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Latino Caregivers Experiences with Transitioning Children from Pediatric to Adult Disability Services

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2020

Abstract

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MPhil, Walden University, 2019

MSW, Marywood University, 2001

BA, Bloomsburg University, 1995

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Human and Social Services, Family Studies and Intervention Strategies

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Abstract

Caregivers for children with disabilities may experience caregiver burden when transitioning their offspring to adult healthcare services. As the Latino population in the United States increases, so will the numbers of Latino caregivers of children with disabilities. This research described the experiences of Latino female caregivers who transitioned their children from pediatric to adult healthcare services. General systems theory was used to guide this research. The hermeneutical phenomenological approach was used to describe Latino female caregiver's experiences involving transitioning children with disabilities from pediatric to adult services. Bryman's 4 stages of data analysis were used to assist with thematic content analysis once data were gathered from interviewing participants. The following 5 themes emerged as a result of the data analysis: effects of the transition process on the caregivers, sources of information regarding the transition process, support received during the transition process, challenges during the transition process, and recommendations to assist caregivers during the transition process. Findings from this study provide information regarding the challenges that Latino caregivers experienced as they transitioned their children with disabilities into adult health care services. Human services and other professionals could promote social change by using the information to advocate for changes in policies and procedures that ease the process of transitioning children with disabilities into adult health care services, which would further promote social change by reducing the burden that caregivers endure when making the transition.

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Dedication

I dedicate this dissertation to my husband, Eddie, who has been by myside since my journey began and stayed with me to fulfill my accomplishments. Also, I dedicate this study to my three children, Miguel, Angel Marie, and Adam who served as my motivation to accomplish this study and provide valuable information to the world. Furthermore, I dedicate this study to my parents and the rest of my family who gave me encouragement, support, and feedback every time they saw me to keep going and finish.

Acknowledgments

I am very thankful for the dissertation committee for being present and supportive during this dissertation process. I want to thank my dissertation chair, Dr. Sandra Harris who kept pushing me not to give up and motivating me when I felt defeated during this journey. Dr. Harris is a wonderful leader, mentor, and inspirational person that I learned from and appreciate due to her countless time and efforts with me.

I want to thank my dissertation committee member, Dr. Tracey Phillips, for agreeing to be on the committee. Dr. Phillips has been very essential in my dissertation process and I thank you for always communicating with Dr. Harris to help me finish the dissertation. I know you have a lot of other responsibilities but you taking the time to serve on my dissertation committee will never be forgotten.

I want to thank the university research review committee member, Dr. Andrew Garland-Forshee for being a member of the committee. Thank for you input and timely feedback.

Finally, I would like to thank the Latino participants and community offices who gave their time and shared their experiences me. I have spoken to many individuals in my journey about your experiences. I have learned a great deal and hope the information will serve a great purpose to create social change in our communities.

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Chapter 1: Introduction to the Study

Introduction

Caregivers experience a great deal of stress while caring for children with disabilities (Goudie, Narcisse, Hall, & Kuo, 2014; Kyzar, Turnbull, Summers, & Gómez, 2012; Yousafzai, Farrukh, & Khan, 2011; Zan & Scharff, 2015). These sources of stress among caregivers are related to parenting, financial burdens, and the inability to have a life outside the home while providing care to a child with disabilities (Goudie et al, 2014; Paczkowski & Baker, 2008; Zan & Scharff, 2015). While there is a great deal of literature on the stress that caregivers experience while caring for their children with disabilities, there is little available research which addresses the experiences of Latino caregivers who provide care for children with disabilities. My study will contribute to the literature by focusing on the experiences of Latino female caregivers while transitioning their children with disabilities from pediatric to adult services.

In this chapter, I will present the background for the study, problem statement, and purpose of the study. The theoretical framework in this study will be a guide for the nature of the study to help answer the research question. Also, I will discuss the definitions, assumptions, scope and delimitations, limitations, and significance of the study.

Background

Providing care to children is a typical part of parenting. However, when caregivers provide an extraordinary level of care to a child with functional limitations and disabilities, parents can experience unique stressors associated with providing that care

(Dambi et al, 2016). Goudie et al. (2014) reported that caregivers of children with disabilities had two times more financial and psychological stress compared to caregivers of children without disabilities. Edelstein, Schippke, Sheffe, and Kingsnorth (2017) found that caregivers of children with disabilities experienced stress related to finances, specialized care needs for medical complexities of the child, access to services and amount of time spent with the child (Edelstein et al.,, 2017). The families use of interventions related to streamlining of services helped reduce caregiver stress but did not eliminate stress (Edelstein et al., 2017).

Kyzar, Turnbull, Summers, and Gómez (2012) completed a synthesis of the literature that focused on families of children with severe disabilities and how the unmet needs of the children affected family functioning, family satisfaction, family quality of life, and family stress. Results showed that family support was a major factor related to positive family functioning. The more sources of support available for caregivers, the higher levels of family satisfaction and the less likelihood of caregiver burden/stress (Kyzar et al., 2012). Kyzar et al. (2012) recommended that future research should consider the use of family systems theory as a theoretical lens for a study on family support. A major limitation to the study was the lack of varying ethnic populations represented in the sample. A recommendation was that future studies should focus on culturally diverse populations residing in the United States (Kyzar et al., 2012). My proposed study will expand on the literature by focusing on the experiences of Latino caregivers.

Sonneveld, Strating, van Staa, and Nieboer (2013) focused on the experiences of parents of adolescents with chronic conditions during the transition of services. Findings revealed that parents were not satisfied with the coordination of transition services among medical providers. Several medical providers who participated in in the study shared that they too perceived the coordination for transition of services from pediatric to adult services had some limitations based on adolescence lack of ability to practice self-care and parents inability to parent the adolescent. Results from the study revealed there was a need for improvement of care delivery processes with the coordination of transition services for both parents and medical providers (Sonneveld et al., 2013). My proposed study will focus on Latino caregivers' perspectives of transition services as they navigated through the process of transitioning their children from pediatric to adult services.

Problem Statement

Advances in medical research in recent decades have increased lifespans of children born with many medical disabilities. As a result, many more children with disabilities are for the first time living into adulthood (Baines, 2009; Marti-Morales & Rohrer, 2014; Perrin, 2012). Although cutting edge treatment has made life extending interventions available to children with disabilities that previously prevented most from surviving childhood, the long term supports now necessary to sustain people with disabilities through adulthood has not kept pace with the need. Several researchers have noted that caregivers who attempt to locate specialized health services for children with disabilities when the children move into adult services may encounter difficulties in locating appropriate care because there are fewer specialists treating adults than children with many severe disabilities (Khanna, Ganjiwale, & Nimbalkar, 2015; Marti-Morales & Rohrer, 2014; Perrin, 2012). Latino caregivers may face additional challenges when transitioning their children's care due to language and cultural barriers (Gallo, Penedo, de los Monteros, & Arguelles, 2009). Latino female caregivers may experience additional burdens such as parenting issues, financial strain, childcare issues, and lack of a social life when providing care to children with disabilities (Goudie et al., 2014; Kyzar et al., 2012; Paczkowski & Baker, 2008; Yousafzai et al., 2011; Zan & Scharff, 2015). Caregivers who provide care to children with disabilities may suffer from stress and caregiver burden, which in turn may result in them neglecting their own physical and mental healthcare needs (Kyzar et al., 2012; Wulffaert, Scholte, & Van Berckelaer-Onnes, 2010).

During my search of literature, I was unable to locate any research which focused on the experiences of Latino caregivers while navigating services for their children as the children transitioned into the adult healthcare system. A thorough review of the literature revealed there is a gap in research regarding the lived experiences of ethnic minority groups as they navigate the healthcare system in the US when their children with disabilities transition into adulthood. This study will focus on Latino female caregivers' lived experiences during the navigation of healthcare services for their children as the children turn 18 years of age.

Purpose of the Study

The qualitative phenomenological study took a hermeneutical approach to explore the lived experiences of Latino female caregivers while navigating the healthcare system to transition their children with disabilities into the adult services system. To study this phenomenon, I interviewed Latino female caregivers who have navigated the healthcare system to locate services for their adult offspring with disabilities. Participants were recruited from the Lehigh Valley area in Pennsylvania. Sonneveld et al. (2013) suggested a need for improvement of streamlining of services during the transition for adolescents and parents from pediatric to adult services. Findings from the study can demonstrate best practices for the process of transitioning services for children with disabilities into the adult services system.

Research Question

What were Latino caregivers' experiences with navigating medical and social services for children with disabilities when those children turn 18 years of age and transitioned to adult services?

Theoretical Framework for the Study

The theoretical base for this study is rooted in systems theory. Systems theory, developed by von Bertalanffy addressed the interconnected parts and interrelationships among elements of various systems. The theory has been foundational for use in many different fields within the sciences. Specifically, general systems theory (GST) provided the foundational basis for the research regarding experiences of Latino female caregivers while transitioning their children with disabilities from pediatric to adult services.

Ludwig von Bertalanffy introduced the concept of GST as early as 1937 (Bertalanffy, 1972).The major premise of GST is that multiple systems of an organization share organizing principles. Another premise of GST is on how the attributes from various fields of discipline interconnect to one another to create a holistic approach. The attributes interacting in a system can be closed, open, and isolated systems. In GST, the open system refers to interaction between attributes and their surroundings. For this study, the caregivers need to navigate systems in their environment. (Mele, Pels, & Polese, 2010; Pouvreau, 2014; Rousseau, 2015).

For this study, principles of GST were used to determine the experiences mothers face when attempting to transition their children with disabilities from pediatric to adult services within the healthcare system. Findings revealed that the mothers had to navigate through multiple organizations and processes to obtain the needed adult services after the children reached age 18 years of age. The results from this study could be used to develop recommendations for programs, services, and information to make transitions smoother for caregivers. Further details regarding this theory are presented in Chapter 2.

Nature of the Study

This study was a qualitative inquiry a phenomenological hermeneutic approach. A qualitative study involves using open-ended, exploratory, and descriptive research to examine individuals or groups of people’s social problems (Yilmaz, 2013). The phenomenological approach involves focusing on a person’s lived experience of an event during a specific time frame (Marshall & Rossman, 2014; Sloan & Bowe, 2014). The phenomenon of interest for this study was Latino caregivers’ experiences with the process of transitioning their children with disabilities to adult services programs. The specific time frame will be the point at which the Latino caregivers were informed by their pediatricians of the need to transition the child with disabilities to adult services. Therefore, the phenomenological approach was well-suited for this study because it allowed me to examine Latino caregivers' lived experiences of transitioning their children to adult services.

The hermeneutical approach allows a researcher's attempts to make meaning of or interpret participants' lived experiences of a phenomenon (Sloan & Bowe, 2014). I chose this approach for my study because I was interested in Latino caregiver's' lived experiences of transitioning their children with disabilities to adult services. This study adds to the literature regarding Latino experiences involving transitions because empirical data that can be used to support recommendations for solutions to the challenges caregivers face during this time period in their lives.

The sample size in the qualitative study needs to have enough participants so that the information gathered is sufficient for achieving saturation without becoming repetitive (Mason, 2010; Dworkin, 2012). I gathered sufficient data to achieve saturation for my study by using 10 participants. Participants' experiences were captured using semi structured interviews through the use of an audio recording device. The voice recordings were transcribed. Transcriptions were used for the data analysis. Participants were Latino female caregivers of adult offspring between the ages of 18 to 24 years with disabilities.

Definitions

Identified terms and definitions are for the purpose of this study:

Disability: The Office of Social Security (2017) defined a disability as a physical or mental condition that creates limitations which persist for 12 months or longer.

Latinos: The United States Bureau Census (2017) defined Latinos as people who speak Spanish and are descendants from Central America, Cuba, Dominican Republic, Mexico, Puerto Rico, Spain, and South America.

Assumptions

There are three assumptions associated with hermeneutic phenomenological studies. The first assumption was that a sufficient number of participants from Latino decent who fit the inclusion criteria for the study volunteered to take part in the research. The second assumption was that participants openly shared their firsthand experiences involving this topic. The third assumption was that participants accurately remembered their experiences. Assumptions help to explain the study adequately and recognize common experiences.

Scope and Delimitations

This study examined the lived experiences of Latino female caregivers who transitioned their children with disabilities from pediatric systems to adult systems of care. In order to participate in this study, participants had to meet the following criteria:

1. Participants were Latino female primary caregivers of children with disabilities who transitioned from pediatric to adult services within the last 6 years.
2. Children with disabilities were not older than 24 years old as medical insurance rules change for dependents after24 years based on the ACA.

3. Children with disabilities had physical and/or emotional disabilities.
4. Participants were fluent in English.

One delimitation in the study involved participants' inability to read or write in English. If potential participants were not proficient in English, they were excluded from participating in the research. The delimitation were addressed during the prescreening of potential participants to determine whether they fit inclusion criteria for the study. Participants who speak Spanish only were excluded from participating in the study.

Limitations

There were several limitations associated with this study. The first limitation was that the inclusion criteria was too narrow for the Lehigh Valley area, which created difficulties in securing the targeted number of participants. In addition, Latino caregivers may have trust and immigration issues. Identifying Latino caregivers who met criteria through medical offices in the Lehigh Valley area in a timely manner prolonged the duration of the research. The narrow criteria of a Latino female caregiver who transitioned a child with disabilities from pediatric to adult services added to the length of time to gather data prolonging the study. In addition, experiences of caregivers were the focus of the research and not the experiences of medical providers, human services professionals, or the offspring with disabilities. Therefore, the focus on the parents' experiences may pose limitations on the transferability of results from the study.

This study was limited to caregivers of Latino ethnicity. Consequently, potential findings from this study may not be transferrable to other caregivers of other ethnic or racial groups. Also, this study was qualitative in nature and findings were bounded by interpretations which cannot be transferrable to a quantitative analysis based on statistically analysis and not thematic content.

Personal bias is a limiting factor in this researcher, because I am also a Latino with adult children with special needs. To address this bias, I kept reflective journal notes as I gathered information from participants and transcribed and data and analyzed data. Journal notes helped me control my bias. Upon analyzing my reflective journaling process and entries, I reviewed how I felt during the study. My journal notes helped with controlling my bias throughout the study as I maintained an audit trail to maintain credibility of this qualitative research. The audit trail was an assortment of resources and notes used within my research process showing how my assumptions and decisions were made within the study.

Significance

This study is needed in order to gather information regarding challenges that Latino parents experience while navigating the process of transitioning their children with disabilities from child to adult health and social services. The results of this study can lay the groundworks to advocate for the development or revision of new policies, procedures, or interventions for medical services and other professionals. New developments and revisions of such policies and procedures could remove specific barriers for Latino mothers and other caregivers of children with disabilities. Findings from this study is useful to support in improving communication and coordination between pediatric and adult systems with revising protocols on the transition process. The results of this study could be used to promote social change through the review of current programming or development of programs and educational seminars to provide information to caregivers of children with disabilities to aid with the transitioning services for children with disabilities to adult healthcare systems.

Summary

Chapter 1 introduced societal issues involving caregivers experiencing stress and burden when raising a child with disabilities. This study gathered the experiences of Latinos for the first time. These results inform practice improvement or policy changes that can remove particular barriers Latino caregivers experience while transitioning their children from pediatric to adult services. These experiences can help begin discussions among various medical providers regarding improving procedures and processes for transition services.

This chapter included the introduction of the study and background, problem statement, purpose of the study, and research question. Also, Chapter 1 introduced the theoretical framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance to the study. Chapter 2 includes the literature review and information regarding the theoretical framework of the study.

Chapter 2: Literature Review

Introduction

Caregivers of children with disabilities may suffer from caregiver burden related to parenting, financial stress, childcare, poor socialization skills, and poor self-care (Goudie et al., 2014; Kyzar, Turnbull, Summers, & Gómez, 2012; Paczkowski & Baker, 2008; Wulffaert, Scholte, & Van Berckelaer-Onnes, 2010; Yousafzai, Farrukh, & Khan, 2011; Zan & Scharff, 2015). After children with disabilities turn 18 years old, caregivers must transition them from pediatric to adult services. Caregivers can face difficulties with caregiver burden when attempting to follow through with the process of transitioning from pediatric to adult services for their children. Caregivers attempting to find specialized health care options for children with disabilities may have difficulties as the child approaches adulthood (Khanna, Ganjiwale, & Nimbalkar, 2015; Marti-Morales & Rohrer, 2014; Perrin, 2012). Special populations such as Latino caregivers have additional challenges stemming from cultural and language barriers (Gallo, Penedo, de los Monteros, & Arguelles, 2009). The purpose of this phenomenological qualitative study is to explore the lived experiences of Latino female caregivers while navigating the healthcare system as their children with disabilities transition into the adult services system.

