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Exploring Healthcare Transitions and Health Equity: An Integrative Review

Susan Ann Jordan
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Susan A. Jordan

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the review committee have been made.

Review Committee
Dr. Michael Brewer, Committee Chairperson,
Public Policy and Administration Faculty

Dr. Amy Wilson, Committee Member,
Public Policy and Administration Faculty

Dr. Frances Goldman, University Reviewer,
Public Policy and Administration Faculty

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Abstract

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by

Susan A. Jordan

MS, University of Nebraska, 1998

BS, University of Maine, 1993

Dissertation Submitted in Partial Fulfillment

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Abstract

Compared to their typically developing peers, adolescents, and emerging adults with special healthcare needs (AEA-SHCN) disproportionately experience healthcare transition (HCT) disparities and poor access to adult care. Theoretical models that describe how access gaps develop and strategies to address unmet HCT needs are not well understood. While HCT researchers describe both system and patient healthcare barriers, a comprehensive approach that discovers how these factors interact and interfere remains misunderstood. An integrative review (IR) was conducted to understand the multiplicity of these factors. An intersectional theory (IT) provided further clarity on how key findings influence patient HCT experiences. Several themes were found to intersect and thus increase the HCT complexity, particularly for patients with social disadvantages. Communication gaps, mismatched goals/expectations, and poorly defined roles were common themes. Poor health equity, disparities in access, and inadequate HCT support intersected with poor patient HCT experiences, while youth with stigma-related diseases were most at-risk for poor provider-relationships. The thematic synthesis provided granularity to these experiences with characterizations as fear, loss, and uncertainty with access change. Social change implications underscore the need to reframe poor patient HCT experiences as potential opportunities for health policy advocates and clinicians to address unmet HCT needs.

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Dedication

This manuscript is dedicated to each of my special needs children who have inspired me to learn more about myself and become a better caregiver.

Acknowledgments

I want to take this opportunity to acknowledge Dr. Brewer, my committee chair, for his willingness to support this project and to each of my committee members for their review and interest in this topic

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Chapter 1: Introduction to the Study

Introduction

As life expectancies of children with congenital and chronic health conditions improve, access to developmentally appropriate care has become an increasingly important topic among clinicians and policymakers alike (intellectual developmental delays, technology dependent, insurance/Medicaid and guardianship process; Perrin, Anderson, & Van Cleave, 2014; Warnes, 2005). A healthcare transition (HCT) process is generally recognized as a gradual shift in healthcare access from pediatric to adult care systems (Bloom et al., 2012). Annually, there are approximately 750,000 adolescents and emerging adults (AEA) with special healthcare needs (AEA-SHCN) who enter the adult care system (Davis, Brown, Taylor, Epstein, & McPheeters, 2014). Unfortunately, despite a progressively larger (and generally, more predictable) influx of young patients with special healthcare needs (SHCN), the expectation that youth will experience uninterrupted access has not yet been realized (Gold, Boudos, Shah, & Rossi-Foulkes, 2017).

Admittedly, there are multiple factors involved in defining a successful HCT (Davis et al., 2014). However, one of the first objectives in describing the HCT process is to define at-risk populations and to identify those most likely to become lost to follow up (LTF; Hettel, Tran, Szymanski, Misseri, & Wood, 2018). The AEA-SHCN patient population comprises two distinct demographics: Adolescents and emerging adults (Arnett, 2007). Ideally, adolescents (beginning with age 12 to 14) with or without SHCN will gradually need to prepare for adult care while they are still in pediatrics (Díaz-González de Ferris et al., 2017). On the other hand, emerging adults (EA) with SHCN, (ages 18 to 25) who remain in pediatric care are more likely to lack the functional capacity, family support, and independence for a timely adult care transfer (Garvey et al., 2014). There are significant numbers of EA with SHCN who delay entry into adult care and unfortunately, experience an abrupt termination in healthcare access or are LTF (Colver & Longwell, 2013). In general, once an EA patient exits from pediatric care, social and system barriers commonly interfere with access which can lead to prolonged healthcare gaps, and a reduction in health status (Timberlake, Corbett, Costabile, & Herndon, 2015). While the extant HCT literature continues to describe healthcare vulnerabilities, the difficulty patients and families face can have far-reaching effects in healthcare access and health equity (Crump, 2018).

It has long been recognized that the HCT field lacks theory-driven approaches to describe HCT process for most vulnerable populations (Betz et al., 2014; Bollegala & Nguyen, 2015). Due to this, the interaction between (or amongst) population health variables is not well understood (Betz, Nehring, & Lobo, 2015; Mahan, Betz, Okumura, & Ferris, 2017). To close this knowledge gap and improve understanding of the patient population, an intersectional model underpins this integrative review (IR) study. The intersectional theory postulates that individual, group, and structural factors exist *not* as fixed societal, institutions or risk categories, but as dynamic systems of social inequality and poor access among disadvantaged populations (i.e., patients with disabilities; (Crenshaw, 1989; Evans, Williams, Onnela, & Subramanian, 2018). With this multidimensional framework in mind, the HCT process itself can be viewed as a healthcare *intersection*, a socially constructed point where multi-level patient and systematic barriers converge, and subsequently influence the experience of care (Cole, 2009; Evans et al., 2018). Undoubtedly, acquiring more insight into healthcare access difficulties and the impact on disadvantaged populations is a worthy and enduring factor in positive social change among young patients with SHCN (Cheak-Zamora, Yang, Farmer, & Clark, 2013). With such a complex and multifaceted concept, an IR is uniquely designed to gather and synthesize evidence into *one* in-depth review (Holly & Anef, 2013). This chapter includes a discussion of the research problem and introduces the study's theoretical foundation. This chapter also includes a discussion of the role of HCT in healthcare and concludes with a section on the chosen methodology.

Background of the Study

Due to technological advancements, a remarkable 95% of the AEA-SHCN patient population with acquired, congenital, or chronic health conditions (for example, cystic fibrosis, sickle cell disease, and heart defects) will likely live well into their adult years (Committee on Children with Disabilities and Committee on Adolescence, 1996; Perrin, Bloom, & Gortmaker, 2007; Quinn, Rogers, McCavit, & Buchanan, 2010; Warnes, 2005). There are now many more adults with CHD than children or adolescents (Hays, 2015; Hoffman, Kaplan, & Liberthson, 2004; Warnes et al., 2001). As with most vulnerable populations, healthcare access is a vital component in protecting health status throughout life (Bloom et al., 2012; Newacheck, McManus, & Fox, 1991; Perrin, Boat, & Kelleher, 2016; Strickland et al., 2009; Zickafoose & Davis, 2013). While healthcare access and HCT planning go hand in hand, the AEA-SHCN patient population is less likely to receive timely transition support (Lebrun-Harris et al., 2018). Moreover, it is often left up to patients and their caregivers to address many of the common HCT barriers (i.e., poor access, cost, lack of trained providers, and limited organizational support; Anderson, Sosnowy, Kuo, & Shattuck, 2018; Valenzuela et al., 2014). Still, the HCT process is predominantly triggered by *chronological age* with much less emphasis on developmental readiness as pediatric health experts suggest (Gibson, 2018; Mahan et al., 2017; Wells & Manning, 2017). A time-limiting HCT policy (i.e., age limits) without adequate transition support, not only shifts the burden onto patients, but also increases the risk for abrupt care transfers and patients becoming (LTF; Heery, Sheehan, While, & Coyne, 2015; Lotstein et al., 2013). Moreover, sudden transfers into adult care can occur if patients' disease complications deteriorate with little time for preparation or collaboration amongst providers (Fernandes et al., 2012). Once in adult care, patient health status can change dramatically with concomitant risks to poor outcomes (Sadun, Chung, & Maslow, 2019).

As more HCT research emerges, it is becoming increasingly clear that the AEA-SHCN population lag behind their typically-developing peers in timely access to adult care (Lemly, Weitzman, & O'Hare, 2013). Furthermore, data suggest that a mismatch in healthcare practices can also impede progress in coordination across multiple systems of care (Noyes, Pritchard, Pritchard, Bennett, & Rees, 2018). While standardized protocols or policies typically outline the steps involved in optimal transitional care, the delivery of HCT services is sporadic with limitations in their practical application (Gold et al., 2017). Sadly, multilevel barriers have shown to deteriorate patient health status, disrupt care continuity, and lower a patient's quality of life (Cramm, Strating, Sonneveld, & Nieboer, 2013; Feinstein, Rabey, & Pilapil, 2017; Lotstein, Kuo, Strickland, & Tait, 2010; Williams, 2009; Williams, 2015). Hence, the current challenge exists to not only understand HCT experiences but also to address patient's unmet healthcare needs holistically as youth seek more independence (Bower, Whishaw, Dowling, & Heloury, 2019). An urgent need exists to grasp the meaning of poor experiences against the backdrop of an increased number of youth with congenital conditions living well into their adult years (Okumura, Hersh, Hilton, & Lotstein, 2013; Perrin et al., 2007).

In a health equity paradigm, suboptimal HCT experiences could be considered broad indicators of further systematic healthcare barriers (Sharma, O'Hare, Antonelli, & Sawicki, 2014; Stewart, 2013; Watson, Parr, Joyce, May, & Le Couteur, 2011). It has become apparent that the AEA-SHCN population (most of which are considered socially and medically vulnerable) suffer worse access disparities than their similarly aged peers (Lotstein et al., 2010; Walsh, Jones, & Schonwald, 2017). Additionally, the HCT research has mainly concentrated on the patient-level support (i.e., readiness assessments and the degree of family care) while systematic barriers are far less appreciated (Stewart, 2013). A contextual synthesis is needed to shed light on the totality of ways that suboptimal HCT experiences interact with multiple barriers within the healthcare setting (Ciccarelli, Brown, Gladstone, Woodward, & Swigonski, 2014; DiFazio, Harris, Vessey, Glader, & Shanske, 2014).

Problem Statement

Despite decades of HCT research aimed at improving the HCT process, the AEA-SHCN population continually experience HCT difficulties accessing developmentally appropriate healthcare (Lotstein et al., 2009; Paine et al., 2014; Park, Scott, Adams, Brindis, & Irwin, 2014; Porter, Wesley, Zhao, Rupff, & Hankins, 2017; Quinn et al., 2010). Thus far, HCT research efforts have mainly identified HCT process improvements with a limited appreciation for the practical, clinical, or ethical ramifications of suboptimal HCT experiences and poor access (Bogossian, Gorter, & Racine, 2018; Paul et al., 2018; Pordes, Gordon, Sanders, & Cohen, 2018). Additionally, theoretical models that underpin the HCT process do not account for the intersectional complexity of social or contextual factors involved in healthcare transfers (Betz et al., 2014; Hankivsky et al., 2017). While many HCT policy, patient, and system-level barriers have been identified, an integrative review (IR) that includes an examination of suboptimal HCT experiences in the context of a multidimensional framework remains poorly described (DiFazio et al., 2014; Fenton, Ferris, Ko, Javalkar, & Hooper, 2015; Hepburn et al., 2015). A health disparity framework not only provided a unique opportunity to gain further insight on many of the well-known risks in poor outcomes (social disadvantages, inadequate availability of providers, and limited or ineffective patient-provider communication) but also the implications for future healthcare access (Holly & Anef, 2013; Krahn, Walker, & Correa-De-Araujo, 2015; Whittemore & Knafl, 2005). An IR methodology that included an examination of the dynamic relationship between population and structural level influences was long overdue.

Purpose of the Study

The purpose of this study was to understand how structural, social, and health system factors impacted the AEA-SHCN population-based HCT experiences in a health equity context. Unfortunately, the overarching relationship between suboptimal HCT experiences and poor transitional care has not yet been fully acknowledged (Sheehan, While, & Coyne, 2015). While multiple factors (or barriers) have been cited, full consideration for the suboptimal HCT experiences in the healthcare equity realm remains poorly described (Gray, Schaefer, Resmini-Rawlinson, & Wagoner, 2017; Grimsby, Burgess, Culver, Schlomer, & Jacobs, 2016). Likewise, the role of using HCT experiences as a pathway to understand how HCT disparities emerge in the AEA-SHCN is equally as mystifying (Betz, 2004; Goodhand, Hedin, Croft, & Lindsay, 2011; Ladores, 2015). In this vulnerable population, it is well-known that HCT disparities and the poor healthcare access follow a similar trajectory, however designs that examine these constructs in the setting of poor HCT experiences have been underappreciated (Anderson et al., 2018; Krahn et al., 2015). This gap makes the IR an ideal methodology to synthesize data from multiple designs and to explore this complex phenomenon. It has become apparent that HCT guidelines that primarily address patient or provider awareness and education lack real-world significance and thus, remain insufficient to address HCT disparities at multiple care levels (Bauer, 2014; Kerr, Price, Nicholl, & O'Halloran, 2017).

Research Question

How could an examination of the HCT experiences among the AEA-SHCN population improve our understanding of the structural, patient, and health system-led factors from a health equity perspective?

Theoretical Framework

In what began as a feminist theory that defended gender equality in the early 1960s, an intersectional approach provided a much-needed explanation of how embedded legal discriminatory practices and popular social movements of the time undermined civil liberties among marginalized populations (Carbado, Crenshaw, Mays, & Tomlinson, 2013). In several seminal publications, Crenshaw (1989) first coined the term *intersection* to embody the social ostracism of African American women through prejudicial social systems, civil unrest, and poor treatment and experiences (Crenshaw, 1989). This first framework described how social group vulnerabilities were manipulated and later exploited by the socially advantaged to further undermine population equity (Bauer, 2014; Carbado et al., 2013; Krieger, 2012). Today, contemporary intersectional theorists generally believe health and disease comparisons that are primarily based on race or socioeconomic status (SES) can at best stymy positive social change (Green, Evans, & Subramanian, 2017). Intersectional theorists also suggest that comparative analyses based on factors such as race, gender, and social factors obscures the embedded institutional biases that have historically restricted opportunities and access for societal advancement among disadvantaged groups (Carbado et al., 2013). Epidemiology studies, (although well-intended) compare health differences based on SES, or (other social factors) masks the pre-existing structural inequalities that surround healthcare access and quality (Green et al., 2017). Unfortunately, longitudinal studies that are designed as dichotomies (particularly those that compare demographical data) often negate the contextual experiences that are inextricably linked to healthcare perceptions and behaviors (Bauer, 2014; Bowleg, 2017; Krieger, 2012). Likewise, in structurally-biased institutions (those that favor stakeholder knowledge, privilege, and resources) are likely contributing to disparities in healthcare experiences based on social strata (Bauer, 2014; Krieger, 2012). Generally, an intersectional theoretical approach is used to consider contextual experiences as the nexus between (and amongst) multiple social and system dynamics that simultaneously influences institutional behaviors (Bauer, 2014). Interestingly, this perspective aligns with classic transitional theory whereby multiple care pathways reflect an integration of stakeholder (patients, families, healthcare providers, and community resources) influences, and the social conditions that govern healthcare systems (Geary & Schumacher, 2012).

In this IR study, I focused on patient HCT experiences and stakeholder perspectives on the transition process to potentially elicit social and structural differences using a health equity lens (Gulley et al., 2018). While the AEA-SHCN population tends to experience more difficulty accessing the healthcare system, theoretical frameworks that study the contextual and dynamic healthcare experiences simultaneously are slow to emerge (Reiss & Gibson, 2002; Valenzuela et al., 2014; Wojciechowski, Hurtig, & Dorn, 2002). I applied an intersectional theoretical framework to examine, reframe, and ultimately interpret suboptimal HCT experiences using this perspective. Admittedly, HCT researchers have acknowledged the need to reexamine access difficulties with more emphasis on the unfair HCT practices that most assuredly crossover into health equity realms (Freeman et al., 2017). In this study, I contributed to the HCT research portfolio by shifting how the study of suboptimal HCT experiences were viewed: as potential evidence that involved the discriminatory healthcare practices which disproportionately impacted the disadvantaged AEA-SHCN patient population (Aldiss et al., 2015; Viruell-Fuentes, Miranda, & Abdulrahim, 2012).

Nature of the Study

The AEA-SHCN population encounters structural, social, and system obstacles throughout the HCT process (Hergenroeder, Wiemann, & Cohen, 2015). However, little is known about how patient experiences reflect the perceived barriers and the subsequent effect on adult care access (Andreoni et al., 2013; Turchi, Berhane, Bethell, & Pomponio, 2009). I used an IR methodology (systematic qualitative approach) to guide this inquiry.

While the inclusion of multiple study modalities can raise validity questions, an IR that is well-defined has the potential to improve the research's relevance in helping to solve real-world problems and while also contributing to the body of knowledge (Whittemore & Knafl, 2005). An IR is also suitable for topics with knowledge gaps between theory and practice; a recognized shortcoming in the healthcare transition fields (Novick, 2010).

An IR methodology began in the nursing field based on research translations needs; it offered practical guidance that is clinically relevant and scientifically based (Kirkevold, 1997). Incidentally, the lack of viable data-driven outcomes post-transition pose risks for these patients given their vulnerability that extends well into young adulthood (Zhou, Roberts, Dhaliwal, & Della, 2016). In all, an IR methodology is aptly suited to gather both illness-specific HCT data as well as to examine a range of common access barriers, poor transfers, and experiences across multiple research domains (Coyne, Hallowell, & Thompson, 2017). Furthermore, patients with SHCN consider access to appropriate care and overall satisfaction as salient predictors in quality of life (Coyne et al., 2017). In short, this IR's approach sheds light on the overall impact of contextually-based HCT experiences using a health equity framework (Bailey et al., 2017).

Previously published HCT literature is considered secondary data. Secondary data are particularly helpful to efficiently evaluate the role of current patient care guidelines and to determine if the intent is consistent between research, theory, and practice (Glaser, 1998; Whiteside, Mills, & McCalman, 2012). The IR process is characterized as having both a data synthesis function as well as research translation purpose (Whittemore & Knafl, 2005). Additionally, I also conducted a thematic synthesis and compared those results with the IR study findings. An IR that includes a comparative verification process can play an integral role in enhancing validity, and capturing a different view of the problem (Barnett-Page & Thomas, 2009).

In general, there are three steps involved in conducting a thematic synthesis: the development of free codes, descriptive themes, and analytical themes. Each new step brings researchers closer to a deeper and more conceptual understanding of the data (Barnett-Page & Thomas, 2009). Free codes are generally referred to as new themes that closely resemble the original text. Descriptive themes represent groups that are organized by text similarities (previously known as free codes) both crucial steps to the last step (Barnett-Page & Thomas, 2009). Finally, to derive analytical themes researchers begin by collapsing and overlapping the descriptive codes using an inductive process (Barnett-Page & Thomas, 2009). The synthesized evidence is then interpreted and integrated into a conceptual understanding of the data that better informs the research question (Barnett-Page & Thomas, 2009). This process typically yields a synthesis, rather than a summary of previously reviewed data (Barnett-Page & Thomas, 2009). Each step of the thematic synthesis builds upon one another with repetitive steps that result in a comprehensive review of the evidence (Britten et al., 2002). A thematic synthesis is a research translation methodology that borrows techniques from both grounded theory and meta-ethnography in an original interpretation of the data (Noblit & Hare, 1988; Thomas & Harden, 2008).

Definitions of Terms

Like most fields, there are specific terms utilized within the discipline to delineate their meaning and application throughout the study.

Adolescent and emerging adult with special health care needs (AEA-SHCN): This term includes youth with congenital, acquired, and chronic health problems who require more complex healthcare services than their healthy peers (McPherson M, 1998; McPherson, Thaniel, & Minniti, 2009). In this study, any disease-related health problems that contribute to childhood impairments in functioning, cognition, development, and behavioral/emotional needs are included in the AEA-SHCN population (Kelly, Golnik, & Cady, 2008; Stille et al., 2018; Zickafoose & Davis, 2013).

Care coordination: This term denotes a broad level of primary medical, and specialty care communication that occurs between healthcare providers and across health systems to promote care continuity (American Academy of Pediatrics Committee on Children with Disabilities, 2005; Antonelli, McAllister, Popp, & Fund, 2009).

Disability: Disability is defined as mental, or physical impairment that substantial limits an individual's functional capability in daily life (United States Department of Justice & Civil Rights Division Public Access Section, 2005).

Disease self-management: This term refers to the degree to which patients demonstrate knowledge and practical application of specific self-care skills to improve acute and chronic health conditions (Beacham & Deatrick, 2013).

Healthcare transfer in care: This term refers to a process that occurs when patients move into different systems of care, based primarily on chronological age (Burke, Spoerri, Price, Cardosi, & Flanagan, 2008).

Healthcare transition readiness: This term is defined as the process by which youth acquire the necessary skills in self-management, advocacy, and independence to make informed healthcare decisions before an adult care transfer (Institute of Medicine, 2007).

Healthcare transition: This term refers is defined as the process of obtaining developmentally appropriate healthcare throughout each life-stage (Blum et al., 1993).

Health inequities/health disparities: This term applies to social groups whereby health status and outcomes are shaped by systematic-level discrimination based on severe imbalances in wealth, power and prestige (Braveman, 2006).

Institutional Racism: This term refers to any specific policy and procedure between and among state or non-state institutions that is intended to exclude or enlist groups based on presumptions of racial and ethnic membership or orientation (Krieger, 2014).

Medical home concept: This term applies to the comprehensive healthcare delivery model that is designated as a primary source of healthcare services for pediatric or adult care settings (Sia, Tonniges, Osterhus, & Taba, 2004).

Racism: A term used to exclude individuals or groups based on their phenotype and restricts people's access and opportunities to express political, social, cultural, and economic liberties in public life (International Council on Human Rights Policy, 2000).

Structural Racism: This term refers to a mutually-reinforcing system of inequality that preferentially distributes and redistributes benefits to the privileged at the expense of the underprivileged (Bailey et al., 2017).

Assumptions

Like most research undertakings, the researcher first discloses several basic assumptions to help frame results and any implications in the proper context (Britten et al., 2002; Thomas & Harden, 2008). Therefore, one of the main assumptions in this research endeavor was that the HCT experiences among AEA-SHCN patients were fundamentally comparable and therefore amenable to a synthesis. Moreover, the perceptions and attitudes published in the HCT literature reflect the totality of HCT experiences and thus address the research question (Anthony et al., 2009; Sonneveld, Strating, van Staa, & Nieboer, 2013). I also assumed that the underlying theoretical construct illuminated the previously unidentified practices (Carbado et al., 2013). In this case, I applied an intersectional theory (in the dynamic healthcare context) with the assumption that it supports a theoretical understanding of HCT experiences. Under the health disparity model, poor health and disease trajectories predominantly impact the underserved and vulnerable populations (Bailey et al., 2017; Richardson & Brown, 2016). With this background, I assumed that the HCT experiences and the emerging themes reflect the contextual and conceptual understanding of patient challenges and difficulties in the HCT process.

Scope and Delimitations

The scope of this IR pertains to the development of a synthesis that is based on the structural, social, and health system factors that impact the AEA-SHCN population-based HCT experiences, perceptions and outcomes. Based on an expert consensus of HCT recommendations, the target population of youth who require HCT support are most likely to fall between the ages of 12 to 26 years of age in youth with SHCN (Reiss, Gibson, & Walker, 2005). Therefore, I chose this exact age range and defining characteristics based on the recommended age category. The HCT process should begin in early adolescence and extend throughout young adulthood or until a transfer is complete (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002). It is well established that the AEA-SHCN population is a varied patient group that comprises of a variety of ages, diagnoses, and healthcare needs (Wise, 2007). As such, this patient group typically experiences a longer maturation process which lends support for a broadly-defined age category as applied in this study (Sawyer, Azzopardi, Wickremarathne, & Patton, 2018). Aside from chronological age criterion, the inclusion of patient experiences (and the factors that shape them) were crucial to the study of the contextual and social parameters. While the care transitions are common across healthcare settings (for example, hospital to home), I only examined transitions that occur from pediatric to adult care in the outpatient primary care setting.

An intersectional model is used to reframe study findings as contextual experiences based upon a specific social equity approach (Tkachenko, Hahn, & Peterson, 2017). In examining the AEA-SHCN population vulnerabilities, the social and structural factors are closely aligned with an experience-based framework (Bowleg, 2017). Given this particular focus, HCT data from typically-developing adolescents was excluded (Hogan et al., 2013). Similarly, studies conducted on different populations, such as terminally-ill patients were eliminated. Also, research conducted outside of the outpatient clinical setting such as inpatient, skilled nursing or home healthcare digressed from the original context and thus eliminated (Novick, 2010).

Furthermore, the IR methodology began in the nursing field to primarily and expeditiously address practice-based knowledge gaps in clinical settings (Fineout-Overholt, Melnyk, Stillwell, & Williamson, 2010; Russell, 2005). Finally, recommendations for HCT improvements that specifically speak to patient experiences and factors that facilitate access are discussed in study conclusions. In summary, both HCT theoretical and practice-based approaches are needed to address multiple service gaps that closely align with the AEA-SHCN population needs within the intersectional health equity framework.

Limitations

An inherent methodological difference between an IR and other systematic reviews can limit the generalizability (or the applicability to other inquiries using similar populations and constructs; Leung, 2015). An IR is a systematic review that considers a greater swath of the available literature in exchange for a tightly defined scope and discussion (Cooper, 1982; Torraco, 2005). It is important to declare that all of the selected journal articles must directly discuss the primary HCT construct (Whittemore & Knafl, 2005). Another potential limitation is the lack of consensus in quality appraisal (tool(s); Hopia, Latvala, & Liimatainen, 2016). To address this ambiguity and enhance validity, the Mixed Methods Appraisal Tool (MMAT) (see Appendix B) was used to conduct the quality appraisal (Pluye & Hong, 2014). This tool scrutinized the quality of multiple research designs (qualitative, quantitative, and mixed methods) and consolidated them into one comprehensive table (Pluye & Hong, 2014). Another helpful feature of this tool was an easily identifiable scoring method (expressed as a percentage) which reflected the number of quality benchmarks met in each source (Hong et al., 2018).

The screening process was an important step since the bulk of HCT literature contains systemic reviews and retrospective designs, many of which have both, quality and transferability concerns (Jones et al., 2017). In addition, these HCT research limitations and a lack of efficacy-related outcomes can contribute to conceptual ambiguity and data misinterpretations (Aldiss et al., 2015; Ladores, 2015). Altogether, many of these uncertainties signal that the HCT field is in an early stage of exploration (Betz, Nehring, et al., 2015). Finally, this HCT review is subject to this researcher's bias based on pre-existing knowledge and familiarity with the HCT process and care access concerns (Britten et al., 2002; Lotstein et al., 2010). While my familiarity and preconceived notions about the overall healthcare system is noteworthy, my access (primarily determined by military retiree benefits and entitlements) pose significant access limitations. To counteract my underlining experiences of healthcare and HCT biases, I annotated or 'bracketed out' personal experiences to clarify for the research audience, my personal views, and background (Creswell, Hanson, Clark Plano, & Morales, 2007). All decision points created throughout the process were documented and kept as study records to ensure IR qualitative study fidelity (Anthony et al., 2009; Padgett, 1998). Conveniently, in the NVivo program there exists a memo tab that allows researchers to document ongoing progress, interpretations, and any subjective information throughout the research process.

Significance and Social Change Implications

The primary intent behind HCT national policy is to establish developmentally appropriate healthcare access for all youth as they enter young adulthood without any disruptions (United States Department of Health and Human Services, 2014). Additionally, it is firmly established that access to primary and specialty care is a vital component in protecting the health status of the AEA-SHCN patient (Davidson, Doyle, & Silver, 2015). Given that a well-organized HCT process is standard practice, the goal of this study is to elaborate on how patient HCT experiences can inform access barriers and document further healthcare disparities (Sheehan et al., 2015). Additionally, an examination of HCT process has implications for healthcare equity due to the sheer complexity of care navigation between two different systems of care (Krahn et al., 2015; Prokup, Andridge, Havercamp, & Yang, 2017). Several of those care differences relate to procedure/episodic focus, privacy issues, and healthcare policies between pediatric and adult healthcare systems (Mulukutla & Fegan-Bohm, 2019). Unfortunately, shortages of adult and specialty care providers combined with health coverage changes contributes to poor transfers, most notably limited patient engagement with the healthcare system and poor retention in care (Grimsby et al., 2016; Heery et al., 2015; Kovacs & McCrindle, 2014; Olds et al., 2014).

