

Transition to Adulthood for Young People with Medical Complexity:
An Integrative Literature Review

By

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Abstract

Due to medical and technological advances over the last several decades and increases in survival rates, many young people with medical complexity are surviving into adulthood. Over the last decade, there has been an explosion of literature focusing on the transition to adulthood for young people with chronic conditions, but with proportionately little focus on this complex population. This project explores how existing empirical literature on the transition to adulthood for young people with medical complexity can inform Advanced Practice Nurses (APNs) using Whittemore and Knafl's integrative literature review approach. Cohen and colleagues' definitional framework was used to define medical complexity. This review was further informed by Meleis' Transition Theory and Bronfenbrenner's Bioecological Theory of Human Development. Three themes emerged from the data synthesized from 10 qualitative and one quantitative study: it's like falling off a cliff, the paradox of independence, and it takes a village. The findings of this review generally supported and were supported by the theoretical perspectives that informed this review; however, the findings also emphasized the unique nature of proximal processes and developmental trajectories of young people with medical complexity. Recommendations for APNs based on the findings focus on advocacy, capacity-building, education, and program development and evaluation. The findings of this review also illuminated the existence of ethical issues in transition and the necessity of systems leadership for policy change. Finally, recommendations for future research are offered with a focus on determinants of health, psychosocial concerns, parent needs and future planning, and program development and evaluation.

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Area of Interest

At the age of 14, I stepped into my first volunteer position providing one-on-one support to children with cerebral palsy in summer camps. In the years that followed, I continued to volunteer and work in multiple capacities with children and youth with disabilities, some with complex medical needs, in recreation, respite, hospitals, and home care. My work in this field developed into a passion for improving the care of individuals with complex chronic conditions. During my experiences as a new graduate nurse in an adult float pool¹ in Ontario, Canada, I encountered many young adults with childhood-onset complex chronic conditions who, alongside their families, were having difficulty muddling through the adult health care and community service systems. These experiences led to a realization that these individuals are not necessarily understood by those in the adult health care system, the community, or greater society, which, in turn, led to an exploration of how these individuals are assisted in navigating the transition to adulthood.

Transition from pediatric to adult care has gained increased attention in the literature over the last decade. It is estimated that up to 18% of adolescents in North America have some sort of special health care need or disability and over 90% of these children will survive into adulthood (Betz, 2013; Pinzon & Harvey, 2006). This increase in survival rates has led to a major gap in services for these children as they become young adults as the adult system is not adequately equipped to meet the needs of these young people (Hamdani, Jetha, & Norman, 2011).

The literature on transition to adult care heavily focuses on “children with special health care needs (CSHCN)....who have or are at risk for chronic conditions and require health care beyond that required by children generally” (Cohen et al., 2011, p. 529). This definition can include any clinical situation from food allergy to ventilator-dependence; however, those young

¹A float pool, or resource team, is a team of nurses employed by a hospital or group of hospitals to provide staffing coverage on a variety of units. Nurses are cross-trained to multiple specialties. In this particular adult float pool, I was cross-trained to 25 different floors in two hospitals.

people with the most complex and fragile conditions require increased consideration. As such, the focus of this review will be on this subgroup of young people with medical complexity.

Young People with Medical Complexity

I have chosen the term *young people* to represent my population of focus. This term has been used in the literature to describe children, adolescents, and young adults; however, it has most often been used to describe adolescents or young adults. A search of the Cumulative Index of Nursing and Allied Health Literature (CINAHL) for the term “young people” obtained over 6000 results. Of these results, over 70% referred to adolescents or young adults as “young people”. As transition frequently continues beyond adolescence and into young adulthood, I will be taking into account adolescent and young adult perspectives in this literature review. Therefore, I have chosen to define my population of focus as “young people with medical complexity”, which encompasses adolescents and young adults. For the purposes of this project and to align with current literature, I will consider adolescents and young adults 15-30 years of age as young people.

Dr. Eyal Cohen and colleagues have developed a definitional framework of children with medical complexity for use in research and clinical settings (Cohen et al., 2011), which I have chosen to define young people with medical complexity. Features of this subpopulation fall into four domains: chronic conditions, needs, functional limitations, and health care use. In a retrospective study of hospital discharge data from 2005 to 2007 in Ontario, Canada, it was estimated that, based on this definition, children with medical complexity constitute less than 1% of children in Ontario and yet, the cost of care for these young people accounted for approximately one third of all pediatric health care expenditures over the study period (Cohen et al., 2012). Despite the relatively small numbers of children with medical complexity, the cost to

the system was significant, which points to a need for an increased focus on quality care of this unique population across settings (Cohen et al., 2011; Cohen et al., 2012).

Chronic conditions

Young people with medical complexity must have one or more complex chronic conditions. Cohen et al. (2011) describe these chronic conditions as “either diagnosed or unknown, that are severe and/or associated with medical fragility” (p. 531). Examples of chronic conditions include cerebral palsy or other brain anomalies, genetic disorders with severe phenotypic characteristics, metabolic disorders, complex congenital heart defects, malignancies, and even severe autism spectrum disorders. Mental health conditions are not included in this framework, aside from those associated with severe autism.

Needs

Young people with medical complexity also have substantial family-identified service needs (Cohen et al., 2011). These needs can be related to medical care (including medications and surgeries), allied health services, or educational and community support. These needs have a significant impact on the young person and family including time commitments, complex care coordination needs, and financial burdens (Cohen et al., 2011). These needs are also constantly changing and evolving and require frequent re-evaluation.

Functional limitations

Functional limitations for these young people can be medical, developmental, or both. They affect bodily functions, the ability to perform activities of daily living, and the ability to participate in social and family activities (Cohen et al., 2011). Medically, functional limitations can be related to feeding or breathing. These young people may require technologies such as feeding tubes, tracheostomies, ventilators, fecal ostomy systems, or ventriculoperitoneal shunts

to maintain bodily functions. Developmentally, functional limitations can occur in any combination of motor, speech, social, or cognitive domains. It is important to note that not all young people with medical complexity have an intellectual disability, though many may have a delay in any one of these domains (Cohen et al., 2011). These functional limitations can also vary widely over a lifetime and require frequent assessment and coordination to address.

Health care use

Young people with medical complexity also have ongoing health care service involvement. There are three main domains of health care use: providers, health services, and interrelated services (Cohen et al., 2011). Providers include primary care providers, subspecialty physicians, nursing, and allied health professionals. Health services include hospitals, clinics, laboratory and diagnostic imaging services, schools, respite, and rehabilitation. Finally, interrelated services are related to family supports, behavioural health, and transportation (Cohen et al., 2011). The key is that these services are utilized on an ongoing basis.

Overall, Cohen et al.'s (2011) definitional framework provides a foundation to define medical complexity and to consider the diverse context of these individuals and their families as they transition to adulthood and adult care.

Becoming Adults with Medical Complexity: A Critical Situation

Technological and scientific advances in the field of pediatric long-term conditions are transforming outcomes for young people with medical complexity (Cook, 2013). For example, young people with neuromuscular disorders that were previously fatal in childhood are now living well into their third or fourth decades. In the context of Duchenne muscular dystrophy, treatment with steroids such as prednisone or deflazacort has slowed the degenerative nature of muscle weakness. As a result, these young men are now living into adulthood while two decades

ago those who did survive into adulthood often required mechanical ventilation to sustain life (Camfield & Camfield, 2011). These young men and their families will now need to navigate the adult system to attain developmental goals while coping with the degenerative nature of their condition. In addition, technology has enabled many of young people with respiratory insufficiency associated with conditions such as bronchopulmonary dysplasia, cerebral palsy, or spinal muscular atrophy to live longer. In the period between 2000 and 2010, the United Kingdom saw a 600% increase in children living with long-term ventilation (Wallis, Paton, Beaton, & Jardine, 2011). This is a startling statistic and paints a picture of a situation in which an even greater number of young people with medical complexity may require support in transition to adulthood and adult care.

It is well-documented that adults with childhood-onset chronic conditions often have increased rates of health concerns, increased unemployment, and decreased education attainment (Betz, Lobo, Nehring, & Bui, 2013; Blomquist, 2007). This suggests an inherent complexity of the transition to adulthood for individuals with complex chronic conditions and a great need for holistic and comprehensive services that promote successful transition and attainment of developmental tasks and quality of life in adulthood (Betz, 2013; Betz et al., 2013). Studies conducted over the last decade have universally described a lack of preparation, services, and supports for adolescents with chronic conditions or disabilities as they transition to adulthood (Doug et al., 2009; Stewart et al., 2010). Some have even gone as far as to call this lack of services a public health crisis (Betz, 2013), in which these lack of formalized systems of care creates disruptions in access to services leading to poor outcomes for these individuals. It is paramount that all health care providers work to address this public health crisis (Betz, 2013).

Transition to Adulthood

The literature on transition to adulthood is plentiful; however, proportionately few studies exist specific to young people with medical complexity in both the research and expert opinion literature (Cohen et al., 2011). As a result, I will provide some general background on the transition to adulthood that is relevant to young people with medical complexity and the scope of this literature review.

Transition is defined in the nursing literature as “a passage or movement from one state, condition, or place to another” (Schumacher & Meleis, 1994, p. 573). More specifically, in the context of health care, transition to adult care is defined as “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive” (Blum et al., 1993, p. 570). These definitions have traditionally served as a starting point for most research into transition to adulthood and adult care over the last decade.

The transition from adolescence to adulthood is often characterized as a developmental process. The time between late adolescence and early adulthood has been described as a time of identity exploration, a time of instability and change, and a time for the development of self-reliance (Betz et al., 2013). This time is further characterized as an age of feeling in-between worlds and an age of choices and possibilities (Betz et al., 2013). For young people with disabilities or chronic illness, this developmental transition also involves a service-delivery component as movement between pediatric and adult services across sectors is initiated at a similar time; these young people will continue to require support across sectors to be successful in adulthood (Labhard, 2010; Stewart et al., 2010). Experts in transition and developmental psychology alike advocate for the consideration of person-environment interactions during

developmental transitions. Bronfenbrenner (2005) suggests that human development results from effective and reciprocal person-environment interactions. This environment includes individuals, groups, communities, services (including health care systems), and society (Bronfenbrenner, 2005). From this perspective, developmental transitions cannot and should not be viewed exclusive from service-delivery transitions.

Transition experts have recently called for consideration of the complexities of person-environment interactions for the transition to adulthood for youth with disabilities (Stewart, Gorter, & Freeman, 2013). For young people with disabilities or chronic conditions, there is growing evidence of the profound and dynamic effect of the environment on developmental outcomes, in addition to the effects of their health conditions on development (Rosen, 2004; Stewart et al., 2013). For example, sociocultural environmental factors related to social isolation and lack of experience related to daily activities can influence transitions to adulthood (Blum, Kelly, & Ireland, 2001; Gorter et al., 2011). As a result, it is imperative to take this multiplicity into consideration when considering the transition to adulthood for young people with medical complexity.

Despite the growing popularity of this perspective, researchers have rarely considered the transition to adulthood across developmental domains and service sectors simultaneously, instead focusing mainly on health care service transitions (Betz et al., 2013). Based on this perspective, health care providers, including nurses and advanced practice nurses, cannot hope to address these types of transition separately. Assuming the goal of nursing is to enhance health, well-being, quality of life, and the human experience as a whole, it must then follow that these types of transition be considered together to enable the achievement of goals and outcomes in all domains for young people transitioning to adulthood.

Holistic Approaches to Transition

In order to consider developmental and service-delivery transitions together, transition experts advocate for a holistic approach to transition that consists of services and support that spans developmental, behavioral, health, and psychosocial aspects of an individual's life (Betz, 2013; Labhard, 2010). Many professional organizations have produced position papers and guidelines for transition care, each with slightly different principles and guidelines. In addition to access to appropriate health care services, these papers revolved around two overarching themes: realization of personal potential and addressing psychosocial needs. These position papers also explicate that services supporting transition to adulthood should be flexible, broad, comprehensive, and collaborative (Betz, 2007; Kaufman & Pinzon, 2007; Rosen, 2004; Rosen, Blum, Britto, Sawyer, & Siegel, 2003; Stewart et al., 2010).

Realizing personal potential. Understanding and achieving personal potential in the areas of education, recreation, or vocation is an important part of a holistic approach to the transition to adulthood (Kaufman & Pinzon, 2007). For young people with disabilities, access to services to support goals in these areas is essential. Many of these goals have an underlying focus on participation, but Kraus de Camargo (2011) cautions that this participation should be based on freedom of choice for the young adult and their parents. Furthermore, this participation should be meaningful to the young person (Kaufman & Pinzon, 2007; Rosen et al., 2003). Thus, goals related to personal potential should be developed using an individualized approach.

In addition, realization of personal potential will depend on attainment of skills for self-management to maintain health and quality of life (Betz et al., 2013). Degree of independence in this area will vary based on specific needs and abilities. From a health care perspective, self-management consists of understanding one's condition and the management of health needs

including how to navigate the health care and community services systems, order medications and supplies, and express needs to new providers (Rosen, 2004; Labhard, 2010; Stewart et al., 2010). Self-management also involves acquisition of skills for independence and self-care (Betz et al., 2013; Ridosh, Braun, Roux, Bellin, & Sawin, 2011; Stewart et al., 2010). Stewart et al. (2013) suggest that a positive developmental approach through building capacity has great potential to improve self-management in young people with disabilities and chronic conditions. In addition, capacity for self-management is influenced by contextual factors including personal characteristics and the environment (Stewart et al., 2013). This is particularly important for young people with medical complexity due to their often intense reliance on technology and high health service usage.

These contextual factors, especially related to lifestyle, the environment, and biology, can also impact overall health and quality of life (Public Health Agency of Canada, 2013). There is an expanding body of literature suggesting that it is not only provision of health care that promotes health. The Public Health Agency of Canada (2013) describes 12 key determinants of health: income and social status; social support networks; education; employment/working conditions; social environments; physical environments; personal health practices and coping skills; healthy child development; biology and genetic endowment; health services; gender; and culture. These determinants have been studied in groups of young people with chronic conditions and disabilities; however, few authors have considered broader impacts for young people with medical complexity (Mesman, Kuo, Carroll, & Ward, 2013). Despite this gap in the literature, one can hypothesize the impact on some of these determinants on the health of young people. For example, the physical environment can affect health in terms of mobility and infection prevention; income would be even more important for young people with medical complexity

and their parents due to the costs associated with medical complexity (Cohen et al., 2011).

Despite this paucity of literature, there is growing evidence of the relationships between these determinants and disability. For example, in a 2006 profile of disability in Canada, post-secondary school attendance was significantly less for young people with disabilities than for those without disabilities (Statistics Canada, 2013). Youth and young adults with disabilities also reported wanting to participate more in social activities but that their condition, costs, and support needs prevented them from doing more (Statistics Canada, 2013). Looking further into adulthood, just over half of adults age 25-54 with severe disabilities participated in the workforce compared to 74.9%-84.1% for adults with mild disability and 83.1%-93.4% for adults with no disability (Statistics Canada, 2013). Income was also significantly less for adults with disabilities than for those without disabilities (Statistics Canada, 2013). Overall, these statistics paint a picture of inequities in determinants of health related to employment, education, income, and social activities. Although many of these statistics were not described in relation to severity, I would expect that these inequities would be even more significant for young people and adults with the most severe complex disabilities. As a result, it is imperative that determinants of health be considered alongside developmental and medical perspectives during the transition to adulthood.

Psychosocial concerns. In their position paper, Rosen et al. (2003) suggest that transition services should consider concerns common to all young people regardless of health such as growth and development, sexuality, and friendships and peer support. Despite the recognition of the importance of psychosocial concerns in the transition to adulthood, psychosocial concerns often do not receive enough attention in the literature due to the complexity of chronic conditions in these young people (Stewart et al., 2010). Young people with chronic conditions also

frequently experience stigma and marginalization as adolescents, which present a substantial challenge in transitioning to adulthood and attainment of personal potential (Sawyer, Drew, Yeo, & Britto, 2007; Ridosh et al., 2011; Stewart et al., 2013).

Barriers to Transition

Barriers to successful transition to adulthood have been identified across the transition literature for individuals with disabilities with varying abilities, cognitive status, and complexity. It is unclear whether these barriers are similar specifically for young people with medical complexity; however, the breadth of the literature can inform nurses of the potential barriers to transition for these individuals. Much of the transition literature to date, especially qualitative studies, focuses on what is not working, or in other words, what hinders transition. An understanding of barriers to successful transition can inform nurses on domains on which to focus their efforts while also taking a positive approach (see for example Stewart et al., 2013). Barriers to successful transition can be divided into individual barriers, familial barriers, and systemic barriers.

Individual barriers have been described in terms of personal characteristics or developmental tasks. Personal characteristics as barriers, which could not be changed, include complexity and severity of the young person's condition (Caton & Kagan, 2007; Kelly, Kratz, Bielski, & Rinehart, 2002). Lack of achievement of developmental tasks as a barrier was related to characteristics such as readiness, advocacy and self-care skills, or adequacy of peer support and social inclusion (Ridosh et al., 2011; van Staa, van der Stege, Jedeloo, Moll, & Hilberink, 2011). These characteristics are more easily modified or improved but can still serve as a barrier if preparation is ineffective (Ridosh et al., 2011; van Staa et al., 2011).

