty et al., 2020). Some challenges of

shepherding youths with intellectual disabilities into adulthood include increased stress, financial burden, and burnout (Lee et al., 2022; van Beukering et al., 2021). Based on literature, lived experiences of caregivers providing care for adolescents with acquired intellectual disability have not been sufficiently explored.

This chapter includes the background, problem statement, and purpose of the study as well as an overview of the theoretical framework, definitions, assumptions, scope, and delimitations. Research questions along with the nature and significance of the study are stated.

Background

Nearly 13% of the U.S. population has a disability, with 6.5 million people having intellectual disability (Houtenville et al., 2021). Intellectual disability is the most common type of developmental disability (McConkey & Menke, 2020). Causes include genetic malformations, complications during pregnancy or during the birthing process, or problems after birth involving disease or poverty (Ţarcă et al., 2021). There is no cure for intellectual disability, making some level of support necessary throughout the life course. Caregivers such as parents, siblings, and friends are most often responsible for providing needed support.

Transition research on adolescents with a disability to explore various angles of the process was conducted. Boehm (2021) found faith positively impacted family quality of life (FQOL) and dissatisfaction with emotional and instrumental support needs has a negative impact. They suggested needs of caregivers be identified and tailored as appropriate. Culnane et al. (2022) found caregiver burden was linked to level of unmet

needs of adolescents and suggested interventions be developed to reduce the burden on caregivers.

Fernandez-Avolos et al. (2020) suggested self-determination life skills be taught early and often and parents should be supported in developing these skills in their children.

Ee et al. (2021) found caregivers of persons with intellectual disabilities required support more than others and needed to be more aggressive in terms of pursuing support services. Communication affects perceptions of support (ee et al., 2021). According to Duis et al. (2022), caregivers and adolescents with intellectual disability perceived burdens to be extreme and experienced dissatisfaction with provider services at the time of transition from pediatric care. Better support for caregivers at the time of transition can be used as a strategy to improve outcomes and lessen burdens (Duis et al., 2022).

Kruithof et al. (2021) noted people with disabilities have poorer health-related outcomes. Some disparities are preventable, and caregivers often lack appropriate resources (Kruithof et al., 2021).

King et al. (2020) found parents caring for children with traumatic brain injuries felt ill-equipped and abandoned after leaving hospital care. Coordination of healthcare, information support, and emotional support were most needed (King et al., 2020). Needs of parents that occur after the event should be regularly assessed because they may change (King et al., 2020).

Hotez (2021) found service systems must be comprehensive, practical, and easily accessible. Hotez posited assessing needs of caregivers is critical to developing effective service plans and avoiding out-of-home living arrangements.

Problem Statement

Nearly 3% of the U.S. population has an intellectual disability (Patrick et al., 2020). Intellectual disability is defined as having an issue with cognition associated with a below-average IQ of less than 75 and adaptive behavioral issues that present before age 18 (Kruithof et al., 2021). Children with intellectual disability eventually become adults with intellectual disability who are still in need of various caregiver supports (Hegedus, 2022). Whether an adolescent with intellectual disability lives inside or outside of the home, their caregivers are typically with them throughout the transition process from adolescence to adulthood (Kokolo, 2022).

The transition process to adulthood is often complicated for caregivers and adolescents, causing them to need and seek support (Machalicek et al., 2022). A dearth of research exists on experiences of caregivers of adolescents who are born with intellectual disability; based on literature, scant research exists on experiences of caregivers of adolescents with acquired intellectual disability. Understanding caregivers' experiences is critical to identifying their needs and providing adequate support in their caregiver roles (Zablotsky et al., 2020). Needs of caregivers of adolescents with acquired intellectual disability during the transition process may be different from support needs of caregivers of adolescents who are born with intellectual disability. Potential differences may leave them ill-prepared to facilitate the transition process without adequate support. I explored

how caregivers of adolescents with acquired intellectual disability experienced their caregiving roles through the transition process, perceived support, and development and implementation of transition plans for young adults in their care.

Purpose of the Study

The purpose of this phenomenological study was to investigate lived experiences of caregivers of adolescents with acquired intellectual disability as they transition from adolescence to adulthood. Phenomenology is a qualitative research approach that involves understanding and describing the essence of human experiences as perceived by participants (Park et al., 2021). The research design for this study was qualitative and specifically phenomenological, aiming to explore rich and detailed narratives of caregivers. In-depth interviews were chosen as the data collection method for in-depth explorations of participants' experiences in their own words. Additionally, these interviews facilitated direct interactions between myself and participants, allowing for immediate clarification.

Research Questions

The following research questions were used to guide this study:

RQ1: What do caregivers of adolescents with acquired intellectual disability experience as they support adolescent transitions into adulthood?

RQ2: How do caregivers of adolescents with acquired intellectual disability experience social support for their caregiving role during the adolescent transition process to adulthood? RQ3: How do caregivers of adolescents with acquired intellectual disability experience development and implementation of adolescent transition plans?

Conceptual Framework for the Study

The social support theory was used as the theoretical framework. This theory involves dynamics of social relationships, encompassing two primary constructs: social integration and functional support. Social integration refers to the degree of participation or position among one's relationships, while functional support concerns effective aid that is received as compared with perceived assistance from individuals requiring help (Lee et al., 2021). Social support, which is associated directly with improving health outcomes, is an interactive communicative process that enhances deliverability of appropriate support. It has been used as a lens to study experiences and needs related to transition. It has also contributed to the study of stress management, coping strategies, and health problems.

Cook and Hole (2021) found parents of adolescents with severe intellectual disabilities may be vulnerable to alterations in their informal social support networks. They suggested researchers who investigate families of children with intellectual disabilities should use multiple measures of social support in their studies to offer a more complete understanding of caregivers' experience.

Nature of the Study

In this study, I used a qualitative phenomenological research design. The qualitative approach was used for a deeper exploration of the topic. Understanding caregivers needs, how they access and experience supports to address their needs, and how they implement support is important to know when seeking to develop appropriate programs and policies for this population of caregivers.

Definitions

Adolescent: A youth between the ages of 14 and 22. This study involved exploring caregiver experiences of adolescents in this age range who have an acquired intellectual disability.

Adulthood: According to the Individuals with Disabilities Education Act (IDEA), adolescents become adults at 22 (Campas, 2023). The transition plan ends at that point, and the young adult is responsible for their wellbeing.

Caregiver: A family member, extended family member, or friend of an individual with a disability who helps the person with daily activities (Burke et al., 2021). In this study, caregiver refers to someone serving as the primary person caring for or providing support for adolescents with acquired intellectual disability as they transition to adulthood.

Individualized education plan (IEP): Educators are mandated per the IDEA to develop an IEP for students with a disability as early as 14 but no later than 16 (Mello et al., 2020). The plan is typically developed in collaboration with students and their parents. It is used to guide the transition process to adulthood and is based on students' needs and desires.

Intellectual disability: A mental condition affecting intellectual functioning and adaptive behavior which occurs before age 18. Intellectual functioning is characterized by having an intelligence quotient of less than 75 and difficulty involving adaptive behaviors such as social skills. It is a disability that is characterized by significant limitations in

intellectual functioning and adaptive behavior, hindering everyday social and practical skills (Jenaro et al., 2020).

Transition: The process of moving from childhood to adulthood. Transition goals are commonly set involving employment or secondary education, independent living, social life, and health (Patrick et al., 2020). Individual needs and desires define success.

Assumptions

For this study, I assumed participants responded honestly to all questions and conveyed their experiences openly, efficiently, and effectively. Medical records were not reviewed; therefore, I assumed participants accurately reported their adolescents' diagnoses. Additionally, in-depth interviews are considered a valid form of data collection when using a qualitative research approach.

Scope and Delimitations

I focused on 11 caregivers of adolescents with acquired intellectual disability who were transitioning to adulthood. A small number of participants is appropriate when using a phenomenological research approach. Participants had to have been currently or previously responsible for a youth between 14 and 22. This age group was chosen because the IDEA suggested transition plans be developed and implemented as early as 14 but no later than 16 and last until 22 (Mello et al., 2020). This allowed for caregiving to be explored during various stages of the transition process from high school and college to employment.

Limitations

I only examined experiences of caregivers of adolescents between 14 and 22 with acquired intellectual disability. Other than interview and data collection activities related to this study, no previous or ongoing contact occurred with participants. Additionally, I am the parent of a young adult with a brain tumor; however, he has never been diagnosed with intellectual disability. To control my biases, I employed the commonly used strategies of keeping a journal and bracketing prior experiences as a parent of a child who has had a potentially disabling event.

Significance

The prevalence rate of intellectual disability among children in the United States ranges from 8.7 to 36.8 per 1000 (Gervais et al., 2023). Their overall needs must be ascertained, planned for, and met. Caregiver support is likely required throughout adulthood.

A coordinated, comprehensive, and accessible support system that effectively meets caregivers' needs has been suggested to aid the transition process. Findings of this study may offer insights regarding needs of caregivers caring for adolescents with acquired intellectual disability through the transition process to adulthood. Moreover, findings could be helpful for developing programs supporting inclusion efforts, accessibility, and independent living. This pool of caregivers may most need specialized resources and support. Therefore, it is significant to know their points of view.

Findings of this study may fill a void in literature by depicting the role of caregivers caring for adolescents with acquired intellectual disability as they become

adults. Healthcare providers may learn about lived experiences of this set of caregivers. With this information, medical professionals may provide resources to fit their needs. Social workers and mentors may also benefit from learning about needs of this population. This knowledge may lead them to develop and implement tailored supports, programs, and policies. Furthermore, educators may use findings to develop comprehensive caregiver transition plans.

Through this study, I hoped to spotlight experiences of this set of caregivers. It may help healthcare providers, social workers, and educators improve their services. Implementing policies, systems, and environmental strategies could influence wellness of caregivers and their charges.