The next section describes literature search strategies. Following that is a focus on the theoretical foundation of GST. Next is information on caregiver burdens and stress when caring for children with disabilities. The final part of Chapter 2 focuses on the transition process from pediatric to adult systems for children with disabilities turning 18 years of age.

Literature Research Strategies

During research for articles for the literature review, I found articles related to the topic of this study by exploring the Walden University database and BioMed Central. I accessed the following databases through the Walden University Library: EBSCOhost, SAGE Journals, European PMC, and Google Scholar. Key search terms used in the study were *disabled children*, *transitions, healthcare transition*, *transition process*, *caregiver burden*, *adolescent children transition, adolescent transition, parenting chronic conditions, adolescents with special healthcare needs, children disabilities, gaps in transitional care, family support, female caregiving, culture and child, Latino children with disabilities,* and *Latino caregivers.* As I continued to review articles for research, I checked references in journal articles, and those references led me to review additional articles related to my topic including research involving populations located outside of the United States. Due to limited research within the United States, I included additional articles on populations located in other countries. Additional studies were conducted in the Netherlands, Pakistan, and Sri Lanka.

Theoretical Foundation

The framework for this research is based in general systems theory (GST). GST was first introduced by Ludwig von Bertalanffy in 1937 (Bertalanffy, 1972). Originally, GST was used to explain the interconnected parts and interrelationships among elements of various systems (Bertalanffy, 1972).

General system’s theory has since been adapted for use in many different fields. The major premise of GST in research is to demonstrate the relationships between principles, properties, and laws that are characteristics of a structure or behavior (Pouvreau, 2014; Rousseau, 2015). Therefore, the principles of GST are useful when focusing on the supporting and complementary roles of professionals from a variety of disciplines as they communicate with one another to help connect among systems (Caws, 2015; Mele et al., 2010; Rousseau, 2015).

Mania-Singer (2017) conducted a qualitative case study using sociograms, observations, surveys, interviews, and document reviews with GST as the theoretical foundation to examine how interactions occurred among branches of school systems. Findings showed that infrequent communication between members of the district central office and principals resulted in poorer school performance. Higher performing schools were shown to have greater opportunities to contribute to decision making. These chances to interact between the school and the district had a positive impact on the transfer of knowledge and communication and hinder school-level development efforts (Mania-Singer, 2017). GST was instrumental in understanding the various interactions among systems. While the topic of study is different, the methodology employed in the Mania-Singer (2017) study was instrumented in determining the methodology to employ for my research.

Yasar (2017) qualitative study used GST to examine preschool teachers' classroom management experiences related to one another through the systems of structural family therapy, classroom, and family belongingness. Yasar’s research team interviewed eight preschool teachers from Yuregir, Adana twice within same year, Interviews focusing on identifying classroom management methods and investigating the types of management problems that arise in each classroom. Yasar (2017) found that teachers with authority, clear rules, and consistency in the classroom tended to have students who formed a sense of family belongingness in the classroom with minimal behavioral problems. The researcher was able to use GST to show how the systems, teacher and classroom context, interacted to evaluate the students' behaviors.

The GST can be used to explain how professional systems work together for serving Latino families of children with disabilities when parents transition those children to adult healthcare services (Marsh, & Rodrigues, 2015). Such information could be used to determine which services from which agencies in the general healthcare system are needed to make the transition smoother for the caregivers. The information could also potentially be used to reveal the need for better collaboration and communication among agencies involved in the transition of services.

Disabilities

The Office of Social Security (OSS) (2015) defined a disability as a physical or mental condition that creates limitations which persist for 12 months or longer of a person's life. The disability could be severe enough that it may shorten the person's life span (Office of Social Security, 2015; Tan, Docherty, Barfield, & Brandon, 2012). A person with disabilities may have to rely upon caregivers to assist with meeting their daily life needs. The caregivers may be responsible for administering the person's medical treatment plan, managing their finances, and applying for any additional community service support (Goudie et al., 2014). The caregivers may also be tasked with finding other resources to support the family such as support services, medical specialists, education systems, and training resources (Bourke-Taylor & Pallant, 2013). If a person has a disability, caregivers may be responsible for lifelong demands to help the person with disabilities as they age (Bourke-Taylor & Pallant, 2013). As medical research continues to expand, people with disabilities are living longer lives despite their chronic medical condition in comparison to previous years (Baines, 2009; Perrin, 2012).

Latino Caregivers

Latinos are the fastest growing population in the United States (Van Hofwegen & Killion, 2011). Latinos comprise of 50.5 million residents in the United States (United States Census, 2017). According to the United States Census Bureau (2017), Latinos can be of any race, but are defined as an ethnicity that includes one or both of the following two elements: a) Latinos are individuals who speak Spanish (United States Bureau Census, 2017), and b) Latinos are also descendants from Central America, Cuba, Dominican Republic, Mexico, Puerto Rico, Spain, or South America (United States Bureau Census, 2017).

A caretaker/caregiver is defined as a person such as a parent, custodian, or guardian who is responsible for the well-being and welfare of a minor in a residential setting (Hamacher, 2015). One of the caregiver’s responsibilities is to provide care for a child with disabilities as he or she turns into an adult. The Latino caregiver for this study will be defined as a person who identifies their ethnicity as Latino with the ability to speak the Spanish language, and the responsibility to provide care to a minor in their home.

The Latino caregiver has cultural beliefs, values, and a language that differs from the mainstream American culture that can create additional stress while caring for their offspring with disabilities (Sherrill & Mayo, 2014). According to Mclaughlin et al., (2013), the experiences ethnic minority caregivers of children with disabilities has not been studied adequately. This study addresses that gap in the literature. The ethnic minority group for this study will be female Latino caregivers who were transitioned their offspring to adult healthcare for medical services.

Transition of Services

Like most children, children with disabilities see a pediatrician for routine and specialized medical care from the time they are born to approximately 18 years of age (Uhl, 2014). The United States law dictates that a person who is 18 years of age or older is an adult. In the medical industry, a child needs to transfer from pediatric services to adult services upon reaching their 18th birthday (Bailyn, 2012; Berg-Kelly, 2011; Uhl, 2014). Because a child with disabilities may not have the capacity to make these types of decisions, the caregiver becomes responsible for arranging the transfer of services from pediatric medical services to the adult healthcare system (Whitenack, 2014).

Many caregivers of children with disabilities find themselves overwhelmed with the day to day maintenance required of ensuring the wellbeing of their children, themselves and their families. During the process of transition, caregivers must complete multiple additional new steps related to transferring medical, education, and other records from one system to the other which must occur at a specific time frame to be successful (Cline & Greene, 2014). Other areas of transition include locating a new adult physician or specialist who can meet the needs of the youth with disabilities, obtaining or transferring medical insurance assistance, securing legal guardianship, navigating human services offices, applying for social security, seeking school or day programming, and selective service registration (Fair, Albright, Lawrence, & Gatto, 2012). Some caregivers may encounter various problems during this transition time related to caregiver burden. Caregiver burden can be psychological stress, financial stress, or inadequate supports that overwhelm the capacity of the caregiver to meet all of the needs in a timely manner (Kaur, 2016; Kyzar et al., 2012; Roth, Fredman, & Haley, 2015; Zan & Scharff, 2015). If caregiver burden occurs, the completion of the transition period and appropriate engagement of adult services for their offspring can get delayed.

Literature Review Related to Key Concepts

Research has revealed that caregivers who attempt to locate specialized health services for children with disabilities when the children move into adult services may encounter challenges in locating appropriate care (Marti-Morales & Rohrer, 2014; Perrin, 2012). Caregivers who provide care to children with disabilities may encounter burdens which negatively affect their health and the health outcomes of their children (Perrin, 2012). According to Perrin (2012), caregivers experience stress, related to caring for their families and trying to provide adequate care for children with disabilities (Perrin, 2012; Dembi et al., 2016). The next section focuses on the literature related to caregiver burden and stress while providing care to their child with disabilities and the transition process pediatric to adult systems.

Sources of Caregiver Burden

Caregiver burden can be severe based on the type of disability a child in their care may have (Kaur, 2016). Caregiver burden can be in areas of financial, psychological, and physical stressors (Kaur, 2016). For this study, the areas of caregiver burden have been identified are cultural and language barriers, financial, emotional/psychological, inadequate social support, and barriers to obtaining care.

Culture and language barriers. Many Latino caregivers face challenges in obtaining care for children transitioning into adult services due to language and cultural barriers (Gallo, Penedo, de los Monteros, & Arguelles, 2009). Latinos and other ethnic minorities may face life-long racism, social inequality, and oppression (Gelman, Sokoloff, Graziani, Arias, & Peralta, 2014). Latino inequality trends in the United States have shown that acculturation issues, poor access to food, lack of access to health insurance, and having lower socioeconomic status adds to the difficulty of gaining access to appropriate care for their love ones, which adds to caregiver burden (Corvin et al., 2017).

Meyer, Geller, He, González, and Hinton (2014) studied the relationship between acculturation and depression issues in Latino caregivers. The authors completed a quantitative study to engage 94 Latino caregivers of older individuals with and without dementia. Results showed that language acculturation, age, marriage or cohabitating increased the likelihood of depression in the Latino caregivers. Another result was that language acculturation increased depression in the older caregivers (Meyer, Geller, He, González, & Hinton, 2014). This study is relevant to my research as caregivers appear to suffer from language acculturation which may be part of the caregiver burden that may be an experience that occurs during the transition process for any of the Latino caregivers (Meyer et al., 2014).

Long, Kao, Plante, Seifer, and Lobato (2015) studied relationships on maternal distress, culture, socioeconomics, and child factors for caregivers of children with intellectual disabilities (ID). The study used 192 Latino and non-Latino White caregivers with children of ID and children without ID. The participants reported on child behavioral issues, child adaptive functioning, familism, language acculturation, and maternal distress. Results showed that Latina caregivers who had children with ID had more child behavioral issues, maternal stress, high familism, and decreased English usage than non-Latino White caregivers with children who did not have ID. The results supported the notion that cultural influences provided a higher level of distress in Latina mothers with children who have ID.

Reira et al. (2015) completed a qualitative study on limited English proficiency (LEP) caregivers who cared for children with asthma difficulties. The researchers used semi-structured interviews along with focus groups to gather information on pediatric medical encounters in the health care system from the caregiver’s perspective. Results showed that LEP caregivers had caregiver burden related to emotional stress, physical changes in their child’s asthma due to breathing difficulties, and language barriers. The language barriers added more complexities to the caregiver burden as LEP caregivers shared their perceptions of interpreters being used in the health care systems, delays in medical care, trust issues with interpreters, and coping with emotional responses. Recommendations from the study were to incorporate education on language barriers and create more appropriate asthma action plans that caregivers can understand (Reira et al., 2015). This study is relevant to my study as it focuses on LEP caregivers who were Latinos and barriers they encountered because of their language preference when dealing with medical offices. My study focuses on experiences of Latino caregivers of offspring with disabilities as they navigate the healthcare system including their experiences interacting with medical professionals and interpreters.

Anania, Nageswaran, Miller-Fitzwater, and Golden (2014) studied Latino families of children with complex chronic medical conditions and how caregivers' cultural beliefs affected their interactions with health care services. Targeted participants for the study were 22 Latino families who were participating in community-based care coordination program. Results showed that language barriers, lack of literacy on health care issues, and inadequate knowledge of the services available for their children in the US were major sources of stress for those families. Additional results showed that cultural beliefs such as beliefs in strict gender roles, mistrust of the medical community, and beliefs in folk illness influenced the caregivers' decision-making regarding end of life preparations for the child. The researchers (Anania et al., 2014) offered several recommendations to the health care systems which service Latino communities including developing policies or practices that are sensitive to how Latino cultural beliefs affect their access to and receptivity to health care systems. This article is important to my study as the information showed how cultural disconnects impacted Latino access to health care.

Financial burdens. Zan and Scharff (2015) studied both the financial and time burdens encountered by caregivers who provide care to children with disabilities. The researchers conducted a quantitative analysis of data from the 2003 to 2006 National Health Interview Survey along with 2004–2008 Medical Expenditure Panel Survey. The sample for this study was 33% Latino which represented the largest minority group in the study. Researchers found that caregivers of children with disabilities suffered greater financial burdens compared to caregivers with healthy children. The added financial burdens among families with children with disabilities were primarily related to the health care costs and out of pocket costs for the families due to the medical disability. The other finding of this study was the concept of time burden. The time burden was associated with missing time from work or school days due to the number of doctor visits required for the child with disabilities, which varied based on the disability. Zan and Scharff (2015) further shared that the severity of the child's disability impacts the level of caregiver burden in various degrees. Limitations to the study were that financial and time burdens were not consistent for the caregivers. Another limitation was the researcher's inability to control for the variances between the children's disabilities, which led to varying degrees of caregiver burden. The Zan and Scharff (2015) study is relevant to my research because it addressed the caregiver burden faced by Latinos who care for their children with disabilities.

Saunders, Tilford, Fussell, Schulz, Casey, and Kuo (2015) focused on caregivers of children with autism spectrum disorder (ASD) and intellectual disabilities (ID) to document whether the caregivers financial and employment burdens due to the needs of the children. Saunders et al. (2015) conducted a secondary analysis of data from the National Survey of Children with Special Health Care Needs from 2009 –2010, which contained information from 40,242 interviews. Results revealed that caregivers of children with ASD, ID, and any combination of ASD/ID all suffered some level of financial stress. The financial stress resulted in caregivers needing to reduce work hours or stopping work altogether depending on the level of the child's disability. An increase in financial stress was seen more often among caregivers who had children with the combination of ASD/ID (Saunders et al., 2015). Saunders et al. (2015) is related to my research because it documented the financial burdens families encounter when caring for children with disabilities.

Goudie et al. (2014) studied how the level of stress because of health concerns affect a caregiver's ability to provide care to a child with disabilities. The authors conducted a secondary analysis of data from the 2010 Ohio Family Health Survey. Results from the data showed that of caregivers with healthy children were more likely to experience less stress in comparison to caregivers of a child without a disability. The data also showed that caregivers of children with disabilities encountered twice the amount of stress associated with finances and the caregivers decreased emotional well-being. Limitations of the study were that caregivers were not identified as primary or secondary caregivers. Goudie et al. proposed that further studies should look more into the mental health versus physical health and well-being of the caregiver of a child with disabilities. Another limitation was that the data represented caregivers from Ohio, however the researchers suggested the outcomes of this study may be representative of what the rest of the caregivers go through in the United States (Goudie et al., 2014). Goudie et al. (2014) is important to my proposed study to in that it identified that caregivers of children with disabilities experience multiple sources of stress.

Stress. Several researchers have reported that caregivers who provide care to children with disabilities may suffer from family stress (Kyzar et al., 2012; Wulffaert, Scholte, & Van Berckelaer-Onnes, 2010). The elevated stress levels can create negative health outcomes for the caregiver, thus also jeopardizing the wellbeing of the child (Roth, Fredman, & Haley, 2015). The stress experiences by caregivers is often associated with internal factors that create emotional instability and the caregivers' inability to cope with the emotions (Roth et al., 2015).

Yousafzai et al. (2011) completed a qualitative study that focused on challenges of caregiving for mothers of children with disabilities in Pakistan. The data collection occurred during group sessions of 12 female caregivers over an 18-week time period. The results showed that all of the mothers experienced anxiety and stress. The anxiety and stress came from the lack of appropriate services for their children in the areas of medical care, rehabilitation, and education. Also, caregivers reported stress from lack of support for themselves (Yousafzai et al., 2011). This research article is relevant to my study as the findings revealed the sources of stress associated with caregivers attempting to locate appropriate services for their offspring with disabilities. Caregivers may encounter similar problems and stressors when going through the process of transitioning their children with disabilities to adult services.

Knock, Kline, Schiffman, Maynard, and Reeves (2011) studied caregiver burden and problems associated with caregiver experiences while providing care to children with schizophrenia-spectrum disorders. This qualitative study consisted of interviews from 10 caregivers. Results revealed that the majority areas of caregiver burden were associated with the emotional burden of providing care to their children, demands placed on their lives while caring for their children, and the sacrifices they made when caregiving. Also, the data revealed that caregiver burden increased when the mothers experienced difficulties accessing mental health services for their children (Knock et al., 2011). This study is significant to my study as it addressed emotional caregiver burden and difficulties accessing services for their child as obstacles for caregivers.