Familial barriers include lack of family support, caregiver knowledge of complex

conditions and supports, and overprotection (Betz, 2007; Kelly et al., 2002; Labhard, 2010; Rosen, 2004). Similarly, overprotection can put a strain on parent-youth relationships, which can impede young people's ability to achieve independence (Magill-Evans, Wiart, Darrah, & Kratochvil, 2005). Another common theme throughout transition studies was the lack of desire by young people and their parents to let go and to embrace change (Sawyer & MacNee, 2010; Stewart et al., 2013; Wong et al., 2010).

Barriers such as lack of knowledge, overprotection, and lack of desire to embrace change could be a result of the movement into the adult system as this system is not designed to meet their needs (Brown et al., 2010; Hamdani et al., 2011). Furthermore, the adult system differs in terms of coordination, quality of services, and philosophy of care (Betz, 2007; Doug et al., 2009; Kelly et al., 2002). As many adult physicians are not familiar with complex chronic conditions of childhood, family support and knowledge would be integral to success. Furthermore, lack of desire to let go could be similarly explained if families realized that the difference between the pediatric and adult system would result in their needs not being met.

In addition to these systemic barriers, societal attitudes towards disability and expectations of independence were cited as barriers to transition (Hanson, 2003; Stewart et al., 2010). This is especially important: if individuals, groups or society believe that these young people are not capable, this could present barriers to acquiring the supports needed for success. Regardless of the type of barrier present, these barriers have the potential to affect the ability to transition and the overall health and well-being of the young adult during and following transition (Stewart et al., 2010).

In conclusion, the literature on young people with disabilities or chronic illness can provide a background on the transition to adulthood that has relevance to young people with medical

complexity despite the paucity of literature specific to this population. Despite the relatively small numbers of young people with medical complexity, the needs and costs of care are substantial and with advances in technology, these numbers will only continue to grow (Cohen et al., 2012). As these young people move from adolescence to adulthood, service-delivery transition should be considered part of this developmental transition. Due to the complexity of the needs of young people with disabilities and chronic illness, discussions of individual, familial, and systemic barriers to successful transition are plentiful in the literature. Transition experts have advocated for holistic approaches to transition that address personal potential, environmental factors, and psychosocial concerns for health, quality of life, and development across sectors (Betz, 2013). Despite the arguments in support of this perspective, there is a need for additional research to explore the utility of this perspective in facilitating the transition to adulthood, especially for young people with medical complexity.

Research Question and Objectives

The research question that guided this integrative review was *How does the literature inform advanced practice nurses (APNs) on the transition to adulthood for young people with medical complexity?* Specific objectives included:

- To review the existing literature on the transition to adulthood for young people with medical complexity;
- To consider the findings from the perspective of Transition Theory (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000) and the Bioecological Theory of Human Development (Bronfenbrenner, 1994, 2005);
- To utilize these findings to inform advanced practice nursing on the transition to adulthood for young people with medical complexity.

Theoretical Perspectives

Transition Theory

The middle-range Transition Theory was developed by Meleis and colleagues in which they argue for transition as a central concept in nursing (Schumacher & Meleis, 1994). This theory describes the process experienced by individuals when their health and illness states change. Transitions can be developmental, health-illness, situational, or organizational (Meleis et al., 2000). For the purpose of this project, I will be considering Transition Theory in the context of the transition from adolescence to adulthood, which, as described in previous sections, can be defined as a developmental and situational (service-delivery) transition.

Transition Theory consists of many assumptions concerning the process of transition. The assumptions are implied based on assertions made throughout the description of the theory (Im, 2014; see also Meleis et al., 2000). These assumptions include:

- Transitions are considered complex and multidimensional, characterized by flow and movement over time (Meleis et al., 2000);
- Transitions involve the process of change in life patterns and can cause changes in identity, roles, abilities, and patterns of behaviour (Im, 2014, Meleis et al., 2000);
- Human beings are active beings who perceive and attach meanings to health and illness situations (Meleis et al., 2000; Schumacher & Meleis, 1994).
- The goal of transitions is to avoid vulnerability, which is “related to transition experiences, interaction, and environmental conditions that expose individuals to potential damage, problematic or extended recovery, or delayed or unhealthy coping” (Meleis et al., 2000, p. 12).

Transition Theory consists of five components: (a) types and patterns of transitions; (b)

properties of transitions; (c) transition conditions; (d) patterns of response; (e) nursing therapeutics (Meleis et al., 2000).

Types and patterns of transitions. Transitions can be developmental, health or illness-related, situational, or organizational (Meleis et al., 2000). Examples used by Meleis et al. (2000) to illustrate components of their theory include immigration, menopause, becoming a mother, and normalization in parents whose child is diagnosed with a congenital heart defect. Patterns of transitions include multiplicity and complexity. The pattern of multiplicity suggests that individuals can experience multiple transitions at once. In the context of transition to adulthood, several transitions can occur simultaneously—for example, health care transition and education (school) transition. The pattern of complexity simply acknowledges that many factors can affect the experience, process, and outcomes for an individual in transition. This concept was not further described in the works of Meleis and colleagues.

Properties of transitions. Properties of transitions include: awareness, engagement, change and difference, time span, and critical points and events. Awareness is defined as the recognition that one is in transition. Meleis et al. (2000) assert that the “level of awareness is frequently reflected in the degree of congruency between what is known about processes and responses and what constitutes an expected set of responses and perceptions of individuals undergoing similar transitions” (p. 17). Engagement is synonymous with involvement in the transition process and the level of engagement will differ based on one’s awareness (Meleis et al., 2000). Change and difference are also important properties of transition. Important components of change are the nature and temporality of the change, the perceived importance of the change, and norms and expectations related to the change (Im, 2014; Meleis et al., 2000). Change is related to critical events and disruptions in relationships and routines (Meleis et al.,

2000). The difference associated with transition can lead to unmet expectations, feelings and bring perceived as different, and seeing things differently. It is important to note, however, that transition involves change but not all change is a transition (Meleis et al., 2000).

Transition involves flow and movement over time. Bridges (1991) suggests that transition is a time span with an identifiable start and end point, but Meleis et al. (2000) assert that it may not be possible and even counterproductive to place boundaries or time frames on transition. Finally, critical points or events may signal the start of transition, increased awareness, increased engagement, or stabilization (Meleis et al., 2000). Each critical point should receive different attention from the nurse.

Transition conditions. Transition conditions are facilitators and barriers to transition. These conditions can be personal, community, or societal. Personal conditions include meaning, cultural attitudes, socioeconomic status (SES), and participation and knowledge. Meleis et al. (2000) emphasize the importance of understanding the meaning of transition from the point of view of those experiencing it as this meaning can serve to facilitate or hinder the process. In addition, cultural attitudes and SES can facilitate or hinder successful transition (Meleis et al., 2000). Finally, participation in and knowledge of the transition process in the form of what to expect in and strategies to support transition can serve to facilitate or hinder the process. Community conditions include resources, social supports, and information that can support successful transition (Im, 2014). Societal conditions are facilitators or barriers related to societal ideologies, stigma, and social and health inequities (Im, 2014; Meleis et al., 2000).

Patterns of response. In Transition Theory, health and perceived well-being are general outcomes of transition. Patterns of response consist of process indicators that move a person towards health or vulnerability and outcome indicators that reflect a successful transition (Meleis

et al., 2000). Process indicators include feeling connected, interaction, becoming situated in terms of time, space, and relationships, and developing confidence and coping (Meleis et al., 2000). Outcome indicators include mastery and fluid integrative identities. Mastery can include monitoring symptoms, taking action, making adjustments, accessing resources, negotiating the system, or self-care (Im, 2014; Meleis et al., 2000). Fluid integrative identities as an outcome indicator in Transition Theory is another way of saying that an indicator of successful transition is identity reformulation (Meleis et al., 2000).

Nursing therapeutics. This is an important yet relatively underdeveloped component of Transition Theory. In Meleis et al.'s (2000) articulation of the theory, nursing therapeutics involves assessment of readiness and preparation for transition. Assessment of readiness should involve a multidisciplinary approach that requires a comprehensive understanding of client needs and includes all elements of transition conditions (Im, 2014). Preparation for transition is often in the form of education and requires sufficient time to ensure adequate preparation (Im, 2014; Meleis et al., 2000).

Transition Theory, nursing, and medical complexity. In her various works, Meleis describes transitions as a central concept in nursing and argues that nurses are often caregivers for clients and families during transitions (Meleis et al., 2000; Meleis & Tragenstein, 1994; Schumacher & Meleis, 1994). In the current landscape of the health care system, clients and families are often in transition. For example, a middle-aged woman with progressing multiple sclerosis may be in a health-illness transition as her condition progresses, a developmental transition as she goes through life changes, and even a situational transition if she cannot manage to live independently in her own home. Nurses in a variety of settings would be highly involved in the care of such a client in all of these types of transition.

Young people with medical complexity experience developmental and situational transitions as a result of their age and developmental trajectories. They may also simultaneously undergo health-illness transitions if their medical status changes. By virtue of the complexity of their chronic conditions, these young people will encounter nurses in a variety of settings including inpatient hospital settings, outpatient clinics, and home care. These nurses are at the forefront of their care and have the opportunity to work with these young people during and beyond many transitions in their lives. As a result, consideration of theoretical perspectives that align with this view of transition could serve to improve nurses' abilities to work with these young people and their parents.

The Bioecological Theory of Human Development

The Bioecological Theory of Human Development, hereafter referred to as Bioecological Theory, was introduced in its original form in the 1970s by Urie Bronfenbrenner. Bioecological Theory has its roots in developmental psychology and was developed in response to the restrictive scope of developmental psychology at the time (Bronfenbrenner, 1994). The goal of Bioecological Theory is to provide a framework for the study of human development over time (Bronfenbrenner, 2005).

Bronfenbrenner has been credited with the introduction of context into developmental science research and into commonplace developmental psychology (Darling, 2007). For Bronfenbrenner, development occurs over time and is affected by characteristics of the person and environment with the goal of achieving developmental outcomes. Furthermore, it is not simply the objective properties of a person or environment that affects human development, but also how a person subjectively experiences the environment (Bronfenbrenner & Morris, 2006). It is the combination of the objective and subjective aspects that has an impact on human

development.

It is also important to note that biological factors and evolutionary processes set limits on human development and can affect environmental conditions and experiences required to actualize personal potential (Bronfenbrenner & Morris, 2006). This is an especially important consideration when working with children and adolescents with multiple complex chronic conditions associated with medical complexity.

There are four properties in Bioecological Theory: processes, person, context, and time. These properties are not mutually exclusive, instead interacting to affect human development.

Processes. Processes are forms of interaction between the person and the environment over time (Bronfenbrenner & Morris, 2006). Effective interactions between person and environment are called proximal processes (Bronfenbrenner, 1994). Examples of proximal processes include feeding a baby, play, reading, making plans, acquiring new knowledge, or learning (Bronfenbrenner & Morris, 2006).

Person. This property concerns the characteristics of the developing person, of which there are three categories. First, character and personality can initiate proximal processes in a particular developmental domain (Bronfenbrenner & Morris, 2006). Second, resources of ability, experiences, knowledge, and skill are required for effective proximal processes (Bronfenbrenner & Morris, 2006). Third, demand characteristics affect the social environment and can, by extension, affect the execution of proximal processes (Bronfenbrenner & Morris, 2006).

Context. Context, also known as the ecological environment, consists of a set of nested sub-environments. The microsystem involves face to face settings and factors such as hecticness, chaos, and instability in these settings (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006). In other words, the microsystem is made up of all the individuals or groups, as well as factors

outside the people involved, with whom the developing person has direct contact. These individuals and groups can facilitate or inhibit engagement of the developing person in more complex interactions with the environment (Bronfenbrenner, 1994). Examples of microsystems are family and school.

The mesosystem is a system of microsystems and involves processes taking place between two or more settings containing the developing person (Bronfenbrenner, 1994). An example is the relationship between the home and school. In the exosystem, processes take place between two or more settings, in at least one of which the developing person is not involved directly (Bronfenbrenner, 1994). Examples of exosystems include the relationship between home and parent workplace and the relationship between home and family social networks.

Macrosystems are defined as the overarching pattern of the previous three systems in a given culture, particularly values, beliefs, bodies of knowledge, resources, and lifestyles (Bronfenbrenner, 1994).

The chronosystem and time. The chronosystem consists of changes in both person and environment over time, both within and across generations (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006). This concept of time is the fourth property in Bioecological Theory and is made up of microtime, mesotime, and macrotime. Microtime describes the continuity in proximal processes (Bronfenbrenner & Morris, 2006). Mesotime consists of the periodicity of these interactions over broader time intervals (Bronfenbrenner & Morris, 2006). Macrotime describes the more widespread changes in expectations and events in larger society (Bronfenbrenner & Morris, 2006).

Bioecological Theory consists of two main propositions that bring together the four theoretical properties in this theory. The first proposition is that development occurs through

complex reciprocal interactions between the developing person and components of the person's environment (Bronfenbrenner & Morris, 2006). In order to produce desired developmental outcomes, these interactions must become more complex as the person develops. The second proposition explicates the four properties' effect on human development in that the form, power, content and direction of effective proximal processes that give rise to human development and the achievement of developmental outcomes are determined by the characteristics of the developing person, the environment, the specific developmental outcomes, and changes in social context (Bronfenbrenner & Morris, 2006). As a result, the four properties of processes, person, context (environment) and time, taken together, have the power to enable professionals to understand and affect human development.

Bioecological Theory and nursing. Although Bioecological Theory was originally developed for and is most often used in the field of developmental psychology, it has been described as having an interdisciplinary and integrated focus (Bronfenbrenner & Morris, 2006; Miles & Holditch-Davis, 2003) and, thus, can also have important applications in the discipline of nursing. Developmental milestones and outcomes associated with adolescence and young adulthood have been linked to inequities in the determinants of health and can have a profound effect on health and quality of life in adulthood (Currie et al., 2012; Stam, Hartman, Deurloo, Groothoff, & Grootenguis, 2006). Furthermore, caring for children, adolescents, and young adults in any setting, especially in the community, requires a holistic perspective in which the primary concern of the nurse is physiological function and growth, health and illness, and cognitive and social abilities (Miles & Holditch-Davis, 2003), all of which are affected by the achievement of developmental milestones. Thus, nurses should consider integrating the promotion of healthy child and adolescent development in their practice.

Bioecological Theory and the transition to adulthood. The congruence between Bioecological Theory and the process of transitioning to adulthood relies on the view of the transition to adulthood as a developmental transition involving the movement of the individual from one developmental stage to another and of which health care transition is a component. Stewart et al. (2009) describe transition to adulthood in this manner through the use of a lifecourse approach, which provides a developmental lens through which the transition needs of individuals can be assessed, conceptualized, and addressed.

Despite the apparent applicability of Bioecological Theory, it has rarely been used to inform research or literature reviews on the transition to adulthood (e.g. Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Wang et al., 2010). Wang et al. (2010) conducted an extensive literature review to explicate the utility of Bioecological Theory in understanding key concepts of and developing interventions for the transition to adulthood for adolescents with disabilities and special health care needs. This review reinforced considerations for providers related to the multiple nested environments of which the individual is a part, the interactions between person and environment, and the person-centered nature of the model (Wang et al, 2010), all of which are also important considerations in nursing. Most importantly, Wang et al. suggest that Bioecological Theory reinforces that providers and researchers must always consider individual concerns about transition. Overall, Bioecological Theory can serve as an appropriate and useful framework for understanding and approaching the transition to adulthood.

Congruence of Theoretical Perspectives

I have used two theoretical perspectives originating in different disciplines to inform my work. By considering the Bioecological Theory of Human Development to supplement the nursing theoretical perspective provided by Transition Theory, I was able to develop a more

complete picture of the transition to adulthood as primarily a developmental transition while also considering the other underlying transitions that young people with medical complexity might experience. In bringing two theoretical perspectives to my work, however, it is important to have congruence between the two perspectives to provide consistency in my interpretations of the findings of this review. In the remainder of this section, I will discuss three areas in which Transition Theory and Bioecological Theory are congruent: transition to adulthood as a developmental transition, a positive approach, and theory components.

Most importantly, and as previously discussed, the transition to adulthood is foremost a developmental transition but cannot be considered separately from situational (service-delivery) transitions. Young people with medical complexity may experience situational and sometimes even health-illness transitions simultaneous to the developmental transition. Perspectives drawn from Transition Theory enabled me to understand the multiplicity of these transitions while perspectives drawn from Bioecological Theory provided support for the consideration of developmental and situational transitions together. Bioecological Theory also supports the notion that effective person-environment interactions can produce developmental outcomes related to becoming an adult (Bronfenbrenner, 1994). In the context of this theory, changes in the environment with which the young person interacts cannot be considered separately from developmental goals. Overall, Transition Theory and Bioecological Theory each support the notion of considering developmental and situational transitions together.

