TRANSITION CARE FOR YOUNG ADULTS WITH COMPLEX CHRONIC CONDITIONS EXITING PEDIATRIC CARE: IMPLICATIONS FOR PRIMARY CARE PROVIDERS

by

Emily Sarah Leake

BScN, Langara College, 2010

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Abstract

Due to advances in medicine, more children with complex chronic conditions are living longer requiring them to transition into adult health services. The health care transition process can be inconsistent due to inadequate planning, poor service coordination or absent because of a lack of resources, and gaps in professional experience, education and training. This process is further complicated by the physical and psychosocial changes associated with adolescence. Such changes result in challenges with treatment and disengagement with care. For adolescent populations with a specific disease i.e. diabetes, focused transition programs exist that involve primary and specialist providers with expertise. However, in those with co-morbidities transition programs are limited or absent resulting in young adults with complex chronic conditions leaving pediatric specialty services without a coordinated approach to their care. In conjunction with specialist provider changes there is little information available to guide primary care providers as to how to coordinate care for these young adults during this critical time of change. The purpose of this capstone is to identify strategies that primary care providers can use to enhance the transition process for young adults with complex chronic conditions exiting out of pediatric services. Twelve articles were analyzed utilizing Whittemore and Knafl's (2005) approach to the integrative literature review. Results suggest that the transition process for this population are multifaceted, but are largely affected by a fragmented health system that impedes communication and coordination of care. Primary care providers are encouraged to be aware of the impact these factors have on the quality of care and health outcomes of their clients. Further, recommendations for enhancing the transition process are discussed, and strategies for the primary care setting are presented.

Keywords: primary care, health care transition, complex chronic conditions

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Glossary

Adolescence: The period of life between childhood and the world of work, independence, and adulthood. It begins with the onset of puberty and ends when an adult identity and behaviors are attained (Canadian Pediatric Society [CPS], 2003; Paone & Whitehouse, 2011).

Congenital anomalies: Abnormalities that are present at birth, even if not diagnosed until months or years later. They are usually structural in nature and can be present from the time of conception, but largely occur in the embryonic period or in the early fetal period (Public Health Agency of Canada [PHAC], 2014).

Chronic: Persisting for more than 3 months, often for the remainder of a person's lifetime (Myers et al., 2006).

Co-morbidities: The presence of one or more additional diseases co-occurring with a primary disease (Valderas, Starfield, Sibbald, Salibury, & Roland, 2009).

Complex Chronic Conditions: Any medical condition that can reasonably be expected to last at least 12 months (unless death intervenes) and involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center (Freudtner, Christakis, & Connell, 2000; Goossens, Bovijn, Gewillig, Budts, & Moons, 2016).

Family Centered Care: A philosophical approach that respects and supports the central role that families play in their young adult's life. It is care marked by respect, information sharing, collaboration, confidence building and family to family support (Paone & Whitehouse, 2011).

Family Nurse Practitioner: Registered nurses who have successfully completed graduate level education and training in advanced practice nursing. They provide care from a holistic nursing perspective, integrated with the autonomous diagnosis and treatment of acute and chronic illnesses, including prescribing medications and interpreting diagnostic tests (British Columbia College of Nurse Professionals [BCCNP], 2018b).

Health Care Transition: The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to the adult-oriented health care system (Blum et al., 1993).

Health Promotion: Health promotion is the process of enabling people to increase control over, and to improve their health (World Health Organization [WHO], 1998).

Multidisciplinary: When professionals from various disciplines work together to provide continuous, comprehensive care that addresses as many of the patient's needs as possible (Mitchell, Tieman & Shelby-James, 2008).

Multimorbidity: Having two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life and that require complex healthcare management, decision-making, or coordination (National Quality Forum, 2012, p.7).

Pediatrician: A doctor who specializes in the care of infants, children, and adolescents up to approximately age 19 years. Like other medical specialists, pediatricians train for an additional 4 to 6 years after obtaining their medical degree. General pediatricians see patients with a wide range of problems, such as prematurity, acute and chronic medical illnesses, developmental disorders, mental health challenges, diabetes, cancer, complex heart disease, asthma and allergies (British Columbia Pediatric Society [BCPS], n.d.).

Pediatric Subspecialist: A pediatrician who cares for infants, children, and adolescents with very specific and/or complex needs (BCPS, n.d.).

Patient Centered Care: An approach to care where the patient's specific health needs and desired health outcomes are the driving force behind all health care decisions. A mutual partnership between patients and health care providers ensures that providers treat patients from both a medical and psychosocial perspective including their emotional, mental, spiritual, social and financial needs (Canadian Interprofessional Health Collaborative, 2009).

Primary Care: The delivery of community-based clinical health-care services (Canadian Nurses Association [CNA], 2015).

Primary Care Provider: Health professionals trained in family medicine, who take primary responsibility for an established group of patients for whom they provide: longitudinal person-focused care; comprehensive care for most health needs, first contact assessment for new health care needs; and referral and coordination of care when it must be sought elsewhere (BCCNP, 2018a).

Primary Health Care: Essential health care (promotive, preventative, rehabilitative, and supportive) that focusses on preventing illness and promoting health with optimal individual and community involvement. It is both a philosophy and approach that provides a framework for health care delivery systems (BCCNP, 2018a).

Self-management: Is the patient's ability to manage a chronic health condition through problem-solving, decision-making, and self-tailoring. Self-management can be supported by knowledge-based education, psychological treatment, and technical skill building (Paone & Whitehouse, 2011, p.14).

Shared Care: Combines the skills and knowledge of a range of health professionals who share joint responsibility to manage an individual’s condition. It also includes monitoring and exchanging patient data and sharing skills and knowledge between disciplines (Paone & Whitehouse, 2011, p.14).

Transfer: A discrete event occurring within transition involving the actual hand-off from pediatric to adult provider (Gray, Schaefer, Resmini-Rawlinson, & Wagoner, 2018).

Transition Care: The work undertaken by health care providers to prepare youth with chronic health conditions for the adult health care system and the management of their health condition into adulthood (Gravelle, Davidson, & Chilvers, 2012).

Transition Readiness: The process of building the capacity of adolescents and those involved in their care to prepare for, enter, continue, and complete transition. It involves multiple components, is measurable and potentially modifiable (Campbell et al., 2016).

Young Adults: A newly recognized stage in later adolescents into young adulthood, from 18-24 years of age, distinctly different from both adolescence and adulthood behaviorally, demographically and subjectively. Although they feel they should make their own decision, “emerging adults” may not yet feel committed to adult standards of behavior and an adult level of responsibly (Paone & Whitehouse, 2011, p.13).

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Chapter I: Introduction

This chapter offers an introduction to the key areas within this literature review. Specifically, it introduces the ideas, concepts and challenges linked to: the aim and rationale of health care transition; offers an introduction to complex health conditions; situates the complexity of chronic conditions in clinical practice and patient experience discourse; and discusses the role of primary health care in transition and ongoing care of young adults with complex chronic conditions.

The transition to adulthood is a critical time for everyone to build independence, experience new things, and become self-sufficient. Individuals with complex chronic conditions withstand additional challenges as during this stage of life they also risk facing a discontinuity of care (Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009). A complex chronic condition is defined "as any medical condition that can reasonably be expected to last at least 12 months and involves either several different organ systems or one organ system severely enough to require specialty care, decision-making, or coordination" (Goossens et al., 2016; National Quality Forum, 2012, p. 7). Health care transition is recognised as a challenging process that involves facilitating appropriate levels of independence and support for these young adults, with the goal of achieving optimal health and quality of life (Child Health BC, 2018). Therefore, as these individuals mature to adulthood, it is crucial that their clinical care remains comprehensive, coordinated and uninterrupted.

The continuous advancement of pediatric health services and medical technology have contributed to an increased life expectancy for children living with various complex chronic conditions, enabling them to live much longer, into adulthood (Goossens et al., 2016;

Roebroeck et al., 2009). While advances in health care have provided breakthrough treatments for patients, they also pose a new challenge in that an increased number of young adults with complex chronic conditions transition from pediatric to adult-oriented care. Over 2,000 young adults with chronic and ongoing medical needs are discharged from pediatric care each year in British Columbia (BC) (Child Health BC, 2018). Such increases in survival rates into young adulthood have increased populations of adults living with complex chronic health conditions by more than 60% over the past decade (Child Health BC, 2018).

As a result of increased survivorship the mapping and reporting of outcomes, following transition, for young adults with complex conditions, is a developing area of research (Zhou, Roberts, Dhaliwal, & Della, 2016). Literature has shown that many young adults with complex chronic conditions do not receive adequate preparation or guidance to help them successfully transition to adult-oriented services resulting in fragmented care and poor health outcomes (Kuo, Ciccarelli, Sharma, & Lotstein, 2017; McManus, Fox, O'Connor, Chapman, & MacKinnon, 2008; Paone & Whitehouse, 2011). Within the context of the general BC population, 4.8 billion (Statistics Canada, 2018), the numbers of young adults with complex chronic conditions, albeit small, is increasing. In light of emerging evidence, it is recognized that these individuals are ill-equipped and underprepared for the responsibilities and expectations of the adult health care system (Paone & Whitehouse, 2011; Zhou et al., 2016).

Health care transition is a process that involves the movement of young adults with chronic physical and medical conditions from pediatric to adult-oriented health services (Blum et al., 1993; Fair et al., 2016). The need to provide transition care to adolescents and young adults was recognized over three decades ago by Zhou et al., (2016), which highlights this is not a new phenomenon. However, transition remains a complex process that requires early initiation, planning, coordination, and collaboration among multiple providers prior to the final transfer of care (American Academy of Pediatrics [AAP], American Academy of Family Physicians [AAFP], & American College of Physicians-American Society of Internal Medicine [ACP-ASIM], 2002; Canadian Association of Pediatric Health Centres (CAPHC), 2017; Mubanga, Baumgardner, & Kram, 2017; Paone & Whitehouse, 2011). Furthermore, this process is complicated by the physiological, cognitive and psychosocial changes or maturation associated with adolescence development (Ozdemir, Utkualp, & Pallos, 2016). At this stage of development, the adolescent appears as an adult, but may lack the capability of thinking and behaving like an adult (Ozdemir et al., 2016). As such, key principles of health care transition can be affected including assuming responsibility for current care, care coordination, and future health care planning; increasing autonomy, personal responsibility, and self-reliance; and acquiring self-management skills and condition-related knowledge (CAPHC, 2017; Wang, McGrath, & Watts, 2010). In addition, at this stage of life, these individuals are just as likely or more likely, to engage in risky behaviours such as unprotected sexual activity and experimenting with tobacco, alcohol, and illicit drug use as compared to those without chronic health conditions (CAPHC, 2017). Therefore, throughout adolescence youth with complex chronic conditions are more vulnerable to a range of health care difficulties including; lapses in care, increased emergency room visits, and recurrent hospitalizations which ultimately can lead to disengagement in health seeking behaviour and access with health care services (Vaks et al., 2016).

Transition clinics, programs, and clinical fellowships exist in Canada for specific chronic conditions such as diabetes and cystic fibrosis (Gravelle, Paone, Davidson, &

Chilvers, 2015; Oswald et al., 2013; SickKids, 2014a). These initiatives have developed a robust transition process in some provinces and geographical areas, improving care efficiency for health care providers and transition outcomes for individuals with disease-specific conditions (Gravelle et al., 2015; Viner, 1999). However, for adolescents transitioning into young adulthood with co-morbidities such services can be absent or fragmented (Viner, 1999), with little or no inclusion of the primary care provider (Scal, 2002) who by this stage has become their main health care connection. Regular provider contact and health promotion education are critical at this stage of life as evidence confirms that young adults with complex chronic conditions are more likely to be less adherent to medications and attend follow-up appointments after the transfer of care, impeding the management of their condition and placing their health at risk (CAPHC, 2017; Vaks et al., 2016).

In my practice as a registered pediatric nurse at BC Children's Hospital (BCCH), I have witnessed first-hand the impact that the health care transition process has on the family, young adult, and health care team. I have spent time working in the hospital's pediatric nephrology and oncology outpatient clinics, where patients were well supported and prepared for their transition. However, transition care for children with especially rare or more complex chronic conditions such as metabolic disorders, spina bifida, cerebral palsy or those born with chronic health issues due to significant prematurity continue to be fragmented or absent. These populations have no standard transition process and experience delayed transition or haphazard care, placing added stress on the patient, family, and health care providers. Challenges exist on both sides i.e. providing and accessing/receiving care, since professionals with pediatric training can feel ill-equipped preparing and meeting young adult goals while the young adult experiences barriers to accessing and engaging with a health system that cannot support their unique health and wellbeing needs.

Understanding the individual experience, as well as that of their caregiver, is critical in examining the process of transition. A significant body of literature identifies the lived experience of young adults with complex chronic conditions transitioning into adult-oriented care. Such studies examine the psychosocial factors that influence the transition process (Birnkrant et al., 2018; Blum, 1995; CAPHC, 2017; Kaufman, Pinzon, & CPS, 2018; Paone & Whitehouse, 2011; Reiss, 2012; Wong et al., 2010), and the general benefits of continuous care within this population (CAPHC, 2017; Goossens et al., 2016; Paone & Whitehouse, 2011). However, few studies focus on bringing these bodies of evidence together to address how practitioners can best incorporate this information across the scope of clinical practice (AAP, AAFP, & ACP-ASIM, 2011; Bhawra, Toulany, Cohen, Hepburn, & Guttmana, 2016; CAPHC, 2017; Kuo et al., 2018; Mubanga et al., 2017; Vaks et al., 2016). While specialist providers may have had greater capacity to shift transition services in light of evidence (Potosky et al., 2011; Scal, 2002) often, the primary provider is a minor contributor or absent from studies (Scal, 2002). Within BC the health delivery model recognizes that the primary care provider is both the entry point into the health system and the central hub for coordinating care, therefore, it is vital that primary care providers have an evidence-informed approach to addressing barriers associated to health care transition for this population. Further, within the scope of primary care practice, primary care providers such as family nurse practitioners, are responsible for managing routine health surveillance, screening and long-term follow-up for individuals across their lifespan (BCCNP, 2018b; Meacham et al., 2012). As such, I believe that family nurse practitioners within a multidisciplinary setting are in an ideal position to support young adults with complex chronic conditions undergoing health care transition as they are able to provide a sense of consistency and familiarity during times of vulnerability, i.e. transition.

The purpose of this paper is to conduct an integrative literature review in order to answer the following question: “What are the strategies primary care providers can use to enhance the transition process for young adults ages 15-25 years with complex chronic conditions exiting pediatric services?” The following sections of this paper will provide an overview of concepts and background information on young adults and complex chronic conditions. Then, in order to relate the issue to practice in BC, an explanation on how the health care transition process for young adults with complex chronic conditions is currently being managed within the province will be provided, along with an explanation of the different roles of each provider involved. Importantly, barriers and facilitators towards health care transition will be explored. This will be followed by Chapter 3, which will outline the methods used for the integrative literature search, including a table summarizing the search process. Next, the findings of the literature search will be presented and analyzed in Chapter 4, followed by a discussion of their significance and relevance to primary care providers in Chapter 5. Finally, the limitations of this paper will be discussed and areas for further research and future practice considerations will be addressed.

Chapter II: Background and Context

Complex chronic conditions come with extraordinary physical, emotional, societal, and financial challenges (AAP, AAFP, & ACP-ASIM, 2002; Mubanga et al., 2017; Paone & Whitehouse, 2011). As more children with complex chronic conditions survive into adulthood, health care providers face the challenges of determining how and when to best prepare these individuals for transitioning into the adult health care system. The prevalence (i.e. epidemiology, impact and risk), complexity, context, barriers, and impact of transition for providers and individuals are explored in the following chapter. Parallels are drawn between 'complex chronic conditions' and 'chronic conditions' since specific epidemiological data linked to complexity is absent. Finally, this chapter illuminates the complexity of multidisciplinary care and explores the role of the nurse practitioners within the context of primary care as proponents to transitional care.

Epidemiology, Impact, and Risk Factors

In Canada, approximately 140,000 children and young adults have a physical or intellectual disability and a staggering 77% of these children have three or more disabilities (Health Canada, 2007). Among this population of children, 117,510 of the disabilities are chronic impacting the young individual's health and development long-term (Health Canada, 2007). Further, there are approximately 30,000 premature births in Canada per year (Statistics Canada, 2016). Studies have shown that infants born before 37 weeks of pregnancy are at higher risk of developing various chronic health conditions as a result of chronic lung disease, cardiovascular disorders, and congenital anomalies (HealthLink BC, 2017; Statistics Canada, 2016). Despite increased health risks, premature infants in Canada continue to have a high survival rate (HealthLink BC, 2017). For example, it is estimated that eight out of ten infants born at 25 weeks of pregnancy and five out of ten infants born at 24 weeks of pregnancy are now expected to survive into adulthood (HealthLink BC, 2017). The extent of complex chronic health needs, however, is difficult to determine. Evidence indicates that approximately four out of ten premature infants weighing less than two pounds at birth are likely to have one or more moderate to severe health condition by the age of eight years (HealthLink BC, 2017).

Overall, it is estimated that 20% of young Canadians and their families are affected by chronic conditions and disability requiring access to and utilization of extensive health care services over their life time (Health Canada, 2009; Okumura et al., 2010). These statistics only account for a small number of the many chronic conditions affecting children in Canada. Both congenital anomalies and childhood chronic conditions are associated with increased morbidity and mortality, as well as increased risk for subsequent adult-onset chronic disease (WHO, 2005).

In addition to these health effects, chronic conditions have social and financial burdens on the affected individual and their families, and place added costs on society in regards to education and health care services (Health Canada, 2009). Individuals with chronic conditions are often dependent on medical equipment and require ongoing emotional, physical, and financial assistance throughout their lifetime. For example, individuals with spinal muscular atrophy, who have limited mobility and respiratory function, may be wheelchair and ventilator dependent requiring 24-hour assistance from family or caregivers (McLaughlin et al., 2014). Moreover, evidence reports a correlation between poverty and chronic illness (Health Canada, 2009; WHO, 2018). Canadian statistics report that family incomes of those with chronically ill children average one-third less than that of families of an equivalent size with healthy children (Health Canada, 2009). Individuals with lower socioeconomic status are much more vulnerable to chronic conditions due to greater exposure to risks, decreased access to health services, and increased psychosocial stress (WHO, 2005). These data highlight the prevalence of chronic conditions among young Canadians and their families, as well as the significant impact they have on an individual's overall wellbeing. The care required for this population is often complex and burdensome, involving ongoing physical and emotional support of their parents or caregivers, as well as the support and care of the Canadian health system (Paone & Whitehouse, 2011).

Complex Chronic Conditions

As the epidemiology of childhood chronic conditions have changed, young adults with complex chronic conditions have emerged as a special interest for health care delivery (Goossens et al., 2016; Scal, 2002). Individuals with complex chronic conditions withstand similar challenges to those with chronic conditions. Since these conditions affect more than one bodily system, individual's often experience motor, sensory, communicative, or intellectual impairments and may have complex limitations in self-care functions (Raina, O'Donnell, Rosenbaum, & Wood, 2005). Due to their multifaceted health care needs, these individuals require extensive care teams that collaborate and work together alongside the patient and their family.