Huang, Yen, Tseng, Tung, Chen, and Chen (2014) studied caregivers of children with autism and the parental stress related to the emotional and behaviors displayed by the child. The researchers interviewed the caregivers using the Childhood Autism Rating Scale. The caregivers filled out the Strength and Difficulties Questionnaire and the Parenting Stress Index Short Form. Findings showed that caregivers who had children with mild to moderate autism in the home felt less stress in comparison to parents of children with severe autism. Results also revealed that the children's behavior predicted the level of stress in the parent and child relationships and as well as the level of stress in the children. The study is relevant to my study as caregivers of children with disabilities can impact emotional stress while caregiving.

Inadequate social support. Researchers have indicated that poor social support has a negative impact on caregivers of children with disabilities as they experience stress (Kyzar et al., 2012). Kyzar et al. (2012) completed a literature review of articles published between 1990 and 2010 that focused on the relationship between caregiver support and caregiver outcomes for those who provided care to children with disabilities. Results from the literature review showed that increased caregiver support is related to improved caregiver outcomes. Findings revealed that a caregiver’s major source of caregiver support were family, friends, or professional. The categories of caregiver support included emotional, physical, material, and informational support. Caregivers received 57% of emotional support by talking to someone and 57 % of material support to get basic needs met. The data also revealed that impact of physical and informational support was less effective in improving caregiver outcomes than emotional support. There are several limitations to the Kyzar et al. (2012) study. One limitation is there was no information about the caregivers of children with moderate, severe or multiple disabilities. Another limitation is the results lacked information on the ethnicity of groups included in this study. Furthermore, the study had no information on the caregiver’s financial and employment status. Also, the study did not show caregivers’ experiences when transitioning their children with disabilities from high school to adulthood services (Kyzar et al., 2012).

Tsai and Wang (2009) studied the connection between caregiver’s strain and social support among caregivers with children with ID in Taiwan. Tsai and Wang (2009) interviewed 127 mothers and used the Caregiver Strain Index, Social Support Scale, and three open-ended questions. Results indicated that mother's caregiving children with ID have a higher level of strain and have insufficient social support. Caregivers strain was founded to be the mothers' health, time spent caregiving, social support and the severity of the ID of the child. Tsai and Wang (2009) recommended healthcare providers to develop interventions and preventive care measures to aid with the mothers of children with ID increase their quality of life. This study revealed strains associated with health, time, and social support in Taiwanese culture and it would be interesting to see if similarities will occur in the Latino culture through their experiences caregiving.

Wijesinghe, Cunningham, Fonseka, Hewage, and Ostbye, (2015) conducted a mixed methods study on 375 caregivers of children with cerebral palsy in Sri Lanka to examine problems associated with caregiver burden. The researchers used the Caregiver Difficulties Scale to gather data. Results showed that level of caregiver burden was higher when associated with low income families, rural residents, having a male child, and the severity of the disability the child has endured. Caregiver burden was low when spousal support was present in the home. The researchers suggested the use of a psychosocial interventions to improve social support for caregivers in order to reduce stress for caregivers. A limitation of the study was the fact that cross sectional nature of the study and the potential varied demographic background of the participants. One coping intervention may not be enough for a caregiver if there are many factors associated with the caregiver burden and the needs of the child with disabilities (Wijesinghe et al., 2015).

Barriers to obtaining care. The literature review revealed the most common barriers to obtaining care for their children that caregivers experienced including type of medical insurance, access to medical insurance, and transportation. Bisgaier and Rhodes (2011) conducted 546 telephone calls to medical facilities to determine whether the type of health insurance affected access to medical care for children with disabilities. Findings showed that medical providers were less willing to accept publicly funded medical insurance, creating barriers for parents of children with disabilities who had publicly funded medical insurance. The authors also discovered that children with disabilities who have publicly funded medical insurance have longer wait times to be seen by a specialist compared to children with private medical insurance. The barriers to obtaining medical treatment caused additional stress and caregiver burden for the parents. This research is relevant to my study because it revealed that caregivers often experienced delays obtaining specialty medical care for their child with disabilities. This suggests it is likely that the caregivers experience similar delays when transitioning their children with disabilities to services in the adult health care system.

Maxwell, Cortés, Schneider, Graves, and Rosman (2011) studied how the Affordable Care Act helped Latinos (least likely of any American ethnic group to have health insurance) obtain medical insurance to increase healthcare access. Results revealed that while the Affordable Care Act reduced the number of uninsured Latinos the disparities continue. Limited cultural and language English proficiency, not having an identified medical provider, and not following through on appointments due to costs were the major barriers to obtaining insurance and access to health care in this study. The researchers recommended the creation of a national health care system with simple enrollment and re-enrollment practices, easier selection of medical providers, and an easier navigation system (Maxwell et al., 2011). This study is important to my research as Latino families are less likely to have access to health insurance than other families, and therefore will experience caregiver burden because of medical insurance barriers and selecting a provider as part of the transition of services from childhood to adulthood.

Manos, Leyden, Resendez, Klein, Wilson, and Bauer (2016) conducted a study to determine what services were needed to improve low income immigrant Latino families' access to medical insurance in California. Results showed that the 83% of Latino families were eligible for health care insurance for their children, however 28% of their children were not enrolled in health insurance. The children who were not enrolled in health care coverage were less likely to go the doctor's office, and when they do, they have increased medical costs. Families who had difficulties with enrollment forms, the enrollment process, and having adequate documentation to secure healthcare coverage, are more likely to have children with no health care coverage. Latino mothers expressed a preference for having organizations assist with the health care insurance application process. The researchers recommended that human services organizations should provide outreach services to reach out to Latino communities to assist with increasing enrollment of health care insurance for the Latino children (Manos et al., 2016). This article is relevant to my study as Latino families are more likely than other families to not have health insurance when transitioning from pediatric services to adult services, which can negatively impact the transition experiences.

Fortuna, Halterman, Pulcino, and Robbins (2012) completed a study using data from the National Ambulatory Medical Care Survey and National Hospital Ambulatory Medical Surveys. The data were collected from 1998 to 2008 on young adults ages 22 to 30 years showing that 1.3% of young adults were unable to transition out of their pediatrician office to adult care services. The young adults who continued to be seen in pediatrician offices were more likely to have a chronic disease public Medicaid or no medical insurance, which had a strong association with the delay of transition (Fortuna, et al., 2012). This study is relevant to my dissertation because it suggests that the severity of chronic disease and type of health insurance are related to a delay in transitioning services.

Syed, Gerber, and Sharp (2014) completed a synthesis of literature from 61 studies to examine how transportation barriers affected access to health care services. The synthesis showed that transportation barriers negatively impacted access to health care, and that families from low income areas and those who were uninsured or under insured were most affected. The data also revealed that ethnic minorities such as Latinos had the most difficulties accessing care for patients in their families. Also, individuals who were female, older, and lacked education encountered the most transportation barriers. This study is important for my research as transportation barriers could negatively impact the Latino caregivers as they attempt to transition their children from pediatric to adult healthcare services.

Transition Process from Pediatric to Adult Systems

The process for transitioning children with disabilities from the pediatric to adult systems is multi-faceted and complex, which can create caregiver burden. Children with disabilities can sometime remain with pediatricians past their 18th birthday due to the nature of the illness and their medical insurance (Bisgaier & Rhodes, 2011; Patrick & Freed, 2012). If the child with disabilities has no insurance or has public assistance insurance, the child can be delayed with transitioning to adult medical services (Bisgaier & Rhodes, 2011; Patrick & Freed, 2012). Any delays with transitioning of services for a child with disabilities from pediatric to adult systems can impact the delivery of appropriate services in health care systems, human service agencies, school programs, and the department of welfare (Halfon, et al., 2012).

The process for transitioning a child with disabilities to adult health care services is driven by the caregiver's ability to follow recommendations for making the transition (Sandburg, 2010). The caregiver of the child with disabilities completes the transition process on the behalf of the child (Ness, 2011). The caregiver may try to cope with increased stress or burden when barriers arise during the transition time (Ness, 2011). Human services agencies located in the community can help decrease the caregiver burden by providing assistance with paperwork, helping families find social support services that they may qualify for, assisting in identifying appropriate medical providers that meet the need and insurance requirements, providing transportation assistance if they are able to assist the caregiver (Hasenfeld, 2010).

Marsh and Rodrigues (2015) examined the transition experiences of adolescents with life- long physical disabilities. The researchers interviewed the adolescents facing transitions to becoming an adult, parents as caregivers to adult children, and professionals supporting the transfer of services. These researchers found that supportive services organizations involved in the transition process needed to be held more accountable to ensuring transition times are met for clients. Focus areas identified as barriers were the lack of transparency with the clients and client difficulties in following a transition plan. The consistent theme that emerged from March and Rodrigues (2015) study was the clients, caregivers, and professionals all exhibited tension with one another and triangulation behaviors emerged among them, which added the difficulties with the transition process. This study is relevant to my study as the focus of the study is experiences by the caregiver during their child with disabilities transition time.

Berg-Kelly (2011) focused on processes related to transitioning children with disabilities from pediatric to adult services from the perspective of the medical teams. The author used content analysis of interviews with professionals involved in the transition process. The findings showed that the pediatric and adult team met two days prior to transition of services to discuss the child with disabilities and the transition plan. Participants agreed that the age of 18 years was an acceptable age for transitioning the child with disabilities to the adult services system and that pediatric teams need to educate families prior to the transition process. Other findings suggested to create a psychosocial plan, self-referral note, and joint small group discussions would aid in the transition process. This study focused on the perspective of the medical teams and did not focus on the perspective of the caregivers who completed the transition for the child with disabilities (Berg-Kelly, 2011).

Previous research by Wijesinghe et al. (2015) indicated that the use of an intervention like social support can help with caregiver burden. This article represented a possible intervention by having the medical office take the lead of the transition for the caregiver. The use of the medical office taking the lead can help the caregiver have less of a burden with medical transfers to adult medical offices however may not be enough for caregiver burden issues associated with the community service offices. This article is relevant to my research because I will get the perspective of the caregiver to see if the transition for their child was successful at the age of 18 and if an agency helped that will come out in the research data.

Sonneveld et al. (2013) focused on the experiences of transitioning children with disabilities from pediatric to adult services from the perspectives of the adolescents with disabilities, their parents, and medical providers. Surveys were used as data collection tools. The results showed that the parents were more successful in managing the transition process when they were in charge than when the medical providers were involved in managing the transition process. Also, the adolescents with disabilities, the parents, and the medical providers all agreed that there was a need to improve transition services to smooth the process for all parties involved in the transition (Sonneveld et al., 2013). This research is relevant to my dissertation because it is explored experiences from the caregiver perspective during the transition time, which is the focus on my study.

Ishizaki, Maru, Higashino, Katsumoto, and Nagahama (2012) focused on perspective of transitioning children with disabilities from a medical provider's perspective in Japan. Participants were 41 pediatricians and 24 nurses who provided medical care to adolescents with disabilities. These medical providers were asked their viewpoints regarding how children with disabilities transitioned to adult practices within their practice setting. The transition process consisted of self-care instructions for the child with disabilities or their caregivers. Some nurses implemented their own transition program within their practice by using transition manuals. All participants admitted to not having a functioning transition program among all practices. Seventy five percent of doctors and 100% of nurses surveyed felt a transition program should be implemented to help with the transition from pediatric and adult services. Ishizaki et al. (2012) concluded that creating a pediatric-adult healthcare network would benefit the child and caregiver transitioning between pediatric and adult practices. They suggested there should also be services to help with meeting the psychosocial needs of families. The medical providers from Japan appear to share similar thoughts as in other countries that a transition plan or service would be beneficial for all parties involved in the child with disabilities during the transition process. The essence of the study is if a transition program exists to include psychosocial needs than caregiver burden may be less during this life stage event of transition.

Van Staa, Jedeloo, van Meeteren, and Latour (2011) researched on the pediatric to adult transition practices in Netherlands. The study focused on the experiences of children with disabilities, their families, and medical providers during the transition.

Caregivers reported feeling lost during the transition time. They also reported cultural differences, and navigation barriers. These feelings reported by caregivers add to their burden. Medical providers feared the children with disabilities and their caregivers would not engage well at the new adult practice. Other results indicated that caregivers along with the children with disabilities wished they were prepped better on what the transition process to adult practice would look like ahead of time. In addition, the caregivers and children with disabilities would benefit from early communication between the pediatrician office and adult medical offices prior to the transition process. The authors felt the transition should be a gradual process that introduced at a younger age in order for to establish rapport between child, caregiver, and all medical providers to engage in a successful transition process (Van Staa et al., 2011). The study in the Netherlands confirmed a transition program can work if education of the process occurred earlier with all parties involved in the care of the child with disabilities. This study is relevant to my research as it shows experiences that caregivers go through in the Netherlands may be similar to transition in the United States. I want to capture experiences of the Latino caregiver during the transition process in the United States.

Summary and Conclusion

When the transition from pediatric to adult healthcare services occurs for a child with disabilities at age 18 years, caregivers have to complete multiple steps to transition medical, educational, and psychosocial systems from the pediatric system to the adult system. Caregivers encounter many burdens related to problems with finances, emotional strain, psychological stress, inadequate social support, and barriers to obtaining care

(Kaur, 2016). The transition process has many important steps to complete and is best to occur at a certain age to ensure the best lifelong outcome for the child (Cline & Greene, 2014). A Latino caregiver attempting to transition services for their child with disabilities can encounter barriers and caregiver burden due to cultural and ethnic differences (Mclaughlin, Bowering, Crosby, Neukirch, Gollub, & Garneau, 2013).

The objective of this study is to explore the lived experiences of Latino female caregivers while navigating the healthcare system as their children with disabilities transition into the adult services system. To study this phenomenon, Latino female caregivers who have navigated the healthcare system to locate services for their adult offspring with disabilities will be recruited from the Lehigh Valley Area in Pennsylvania. Findings from the study may be instrumental in identifying some potential areas for improvement.

Chapter 3 includes the design and rationale for the study to identify the qualitative method used to support the understanding of the Latino caregiver experience. This chapter will focus on the details of the research design, rationale, role of the researcher, in depth look at the methodology, and issues of trustworthiness within this study. Also, the chapter includes precise information regarding the participants, the procedure of selecting and interviewing participants, and the criteria by which I tested interview questions. In addition, there is a detailed explanation of the phenomenological method of data analysis and details of the analysis in Chapter 3. Finally, the chapter includes a discussion on the issues of credibility, transferability, dependability, and confirmability.

Chapter 3: Research Method

Introduction

The purpose of this qualitative hermeneutical phenomenological study was to explore the lived experiences of Latino female caregivers while navigating processes of transitioning their children with disabilities into the adult healthcare system. The Latino female caregivers had transitioned their 18-year-old adult child with disabilities for this study. This chapter will focus on the details of the research design, rationale, role of the researcher, methodology, and issues of trustworthiness related to this study.

Research Design and Rationale

This study is a qualitative inquiry involving a phenomenological hermeneutic approach. Qualitative research is frequently used to examine social problems (Kafle, 2013). Qualitative research allows researchers to study various phenomena to obtain valuable, in-depth, and detailed information (Davidsen, 2013; Kafle, 2013). Information gathered from fieldwork observations, open-ended interviews, and written records are analyzed to identify patterns and themes regarding what Latino caregivers experienced when they transitioned their offspring with disabilities to adult services.

Phenomenological research focuses on a common event shared by different participants and is useful for studying people's perspectives on common lived experiences (Kafle, 2013; Marshall & Rossman, 2014; Sloan & Bowe, 2014). The phenomenological approach was appropriate for determining participants' shared meanings involving Latino caregivers' perspectives as they go through the process of transitioning a child with disabilities to adult services after the child reaches age 18 years.

The hermeneutical approach relates to researchers' attempts to interpret description of participants' experiences of a common phenomenon (Kafle, 2013; Sloan & Bowe, 2014). The implementation of the hermeneutical approach enables researchers to gather meaning of lived experiences of individuals through examining their narrative accounts by analyzing intricate details involving their experiences (Kafle, 2013). For this study, I used the hermeneutical approach to interpret the documented stories of how Latino caregivers experience the transitioning process involving moving their children with disabilities to adult healthcare services.