Summary

The purpose of this study was to identify and synthesize the structural, social, and health system factors that impacted population-based HCT experiences within a health equity framework. Surprisingly, studies that examine HCT experiences in the context of poor healthcare equity are limited (Bauer, 2014; Chu, Maslow, von Isenburg, & Chung, 2015; Watson et al., 2011). This IR approach synthesized not only HCT text evidence into increasingly more insightful interpretations but also informed the meaning of AEA-SHCN population experiences (Bearman & Dawson, 2013). The AEA-SHCN population face multiple challenges in accessing developmentally appropriate care (DiFazio et al., 2014). Structural, social, and system barriers interfere with the HCT process; however, an examination of this multifactorial interaction has not been thoroughly conducted (Lemly et al., 2013). Unfortunately, HCT experiences bear little resemblance to the seamless and uninterrupted pediatric transfer to adult care as recommended by healthcare experts and clinicians alike (Committee on Children with Disabilities and Committee on Adolescence, 1996; Cooley, Sagerman, & American Academy of Pediatrics, 2011). Despite an increased awareness by multiple stakeholder groups (patients, policy makers and healthcare providers) the potential health equity issues have also been raised as gaps between recommendations and practice persists (Rast, Shattuck, Roux, Anderson, & Kuo, 2018). The next chapter discusses health equity as it relates to HCT research and practice with an historical and contemporary review of HCT care and impact on healthcare access.

Chapter 2: Literature Review

Introduction

The purpose of this study was to identify and synthesize the structural, social, and health system factors that have impacted population-based HCT experiences in a health equity context. While research has confirmed that a variety of factors influence the HCT process, access difficulties, poor care coordination, and overall patient uncertainty with the process are commonly implicated in the HCT literature (Begley, 2013; Javalkar et al., 2016; Zhou et al., 2016). Most recently, published HCT data suggested that nearly 20% or 14 million households have at least one child (below the age of 18) with SHCN (United States Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2014). Annually, half-million youth with SHCN turn 18 and thus, become eligible for adult healthcare services (McPheeters et al., 2014). Despite the well-established HCT role in pediatric to adult continuity of care, once patients leave their pediatrician, they encounter healthcare access difficulties (Gray et al., 2017; Valenzuela et al., 2014). This brief, yet meaningful background provides a glimpse into the challenges that families face negotiating between two complex and yet, distinctive healthcare systems.

The next section begins with a brief discussion of the search strategy and the theoretical basis for conducting this IR. Secondly, to lay a foundation for this study, I examined the historical and contextual research found in the HCT literature and discussed potential overlaps with the current IR. Finally, I examined previous work using the theoretical model in health disparity research.

Literature Search Strategy

While there are multiple ways to conduct a search strategy. Torraco (2005) suggested researchers adopt a "guiding theory" (p. 359). This approach not only delineates the pathway forward but also orients the researcher toward their chosen underlying study premise (Torraco, 2005). There is a well-entrenched pattern of suboptimal HCT experiences in the AEA-SHCN population, however social, system, and patient factors have not been systematically explored nor have social identities (i.e., sociodemographic factors, limited healthcare infrastructures, and unmet healthcare needs) been examined using a healthcare equity lens (Crump, 2018; Krahn et al., 2015; Torraco, 2016). It is these contextual aspects of HCT experiences that I focused on throughout this study.

The first step was to identify several keywords that are consistent with the research question and the overall scope. I used the following keywords for my literature search: *healthcare or health care transition*, *special health care need*, *disability, health care transition process, health care access/transfer and youth with special healthcare needs*, *youth, young adult, and emerging adult with complex care needs, and disability*. I conducted a comprehensive search in these databases: Google Scholar, CINAHL & MEDLINE, PubMed, ScienceDirect, and SAGE journals. I also conducted a hand search whereby the references of previously included articles were further scoped for review and possible inclusion. The hand search process is commonly practiced by researchers and well-known to elicit key references not triggered by automatic search engines (Horsley, Dingwall, & Sampson, 2011). Nevertheless, I created several computerized notifications through many of the well-known databases (Mendeley, Google Scholar, and PubMed).

Equally important to this study, however, was the theoretical foundation. Healthcare disparities found throughout this population are commonly involve patient, family, and healthcare system factors (Garcia-Huidobro, 2019). An IT framework was chosen based on the need to harness all of these social experiences into one comprehensive review. To that end, the next section begins with a robust explanation of intersectional theory (IT) and the rationale for the selection. Throughout the next chapter, I have also included several of the ongoing HCT research dilemmas and discuss several reasons for the IR methodology.

Theoretical Foundation

In this integrative review (IR) I viewed the HCT experiences through the lens of an intersectional perspective. Using an intersectional theory I considered how the accumulative impact of historical and present-day group marginalization has on social mobility and equality (Crenshaw, 1989; King, 1988). Crenshaw (1989) first described the phenomenon as a simultaneous expression of multiple social group experiences that are dynamically shaped by differences in identity and disadvantage (Cole, 2009). Historically speaking, traditional intersectional theorists believed that inherent discrimination and prejudicial decisions (that were largely propagated by legal/jurisdictional institutions) made biased decisions based on the nature of someone’s gender, social class, and racial/ethnic background or social individual/group category (Cole, 2009; Crenshaw, 1989). Today, intersectional theorists are also particularly interested in the totality of ways that structural discriminatory practices and policies influence access to health, housing and other social institutions (Carbado et al., 2013). While people might occupy one or more social identities (based on income, gender, race, or citizenship) the presence and levels of advantage impacts their present and future opportunities in society (Crenshaw, 1989).

Major Theoretical Propositions

Using an intersectional framework (in the healthcare context) I captured the influential ways that discriminatory (or preferential) practices, behaviors, and experiences limit access and care in systems of oppression or injustice (Bauer, 2014; Jackson & Williams, 2006). With an IT background, I enhanced understanding of a health equity perspective, which is the notion that multiple social and contextual factors impact individual (as well as group) social identities in ways that inform their experiences (Hogan et al., 2013). In the HCT field, researchers might study how an intersectional perspective can further describe the implications of structural barriers (such as abrupt change in healthcare providers or complex coverage insurance plans) has on health equity and overall access policies.

Within an unjust system of care, patient and social group experiences are intertwined with poor knowledge of treatment options and limited system support (Bauer, 2014). By taking this one step further, the intersecting factors such as low-SES, and racial/ethnic/non-English speaking patients are no more important than other disadvantages in predicting group experiences; instead, it is the intersection of the relevant contextual factors and practices (and their implications thereof) that is most suggestive of healthcare disparities and social inequalities (Bauer, 2014; Krieger, 2012). Longitudinally, there is still much to learn about differential access to HCT services and appropriate adult care, as strategies to improve healthcare outcomes and close these health equity gaps are slow to emerge in the HCT field (Colver et al., 2018). The HCT experiences among the AEA-SHCN population are markedly difficult and fraught with system complexities that have been likened to “falling off a cliff” (Joly, 2014, p. 1). They include: prolonged delays/unmet HCT needs, health status declines, increases in urgent care, poor access/public insurance type or no insurance coverage, and continued pediatric care despite patient is an adult (Crowley, Bosslet, Khan, Ciccarelli, & Brown, 2018).

The study of healthcare inequalities is not necessarily unique in public health policy research. On a macro level, public health disparities and poor distribution of healthcare resources exist across the social strata and thus, share relevancy with this study (Marmot, 2007). The AEA-SHCN population-based HCT experiences could reflect multiple social and system disadvantages that become apparent in the healthcare context (Javalkar et al., 2016). Patient self-care, for example, was a consistent research theme in the HCT literature; however, the implications of poor access based on income barriers, degree of chronic illness/patient capacity, and other sociodemographic predictors was also limited (Javalkar et al., 2016). In a multidimensional framework, healthcare disparities are viewed as structural or institutional biases and barriers that intersect with social group experiences in the healthcare setting (Bailey et al., 2017). Structural-level discrimination manifests by historically held injustices that proliferate in healthcare settings; that is institutional factors that support identities/groups or systems of social inequality (race, SES, sociodemographic and culturally-held biases; Bailey et al., 2017; O'Sullivan-Oliveira, Fernandes, Borges, & Fishman, 2014). Therefore, structurally-based healthcare inequities arise in part due to healthcare policies and decisions that restrict and isolate social groups based upon a complex array of disadvantages, social biases/discrimination and poor healthcare access (Green et al., 2017).

Using an intersectional theoretical lens allows researchers to view healthcare systems as potential *structural or institutional* sources of discrimination that impact daily medical policies and decisions (Bailey et al., 2017). According to Cole (2009) intersections are social constructions where individual/group interactions occur within contexts that exploits disadvantage and attempts at help-seeking behaviors or experience (Cole, 2009). In the HCT process, patient factors, structural and system-related contingencies continually influence the AEA-SHCN population healthcare experiences (Hogan et al., 2013). Policies addressing chronological age-cut offs for example, establish healthcare eligibility but also introduces access barriers and creates further burdens for patients with abrupt transfers to adult care upon reaching majority age (Krahn et al., 2015; Krieger, 2012). Unfortunately, the application of intersectional theory in the healthcare setting is rather limited; the following discussion describes how the use of IT could have enhanced understanding of how disparity research, access to healthcare, and health outcomes (Bailey et al., 2017; Hankivsky et al., 2017).

It is firmly established that there are disparities in HCT services and access to care; however, disparities still exist mostly among vulnerable patients based on racial group identities, gender, sociodemographic, education attainment, health conditions, and poverty levels (Eilenberg, Paff, Harrison, & Long, 2019). While racial differences in healthcare access can account for approximately 25% of access disparities, poor education, gender (male), and living in the southern regions of the United States can have a profound effect on long term access and engagement in care (Richmond, Tran, & Berry, 2011). In a subsequent study, healthcare disparities in access persisted despite the availability of patient-centered medical homes (PCMH) a single point of family healthcare access near where patients reside (Richmond, Tran, & Berry, 2012; Strickland et al., 2009). In studies that examined young adults with sickle-cell disease (SCD) data revealed that only 60% of pediatric providers referred patients to adult providers despite the availability of adult providers noted in the study (Sobota, Neufeld Ellis, Sprinz, & Heeney Matthew, 2011). Unlike other chronic genetic disorders, SCD disproportionately effects Non-Hispanic African-Americans, (which in advanced stages can lead to early complications such as chronic pain, strokes, and other organ-related dysfunctions in the vascular system; Jenerette & Brewer, 2010).

While HCT challenges across the AEA-SHCN population do exist, SCD is an especially poignant example of structurally and systematically biased or discriminatory healthcare (Jenerette, Brewer, Edwards, Mishel, & Gil, 2013). Jenerette and Brewer (2010) referenced discriminatory practices as “stigmas or social disqualifications” (p.1050) based on medical condition. Stigmas, (as defined in this study and elsewhere) were associated with more advanced stages of SCD; however, the negative beliefs held among poorly informed or skilled healthcare providers replicated those beliefs (Evans et al., 2018; Weiss, Ramakrishna, & Somma, 2006). In other SCD studies that involved inexperienced clinicians (typically non-hematologists) primary care providers perceived that SCD patients as ‘drug-seeking’ based on the frequency of unmet pain management needs as the chief presenting complaint (typically in urgent care settings; Mulchan, Valenzuela, Crosby, & Diaz Pow Sang, 2016). When viewed through an intersectional theoretical lens, we see that discriminatory practices (for example, provider-held perceptions toward SCD patients) reflects poorly informed or trained providers, a factor involved in healthcare disparities (Mulchan et al., 2016). Youth with neurodevelopmental disabilities (NDD) are a subgroup of the AEA-SHCN population that are especially vulnerable to societal related stigmas, loss in health coverage, and poor access (Racine et al., 2014). In a most recent review of patients with Autism and intellectual disability (ID) patients with ASD were more likely to lose their healthcare coverage or become disenrolled as they matured into young adults (Shea et al., 2019). Authors surmised that ASD patients were treated similarly to that of youth with behavioral health needs and thus, specificity for this group's unique needs went unnoticed as factors in poor healthcare and coverage retention (notably in mental healthcare) took effect (Shea et al., 2019). A systematic review of ID patients (from within and outside United States) also revealed insufficient transitional care for this population due to the lack of appropriate healthcare services, poor physician support or knowledge of the HCT process to address complex needs (Brown, Macarthur, Higgins, & Chouliara, 2019). Ethical concerns have been raised not only for this issue but the need to better support patient rights with shared decision-making between provider, patient and parent/caretaker as they approach adult age (Díaz-González de Ferris et al., 2017; Larivière-Bastien, Bell, Majnemer, Shevell, & Racine, 2013). Unfortunately, the HCT literature lacks both policy and practice-based approaches for working with emerging adults with NDD or ASD with unmet HCT needs and access concerns (Racine, Larivière-Bastien, Bell, Majnemer, & Shevell, 2013).

Theory Rationale

While HCT evidence suggests that patient access disparities and suboptimal experiences exist, a theoretical basis for understanding the health equity implications of differential access in healthcare has not yet emerged (Schwartz et al., 2013). Unlike epidemiological models that discuss social categories as *risks* (such as race, income status and disease status), intersectional theory treats these same groupings as dynamic mechanisms of privilege and oppression (Evans et al., 2018). There are several ways in which discrimination (a form of social inequality) impacts health and opportunity. However, researchers stress that to study the ill effects of discrimination on health requires an exploration of the lived experiences of classism, sexism, and racism along with their restrictive (often oppressive) societal meaning and social rules (Krieger, 2012). With an intersectional framework, unmet HCT needs and disease severity are viewed as *disadvantages* in the AEA-SHCN population (Viruell-Fuentes et al., 2012). In short, the application of intersectional theory is a novel way to view HCT disparities and one that could add further insight into understanding root causes of poor access and experience (DiFazio et al., 2014; Nakhla, Daneman, To, Paradis, & Guttmann, 2009; Okumura et al., 2013).

Literature Review

Early social justice and IT theorists were initially interested in how gender, class, and racial biases measured up against equal protection statues of the time and the legal depth with which to represent female survivors of abuse and marginalization (Crenshaw, 1989). Likewise, the AEA-SHCN population face uncertainty in healthcare access as HCT research has firmly established that difficulty with care navigation and poor retention in care has persisted despite more awareness on the issue (Gray et al., 2017; Sheehan et al., 2015). Special needs' youth with social disadvantages (low-SES, limited coverage or sociodemographic concerns) routinely encounter insidious structural complexities that interfere with access, care, and treatment options or benefits in the healthcare context (Abel et al., 2015; Williams, 2009). While the study of discriminatory practices and poor health equity continues to raise public health and policy concerns, there is a pressing need to examine the structural or institutional level barriers in this underappreciated area (Bailey et al., 2017).

Today, health and policy researchers have just recognized how IT theory could enhance health disparity in multiple social contexts (Bauer, 2014). In general, healthcare system complexities are potential sources of health disparities since access, and self-care skills are crucial for a successful HCT (Gray et al., 2017; Oswald et al., 2013). Pediatric providers with minimal experience or familiarity with the HCT process leave this burden up to their patients with SHCN and families regardless of age (Prokup et al., 2017). Another example is found in the consistent shortages of adolescent and adult healthcare clinicians with specific training treating patients with developmental or congenital diagnoses, which are risk factors in delays in access to appropriate care (Nehring, Betz, & Lobo, 2015; Volertas & Rossi-Foulkes, 2017). A lack of non-physician clinical personnel that are dedicated to the HCT role and services also limits organizational capacity to assist these patients (Ferris & Mahan, 2009; Sable et al., 2011). As a result, providers are less likely to approach adolescent patients with unmet needs (Berry et al., 2011). Sadly, AEA-SHCN patients are more likely to have providers who might perceive this population to be 'non-adherent' or 'burdensome' based on a complex array of unmet healthcare needs in the setting of limited access (Campbell et al., 2016; Gray et al., 2017; Szalda et al., 2015). Overall, the health system complexities (such as provider shortages, poor organizational HCT support or lack of familiarity with HCT process) compound the barriers, and place heavy burdens onto patients to navigate between pediatric and adult care settings with little knowledge of how to do so (Agarwal, Hilliard, & Butler, 2018; Davidson et al., 2015; Krahn et al., 2015).

IT and Discrimination in Healthcare

According to Bowleg (2012) an intersectional model can reframe individual and group disadvantages as multidimensional as a way to fully understand how disparities impact access and capacity for self-care (Bowleg, 2012, 2017). Health systems or organizations are often reluctant to accept that structural biases could be a factor in poor experiences (Hogan et al., 2013). We also know that provider-held prejudices against patients with profound needs impacts healthcare access and further risks poor healthcare quality and disparities among vulnerable populations (Hogan et al., 2013; Williams & Mohammed, 2009). Among disadvantaged African American female patients, those who perceived discrimination by healthcare personnel became disinterested in seeking preconception care, a known risk factor for infant prematurity (Hogan, Griffioen, & Selameab, 2018). Intersectional analyses within this same population also revealed that low prenatal utilization rates were based on patient perception of discriminatory treatment (Hogan et al., 2013). Evidence suggests discrimination (experienced by patients during the encounter) could very well be linked to poor patient treatment, insurance type, and race, all of which, might reflect a structural discriminatory environment (Ward, Mazul, Ngui, Bridgewater, & Harley, 2013). In general, the abovementioned study examined how patient perceptions of discriminatory practices (identified through an intersectional theoretical approach) can improve our understanding of how healthcare disparities develop and reciprocate in healthcare utilization among disadvantaged groups (Hogan et al., 2013; Jackson, Rowley, & Curry Owens, 2012). IT captured what other disparity research designs might not have shown; a persistent need to reexamine social discrimination and structural/institutional factors that impact suboptimal experiences and thus, modulate access and outcomes (Becares & Atatoa-Carr, 2016; Richardson & Brown, 2016; Ward et al., 2013). Youth with sickle cell disease (SCD) (which mostly impacts patients of African descent) have reported discrimination from their providers (Haywood, Williams-Reade, Rushton, Beach, & Geller, 2015; Kaye, 2006). Finally, most recently, data from adolescents (ages 12−17) males with SHCN, revealed that more unmet healthcare needs were mostly concentrated among medically complex care adolescents whose families were also considered low-income (Paramsothy et al., 2018). Authors suggested that HCT services and community resources should be accessible to those with more severe conditions to include those with social disadvantages (Paramsothy et al., 2018).

Moreover, Etherington (2015) found that psychological markers of health and wellness (self-efficacy and health status perceptions) did not benefit African American, and White women equally (Etherington, 2015). Authors further noted that White women perceived a higher level of well-being (that often accompanies increased SES levels) than did other social groups (Etherington, 2015). In other words, feelings of self-worth between two racially diverse female groups did not correlate equally as income levels rose (Etherington, 2015). These findings could suggest that structural injustices eroded feelings of well-being among African American women in a different manner as opposed to White females based on a confluence of gender, SES and psychosocial health status (Etherington, 2015). Likewise, among youth who received organ transplants, those who experienced earlier complications were more likely to be African American patients with publicly-funded insurance (Andreoni et al., 2013). While more research is needed to confirm these emerging social and health disparities, African American patients appear to be at a significant disadvantage (as measured by disease-related outcomes) based on race, resources and access (Andreoni et al., 2013). Moreover, a loss of health coverage following kidney transplants (often associated with poor medication access) is a significant factor in healthcare-related outcomes among a fragile health population (Andreoni et al., 2013).

Despite more research interests in understanding the nexus between social justice issues and health status, the use of an IT framework to explore predicators of proper healthcare utilization is not well described (Jackson et al., 2012). However, according to Richardson and Brown (2016) a "*multiplicative*" (p. 425) effect could suggest that structural racism is omnipresent, and predicated on social determinant theory (Richardson & Brown, 2016). This is a particularly useful concept for studying the accumulative impact of a lifetime of disease, poor healthcare treatment histories or access, and disease trajectories among socially-vulnerable populations (Jackson et al., 2012). Moreover, in studies that examine African American patients with human immunodeficiency virus or HIV (who might also be living in predominantly poor neighborhoods) patient perceptions of distrust toward medical care and providers has been shown to negatively influence utilization of antiretroviral drug therapy or (ART; Freeman et al., 2017). Unfortunately, without drug therapy, the risk for the conversion of HIV to AIDS is significantly increased (Bradley et al., 2014; Freeman et al., 2017). Finally, in an examination of hypertensive risk factors, the combination of race, lower SES, cardiac risks *and* a strong history of social inequality were all highly correlated with an increased disease-risk (Richardson & Brown, 2016). In short, an IT approach is aptly suited to capture the accumulative impact of a discriminatory structural healthcare landscape that is, the insidious manifestations of institutional bias that infiltrate public health services and undermine help-seeking behaviors among those who often could benefit the most (Hogan et al., 2013). Immigrant data also suggests that social determinants (SES, healthcare access, and living conditions, etc.) are highly correlated with poor health, similar to what marginalized native-born groups experience (Viruell-Fuentes et al., 2012). Despite poor health outcomes in immigrant populations, minimal research exists on how intersectional theory could bolster understanding of how structural healthcare discrimination impacts healthcare utilization (Viruell-Fuentes et al., 2012). Traditionally, epidemiological theorists point to risk-reduction as it relates to acculturation (i.e., the process of cultural adaptation) to describe immigrant health disparities (Williams & Collins, 1995). Unfortunately, this model does not adequately describe health decline or poor healthcare access observed in immigrant and refugee populations (Lopez-Class, Castro, & Ramirez, 2011).

Population health researchers and intersectional theorists are now leaning toward the concept of residential *segregation* (an ecological clustering of immigrant communities whereby two or more homogenous groups reside) which is one of the leading factors in the erosion of health in these social groups (White, Haas, & Williams, 2012). Within these communities, inadequate housing, low SES levels, limited job growth, and inadequate healthcare access are commonly associated with poor health outcomes (Edberg, Cleary, & Vyas, 2011; Viruell-Fuentes et al., 2012; Williams & Mohammed, 2009). Within public health fields, support is growing for enhanced social and contextual models that account for the simultaneous exposure to poor social integration and health status among marginalized groups (Bernstein, Park, Shin, Cho, & Park, 2011; Institute of, 2003; Institute of Medicine, 2003; Institute of Medicine Committee on, Eliminating, & Ethnic Disparities in Health, 2003; Viruell-Fuentes et al., 2012; White et al., 2012).

Unfortunately, it is not surprising, that the role of discrimination and social disadvantage in the AEA-SHCN population is not well recognized within the HCT literature (Ciccarelli et al., 2014; Perrin et al., 2007). While expert HCT recommendations call for early exposure to transition education, the AEA-SHCN patient will often lag behind their peers in readiness and transfer to adult care (Fortuna, Halterman, Pulcino, & Robbins, 2012; Heery et al., 2015). Moreover, ethical questions have been raised regarding transitional policies that urge a healthcare transfer *without* first identifying an adult care provider (Diaz-Gonzalez De Ferris, Alvarez-Elias, Ferris, & Medeiros, 2017; Nehring et al., 2015). Furthermore, the AEA-SHCN population is a diverse group; comprised of multiple chronic illnesses, SES groups, ethnic backgrounds, and gender identities; still, the HCT experiences are similarly challenging and disparaging (Abramowitz, 2018; Lemly et al., 2013).

Unfortunately, while the study of intersectional theory in healthcare equity is underappreciated, SES and other socioecological factors are predict differences in access to care (Fairbrother, Dougherty, Pradhananga, & Simpson, 2017). Indeed, in the AEA-SHCN population, evidence of social disadvantages and system barriers play a central role in understanding poor population transition experiences (Hankivsky et al., 2017; Kuo, Anderson, Crapnell, Lau, & Shattuck, 2018).

HCT: An Historical Perspective

Over the past several decades, technological, medical advances have led to a remarkable survival rate within the AEA-SHCN population (Newacheck et al., 1991; Perrin et al., 2007). As the population continues to grow, the need for a coordinated HCT has become a healthcare priority among various stakeholders (West & Mogayzel, 2016). Despite increasing numbers of AEA-SHCN patients entering the adult care system, the vision of a comprehensive, collaborative and seamless HCT process has not yet been realized (Nehring et al., 2015).

A consensus statement released by the American Academy of Pediatrics (AAP) indicates that the provision of HCT services are markers of high-quality care within medical home (MH) clinics (Cooley et al., 2011). MH clinics are designed to bridge HCT gaps and promote access to foundational patient/family-based medicine (Kelly et al., 2008; Sia et al., 2004). Unfortunately, the provision of HCT is hardly assured with less than half of the transitional-age youth receiving HCT guidance, a finding that applies across primary care (Richmond et al., 2012). Additionally, MH (Ackerman & Gleason, 2018) clinics function to provide access to specialty care, however evidence suggests poor communication hinders transitional care between multiple systems of care .

An HCT is both a process, as well as an event (Annunziato et al., 2013; Reiss et al., 2005). However, access to developmentally appropriate care is a chief underlying goal (Davis et al., 2014). The HCT process is delineated by a series of coordinated and (not necessarily linear) steps that proceed throughout several years before an actual transfer takes place (Betz, 2017; Schwartz et al., 2014). However, patient quality of life (an essential theme over the lifespan) has been shown to be inextricably linked to patient self-care and overall capacity or functioning (Cramm et al., 2013). In other words, the acquisition of self-care skills is akin to patient perceptions of quality of life (Fair et al., 2016). HCT researchers agree that the HCT process is not simple; quite the contrary, since change during adolescence involves not only patient/parent relationships but also motivation and capacity for self-care (Betz, 2017; Huang et al., 2011). Unfortunately, best practices in the provision and delivery of HCT services has not yet been fully realized (Boudreau et al., 2014; Sawicki, Ostrenga, et al., 2017; Sharma, O'Hare, et al., 2014).

HCT Disparities and System Factors

Many leading healthcare organizations consider the AEA-SHCN population as ‘health fragile’ and yet on a continual basis, patients, and their families encounter health system obstacles during, and post-transition (Bollegala & Nguyen, 2015). These delays and gaps in timely healthcare access pose health risks upon reentry and increase the likelihood of patients dropping out of care completely (Heery et al., 2015). Youth with congenital conditions (heart disease, cystic fibrosis, sickle cell) require a consistent level of healthcare and yet abrupt disruptions in care that intersect with social disadvantages transitions in care are commonplace (Andreoni et al., 2013; Bryant, Young, Cesario, & Binder, 2011; Lotstein et al., 2013; Okumura et al., 2013; White & Ardoin, 2016). In one of the few randomized HCT controlled trials (RCT) revealed that a highly structured

HCT program reduces excess time between pediatric and adult care transfer, however insurance coverage for multiple care appointments was uncertain and thus remained was not addressed (Mackie et al., 2018). Healthcare organizations that lack a fully integrated system of care, (an especially problematic for those with intellectual disability) increases the likelihood of gaps and patients being lost to follow up (LTF; Ervin, Hennen, Merrick, & Morad, 2014). Furthermore, adult patients still in pediatrics are more likely to be disadvantaged (insurance instability, unfamiliarity with disease/condition, low family support, and low-socioeconomic status) and thus at-risk for poor care continuity (Javalkar et al., 2016).

A stark reminder of HCT disparities is found among youth with congenital heart disease (CHD) who despite a 95% childhood survival rate, often experience prolonged delays between pediatric and adult care that is developmentally appropriate access (Lee et al., 2017; Stewart et al., 2017; Wacker et al., 2005). Adolescents diagnosed with autism spectrum disorders (ASD) are also vulnerable to poor access since evidence suggests ASD and those with intellectual/developmental disability (IDD) patients are unlikely to receive HCT or care coordination services they need (Cheak-Zamora & Teti, 2014; Stewart, 2009; Walsh et al., 2017). Additionally, poor physician awareness for using technology to identify HCT needs is commonly observed in complex healthcare systems, an especially useful tool for transferring patients to an adult provider (Burke et al., 2018; Davis et al., 2014). While the Academy of Pediatrics (AAP) discourages arbitrary age limits, many pediatric health systems still impose such eligibility age-based standards; however, this practice is widely known to further disrupt healthcare access and introduce unnecessary health risks (Dwyer-Matzky, Blatt, Asselin, & Wood, 2017; Lemly et al., 2013). To complicate matters, the pediatric health system does not reward providers with viable economic incentives and does not have an adequate infrastructure or resources to address an intensive need-based patient population (Betz, Smith, Van Speybroeck, Hernandez, & Jacobs, 2015; Nehring et al., 2015; Sharma, O'Hare, et al., 2014; Sharma, O'Hare, O'Connor, Nehal, & Okumura, 2017). Fortunately, newer evidence suggests that a delayed-age transfer policy might reduce unnecessary clinical risks and stabilize care across the healthcare continuum for youth with SHCN or chronic conditions (Yassaee, Hale, Armitage, & Viner, 2019). Fortunately, evidence supporting flexible health system policies (such as those with a developmental and chronological focus) are growing to improve self-care skill development and increase patient engagement during late adolescence (Stollon et al., 2017).

