

2021

Unmet Needs of Children With Special Health Care Needs When Transitioning to Adult Services

Kiara Monee Moseby
Walden University

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Walden University

College of Health Professions

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Kiara Moseby

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Walden University
2021

Abstract

Unmet Needs of Children With Special Health Care Needs When Transitioning to Adult

Services

by

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MBA/MHA, University of Phoenix, 2017

BA, California State University, Sacramento, 2015

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Healthcare Administration

Walden University

August 2021

Abstract

Health care transition planning could help decrease health care disparities among those who identify as an individual on the autism spectrum; however, less than a quarter of the adolescent population living with autism spectrum disorder receive transition planning. Decreasing health care disparities could lead to an increase in health care quality and longevity. The purpose of this study was to analyze if there was a relationship between (a) the number of physician visits, (b) if the physician treats only children, (c) if the physician talks about the child seeing physicians who treat adults, (d) if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and if (a) the physician helped the child develop skills to manage their health and (b) if the physician worked with the child to understand health care changes for both children with and without special health care needs. Secondary data from 5,638 parental respondents of children aged 17 years old to the 2017 National Survey of Children's Health (NSCH) were used to conduct this quantitative analysis employing chi square tests guided by the Donabedian structure/process/outcome model. The findings support the hypothesis that a statistically significant relationship does not exist between the dependent variables and covariates. Future research could incorporate physician response data or racial and socioeconomic variables to find further significance. The findings of the study can positively influence social change by allowing health care administrators to implement initiatives within their organizations to further the improvement of transitional planning for adolescents.

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Dedication

In loving memory of my sons, Marcus and Malachi, and my grandparents, Olan Bailey, Cleo Moseby, and Anthony Moseby. I dedicate this doctoral study to my family and close friends. To my mom, none of this would be possible without you. To my best friends, my sisters, I share this accomplishment with you. I dedicate this body of work to my baby boy, Khari. Everything I do is for you. You are my inspiration, my strength to continue. I love all of you who have been an asset to my accomplishments.

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Next, I'd like to thank my parents, Vicky and Phil Moseby. Since I can remember, you both have always been there to push me to succeed academically. Thank you for supporting me mentally, emotionally, and financially. Without your contributions, this accomplishment would not have happened.

To my son, Khari. Thank you for giving me the push I need to reach the finish line. It was not easy being a full-time mom and student, but we did it. Your mommy is a doctor!

To my village of relatives, friends, and associates, thank you. I have always said that this accomplishment is not just mine, it's ours.

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Section 1: Foundation of the Study and Literature Review

Transition planning for children with special health care needs (CSHCN) is a national priority (The Office of Disease Prevention and Health Promotion, 2019). Less than a quarter of adolescents with autism spectrum disorder (ASD) receive health care transition planning (Cheak-Zamora & Thullen, 2013). Muskat et al. (2015) discussed that guardians of children with ASD have been more likely to describe their child's health as "fair" or "poor" in comparison to parents of children without ASD who reported their child's health as "excellent." Findings have suggested an increasing prevalence of unmet health care needs, health care utilization, and health care access amongst CSHCN (Karpur et al., 2019). Muskat et al. expressed that it is crucial to understand the experiences of those CSHCN who visit health care facilities to address their multifaceted health-related needs.

Focusing on children aged 17, in this study I examined the unmet health care needs faced by CSHCN compared to non-CSHCN with physician involvement when transitioning to adult primary care from pediatric primary care. In this section, I introduce the problem and purpose of the study. The theoretical framework and the nature of this study are also discussed. Then, I provide an overview of relevant literature; define key terms used in this study; present the assumptions, scopes, and delimitations.

Problem Statement

The American Academy of Pediatrics (2018) stated that only 15% of youth with special health care needs receive transition planning assistance from their health care

providers. The transition from pediatric to adult health care is vital to CSHCN. Dern and Sappok (2016) stated that children with intellectual or developmental disabilities were more likely to have unmet medical care needs. Research on improving health service access for this vulnerable population has been scarce. In 2016, the United States Census Bureau's (2017) American Community Survey estimated that 12.8% of the population had an intellectual disability. The Health Care Transitions Network (2015) stated that 66,000 CSHCN turn 18-years-old every year, and, therefore, transition out of pediatric care to adult care services.

Health care administrators shape policy and make the necessary changes to improve the health care system. According to Walsh et al. (2017), health care policy makers should increase the uniformity of transition planning services offered throughout the pediatric sector to ensure that all adolescents approaching adulthood have the necessities to transition to adult health care services successfully. With the data from this study, I sought to help health administrators shape existing policies and implement new policies to meet the needs of CSHCN better.

Lack of relevant data left past researchers without key information to assess unmet needs in transition planning. Walsh et al. (2017) researched the overall transition core outcomes among youth with ASD, but patient experiences, health care outcomes, and the unmet needs in existing health care transition approaches were not examined because their data came from 2009. Sharby et al. (2015) studied ways to reduce disparities in receiving health care transition planning services for CSHCN through communication strategies and awareness. However, they did not give attention to the

relationship between transition planning and health outcomes for CSHCN, specifically with physician involvement.