Children and adolescents with suspected complex chronic conditions in BC are referred to a pediatrician by their primary care provider within the community and then further referred for pediatric subspecialty care at BCCH or other pediatric clinics throughout the province (Provincial Health Services Authority [PHSA], 2018a; BCPS, n.d.; Paone &

Whitehouse, 2011). The pediatric multidisciplinary team caring for these children generally consist of physicians, nurse practitioners, nurses, social workers, dieticians, psychologists, physical therapists and occupational therapists (PHSA, 2018a). Together this team becomes a significant support system for these patients and their families. Unfortunately, once young adults are discharge from pediatric services, care becomes increasingly more challenging because the adult health system does not have access to the same resources as pediatric services (Paone & Whitehouse, 2011). Additionally, the complexity associated with managing multiple issues can be overwhelming for adult-oriented providers who may lack experience and education caring for this population (Mubanga et al., 2017; Paone & Whitehouse, 2011)

At present, the most common complex chronic conditions seen in pediatric care are cardiovascular, congenital, neuromuscular, respiratory, and oncological (Goossens et al., 2016). For many years, infants born with such conditions rarely reached the age of majority. Now, with early interventions and rapid advancements in medical technology, individuals with complex chronic conditions are living into adulthood. For instance, every year over 120 children are born in Canada with spina bifida (CanChild, 2018). This condition, like many other complex chronic conditions, was historically recognized as a pediatric illness. However, over the last decade, the life expectancy has significantly increased from early childhood to mid-thirties (CanChild, 2018; Paone & Whitehouse, 2011; Squiers, Lutenbacher, Kaufman, & Karp, 2017). Additionally, 53% of men with muscular dystrophy are now living in to their thirties and beyond (Birnkrant et al., 2018; Paone & Whitehouse, 2011). With this recent increased survival rate, it is perhaps not surprising that questions are arising in terms of 'how to' best support and medically care for these young adults with complex chronic conditions as they transition into adulthood.

Health Care Transition in BC

From birth until adolescence individuals with complex chronic conditions are cared for in a holistic manner under multidisciplinary pediatric services, where both their physical and emotional needs are addressed using a patient and family centered approach (Zhang-Jiang & Gorter, 2018). However, national pediatric health care regulations in most countries do not allow continued access to pediatric care once patients reach the age of 16 years (Rutishauser, Sawyer, & Ambresin, 2014), in BC this age is slightly higher at 17 years for inpatient care and 19 years for outpatient care (PHSA, 2018b; BCPS, n. d.). Therefore, as an increasing number of individuals with complex chronic conditions live longer, increasing number of young adults with complex conditions are exiting pediatric services. In 2006 a total of 790 young adults transitioned from BCCH to adult-oriented care, this number increased in 2011 by 64% and it is now estimated that approximately 2000 young adults will continue to transfer annually (Child Health BC, 2018; Paone & Whitehouse, 2011).

Evidence suggests young adults with complex chronic conditions face greater challenges during the health care transition process (AAP, AAFP, & ACP-ASIM, 2002; Squiers et al., 2017). As such, patients may forgo regular care once they are discharged from pediatric services, ultimately resulting in a decline in health and reduced quality of life as they age (Campbell et al., 2016; Okumura, Hersh, Hilton, & Loststein, 2013; Squiers et al., 2017; Viner, 19999). The exact age of transfer to adult-oriented services has always been at question (Zhou et al., 2016). Late transfer can result in poor patient outcomes (Zhou et al., 2016), while others argue that early transfer could be associated with increased risk of psychosocial issues (Helgeson et al., 2013). It is understood that the age of transfer should be individualized to the patient and that optimal health care is achieved when they receive medically and developmentally appropriate care (AAP, AAFP, & ACP-ASIM, 2011; Paone & Whitehouse, 2011).

While there is no set definition of what constitutes successful health care transition for this population, it is well recognized that identifying the needs and goals of these young adults prior to exiting pediatric services is essential for maintaining positive health outcomes and improved quality of life (Ferris et al., 2015). The overarching goal is to maximize lifelong functioning and well-being for all young adults, whether they have a complex chronic condition or not (AAP, AAFP, & ACP-ASIM, 2011). Attributes of effective transitions include flexible, individualized, and continuous clinical care managed by health care providers who have a thorough understanding of the patient's unique medical and psychosocial needs (Blum et al., 1993; Bloom et al., 2012; Paone & Whitehouse, 2011). This process further includes self-management education, goal-setting, an assessment of the patient's readiness for transition, and a concise and complete discharge summary prior to transfer (AAP, AAFP, & ACP-ASIM, 2011; Bloom et al., 2012; Hergenroeder et al., 2015; Paone & Whitehouse, 2011). Specifically, a comprehensive and systematic process is needed that begins in pediatric care to help patients and their families learn the appropriate skills and knowledge necessary to independently manage their condition within a new health system (Paone & Whitehouse, 2011).

A number of guidelines and tools are available to assist health care providers with initiating transition care and support, when to assess patient's readiness for transition i.e. ON TRAC2, Got Transition, Bright Futures, and Good 2 Go (AAP, 2018; Mahan, Betz, Okumura, & Ferris, 2017; PHSA, 2018a; SickKids, 2014b; The National Alliance to Advance Adolescent Health, 2018). This being said, evidence states that only a small portion of young adults with complex chronic conditions are receiving adequate transition support, and that both pediatric and adult providers feel unprepared to address transition issues with their patients (Bhawra et al., 2016; Davis, Brown, Taylor, Epstein, & McPheeters, 2014; Hergenroeder, Constance, Wiemann, & Cohen, 2015; Kuo et al., 2018).

In BC, within current health care models children with complex chronic conditions are managed by a pediatrician or shared between a pediatrician and primary care provider. As such, transition care is typically initiated by the pediatrician who, due to the young person's complex health history, has had more regular direct contact with their care. This provider then collaborates with the necessary pediatric subspecialists to gather collateral and prepare transfer documents (Paone & Whitehouse, 2011). This process can be challenging and is time consuming as it involves coordinating and collaborating with multiple providers situated in pediatric organizations and adult settings. Nonetheless, it can be common practice within some contexts for pediatricians to place the responsibility of transition over to the adolescent's primary care provider (BC Medical Association [BCMA], 2012). Difficulties arise for primary care providers when they have had limited contact with the patient and family since referral to either the pediatrician or pediatric subspecialty services (Scal, 2002). This disengagement between patient and primary provider adds to the complexities of the situation since the needs of the young person are limited to the provider sharing information with adult services (BCMA, 2012). Despite these challenges, the transfer of care continues to be essential for these young adults as pediatricians and pediatric subspecialists are not equipped to continue providing the necessary health screening or routine medical care that is needed for these patients as they mature in to adulthood (Mubanga et al., 2017).

While evidence supports that transition is the best way to provide continuous, holistic, and comprehensive care to this growing population, there continues to be many barriers which hinder the overall process.

Barriers in Health Care Transition

Barriers to accessing quality and evidence-informed transition programs at the medical provider level are only a part of the difficulties young adults with complex chronic conditions face. As an emerging population, the unique social and health needs of this population continue to be poorly understood by both pediatric and adult-oriented providers. Young adults have to begin to learn to navigate new systems and need guidance on how to achieve this with confidence and certainty (Kaufman et al., 2018; Reiss, 2012; Squiers et al., 2017). Furthermore, all providers included in the young adult's care need to have a clear understanding of their role, accountability, and responsibility to communicate with the young person as well as their care coordinator. This is critical because the care coordinator, as part of the transition process, has shifted from the pediatrician to the primary care provider, which results in role uncertainty for everyone involved (AAP, AAFP, & ACP-ASIM, 2011; Paone & Whitehouse, 2011). Additionally, these issues are exacerbated by the major differences between pediatric and adult-oriented health care systems. In learning to navigate the complexity of new relationships, the skills required by young adults with complex needs are informed by their prior experiences. It is at this point that the variation between pediatric and adult service provision is most noticeable. Moreover, these variations between service provision are further impacted by the lack of communication between health care providers and care settings.

Pediatric to adult health care systems. Several differences between pediatric and adult health care systems exist because of the philosophy of the organizations and the professionals focus working in these settings (Kaufman et al., 2018; Kirk, 2008; Paone & Whitehouse, 2011). Many young adults have reported that during transition these differences were dramatic and daunting (Campbell et al., 2016; Kirk, 2008). Firstly, the focus of care changes from patient and family centered which includes parental involvement in decision making, to strictly patient centered requiring autonomous, independent skills of the young adult (BCMA, 2012; Kaufman et al., 2018). This change of approach can be challenging and anxiety provoking for the young adult, their family, and their pediatric providers (Kirk, 2008; Zhou et al., 2016). Pediatric providers may question adult-oriented provider's expertise in childhood conditions and therefore have difficulty letting go of their long-term patients in fear of their health declining (Bloom et al., 2012; Mubanga et al., 2017; Nehring, Betz, & Lobo, 2015; Zhou et al., 2016). Similarly, added stress is placed on adult-oriented providers receiving these patients into their practice as more often than not the young adults lack knowledge about their own condition and are unprepared or unable to take on the responsibility of autonomous decision making (CAPHC, 2017; Kaufman et al., 2018; Mubanga et al., 2017). Secondly, the pediatric multidisciplinary approach to care that promotes collaboration among providers changes to adult providers who generally work independently and separately from one another (Paone & Whitehouse, 2011). This places the young adults care management at risk of becoming fragmented and uncoordinated among all necessary providers. Thirdly, essential services such as respite care, insurance, and community supports are greatly reduced and more difficult to access or absent within the adult health care system resulting in increased family fatigue and financial strains (Bloom et al., 2012; Kaufman et al., 2018; Paone & Whitehouse, 2011). Such differences between the mandate and function of pediatric to adult health systems impact the young adult, their families, and health care providers during the entire transition process. Evidence has shown that while these three factors can each play a major role in transition, failure to address such concerns results in disengagement with secondary care providers in adulthood (Kaufman et al., 2018). The differences between pediatric and adult health care systems in BC that influence health outcomes for young adults with complex chronic conditions before, during, and after health care transition are summarized in Table 1, below.

Table 1

Differences Between Pediatric and Adult Health Care Systems in British Columbia

Pediatric Health Care System	Adult Health Care System
Family centered care	Patient centered care
Parent or guardian promotes, prompts, and encourages care and medication management to safeguard adherence and has a strong advocacy role.	Patient is assumed and often expected to be knowledgeable about their condition and direct their own care.
Parent or guardian attends medical appointments alongside patient. Legal implications linked to consent and decision making capacity.	Attending medical appointments independent from family or guardian is strongly recommended and actively encouraged.
Multidisciplinary approach by a range of health care providers.	Referral process to adult specialists and other allied health professionals as needed. Majority of providers work independently and separately from one another.
Family insurance coverage	Independent insurance services
Subspecialists with wealth of knowledge around rare complex conditions	Health care providers lack experience and knowledge with childhood complex conditions due to limited numbers of patients with such complexity
Developmentally appropriate care that focuses on all aspects of wellbeing.	Lack of experience providing young adult friendly care. Medically focussed, goal is to reduce risks of long term complications.

Note. Table adapted from Paone and Whitehouse (2011) ONTRAC summary report on developing a transition initiative for youth and young adults with chronic health conditions and /or special needs in B.C.

Adult-oriented services. In addition to the differences between pediatric and adult health care systems, other barriers stem from hesitation by adult-oriented providers on the receiving end of the transfer largely due to issues around education and experience (Kuo et al., 2018; Mubanga et al., 2017; Okumura et al., 2010). At present there is a lack of training in congenital and childhood conditions for adult-oriented providers, as well as a lack of time and reimbursement for the extra hours needed to successfully coordinate care (AAP, AAFP, & ACP-ASIM, 2011; Betz, 2004; Hergenroeder et al., 2015; Kuo et al., 2018; Mubanga et al., 2017). Further, adolescence itself is a transitional stage of physical and psychological maturity including the development of adult behaviors (CPS, 2003; Paone & Whitehouse, 2011). As such, this point in time represents a window of opportunity to promote healthy behaviours (Campbell et al., 2016; Paone, Wigle, & Saewyc, 2006) and developmentally appropriate health education areas in which adult-oriented providers may not be confident in leading discussions (Bloom et al., 2012). For these reasons, it is challenging for pediatric providers to find appropriate adult specialists that are both experienced in their patient's area of specialized care and willing to take on new patients (AAP, AAFP, & ACP-ASIM, 2011; Mubanga et al., 2017), therefore further delaying the transition process and transfer of care.

Information exchange and communication. Among the common barriers to effective health care transitions are the challenges with patient information sharing and communication between health care providers and care settings. While collaboration across care settings and direct communication between providers is fundamental for providing comprehensive care to complex patients, studies have identified that this is time consuming and, at times, near impossible (Coleman & Berenson, 2004; Loeb, Bayliss, Candrian, deGruy, & Binswanger, 2016). This is largely due to inadequate systems for delivering information reliably between providers, as well as the general challenges around connecting with busy specialists (Mahan et al., 2017). Health care systems vary widely in their resources and ability to implement transition-related interventions such as standard transition policies and electronic health systems (Ferris, Ferris, Okumura, Cohen, & Hooper, 2015; Mahan et al., 2017). There is no universal electronic health record (EHR) system with connectivity across care settings (Coleman & Berenson, 2004). For example, larger, integrated health facilities have EHR systems and access to multiple subspecialists who can easily communicate within a single system and are able to readily access customary transition tools through their EHR system (Mahan et al., 2017). This allows for improved collaboration and communication between services as all providers have timely access to the patient’s medical records (Coleman & Berenson, 2004). Meanwhile, smaller facilities such as primary care clinics and those in rural or remote areas, do not always have access to such EHR systems, especially systems with connectivity beyond the clinic or office, resulting in limited coordination among services and less reliable methods for transferring and accessing patient medical information (Campbell et al., 2016; Ferris et al., 2015; Loeb et al., 2016).

Similarly, there is a lack of direct one-on-one communication between pediatric and adult providers during the health care transition process, further enhancing the potential for redundancies or lapses in care (Hergenroeder et al., 2015; Looman et al., 2013; Mubanga et al., 2017). Health care transition is a continuum that requires communication, collaboration, and coordination between well-trained primary care providers and specialists in both pediatric and adult-oriented services, even after young adults have transferred (Mahan et al., 2017; Paone et al., 2006). Thus, this general lack in communication is critical to note as care can be compromised if patient information is not transferred in a timely manner as the patient’s medical file must be recreated or updated with the potential for errors (BCMA, 2012; Coleman & Berenson, 2013). Moreover, the quality of care delivery may also be affected when primary care providers or adult specialists are unable to readily consult with prior pediatric providers or subspecialists for support (Okumura et al., 2010), placing the health and safety of the young adult at risk.

Health Care Transition and Primary Health Care

Historically, the majority of programs developed to enhance health care transition for this population have been disease-specific or subspecialty-specific and based within tertiary services with very little focus on primary health care (Bhawra et al., 2016). It is debated whether transition care should be the responsibility of specialists in an outpatient setting or primary care providers within the community. Although specialists are best suited to create and update condition-specific needs for transition care (Potosky et al., 2011), evidence states that primary care providers should take on greater responsibility in order to optimize medical care and address the psychosocial aspects associated to these young adults (Paone & Whitehouse, 2011; Potosky et al., 2011; Scal, 2002).

Primary health care refers to health services that focus on protecting and promoting the health of individuals within a community setting. It is often the entry point to the health care system and provides comprehensive, accessible, community-based care for individuals throughout their life (BCCNP, 2018a). Traditional primary health care models have been scrutinized for being too medically focused and provider driven (CNA, 2015). However, in order to meet the increasing needs of patients, primary health care services have evolved to focus on effective team-based care that is multidisciplinary and patient-centered. Multidisciplinary working is defined as a group of individuals with varied but complimentary experience, qualifications, and skills that work together to achieve a mutual goal (Mitchell et al., 2008). In the context of a complex health care system, an effective multidisciplinary team-based (MDT) approach to care is crucial for ensuring patient safety. Delineation of roles and responsibilities in the MDT can limit miscommunication which reduces patient risk (Babiker et al., 2014). This model of care is being utilized throughout BC with a recent announcement by the provincial government for greater expansion and integration over the next three years (Province of BC, 2018). The goal for this redevelopment is to improve access to and coordination of care, and to support patients and their families by providing comprehensive longitudinal health services (BCCNP, 2018b). In BC, a large portion of primary care providers such as family physicians and nurse practitioners work in MDT models of care. The following section will provide details around the nurse practitioner role within a multidisciplinary setting.

The nurse practitioner role has been recognized as a valuable addition to health care reform. Fueled by an increased demand in care and a decrease in resources (Battle Haugh & Mildon, 2008), an enhanced interest and political will to move away from the medical model of health to a more holistic and upstream approach has become a priority. This has generated the support for primary health care reform and ultimately led to the integration of nurse practitioners in Canada (Archibald & Fraser, 2012;). Nurse practitioners are health care professionals with a master's level of education who can work independently, or collaboratively with physicians and other health care professionals, to provide care throughout an individual's life (BCCNP, 2018b). This care includes diagnosing and treating illnesses, ordering and interpreting tests, prescribing medications, making referrals, consulting with medical specialists, and performing minor medical procedures as necessary (BCCNP, 2018b). Separate from other practitioners, the emphasis of nurse practitioner practice includes health promotion, disease prevention, and illness management (CNA, 2015). In BC, nurse practitioners work with patients of all ages in both acute and community settings and are recognized as an essential member of health care teams. With a goal of comprehensive, high-quality care and a focus on social determinants of health, nurse practitioners appear to be an asset for co-managing transition care for young adults with complex chronic conditions.

Aside from the complexities associated with these young adults' health, the issue surrounding transition care for this population is also intrinsically tied to psychosocial factors that impede the transition process and further impact their wellbeing. Moreover, the primary care setting is typically the central site for health promotion and longitudinal care. Considering this, understanding and addressing the factors associated with health care transition for young adults with complex chronic conditions aligns well with the purpose of primary health care. For the remainder of this paper, the term primary care provider will be used and will refer to both family physicians and family nurse practitioners.

In summary, transition planning, when present at all, can be inexplicit, incomplete, or delayed, and when possible, the transfer of care to an adult-oriented provider and to adult specialists involves more of a drift away from pediatric care rather than a clearly planned and executed hand over. (AAP, AAFP, & ACP-ASIM, 2011). This background review aimed to identify and describe the multifaceted and challenging nature of complex chronic conditions, explore and understand the needs, organizational system influences, and impact of transition for individuals, their families, and providers thereby resulting in the formulation of the question "What are the strategies primary care providers can use to enhance the transition process for young adults ages 15-25 years with complex chronic conditions exiting pediatric services?"

The following chapter will describe the search methods conducted for this integrative literature review that examine current practices and strategies to enhance the health care transition process for young adults with complex chronic conditions exiting pediatric services.