Other qualitative methods were considered for this study, but those methods seemed inappropriate for gaining insight on the Latino female caregiver's experience. Narrative research involves examining the life of a person (Lewis, 2015). For this study, the focus is on the Latino female caregivers' experiences related to transitioning their children with disabilities from pediatric to adult services. Therefore, narrative inquiry is not appropriate for this study as the research was not about examining peoples' lives. Grounded theory research focuses on a theory, process, or concept which comes from the grounded experiences of participants (Higginbottom & Lauridsen, 2014). The researcher attempts to use these experiences to determine or explain a theory that is developed that may help the population being studied. Grounded theory is not appropriate for this study because I am not attempting to develop a theory. The focus of ethnographic research is related to a specific culture of a specific group (Lewis, 2015). The researcher needs to describe and interpret patterns and group sharing involving a cultural phenomenon (Lewis, 2015). In the case of the Latino female caregivers' experiences, other cultural groups in the Unites States may experience similar challenges in terms of transitioning children to adult disability services. As such, ethnography is not warranted for this study. Case study research focuses on a real-life situation, case, context, or setting in which a story is developed. The researcher needs to approach case study research from a broad to narrow focus; however, various types of information can come from one case. The research is narrow in focus in terms of information gathering; consequently, the case study method is not appropriate for this study.

Research Question

What were Latino caregivers' experiences with navigating medical and social services for children with disabilities when those children turned 18 and transitioned to adult services?

Role of the Researcher

For 7 years, I served as a social worker providing care and support to families of children with disabilities. In my role as a social worker, I provided support for transition services on a limited basis. The transition support I provided consisted of giving the caregiver a list of adult primary care physicians to transfer to, as well as a list of reminders of areas to focus on such as insurance, schooling, social security, and selective services that needed to be completed as part of the transition process.

I bracketed any previous experiences to prevent any bias or influences from my transition experiences with children or transition workers. In addition, I was self-critical, self-aware, and transparent during the study to control for any biases during my interactions with participants and the data analysis phase. I rigorously adhered to the interview questions that were approved by the Institutional Review Board (IRB). Interviews were recorded to help control for any biases and promote transparency. Recordings were transcribed word for word. The data analysis phase was documented to control for biases and influences.

Methodology

Participant Selection Logic

According to the United States Census Bureau (2017), 363,147 people reside in Lehigh County and 302,294 reside in Northampton County. An estimated 23.3% of Lehigh County's population are Latinos, and in Northampton County, 12.9% are Latinos, representing a larger proportion of the population than Pennsylvania in general, and, in the case of Lehigh, commensurate with the US in general (United States Census Bureau, 2017). Approximately 10.6% of individuals under the age of 65 residing in Lehigh County have a documented disability, and 8.3% of participants in Northampton County have a documented disability (United States Census Bureau, 2017). Therefore, it seemed that recruiting participants from Lehigh and Northampton counties in Pennsylvania would provide a large enough sample of potential participants for this study. All participants were Latino female caregivers who had at least one child with a disability who transitioned from pediatric to adult services within the last 6 years. Also, participants needed to be fluent in speaking, reading, and writing English.

Sampling

For this study, purposeful sampling was used to acquire the participant needed for the study. Purposeful sampling fits the study as the participants had to fit a specific criterion of the phenomenon being studied (Palinkas, Horwitz, Green, Wisdom, Duan, & Hoagwood, 2016). The participant needed to be knowledgeable of the phenomenon experience, have the ability to participate, and communicate their experiences to be part of the study (Palinkas et al., 2016). Participants were chosen purposely due to common experiences and not at random.

For this study, purposeful sampling was used to recruit Latino female caregivers of who transitioned their child with disabilities from pediatric to adult services. Purposeful sampling enabled me to recruit participants who experienced of the same phenomenon of interest, which increased the likelihood that I collected information that describes the female Latino's experience with the phenomenon being studied. Because the intent of this research is to document multiple experiences of the same phenomena, it is more important for participants to self-select based on meeting all study criteria than to be randomly selected to answer less specific questions (Onwuegbuzie, & Leech, 2007; Ritchie Lewis, Nicholls, & Ormston, 2013).

Participants recruited from Lehigh Valley Area Lehigh and Northampton Counties in Pennsylvania. Special permission from local community human services agencies were obtained through letters of agreement to assist in recruitment for the study prior to any outreach efforts. I contacted the pediatric and adult offices who serve Latino children with disabilities and gained permission to recruit participants from their client list for this study. Specifically, I gained permission to post information/flyer in waiting rooms regarding the study in attempts to get volunteers to participate in the study (see Appendix A).

Sample Size

The sample sizes for qualitative studies ranges from 5 to 50 participants depending on the research method employed and the intended breadth or depth of analysis (Dworkin, 2012; Ritchie et al, 2013). Because this study is designed to document a variety of experiences regarding a common phenomenon, using a small sample for this study is warranted (Dworkin, 2012). Smaller sample sizes lend themselves to the researcher's ability to provide thick, rich descriptions of information that explain the participants' experience and descriptions of a phenomenon (Yilmaz, 2013).

Using smaller sample sizes helps researchers obtain more descriptive material in order to identify meaningful themes to answer the research question (Mason, 2010; Dworkin, 2012). The small sample size helps reduce redundant information from occurring in the data gathered during the interviews (Mason, 2010; Dworkin, 2012). However, the sample size in the qualitative study needs to be sufficient enough so the information gathered is useful without becoming repetitive (Mason, 2010). Mason (2010) conducted research analysis on rules for research samples and he determined for phenomenological studies a minimum of 5 to 25 participants are appropriate for the sample size. Using guidelines for samples size, I recruited 10 participants.

Saturation is achieved when and no new concept or themes emerge during data analysis (Cleary et al., 2014). The primary goal of data analysis in qualitative research is to achieve saturation. The sample size must be large enough for saturation within participants' responses (Cleary et al., 2014). By using 10 participants in the study, I gathered rich amounts of information from participants that provided saturation.

Instrumentation

I used semi-structured interviews to collect data for the study. Interviews are widely used in the social sciences as a method to gather information about participants' experiences (Brinkmann, 2016). The interview process consists of two individuals exchanging information via communication through questions and answers to gather meaning concerning a particular topic (Brinkmann, 2016; Janesick, 2011). I developed the interview protocol as well as the interview questions that were asked during the study (see Appendix E).

The interview questions were open-ended for the purposes of gathering descriptive information. Participants were able to share various experiences to answer the research question (Brinkmann, 2016; Gustafsson, Blanchin, & Li, 2016). The interview used was a semi structured format to allow for flexibility and clarifying questions will be asked as needed (Franssen, Maaskant, & van Schrojenstein Lantman-de Valk, 2011). The researcher asked follow-up questions throughout the interview or asked for clarification from participants upon answering the questions for a better understanding of the information captured within the interview (Janesick, 2011).

In addition to the interview protocol, I used an audio recorder to record interview questions and answers during the interview. Using the audio recorder as a tool is less intrusive than video recorder and user friendly during an interview. The audio recorder held recorded information from the interviews so the participant responses could be transcribed for later data analysis. I had consent forms for participants to sign in order to participate in the interview process and to explain and provide consent for the audio recording tool to be present during the interview. A copy of the consent form can be found in Appendix C.

The literature review revealed little qualitative research on the experiences of female Latino caregivers as they transitioned their offspring to adult healthcare services. Several researchers who have studied family caregiving and transition services for children suggested that using an interview as an instrument was beneficial to gathering data, which prompted me to use interviews to collect data (Berg Kelly, 2011; Huang et al, 2009; Van Hofwegen & Killion, 2011; Van Staa et al, 2011). Because my research question is unique, a specific instrument was designed specifically for this study consisting of eight semi-structured questions.

Due to the development of a researcher developed instrument, content validity needed to be established to help control validity of the instrument (Burton, & Mazerolle, 2011). The instrument created for this study was validated for face validity and content validity by using experts from Walden University Human Services Department who reviewed the tool. Feedback from the experts from Walden on the instrument were incorporated into my study prior to conducting interviews and improving the face validity of my instrument (Kartal, Ozdemir, & Yirci, 2017). Once the instrument was validated for face and content, then a pilot study was conducted to test the tool.

Pilot Study

Using a pilot study enhanced the credibility and confirmability of the outcomes (Simon, 2011). A pilot study is a smaller version of a study that researchers use to prepare and field test for the main study (Simon, 2011). My pilot study allowed me to determine whether the interview protocol and recruitment procedures worked effectively for the targeted participants (Thabane et al., 2010). I used information from the pilot study to determine whether I needed to make slight changes in recruiting procedures, participant instructions, or data collection procedures. For the pilot study, I recruited 20 percent of total number of participants who I intended to interview for the complete study, which equaled two persons.

Procedures for Recruitment, Participation, and Data Collection

This study used a semi-structured interview protocol to gather information on Latino caregivers' experiences with navigating medical and social services for children with disabilities when those children turn 18 years of age and transition to adult services. The following outlined procedures for recruitment, participation, and data collection were used as a chronological guide to ensure the proper steps were followed. First, letters of agreements were gathered from local community human services agencies to request permission to post an announcement/flyer in the office to recruit participants. Once those were signed, flyers with the researcher's phone number and email to make contact if interested in study participation were distributed to agencies that signed the letter of agreement. A copy of the recruitment flyer is located in Appendix A. Then, I submitted an application to the Walden University IRB at to gain approval to conduct research with human subjects.

Recruitment

Two participants were recruited for the field test of the interview questions. I determined that the participants met the inclusion criteria during a phone call used to set up an interview to participate in the study. I used a prescreening checklist to ensure the participant meets the criteria for the study (see Appendix B). After the participant agrees to the pilot test, I invited the Latino female caregiver to communicate with me to arrange an interview. I followed up with the participant via a telephone call if I did not hear from participants within one week of the initial contact to determine their interview date for participation in the study. The interested Latino female caregivers contacted the researcher to set up a time and location for the interview at one of the selected offices closest to the participant.

The participant signed consent forms at time of interview (see Appendix C). The participant was given a copy of consent form and letter for their own records, and the original form was retained as part of the research materials. The researcher then asked for permission to audio record the interview. Upon getting permission, researcher turned on audio recorder. Then, the participant completed a participant demographic form. The form is located in Appendix D. After all of those forms were completed, the interview began, the interview consisted of questions found in Appendix E within the interview protocol.

After the pilot test was completed using the interview questions, I informed experts of the feedback from the pilot test. If the pilot test showed an inappropriateness of the questions, I would have changed the questions to better match the study and re-conduct a new pilot test. When I gained approval from experts about the field test being successful then I proceeded to the main study and began recruitment of nine additional participants. If not enough participants engaged in the interview process or dropped out of the study, the researcher contacted community human service offices to repost for recruitment of additional participants.

Data Collection

Data was collected using semi structured interviews. During the data collection phase, I documented in field notes any personal feelings that occur. I used field notes to document my feelings and thoughts during the interview process during each interview. By using field notes, I was able to bracket any personal biases that arose during the data analysis, the field study notes were added to the data analysis phase. I used an audio recording device to capture the information gathered during the interview and transcribed the audio recordings myself into a Microsoft Word documents.

Data Analysis Plan

After all information has been transcribed into Microsoft Word documents, I imported the information to NVivo software (QSR, 2014). The NVivo computer software package was used to store information for coding purposes (QSR, 2014). The data analysis stage consisted of coding detailed accounts from the interviews of participants in data collection phase (Jamieson, 2016). Using NVivo, the interview questions served as a central code or theme in the system (Janesick, 2011). The central code or theme were given a designated color of codes that attach to the question to help differentiate themes in the analysis phase (Janesick, 2011).

Additional data was kept in memos on the NVivo software that explained my decisions regarding coding. Other information stored in memos reflected my thoughts captured from the field notes. I assessed the accuracy of the data gathered by member checking the results to confirm what the participants meant during the data collection. I used inductive analysis as I formulated themes from the data collected during data analysis (Jamieson, 2016). NVivo was used to organize and store the information from the data analysis phase.

I used the Bryman's four stages of data analysis to assist with thematic content analysis and subsequent coding. The stages consisted of reading the entire text of the transcriptions, re-reading entire texts of the transcription, identifying themes or patterns, coding the texts, and relating general theoretical ideas (Gibbs & Taylor, 2010). Reading, the first stage of analysis using Bryman's approach, began the immersion process of becoming familiar with the material that was gathered for the study (Jamieson, 2016). While reading all transcriptions, I made notes during this process to identify emerging themes or patterns of words. The notes reflected the occurrence of themes, any unusual events, or grouping of or words related to the research question (Gibbs & Taylor, 2010). Also, the notes I took were able to show any resembling information that was important for thematic coding analysis.

Rereading the transcriptions, the second stage of Bryman's four stages, helped bring the data analysis to a deeper level for the purpose of further identifying patterns and themes across the interview responses (Jamieson, 2016). While rereading the transcripts, I created notes of the information that was transcribed in attempts to see patterns emerging. The notes or marks on the transcriptions consisted of highlighting, underlining, or circling key words. Other marks consisted of making notes in the margins or categorizing codes (Gibbs & Taylor, 2010). When completing this second stage, I began to notice resembling information or patterns in the interview information which contributed to identifying possible codes (Jamieson, 2016). Also, NVivo was used to assist this researcher with identifying themes by using the queries function to generate frequency counts of words or phrases (QSR, 2014). The queries function was used to look for recurring words and phrases that were then used to develop other themes to code for the study (QSR, 2014). I developed a code book to assist in the coding process to help keep track of developed codes from themes established in the data analysis phase.

The third stage consisted of coding the text in the transcriptions through open, axial, and selective coding steps. The initial step of open coding began with chunking information from the interviews into classifications, themes, or groupings using thematic analysis to identify impressions within the data that defines the concept being studied (Córdova & Cervantes, 2010; Gibbs & Taylor, 2010). After the initial open coding was complete, the axial coding began in the analytical phase. The axial coding entailed the development of recognizing relationships between the open codes. By making the initial impressions, the researcher developed subcategories within the data which confirmed the categories representing the interview answers (Córdova & Cervantes, 2010). NVivo was instrumental to further assist in coding themes during the axial coding process.

The fourth and final stage of analysis was selective coding. This stage consisted of grouping the themes identified in the third stage of analysis into categories to help find the meaning related to the participants responses (Gibbs & Taylor, 2010; Jamieson, 2016; Janesick, 2011). The emergent themes provided answers to the research question.

Issues of Trustworthiness

The types of trustworthiness that are relevant for this qualitative study are credibility, transferability, dependability, and confirmability. In a qualitative study, issues of trustworthiness begins with viewpoints that come from the researcher during the completion of rigorous field work (Cope, 2013; Yilmaz, 2013). To increase trustworthiness in the qualitative study, the researcher remains objective during the interview stage, data collection, and analysis to accomplish valid outcomes for the study (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014).

Credibility

Credibility refers to on the researcher's ability to show authenticity and accuracy of the research findings (Statistics Solutions, 2017). Authenticity and accuracy stems from how the information was gathered in the study from the participants and how the researcher interprets the information (Cope, 2014). The researcher's interpretations are essential to see how the development of categories were formed to distinguish the connections with the themes during the data analysis phase (Elo et al., 2014). Using a reliable resource such as an audit trail that shows descriptive steps conducted during the study to discover the themes and categories from the data collected can ensure greater accuracy of interpretation of the data (Cope, 2014). The credibility of this study will be enhanced through the use of the reflexive journal, data triangulation, prolonged contact with participants, and member checking.

A reflexive journal can be used to increase credibility of the data and findings. Such a journal is used by researchers to disclose any biases they may have associated with the research study by documenting any feelings or thoughts in a journal during the information gathering phase and data analysis phase (Cope, 2014). The researcher documents in journal notes different ways of thinking used throughout the research (Cope, 2014). The journal notes help manage bias in the study by bracketing perceptions and subjectivity to show transparency within the study (Cope, 2014). The journal notes can be used to document the quality of work a researcher has completed for the study and can help serve as a quality check for credibility in a qualitative study (Miles, Huberman, & Saldana, 2014).

Data triangulation is another method I used to enhance the accuracy and credibility of information collected in a study. Triangulation is the process of integrating multiple data sources together in order to have a better understanding of the topic being studied (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neveille, 2014; Cope, 2014). The use of triangulation in a qualitative study helps address the credibility issue by converging the information from multiple sources in an effort to verify specific data points by confirming their presence through multiple sources (Carter et al., 2014). I used participant's interviews, transcriptions, field notes, and journal notes as multiple data sources to triangulate and corroborate the data collected during the study (Cope, 2014).

Another method of building credibility I employed was through prolonged contact with the participants. Prolonged contact with participants helps with building trust to assist with gathering valuable thorough information during the interview phase (Cope, 2014). I promoted prolonged contact by engaging with participants interviews that last up to an hour or more as permitted by the participants. The one- hour time allotted helps the participant to gain trust and share their experiences for the purpose to answer the research question.