Of all the AEA-SHCN patient population, those in the foster care systems (most of which have unmet mental health needs) are the *least* likely to receive HCT planning services (Paul, Street, Wheeler, & Singh, 2014). This an alarming disparity given that healthcare services for youth in publicly-funded programs phases out of by age 18 to 21 years (Shaw, Asomugha, Conway, & Rein, 2014). Regrettably, young adults without an established adult care provider will likely lose *both* primary and behavioral health care services upon reaching majority age (Collins, Rasmussen, Garber, & Doty, 2013). Additionally, young adults with behavioral healthcare needs often do not continue to seek care as adults (Barr et al., 2017). Unmet behavioral healthcare needs are particularly problematic since ongoing treatment and collaboration between primary and psychiatric care is often needed to fully support this high-risk group (Schraeder & Reid, 2017). Furthermore, as the AEA-SHCN patient matures, those with preexisting behavioral healthcare needs also tend to have physical health risks, which will invariably increase healthcare costs and medical complexity going into adulthood (McManus & White, 2017). Youth with severe emotional disturbances (SED) are particularly vulnerable to unmet behavioral healthcare needs with only one of every three receiving services as adults (Centers for Medicare and Medicaid Services, 2013; Davis et al., 2014). Unfortunately, the vast majority adults with SED (two out of every three young adults) will have lost their behavioral health coverage, a stark reminder of their vulnerability to attrition (Collins et al., 2013). Overall, the AEA-SHCN population (which includes those with behavioral health needs) have significant skill limitations in both help-seeking and obtaining healthcare services on their own (Uzark et al., 2015; Uzark & Wray, 2018).

Based on the preponderance of the evidence, the burden to seek, coordinate, and transfer healthcare services trickles down to patients and their families (Berry et al., 2011; Szalda et al., 2015). Evidence also suggests low-income AEA-SHCN patients experience significant difficulty managing their self-care needs while navigating a complex healthcare system (Berry et al., 2011; Szalda et al., 2015). Despite the wide availability of HCT program guidance (mostly designated for healthcare provider use), poorly structured HCT programs and inadequate anticipatory guidance from providers does little to prepare families for adult care or improve self-care beliefs among AEA-SHCN population (Gabriel, McManus, Rogers, & White, 2017; McPheeters et al., 2014; Squiers, Lutenbacher, Kaufman, & Karp, 2017). Needless to say, the HCT process can be complex, susceptible to medical errors, and insufficient to properly prepare and transfer patients with a high level of coordination and transition planning needs (Berry et al., 2011; Coleman Eric & Boult, 2003; Fishman, Ziniel, Adrichem, Fernandes, & Arnold, 2014; Sharma, O'Hare, et al., 2014).

Not surprising, best practices in the provision of HCT services to improve and mitigate disparities remains largely inconclusive (Agarwal et al., 2018). It also appears that patients and families are shouldering much of the responsibility in the coordination of care between pediatric and adult care systems with little support and at times with suboptimal results (Barr et al., 2017; Ferris & Mahan, 2009). With few exceptions, AEA-SHCN patient groups are unlikely to receive timely HCT services, which could contribute to gaps in healthcare access and unmet primary and behavioral health needs at a crucial life stage (Srinivasan & Williams, 2014).

Fortunately, health disparity or health equity research has experienced an enlightened view as of late (Fairbrother et al., 2017). Health policy researchers have begun to acknowledge that a one-dimensional view does not adequately capture the extent of the disease burden and the contextual or socioecological influences that disproportionately expose disadvantaged social groups to further healthcare gaps (Crenshaw, 1991; Srinivasan & Williams, 2014). Theoretical models that move away from conventional thinking on health disparities (i.e., single-axis orientation like racial, and ethnic backgrounds) is sorely needed and yet remains controversial (especially in healthcare fields; Srinivasan & Williams, 2014; Williams & Mohammed, 2009). More broadly speaking, improvements in access through enhanced HCT provisions, fosters patient, community, and systems-level approaches (Shattuck, Lau, Anderson, & Kuo, 2018). Moreover, both the National Institutes of Health (NIH) and the World Health Organizations' (WHO) share in their unyielding view toward health equity and thus fully embrace a sociodemographic theory of health (Srinivasan & Williams, 2014; World Health Organization, 2013).

HCT and Health Policy

On a historical level, disability policy reform did not get a strong foothold in the political discourse until the early 1970s just as societal norms on individualism shifted toward full inclusion (Olkin, 1999). At that time, this meant that people of all ages with social, physical/functional and intellectual disabilities should enjoy the same access and opportunity as everyone else (Olkin, 1999). An inclusive paradigm profoundly effects societal norms/expectations as fundamental accommodations for people with multiple physical and intellectual challenges are crucial if society is to support those with disabilities and ultimately improve their quality of life (Oliver, 1996). Regrettably, it would take another two decades however before the public and social policy arms of government (legal precedent, known as the Americans with Disabilities Act, 1990) to catch up and coalesce around the ideals of equal protection and expression for the disabled population (Iezzoni & Freedman, 2008; Social Security Administration Office of Disability Programs, 2003). Societal recognition for those with disabilities has progressed, just as policies that support better access have become legally and socially entrenched (Oliver, 1996).

Access to primary health care improved during the 1960s and 1970s, has given rise to reduced morbidity and mortality rates (Starfield, Shi, & Macinko, 2005). However about this time, specialization within the most medical fields also began to emerge (Starfield et al., 2005). Over time, several medical subspecialties began to crop up in what are now referred to as family practice, internal medicine and pediatrics

(Starfield et al., 2005). The specialist provider model now operates alongside the primary care one (Cooper, Getzen, McKee, & Laud, 2002; Starfield et al., 2005). In the late 1970s, efforts by the IOM to stem the proliferation of the medical specialist model were unsuccessful as the precedent toward a higher level of specialization was well-entrenched in medical training and healthcare (Institute of Medicine, 1969; Starfield et al., 2005).

If we consider for a moment the deeply rooted medical specialty care system, and the goals of HCT; we see a fundamental mismatch emerge as specialists have little to no stake in the goals HCT (Bloom et al., 2012; Donaldson, Yordy, Lohr, & Vanselow, 1978; Starfield, 1978; Starfield et al., 2005). Indeed, the number of primary care providers is not expected to expand in the future, thus the development of coordination models in primary care is likely to remain stagnant (Stein, Perrin, & Iezzoni, 2010). In two recent studies, patients, providers, and parents all differed on the goals and expectations of an HCT process, which has been shown to contribute to uncertainty and hamper transition progress (Sawicki, Kelemen, & Weitzman, 2014). Evidence also shows that providers are unfamiliar with HCT process, and are unlikely (in a routine well-child visit) to discuss HCT support or address unmet transition needs (Szalda et al., 2015). Aside from provider uncertainty, further ethical concerns emerge among patients and their families who might lack the self-advocacy skills needed to successfully obtain (much less coordinate) care between multiple providers (Raina, Wang, & Krishnappa, 2017; Raina, Wang, Krishnappa, & Ferris, 2018). Disappointedly, medical home models have not adequately fulfilled the void in transitional healthcare despite the family-centered care setting (Lemly et al., 2013). Historically, provider-patient trust has been shown to be an influential factor in the HCT timing and quality care (Fegran, Hall, Uhrenfeldt, Aagaard,

& Ludvigsen, 2014). Evidence suggests that providers and patients experience a similar sense of reluctance and loss leading up to a HCT (Cheak-Zamora & Teti, 2014). In a national sample of physicians, only 55% were willing to accept new young adults with SHCN as into their primary care practices which has contributed to access barriers in this population (McLaughlin et al., 2014). While patients often feel abandoned in the process, increased collaboration between pediatric and adult care systems has been shown to decrease gaps and ease patient transfers (Bridgett, Abrahamson, & Ho, 2015; Fishman et al., 2014; Garvey et al., 2014).

HCT Implications and Federal Policy

One of the more prominent factors used to bolster an HCT health policy agenda are disturbingly poor health trends observed in young adults in their prime years (Irwin, 2010). In general, the 18 to 24 year old young adult of United States population (both typical and those considered in the AEA-SHCN population) share more disease burden than both their younger or older counterparts (Bloom et al., 2012; Davis et al., 2014; Perrin et al., 2007). While health experts agree that policies which classify the AEA-SHCN population as *underserved* might improve healthcare access, healthcare reform efforts at the national level have received little traction (Krahn et al., 2015). The AEA-SHCN population is considered vulnerable to poor health outcomes, healthcare disparities, and further disabilities, and yet a health policy agenda that earmarks resources explicitly for this group has not yet been approached (Krahn et al.). System barriers such as reduced funding streams, insufficiently trained providers, and age eligibility criteria are known to interfere with access to primary care (Stroud, Walker, Davis, & Irwin, 2015). These barriers, not only impact active youth engagement, for example, the inadequate provision of healthcare privacy, but also expose a healthcare infrastructure that is not adequately preparing the AEA-SHCN patient population for their adult self-care role; a fundamental tenet of most HCT programs (McKee, Rubin, Campos, & O'Sullivan, 2011). In the post-transition phase, for example, it is well established that late entry into adult care has shown to deteriorate health outcomes, especially among those with progressive or congenital disorders diabetes, heart defects, and the more recently recognized youth with gender dysphoria (Abramowitz, 2018; Kovacs & McCrindle, 2014; Little, Odiaga, & Minutti, 2016; Zhou et al., 2016). While the underpinnings of these negative health trends are likely to be multifactorial and inherently complex, poor retention of healthcare coverage or underinsurance has repeatedly emerged as a critical factor in the post-transition (Oswald et al., 2013).

While researchers suggest HCT structured approaches and programs are needed, healthcare coverage is a reliable indicator of future care access (Oswald et al., 2013; Wiemann et al., 2015). It is estimated that the AEA-SHCN population without coverage (or who are underinsured) are more likely to have unmet HCT and lack access to high-quality care (Oswald et al., 2013). Forty-one percent of the 14 million AEA-SHCN population lack sufficient health coverage to access high-quality and appropriate care, a factor that persists throughout adulthood (Preskitt, McEldowney, Mulvihill, Wingate, & Menachemi, 2013). In a 10 year longitudinal study, researchers found that in this population just over half-million *adult* patients with SHCN continued to seek care from a pediatrician (Fortuna et al., 2012). Evidence indicates that factors such as poorly established access with appropriate providers who accept young adults (18 to 25 years old) and health insurance instability are common barriers in this population (Callahan &

Cooper, 2005; Fortuna, Robbins, & Halterman, 2009; Irwin, 2010; Park & Irwin, 2008). Not surprising, the complete loss of healthcare coverage will often disrupt access and care continuity (Dwyer-Matzky et al., 2017). Regrettably, a mere 15% of youth (13 to 17 years old) had ever anticipated the need to discuss adult coverage with their providers (Lotstein et al., 2010). In the older cohort group (19–23 years old), a loss of primary healthcare access was associated with overall health status declines and a leading factor in unmet specialty and mental health services (Ngui & Flores, 2007; Okumura et al., 2013).

The Patient Protection and the Health Care Affordability Act, or otherwise known as the Affordable Care Act extends healthcare coverage to young adults (up to age 26) under the dependent law provision (Act, 2010). Although still controversial, recent evidence suggests that improvements in healthcare access and coverage have been observed in the young adult population with SHCN (Centers for Medicare and Medicaid Services, 2013; Chan, Gindling, & Miller, 2018). Under the entitlement expansion statute, political support continues to diminish that calls on states and municipalities to modify their healthcare coverage expansion plans to include this key provision (Collins et al., 2013). Medicaid, a joint federal and state public-funded program has historically covered the largest segment of low-income children and youth with and without SHCN (Collins et al., 2013). Sadly, in states that opt-out of entitlement expansion programs (i.e., Medicaid), (under ACA) the risk that disadvantaged youth will lose access increases (Collins et al., 2013). Despite federal legislative efforts (like ACA) to lower healthcare costs and disease burden (especially for young adults), this cohort's financial status has shown to be directly linked to their medical decision-making (Collins et al., 2013). Still, it deserves mention that healthcare access does not necessarily translate into better health for the young population (Perrin et al., 2016). Indeed, health and social policies (i.e., social determinants of health) that address impoverished conditions within the communities and families they serve can further influence health status among adolescents into young adulthood (Perrin et al., 2016). Interestingly, the Healthy People 2020 Objectives, (widely considered the nation's leading health policy/agenda), currently supports the development of specific HCT objectives for all transitional-age youth (Kraus de Camargo, 2011; United States Department of Health and Human Services, 2014). Despite more HCT awareness and support, however, measurable outcomes and clinical modalities are limited and mostly still in an exploratory phase (Cardell, Clark, & Pett, 2015; Pierce & Wysocki, 2015; Stewart et al., 2017; Zhou et al., 2016). .

The Accountable Care Organizations or ACOs (a relatively new policy structure authorized under the Affordable Care Act) (Public Law 111-148) requires the Centers for Medicare and Medicaid (CMS, a federal agency that administers health care entitlement programs) to establish Shared Savings Programs for Medicare recipients and a demonstration project for the pediatric population (Library of Congress, 2010). With the resurgence of healthcare cost containment (i.e., appropriate care utilization) and enhanced access to care standards, stakeholder interest in HCT interventions has remained intact, despite the political volatility of healthcare legislation (Bartels, Gill, & Naslund, 2015). Essentially, ACOs are provider-led healthcare groups that contract with private or public payers to deliver cost-effective and high-quality healthcare to a well-defined patient population (primarily Medicare beneficiaries; Chesney & Lindeke, 2012). ACO healthcare groups administer care to meet the comprehensive care needs of high-risk adults (Medicare-eligible patients). However, cost-cutting measures, (for example, limitations in provider networks and treatment options for AEA-SHCN populations) has many policy advocates concerned about access and capacity for health equity (Chesney & Lindeke, 2012). Still, recent evidence suggests that more structured policy approaches for curtailing the growth of healthcare costs is a viable alternative in the provision of quality pediatric care (Kelleher et al., 2015). Other policy initiatives like Care Transitions Intervention (CTI) is a cost containment initiative designed to address readmission rates after hospital discharge, a particularly vexing problem among Medicare recipients can also deliver quality access for younger cohorts (Basso Lipani, Holster, & Bussey, 2015). Similar CTI, the AEA-SHCN population should catalyze support for HCT policy approaches that address a lack of HCT services with the purpose of tracking youth after pediatrics and reducing prolonged gaps in care or poor healthcare utilization (i.e., emergency room use; Naylor & Berlinger, 2016).

It is becoming increasingly clear that adolescents and young adults who have not established adult care prior to reaching the age of majority could experience an abrupt loss in pediatric provider access with a substantial likelihood of an urgent care need before or during the transitional period (Lotstein et al., 2013; Nakhla et al., 2009). As healthcare continues to grow more complex, HCT policies and initiatives that are specific and practical and can demonstrate value-added benefit might increase growth in HCT services for AEA-SHCN population (Sharma, O'Hare, et al., 2014). Practical approaches, for example the coordination of care before and during a HCT is gaining support among pediatric specialty providers (Sandler & Garvey, 2019). And with the advent of simultaneous billing policies, providers (both in pediatric and adult provider clinics) could enhance value-based care and help pave the way for improvements in the integration of HCT services across the healthcare continuum (Sharma, O'Hare, et al., 2014).

Still, potential policy approaches also introduce the delivery of HCT services as a complex system; an interconnected network that integrates *both* pediatric and adult care systems together (Geary & Schumacher, 2012; Hamdani, Jetha, & Norman, 2011). Using this paradigm shift, clinical administrators, healthcare practitioners, and health policy analysts could identify factors within the system that influence outcomes (both predictable and unpredictable) as well as identify health system barriers at the time of care (for example, identify an adult provider before transfer and assess if future health coverage will present access obstacles; Hamdani et al., 2011). Moreover, strategies that move away from arbitrary age-cutoffs (which unduly burden disadvantaged patients with the fewest healthcare options) could improve access and healthcare equity as well as help pave the way for policy change (Lotstein et al., 2010; Sosnowy, Silverman, & Shattuck, 2017). A growing consensus of physicians have proposed the removal of age restrictions entirely and instead suggest that patients should remain with their sub-specialty provider throughout young adulthood (Schor, 2015). Admittedly, close collaboration with primary adult providers is a key provision of this proposal. Regardless, there is a pressing need to identify system factors that impact the availability, delivery, and utilization of HCT services, a particularly relevant issue in designing HCT program interventions (Hamdani et al., 2011; Kichler & Pierce, 2019; Wells & Manning, 2017).

Another example of using existing policy structures to advance transitional care is the use of electronic health records (EHR) in the implementation of meaningful use (MU) policy (Sharma, O'Hare, et al., 2014). While implementation of MU policy is a more significant component of an ongoing national pediatric restructuring effort, patient portal systems (required for MU) introduces patients and families to an online healthcare record (Turchi et al., 2014; Wang, McGrath, & Watts, 2010). In a large teaching hospital, for example, a facility-wide process improvement initiative was conducted to implement MU policy that included upgrading and standardizing EHR visit discharge care summaries to include HCT plans (Lee et al., 2017). Although HCT planning was not a primary goal, researchers noted that using visit summaries to engage patients and encourage collaboration amongst providers, parents and patients increased HCT awareness (Lee et al., 2017). It has become apparent that the provision of HCT services nestled within an existing care coordination policy might increase HCT awareness and thus, promote the provision of HCT services (Ciccarelli et al., 2014; Turchi et al., 2009). Admittedly, while gaps in the delivery of HCT care are widespread, policies that leverage collaboration, identify revenue streams, and support HCT awareness throughout the clinical pathway of care are vital to the long-term survivability (Hepburn et al., 2015; Sharma, O'Hare, et al., 2014).

Overview of HCT Models

On a practical level, the overall benefit of a well-organized HCT program seems intuitive. Patients and their families often appreciate (and are surprisingly satisfied) when they receive HCT services (Harhuis, Cobussen-Boekhorst, Feitz, & Kortmann, 2018). Unfortunately, patients and their families often do not fully grasp the role of HCT services, or their responsibility in the process (Kuhlthau et al., 2016). While the primary purpose of HCT planning is to prepare and ultimately transfer patients and families to appropriate level care, empirical evidence supporting one program or approach over another remains inconclusive (Betz, O'Kane, Nehring, & Lobo, 2016; Lotstein et al., 2010; Lotstein, McPherson, Strickland, & Newacheck, 2005).

Complex care needs (characterized as those with multiple impairments in daily living, neurological disorders, and technology dependent) represent just a small percentage of the AEA-SHCN population (Cohen et al., 2011). However, their care coordination needs (particularly as they reach adulthood) are intense with correspondingly high healthcare utilization rates (Cohen et al., 2011). Unfortunately, even within this high-risk group prolonged disruptions in care are common which significantly impacts the risk for morbidity mortality concern (Lotstein et al., 2013). Therefore, HCT support is crucial for this high-risk group (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians Transitions Clinical Report Authoring Group, 2011; Wells & Manning, 2017). In one of the few interdisciplinary research models studied in this population, researchers determined that HCT population needs exceeded that of both the pediatrician and adult primary care physician (Ciccarelli, Gladstone, & Armstrong Richardson, 2015). Researchers further demonstrated that a specialized team of providers with training in transition support was needed to successfully transfer patients and their families into the appropriate care level (Ciccarelli et al., 2015). Most recently, in a HCT consult model, results suggest that an interdisciplinary team of providers can assist with coordination of healthcare needs based on patients with the highest complexity of care (intellectual developmental delays, technology dependent, insurance/Medicaid and guardianship process; Razon et al., 2019).

A collaborative care approach, or what is known as an intergenerational framework, also integrates the HCT services gradually throughout pediatrics and adult healthcare (Kingsnorth et al., 2011). In an evaluation study of this approach, success largely depended on organizational compatibility (pediatric and adult care systems) and supportive HCT infrastructure needed to facilitate program activities (Kingsnorth et al., 2011). Researchers identified several incongruent HCT policies and practices as significant barriers to program development and sustainment (Kingsnorth et al., 2011). In a retrospective study, although HCT program participants were generally satisfied with HCT services, it did not translate into improved understanding of their illness or medication regimens (Margolis et al., 2017). However, in Mackie et al. (2018) a nurse-led HCT program demonstrated that HCT support can enhance patient self-care but also reduces excess time between appointments (i.e., increase in patient's capacity to navigate the healthcare system; Mackie et al., 2018). Similarly, in an embedded HCT transition specialist model, it was shown that transition services offered (at the time of primary appointment) improved patient outcomes and increased the availability of resources for program sustainment (Betz, Smith, et al., 2015). Researchers concluded that HCT support services nestled within an outpatient primary or specialty clinic visit is a viable strategy to engage patients and generate resources for program stability (Betz, Smith, et al., 2015).

Finally, Six Core Elements, developed by the federal Maternal and Child Health Bureau (MCHB), is an HCT evidenced-based process improvement program that describes transition steps for patients and providers alike (McManus, White, Pirtle, et al., 2015). As a result of this collaborative project (among both federal and state stakeholders) a comprehensive online transition resource center was created to inform practice guidelines for physicians, administrators, and clinicians to socialize throughout the organization (GotTransition.org, 2014). In a cross-sectional design, participants, (youth aged 12 years and up) family members, and providers were all largely unfamiliar with the HCT steps and unable to identify transition needs (Davidson et al., 2015). It is widely known that program implementation and evaluation efforts vary considerably (Wells & Manning, 2017). In another study for example, it was revealed that the initial implementation of HCT steps were successful but many providers were still unable to transfer their patients to adult care clinics based on healthcare system factors, most notably, insufficient level of adult providers (McManus, White, Barbour, et al., 2015).

After 20 years of expert HCT recommendations and programs, the availability of clinically relevant transition services are not widely available or equitably distributed based on a myriad of social, patient and health system factors (American Academy of Pediatrics et al., 2011; United States Department of Health and Human Services, 2014). Furthermore, identifying patient and system barriers that impact HCT experiences is only the first step. A broadened HCT agenda that considers healthcare access, patient capacity levels, and other SES disadvantages could be influential in the success rate of transfers or the interventions (Feinstein et al., 2017). Unfortunately, not only are transitional needs of disadvantaged populations misunderstood, but awareness of the social factors that influence and intersect in the clinical setting is also poorly recognized (Betz, Lobo, Nehring, & Bui, 2013; Stewart et al., 2017). Thus, in the AEA-SHCN population, a pressing need exists to develop and track meaningful patient HCT measures, and improve the quality of healthcare practices across the healthcare care continuum if we are address HCT disparities (Wells & Manning, 2017).

Conclusion

Despite the availability of easily accessible transition resources, the provision of HCT services is still generally inadequate with considerable variation in program delivery and implementation (Gold et al., 2017). In the clinical setting, the AEA-SHCN population-based transfers are primarily based on chronological age (Farre & McDonagh, 2017). However, abrupt transfers to adult care can be triggered by disease complications that arise in adolescence and young adulthood (Kerr et al., 2017; Stewart, 2013; Stewart et al., 2017). While the efficacy of HCT process is still unclear, poor patient readiness, unplanned transitions, health deteriorations, prolonged gaps, and poor access in care are all far too common (Hays, 2015; Sable et al., 2011). Research into understanding patient-specific HCT experiences, unmet clinical needs, and the impact on post-transitional outcomes are crucial in identifying those most at-risk for poor follow-up and disease trajectory (Mahan, Betz, Okumura, & Ferris, 2017; Zhou et al., 2016).

An IR research methodology was an ideal approach in this synthesis and translation of practice-based solutions (Thomas & Harden, 2008). One of the hallmarks of an IR approach is the potential to integrate and interpret scientific knowledge and evidence into practice-based applications (Pentland et al., 2011). Additionally, utilizing tailored HCT care and services among patients with poor access and other social disadvantages in the setting of system-level barriers is not well understood in healthcare (Chakraborty & Van Dyke, 2013; Chin et al., 2012; Garvey et al., 2014; Stewart et al., 2014). Access to developmentally appropriate care presents challenges for *all* adolescents. However, the data suggest that the AEA-SHCN population has an increased risk for poor continuity of care and prolonged gaps between multiple systems of care (pediatric and adult care; Stewart et al., 2014).

Despite an increase in HCT awareness, health system complexities contribute to difficulties with system navigation that disproportionally impact the AEA-SHCN population (Chakraborty & Van Dyke, 2013; Krahn et al., 2015). In vulnerable populations, addressing HCT disparities is a pressing health policy dilemma (Sharma, O'Hare, et al., 2014). Unfortunately, the delivery of HCT services is met with system and patient-related obstacles that warrant further research attention as the risks for early care termination and delays signal unmet HCT needs (Krahn et al., 2015).

The next chapter serves as a blueprint for conducting this IR study. Beginning with an introduction, the next several pages thoroughly describes the IR research design and lists in sequential order the five-step process necessary to conduct this study. Additionally, the following chapter addresses the inclusion and exclusionary criterion, as well as discusses the data analysis procedures. Finally, to protect study fidelity, the procedures for gathering and comparing the findings are reviewed as part of the overall research plan.

Chapter 3: Research Methods

Introduction

The purpose of this study was to identify and synthesize the structural, social, and health system factors that impacted population-based HCT experiences in a health equity framework. Overall, the HCT literature suggests that a lack of structural-level support (i.e., pediatric and adult transition services and congruent policies) impractical approaches, and sparse organizational resources continue to hamper HCT improvements for many vulnerable youth populations (Anderson et al., 2018; Annunziato et al., 2013; Brenner et al., 2018; Chakraborty & Van Dyke, 2013; Gabriel et al., 2017). The multi-level healthcare system complexity not only highlights the patient access burdens (especially after age 18) but also undermines patient trust (Cheak-Zamora & Teti, 2014; Uzark & Wray, 2018). Moreover, patients with increasing levels of social disadvantage (lower SES level) often do not receive transition support and therefore have a far greater risk of being lost to follow up or otherwise might experience prolonged gaps in care (Gray et al., 2017; Machado, Galano, de Menezes Succi, Vieira, & Turato, 2016).

This brief introduction not only emphasizes the problem of poor continuity of care but also illuminates the urgent need for an increased level of structure in HCT programming while compelling organizational policies to target vulnerable patients (Aldiss et al., 2015; Okumura, 2018). To undergo the IR process, I first reviewed the study’s purpose, problem, design, and the role of the researcher. Secondly, I researched strategies that could potentially reduce bias. Thirdly, I described the five-stage IR methodology and the conceptual foundation that distinguished this design from other systematic reviews. Finally, I described the procedural steps needed to execute this study and recognized ways that I enhanced study credibility.

Until recently, the link between patient experiences and clinical outcomes was largely overlooked (Betz et al., 2013). Presently, healthcare priorities dictate that robust patient-centered approaches are available to comprehensively target transitional needs of patients with SHCN (United States Department of Health and Human Services, 2014). While HCT researchers agree that multiple barriers do interact simultaneously to impact HCT care, the exact mechanisms and health implications largely go unrecognized (Davis et al., 2014). Given the poor preparedness, health policy advocates remained concerned that a chronological age policy does not promote health equity especially for vulnerable groups (Chu et al., 2015; Stewart, 2013). Nonetheless, the demand for improved HCT processes has spurred on more public policy interests into understanding the nature of the poor patient experiences and the precipitating factors that might signal them (Betz et al., 2013; Betz et al., 2016).

Research Design and Rationale

The primary research question was: How could an examination of the HCT experiences in the AEA-SHCN population improve our understanding of the structural, patient, and health system-led factors from a health equity perspective? Evidence suggests that mitigating access barriers while also preventing patients from being lost to follow-up are two effective practices in HCT programming (Kuo, Crapnell, Lau, Anderson, & Shattuck, 2018; McManus et al., 2013). Using an IR to examine the role of HCT in improving healthcare access was a complicated undertaking; however, there is a pressing need to evaluate how patients with more complex care needs experience the process over time (Lemke, Kappel, McCarter, D’Angelo, & Tuchman, 2018). Aside from the design’s utility and flexibility, the synthesis and translation of study findings are both crucial for deciphering the HCT evidence and seeking clarity on clinical practice HCT recommendations (Torraco, 2016). Essentially, IR designs are practical but also specific to address real-world problems (Holly & Anef, 2013). Additionally, the IR methodologies are used to understand complex phenomena, to identify new research directions, and to inform public policy (Thomas & Harden, 2008). IR designs often yield new interpretations and uncover potentially new research directions (as was the case for this IR study; Torraco, 2016). Finally, unlike most systematic reviews, the IR investigative process is conducive to one reviewer based upon a well-defined purpose and specific need for evidence-based practices, and novel recommendations (Holly & Anef, 2013).