Summary

In this chapter, salient issues involving caring for youths with acquired intellectual disability were presented. Also, lack of research on experiences of caregivers caring for adolescents with acquired intellectual disability through the transition process to adulthood was highlighted. The purpose of this phenomenological study was to understand needs and experiences of this set of caregivers and address the phenomenon through their points of view. Their emotions, experiences, and opinions were explored. It is hoped that this research study has added to the existing body of knowledge and given insights regarding caregivers' perspective of caring for adolescents with acquired intellectual disability as they become adults.

To explore lived experiences of caregivers, three research questions were developed for this study. All involved caregivers and helped to guide the study.

Specifically, it was of interest to highlight what caregivers experienced throughout the transition process while they provided support to adolescents, their experiences with social support, and experiences with developing and implementing transition plans.

This study will lead to a more thorough understanding of caregivers and their experiences and needs serving in parenting roles for youths with acquired intellectual disability while they transition to adulthood. Implications for social change include the potential to increase awareness that leads to resources that are unique to this population.

In Chapter 2, literature is explored regarding caregiving and how it is pertinent to caring for adolescents with acquired intellectual disability. Characteristics of intellectual disability, caregiving, and transition are addressed. Specifically, caregiving is discussed within the context of social support.

Chapter 2: Literature Review

The literature review includes important information based on experiences of caregivers who are supporting adolescents with an acquired intellectual disability as they transition to adulthood. Experiences of caregivers who are supporting adolescents with an acquired intellectual disability during the transition process have not been fully documented in literature. The purpose of the phenomenological study was to address the gap in literature by exploring this topic.

Intellectual disability influences the lifespan of individuals, thereby making transition issues critically important for both adolescents and caregivers (Dean et al., 2021). There is a need for transition plans that include trustworthy communication as well as seamless and consistent provision of care, in order to support caregivers in providing care and improve transition outcomes (Dada et al., 2020; Dubé et al. 2019; DuBois et al. 2021; Fernández-Ávalos et al., 2020).

Caregivers can be parents and other family members, such as siblings, grandparents, or friends as well as individuals who are hired to care for adolescents (Dubé et al., 2021). Basically, anyone in a parenting role is considered a caregiver.

Requirements of caregivers for adolescents with an acquired intellectual disability may be different than caregiver for adolescents without disabilities. Furthermore, this segment of caregivers may need different supports than caregivers of adolescents born with intellectual disability. For the study, caregivers supporting adolescents during transition phases were investigated. In the literature review, an overview of intellectual

disability, caregiving, and transition issues was highlighted. The conceptual framework for the study was also discussed.

Literature Search Strategy

In this study, I used the following databases: Thoreau, ERIC, MEDLINE, PsycINFO, SAGE Premier, ScienceDirect, ProQuest, and Google Scholar. Search terms were: *caregiver*, *caregivers*, *carer*, *carers*, *parent*, *parents*, *disability*, *intellectual disability*, *acquired intellectual disability*, *social support theory*, *social support*, *life course*, *lifespan*, *transition*, *transition plans*, *transition planning*, *adulthood*, *adolescent*, *teen*, *young adult*, *adulting*, *emerging adult*, *needs*, *support*, and *communication*.

Based on research, limited information was obtained pertaining to experiences of caregivers who facilitated the transition process of adolescents with acquired intellectual disability. For the study, a literature review was used to examine experiences of caregivers as they facilitated the transition process, with a focus on transition plans and formal and informal support needs. Search words were used individually or grouped. The search yielded approximately 250 articles.

Theoretical Foundation

Historically, the concept of social support has been used by researchers in various ways. It was used in the late 1800s and early 1900s in social, philosophical, theological, and political literature.

Carter (2021) suggested the process of seeking social support is similar to the process of seeking cooperation. McDaniel (2022) proposed occasional criminals need constant social support to avoid criminal behavior.

The role social support has in terms of minimizing, mediating, or buffering stress, as well as how it influences health and affects losses and gains during life, has been studied by researchers. Zhao et al. (2021) explored stress' impact on the psyche and health of socioecological groups and suggested social support is complex. Multiple avenues to provide aid during life events may be warranted. Social support does not interact directly with stress but serves as a counterbalance. Koay and Dillon (2020) posited emotional support, instrumental aid, and empathy should most effectively alleviate the impact of physical and emotional stress. Policies should be developed and programs should be implemented that are focused on inequalities and conditions that put people, including children, at risk for stress.

For this study, the social support theory was the conceptual framework because it was best suited to capture caregivers' lived experiences and possible support needs in terms of caring for adolescents with acquired intellectual disability transitioning to adulthood. The social support theory involves focusing on wellbeing and social support networks. It can be used to show how parents cope with raising adolescents with intellectual disability. The theory has been used to describe how caregivers access and use social support networks based on their needs. Social support has been defined as information individuals use to confirm that they are loved, cared for, and esteemed. Social support can impact health. Masefield et al. (2020) reconceptualized social support as coping assistance for distressed persons.

Social support theory can be used to explore the lived experiences of caregivers of adolescents with acquired intellectual disabilities in a meaningful way. Caregivers of a

child with a disability can feel abandoned by social support networks when their adolescent is emerging into adulthood (Williams et al., 2022). When provided with access to the appropriate social support, caregivers experience less stress and more self-confidence in their abilities to facilitate the transition process for their adolescent. .

Support is required from a variety of sources to ensure that both the caregivers and adolescents needs are met. Having access to social support resources can lessen the feeling of isolation. Family members, extended family, colleagues, peers, professionals, providers, faith-based organizational leaders, colleagues, community members, and the broader community serve as social support resources.

There are two categories of social support: formal support and informal support (Shepherd et al., 2020a). Support received from providers or professionals is formal support. Support from family members, friends, or other individuals is informal support. Informal support is a good source of emotional support for caregivers. In contrast, formal support has been used as a source of instruction regarding how to care for a child with an intellectual disability (Dunst, 2023). Access to social support and resources has been shown to increase caregiver confidence in the transition planning process.

Four types of social support exist (Shepherd et al., 2020a). The four types of social support are emotional, instrumental or tangible, informational, and appraisal support. Emotional support is when an individual expresses empathy and concern. Listening to concerns and providing encouragement is an example of emotional support. This type of support allows the caregiver to know they matter. Instrumental support involves providing tangible items such as goods, services, or financial support to

the caregiver. Providing respite for a caregiver is an example of instrumental support. Informational support is giving advice, guidance, or suggestions. Appraisal support is encouraging caregivers to assess their caretaking skills and abilities.

Transitioning to adulthood is fraught with challenges for adolescents and parents (Balser et al., 2023; Kerr et al., 2022; Roos & Søndenaa, 2020). It has been found that the transition process can be more difficult for adolescents with a disability and their caregivers. The question arises if the same situation exists for caregivers of adolescents with an acquired intellectual disability. Nucifora et al. (2022) posited that caregivers of children with an intellectual disability require adequate support during the child's lifespan, noting that the level of support may be different based on the severity of intellectual disability. Severity may also impact caregivers of an adolescent with acquired intellectual disability.

Williams et al. (2022) found that social support and services could influence mental health, physical health, and family finances. They found that family members who were more involved in the receipt of services and support, reported more favorable perceptions regarding the services and support received as well as the overall outcome. They posited that the need for tailored support and services is high. They further recommended a strategy for implementing caregiver assessments to understand the needs of the caregivers and adolescent being supported, the services desired by the caregivers and adolescent, and frequent updates.

Sutherland et al. (2023) conducted a qualitative research study and concluded that caregivers of a family member with an intellectual disability accompanied with

challenging behavior needed appropriate high-quality services and support. Even with the stress of caring for a child with an intellectual disability and challenging behavior, caregivers found joy in their caregiving role. Receipt of the support allows the caregivers to discover the joy and use this joyful feeling to be better advocates for the child.

Leggett et al. (2020) found that individual sources of informal support mitigated caregiver burdens differently. They examined informal support, specifically from spouses, children, and parents of caregivers. They found that perceived helpfulness from spouses had the most effect on lessening feelings of burden. Informal support from children had some mitigating effect and support from parents did not have a significant effect. The mitigating effect from spouses was void if the child also had behavioral problems. To that end, they suggested that clinicians assist caregivers in strengthening their support network and locating various sources of support.

Reynolds et al. (2022) conducted a literature review to aid in developing a strategic plan targeting the experiences of family caregivers and support. They discussed caregiving using an ecological framework. They found that support needs for families can vary within the different levels of the ecological system and should be tailored accordingly. Further, they suggested that family diversity, culture, and religion should be considered when developing and implementing support services. Noting supports and services are accessed, utilized, perceived, and received differently.

Reynolds et al. (2022) also found that peer-led services promoted well-being in caregivers; thus, they suggested incorporating peer-led services into programs. They also found that lower-income families accessed services less than higher-income

families. Finally, the researchers highly promoted transition planning throughout the lifespan of the individual with intellectual disability to support caregivers.

Bullen et al. (2022) conducted a study with 78 families of children ages two years to six years of age in the United States. They found that both informal and formal support was utilized and helpful. In the study population, it was found that pediatricians, professional helpers, and spouses were utilized by caregivers more than other individuals. They also found that professional helpers, spouses, and professionals at schools or daycare centers were the most helpful. To that end, the utilization and helpfulness depended on the life circumstances experienced by the family or caregiver in need. For example, they noted that caregivers of a child with intellectual disability and behavioral issues reported accessing formal support more often and found it helpful.

Bullen et al. (2022) found that the more sources of support were utilized, the more the caregiver reported liking the support. Poorer families accessed less than wealthier families. They surmised that poorer families may need more support. Additionally, they posited that two-parent households appeared to be better able to access and use formal and informal supports. If caregivers had a positive experience during the child's diagnosis, they were more likely to utilize formal support. Ultimately, the researchers found that it was essential to know what the helpful supports were and tailor them toward the intended recipients and for the correct stage of life.