Member checking was another way of establishing credibility I used in this qualitative research. Using member checking in my study helped validate the information provided to me by the participants. Member checking consists of participants meeting with the researcher after the data has been recorded and reviewed to confirm the information that was shared during the interview by reviewing the transcriptions (Birt, Scott, Cavers, Campbell, & Walter, 2016). During the member checking process, the participants double checked the transcriptions to ensure that the transcriptions accurately represented their thoughts and intended communication (Birt et al, 2016). This researcher met with participants individually to go over their transcriptions as a basis for member checking for accuracy prior to the data analysis phase (Birt et al., 2016).

Transferability

Transferability refers to the degree to which the results may be relevant to others with related experiences or the degree to which findings from a study can be applied to other groups or settings (Cope, 2014; Elo et al., 2014; Yilmaz, 2013). The processes utilized in the study yielded comparable results in a similar situation that could be duplicated under equivalent circumstances (Elo et al., 2014). I ensured transferability by creating journal notes on my experience within the study. Any reflections of my feelings captured in journal notes throughout the data collection and analysis process were incorporated into the study in attempts to develop thick descriptions (Cordova & Cervantes, 2010; Yilmaz, 2013).

Use of thick text descriptions is also a technique that I used to increase transferability of findings from this study. Thick text descriptions are descriptions of the people, context, and events that are applicable to other similar settings and situations (Yilmaz, 2013). During the interview process between the researcher and the participants, the outcomes of the interview were developed into the thick descriptions of the life experience of the people I interviewed (Quinney et al., 2016). Since I used the method of purposeful sampling, I was able to capture the thick text descriptions, since this sample represents only individuals who experienced the phenomena being studied (Palinkas et al., 2016). If the researcher shares details of a description from a purposeful sampling of participants, then transferability occurs with the phenomena (Anney, 2014). With these two techniques, the research outcomes can be used as a guideline, making them transferable to Latinos in other settings, or potentially other ethnic population's experiences.

Dependability

Dependability helps with issues of trustworthiness of data and results within a qualitative study. The process of dependability relies on making decisions on, warranting, and using research strategies (Yilmaz, 2013). Evaluation of these research strategies help develop the procedures and approaches explained by the researcher (Yilmaz, 2013). To confirm if the procedures and approaches are dependable, the use of a reliable audit process needs to be included (Yilmaz, 2013). The use of audit trails and triangulation are two tools that I used to increase dependability in this research. An audit trail refers to the extensive documentation completed by the researcher throughout the research study

(Cope, 2014). Audit trail documentation includes the field notes, journal notes, and interview transcripts to document details of the research (Cope, 2014). I used field notes when interviewing participants, journal notes to include my feelings and thought process during the research process, and transcriptions from audio recordings to develop my audit trail.

Triangulation is the process of using numerous resources to draw assumptions about findings from a study (Cope, 2014). Using triangulation, the researcher uses numerous methods of data gathering techniques in an attempt to obtain comprehensive understanding of the phenomenon (Cope, 2014). The data using in triangulation can encompass interviews, observations, notes and journal recording during the research (Cope, 2014). I will combine my field notes, journal notes, and transcriptions to gain a comprehensive view of all the information about the phenomena being studied to verify dependability of my analysis through the use of triangulation (Cope, 2014; Yilmaz, 2013). I will also triangulate my findings with the literature and theoretical framework in Chapter 5.

Confirmability

Confirmability occurs when the researcher demonstrates the information provided within the study is from the participants' and not from the researcher's viewpoint so the results can be confirmed or corroborated by others (Cope, 2014; Yilmaz, 2013). To achieve confirmability, I will use reflexivity to enhance findings from this study. To help any validity or reliability concerns, the researcher needs to explain and document ethical standards that have been followed in the study through their reflexive journaling process

(Bonsmann, 2010; Cope, 2014). The researcher is considered as the instrument in the study and needs to aware of their feelings and experiences by documenting in a reflexive journal (Cope, 2014). The researcher needs to describe reflexivity by showing their own reflections within journal notes to prevent unbiased behaviors as a method of confirmability for the study (Birchall, 2014). By the researcher showing reflexivity in the study, the researcher can bracket their notes and be objective to increase confirmability (Cope, 2014). I maintained a journal with my reflections, thoughts, feelings and notes in attempts to bracket opinions, experiences, and bias (Cope, 2014).

Ethical Procedures

Walden University uses established guidelines to ensure ethical research which I followed. This study had minimal risk for exposing confidential information. The methods used for research had no identifiable increased stress connected with the participation. There was no imposition of privacy, likelihood for financial loss, or danger of unpleasant well-being stemming from participation in this study. Participants were thoroughly informed of their ability to discontinue their participation in the study at any time. There were no financial or other incentives offered during the study to either participants or local community human service offices.

Ethical Protection for Participants

Confidentiality**:** Walden University's ethical standards require participant confidentiality especially regarding identity and personal information (Kafle, 2011). Any of the participant's identifiable information remained confidential and was secured separately from their responses during the study. During the study, each participant was given a de-identified alias represented by a letter and number. The first participant interviewed was assigned participant A01 and so on. All participants were informed of the safeguards used to maintain their confidentiality.

All information obtained during the study was held in my home on a computer hard drive. The hard drive that housed the information from the study remained in a secure setting in a locked home office. The hard drive was secured by password which was shared with no one. All files, transcripts, and audiotapes associated with this research have been locked in the researcher's home office within a locked cabinet. All information will continue to be archived in locked files for up to five years after which time the information will be destroyed from the hard drive along with items locked in file cabinet.

Summary

Chapter 3 presented the rationale for the research along with the methods that were used to conduct this phenomenological research study on Latino female caregivers transitioning their child with disabilities. The purpose of this study is to answer what Latino caregivers experience with navigating medical and social services for children with disabilities when those children turn 18 years of age and transition to adult services. This chapter presented the research design, rationale, role of the researcher, an in depth look at the methodology, areas to increase trustworthiness of this study and ethical considerations. The next chapter contains information of the data analysis plan along with using Bryman's four stages of data analysis to assist with thematic coding.

Chapter 4: Results

Introduction

This qualitative hermeneutical phenomenological study investigated the lived experiences of Latino female caregivers as they transitioned their children with disabilities from pediatric systems to adult healthcare systems. The research question addressed in this study was: What were Latino caregivers' lived experiences regarding navigating medical and social services for children with disabilities when those children turned 18 and transitioned to adult services? Chapter 4 identified details of the research related to the pilot study, setting, demographics of participants, data collection, data analysis, evidence of trustworthiness of the study, and results.

Pilot Study

Prior to beginning the pilot study, I developed the interview protocol. The protocol was approved for face and content validity by two experts from Walden University Human Services Department, my dissertation chair and dissertation committee member. The interview protocol was assessed for its face and content validity by experts to see if questions were relevant to the participants' ability to answer questions related to the study. One recommendation was to remove the prescreening questionnaire regarding the child's disability as the participant was the caregiver and not the child. Questions regarding children's type of disability was identified in participants' demographic information.

The pilot study ensured interview questions were appropriate for the study. I used information from the pilot study to determine that recruiting procedures, participant instructions, and interview questions were appropriate for obtaining desired information for the study. I recruited and interviewed two participants to test the interview protocol to ensure it would be appropriate for collecting data for the study. The interactions I had with participants through data collection revealed that the interview protocol was appropriate for the study. The two participants answered all questions and reported they understood the questions and appeared to be genuine with their answers. I did not make any alterations to interview questions or to any of the steps of the recruitment process. Participants' data in the pilot study were included in study results. Those participants are labeled as P1 and P2 in the results.

Setting

I recruited participants for this study from Lehigh and Northampton counties, Pennsylvania. Participants were recruited using flyers posted at community agencies within these two counties. Participants were interviewed on an individual basis in private rooms within offices at one of the two participating social service agencies located in one of the two counties. All interviews were recorded via an audio recorder.

It was important that I separated my background from the study by disclosing to participants that I have been an LCSW due to previous work in a large hospital system, but my role in this study is solely as a researcher and not as an employee of the participating agencies. I bracketed my thoughts and beliefs during and after interviews to separate my thinking from participants' responses. At the beginning of each interview, I explained to each participant that I had a list of 11 questions that would be used for data collection. I restricted my probing questions to clarification of responses to interview questions. I used field notes during and after interviews to capture any valuable information such as body language and tone during interviews. Field notes captured additional data that were included in data analysis during the coding process. In addition, I documented in my field notes my personal beliefs about systems and transition time to bracket my feelings during the data collection phase.

Demographics

The sample size for this study called for 10 participants. During the prescreening process, only 10 participants met the inclusion criteria for participating in the study. The 10 participants were assigned a letter and number (P1 to P10) to help maintain confidentiality. I collected information regarding how long transitions took to occur, the amount of time that had passed since the transition, the severity of the child's disability, and types of disability (see Table 1).

Table 1

Key Characteristics of Study Participants and their Children

Participant	Length of Transition in (Month)	Time since Transition (Months)	Severity of Child's Disability	Medical Services needed for Transition
P1	3	72	Moderate	Psychological
P2	60	36	Moderate	Psychological
P3	24	60	Mild	Medical
P4	24	12	Severe	Psychological
P5	4	8	Severe	Medical
P6	6	3	Mild	Medical
P7	12	120	Mild	Psychological
P8	8	24	Moderate	Psychological
P9	12	24	Severe	Psychological
P10	9	42	Mild	Psychological

Table 1 shows the fastest time a participant successfully completed the transition process from pediatric to adult services for their child with disability was 3 months. The longest amount of time spent in the transition process was 60 months. Participant 1's child remained with the same primary care physician, which may have contributed to her shorter transition. Participants 2's child required more specialty services, creating a longer time to transition. The shortest amount of time since the transition process was 3 months, and the longest amount of time since the transition process was 120 months.

Severity of disability of was classified as mild, moderate, or severe. Four participants indicated that their children had mild disabilities at the time of transition. Three participants indicated that their children had moderate disabilities at the time of transition. Three participants indicated that their children had severe disabilities at the time of transition. Services the children with disabilities needed were medical, intellectual, or psychological. Three participants revealed that healthcare services were due to physical health conditions. The remaining seven participants revealed that healthcare services were related to their children's psychological conditions. No participant identified the need for healthcare services due to their children's intellectual disabilities.

The information in Table 2 shows the demographic descriptions of the participants. The youngest participant was 38 years old and the oldest participant was 45 years old. All participants had from one to five more children in the home along with the child with a disability. Two participants worked part time and eight participants worked full time during the transition process. Participants during transition reported marital status including single, married, separated, or divorced. Three participants identified themselves as single. Four participants indicated that they were married, and one participant was separated from her significant other. Another participant identified as being divorced. All participants were mostly from Puerto Rico, with the exception of one participant who identified as both Puerto Rican and Costa Rican.

Table 2

Demographic Information of Participants

Participant in Study	Age	Number of Other Children in the Home	Employment Status	Marital Status	Country of Origin
P1	43	1	full time	married	Puerto Rican
P2	41	3	full time	single	Puerto Rican
P3	44	5	full time	married	Puerto Rican
P4	38	2	full time	separated	Puerto Rican
P5	38	3	part time	married	Puerto Rican
P6	39	1	full time	single	Puerto Rican
P7	41	1	full time	single	Puerto Rican
P8	42	2	full time	divorced	Puerto Rican
P9	45	3	part time	married	Costa Rican/ Puerto Rican
P10	43	3	full time	married	Puerto Rican

Data Collection

I gathered data for this study from 10 Latino caregivers of children with disabilities who had transitioned their children from pediatric to adult services. All participants volunteered for the study and did not receive any incentives for their participation. Flyers were sent electronically via email to human services organizations to post in their waiting rooms and their social media. Participants who were interested in participating in the study self-selected by calling the number on the flyer. All potential participants were prescreened. If the participant was eligible for the study, an appointment was made with them for the interview with me. Individuals who participated in the study shared the flyer's phone number with other individuals to call me for prescreening. As other potential participants called the flyer phone number and became eligible for the study created a snowball sampling effect.

IRB approval for this qualitative study was granted on August 20, 2018 to proceed with data collection phase. The first participant was not interviewed until October 14, 2018. The last interview conducted was on January 5, 2019. All participants were interviewed individually during a face-to-face, semi structured interview using the approved interview protocol. All interviews lasted for less than 60 minutes. I transcribed each recorded interview by using Dragon Naturally Speaking Software. After transcribing the interviews, transcriptions were double checked again with the Sound Organizer 2 software.

Member checking of transcriptions consisted of follow up appointments with all participants. During these appointments, participants were given a hard copy of their transcriptions to review for accuracy after being transcribed from the audio recorder. Each participant read their transcription to identify any statements needing correction. Participant 9 corrected one spelling mistake the document. Participant 10 corrected incorrect spelling or verb tense in six areas on transcriptions. No other participants identified errors regarding their transcriptions. All participants received a token of appreciation, a gift card, after reviewing their transcriptions for their participation in the study. Once all information was approved by participants during the member checking phase, data analysis began.

Data Analysis

I used Bryman's four stages of analysis to analyze the data collected in this study. The first stage is reading the entire text of the transcriptions. The second stage is re-reading entire texts of the transcription. The third stage is identifying themes or patterns in the data. The fourth stage is coding the text using open, axial, and selective, and relating general theoretical ideas (Gibbs & Taylor, 2010). I recorded all steps and information of data analysis using a notebook. In addition, I have analyzed the data to develop the answers to the research question based on the participant's experiences (Ezzy, 2013). I began by separating all 11 questions and answers and placed each question on separate pages in the notebook with the corresponding answers from all 10 participants.

The second stage of Bryman's approach is re-reading the transcriptions. As I re-read transcriptions, I created notes regarding observation of emerging patterns. The patterns were noted by highlighting, underlining, and circling key phrases and words that expressed similar content (Gibbs & Taylor, 2010). I used various symbols to begin to differentiate patterns among the question and answers. This was repeated with each of the 11 questions.

Bryman's next stage consists of open and axial coding (Gibbs & Taylor, 2010). Open coding consists of chunking related pieces of information into classifications, themes, and groupings (Córdova & Cervantes, 2010; Gibbs & Taylor, 2010). During the open coding phase, I narrowed down the number of symbols into codes of smaller chunks of information for each of the questions. Appendix F represents a summary of the initial chunking of data into categories during the data analysis. Next, I completed the axial coding process. During the axial coding process, I identified relationships between the various open codes. I grouped the related codes and subcategorized them to make the results more concise (Córdova & Cervantes, 2010; Gibbs & Taylor, 2010).

For the final stage of selective coding, I reviewed all information in the subcategories. During the selective coding stage, I reduced the data to the following five themes: effects of the transition process on the caregivers, sources of information regarding the transition process, supports received during transition process, challenges encountered in the transition process, and recommendations to assist caregivers with the transition process. These themes were used to answer the research question**.**

Evidence of Trustworthiness

After completion of my research, I felt it was important to establish trustworthiness within this qualitative study. Within my research, I was able to enhance the trustworthiness of the findings because as I was able to document objectivity during the interview data collection phase and data analysis because of the notebook where I bracketed my reflections, and from the disclosure statements shared with the participants. These efforts served to achieve valid outcomes needed for the study (Elo et al., 2014).

Credibility

To confirm credibility in this study, I used a reflexive journal to document all field notes and personal feelings. The reflexive journal allowed me to bracket my personal information so it would help separate any bias during the interviews and data analysis phases for the study. In the data analysis phase, I was able to develop an audit trail within the reflexive journal to show the steps taken to shield any personal bias during the analysis process. The audit trail shows how the themes and subcategories were developed within the analysis phase (Cope, 2014).

Another tool used to enhance credibility of data collected in the study was the use of member checking. Participants validated the written transcriptions by using the member checking process. Each participant was contacted and asked to review their transcribed interviews to confirm the answers written in the transcription is what they said during the interview. Two participants made corrections, all of which were grammatical and not substantive. The updated corrected information was used in the data analysis phase of the study.

Transferability

Transferability occurs when information from a study can be applied to other groups or settings (Cope, 2014; Yilmaz, 2013). I used a purposeful sampling of only Latino caregivers to gather information on a particular type of experience. The purposeful sampling was specific to a particular culture and life stage of the participant navigating services for their child with disability (Lewis, 2015). Since the sampling is particular to a specific culture, these results will likely be transferable to other Latinos in other locations navigating the same life stage. During interviews, I was able to document my responses in my reflective journal and create reflective notes on the information gathered from the interview phase. Also, in the interview phase, I used thick text descriptions from the interview process to write the transition experience that occurred with the participant.