Second, both theories support a positive approach. The focus of Transition Theory is the promotion of healthy transitions through nursing therapeutics informed by an understanding of properties of transition, transition conditions, and process/outcome indicators (Meleis et al., 2000). Furthermore, Schumacher and Meleis (1994) describe the goals of nursing therapeutics

related to transition as “promotive, preventive, and interventive” (p. 125). In other words, Transition Theory promotes a proactive approach as opposed to a reactive approach. Similarly, Bioecological Theory focuses on effective proximal processes. Nurses can use this theoretical perspective to inform interventions to promote achievement of developmental outcomes. In addition, the propositions of Bioecological Theory support the notion that the power of proximal process lies in positive environments (Bronfenbrenner & Morris, 2006). In other words, positive interactions and positive environments increase the power of proximal processes to influence developmental outcomes.

Finally, there is congruence between components in each theory. A particular component that is fundamental to my work in this review is that of meaning and subjectivity. These concepts, although described slightly different in each theory, are integral to understanding the findings of this review. In Transition Theory, meaning is described as people’s subjective interpretation of a future or current transition and the effect this might have on their lives (Schumacher & Meleis, 1994). Meleis et al. (2000) stress the importance of meaning throughout their description of the theory, which lies in understanding transitions from the point of view of those living the transition and recognizing that meanings attributed to the transition experience can facilitate or hinder the process (Meleis et al., 2000). Meaning is also described similarly in Bioecological Theory in that how a person subjectively experiences the environment also has an impact on human development (Bronfenbrenner, 2005). For example, if a person attributes a negative experience to a particular component of the environment, any interactions with that environment may not be effective to produce desired outcomes. Overall, the concept of meaning is important and consistent in both theories.

In addition to meaning, there is congruence between the concept of transition conditions

in Transition Theory and the properties of person and context in Bioecological Theory in that personal, community, and societal conditions in Transition Theory correspond with attributes of the person and context in Bioecological Theory. In addition, Bioecological Theory can provide an extension to the concept of transition conditions in that it is not simply these conditions that could facilitate or impede transition, but instead the interactions between the person in transition and these conditions. Overall, there is congruence between Transition Theory and Bioecological Theory in terms of focus of the theories, practical approaches in the theories, and concepts in the theories.

Methodological Approach

I chose an integrative literature review methodology for this review as it allows for inclusion of research using diverse methodologies and provides the opportunity to understand the phenomenon of interest from a variety of perspectives (Whittemore & Knafl, 2005). Integrative reviews can have multiple purposes including defining concepts, reviewing theories or evidence, or analyzing methodological issues (Whittemore & Knafl, 2005). It is important in integrative reviews to use explicit and systematic methods. As a result, Whittemore and Knafl (2005) propose a five-stage framework to enhance rigour in these reviews. This is the framework I used to complete this review.

Problem Identification Stage

The problem should be clearly stated and variables of interest should be well-specified (Whittemore & Knafl, 2005). In this review, the problem was clearly defined: with more young people with medical complexity transitioning to adulthood, APNs will require knowledge of transition process for this population to assist young people and their parents throughout the transition process. The purpose of this review, as previously stated, was to review the literature

on the transition to adulthood for young people with medical complexity and consider this literature collectively to inform advanced practice nurses on this process. I chose to complete an empirical review (Whittemore & Knafl, 2005) to maintain a focus on empirical literature instead of expert opinion.

In addition, Kirkevold (1997) as cited in Whittemore and Knafl (2005) advocates for locating integrative reviews in an explicit philosophical or theoretical perspective. I chose to integrate two theoretical perspectives to inform this review: Meleis' Transition Theory and Bronfenbrenner's Bioecological Theory of Human Development. Through the use of these two theories, I was able to consider the transition to adulthood in the context of health and human development simultaneously.

Literature Search Stage

A well-defined literature search strategy is essential in integrative reviews (Whittemore & Knafl, 2005). In addition, Whittemore and Knafl (2005) suggest a comprehensive search using at least two or three strategies and all decisions should be made explicit. I chose to search two online databases: the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and Medline. I also completed an ancestry search of included articles from these databases for additional articles for inclusion. My inclusion criteria were as follows: (1) articles published 2003 or later; (2) research articles including evaluation studies, excluding theoretical articles and expert opinion; (3) participants fit Cohen et al.'s (2011) definitional framework (see Appendix A). The year 2003 was chosen as around that time two landmark collaborative position papers were published calling for a renewed focus on the transition to adult care (e.g. Rosen et al., 2003). I chose to include evaluation studies as research as these studies can provide additional insight into the perspectives of young people and their parents experiencing a particular program

or intervention. Participant characteristics for each study were examined. Studies were included if at least 25% of participants could be considered medically complex according to Cohen et al.'s (2011) framework. I believed that this proportion would provide sufficient and relevant information related to my population of interest. If proportions were unclear, I used my personal clinical experience to make a judgment on inclusion or exclusion based on descriptions of participant characteristics.

Defining adequate key terms for database searches was a challenge as my population of focus includes a wide variety of diagnoses. In addition, diverse terminology is used in databases and articles to describe young people with medical complexity (Cohen et al., 2011; Cohen et al., 2012). I used the following groups of key terms in various combinations:

- *medical complexity, medically fragile, complex chronic, complex, chronic disease, disability;*
- *adolescent, young adult;*
- *transition, transition programs, health transition, adolescent health services, and continuity of care.*

The terms *palliative* and *hospice* were added in subsequent searches as I discovered through exploration of the background literature that studies of pediatric hospice and palliative care could also include young people with medical complexity. The initial search to determine key terms occurred in January 2014, with subsequent searches in March and April 2014. The search in March 2014 included initial key terms; the key terms *palliative* and *hospice* were added in April 2014. I kept detailed records of the literature search process using EBSCO saved searches and journaling. See Figure 1 for search results from March 2014 and Figure 2 for results of adding the two additional key terms.

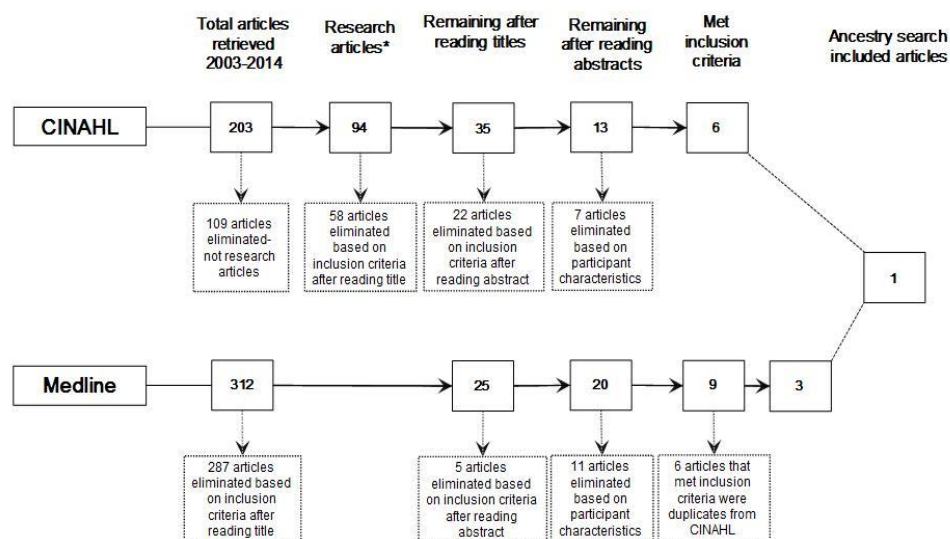


Figure 1: Results of March 2014 search of CINAHL and Medline. *Note: CINAHL has a limiter for “research articles”, which was used to narrow list of potential articles. (Final result=10 articles)

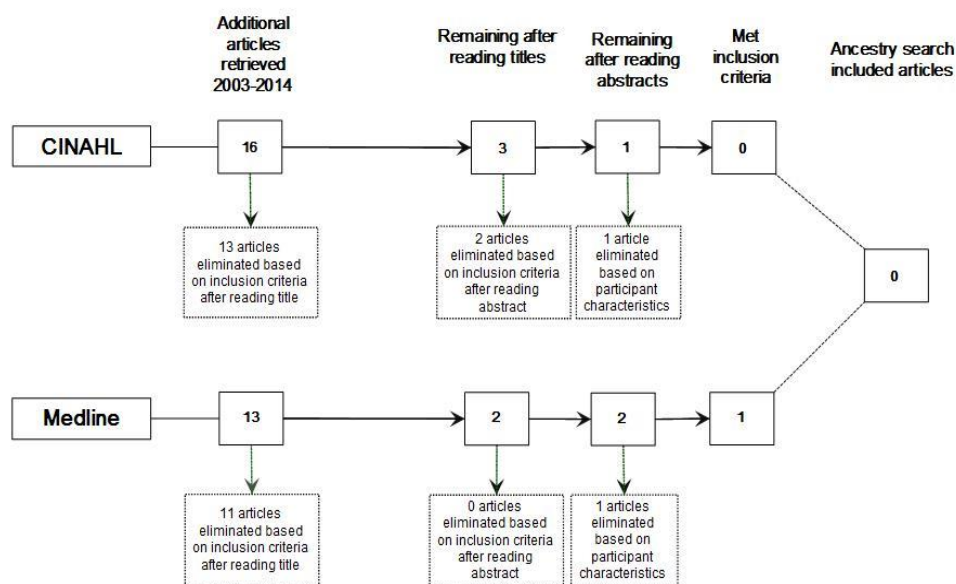


Figure 2: Additional results obtained from adding *palliative* and *hospice* as key terms. (Final result=1 additional article)

Overall, a total of 11 articles were selected for inclusion. See Appendix B for a summary of each study, including participant characteristics used to judge inclusion.

Data Evaluation Stage

In the data evaluation stage, Whitemore and Knafl (2005) suggest assigning quality scores to each article and that if two different types of studies are included, two frameworks for evaluating quality may be used. Included articles were qualitative and quantitative, so I chose to use critiquing frameworks specific to qualitative or quantitative research to evaluate the appropriate studies. To accomplish this, I employed frameworks for critiquing qualitative research and quantitative research from LoBiondo-Wood and Haber's (2013) text; however, I added an additional criterion to each framework for applicability to the review and to practice as Whitemore and Knafl (2005) suggest that informational value is also important.

When included studies are of similar design, Whitemore and Knafl (2005) suggest that incorporating quality scores into the design may be useful. I assigned quality scores out of 20 to each study. If the criterion was covered completely, full points were assigned. If not, then partial or no points were assigned to that category. I set a score of 10 as a cut-off for inclusion; however, all studies exceeded this cut-off. See Appendix C for the critiquing frameworks used.

Based on evaluation of the retrieved studies, I chose to exclude provider perspectives from my analysis for multiple reasons. First, only four studies included perspectives of providers. One study (Kirk & Fraser, 2014) was specific to hospice providers, which is outside the scope of my review. In addition, Sonneveld, Strating, van Staa, and Nieboer (2012) utilized a non-validated instrument to collect data from providers, which left me lacking confidence in findings associated with the provider perspectives in this study. Finally, in Rehm, Fuentes-Afflick, Fisher, and Chesla (2012), provider perspectives were rarely differentiated from youth and parent

perspectives. As a result, the interpretation of provider perspectives was not feasible given the studies chosen for inclusion.

Data Analysis Stage

In this stage, data is “ordered, coded, categorized, and summarized” to come to a conclusion (Whittemore & Knafl, 2005). This stage is further broken down into data reduction, data display, data comparison, and conclusion drawing.

Data reduction. Data reduction involves extracting and coding the data. First, an overall classification system needs to be determined (Whittemore & Knafl, 2005). For this review, I chose to classify the studies as qualitative or quantitative and then further classified the qualitative studies based on key informants: young people, parents, or both. Due to the exploratory nature of my research question, data pertaining to the broad perspectives of young people or their parents on the transition process were extracted and reduced to a 1-2 page summary. Categories for coding were developed based on concepts from the two theories and concepts related to young adult development and determinants of health identified from the background literature.

Data display. In data display, data is assembled from individual sources (Whittemore & Knafl, 2005). I assembled the coded data in a spreadsheet to allow for easy organization and grouping by category. I also designed the spreadsheet to allow for tracking of article of origin and key informant (young person or parent). Data from the single quantitative study included in this review was compared to the collectively assembled data from qualitative studies based on coded categories.

Data comparison. Data comparison is an “iterative process of examining data displays... in order to identify patterns, themes, or relationships” (Whittemore & Knafl, 2005, p. 551). My

goal in this stage was to take the particulars of the studies to general interpretations (Whittemore & Knafl, 2005). Various strategies suggested by Whittemore and Knafl (2005) were employed including identifying patterns across studies, clustering related categories, and concept mapping. After identifying patterns across studies, I clustered the categories (e.g. feeling-related categories, independence-related categories, obstacles) to form 5 initial themes. These themes were: the paradox of independence, difference and change, overcoming obstacles, becoming situated in the adult world, and system changes are necessary. As I began to develop these broader themes, I employed concept mapping to enable further examination of the data.

During this stage, I initially considered young people's and parents' perspectives separately; however, I found these perspectives were more similar than different. There were only a few instances outside the realm of service delivery and system navigation in which young people's and parents' perspectives differed. From a service-delivery and systems perspective, however, it appeared that it did not matter who was directly involved with navigating the system: the underlying perceptions were similar. Therefore, as I continued the data analysis process, I considered these perspectives together while also keeping track of the differences.

Conclusion drawing and verification. This stage involves taking interpretations to a higher level of abstraction and verifying interpretations with primary sources (Whittemore & Knafl, 2005). Whittemore and Knafl (2005) caution that, at this stage, care needs to be taken not to get locked into a particular way of thinking. At this stage, I stepped away from my initial conceptualizations and theoretical perspectives and examined patterns within and between the categories and five initial themes, reworking the themes to generate three final themes. Conclusions were verified by returning to the primary sources for verification and to explore any conflicting data. Finally, as part of this verification process, I developed a final version of my

concept map (see Appendix D) reflective of the three themes: *it's like falling off a cliff, the paradox of independence, and it takes a village.*

Presentation of Findings

Presentation of findings could be in diagrammatic or table form and should consist of explicit details from primary sources to support conclusions (Whittemore & Knafl, 2005). The presentation should also be in-depth and lead to a new understanding of the phenomenon (Whittemore & Knafl, 2005). I presented my findings in the form of a concept map (Appendix D) and in narrative form in a subsequent section. In my discussion, I emphasize the applicability of the findings to the two theoretical perspectives, implications for practice, ethics and implications for policy, and recommendations for future research as suggested by Whittemore and Knafl (2005).

Findings

Overall, 11 articles were included in this review. Ten articles were qualitative studies and one was a quantitative study. The qualitative studies used varied methodologies including grounded theory, descriptive case study design, qualitative descriptive evaluation, phenomenology, ethnography, and narrative analysis. One study did not define a specific qualitative methodology. The quantitative study was a secondary analysis of data from a larger evaluation study. The purposes of the studies were also varied but focused primarily on health care transition (5), priorities, facilitators, and/or barriers (4), broad experiences and meaning of adulthood and transition (3), evaluation of an intervention or perceptions of a program (2), and parent-youth relationship dynamics during transition (1).

The included studies were also geographically diverse. Studies were conducted in Canada (5), the United States (3), the United Kingdom, specifically in northern England (2), and the

Netherlands (1). The characteristics of young people varied in terms of diagnosis and functional limitations across studies; however, at least a sub-group of, if not all, participants in each study fit the definition of medical complexity. Studies also varied in terms of key informants: young people (1), parents or guardians (3), young people and parents (3), or young people, parents, and providers (4). Combining characteristics of young people across studies, approximately 40% were under the age of 18 and the remaining participants were age 18-30. For a summary of the characteristics and findings of each article, see Appendix B. Overall, the results of these 11 studies were synthesized to define three themes: *It's like falling off a cliff*, *the paradox of independence*, and *it takes a village*.

It's Like Falling Off a Cliff!

Young people with medical complexity and their parents described the transition to adulthood as similar to falling off a cliff, specifically the process of *being pushed off a cliff*, *falling into the abyss*, and *landing at the bottom*. These descriptions were more specific to service-delivery transitions; however, it was clear that successful service-delivery transitions were essential for health, quality of life, and goal attainment. As a result, understanding how young people and their parents perceive and experience this process was central to many of the studies in this review.

First, young people and their parents felt as if they were *being pushed off a cliff*. This push took the form of a critical event, such as age or a health crisis, which initiated movement from the pediatric to the adult system (Davies, Rennick, & Majnemer, 2011; Kirk, 2008; Meleis et al., 2000). Some young people and parents were aware of the inevitable transition while others were not (Kingsnorth, Gall, Beayni, & Rigby, 2011; Kirk, 2008). Regardless of the specific critical event or one's awareness of the inevitability of transition, the transition was characterized

by feelings of abandonment and loss, similar to the feeling of being pushed off a cliff or losing your grounding.

Young people and their parents described feelings of abandonment due to a perceived lack of preparation for the transition by pediatric providers, often without referrals to adult providers (Cook, Siden, Jack, Thabane, & Browne, 2013; Davies et al., 2011; Schultz, 2013). In addition, young people and their parents experienced feelings of loss of the trusting relationships they had built with their pediatric providers over the course of their lives (Davies et al., 2011; Young et al., 2009). This loss led to feelings of uncertainty over what would happen in the adult system. Overall, young people and their parents generally experienced a sense of abandonment and loss as they were pushed off the cliff.