Literature Review

Intellectual Disability

Formerly, the term intellectual disability was known as mental retardation, (Grigal et al., 2021). Intellectual disability is often seen with the term developmental disability. According to Grigal et al. (2021), developmental disabilities encompass intellectual and physical disabilities. Intellectual disabilities do not include physical disabilitiesbut this does not preclude a person from having other disabling conditions, such as sensory limitations.

Schalock and Luckasson (2021) noted that the definition of intellectual disability, as developed by the American Association on Intellectual and Developmental Disabilities (AAIDD), is the most commonly used and accepted definition in the United States. It is defined as having limitations in functional and adaptive behavior before age 18 and having an intelligence quotient (IQ) of less than 75 (Schalock & Luckasson, 2021). Intellectual disability can bring about issues of performing everyday functions that involve some level of cognitive ability, such as problem-solving, which are all related to executive functioning. Intellectual disability can also influence social, conceptual, and practical domains by manifesting as struggles with independence, interpersonal skills, and abilities to care for self. All are related to adaptive behavior. They noted that having an established, agreed upon, and widely used definition of intellectual disability is essential to understanding the condition and assisting others working in the field.

Using data from the National Survey of Childrens Health (NSCH) and the National Health Interview Survey (NHIS), Russell et al. (2023) found the prevalence of

intellectual disability in the United States to be 12.1 per 1000 children using the NSCH survey and 12.2 per 1000 children using the NHIS survey. They reported that the surveys included data for children ages two to 17. Although the surveys used different data collection methods, it was determined that the estimates remained similar in each subgroup examined. The researchers suggested that exploration of the data could be used to gain a better understanding of the needs that people with intellectual disability have. Similarly, exploring data could be used to discover the needs of caregivers.

History of People with Intellectual Disability in Society

The history of people with intellectual disability in society is a tumultuous one (Gopalan, 2022). This population has not always been treated with respect, dignity, or kindness. The Romans and Greeks considered anyone with a disability to be inferior. Romans were said to have kept people with disabilities as objects to be laughed at. Aristotle suggested that children with a disability should be left out in the elements to die, and Spartans legally required parents to do so.

With the rise of Christianity, the notion of taking care of people with disabilities increased. Separation and fear ebbed and flowed through the centuries. Asylums, idiot cages, and institutions were used to house people with intellectual disability. In the early 20th century, it was policy for providers to encourage parents to institutionalize their disabled children. Housing for this population was often limited and vile. Residents were abused and provided little to no structured opportunities to engage with fellow residents or others.

People with intellectual disability were labeled and referred to as idiots, morons, feebleminded, abnormal, degenerate, mongoloid, imbecile, defective, retarded, and later handicapped (Shaw et al., 2021). They were feared by society and by their own families. Sterilization became a common practice that was supported by law. This practice was spurred by the initial belief that people with intellectual disability would birth only children with a disability. Then, concerns arose about people with intellectual disability birthing children without a disability who had to be reared by them. This population was also feared to be homicidal, and because of that, their families were afraid to keep them at home.

In the late 1900's through to the 2000's, with the use of the terms retarded, handicapped, and then intellectual disability, policies began to be more positive. Parent advocacy groups such as the National Association of Retarded Children (NARC) began to form, and their voices were being heard (Jarrett & Tilley, 2022). Even so, people with intellectual disability were not fully respected in society because their voices were not being heard. They were not included in discussions. Movements such as the People First Language, which puts the person before the disability, and Nothing About Us Without Us, which emphasizes that people with a disability know best about what they need and should be included in anything that affects them started. Both preached that people are more than their condition and encouraged inclusiveness.

Causes and Characteristics of Intellectual Disability

According to Patel et al. (2020), there are different causes for intellectual disability, including genetics, illness, accidents, and more. They described Down

syndrome as a genetic syndrome known to be associated with intellectual disability. They also cited illnesses, such as meningitis and measles. Traumatic brain injuries and exposure to harmful toxins are other causes of intellectual disability. Poorly developed or malformed brains, exposure to toxic substances, such as alcohol to a fetus, and pregnancy or delivery complications have been causes.

The severity of intellectual disability can indicate the degree to which a person with intellectual disability functions and adapts. The levels of severity are mild, moderate, severe, and profound. People with a diagnosis of mild intellectual disability have been found to experience more independence when provided with the appropriate support (Neuman, 2020). This should be taken into consideration when developing programs and interventions for caregivers of people with an intellectual disability. As severity increases, the need for support may increase.

Adaptive Behavior

The American Association on Intellectual and Developmental Disabilities (AAIDD) defines adaptive behavior as the collection of conceptual, social, and practical skills learned and performed by people in their everyday lives. Skills that could be impacted include time, problem-solving, and personal care. Researchers have explored how adaptive behavior fits into the attainment of resources. Koay and Dillon (2020), in a population of adolescents with Autism and their parents, specifically looked at the attainment of resources during the transition period and found that youth with adaptive behavior problems needed more services and reported more unmet service needs; that they are at risk for poor transition outcomes, and their parents expressed more significant

levels of anxiety. They highlighted that the transition period can be highly stressful and suggested that attention be paid to this group earlier in the transition process and be specific to their needs.

Spencer González et al. (2020) studied how transition affects families of adults with Down Syndrome and found that planful transitions have better outcomes than demand transitions. The ability to adapt to the change has played a role for the family, the adult with Down Syndrome, and the residential staff. They found that adults with intellectual disability may benefit from social support networks facilitating their ability to adapt to new environments.

Intellectual Functioning or Cognition

The AAIDD refers to intellectual functioning as "…general mental capacities, such as learning, reasoning, and problem-solving". They also call it intelligence, which can be measured through an IQ test. The intellectual functioning levels of a person with ID can affect caregivers. Singh et al. (2022) found that caregivers of a child with ID who has lower intellectual functioning report more burden and psychiatric distress. They posit that this category of caregivers may be less efficient in caring for their child. Routine assessment should be conducted and aide provided to help them cope.

Adams et al. (2023) conducted a study on the interrelationships between motor, cognitive, and language development. They found that children with cognitive delays were slower to develop motor skills. They investigated the level of engagement children with profound and multiple disabilities had in family activities. They discovered that families spent much time adapting family activities to meet the childs level of function.

As shown above, adaptive behavior and intellectual functioning can impede a child's development. It may hinder progress in the transitioning process to the adult world. Caregivers and the adolescent may need to identify and procure appropriate support services. Planning is essential in preparing for the adult phase of life.

Transition Planning

Three percent (3%) of the United States population has an intellectual disability (Patrick et al., 2020). Just as children without a disability grow and mature, children with a disability do the same. Specifically, adolescents with an acquired intellectual disability grow into adults with an acquired intellectual disability. The transition process to adulthood can be challenging for adolescents and caregivers. As adolescents transition, they continue to need support and guidance from caregivers (Boehm, 2021) regardless of whether the adolescent with acquired intellectual disability lives inside or outside of the home. Caregivers are an essential source of support and continuous care for the adolescent during the transition to adulthood.

Based on difficulties associated with the transition process, caregivers seek social support, services, and resources to assist them. When an adolescent transitions from pediatric to adult medical services, caregivers have noted that they feel abandoned (Dubé et al., 2021). Once the adolescent is considered an adult, communication is directed toward the adolescent at the exclusion of the caregivers. Caregivers are still relied upon by the adolescent for assistance. Separation from school-based care is similar.

Mallette et al. (2020) noted that caregivers may have a sense of loss because they have lost an essential piece of emotional and informational support with the provider at a

life stage that can be tumultuous. They suggested that support includes consistent communication, parental and child involvement, provider input, and seamless, comprehensive transfer of services. This is where transition plans become important. Vanegas et al. (2022) suggested that transition plans are developed and implemented early with shared input from the caregiver, adolescent, and providers, then revisited at each phase in the adolescent's life to maintain relevancy.

Research has shown that individuals caring for a person with intellectual disability may experience social isolation, struggle with accessing support services, and experience adverse family impacts such as strain on finances or relationships. Those in a caregiving role may often worry about the future of their loved one with intellectual disability as they age into adulthood. Understanding the experiences of caregivers of youth with intellectual disability who are transitioning to adulthood is critical to providing appropriate services to fit their support needs throughout the life span (Jenaro et al., 2020). It is paramount to develop plans that can adequately prepare the parent and youth for emergence into the adult world.

Development and Implementation of Transition Plans

Transitioning to adulthood is a significant change (Lee et al., 2021). Transitioning is more than moving from pediatric care to adult medicine, nor is it as simple as completing public school or primary education. Adolescents with an intellectual disability often live at home and require care or support throughout their life.

Caregivers of children who are born with an intellectual disability are provided with resources and plans to guide them throughout the childs development from an early

age. Via the Individuals with Disabilities Education Act of 2004 (IDEA), leaders in the educational system are mandated to utilize the individualized education plan (IEP). IDEA recommends that transition planning begin at age 14 and mandates that an active plan regarding the adulting phase be in place by age 16 to carry the youth through age 22.

Individualized Education Plans can be developed to contain resources available to students with intellectual disability and their family members, including special accommodations offered by the school systems (Mello et al., 2020). IEPs are invalid once the adolescent leaves school or ages out. Caregivers and students will lose familiar support. The researchers posit that the caregivers will struggle to collect services making the need for comprehensive transition planning even more critical. Caregivers are often left unprepared and anxious regarding the future of their loved ones.

The period that students with intellectual disability separate from the school system and transition from pediatric care to adult medicine has been called the "black hole" (Reneses et al., 2022). The researchers recognized that this period can be traumatic. They recommended using a holistic approach to support and aid caregivers during the phase. They suggest implementing a multilevel multisectoral ecological approach for providing support to caregivers. IEPs are separate from medical planning. Medical planning aids the provider, adolescent, and caregiver in planning for transitioning from pediatric care to adult medicine. As the youth ages, the caregiver is likely managing an IEP and medical plan simultaneously.