Chapter III: Methods

This chapter will proceed to discuss the integrative literature review and the search strategies used in order to select the final studies chosen for analysis. An integrative literature review was conducted in order to obtain a better understanding of the current practices around health care transition for young adults with complex chronic conditions. Further, to explore practice strategies that may be used by primary care providers to enhance the transition process for this population. The topic under review was guided by the following question: “What are the strategies primary care providers can use to enhance the transition process for young adults ages 15-25 years with complex chronic conditions exiting pediatric services?”

An integrative literature review is a specific review method that enables one to synthesize literature from a variety of research methodologies including qualitative, quantitative, and mixed-methods studies (Whittemore & Knafl, 2005). Integrative literature reviews differ from other review methods as they combine data from both theoretical and empirical sources in order to provide an enhanced understanding of the topic at issue (Whittemore & Knafl, 2005). Therefore, an integrative literature review was selected since a broad spectrum of research can then be synthesized and subsequently findings applied toward clinical practice improvements, health policy changes, and evidence informed practice initiatives (Whittemore & Knafl, 2005). It is important in integrative literature reviews to use explicit and systematic methods. As a result, Whittemore and Knafl (2005) propose a five stage framework to enhance rigour within these reviews.

Whittemore and Knafl’s (2005) methodological framework involves the following five stages: 1) problem identifications, 2) literature search, 3) data evaluation, 4) data analysis, and 5) presentation. The background section outlines the clinical challenges; increasing survivorship of young adults with complex chronic conditions exiting pediatric services requires primary care providers to be knowledgeable of and skilled in the transition process thereby assisting young adults to access and utilize adult health care services. This chapter will address the second, third, and fourth stages of Whittemore and Knafl's approach to the integrative literature review. The following chapters will then present the fifth and final stage.

Literature Search

A well-defined search strategy is essential in integrative literature reviews (Whittemore & Knafl, 2005). Further, Whittemore and Knafl (2005) recommend a comprehensive search using at least two or three strategies and all decisions should be made explicit. Therefore, the literature search was conducted in three stages; stages one and two were to search material via electronic databases, and stage three was to identify literature through hand searching, reviewing grey literature, and networking approaches. The electronic databases searched were Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, PsychINFO, and Joanna Briggs Institute. These databases were chosen for their extensive inclusion of health care and psychological journals. Next, in order to guide the literature search, a clear inclusion and exclusion criteria were created that were specific to the aim of this project. The criteria were informed by the background reading and selected in order to ensure a wide range of the literature was identified, while maintaining a focus that is also relevant and current. Attention to inclusion and exclusion criteria took precedence throughout all stages of the literature search and duplicate or unrelated articles were eliminated. The following section of this chapter further discusses the literature search process conducted for this paper.

Inclusion and exclusion criteria. The literature search for this topic was conducted to identify sources that addressed strategies that primary care providers can use to enhance the health care transition process for young adults with complex chronic conditions exiting pediatric services. Research on health care transition has become an increasingly popular topic over the past decade, as such, for the initial search of the databases, dates were set from 2007-2017. Due to the high volume of results after the initial search, dates were changed to include material published only between 2012 and 2017. This helped to narrow down the search and capture the most current information, whilst maintaining a broad understanding of the evolution of this topic. Eligible studies had to be published, written in the English language and conducted within the United States, Australia, or Western Europe, as these health care systems are similar to Canada. Any findings conducted outside of these areas were not included in the final results.

Both male and female participants were included between the ages of 15-25 years that were in the process of or had already transitioned from pediatric to adult-oriented care and required ongoing clinical support. Studies were excluded if they addressed only educational or vocational service transitions and outcomes, rather than health care. All participants had to have a complex chronic condition, as defined in the glossary of terms provided at the beginning of this paper, such as multimorbidity, congenital anomalies, cerebral palsy, muscular dystrophy, or spina bifida. Multimorbidity was defined as, "…having two or more concurrent chronic conditions that collectively have an adverse effect on health status, function, or quality of life that require complex health care management, decision-making, or coordination” (Nation Quality Forum, 2012, p. 7). Any literature that specifically identified asthma, diabetes, cardiac, and/or oncology conditions individually were excluded. Studies were not included if participant characteristics or medical conditions were unclear or not discussed in studies. Studies were excluded if they focused primarily on individuals with cognitive impairment as such conditions require additional interventions and supports during the transition process associated to guardianship, medical decision-making and health management which exceed the limits of this paper.

Studies that addressed provider, patient, or patient and family perceptions of health care transition were included. Any studies that only discussed family member’s perceptions were removed. Lastly, any type of supportive intervention that was specifically directed towards the transitional process between pediatric and adult health services for patients with complex chronic conditions were included. Studies specific to the use of multidisciplinary teams, nurse practitioners, and primary health care were of high priority. Inclusion and exclusion criteria are summarized in Table 2, below.

Table 2

Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
Years of publication: 2012- 2017	Publications older than 5 years
Ages 15- 25 years	<15 years or >25 years
In the process or has already transitioned	Not in the transitional process yet
Chronic non-specific conditions, complex conditions, or multimorbidity	Articles that include **only** common conditions; diabetes, cystic fibrosis, asthma, cardiac, and/or mental health
Patients who may require physical assistance, but are able to make decisions independently	Articles only discussing patients who are cognitively impaired
Health care provider, patient and family, or patient-only perceptions	Articles only discussing family members perceptions
Conducted within North America, Western Europe, Australia, and New Zealand	Conducted outside of inclusive countries
Published reports	Unwritten materials
Publication language: English	Non-translated reports
Studies examining health care transition for young adults with complex chronic conditions	
Studies that discuss: health care transition strategies, primary health care, specialists to primary care provider, nurse practitioners, care coordination, multidisciplinary teams	

Stage one: Searching electronic databases. Stage one of the literature search was conducted using multiple resources. Search terms were obtained through key terms and concepts derived from the research question and topic of this paper. The PIO; population, intervention, and outcome, format was used to create the initial question and determine the aim for the search strategy. The PIO format was effective in identifying the key terms to be included in the literature search and applicable for developing search criteria with more detail (Grove, Burns, & Gray, 2013). Next, a concept map was developed to help broaden the search and generate more key words by using parallel terms. The final key terms used were: transition of care, health care transition, young adults, adolescents, multimorbidity, multiple chronic conditions, continuity of patient care, care coordination, primary health care, nurse practitioner, primary care provider, and family physician. Boolean operators, ‘OR’ and ‘AND’, were used to combine key terms and link relationships between concepts while searching the databases. Using the ‘OR’ operator helped to expand the search compared to searching terms individually, while the ‘AND’ operator combined terms to narrow the results and gather more specific findings. The total number of studies found during the initial search was 7,344. Appendix A depicts the key terms used, the searches conducted, and the number of results obtained from each.

Inclusion and exclusion criteria were applied to the initial literature search results and any duplicate studies were eliminated. The titles of the studies were then scanned for relevancy based on the key terms. Any studies that did not contain the appropriate terms or relevant subjects were eliminated. 6,827 studies were eliminated at this stage, leaving 517 remaining articles for further evaluation.

Stage two: Screening abstracts and in-depth review. Stage two of the search strategy included filtering through the remaining studies from the electronic database searches by rescreening titles and reviewing the abstracts. This eliminated 319 studies, resulting in 198 studies for final review. The 198 final studies were then examined for relevance by re-reading abstracts and by scanning whole papers to assess the quality of the evidence and relevance to the research question. At this point in time, among the 198 final studies, two systematic reviews (Betz, Lobo, Nehring, & Bui, 2013; Gabriel, McManus, Rogers, & White, 2017) were noted to include one study from Japan and one study from Hong Kong in their analysis. Despite these countries being outside of the inclusion and exclusion criteria of this integrative literature review, I chose to keep both reviews due to their high relevance to the research question. This process resulted in the elimination of 187 studies, and the selection of 11 applicable studies.

Stage Three: Hand searching, grey literature and networking. At this point, reference lists of the remaining 11 studies were scanned for seminal studies to ensure data saturation. The screening process as well as inclusion and exclusion criteria that were used in stages one and two were also applied to any articles located from the reference lists. After the screening process, one study was kept from hand searching resulting in a total of 12 studies. This search, along with stages one and two, are demonstrated through a flow diagram in Appendix B.

To find grey literature that was applicable to this topic, a Google search was conducted using key terms: health care transition and young adults and complex chronic conditions. This search identified the following websites: BC Medical Association, SickKids “Good 2 Go” Transition Program, BCCH “ONTRAC” Transition Program, The Canadian Association of Paediatric Health Centres, and The American Academy of Pediatrics. From these websites, five reports were found. Two of these reports were older than 2012 and three did not include relevant information around strategies for primary care providers, therefore, these sources were used for the background and context of this paper.

Finally, Ciara McGeough, senior practice leader for Youth Transitions and Ambulatory Care Services at BCCH, was contacted by email and phone for further collateral around current transition practices in BC. One article was recommended by Ciara McGeough and used in the background section of this paper. The search strategy for grey literature and networking approaches are depicted by a second flow diagram in Appendix B.

In total, 12 published pieces of work were included in this integrative literature review and include: 3 systematic reviews and 9 primary studies. All searches were conducted between September 2017 and February 2018.

Data Evaluation

In the data evaluation stage, Whittemore and Kafl (2005) suggest assigning quality scores to each article and that if two types of studies are included, two frameworks for evaluating quality may be used. As such, the literature collected for this review was assessed for methodological rigor, validity, and strength of evidence utilizing quality criteria instruments. The textbook by Hoffman, Bennett, and Del Mar (2013) was used to assess each articles level of evidence (see Appendix C). While, depending on the study, the Critical Appraisal Skills Programme (CASP) systematic review checklist (2018), the CASP (2018) qualitative checklist (see Appendix D), and the Maryland Scientific Methods Scale (Madaleno & Waights, n.d.) (see Appendix E) were applied to guide the critical appraisal process. The quality scoring of each article is located in the literature matrix in Appendix F.

Data Analysis

In the data analysis stage, information is "ordered, coded, categorized, and summarized" to come to a conclusion (Whittemore & Knafl, 2005, p. 550). This stage of the integrative literature review involved critically analyzing each of the final 12 studies by creating a literature review matrix (see Appendix F). Headings of each column within the literature review matrix included author, title, study aim, study design, quality and reliability scores, relevant findings, and limitations and implications for future research of each study. This approach provided a clear and organized lay out of extracted data, which were then compared and grouped into four common themes: relationships, fear and anxiety, preparedness, and communication and collaboration. Further analysis of these themes and the results are discussed in the following chapter, Findings.

Chapter IV: Findings

The purpose of this integrative literature review was to collect and critically examine current data on health care transition and primary care management within the context of young adults with complex chronic conditions exiting out of pediatric services. The analysis was guided by the following research question: “What are the strategies primary care providers can use to enhance the transition process for young adults ages 15-25 years with complex chronic conditions exiting pediatric services?” The search methodology described in chapter two resulted in a total of 12 studies. These final studies met the inclusion criteria, were evaluated using CASP (2018) tools and quality metrics and are subsequently further analyzed and reported in this chapter.

Broadly, the studies comprised of a range of methodologies. Four of the 12 studies are methodologically characterized as qualitative studies. More specifically these were grounded theory (Aldiss et al., 2015; Okumura, Saunders, & Rehm, 2015) and descriptive (Berens & Peacock, 2014; Syverson, McCarter, He, D’Angelo, & Tuchman, 2016) methodologies to generate data. From the remaining eight studies, five were quantitative using a range of approaches; time-series (Ciccarelli, Brown, Gladstone, Woodward, & Swigonski, 2014; McManus et al., 2014), cross-sectional (Rutishauser, Sawyer, & Ambresin, 2014), and surveys (Chung, Jasien, & Maslow, 2017; Maddux, Ricks, & Bass, 2015). Three systematic reviews completed between 1995-2016 were included (Betz et al., 2013; Gabriel et al., 2017; Nehring et al., 2015).

In order to ensure that the findings were applicable to the Canadian health system, the geographical nature of each study was considered. Seven (58%) of the individual studies included in this paper were conducted in the United States (Berens & Peacock, 2014; Chung et al., 2017; Ciccarelli et al., 2014; Maddux et al., 2015; McManus et al., 2014; Okumura et al., 2015, Syverson et al., 2016), one (7%) was conducted in Switzerland (Rutishauser et al., 2014), and one (7%) was conducted in the United Kingdom (Aldiss et al., 2015). The three (25%) systematic reviews (Betz et al., 2013; Gabriel et al., 2017; Nehring et al., 2015) included data from all of these countries, as well as Canada, Hong Kong, and Japan. Further information regarding each papers study aim, sampling, methodology, key findings, limitations and future research can be found in the literature review matrix (see Appendix E).

The literature analysis resulted in four common themes that influenced health care transition and were related to the research question: 1) Relationships 2) Fear and Anxiety 3) Preparedness and 4) Communication and Collaboration. These four themes were derived from the analysis of the studies' purpose and findings. It is important to note that in some instances, findings encompassed more than one theme. While there were a large number of specific study findings, contextual issues, and social complexities associated to health care transition for young adults with complex chronic conditions, these were consolidated and grouped into the four broad themes. Each of these themes had the capacity to influence health care transitions for young adults. Additionally, these themes organize the following presentation of the findings and act as a guide for the discussion portion of this paper that will further explore their influence on health care transition and primary care management. The following sections will examine the themes in greater detail specifically highlighting where they were comprised of sub-themes. The sub-themes were composite parts of the theme but as viewed from a specific perspective i.e. that of the young adult, parents, or professional.

Relationships

For the context of this integrative literature review, relationships refer to the relation connecting, supporting, or binding participants; family, young adults, or health care providers, involved in the health care transition process. Relationships were a prominent theme identified in four of the 12 final studies (Aldiss et al., 2015; Nehring et al., 2015; Okumura et al., 2015; Rutishauser et al., 2014). This theme was dominant in the analysis and crossed a range of study methodologies. The significance of this theme was linked to understanding how relationships impacted young adults during the transition process in order to identify strategies for primary care provider's engagement. This section of the integrative literature review is broken down into two sub-themes: Parent-patient relationships and provider-patient relationships. Understanding how dyad relationships of parent-patient relationships and provider-patient relationships directly influenced young adults with complex chronic conditions during the health care transition process was critical in planning primary care management.

Parent-patient relationships. The parent-patient relationship was discussed in three studies (Aldiss et al., 2015; Nehring et al., 2015; Okumura et al., 2015). Overprotection from parents towards children was considered as 'sheltering' by Okumura et al. (2015, p.720) with the authors concluding that shielding children and youth from taking part in their own health responsibility negatively impacted the transition process. This became increasingly apparent at key stages for example, reaching the age of majority forces the now, young adult, to take on adult responsibilities they feel unprepared for (Okumura et al., 2015). These results were supported by the systematic review conducted by Nehring et al. (2015) as four of the 55 studies analyzed identified 'excessive involvement of parents' as a barrier to implementing health care transition as it inhibited young adults from taking an active role in their own care (p.738).

Conversely, results from the qualitative studies by Okumura et al. (2015) and Aldiss et al. (2015) found that the value of having parental presence and family involvement was a key component for overcoming barriers prior to, during, and after the transfer to adult-oriented services. Aldiss et al. (2105), aimed to create standard benchmarks, informed by primary and secondary data, to facilitate improvements in the quality of transition care for young adults and their families. Data from stakeholders in transition care (n=21), health care providers (n=36 with 5 being doctors), and young adults with complex chronic conditions (n=9) and their mothers (n=9) were collected through focus groups, workshops, and finally interviews with young people (n=4) and mothers (n=2). Responses from the mothers, health care professionals, and stakeholders all reported that family members should be involved throughout the transition process and that family involvement was critical to facilitating the transfer of responsibility of care over to the young adult. As such, parental involvement was recommended by authors of the study (Aldiss et al., 2015) as a benchmark for transitional care best practice.

Okumura, Saunders, and Rehm's (2015) study further identified that relationships between providers, young adults, families, and community services were strongly influenced by advocacy. The purpose of this qualitative study was to develop a better understanding of how family (n=9), health care professionals (n=12), and community services providers (n=7) worked together to best assist young adults with complex chronic conditions (n=13) during the transition process by conducting 41 in-depth interviews within the San Francisco Bay area. The researchers used a grounded theory design to explore the experiences of the participants involved. Young adults ages 16-25 years with complex chronic conditions who had either recently transitioned or were preparing to transition to adult-oriented care were included. Parents, health care providers, and community service members who delivered care to young adults with complex chronic conditions in outpatient, inpatient, or community care settings were also included. The collected data was analyzed using the software program Atlas-ti and strategies such as review by others were used to ensure rigor and trustworthiness (Okumura et al., 2015).

The results from the 41 in-depth interviews collected and analysed by Okumura et al. (2015) elicited a variety of issues associated to health care transition. Most reflected common concerns around three major categories; fighting for healthcare, obtaining resources, and getting ready for transition (Okumura et al., 2015). The authors identified transition advocacy as a common tie among all three important social processes and as a critical component for an effective transition, which resonates with Ladores (2015) concept analysis of transition. Furthermore, Okumura et al. (2015) noted that young adults reported having improved transition outcomes and success overcoming barriers when they had a family member fighting for their needs as this ensured their voices were heard by medical teams and that they were included in the transition planning. A family member with strong advocacy skills was especially important for individuals with developmental disabilities who were unable to articulate their needs by themselves. Additionally, this form of advocacy was thought to bridge access to necessary resources that were routinely reduced and difficult to obtain once the young adult reached the age of transfer (Okumura et al., 2015). Young adults' capacity to self-advocate was heightened when they had strong familial and social supports. Moreover, when others effectively advocated for those with complex needs this ensured that the voices of the young adults were heard. Such acts of role-modeling behaviours appeared to support the young adults to learn to speak for themselves whenever possible, which facilitated developmentally appropriate transitioning to adult-oriented services in efficient and effective ways.

The role of the researchers in Okumura et al.'s (2015) study were not discussed, nor were any potential biases or influences mentioned which, were both weaknesses impacting study validity. In addition, interviews were limited to individuals living in California, thus affecting the generalizability as the results may not reflect the same experiences of those living in BC in which the health system is government directed and supported. Strengths of the study included the method used, as well as the inclusion of nurse practitioners within the recruited health care professionals and the diverse representation of complex chronic conditions (i.e. cystic fibrosis, spina bifida, cerebral palsy, and myasthenia gravis) within the study participants. Overall, contrasting results were found between these three studies (Aldiss et al., 2015; Nehring et al., 2015; Okumura et al., 2015), suggesting that the parent-patient relationship can both hinder and facilitate health care transition for young adults with complex chronic conditions.