After being pushed off this cliff and out of the pediatric system, young people and their parents were *falling into the abyss* of an unknown and unfamiliar system, unsure of what to expect. They almost universally described a stark contrast between the system with which they were familiar (top of the cliff) and this new and foreign system (the abyss). Young people and their parents contrasted the pediatric and adult systems in terms of provider characteristics, service organization, coordination, and how they were viewed as patients. They described pediatric providers as friendly, supportive, and adaptive, while respectfully valuing the opinions and expertise of young people and their parents (Davies et al., 2011; Kirk, 2008; Reiss, Gibson, & Walker, 2005). In contrast, young people and their parents viewed adult providers as lacking knowledge of childhood-onset complex chronic conditions (Cook et al., 2013; Reiss et al., 2005; Young et al., 2009). Also, young people were followed in terms of pieces as opposed to a whole person (Davies et al., 2011).

Services were also organized differently in pediatric and adult systems. In pediatrics, care

was organized and coordinated, provided in one location with all subspecialty providers in one place (Davies et al., 2011; Reiss et al., 2005; Young et al., 2009). Furthermore, young people viewed pediatric hospitals as protective and warm, an environment in which they felt comfortable and safe (Kirk, 2008). In the adult system, however, young people and their parents viewed care as fragmented, disorganized, and disease-centered (Cook et al., 2013; Reiss et al., 2005; Schultz, 2013).

Finally, young people were seen differently in the adult system. For some, this difference was positive while for others it was negative. In a positive sense, young people received more autonomy in decision making and more privacy when possible—they were seen as adults (Cook et al., 2013; Kirk, 2008). It was important for these young people to be enabled to make their own decisions or at the very least participate in these decisions (Cook et al., 2013; Kirk, 2008; Magill-Evans et al., 2005). Many others, however, felt their opinions and expertise were not valued the same way as in the pediatric system (Davies et al., 2011; Reiss et al., 2005). In addition, one young adult described: “the doctors who specialize in ‘normal’ things sometimes look at me like I have a disability and I deserve to be treated differently because of that” (Cook et al., 2013, p. 6). Overall, these young people and their parents are falling into an abyss of unfamiliarity and change.

After falling into the abyss, young people and their parents eventually terminated ties with the pediatric system effectively *landing at the bottom* of the cliff in the adult system. At this time, young people and parents often felt like asking: “we’ve landed, but now what?” Landing was associated with feelings of uncertainty and fear of the unknown. They recognized needs as complex and multifaceted but were uncertain of how all their needs would be met in this new system (Davies et al., 2011; Kingsnorth et al., 2011; Kirk, 2008; Schultz, 2013). Many

experienced rejection from pediatric hospitals as adults while adult providers and hospitalists were afraid to treat them (Davies et al., 2011; Young et al., 2009). One parent described: “the professionals, they scare me because they are not very knowledgeable. ...They see a wheelchair and they run. ...You can see the look their eyes... the look is scared...” (Young et al., 2009, p. 352). These experiences resulted in uncertainty for young people and their parents in the adult system.

Many were also unsure of what options were available to them and what services they were eligible for (Rehm et al., 2012). Even when options were available, young people and their parents were unsure of how to access what they needed (Young et al., 2009). Finally, some parents, especially those caring for young adults with severe intellectual or multiple disabilities, worried about the *what ifs* and were unsure of where to turn when something changed (Davies et al., 2011; Schultz, 2013). For example, a parent described

When he has GI problems it affects his seizures, and when he has seizures it affects his breathing. Who do I call first? GI, respirology or neurology? When I finally reach someone, and if they make a medication change, then it might affect his other medications. Then what? (Davies et al., 2011, p. 36)

Overall, the landing in the adult system was full of fears, uncertainties, and unknowns; however, these feelings were not restricted to the health care system. Instead, these feelings were complicated by the inherent complexity in attaining independence in the adult world.

The Paradox of Independence

For young people with medical complexity, independence necessitates dependence on individual supports, services, and systemic resources. This dependence is individualized and multifaceted, being affected by individual definitions of independence and medical condition. It

is this dependence as a requirement for independence that constitutes this paradox for these young people (Cook et al., 2013).

For some young people and their parents, independence meant being out in the world on their own, whether this meant living completely on their own or living in a supported-living situation (Rehm et al., 2012). For others, independence signified having a normal life and functioning as independently as possible as a member of society (Cook et al., 2013). Some had broad goals of attending post-secondary education, obtaining employment, and participating in society (Cook et al., 2013) while others had slightly different but still significant goals, such as finding a “little niche where she is comfortable and productive” (Rehm et al., 2012, p. E67).

Goals for independence also differed based on young people’s cognitive capacity as well as parent perceptions of their abilities. Young people with mild or no intellectual disability generally viewed independence as the ability to function as independently as possible as a member of society (Cook et al., 2013; Magill-Evans et al., 2005). On the other end of the spectrum, parents of young people with moderate to severe intellectual disability recognized the complex and intensive needs of their adolescent or young adult and viewed independence in light of the young person’s abilities (Magill-Evans et al., 2005; Rehm et al., 2012). For example, parents in Rehm et al.’s (2012) study viewed independence as likely partial, but recognized that living away from home provided their young adults with increased satisfaction. In contrast, other parents recognized that continued total dependence would be necessary for their young adult (Davies et al., 2011; Schultz, 2013).

There were times, however, when young people’s goals for independence and views of their abilities did not align with their parents’ goals and views, creating conflict and barriers to independence (Magill-Evans et al., 2005). For example, in Magill-Evans et al.’s (2005) study, a

young woman who used a power wheelchair and a communication device wanted more independence and autonomy; however, her mother saw her as helpless and vulnerable and did not give her independence. In contrast, parents of another young woman with significant physical and intellectual disabilities built an apartment adjoining their home for their daughter, hired personal care attendants, and based decisions regarding her activities on what young people her age without disabilities were doing (Magill-Evans et al., 2005). Regardless of the specific goal, independence will necessitate dependence on individual supports, services, and systemic resources.

Dependence on individuals such as family and friends was multifaceted. Due to their physical and medical needs, many young people with medical complexity required caregivers or family for ongoing physical and personal support (Cook et al., 2013; Davies et al., 2011; Kirk, 2008). For those who have the ability to take on elements of self-care, parents often served as a coach, providing the support needed to acquire self-care skills and manage their conditions (Kirk, 2008; Reiss et al., 2005). In addition to self-care, many parents continued to play a role in the management of health and financial needs, acknowledging that their adolescent or young adult may never be completely independent of them (Davies et al., 2011; Magill-Evans et al., 2005; Rehm et al., 2012). Few parents discussed role changes, but the majority of those who did wondered whether their role as a parent would ever really end, as they expected their adolescent or young adult to require ongoing support in adulthood beyond the normal parent-adult child relationship (Davies et al., 2011; Magill-Evans et al., 2005; Rehm et al., 2012). For example, one parent in Davies et al.'s (2011) study was worried about how things might change as she and her husband got older. Overall, young people and parents recognized the need for continued individual support to move toward independence.

In addition to individual support, dependence on services across sectors is required for independence. Many young people and their parents expressed that the presence of support workers or nursing staff was important to facilitate independence, attend school, and participate in society (Cook et al., 2013; Kirk, 2008; Magill-Evans et al., 2005). Many young people with medical complexity were also often heavily reliant on medical equipment and technology both to sustain life and to live independently (Cook et al., 2013; Kirk, 2008). Transportation to appointments was also an issue for a group of participants in Cook et al.'s (2013) study:

Getting to doctors' and service providers' offices is a Herculean effort, requiring special transportation accommodating their power wheel chairs, organization of their supplies and equipment, and availability of parents, partners, or care aides to attend the appointments with them. (p. 5)

Overall, access to services is integral to support independence.

Beyond self-care and medical needs, some young people with medical complexity were dependent on high school and community programs that provided training in life skills or other meaningful activities, though participants mentioned these types of services in only three studies (Cook et al., 2013; Kingsnorth et al., 2011; Rehm et al., 2012). In reality, however, many young people and parents had great difficulty finding and accessing meaningful and appropriate programs to suit their needs (Cook et al., 2013; Kingsnorth et al. 2011; Rehm et al., 2012).

In addition to personal support services and community programs, independence required dependence on services designed to support education and employment. Not all young people with medical complexity described goals for education or employment, but those who did described the need for academic and physical accommodations, which ranged from provision of adaptive equipment or testing to access to facilities for bowel and bladder care that could

accommodate their wheelchair (Cook et al., 2013). The presence of these support services was attributed to successful educational and employment experiences (Cook et al., 2013; Rehm et al., 2012).

Housing services were also essential for those wishing to live away from home. Young people and parents described different options for housing away from home including living in a house or apartment with dependence on support workers, supported living arrangements, and institution-based living (Cook et al., 2013; Magill-Evans et al., 2005; Rehm et al., 2012). For some, accessing these options was easy while for others, access to appropriate housing was elusive (Cook et al., 2013; Rehm et al., 2012). Although the availability of services addressing appropriate housing is of the utmost importance for young people with medical complexity who seek independence as living away from their parents, this goal remained elusive for many young people.

In addition to individual and service supports, independence necessitates dependence on systemic resources such as funding. Young people with medical complexity and their parents described the burden of costs associated with renting or purchasing medical and lift equipment, housing, nurses or support workers, formal legal or financial arrangements, and insurance coverage (Cook et al., 2013; Rehm et al., 2012; Reiss et al., 2005; Schultz, 2013). Many reported that limitations in funding had the potential to limit independence. In the United States, for example, most young people with medical complexity will qualify for Supplemental Security Income and other government-assisted programs such as Medicaid; however, these funding options often do not cover all the expected or unexpected costs associated with medical complexity, resulting in limited ability to obtain supports for independence (Rehm et al., 2012). Young people and parents often knew that some sort of funding was available but experienced

difficulties with access to and procurement of information about funding, thus limiting independence.

Overall, independence for young people with medical complexity involves dependence on a variety of supports, services, and funding to attain goals of living away from home, living a normal life, and attaining personal goals; however, independence remained elusive for many young people with medical complexity, despite a desire for independence.

It Takes a Village

It takes a village to support young people during and after the transition to adulthood. This was perceived to *Start with respect*. Young people and their parents described experiences of being devalued as patients or students, with their physicians or professors providing information to their parents or caregivers and not to them (Cook et al., 2013; Kirk, 2008). Furthermore, young people and their parents wanted to be respected as equal partners in the process of navigating the health care system and working with providers perceiving success as dependent on these partnerships (Cook et al., 2013; Davies et al., 2011; Reiss et al., 2005). Overall, young people and their parents want to be respected as individuals and as equal partners in care.

Once respect is established, *a team effort* is required to situate young people with medical complexity in the adult world. This team effort consists of collaboration between young people and their families, providers, and services, and begins with young people and their parents acquiring advocacy skills. Some young people could self-advocate while others relied on their parents (Cook et al., 2013; Kingsnorth et al., 2011; Schultz, 2013). Advocacy was often equated with fighting for services or fighting to have opinions respected (Cook et al., 2013; Davies et al., 2011; Young et al., 2009). To accomplish this, young people or their parents had to take charge

of locating information and services and had to educate their providers (Cook et al., 2013; Davies et al., 2011; Kirk & Fraser, 2014). This took a great deal of time and effort, sometimes requiring significant creativity (Cook et al., 2013; Kingsnorth et al., 2011). Many parents who advocated for their young people were overwhelmed by the enormity of the task, persevering because they had no choice. This perseverance significantly contributed to the ability to access services and supports when they existed (Cook et al., 2013; Davies et al., 2011; Kingsnorth et al., 2011). Most importantly, young people and their parents in these studies “never [gave] up fighting” (Cook et al., 2013; p. 6).

In addition, the support network of family members and other parents was invaluable for many parents of young people with medical complexity and developmental disabilities (Davies et al., 2011; Kingsnorth et al., 2011; Kirk & Fraser, 2014; Schultz et al., 2013). This support network provided comfort, as a reminder that they were not alone. Formal support such as parent peer support groups enabled parents to develop increased awareness of their own expertise and their young adult’s transition needs, leading to a greater understanding of the need for advocacy and the enormity of the task of transition planning (Kingsnorth et al., 2011). Overall, formal and informal support for parents facilitated a feeling of oneness as well as the ability to share resources and ideas for finding and accessing appropriate services.

Both pediatric and adult providers were also a significant part of this team effort. Young people and their parents expected involvement of pediatric providers in the process of transition planning; however, many expressed frustration with inadequate preparation (Davies et al., 2011; Kirk, 2008; Sonneveld et al., 2012). This lack of preparation consisted of lack of involvement, confusion, or lack of information (Davies et al., 2011; Kirk, 2008; Schultz, 2013). Young people and their parents suggested improvements in these areas such as having someone who can assist

with coordination or attending parent peer support groups (Davies et al., 2011; Kingsnorth et al., 2011; Young et al., 2009). Although their suggestions were specific to pediatric providers, young people and their parents also recognized the contribution of adult providers in the transition experience.

Young people and their parents described a vast array of characteristics that they would want in an adult provider. First, they wanted a trusting relationship (Cook et al., 2013; Kirk, 2008; Young et al., 2009). They also described other characteristics such as the use of humor and adequate listening skills (Kirk & Fraser, 2014; Rehm et al., 2012). In other words, they wanted someone with good social skills who would listen to them and talk about the more sensitive issues (Cook et al., 2013; Kirk & Fraser, 2014; Sonneveld et al., 2012). Across all studies, however, such provider relationships in adult care were often scarce, as was communication or coordination between providers within or between systems.

Young people and their parents also viewed coordination within and outside the health care system as important in this team effort. During the transition planning process, however, coordination and ownership for transition planning were lacking (Davies et al., 2011; Kirk, 2008; Kirk & Fraser, 2014). Coordination between subspecialty providers in the adult system was also viewed as lacking as these providers often were not at a single location and communication between these providers was almost nonexistent (Cook et al., 2013; Davies et al., 2011; Sonneveld et al., 2012). In addition, access to the allied health professionals who were so instrumental in improving quality of life in pediatrics was also limited (Young et al., 2009). Young people and their parents perceived this fragmentation as confusing: “The agencies were like the right hand didn’t know what the left hand did... it’s just a lack of information...there’s nothing that ties all the strings together” (Schultz, 2013, p. 363). As adequate coordination and

communication were not a reality, young people and their parents perceived that their experiences in the adult system as well as their overall health would be improved with the development of multidisciplinary clinics in adult settings (Cook et al., 2013; Young et al., 2009). Overall, coordination and communication were important for young people and their parents in terms of a team effort.

Finally, this *team effort* included a plethora of services to support the attainment of goals and the maintenance of health and quality of life. Young people and their parents described either a lack of services to support their needs or a lack of information on how to find and access these services (Cook et al., 2013; Kirk, 2008; Schultz, 2013). As previously discussed, availability of these services is crucial to become independent and maintain quality of life in the adult world. Thus, it is imperative that young people and their parents have access to appropriate services and possess the knowledge of how to navigate the adult system.

Finally, it was evident that individuals and groups in the village cannot be successful without adequate knowledge. This *knowledge replaces fear and uncertainty*. As previously described, the transition experience caused distress and anxiety for young people and their parents, but with additional knowledge, many implied that this feeling could be changed. Young people and their parents perceived that additional information about transition and about adult services, including how the process works and the magnitude of the process, would have eased many of their fears and frustrations with the transition process (Cook et al., 2013; Young et al., 2009). More importantly, accurate information about adult services was necessary to understand what is out there and to assist in planning for “what ifs” (Kirk & Fraser, 2014; Young et al., 2009). Overall, they needed strategies to support them during and after transition.

Young people and their parents suggested many strategies that would have helped them.

One parent suggested that a website or database be set up that lists and describes eligibility requirements for services across sectors in the adult system (Schultz, 2013). Most importantly, parents perceived the role of coordinator or “quarterback” as important to them (Schultz, 2013; Young et al., 2009). They wanted someone to turn to who knows the system and could provide information on services, how to access them, and how to advocate for services independently (Cook et al., 2013; Schultz, 2013; Young et al., 2009).

In addition, the feelings of abandonment and uncertainty resulting from the movement to the adult system were perpetuated by a lack of expertise of adult providers. Young people and their parents perceived that adult providers should be trained on pediatric conditions. These young people and their parents believed that acquisition of this knowledge would assist in negating some of the fears adult providers had about caring for these young people (Cook et al., 2013; Young et al., 2009).

In conclusion, young people with medical complexity felt like they were falling off a cliff as they transitioned to adulthood and adult care. As they were pushed off the cliff into the abyss of the adult world, they described feelings of abandonment, loss, and uncertainty. Landing in the adult world, young people began to experience the paradoxical nature of attaining independence, in which they were dependent on individuals, services, and systemic resources to be independent and live a normal life. It takes a village to overcome the paradox of independence, to transition to adulthood and to become situated in this new and foreign adult world. Through adequate family and provider support, coordination, access to services, and provision of knowledge, young people and their parents believed that this village could help them be successful in this new world and negate the feelings of abandonment, loss and uncertainty.

Discussion

Summary and Discussion of the Findings

The findings of this review suggest that young people with medical complexity and their parents view the transition of adulthood as a tumultuous time of struggles, change, and learning. Transitioning to adulthood felt like falling off a cliff into the abyss of a new and unfamiliar world. Once young people and their parents landed in the adult system, independence necessitated dependence on individual, family supports, services, and systemic resources and that it would take a village to become situated in the adult world.