Research aimed at capturing the perspectives of pediatric providers about the transition to adult health care for youth with ASD would hopefully reveal potential strategies to help facilitate the health care transition process. Strategies that could be helpful included transition-specific appointments, checklists, and written medical summaries (Kuhlthau et al., 2015). Walsh et al. (2017) discussed that administrators and policy makers should incorporate training opportunities, including the development of transition-specific curriculum for interdisciplinary providers with greater emphasis on transition planning at local and national health care conferences, increased focus on a transition curriculum for medical residents, and community outreach to pediatric health care providers. In the current study, I attempted to fill the knowledge gap by determining differences in health care provider involvement when both CSCHN and non-CSHCN transition from pediatric primary care to adult primary care. According to Vohra et al. (2014), if such differences existed, including between the perceptions of guardian needs and the type of health care needs of these children, they would help health care providers and policy makers design programs that might address core deficits in areas of services provision, care coordination, and shared decision making, leading to improvement in health outcomes for CSHCN.

Purpose of the Study

The purpose of this quantitative study was to evaluate the unmet needs of CSHCN compared to non-CSHCN when receiving services under a pediatric primary care

provider to make the necessary transitions to adult primary care. Uniformity in pediatric transitioning for both CSCHN and non-CSHCN could increase the equality amongst both populations and potentially decrease any health disparities experienced. This study focused attention on the dependent variables of (a) the number of physician visits, (b) if the physician treats only children, (c) if the physician talks about the child seeing physicians who treat adults, and (d) if the physician worked with the guardian to create a plan that identifies specific health goals or needs.

The accessibility of information to the patients in terms of outcome, service quality, and satisfaction are additional factors that could have affected the existence of unmet needs and would have affected the independent variables of (a) if the physician helped the child to develop skills to manage health and (b) if the physician worked with the child to understand health care changes. Secondary data from the NSCH were used in this study focusing on years 2017 to 2018. By evaluating the relationships between the variables, I determined how they contributed to CSCHN and non-CSHCN when transitioning from pediatric primary care to adult primary care.

Research Questions and Hypotheses

The study was guided by the following research questions and their corresponding hypotheses:

RQ1: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that

identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN?

H₀1: There is a not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN.

H_a1: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN.

RQ2: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN?

H₀2: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician

worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN.

H_{a2}: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN.

RQ3: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN?

H₀₃: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN.

H_{a3}: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians

who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN.

RQ4: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN?

H₀4: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN.

H_a4: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN.

Theoretical Framework

I used the Donabedian structure/process/outcome (SPO) model to guide the study. The framework described by Donabedian has a three-part approach that makes quality assessment possible for assuming structure and influencing process that affects the outcome (Liu et al., 2013). In the Donabedian SPO model, structure is defined as features of the health care delivery system, including those individuals responsible for providing services. In the framework, it is proposed that structure and process are associated with the determined outcome/s.

Structural measures for the current study were determined by several variables, including the number of physician visits for both CSCHN and non-CSHCN, the physician's patient population, and if the physician spoke to the child about seeing physicians who treated adults. Structural measures provide consumers with a sense of a health care provider's capacity, systems, and processes to provide high-quality care (U.S. Department of Health & Human Services, 2019). Process measures in this study indicated what a provider did to maintain or improve health. Improvements would be determined if the physician helped the child to develop skills to manage health and understand health care changes. The outcome measures in this study reflected the impact of the health care service or the intervention on the health status of patients. Furthermore, the measures were derived from the effects of health care on the health status of CSCHN patients, including changes in health status, knowledge, satisfaction, and quality of life.

Nature of the Study

In this study, I used a quantitative approach to uncover the unmet needs of CSHCN compared to non-CSHCN when transitioning to adult health care services. To answer the research questions and test all hypotheses, I collected quantitative data related to participants with ASD and parent or caretaker responses to questionnaires and surveys.

Literature Search Strategy

The study addressed the association between (a) the number of physician visits, (b) if the physician treats only children, (c) if the physician talks about the child seeing physicians who treat adults, (d) if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and if (a) the physician helped the child develop skills to manage their health and (b) if the physician worked with the child to understand health care changes for both children with and without special health care needs when transitioning from pediatric primary care to adult primary care for both CSHCN and non-CSHCN. To find relative literature for this study, I searched for peer-reviewed articles in online databases, such as ProQuest, EBSCO, NCBI, and Google Scholar. Other relevant resources were government-published reports and statistical reports provided by the U.S. Census Bureau and the 2017 National Survey of Children's Health. I used the following keyword search terms to locate literature: *autism, children with special health care needs, Donabedian SPO Model, health care access, health care quality, health disparities, and pediatric transition planning.*

Literature Review

In this literature review, I aimed to synthesize past and present literature and research that addressed health care provider involvement experiences when both CSHCN and non-CSHCN receive primary care services and focusing on factors including health care needs, disparities, access, and quality as well as how to address and restructure them. Sharby et al. (2015) believed that factors such as these can be modified at an individual level and have the potential for significant impact. With this study, I planned to fill the gap in the literature through quantitative research that centered on CSHCNs and non-CSHCNs as they transitioned from pediatric primary care services to adult primary care services to identify differences in their health care experiences. The results addressed the existing barriers in the health care system to help shape future policies for all persons with disabilities.

CSHCN

CSHCN are identified as individuals ages 17 and under who are at risk for, or having already been diagnosed with, a chronic developmental, physical, behavioral, or emotional disability that requires increased health care services. According to the Centers for Disease Control and Prevention (2020), about 1 in 54 people are diagnosed with ASD in the United States.