Provider-patient relationships. Three studies (Nehring et al., 2015; Okumura et al., 2015; Rutishauser et al., 2014) discussed the relationship between health care providers and young adults. A barrier to building new relationships with adult providers hinged on the close relationships young adults had with their pediatric providers (Nehring et al., 2015; Okumura et al., 2015; Rutishauser et al., 2014). Pediatric providers often spent time (Okumura et al., 2015) and effort in building trust with the young adult and their family. As such, these strong attachments (Nehring et al., 2015) between pediatric providers and young adults impinged on the transition process (Nehring et al., 2015; Okumura et al., 2015). The tight knit nature of these relationships made connections with new adult-oriented providers almost impossible (Okumura et al., 2015). Additionally, cutting ties between pediatric providers and the young adult and family were extremely difficult (Nehring et al., 2015; Okumura et al., 2015). Okumura et al. (2015) further identified that there were no clear boundaries that ended the relationship between the pediatric provider and the young adult, thus compromising the relationship between the young adult and the new adult-oriented provider.

Feeling at ease with the pediatrician was the most important barrier to effective transition identified in a quantitative cross-sectional study by Rutishauser, Sawyer, and Ambresin (2014). In this study the researchers sought to compare perceived barriers and preferred age for successful transition to adult-oriented care between adolescents with complex chronic conditions before and after transfer. The overall aim was to examine whether perceptions of young adults prior to transfer may be influenced by their upcoming transfer and modified by their experiences after transfer. A cohort of 283 pre-transfer patients and 89 post-transfer patients were recruited from subspecialty clinics (i.e. cardiology, endocrinology, pulmonology, nephrology, neurology, gastroenterology, and rheumatology) at two university children's hospitals in Switzerland. The specialties included were chosen because of their large numbers of long-term patients with complex chronic conditions. An anonymous 28-item (29 items for post-transfer group) study specific questionnaire was used to compare the two groups. The development of the questionnaire included a literature search, expert opinion, and focus interviews with young people with complex chronic conditions. The questionnaire was designed as a descriptive tool and the response options were designed to suit the purpose of the study, using Likert scale responses. Further, data were analyzed using SPSS 19.0 (SPSS Inc., Chicago), frequency analysis, applying t-test for continuous variables and Pearson's chi-square for categorical variables.

The results of the study, (Rutishauser et al., 2014), demonstrated that 48% of the pre-transfer group and 32% of the post-transfer group believed that feeling at ease with the pediatrician was the most important barrier to transfer, however, the odds were two times higher for the pre-transfer group (OR=2.03, 95% CI 1.12-3.71). Anxiety and lack of information were also rated as similarly important in both groups (OR=0.67, 95% CI 0.35-1.28 and OR=0.71, 95% CI 0.36-1.38). Both of these topics will be further discussed in the following themes of this chapter. A strength of the study by Rutishauser et al. (2014) was the non-disease-specific recruitment strategy used, as this allowed for a large and diverse sample to be recruited. The overall evidence from this study would have been strengthened and more applicable to my research question if conducted within the primary care setting rather than two Swiss pediatric university hospitals, thereby limiting the generalizability. Further limitations included the cross-sectional nature of the study design preventing any conclusion regarding causality. Moreover, very little data were provided in regards to the selection process of participants which places the study's outcomes in question.

From this data, understanding the value of feeling at ease with the pediatrician underlines the importance of helping the young adult build strong and trusting therapeutic relationships with their future providers. In regard to promoting effective termination of the pediatric relationship, Nehring et al. (2015), Okumura et al. (2015), and Rutishauser et al. (2014) recommend initiating transition planning early in order to establish a mutual understanding and awareness that termination of the existing therapeutic relationship is inevitable. Okumura et al. (2015) and Rutishauser et al. (2014) further suggest setting a final termination date for pediatric relationships and scheduling an appointment for both parties to say their final farewells. Okumura et al. (2015) and Rutishauser et al. (2014) hypothesize that by doing this, young adults may have an easier time facilitating trust with new providers, reducing the level of anxiety associated to the change in provider relationships.

Fear and Anxiety

Fear and anxiety was the second theme prominent in both qualitative and quantitative studies, and one systematic review (Betz et al., 2013; Okumura et al., 2015; Rutishauser et al., 2014). It was evident from the literature, that some young adults and their families were aware of the inevitable transition, while others were not. Regardless of awareness, health care transition was frequently characterized by feelings of fear and anxiety. This theme is relevant to the research question because in order to best meet the needs of these young adults, primary care providers must have a thorough understanding and awareness of the different psychological and social factors that influence young adults and their families during this critical time of change. As such, personal experiences of fear and anxiety associated to the transition process will be further discussed through the following supportive themes: patients' perceptions and experiences, and parents' perceptions and experiences.

Patients' perceptions and experiences. Young adults expressed mixed feelings towards the idea of health care transition in all three studies (Betz et al., 2013; Okumura et al., 2015; Rutishauser et al., 2014). These feelings stemmed from fear and anxiety as young adults faced uncertainty and had to learn how to wrestle with these uncomfortable emotions (Betz et al., 2013; Rutishauser et al., 2014). In addition, they were anxious about the transition process and felt fearful since they did not know how to appropriately navigate the adult health system (Okumura et al., 2015).

In the aforementioned cross-sectional study conducted by Rutishauser et al. (2014), participants reported that feeling unprepared, uninformed, and uncertain as to what to expect in the adult health system increased anxiety, which represented a significant barrier towards successful transitioning. It was reported that only 50% of the pre-transfer participants had discussed transition with their pediatrician, while only 10% of the post-transfer participants believed they had their first discussion about health care transition before 16 years of age (Rutishauser et al., 2014). These results resonated with findings from Betz, Lobo, Nehring, and Bui's (2013) systematic review as a 'lack of information'. Here the authors identified 12 of their 35 included studies reported young adults felt lost or ill-equipped for the changes they would encounter during the transition process (Betz et al., 2013). Further, young adults in Rutishauser et al.'s (2014) study reported being fearful of receiving new treatments in the adult health system and being concerned that their medical records may get lost during the transfer, exacerbating feelings of anxiety. Interestingly, these results were similar between pre- and post-transfer participants; (OR=0.67, 95% CI 0.35-1.28 and OR=0.71, 95% CI 0.36-1.38), suggesting that the perceived barriers on pre-transfer participants were not strictly the result of anxiety around upcoming changes. This draws attention to the significant effect health care transition has on the lives of these young adults.

In addition, pre-transfer participants were hesitant about the thought of the upcoming transition (Betz et al., 2013; Rutishauser et al., 2014). Specifically, young adults were uncertain about receiving their future care in an unfamiliar environment (Betz et al., 2013) and concerned about the future of their health status (Betz et al., 2013; Rutishauser et al., 2014). Potential exposure to infection and the possibility of deteriorating health and its effect on the young adult's lifestyle were two prevalent concerns in the literature (Betz et al., 2013; Rutishauser et al., 2014). These participants were labelled as 'worried and insecure' (Betz et al., 2013), with authors concluding that pre-transfer young adults were anxious around the unknown long-term consequences of having complex chronic conditions. It was evident from the results in both studies (Betz et al., 2013; Rutishauser et al., 2014) that an overlap in care or having the young adult meet their adult provider prior to the final transfer helped to reduce these fears. Furthermore, both Betz et al. (2013) and Rutishauser et al. (2014) suggest that teaching these young adults the skills to independently manage their own conditions may enable them to better negotiate the adult health system and could be expected to further reduce anxiety both prior to and after the final transfer.

Young adults in the qualitative study by Okumura et al. (2015) found the change in expectations to be abrupt and challenging, which made the young adults feel apprehensive towards transition. These feelings were heightened depending on the extent of involvement from family members and pediatric providers. For example, 'sheltering' (Okumura et al., 2015. p.720) from parents made the transition harder on young adults as it prevented the young adult from taking on any form of responsibility prior to the transfer, therefore increasing feelings of anxiety and apprehension towards the transition process. In addition, pediatric providers who were over-involved and fearful of transferring their patients made the transition process confusing and difficult for young adults as the boundaries between the responsibilities of pediatric and adult care providers became blurred (Okumura et al., 2015). The results from Okumura et al.'s (2015) study suggested that the way families and health care providers coped with transition themselves indirectly influenced the young adult's emotional and developmental growth.

Parents' perceptions and experiences. Parents perceptions and experiences were briefly highlighted in the aforementioned study by Okumura et al. (2015). Similar to young adults, family members of young adults with complex chronic conditions reported that adult care providers gave little to no support for managing new medical equipment or accessing eligible services within the adult community. This resulted in feelings of fear and intimidation (Okumura et al., 2015) as parents were left to figure out the system on their own. Navigating through a new community of different retailers and trying to determine which kind of equipment was best suited for their now young adult was both challenging and isolating. Furthermore, the lack of coordination and follow through in services (Okumura et al., 2015) resulted in delays and potential health complications for the young adult post transfer. It is important to point out that a purposive sample was used in this study (Okumura et al., 2015), as such these findings may not be generalizable to all caregivers of young adults with complex chronic conditions. This being said, the overall results identify that the psychological well-being of young adults (Betz et al., 2013; Rutishauser et al., 2014) and family members (Okumura et al., 2015) during the health care transition process are strongly attributed to a general lack of information and preparation from both pediatric and adult health care providers.

Preparedness

For the purpose of this paper, preparedness refers to the state of being prepared for health care transition. This was a frequent theme identified in nine of the final twelve studies: three of the qualitative studies (Aldiss et al., 2015; Okumura et al., 2015; Syverson et al., 2016), three of the quantitative studies (Maddux et al., 2015; Rutishauser et al., 2014; Chung et al., 2017), and all three of the systematic reviews (Betz et al., 2013; Gabriel et al., 2017; Nehring et al., 2015). Preparation was recognized by young adults (Aldiss et al., 2015; Betz et al., 2013; Gabriel et al., 2017; Maddux et al., 2015; Okumura et al., 2015; Rutishauser et al., 2014; Syverson et al., 2016), family members (Aldiss et al., 2015; Okumura et al., 2015), and health care providers (Aldiss et al., 2015; Chung et al., 2017; Maddux et al., 2015; Nehring et al., 2015) as a facilitator for successful health care transition. Data on transition preparation initiatives in acute and primary care settings are essential to informing future program development to ensure that the needs and expectations of young adults, families, and health care providers are met.

This theme is supported by two sub-themes which emerged as factors influencing transition preparation in both young adults and health care providers; anticipatory guidance and health promotion for patients, and health care provider training and proficiency. Anticipatory guidance and health promotion refer to information given by the health care provider to young adults and their families in order to prepare them for the expectations of transition (Aldiss et al., 2015; Betz et al., 2013), encourage independence of their own care (Syverson et al., 2016), and promote optimal health outcomes (Maddux et al., 2015). This may include details about health care transition, information about the young adults' condition, and the development of self-management skills. Health care provider training and proficiency refers to the skills, knowledge, and qualifications of health care professionals within the practice of transition care (Nehring et al., 2015).

Anticipatory guidance and health promotion for patients. Seven studies identified the need for improved transition preparation, planning, and support for young adults with complex chronic conditions (Aldiss et al., et al., 2015; Betz et al., 2013; Gabriel et al., 2017; Maddux et al., 2015; Okumura et al., 2015; Rutishauser et al., 2014; Syverson et al., 2016). At present little is known about the level and type of transition preparation (Maddux et al., 2015) being delivered by health care providers and whether or not it is consistent across practice settings. As such, Maddux, Ricks, and Bass (2015), sought to examine the range of transition services provided by pediatric primary care providers. Surveys were distributed to 645 pediatric primary care providers across two states in the Midwest. A cohort of 248 pediatric primary care providers responded working in either community or tertiary practice settings. From these results, 61.2% (n=152) of the pediatric providers reported that they were providing some form of transition preparation, planning, or support to patients prior to transfer. The majority of these respondents endorsed providing a list of adult providers (n=50) and transferring patients' medical records (n=30), while only 8.6% (n=13) admitted to communicating with the receiving adult provider and 2% (n=3) discussed differences between pediatric and adult care settings (Maddux et al., 2015). Although more than half of the respondents in this study provided some form of transition preparation, the extent and type were inconsistent. Furthermore, despite the known benefits of transition preparation for patients with complex chronic conditions, 40% (n=99) of pediatric providers did not provide any form of support to their patients prior to the final transfer. Interestingly, Maddux et al. (2015) found that, despite the wide variance in transition preparation, nearly all of the pediatric providers' reported educating patients on lifestyle and risk-taking behaviours such as safe sex 96.4% (n=239), pregnancy 83.5% (n=207), smoking 99.2% (n=246), alcohol use 97.2% (n=241) and drug use 95.6% (n=237) prior to transfer. This was a positive response as such topics can be difficult to raise with young people yet are critical for developing adult roles and responsibilities as well as maintaining future health outcomes (Maddux et al., 2015). The authors of this study (Maddux et al., 2015) further established that primary care providers had a vital role in initiating and continuing comprehensive lifestyle discussions throughout the young adults' lifetime. One notable limitation of this study was the lack of information on demographic characteristics which restricts the ability to draw conclusions and comparisons across practice settings. For instance, further details on each of the practice settings would have provided a better understanding of whether transition services differed between pediatric primary care providers working in community clinics as compared to those working in private practices or tertiary settings. Despite this limitation, this study highlighted the inconsistencies of transition preparation, which may contribute to young adults' quality of life or desire to seek follow-up care within the adult health system.

Similar results arose in the qualitative study by Syverson et al. (2016) who aimed to evaluate the frequency of health care transition anticipatory guidance delivery and its' impact on young adults with complex chronic conditions. From a total of 209 young adults ages 16-22 years with low to high care needs, 64% (n=134) responded that they had not discussed transition with their health care provider, 43% (n=90) or their changing health care needs, with only 57% (n=119) were 'usually' or 'always' being encouraged to take responsibility of their care. Specific to the young adults with high care needs (n=48), 54% (n=26) of these participants had not talked about changes to adult care, however, these numbers were much less than young adults with lower care needs. These results indicate that individuals with higher care needs may in fact be receiving more anticipatory guidance compared to young adults with lower care needs prior to transfer. This being said, the overall percentage of participants with high care needs receiving transition anticipatory guidance was still rather low (Syverson et al., 2016). In addition, data indicated that young adults with higher care needs who discussed transition with their health care provider had significantly higher ratings of perceived transition readiness (95% CI=4.4-8.4). This group had much higher ratings of transition readiness and likelihood of transition success as compared to those who had not receive any form of transition care (95% CI=4.7-7.7; 95% CI=6.5-8.6). The cross-sectional design of this study limits the ability to measure longitudinal data. Moreover, participants of this study were predominantly African-American and from lower socioeconomic status, therefore limiting the generalizability of the data.

Correlation between transition preparation and young adults' perceived transition readiness was supported in five additional studies (Aldiss et al., 2015; Betz et al., 2013; Gabriel et al., 2017; Okumura et al., 2015; Rutishauser et al., 2015). The variance in transition readiness among young adults appeared to be highly dependent on their perceived self-efficacy in self-management skills (Gabriel et al., 2017; Rutishauser et al., 2015). A need for more clinical information about the young adults' conditions and clinical management was noted in three of the studies (Aldiss et al., 2015; Betz et al., 2013; Okumura et al., 2015) as both young adults and families reported that preparation contributed to self-reliance, thereby reducing apprehensions related to health care transition.

Overall, data suggested that structured transition interventions that include anticipatory guidance and the development of self-management skills have a strong effect on young adults' comfort level and their perception of successful transition. From these results, authors (Gabriel et al., 2017; Syverson et al., 2016) hypothesized that both education and counselling resulted in higher rates of transition success and decreased morbidity and mortality in young adults with complex chronic conditions.

Health care provider training and proficiency. Four of the eight studies (Aldiss et al., 2015; Betz et al., 2013; Chung et al., 2017; Nehring et al., 2015) investigated health care provider experience and knowledge in providing transition services to young adults with complex chronic conditions. The studies included in this sub-theme explored health care providers' experience with and level of comfort in providing transition care (Chung et al., 2017; Nehring et al., 2015), and desirable attributes of providers who delivered or were projected to deliver transition care (Aldiss et al., 2015; Betz et al., 2013).

In the systematic review conducted by Nehring, Betz, and Lobo (2015) four of the 55 studies investigated adult provider competency in transition care. Results found that training in transition care is limited for both pediatric and adult providers. This being said, more pediatric providers reported having some form of health care transition training included in their residency as compared to adult providers (93% vs. 13.8%) (Nehring et al., 2015). In addition, adult providers are at a greater disadvantage as they have limited exposure to and experience with young adults with complex chronic conditions. As such, professional reluctance from adult providers towards providing transition care for this population was eminent throughout the review (Nehring et al., 2015). These opinions largely stemmed from adult providers' professional judgement that they lacked the proficiency to be competent and safe providers (Nehring et al., 2015). Furthermore, authors found that adult providers' comfort level for delivering transition care was heavily dependent on the level of medical complexity of the young adult and the level of support available to the provider (Nehring et al., 2015). Similarly, pediatric providers reported feeling uncomfortable handing care over to adult providers as they believed that adult providers would not deliver comparable levels of care to their patients (Nehring et al., 2015). Comparable results were found in the quantitative study conducted by Chung et al. (2015) in that 75% of internal medicine residents reported being inadequately prepared to care for young adults with complex chronic conditions, further identifying that approaches for training health care providers in transition care have not been effectively established. Recommendations from Nehring et al.'s (2015) systematic review included creating criteria for the transfer of care for young adults with complex chronic conditions, pre-service training opportunities and continuing education sessions for practicing providers.

In addition to health care provider level of comfort in transition care, 10 of the 35 studies analyzed in Betz et al.'s (2013) systematic review discussed desirable health care provider attributes perceived by young adults. Young adults reported that having a provider who delivered care throughout their life was of utmost importance. Good listening skills and the ability to show empathy were also desirable. Participants in Aldiss et al.'s (2015) study supported these results by adding that young adults felt their voices were heard when providers took the time to listen and subsequently used this information to "learn from the young people" (p.639). It was also identified that young adults responded more favourably to providers who viewed them as normal young adults, rather than having their condition define them (Aldiss et al., 2015). Finally, knowledge about the young adult's condition, as well as developmentally appropriate issues such as lifestyle behaviours and sexual health education were recognized as essential attributes by both the young adult and their families before, during, and after health care transition (Aldiss et al., 2015; Betz et al., 2013). These data highlight the relationship between the health care provider's attitude and approach to care, and its impact on transition care for young adults.

Communication and Collaboration

The fourth theme identified within this integrative literature review emphasized the benefits and challenges associated to communication and collaboration (Aldiss et al., 2015; Berens & Peacock, 2015; Betz et al., 2013; Chung et al., 2017; Ciccarelli et al., 2014; Maddux et al., 2015; McManus et al., 2015; Nehring et al., 2015; Okumura et al., 2015). For the purpose of this review, communication refers to the sharing of information between health care providers, young adults, and families. Collaboration refers to joint communication and decision-making with the expressed goal of working together towards identified health outcomes, while respecting the unique qualities and abilities of each team member (BCCNP, 2018a). This theme will be supported by two sub-themes: provider-provider communication, and provider-parent communication.