In falling off the cliff, young people and their parents experienced feelings of abandonment and loss. They felt abandonment due to the lack of preparation in the pediatric system and rejection from providers who lacked knowledge about their condition and loss of the trusting relationships they had built with providers. These feelings are not unique to young people with medical complexity. In their recent qualitative metasynthesis, Fegran, Hall, Uhrenfeldt, Aagaard, and Ludvigsen (2014) noted similar findings across studies focusing on various chronic somatic diseases.

The feeling of falling into the abyss of an unknown and unfamiliar system has also been described in transition literature across populations. In this review, study participants described a contrast between pediatric and adult systems of care in relation to provider characteristics, service organization and coordination, and how they were viewed as patients. Young people with HIV, congenital heart disease, and other chronic illnesses have similarly described transition to adult care as entering a different culture (Moons et al., 2009; Tuchman, Schwartz, Sawicki, & Britto, 2008; Weiner, Kohrt, Battles, & Pao, 2009). For some young people and parents, the movement to the adult system came as a shock, as if young people and their parents simply did not know what to expect. This speaks to a lack of preparation for the process of transition, which

is an issue faced by many young people with a variety of chronic illnesses (Betz et al., 2013; Soanes & Timmons, 2004).

Uncertainty and fear of the unknown for young people with medical complexity and their parents were described in terms of “what ifs” specific to health status and access to services. Fear and uncertainty have also been described across chronic illness groups (Betz et al., 2013). In these studies, fear and uncertainty related to unfamiliarity with new settings and unknowns in health status (Jedeloo et al., 2010; van Staa et al., 2011). Despite these commonalities, feelings of fear and uncertainty appeared to be more complex for young people with medical complexity due to the plethora of professionals and service providers involved in their care and were perpetuated by difficulty accessing services.

The second theme indicated that independence necessitates dependence on individuals, family support, services, and systemic resources. Differing views of independence were expressed by young people and their parents, most often reflecting the cognitive status of the young person or parent views of the young person’s abilities. I found it interesting, but not surprising, that in studies involving parents of young people with severe intellectual disabilities, parents did not mention independence in any way (Davies et al., 2011; Schultz, 2013). This may be the result of the studies’ specific focus on health care transition or the parent perceptions of their young person’s continued total dependence on others in adulthood, although the specific reason for this gap remains unclear.

Young people who sought to be as independent as possible required individual supports and services across domains. The level of dependence on such services as described by study participants was higher than for young people with chronic illnesses without medical complexity or developmental disability, for whom self-management is more highly emphasized (Betz et al.,

2013; Jedeloo et al., 2010). Considering this transition literature across diagnostic groups, the concept of paradox related to independence appears to be unique to young people with medical complexity and may also be relevant for young people with severe developmental disabilities without medical complexity.

It was also interesting to note that the most significant components of the paradox of independence were dependence on support for self-care and services for health and finances. Discussion of needs related to housing, education, employment, and meaningful activities were not consistent across studies despite the known importance of these needs for health outcomes and quality of life (Public Health Agency of Canada, 2013). In fact, in the studies in this review that exclusively involved young people with severe intellectual disabilities, parents made little mention of these areas (Davies et al., 2011; Schultz, 2013). In addition, in many of the other studies in this review, young people and parents continued to focus primarily on health care transition experiences. This could be partially explained by the purposes of these studies, but could also be related to the complexity of young people's conditions or parent perspectives of personal potential.

In addition, other important considerations for developmental outcomes and determinants of health were rarely discussed. For example, social support and social environments in terms of social activities, friendships, relationships, and sexuality are important developmentally and as determinants of health (Public Health Agency of Canada, 2013; Rosen et al., 2003), but were rarely discussed. One parent involved in Rehm et al.'s (2012) study suggested that schools should improve education about sexuality especially for young people with developmental disabilities and another spoke of how it was important that her son was able to develop social skills and friendships; however, there was a significant gap related to friendships, relationships,

and sexuality in the other studies in this review. There are several possible reasons for this gap specifically related to relationships and sexuality, including the stigma associated with sexuality education about relationships and sexuality, young people's perceptions of ability to engage in relationships and intimacy, or parent perceptions of ability and vulnerability. Overall, the results demonstrate that independence necessitates dependence; however, young people and parents focused on some of these issues superficially. As a result, this concept of paradox related to independence requires further development.

Finally, it takes a village to support the transition to adulthood. This starts with respect for young people and their parents, their expertise, and their opinions. A coordinated team effort including providers, family support, and services was necessary for young people and their parents to feel situated in the adult world. Furthermore, young people, their parents, and providers, require knowledge, which has the potential to negate the fear and uncertainty associated with transition.

This concept of a village is obviously the ideal- respect is ideal; a team effort is ideal; knowledge and expertise are ideal. This is what young people and their parents wanted, but it was not reality for most. This village as perceived by young people and their families does not appear to be a true village. A team effort is not just having all these different parts accessible; fragmentation does not support young people and their families. Collaboration, accessibility, and communication are what *should* define the village. This has been supported by position statements and best practice guidelines from the Canadian Pediatric Society (Kaufman & Pinzon, 2007), Rosen et al. (2003), and the Registered Nurses' Association of Ontario (2014).

It was also clear from the findings that it takes a village in two different ways—it takes a village to plan transition and it takes a village to *sustainably* situate and support these young

adults in the adult system. Transition to adulthood is not a static or finite process—it is continuous and, I argue, without a true endpoint. Even if young people and their parents become situated in the adult system, a health status change or other critical event can perpetuate the same feelings of abandonment or uncertainty experienced during the initial process. For example, if a few years after transition to adult care, a young person begins to experience an exacerbation of previous orthopedic concerns, even though they had not seen their pediatric orthopedic surgeon in years, they are left to navigate the adult system to find one who is comfortable with his or her condition, which is something parents worried about (Davies et al., 2011; Reiss et al., 2005). As a result, these young people and their parents require a village that can support them during *and* beyond the initial landing in the adult system. Unfortunately, the current system is set up in such a way that the village that plans transition is not necessarily the same one that will situate and support the young adults in the adult system.

Overall, the findings of this review suggest that the transition to adulthood is a stressful process for young people with medical complexity and their parents. There appeared to be a lack of preparation and support for young people and their parents during this process, which only served to perpetuate feelings of falling off a cliff. It was evident that a plethora of factors need to be considered as part of this process for young people with medical complexity across developmental, health, and service domains; however, factors related to the health care system were the most significant for young people and their parents. As a result, it is apparent that changes must occur in how this process is handled in the pediatric and adult systems in order to change the cycle of feelings of abandonment, loss, and uncertainty.

Broader Implications and Utility of Theoretical Perspectives

Meleis' Transition Theory and Bronfenbrenner's Bioecological Theory of Human

Development informed and are informed by the results of this review. These two theories informed my thinking throughout the development of this project, especially throughout the data reduction phase. Since my research question was quite broad, these theories, in part, informed what data was extracted from the articles for analysis. In the following section, I will describe how the findings relate to these theories and any gaps or inconsistencies in the findings specifically related to the theories.

Transition Theory. Transition Theory has excellent potential to inform knowledge and practice related to the transition to adulthood for young people with medical complexity; however, this theory is not often used to inform research or practice related to this particular transition. Despite the lack of consideration of this theory in literature on the transition to adulthood, the findings of this review reinforce the utility of Transition Theory when considering the transition to adulthood.

Based on the findings of this review, it is apparent that the utility of Transition Theory lies in its ability to inform practice. In Transition Theory, nursing therapeutics represents what nurses can do to facilitate successful transition (Schumacher & Meleis, 1994). As nurses develop and implement therapeutic interventions for transition, they must be aware of the other properties, conditions, and indicators of transition and consider these components at all stages of transition. For young people and their parents, transition represented a time of difference and change in provider relationships and routines for accessing required services. These differences led to the feelings of abandonment, loss, and uncertainty as they were not adequately supported during or after transition. As a result, assessment and planning for transition should include consideration of all potential changes in routines that could result from the transition.

Nurses also need to consider transition conditions as part of the assessment and planning

process (Im, 2014). In other words, nurses need to be aware of potential facilitators and barriers to transition for this population. Many barriers to successful transition have been identified in this review including the availability of and access to services, meanings and feelings attributed to the process, and knowledge of the young person's condition and the transition process.

Similarly, access to a knowledgeable provider and communication were important facilitators.

In addition, nurses need to consider process indicators that move people toward health or vulnerability (Meleis et al., 2000). The process indicators of feeling connected, interactions, and confidence were evident in this review. Specifically, young people and their parents described how they did not feel connected to providers and services in the adult system (Schultz, 2013; Young et al., 2009). Their frustrations with finding or accessing services in the adult system spoke to ineffective interactions. It was also clear from the findings of this review the acquisition of knowledge and expertise was important in facilitating confidence. Overall, feeling connected, effective interactions and confidence were important to achieve outcomes.

Finally, the findings of this review reinforced the outcome indicator of mastery. Young people and their parents had difficulty accessing services in the adult system, which limited their success. As a result, nurses should develop transition assessments and plans with mastery as an important outcome indicator as independence and success in the adult system for young people and their parents required mastery of the system. Overall, Transition Theory provides a useful perspective for considerations in assessment and planning for the transition to adulthood.

Bioecological Theory of Human Development. Although somewhat less practice-oriented, Bioecological Theory also has great potential to inform nurses on the transition to adulthood as a developmental and situational transition. There are several instances in which the results of this review align with perspectives of Bioecological Theory. First, the negative

experiences of young people and their parents have the potential to limit effective proximal processes (Bronfenbrenner & Morris, 2006). In other words, young people or their parents may not want to initiate interactions with their environment due to negative feelings and frustration, which can limit successful achievement of developmental outcomes.

With regards to the developmental outcome of independence, each type of support on which young people were dependent aligns with one of the nested sub-environments described in Bioecological Theory, which is illustrated in Figure 3. The microsystem involved individual supports for self-care and decision-making, services, providers, education, and employment settings; the mesosystem involved interactions between home and school or home and hospital; the exosystem involved interactions between settings such as support services and funding agencies or family and their support networks. In the context of Bioecological Theory, interactions between the developing person and the environment can affect the ability to achieve developmental outcomes such as independence and a normal life.

What is interesting in terms of the findings of this review is that when considering the developmental outcomes and proximal processes for the developing person with a moderate to severe intellectual disability, it was often interactions between family and the environment that were integral for achieving some type of independence or normalcy. For example, parents were often decision-makers for these young people and were the ones arranging other interactions between their young adult and the environment in order to help them achieve their goals.

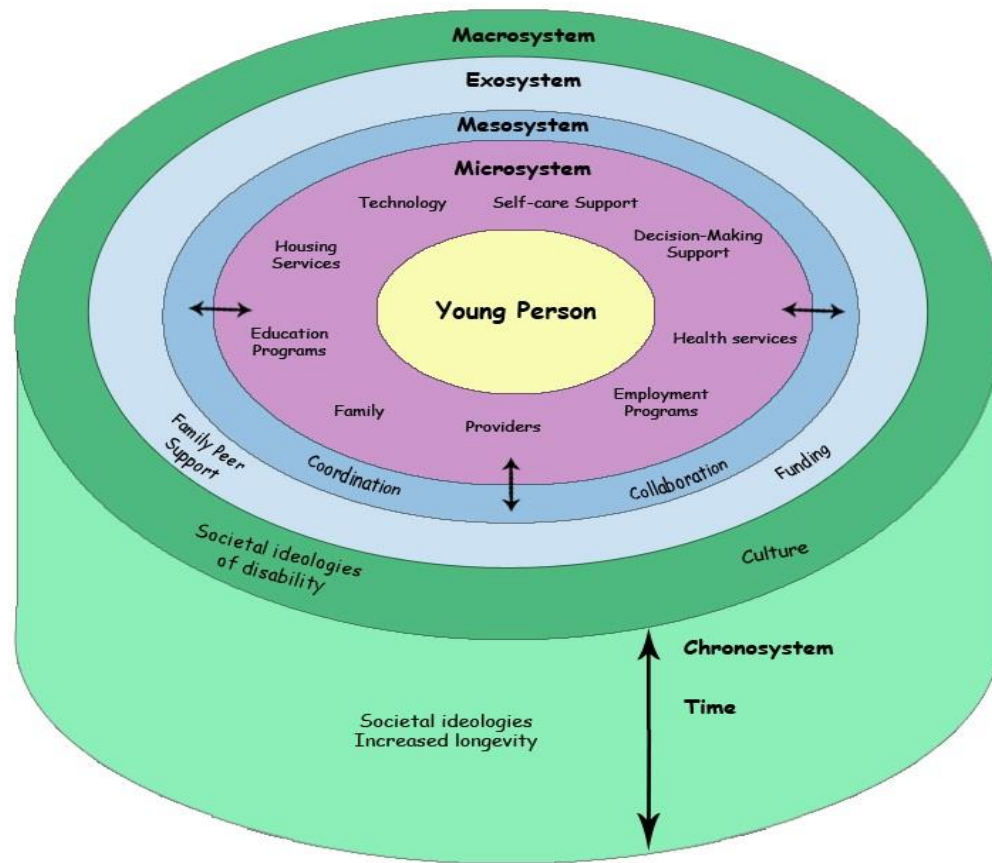


Figure 3: The context of young people with medical complexity based on the Bioecological Theory of Human Development. Adapted for this review from Bowes and Hayes (1997).

One area in which the findings of this review do not align with, or perhaps extend, the propositions of Bioecological Theory is that of microtime (continuity of proximal processes) and mesotime (periodicity of proximal processes over larger time intervals) (Bronfenbrenner, 2005). For young people with medical complexity, many proximal processes do not just facilitate the achievement of developmental outcomes. It appears that they must also be sustained for as long as the young person wants to maintain the level of independence or normalcy achieved through the initial proximal processes. For example, to be independent, young people required sustained interactions with caregivers in their microsystem to maintain a certain level of independence. If this interaction was to end, it is possible that these young people would not be able to maintain

independence.

In addition, the findings of this review can be examined from the perspective of a broader cultural and historical context using the concepts of the macrosystem and macrotime. In terms of cultural impacts on proximal processes as part of the macrosystem, only one study made mention of cultural differences. In Rehm et al. (2012), cultural differences existed in independent living and housing goals for young people and families of African American and Asian American descent in that the goals of young people were to continue to live at home with family support as opposed to moving away from their parents. It was interesting that cultural differences were not discussed in other studies; however, Rehm et al.'s study was an exceptionally large ethnographic study including participants with various cultural backgrounds. Other studies in this review involved participants with varied cultural backgrounds; however, the sample sizes may have been too small to determine any emerging themes related to culture. In addition, not every study discussed differences and contradictions in the findings. Overall, cultural issues are an important component of Bioecological Theory; however, there was a paucity of findings related to cultural impact on this issue in the studies in this review.

In terms of macrotime and historical context, it appears that, among all the studies in this review, some of the feelings of abandonment, uncertainty, and fear were a result of knowledge that young people and their parents were moving into a system not designed to meet their needs, especially related to health care and, to a lesser extent, independence, education, and employment. This particular finding can be placed in a broader historical context. Even one or two generations ago, children with medical complexity were not expected to survive into adulthood (Feudtner et al., 2001 as cited in Nageswaran, Ip, Golden, O'Shea, & Easterling, 2012). In addition, views of disability have changed substantially over the last two generations

and, I argue, the system has not kept up with the changes in ideologies. There has been a shift over the last several decades from a medical model of disability to a social model of disability in which participation is emphasized (Hayes & Hannold, 2007). Significant progress has been made in terms of encouraging participation in education, employment, and independent living; however, policy-makers and service providers have rarely considered the intricate needs of young people with medical complexity (Joly, 2014). In addition, it is unclear whether this could be further explained by societal views of ability to participate for young people with medical complexity. As a result, some of the findings of this review could be explained in light of the historical context of disability supports and survival rates of young people with medical complexity (see Figure 3).

Overall, Bioecological Theory aligns well with the findings of this review. Particularly, the themes it's like falling off a cliff and the paradox of independence demonstrate the importance of considering effective person-environment interactions that promote a healthy transition to adulthood. The findings did differ slightly from current conceptualizations of proximal processes in that dependence on the person-environment interactions would always be required for young people with medical complexity to maintain achievement of many developmental milestones. Despite this difference, Bioecological Theory provided a useful lens through which developmental transitions can be considered for this population.

Implications for Advanced Practice Nurses

It has become clear from the experiences of uncertainty, fragmentation, and paradox that many of these issues originate at the systems level and changes at this level are needed. This will be discussed further in the ethics and implications for policy section; however, system changes can take significant time to become reality. As a result, APNs must also consider how they can

work within the current system and help young people and their families to do the same. So if APNs cannot fix the system, what can be done at other levels to improve the experiences of young people with medical complexity and their parents?