Renesas et al. (2022) suggest that service providers explore more than the primary markers of successful transition: employment, independence, and relationships. They

encourage providers to develop services and programs that consider caregivers' goals for their loved ones, accounting for the adolescents' desires and abilities. Employing this strategy may lead to successful transitions that are both desirable and more sustainable because they are based on the support needs of the youth and their caregivers.

Communication

Communication helps manage perceptions of support in caregivers of adolescents born with intellectual disability (Sapiets et al., 2020). Thus, communication with providers and others is essential to reduce stress on the caregiver. The researchers suggest that school staff charged with helping to develop transition plans be given continued professional development in the process and training on establishing and sustaining effective communication with parents.

When the adolescent reaches transition age, the support system established to assist while the child is a minor dissipates. Researchers reported that caregivers need more communication with providers and educators regarding the adult roles their child will need to be prepared to handle (Montiel-Nava et al., 2020). Without proper planning, the lack of support may leave caregivers with several unmet needs or support.

Transition planning should start early and include caregivers, adolescents, and health and service providers to support caregivers better and plan for their needs. Montiel-Nava et al. (2020) encouraged early transition planning, so services are planned and implemented to minimize confusion. They posit that support should be developed for various stages across the lifespan and implemented at all levels of society.

Raley et al. (2020) reviewed the impact of guardianship on students covered by the Individuals with Disabilities in Education Improvement Act (IDEIA) in the transition process. They found there to be confusion among educators and parents in understanding, interpreting, and incorporating its use in transition planning. Per IDEIA, educators must inform parents when their child reaches the age of 18, the child will be solely responsible for making decisions about their education and that they will no longer qualify for some state-sponsored services provided at no cost or reduced cost to families. The researchers found this notification to cause great angst in parents.

To that end, they discovered that educators suggested guardianship to mitigate this issue. However, when parents filed and received guardianship, it caused the unintended negative consequence of removing the youth from the decision-making process about their own life. Raley et al. (2020) cited an example of this happening to a family, causing them to return to court to cancel guardianship and later include extra decision-making support into the plan. Even with good communication, there can be some form of confusion. It is essential to understand what all parties genuinely desire and define as successful transition planning.

Summary and Conclusions

Chapter 2 involved reviewing constructs of the social support theory, specifically, social support as it relates to caregivers, characteristics of intellectual disability, causes of intellectual disability, diagnosis of intellectual disability, transition planning, communication, and caregiver needs regarding caring for adolescents during transitions to adulthood. An overview of the history of intellectual disability was also provided.

The literature review included evidence regarding caregivers facilitating the transition process of adolescents with acquired intellectual disability. Attention was given to transition-specific issues that caregivers of adolescents with intellectual disability may experience. Caregivers of adolescents with acquired intellectual disability were rarely highlighted in literature, especially in terms of transition processes. When experiences of caregivers during the transition stage were mentioned in literature, experiences related primarily to caregivers of children with autism spectrum disorder, not acquired intellectual disability.

Although studies exist regarding caregiver experiences, limited information was found regarding how caregivers of adolescents with acquired intellectual disability experience transition planning. This study was an opportunity for caregivers to share their unique experiences regarding this process. There are also several studies on caregiver support needs and transition outcomes. However, researchers have mainly focused on caring for adolescents with different disabilities or those who are born with a disability.

Caregivers of adolescents with acquired intellectual disability begin on a different trajectory with their children. This subset of caregivers may not be privy to accommodations or supports that caregivers of children who are born with a disability had. If the event causing diagnosis of intellectual disability occurred during the later teen years, caregivers would have less time to become adjusted and access resources.

Chapter 3: Research Method

The purpose of this phenomenological study was to understand lived experiences of caregivers of adolescents with an acquired intellectual disability while they transitioned to adulthood. I attempted to understand what caregivers face throughout this process. The methodology and design are presented in this chapter, along with research questions, my role as the researcher, and a detailed description of data collection and data analysis procedures. Furthermore, I discuss ethical issues regarding objectivity and confidentiality.

Research Design and Rationale

A qualitative research method was used to gain an in-depth understanding of lived experiences of caregivers supporting adolescents with acquired intellectual disability through the transition process to adulthood. A systematic approach such as qualitative research can be used to reveal responses to specific phenomena. Qualitative research is used to study a small sample of a target audience to guide and support responses. The target audience for this study was caregivers of adolescents with acquired intellectual disability who are supporting them through the transition to adulthood.

Qualitative methods are used to inquire about a specific phenomenon of interest. It is advantageous in that it affords the ability to provide deep and complex descriptions of how individuals are experiencing a phenomenon. Through this approach, insights were formed about how caregivers experienced supporting adolescents with acquired intellectual disability. Qualitative research involves holistic and organic views of how

individuals experience phenomena of interest in natural settings. It allows for a better understanding of issues according to the individuals experiencing it.

A phenomenological approach was used for this study to gain in-depth insights from caregivers. I needed to initiate the study with an open mind and avoid preconceptions. When employing phenomenology, the researcher relies more on interviewing and less on observations of participants. Interviews were audio recorded to capture details. This was done to gain a pure understanding of the phenomenon through the lenses of participants.

Phenomenology involves exploring and understanding how individuals apply meaning to phenomena. Experiences of individuals are brought to life through interpreting their stories.

Since vulnerability permeates other parts of mothers caring for adult children, it should be considered when providing support to them to alleviate anxiety (Roling et al., 2019).

Phenomenology involves explicitly investigating and directly describing a phenomenon consciously experienced by individuals exposed to it. Therefore, a phenomenological design was used for this research to understand and describe meanings of lived experiences of caregivers caring for adolescents with acquired intellectual disability throughout the transition process to adulthood. Caregivers were interviewed using open-ended questions about their experiences.

Role of the Researcher

Qualitative researchers are considered the primary instrument in data collection. To do this, interactions with participants was necessary. It was expected that a complete understanding of the phenomenon would be gained through narratives shared by participants.

With phenomenological research, researchers ask questions, probe, and listen in order to understand participants' experiences. Trust and rapport with participants were sought to ensure comfort with the process. By doing so, I expected participants to respond honestly and divulge information openly and validly. Furthermore, my role as the researcher in this study was to gain insights regarding this topic via in-depth interviews. Participants were probed for specific details with the intent to elicit enough information to describe their experiences.

All researchers have biases when conducting studies, and their biases may be reflected in data collection and analysis processes (Zhao et al., 2021). To minimize bias in the study, bracketing was used. Several methods can be used to bracket, notably writing memos, interviews, and journaling. Researchers heed when and where these biases appear so they are careful not to let them overshadow what participants shared. A journal was kept bracketing personal prejudices in order to avoid bias in terms of interpretation of participant experiences.

Methodology

Participant Selection

A purposeful criterion sampling method was used for this study. All participants were primary caregivers or parents, had been in their roles after an intellectual disability was acquired, served in these roles as their charges were becoming adults (specifically between 14 and 22), and spoke English. Participants were excluded if they did not meet criteria or had no phone access. A contingency strategy of snowball sampling was initiated to increase identification of appropriate cases and boost recruitment numbers.

Participants were recruited using Facebook through online caregiver support groups. Initial connections with Facebook support group administrators were sought to gain approval to recruit. Once approved, a description of the research topic was posted for the group with all study specifics, including my contact information.

Institutional Review Board (IRB) approval was obtained from Walden University before recruitment began. Once approved, Facebook caregiver support group administrators were contacted to distribute recruitment material. Caregivers who responded to recruitment material by direct contact via email or phone received invitations to participate and were given the approved informed consent form to review.

I screened each participant to ensure that they met the criteria. Caregivers meeting the criteria were emailed the consent form to review again. An email consent from the participant was returned to the researcher making a hard copy signature not required. The form clearly outlined the goals and methods of the study, included a statement regarding

incentives, and informed the participants that they could decline or withdraw at any time without penalty. The interviews were completed by telephone.

Saturation is critical in qualitative research. It was reached when the participants were sharing no new information. Eleven participants were recruited and an in-depth interview was conducted.

Instrumentation

I used an interview as the instrument to collect data. Interviews are appropriate for qualitative research (George, 2022). I designed the interview instrument using an example given to the researcher by my Chair. Questions were developed and relevant to the topic. The instrument was reviewed and approved by the Chair and by the Walden Institutional Review Board. Each participant signed an informed consent and agreed to be interviewed. Originally, the interview was to take place in person. However, because of the pandemic, the interviews were conducted by phone. The interviews took 60 minutes to conduct.

Data Analysis Plan

The Moustakas method was followed. It has been used as a way to explore and discover how a phenomenon is experienced (Mihalache, 2019). As such, it is appropriate for this study.

After data collection was completed and the interview transcripts were transcribed, each participant was assigned a pseudonym to ensure that their identity remained hidden. The first step of data analysis involved thoroughly reviewing all transcripts to get insight into what each participant said. The following step was to

identify words and statements in the transcripts that were meaningful for the phenomena under investigation. These statements were called "horizons" (Mihalache, 2019). Each horizon was labeled to emphasize its importance, while the unnecessary elements were omitted. Then, the horizons were grouped into themes. These themes can be considered common threads or shared experiences that the caregivers present, encompassing various feelings, thoughts, actions, and emotions. The last part of the data analysis plan was developing accounts for individual caregivers' experiences based on identified themes. This step aimed to gain a refined insight into each caregiver's views and highlight all common themes. Quotes taken from the transcripts of interviews were used to encapsulate the nature of this phenomenon and help describe it.

NVivo was the primary data collection and management software. It offered efficient information organization and easy retrieval throughout the analysis process. Microsoft Word and Excel were also used as backup tools to facilitate data organization. A structured data analysis plan helped to find meaningful insights.