Provider-provider communication. Poor communication between health care providers and incomplete handover of patient information were factors that contributed to ineffective health care transitions in four of the final studies (Aldiss et al., 2015; Betz et al., 2013; Maddux et al., 2015; Nehring et al., 2015). In the qualitative study by Aldiss et al. (2015), focus groups involving health care providers (n=36) discussed barriers and facilitators to implementing transition services within their practice sites. Such initiatives included holding transition days for families and joint transition clinics including pediatric and adult providers. Surprisingly, the results of the study indicated that such initiatives were not shared between teams, for example health care providers within the same hospital were unaware of what colleagues from different specialities had already implemented (Aldiss et al., 2015). This lack of communication and collaboration among providers resulted in redundancies and wasted efforts as services were attempting to develop initiatives that either had already been put into place or previously tried and failed with other services (Aldiss et al., 2015). These results highlight a need for health care providers to share and compare successful and unsuccessful transition initiatives between other health care services. Aldiss et al. (2015) hypothesized that information sharing would result in a sense of consistency and support development of best practice initiatives. A strength of this study was the inclusion and praise of primary care providers. For example, further results from the focus groups involving health care professionals addressed the importance of young adults having a primary care provider and ensuring their inclusion early in transition care. Having care provided by a primary care provider closer to home was considered a key element in saving resources and time for young adults and the health team. A limitation of this study was the small sample size of young adults (n=9) and the lack of complexity among each of their chronic conditions (i.e. cystic fibrosis, juvenile arthritis, diabetes, chronic fatigue syndrome, and multiple allergies).

A lack of communication between pediatric and adult providers was identified as a result of an emerging field of practice within an unprepared system of care, discussed in one quantitative study (Maddux et al., 2015) and two of the systematic reviews (Betz et al., 2013; Nehring et al., 2015). Maddux et al.'s (2015) quantitative study emphasized that fewer than 10% of pediatric providers (n=248) within a primary care setting reported having direct communication or correspondence with the receiving adult provider before, during, or after the transfer of care. These results resonated with the systematic review conducted by Nehring et al. (2015) as six of the 55 final studies identified a lack of communication between pediatric and adult-oriented providers as a system-level barrier that further complicated the coordination of services. Difficulties accessing medical records was also reported as a significant barrier affecting communication and coordination. Aldiss et al., 2015 determined that these barriers were largely the result of a care system that was unprepared to support the provision of transition services. Four of the 35 studies analyzed in Betz et al.'s (2013) review noted that ongoing communication between pediatric and adult-oriented providers was essential for care coordination and for overcoming barriers towards successful transitions.

Conversely, a collaborative approach to care was established as a successful strategy for enhancing health care providers' communication skills and knowledge in transition care for young adults with complex chronic conditions. Berens and Peacock's (2015) qualitative study with a cohort of n=253 participants including a range of conditions; cerebral palsy (n=80), Down syndrome (n=54), spina bifida (n=52), genetic conditions not otherwise specified (n=50) and autism (n=17) emphasized the value in strong working partnerships. Continued communication was critical when the complexity of the patient extended beyond the scope of the primary care provider. For example, when patients have complex comorbidities i.e. sleep apnea or relied on medical equipment (i.e. gastrostomy tubes). Authors stressed the necessity of pediatric and adult-oriented specialist support to discuss potential risks, required health screening, and management of secondary diagnoses.

Chung et al. (2017) sought to improve interdisciplinary communication between pediatric and adult medicine residents' and establish a pattern of productive collaboration by implementing training programs within a multidisciplinary transition clinic. Pre-clinic and post-clinic surveys were used to collect data on health care providers' experiences, changes in attitudes, and transition care preparedness. Study data were collected using REDcap (Vanderbilt University, Nashville, TN) electronic data capture tools, while survey responses were analyzed using paired t tests. Between pre- and post-clinic assessment, trainees reported statistically significant improvement in preparedness for communicating with colleagues in other disciplines ($P<0.01$), counseling young adults and families ($P<0.01$), and receiving young adults with complex chronic conditions into care ($P=0.04$). Although the health care providers in this study did not represent primary care providers, the overall findings demonstrate a positive response to the dyadic model of transition care training. Key limitations of this study included it being restricted to one setting, as well as the use of surveys to solicit self-assessed changes in attitudes and confidence (Chung et al., 2017).

Results from Chung et al.'s (2017) study were similar to those in an earlier quantitative study conducted in the United States by Ciccarelli, Brown, Gladstone, Woodward, and Swigonski (2014). Collaborative approaches to care provided an effective model in sharing knowledge among health care professionals. Ciccarelli et al. (2014) used an implementation science approach to develop a statewide transition support program for 129 young adults with complex chronic conditions (71 of which consented to participate in the study). Training in transition care drew on education from a range of disciplines and providers (i.e. patient advocates, nursing, medicine, and social work). As health care professionals acquired new experiences and knowledge in transitional care delivery, this was subsequently disseminated with their wider networks. Additional resources such as evidence-based chronic condition handouts and device information sheets, medical summaries, care plans, and transition goals were used to effectively communicated between services and embed training programs in provider settings (Ciccarelli et al., 2014).

Lastly, a quantitative study performed by McManus et al. (2015) examined the relationship between quality improvement activities between pediatric and adult primary care practices and their effect on health care transition. The authors aim was to determine whether pediatric, family medicine, and internal medicine provider's participation in a two year learning collaboration would improve the delivery of transition services for young adults with complex chronic conditions. This time series comparative study involved five primary care centers in the district of Columbia which adopted the 'Six Core Elements of Health Care Transition', a quality improvement intervention modeled after the AAP, AAFP, and ACP-ASIM 2011 Clinical Report on Transition (McManus et al., 2015, p.74) to assess quality improvement in the development of a transition policy, transitioning youth registry, transition preparedness, transition planning, transfer of care, and transition documentation. Each center evaluated their practice on the Core Elements using Health Care Transition Index and feedback was provided via structured interviews. The evaluation was completed three times over the course of two years. Results of the study identified improvements in all six transition quality indicators in both pediatric and adult practices. Results of the study determined that staff knowledge about health care transition doubled within six months of the intervention and within 22 months all five care centers developed transition policies and were assessing young adults for self-management and health system navigation skills (McManus et al., 2015). Further, all care centers highlighted the significance of senior leadership support and the importance of a team-based approach for best practice. A lack of time and payment for the added transition work and a lack of functionality of electronic health records for tracking transition progress were noted as critical challenges affecting the coordination between sites (McManus et al., 2015). These positive results indicate the feasibility of an organized transition process using a collaborative approach between pediatric and adult primary care. However, better methods need to be established for the transfer of information between clinic sites in order to improve communication and coordination of care during health care transitions.

Provider-parent communication. The qualitative study conducted by Okumura et al. (2015) identified that navigating young adults through the transition process was further complicated by a lack of communication between health care providers and families. Many parents of young adults with complex chronic conditions did not feel well supported during the health care transition process, which resulted in feelings of frustration and abandonment (Okumura et al., 2015). One parent in Okumura et al.'s (2015) study expressed a desire for a more accessible care system, that would reach out and offer services instead of waiting for parents or young adults to ask for it. These feelings were found to be more prevalent among families with added social barriers such as lower socioeconomic status, language barriers, or lower education levels. As such, these individuals felt more intimidated asking for help or felt less entitled to health services and support (Okumura et al., 2015). The results from this study highlight the relationship between provider interactions, communication, and access to care.

Communication and collaboration are two factors affecting health care transitions for young adults with complex chronic conditions. Examples of both the benefits and challenges associated to these factors are summarized in the above nine studies. Communication and collaboration are critical elements within clinical practice that contribute to health care transition outcomes for young adults and their families.

To summarize, this analysis has provided a critical review of four broad themes identified within the 12 final studies. In consideration of my research question: "What are the strategies primary care providers can use to enhance the transition process for young adults ages 15-25 years with complex chronic conditions exiting pediatric services?” This analysis considers the factors influencing young adults during their health care transition process, the psychosocial issues associated with ineffective health care transitions, the significance preparation has on both health care providers and the young adult and the dynamics involved in communication and coordination of care. The following chapter provides an in-depth discussion of these findings, further exploring the relationship these themes have on health care transition and primary care management. The chapter will then conclude with recommendations for clinical practice, and limitations and recommendations for future research.

Chapter V: Discussion

This integrative literature review was conducted to synthesize the research evidence from 2012-2018 on primary care management of health care transitions for young adults with complex chronic conditions exiting out of pediatric services. Young adults with complex chronic conditions have a rate of survival and functional health status that was not experienced in the past. The need for their transition to adult care has posed numerous challenges for health care professionals. By providing insight from the perspectives of key stakeholders involved in the transition process- young adults, parents, and health professionals- this literature review has identified four key themes: relationships, fear and anxiety, preparedness, and communication and collaboration.

It is evident throughout the results of this review that the identified themes are interrelated as well as persist at the micro, meso, and macro level. These themes continue to interfere, focus, and question the delivery and implementation of transition services and care for young adults with complex chronic conditions. This is particularly salient as linked to experiences of communication between health care providers, young adults, and their families. Communication was a driver between the micro, meso, and macro levels of engagement, in developing relationships, embedding evidence-informed practice, sharing knowledge, and improving coordination of care. Analysis of the literature found that relationships with young adults can both hinder or facilitate transition preparation, which in turn can induce fear and anxiety in the young person as they transfer into the unfamiliar environment of the adult health system. While every individual experiences their own personal and condition-specific challenges, certain barriers transcend chronic conditions such as relationships, fear and anxiety, preparedness, and communication and collaboration. These factors were captured throughout the integrative literature review and represented the themes within the chapter, findings.

This chapter will discuss the importance of health care transition, the application of the results of this integrative literature review and their relevance to clinical practice followed by key recommendations for primary care practice. Finally, this chapter will conclude with a discussion of the limitations of this integrative literature review providing further recommendations for professional development, policy, and future research on the topic of health care transition for young adults with complex chronic conditions.

Relationships

Relational barriers fostering dependency were cited in several reviewed studies (Nehring et al., 2015; Okumura et al., 2015; Rutishauser et al., 2014) as impediments to adopting self-management skills. The young adult's relationship with both their family members and pediatric providers were found to influence the young adult's ability to be autonomous with their own care. Family members who took full responsibility of their child's care did not encourage self-reliance and often took on elements of care that would have otherwise been suitable for the young adult to manage independently (Nehring et al., 2015; Okumura et al., 2015). While no recommendations in the literature were directly linked to the parent-patient relationship, this remains an important dynamic for primary care providers to be cognizant of when educating young adults with complex chronic conditions on health care management issues as part of assessing for transition readiness. Therefore, it is necessary to involve family members in the transition planning. Such individuals can be a resource for both youth and the provider as a result of their longitudinal expertise caring for their child. As families learn to navigate this space primary care providers can bolster the gradual shift in responsibility towards the young person further enhancing the adolescent's health management responsibility. An example of how primary care providers can navigate shifting support approaches while nurturing relationships is via developing opportunities for one on one appointments without the presence of a family member or caregiver (Nehring et al., 2015). This approach can help promote effective development of health literacy and advocacy skills in the young adult prior to transfer. An awareness of the patient-family-centered approach to care and the vital role families have in the lives of young adults with complex chronic conditions is critical during health care transition. Results from this review (Aldiss et al., 2015; Okumura et al., 2015) suggest that family members or other individuals with emotional ties to the young adult may play an instrumental role in perceived encouragement and influence on overall behaviours. As such, endorsing patient-family-centered care within the primary care setting may open the door to establishing partnerships between parents and primary care providers. Building and sustaining such approaches can foster partnerships that, if continued, are likely to facilitate health care transition and enhance outcomes for young adults.

Similar issues were highlighted in the literature related to provider-patient relationships. Young adults and families were apprehensive about ending their trusting, long-term relationship with pediatric providers which often interfered with the development of new provider relationships (Aldiss et al., 2015; Betz et al., 2013; Nehring et al., 2015; Okumura et al., 2015). Pediatric providers also feared that adult-oriented providers would either demand a level of independence that the young adult could not possess or that the young adult's health would decline due to the adult-oriented providers lack of experience working with this complex population (Nehring et al., 2015). The literature found that an overlap in care through joint clinics between pediatric and adult-oriented providers or meeting adult-oriented providers before transfer has the capacity to ease young adults, family members, and pediatric providers concerns when faced with uncertainty (Aldiss et al., 2015; Berens & Peacock, 2014; Betz et al., 2013). In addition, establishing a system of communication where primary care providers check in to ensure young adults attend their first adult-oriented specialist appointment may reduce feelings of abandonment and promote trust between the young adult and primary care provider. Finally, the literature highlighted the importance of scheduling end dates that represent the last visit with pediatric providers. This may help instill boundaries between providers and young adults and limit the chance of the pediatric provider relationship interfering with the young adult's relationships with future providers (Nehring et al., 2015; Okumura et al., 2015; Rutishauser et al., 2014).

Fear and Anxiety

A lack of understanding of the major service systems and life changes young adults and their families were to experience was evident throughout the literature. As such, greater recognition needs to be placed on providing information to young adults and their families about the transition process, the adult health system, and community supports available post transfer. Fear and anxiety around health care transition was common throughout the reviewed literature (Betz et al., 2013; Okumura et al., 2015; Rutishauser et al., 2014). It is reasonable to consider that pediatric provider's ambivalence and apprehensions towards adult care may inadvertently communicate to young adults and their families that transition is something to be feared. Detailed information about the adult care system and why health care transition is necessary (i.e. developmentally appropriate care and adult medical services) may reduce such fears and build an understanding around the need for transition. Using positive language whenever discussing health care transition and viewing the change as a positive step in the young person's life may help to reduce any negative connotations associated with the transition process. Moreover, connecting young adults and their families with peers who have transferred into adult-oriented care may relieve anxieties and help to establish connections within the adult community. For example, the use of peer support workers for assisting young adults transitioning into adult mental health services was evaluated in a study by Oldknow, Williamson, and Etheridge (2014). Authors concluded that peer support workers were a valuable asset for promoting patient involvement and reducing perceived barriers towards health care transition (Oldknow et al., 2014). Although this study was conducted in the United Kingdom it suggests that the use of peers may be beneficial for young adults with complex chronic conditions transitioning into adult health services.

Preparedness

The literature identified that providing young adults with clear and comprehensive information about their conditions and its implications on their physical, sexual, and mental wellbeing translates into confidence within the health care setting (Betz et al., 2013; Maddux et al., 2015; Syverson et al., 2016). Furthermore, this confidence, alongside knowledge about the adult health system, had a positive effect on young adults fears and anxieties towards health care transition (Betz et al., 2013; Maddux et al., 2015; Nehring et al., 2015). Young adults who were able to clearly explain their diagnosis, manage their basic care, and were informed of the expectations of the adult care system reported feeling more comfortable and prepared for transition (Aldiss et al., 2015; Betz et al., 2013; Maddux et al., 2015). As such, the results of this review demonstrate an urgent need for consistent delivery of developmentally appropriate and comprehensive transition education and preparation that begins early in adolescence and continues throughout the young person's lifetime. This being said, a discrepancy between best practice and real-life practice for delivering transition care was also identified in the reviewed literature (Maddux et al., 2015; Syverson et al., 2016). The frequently cited report on health care transition by AAP, AAFP, and ACP-ASIM (2011) identifies that comprehensive transition preparation and planning is critical for all young adults prior to transferring to adult-oriented care. However, it was reported in Maddux et al.'s (2015) study that just under half of pediatric providers failed to deliver any form of support to their patients. It was further reported that transition preparation largely consisted of a list of adult referrals and transferring records (Maddux et al., 2015), suggesting that comprehensive transition care is rarely being delivered. This level of transition care may be suitable for those with minor health needs, however, young adults with complex chronic conditions require a higher level of support and would benefit from such as per the results of this literature review. While it is well-known that young adults benefit from comprehensive transition planning and preparation, health care providers, pediatric, adult, and primary care alike, all lack either the experience, exposure, or knowledge in the field of transition care (Chung et al., 2017; Nehring et al., 2015; Okumura et al., 2015). As such, there is a clear need for training and ongoing education in transition care for all health care providers, particularly primary care providers and adult-oriented providers. Advocating for training opportunities and accessing available resources such as the Rapid Access to Consultative Expertise (RACE) line (Providence Health Care, Shared Care Partners for Patients, & Vancouver Coastal Health, n. d.), and workshops or webinars affiliated with transition care may help enhance primary care providers knowledge base and increase awareness around the need for improved training and educational opportunities within this field of care. In addition, issues continue to persist at the meso system-level, regular training for primary care providers must be established for those who have traditionally cared for these young adults, as well as for those who will be increasingly called on to care for this unique population. While training in transition care is crucial, it is essential that providers are also knowledgeable in adolescent health specifically managing psychosocial and behavioural issues, particularly around sexual and reproductive health. Primary care providers may choose to initiate the delivery of self-management skills to support young adults in ways that enable them to practice the role of health responsibility. Furthermore, to initiate change at the macro policy-level, primary care providers individually or through their colleges such as the BC College of Family Physicians and BC College of Nursing Professionals, can partner with organizations such as Inclusion BC (2018) and Community Living BC (2018) in order to improve advocacy and awareness around the vocational, educational, and housing needs of young adults with complex chronic conditions.

Communication and Collaboration

Strong communication skills, multidisciplinary collaboration and consultation are key success factors in health care transition. A quantitative study by Chung et al. (2017) identified that multidisciplinary collaboration can positively influence health care provider's knowledge and confidence in transition care. This sharing of knowledge can enhance skills, provide support, and foster connections between providers. Unfortunately, the literature also identified that very few providers engage in direct communication (Maddux et al., 2015). This lack of communication was further influenced by inadequate EHR systems that cannot be universally accessed across care settings (Bahan et al., 2017; Coleman & Berenson, 2004). Such initiatives are crucial for transferring medical information, tracking the transition process, and staying informed in the young person's care management. Existing EHR systems need to be adapted to implement standard transition templates that support personalized care planning and allow for secure universal access among all providers. Having an established EHR system that is easily accessible with embedded personalized transition tools will improve coordination of care and promote consistency among health care professionals.

There are many confounding factors affecting the health of these young adults which thereby inhibit the transition process (Kaufman et al., 2018; Paone & Whitehouse, 2011). As such, the quality of communication between the health care provider, the patient, and their family was a critical component to successful health care transitions identified in the literature (Okumura et al., 2015). Collaborating with young adults and their families by including them in the decision-making process, while also inquiring about other aspects outside of the young adult's medical needs may help support primary care providers in bridging this gap in communication. Primary care providers must be cognizant of how social support, health behaviours, and material circumstances interact to influence health outcomes for these young adults (Kaufman et al., 2018). Asking the right questions and having an awareness of available community supports will ensure care is directed around the young person. Additionally, it will improve access to local services resulting in more comprehensive, high quality care. The Responsive Intersectoral Children's Health, Education, and Research (RICHER) Initiative in Vancouver's Eastside is an excellent example of interdisciplinary partnerships within a community setting. They work together using the expertise and resources available to reduce barriers and address the unique needs of children, youth, and families in Vancouver's inner city areas (Lynam et al., 2010). A similar collaborative program that focuses on transition care would benefit young adults with complex chronic conditions and their families as they prepare to exit pediatric services. Primary care providers and specialists with an interest in this field of care may choose to rally together to advocate for the needs of this complex population by speaking with fellow professionals, community partners, and local Members of the Legislative Assembly (MLA) about establishing a similar MDT concept within the community informed by the positive results seen with RICHER.