Although the literature and many position statements break down the role of the APN in a plethora of different categories, these role attributes can be described in terms of clinical expertise, leadership, and scholarship. Clinical expertise involves advanced knowledge of specific specialties or theoretical perspectives attained through a combination of experience and graduate education (Canadian Nurses Association (CNA), 2014; National CNS Competency Task Force, 2010). APNs enact leadership through role modeling, mentoring, facilitating access to services, developing partnerships, and implementing change (CNA, 2008, 2014; Lyon, 2010). Finally, APNs can contribute to research and scholarship by generating new knowledge, critiquing or synthesizing existing research, or disseminating new knowledge and perspectives (CNA, 2008, 2014; National CNS Competency Task Force, 2010). Overall, the APN can utilize all three of these role attributes to improve the experiences of young people with medical complexity transitioning to adulthood.

Based on the results of this review, capacity-building should be one of the most important building blocks to success in the adult world. This can occur at the individual, community, or systems level; however, for the purpose of this project, I will focus on building individual capacity. Regardless of level, however, capacity-building interventions have potential to negate some of the feelings associated with the transition to adulthood. Stewart et al. (2013) advocate for a strengths-based capacity-building approach to transition preparation in which capacity is built on relationships and experience inherent in daily life. Furthermore, practice informed by Bioecological Theory can also serve to build capacity if interactions with the environment are

effective and experiences of young people and their parents are positive. By building capacity, APNs can provide the tools needed to be successful in the adult world. Not only does capacity-building fit with a developmental and person-centered approach, it also serves to negate some of the paradox of independence as the goal of this approach would be to make young people and their families as independent of the APN as possible.

APNs in pediatric and adult settings can provide interventions for capacity-building. In pediatrics, the focus should be on education on what to expect, goal setting, and beginning capacity-building including providing options to facilitate initial transition and skills to navigate the system. APNs in adult settings can also play a crucial role in facilitating successful transition to adulthood through continuing the process of capacity-building, building on self-advocacy skills, and educating young people, parents, and providers. Regardless of practice setting, APNs can use their expertise along with leadership and teaching abilities to take on the role of advocate, educator, or program developer.

APN as advocate. Advocacy is an important component of the APN role. The CNA (2014) defines advocacy as “actively supporting, protecting and safeguarding a client’s rights and interests; supporting others in speaking for themselves; or speaking on behalf of those who cannot speak for themselves” (p. 9). APNs can advocate for young people and their families in the areas of client-centered care, access to services, and human or material resource allocation to improve outcomes (CNA, 2014). Based on the findings of this review, the role of advocate as part of the village is one of the most important for the APN. The APN as advocate would be part of their village, help them find and access other parts of the village, and promote collaboration within the village. The role of advocate would be particularly ideal for APNs who have the expertise and level of education to understand the intricate developmental, health care, and

psychosocial needs of this population and consider the components of the village that will facilitate success in adulthood from a multidisciplinary perspective.

It should perhaps be made clear, however, that in suggesting the role of APN as advocate I am not implying that the APN does everything for young people and their parents. Ideally, the APN would work with young people and their parents to build capacity to navigate the adult system and self-advocate, slowly helping them become more independent of the APN. Eventually, the goal would be for the APN as advocate to be available as a consultant for young people and their parents for support and advocacy when needed. An important part of this process should also include providing options to young people and their parents to facilitate the development of self-advocacy and decision-making skills, which were identified by young people and parents as important in the transition to adulthood (Cook et al., 2013; Kingsnorth et al., 2011; Schultz, 2013).

APN as educator. The APN also has an important role in education of young people, their parents, and health care and service providers. As demonstrated in the findings of this review, knowledge has the potential to replace or decrease fear and uncertainty. Many of the feelings related to falling off the cliff were a result of lack of knowledge of the transition process and existing resources, confusion as to how to navigate the system, and lack of communication with and coordination between providers. As such, education might include what to expect in the abyss of the adult world, how to set reasonable and achievable goals, and how to navigate the adult system. This knowledge may not completely negate the feelings of fear and uncertainty as there will always be an element of change associated with the transition to adulthood; however, provision of this knowledge has the potential to reduce some of the negative feelings associated with transition.

As part of the collaborative team effort, young people and their parents articulated the importance of self-advocacy in becoming situated in the adult world (Cook et al., 2013; Davies et al., 2011; Young et al., 2009). It is important, though, to realize that ownership for education in this area must be taken by providers in all settings—it should not solely be the responsibility of pediatric APNs. Capacity and self-advocacy skills require building over time as situations change. Thus, self-advocacy should be an important educational focus for the APN in pediatric and adult settings.

In a recent concept analysis of self-advocacy in cancer survivors, Hagan and Donovan (2013) described antecedents and defining characteristics of self-advocacy. These antecedents, which are required for self-advocacy to occur, included (1) attitudes and beliefs of the individual, (2) learned skills such as navigating the system, communication, negotiation, information seeking, and problem solving, and (3) availability of supports (Hagan & Donovan, 2013). Characteristics of self-advocacy included thoughts and cognition (e.g. prioritizing, empowerment), actions for self, and utilization of resources (Hagan & Donovan, 2013). The extensive literature on the concept of and teaching self-advocacy in the area of special education supports the description of self-advocacy in this concept analysis (see for example Kleinert, Harrison, Fisher, & Kleinert, 2010; Test, Fowler, Brewer, & Wood, 2005).

Based on this description, in order to self-advocate, young people with medical complexity and their parents need to be self-aware and acquire the skills needed to navigate the system and communicate effectively with their village. They should also be able to participate as part of the team effort, problem-solve, and use existing resources. The APN could design evidence-based interventions based on the antecedents and characteristics of self-advocacy to support young people and their parents in acquiring these skills.

In addition to teaching self-advocacy skills to young people and their parents, the APN also has an important role in educating other health care professional and service providers in the adult world as to the complex and intricate needs of young people with medical complexity and their parents. Young people and their parents perceived a lack of adult provider knowledge and expertise as a barrier to a team effort (Cook et al., 2013; Davies et al., 2011; Sonneveld et al., 2012). All members of the village should have the knowledge to provide quality care and support to young people and their parents. As a result, APNs with expertise in caring for young people with medical complexity and their parents have a responsibility to build capacity of their colleagues and other professionals through education on the needs of this population. This could be accomplished through presentations at interdisciplinary conferences, guest lecturing in academic institutions, and publications in interdisciplinary academic journals. In addition, to reach front-line staff across sectors, APNs could design in-services for different provider groups across sectors.

Overall, APNs as educators have multiple roles in facilitating successful transition for young people with medical complexity. APNs are well-positioned to facilitate the acquisition of self-advocacy skills for young people and their families through the development, implementation, and evaluation of teaching interventions for self-advocacy. APNs also have the responsibility to advocate for these young people through providing education to other health care and service providers to negate some of the fear and uncertainty perceived by young people and their parents in the adult system.

Program development and evaluation. So far, I have discussed several distinct roles of the APN in supporting the transition to adulthood for young people with medical complexity. The findings of this review emphasize the complexity of transition for these young people and

demonstrate a need for more formalized multidisciplinary multi-sector collaborative programs to support the transition to adulthood.

The findings of this review suggest that transition programs for young people with medical complexity should take a holistic approach to include health care, independent living, education, employment or meaningful activities, housing, and finances. As described earlier in this discussion, providing resources in each of these categories may not be enough. As a result, these programs should also include components such as support groups (e.g. Kingsnorth et al., 2011), capacity-building interventions, and self-advocacy interventions. Finally, a multidisciplinary and multi-sector collaborative approach to transition also has potential to improve the transition process as young people and their parents were often concerned about lack of communication and coordination during and after transition (Davies et al., 2011; Sonneveld et al., 2012; Young et al., 2009). Since it takes a village to transition to adulthood and become situated in the adult world, the APN cannot hope to do this alone; however, APNs can develop and lead such programs by virtue of their leadership skills and breadth of knowledge and expertise.

Regardless of the specific role of the APN as self-advocate, educator, or program developer, the use of technology can also play a role in facilitating successful transition. First, communication between providers can be improved through use of electronic medical record systems such as Epic for documentation and communication between subspecialty providers and services in different settings. In addition, several parents suggested the development of websites or databases to facilitate access to information about resources in the adult system (Schultz, 2013). The development of a website for use by young people and their families would need to be regional in nature since services are different region-to-region or county-to-county. An APN

at Shriners Hospital for Children in Portland, Oregon has developed a large transition resource listing using a concept mapping program (FreeMind©) that lists resources across sectors for Oregon, Washington, Idaho, Alaska, British Columbia, and Russia (Labhard, 2010). Although this resource is not readily accessible to young people or their parents, the APN and care coordinators within the hospital have access to this resource and can use it to provide options for young people and their families for resources in the adult system. It is also possible that such a program could be modified and implemented for young people and their parents to access.

An additional consideration for APNs when developing transition programs involves program evaluation. Two of the studies in this review were evaluations: one was a qualitative evaluation of a parent peer support group in Ontario, Canada; the other was a secondary analysis of data from a survey-based evaluation study of a transition program in the Netherlands. In these studies, a specific intervention or component of the program was evaluated.

Other evaluation studies of transition programs focused on other populations have been published in peer-reviewed journals (e.g. Chaudhry, Keaton, & Nasr, 2013; Jurasek, Ray, & Quigley, 2010); however, the methods employed and outcomes evaluated in these studies were as varied as the programs themselves. Outcomes in these studies were often assessed using questionnaires soon after transfer to adult care and focused on satisfaction, diagnosis-specific knowledge, perceived health, and independence. In addition, a research team at Bloorview Research Institute in Ontario, Canada has set out to complete a first-of-its-kind prospective longitudinal mixed methods evaluation of a transition program for adolescents with Spina Bifida, Cerebral Palsy, and Acquired Brain Injury of Childhood (Tsybina et al., 2013). The results of and lessons learned from the evaluation study described in Tsybina et al. (2013) have potential to inform APNs as to future directions in evaluation of transition programs.

Despite varied attempts at evaluation, these evaluations often exclude those who are involved in the program and do not take into account complex contexts. Several other approaches to evaluation, such as participatory or developmental evaluation, may have utility for transition programs and services. In particular, I believe participatory approaches have great potential as such approaches are geared toward social change, empower and give a voice to those involved, and can build capacity (Hills & Mullett, 2000). For example, Wynn, Stewart, Law, Burke-Gaffney, and Moning (2006) used a participatory approach to develop and evaluate a capacity-building intervention for youth with disabilities and their parents. Overall, the continued challenge for the APN would be to determine what defines success for the young people who participate in the program and, as a result, what should be evaluated and how.

In summary, APNs in pediatric and adult settings can take on the role of advocate, educator, or program developer with the goal of improving the transition process and outcomes for young people and their parents. APN interventions should not be focused only on *doing for*. Instead, APNs should focus on building capacity and self-advocacy skills to enable young people and their parents to navigate the system to the best of their abilities while providing support during and after transition to improve long-term outcomes.

Ethics and Implications for Policy

As previously mentioned, systems issues appear to be at the heart of the experiences of young people with medical complexity and their parents. In discussing implications for APNs, I described how APNs can help young people and parents work within the current system; however, APNs such as clinical nurse specialists should play a key role in systems leadership (CNA, 2014). The CNA (2014) defines systems leadership as including “the ability to manage change and influence clinical practice and political processes both within and across systems” (p.

6). APNs can accomplish this through advocacy for and promotion of access to services (CNA, 2014). The findings of this review demonstrate a need for systems leadership for change to address the negative experiences of young people and their parents. In this section, I will discuss some of the ethical concerns inherent in the findings of this review and the implications for policy.

Young people and their parents experienced issues with access to appropriate services in a system that is not designed to meet their needs. If these young people and their parents cannot access appropriate services, inequities in access are created and, in turn, lead to inequities in health (Joly, 2014). This represents an ethical concern in that young people and their families have the same rights to appropriate health care, education, independence, and other services as anyone else, yet the system is not set up to address the needs of this population. Therefore, changes at the organizational and systems policy levels are necessary.

The findings of this review suggest several areas of potential improvement at the policy level. First, policy is needed that acknowledges the increasing complexity of the needs of young people transitioning to adulthood. It appears that with all of the advances in technology and the focus on keeping children alive, few have considered the broader systems impacts for the future. For example, the complexities of health care needs of these young people can be addressed by developing organizational policy that promotes integrated multidisciplinary clinics and services in the adult system. As a result, policy should reflect the complexities of the biopsychosocial needs of this population.

In addition, policy is needed that promotes collaboration and communication between sectors, considers the needs of young people and their parents across sectors, and provides the resources to improve access to appropriate services in all sectors. There has been an increasingly

strong push for the adoption of systems thinking perspectives and complexity theory to inform policy development related to health care transition (Hamdani et al., 2011). Such perspectives could also be useful in informing policy that will encourage collaboration and communication across sectors. Not only can such policies help address some of the issues with collaboration and communication, they also have the potential to bring greater visibility to potential areas for intervention in all sectors and the impact of policy changes across sectors.

Overall, the findings of this review suggest that systems improvements are necessary. APNs can improve outcomes and help reduce inequities in access to services through advocacy and leadership at the organizational and systems levels and through knowledge translation activities geared towards changing thinking about the needs of this population. Involving young people and their parents in such initiatives may also provide additional strength to the collective voice required for change.

Recommendations for Future Research

Through this integrative review, I have described the experiences of young people with medical complexity and their parents during the transition to adulthood and identified gaps in knowledge and practice related to this process. From this analysis, two areas for future research have emerged: gaps in knowledge of the transition experience and development of effective programs, models, and interventions.

I have identified multiple gaps in the findings of this review that require further exploration. Social support and social environments in terms of social activities, friendships, relationships, and sexuality are important developmentally and as social determinants of health (Public Health Agency of Canada, 2013; Rosen et al., 2003), but were rarely discussed in the studies in this review. One parent involved in Rehm et al.'s (2012) study suggested that schools

should improve education about sexuality especially for young people with developmental disabilities; however, there is a significant gap related to friendships, relationships, and sexuality in the other studies in this review. As a result, additional research is needed to understand these psychosocial needs.

Other important components of development and determinants of health, although discussed in some studies, require further exploration. For example, aside from the insights gained from several studies about meso and macro level issues, it remains unclear how young people with medical complexity experience education, employment, and social activities in the adult system. In addition, continued parent involvement as a caregiver for young adults with severe disabilities was rarely discussed. Many young people with medical complexity will continue to require support in adulthood due to their functional limitations and complex needs (Cohen et al., 2011). As a result, support should include considerations for future planning such as guardianship and personal support. This represents a gap in the literature in terms of considerations of future planning for this population and a need for additional research.

Furthermore, other than in the two evaluation studies included in this review, young people and their parents did not mention receiving any formal transition preparation, which is interesting considering the increased push for the development of formalized transition programs in recent years. As a result, the experiences of young people and their parents who had formal transition preparation were underrepresented in this review, representing a need for additional research. Finally, the concept of paradox as it relates to independence and a normal life requires additional exploration, as this concept has only been described superficially in a few studies related to this population (Cook, 2013; Freyer, 2004). Overall, there are many areas for future research related to gaps in the findings of this review.

The findings of this review also led to suggestions for specific roles for APNs as part of the team effort before, during, and after initial transition. In an earlier section, I propose the role of APN as advocate. Although APN competency documents support advocacy roles for APNs, the role of APN as advocate in the adult system for this population is scarce. As a result, additional research into the potential effectiveness for this particular role in the adult system is required.

Over the last five years, many children's hospitals have pushed to develop and implement transition programs; however, many existing programs and models have not been empirically tested for effectiveness (Betz, 2013; Grant & Pan, 2011). Program development was an important recommendation for practice resulting from the findings of this review. As a result, an accompanying recommendation for research involves developing and testing models of care and transition programs, including specific interventions that have the potential to support building capacity and self-advocacy skills.

There is potential for research across paradigms to develop knowledge related to the transition to adulthood. It may be useful for researchers to explore the potential of participatory action research in the development and testing of effective transition strategies. Not only could such research be beneficial in bringing about the system changes that are required to improve transition experiences, it also has potential to increase self-awareness and self-advocacy skills in young people and parents who participate in such research—a notion supported by CanChild's Best Journey to Adulthood Best Practice Guidelines (Stewart et al., 2009). Overall, considering the findings of this review alongside implications for practice and policy, additional research is needed to develop knowledge to inform nurses and APNs who support young people with medical complexity during and after the transition to adulthood.

Limitations

There are several limitations to this review, which can be attributed to methodology or gaps in the existing literature. There are several methodological weaknesses of integrative literature reviews in general. Most notably, there is a certain complexity to combining quantitative and qualitative literature in terms of data evaluation and data analysis. Specific methods for data evaluation and data analysis for integrative reviews are not well-developed, which can lead to bias or error in the results of the review, especially if methods and decisions are not explicitly described (Mallidou, 2014; Whitemore & Knafl, 2005).

In addition, search strategies should, ideally, be comprehensive with explicit inclusion criteria and search strategies (Whitemore & Knafl, 2005). Although I explicitly defined my inclusion criteria, searched two online databases, and completed an ancestry search, it is still possible that my collection of retrieved primary sources was incomplete due to the nature of my population of focus. Unlike many reviews that define population of focus based on diagnosis or setting, I defined my population based on a definitional framework that is broad and based on severity and functional limitations rather than diagnosis. Therefore, it is possible that despite the extensive amount of time spent determining key terms for the search strategy some articles did not fall under any of the key term categories I defined. In addition, by using 25% as a cut-off for inclusion based on participant characteristics, some findings may have emerged due to inclusion of perspectives of young people without medical complexity. Despite this possibility, findings drawn from studies with more varied participant characteristics were generally consistent with studies that included higher proportions of young people with medical complexity.