Dependability

Having dependable procedures and approaches helps increase trustworthiness of a study (Yilmaz, 2013). I used an audit trail to enhance the dependability of the results. The audit trail consisted of extensive documentation of the steps completed during recruitment of participants, interview protocol, data collection, and data analysis of the study (Cope, 2014). My audit trail documentation included field notes, journal notes, and interview transcripts of the data collection. Also, the audit trail consisted of the steps and my decisions made during data analysis. I used my field notes when interviewing participants, journal notes to include my feelings and thought process during the research process or post interview, and transcriptions from audio recordings to develop my audit trail. Audit trials continued to be used in the data analysis portion of the study for document steps of coding and theme processing. Further information on the triangulation of my findings will be in the literature and theoretical framework in Chapter 5.

Confirmability

Confirmability begins with the objective views of the researcher within the study (Yilmaz, 2013). The audio recording of interviews allowed the collection of data from the participant’s viewpoint. The transcriptions of the recordings verified by the participants themselves in the data analysis phase to show the information stemmed from the participant’s transcriptions, reinforcing confirmability. I have audit trails to confirm my use of audio recordings, transcriptions, and notes to increase confirmability on how themes emerged in the data analysis. I used reflexivity to separate my opinions through documenting in a journal to bracket information away from the data analysis phase to increase confirmability. The bracketed information remained separate from the data analysis phase as the analysis focused on the data from the participant's transcriptions.

Results

After using the Bryman's stages of analysis, I was able to develop a summary of the initial chunking of data into categories of information reflected in Appendix F. As a result of the data analysis, I identified the following five themes: effects on caregiver, sources of information regarding transition process, supports received during the transition process, challenges, and recommendations to assist caregivers. See Table 3 for a summary of themes that resulted from the selective coding process.

Table 3

Emergent Themes

Major Themes (from selective coding)	Subthemes (from axial coding)
Effects on caregiver	Difficulties
	difficulty letting go
	number of transition points
	maintaining medical coverage
	continued parenting
	Personal hardships
	making choices for child

	taking time off from work financial strain Stress personal emotional instability frustrations
Sources of information regarding transition process	Doctor’s office Personal initiatives No information received
Support received during transition process	Lack of supports Types of support (family, doctor’s office, social worker)
Challenges	Obtaining needed healthcare Taking time off from work
Recommendations	Communication with child about transition Preparing for transition Resources for transition

Effects of Transition Process on Caregivers

Five participants in the study described how they were affected by the transition process. The main areas that participants noted were the difficulties they encountered during the transition, the personal hardships they endured during the transition, and the stress they experienced while transitioning a child from pediatric to adult services. Examples of those experiences are listed in the following paragraphs.

Difficulties during transition process. Six participants described having difficulties with the transition as it was hard or difficult for them to engage in the transition process. The primary difficulties stemmed from caregivers having to let go of the child with disability as the adult child has to function independently at the doctor's office. For instance, Participant 1 indicated:

> I would say the only thing that I remember that bothered me the most was when the provider which try to have me exit the room to ask my daughter personal questions. I actually exited the room and thought that she wasn't comfortable. I felt the provider asking me to step out was not right because I feel that even though she was transitioning she still my child.

Participant 2 explained her feelings related to her child being considered an adult: That I had no longer authority over her now in the doctor's office. She was considered an adult and I had no say anything anymore now. It was like if I was the outsider, I was no longer her mom.

Participant 6 noted, it's been a little difficult for me because my daughter is a teenager. It is a little harder for me as she is lacking independence. I have to do things for her because she's not there yet emotionally. In addition, Participant 3 stated: Little hard to let go because I'm mommy and I used to doing everything for him. So, it was little harder for me, but I had to teach him to spread his wings. Participant 10 further stated:

> It's hard to leave my child on their own to make decisions. I still make the calls for my child. I have to ask my child 1000 questions to find out what happened at

> the appointment. I text my child, don’t forget to ask about this. I feel you are there with them at the appointment but you’re not which makes it harder.

Another difficult component in the transition process for caregivers were the number of transition areas or system navigations that needed to be completed by the caregiver. The following comments from Participant 4 reflects the number of different offices or agencies a parent might have to contact in order to transition a child form pediatric to adult social and medical services:

> My daughter needs medical and everything and the school does not give therapy at the school. The school covers the education component of the transition. It is frustrating and stressful as my daughter is going to transition with Office of Vocational Rehabilitation (OVR). OVR is taking a year and a half. OVR found an agency to do an evaluation for a job coach. They finally they sent a person who came out to interview me. She quit the next day and I am waiting for someone else. The county has to approve her for waiver to get job coaching.

Other areas of difficulty for caregivers were maintaining medical insurance for their child and continued parenting of child with disability. According to Participant 5, it has been a little difficult to get him transitioned into to adult programs because of him being away at school and it’s so far from our household. I’ve been having issues trying to get him covered under medical coverage.

Personal hardship for the caregiver. Results from this study revealed that transitioning a child with disabilities from pediatric to adult services resulted in personal hardships for some participants. Those personal hardships were the lack of services and/or financial strains. One participant verbalized having less access to services after the child transitioned to adult services. Participant 2 shared: When it’s an adult I think there’s less help. I think there’s more help and more resources for when the minor. I think that was more of my hardship.

The transition process requires numerous appointments with a variety of providers from the pediatric and adult care services communities. A participant described having to make a choice with taking time off from work or canceling the appointment for the child with disabilities creating increased financial hardship. Participant 7 indicated: I have to call off work or leave early or sometimes not even take him to the appointments because of the hardship it creates for me.

Stress in making the transition. Participants reported feeling stress and psychological distress during the transition time. Participants described the stress as frustrations and their own emotional instability as their own anxiety became worse during the transition time. Participant 4 described the frustrations she experienced as she worked through the transition process by stating the following: It is very stressful and frustrating. Something like this should be pretty simple if there’s certain people who are ready for adult services. A notable source of psychological distress stemmed from the loss of county assistance with health insurance after her the child with disabilities turned 18 years old. Participant 5 said, it stresses me out emotionally because I worry that if something happens to him, he doesn’t have any health insurance coverage. Another example of stress that occurred for a participant was when a new diagnosis/medical condition with the adult child with disabilities occurred during the transition time.

Participant 9 stated: I was affected a lot mentally because my daughter received a new diagnosis in the middle of her transition process due to a mental health episode. The mental health episode negatively affected me and my family.

Sources of Information Regarding the Transition Process

The data gathered during the transition process varied among respondents sampled. Several participants indicated that they received information regarding the transition process from pamphlets, from doctor offices, and from friends. Five participants indicated they did not receive any information or resources while the other five participants received information from pediatric offices. Nine participants sought out their own resources through asking questions and doing their own research on transitioning.

Received information from doctor's office. Some participants indicated they received information regarding the transition from various doctor's offices. The information consisted of pamphlets, lists of doctors that provide adult services, and advice on next steps for transition for their child with disabilities. Participant 2 indicated: I received a pamphlet where it tells you that like there no longer a minor from my child's pediatrician and needing to transition my daughter as they do not serve adult patients. Participant 3 reported that similar information was provided to her at the doctor's office: The pediatric office gave us doctor's names and they gave us some pamphlets. They recommended some doctors and answered any of the questions that we may have had. Participant 4 shared that the medical doctor we had switched us over when my child was 17 to a regular doctor for adult care because she was an adolescent. Participant 8 indicated receiving information regarding adult specialists: We got paperwork with the listings of dentist that the listing of family practice providers with the listings of any type of specialty providers and with the numbers and also they informed us to contact the insurance company to see who contracts with the insurance company so it's a pretty easy so far have they been very helpful and informative.

Personal initiatives. Several participants located information themselves to help with the transition process. Participant 6 explained using social media as her source of information for transition: Well online and I think your cell phone is wonderful and you can actually Google everything. Some participants asked for information from various professionals at the pediatric or adult medical offices, case managers, and from peers. Some participant's shared statements on how they got sources of information for transitioning from medical offices: Participant 2 I asked current medical provider's office who gave me information to choose from to locate services for my child. Participant 10, I contacted the adult doctor's office to get information on how to transition my child to their office. Participant 4 indicated her sources of information came from the county office: I got a lot of my stuff from the county itself and thru my support coordinator from quality progressions. Participant 5 reported her source of information came for a case worker: I really have done is talked to my caseworker about what steps I can take to get him covered as an adult as compared to as a child again because he's away it's a little part of the county than mine to get this coverage process. Participant 9 shared that her child's mental health providers was her source of information: My friends and a couple of psychiatrists gave me a little bit of information on transition that I might be able to work with.

No information received. Five participants shared that they received no information during the transition process. Participant 1 As far as the transition honestly, I don't recall anything out of the norm not that I can think of. Other participants indicated not receiving any information from the pediatric offices. Participant 4 I got nothing from her medical office. Participant 5 Honestly, I did not receive anything from his pediatrician. I received no information. Participant 6: I received no information from my pediatrician office. Participant 7: They told me to just keep going to therapy. That's about it. Participant 10: I received none from my pediatric office.

Support Received During Transition Process

Participant comments regarding the support they received during the transition process varied. Six out of 10 participants indicated that they did not receive any support during the transition process. Four participants indicated they did receive some sort of support.

Lack of Support. Many participants reported not receiving any support during the transition process. Participant 1 indicated; I would have to say that was nonexistent. I don't think I had any. Participant 2 answered: I didn't request any support was just myself I didn't request any from either doctor. Participant 4: Not much I had to deal with it myself. Participant 7: Not really have much not that much, I just really went on my own. Participant 9: I didn't receive any support for myself and because I was able to handle it. I was able to handle it mentally but at times I was like maybe I should've got some kind of help.

Types of support received. Some participants indicated that they did receive supports during the transition process. Some participants indicated that the pediatric office provided support for caregivers through phone calls or providing access to a liaison. According to P3: The doctor's office would call us to ask questions and make sure the appointments were scheduled and to see how he was doing. Participant 8 was offered a liaison: The nurse told us that we can get like the liaison type case manager person that would help us if we needed help. Other participants indicated that they received support from family members. Participant 5: I have family support for us to help accommodate everything for him. Participant 6 also indicated the following regarding family support: Her father and family were her support system.

Challenges encountered During the Transition Process

Participants reported encountering challenges during the transition process. The challenges with obtaining adequate medical care and the challenges taking off from work were the primary challenges reported during the transition time.

Obtaining needed healthcare. Two participants identified challenges with obtaining needed health care for their children with disabilities upon turning 18 years of age. Participant 4 indicated: She's had an issue and was placed into the hospital. The issue was my daughter acts much younger for her age due to developmental delays which qualifies her for a psychiatric unit under 21. My daughter is violent and needs to be placed on the adult psychiatric unit. This created obstacles with delay in care with appropriate placement. Participant 5 shared a challenge with the county obtaining healthcare: The county office created problems by cutting off the health insurance because of my child's finances being counted as family income adding to delays in medical care.

Taking time off from work. Two participant's identified challenges with not being able to take time off from work. Participant 4 had a challenge with having to attend many meetings relating to her child's care during the transition time. Also, the nonstop meetings with the school and the county to help problem solve my daughter's case created barriers with my employers due to missing so much work. Participant 7 shared challenges with her employer and taking time off: Time was an issue at work as I had to take my child to appointments and employers were not accommodating with my needs.

Recommendations to Assist Caregivers with the Transition Process

Nine participants had suggestions for parents who must transition their children from pediatric to adult services. Suggestions focused on communication with your child with disabilities about transition, preparing for transition, and using resources during transitions.

Communication with the child about transition. Three participants had suggestions for family members to communicate with the child with disabilities about transitioning from pediatric to adult services when the child reaches age 18. Participants shared suggestions on communication with their child: Participant 1 recommended: Parents to have communication with the child about the openness with welcoming to the transition. I think that really helps the process. Participant 2 recommended communication with the child: I think it’s more about having the communication with a child that’s transferring from pediatric to adult services. I think it’s more communication between you and the child is more important and then you can overcome the transition process. Participant 3 recommended start conversation early with your child: Start talking to your child in the early teenage years preparing them for transition, having them call for doctor’s appointment, and answer questions when doctors are talking to them to help with the transition process.

Preparing for transition. Participants indicated preparing ahead of time will help with the transition process. Five participants shared parents need to educate themselves by gathering information on the transition process to help with the transition for their child with disabilities. Participant 4 indicated: Start educating yourself so talk to a support’s coordinator by reaching out to the county to start looking early about services needed to transition. We need to make the transition as smooth as possible. Participant 5 recommended preparing for transition early on: I would suggest that 16 or before they turn 17, start looking into what will happen when they turn 18 to make sure that once they turn 18, they are not surprised about the transition. Participant 7 indicated: To try to get all the information that is available and see what people could actually help them like an actual case worker for the transition. Participant 8 shared: Don’t be afraid to ask questions at the doctors. If you don’t feel comfortable with the answers, seek out someone else or ask to speak with some type of care manager or other type of social workers as they know of agencies and services that are available. Participant 10 expressed: They really should prepare themselves to be on their own during transition.

Resources for transition. Two participants indicated to use resources to help with the transition process. Participant 6 recommended joining a support group: To ask as many questions as you can to join support groups. We have many here where you to meet people. Get help, support, and encouragement like support groups for transition. Participant 10 recommended using internet: To always ask questions and to use google as a kind of guide for transition.

Textural Descriptions of Participants by Themes

Results from the data analysis revealed that the overall experience of Latino caregivers who transitioned children with disabilities from pediatric to adult services was a difficult one. Latino caregivers identified experiences associated with effects on caregivers during the transition process, useful resources during the transition process, supports needed for caregivers during the transition process, challenges encountered during the transition process, and recommendations to assist caregivers for the transition process. I present brief textural descriptions for each of the participants in the paragraphs the follow. The textural descriptions are followed by the composite, structural description of the participants' experiences.

Participant 1. Participant 1 was a 43-year-old Puerto Rican mother who is married and works full time. The participant has one other child in addition to her daughter who has a moderate psychological disability. This mother reported transitioning her daughter within 3 months after the child with disabilities turned 18 years old. The participant completed the transition process 72 months prior to the completion of the interview. This participant reported that her overall experience with transitioning her daughter was not difficult at all. The participant explained that her daughter's transition was not intense even though she had no resources or supports to use. Participant admitted to not liking medical provider's interactions with her as she was asked to leave her child's room. Participant recommended that caregivers need to have a good open relationship with their child.

Participant 1 had no adverse effects on her caregiving during the transition time. Participant 1 had no useful resources during the transition time, however felt she could have benefited from education on the transition process from the medical office. Participant had lack of supports during the transition time. Participant admitted feeling personally uncomfortable with medical providers separating her from her child with disabilities during the transition time. This participant recommended that other caregivers build strong relationships with their children with disabilities prior to going through the transition to adult medical services.

Participant 2. Participant 2 is a 41-year-old single Puerto Rican mother who works full time. She has three other children in addition to her daughter with a moderate psychological disability. This mother reported transitioning her daughter within 60 months after the child with disabilities turned 18 years old, which was 36 months prior to the completion of the interview. The participant reported that the transition took a long time because she relocated from another state and was not familiar with services offered in the new state. This participant reported that her overall experience with transitioning her daughter was satisfactory. Participant 2 explained that she was not provided any information regarding her daughter's transition from pediatrician to adult services.

Participant 2 did seek out information from medical staff from the adult offices. Participant 2 indicated that she did not receive any support during the transition to adult medical services. This participant admitted grieving the loss of her day to day management role as her child transitioned to adult care and its ensuing responsibilities. Participant 2 recommended that caregivers need to begin to let go of their children as they become an adult and support them in finding their independence.

Participant 2 explained that she expected more help with transition process. The participant did receive minimal information from the pediatrician office in the form of a pamphlet that indicated her child is no longer a minor but an adult. The participant sought out information on her own by speaking with adult medical offices to help her with the transition process. Participant 2 indicated her support biggest challenge was understanding that her child is an adult and she needed to let her go.

Participant 3. Participant 3 is a 44-year-old Puerto Rican mother who is married and works full time. She has five other children besides her son who has a mild medical disability. This mother reported transitioning her son within 24 months after the child with disabilities turned 18 years old which was 60 months prior to the completion of the interview. This participant reported that her biggest challenges were teaching him about managing his own medication, calling doctors, and completing consent forms. She explained that her son's transition process was initiated by the pediatric office. The participant shared that the pediatrician's office was a source of support through the transition process. Participant 3 also found allowing her son to make his own decisions at the adult medical services, and the confidentiality barrier at adult medical offices difficult for her. Participant 3 recommended that caregivers need to let go and teach their children independence early, such as making their own calls, and educating their child early on about the medical systems.