Issues of Trustworthiness

Trustworthiness is a critical aspect of qualitative research that proves the findings are valid and reliable. Four critical trustworthiness factors are credibility, transferability, dependability, and confirmability. Credibility was attained through triangulation. Research questions were reviewed from multiple angles. Triangulation involved more people and different analysis methods, enabling rigor in the study by offering a more comprehensive picture of what individuals have gone through. Participants were given

the opportunity to review their interview summary and make changes as needed. This brought sincerity and credibility to the findings.

The second dimension is transferability. Transferability refers to providing full accounts that would enable this study's results to be used outside its setting. Using themes derived from the words of participants also increases transferability. The third dimension is dependability. It concentrates on the quality of data collection and analysis processes. I maintained dependency since the records of interviews, journals, and notes were accurate. The fourth dimension demands a lack of bias and fairness from the researcher to establish confirmability. Reflective journaling removes bias from data collection and analysis. I kept a journal and bracketed.

Ethical Procedures

IRB approval was obtained before beginning the study. Once approved, I began the recruitment process. Upon identification of study participants, I screened each participant by phone to discuss the details and specific purpose of the study and the protection procedures. Only English-speaking caregivers of an adolescent with acquired intellectual disability serving as a carer for the youth through the transition process to adulthood were eligible to participate in the study. Purposeful sampling was used to identify a suitable pool of candidates. After candidates were selected to be participants, they were given consent forms, and consent was obtained. They were notified of their right to withdraw or refuse to participate at any time, the limitations to confidentiality were shared, and they were informed that no incentives were being provided for

participation. It was not anticipated that any risk would be associated. The IRB made a final determination, and the guidance was followed.

Confidentiality was addressed using code names instead of real names. Participants were made aware of this. All documents, audio recordings, transcripts, and journals were stored in a locked file cabinet and external hard drive. The external hard drive was password-protected.

Summary

The purpose of this study was to explore lived experiences of caregivers caring for adolescents with acquired intellectual disability as they transitioned into adulthood. Chapter 3 includes an outline of the phenomenological design and its appropriateness for this study. This design was used to capture meanings of experiences of this population of caregivers. A description of how participants were identified through purposeful criterion sampling, process for how data were collected and analyzed, and proposed methods for handling ethical issues were addressed. Data were collected by conducting in-depth interviews and maintaining field notes. Interviews were audio recorded, transcribed, and analyzed for emerging themes to capture the essence of meanings of lived experiences of caregivers. I also described how trustworthiness was ensured.

Chapter 4: Results

I aimed to describe lived experiences of caregivers of adolescents with acquired intellectual disability throughout the transition from adolescence to adulthood. Eleven caregivers participated in the study. This chapter includes a discussion of participant demographics and characteristics, data collection methods, data analysis, proof of trustworthiness, and study results.

Setting

Due to the COVID-19 pandemic, participants were interviewed via phone. I conducted interviews in a comfortable, well-lit, and quiet room without interruptions. All participants were encouraged to seek similar settings wherever they were located to complete interviews. Although nonverbal communication cues could not be determined, copious notes were taken to accompany audio recordings.

Demographics

The choice of 11 participants for the study was based on purposeful sampling. Nine participants were female, and two were male. Eight were Black, one was White, one was biracial (Black and White), and one was unknown. Not all caregivers were related to their charges. Race or nationalities of participants did not always match who they cared for.

There were 13 adolescents in all. Three were female and 10 were male. Two caregivers cared for two separate adolescents. Caregivers with more than one adolescent in their care looked after both male and female adolescents (see Table 1).

Table 1

Demographic Information

Participant	Gender	Relationship	Gender of Adolescent
Barbara	Female	Parent	Female
Alice	Female	Paid Caregiver	Both
Kay	Female	Family Friend (Former Social Worker)	Male
Danny	Male	Parent	Male
Sonya	Female	Parent	Male
Robert	Male	Sibling	Male
Felicia	Female	Family Friend (Educator)	Male
Tricia	Female	Parent	Male
Vivica	Female	Educator	Both
April	Female	Parent	Male
Shannon	Female	Sibling (Former Social Worker)	Female

Data Collection

Data for this study were collected from 11 participants who met study criteria as outlined in the flyer and informed consent form (see Appendix B). The flyer was posted on Facebook intellectual disability support group pages and the Walden University participant pool. Participants contacted me by email and telephone. I briefed each candidate on the study and then agreed on a date and time to conduct interviews. It took from a day to a week to set interview dates and times.

To provide data, each caregiver participated in phone interviews that lasted between 45 and 60 minutes. The interviews were conducted over a period of approximately a year. As per the IRB (#04-13-20-0473808), interviews occurred at agreed upon times in locations that ensured privacy and confidentiality. After a brief warm up and welcoming chat to relax participants, they were asked 15 interview questions (see Appendix C). There were follow-up questions during interviews that were used to allow for development of in-depth understanding of information given by caregivers.

Interviews were digitally recorded and then transcribed. During the entire data collection and dissertation development process, I was the only person who had access to data. All audio phone recordings, informed consent forms, and transcripts were kept on a password-protected computer. After transcription, electronic data remained in NVivo which is only accessible via the same password-protected computer.

Interviews were summarized, and each participant was asked if they wanted to review a summary of their interview to make any corrections. Only one accepted the offer. However, this participant did not provide any further information or changes.

Data Analysis

Moustakas' phenomenological process and steps for organizing and processing information were employed. I kept a diary, reread transcripts, and listened to subsequent interviews several times shortly after completion to reflect on caregiver perspectives. Once interviews were completed, audiotaped recordings were assessed using a balanced perspective to focus on views involving caring for adolescents with acquired intellectual

disability. Audio was uploaded into NVivo. Then, draft transcripts of the interviews were developed from the uploaded audio and saved.

Initially, interview transcripts were individually reviewed for clarity, missing information, and errors. After completing this process, each interview was reviewed again to understand data and identify codes fully. Expressions of participant experiences as caregivers of adolescents with acquired intellectual disability were segmented, listed on sticky notes, and charted along with identified overlapping, repetitive, and redundant statements. Irrelevant statements were also identified and discarded. This left pertinent codes regarding the phenomenon.

When looking at participants' experiences, themes were identified and color-coded based on commonalities in data. A theme was identified when at least six participants identified the same or similar unit of meaning during interviews. After core themes were identified through sharing of lived experiences of caregivers of adolescents with acquired intellectual disability, titles were created to capture themes' essence. Then, data were reviewed in addition to quotations that supported themes. The data analysis process resulted in three primary themes: knowledge and meaning of caregiving, transition plan development and implementation experience, and social support systems.

Evidence of Trustworthiness

Four factors of trustworthiness were addressed. First, credibility through triangulation was reached by reading interview summaries multiple times, using different data collection and analysis methods, and allowing participants to review interview summaries. Second, identifying themes based on words and thoughts of participants

proved transferability. Third, dependability was evidenced by using various data collection and analysis procedures. Interview data were collected and tracked using NVivo, and a journal with written notes was maintained. This aided in accurate and reliable thematic analysis of data. Fourth, journaling was done to remove bias from data collection and analysis processes. By doing this, confirmability was achieved.

Results

RQ1

Theme 1: Knowledge and Meaning of Caregiving

The data indicated that the caregivers had various levels of knowledge and meaning of caregiving. They provided information regarding who they cared for and why they cared for them. Some gave examples of their knowledge.

IQ1 – What do you know about caregiving?

This question was asked to learn what the participants believed caregiving to be and how they operationalized it when caring for others. Ten of the 11 caregivers responded that they knew about caregiving. One caregiver likened knowledge only to formal training. They all appeared to have some knowledge and experience of caregiving even when they did not think so because their responses paralleled each other. Two supporting are below:

Vivica said, "What I know about caregiving is you are taking care of someone who, for some reason or another, is unable to take care of themselves, and you are providing the care that they need to keep them safe."

Robert said, "I do not know a whole lot about caregiving. All my experience with it is not really from any school; it is just from experience trying to care for someone. I've had to learn all of it through experience."

IQ2 – What does caregiving mean to you?

All 11 caregivers could explain what caregiving meant to them.

Vivica said: "It means that I'm being trusted to care for someone who cannot care for themselves. Caregiving is just being able to give someone some quality care when they cannot."

Danny said: "Caregiving means you take care of someone. To me, caregiving means I must take care of my son because there are things he cannot do. Some things he cannot do well. I must be there for him."

Barbara said: "Caregiving means caring for my daughter when she cannot care for herself. I will always be there to take care of her."

April said: "Caregiving, to me, means someone willing to take on the responsibility to care for another individual. That means someone you know. When you break down the word care, it means showing compassion or concern. A giver is giving of yourself and your time to help for the well-being of another individual. That's the way I am a caregiver."

Subtheme 1: Responsibility to Care for Adolescents

The participant's interpretation of caregiving may have differed. However, they appeared to have a sense of responsibility to provide care for their adolescent with acquired intellectual disability. The sample responses below support this analysis:

Danny said: "I'm a parent, and caregiving is part of the role. I am responsible for taking care of my child."

Tricia said: "I am his mother. It is my responsibility to care for him, and I will be his caregiver as long as I can."

Barbara said: "She is my child. I am responsible for ensuring she is ok and provided for."

Sonya said: "He needs me. I am his mother. I am responsible for taking care of him."

Alice said: "It's not just my job to care; I am responsible for providing for the young people I care for because I want to. I am attached."

Kay said: "I am a close friend of the family. I am his Godmother. I love him, and I am responsible for doing whatever I can. As a former social worker, I may be able to help get what he needs and whatever my friends need easier."

Shannon said: "My sister had a lot of things going on emotionally and mentally in addition to the intellectual disability. Although it was tough, it was my responsibility, as her sister, to help. Plus, being a former social worker, I could use the resources that I still have."