Primary Care Practice

Primary health care, as compared to a predominant reliance on subspecialty-based care, is key for providing continuous, high-quality care to patients with chronic conditions (Okumura et al., 2010). Primary care providers play a pivotal role in health promotion and care coordination for patients with chronic conditions. As such, it is alarming that the literature from this review indicates that young adults with complex chronic conditions have difficulty finding primary care providers (Nehring et al., 2015). It is unclear from the literature whether this is strictly a result of provider inexperience and a lack of exposure working with complex young adults or a result of a shortage in primary care providers, or both. Either way, I suspect that as the role of the nurse practitioner gains increasing recognition and more young adults with complex chronic conditions continue to transfer over to adult care, this will change for the better. As increasing numbers of nurse practitioners enter practice one recommendation would be to connect pediatric specialty care services with a network of primary care providers who are willing to take on their transitioning patients. These specialists could partner with the primary care providers, in person or via telehealth, by gradually handing over care and acting as mentors for future questions or concerns around the young person’s care. This could offer primary care providers a sense of support when taking on such complex clients and ensure that all young adults exiting pediatric specialty services are connected to care.

Aligning with the literature, there are four pertinent factors to the success of primary care providers practicing in transition care. Firstly, all young adults with complex chronic conditions should have a primary care provider by early adolescence. The second, primary care providers must be aware of the psychosocial and medical needs of these young adults. Thirdly, primary care providers need basic training in complex childhood conditions and transition care, with ongoing opportunities for continuous education and support. Specifically, multidisciplinary specialist teams have a responsibility to support primary care practitioners by providing educational opportunities. Lastly, primary care providers need to consider what their needs are in order to work in partnerships with allied health professionals to ensure early inclusion in the young person’s life. This will not only enhance coordination among medical providers, but also promote consistency, support, and trust between primary care providers, allied health professionals, young adults, and their families.

Through proactive partnerships with allied health professionals, primary care providers can be confident, competent, and willing components in the transition process working with young adults with complex chronic conditions. Furthermore, models of care that do not include primary care providers are more likely to exclude a large portion of young adults who are unable or unwilling to maintain follow-up in centralized, urban settings. Thereby, placing these individuals at further risk for delayed treatment and fragmented care once they are discharged from pediatric services.

Recommendations for Primary Care Practice

Based upon the aforementioned results, a set of recommendations have been generated according to the themes of this paper to assist primary care providers in enhancing the health care transition process for young adults with complex chronic conditions exiting out of pediatric services. Young adults with complex chronic conditions have distinct health needs, however, they also require the same psychosocial education (i.e. sexual health and risk behaviours) and general preventative health measures as healthy young adults. Current services are failing to meet the needs of these young adults and their families, as evidenced by the low rates of successful transitions for young adults with complex chronic conditions, poor health outcomes, inconsistent receipts of transition preparation, and the limited available evidence to guide primary care providers on how to best care for this unique population (Betz et al., 2013; Maddux et al., 2013; Syverson et al., 2016; Wang et al., 2010). The results from this integrative literature review demonstrate that the transition process for young adults with complex chronic conditions are multifaceted but are largely affected by a change in relationships and a fragmented health system that impedes communication and collaboration among those involved. While a full discussion of strategies aiming to change the organizational and system-level issues is beyond the scope of this paper, the results from this review nevertheless suggest that there are gaps at the patient-provider level of care. As such, the following strategies may aim to increase the primary care provider's ability to better address the health care transition needs of young adults with complex chronic conditions, and to enhance the coordination of care between adult and pediatric providers. The recommendations for primary care practice are summarized in Table 3.

Table 3

Recommendations for Primary Care Practice

Theme	Recommendation	Action/Rationale
- **Relationships**	1. Access support to attain and maintain working partnerships and open communication with allied health professionals.	1. Promote connected care by remaining in contact with both pediatric and adult specialists for support and advice with care management.
	2. Endorse a patient-family-centered approach to care.	2. Individualize care, that includes both the adolescent and family in transition process.
	3. Encourage young adult to set final date with pediatric providers.	3. Setting a final date will create clear boundaries and make it easier for young adult to establish new relationships with adult-oriented specialists.
	4. Organize meet and greet with adult-oriented specialists prior to transfer.	4. Connect with receiving specialist to introduce self as primary care provider. Recommend a meet and greet with the young adult prior to the final transfer.
- **Fear and Anxiety**	1. Assess the adolescent and young adults coping skills.	1. Offer counseling options to adolescents and young adults to establish effective coping skills prior to transfer.
	2. Screen for anxiety and secondary mental health conditions before, during, and after final transfer.	2. Use tools such as modified PHQ-9 and SCARED (AAP, 2012).
	3. Ask the young person or family member about any fears associated with health care transition.	3. Develop individualized transition plan with goals. -Connect young person and family members with peers who have already transitioned.

	4. Provide information about the adult health system and associated expectations.	4. Initiate discussion. Schedule appointment outside of the clinic to tour adult care facility or clinic.
• **Preparedness:** *-Transition preparation* *-Provider Training and Education*	1. Begin transition preparation in early adolescence.	1. Begin discussing health conditions and basic care management early on.
	2. Promote independence and provide education on transitioning responsibility.	2. Encourage adolescent to learn about their conditions and educate family members around the importance of independence and self-efficacy in the young person.
	3. Schedule one to two appointments annually for transition care beginning in early adolescence.	3. Make longer (30 minute) appointments when discussing transition care. (i.e. Ten minutes with family member, ten minutes alone with young adult, five minutes together, and five minutes to answer further questions).
	4. Leave time during appointments for one-on-one conversations with adolescent and without family members.	4. Allocate some time during appointments to see adolescent alone. Initiate this early on to build comfort and confidence in the young person.
	5. Assess transition readiness annually.	5. Access online tools to assess adolescent's readiness for transition.
	6. Advocate for educational and training opportunities in transition care and childhood complex conditions for health care providers.	6. Take an active role in advocating for improved funding and opportunities in transition education.
	7. Participate in continuous education.	7. Seek out and participate in available webinars, online modules, or workshops on transition related learning

		opportunities through AAP, BCCNP, or BCCH.
- **Communication and Collaboration**	1. Use clear, developmentally appropriate language.	1. Refrain from using medical jargon. Use language that the adolescent can understand and relate to.
	2. Show warmth and empathy towards young adults and their families.	2. Use active listening skills.
	3. Initiate health care transition discussion early.	3. Start a casual discussion about health care transition by the age of 12 years *(if applicable).* Inquire about whether this has been discussed at all with the child's specialists.
	4. Provide information on adult health system to young adult and families.	4. Provide pamphlets on the adult facility and answer questions regarding the differences between health systems and expectations.
	5. Include young adult in decision-making process.	5. Ask the young adult what their health care goals are and how they would like to achieve them. -Provide the young adult with available options.
	6. Stay informed with medical and community contacts.	6. Connect with specialists (pediatric and adult) and request medical summaries as needed. -Provide medical summaries to future providers and the young adult. -Keep up-to-date with local resources and community support services.

	7. Collaborate with colleagues and allied health professionals.	7. Include all members of the team by establishing clear roles and delegating transition-related tasks for more comprehensive transition care. (i.e. include nursing for transition teaching and social work for discussing community services, housing, insurance changes, and vocational needs).
	8. Call young adult after first appointment with adult-oriented specialist to follow-up.	8. Following up to ensure appointment was attended.

Recommendations for Education and Professional Development

First and foremost, health care transition, adolescent health, and a basic introduction to childhood complex conditions should be included in all modern Canadian medical and health science programs, specifically nurse practitioners, social work, and physicians. This is especially important as health care providers will continue to see increasing numbers of this population as time goes on. In BC, nurse practitioners are expected to participate in continuing education as part of the BCCNP (2018b) nurse practitioner licensing requirements. As such, ongoing educational opportunities should be available through health authorities to ensure knowledge is up-to-date and that providers are delivering best practice evidence-based care. This is especially important for primary care providers and adult-oriented specialists as they may not be exposed to this population on a regular basis in their current practice settings. Group workshops, online modules, or classes through local universities, BCCNP, and online continuing education websites may be useful resources for support. Furthermore, creating shadow experiences with pediatricians may be beneficial for both learning purposes and building rapport between health care professionals. Knowledge and comfort typically comes with consistent exposure and experience, however, opportunities for continuous education will provide further leverage for primary care providers to enhance these skills and develop confidence. It is recommended that primary care providers seek out educational opportunities on transition care where available and continue to share best practice initiatives with colleagues and other health professionals in order to bring awareness to the needs of this unique population.

Recommendations for Policy

Nurse practitioners, as primary care providers, are essential advocates for health care transition policy and program development (Chilton, 2014). With their academic and clinical background, they have the ability to advocate for current health issues and present cases for passing legislation (Chilton, 2014). As mentioned earlier, primary care providers with an interest in complex chronic conditions and health care transition could be supported to collaborate together to create a network for increasing awareness on the importance of integrating health care transition into all aspects of pediatric, adolescent, and young adult health care practice (Reiss & Gibson, 2002). Those with first-hand experience caring for children and young adults with complex chronic conditions can use their knowledge and understanding to inform the public and local MLA's regarding how legislation can impact these individuals. There have been substantial changes made over the past few decades at the systems level on the pediatric end of the transition continuum in developing family-centered, community-based care that is coordinated among services (Reiss & Gibson, 2002). However, much improvement is needed at the adult-oriented end of the continuum to ensure that health care services and community supports remain accessible and coordinated for these young adults and their families.

Recommendations for Future Research

Future research that provides further emphasis on effective collaborative strategies, would be beneficial for practice, as would studies which include examining approaches to supporting and evaluating primary care practice. Results from the literature identified that pediatric providers, despite the infrequency, appear to be taking on the primary responsibility for providing transition care to young adults and their families (Maddux et al., 2015; Syverson et al., 2016). This is likely a result of training and expertise, however, it raises the question of whether young adults would receive more comprehensive transition preparation if the responsibility was shared among all staff (i.e. nursing and social work) (Maddux et al., 2015). This is plausible as a lack of time and reimbursement methods were frequently mentioned in the literature (Maddux et al., 2015) as barriers to providing effective transition care and support to young adults with complex chronic conditions. Furthermore, there is currently very little data that informs primary care providers or families about the importance of primary care practice for young adults with complex chronic conditions.

In addition, the literature has identified a need for longitudinal research on transition care outcomes that are measurable and specific to the young adult (Crowley et al., 2011; Looman et al., 2013; Nehring et al., 2015). Identifying specific measureable outcomes that track the health status of young adults with complex chronic conditions over time can be difficult compared to those who are less medically complex (i.e. diabetes and blood sugars). Further, a clear definition of what constitutes success that can be compared across the population is needed. With this in mind, alternative outcomes such as health care service utilization (location and level of care), and the young adult’s functional status and quality of life as they continue into the adult health system would be beneficial to measure long-term (Looman et al., 2013).

There is a clear need for further research around alternative funding models that promote the delivery of quality care by using a collaborative, patient-family centered approach. Current funding models reward providers for seeing more patients and fail to reimburse efforts made for coordination of care to ensure gaps in care delivery and duplication of services are prevented (Looman et al., 2013). Health care reform is currently driving changes in health care delivery and reimbursement methods. As such, health care services are slowly moving away from fragmented, multiple provider care towards a MDT approach, and therefore, funding models are also shifting from a fee-for-service method to blended or bundling strategies (Looman et al., 2013). Future research on reimbursement methods that focus on providing complex patients with the time and quality of care they require and further data on the cost-effectiveness of the primary care provider contribution to care management would benefit the field of health care transition for this population.

Finally, there is a significant need for research on best practice transition initiatives (Aldiss et al., 2015) and guidelines. The literature has identified many readily available transition tools (i.e. Got Transition, Bright Futures, and ONTRAC2) for health care providers, yet, very few appear to be accessing them (Maddux et al., 2015). The literature did not provide clear reasons for why these resources are not being used, however, it is possible that health care providers may not be aware of them, lack the time to seek out and implement tools into their practice, or simply may not feel they are necessary. Further research on the use of these tools may identify ways to increase provider use and implement changes so that transition tools can better address the unique needs of young adults with complex chronic conditions.

Limitations

This integrative literature review is not without its limitations. In general, there are numerous methodological weaknesses of integrative literature reviews. For example, the act of combining quantitative and qualitative literature and systematic reviews in terms of data evaluation and data analysis can be quite involved. Certain methods for data evaluation and data analysis for such literature reviews are not well established, which can lead to bias or error in the final results, particularly if the author's methods are not clearly explained (Whittemore & Knafl, 2005). Furthermore, the search strategies used should be comprehensive with clear inclusion and exclusion criteria (Whittemore & Knafl, 2005). Even though I developed an extensive table of inclusion and exclusion criteria, searched four online databases, performed hand searching, and networked with key stakeholders involved in health care transition, it is still possible that data saturation was not fully achieved due to the nature of the population at focus and the vast amount of available literature.

In addition, unlike most literature reviews that define the population of focus based on a specific diagnosis or setting, the population of this paper was based on severity, number of comorbidities, and functional limitations rather than a diagnosis. As a result, it was impossible to include all childhood complex chronic conditions within this paper, thereby limiting the generalizability of the study's findings. Further, very few studies were specific to primary care or primary care providers, however, the majority of the studies were in some form relevant to primary care practice. Lastly, there was potential bias in this project as the author has experience personally and professionally with health care transition and complex chronic conditions. Despite being cognizant of this and taking steps to avoid bias, these experiences may have skewed the interpretation of the literature and results.

Chapter VI: Conclusion

This integrative literature review sought to answer the research question: “What are the strategies primary care providers can use to enhance the transition process for young adults ages 15-25 years with complex chronic conditions exiting pediatric services?” A systematic search of the contemporary literature identified 12 studies. Analysis of the studies highlighted four key themes: relationships, fear and anxiety, preparedness, and communication and collaboration. It is evident from the analysis of the literature that health care transition for young adults with complex chronic conditions is complicated by their psychosocial development and extensive health and service needs. There is no doubt that this population will continue to grow as access to care delivery and medical technology continue to expand. Health care transition is a team effort, however, primary care providers when encouraged and supported by multi-professional teams can act as the navigator to ensure transition care is executed and the young person’s needs are being met. Utilization of best practice initiatives in primary care could improve quality of care and greatly benefit young adults with complex chronic conditions and their families. Furthermore, additional resources will need to be devoted to practitioner (i.e. pediatric, adult, and primary care providers) education to increase the number of providers able to take on these complex patients and the support from relevant clinical networks, initiatives, and research to achieve this goal. Finally, system-level changes are needed in order to address policy, funding, and organizational issues. Overall, health care transition for young adults with complex chronic conditions is an area of medicine still in its infancy and is an area in which nurse practitioners and primary care providers alike can deliver leadership and knowledge development moving forward.

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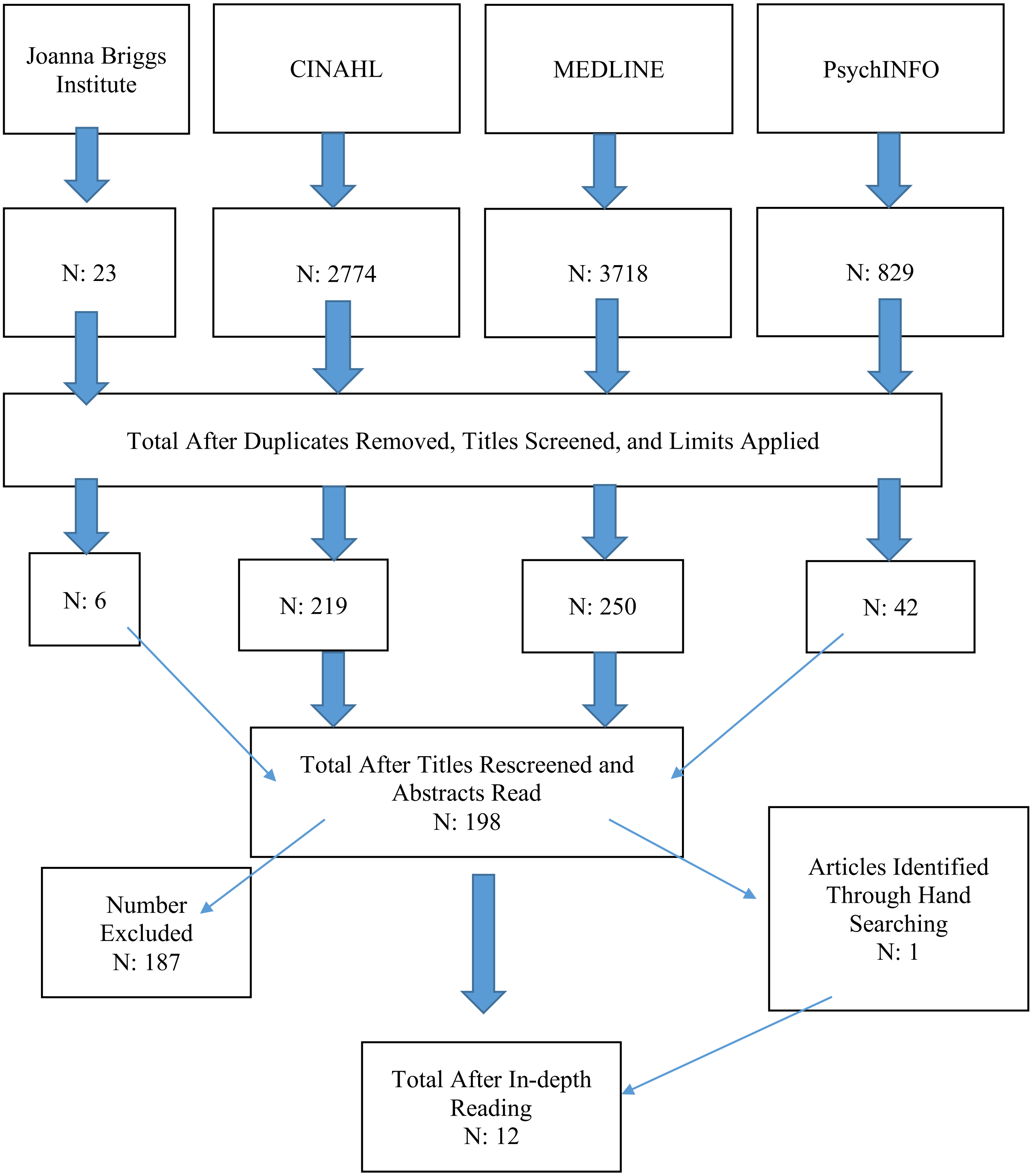
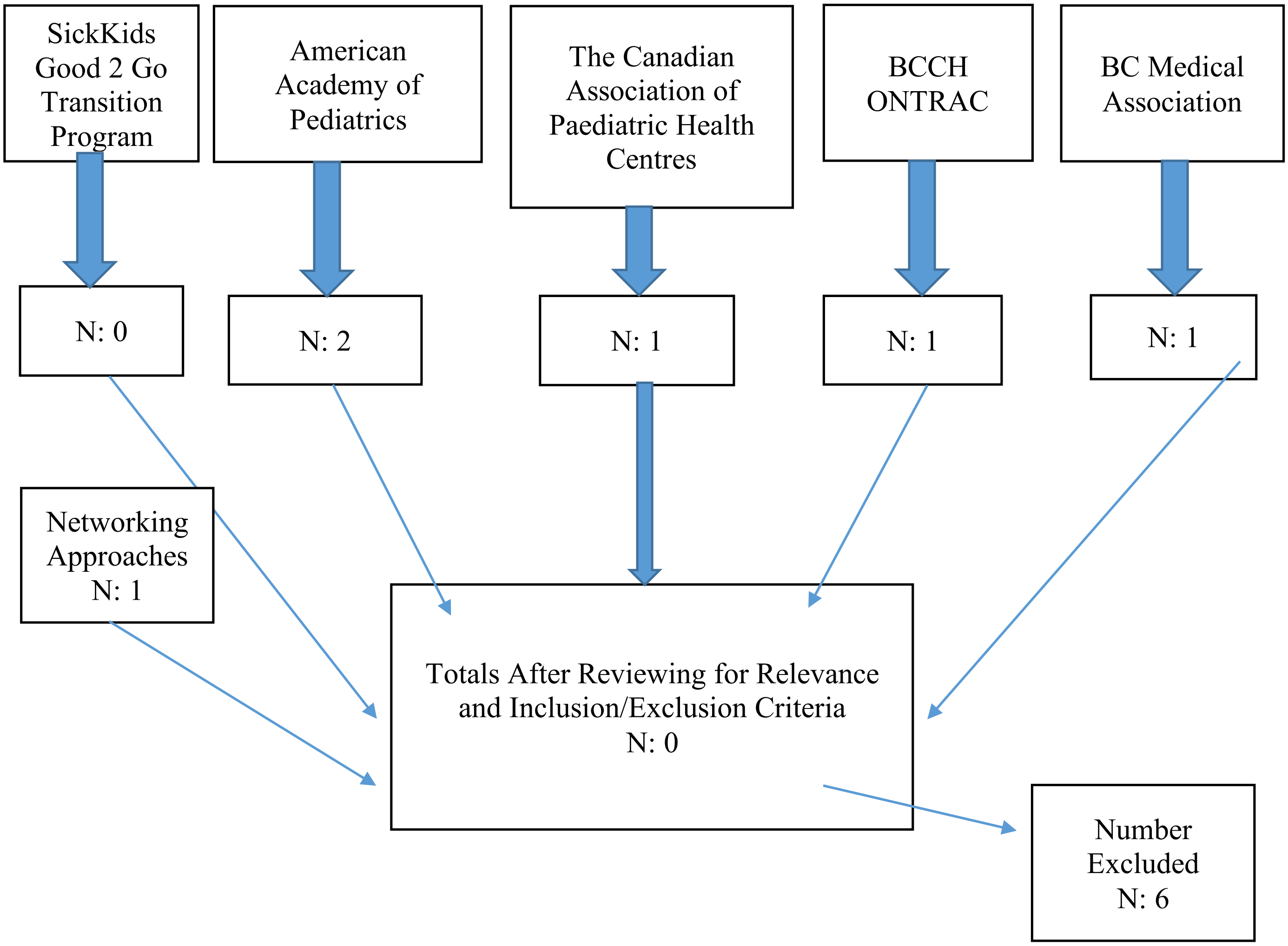
Appendix A: Database Search Strategy and Results