Previous research shows that CSHCN use more health care services than non-CSHCN. Sannicandro et al. (2016) compared the health care utilization of CSHCN in 2005-2006 and 2009-2010 surveys. The authors found that children who have limitations in their daily activities are at an increased risk of receiving delayed, or often, neglected

care. Compared to 2005-2006, children in 2009-2010 were shown to have more significant unmet needs and less care coordination of health care services when attempting to access services. It was further revealed that access to health care services was limited to children with certain socio-demographic characteristics. Additionally, unmet needs were associated with the severity of the child's disability and health insurance. Their study results offered evidence that children with disabilities were also receiving less help coordinating care and accessing medical home services. To attain better health care quality, the health care service utilization of CSHCN needs to improve.

Needs in Health Care

Chiri and Warfield (2011) claimed that children with ASD utilized health services at a significantly greater rate than those without ASD by conducting research focused on the unmet health care needs of children with ASD, a critical marker of access to health care. Their study addressed four core health care services: routine preventative care, specialty care, therapy services, and mental health care. The study's subjects included three health condition groups that were utilized to compare their experiences with unmet needs and the specific access problems as analyzed by the guardians. In their findings, Chiri and Warfield assumed additional problems existed surrounding provider-based access, including locating providers experienced with ASD and that unmet needs varied by service type. The authors found that CSHCN were reported to have unmet needs for both therapy and mental health care services. It could be presumed that the higher occurrence of unmet needs in these two types of health care services could suggest that they are less accessible or the presence of other restrictions. Chiri and Warfield

concluded that CSHCN showed a pattern of having more significant difficulties when accessing care because the population has a higher risk of having delayed or forgone care.

Another assessment of needs in health care was conducted by Benevides et al. (2015), who revisited the focus of Healthy 2020, an initiative to minimize health disparities and improve access to services. The authors found that the demand for services and recommendation for those needs were problematic. Among all CSHCN, those with ASD were reported to have a higher need for health care services, specifically behavioral and therapy. Benevides et al. goes on to find that CSHCN with public health insurance had fewer unmet needs than those with private insurance. This suggested that having public health insurance could be protective against unmet needs. Poverty level although not associated as an unmet need in this study, could be used to recognize the needs for CSHCN as well as their access to care.

Health Disparities

Disparities in health care are the differences in health access and the outcomes between specific populations and the general population (Sharby et al., 2015). CSHCN often require more and occasionally different interventions and accommodations to receive adequate health care services. Sharby et al discussed that unfair treatment brought on by assumptions and stigmas by physicians contributes to the population's disinterest in receiving follow-up care. Furthermore, these inadequacies have sometimes led to misdiagnoses; fewer preventative measures; and, ultimately, fewer health care visits from CSHCN who are less inclined to return to a provider who cannot treat them accordingly.

For further understanding of health disparities, Bishop-Fitzpatrick and Kind (2017) conducted a review to discover what is known about the disparities individuals with ASD encounter in the health care system. Utilizing the fundamentals causes model coined by Link and Phelan in 1995, the authors determined health disparities are appropriate in understanding the occurrence of adverse health outcomes and that those disparities determine the extent to which individuals with ASD can avoid risk. Their findings suggest that the presence of health disparities in ASD is found early on in life and is associated with decreased access and quality of health care. Bishop-Fitzpatrick and Kind found that with the existing model, gaps remain in the literature that hinder the thorough identification of treatment targets and the development of prevention and intervention programs.

Quality of Care

Cheak-Zamora and Thullen (2016), using caregiver reports on children aged 0-17 years old from the 2009-2010 National Survey of CSHCN, conducted a cross-sectional study that focused on health disparities within six quality and access indicators to improve care for CSHCN. The indicators were partners in decision making, medical home, health care transition services, community-based services, adequate health insurance, and early and continuous screening. The authors found that narrowing down the subjects allowed them to address barriers that affected the ability to achieve community-based, coordinated care. Findings of the study suggested that CSHCN were less likely to receive quality health care in comparison to non-CSHCN. It was presumed from the study that CSHCN were found to have substandard access to and quality of

health care services compared to non-CSHCN. Further access and quality of care could be dependent on the child's health condition, functioning level, health insurance, income level, and region of residence. Disparities were found to be different amongst the six quality indicators in their study. Cheak-Zamora and Thullen identified that the lack of quality care proved to influence the rate of emergency room admissions, parental satisfaction, family burden, and worsened medical issues. Further research could determine the extent to which poor quality of care impacts CSHCN compared to the general population. Interventions, including care coordination and transitional services, could ensure quality services and be used to educate parents/guardians to involve them in health care decision making.

Access to Care

Dern and Sappok (2015) researched the experiences of autistic self-advocates and practitioners' clinical experiences in relation to disparities in health care for people on the autism spectrum. They found that difficulties in accessing health care services might be due to an autistic disability. The autistic disorder includes hypersensitivity and hyposensitivity to sensory stimuli, lack of focused attention, difficulties in generalizing and awaiting modifications, and difficulties planning and implementing actions. With the stated problems, providers may not be equipped to provide services to individuals with autism. Dern and Sappok's findings suggested that providers have the same amount of knowledge on autism as the public.

Implemented strategies to help deal with both perceptual and communicative barriers of autism may be pivotal in improving access to health care for autistic adults

(Dern & Sappok, 2015). The authors described how presently there is a lack of specific medical services for people with intellectual disabilities and challenging behaviors. It can be presumed that individuals on the autism spectrum tend to have more health issues than those not affected by autism. Accessing health care services is challenging for all, but even more strain is placed on those affected by a chronic condition. It is implied that increasing access to the health care system will improve the diagnosis and treatment of mental and somatic illnesses. Dern & Sappok's findings suggested that strategies of perceptual and communicative peculiarities of autism can improve access to health care for adults with autism.