There were also limitations in terms of the characteristics and content of the retrieved articles. First, most included articles were strongly system-focused in that participants either

described or were prompted to describe their experiences of service-delivery transitions, especially in the health care system. In addition, although four retrieved articles described provider perspectives, I did not include these perspectives in this review due to limitations identified during the literature search and data evaluation stages of the review. These perspectives could provide additional insight into some of the systems issues that were at the forefront of this review. Finally, although authors generally reported the gender of participants and some authors reported sociodemographic data related to culture, they did not discuss transition experiences in the context of gender or culture, except briefly in one study. As a result, the findings of this review cannot be interpreted in the context of gender or culture.

Conclusion

In conclusion, the transition to adulthood for young people with medical complexity is complicated by their complex chronic conditions and high health care and service needs. With technological advances, these young people are living longer and will most likely continue to require significant support in adulthood. Through this integrative literature review, I found that young people with medical complexity and their parents have significant transition needs that are not always met. For these young people, independence, regardless of definition, necessitates dependence on a variety of individuals and services. It takes a village to facilitate independence and maintain young people's health and quality of life in adulthood. It was clear, however, that a gap exists between how young people and their parents experience the transition to adulthood and what they believed would facilitate success.

The findings of this review also demonstrate the applicability of Transition Theory and Bioecological Theory for APNs working with young people with medical complexity in transition. The findings of this review combined with these theoretical perspectives provided

support for the proposal of several roles for APNs in the pediatric and adult systems: APN as advocate, APN as educator, and program development and evaluation. In addition, many of the issues identified in this review require intervention at an organizational or policy level. Although the findings of this review provide background for APNs working with young people with medical complexity, additional research is needed on psychosocial needs and determinants of health, parent caregiving needs, and program development and evaluation. Finally, several proposed ideas in this review need further exploration: the paradox of independence and the role of APN as advocate. Overall, the field of transition to adulthood for young people with medical complexity is still in its infancy and is an area in which nurses can provide leadership and knowledge development moving forward.

References

- Betz, C. L. (2007). Facilitating the transition of adolescents with developmental disabilities: Nursing practice issues and care. *Journal of Pediatric Nursing*, 22(2), 103-115.
doi:10.1016/j.pedn.2006.07.006
- Betz, C. L. (2013). Health care transition for adolescents with special healthcare needs: Where is nursing? *Nursing Outlook*, 61(5), 258-265. doi:10.1016/j.outlook.2012.08.009
- Betz, C. L., Lobo, M. L., Nehring, W. M., & Bui, K. (2013). Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook*, 61, 311-336. doi:10.1016/j.outlook.2013.01.008
- Blomquist, K.B. (2007). Health and independence of young adults with disabilities: Two years later. *Orthopedic Nursing*, 26, 296–309. doi: 10.1097/01.NOR.0000295957.71579.48
- Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, 14, 570-576. Retrieved from <http://www.sciencedirect.com.ezproxy.library.uvic.ca/science/article/pii/S1054139X9390143D>
- Blum, R.W., Kelly, A., & Ireland, M. (2001). Health-risk behaviors and protective factors among adolescents with mobility impairments and learning and emotional disabilities. *Journal of Adolescent Health*, 28, 481–490. 10.1016/S1054-139X(01)00201-4
- Bowes, J. M., & Hayes, A. (Eds.). (1997). *Children, families, and communities: Contexts and consequences*. South Melbourne: Oxford University Press.
- Bridges, W. (1991). *Managing transitions: Making the most of change*. Menlo Park, CA: Addison Wesley.

- Bronfenbrenner, U. (1994). Ecological models of human development. In M. Gauvain & M. Cole (Eds.), *Readings on the development of children*, (2nd ed, pp. 37-43). New York: Freeman. Retrieved from <http://www.psy.cmu.edu/~siegle/35bronfenbrenner94.pdf>
- Bronfenbrenner, U. (2005). The bioecological theory of human development. In U. Bronfenbrenner (Ed.), *Making human beings human: Bioecological perspectives on human development* (pp. 3-15). Thousand Oaks, CA: Sage Publications.
- Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner (Ed.), *Handbook of child development: Vol. 1. Theoretical models of human development* (6th ed., pp. 793-828). Hoboken, NJ: Wiley.
- Brown, A., Katherine, W., Allen, K., Quach, U., Chiu, E., & Bialystok, L. (2010). Turning the social determinants of health to our advantage: Policy fundamentals for a better approach to children's health. *Healthcare Quarterly*, 14, (Special Issue October), 69 – 75.
doi:10.12927/hcq.2010.21985
- Camfield, P., & Camfield, C. (2011). Transition to adult care for children with chronic neurological disorders. *Annals of Neurology*, 69(3), 437-444. doi: 10.1002/ana.22393.
- Canadian Nurses Association (CNA). (2008). Advanced practice nursing: A national framework. *Canadian Nurses Association*. Retrieved from http://www2.cnaaiic.ca/CNA/documents/pdf/publications/ANP_National_Framework_e.pdf
- Canadian Nurses Association (CNA). (2014). Pan-Canadian core competencies for clinical nurse specialists. *Canadian Nurses Association*. Retrieved from http://cna-aiic.ca/~media/cna/files/en/clinical_nurse_specialists_convention_handout_e.pdf
- Caton, S., & Kagan, C. (2007). Comparing transition expectations of young people with

- moderate learning disabilities with other vulnerable youth and with their non-disabled counterparts. *Disability and Society*, 22(5), 473-88. doi: 10.1080/09687590701427586
- Chaudhry, S. R., Keaton, M., & Nasr, S. Z. (2013). Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatric Pulmonology*, 48, 658-665. doi: 10.1002/ppul.22647
- Cohen, E., Kuo, D. Z., Agrawal, R., Berry, J. G., Bhagat, S. K. M., Simon, T. D., & Srivastava, R. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*, 127(3), 529-538. doi: 10.1542/peds.2010-0910
- Cohen, E., Berry, J. G., Camacho, X., Anderson, G., Wodchis, W., & Guttman, A. (2012). Patterns and costs of health care use of children with medical complexity. *Pediatrics*, 130, e1463-e1470. doi: 10.1542/peds.2012-0175.
- Cook, K. (2013). *Experiences of young adults with pediatric life threatening conditions transitioning from pediatric to adult services: A case study*. (Unpublished doctoral dissertation, McMaster University). Retrieved from <https://macsphere.mcmaster.ca/handle/11375/13337>
- Cook, K., Siden, H., Jack, S., Thabane, L., & Browne, G. (2013). Up against the system: A case study of young adult perspectives transitioning from pediatric palliative care. *Nursing Research and Practice*, 2013, 1-10. doi: 10.1155/2013/286751
- Currie, C., Zanotti, C., Morgan, A., Currie, C., de Looze, M., Roberts, C., ..., Banekow, V. (Eds.). (2012). *Social determinants of health and well-being among young people. Health behaviour in school-aged children (HBSC) study: International report from the 2009/2010 survey*. Copenhagen: WHO Regional Office for Europe. Retrieved from

- http://www.euro.who.int/__data/assets/pdf_file/0003/163857/Social-determinants-of-health-and-well-being-among-young-people.pdf
- Darling, N. (2007). Ecological systems theory: The person in the center of the circles. *Research in Human Development, 4*(3-4), 203-217. Retrieved from [http://www.uamont.edu/facultyweb/brown/PSY4683/Darling\(2007\).pdf](http://www.uamont.edu/facultyweb/brown/PSY4683/Darling(2007).pdf)
- Doug, M., Adi, Y., Paul, M., Kelly, D., Petchey, R., & Carter, Y. (2011). Transition to adult services for children and young people with palliative care needs: A systematic review. *Archives of Disease in Childhood, 96*, 78-84. doi: 10.1136/adc.2009.163931
- Davies, H., Rennick, J., & Majnemer, A. (2011). Transition from pediatric to adult health care for young adults with neurological disorders: Parental perspectives. *Canadian Journal of Neuroscience Nursing, 33*(2), 32-39. Retrieved from <http://web.ebscohost.com.ezproxy.library.uvic.ca/ehost/pdfviewer/pdfviewer?sid=84297013-dbbb-4f29-a771-3086ad186043%40sessionmgr15&vid=2&hid=24>
- Fegran, L., Hall, E. O. C., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: A qualitative metasynthesis. *International Journal of Nursing Studies, 51*, 123-135. doi: 10.1016/j.ijnurstu.2013.02.001
- Feudtner, C., Hays, R. M., Geyer, J. R., Neff, J. M., & Koepsell, T. D. (2001). Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services. *Pediatrics, 107*(6), e99. doi: 10.1542/peds.107.6.e99.
- Freyer, D. (2004). Care of the dying adolescent: Special considerations. *Pediatrics, 113*, 381-388. doi: 10.1542/peds/113/2/381
- Gorter, J.W., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: Care, health and

- development. *Child: Care, Health and Development*, 37, 757–763. doi:10.1111/j.1365-2214.2011.01336.x
- Grant, C., & Pan, J. (2011). A comparison of five transition programmes for youth with chronic illness in Canada. *Child: Care Health and Development*, 37, 815-820. doi:10.1111/j.1365-2214.2011.01322.x
- Hagan, T. L., & Donovan, H. S. (2013). Self-advocacy and cancer: A concept analysis. *Journal of Advanced Nursing*, 69(10), 2348–2359. doi: 10.1111/jan.12084
- Hamdani, Y., Jetha, A., & Norman, C. (2011). Systems thinking perspectives applied to healthcare transition for youth with disabilities: A paradigm shift for practice, policy and research. *Child: Care Health and Development*, 37, 806-814. doi:10.1111/j.1365-2214.2011.01313.x
- Hanson, M.J. (2003). Twenty-five years after early intervention: A follow-up of children with Down Syndrome and their families. *Infants & Young Children*, 16(4), 354–365. Retrieved from <http://cehs.unl.edu/ecse/960/Hanson.pdf>
- Hayes, J. & Hannold, E. M. (2007). The road to empowerment: A historical perspective on the medicalization of disability. *Journal of Health and Human Services Administration*, 30(3), 352-377. Retrieved from <http://www.jstor.org/stable/25790713> .
- Hills, M., & Mullett, J. (2000). *Community-based research: creating evidence-based practice for health and social change*. Victoria, BC: University of Victoria, Community Health Promotion Coalition. Retrieved from <http://moodle.uvic.ca/>
- Im, E. (2010). Transition theory. In M. R. Alligood & A. M. Tomey (Eds.), *Nursing theorists and their work* (7th ed., pp. 416-433). Maryland Heights, MO: Elsevier.
- Jedeloo, S., van Staa, A., Latour, J. M., & van Exel, N. J. (2010). Preferences for health care and

- self-management among Dutch adolescents with chronic conditions: A Q-methodological investigation. *International Journal of Nursing Studies*, 47, 593-603. doi: 10.1016/j.ijnurstu.2009.10.006
- Joly, E. (2014). *Access to services for young adults with medical complexity: An ethical analysis from a social justice perspective*. [submitted for consideration for Nursing Ethics student essay prize]
- Jurasek, L., Ray, L., Quigley, D. (2010). Development and implementation of an adolescent epilepsy transition clinic. *Journal of Neuroscience Nursing*, 42(4), 181-189. doi: 10.1097/JNN.0b013e3181e26be6
- Kaufman, M., & Pinzon, J. (2007). Transition to adult care for youth with special health care needs. *Pediatrics and Child Health*, 12, 758 - 788. Retrieved from <http://www.cps.ca/documents/position/transition-youth-special-needs>
- Kelly, A. M., Kratz, B., Bielski, M., & Rinehart, R. M. (2002). Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics*, 110(6), 1322-1327. Retrieved from http://pediatrics.aappublications.org/content/110/Supplement_3/1322.full.pdf
- Kingsnorth, S. Gall, C., Beayni, S., & Rigby, P. (2011). Parents as transition experts? Qualitative findings of a pilot parent-led peer support model. *Child Care Health and Development*, 37(6), 833-840. doi: 10.1111/j.1365-2214.2011.01294.x
- Kirk, S. (2008). Transitions in the lives of young people with complex healthcare needs. *Child Care Health and Development*, 34(5), 567-575. doi:10.1111/j.1365-2214.2008.00862.x
- Kirk, S., & Fraser, C. (2014). Hospice support and the transition to adult services and adulthood

- for young people with life-limiting conditions and their families: A qualitative study. *Palliative Medicine*, 28(4), 342-352. doi: 10.1177/0269216313507626.
- Kirkevold, M. (1997). Integrative nursing research: An important strategy to further the development of nursing science and nursing practice. *Journal of Advanced Nursing*, 25, 977–984. doi: 10.1046/j.1365-2648.1997.1997025977.x
- Kleinert, J. O., Harrison, E. M., Fisher, T. L., & Kleinert, H. L. (2010). "I can" and "I did": Self-advocacy for young students with developmental disabilities. *TEACHING Exceptional Children*, 43(2), 16-26, Retrieved from <http://www-tep.ucsd.edu/about/Courses/EDS382/EDS%20382%20Class%204/I%20Can%20and%20I%20Did-Sel.pdf>
- Kraus de Camargo, O. (2011). Systems of care: Transitions from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health. *Child: Care, Health and Development*, 37, 792 – 799. doi:10.1111/j.1365-2214.2011.01323.x
- Labhard, S. (2010). Transitioning to adulthood with disabilities: A holistic approach. *Topics in Spinal Cord Injury Rehabilitation*, 16(1), 1-16. doi: 10.1310/sci1601-1
- LoBiondo-Wood, G., & Haber, J. (Eds.). (2013). *Nursing research in Canada: Methods, critical appraisal, and utilization* (3rd ed.). Toronto: Elsevier.
- Lyon, B. L. (2010). Transformational leadership as the clinical nurse specialist's capacity to influence. In J. S. Fulton, B. L. Lyon, & K. A. Goudreau (Eds.), *Foundations of clinical nurse specialist practice* (pp. 149-157). New York, NY: Springer Publishing Company.
- Magill-Evans, J., Wiart, L., Darrah, J., & Kratochvil, M. (2005). Beginning the transition to adulthood: The experiences of six families of youth with cerebral palsy. *Physical and Occupational Therapy in Pediatrics*, 25(3), 19-36. doi:10.1300/J006v25n03_03
- Mallidou, A. A. (2014). Mapping the landscape of knowledge synthesis. *Nursing Management*

- (UK), 21(5), 30-39. doi: 10.7748/nm.21.5.30.e1242
- Meleis, A.I., & Trangenstein, P.A. (1994). Facilitating transitions: Redefinition of the nursing mission. *Nursing Outlook*, 42, 255-259. doi: 10.1016/0029-6554(94)90045-0
- Meleis, A. I., Sawyer, L. M., Im, E., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, 23(1), 12-28. doi: 10.1097/00012272-200009000-00006
- Mesman, G. R., Kuo, D. Z., Carroll, J. L., & Ward, W. L. (2013). The impact of technology dependence on children and their families. *Journal of Pediatric Health Care*, 27(6), 451-459. doi: 10.1016/j.pedhc.2012.05.003
- Miles, M. S. & Holditch-Davis, D. (2003). Enhancing nursing research with children and families using a developmental science perspective. *Annual Review of Nursing Research*, 21(1), 1-20. Retrieved from <http://www.ingentaconnect.com/content/springer/arnr/2003/00000021/00000001/art00002>
- Moons, P., Pinxten, S., Dedroog, D., Van Deyk, K., Gewillig, M., Hilderson, D., & Budts, W. (2009). Expectations and experiences of adolescents with congenital heart disease on being transferred from pediatric cardiology to an adult congenital heart disease program. *Journal of Adolescent Health*, 44(4), 316–322. doi: 10.1016/j.jadohealth.2008.11.007
- Nageswaran, S., Ip, E. H., Golden, S. L., O'Shea, T. M., & Easterling, D. (2012). Inter-agency collaboration in the care of children with complex chronic conditions. *Academic Pediatrics*, 12(3), 189-197. doi: 10.1016/j.acap.2012.02.007
- National CNS Competency Task Force. (2010). Clinical Nurse Specialist: Core Competencies. *National Association of Clinical Nurse Specialists*. Retrieved from <http://www.nacns.org/docs/CNSCoreCompetenciesBroch.pdf>

- Pinzon, J., & Harvey, J. (2006). Care of adolescents with chronic conditions. *Pediatrics and Child Health, 11*, 43-48. Retrieved from <http://www.cps.ca/documents/position/care-of-youth-chronic-conditions>
- Public Health Agency of Canada (2013). *What makes Canadian's healthy or unhealthy?* Ottawa: Public Health Agency of Canada. Retrieved from <http://www.phac-aspc.gc.ca/phsp/determinants/determinants-eng.php>
- Registered Nurses' Association of Ontario. (2014). *Care transitions*. Toronto, ON: Registered Nurses' Association of Ontario. Retrieved from http://rnao.ca/sites/rnao-ca/files/Care_Transitions_BPG.pdf
- Rehm, R. S., Fuentes-Afflick, E., Fisher, L. T., & Chesla, C. A. (2012). Parent and youth priorities during the transition to adulthood for youth with special health care needs and developmental disability. *Advances in Nursing Science, 35*(3), E57-E72. doi: 10.1097/ANS.0b013e3182626180
- Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics, 115*(1), 112-120. doi:10.1542/peds.2004-1321
- Ridosh, M., Braun, P., Roux, G., Bellin, M., & Sawin, K. (2011). Transition in young adults with spina bifida: A qualitative study. *Child: Care, Health and Development, 37*(6), 866-874. doi: 10.1111/j.1365.2214.2011.01329.x
- Rosen, D. S. (2004). Transition of young people with respiratory diseases to adulthood. *Pediatric Respiratory Reviews, 5*, 124-131. doi:10.1016/j.prrv.2004.01.008
- Rosen, D. S., Blum, R. W., Britto, M., Sawyer, S. M., & Siegel, D. M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions. *Journal of Adolescent Health, 33*(4), 309-311. doi:10.1016/S1054-139X(03)00208-8