Participant 4. Participant 4 is a 38-year-old Puerto Rican mother who is separated from her husband currently and works full time. She has two other children besides her daughter who has a severe psychological disability. This mother reported transitioning her daughter within 24 months after the daughter with disabilities turned 18 years old, which was 12 months prior to the completion of the interview. The severity of her daughter's disability contributed to the extreme difficulty she experienced during the transition process. The county support coordinator was the only professional who handled her daughter's complex transition, which was not enough support to eliminate stress and frustration for her. Participant 4 indicated the main source of her stress and frustrations were related to the coordinator not knowing how navigate the transition process well. Participant 4 admitted to not having any social or emotional support that she needed for herself during the transition time. Participant 4 reported challenges/obstacles related to too many meetings with community agencies taking her away from her job. This participant recommended that caregivers need to start thinking about transition at an earlier age for the child, and to get the county to better prepare workers assisting with transition.

Participant 4 reported that she did not have all the information she needed to complete a successful transition. One useful resource she had during the transition time was a supports coordinator that helped her. The challenge the participant went through was with navigating the medical systems that delayed her daughter's medical care. Participant 4 recommended that other caregivers should begin thinking about their child's future regarding transition of services before the transitioning process to adult services begins.

Participant 5. Participant 5 is a 38-year-old Puerto Rican mother who is married and works part time. She has three other children besides her son who has a severe medical disability. This mother reported transitioning her son within 4 months after the child with disabilities turned 18 years old. The participant completed the transition process 8 months prior to the completion of the interview. This participant described her overall experience with transitioning her son was a little difficult. This participant explained that her son's transition was prompted by the county and not the pediatric office. Participant 5 indicated to having family support from her husband to help through the transition time. Participant 5 recommended that caregivers need to begin understanding about transition prior to the child's 18th birthday. Also, participant recommended the county needs to invest in better services for adult children with disabilities.

Participant 5 indicated that the transition process did not significantly increase her stress level, so stress was not a major difficulty for her. The participant received any information to help her with the transition. During the transition process, Participant 5's child lost access to county funded health insurance, which created a financial hardship for the family. Participant 5 recommended that other caregivers begin discussing the transition process with their children as early as when the child turns 16 years of age.

Another recommendation was that community and county agencies should have more information on transitioning for the child with disabilities upon turning 18 years old to assist caregivers.

Participant 6. Participant 6 is a 39-year-old single Puerto Rican mother who works full time. She has one other child besides her daughter who has a mild medical disability. This mother reports transitioning her daughter within 6 months after the child with disabilities turned 18 years old. The participant has completed the transition 3 months prior to the completion of the interview. This participant described her overall experience with transitioning her daughter as a little difficult. This participant explained that she was not provided any information on how to transition her daughter from her pediatric providers, but she took the initiative and went to the internet for information. This participant relied on herself and her family for support during the transition process. Participant 6 admitted her most substantial obstacles in the process were her personal feelings of letting go of her child as she transitions to functioning as an adult. The participant admitted to experiencing increased stress during the transition process due to her own difficulties with accepting her child as an adult. This participant recommended that other caregivers join a support group during the transition process.

Participant 7. Participant 7 is a 41-year-old single Puerto Rican mother who works full time. She has one other child besides her son who has a mild psychological disability. This mother reported transitioning her son within 12 months after the child with disabilities turned 18 years old. The participant completed the transition process 120 months prior to the completion of the interview. This participant described that her overall experience with transitioning her son as a little difficult. Participant 7 indicated that her child's mental health office was a resource during the transition. Participant 007 described her most significant obstacle was the time away from work because she had to miss work for her child's appointments. This created a strain at her job resulting in a hardship with her finances.

Participant 7 felt that the combination of the changes accompanying the transition and the increased responsibilities of being a single parent made this period particularly difficult for her. Effects of caregiving impacted her in two ways, a hardship with the changes associated with the transition process and very hard due to being a single parent. She indicated her support came from the mental health office, but she felt she needed more support for the transition process. Participant 7 suggested that gathering all the information ahead of time would assist the caregiver to prepare for the transition process.

Participant 8. Participant 8 is a 42-year-old Puerto Rican mother who is divorced and works full time. She has two other children besides her son who has a moderate psychological disability. This mother reported transitioning her son within 8 months after the child with disabilities turned 18 years old. Participant 8 completed the transition process 24 months prior to the completion of the interview. She reported that her overall experience with transitioning her son was not as difficult as she thought it would be. She reported she received both information and support from the pediatrician's office. Participant 8 indicated her greatest obstacles were with her son following through with making appointments. Participant 8 recommended that caregivers ask questions and request a case manager to help with the transition process.

Participant 9. Participant 9 is a 45-year-old mother who identified as being Costa Rican and Puerto Rican. She is married and works part time. She has three other children besides her daughter who has a severe psychological disability. This mother reported transitioning her daughter within 12 months after the child with disabilities turned 18 years old. The participant completed the transition process 24 months prior to the completion of the interview. Participant 9 described her overall experience with transitioning her daughter was a little difficult. Participant 9 explained that she felt supported by her daughter's mental health office during her daughter's transition process. She indicated that the mental health office provided support and feedback on how to navigate the transition process. Participant 9 admitted her own mental health issues presented challenges with understanding the transition process. Participant 9 recommended that caregivers should get custody, legal guardianship, of their adult child in attempts to be the decision maker in the adult systems and not the adult child with disabilities. Participant 9 indicated that the effects of caregiving caused her to be emotional and stressed during the transition process. The participant's daughter's mental health office provided Participant 9 support during the transition process.

Participant 10. Participant 10 is a 43-year-old Puerto Rican mother who is married and works full time. She has three other children besides her daughter who has a mild psychological disability, including a boy who also has a psychological disability. For the purposes of this study, Participant 10 only described the experiences related to her daughter's transition period. Participant 10 reported transitioning her daughter within 9 months after the child with disabilities turned 18 years old. The participant completed the transition process 42 months prior to the completion of the interview. Participant 10 described her overall experience with transitioning her daughter as good but hard at times. Participant 10 explained that she received support with her daughter's transition from the school her daughter attended. Participant 10 felt she had no support during the transition process from the medical system. She indicated she had challenges getting information on her daughter from the doctor. Participant 10 recommended that caregivers need to be better prepared for the transition process and need to ask questions.

Structural-Textural Description

The results of the data analysis showed five major themes: 1) effects of the transition process on the caregiver, 2) sources of information regarding the transition process, 3) supports received during the transition process, 4) challenges encountered during the transition process, and 5) recommendations to assist caregivers with the transition process, that showed the experiences of what caregivers go through during the transition process with their child with disabilities. The difficulties that most affected the transition process for Latina caregivers were personal hardship of letting go and increased stress from the complicated process. The most common sources of information regarding the transition process were information received from the doctor's office or information gathered through personal initiative. The most commonly reported challenges for caregivers during the transition process were obtaining needed healthcare and taking time off from work. The most common recommendations to assist caregivers during the transition time were for increased engagement from family and from community agencies.

The main areas they noted were suffering personal hardships due to lack of adult services and financial strain. But, in the study, 50% of the participants reported personally being affected by caregiving during the transition process. Caregivers' identified letting go of making decision for their child with disabilities during the transition process as a significant source of stress because the caregiver is no longer the decision maker for the child's medical care. Some caregivers indicated that they felt their children with disabilities were not quite ready to make decisions regarding their medical care, however the caregivers had to come to terms with letting their children make their own decisions without consulting with the parents. Some caregivers would like to continue to make decisions for their child, but adult systems do not permit the caregiver to make decisions when the child turns 18 years of age unless the parent has been granted legal guardianship.

All participants identified financial strain associated with transitioning their children from pediatric to adult services as a significant source of stress. The financial strain they described stemmed from having to miss work because of multiple new appointments needed for the child with disability to complete the transition process, resulting in participants' losing money or income for their household. Compounding that participants indicated losing time because of so many long appointments also added to the financial strain.

Another source identified stress came from frustrations and psychological distress due to delays within systems. Some participants indicated that the emotional instability and psychological stress was caused by county and school systems making decisions without involving the caregiver in the process. For example, one participant reported the county system placing her child with a disability on a waiting list for adult services without informing the caregiver of long delays in receiving adult services. Another participant reported the county discontinued services for the child with disability without informing the family in a timely manner.

Participants reported that the most useful sources of information that they received were from doctor's office and information they gathered through their own personal initiative. Caregivers also identified not receiving any information on resources during the transition process. Half of the participants reported they received resources from their pediatrician's office about the transition process which participants indicated was useful. However, all of the participants communicated the need for more information and resources to help guide parents through the transition process.

All participants indicated needing supports for caregiving during the transition process. A total of 60% of the participants indicated they did not receive any direct support from pediatric or adult offices or their families regarding caregiving, financial support or paperwork during the transition process. Participants did report pediatric providers provided information from the pediatrician about transitioning their child with disabilities to adult offices. Participants who did receive support from family indicated that the support helped to reduce the emotional distress they may have been going through during the transition process.

All participants reported challenges with obtaining needed health care for their children. Obstacles included delay of services and in obtaining medical insurance for health care services. Another challenge identified is taking time off from work during the transition process. Participants identified challenges with employers who either gave participants hard time with leaving work for appointment or losing income because of loss of time from work.

Each participant had recommendations to assist caregivers with navigating the transition process. Recommendations are for family and community agencies. A recommendation for the transition process is to communicate with your child about the transition process. The participants recommended preparing for the transition process by gathering information and asking question early on prior to any transition steps. Furthermore, resources for transition such as the internet and support group may be helpful during the transition process. All recommendations are to aid other family members to navigate the transition process.

Summary

Transition experiences can vary for caregivers when their child with disabilities needs to transition from pediatric services to adult services upon turning 18 years of age. After gathering data from 10 Latino caregivers with children of disabilities who transitioning their children from pediatric or adult services, I completed the Bryman's four stages of analysis. After completion of the stage analysis, five themes were identified as the result of the analysis. Participant's experiences related to transitioning their child with disabilities impacted effects of the transition process on the caregivers, sources of information regarding the transition process, supports received during the transition process, challenges encountered during the transition process, and recommendations to assist caregivers with the transition process.

In Chapter 5, I will focus on interpreting the findings of the study and comparing them to the literature peer review described in Chapter 2. I will analysis and interpret the theoretical framework. I will describe any limitations to the study regarding any trustworthiness concerns. I will describe any recommendations for further research. Also, I describe any positive implications for social change and recommendations for practice.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this qualitative hermeneutical phenomenological study, I explored the lived experiences of Latino female caregivers while navigating the process of transitioning their children with disabilities into the adult healthcare system. I interviewed 10 Latino female caregivers who have navigated the pediatric to adult healthcare system for their adult children with disabilities. Participants were recruited from both Lehigh and Northampton counties in Pennsylvania. The specific time frame studied was the point at which the Latino caregivers were informed by their pediatrician to transition their child with disabilities to adult services.

I chose this approach for my study because I was interested in Latino caregiver's' lived experiences of transitioning their children with disabilities to adult services. Previous research suggested a need for improvement in the transitioning of services for adolescents and parents however literature also showed a lack of ethnic populations being studied on the transition process from pediatric to adult services. Upon gathering the data, I completed Bryman's' stages of data analysis.

The data analysis revealed five emergent themes regarding Latino female caregivers' experiences with transitioning their children with disabilities to adult health care services. The five major themes were: effects on the transition process on the caregivers, sources of information regarding the transition process, supports received during the transition process, challenges encountered during the transition process, and recommendations to assist caregivers with the transition process.

Interpretation of Findings

Three themes that emerged from this data were consistent with the themes from the literature review. Similarities and differences between these data and the literature I reviewed are expanded upon below.

Theme 1: Effects of the Transition Process on the Caregiver

The words participants described used to describe the transition process included, a little hard, little difficult, and horrible. These sentiments from the participants in this study were consistent with findings from other researchers who investigated processes associated with transitioning children with disabilities to the adult healthcare system. Marsh and Rodrigues (2015) study that showed participants described the transition process as having been difficult. Betz et al. (2015) also reported that caregivers reported facing difficulties when attempting to transition their children from pediatric to adult services. Khanna et al. (2015) found that caregivers in their study found it especially challenging to find specialists in adult systems for children needing specialized healthcare.

Many hardships described by participants in this study were particular to the caregiver herself, rather than her child. The most commonly described hardship for caregivers included anxiety and sadness regarding losing responsibility for decision-making for their child because the child became a legal adult. Most caregivers also reported that the process itself created financial hardship for their families because the number of in person appointments needed to complete the process required many hours and days off from work, which most could not afford and often created strain at work for the parents. This was consistent with Corvin et al. (2017), who confirmed common hardships related to competing demands about making choices about medical demands of the child and financial strains placed on the household.

Zan and Scharff (2015) also discussed the financial burden related to high health care costs for caregivers with children with disabilities as a factor during the transition. Goudie et al. (2014) reported that caregivers of children with disabilities encountered twice the amount of stress associated with finances, which was confirmed by the data I collected.

Participants described the psychological distress that they experienced during the transition. Also, participants identified frustrations with the transition process. In this study, 30% of the participants shared the emotional stress with the transition process. Kaur (2016) said that caregivers of children with mental health disabilities had psychological discomfort associated with caregiving. Haung et al. (2014) also found caregivers experienced psychological distress when caring for offspring with more severe disabilities. . Findings from this study also revealed that some participants experienced more stress with adult children with moderate to severe psychological needs during the transition process.

Theme 2: Sources of Information Regarding the Transition Process

Five participants shared that they received some form of information such as pamphlets, contact information, and listings of specialists from their pediatricians. This is consistent with Ishizaki et al. (2012) who identified doctor’s offices providing transition manuals with information on the transition process to caregivers to aid in the transition process.

The majority of the participants sought out information by using their own personal initiatives, as no one offered information to the participants on the steps needed to transition their children with disabilities to adult services. Van Staa, et al. (2011) reported that caregivers in their study reported wishing they were prepped better on how the transition process works, which is consistent with the findings in my study.

Six participants took the initiative to seek out services on their own, either because the guidance they were provided was incomplete, or they were not offered guidance from any of their providers at the time. Some of the steps participants took to find services included contacting pediatricians, adult mental health offices, and school health centers to figure out the transition process. Also, participants reported seeking out information from community agency offices such as program coordinators and county offices. Sonneveld et al. (2013) showed that caregivers who used coordinators to assist with the transition process felt less confused and more confident during the transition process. While most participants in my study did not have access to coordinators to assist in the process, one participant stated that having a coordinator to assist would have been helpful.

A significant tool, two participants reported using was online social media to gather information to help them with transition services. They used social media platforms such as Google to educate themselves about what is entailed in the transition process. The personal initiative on using social medical platforms is new information that will be added to the literature during the transition process.

Theme 3: Supports Received During the Transition Process

Six participants reported they did not feel supported during the transition time and hoped for some type of support such as family, doctor, or social workers who could accompany and advise them. Wijesinghe et al. (2015) said that caregiver burden increases in caregivers when supports are lacking when caring for a child with severe disability. Because 6 out of 10 of the participants in my study indicated they did not feel supported in this process which increased stress for the caregiver, my findings are consistent with those reported in the literature.

Four participants' identified notable supports that helped them through the transition. The supports they identified included family members, doctor's offices, and social workers. Kyzar, Turnbull, Summers, and Gómez (2012) synthesis of a variety of studies and determined the most common supports came from family, friends, and professionals for caregivers with a child with disabilities. Wijesinghe et al., (2015) identified that spousal support helped caregivers with children with disabilities. The supports identified by the four participants in my study are consistent with the type of supports most common in the literature.

Theme 4: Challenges During the Transition Process

Challenges that arose from my study about transitioning children with disabilities from pediatric to adult services focused on obtaining needed healthcare and taking time off from work. Two participants shared challenges with delays in medical care for the child with disabilities because of developmental delays upon turning 18 years old. Fortuna et al. (2012) reported the delay of transition services for children with disabilities from pediatric to adult medical services was related to the presence of chronic illnesses such as developmental delays, which was consistent with my findings. Two participants reported there were delays in accessing medical care for their child due to the loss of medical insurance for their child as part of the transition because of the onset of the age of the child. Bisgaier and Rhodes (2011) reported that medical insurance challenges occurred when trying to locate a medical doctor who is willing to accept their medical insurance or provide services to a child with no insurance. This was also consistent with the experiences of [number] of participants in my study. Additionally, two participants shared similar delays in adult services due adult medical offices not being adequately prepared to handle their child with disabilities.