Access to quality health care services can be associated with better health outcomes for CSHCN. Cheak-Zamora and Thullen (2016) found that while access to health care services were high, caregivers of CSHCN reported lower rates of quality care. The authors found that CSHCN's access and quality of care varied based on the child's diagnosis, functional level, health insurance status, caregiver's income level, and the region of residence. Inadequate access and quality of care for CSHCN could pose threats such as provider shortages, unsuccessful coordination, and insufficient health insurance coverage. Limited access to preventative and primary care services can lead to increased consumption of high-cost health care services, decreased functional level, and avoidable death.

Caregiver Perception

Mendes (2016), using a qualitative descriptive design, sought to plan effective interventions that could promote health parity for CSHCN by understanding social and

environmental factors that impede their ability to access care. The author's focus group consisted of African American parents of CSHCN. Mendes found that along with social and environmental factors, other factors, including personal, institutional, and medication hesitation, pose a threat to health care access. Compared to different populations, African American CSHCN faced disparities in health care coordination because they were less likely to receive family-centered care. Future research that focuses on school, Medicaid, and care coordination difficulties should be addressed with care managers to ensure that CSHCN receive proper care.

Donabedian SPO Model

Block's (2006) dated literature on Donabedian discussed Donabedian's work in health care management as being focused on the following nine steps to assure the quality of health care delivery when monitoring clinical performance: (a) determining what to monitor, (b) determining priorities in monitoring, (c) selecting an approach to assessing performance, (d) formulating criteria and standards, (e) obtaining the necessary information, (f) choosing when to monitor, (g) choosing how to monitor, (h) constructing a monitoring system, and (i) bringing about a behavior change. Block further discovered that outcome assessment was favored over structure and process because of its ability to assert what matters most is the effect of the health care delivered on the patient's health and well-being.

Block found no defined beginning or ending in the relationship between the three approaches; however, what could be defined was how a series of causes and effects is configured using the approaches. Relevant gaps found in Donabedian's work suggest a

lack of emphasis on patient centeredness. Presently, there is an increasing shift of power in the pursuit of quality that was not included in Donabedian's model when first introduced. It was also found that although the model itself is simplistic and intuitive, historically it has not been understood or used appropriately (Block, 2006).

Definition of Terms

The following defined terms were used throughout this study:

Age: An individual's development measured in terms of the year's requisite like the development of an average individual (Merriam-Webster, 2017).

ASD: A developmental disability that causes significant social, communication, and behavioral challenges (Centers for Disease Control and Prevention, 2020).

Communication between the physician and child about the transition to a physician who treats adults: A discussion regarding care changes prior to a child becoming of age to transition away from pediatrics.

Donabedian SPO model: A measure used to assess and compare the quality of health care organizations, classified as either a structure, process, or outcome measure (Agency for Healthcare Research and Quality, 2015).

If the guardian received a health care plan that identifies specific health care needs: How much knowledge a guardian withholds regarding what the physician has communicated with the child on managing health and understanding the evolvement of care.

Number of physician visits: The numerical value indicating the number of times an individual frequents a physician's office.

Pediatrics: The specialty of medical science concerned with the physical, mental, and social health of children from birth to young adulthood (American Academy of Pediatrics, 2015).

Physician helped the child develop skills to manage health: If the physician communicated with the child in understanding how to maintain health and routine preventative care.

Physician's patient population: The demographics and other particulars of a population being serviced. Examples include ethnicity, socioeconomic status, or population density (Bowen, 2020).

Physician worked with the child to understand health care changes: If the physician communicated with the child in understanding any evolvement of care.

Primary care: Care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom, or health concern not limited by the problem origin, organ system, or diagnosis (American Academy of Family Physicians, 2020).

Assumptions

This study was contingent on finding relative data that displays variation amongst CSHCN and non-CSHCN and whether physicians worked with them to develop skills to manage health and understand health care changes. Using data from the 2017 NSCH in conjunction with the Donabedian SPO model, I uncovered the differences in health care experiences by the two parties. Bishop-Fitzpatrick and Kind (2017) discussed that to understand the emergence of health disparities in CSHCN, and to identify compliant

treatment targets that have the potential to reduce health disparities, proximal causes must be investigated.

Scope and Delimitations

This study aimed to uncover the unmet needs that CSHCN face when transitioning to adult health care services in comparison to non-CSHCN. Secondary data from parental/guardian surveys from 2017 was utilized. This study provided results that determined a relationship, if any, between the number of physician visits, the physician's specialty, the physician's treatment approach in transitioning the child to post pediatric care, and the approach in assisting in the development of essential skills to manage health as well as understanding health care changes for both CSHCN and non-CSHCN.

Significance, Summary, and Conclusions

The significance of the study provided health care administration leadership with the information needed to improve health care delivery for the ASD population. Whether it was developing a new policy or introducing new interventions within health service organizations, utilizing all types of health care services could be achievable by all. The proposed study was useful for positive change because it indicated how physician involvement with the transition from pediatric to adult care should be addressed and changed. This study played an essential role in producing evidence that contributed to the comparison of CSHCN and non-CSHCN regarding health care utilization and quality. Information provided from these conclusions would impact public policy by providing information about how different factors, such as if the physician helped the child to develop skills to manage health and if the physician worked with the child to understand

health care changes, influences transitions from primary pediatric to adult care for CSCHN and non-CSHCN. The data contributed to understanding this population's unmet medical needs by comparing the noted health care utilization of CSCHN and non-CSHCN between August 2017 and February 2018. This study influenced positive social change by inspiring policy and programmatic interventions that could reduce unmet health care needs while strengthening the health care system's capacity (Karpur et al., 2019).