Subtheme 2: Motivation and Caring about Adolescent Wellbeing

Four caregivers felt that caregiving was more than a role or a responsibility. They also focused on the adolescent's well-being. Below is a sample of the responses that supported this analysis:

Sonya said: "It means multiple things. You're also that person who pushes them through therapy or surgery, encouraging them to do their best. I motivated him to be responsible for as much of his well-being as possible."

Felicia said: "To me, it is about helping them to have a better life. We have to help them and their families or teach them and their families to do such things to let them have the best life they will have. If I don't do my part and encourage him, what will happen? His well-being, all of their well-being, is essential to me."

Danny said: "It is about complete well-being, and that's beyond physical. It's a long-time job. It is not just when they are children. It goes into adulthood."

Robert said: "Besides taking care of some of a person's basic needs, it means ensuring their well-being at the current moment is maintained and that they can maintain their well-being when I'm not around in the future."

IQ3 – What do you know about acquired intellectual disability?

All the participants responded to this question. For those who did not know what acquired intellectual disability meant, it was explained to them, and examples were provided as needed. Four expressed that they did not know what acquired intellectual disability was; four were slightly familiar, and the remaining three expressed that they knew what it was.

Danny said: "Not a lot. My son had a tumor that had to be removed and left him with some disability around executive functioning. It's long-term. Being long-term, we have to figure out what to do for him so that he can take care of himself in the future. We

had a plan, and we still try to follow it. I was nervous about it because this all happened so late. He was already a teen in high school."

April said: "I won't say that I am a full-blown encyclopedia on acquired intellectual disability. My son had terrible seizures that caused his intellectual disability. After getting him tested, I learned that he would not be like other kids his age and that he would always need help because of what the seizures had done to his brain."

Kay said: "My Godson has seizures. His intellectual disability was caused by having seizures. Once his parents got him tested, they told me that he would always be unable to care for himself fully. Having been a social worker for patients with similar diagnoses, I knew this was true."

RQ2

Theme 2: Transition Plan Development and Implementation Experience

The official name for a transition plan is an Individualized Education Program, also known as an IEP. For purposes of this research, the term transition plan is used. Some caregivers explained that they were familiar with transition planning, development, and implementation. Others believed they were not. The caregivers had mixed feelings about them for various reasons, including stigmatization. Some stated that it took more work to meet specific needs, even if included in the plan. Some also believed transition plans could have been more helpful.

IQ4 – What do you know about the transition process to adulthood for an adolescent with acquired intellectual disability?

All 11 participants answered this question. Analysis indicated that, at times, the transition process could be complicated for the adolescent with acquired intellectual disability as well as for the caregiver. Specifically, seven caregivers explicitly stated that the transition process could be complicated to manage. Yet some appeared to believe that it is doable with assistance, coping, other options, or resources. This was shown in the following caregiver quotes:

Sonya said: "I know enough, and I had workarounds".

April said: "Children with intellectual disabilities sometimes are stuck in this box where pediatricians are not necessarily on board with them taking the risk to move on to that next stage of adulthood. I do know it can be difficult to transition. So, some of the adolescents are typically delayed out of care and concern. They only make that transition promptly if the caregiver is very strategic. All of us are overly nurturing to the point that it's handicapped the ability for the transition to take place smoothly."

Robert said: "The transition process can be tough. It might take more time for them to build some of the skills necessary to be an independent adult or their acquisition just might be a bit delayed. He might need more guidance to reach goals."

Felicia said: "Caring for an adolescent who is getting older can be hard. Help might be needed. We made contact and stayed in touch with those there to assist you if

you need it to make those transitions. The social worker gave us State information that we were able to use as he became an adult in life, if he needed it."

IQ5 – What does the transition process to adulthood for an adolescent with acquired intellectual disability means to you? And how have you experienced it?

All 11 participants responded to part one of this question, and their responses varied. However, only three answered part two of this question. Analysis of the caregiver responses to this question indicated that their adolescent is growing up and that they must be guided through the process to ensure that their needs are obtained and met. Transition for this population appeared to be lifelong; thus, care or support would be needed. Furthermore, solutions need to be something that can be carried out with ease. The below caregiver quotes supported the analysis:

Barbara said: "It means ensuring my daughter has what she needs her entire life."

April said: "It means preparing the child to become independent. It hasn't been a remarkable experience for us because I think we still live in fear of my son's ability to care for and provide for himself independently. It makes the transition difficult. We know that he requires additional care. If something happened to me or his dad, what would he do? Getting him into vocational training has been challenging because he gets excited, but that has been a horrible experience for us because they never follow through."

Vivica said: "It means ensuring they have the skills to succeed in adulthood. Can they do the basic things? Do they have life skills? Do they have proper training to get a job to take care of themselves and be as independent as they can on their level?"

Felicia said: "We are constantly helping them transition, learn living and academic aspects that they will need to transition on in life."

Subtheme 3: Assistance After High School

The adolescents being cared for by caregivers participating in this study may have started life without a disability; however, after acquiring it, they will live with it for the remainder of their lives. To that end, caregivers indicated they worry about the adolescent long-term. Some of them hope that the plan will be sustainable. They also hoped that support connections could be maintained after high school. However, after high school, obtaining the support needed seemed to be sketchy.

Danny said: "Not wanting to be placed in a black hole and forgotten after high school. What if we need help?"

Kay said: “I hope that we can continue to meet the goals in the plan because I worry that he won’t get the same help after he graduates. His well-being is important.”

Robert said: “He is my brother. I love him and worry about him. However, I can’t do it on my own. Who do I call after he finishes school? I mean, can I? Is that allowed?”

April said: "A transition plan was developed to help him transition from high school to being independent and on his own. After high school was over, we were left on our own. I don't feel like we had the support needed where transitioning was concerned. His neurologist had a sound system in place to assist him in becoming more independent."

IQ6 – What do you know about transition plans?

All participants responded to this question, with two responding that they had limited knowledge, making nine out of the eleven have some knowledge and awareness of transition plans. Analysis of the responses showed that even those caregivers who said that they had little knowledge, felt that it was essential to have a transition plan for an adolescent with acquired intellectual disability as they grow into adulthood. One caregiver did not have a favorable view of transition plans developed in an educational setting. However, she ultimately developed one for her son with input from her family. The below quotes showed responses of caregivers supporting the analysis:

Barbara said: "I don't know much about a formal plan. My family and I did what we had to do to care for her. I wish we had a formal plan."

Robert said: "Being involved in the planning stage would have been useful to him as a caregiver. It would have been easier. I did what I could."

Danny said: "That transition plan was set up to prepare him to succeed, move on, and enroll in school. I felt the school system was perfect once they knew what they were dealing with because it wasn't readily apparent to me. No one knew if he would go to college or trade school or anything like that. It would have been nice to have some resources that could give us ideas on how he could get into colleges, trade schools, or whatever he wanted to do and have support once he left high school. I don't want to rate the school system, but the whole idea of once they're gone, we're done with them. It doesn't work for parents because they have had our children for quite a long time. It would have been nice to see what transition plans look like when he is out of high school

and moving on to adulthood. We would love to have seen them be more engaged to ensure that once they moved on, they were also successful."

Sonya said: "I was always told about them, but in the context of you never really want your child to be on a plan because it stereotypes your child, and they code your child to be something that they're not. I didn't want to put him on a plan. I was always under the impression that they limit you.

We worked more with him, and I also found some tutors. So, between his mother, grandmother, or dad, we always had a book to read or a math book. We just continually studied."

IQ7 - Tell me about your experience developing a transition plan?

Ten of the participants responded to this question, and one did not. Responses varied. However, out of the 10 respondents, seven believed the transition plan development process was worth it. This would have been more significant if they had believed the plan was solid and communication and collaboration between all parties were good. The below quotes indicated the caregivers' responses supporting the analysis:

April said: "We worked with the social worker at the school to develop the IEP. We talked about his needs, strengths, weaknesses, and what it would take to get him to a place of independence where he could operate and function as an adult. When we were halted, it was a little depressing for him and us because we thought it would allow him to gain some skills and experience to help him become more independent. He wanted to work and live on his own. You know, outside our house, but that was all stopped."

Sonya said: "I opted out. I met two times with the teachers. They spoke about the plan, and I didn't feel it would allow the student to continue growing. I didn't think the plan would be challenging enough."

Danny said: "There was no experience developing a plan other than in my head. In my head, I was always thinking about what his mother could do that would set him up to be successful. Your questions are making me think about ways the system could have been more beneficial to my son."

IQ8 – Tell me about your experience developing a transition plan?

All participants responded to this question. Analysis of participants' responses indicated that experiences were mixed. Six participants had little problem implementing the plan, especially when they had help doing so; four had problems implementing portions of the plan; and three had issues sustaining what was implemented. Some participants fell into multiple categories. Furthermore, there were concerns about policies and rules. The below quotes indicated the caregivers' responses supporting the analysis:

April said: "I worked hand in hand with the social worker at the school on the implementation plan. It was done jointly with us to carry out the different activities because it worked."

Sonya said: "So, the actual plan for the school I did not implement, but the plan we did for home is what we used. We based the home plan on what they were recommending from school, and with my mom and my stepfather being scholars, we developed something at home. We implemented that one. We would do practice testing at

home. Mommy would sometimes pop up at his school and sit in some classes to see how he was learning in the various environments."

Alice said: "I do my best, but there are rules and regulations in a facility. Plus, residents have families. There are limits to what I can do. I implement what I can."

IQ9 – Describe a time when you had to advocate for your adolescents' resource needs when developing the transition plan? And what was the outcome?