A purpose-driven search strategy focuses on the most relevant evidence and generally not exhaustive (Patton, 1999). This IR study utilized purposeful sampling based on the need to pinpoint the most relevant articles found in the HCT literature. Likewise, the data analysis plan was specific, but one that required primary source evidence whenever possible. According to Whittenmore and Knalf (2005) the outcome of the analysis phase is to generate comprehensive, informative, and meaningful data interpretation that can be integrated into an overall synthesis. To uphold integrity with the IR process, I utilized the data analysis method set forth in the IR approach. However, during this phase, I also generated a comparative dataset using a thematic synthesis (Thomas & Harden, 2008). Using an additional procedure not only supported the verification process, but also bolstered study credibility (Britten et al., 2002). A thematic analysis, (much like qualitative content analysis) consists of an inductive analysis of emerging conceptual data that best describes the phenomenon (Fereday & Muir-Cochrane, 2006). However, this reflexive process also provides an opportunity to reassess study content and the overarching categories from the IR process, a crucial step in bolstering study credibility (Fereday & Muir-Cochrane, 2006). Therefore, the second step is to look for commonalities and overlapping themes in preparation for the third step (Britten et al., 2002; Thomas & Harden, 2008). In the final steps, only translational concepts remain; which are the interpretations of the summative themes (Britten et al., 2002; Dixon-Woods et al., 2006; Thomas & Harden, 2008).

In this study, I chose an IR design based on methodological versatility to accommodate mixed designs and theories into one comprehensive review. Systematic approaches are helpful for incorporating several methodologies into one comprehensive review (Torraco, 2016). This aspect is crucial in fields where there are specific knowledge gaps between theory and practice, or, in relatively new areas, such as HCT discipline (Torraco, 2005). Aside from these well-known attributes, HCT policy and research analysts are becomingly increasingly concerned that poor healthcare equity among disadvantaged populations with SHCN is an independent risk factor in poor quality care (Krahn et al., 2015). The third advantage of the IR methodology is to shed light on little-known aspects of research problems with a specific goal toward alternative interpretations (Torraco, 2016). The IT paradigm not only aligns with the IR process but also describes the overlapping conceptual space between poor health equity and differential access (Bauer, 2014; Cheak-Zamora et al., 2013). The IR methodology is unique within the systematic review approaches as it can conceptualize complex data around a guiding theory and synthesize as one analysis (Torraco, 2005).

HCT research lacks an empirical, practical and evidenced-based approach for integrating HCT services into a clinical setting (Campbell et al., 2016). Likewise, widespread challenges exist for not only tracking HCT patients after leaving pediatrics, but also for developing outcomes measures, and gathering comparison data for adequate evaluation efforts (Wells & Manning, 2017). An IR is an appropriate choice when researching and collecting best practices for making decisions, and for exploring persistent knowledge gaps within an health equity-based model (Torraco, 2005). A theoretical link between HCT experiences and the population health equity is still poorly understood (Srinivasan & Williams, 2014).

The knowledge gained could potentially provide further insight into the role of poor healthcare equity during a pivotal time (Krahn et al., 2015). Early exposure to health risks and complications tends to prematurely erode health and longevity (Krahn et al., 2015; Prokup et al., 2017; Siminski, 2003). The World Health Organization (WHO) initiative into life-course perspectives purports that more global approaches are needed to fully describe how impairments/disabilities in physical and mental health disorders accumulate throughout life, and in turn, influences individual efforts at societal engagement or self-improvement (World Health Organization, 2001).

Researcher Role

My role was that of a participant-observer; knowledge was derived from my overall familiarity with the phenomenon and personal connection to the topic. My background impacted not only my methodological decisions but also the lens with which

I reviewed and analyzed the data. Given this dilemma, transparency was an essential element which required adequate attention with both the decision-making process as well as determining the significance of any preliminary findings (Bearman & Dawson, 2013).

My role was to conduct a comprehensive search for HCT research that explored HCT experiences, access, and outcomes. Like most research endeavors, being transparent plays a crucial role for documenting study procedures, collecting data, and interpreting study findings (Russell, 2005). Another important component of my role was to reflect on my own experiences and to acknowledge any preconceptions and potential biases that I might have with this research topic. Qualitative study fidelity through the bracketing process and the creation of researcher memos throughout the review was vital in building research quality, dependability, and ethical reporting (Creswell, 2012). I met this requirement by documenting my observations, experiences and overall impressions of emerging themes within the NVivo program. While using a wide variety of scholarly resources is consistent with high quality systematic reviews; however, to judiciously and accurately synthesize, and contribute to the literature often requires researchers to embrace their role in the research process (Xu & Storr, 2012). With both a personal connection and healthy respect for the IR field, my due diligence to the research process was my utmost concern. Overall, the IR methodology is quickly becoming a preferred method for researching fields still in an exploratory phase or in the clinical setting to increase the likelihood of ethical decision-making (Betz et al., 2016; Whittemore & Knafl, 2005).

Potential Researcher Biases

Like most of the HCT data suggests, it was (and still is) difficult to establish and locate appropriate healthcare providers experienced in the care of special needs' children (English, Park, Shafer, Kreipe, & D'Angelo, 2009). As a healthcare provider, I benefitted from a general healthcare background which provided a general foundation for navigating the health system (during and post-transition). However, I too encountered confusion, significant delays, and disruptions based on many insurance coverage limitations and choices in providers. Ultimately though, it was the health insurance stipulations that determined many of the healthcare options and access to care.

Sadly, I experienced the entire gamut of poor healthcare experiences both with the HCT process and limitations in access. It appears the complexity of the HCT process is primarily underestimated and therefore vulnerable to abrupt access changes, which leaves individuals and families vulnerable to gaps and ultimately responsible for obtaining the appropriate healthcare access (Ersig, Tsalikian, Coffey, & Williams, 2016). This review, (although relevant to me personally) requires that I acknowledge these healthcare experiences, both to inform readers of my potential prejudices, and to enhance dependability in the final report. Through ethical reporting practices, anticipating researcher-based biases increases both a researcher's creditability and confidence among the readers in study findings (Bearman & Dawson, 2013). According to Creswell, without these acknowledgments, readers are left with more questions than answers; which adds room for partiality that can cloud results, favor certain conclusions, and further skew research findings (Creswell, 2012). My motivation to tackle this topic was spurred on by my curiosity and personal connection to this topic. However, this connection necessitates full disclosure of my background and acknowledgement of my partiality.

Methodology

The primary question that drove this IR study was to examine the HCT experiences among the AEA-SHCN population to improve understanding of the structural, patient, and health system-led factors from a health equity perspective. Rival, novel and alternative interpretations could potentially facilitate a deeper understanding of patient experiences and the complex factors that have surrounded them for decades (DiFazio et al., 2014; Prokup et al., 2017; Toomey, Chien, Elliott, Ratner, & Schuster, 2013). The IR approach is flexible enough to accommodate different designs, and yet, highly specific to tease out complex factors that interact with the phenomena of interest (Whittemore & Knafl, 2005).

The IR methodology, which was initially developed by Cooper (1982) and later updated by Whittemore and Knafl (2005) has been has been useful in seeking practice-based solutions in both classical and emerging fields (Cooper, 1982; Tkachenko et al., 2017; Whittemore & Knafl, 2005). One obvious advantage for the IR approach is the capability of using a vast array of empirical evidence with different methods to address specific questions (Hopia et al., 2016). This feature not only improves the rigor but also tackles some elements of bias due to the consideration or anticipation of rival interpretations (Cooper, 1982; Whittemore & Knafl, 2005). Additionally, IR studies generally extract crucial information to bolster a specific purpose from a broad array of evidence (Torraco, 2005). Like many systematic reviews, the IR methodology follows a logical and transparent process for collecting, screening, and analyzing data, however, the most critical stage is first defining the problem (Cooper, 1982; Whittemore & Knafl, 2005). The IR process has five distinct stages: identify the problem, literature search, data evaluation, data analysis, and present conclusions or findings. However, within each of these phases, there are several critical decision points that require the researcher to fully explore and describe using the qualitative memo format. Based on advantages and characteristics of this methodology.

Phase I: Problem Identification

This phase involved both the identification of the problem and a fully described search strategy (Whittemore & Knafl, 2005). The bulk of HCT research suggests that vulnerable populations of youth with SHCN are not receiving HCT services and face difficulty with appropriate healthcare access at transitional age (Lebrun-Harris et al., 2018). Factors that provide more granularity to these HCT experiences have not been adequately described nor has this area been viewed through a health equity lens (Jolles, Lee, & Javier, 2018). Admittedly, the study of HCT is a broad area, however, using patient experiences to inform how structural and patient-led barriers influence healthcare access and equity is a novel approach, one not previously explored (Racine et al., 2014). More specifically, incorporating an IT framework involves understanding how structural, social, and health system barriers influence patient access and HCT experiences. According to Cooper (1982), the original framer of the IR approach, the inclusion of both an operational and theoretical problem enhances validity (Cooper, 1982).

In the early stages, it was crucial for me to conduct a thorough search in a variety of scholarly journals. The databases that I routinely visited were as follows: Google Scholar, PubMed, Cumulative Index of Nursing and Allied Health Literature (CINHAL), MEDLINE, Political Science Complete, and ProQuest. In general, I included sources between years 2012 to 2018. This 6-year span in the HCT research literature depicted the early challenges of access to care in the AEA-SHCN population (Cooley et al., 2011; Garvey et al., 2012).

Phase II: Literature Search

To fulfill the purpose of this phase, I conducted a thorough literature search based on several key terms and criteria. Overall, I generated a robust list of articles based on the following key: *Healthcare transition* AND *youth with special healthcare needs, disabilities and complex medical care (CMC)*. The ancestry method proved particularly useful strategy for systematically reviewing and tracing original theoretical works found in primary sources (Cooper, 1982). In IR approaches, it is critical that researchers include theory origins, especially since this methodology examined both practical and theoretical problems from different perspectives (Russell, 2005). Additionally, only peer-reviewed and empirically-based studies were extracted to ensure original results were analyzed within the following areas of concern; patient HCT experiences, perceptions, and overall impressions of HCT care. Articles addressed HCT care experiences, perspectives or outcomes among patients with SHCN between the ages of 12 to 26 years of age. Additionally, only studies originating in the United States (US) were considered for inclusion. As per the IR method, quantitative, qualitative or mixed methods studies were considered for inclusion and generally added to the overall strength of study (Hopia et al., 2016).

The Preferred for Reporting Systematic Analysis (PRISMA) flowchart was used to visually display the research selection process (Liberati et al., 2009; Moher, Liberati, Tetzlaff, Altman, & Group). This is known as the PRISMA flowchart (see Figure 2).

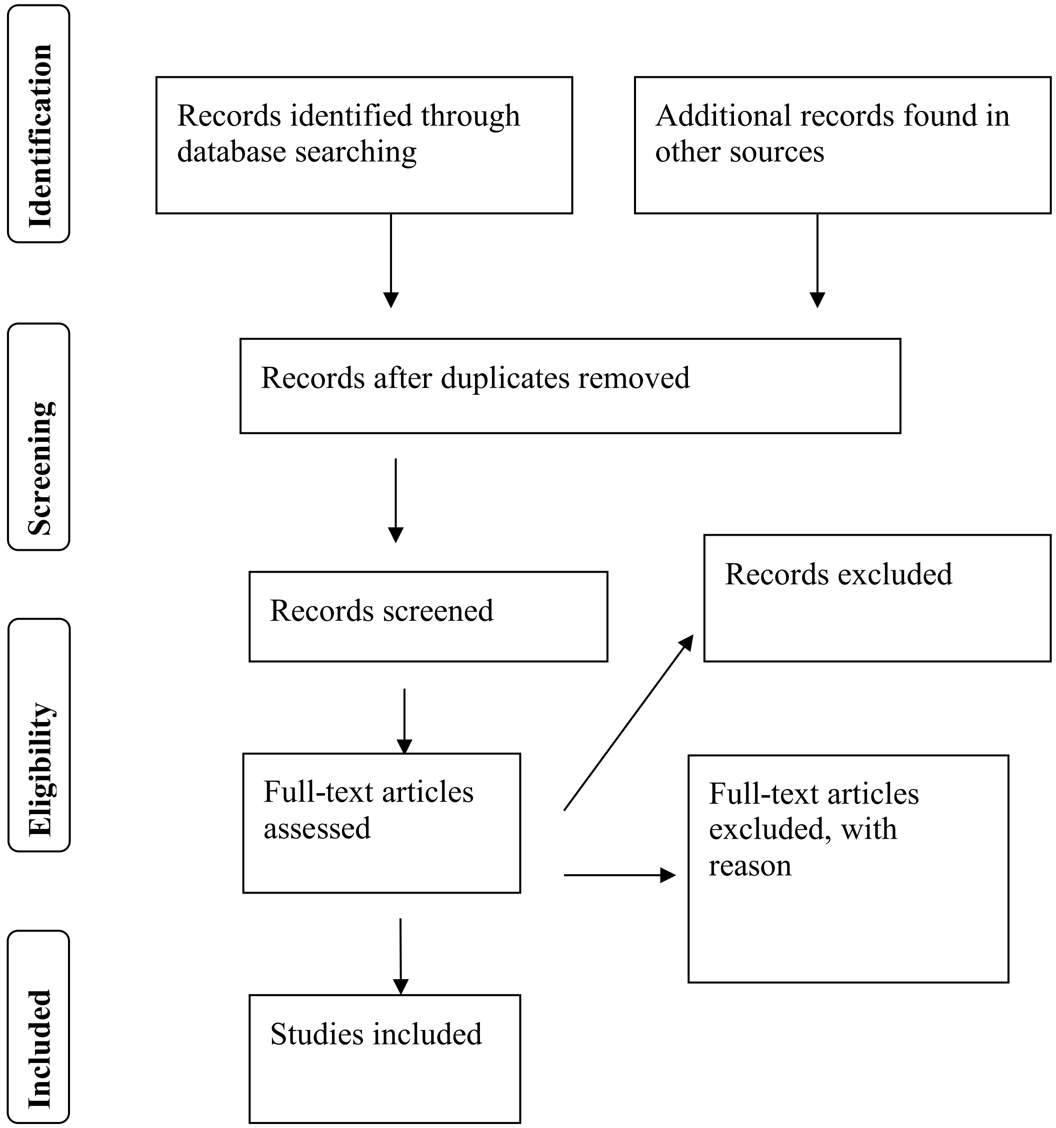

Figure 1. PRISMA flow diagram

Purposive Sampling Rationale

In an IR approach, purposeful sampling is a popular research strategy that can capture a diverse array of articles for a comprehensive understanding of the topic (Hannes, Booth, Harris, & Noyes, 2013). To this end, relevant articles were selected based on a carefully developed search strategy, one that is central to phenomena (see Appendix A for complete list of selected sources; Maxwell, 2013; Palys, 2008). In this case, the sampling strategy is not necessarily considered exhaustive; rather, it reveals a conceptual saturation; an iterative search process that extracts a range of articles that each contribute to a comprehensive interpretation of the problem (Thomas & Harden, 2008). To this end, timely empirical data that is central to understanding HCT patient experiences, perceptions or interpretations were included. Conversely, expert opinions and healthcare policy or position statements from pediatric and adolescents organizations (i.e., American Academy of Pediatrics) were excluded from analyses based on their non-empirical nature (Whittemore & Knafl, 2005). Table 1 (found below) contains the inclusion and exclusion criteria. Appendix D contains a complete list of excluded sources.

Table 1

Table of Inclusion and Exclusion Criteria

Inclusion	Exclusion
Peer-reviewed journals	Hospital patients or youth in foster care
Transitioning Youth/Children	*Typical* Adolescents/Children
Discuss HCT Experiences, Perceptions or outcomes in Combinations of Youth, Providers and Parents	Literature Reviews/Gray literature or Editorials and Non-HCT Experiences, studies
Target population (14-26 years of age)	Provider or Caretaker only (without youth)
English Language	

Setting Rationale

The literature search phase also identifies the setting/jurisdiction parameters. The following description provides multiple examples of healthcare settings that are considered beyond the scope of this review. Healthcare access involves not only family, or individual resource allocation but also sociodemographic characteristics or conditions that determine the extent of self-expression and opportunities for self-improvement (Zajac, Sheidow, & Davis, 2015). In this case, articles examining the AEA-SHCN population who are also considered justice-involved or in foster care were excluded. This IR study also excluded studies that examined inpatient and outpatient transfers, or other healthcare facilities as they were considered beyond the scope of this review. Many of these settings included; behavioral healthcare units, inpatient settings, hospitalized/hospice care, and long-term care facilities.

Phase III: Data Evaluation

The data evaluation was a critical phase in the appraisal process. In this step, I determined quality ratings based on an appraisal tool (MMAT) designed to accommodate multiple data sources (Whittemore & Knafl, 2005). The Mixed Methods Appraisal Tool (MMAT, version 2018) (see Appendix B) was used to determine the quality of multiple designs based on an overall score (Pluye & Hong, 2014). The MMAT tool was developed at McGill University, Center for Participatory Research in Canada to overcome the potential problems associated with comparing and evaluating multiple research designs or reviews (Pace et al., 2012). The purpose of this tool is to allow researchers to appraise all of the selected articles using one standardized form. In developing the MMAT, researchers found that there were five specific study types that emerge most frequently: qualitative, quantitative/randomized controlled, quantitative/non-randomized controlled, observational/descriptive and mixed methods (Pluye & Hong, 2014). Consequently, each has a specific set of probing questions that pertain to the respective study domains (Pace et al., 2012). According to standardized instructions, the first critical stage is to screen the articles based on the two initial questions found on the top of the MMAT. Based on the outcome of the screening process, the appraisal score is then determined by the number of benchmarks found in each study type.

Due to the tool's versality, the MMAT process has become a popular tool for appraising quality among many review types, not just the IR (Pluye & Hong, 2014). The MMAT has been validated against empirical data and undergone expert opinion consensus as per the developer's use provisions. While a customized scoring method is voluntary and based on project needs, the MMAT has been used by researchers to calculate a score based on the number of criteria met, that is a percentage (0%, 25%, 50%, 75%, or 100%; El-Awaisi, Joseph, El Hajj, & Diack, 2017). In each domain, there are five questions which sets the stage for an easy and convenient way to estimate study quality. Articles that scored below 25% could be indicative of low quality. However, framers of the original tool suggest that researcher judgement should prevail on whether sources should be eliminated based on this assessment (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009).

Phase IV: Data Analysis

Once the inclusion and exclusion criteria have been applied, articles were then organized, categorized, and prepared for the coding process (Whittemore & Knafl, 2005). The analysis phase has five contiguous steps: data reduction, consolidation, display, conclusion, and verification (Whittemore & Knafl, 2005). With this systematical process, each step builds upon the one previous to yield several higher-order themes (Whittemore & Knafl, 2005). This was an iterative process that involved constant comparative methods used for gathering themes while integrating them to an interpretative summary (Whittemore & Knafl, 2005). A final step in data analysis is a verification process (discussed later in the chapter). To fulfill this phase and bolster credibility, a thematic synthesis was conducted to accomplish this task.

A thematic synthesis is a methodology that is specific to qualitative systematic reviews whereby data concepts are constructed based on a line-by-line descriptive coding of primary source data (Britten et al., 2002). To facilitate the analysis more efficiently, a computer-assisted qualitative data analysis software (CAQDAS), the NVivo program 12.0, by QSR International was used to code text and consolidate themes (Thomas & Harden, 2008). Generally, the coding process involved three sequential steps: free, descriptive codes and analytical themes (Thomas & Harden, 2008; Thomas et al., 2004).

As passages are coded and folded together, they are reduced and interpreted through the study's theoretical framework (Min, Anderson, & Chen, 2017). The sources included in the analysis were imported into NVivo Program for further evaluation. Conversely, sources not meeting the basic criteria were eliminated along with a rationale (see Appendix C). Text-based searches for HCT factors, experiences, and outcomes was based on the findings/discussion sections found in each article. Once coded passages were identified and reorganized into codes or nodes (parent or child) as per NVivo program (NVivo Qualitative Data Analysis Software, 2014).

In the early coding process, overlapping data/themes emerged and contributed to the development of an analytical and theoretical synthesis (Britten et al., 2002; Thomas & Harden, 2008). However, as per the thematic analysis protocol, analytical themes were retained (Britten et al., 2002; Dixon-Woods et al., 2006; Thomas & Harden, 2008). As previously mentioned, this research analysis phase was facilitated by NVivo for the purpose of organizing the data, creating codes, and interpreting their meaning. However, in data verification, a comparison of overarching themes (generated by an IR synthesis and thematic process) reflect the triangulation strategy (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). In triangulation theory, researchers use multiple theoretical schemes to generate comparative data to estimate convergence and consistency amongst the different processes (Carter et al., 2014; Denzin, 2009).

The Rationale for Selection Criteria

Overall, each of the selection criteria was based on a robust research foundation that is diverse and specific to the population of interest; however, still in need further theory exploration. The selection criterion was based on the underlying study aims; to generate evidence that best informs the meaning of the HCT experiences and factors that influence future healthcare access. With this basic framework in mind, each source that generally described the HCT experiences, outcomes and influential factors was included in the study. Among several sources, poor patient access, limited quality programs, and inadequate receipt of supportive transfer services were among the most common factors in patient readiness (Betz, Smith, et al., 2015; Cohen et al., 2015). Additionally, the criteria used in several of the HCT process improvement studies, interventional, and outcome programs were also considered for inclusion (Bowmer, Sowerby, & Duff, 2018; McManus, White, Pirtle, et al., 2015).

Issues of Trustworthiness

An overarching goal of the IR process was to provide a synthesis of the research problem. Generally, this involved identifying relevant articles, coding data into themes, and developing a synthesis that supports conclusions (Whittemore & Knafl, 2005). Across most fields and disciplines, establishing credibility involves being confident in the research process and thus in the study's conclusions (Korstjens & Moser, 2018). As previously mentioned, triangulation is a popular method for enhancing credibility and integral in this IR's overall verification process (Lincoln & Guba, 1985). To this end, the study results (from the IR and thematic data) are found in the analysis phase. Additionally, researchers suggest that using several methodologies in one IR design can enhance rigor and contribute to the veracity of study conclusions (Miles, Huberman, & Saldana, 2014; Popay, Rogers, & Williams, 1998; Whittemore & Knafl, 2005)

In qualitative research, establishing dependability involves being consistent throughout the research process while documenting meticulous notes to ensure transparency (Korstjens & Moser, 2018). It is commonplace for researchers to document their personal familiarity with the topic and to reflect on those experiences through the use of a common audit trail (Rodgers & Cowles, 1993). To that end, I used the NVivo program to provide not only a foundational platform to document research decisions, but also to reflect on the struggle with adult healthcare access. Finally, the transferability in qualitative research directly relates to generalizability in quantitative inquiries (Korstjens & Moser, 2018; Lincoln & Guba, 1985). As with most other systematic reviews, strict adherence to specific criteria and methodologies establishes the study's credibility (Leung, 2015). This IR's search strategy was based on a particular research aim and thus it is likely too premature to apply these IR study findings across a broad audience. Furthermore, as the youth population grows more diverse, a pressing need exists to not only track their healthcare experiences but also to improve access to quality-based transitional care regardless of different illnesses or health vulnerabilities (United States Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2013). In general, this IR would best support a renewed research agenda, whereby both context and patient experiences are considered within a health equity framework. Besides, the development of HCT policies that target youth with SHCN, and other disadvantages is a timely topic with research implications for many healthcare fields with interest in increasing health equity.

Phase V: Present conclusions

Within the present conclusory phase, the final step was to discuss a synthesis in the context of concerns/limitations, and still contribute to a fresh view of the data. This section involved developing meaningful conclusions based on the underlying meaning of the data but also to generate specific improvements or recommendations for future work (Whittemore & Knafl, 2005).

Relevance to HCT Field

This study was the first to examine a range of relevant themes using the IT framework. This study described many of the system factors encountered by patients in the healthcare setting that influence access and delivery of HCT with a health equity perspective. An IR approach was useful in flushing out evidence that improved overall understanding of the factors that surround the HCT process.

Protections and Ethical Considerations

The institutional review board (IRB) is a committee assembled (typically found in healthcare, or academic institutions) that works independently to protect research participants against harm, and ensures ethical and regulatory requirements are met before researchers carry out proposed research plans or protocols (Grady, 2015). Since this research does not involve human subjects directly (that is, just full-text information found in each of the selected articles) the IRB granted approval for this research under # 11-28-18-0226404 based on minimal risk.

Summary

While access to high quality pediatric care has led to the burgeoning population of young people with SHCN, a seamless transition to adult care still evades most youth regardless of their underlying health status (Garvey et al., 2013; Lebrun-Harris et al., 2018). Pediatric and adult care organizations recommend that access to HCT services begin in the early teenage years and culminate with an adult care transfer into young adulthood (American Academy of Pediatrics et al., 2002). Regrettably, the evidence demonstrates that there is still much room for improvement into not only understanding the extent of unmet HCT needs in the AEA-SHCN population but also in developing structured programs that facilitate communication and collaboration across each system of care (Chu et al., 2015). While researchers continue to examine the constellation of factors involved in individual HCT readiness, there is still a paucity of evidence in determining what constitutes a successful long term transfer to adult care (Burke et al., 2018; Rachas et al., 2016). In the short term, the social and contextual factors play an integral role in patient healthcare retention and disease outcomes (Hilliard, Harris, & Weissberg-Benchell, 2012; Zhong et al., 2018).

In short, the HCT process is complex with several interconnected components requiring a flexible, yet, specific research methodology by which to examine the apparent disconnect between HCT theory and application. Fortunately, the IR process is uniquely suited to investigate clinical practice gaps and to find real-world solutions for several of these unanswered dilemmas (Holly & Anef, 2013). The IR approach has been useful across many professions and disciplines where a deeper look into the surrounding controversies have stimulated future research directions (Torraco, 2016). The next chapter provides the bulk of the analyses and helped pave the way for a comprehensive discussion of this study's conclusions in the final chapter.

Chapter 4: Results

Introduction

In the IR approach, the process of isolating study themes was one of the first and most crucial steps toward crafting a well-constructed synthesis. Therefore, the purpose of this study was to identify and synthesize the structural, social, and health system factors that impacted population-based HCT experiences using a health equity framework. In doing so, I gained a deeper appreciation of the population by identifying factors that influenced HCT patient outcomes. However, to describe my overall interpretation and research inquiry, I first needed to fully declare the underlying research question and the study's parameters.

The fundamental question was to explore how the study of HCT experiences in the AEA-SHCN population could elicit a deeper understanding of the structural, patient, and system-led barriers using a health equity lens. Given the need to approach this topic in a stepwise manner, I first sought to identify the sources of evidence that emerged from the search process, and then I delved into the analysis. Secondly, I addressed the issue of data trustworthiness by using an integrated display of patterns outlined in the IR process. Thirdly, I conducted a thematic synthesis to generate a comparative dataset by which to evaluate trustworthiness from the IR. Moreover, finally, by using an IT contextual framework, I incorporated the most relevant population and conceptual themes into a single comprehensive synthesis.

Setting and Demographics

For this study, I reviewed previously published literature on the adolescent and emerging adult population (ages 12 to 26 years of age) with SHCN. In studies where researchers examined the impact of HCT services in patient experiences, outcomes, and future adult care access were of particular interest. Additionally, I focused on interventional and case studies that investigated the HCT experiences and healthcare disparities of pediatric patients and their caregivers. Overall, 50 studies met the inclusion criteria. However, several studies were either retrospective designs (reported on the HCT experiences or outcomes after patients had left pediatrics) or were cross-sectional with insufficient sample descriptions or demographical information. Alongside these limitations was the surprisingly frequent use of homogenous samples found among some of the studies. Across studies, participants were predominantly Caucasian with private insurance, while others examined patients on public entitlement programs (i.e., Medicaid recipients) with known limitations in access. Fortunately, the IR approach allows more flexibility in the inclusion criteria increasing the variety of designs and participant populations for review. The IR format supported a broad definition of childhood conditions/diagnoses, HCT services, and demographics to support a comprehensive review. In the next section, I discuss the data collection and selection process used in this review.

Data Collection

To begin phase three, I conducted several searches in five respectable databases using a variety of keywords. These databases were as follows: Google Scholar, CINAHL/Medline, ProQuest Health, and SAGE Premier. Since this topic also covered health policy, I included the Political Science Update database. Together, these databases yielded over 147,000 hits. Realizing this result was too broad, I narrowed down this number by specifying the age criteria, demographics, and the specific clinical context.