Transitioning from pediatric primary care services to adult primary care services for both CHSCN and non-CSHCN posed challenges for both parties. Looking at literature from past and present researchers assisted in taking a closer look at different factors that affect the patient experiences including needs, disparities, access, and quality. Due to the limitations noted amongst the articles, the study planned to fill the gap of finding out if a difference of experience exists for primary care. The following section planned to provide an overview of the research design of the study as well as provide an overview of the data collection process.

Section 2: Research Design and Data Collection

The purpose of this study was to evaluate the unmet needs of CSHCN compared to non-CSHCN when receiving services under a pediatric primary care provider to make the necessary transitions to adult primary care. I employed a quantitative, correlational research design using survey methodology in this study guided by the Donabedian SPO model. The dependent variables were (a) the number of physician visits, (b) if the physician treats only children, (c) if the physician talks about the child seeing physicians who treat adults, and (d) if the physician worked with the guardian to create a plan that identifies specific health goals or needs. The covariates were (a) if the physician helped the child to develop skills to manage health and (b) if the physician worked with the child to understand health care changes. In this section, I discuss the research design and rationale, target population, setting and sample, instruments and materials, and threats to validity. Previous studies using the Donabedian SPO model are reviewed to offer comparable results.

Research Design and Rationale

I used a quantitative methodology utilizing correlation and regression analysis of secondary data for this study. The correlational research design helped address the research questions focusing on potential relationships existing between the number of primary care physician visits, physician's specialty, physician's treatment approach in transitioning the child to post-pediatric care, and approach in assisting in the development of essential skills to manage health as well as understanding health care changes for both CSHCN and non-CSHCN. Ultimately, I evaluated the unmet needs of CSHCN compared

to non-CSHCN when transitioning to adult primary care from pediatrics. To create a positive social change with the targeted population, relevant results for utilization were explored.

I retrieved the data for this study from the Data Resource Center for Child & Adolescent Health, specifically the NSCH. The information was recorded and appeared in a public use file. Secondary data were used so there were no time or resource constraints for the correlational research design. The design was the most suitable for the research because it is used for the study of the relationship between unmanipulated variables without the use of random assignment.

Methodology

Target Population

In this study, I focused on children, both with and without disabilities, aged 17, which is the age the transition from pediatric to adult primary care begins. Data were collected from the United States and U.S. Virgin Islands. Of the data, 5,638 participants were at the transitioning age of 17. I did not exclude data based on participant demographics. Demographics included physical and mental health status, health insurance, health care use, access to health care, medical home, family functioning, parental health, and neighborhood characteristics.

Sampling

I used secondary data originally collected in survey sampling for the 2017 NSCH. Between August 2017 and February 2018, participants were mailed an invitation to complete a household screener and then a child-level questionnaire. To increase the

sampling efficiency, data were used to determine addresses that were more likely to be households of children aged 0-17 years. In 2017, 59,135 households were screened for age-eligible children. Of that amount, 58,510 initial screeners were completed. A total of 21,599 child-level topical questionnaires were completed for non-CSHCN and 4,912 topical questionnaires were completed on CSHCN.

Instrumentation and Operationalization of Constructs

I used the 2017 NSCH as the secondary data set for this study because it reflected changes that were consistent with federal policy and programs, an updated understanding of both topics and questions, and emerging priorities as identified by stakeholders. Once the correlation and regression analysis calculations were completed using Statistical Package for the Social Sciences (SPSS) I was able to determine whether to reject the null hypotheses.

The 2017 NSCH sample frame was developed by both the Edited Master Address File Extract created by the Demographic Statistical Methods Division of the U.S. Census Bureau and a file of administrative flags created by the U.S. Census Bureau's Center for Administrative Records Research and Applications. The population of interest for the 2017 NSCH were all children under the age of 18 who resided in the United States on the survey date. The survey was intended to identify households with children and provide information about household access to the internet, a vital piece for data collection.

Data Analysis Plan

For this study, I used SPSS software to conduct a correlational regression analysis. The results were interpreted to determine whether the null hypotheses should be rejected. The data were cleaned to solely focus on participants of the age of 17. The study was guided by the following research questions and their corresponding hypotheses:

RQ1: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN?

H₀1: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN.

H_a1: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN.

RQ2: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN?

H₀2: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN.

H_a2: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN.

RQ3: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN?

H₀₃: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN.

H_{a3}: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN.

RQ4: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN?

H₀₄: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific

health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN.

H_{a4}: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN.

Using SPSS to process the statistical data, I employed chi-square tests for calculations because the data met the assumptions. The variables were either measured at an ordinal or nominal level and consisted of two or more categorical, independent groups.

Threats to Validity

Because the study was correlational, there was low internal validity; however, there was a chance for high external validity. A potential threat to the validity of the study could have also come from survey biases from the population. The data considered the parental perception of physician performance. The samples used were large enough to reduce the effect of survey bias within this study.