Search Terms	**Data Bases**	**N**
Transition of care Health care transition	- Joanna Briggs Institute	20 3
Transition of care **OR** Health care transition **AND** Young adults **OR** Adolescents	- CINAHL complete - MEDLINE with full text - PsychINFO	835 898 820
Transition of care **OR** Health care transition **AND** multimorbidity **OR** multiple chronic conditions	- CINAHL complete - MEDLINE with full text - PsychINFO	11 10 9
Transition of care **OR** Health care transition **AND** primary health care **OR** nurse practitioner **OR** primary care provider **OR** family physician	- CINAHL complete - MEDLINE with full text - PsychINFO	337 302 0
Transition of care **OR** Health care transition **OR** continuity of patient care **OR** care coordination **AND** primary health care **OR** nurse practitioner* **OR** primary care provider **OR** family physician	- CINAHL complete - MEDLINE with full text - PsychINFO	1591 2508 0
Totals:	- CINAHL complete - MEDLINE with full text - PsychINFO - Joanna Briggs Institute	2774 3718 829 23
Totals after duplicates removed, titles screened and limits applied (Dates changed):	- CINAHL complete - MEDLINE with full text - PsychINFO - Joanna Briggs Institute	219 250 42 6
	Electronic Database Search Results	
Total From Databases:		7,344
Totals kept after duplicates removed, titles screened and limits applied		517
Total kept after titles rescreened and abstracts read		198
Total kept after in-depth reading		11
Total after in-depth reading & hand-searching		12

Appendix B: Literature Search Flow Diagram



Grey Literature Search Flow Diagram



Appendix C: Level of Evidence Table

Level I	Evidence from a systematic review of all relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines based on systematic reviews of RCTs.
Level II	Evidence from at least one well-designed RCT.
Level III	Evidence from controlled trials without randomization. (ex. Quasi-experimental study)
Level IV	Comparative study with concurrent controls: • Non-randomized • Experimental trial • Cross- sectional study • Cohort study • Case-control study • Interrupted time series without control group
Level V	Evidence from systematic reviews of descriptive and qualitative studies.
Level VI	Evidence from a single descriptive or qualitative study.
Level VII	Evidence from the opinion of authorities and/or case reports of expert committees.

Adapted from Hoffman, T., Bennett, S., & Del Mar, C. (2013). Evidence-based practice: Across the health professions (2nd ed.). New South Wales: Australia.

Appendix D: Critical Appraisal Skills Program (CASP) Systematic Review Checklist

Three broad issues need to be considered when appraising systematic reviews:

- Section A: Are the results of the study valid?
- Section B: What are the results?
- Section C: Will the results help locally?

Section A: Are the results of the review valid?	
1. Did the review address a clearly focused question?	Yes Can't Tell No
2. Did the authors look for the right type of papers?	Yes Can't Tell No
Is it worth continuing?	
3. Do you think all the important, relevant studies were included?	Yes Can't Tell No
4. Did the review's authors do enough to assess quality of the included studies?	Yes Can't Tell No
5. If the results of the review have been combined, was it reasonable to do so?	Yes Can't Tell No
Section B: What are the results?	
6. What are the overall results of the review?	Yes Can't Tell No
7. How precise are the results?	Yes Can't Tell No
Section C: Will the results help locally?	
8 Can the results be applied to the local population?	Yes Can't Tell No
9. Were all important outcomes considered?	Yes Can't Tell No
10. Are the benefits worth the harms and costs?	Yes Can't Tell No

(CASP, 2018)

CASP Qualitative Study Checklist

Three broad issues need to be considered when appraising qualitative studies:

- Section A: Are the results of the study valid?
- Section B: What are the results?
- Section C: Will the results help locally?

Section A: Are the results of the study valid?	
1. Was there a clear statement of the aims of the research?	Yes Can't Tell No
2. Is a qualitative methodology appropriate?	Yes Can't Tell No
Is it worth continuing?	
3. Was the research design appropriate to address the aims of the research?	Yes Can't Tell No
4. Was the recruitment strategy appropriate to the aims of the research?	Yes Can't Tell No
5. Was the data collected in a way that addressed the research issue?	Yes Can't Tell No
6. Has the relationship between researcher and participants been adequately considered?	Yes Can't Tell No
Section B: What are the results?	
7. Have ethical issues been taken into consideration?	Yes Can't Tell No
8. Was the data analysis sufficiently rigorous?	Yes Can't Tell No
9. Is there a clear statement of findings?	Yes Can't Tell No
Section C: Will the results help locally?	
10. How valuable is the research?	Yes Can't Tell No

(CASP, 2018)

CASP Cohort Study Checklist

Three broad issues need to be considered when appraising cohort studies:

- Section A: Are the results of the study valid?
- Section B: What are the results?
- Section C: Will the results help locally?

Section A: Are the results of the study valid?	
1. Did the study address a clearly focused issue?	Yes Can't Tell No
2. Was the cohort recruited in an acceptable way?	Yes Can't Tell No
Is it worth continuing?	
3. Was the exposure accurately measured to minimize bias?	Yes Can't Tell No
4. Was the outcome accurately measured to minimize bias?	Yes Can't Tell No
5. a) Have the authors identified all important confounding factors? b) Have they taken account of the confounding factors in the design and/or analysis?	Yes Can't Tell No Yes Can't Tell No
6. a) Was the follow up of subjects complete enough? b) Was the follow up of subjects long enough?	Yes Can't Tell No Yes Can't Tell No
Section B: What are the results?	
7. What are the results of this study?	Yes Can't Tell No
8. How precise are the results?	Yes Can't Tell No
9. Do you believe the results?	Yes Can't Tell No
Section C: Will the results help locally?	
10. Can the results be applied to the local population?	Yes Can't Tell No
11. Do the results of this study fit with other available evidence?	Yes Can't Tell No
12. What are the implications of this study for practice?	Yes Can't Tell No

(CASP, 2018)

Appendix E: Maryland Scientific Methods Scale

Level 1	Either A) a cross-sectional comparison of treated groups with untreated groups, or B) a before-and-after comparison of treated group, without an untreated comparison group. No use of control variable in statistical analysis to adjust for differences between treated and untreated groups or periods.
Level 2	Use of adequate control variables and either A) a cross-sectional comparison of treated groups with untreated groups, or B) a before-and-after comparison of treated group, without an untreated comparison group. In A) control variables or matching techniques used to account for cross-sectional differences between treated and control groups. In B) control variables are used to account for before-and-after changes in macro level factors.
Level 3	Comparison of outcomes in treated group after an intervention, with outcomes in the treated group before the intervention, and a comparison group used to provide a counterfactual (e.g. difference in difference). Justification given to choice of comparator group that is argued to be similar to the treatment group. Evidence presented on comparability of treatment and control groups. Techniques such as regression and (propensity score) matching may be used to adjust for difference between treated and untreated groups, but there are likely to be important unobserved differences remaining.
Level 4	Quasi-randomness in treatment is exploited, so that it can be credibly held that treatment and control groups differ only in their exposure to the random allocation of treatment. This often entails the use of an instrument or discontinuity in treatment, the suitability of which should be adequately demonstrated and defended.
Level 5	Reserved for research designs that involve explicit randomization into treatment and control groups, with Randomized Control Trials providing the definitive example. Extensive evidence provided on comparability of treatment and control groups, showing no significant differences in terms of levels or trends. Control variables may be used to adjust for treatment and control group differences, but this adjustment should not have a large impact on the main results. Attention paid to problems of selective attrition from randomly assigned groups, which is shown to be negligible importance. There should be limited or, ideally, no occurrence of contamination of the control group with the treatment.

(Madaleno & Waights, n.d.)

Appendix F: Literature Review Matrix

Author/Title/Year/ Country	Aim/Setting	Study Design	Characteristics of Studies & Quality Assessment	Themes/Strategies	Limitations/ Future Research
1.Aldiss et al., (2015) Transition from Child to Adult Care- It's Not a One-Off Event': Development of Benchmarks to Improve the Experience. United Kingdom	To develop and nationally disseminate a clinical practice benchmarking tool to support the structured comparison and sharing of good practice in the transition of young people from child to adult health services. Setting(s): University National Health Services Hospital Trusts Hospital Education Centre Sports Centre	Qualitative: Grounded Theory design using focus groups, workshops, and interviews	Level of Evidence: VI CASP Score: moderate Ages: 13-21 years Study Size: Stakeholders n=21 Health Professionals n=36 Young People n=13 Parents n=11 Conditions Included: Cardiac Juvenile Arthritis Cystic Fibrosis Chronic Fatigue Syndrome Multiple Allergies Asthma Diabetes	Themes: 1)Fear & Anxiety -Loss of relationships with pediatric team -Fear of letting go and placing trust in new provider -Fear of the unknown and what to expect in adult care 2)Preparedness -Preparation required to ease anxiety -Involve young adult -Want information early on for time to prepare -Gradual process that gradually promotes health responsibility (family-centered to patient-centered) -Information about what to expect in adult services -Individualized transition care	Limitations: Small population size Future Research: Further research is needed that looks at how the benchmarks work in clinical practice.

				3)Communication & Collaboration -Use of consistent staff that know young adult and their medical history -Interpersonal skills; developmentally appropriate care and language -Coordination between services -HCP training and awareness about transition care and adolescent health Strategies: 1)Schedule visit to say goodbye to pediatric team 2)Active listening 3)Encourage joint visits 4)Use of tools 5)Refrain from medical jargon and offer information in other medias 6)See young person alone 7)Schedule appointments specifically for transition care	

2.Berens & Peacock, (2014) Implementation of an academic adult primary care clinic for adolescents and young adults with complex, chronic childhood conditions. United States	To describe the development and implementation of the Transition Medicine Clinic, its patient population and their resource needs, and lessons learned. Setting(s): Transition Medicine Clinic in Houston, Texas	Qualitative: Retrospective descriptive	Level of Evidence: VI CASP Score: moderate Study Size: n=332 Ages: 14-54 years Gender: equal Conditions Included: Spina Bifida(52) Cerebral Palsy(80) Down Syndrome(54) Genetic Conditions(50) Medically Fragile(39) Autism(17)	Themes: 1)Relationships -Strong relationship should be maintained with relevant specialists for support -Open communication among all providers, include PCP early on -promote care coordination through emails, telephone calls, and telehealth meetings 2)Preparedness -Finding co-management opportunities to be difficult due to the complexity -Lack of disease familiarity within this population by most community PCPs and adult providers -Lack of experience working with young adults and addressing their psychosocial needs -Low rates of PCPs accepting new patients Strategies: 1)More vigorous management and screening of secondary health conditions 2)Inclusion of sexual health education	Limitations: Generalizability was affected as the study was a natural product of localized circumstances. -Initiated by community interests and passion -Received grant funding, otherwise not financially sustainable under current reimbursement models -College has a well-established Med-Peds program with numerous other HCPs in training. Future Research: Research that evaluates outcome measures such as ER utilization frequency and hospital admissions.

				3)Patient-family-centered care -Young adults with intellectual disability require more family involvement and more proactive management -Promote independent self-care with a printed copy of care plan at each visit or use of online resources. 4)Familiarize self with medical devices (i.e. gastrostomy tubes) incase issues arise and necessary patient resources 5)Longer appointments 6)On-the-job training for HCPs 7)Use of joint clinics 8)Multidisciplinary approach -Patients saw an average of 3.8 subspecialists in study, each specialist required its own transition plan. 9)Case management meetings and patient registry organized by disease	

3.Betz et al., (2013) Voices not heard: A systematic review of adolescents’ and emerging adults’ perspectives of health care transition. United States, Canada, European Union, Australia, and Hong Kong	To evaluate the research on health care transition for adolescence (13-18 years) and emerging adults (19-29 years) with special health care needs from their perspective. Setting(s): Pediatric clinics, adult clinics, specialty clinics, and community-based transition coordination programs.	Systematic Review of: Quantitative -Cross-sectional (12) -Longitudinal (3) Qualitative (10) Mixed- methods (9) Program evaluation (1) All but one study used descriptive designs.	Level of Evidence: V CASP Score: strong Dates Reviewed: 2005-2012 Articles Reviewed: United States n= 10 International n=25 Total: n=35 Ages: 9-34 years Conditions Included: Blood Disorders (4) Cystic Fibrosis (2) Organ Transplant Recipients (2) Rheumatoid Arthritis (4) Irritable Bowel Syndrome (2) HIV (3) Congenital Heart Disease (5) Endocrine (8) Spina Bifida (1) Brain Tumors (1) Epilepsy (1) Mental Health (2) Unidentified (5)	Themes: 1)Relationships -Concerned about the implications for changing the nature of their relationships with their parents, peers, and providers -Uncertain about obtaining care in an unfamiliar setting and leaving pediatric providers 2)Fear & Anxiety -Feelings of abandonment -Fearful about future health status 3)Preparedness -Comfort with HCT influenced by confidence in perceived self-efficacy -Interdisciplinary transition clinic increased HCT preparation and self-management skills -Transition preparation lacked details needed to better anticipate the service changes -Need information about transition care, community referrals, and adult services earlier on	Limitations: Lack of information about ethnicity, mental age, and academic preparation makes it difficult to replicate or compare studies. None of these studies included young adults with intellectual and developmental disabilities Majority of studies had small sample sizes and were descriptive designs Younger transition- aged adolescents lack the skills to adequately make quality assessments of services. Majority of findings were generated from international studies. Limited description of reliability and validity of tools used. Future research: Additional tools that measure transition readiness and outcomes are needed. Research that examines the services and/ or supports

				-Improved HCP knowledge around complex chronic conditions -Service coordination among health care, education, and employment services -Adjunct support services and sexual health education Strategies: 1)Encourage meeting new providers & visiting adult care setting prior to transfer 2)Early initiation in transition planning; provide more detailed information around what to expect in adult services early on. 3)Individualized care plans 4)Involve young adult in care decision-making process 5)Active listening and Empathy 6)Provide adjunct support services and sexual health education 7)Promote transfer time for when young adult is in a healthy, stable state	required to become self-sufficient with care needs is imperative. Research that includes larger and more diverse samples of young adults in terms of socioeconomic status, ethnicity, and disease-specific conditions are warranted Qualitative and quantitative methods with more robust validity and reliability metrics Further research that considers patient's perspectives related to the transition phase is needed to develop evidence- based guidelines. Research that follows young adults after transition is needed to know what physiological and psychosocial outcomes are achieved

				8)Promote autonomy and self-management skills early on	
4.Chung et al., (2017) Resident Dyads Providing Transition Care to Adolescents and Young Adults with Chronic Illnesses and Neurodevelopmental Disabilities United States	Sought to improve pediatric and adult medicine residents' interdisciplinary communication and collaboration. To implement a collaborative model for training child and adult-focused residents in transition care to fill a substantial gap, as well as to establish a pattern of productive collaboration between pediatrics and adult medicine providers. Setting: Transition clinic	Quantitative: Quasi-experimental using pre & post-test surveys	Level of Evidence: IV MSMS Score: Level 2 Ages: 16-26 years Sample Size: Residents n=46 Young adult: Not specified Conditions Included: Diabetes Mellitus Epilepsy Neurological Disorders Mental Health	Themes: 1)Preparedness: -Positive outcomes (improved confidence and knowledge) in self-assessed preparedness to provide transition care and engage colleagues around the care of shared patients. 2)Communication & Collaboration -With increased transition care training using the dyadic model, internal medicine trainees reported statistically significant improvement in preparedness for communicating with pediatric providers (p<.01), counseling young adults and families (p<.01), and receiving young adults into care (p=.04) -Pediatric trainees reported statistically significant improvements in preparedness for communicating with adult providers (p<.01), and counseling families and preparing patients to transition (p<.01) Strategies: 1)Inquire about young adult's understanding of their health conditions and prognosis, self-	Limitations: Single institution study; outcomes limited to self-assessment of efficacy and attitudes Small number (n=25) of post-clinic survey results Future Research: Further exploration of the dyadic training model that includes assessments that measure sustained behavioral changes and further longitudinal studies are required.

				care management and health care navigation skills 2)Discuss personal goals and QOL 3)Discuss social supports and pertinent relationships 4)Development of interdisciplinary clinics using a dyadic teaching model between pediatric and adult providers	
5.Ciccarelli et al., (2014) Implementation and Sustainability of Statewide Transition Support Services for Youth with Intellectual and Physical Disabilities. United States	To describe the development of ambulatory consultative transition support services using an implementation science approach. Setting: Ambulatory Consultative Transition Clinic	Quantitative: Quasi-experimental time series	Level of Evidence: III MSMS Score: Level 2 Ages: 11-23 years Gender: 46% female Sample Size: n=71 (consented) Conditions Included: Cerebral Palsy Down Syndrome Intellectual Disability Autism Spina Bifida Angelman Syndrome Neurological Traumatic Brain Injury	Themes: 1)Preparedness -Majority of young adults and families felt underprepared -Lack of time to address transition in pediatric primary care settings and lack of experience caring for adolescents in adult primary care setting are notable specific barriers affecting preparation -Involve young adult and family when creating medical summary and health care transition plan 2)Communication & Collaboration -Transition support programs promote collaboration	Limitations: Referral bias of youth who have more high intensity and complex needs Despite value of initiating transition early, average age of program entry n=16.6 years Problems with future planning occurring during periods of instability when patients with complex health needs and their families arrive during crisis. Primary care providers do not yet have high familiarity with transition knowledge and recommendations to provide this service to patients without other education or support.