Another challenge for participants was taking time off from work. Taking time off from work added challenges to the participant in the transition process. Zan and Scharff (2015) showed missing time from work due to the number of doctor visits and impacted the caregiver. Saunders, et al. (2015) discovered caregivers with children with disabilities reduce work hours due to taking time off to take child to medical visits. Two participants shared similar outcomes with missing work for medical appointments or meetings with adult services. Participants shared similar challenges during the transition process as seen in previous literature.

Theme 5: Recommendations to Assist Caregivers During the Transition Process

The participants in this study all made recommendations to assist other caregivers going through this process based on their experiences. These recommendations focused on three key areas: preparing the child for the change in routine and added responsibilities, educating oneself regarding the logistics of the process, and securing supportive resources for the caregiver during the process. Van Staa et al. (2011) found that early communication between caregiver and child with disabilities about the changes that will happen as part of the transition helped with the transition process. Specifically, Van Staa et al. (2011) reported that when the caregiver and child are able to discuss the transition with the pediatrician and the adult medial office all parties involved benefit from the conversations. Five participants recommended preparing ahead of time with the child will help with the transition process.

Participants indicated to use resources to help with the transition process. Two participants shared they felt that using or creating support groups comprised of other caregivers would have eased some of the stress of the process. Two participants also recommended educating oneself about all of the documents and appointments involved in the process ahead of time to better understand what to do would be very helpful. During my literature review, neither the use of support groups nor social media were identified as resources for the transition process. These two resources, support groups and internet/social media platform is new information that will be added to the literature to help fill in the gap regarding resources to be used in the transition process.

Limitations of the Study

There are several limitations associated with this study. The selection criteria were very specific and recruiting participants took longer than previously anticipated, but I was able to successfully recruit an appropriate number of participants who met all of the selection criteria. I prescreened approximately 25 potential participants to only have 10 qualify for the study. Due to prescreening process and collection of data from the participants, the process lasted approximately 3 months. The prescreening delays were largely due to finding a large enough sample of Latino caregivers who had the ability to speak, read, and write English. This created delays on the front end during the data collection period as the Latino participants needed to be fluent in English.

Another limitation was the participants needed to reside in Lehigh or Northampton Counties in Pennsylvania. Participants had to have transitioned their child with disabilities from pediatric services to adult services within these county areas. The study limited the data collection to Latino caregivers and not their children with disabilities, medical offices or human service offices involved in the transition process.

A third limitation was that this study was restricted to Latino caregivers with children with disabilities. Participants were selected to represent the Latino population. Subsequently, potential findings from this qualitative study may not be transferrable to caregivers of other ethnic or racial groups.

Recommendations

This study used interviews to explore 10 Latino caregivers’ experiences with transitioning their child with disabilities from pediatric to adult services. Future qualitative research includes male caregivers' experiences transitioning a child with disabilities from pediatric to adult services. Gathering a male caregiver's perspective would add to literature by showing experiences from both genders during the process of transitioning a child with disabilities from pediatric to adult services. This would allow the opportunity to look if there is a difference of experiences between the two genders and their experiences transitioning a child with disabilities from pediatric services to adult services which can be a mixed methods research if a comparison is explored.

In my study, participants had to be both Latino and English speaking to be included. Another recommendation is to conduct a similar qualitative study design as this one but including participants who speak only Spanish. Spanish speaking participants or another ethnic population for whom English is not the primary language can bring new information about populations not included in the current literature on this topic. With this new research recommendation to focus on Spanish speaking caregivers with children of disabilities may enlighten if language barriers and cultural difference experiences occur during the transition time.

Implications

Positive Social Change

The participants in this study clearly identified increasing communication with their child with disabilities regarding the transition process at an early age as an essential component of a smooth transition. Talking about the process with the child in advance not only helps the child prepare for change and build greater skills of independence, it also helps the caregiver build confidence in their child's capacity and identify early areas that need support. Additionally, by communicating freely about this in advance, it should also help to reduce the fear, anxiety and sadness caregivers felt in lessening their responsibility for their adult child's care. The caregiver can also get assistance from the pediatrician on how to talk with the child during a well child check exam. Also, the use of counseling therapy as needed to discuss transition parts of the child life if adjustment issues occur would be beneficial. Furthermore, resources available through the school district represent another avenue to learn about the transition process for both caregiver and child.

During the communication between caregiver and child, visual aids such as pamphlets, lists of adult offices or internet resources, or a book on transition from pediatric to adult service resources can be provided to the caregiver and child to better ease with the transition process. These types of resources may ease the transition process as the caregiver and child would have something concrete to reference to during the transition process. These resources ideally should come from the organizations that work with the caregiver and child during the transition time and should be readily available and free of charge. Example of organizations where these types of materials should be available include pediatrician's offices, schools, and human services providers.

Human services agencies within the community can help provide the necessary services to assist in supporting the caregiver (Hasenfeld, 2010). For example, if human services agencies would identify a person whose job is to help coordinate these transitions for families, such as stocking and distributing informational pamphlets on all areas for transition from various pediatric settings to adult settings. Creating a new position or improving existing programs, policies or processes to include the distribution of this information would create the positive social change in the community. This positive change in the community will help decrease care giver burden and support caregivers who need to transition their child with disabilities from pediatric services to adult services, creating a better situation for families and providers.

Importance of Theory

The theoretical framework that guided this study was systems theory by von Bertalanffy (Bertalanffy, 1972). The original systems theory focused on the interconnected parts and interrelationships among elements of various systems. In this study, I was interested in using GST because I was interested in identifying points of dissonance and resonance between the multiple systems that are necessary to provide care for a child with disabilities both from the pediatric realm and the adult realm. While the structure of the research tool was designed to identify these connection and disconnection points, I found very few if any points of connection between and across systems. Instead, I found that the Latina caregivers themselves had to build the bridges themselves from pediatric services to adult services. In analyzing the responses from the participants in this study, it is clear they encountered challenges navigating between the systems. The most harmful disconnects described were difficulties described in obtaining needed health care for their children. Latina caregivers indicated that the child diagnosis delayed the adult medical office from accepting them due to lack of experience with the medical condition. Providing adult medical offices with the same materials about the transition process recommended for families and pediatric offices will help to better prepare them to care for people with disabilities at the age of 18 so there is no lapse in medical care.

Another bridge that caregivers needed to build themselves during the transition time was between the caregivers, employer, and medical offices. Participants shared that taking time off from work created strained relationship with their employers due to the multiple appointments required at medical offices during regular business hours. All of the participants described themselves as in the middle of all these systems to effectively navigate for the child with disabilities. A relatively inexpensive but effective intervention that could improve the process for caregivers could be if medical providers' offices could prompt the caregiver to complete is a Family Medical Leave Act form (FMLA). The FMLA form can be the bridge between the systems: caregivers, employer, and medical office, reducing conflict, easing stress, and likely improving the process for all parties. The FMLA can be requested by the caregiver from her employer and given to the medical provider to complete. While increased family caregiving needs are an approved use of FMLA, few workers are aware of it and few medical providers suggest it as a tool. By applying for this benefit for this situation, the employer can accept the form, so caregiver does not miss so much work unless necessary.

. When reviewing the information during the transition process, five of the caregivers reported no one offered them information to transition their child with disabilities. However, six caregivers sought out information on their own to figure out the process for transitioning their child with disabilities to adult care. With the GST premise, the caregivers used personal initiative and sought out information from various systems, becoming the bridge between systems themselves. The established systems the participants reported interacting with included medical offices, case managers from both county systems, and social media to access help among. Participants used their personal initiatives to help themselves.

According to premises of GST, a system is a multifaceted set of interactions of elements among closed, open, and isolated systems (Mele, Pels, & Polese, 2010; Pouvreau, 2014; Rousseau, 2015). The lack of supports offered to the Latino female caregiver during the transition process are consisted with to the isolated closed systems. These themes emerged from the premises of GST.

Significance to Practice

The focus of this study's findings can be used for both pediatric and adult system offices to increase a better experience for Latino caregiver transitioning their child with disabilities at the age of 18. One recommendation of this study is to educate the caregivers, healthcare offices, and human service offices with results of the study so they can decide if any improvement areas need to occur in attempts to decrease caregiver burden during the transition time of a child with disabilities at age 18. In addition, planning and advocating for changes in policies and programs for improved transition services to help aid the caregiver during transition time with their child with disabilities.

Conclusion

The purpose of this qualitative hermeneutic phenomenological study was to document the lived experiences of Latino caregivers while navigating transitioning care from pediatric providers to adult care services for their children with disabilities when those children turn 18 years of age. This study identified concrete, inexpensive and practical interventions pediatric and adult care providers can implement that would ease the caregiver burden within the pediatric and adult systems. In the short term, these interventions require that medical practices become proactive in asking questions rather than reactive in answering questions that come from caregivers. In the long term, these interventions present opportunities for policy change that could create inexpensive and simple standards of routine care during annual wellness visits that could dramatically improve the lives of children with disabilities and their families as well as improving the quality of care and transition process for pediatric and adult care providers.

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Appendix A: Flyer

Be part of an important research study.

1. Are you a Latino female primary caregiver of an offspring with a disability that transitioned from pediatric to adult services within the last 6 years?
2. Is your offspring with disabilities who has transitioned older than 18 but under 24 years old?
3. Does your offspring with disabilities have either physical and/or emotional disability?
4. Are you a Latino female caregiver that speaks, reads, and writes in English?

If you answered YES to these questions, you may be eligible to participate in the research study.

The purpose of this research study is to explore the lived experiences of Latino female caregivers navigating systems to transition their children with disabilities into the adult services system.

Latino female caregivers over the age of 18 years old are eligible to participate.

This study is being conducted by Gloria Velazquez through Walden University.

Please contact Gloria Velazquez at (xxx) xxx-xxxx or email to xxxxx.xxxxxxxxx@xxxxxxx.xxx for more information about the study.

Appendix B: Prescreening Checklist

Name: ___________________________________

Date: ____________________________________

Screener: __________________________________

1) Are you a Latino female primary caregiver? Yes or No
2) What is your ancestry country of origin?

   ____

3) Are you a Latino female primary caregiver of an offspring with a disability that transitioned from pediatric to adult services within the last 6 years? Yes or No
4) Is your offspring with disabilities who has transitioned older than 18 but under 24 years of age? Yes or No
5) Does your offspring with disabilities have either physical and/or emotional disability? Yes or No
6) Are you a Latino female caregiver who speaks, reads, and writes in English? Yes or No

If participant passes preliminary checklist, assign participant patient identification number for study:

____

Appendix C: Consent Form

You are invited to take part in a research study explores the lived experiences of Latino female caregivers while navigating the transition process as their children with disabilities move into the adult services system. The researcher is inviting Latino female caregivers who have at least one offspring with a disability who transitioned from pediatric to adult services within the last 6 years to be in the study. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Gloria Velazquez, who is a doctoral student at Walden University. You might already know the researcher as a Licensed Clinical Social Worker, but this study is separate from that role.

Background Information:
The purpose of this study is to focus on Latino caregivers' perspectives of transition services as they navigate through the process of transitioning their children from pediatric to adult services.

Procedures:
If you agree to be in this study, you will be asked to:

- Participate in a pre-screening interview
- Communicate with researcher to arrange an interview date and location.
- Sign consent forms at time of interview.
- Review a letter that explains the proposed study at time of interview.
- A copy of consent form and letter will be provided.
- Permission to use audio recorder during interview.
- The interview consists of 11 questions and will last for approximately one hour.
- I will contact you for second meeting i to review transcriptions from the first interview.

Here are some sample questions:

- Describe your overall experience with transitioning your child with disabilities from pediatric services to adult services?
- How were you personally affected by the experience of transitioning your child with disabilities from pediatric services to adult services
- What information did you receive from the pediatric physician services regarding the steps needed to make the transition from pediatric to adult healthcare services?

Voluntary Nature of the Study:
This study is voluntary. You are free to accept or turn down the invitation. No one at any of the Human Service Agencies will treat you differently if you decide not to be in the study. If you decide to be in the study now, you can still change your mind later. You may stop at any time. The researcher will follow up with all volunteers to let them know whether or not they were selected for the study.

Risks and Benefits of Being in the Study:
Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as stress or becoming upset. Being in this study would not pose risk to your safety or wellbeing.

The benefits to this study are for the larger community.

Payment:
There will be a $20 gift card to Wawa to be given to participants as a token of appreciation for participating in the study.

Privacy:
Reports coming out of this study will not share the identities of individual participants. Details that might identify participants, such as the location of the study, also will not be shared. The researcher will not use your personal information for any purpose outside of this research project. Data will be kept secure by password protection on a computer. Any files, transcripts, and audiotapes will be locked within a filing cabinet in a secured office. The use of alias for participant's information will help with keeping information unidentifiable. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:
You may ask any questions you have now. Or if you have questions later, you may contact the researcher via _xxx-xxx-xxxx and/or xxxxx.xxxxxxxxx@xxxxxxx.xxx. If you want to talk privately about your rights as a participant, you can call the Research Participant Advocate at my university 1-800-925-3368 ext. 312-1210 or email address irb@waldenu.edu. Walden University's approval number for this study is **IRB will enter approval number here** and it expires on **IRB will enter expiration date.**

The researcher will give you a copy of this form to keep.

Obtaining Your Consent

If you feel you understand the study well enough to make a decision about it, please indicate your consent by signing below.

Printed Name of Participant ______________________________

Date of consent ______________________________

Participant's Signature ______________________________

Researcher's Signature ______________________________

Appendix D: Participant Demographic Information

Date of Interview: ____________________________

Time of Interview: __________________

Place: _____________________________

Participant Identification Number: ___________________

How long did it take make the transition from pediatric to adult healthcare services?

____

Length of time since transitioning offspring to adult services:

____

Severity of disability of offspring making the transition from pediatric to adult health care services (mild, moderate, severe) _______________________

Types of medical services needed for offspring making the transition from pediatric to adult health care services (medical, intellectual, psychological):

____

Age of Interviewee: ________________________

Number of Other Children/Offspring in Home: ________________________

Employment Status: ________________________
Marital Status: ________________________

Appendix E: Interview Protocol

1. Describe your overall experience with transitioning your child with disabilities from pediatric services to adult services?
2. How were you personally affected by the experience of transitioning your child with disabilities from pediatric services to adult services
3. What information did you receive from the pediatric physician services regarding the steps needed to make the transition from pediatric to adult healthcare services?
4. Where did you go to get information about the actions needed to make the transition from pediatric to adult healthcare services?
5. What support did you have during the process of transitioning your child from pediatric services to adult services?
6. What barriers did you encounter when engaging with adult medical systems for your child/offspring during the transition?
7. What major challenges did you face in making the transition from pediatric to adult healthcare services?
8. How did you overcome the challenges of making the transition from pediatric to adult healthcare services?
9. What information would have made it easier for you to make the transition from pediatric to adult healthcare services?
10. What suggestions do you have for other parents who must the transition their children from pediatric to adult healthcare services?
11. Is there anything you would like to add to this interview?

Appendix F: Results of Chunking from Open Coding

Participant Question	Chunking Categories
Overall Experience	Not difficult, okay, good, easier than expected
	Horrible, little difficult, little emotional
	Teaching meds, calling doctors, consents
Personally Affected	Transition ok, fine
	Difficult, hardship, little hard, hard
	Stressful, frustrating, effects
emotionally	
	Not completing transition
Info Received	None
	Pamphlets, doctor gives info, list provided, therapist friend
	Keep going to therapy
Went for Info	Never did
	Doctor office, mental health office
	County, case worker
	Online, google
Supports	No supports

	Doctor’s office
	Family
Barriers	Doctor’s office separate us, exit room
	Child alone in room
	No authority, not on HIPAA
	Loss of services
	Income Issues
	None
Major Challenges	Exit room of child
	Letting go
	Nonstop meetings, appointments
	Cannot accommodate services
	Finances
	Time
	Handling of child
Overcoming Challenges	Didn’t have any, no challenge
	Talking to child
	One day at a time
	Getting support from other agencies
	Still working on challenges
	Ask questions

	My job, my schooling
	Hardship with missing work
	Don’t have a choice
Made it Easier	More education, information
	Delivery of news by doctor, county
	Starting early, age 14 to prepare
	Pamphlet, online, tools
	Someone to take to appointments
	Adequate information provided
	Changes in HIPAA Law
Suggestions	Open relationships with child, communication with child
	Start prepping in early teenage years, think about child future
	Support coordinator, caseworker, case manager, social worker, someone to guide
	Ask many questions
	Join support group
	Get custody of young adult
	Google
Anything to Add	No

	Have a good relationship with child
	Letting go
	County to be better
	Learn from others
	Prepare child