Ethical Procedures

The NCHS Research Ethics Review Board and the National Opinion Research Center Institutional Review Board approved the procedures and modifications used in this study. Participation in the survey was voluntary, and all individually identifiable information collected remained confidential. Consent scripts informed respondents of the

voluntary nature of the survey to assure that their responses would be kept confidential. The NCHS stated that the risk of inadvertent disclosure of confidential information regarding individual respondents is higher with a publicly released data set that includes detailed geography variables, a detailed and extensive set of survey observations, or a sizeable proportion of the total population of interests (Centers for Disease Control and Prevention, 2017). This secondary set was coarsened by suppressing variables into one to reduce the risk of inadvertent disclosure. I did not begin data collection for this study until receiving approval from Walden University's Institutional Review Board (Approval No. 04-02-21-0915600).

Summary

In this study, I evaluated the unmet needs of CSHCN compared to non-CSHCN when receiving services under a pediatric primary care provider to make the necessary transitions to adult primary care. I employed a quantitative, correlational research design with guidance from the Donabedian SPO model. In SPSS, a chi-square test was performed to determine the relationships between dependent variables and covariates. The target population was children aged 17 who were transitioning from pediatric primary care to adult care. There could have been a threat to the external validity of this study with survey bias; however, with a large population, the existence of the threat was limited. Previous studies were followed for comparable results.

Section 3: Presentation of the Results and Findings

The objective of this study was to evaluate the unmet needs of CSHCN compared to non-CSHCN when receiving services under a pediatric primary care provider to make the necessary transitions to adult primary care. The research questions associated with this study addressed determining if a relationship existed between the dependent variables of if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, and if the physician worked with the guardian to create a plan that identifies specific health goals or needs and the independent variables of the physicians approach in assisting in the development of essential skills to manage health for CSHCN and approach in assisting in the understanding of health care changes for CSHCN.

In this section, I discuss the secondary data and the results from SPSS before concluding with a summary of the analysis.

Data Collection of Secondary Data Set

Obtaining access to the secondary data for the study took a short amount of time. Upon accessing the Child and Adolescent Health Measurement Data Resource Center for Child and Adolescent Health, I completed a Data Use Agreement and retrieved access to all data sets and accompanying documents. The 2017 data were used in this study because it reflected changes consistent with federal policies.

Once the data were retrieved and imported into SPSS, I reduced the data to focus solely on the variables of interest in the study. In the 2017 NSCH survey, 21,599 respondents were non-CSHCN and 4,912 respondents were CSHCN. Since I was only

focused on children aged 17 in this study, the data were reduced to 5,638 to reflect that. To avoid inaccuracies throughout the data analysis, missing data needed to be removed. A 100% response rate from both CSHCN and non-CSHCN participants would be required before conducting the analysis. With further condensing, the final sample size was 2,398.

CSHCN Frequencies

For CSHCN respondents, 901 had a 100% response rate. For the first variable, physicians who treat only children, all 901 chose “yes.” Due to their responses, I excluded that variable from the statistical analysis because it would be constant. Next, for the variable of physicians talked to child about seeing physicians who treat adults, 38% of respondents said “yes,” while 62% said “no.” For the variable of physician visits – how many times, 5.3% had zero visits, 57.4% had one visit, and 37.3% had two or more visits. For the variable of if the physician worked with guardians to create a plan that identifies specific health goals or needs, 14.4% of guardians said “yes,” while 85.6% said “no.” For the independent variable of if the physician worked with the child to gain skills to manage health, 68.1% reported “yes,” 20.6% reported “no,” and 11.2% reported that they did not know. Lastly, concerning the variable of if the physician worked with the child to understand health care changes, 39.2% said “yes,” 40.0% said “no,” and 20.9% said they did not know.

Non-CSHCN Frequencies

For non-CSHCN respondents, 1,497 had a 100% response rate. For the first dependent variable of physicians who treat only children, all 1,497 chose “yes.” Again,

due to their response, I excluded this variable from the statistical analysis because it was a constant. Next, for the physicians talked to child about seeing physicians who treat adults variable, 38.1% of respondents said “yes,” while 61.9% said “no.” For the variable of physician visits – how many times, 4.6% had zero visits, 75.6% had one visit, and 19.8% had two or more visits. For the if the physician worked with guardians to create a plan that identifies specific health goals or needs variable, 5.2% of guardians said “yes,” while 94.8% said “no.” For the independent variable of if the physician worked with the child to gain skills to manage health, 55.5% reported “yes,” 25.8% reported “no,” and 18.7% reported that they did not know. Lastly, concerning the if the physician worked with the child to understand health care changes variable, 38.2% said “yes,” 36.6% said “no,” and 25.6% said they did not know.

Statistical Assumptions

I conducted a Pearson’s chi-square test of association in this study to determine the relationship between both the dependent and independent variables. This test was preferred because the data met the following assumptions:

1. All the variables, both independent and dependent, were categorical measuring at a nominal or ordinal scale.
2. The variables had at least two categories, meaning the variables had responses of “yes,” “no,” or “don’t know.”

Test of Hypotheses

CSHCN

Research Question 1 and its corresponding hypotheses were:

RQ1: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN?

H_0 1: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN.

H_a 1: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSCHN.