			Osteogenesis Imperfecta Prader Willi Syndrome Corpus Collosum Agenesis Tetrasomy 18	between academic and community partners -MDT approach that uses specialists, PCP, nursing, and SW together -Integrate perspectives of multiple providers to connect new knowledge and develop deeper understanding -Distribute medical summary and HCT plan among all providers to ensure everyone is aware of young adults past and current health history -Promote HCP meetings to review client and clarify goals of care -Use tools: Primary and preventative care guidelines -One-page evidence-based chronic condition handouts and device information sheets distributed along with patients summary and health care transition plan to new adult PCPs and adult specialists for educational purposes Strategies: 1)MDT approach with cross-training and overlapping of role responsibilities (PCP,	Future Research: This type of regional transition support program (consultative health care transition support program within medical homes) should be further explored as an important resource for primary care practices. Additional research on self-management program activities for young adults with complex chronic conditions is also needed.

				nursing, patient advocates, and SW) 2)Use of at least one of the 'Six Core Elements of HCT' from GotTransition 3)Ensure young adult has a medical summary that is portable and easily accessible to all providers. Request documents from specialists as needed 4)Discuss health care transition plan by 14 years of age. Create document with specialists, nurses, and SW that consists of current state, future goals, action plans, recommendations, and needed services (health, education/employment, independent living, and community participation) 5)Apply same primary and preventative care guidelines to ensure recommended routine care is achieved. Address acute and chronic medical issues as needed 6)Advocate for a care coordinator to take on supportive role for family/young adult and navigate system during HCT	

				7)Embrace 'whole life' approach to services, rather than strictly medical approach. (Include medical and psychosocial management) 8)Advocate for more collaborative educational opportunities for primary care providers that increase knowledge base around childhood illnesses	
6.Gabriel et al., (2017) Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review. United States United Kingdom	To identify statistically significant positive outcomes in pediatric-to-adult transition studies using the triple aim framework of population health, consumer experience, and utilization and costs of care.	Systematic Review of: Quasi-experimental using pre-post population cohorts or retrospective cohorts (33) RCT (2) Prospective Cohort studies (8)	Level of Evidence II CASP Score: strong Dates Reviewed: 1995- 2016 Articles Reviewed n=43 Ages: Not specified Sample Sizes: 100 or more participants in one quarter of the 43 studies Conditions Included: Diabetes Mellitus Gastrointestinal Conditions Transplant Recipients	Themes: 1)Preparedness -Structured transition interventions have resulted in statistically significant beneficial outcomes; 28 of the 43 (65%) -20 of 37 studies (54%) found improvements in population health related to improved adherence to care, QOL, mortality reduction, and self-care skills measured through disease knowledge -35 out of 43 studies described transition preparation activities as an important transition intervention -Readiness and self-care assessments mentioned in 16 of the 43 studies	Limitations: Studies lacked detailed descriptions of their transition process, making categorizing similar transition interventions difficult and linking outcomes to a specific transition process impossible. -Majority of studies (n=38) only evaluated transition interventions for young adults with a single condition, thus limiting applicability for complex chronic conditions. -Many studies used data collection methods of unknown or untested validity and reliability. Future Research:

			Juvenile Idiopathic Arthritis Neurological	-Use of tools, one-on-one time with provider, online resources, and increased autonomy 2)Communication & Collaboration -Explicit communication between pediatric and adult care providers, mentioned in 24 of the 43 studies -Transfer/medical summaries mentioned in 20 of the 43 studies -Designated coordinator to assist with HCT in 18 of the 43 studies Strategies: 1)Include self-management and disease education into practice. 2)Advocate for transition programs and transition coordinators 3)Build partnerships with providers; pediatric and adult, to improve coordination of services 4)Use of tools to promote communication	-The measures used to evaluate HCT interventions were widely variable and seldom addressed all 3 triple aim domains. -Several issues need to be considered in terms of measures related to adherence to care, perceived health and quality of life, and self-care skills. -Very few chronic conditions have disease-specific adherence to care measures, such as HbA1c for those with diabetes or tacrolimus levels for those who have received a transplant. Consideration of medication adherence before and after transfer may benefit research. -Almost two-thirds of the 43 studies included in this review reported positive outcome results, however the state of transition intervention research is still in its infancy. More longitudinal research is warranted. -Future studies evaluating transition will benefit from

				5)Establish plans of care and involve young adult 6)Orient to adult system 7)Link to community resources	providing more detailed descriptions of their interventions. -Consideration should be given to incorporating self-care skills, not only disease-specific skills. -Obtaining anonymous youth and parent feedback will be critical for continuously refining pediatric-to-adult transition interventions
7.Maddux et al., (2015) Preparing Patients for Transfer of Care: Practices of Primary Care Pediatricians United States	To examine transition practices in pediatric primary care Setting: Primary care pediatric clinics, including private practice sites, hospitals and academic medical centers	Quantitative Non-experimental design using anonymous surveys	Level of Evidence: IV MSMS Score: Level 1 Ages: N/A Sample Size: n=248 primary care pediatricians Conditions Included: Chronic GI conditions	Themes: 1)Preparedness -61.2% of primary care pediatricians provide planning, preparation, or support to patients before transfer -40% admitted to not providing any preparation or support From the 61.2%: -32.8% provided names of adult providers as potential referrals -Only 15.1% transfer medical records to the receiving provider	Limitations: Absence of demographic characteristics on respondents limits ability to draw conclusions and comparisons across sites. i.e. information on practice settings would allow better extrapolation of whether transition practices differ between primary care pediatricians in medical centers, hospitals, and private practices. Data on patient population treated at each site was not collected. Unclear what proportion of pediatric PCPs provider routine care to youth with chronic health conditions and whether the level and type

				-8.6% discuss different provider types with young adult -2.6% encourage meeting young adult without parent's present -1.3% use transition tools -Educating young adults about lifestyle behaviors is essential for preparation for assuming adult roles and responsibilities 2)Communication & Collaboration -8.6% speak directly with receiving adult provider -If transition planning is occurring in primary care settings, specialty care efforts might emphasize importance of having a PCP, thereby ensuring that comprehensive care is provided -Primary care pediatricians currently taking primary role for transition planning, yet 40% are not doing this Strategies: 1)Initiate transition planning in primary care setting	of transition planning differs based on the health status of patients. Future Research: More focus needs to be placed on educating health care providers on transition care

				2)Communicate directly with other providers to promote coordination and clarity 3)Become familiar and use transition tools 4)Address psychosocial needs and provide education around lifestyle behaviors 5)Interdisciplinary approach -More comprehensive preparation can be achieved when everyone works together (nurses, SW, specialists) 6)Advocate for more educational opportunities around transition care	
8.McManus et al., (2014) Pediatric to Adult Transition: A Quality Improvement Model for Primary Care. United States	To determine whether pediatric, family medicine, and internal medicine practices participating in a 2-year learning collaborative (LC) would improve the delivery of transition services for youth with chronic conditions. Setting: Five academic primary care practices in Columbia	Quantitative Quasi-experimental design (time-series comparative study)	Level of Evidence: III MSMS Score: Level 2 Ages: 14-24 years Conditions Included: Chronic Physical, Developmental, and Mental Health Conditions	Themes: 1)Preparedness -Use of transition readiness assessment 2)Communication & Collaboration -Use of portable medical summary with transition action plan and online registry -Create systematic method for tracking transitioning youth with chronic conditions Strategies:	Limitations: Small number of participating sites (n=5) and small number of youth and young adults in the project (n=400 in three pediatric sites and n=128 in two adult sites) Population represents only a small geographical area limiting generalizability

				1)Early initiation: start transfer preparation no later than 14 years 2)Identify adult specialists early and choose a navigator 3)Use of tools 4)Ensure transfer checklist is completed prior to the first adult care visit 5)MDT approach 6)Incorporate the Six Core Elements as part of routine primary care	
9.Nehring et al., (2015) Uncharted Territory: Systematic Review of Provider's Roles, Understandings, and Views Pertaining to healthcare transition Countries: United States (26) Other nations (27): Australia Canada Europe Japan	This systematic review is designed to answer: 1)What is the state of the healthcare transition science pertaining to the role of providers involved in this specialty area of practice 2)What research problems or questions have been investigated pertaining to providers involved with healthcare transition? 3)What evidence has been generated that can be applied to improve the	Systematic Review of descriptive and qualitative studies including: Descriptive qualitative Descriptive chart review Descriptive program evaluation Descriptive mixed-methods Descriptive cross-sectional survey	Level of Evidence: V CASP Score: strong Dates Reviewed: 2004-2013 Articles Reviewed: n= 55 Ages: Not specified Professional Disciplines Sampled: Pediatricians (10) Adult medical providers (4)	Themes: 1)Relationships -Attachment to pediatric provider and setting -Over the top parental involvement that impedes independence 2)Fear & Anxiety -Fear of letting go of pediatric provider and vice versa -Pediatric providers lack of confidence in adult providers 3)Preparedness -Practice limitations of adult providers	Limitations: Ages in studies were not specified in systematic review Majority of the studies reviewed were composed of small convenience samples making generalizations to other provider populations not feasible None of the studies included were RCTs or intervention studies Limited description of reliability and validity of

	healthcare transition training or service competencies of pediatric and adult healthcare professionals? 4)What evidence can be applied to the provision of healthcare transition services for youth with complex conditions?	Research methods Semi-structured interview Survey questionnaire Structured questionnaire for interview Focus groups Chart reviews Pre- and post-tests	Pediatrician & Adult physicians (4) Interdisciplinary members (SW, nurses, pediatricians) (24) Adult & Pediatric interdisciplinary (1) Conditions Included: Cardiac Spina Bifida Gastroenterology Cystic Fibrosis Transplant Recipients Rheumatology HIV Endocrine	-Limited clinical training and experience working with young adults with complex chronic conditions -Inadequate resources and training opportunities -Comfort level was associated to level of complexity and the setting (whether or not there was access to back up medical specialty support) 4)Communication & Collaboration -Insufficient lines of communication between pediatric and adult providers Strategies: 1)Use of tools 2) Advocate for care coordinator (SW, nurse, peer navigator, etc.) 3)MDT approach 4)Acknowledge level of anxiety and fear in family and young adult 5)Early initiation of transition preparation	tools used in multiple of the articles *Future research:* Further evidence is needed to support the use of intervention approaches and to develop training models that will support the learning needs of interdisciplinary providers entering this field of practice Studies that explore the effectiveness of training curriculums using various instructional methodologies for health networks and community-based interdisciplinary pediatrics and adult providers Research would be strengthened with additional provider sample demographic Studies that enable longitudinal tracking of young adults into the adult system of care to determine the extent of successful outcomes Collaborative investigations that include both pediatric and adult

				6)Encourage family to set a final ‘goodbye’ visit with pediatric providers 7)Advocate for and participate in ongoing transition care educational opportunities for primary care providers	researchers utilizing an interdisciplinary framework corresponding to clinical practice settings
10.Okumura et al., (2015) The Role of Health Advocacy in Transitions from Pediatric to Adult Care for Children with SHCN: Bridging Families, Provider, and Community Services United States	To develop a theoretical understanding of how family, healthcare providers and community partners can support young adults with special health care needs during the transition to adult-oriented services. Setting: Subspecialty clinics & community agencies	Qualitative: Grounded theory design using semi-structured interviews and field notes	Level of Evidence VI CASP Score: strong Ages: 16-25 years (pre/ post transition) Sample Size: Young adults n=13 Parents n=9 Healthcare providers (NPs, adult and pediatric nurses, social workers, and physicians) n=12 Community service providers n=7 Conditions Included: Cystic Fibrosis Congenital Heart Disease Diabetes Mellitus	Themes: 1)Relationships -Provider relationships both barrier/facilitator when it comes to building independence - ‘Sheltering’ young adults can limit independence and development of self-management skills -Young adults often felt unheard, strong familial presence was useful for advocating needs 2)Fear & Anxiety -Many young adults did not know how to navigate system which elicited apprehension and anxiety towards the change -Families anxious around finding and accessing adult community services and resources alone 3)Preparedness	Limitations: Results have limited generalizability to all chronic conditions and other healthcare systems as individuals were from California only and sampling frame was based on a purposive sample Interviews were based on self- reported experiences Future research: Research that evaluates the effectiveness and role of persons who can perform transition advocacy during the transition process is needed

			Spina Bifida Intellectual Disability Cerebral Palsy Inflammatory Bowel Disease Myasthenia Gravis	-Poor preparation includes lack of transfer planning to adult providers, poor preparation in gaining self-management skills, and a general lack of medical knowledge 4)Communication & Collaboration -Fighting health care; constant struggle to access services and receive care that meets their needs due to lack of collaboration among services -Conflicts between families, providers, young adults, and medical resource suppliers due to lack of communication Strategies: 1)Advocate for clients' transitional needs and encourage young adults to develop strong advocacy skills 2)Ensure young adults have an advocate or someone that is supporting them during transition process if parent is not present 3)Be aware of additional barriers that may further implicate transition process for young adults and families such as stigma, poverty,	

				language skills, and cultural barriers 4)Encourage young adult and families to front load resources prior to exiting pediatric services 5)Advocate for improved funding and access to resources in adult services 6)Initiate healthcare transition discussions and planning early on to promote the development of independence and disease management skills 7)Include young adults and families in transition care.	
11.Rutishauser et al., (2014) Transition of young people with chronic conditions: a cross-sectional study of patient perceptions before and after transfer from pediatric to adult health care. Switzerland	To compare perceived barriers and preferred age for successful transition to adult health care between adolescents with chronic disorders pre-transfer and post-transfer. Setting: Two Swiss pediatric hospitals	Quantitative Cross-sectional study	Level of Evidence: IV MSMS Score: Level 2 Sample Size: -Pre-transfer n=283 -Post-transfer n=89 Ages: 14-25 years Conditions Included: Diabetes Cardiology	Themes: 1)Relationships -Majority (48%) pre-transfer and (32%) post transfer reported that their rapport with the pediatrician acted as a barrier to transition -Felt at ease with pediatrician 2)Fear & Anxiety -Anxiety largely associated to lack of information, mentioned by both pre- and post-transfer responses -Change in therapies, loss of health records, and change in	Limitations: Study design precludes any conclusion regarding causality. Generalizability is limited as based on two Swiss hospitals. Psychosocial maturation and personal circumstance were not measured in regards to preferred age of transition Future research:

			Nephrology Gastroenterology Cystic Fibrosis Neurology Rheumatology	health status also produced anxiety -Meeting adult providers beforehand may relieve anxiety -Joint meetings with pediatric and adult providers reduced anxiety and fear 3)Preparedness -transition readiness highly dependent on young adults perceived self-efficacy in self-management skills Strategies: 1)Take time to build rapport 2)Encourage building autonomy and developing self-management skills 3)Encourage young adult and families to meet with adult providers prior to official transfer 4)Encourage transfer no sooner than 19 years	Longitudinal cohort study that tracks opinions throughout transition phase A randomized controlled trial comparing younger and older age at transition or testing different models of transition support within either pediatric or adult care settings
12.Syverson et al., (2016) Adolescents' perceptions of transition importance, readiness, and	To evaluate the frequency of HCT anticipatory guidance delivery and the effect it has on participants' perceptions of HCT.	Qualitative Cross-sectional design	Level of Evidence: VI CASP Score: moderate Ages:	Themes: 1)Preparedness -43% had not discussed their changing health care needs with their provider	Limitations: Cross-sectional design limited ability to assess whether a participants' perceptions of transition readiness have any

likelihood of future success: The roles of anticipatory guidance. United States			16-22 years Sample Size: n= 209 Conditions Included: High fx (n=84) Learning Disabilities ADHD Chronic Conditions (n=22) Cerebral Palsy Turners Syndrome Autism Anxiety Depression Congenital Anomalies Complex (n= 55) Related to prematurity or prenatal/perinatal insults Genetic Conditions Autism Highly Complex (n=48) Multisystem Organ Involvement ESRD Heart Failure Pulmonary HTN Severe MD	-64% had not discussed transition -Those who discussed transition and their changing health needs with their provider had significantly higher ratings of perceived likelihood of transition success and transition readiness compared to others (95% CI=4.7-7.7; 95% CI=6.5-8.6) -57% reported "always" or "usually" encouraged to take responsibility for their health care needs -Larger portion with high care coordination needs reported unmet anticipatory guidance -Youth attend fewer preventative care visits as they progress through adolescent years and provision of anticipatory guidance at these visits was quite low -Self-management encouragement from providers does not appear to affect young adults' perceptions of transition process as compared to encouragement from family members	association with the study's outcomes -Poor generalizability due to ethnic background and socioeconomic standpoint. Future Research: Longitudinal data that evaluates changes in young adults' perceptions of the HCT process over time, with a goal to measure long-term health outcomes of anticipatory guidance and self-management encouragement is needed.

				Strategies: 1)Family-centered care was associated with higher rates of encouragement to take responsibility for care -Family members may play an instrumental role in both perceived encouragement and influence on overall behavior 2)Discuss transition process & promote self-management skills by the age of 12 years (especially those with higher care coordination needs)	