With more refinement and improvements in the keyword selection (previously described in Chapter 3) process, I identified 476 research articles. With several more levels of scrutiny, I identified 63 more sources of evidence for the pre-screening of all articles. However, after a full sweep of this database, I eliminated 13 additional articles and documented the reasons for doing so. In short, 50 sources met the inclusion criteria (see Figure 2 below).

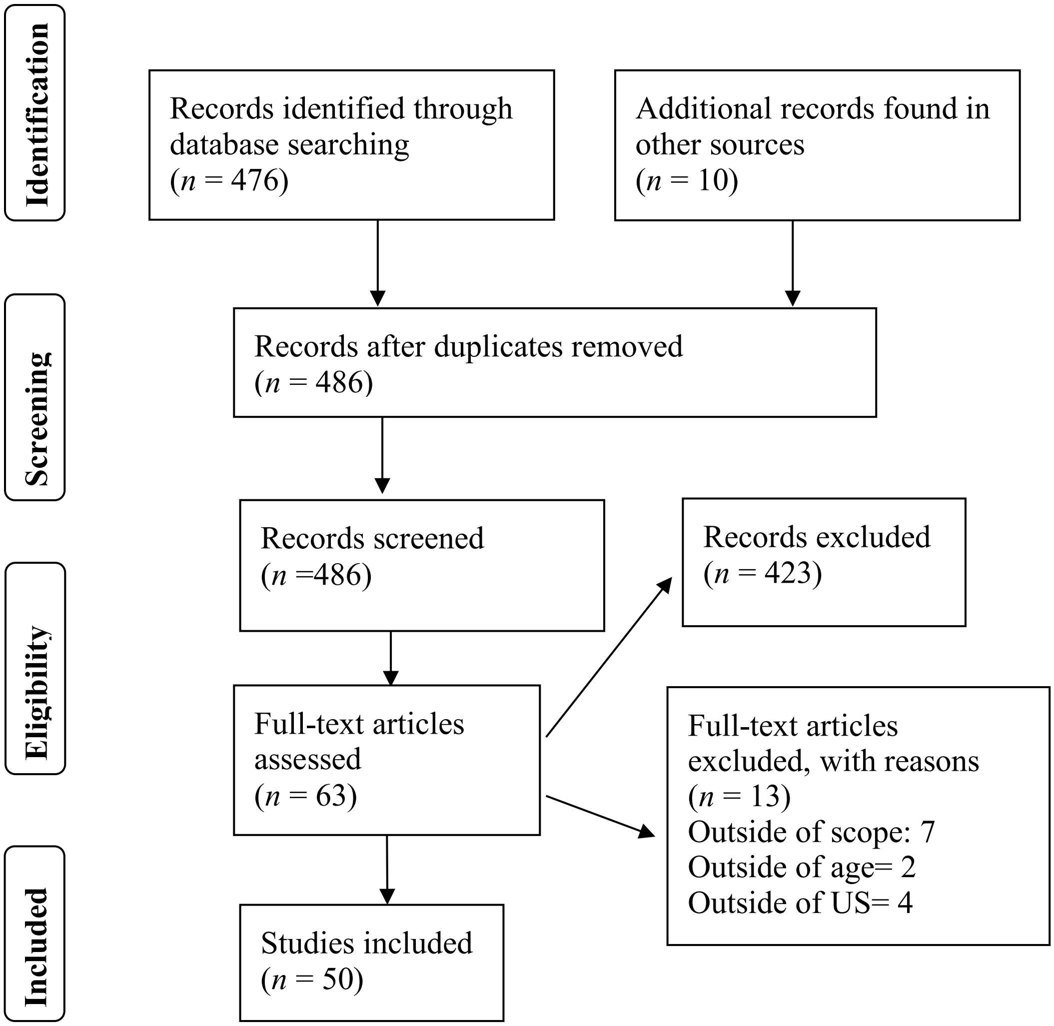

Figure 2. PRISMA flow diagram for inclusion process.

Data Analysis

According to the IR protocol, the fourth phase was the data analysis process. With this step, there are five coordinated stages: data reduction, consolidation, display, conclusion, and verification (Whittemore & Knafl, 2005). To begin this analysis, I first created files/cases in the NVivo program. To complete this step, I imported all of the relevant articles (to include the abstracts) into the NVivo program. Even before the coding process began, I noticed that this process allowed for comparisons both individually and collectively. In all, the dataset consisted of 30 quantitative, 17 qualitative, and three mixed-methods.

The next step was to determine data quality using the MMAT tool and the corresponding procedures listed on the form (see Appendix B). Additionally, it is important to note that I was granted permission to use this tool provided that I utilize the latest version (2018) of the MMAT tool (see Appendix C). This analysis yielded an overall estimate of quality based on an aggregate of individual scores found in each of the selected sources. While the majority of these sources met at least one of the probing questions found within each domain, only a few sources achieved all of the MMAT standards. Consistent with the bulk of the HCT literature, many of the selected sources were limited in sample size, utilized homogenous groups or convenience samples, and were designed as retrospective inquiries that relied on participant recall of their HCT experience. These quality factors were considered throughout the data analysis process. Therefore, biases in the form of non-responders and poorly representative groups were significant threats to transferability (Pluye et al., 2009).

In some cases, for example, the patients surveyed were those seen at specialty care clinics previously known to researchers. Therefore, based on these reasons, I determined that a marginal quality rating was appropriate for the bulk of selected sources (see Appendix A for a complete listing of IR studies along with the corresponding MMAT score). As previously mentioned, within the HCT literature, quality is an ongoing concern primarily as the number of prospective or controlled studies (often used to justify the provision of clinical services) are few in number (Campbell et al., 2016). The next hurdle in the data analysis phase was to examine the list of codes (complete codebook found in Appendix D) and to discern what patterns emerge from the data. These are the reduction and consolidation steps found in IR's data analysis process. To carry out this critical step, I used NVivo to organize and compare codes in a hierarchical structure. These charts are helpful to visualize patterns or theme nodes. In Table 2, a list of eight codes emerged. These critical areas were also used as the overarching themes that provided structural the coding strategy.

The extracted codes that emerged for this analysis are found below (see Table 2).

Table 2

Table of the Major Codes

Codes	Number of Different Sources	Number of Passages that support Codes
Communication gaps between caregiver, patient, providers	17	20
Disparity in AEA-SHCN	19	23
Social Factors and patient advantages	13	19
Health Equity Missing	16	24
Health System Failures	17	19
Poorly defined HCT Roles	12	15
Shared Decision Patient Engagement Disparity	12	14
System vs. patient-level change	15	22

According to the IR framework, an acceptable strategy for displaying data and making comparisons is to organize the data around emerging patterns, categories, or subgroups (Whittemore & Knafl, 2005). With this approach intact, I integrated the leftover codes (moderate and marginal/minimal supported codes) into the structural organization previously discussed (see a listing of marginal and minimal codes in Appendix F, and G respectively). The results of the combined coding process using the hierarchical structure was an important step in the reduction method (see Appendix H). To illustrate this process on a conceptual level, I described the HCT age-based policy and the associated themes.

The HCT age-based policy is consistently applied in pediatric care settings to determine patient eligibility and access (Oswald et al., 2013). However, strict adherence to this policy (chronological age rather than developmental) translates into poor HCT readiness, abrupt transfers, and limited care options (particularly for disadvantaged youth with SHCN; Javalkar, Fenton, Cohen, & Ferris, 2014; Oswald et al., 2013; Reiss et al., 2005). Understandably, an age-based standard such as this also intersects with the HCT adult care planning process (Oswald et al., 2013). Moreover, the self-care skills needed for adult care, (such as navigating adult care, understanding healthcare insurance process, and knowing when to call a provider) are considered more advanced and thus unlikely to be obtained (Syverson, McCarter, He, D'Angelo, & Tuchman, 2016). Consequently, this population tends to lag behind their typically-developing peers in skill acquisition, self-management, and timely transfers to adult care (Gray et al., 2018; Syverson et al., 2016). Not surprising, many codes are interrelated; however, they all contribute to health equity themes. This particular process is known as hybrid coding since the emerging patterns (major source codes previously mentioned) are used in the organizational structure for the secondary codes (in this case moderate and minimal codes; Fereday & Muir-Cochrane, 2006). Ironically, this hybrid process also reflects an inherently non-linear relationship between a patient’s disease self-care knowledge, skill, and overall readiness for the adult care setting (Betz, 2017). Thus, the HCT preparation and transfer process is complex and involve many sociodemographic as dynamic predictors of success (Oswald et al., 2013).

Evidence of Trustworthiness

Credibility, transferability, dependability, and confirmability are four important elements that qualitative investigators establish in their research to increase confidence with their readers (and themselves) of the study’s trustworthiness (Lincoln & Guba, 1986). Credibility (or believability) was one of the first elements that I tackled to building trustworthiness. I have found that being transparent is an important research guidepost, especially for making decisions, interpreting data, and contributing to credibility. To this end, any preliminary findings (such as data listed on the Appendices F–M) were generated by using hierarchical charting found in the NVivo program. The NVivo data analysis software is commercially available (through the QSR International corporation) for qualitative researchers to assist with organization, analysis, and interpretation of data illustrative or audio information (illustrative or audio information; NVivo Qualitative Data Analysis Software, 2014). Hierarchical charts (created in the NVivo program) assisted in the inspection of data by expeditiously looking for patterns to identify the range and strength of codes found amongst the sources. Thus, aside from using scholarly databases and citing work appropriately, I also employed more than one method for gathering and comparing data/results. This process not only bolstered credibility but also provided a comparative dataset needed gaining further insight into unique HCT experiences. Much like member-checking for assuring accuracy in qualitative interviewing procedures, triangulation is essentially a comparison of results using two distinct processes while also closely inspecting data for any emerging perspectives in a parallel process (Flick, 2009). The specified five-step data analysis process (reduction, consolidation, display, conclusion, and verification) along with a thematic synthesis represent methods for building credibility through comparative means (Korstjens & Moser, 2018). Given the relevance of this recommendation, I compared both the IR and thematic results in a side-by-side comparison. Throughout each process, open codes were evaluated, grouped and interpreted through the study's framework. In systematic reviews, utilizing a constant comparative methodology to address the research question and promulgate knowledge is consistent with high-quality reviews (Patton, 1999).

In qualitative research, transferability refers to the degree to which study results can be extrapolated to other populations of interest (Korstjens & Moser, 2018; Lincoln & Guba, 1985). While the IR approach introduces a variety of sources, each with contextual differences, this feature greatly limits the generalizability (Whittemore & Knafl, 2005). With this existing limitation, I carefully considered the study's alignment between purpose and the selection criteria to ensure congruency with a health disparity framework. While vulnerable populations might have similar predisposing factors, this particular inquiry advanced an intersectional approach for understanding the relationship between social disadvantages on healthcare experiences and future accessibility. Thus, study findings would only apply to youth with SHCN during a transitional healthcare timeframe. As the youth population with SHCN matures and diversifies (both in treatment needs and sociodemographic ways) efforts to understand how these differences impact healthcare experiences, access, and social vulnerabilities are unique and often underappreciated (Zickafoose & Davis, 2013). Thus research to study population distinctness is just on the cusp of our collective understanding of healthcare equitability among youth with SHCN (United States Department of Health and Human Services et al., 2013).

While research dependability involves being consistent with research decisions and confirmability upholds data integrity, both can benefit from an audit trail (Morrow, 2005). An audit trail establishes a running record of the researcher's decisions needed to execute the study and gather any logical data-driven conclusions (Given, 2008). Therefore, in addition to jotting down the results of my literature searches, I also displayed open codes, categorized them, and initially described any observations that contributed to the main themes. I also kept memos on the source content and those decisions needed for their inclusion. In the next section, I discussed the study findings according to the underlying IR framework.

Study Findings

By using an intersectional framework, I captured four overriding (and interrelated) themes that undoubtedly influenced population-based HCT experiences and access to services. The first theme was communication gaps, which were particularly detrimental to vulnerable patients during the HCT process (i.e., unmet HCT needs). The second major theme was healthcare disparities; commonly observed in youth with social disadvantages and those with disease-related stigmas. Health equity emerged in four distinct ways: provision of complex care, HCT roles, patient-provider relationships, and pediatric age-cutoff policies. Finally, the last theme was the merging of system and patient factors in the research and development of HCT improvements. As briefly as this introduction is, it is not surprising to learn that each of these themes is rather complex. For this reason, I addressed the overriding themes as they emerged and used the supporting evidence from the HCT literature to reaffirm their significance.

One of the most critical themes revealed throughout this IR study was communication gaps; observed as mismatched goals and expectations between patients and caregivers, as well as a poor collaboration amongst the entire healthcare team. This was a consistent level problem commonly found throughout the HCT literature (Cheak-Zamora & Teti, 2014; Pyatak et al., 2017). The notion that providers' lacked relevancy in understanding the realities of everyday life of those with SHCN was not surprising. It seems that providers were perceived as being further removed from what it means to be young and have a disability (Garvey et al., 2014; Polfuss, Babler, Bush, & Sawin, 2015). Provider-led misunderstandings of young adult HCT needs, lifestyles, and risk-behaviors were also shared trends. Young adult patients with SHCN perceived inadequate provider transition support during their most vulnerable college years, for example, disease implications for certain high-risk behaviors were mostly absent from the HCT preparation process (Garvey et al., 2014). Female patients also experienced inadequate anticipatory guidance on their expectations for future reproductive healthcare needs and the impact on their chronic illness (Fernandes et al., 2014). Mismatches in HCT program support and poorly aligned goals between stakeholders was crucial in understanding the HCT perceptions and patient experiences (Pyatak et al., 2014; Sawicki, Kelemen, & Weitzman, 2014).

Population-based healthcare disparities also played a central role in identifying inadequate transition support (Carroll, 2015; Fair, Goldstein, & Dizney, 2015). Poor healthcare continuity across multiple systems of care (pediatric through adult care) and poor coordination during an HCT was the most common (Lemke et al., 2018). However, healthcare disparities also exist for specific racial/ethnic groups, disease states/conditions, youth from low-income backgrounds or families enrolled in public assistance programs (Eilenberg et al., 2019). Among African American youth with SHCN, communication in the form of shared decision making (SDM) (a practice that embraces patient/family input) was not as useful as it was with Caucasian patients (Jolles et al., 2018). Researchers surmised that the SDM communication style for African American patients was incongruent with the goals of healthcare communication, particularly since at-risk patients might have experienced a history of healthcare access challenges (Jolles et al., 2018). While HCT is a vulnerable timeframe for most participants, patients with healthcare uncertainties display more concerns and thus report less overall satisfaction with transitional care process (Jolles et al., 2018). Similar to shared goals and expectations, understanding the meaning of HCT success could serve as a potential source of strength and collaboration between patients and providers, particularly for those with a history of poor healthcare communication and experiences (Porter et al., 2017).

The second overriding theme was healthcare disparities. As previously mentioned, healthcare disparities (especially, during the time of HCT) can profoundly impact youth with certain illnesses; more specifically those with sickle cell disease (SCD), Autism, and HIV (Haywood et al., 2015; Mulchan et al., 2016; Telfair, Ehiri, Loosier, & Baskin, 2004; Tepper, Zaner, & Ryscavage, 2017). While far less is known about the implications of disease-related stigmas, (particularly biases present in institutional, systematic, and societal domains) the effect on quality and support is pervasive (Findley, Cha, Wong, & Faulkner, 2015; Geerlings et al., 2015; Haywood et al., 2015). Recent evidence suggests that poor communication of treatment options and little sensitivity by providers can undermine HCT readiness, increase healthcare gaps or delays, and result in poor retention in care (Griffith et al., 2019; Labore, Mawn, Dixon, & Andemariam, 2017; Porter et al., 2017; Ryscavage, Macharia, Patel, Palmeiro, & Tepper, 2016). In this population, it has become apparent that healthcare disparities have become a rather intractable issue; partially due to the insidious nature and the sheer volume of youth with chronic disease (Agarwal et al., 2018).

Health equity was a third and crucial theme in this study's framework. Four main elements comprised health equity: provision of care for medically-complex patients, role delineation, patient-provider relationships, and pediatric age-cutoffs. While the definition of medical complexity lacks expert consensus (in so far as it is different from SHCN) stakeholders (caregivers, patients, and providers) perceived that HCT preparation and readiness activities (especially youth with cognitive, functional or behavioral delays) are far more *limited* than those with less intensive needs (Beal et al., 2016; Cheak-Zamora & Teti, 2014; Squiers et al., 2017). While evidence is somewhat mixed (partially due to ambiguity of medical complexity) it is apparent that when coordination of care (CC) services are available, *both* (complex care patients and those with less intensive needs) are likely to benefit (especially during a transfer to adult care; Lemke et al., 2018; Seeley & Lindeke, 2017). Indeed, a strong predictor of a successful transfer to adult care was the severity of congenital heart disease (youth with a history of an implantable device; Vaikunth et al., 2018). However, it should be noted that transfer rates have been historically low and this study was no exception; only 39% of the total patient population successfully established adult care despite there being dedicated clinics (Vaikunth et al., 2018). In the HCT literature, only one study examined the HCT experiences and perceptions of patients with life-limiting conditions. Researchers suggested that poor collaboration and a lack of patient self-care skills were threats to health equity (Noyes et al., 2018). Remedies offered included age-expansion policies and targeted HCT services for improving access and closing health equity gaps (Noyes et al., 2018).

The second health equity theme that I discovered was the poorly defined roles and responsibilities in the transition process. The insufficiency and confusion were mostly evident when patients and providers lacked HCT awareness, skill, or understanding of HCT and transfer process (Cheak-Zamora & Teti, 2014; Reiss et al., 2005). Role delineation is an important but complex area of concern; since building strong patient-provider relationships are the cornerstones to HCT preparation, team communication, acknowledgment of patient's health/disease status, and identification of future healthcare needs (Garvey et al., 2014). Given the critical adolescent stage, evidence suggests that facilitating collaborative care relationships and equitable healthcare access begins with the integration of patient-caretaker input into the healthcare transfer process (Carroll, 2015; Fegran et al., 2014; Menon & Afzali, 2019).

Indeed, the HCT experiences and beliefs of youth with perinatally-acquired HIV suggests that an adult care transfer can signal the beginning of adulthood with newfound self-care responsibilities (Fair, Sullivan, Dizney, & Stackpole, 2012). However, as previously discussed, there is a tremendous sense of fear and uncertainty among patients in the loss of their pediatric healthcare team (many of whom have shared experiences since the beginning of their lives; Sharma, O'Hare, et al., 2014). Still, evidence also suggests that although caregivers and patients both have an overwhelming sense of reluctance in leaving pediatrics, the recognition that a continued reliance on pediatric care could stifle growth and independence in patient self-management (Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Sharma, O'Hare, et al., 2014).

The third factor in health equity theme development is the patient-provider relationship. Poor patient experiences and access disparities are major contributors to poor health equity (Carroll, 2015; Jolles et al., 2018). During an HCT, there is a heightened risk of further unmet HCT needs particularly when providers with personal biases intersect with patients that have a history of negative relationships with the healthcare system (Dovidio & Fiske, 2012; Haywood et al., 2014; Porter et al., 2017).

Youth with SCD who have had a history of negative interactions with their providers are more likely to delay care and experience prolonged gaps based on perceived disease-related stigmas (Jolles et al., 2018; Labore et al., 2017). In addition, evidence also suggests that patients with SCD, HIV, and gender dysphoria might experience disproportionally longer wait times in urgent care settings, and endure providers with biases/assumptions about patient non-adherence or drug-seeking behaviors for pain management (Abramowitz, 2018; Elander, Lusher, Bevan, & Telfer, 2003; Saqr, Braun, Porter, Barnette, & Hanks, 2017). Perceptions of trust, knowledge, and sensitivity to the unmet HCT needs of youth (particularly for conditions with social stigmas) are pivotal in supporting equitable relationships and closing institutional disparity gaps (Abramowitz, 2018; Haywood et al., 2015; Labore et al., 2017).

Finally, the fourth issue that impacts health equity was pediatric age cutoffs; used mainly by clinics and pediatric hospitals to determine care eligibility standards (Oswald et al., 2013). As patients mature, their knowledge, communication skills, and overall response to self-management typically improve, mainly after they enter adulthood (Syverson et al., 2016). While age is an important criterion in HCT, anticipatory guidelines and service delivery standards should not be age-dependent (Betz et al., 2016). Furthermore, in a most recent systematic review, researchers found only moderate evidence that supports using an age-dependent policy as a determining factor in pediatric settings (Yassaee et al., 2019). Besides, youth with significantly more disability often require a different set of policy adjustments that consider developmental readiness (Betz et al., 2016). Researchers suggested that HCT policies that include developmental and disease-specific readiness considerations (self-care initiation, healthcare management skills/appointment scheduling procedures, and collaboration with adult care) could improve overall success, (Fair et al., 2012; McLaughlin et al., 2013; Sequeira et al., 2015). Early access to HCT services is a policy-driven process that promotes program parity even for the most vulnerable patients (Gabriel et al., 2017; Seeley & Lindeke, 2017; White & Cooley, 2018).

As more sociodemographic evidence emerges, however, it is becoming increasingly clear that HCT planning and outcomes are evolving along with patient access and transfer needs (Rachas et al., 2016). Thus, an urgent need exists to better understand the salient predictors of HCT readiness and to effectively support a vulnerable population (Javalkar et al., 2016). In HCT readiness or self-management, evidence suggests that patient demographics, living conditions, income, and gender (female) are important predictors of HCT readiness (Javalkar et al., 2016). However, how these sociodemographic factors intersect and simultaneously impact patient experience has not yet been thoroughly examined despite more research attention (Betz et al., 2014) . While HCT readiness is typically understood as an individual or disease-specific concept, socioecological models that stress the importance of looking more broadly at different care domains are warranted (Javalkar et al., 2016). A good example might include an examination of social supports and community resources for vulnerable populations (Pyatak et al., 2017).

Additionally, alignment in HCT readiness goals between patients, caretakers, and providers are essential in advancing readiness and health equity (Gray et al., 2018). Clinicians with knowledge and understanding of the healthcare insurance process, adult healthcare expectations and differences in the delivery of care between pediatric and adult care are facilitators of HCT readiness and thus health equity (Garvey et al., 2014; Gray et al., 2018). Most recently, support is growing for healthcare organizations to better support patients and families with SHCN on privacy laws, healthcare coverage, and care differences between pediatric and adult care (Mulukutla & Fegan-Bohm, 2019).

On the other hand, this notion of HCT readiness lacks consensus (Cooley et al., 2011). In a sample of young adults (predominantly, Caucasian males) with a chronic granulomatous disease (CGD) a rare genetic disorder causing a malfunctioning immune system, most patients were able to navigate the logistical nuances between pediatric and adult care (Margolis et al., 2017). However, most of these same patients lacked knowledge of their disease, medication regimen, and knew little about the purpose of advance directives (Margolis et al., 2017). Still, in another cohort of young adults (ages 19‒27 years) with a history of SCD complications (brain injuries/stroke) patients reported significant healthcare needs (appointment process, medical and medication management) and were profoundly lacking in self-care skills (Abel et al., 2015). While HCT readiness has received a lot of research interest, the application in clinical settings is somewhat limited (Jones, Frey, Riekert, Fagnano, & Halterman, 2018). In one study, patient readiness was loosely defined as a patient’s comfort level for discussing specific concerns with providers (Jones et al., 2018). However, despite a high degree of confidence among youth in voicing their concerns, this patient-provider dialogue did not necessarily translate into improved HCT readiness, medication adherence or appropriate use of clinical services (Jones et al., 2018). Although thoroughly researched and potentially helpful in patient-provider conversations, the clinical relevance of HCT readiness in the prediction of patient outcomes is not entirely understood (Cooley et al., 2011; Jones et al., 2018). Aside from tailoring for disease-specific transition needs, understanding developmental readiness, patient experiences/perceptions of the healthcare process, and their overall maturity level should all be considered before and during the transfer of care (Bond, Shanske, Hoffman, & Ross, 2019; Gibson-Scipio, Gourdin, & Krouse, 2015).

Finally, the last theme that emerged was the intermixing of the healthcare system and patient factors in the development of HCT improvements. Unfortunately, progress in remedying the primary systemic barriers (such as the capability to prepare, transfer, and track patients once they leave pediatric care) is wholly insufficient (Margolis et al., 2017). It seems that without delineated roles and responsibilities (at multiple patient levels) much of the coordination and transition falls to patients and their families (Fenton, Ferris, Ko, Javalkar, & Hooper, 2015). While a few past example HCT programs relied on system support (primarily carried out by highly specialized providers) the numbers of youth outliving their childhood illnesses have exceeded the capacity level of systemic support (Lotstein et al., 2009). While HCT researchers recognize that differentiating the roles and responsibilities in the system and patient-level controls are challenging, developing an infrastructure for tracking patients once they leave pediatric care is an essential step in measuring HCT outcomes (Chu et al., 2015). In the HCT literature, a most recent cohort of young adult patients (aged 16–27 years) 44% of youth (with and without SHCN) remained in care (Hart et al., 2019). It turns out that clinics with high-quality HCT care also had patients with the least number of days between appointments (pediatric and adult) and remained actively involved in adult care (Hart et al., 2019).

Understanding transition experiences in the setting of institutional, patient, and system-led factors is an important undertaking and one that has not been fully acknowledged in a health equity paradigm. As previously discussed, I explored this topic using the five-step IR process. During the analysis phase, however, I determined that a thematic analysis was necessary to not only compare results but also to satisfy the IR verification process.

Thematic Synthesis

Much like the IR data analysis, a thematic synthesis uses transparent coding to enhance credibility and confirmability (Thomas & Harden, 2008). Thirteen of the most highly relevant articles were used to conduct this step (see Appendix I). As previously stated, this decision was based on the need to have a comparative dataset for verification purposes. Clearly, from Table 3 (found below) there are four authors who shared the majority of the assigned codes with no additional new codes used in the analysis. Based on the non-emergent code saturation theory, the decision was made to utilize codes from these four authors to conduct the thematic analysis (Given, 2008).

Table 3

Sources and Range of Codes in Thematic Synthesis

Author, year	Number of Different Codes Used	Number of Supporting References/Passages
*Porter et al., (2017)	12	14
*Garvey et al., (2014)	13	16
*Fair et al., (2012)	12	15
*Cheak-Zamora et al., (2015)	18	23

* denotes authors with most prevalence in both range and number of codes

A complete codebook for the thematic analysis (organized by a range of existing codes) is found as Appendix L. Additionally, Appendix M contains a complete codebook for all selected sources. Much like the IR reduction process, the thematic protocol is conducive to a hierarchical structure. However, as codes are grouped tighter (based on similar characteristics or differences) they are given a *new* descriptive code that encompasses a broader range of concepts (Thomas & Harden, 2008). The development of analytical themes is one of the first steps toward this reduction and synthesis project (Thomas & Harden, 2008 ;see Appendix N coding matrix for the thematic synthesis). This process proved useful as I was able to exclusively focus on the meaning of the HCT experiences in the thematic analysis while also making comparisons with the IR descriptive results. Overall, the results revealed similar findings between the major source codes found in the IR and the main thematic themes (see Table 4). Additionally, Table 4 provides an integrated comparison between the IR and thematic synthesis data. In this matrix, the congruency between the IR results and thematic synthesis was easily identified.