Table 1

Pearson Chi-Square Test (CSHCN) for Managing Health

	Talked About Child Seeing Physicians Who Treat Adults	Physician Visit – How Many Times	Plan Identify Specific Health Goals or Needs
Pearson chi-square	47.879	28.167	38.729
<i>df</i>	2	4	2
Asymp.Sig.	.000	.000	.000

The test for association between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for CSHCN was not significant because all p values were $< .001$, which is less than the level of significance. The null hypothesis is accepted with 95% confidence of not committing a Type I error. It can be concluded that there is no statistically significant relationship between these variables.

Research Question 2 and its corresponding hypotheses were:

RQ2: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN?

H_0 2: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN.

H_a 2: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians

who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSCHN.

Table 2

Pearson Chi-Square Test (CSHCN) for Understanding Health Care Changes

	Talked About Child Seeing Physicians Who Treat Adults	Physician Visit – How Many Times	Plan Identify Specific Health Goals or Needs
Pearson chi-square	100.282	15.052	55.613
<i>df</i>	2	4	2
Asymp.Sig.	.000	.005	.000

Table 2 shows that the results were statistically significant because the asymptomatic significant values for all the variables were less than that of 0.05. There is sufficient evidence to accept the null hypothesis with 95% not committing Type I error. It can be concluded that there is no significant relationship between the variables of if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for CSHCN.

Non-CSHCN

Research Question 3 and the corresponding hypotheses were:

RQ3: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that

identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN?

H_03 : There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN.

H_{a3} : There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN.

Table 3

Pearson Chi-Square Test (non-CSHCN) for Managing Health

	Talked About Child Seeing Physicians Who Treat Adults	Physician Visit – How Many Times	Plan Identify Specific Health Goals or Needs
Chi-square	47.025	37.747	39.063
<i>df</i>	2	2	2
Asymp.Sig.	.000	.000	.000

Based on the results shown in Table 3, the null hypothesis is accepted at the 95% confidence interval. The results indicate that there is no significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians

who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the development of essential skills to manage health for non-CSHCN.

Research Question 4 and the corresponding hypotheses were: RQ4: Does a relationship exist between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN?

H₀4: There is not a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN.

H_a4: There is a statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN.

Table 4

Pearson Chi-Square Test (non-CSHCN) for Understanding Health Care Changes

	Talked About Child Seeing Physicians Who Treat Adults	Physician Visit – How Many Times	Plan Identify Specific Health Goals or Needs
Pearson chi-square	115.949	35.163	71.201
<i>df</i>	2	4	2
Asymp.Sig.	.000	.005	.000

At the 0.05 level, all *p* values for the variables were not statistically significant, and the null hypothesis is accepted at a 95% confidence level. I concluded that there is no statistically significant relationship between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes for non-CSHCN.

Summary

The purpose of this quantitative data analysis was to summarize the variables and descriptive frequencies. I used the Pearson chi-square test to determine the relationships between the dependent and independent variables. Because the variable for the physicians who treated only children had a 100% response rate of “yes,” it was excluded from the analysis and computed as a constant. For all four research questions, I concluded that there was no statistical significance, and the null hypotheses failed to be rejected.

In Section 4, I will discuss the research findings along with the study limitations. Recommendations for further research will also be introduced as will a discussion of how this study can affect positive social change in health care administration.

Section 4: Application to Professional Practice and Implications for Social Change

I conducted this quantitative study to assess the unmet needs of CSHCN compared to non-CSHCN while receiving services from a pediatric primary care provider to make the necessary transition to adult primary care. The purpose was to identify disparities that could be addressed and decreased to create uniformity in pediatric transitioning for all. This study was centered around the dependent variables of (a) the number of physician visits, (b) if the physician treats only children, (c) if the physician talks about the child seeing physicians who treat adults, and (d) if the physician worked with the guardian to create a plan that identifies specific health goals or needs as well as the independent variables of (a) if the physician helped the child to develop skills to manage health and (b) if the physician worked with the child to understand health care changes. I evaluated the transitional needs using secondary data from parent/caretaker responses on the NSCH for both CSHCN and non-CSHCN.

After analyzing the secondary data, I concluded that there was no statistically significant relationship between the dependent and independent variables. Findings revealed that both CSHCN and non-CSHCN experienced health care disparities when transitioning from pediatric to adult primary care. Looking at the frequencies, on average, CSHCN required more physician appointments during the transition process. For all other dependent variables, the percentage averages were roughly similar in response.