All participants responded to this question. Three stated that they needed to advocate for resource needs more when developing the transition plan. However, upon analysis of the caregivers' responses, eleven out of eleven respondents indicated that having some advocacy skills was crucial in gaining the needs you want or prefer for the adolescent. This included the three that did not advocate or did not advocate much. Also, eight participants expressed that knowing what to ask for, how to ask, or when to ask can also help with what is received or how the plan is approved. The below quotes indicated the caregivers' responses supporting the analysis:

Alice said: "I advocate for the kids all the time. They always need something. Being in a facility, I'm not always successful, and it is frustrating because they want to do other things, like work. Sometimes, I don't know what to say to get them what they want. You know, get it approved."

April said: "I didn't have to do strong advocacy because the social worker at his school had worked with him for years and worked with our family to ensure his needs were met. The only issue of advocating that I think I would say that I had to do most was with the portion of the plan that was to work with the rehabilitation office on some of the

job assignments. I could have pushed and advocated even more. "It was approved, but it took a lot to get an assignment. He never got a real placement."

IQ10 – How prepared were you to advocate? And how could you have been better prepared?

All participants answered this question. However, only four explicitly stated that they were prepared to advocate for resources for the adolescent in their care. Analysis of the respondents' answers indicated that it is essential to be prepared to advocate and ask for what is needed. It was their duty to do so. The below quotes indicated the caregivers' responses supporting the analysis:

Danny said: "I was 100 percent prepared to advocate because this is my child, and he is the only person I had a responsibility to advocate for. I never found it difficult or cumbersome because I knew I would advocate for him for the rest of his life. Being a fierce advocate for your child is a duty; it's a responsibility. The only way I could have been better prepared was to know where to get what he needed myself. Not have to ask others."

April said: "I was not prepared to advocate but feel I could have been better prepared. I was 100 percent nurturing. I think I was a handicap to him and myself by being overly concerned about the amount of his disability in conjunction with the intellectual disability. Having others to help me was useful."

RQ3

Theme 3: Social Support Systems

The caregivers consistently mentioned the importance of having support in their caregiving role. They mentioned needing support while caring for the adolescent with acquired intellectual disability and support in obtaining resources needed for the adolescent. Support was in the form of real-time help with caregiving, developing and implementing the transition plan, or having someone to listen to them.

IQ11 – What do you know about social support?

All the participants answered this question. Each participant appeared to know something about social support. Seven participants said explicitly what social support was to them. Analysis of responses to this question indicated that the seven caregivers knew that social support was having someone to help them and stated that it was important to them in their role as caregivers. The below quotes indicated the caregivers' responses supporting the analysis:

Shannon said: "I know a lot about social support personally. Social support is having friends, counselors, and resources in the community, especially respite. Support groups are good for caregivers so that you know you're not alone and that some people have other resources. They have been through what you're going through."

Vivica said: "Social support is critical. Giving each other resources or helping each other out. This is everybody; it is the community. It means we help and support each other."

Danny said: "He had family and the support we built around him, including the school system, medical care, and counseling. It was broad. Some of it I expected, and

some of it I cultivated. I cultivated it with the schools because I didn't feel like they were adequately prepared to deal with his particular disability. With his family, friends, and with his medical doctors, I expected it because these were all people who were invested in him succeeding. They were invested in me too. They helped me help him."

Sonya said: "The state did provide financial support when he was younger. I didn't pursue it when he got older. The school didn't talk about it. I didn't make plans early, not even in high school. There needed to be a follow-up. There was no monitoring to see if we needed to revisit developing an official school plan. That's why I know just this family and people. My family supported me and him. They still do."

IQ12 – What does social support mean to you?

Ten of the 11 participants responded to this question. Upon analysis, the ten who responded felt it meant a lot to them to have support when needed. Furthermore, the 10 participants believed that caregiving is challenging without it. The below sample quotes indicated the caregivers' responses supporting the analysis:

Tricia said: "It means a lot because I get such support from my husband, I get social support from my mom and my kids, and it means a whole bunch to me. I don't know what I would do without it."

April said: "Social support means internal and external support from your family that could come in waves. The support you get from various organizations and various branches of government may provide some sort of support. Even supplemental SSI for people with disabilities. This means you can get support from anywhere."

Shannon said: "It means friends. Someone to talk to, to listen. To help me reason with myself. Caregiving is a challenging job, and you become frustrated and overwhelmed. Having someone to help you sort out what the issue is."

IQ13 – How have you experienced social support in your role as a caregiver to assist you in helping the adolescent through the transition process?

Ten of the 11 participants responded to this question. Analysis of the responses indicated that support was received from various sources. A source of support could have been a family member, educator, faith-based organization, community program, provider, and more. Nine out of the 10 respondents indicated that the support was helpful and experiences were positive. The below sample of quotes indicated the caregivers' responses supporting the analysis:

Danny said: "I think that the biggest support I had was his mom. To have two parents fully engaged in ensuring his needs are met so we can set him up for the future. That's huge because we were divorced. A couple working in tandem to provide support was good, especially someone who knows what the family has been through. As strange as it sounds, as caregivers, you still need that emotional support to give you a shoulder to cry on when you feel frustrated that you are not doing enough for your child."

April said: "Social support for me as a caregiver has been critical because of his disabilities. The insurance for his care and services must be taken care of. Working with social workers and providers helps to navigate the system so that he can continue to get the help and the service that provides his medications, which cost thousands of dollars a month. He has been put in a position to spend zero. As a family, we have done much to

get him where he needs to go. We need help to ensure he gets where he must go. Helping him to get money for his medicine when he was older was good."

Robert said: "Because of how close I am to the person I care for, we have the same social group. Everyone in my social group has been accepting of the person I take care of. My brother can look up to the people I look up to, too. It is not a solo endeavor."

Shannon said: "My support system was helpful. I could rely on my friends to be there. They were there for me when I needed to talk. Caring for my sister's problems would have been tough without them."

IQ14 – How do you perceive the support you received as a caregiver to assist you with the transition process of an adolescent with acquired intellectual disability? Describe what made you perceive it that way.

Ten of the 11 participants responded to this question. Analysis of this question indicated that caregivers generally perceived support to be good. Nine of 10 respondents perceived school support as helpful. Ten out of 10 perceived support from family and friends as consistently well received. All support was appreciated. The below sample of respondent quotes indicated the caregivers' responses supporting the analysis:

Kay said: "From school counselors, for the most part, and for what he has needed or wanted, it has been good. That may change as he gets older and out of school. I'm concerned about them being unable to help us when he graduates. That will be rough for me."

Sonya said: "Initially, the school was supportive, but because we didn't have a plan, they didn't follow up. On a scale from one to five, with five being the best, as he

progressed and we decided not to do a plan, follow-up would be a zero because there was no follow-up. There were no questions after the fact. They didn't keep in touch after the fourth grade. His doctor was supportive and gave me a lot of information. As far as community, his doctors, family, and friends helped."

Robert said: "I am very grateful for the support and knowing that I could rely on others if I needed a specific resource and couldn't provide it on my own. Having other people to talk to work. If I was working on my mental state and well-being, I had someone to help so I wouldn't neglect the other person's well-being."

IQ15 – What did we not discuss that you wish to share?

Seven of the participants had nothing additional to add. Those that did mentioned several issues: being better prepared, parents being barriers in their adolescent's transition process, fear and failure, as well as always being in their adolescent's life. These are important issues and possible topics for future research. The below quotes were the responses of caregivers supporting the analysis of this question:

Vivica said: "The questions asked were very stimulating. They got me thinking about how I can better prepare."

April said: "I think this is a very heated topic, and there is a need for discussion early after the adolescent acquires a disability. Sometimes, we can be a huge part of why the transition is not working or taking place."

Danny said: "We don't talk about fear and failing as a caregiver. What is the definition of success? We don't talk about it, and we should."

Robert said: "I feel like I have a stake in how my brother is doing in adulthood. I'm always going to be a person taking care of him."

Summary

In Chapter 4, I presented findings. Themes and subthemes were paired with relevant research questions. A summary of participant responses was provided. Participant quotes that supported themes were included. In Chapter 5, I interpret findings in relation to the social support theory. I also describe social change implications as well as recommendations for action and further areas of study, study limitations, and a conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Through this phenomenological research study, I intended to depict lived experiences of caregivers of adolescents with acquired intellectual disability when transitioning to adulthood. Three research questions were explored:

RQ1: What do caregivers of adolescents with acquired intellectual disability experience as they support adolescent transitions into adulthood?

RQ2: How do caregivers of adolescents with acquired intellectual disability experience social support for their caregiving roles during the adolescent transition process to adulthood?

RQ3: How do caregivers of adolescents with acquired intellectual disability experience development and implementation of adolescent transition plans?

Findings of the study indicated three significant crucial themes involving this topic: knowledge and meaning of caregiving, transition plan development and implementation experience, and social support systems. Three subthemes were also identified: responsibility to care for adolescents, motivation and caring about adolescent well-being, and assistance after high school.

Interpretation of the Findings

Theme 1: Knowledge and Meaning of Caregiving

Results of this study showed caregivers of adolescents with acquired intellectual disability knew what caregiving was and what it meant to them. These caregivers believed caregiving meant caring for others who could not care for themselves. Because adolescents they cared for had limited cognitive ability and skills in terms of self-care,

participants resolved they would do what was required to ensure adolescents were taken care of during their lifetime. This included enlisting others to assist as needed.

Huang et al. (2020) found Chinese grandmothers who were caregivers for grandchildren with disabilities understood their roles and what it meant, and despite societal perceptions, they continued to care for their grandchildren. They were aware of the stigma associated with having a child with a disability in Chinese culture and experienced shame and suffering because of it. They also worried about their grandchildren being rejected. However, they resolved to deal with difficulties because they believed in family. Their role was not only important to parents, but also important to the stability of the family unit.

It was anticipated that caregivers generally knew what caregiving was. Level of care suddenly changed, leaving caregivers ill-prepared and needing assistance with their caregiving roles. Turan et al. (2021) found when Turkish caregivers of people with epilepsy felt they could not take care of them, they needed assistance. However, the more prepared caregivers were, the less burdensome they believed their caregiving roles to be.