Table 4

Results Matrix of IR Major Source Codes and Thematic Synthesis

Author Year Source Title Purpose	IR Communication Gaps Healthcare Decisions Poorly Defined Roles	IR Social Factors	IR Healthcare Disparities Failures	IR HCT Experience and Healthcare Patient vs. System level Change	Thematic Poorly established partnerships between pediatric and adult care	Thematic Trust, Sensitivity and relationship losses from system factors or access to care changes	Thematic Loss, uncertain about system change that patients knew and understood
Cheak-Zamora, N. C., & Teti, M. (2014) *Autism* You think it's hard now … It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services Purpose: To examine HCT experiences of ASD patients and their caregivers	*Poorly established partnerships between pediatric and adult care Providers lacked understanding of ASD, and patient communication needs hampered by poor level of ASD knowledge and HCT needs	96% White; middle income bracket and 60% in 2 parent households	Disparities in lack of supported HCT services with youth having little recognition of types of skills needed in adult care *Trust, sensitivity, And relationship losses from system factors or access to care changes	HCT Experiences impacted by poorly informed providers *Loss, uncertainty and change in system patients know and understand			

* *denotes congruent themes*

Table continues

Author Year Source Title Purpose	IR Communication Gaps Healthcare Decisions Poorly Defined Roles	IR Social Factors	IR Healthcare Disparities Failures	IR HCT Experience and Healthcare Patient vs. System level Change	Thematic Poorly established partnerships between pediatric and adult care	Thematic Trust, Sensitivity Loss of Relationships from system factors access changes	Thematic Loss, uncertain and change in system patient knew and understood
Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., \& Koegler, E. (2017) *Journal of Pediatric Psychology* Exploration Comparison Adolescents with Autism Spectrum Disorder and Caregiver's Perspectives Transition to Adult Health Care Purpose: Explore experiences as ASD patients and caregivers Transfer to Adult care	Study examined two ASD groups (patient and caregiver) and their perceptions of self-management; 3 issues emerged: Independence, self-efficacy and desire for independence; Suggestions for improved transition to adult care for ASD patients	Homogenous group	*Poorly established networks between pediatric and adult care	*Trust, sensitivity, and relationship losses from system factors or access to care change Access to higher quality care driven by Experience in the system; with little experience communicating with providers; unmet needs			HCT Experiences relate to poorly designs systems for patients with profound needs

**denotes congruent themes*

Table continues

Author Year Source Title Purpose	IR Communication Gaps/Healthcare Decisions/Poor Defined Roles	IR Social Factors	IR Health care Disparity Failures	IR HCT Experience Healthcare Patient vs. System level Change	Thematic Poorly established partnerships between pediatric and adult care	Thematic Trust, sensitivity relationship losses from system factors or access to care changes	Thematic Loss, uncertain and change in system patient knew and understood
Fair, C. D., Sullivan, K., Dizney, R., \& Stackpole, A. (2012) *AIDS* Patient Care and Sexually Transmit Disease (STD) It's Like Losing a Part of My Family': Transition Expectations of adolescents with Perinatally Acquired HIV Purpose: To explore patient perceptions transfer to adult care	Study examined pre-transition adolescent with HIV and their experiences and the expectations of adult care	HIV population with low-income among Guardians Low SES; All patients were perinatally infected; Patients with history of Provider Stigma	*Trust, sensitivity, And relationship losses from system factors or access to care changes				
	*Poorly established partnerships between pediatric and adult care		Lack HCT experience especially among physicians in treating this population			Concerns driven by poor systems and lack of provider training in adult care	

** denotes congruent themes*

Table continues

Author Year Source Title Purpose	IR Communication Gaps Healthcare Decisions Poorly Defined Roles	IR Social Factors	IR Healthcare HCT Experience in Healthcare Patient vs. System Level change Disparities/ Failures	IR HCT Experience in Healthcare Patient vs. System Level change	Thematic Poor partnerships between pediatric and adult care	Thematic Trust, and relationship losses from system factors or access to care changes	Thematic Loss, uncertain and change in system patient knew and understood
Garvey, K. C., Beste, M., Luff, D., Atakov-Castillo, A., Wolpert, H., & Ritholz, M. (2014) *Adolescent Health, Medicine and Therapeutics* Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study Purpose: To uncover HCT experiences in a post-transition Type 1 Emerging Adult Diabetic population	*Loss, uncertainty and change in system patient knew and understood Emerging themes indicating poor HCT planning particularly in referrals to adult providers.	Sample with; highly educated White female patients enrolled in pediatric DM	Patients without adult provider despite being told they are “too old” for primary pediatrics. Vulnerable in college years			*Loss, uncertain and change in system patient knew and understood (poor referrals to adult care)	*Poor continuity of care

** denotes congruent themes*

Table continues

Author Year Source Title Purpose	IR Communication Gaps/Healthcare Decisions Poorly Defined Roles	IR Social Factor	IR Health care Disparity Failures	IR HCT Experiences Healthcare Patient vs. System level Change	Thematic Poorly established partnerships between pediatric and adult care	Thematic Trust, sensitivity, and relationship losses from system factors or access to care changes	Thematic Loss, uncertain of change in system patients knew and understood
Porter, J. S., Wesley, K. M., Zhao, M. S., Rupff, R. J., & Hankins, J. S. (2017) *Journal of Pediatric Psychology* Pediatric to Adult Care Transition: Perspectives of Youth with sickle cell	HCT Experiences impacted by poorly informed providers *Trust, sensitivity, and relationship losses from system factors or access to care changes	SCD ages 18–30 young adults; 100 Black females	*Poor continuity of care leading into adult care	*Poorly established partnerships between pediatric and adult care	*Poor continuity of care	Negative experiences as youth carried over into relationships w/provider as adult patients	
Purpose: To examine HCT experiences of SCD patients and their caregivers	Salient themes indicated that negative medical experiences in relationships with new adult providers			Patients with SCD are discriminated against in multiple care settings			

** denotes congruent themes*

In general, evidence from the thematic synthesis suggested that the role of *trust and relationships* between patients and providers was more prominent than the emerging themes discovered in IR analysis (Fair et al., 2012; Teti, Cheak-Zamora, Koegler, & Maurer-Batjer, 2017). Similarly, in the thematic synthesis, it was evident that *loss, uncertainty, and change in healthcare systems* were major themes whereas in the IR analysis they were used as supporting evidence to further describe communication gaps (Fair et al., 2012; Garvey et al., 2014; Rehm et al., 2012). Finally, *the collaborative care process and the lack of established partnerships* were considered highly relevant in patient expectations and their experiences (Lemke et al., 2018). These results, while focused on the meaning of the HCT experiences, provided a high degree of alignment between the two analyses.

Final IR Phase

The purpose of the final phase was to not only synthesize data (both from IR and thematic synthesis) but also to generate recommendations for future research based on study findings (Whittemore & Knafl, 2005). In reviewing the main themes (along with the supporting data) the AEA-SHCN population shoulder much of the burden to seek, obtain and transfer into adult care both (before and during) an HCT (Cheak-Zamora & Teti, 2014; Squiers et al., 2017). The HCT experiences are fraught with confusion, fear, and uncertainty as patients approach adult age (Anderson et al., 2018; Fernandes et al., 2014). Suffice is to say, patients incurred unforeseen risks during the transitional phase. Similarly, across much of the examined HCT literature, evidence suggests that poorly defined HCT team roles and poor care continuity shift much of the burden to patients and their caregivers to navigate the healthcare system (Teti et al., 2017). Healthcare coverage gaps going into young adulthood only exacerbated these factors and introduced further access barriers (Gray et al., 2018).

In a health equity paradigm, time-limiting HCT policies set by pediatric healthcare organizations introduced healthcare disparities, especially for patients with SHCN with social disadvantages (i.e., low-income, public insurance, and non-English speaking). It is well established that disadvantaged patients might experience difficulty locating adult providers with expertise in treating childhood illnesses (DeBaun & Telfair, 2012; Mulchan et al., 2016). Also, young adults are especially vulnerable to limitations in access and poor HCT planning as locating providers that accept new patients with rare/congenital conditions can be a challenging task given what is known about the healthcare landscape (Paramsothy et al., 2018). Paradoxically, a sense of shared reluctance (providers and patients) can occur as a transition nears delaying further preparation efforts and increasing the risk for an abrupt, *unplanned* change in access (Polfuss et al., 2015). Relationship losses and differences in healthcare culture (between pediatric and adult) also explains why patients and caregivers fear unexpected changes in healthcare access (Sharma, Willen, Garcia, & Sharma, 2014). These influences erode patient trust and confidence in the new healthcare team (Porter et al., 2017; Sawin et al., 2015). Indeed, unclear expectations in the HCT process and abrupt terminations in care increase patient fears (Knapp, Huang, Hinojosa, Baker, & Sloyer, 2013; Speller-Brown et al., 2015). Improper healthcare utilization (i.e., urgent care routes) for routine disease management care incurs greater expenses and causes further delays in patients establishing appropriate primary care (Javalkar et al., 2014; Pyatak et al., 2017; Squiers et al., 2017).

Finally, IT theory examines the constellations of intersecting and contextual factors that influence access and experience (Hankivsky et al., 2017; Sosnowy et al., 2017). Without primary care-based pathways and established partnerships (between pediatric and adult care) transitional-age patients with SHCN and social disadvantages experience different levels of care and access (Syverson et al., 2016). The HCT policies that discriminate based on age introduces further miscommunication among vulnerable patients SHCN (Knapp et al., 2013; Sawicki, Garvey, et al., 2017). Overall, there are inherent risks when patients undergo HCT. However, poor care continuity associated with poor HCT support and access introduces further delays, and that can negatively impact health outcomes (Menon & Afzali, 2019). A comparison of themes in both the IR and thematic synthesis data suggested that forming trusting relationships with primary pediatric or adult providers and establishing quality care access are the population's utmost concerns (Cheak-Zamora & Teti, 2014).

Summary

This IR was undertaken to explore how patient and health system factors impact the HCT experiences among the AEA-SHCN population using a health equity framework. The recognition that multiple factors can intersect and elicit suboptimal patient experiences is just emerging in the HCT literature (Anderson et al., 2018; Crump, 2018; Sosnowy et al., 2017). By using an intersectional framework, I gained a better appreciation of how patient and system factors overlap and dynamically shape HCT experiences (Evans et al., 2018).

The first theme that emerged was communication gaps. Evidence of strained relationships (between providers and patients) and unmanaged expectations gaps in the HCT process were particularly evident as transitional-aged youth entered young adulthood (Cheak-Zamora & Teti, 2014; Pyatak et al., 2017). Limitations in preparing and supporting patients during the HCT process also tended to erode positive patient experiences (Gray et al., 2018). Evidence of HCT disparities in multiple systems of care was mixed. However, patients with specific illnesses and social disadvantages were most at risk for poor care continuity (Lemke et al., 2018). Unfortunately, evidence of healthcare level stigmas was also present. However, they were closely tied to patients with a history of poor provider relationships or those that perceived little sensitivity by their providers (Jolles et al., 2018)

Finally, there was a significant overlap between health equity issues and healthcare disparities; however, this intersection involved socially-disadvantaged patients with specific unmet cognitive, functional or behavioral care needs (Eilenberg et al., 2019). While some evidence also suggested that patients with medical complexity (characterized as intensive medical support) were more likely to transfer to adult care, it is crucial to remember that establishing adult care might not necessarily translate into health status improvements or better patient outcomes (Joly, 2015; Seeley & Lindeke, 2017). Other risks to health equity centered on poorly defined roles amongst the healthcare team, a contributory factor in strained patient-provider relationships (Teti et al., 2017). In some cases, providers and patients delayed transfers due to lack of adult providers, while other patients underwent an HCT not long after reaching adult age (Carroll, 2015). Overall, system adherence to pediatric age cutoffs meant that as patients approached adult age, the expectation was to establish adult care soon after reaching majority age (Fenton et al., 2015). Sociodemographic evidence was found to closely align with HCT readiness (Javalkar et al., 2014; Javalkar et al., 2016). However, HCT readiness is not uniformly applied or understood, and much less is known about this construct and clinical relevance to outcomes (Jones et al., 2018).

Lastly, the thematic synthesis yielded three main themes that were found to support several important findings from the IR process. The first one was that patients with SHCN perceived the HCT experience as a time of loss, uncertainty and change in the healthcare system (Fair et al., 2012; Pyatak et al., 2017). The second main thrust was concerned with trust, sensitivity, and relationship losses, which for vulnerable patients and families, was crucial to them as they look to build new relationships in adult care. The third theme pointed out that poorly established partnerships and limited collaboration (between pediatric/adult care) were not helpful to patients and families when it came time to transition to adult care. These findings were closely aligned with the IR conclusions and the extant HCT literature. However, the thematic synthesis uncovered the meaning of the HCT experience in greater detail.

Despite the widely available HCT guidelines and recommendations, HCT researchers recognize that system and patient barriers must go beyond educational support of providers and patients (Fenton et al., 2015). Unfortunately, the provision, support, and types of HCT services that can improve access to adult care needs further study (Betz et al., 2018). In terms of health equity, the AEA-SHCN population can suffer from social disadvantages which place heavy burdens on patients and their families to undergo the HCT process, often with little care preparation (Garvey et al., 2017). Therefore, it is incumbent upon HCT policy advocates to first recognize the implications of poor access (especially among patients with disadvantages) and secondly, to ensure that patients and families are part of the collaborative care process to improve health equity. In summary, more research interest in the area of HCT policy reform is warranted, given the demonstrated intersections between disease-specific vulnerabilities and social disadvantages (Sandler & Garvey, 2019).

The next chapter discusses the summation of the study’s main contribution to the literature. Additionally, a comparison of IR results with what is known in the literature is customary in scholarly research, as is a brief overview of any inconsistent findings that are certainly worthy of future study. All of this information can be found in the following chapter.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This study involved understanding how structural, patient, and system-led factors impacted transition experiences using a health equity paradigm. Adolescents and emerging adults with SHCN have historically lagged behind their typically developing peers in accessing and establishing appropriate adult care (Lemly et al., 2013). Therefore, health status and healthcare access are inextricably linked. Transitional-age patients and their families are expected to not only undergo an HCT, but also assume greater healthcare responsibility and adapt to the psychosocial stressors of young adulthood (Giarelli, Bernhardt, Mack, & Pyeritz, 2008; Iyengar, Thomas, & Soleimanpour, 2019). Unfortunately, after several decades of HCT research, there are still many unanswered questions about how patients with SHCN experience the HCT process and the degree to which healthcare services have prepared at-risk populations for their transition (Crump, 2018; Krahn et al., 2015; Mulchan et al., 2016). In this IR study, I investigated how intersectional theory could illuminate a greater understanding of the access and equity gaps of the AEA-SHCN population-based on HCT experiences. Recall that intersectional approach reframes multiple and (overlapping) factors as intersections, or as socially constructed points where differential healthcare access and sociodemographic group identities act simultaneously to impact contextually-based experiences in systems of privilege and oppression (Evans et al., 2018).

Main Findings

One of the main findings that emerged was communication gaps, which were found to be problematic not only between patients and caregivers but also among healthcare providers in multiple systems of care. Across much of the HCT examined literature, the patient perceptions based on improvement initiatives reported weaknesses in communication and unmet family expectations of HCT preparation for adult care (Polfuss et al., 2015; Sawicki et al., 2014). At the clinical level, poor collaboration, incongruent healthcare expectations/goals, and miscommunication amongst key stakeholders intersected with suboptimal HCT experiences in the setting of insufficient healthcare support (Gray et al., 2018; Pyatak et al., 2014). Therefore, youth with SHCN perceived HCT transition programming as inadequate, especially during a time of uncertainty and need (Carroll, 2015; Fair et al., 2015). Additionally, patients with SCD, HIV, and gender dysphoria experienced suboptimal outcomes (i.e., poor retention in care, poor HCT readiness/unmet needs, and gaps/delays in access) based on several intersections between racial/ethnic group HCT disparities, institutional or provider-based biases, and social stigmas related to their disease (Abramowitz, 2018; American Academy of Pediatrics & AIDS, 2013; Labore et al., 2017; Porter et al., 2017; Ryscavage et al., 2016). Patients with a history of negative relationships with their providers also exhibited poor experiences and incomplete transfers into adult care (Dovidio & Fiske, 2012; Haywood et al., 2014; Porter et al., 2017).

Health equity was another important theme that emerged from this review. This theme intersected with HCT preparation and readiness (in both leading up to or just after a transfer) as the demand for healthcare access was a primary concern (Squiers et al., 2017). While this particular theme was illness-specific and socially complex, the reduced availability of providers and subsequent access limitations were especially problematic for complex care patients (Fernandes et al., 2012; Vaikunth et al., 2018). While complex care youth are by no means considered a homogenous group, insufficient care, poor adult care preparation, and unmet transition needs are found across a spectrum health conditions (Eaton et al., 2017; Etherington, 2015).

HCT policies (such as the pediatric age cutoffs used primarily in large health systems) also intersected with health equity with suboptimal outcomes (pediatric ineligibility). Strict adherence to age-based policies led to access barriers; patients 18 years and up were required to seek adult care (Cheak-Zamora & Teti, 2014; Oswald et al., 2013; Polfuss et al., 2015). Unfortunately, access challenges going into adult care for youth with and without SHCN (before or during transfer) are well documented in this population (Beal et al., 2016; Cheak-Zamora & Teti, 2014; Squiers et al., 2017). Unfortunately, chronological-based policies with the intent to shift adult-aged patients to adult care have led to unplanned transfers and access disparities (i.e., urgent care routes for health and disease maintenance) in this population (Javalkar et al., 2014; Pyatak et al., 2017; Squiers et al., 2017).

While age is often used as a predictor of HCT initiation and readiness, it does not necessarily translate into improved patient outcomes or aligned with other life events (Eluri et al., 2017). However, using developmental readiness and sociodemographic factors as predictors of healthcare access is a step toward healthcare improvement and system equitability for patients with SHCN (Betz et al., 2016; Bond et al., 2019; Gibson-Scipio et al., 2015; Syverson et al., 2016). Indeed, a successful HCT preparation program is one where many of the intersecting factors are considered (for example, changes in the healthcare insurance process, pediatric/adult healthcare access options, and patient-caretaker input; Cheak-Zamora & Teti, 2014; Garvey et al., 2014; Vaikunth et al., 2018).

Health equity concerns are not exactly mainstream in the HCT research; however, evidence suggests that suboptimal patient experiences precipitate poor health equity, and access disparities (i.e., non-medical factors; Carroll, 2015; Jolles et al., 2018; Srinivasan & Williams, 2014).

Interpretation of Main findings

The findings of this IR study reflect many of the challenges in today's healthcare environment: poor communication, healthcare access disparities, and health equity gaps. As researchers and health policy advocates continue to debate many strategies to close these gaps, patients with vulnerabilities (like youth with SHCN and disabilities) are faced with complex healthcare decisions often without the benefit of much HCT planning or resources. Understandably, the HCT process is a tumultuous and dangerous one for youth with SHCN (particularly, if they forego healthcare; Barr et al., 2017; Dallimore, Neukirchinger, & Noyes, 2018). However, for youth with SHCN, it was advantageous to have a well-established patient-provider relationship during the pediatric growth years. Nonetheless, as transitional-age youth mature into adults, the barriers became more complex and involved multiple sociodemographic factors that are not routinely considered during a clinical encounter (Gray, Schaefer, Resmini-Rawlinson, & Wagoner, 2017).

As widespread (and complex) communication gaps deepen between multiple stakeholders, the complicated issue of healthcare inequality begins to resurface. Youth with SHCN can present with numerous disadvantages and thus may require more system-level healthcare support to appropriately access and obtain the care they need to improve health status. Unfortunately, poorly defined roles and responsibilities in the setting of limited provisions of HCT services creates further difficulty for patients to renegotiate not only new healthcare relationships but also consider other care options (Carroll, 2015; Catena et al., 2018; Fair et al., 2012). Regrettably, most of the AEA-SHCN population were found to have healthcare disparities and unmet HCT needs. While the HCT literature continues to research the development of robust patient education interventions and self-care skills, more emphasis is needed to investigate strategies that tackle healthcare structural or policy issues that influence and shape patient experiences. System-level barriers, for example, healthcare insurance changes, and shortages of providers with expertise in treating congenital conditions significantly limits access. However, both practical and policy strategies to tackle these issues have not yet been fully recognized.

Theoretical Interpretation

On a conceptual level, an IT framework captures suboptimal HCT experiences as both potential indicators and as consequences of poor health equity and insufficient access. With this reframing, the potential to reconsider hidden and overlapping categories of disadvantage (i.e., limited patient capacities, racial/ethnic minorities/non-English speaking groups, limited resources, dependence on public entitlement programs, and low healthcare literacy) can coexist. The healthcare setting is a structural, social, and system-led factor that contributes to complex encounters that occur within systems that favor resources (i.e., inequitable). Not only do providers and patients not fully anticipate the access concerns, but most of what occurs in the healthcare setting is sophisticated and designed around a system of power, knowledge, and resources.

On a thematic level, the meaning of HCT suboptimal experiences, perceptions, and patient expectations was congruent across several studies and throughout the HCT literature. Patients were likely to experience a sense of loss, and uncertainty during prolonged gaps especially, as transitional changes took effect and (often without the benefit of prior planning, resources, or established healthcare partnerships; Garvey et al., 2014). These interrelated factors predispose patients with SHCN to care disparities and potentially poor outcomes that predominantly arise from nonmedical sources (Bower et al., 2019). Patients with less self-care skill or family support, for example, typically encounter more difficulties navigating a complex system of care (Fenton et al., 2015). Another potential area of concern is the impact of institutional and society-held stigmas on suboptimal care and experiences (Andreoni et al., 2013; Green et al., 2017; Mulchan et al., 2016). Unfortunately, there is a limited acknowledgment from the medical community that disease-related stigmas could impact patient care (Acree, 2017; Bailey et al., 2017).

Overall, an intersectional lens focuses on the disproportional impact of healthcare policy changes (such as pediatric eligibility age) on populations with limited healthcare options and the burden these patients have to contend with; many of whom (aside from their SHCNs) also share multiple overlapping categories of social disadvantages (i.e., low SES, ethnic/racial minority background, and non-English speakers). The use of an age-based policy (mostly in hospitals/clinics dedicated to children) has lingered in the HCT field for quite some time, however only just now has this policy been questioned as a potential ethical issue. Likewise, the expansion of the upper-age limits in pediatrics (or subspecialty care) has only recently been raised, despite the historical significance with access gaps in adult-aged patients still in pediatric care (Hardin & Hackell, 2017; Schor, 2015). Interestingly, professional pediatric health organizations' generally disagree with strict age-based transitions, particularly sense collaboration between pediatrics, subspecialty care, and adult providers have not yet been tackled from both a policy or practical standpoint (Hardin & Hackell, 2017; Schor, 2015; White, Greenlee, & Cooley, 2015).

Study Limitations

One of the main concerns with using an IR is the limited generalizability of results. This is mainly due to the IR's flexible selection approach and analysis of multiple design types (Cooper, 1982; Torraco, 2005). I chose this design to garner data from a host of different designs. However, one of the main requirements for using this design was a tightly defined scope. At the same time, however, it is important not to overlook selection bias. Another limitation stems from the nature of an IR and the reliance on previously published studies. Like other systematic reviews, the quality level of the research at hand is a direct reflection of the larger body of literature. Essentially, if the bulk of published research is based on retrospective, non-prospective, or case study designs, then full consideration for this inquiry's findings (and the limitations) is also warranted.

The steps that I took to counteract these limitations entail the use of a quality screening process and researcher disclosure. In the quality appraisal form, I first estimated quality scores for each source, and then compared them as a whole; however, I still logged them in using one validated tool. Additionally, throughout this inquiry, I annotated several quality concerns and personal observations during the research process and described them in detail as the study unfolded. Finally, while most systematic reviews are conducted using several different reviewers, a unique feature to the IR is that a single investigator can perform high-quality review (given there is strict adherence to the IR's criteria and purpose; Holly & Anef, 2013). However, these historical experiences could represent personal biases and thus necessitate full disclosure and the potential threats to objectivity.

Recommendations

As a result of this study, one overall recommendation would be first to reframe HCT research under a health equity umbrella and to use HCT policy decisions, processes, and practices to advance an equitable and appropriate healthcare access agenda for an underserved population. Additionally, while HCT models and quality improvement protocols are helpful (i.e., Six Core Elements) they are not necessarily ingrained or consistent with an organizational structure or system-led transition policies that guide how resources, personnel, and programs are utilized. Secondly, this IR fully reaffirms the strength of the collaborative care process (between pediatric and adult care) in both short-term HCT outcomes and the long-term adult care environment. Finally, future research should explore provider and institutional practices in stigma-related conditions, for example (but not limited to) sickle cell disease, gender identity disorders, and HIV. Fortunately, investigations into understanding care coordination and access among patients with disadvantages already have a strong foothold in health disparity fields, however reframing them as intersecting factors capable of undermining health equity is an underappreciated research area.

Implications for Patients and Caregivers

Youth with SHCN and their caregivers often find that they are in positions of vulnerability in the healthcare setting. This study highlighted that throughout the healthcare process, it was crucial for patients, caregivers, and providers to discuss HCT in the context of coverage and access concerns to primary care or specialty care. In the HCT field, the focus appears to be on the education of patients on self-care. However, adult care expectations and the process of navigating and locating appropriate primary or specialty care does not receive nearly as much emphasis. Another issue that this study raises is the gap between the application of expert recommendations and the implications for policy change in pediatric practice. Though most pediatricians and clinical providers agree with the expert recommendations, they are seldom in positions to implement structural, organizational changes in the pediatric healthcare environment. Key stakeholder involvement (to include patients and families) is crucial to long-lasting change implementation. While self-care skill development is an essential criterion in HCT outcomes, patient engagement (linked to patient experiences) and understanding of the sociodemographic factors that impact capacity is also crucial to comprehensive program development.

Implications for Social Change

Youth with SHCN require a healthcare system they can access with providers who can share their expertise with their patients and caretakers in ways that promote self-care and advance health equity (Cohen et al., 2011). Unfortunately, at the individual care level, patients and caretakers can quickly become overwhelmed both by what providers convey during the healthcare encounter and by what is occurring around them (Cheak-

Zamora & Teti, 2014). A structured HCT process that begins early and outlines clear expectations of each healthcare team member (that is developed with patient-caretaker input) has the potential to facilitate a successful HCT to adult care (Sequeira et al., 2015). However, investigations into tackling how intersecting factors shape HCT experiences, types of services being offered, and their impact on health equity are still needed to improve the HCT experience of care across multiple systems. Unfortunately, providers with little sensitivity or expertise in treating patients and families with stigma-related conditions introduce biases due to their unfamiliarity with congenital conditions. A theoretical model that incorporates various intersecting factors into a comprehensive framework has the potential to demystify the health equity implications associated with healthcare biases and poor practices.

On a practice-based level, providers need to assess, educate, and promote self-care skills as part of an overall adult HCT plan, however, restructuring pediatric care as more collaborative care and overlapping with adult care could improve healthcare retention and engagement (a particularly vexing problem in HCT). Strict adherence to age-based policies that invoke a healthcare transfer at age 18 (even among patients in subspecialty care) could increase the risk of discontinuing access to one or more specialized or primary care providers, introducing more risk to health outcomes (Schor, 2013). Finally, it is incumbent upon researchers, clinicians, and policy advocates to seek healthcare improvement initiatives that target multiple domains (i.e., patient-provider level, healthcare organization, and systems-level) with further healthcare structure or policy involvement (Betz et al., 2016).

Theoretical Implications

Using the intersectional theory proved invaluable as I gained a better appreciation for not only the potential role of the complexity of healthcare but also of health equity. In a practical sense, the healthcare setting is complicated. Surprisingly, there is a limited understanding of how the healthcare environment impacts patients and families with SHCN to obtain needed healthcare services. Intersectional researchers explore how patient experiences and their social disadvantages impact access and equity across multiple environments.

Furthermore, the notion that patients and families with the most needs (social disadvantages, physical and behavioral) often experience more difficulty obtaining HCT needs and services is by itself an indication of poor healthcare equity. Patients with SHCN, for example, might exhibit less overall satisfaction, a factor related to poor access, and unmet HCT. Under an IT approach, healthcare policies that impose specific access or care restrictions can disproportionally burden patients with more physical and social disadvantages and thus, widen health equity gaps.

Conclusion

The HCT process is still a tumultuous time for young patients with SHCN. While identifying patient HCT needs and services is an ongoing (and worthwhile) clinical dilemma, the evidence is still lacking on how patient experiences, healthcare practices/policies, and health equity changes over time. In an IT model, researchers focus on poor disease trajectories (i.e., loss to follow up, poor engagement and retention) among patients who share sociodemographic group identities. Evidence suggests that this population (aside from their disproportion in disease burden) poor experiences that could stem a lack of organizational emphasis on HCT as a healthcare priority. With more importance on structural or policy-based HCT programs at multiple care levels, an improvement in preparation and support efforts for vulnerable populations could be realized. This study warrants more translational research that measures transitional support and benchmarks for organizations as a matter of policy. These might include shifting the from HCT readiness to tracking patients across the healthcare continuum and preventing loss in patient engagement.

With greater emphasis, the HCT policies, resources, and programs should fully support patients and providers in establishing a collaborative care process between pediatric and adult-oriented care. While several examples of HCT program types exist in the literature, the clinical and organizational policy support are rarely considered with the same level of research vigor (much less thoroughly examined from a research angle). Additionally, institutional practices and influences on stigma-related disease warrant further attention; a systematic research approach could uncover care disparities and unmet needs from well-entrenched discriminatory practices that converge among cohorts with the stigma-related disease. Finally, an intersectional approach considers underserved patients as having multiple and overlapping needs that (which during times of uncertainty) likely precede prolonged gaps in care. Therefore, an HCT is by itself an intersectional risk factor that adds complexity to the healthcare encounter. Research into developing policies and HCT services that ameliorate these complex intersections could improve patient experiences while closing health equity gaps.