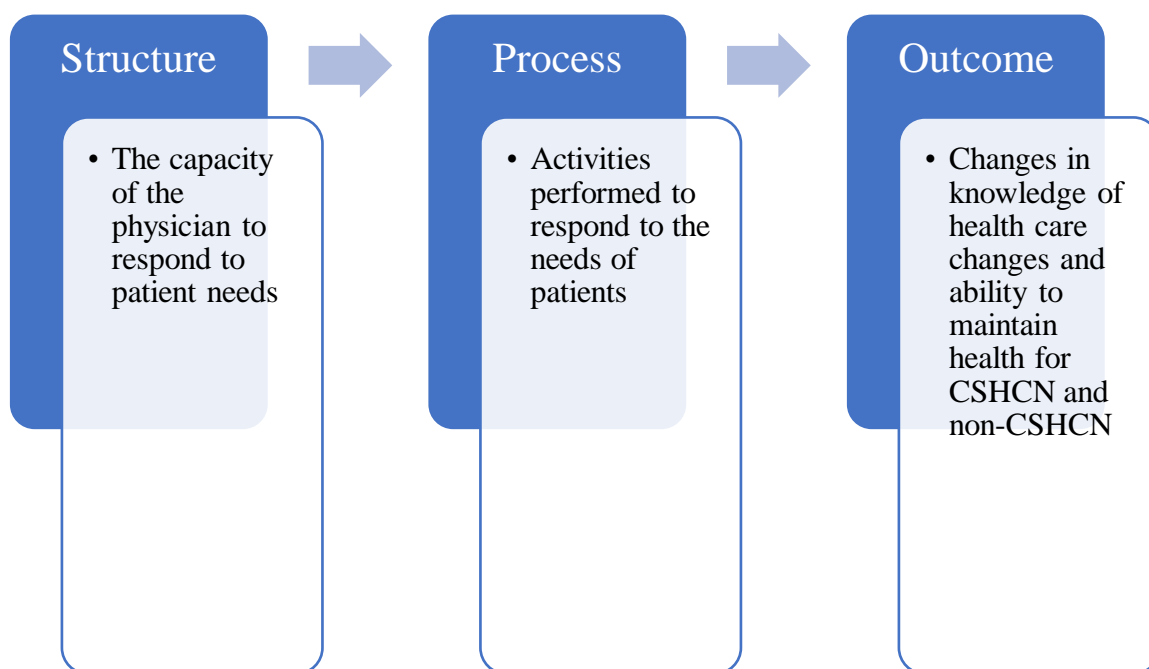
Interpretation of the Findings

The quantitative findings of this study revealed that there was no association between (a) the number of physician visits, (b) if the physician treats only children, (c) if

the physician talks about the child seeing physicians who treat adults, (d) if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and if the physician helped the child to develop skills to manage health and (b) if the physician worked with the child to understand health care changes. The lack of association resulted in me failing to reject the null hypotheses for all related research questions. The results from the Pearson chi-square tests yielded p values less than that of 0.05, suggesting that whether the physician helped the child to develop skills to manage health or if the physician worked with the child to understand health care changes did not affect the above dependent variables for CSHCN and non-CSHCN based on the 2017 NSCH data.

Figure 1

Donabedian SPO Model



Using the Donabedian SPO model with the frequencies found within the data analysis, I assumed that the theoretical framework can be used to improve outcomes in transition planning. For both CSHCN and non-CSHCN, most respondents (i.e., 62% of CSHCN and 61.9% of non-CSHCN) stated that the physicians did not talk to the children about seeing a physician who treats adults. Based on the Donabedian SPO model, the structure of transition planning should be addressed beginning with conversations surrounding transitioning. The process, as seen in the data, showed that physicians did not work with the parents or guardians to create a plan that identifies specific health goals or needs, with 85.6% of CSHCN stating “no” and 94.8% of non-CSHCN stating the same. Based on the outcome, the frequencies showed that a more significant percentage of physicians worked with the child to gain skills to manage health for both CSHCN and non-CSHCN. The opposite is seen for if the physician worked with the child to understand health care changes.

Limitations of the Study

Sannicandro et al. (2016) discussed that secondary data are subject to recall bias and social desirability bias. Parental reporting was conducted in the NSCH, allowing parents to identify their CSHCN. Due to that responsibility, there was a possibility for potential errors in the reporting of health condition diagnosis because certain conditions may be challenging to recall or are overreported. Additionally, with these secondary data, low response rates lead to selection bias on unobserved variables. The data were condensed because many questions were skipped or the guardian was unsure of how to respond.

Recommendations

Thomas et al. (2007) discussed how the lack of appropriate outreach and cultural competency of physicians may contribute to low health care service use. Focusing on disparities within low-income families or racial and ethnic groups could provide more insight into the differing experiences of both CSHCN and non-CSHCN. Findings from this study suggest that future research should focus on the institutionalized discrimination that leads to a general distrust in the health care system. Additionally, future research can be conducted to articulate racial and ethnic families' attitudes towards transition planning within the system of care for CSHCN.

Due to the limitations of this study, further research should consider examining or collecting physician data to limit any biases. Owing to their ability to provide an accurate diagnosis for the children, having physicians' input can help health care administrators better address policy changes.

Implications for Professional Practice and Social Change

The results of this study encourage the continued use of the Donabedian SPO model. The model poses a dominant framework for evaluating health care quality through physician involvement in transitioning from pediatric primary care to adult primary care services. The findings of this study can provide a solid foundation for social change in which health care policies can be created and revised to further the improvement of transitional planning for adolescents. While focusing on CSHCN, policymakers should actively consider their overall well-being. In doing so, measures should be enacted to serve this vulnerable population better. Sannicandro et al. (2016) concluded that policies

should be passed to monitor the progress of health care access and utilization for CSHCN with specific attention given to racial and ethnic disparities. This study provides useful analytical information for health care administrators and their role in policy and quality care measures. Using the findings of this study, health care administrators can develop and implement initiatives within their institutions to improve transition readiness for CSHCN and non-CSHCN.

Conclusion

In this study, I found no evidence of statistical significance between if a physician treats only children, if the physician talks about the child seeing physicians who treat adults, the number of physician visits, if the physician worked with the guardian to create a plan that identifies specific health goals or needs, and approach in assisting in the understanding of health care changes and maintain health for CSHCN and non-CSHCN. The Donabedian SPO model can be used as a mechanism for improving health care access and utilization for children, both those with and without special health care needs. If the evidence generated by this study are repeated with racial and socioeconomic variables or physicians' input, improving the quality of transition planning for pediatrics can be achieved.

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