Sub-theme 1: Responsibility to Care for Adolescents

Participants expressed they expected to be caregivers for the rest of their or their adolescents' lives.

Subtheme 2: Motivation and Caring about Adolescent Wellbeing

Participants expressed they were concerned about adolescents' current and future wellbeing. Some of the concerns involved questions regarding who would advocate for or take care of adolescents when they could no longer do so as well as social life, medical

needs, and education. They also stated knowledge of available resources as well as techniques or strategies would have been helpful when advocating for their needs. They wished they had been more motivated to be forceful so they did not come up against barriers they experienced. Samadi et al. (2020) found that parent caregivers in Iran needed support to maintain motivation to enhance quality of life of their children with disabilities.

Theme 2: Transition Plan Development and Implementation Experience

Participants had mixed experiences regarding transition plan development and implementation. Support provided by school staff and medical providers varied and was not sufficient. Some got precisely what they wanted and needed while others only partially got what they wanted or needed. Their satisfaction with processes and how plans turned out also varied. Bender et al. (2023) found families need more points of engagement from school staff. Brown et al. (2020) found it is vital for healthcare providers to respond to needs of caregivers during transition. Coordinated planning with a person-centered approach and sufficient communication is important in healthcare during the transition process.

Subtheme 3: Assistance after High School

Participants were concerned about being lost to follow up. Some expressed it was uncomfortable to lose help schools provided. However, others established connections with other supports and hoped to maintain those supports for welfare of adolescents. In addition to relationships, some participants hoped that the transition plan was developed in a manner that could be followed after high school. Bender et al. (2023) found school

staff could have helped families develop plans more rigorously by meeting with them more often at various stages of the process. Plans should be tailored to needs of families and adolescents, making it more likely that objectives can be maintained even when they leave school environments. Nurse assistance outside of the school system may be helpful during school years. This plus guidance from school staff while adolescents are in school may be productive. After adolescents leave school, nurses in the medical space can be helpful during various stages of transition throughout their lives.

Theme 3: Social Support System

Participants indicated having a system of social support was crucial to caring for adolescents with acquired intellectual disability. According to Bremer and Brooks (2021), social support yields positive feelings when recipients believe they are not alone and they can rely on others to assist them in fulfilling needs or accessing goods and services when needed.

Advocating and support-seeking go hand in hand (Bremer & Brooks, 2021). Social support networks were helpful to the caregivers in this study when facing challenges. Caregivers with a robust support network appeared to be more successful at meeting the needs of the adolescent with or without school-based or medical provider assistance. Opoku et al. (2020), in their study about the challenges parents of children with intellectual disability face surrounding support services, concluded that increased efforts are needed to develop better social support systems in education. Having a solid social support system is necessary. However, neither study focused on caring for an adolescent with acquired intellectual disability.

Limitations of the Study

There were limitations in this study. The sample size was 11 participants, all of whom volunteered. This could mean they were more amenable to answering questions. The participants were caregivers who had to be English-speaking. Non-English speakers may have had different experiences. Proof of diagnosis was not required to participate. It was assumed that the caregivers shared the diagnosis accurately. The thoughts shared by each caregiver reflected their experiences and perspectives regarding the phenomenon of interest. They may not represent this entire population of caregivers.

All caregivers were recruited and interviewed during the COVID19 pandemic. This was unexpected. No specific questions were asked about their caregiver experiences during the pandemic, which may have impacted their perspectives and responses.

As the researcher of this study and the mother of a child with a brain tumor, I acknowledge such bias as a potential limitation. To mitigate this limitation, I performed bracketing of my prior experiences and judgments. I took note of them. I also interviewed the participants and interacted with them with an open mind seeking to understand each caregiver's experiences.

Recommendations

This phenomenological study focused on the lived experiences of caregivers of adolescents with acquired intellectual disability transitioning to adulthood. The caregivers who participated in the study were the primary caregivers of the adolescent or had a significant caregiving role. Others besides parents can be caregivers. An in-depth focus of

the caregiving experiences of non-parents of adolescents with acquired intellectual disability should be explored.

For this study, adolescence was considered 14 to 22 years old. Future research addressing the lived experiences of caregivers of youth with acquired intellectual disability over the age of 22 is recommended. Exploring the experiences of caregivers of an adolescent with acquired intellectual disability during other stages of life could yield valuable information. Furthermore, the study included mainly female caregivers. Conducting a study of male caregivers of this population could be done. There were two sibling participants in this study. The sibling subset of caregivers of this population should be explored more too.

The participants considered transition plans to be necessary. However, their experience with developing and implementing their respective plans varied. One parent opted out of the formal process involving school assistance. Yet developing a transition plan was still important. This parent developed one with family and friends. A potential area for research could be to explore the experience of caregivers who choose to develop a transition plan without school assistance. Exploring the success of those plans could be another area of research.

Although not a research question for this study, the participants considered the ability to advocate a critical skill. To that end, another recommendation is to conduct a study to explore caregiver comfort and skill in advocating for their adolescent's needs. Comparing advocacy success to meeting the goals of the plan would be of interest too.

Implications

This study promoted social change regarding the lived experiences of caregivers of adolescents with acquired intellectual disability transitioning to adulthood. It highlighted the needs caregivers have while caring for the adolescent. Caregivers knew what caregiving was and what it meant to them. Although caregivers considered transition plans necessary, their ability to develop and implement one differed. Each had established a social support system of both formal and informal support. Informal social support was often helpful whereas, formal social support was not always as helpful as desired.

The insight provided by the participants was valuable in offering a peek into the lived experiences of caregivers in their caregiving role, transition plan development and implementation, and how support systems impact caring for an adolescent with acquired intellectual disability transitioning to adulthood. Understanding the lived experiences of this group of caregivers' aids in understanding how best to support them. What they shared should provide others with information on what resources and types of support these caregivers need.

The implications for social change is that it may increase awareness of this group of caregivers' needs and the support they require to care for their adolescents successfully. This study allowed this subset of caregivers the chance to share their experiences and allowed their voices to be heard. I hope that the findings lead to development of programs or services tailored specifically for them.

The study highlighted what caregivers experienced as they cared for their adolescents. They expressed the need for support. Specifically, support in transition plan development and implementation. Their support systems contained formal and informal support. Although they seemed satisfied with the informal support received from family and friends, formal support from school staff and healthcare providers was not always sufficient or what was wanted. Caregivers may be able to provide complete support to the adolescent in their care with the appropriate type of resources to meet their needs.

Conclusion

The goal of this phenomenological research study was to gain a rich understanding of the lived experiences of caregivers of adolescents with acquired intellectual disability transitioning to adulthood. Through the interviews, it was learned that caregivers understood what caregiving was and that they were aware that caregiving would be needed for the adolescent's lifetime. Caregivers also expressed the need to rely on their social support system in the development and implementation of transition plans. Formal support was not always helpful. This was more evident as the child aged out of pediatric care and high school. Relevant support for this subset of caregivers as they execute their caregiving responsibilities is required and needed.

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Appendix A: Interview Protocol

Hello, my name is Melinda Jordan. Thank you for coming today. The purpose of this interview is to understand your experience in helping your child with intellectual disability transition from adolescence to adulthood; your experience with the development and implementation of a transition plan for your youth; and how you perceive the support you received in assisting your youth throughout the transition process. Feel free to provide open and honest responses. There are no wrong answers. This is not a test of your skills or abilities. Your responses will be kept confidential. You will be assigned a code name. The transcripts and all study documents will be kept in a locked file cabinet.

Tape Recorder Instructions

I will record the interview so that I can obtain details while I focus on a meaningful conversation with you. Our discussion is confidential. I will compile a report that contains all of your statements without any references that identify you or anyone you discuss specifically.

Consent Form

Do you have any questions? If not, please read and sign this consent form before we begin the interview.

Procedure

A one-on-one, in-depth interview will be conducted with each participant by Melinda Jordan. Each interview will be conducted on the phone for approximately 30-60 minutes. Each interview will be audio taped and transcribed verbatim.

The purpose of the study and participants' rights will be explained prior to starting each interview. Informed consents will be obtained from all the participants.

Time will be spent before the start of each interview to build trust and rapport. Participants will be asked open-ended questions regarding their experience with helping their adolescent with acquired intellectual disability transition to adulthood.

Exit Procedure

At the end of the interview, the participant will be reminded that the conversation is anonymous. They are free to contact me if they have questions or concerns. The participants will be reminded that they will be asked to verify their statements and a summary of the description of their statements.

Appendix B: Interview Questions

1. What do you know about caregiving?
2. What does caregiving mean to you?
3. What do you know about acquired intellectual disability?
4. What do you know about the transition process to adulthood for an adolescent with acquired intellectual disability?
5. What does the transition process to adulthood for an adolescent with acquired intellectual disability means to you? And how have you experienced it?
6. What do you know about transition plans?
7. Tell me about your experience developing a transition plan?
8. Tell me about your experience implementing a transition plan?
9. Describe a time when you had to advocate for your adolescents' resource needs when developing the transition plan? And what was the outcome?
10. How prepared were you to advocate? And how could you have been better prepared?
11. What do you know about social support?
12. What does social support mean to you?
13. How have you experienced social support in your role as a caregiver to assist you in helping the adolescent through the transition process?
14. How do you perceive the support you received as a caregiver to assist you with the transition process of an adolescent with acquired intellectual disability? Describe what made you perceive it that way.

15. What did we not discuss that you wish to share?

These questions will enable the participants to freely express their personal experience in their own words. When necessary, additional questions for clarification and elaboration will be asked. Furthermore, silence will be used to prompt participants' recollections of their experience. More general questions will be used to prompt the participants to expand their experience or to redirect the discourse should it become too general; these may include:

1. Tell me more about what you mean when you said....?
2. How did you feel when...?