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Appendix A: Table of Selected Articles for Integrative Review and MMAT Score

Authors/Year	Title	Study Tradition	Source	Purpose	MMAT Score
Abel, R. A., Cho, E., Chadwick-Mansker, K. R., D’Souza, N., Housten, A. J., \& King, A. A. (2015)	Transition needs of adolescents with sickle cell disease (SCD).	Quantitative	Journal of Occupational Therapy	To determine self-care skills in SCD	75%
Agarwal, S., Raymond, J. K., Schutta, M. H., Cardillo, S., Miller, V. A., \& Long, J. A. (2017)	An Adult Health Care-Based Pediatric to Adult Transition Program for Emerging Adults with Type 1 Diabetes	Quantitative	Diabetes Educator	To evaluate a joint (Pediatric to Adult Care) based HCT Program	75%
Amitha Prasad Gumidyala, P., Rachel N Greenley, PhD, Jill M Plevinsky, MA, Natasha Poulopoulos, MS, Jose Cabrera, MD, Diana Lerner, MD, Joshua D Noe, MD, Dorota Walkiewicz, MD, Steven Werlin, MD, Stacy A Kahn, MD. (2018)	Movin' On: Transition Readiness in Adolescents and Young Adults With Inflammatory Bowel Disease (IBD)	Quantitative	Inflammatory Bowel Disease Journal	To examine factors associated with HCT readiness among youth/young adults with IBD	50%
Annunziato, R. A., Baisley, M. C., Arrato, N., Barton, C., Henderling, F., Arnon, R., \& Kerkar, N. (2013)	Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services	Quantitative	Nursing Children and Young People	To compare the use of HCT coordinator on liver transplants patients who transfer to adult care	50%
Applebaum, M. A., Lawson, E. F., & Von Scheven, E. (2013)	Perception of transition readiness and preferences for technology in transition programs: Teens’ ideas for the future	Mixed	International Journal of Adolescent Medicine and Health	To measure youth perceptions and preferences on technology for HCT transfer	50%

Table continues

Beal, S. J., Riddle, I. K., Kichler, J. C., Duncan, A., Houchen, A., Casnellie, L. Corathers, S. D. (2016)	The Associations of Chronic Condition Type and Individual Characteristics with Transition Readiness.	Quantitative	Academic Pediatrics	To assess HCT readiness differences based on chronic disease type	75%
Betz, C. L., Smith, K. A., Van Speybroeck, A., Hernandez, F. V., & Jacobs, R. A. (2016)	Movin' On Up: An Innovative Nurse-Led Interdisciplinary Health Care Transition Program.	Quantitative	Journal Pediatric Nursing Health Care	To assess patient outcomes of the 'Movin up' HCT program	100%
Carroll, E. M. L. (2015)	Health Care Transition Experiences of Young Adults with Cerebral Palsy	Qualitative	Journal of Pediatric Nursing	To discover the lived meaning of HCT experiences among patients with Cerebral Palsy	100%
Cheak-Zamora, N. C., & Teti, M. (2014)	You think it's hard now … It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services.	Qualitative	Autism	To examine HCT experiences of ASD patients and their caregivers	75%
Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., \& Koegler, E. (2017)	Exploration and Comparison of Adolescents with Autism Spectrum Disorder and Their Caregiver's Perspectives on Transitioning to Adult Health Care and Adulthood.	Qualitative	Journal of Pediatric Psychology	To explore healthcare experiences as ASD patients and caregivers Transfer to Adult care	100%

Table continues

Eluri, S., Book, W. M., Kodroff, E., Strobel, M. J., Gebhart, J. H., Jones, P. D. Dellon, E. S. (2017)	Lack of Knowledge & Readiness. transition in youth with Eosinophilic Esophagitis and Eosinophilic Gastroenteritis for Health Care	Quantitative	Journal of Pediatric Gastroenterology	To measure readiness in the Esophagitis and Eosinophilic Gastroenteritis	25%
Fair, C. D., Sullivan, K., Dizney, R., \& Stackpole, A. (2012)	It's Like Losing a Part of My Family': Transition Expectations of Adolescents Living with Perinatally Acquired HIV and Their Guardians	Qualitative	AIDS Patient Care and Sexually Transmitted Disease (STD)	To explore the HCT expectations of patients and guardians in transfer to adult care	75%
Fenton, N., Ferris, M., Ko, Z., Javalkar, K., \& Hooper, S. (2015)	The relationship of health care transition readiness to disease-related characteristics, psychosocial factors, and health care outcomes: Preliminary findings in adolescents with chronic kidney disease.	Qualitative	Journal of Pediatric Rehabilitation Medicine	To assess the associated disease risk factors to HCT readiness among youth with Chronic Kidney Disease (CKD)	75%
Fernandes, S. M., O'Sullivan-Oliveira, J., Landzberg, M. J., Khairy, P., Melvin, P., Sawicki, G. S. Fishman, L. N. (2014)	Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective.	Quantitative	Journal of Pediatric Rehabilitation Medicine	To assess patient and caregiver perception of HCT chronic related services	100%

Table continues

Garvey, K. C., Wolpert, H. A., Rhodes, E. T., Laffel, L. M., Kleinman, K., Beste, M. G. Finkelstein, J. A. (2012)	Health care transition in patients with type 1 diabetes: Young adult experiences and relationship to glycemic control	Quantitative	Diabetes Care	To determine if HCT characteristics and Glycemic control are related	50%
Garvey, K. C., Finkelstein, J. A., Laffel, L. M., Ochoa, V., Wolfsdorf, J. I., & Rhodes, E. T. (2013).	Transition experiences and health care utilization among young adults with type 1 diabetes.	Quantitative	Patient Preferences and Adherence	To assess the relationship between HCT experiences and Healthcare Utilization	75%
Garvey, K. C., Beste, M., Luff, D., Atakov-Castillo, A., Wolpert, H., & Ritholz, M. (2014)	Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study.	Qualitative	Adolescent Health, Medicine and Therapeutics	To uncover HCT experiences in a post-transition Type 1 Emerging Adult Diabetic population	50%
Garvey, K. C., Foster, N. C., Agarwal, S., DiMeglio, L. A., Anderson, B. J., Corathers, S. D. Laffel, L. M. (2017)	Health Care Transition Preparation and Experiences in a U.S. National Sample of Young Adults with Type 1 Diabetes	Mixed	Diabetes Care	To field test e-survey designed to measure HCT experiences in Type 1 Diabetics before and after adult transfer	25%
Gibson-Scipio, W., Gourdin, D., \& Krouse, H. J. (2015)	Asthma Self-Management Goals, Beliefs and Behaviors of Urban African American Adolescents Prior to Transitioning to Adult Health Care	Qualitative	Journal of Pediatric Nursing	To discover HCT experiences and self-care goals among urban African-American youth with Asthma pre and post transfer	25%
Gray, W. N., Reed-Knight, B., Morgan, P. J., Holbrook, E., Kugathasan, S., Saeed, S. A., . . . Hommel, K. A. (2018).	Multi-Site Comparison of Patient, Parent, and Pediatric Provider Perspectives on HCT to Adult Care in IBD	Quantitative	Journal of Pediatric Nursing	To examine perspectives among patients, providers and parents on key areas in HCT success	75%

Table continues

Javalkar, K., Fenton, N., Cohen, S., \& Ferris, M. (2014)	Socioecological Factors as Predictors of Readiness for Self-Management and Transition, Medication Adherence, and Health Care Utilization Among Adolescents and Young Adults With Chronic Kidney Disease	Quantitative	Preventing Chronic disease	To identify whether socioecological factors predict readiness, self-care behaviors and care utilization among youth with chronic kidney disease	50%
Javalkar, K., Johnson, M., Kshirsagar, A. V., Ocegueda, S., Detwiler, R. K., \& Ferris, M. (2016)	Ecological Factors Predict Transition Readiness/Self-Management in Youth With Chronic Conditions	Quantitative	Journal of Adolescent Health	To predict which ecological factors are associated with HCT Readiness and Self-Management	100%
Jones, M. R., Frey, S. M., Riekert, K., Fagnano, M., \& Halterman, J. S. (2018)	Transition readiness for talking with providers in urban youth with asthma: Associations with medication management.	Qualitative	Journal of Adolescent Health	To determine youth readiness for talking with providers about chronic Asthmatic conditions	75%
Jolles-Perez, M., Lee, P., & Javier, J. R. (2018)	Shared decision-making and parental experiences with health services to meet their child's special health care needs: Racial and ethnic disparities	Quantitative	Patient Education and Counseling	To determine if a relationship exists between shared decision making and HCT experiences with unmet healthcare needs	100%
Kellerman Wells, C., McMorris, B. J., Horvath, K. J., Garwick, A. W., \& Scal, P. B. (2012)	Youth report of healthcare HCT counseling and autonomy from their rheumatologist.	Quantitative	Pediatric Rheumatology	To measure unmet HCT needs in youth who see Rheumatologist	75%

Table continues

Knapp, C., Huang, I. C., Hinojosa, M., Baker, K., \& Sloyer, P. (2013).	Assessing the congruence of transition preparedness as reported by parents and their adolescents with special health care needs	Quantitative	Maternal and Child Health Journal	To determine if HCT congruence between parent-child dyads and with special healthcare needs	0%
Labore, N., Mawn, B., Dixon, J., & Andemariam, B. (2017)	Exploring Transition to Self-Management Within the Culture of Sickle Cell Disease	Qualitative	Journal of Transcultural Nursing	To discover the meaning of self-care among youth with sickle cell disease	75%
Lapp, V., \& Chase, S. K. (2018)	How Do Youth with Cystic Fibrosis Perceive Their Readiness to Transition to Adult Healthcare Compared to Their Caregivers' Views?	Quantitative	Journal of Pediatric Nursing	To determine if stage of change in HCT readiness differ between patients and caregivers	75%
Lemke, M., Kappel, R., McCarter, R., D'Angelo, L., & Tuchman, L. K. (2018)	Perceptions of Health Care Transition Care Coordination in Patients With Chronic Illness.	Quantitative	Pediatrics	To determine if care coordination services supports HCT practices in general care setting among youth with Chronic illnesses	75%
Margolis, R., Wiener, L., Pao, M., Malech, H. L., Holland, S. M., \& Driscoll, P. (2017)	Transition From Pediatric to Adult Care by Young Adults With Chronic Granulomatous Disease: The Patient's Viewpoint	Qualitative	Journal of Adolescent Health	To discover the meaning of HCT for those living with Chronic Granulomatous disease (CGD)	25%

Table continues

McLaughlin, S., Bowering, N., Crosby, B., Neukirch, J., Gollub, E., \& Garneau, D. (2013)	Health Care Transition for Adolescents with Special Health Care Needs: A Report on the Development and Use of a Clinical Transition Service	Quantitative	Rhode Island Medical Journal	To pilot-test a HCT model against their healthcare utilization among emerging adults	0%
Mulchan, S. S., Valenzuela, J. M., Crosby, L. E., & Diaz Pow Sang, C. (2016)	Applicability of the SMART model of transition readiness for sickle-cell disease.	Qualitative	Journal of Pediatric Psychology	To discover if the socioecological model supports youth with unmet HCT needs in those with Sickle Cell Disease.	75%
Oswald, D. P., Gilles, D. L., Cannady, M. S., Wenzel, D. B., Willis, J. H., & Bodurtha, J. N. (2013)	Youth with special health care needs: Transition to adult health care services.	Quantitative	Maternal and Child Health Journal	To identify characteristics that define success in HCT services	75%
Paramsothy, P., , M., Lamb., K., Kinnett J. Wolff., J., M., Yang. D., Fox., Sheehan., D. (2018)	Health Care Transition Experiences of Males with Childhood-onset Duchenne and Becker Muscular Dystrophy: Findings from the Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet) Health Care Transitions and Other Life Experiences Survey	Quantitative	Current Muscular Dystrophy (PLoS)	To describe HCT experiences among youth with Duchenne Muscular Dystrophy (DMD)	75%

Table continues

Pierce, J. S., Aroian, K., Schifano, E., Milkes, A., Schwindt, T., Gannon, A., \& Wysocki, T. (2017).	Health Care Transition for Young Adults with Type 1 Diabetes: Engagement Optimal Outcomes	Mixed	Journal of Pediatric Psychology	To identify HCT predicators of among Diabetic patients, parents, and providers	25%
Polfuss, M., Babler, E., Bush, L. L., \& Sawin, K. (2015).	Family Perspectives of Components of a Diabetes Transition Program	Quantitative	Journal of Pediatric Nursing	To assess if perspectives of patients and parent dyads differ in HCT program for diabetes	75%
Porter, J. S., Wesley, K. M., Zhao, M. S., Rupff, R. J., & Hankins, J. S. (2017)	Pediatric to Adult Care Transition: Perspectives of Young Adults with Sickle Cell Disease	Qualitative	Journal of Pediatric Psychology	To retrospectively address patient attitudes on the HCT program for sickle cell patients	50%
Pyatak, E. A., Sequeira, P. A., Vigen, C. L. P., Weigensberg, M. J., Wood, J. R., Montoya, L., Peters, A. L. (2017)	Clinical and Psychosocial Outcomes of a Structured Transition Program Among Young Adults With Type 1 Diabetes	Quantitative	Journal of Adolescent Health	To determine of high-risk Lost to Follow up population differs in outcomes compared to patients in last year in pediatric care	50%
Rehm, R. S., Fuentes-Afflick, E., Fisher, L. T., \& Chesla, C. A. (2012)	Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability	Qualitative	Advanced Nursing Science	To examine the HCT planning needs of families prior to transfer	100%
Ryscavage, P., Macharia, T., Patel, D., Palmeiro, R., \& Tepper, V. (2016)	Linkage to and retention in care following healthcare transition from pediatric to adult HIV care.	Quantitative	AIDS Care	To assess retention in care following HCT to adult HIV care	75%

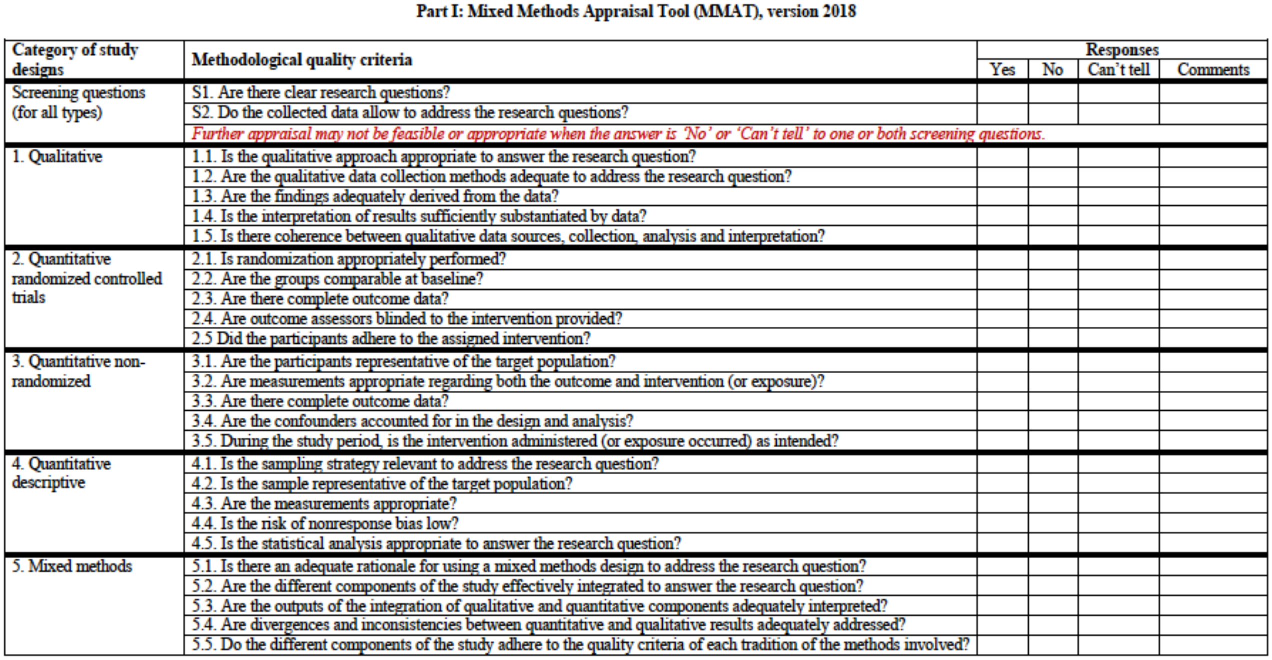
Table continues

Sawicki, G. S., Kelemen, S., \& Weitzman, E. R. (2014)	Ready, set, stop: Mismatch between self-care beliefs, transition skills, and transition planning among adolescents, young adults, and parents	Quantitative	Clinical Pediatrics	To assess the relationship between self-care and readiness among adolescents still in pediatric care.	75%
Sawin, K. J., Rauen, K., Bartelt, T., Wilson, A., O'Connor, R. C., Waring, W. P., & Orr, M. (2015)	Transitioning adolescents and young adults with spina bifida to adult healthcare: Initial findings from a model program	Qualitative	Rehabilitation Nursing	To evaluate HCT program for youth with Spina bifida	75%
Seeley, A., & Lindeke, L. (2017).	Developing a Transition Care Coordination Program for Youth with Spina Bifida	Quantitative	Journal of Pediatric Health Care	To determine if HCT readiness differences exist between and amongst in youth with chronic illnesses	0%
Sequeira, P. A., Pyatak, E. A., Weigensberg, M. J., Vigen, C. P., Wood, J. R., Ruelas, V., Peters, A. L. (2015)	Evaluation of a Structured Transition Program for Young Adults with Type 1 Diabetes	Quantitative	Diabetes Care	To assess whether a structured HCT program for Type 1 DM promotes retention in care during transition	100%
Sharma, N., Willen, E., Garcia, A., & Sharma, T. S. (2014)	Attitudes Toward Transitioning in Youth with Perinatally Acquired HIV and Their Family Caregivers	Qualitative	Journal of the Association of Nurses in AIDS Care	To uncover attitudes of youth with perinatally acquired HIV toward their preparedness to adult care	100%
Sosnowy, C., Silverman, C., \& Shattuck, P. (2017)	Parents, and young adults, perspectives on transition outcomes for young adults with autism	Qualitative	Autism	To explore of patients and caregiver attitudes toward HCT and living independently	75%

Table continues

Speller-Brown, B., Patterson Kelly, K., VanGraafeiland, B., Feetham, S., Sill, A., Darbari, D., \& Meier, E. R. (2015).	Measuring Transition Readiness: A Correlational Study of Perceptions of Parent and Adolescents and Young Adults with Sickle Cell Disease	Quantitative	Journal of Pediatric Nursing	To assess HCT readiness and the relationship between how patients and parents perceive HCT to adult care	100%
Squiers, A., Lutenbacher, M., Kaufman, M. R., \& Karp, S. M. (2017)	Transitioning to an Adult Healthcare System: Barriers and Opportunities for Youth with Spina Bifida.	Qualitative	Pediatric Nursing	To describe characteristics of HCT program for youth with Spina Bifida from family perspective	75%
Syverson, E. P., McCarter, R., He, J., D'Angelo, L., \& Tuchman, L. K. (2016)	Adolescents' Perceptions of Transition Importance, Readiness, and Likelihood of Future Success: The Role of Anticipatory Guidance	Quantitative	Clinical Pediatrics	To determine if Health Care provider discussions influenced readiness and success after HCT to adult care	75%
Vaikunth, S. S., Williams, R. G., Uzunyan, M. Y., Tun, H., Barton, C., \& Chang, P. M. (2018)	Short-term outcomes following implementation of a dedicated young adult congenital heart disease (CHD) transition program	Quantitative	Congenital Heart Disease	To determine which patient outcomes in HCT clinic/program were associated with a transfer to adult care in patients with CHD	75%

Appendix B: Mixed Methods Appraisal Tool (MMAT)

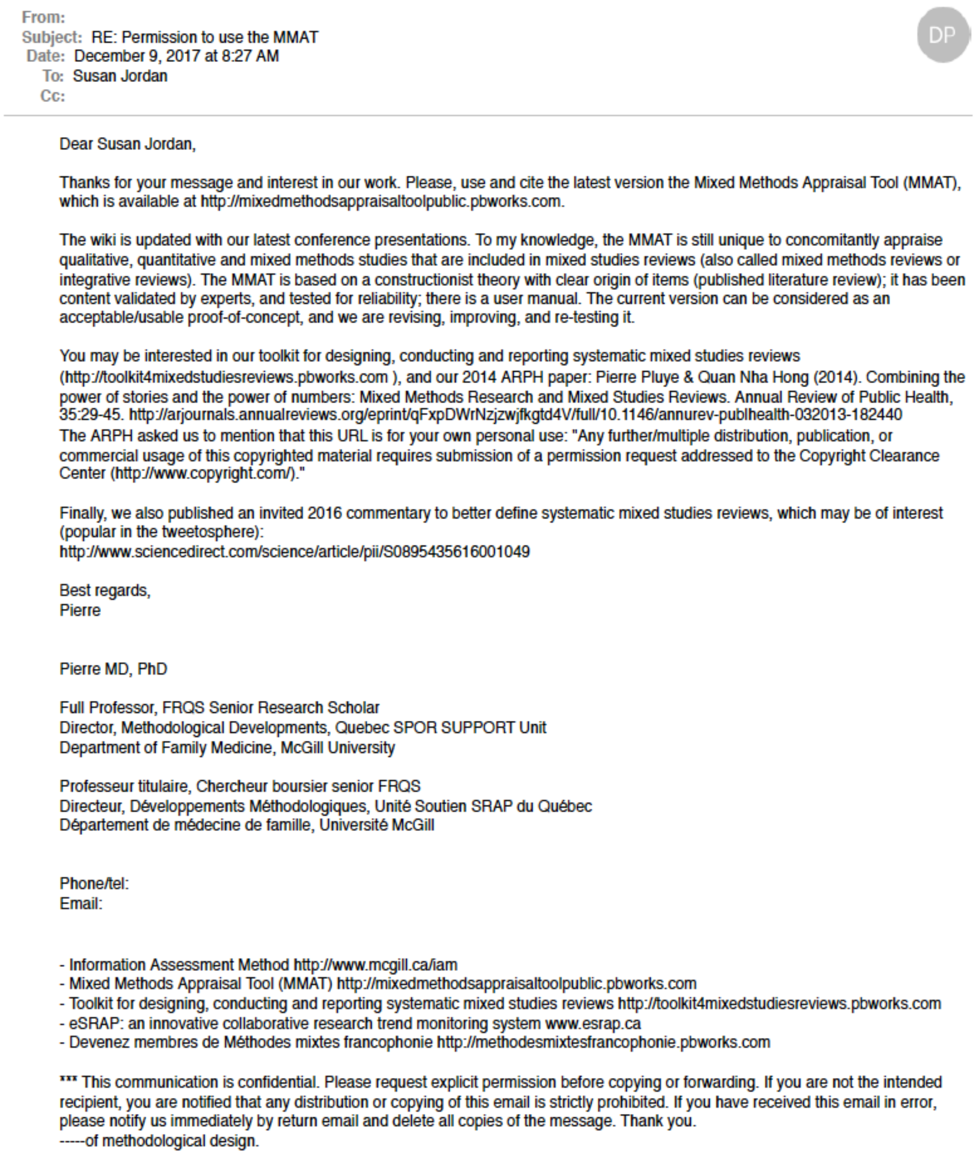


Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Appendix B. Mixed Methods Appraisal Tool (MMAT). Adapted from, "Mixed Methods Appraisal Tool" by Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, Gagnon M-P, Griffiths F, Nicolau B, O'Cathain A, Rousseau M-C, Vedel I., 2018, Canadian Intellectual Property Office, Industry Canada Copyright (#1148552). Used with permission (obtained 12-09-2017)

Appendix C: Permission to use MMAT



From:
Subject: RE: Permission to use the MMAT
Date: December 9, 2017 at 8:27 AM
To: Susan Jordan
Cc:

Dear Susan Jordan,

Thanks for your message and interest in our work. Please, use and cite the latest version the Mixed Methods Appraisal Tool (MMAT), which is available at http://mixedmethodsappraisaltoolpublic.pbworks.com.

The wiki is updated with our latest conference presentations. To my knowledge, the MMAT is still unique to concomitantly appraise qualitative, quantitative and mixed methods studies that are included in mixed studies reviews (also called mixed methods reviews or integrative reviews). The MMAT is based on a constructionist theory with clear origin of items (published literature review); it has been content validated by experts, and tested for reliability; there is a user manual. The current version can be considered as an acceptable/usable proof-of-concept, and we are revising, improving, and re-testing it.

You may be interested in our toolkit for designing, conducting and reporting systematic mixed studies reviews (http://toolkit4mixedstudiesreviews.pbworks.com), and our 2014 ARPH paper: Pierre Pluye & Quan Nha Hong (2014). Combining the power of stories and the power of numbers: Mixed Methods Research and Mixed Studies Reviews. Annual Review of Public Health, 35:29-45. http://arjournals.annualreviews.org/eprint/qFxpDWrNzjzwjfkgtd4V/full/10.1146/annurev-publhealth-032013-182440
The ARPH asked us to mention that this URL is for your own personal use: "Any further/multiple distribution, publication, or commercial usage of this copyrighted material requires submission of a permission request addressed to the Copyright Clearance Center (http://www.copyright.com/)."

Finally, we also published an invited 2016 commentary to better define systematic mixed studies reviews, which may be of interest (popular in the tweetosphere):
http://www.sciencedirect.com/science/article/pii/S0895435616001049

Best regards,
Pierre

Pierre MD, PhD

Full Professor, FRQS Senior Research Scholar
Director, Methodological Developments, Quebec SPOR SUPPORT Unit
Department of Family Medicine, McGill University

Professeur titulaire, Chercheur boursier senior FRQS
Directeur, Développements Méthodologiques, Unité Soutien SRAP du Québec
Département de médecine de famille, Université McGill

Phone/tel:
Email:

- Information Assessment Method http://www.mcgill.ca/iam
- Mixed Methods Appraisal Tool (MMAT) http://mixedmethodsappraisaltoolpublic.pbworks.com
- Toolkit for designing, conducting and reporting systematic mixed studies reviews http://toolkit4mixedstudiesreviews.pbworks.com
- eSRAP: an innovative collaborative research trend monitoring system www.esrap.ca
- Devenez membres de Méthodes mixtes francophonie http://methodesmixtesfrancophonie.pbworks.com

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-----of methodological design.

Appendix D: Complete Codebook for Integrative Review

Code	Number of Different Sources	Number of Passages that Support Codes
# of Visits unrelated to HCT preparation	3	3
Acceptability to provider and participant	3	3
Age at HCT initiation discrepancy	2	3
Communication gaps caregiver and patient	17	20
Continuity of Care	7	7
Delayed care and Stigma	3	3
Developmental Age instead of Chronological	5	7
Discrepancy between adult and pediatric care	4	4
Disparity in AEA-SHCN	19	23
elements of HCT program	3	3
Expectations gaps (provider-patient)	9	12
Factors and Advantages Strong Predictors of outcomes	13	19
Fear or loss of MH, uncertainty	5	7
Gap in HCT preparation and HCT needs	5	6
Gap in Provider Education and Young adulthood lifestyle	2	2
HCT counseling vs. Autonomy and Self-management	8	9
HCT Education programs vs. Experienced-based Learning	2	2
HCT Efficacy and outcome data	1	1
HCT Knowledge poor predictor or marker of readiness	3	5
HCT Policy and Organizational consideration	9	9
Example of Mismatch Age vs. Developmental	1	1
Extending Ages	2	2
HCT process or Transfer uncertainty	4	4

Table continues

HCT readiness limited applicability in outcomes	6	6
HCT service costs and benefit	2	2
Health Equity Missing	16	24
Health System Failures	17	19
Healthcare Utilization Rates and HCT needs	1	1
High costs to poor retention in care	2	2
High Disease burden	6	6
Insurance changes and barriers	3	3
Integration of disease in daily life	1	1
Intersectional Theory	2	2
Lack social support personal and community	6	6
Linking HCT experiences to patient outcomes	7	8
Low-income-SES	1	1
lower SES mean higher burden	1	1
Mismatch HCT needs and Provision	3	4
Mismatch HCT outcomes among stakeholders	1	1
Organizational Support	9	9
Pediatric to Adult Care Change in Climate	2	2
Perceived Quality of Care Coordination and HCT	10	10
Poorly defined HCT Roles	12	15
Population Factors as Influential in Program development	8	11
Practice of HCT and leap to outcomes	6	7
Provider Bias in healthcare decisions	7	7
Quality care and Provider Communication	3	3
Self-Sustaining HCT	2	2
Shared Decision, Patient Engagement Disparity	12	14
Socio-demographical predictors HCT planning	6	9

Table continues

Study data gathered in Post-Transition	4	4
Study originates in Adult care	2	2
Subgroups based on social advantages	3	5
System vs. patient-level change	15	22
Trained clinical staff promotes equity	7	7
Transition planning lowest for more complex patients	7	7
Untrained providers undermine health equity	9	10
Patient Responsibility literate in Healthcare	1	1
Trained Staff links to Community	2	2
Patient Burdens	4	4
Transition perceptions differ patients and caregivers	3	3
Subspecialty care vs. Primary Care	2	2
Viable Disease-specific pathway of care	9	11

Appendix E: Table of Excluded Articles for the Integrative Review

Authors/Year	Title	Study Tradition	Source	Exclusion Rationale
Afzali, A., \& Wahbeh, G. (2017)	Transition of pediatric to adult care in inflammatory bowel disease: Is it as easy as 1, 2, 3?	Review	World Journal of Gastroenterology	Expert Opinion/non-empirical
Betz, C., Smith, K. A., Macias, K., \& Deavenport-Saman, A. (2015).	Testing the Transition Preparation Training Program: Well-being of relationships outcomes	Mixed	Journal of Pediatric Rehabilitation Medicine	Does not discuss HCT experiences
Ersig, A. L., Tsalikian, E., Coffey, J., \& Williams, J. K. (2016).	Stressors in Teens with Type 1 Diabetes and Their Parents: Immediate and Long-Term Implications for Transition to Self-Management	Qualitative	Journal of Pediatric Nursing	Discussed stressors with disease but not HCT experiences
Heery, E., Sheehan, A. M., While, A. E., \& Coyne, I. (2015).	Experiences and Outcomes of Transition from Pediatric to Adult Health Care Services for Young People with Congenital Heart Disease: A Systematic Review	Quantitative	Congenital Heart Disease	Review
Hettel, D., Tran, C., Szymanski, K., Misseri, R., \& Wood, H. (2018).	Lost in transition: patient-identified barriers to adult urological spina bifida care.	Quantitative	Journal of Pediatric Urology	Studies from an adult population (>26-40 years old)

Table continues

Huang, J. S., Terrones, L., Tompane, T., Dillon, L., Pian, M., Gottschalk, M., . . . Bartholomew, L. K. (2014).	Preparing adolescents with chronic disease for transition to adult care: a technology program	Quantitative	Pediatrics	Studies the efficacy of Technology use in HCT counseling
Lotstein, D., Seid, M., Klingensmith, G., Case, D., Lawrence, J. M., Pihoker, C., Corathers, S. (2013).	Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence	Quantitative	Pediatrics	Population study on HCT services but does not discuss HCT experiences
Okumura, M. J., Hersh, A. O., Hilton, J. F., \& Lotstein, D. S. (2013)	Change in health status and access to care in young adults with special health care needs: results from the 2007 national survey of adult transition and health.	Quantitative	Journal of Adolescent Health	Discussed changes in health status and not HCT experiences
Schwartz, L. A., Brumley, L. D., Tuchman, L. K., Barakat, L. P., Hobbie, W. L., Ginsberg, J. P., Deatrick, J. A. (2013)	Stakeholder validation of a model of readiness for transition to adult care.	Mixed Method	Journal of American Medical Association Pediatrics	Did not discuss HCT experiences with all groups
Singh, S. P., \& Tuomainen, H. (2015).	Transition from child to adult mental health services: needs, barriers, experiences and new models of care	Qualitative	World Psychiatry	Study originated outside of the United States
Stephany, H. A., Ching, C. B., Kaufman, M. R., Squiers, A., Trusler, L., Clayton, D. B., Tanaka, S. T. (2015)	Transition of urologic patients from pediatric to adult care: a preliminary assessment of readiness in spina bifida patients.	Qualitative	Urology	Uses combination of secondary and empirical data

Table continues

Stollon, N., Zhong, Y., Ferris, M., Bhansali, S., Pitts, B., Rak, E.,van Tilburg, M. A. L. (2017)	Chronological age when healthcare transition skills are mastered in adolescents or adults with inflammatory bowel disease.	Quantitative	World Journal of Gastroenterology	Discusses characteristics and measures of self-care skill but does not discuss HCT experiences
Swift, K. D., Hall, C. L., Marimuttu, V., Redstone, L., Sayal, K., \& Hollis, C. (2013).	Transition to adult mental health services for young people with Attention Deficit/Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences	Qualitative	BMC Psychiatry	Outside of the United States

Appendix F: Table of the Moderate Frequency Codes

Codes		Number of Different Sources		Number of Passages that support Codes
Continuity of Care		7		7
Expectations gaps		9		12
Factors and Advantages Strong Predictors of outcomes		13		19
HCT counseling vs. Autonomy and Self-management		8		9
Developmental Age instead of Chronological		5		7
Fear or loss of care and uncertainty		5		5
Gap in HCT preparation and HCT needs		5		6
High Disease burden		6		6
Lack of social support familial and community access		6		6
Link HCT experiences to patient outcomes		7		8
Practice of HCT and leap to outcomes		6		7
Trained clinical staff promotes health equity		7		7
HCT Policy and Organizations		9		9
HCT readiness limited applicability in outcomes		6		6
Organizational Support		9		9
Untrained providers undermine health equity		9		10
Perceived Quality of Care Coordination and HCT		10		10
Viable Disease-specific pathway of care		9		10
Programs reflect Populations		8		11
Provider bias decision-making		7		7
Social factors in HCT planning		6		9
Low planning in complex patients		7		7

Appendix G: Table of the Least Frequent Codes

Codes	Number of Different Sources	Number of Passages support Codes
Visits and HCT preparation	3	3
Program acceptable	3	3
Age at HCT initiation	2	3
Delayed care and Stigma	3	3
Changes in adults and pediatrics	4	4
Elements of HCT program	3	3
Provider Gaps in youth daily life	2	2
HCT Education programs vs. Experienced-based Learning	2	2
HCT Efficacy and outcome data	1	1
Transition Knowledge and readiness limits	3	5
Mismatch Age vs. Development	1	1
Extending Ages	2	2
HCT/Transfer uncertainty	4	4
HCT service costs and benefit	2	2
Utilization and HCT needs	1	1
Costs to poor retention	2	2
Insurance changes/barriers	3	3
Integrate disease lifestyle	1	1
Intersectional Theory	2	2
Low SES access disadvantage	1	1
Higher burden in Low SES	1	1
Mismatches Needs/Provision	3	4
Mismatch Outcome Perceptions	1	1
Pediatric to Adult Climate	2	2
Quality Communication/care	3	3
Self-Sustaining HCT	2	2
Post-Transition data	4	4
Study originates in Adult care	2	2
Social advantages groups	3	5
Subspecialty care/Primary Care	2	2
Patient Burdens	4	4
Patient responsibility literacy	1	1
Staff with Community access	2	2
Transition perceptions differ patients and caregivers	3	3

Appendix H: Combined IR Major, Moderate and Minimal Source Codes

Communication gaps
Incompatible HCT expectations Lack of provider education on young adults (provider-patient) #Visits unrelated to HCT preparation
Disparity in the AEA-SHCN population healthcare service provisions
Continuity of care/collaboration Lacking in quality of care Limited coordination of care Limits in how population influences program development Practice of HCT does not necessarily lead to leaps in outcomes Mismatch provision/needs
Health Equity
Limits HCT planning for complex patients Lack of Provider Training and links to community resources Provider bias and stigma/intersectional theory Extending ages in pediatric care
Health System Failures
HCT Policy and organizational consideration HCT readiness limited applicability in outcomes Cost to poor retention/utilization Lack of self-sustaining models
Poorly defined Roles
High disease burden Uncertainty in HCT process (Who does what?) Acceptability to provider and participant
Shared Decision-Patient Engagement Disparity
HCT counseling vs. Autonomy and Self-management education Lack social support-Family and community Age HCT initiation Integration of Self-care daily life-skills programs Responsibility and Health literacy Mismatch in HCT perceptions
System vs. patient-level change
Viable Disease-specific pathway of care Linking HCT experiences to patient outcome Poorly developed HCT Infrastructure (Pediatric and Adult care) Differences between Pediatric and Adult care cultures Insurance changes and barriers entering adulthood HCT Education programs vs. Experienced-based Learning

Appendix I: Table of Selected Thematic Synthesis Articles

Applebaum, M. A., Lawson, E. F., & Von Scheven, E. (2013)	Perception of transition readiness and preferences for use of technology in transition programs: Teens' ideas for the future	Mixed	International Journal of Adolescent Medicine and Health	To measure youth perceptions and preferences on technology use for HCT transfer	50%
Carroll, E. M. L. (2015)	Health Care Transition Experiences of Young Adults with Cerebral Palsy	Qualitative	Journal of Pediatric Nursing	To discover the lived meaning of HCT experiences among patients with Cerebral Palsy	100%
Cheak-Zamora, N. C., & Teti, M. (2014)	You think it's hard now … It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services.	Qualitative	Autism	To examine HCT experiences of ASD patients and their caregivers	75%
Fair, C. D., Sullivan, K., Dizney, R., \& Stackpole, A. (2012)	It's Like Losing a Part of My Family': Transition Expectations of Adolescents Living with Perinatally Acquired HIV and Their Guardians	Qualitative	AIDS Patient Care and Sexually Transmitted Disease (STD)	To explore the HCT expectations of patients and guardians in transfer to adult care	75%
Garvey, K. C., Beste, M., Luff, D., Atakov-Castillo, A., Wolpert, H., & Ritholz, M. (2014)	Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study.	Qualitative	Adolescent Health, Medicine and Therapeutics	To uncover HCT experiences in a post-transition Type 1 Emerging Adult Diabetic population	50%

Table continues

Garvey, K. C., Wolpert, H. A., Rhodes, E. T., Laffel, L. M., Kleinman, K., Beste, M. G. Finkelstein, J. A. (2012)	Health care transition in patients with type 1 diabetes: Young adult experiences and relationship to glycemic control	Quantitative	Diabetes Care	To determine if HCT characteristics and Glycemic control are related	50%
Jolles-Perez, M., Lee, P., & Javier, J. R. (2018)	Shared decision-making and parental experiences with health services to meet their child's special health care needs: Racial and ethnic disparities	Quantitative	Patient Education and Counseling	To determine if a relationship exists between shared decision making and HCT experiences with unmet healthcare needs	100%
Lemke, M., Kappel, R., McCarter, R., D'Angelo, L., & Tuchman, L. K. (2018)	Perceptions of Health Care Transition Care Coordination in Patients with Chronic Illness.	Quantitative	Pediatrics	To determine if care coordination services supports HCT practices in general care setting among youth with Chronic illnesses	75%
Margolis, R., Wiener, L., Pao, M., Malech, H. L., Holland, S. M., \& Driscoll, P. (2017)	Transition from Pediatric to Adult Care by Young Adults With Chronic Granulomatous Disease: The Patient's Viewpoint	Qualitative	Journal of Adolescent Health	To discover the meaning of HCT for those living with Chronic Granulomatous disease (CGD)	25%
Polfuss, M., Babler, E., Bush, L. L., \& Sawin, K. (2015).	Family Perspectives of Components of a Diabetes Transition Program	Quantitative	Journal of Pediatric Nursing	To assess if perspectives of patients and parents' dyads differ in HCT program for diabetes	75%

Table continues

Porter, J. S., Wesley, K. M., Zhao, M. S., Rupff, R. J., & Hankins, J. S. (2017)	Pediatric to Adult Care Transition: Perspectives of Young Adults with Sickle Cell Disease	Qualitative	Journal of Pediatric Psychology	To retrospectively address patient attitudes on the HCT program for sickle cell patients	50%
Rehm, R. S., Fuentes-Afflick, E., Fisher, L. T., \& Chesla, C. A. (2012)	Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability	Qualitative	Advanced Nursing Science	To examine the HCT planning needs of families prior to transfer	100%
Sharma, N., Willen, E., Garcia, A., & Sharma, T. S. (2014)	Attitudes Toward Transitioning in Youth with Perinatally Acquired HIV and Their Family Caregivers	Qualitative	Journal of the Association of Nurses in AIDS Care	To uncover attitudes of youth with perinatally acquired HIV toward their preparedness to adult care	100%
Sosnowy, C., Silverman, C., \& Shattuck, P. (2017)	Parents, and young adults, perspectives on transition outcomes for young adults with autism	Qualitative	Autism	To explore attitudes of patients and their caregivers have toward HCT and living independently	75%

Appendix J: Table of Codes in Thematic Synthesis

Code
Act like adult, treated like adult
Autistic patients lack independence in healthcare as a predictor of dependence
Autonomy, Independence and Family support Dilemma
Care coordination burden falls to patients
Caregiver and Youth fear change and difficulty in communication in adult care system
Caregivers lack support from system and express disappointment in provider role
Fear of leaving due to poor access in patients with Autism
Caregivers unawareness of legal transition at 18; limited support
Chronological transition navigation guardianship lacks preparation and support
Disease specific patient concerns unacknowledged
Gaps in communication between patient and parent in future role at age of majority
HCT approaches and lack of health equity considerations
HCT defined broadly and embedded in more life Skills
HCT to adult care does not correlate with improved disease outcomes
Intersection of HCT policy and system change
Lack of system-based HCT care
Long term emphasis with healthcare as one aspect in comprehensive care and support
*Loss, uncertainty and change in system patient knew and understood
Mismatch and communication gaps between patient, provider and caregiver
Mismatch in HCT goals and services
Mismatch in understanding how youth learn best
Missing research on patient-provider relationship
Negative perceptions of adult care and lack of provider support
Not wanting to grow up
Parent-Caregiver-patient dyads similar concerns and HCT program improvements
Patient Stigma associated with disease and utilization by providers
Perceptions of pediatric vs adult care disparity
Poorly educated providers in adult care
*Poorly established partnership between pediatric and adult care
Provider role, patient role confusion or patient unaware
Provider stigma assumptions last effect on patient relationship with care system
Providers lack skill set, disease specific training and incentive to support HCT youth
Provision of services, support and termination in care represent poor health equity
*Trust, sensitivity and relationship loss change in system

Table continues

Young adult years vulnerable to loss in care
Youth unaware of the HCT process and their role and provider's role

[*] denotes most prevalent themes in both range and frequency

Appendix K: Table of Sources and Range of Codes in Thematic Synthesis

Author, year	Number of Different Codes Used	Number of Supporting References/Passages
Sosnowy et al., (2017)	5	9
Sharma et al, (2014)	8	9
Rehm et al., (2012)	6	7
*Porter et al., (2017)	12	14
Polfuss et al., (2015)	2	3
Margolis et al., (2017)	8	9
Lemke et al., (2018)	5	7
Jolles-Perez al., (2018)	6	8
*Garvey et al. (2014)	13	16
Garvey et al., (2012)	6	7
*Fair et al., (2012)	12	15
*Cheak-Zamora et al., (2015)	18	23
Carroll (2015)	6	7
Applebaum (2013)	5	5

* denotes authors with most prevalence in both range and number of codes

Appendix L: Complete Codebook for Thematic Synthesis by Code

Code	Number of Different Sources	Number of Passages that support Codes
Act like adult, treated like adult	1	1
Advance care planning overlooked	1	1
ASD lack of independence in healthcare predictor of long-term dependence	1	1
Assumptions and adult care implication of delay HCT until 20s,	1	1
Autonomy, Independence and Family support Dilemma	4	4
Care coordination burden falls to patients	1	1
Caregiver and Youth fear change and difficulty in communication in adult care system	3	4
Caregivers lack support from system and express disappointment in provider role in ASD and fear poor access because of this	4	4
Caregivers unawareness legal transition at 18; limited support	1	1
Chronological transition navigation guardianship lacks preparation and support	1	1
Delayed HCT but still teach skills	2	2
Disease complexity coordination services positively influences patient level transition activation	1	2
Disease specific patient concerns unacknowledged	2	2

Table continues

Disparity in healthcare treatment by providers increases dissatisfaction by minority patients	1	3
Gaps in communication between patient and parent in future role at age of majority	2	4
HCT approaches and lack of health equity considerations	3	3
HCT defined broadly and embedded in more Life Skills	3	5
HCT goals relate to independence from parent support	2	5
HCT to adult care does not correlate with improved disease outcomes	2	3
Highest complexity receiving most benefit	1	2
Intersection of HCT policy and System Change	2	2
Intersection of race, disease, system and provider bias	1	1
Lack of system-based HCT care	1	1
Long term emphasis with healthcare as one aspect in comprehensive care and support	5	5
Loss, uncertainty and change in system patient knew and understood	4	6
Mismatch and communication gaps between patient, provider and caregiver	1	1
Mismatch in HCT goals and services	2	3
Mismatch in understanding how youth learn best	1	2
Missing research on patient-provider relationship	1	1
Negative perceptions of adult care and lack of	3	3

Table continues

provider support		
Not wanting to grow up	1	1
Parent beliefs HCT goal include employment and community involvement	1	1
Parent-Caregiver-patient Dyads Similar concerns and HCT program improvements	2	2
Patient low self-care skill	1	1
Patient poor awareness symptoms and disease	1	1
Patient Stigma associated with disease and utilization by providers	2	3
Patients accepting Less from system	1	1
Patients learn system as they go	1	1
Perceptions of pediatric vs adult care disparity	3	3
Poor awareness of insurance needs or change	1	1
Poorly educated providers in adult care	2	2
Poorly established partnership between pediatric and adult care	5	6
Poorly prepared youth reduces impact of family centered care	1	1
privacy concerns and uncertainty with new medical system	1	1
Provider role, patient role confusion or patient unaware	2	3
Provider stigma assumptions last effect on patient relationship with care system	4	4
Providers lack skill set, disease specific training and incentive to support HCT youth	3	3
Provision of services, support and termination in care represent poor health	3	3

Table continues

equity		
Reaching out health information unreliable sources (internet)	1	1
Reoccurring and Universal indicates systems problems	1	1
Self-care skill limited to medication and urgent care	1	1
Self-management and self-efficacy can influence disease outcomes	1	2
System vs. Patient level specificity in determining barriers to HCT	2	4
Trust, sensitivity and relationship loss change in system	4	5
Uninterrupted care as a habit for patient	1	1
Young adult see independence as making own decisions and control over how spend time	3	3
Young adult years vulnerable to loss in care	2	4
Youth unaware of the HCT process and their role and provider's role	3	4

Appendix M: Complete Codebook for Thematic Synthesis by Source

Source	Applebaum (2013)	Carroll (2015)	Cheak-Zamora (2015)	Fair, (2012)	Garvey (2012)	Garvey (2014)	Jolles-Perez (2018)	Lemke (2018)	Margolis (2017)	Polfuss (2015)	Porter (2017)	Rehm (2012)	Sharma (2014)	Sosnowy (2017)
1. Act like adult, treated like adult	0	0	0	1	0	0	0	0	0	0	0	0	0	0
2. Advance Directive care planning overlooked	0	0	0	0	0	0	0	0	1	0	0	0	0	0
3. Autistic patients lack independence in healthcare as a predictor of dependence	0	0	1	0	0	0	0	0	0	0	0	0	0	0
4. Assumptions and adult care implication of delay HCT until 20s,	0	0	0	0	0	0	0	0	0	0	0	1	0	0
5. Autonomy, Independence and Family support Dilemma	0	0	0	0	0	0	0	0	1	0	1	0	1	1
6. Care coordination	0	0	1	0	0	0	0	0	0	0	0	0	0	0

Table continues

burden falls to patients														
7. Caregiver and Youth fear change and difficulty in communication in adult care system	0	0	1	1	0	0	0	0	0	0	0	0	2	0
8. Caregivers lack support from system and express disappointment in provider role in ASD and fear poor access because of this	0	0	1	1	0	1	0	0	0	0	0	0	1	0
9. Caregivers unawareness legal transition at 18; limited support	0	0	1	0	0	0	0	0	0	0	0	0	0	0
10. Chronological transition navigation guardianship lacks preparation and support	0	0	1	0	0	0	0	0	0	0	0	0	0	0
11. Delayed HCT but still teach skills	0	0	0	0	0	0	0	0	1	0	0	0	1	0

Table continues

12. Disease complexity coordination services positively influences patient level transition activation	0	0	0	0	0	0	0	2	0	0	0	0	0	0
13. Disease specific patient concerns unacknowledged	0	0	0	0	0	0	0	1	0	0	1	0	0	0
14. Disparity in healthcare treatment by providers increases dissatisfaction by minority patients	0	0	0	0	0	0	3	0	0	0	0	0	0	0
15. Gaps in communication between patient and parent in future role at age of majority	0	0	3	0	0	0	0	0	0	0	0	1	0	0
16. HCT approaches and lack of health equity considerations	0	1	0	1	0	1	0	0	0	0	0	0	0	0

Table continues

17. HCT defined broadly and embedded in more Life Skills	0	0	0	0	0	2	0	0	0	0	1	2	0	0
18. HCT goals relate to independence from parent support	0	0	0	0	1	0	0	0	0	0	0	0	0	4
19. HCT to adult care does not correlate with improved disease outcomes	0	0	0	0	2	1	0	0	0	0	0	0	0	0
20. Highest complexity receiving most benefit	0	0	0	0	0	0	0	2	0	0	0	0	0	0
21. Intersection of HCT policy and System Change	0	0	1	0	0	0	0	0	0	0	0	1	0	0
22. Intersection of race, disease, system and provider bias	0	0	0	0	0	0	1	0	0	0	0	0	0	0
23. Lack of system-based HCT care	0	0	0	0	0	1	0	0	0	0	0	0	0	0
24. Long term emphasis with	0	0	0	0	0	0	0	1	1	1	1	0	1	0

Table continues

healthcare as one aspect in comprehensive care and support														
25. Loss, uncertainty and change in system patient knew and understood	0	0	2	2	0	1	0	0	0	0	0	1	0	0
26. Mismatch and communication gaps between patient, provider and caregiver	0	0	1	0	0	0	0	0	0	0	0	0	0	0
27. Mismatch in HCT goals and services	0	0	1	0	0	0	0	0	0	0	0	0	0	2
28. Mismatch in understanding how youth learn best	0	0	0	0	0	0	0	0	0	0	2	0	0	0
29. Missing research on patient-provider relationship	0	0	0	0	0	0	0	0	0	0	1	0	0	0
30. Negative perceptions of adult care and lack of provider support	0	0	0	0	0	1	1	0	0	0	1	0	0	0

Table continues

31. Not wanting to grow up	0	0	0	1	0	0	0	0	0	0	0	0	0	0
32. Parent beliefs HCT goal include employment and community involvement	0	0	0	0	0	0	0	0	0	0	0	0	0	1
33. Dyads (Parent patient) Share HCT program improvements	0	0	0	1	0	0	0	0	0	0	0	0	1	0
34. Patient low self-care skill	1	0	0	0	0	0	0	0	0	0	0	0	0	0
35. Patient poor awareness symptoms and disease	1	0	0	0	0	0	0	0	0	0	0	0	0	0
36. Patient Stigma associated with disease and utilization by providers	0	0	0	0	0	0	1	0	0	0	2	0	0	0
37. Patients accepting Less from system	0	1	0	0	0	0	0	0	0	0	0	0	0	0
38. Patients learn as they go	0	1	0	0	0	0	0	0	0	0	0	0	0	0

Table continues

39. Perceptions of pediatric vs adult care disparity	0	0	0	0	0	1	1	0	0	0	1	0	0	0
40. Poor awareness of insurance needs or change	1	0	0	0	0	0	0	0	0	0	0	0	0	0
41. Poorly educated providers in adult care	0	0	1	0	0	1	0	0	0	0	0	0	0	0
42. Poorly established partnership between pediatric and adult care	0	0	0	2	1	1	0	0	1	0	1	0	0	0
43. Poorly prepared youth reduces impact of family centered care	0	0	0	0	0	0	0	0	1	0	0	0	0	0
44. Privacy concerns and uncertainty with new medical system	0	0	0	0	0	0	0	0	0	0	0	0	1	0
45. Provider role, patient role confusion or patient unaware	0	0	2	0	0	1	0	0	0	0	0	0	0	0

Table continues

46. Provider stigmas based on preconceived notions or assumptions have a lasting effect on patient relationship with care system	0	1	1	0	0	0	1	0	0	0	1	0	0	0
47. Providers lack skill set in caring for adolescents and disease specific training and incentives to support HCT youth	0	0	1	1	0	0	0	0	0	0	1	0	0	0
48. Provision of services, support and termination in care represent poor health equity	0	0	1	1	1	0	0	0	0	0	0	0	0	0
49. Reaching out health information unreliable sources (internet)	1	0	0	0	0	0	0	0	0	0	0	0	0	0
50. Reoccurring and Universal systems	0	1	0	0	0	0	0	0	0	0	0	0	0	0

Table continues

problems despite disease -specific pathway of care														
51. Self-care skill limited to medication and urgent healthcare needs	1	0	0	0	0	0	0	0	0	0	0	0	0	0
52. Self-management and self-efficacy can influence disease outcomes	0	0	0	0	0	0	0	0	0	2	0	0	0	0
53. System vs. Patient level specificity in determining barriers to HCT	0	2	0	0	0	0	0	0	2	0	0	0	0	0
54. Trust, sensitivity and relationship losses signal fear and change in system	0	0	1	2	0	1	0	0	0	0	0	0	1	0
55. Uninterrupted care as a habit for patient care	0	0	0	0	1	0	0	0	0	0	0	0	0	0
56. Young adult see independence as making own	0	0	0	0	1	0	0	0	1	0	0	0		1

Table continues

decisions and control over how spend time														
57. Young adult years vulnerable to loss in care	0	0	0	0	0	3	0	1	0	0	0	0	0	0
58. Youth unaware of the HCT process and their role and provider's role	0	0	2	1	0	0	0	0	0	0	0	1	0	0

Appendix N: Thematic Hierarchy by Source and Code

Source	Cheak-Zamora (2015)	Fair, (2012)	Garvey (2014)	Porter (2017)	Hierarchy Code Support
Act like adult, treated like adult	0	1	0	0	1
Autistic patients lack independence in healthcare as a predictor of dependence	1	0	0	0	1
Autonomy, Independence and Family support Dilemma	0	0	0	1	1
Care coordination burden falls to patients	1	0	0	0	1
Caregiver and Youth fear change and difficulty in communication in adult care system	1	1	0	0	2
Caregivers lack support from system and express disappointment in provider role in ASD and fear poor access because of this	1	1	1	0	3
Caregivers unawareness legal transition at 18; limited support	1	0	0	0	1

Table continues

Chronological transition navigation guardianship lacks preparation and support	1	0	0	0	1
Disease specific patient concerns unacknowledged	0	0	0	1	1
Gaps in communication between patient and parent in future role at age of majority	3	0	0	0	3
HCT approaches and lack of health equity considerations	0	1	1	0	2
HCT defined broadly and embedded in more Life Skills	0	0	2	1	3
HCT to adult care does not correlate with improved disease outcomes	0	0	1	0	1
Intersection of HCT policy and System Change	1	0	0	0	1
Lack of system-based HCT care	0	0	1	0	1
Long term emphasis with healthcare as one aspect in comprehensive care and support	0	0	0	1	1
*Loss, uncertainty and change in system patient knew and understood	2	2	1	0	5*

Table continues

Mismatch and communication gaps-patients, providers parents	1	0	0	0	1
Mismatch in HCT goals	1	0	0	0	1
Mismatch in understanding how youth learn best	0	0	0	2	2
Missing research on patient-provider relationship	0	0	0	1	1
Negative perceptions of adult care and lack of provider support	0	0	1	1	1
Not wanting to grow up	0	1	0	0	1
Parent-Caregiver-patient Dyads Similar concerns and HCT program improvements	0	1	0	0	1
Patient Stigma associated with disease and utilization by providers	0	0	0	2	2
Perceptions of pediatric vs adult care disparity	0	0	1	1	1
Poorly trained adult providers	1	0	1	0	2
*Poorly established partnership pediatric and adult care	0	2	1	1	4*
Provider role, patient role confusion or patient unaware	2	0	1	0	3

Table continues

Provider stigma assumptions last effect on patient relationship with care system	1	0	0	1	2
Providers lack skill set, disease specific training and incentive to support HCT youth	1	1	0	1	3
Provision of services, support and termination in care represent poor health equity	1	1	0	0	2
*Trust, sensitivity and relationship loss change in system	1	2	1	0	4*
Young adult years vulnerable to loss in care	0	0	3	0	3
Youth unaware of the HCT process and their role and provider's role	2	1	0	0	3