- Sawyer, S. M., Drew, S., Yeo, M. S., & Britto, M. T. (2007). Adolescents with a chronic condition: Challenges living, challenges treating. *Lancet*, 369, 1481-1489. doi:10.1016/S0140-6736(07)60370-5
- Sawyer, S. M., & MacNee, S. (2010). Transition to adult health care for adolescents with spina bifida: Research issues. *Developmental Disabilities Research Reviews*, 16, 60-65. doi: 10.1002/ddrr.98
- Schultz, R. J. (2013). Parental experiences transitioning their adolescent with epilepsy and cognitive impairments to adult health care. *Journal of Pediatric Health Care*, 27(5), 359-366. doi: 10.1016/j.pedhc.2012.03.004
- Schumacher, K. L., & Meleis, A. I. (1994). Transitions: A central concept to nursing. *Journal of Nursing Scholarship*, 26(2), 119-127. doi: 10.1111/j.1547-5069.1994.tb00929.x
- Soanes, C., & Timmons, S. (2004). Improving transition: A qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *Journal of Child Health Care*, 8(2), 102-112. doi: 10.1177/1367493504041868
- Sonneveld, H. M., Stratling, M. M. H., van Staa, A. L., & Neiboer, A. P. (2012). Gaps in transition care: What are the perceptions of adolescents, parents, and providers? *Child Care Health and Development*, 39(1), 69-80. doi: 10.1111/j.1365-2214.2011.01354.x
- Stam, H., Hartman, E. E., Deurloo, J. A., Groothoff, J., & Grootenguis, M. A. (2006). Young adult patients with a history of pediatric disease: Impact on course of life and transition into adulthood. *Journal of Adolescent Health*, 39, 4-13. doi: 10.1016/j.jadohealth.2005.03.011
- Statistics Canada. (2013). *Disability in Canada: A 2006 profile*. Retrieved from http://www.esdc.gc.ca/eng/disability/arc/disability_2006.shtml

Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, N....Guenther, S.

(2009). *“The Best Journey to Adult Life” for youth with disabilities: An evidence-based model and best practice guidelines for the transition to adulthood for youth with disabilities*. Hamilton, ON: CanChild. Retrieved from

http://transitions.canchild.ca/en/OurResearch/bestpractices.asp?_mid_=2594

Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, N....Guenther, S.

(2010). The transition to adulthood for youth with disabilities: Evidence from the literature. In J. H. Stone, & M. Blouin (Eds.), *International Encyclopedia of Rehabilitation*. Retrieved from <http://cirrie.buffalo.edu/encyclopedia/en/article/110/>

Stewart, D., Gorter, J. W., & Freeman, M. (2013). Transitions to adulthood for youth with disabilities: Emerging themes for practice and research. *The Prevention Researcher*, 20(2), 3-6. Retrieved from http://www.tpronline.org/article.cfm/Transitions_to_Adulthood_for_Youth_with_Disabilities

Test, D. W., Fowler, C. H., Brewer, D. M., & Wood, W. M. (2005). A content and methodological review of self-advocacy intervention studies. *Exceptional Children*, 72(1), 101-125. doi: 10.1177/001440290507200106

Tsybina, I., Kingsnorth, S., Maxwell, J., Bayley, M., Lindsay, S., McKeever, P., ..., Macarthur, C. (2013). Longitudinal Evaluation of Transition Services (“LETS Study”): Protocol for outcome evaluation. *BMC Pediatrics*, 12, 51. doi:10.1186/1471-2431-12-51

Tuchman, L. K., Slap, G. B., & Britto, M. T. (2008). Transition to adult care: Experiences and expectations of adolescents with a chronic illness. *Child: Care, Health & Development*, 34(5), 557–563. doi: 10.1111/j.1365-2214.2008.00844.x.

van Staa, A., van der Stege, H. A., Jedeloo, S., Moll, H. A., & Hilberink, S. R. (2011). Readiness

- to transfer to adult care of adolescents with chronic conditions: Exploration of associated factors. *Journal of Adolescent Health*, 48, 295-302. doi: 10.1016/j.jadohealth.2010.07.009
- Wallis, C., Paton, J. Y., Beaton, S., Jardine, E. (2011). Children on long term ventilatory support: 10 years of progress. *Archives of Disease in Childhood*, 96(11), 998-1002. doi: 10.1136/adc.2010.192864.
- Wang, G., McGrath, B. B., Watts, C. (2010). Health care transitions among youth with disabilities or special health care needs (SHCN): An ecological approach. *Journal of Pediatric Nursing*, 25(6), 505-550. doi: 10.1016/j.pedn.2009.07.003.
- Wiener, L. S., Kohrt, B. A., Battles, H. B., & Pao, M. (2009). The HIV experience: Youth identified barriers for transitioning from pediatric to adult care. *Journal of Pediatric Psychology*, 36(2), 141-154. doi: 10.1093/jpepsy/jsp129
- Whittemore, R. & Knafl, K. (2005). The integrative literature review: Updated methodology. *Journal of Advanced Nursing*, 52(2), 546-553. doi: 10.1111/j.1365-2648.2005.03621.x
- Wynn, K., Stewart, D., Law, M., Burke-Gaffney, J., & Moning, T. (2006). Creating connections: A community capacity-building project with parents and youth with disabilities in transition to adulthood. *Physical and Occupational Therapy in Pediatrics*, 26(4), 89-103. doi: 10.1080/J006v26n04_06
- Wong, L. H., Chan, F. W., Wong, F. Y., Wong, E. L., Huen, K. F., Yeoh, E. K., & Fok, T. F. (2010). Transition care for adolescents and families with chronic illnesses. *Journal of Adolescent Health*, 47, 540-546. doi: 10.1016/j.jadohealth
- Young, N. L., Barden, W. S., Mills, W. A., Burke, T. A., Law, M., & Boydell, K. (2009).

Transition to adult-oriented health care: Perspectives of youth and adults with complex physical disabilities. *Physical and Occupational Therapy in Pediatrics*, 29(4), 345-361.
doi: 10.3109/01942630903245994

Appendix A: Inclusion Criteria

<u>Criterion</u>	<u>Description</u>
Medical Complexity-Complex Chronic Condition	<p>1) <i>Severe Neurological Impairments</i>: Brain tumors; congenital brain anomalies; chromosomal anomaly; other genetic syndromes (eg, Rett syndrome, tuberous sclerosis, etc); acquired brain injury; neurodegenerative metabolic disease; hypoxic ischemic encephalopathy; cerebral palsy with global developmental delay; etc.</p> <p>2) <i>Multiple Congenital Anomalies</i>: Chromosomal anomalies; skeletal dysplasias; overgrowth syndromes; storage disorders; congenital muscle or connective tissue disorders; sequences; associations; teratogens; unknown; etc.</p> <p>3) <i>Complex Congenital Heart Defect</i>: Hypoplastic left heart syndrome; double-inlet left ventricle, other congenital heart diseases; heart transplantation; etc</p> <p>4) <i>Severe Autism or Autistic Tendencies</i>: may be associated with other conditions such as tuberous sclerosis, Rett syndrome, or other neurological disorders.</p>
Medical Complexity-Functional Limitations	<p>1) <i>Developmental Disability</i>: delays in motor skills and issues with mobility, often requiring wheelchair support; verbal or nonverbal, some dependent on assistive technology; variable feeding abilities but often requiring modifications; variable social delays, but often present as integration can be challenging</p> <p>2) <i>Technology Dependence</i>: Enterostomy tubes; suction machines; tracheostomy tubes; ventriculoperitoneal shunts; feeding pumps; home oxygen; implantable cardiac devices; ventilator-dependence, CVLs.</p>
Medical Complexity-Needs	<p>1) <i>Medical Problems</i>: Neurological (seizures, global developmental delay, abnormal tone, behavioral problems, visual/hearing impairment); respiratory (chronic and recurrent pneumonia, reactive airway disease); ear, nose, and throat (sialorrhea, upper airway obstruction); gastrointestinal (gastroesophageal reflux, oromotor feeding problems, constipation); musculoskeletal (scoliosis/contractures); Multiple medications and surgical procedures associated with these needs</p> <p>2) <i>Other family-identified needs</i>: Financial burden; respite; education; support</p>
Medical Complexity-Health care utilization	<p>1) <i>Providers</i>: Medical professionals, nursing, allied health</p> <p>2) <i>Health Services</i>: hospital and community services</p> <p>3) <i>Interrelated services</i>: Family/social support; mental and behavioral health; housing; transportation; faith-based/spiritual</p>
Publication Year	2003 and later
Publication Type	<p><i>Include</i>: Research Studies, Evaluation Studies</p> <p><i>Exclude</i>: Theoretical Studies, Literature Reviews, Expert Opinion</p>

Appendix B: Summary of Included Studies

<u>Article</u>	<u>Purpose</u>	<u>Methodology/ Methods</u>	<u>Sampling/ Characteristics</u>	<u>Findings</u>
<p>Cook et al. (2013)</p> <p>Location: British Columbia, Canada</p>	<p>To explore the experiences of young adults with pedLTC who have transitioned to adult care and the facilitators and barriers to achieving their developmental goals.</p>	<p>Descriptive case study (Yin, 2009) using in-depth interviews (3), followed by an online Bulletin Board Focus Group</p>	<p>Purposeful sample from a pool of graduates of a children's hospice in Western Canada N=10 young adults Age: 19-29 years Sex/Gender: 6 males and 4 females Conditions/Needs: DMD, SMA, brain tumor, Friedrichs Ataxia; 24-hour care, technology dependent</p>	<p>Young adults were up against the system and when faced with gaps in the system, they had to use novel strategies to navigate the system. Varying levels of satisfaction with providers, mostly physicians, as they did not have access to multidisciplinary team. Coordinated and accessible services for health care were lacking and problematic. There were also problems with access to education and social support programs.</p> <p>Young adults also wanted to be respected and valued. They wanted to be treated as able, not disabled.</p> <p>Achieving support for independent living was also problematic: they needed support for personal care, which also required funding.</p> <p>Young adults suggested a team approach, improvements to the education system, and changes in funding.</p>
<p>Davies et al. (2011)</p> <p>Location: Montreal, Quebec, Canada</p>	<p>To gain an in-depth understanding of parents' perceptions of their young adults' transition from pediatric to adult health care services. Aim of design to capture unique and contextual experience while also illuminating shared realities of experience.</p>	<p>Qualitative interpretive design using in-depth semi-structured interviews of parents</p>	<p>Purposive sampling of parents of young adults from an epilepsy clinic N=17 parents of 11 young adults Age (of young adults): 18-21 years Parents: 5 interviews with mother, 5 with mother/father, 1 with grandmother and foster mother Conditions/Needs: Intractable seizures; supervision to full support ADLs, some tube feeding and tracheostomy</p>	<p>Parents felt a sense of abandonment by the health care system. They received little preparation, experienced large gaps between appointments in the pediatric and adult systems, and had difficulties accessing sufficient adult hospital and emergency care.</p> <p>Parents experienced fear and uncertainty during transition. They were unclear of the availability of appropriate services and uncertain of whether their expertise would be appreciated.</p> <p>Parents identified several facilitators of transition: establishing relationships in adult settings, parental resourcefulness, and family support system.</p> <p>Parents perceived several factors that hindered transition: inadequate resources, insufficient coordination, compromised parental health, and vulnerability of the young adult.</p>

<p>Kingsnorth et al. (2011)</p> <p>Location: Toronto, Ontario, Canada</p>	<p>To explore parent experiences of a pilot Transition Peer Support Group</p>	<p>Evaluation study: Qualitative descriptive design using focus groups and field notes</p>	<p>Parents of transition age youth receiving augmentative communication support at Holland Bloorview Kids Rehabilitation Hospital N= 8 parents Sex/Gender: 7 mothers and 1 father Age (of adolescents): 16-21 years Condition/Needs: Complex disabilities with minimal communicative ability</p>	<p>Parents described their journey to awareness. In the beginning, they had a lack of awareness of opportunities and uncertainty about accessing adult programs. Transition planning was an uphill battle. Sharing experience in the parent peer support group contributed to a sense of sameness. Through participation in the group, parents experienced shifting viewpoints and began to envision the future for their child, enabling the development of increased awareness.</p> <p>Active planning involved knowledge building in the form of sharing concrete information about options and resources with the group.</p> <p>Parents described actions taken as a result of attending the group in terms of applying for services and advocacy.</p>
<p>Kirk (2008)</p> <p>Location: United Kingdom (Northwest England)</p>	<p>To understand how young people with complex healthcare needs experiences different transitions</p>	<p>Not specifically stated but in abstract states grounded theory (with evidence of grounded theory principles throughout article) Uses face-to-face in-depth interviews of young people and, if unable to communicate, their parents</p>	<p>Purposive sampling N= 28 young people (n=9 parents served as key informant) Sex/Gender: 17 males and 11 females Age: - 8-11 years: n=9 - 12-15 years: n=11 - 16-19 years: n=8 Condition/Needs: Feeding tubes (19), IV therapy (7), mechanical ventilation (6), tracheostomy (4), O₂ (4), TPN (1), peritoneal dialysis (1)</p>	<p>Moving to adult services was associated with uncertainties. Few underwent formal transition planning and were not involved in the process of transition.</p> <p>Young people and parents described going into a different world in terms of the environment, how services were organized, and how they were seen by providers. Transition also represented disrupted relationships and ways of working.</p> <p>Young people also described moving from parental care to self-care. Managing therapies and devices was important for young people and was negotiated between young person and parent. It was also often determined by readiness to accept responsibility.</p> <p>Involvement in decisions often came after involvement in self-care. Most parents continued to play a role in negotiating the healthcare system.</p>
<p>Kirk & Fraser (2014)</p>	<p>To examine how young people with LLC and their parents experience transition; to identify families' and hospice staff's</p>	<p>Qualitative approach (grounded theory) with semi-structured interviews.</p>	<p>Young people, parents, and staff from one children's hospice; N= 16 young people (9 has parents as key informants), 16 parents,</p>	<p>Families reported a lack of information and lack of coordinated transition planning. Services failed to take responsibility. Time of uncertainty, abandonment, and anxiety. Experienced loss or reduction of services. Hospice setting seen as a place in stability and many thought that hospice should play a role in transition.</p>

Location: United Kingdom	perceptions of family support needs during transition; to identify implications for children's hospices		7 staff Age: 18-31; 4 adolescents and 12 young adults Sex/Gender: 7 female and 9 male Family structure: 8 two-parent and 4 lone-parent Conditions/Needs: DMD, SMA, Down Syndrome, congenital or metabolic	Moving to a different environment described as supporting their autonomy and making them feel like adults. Parents anxious over child staying alone in new hospice. Support needs of young people changing. Increased need for emotional support, conflicts with parents or significant others. Young people needed to discuss feelings with others. Needed information about services available to them for independence. Support needs of parents and siblings changing. Parents still needed emotional support as young people became more independent. Parent peer support was also seen as important. Siblings also continued to need support.
Magill-Evans et al. (2005) Location: Alberta, Canada	To explore the perceived dynamics of relationships between parents and youths with disabilities during the transition to adulthood.	Qualitative phenomenological approach using semi-structured interviews	Recruitment from a pool of 40 youth who took part in a previous study. N= 6 young adults and their parents Age: 20-23 Parent age: 40-54 Sex/Gender: 2 males and 4 females Conditions/Needs: Mild to severe spastic cerebral palsy; some with communication technology or nonverbal, one gastrostomy, one epilepsy and blindness, 2 require 24-hour care	Youth identified need and readiness for increased autonomy. Parents recognized conflict as an indicator of need for increase autonomy. Some parents encouraged their children to make their own decisions, others did not. Opportunities to make decisions and learn from life experiences. Shifting roles and responsibilities of parents. Some parents of youth with more severe disabilities expressed a desire to end responsibilities of caregiving despite continued need for personal care. Families dealt with this in different ways.
Rehm et al. (2012) Location: California, United States	To explore how parents and youth envisioned adulthood and how they prioritized elements of planning for transition	Ethnography; symbolic interactionism; Transition Theory and Ecological Theory guided data collection and analysis	Recruitment from a variety of community and health care settings N= 64 youth, 77 parents, 27 providers, 46 special education teachers Age: 14-17 (23), 18-21 (23) and 22-26 (18) Ethnicity: Youth:	Meaning of adulthood associated with growing independence and self-care, though ongoing need for assistance varied. Uncertainty about long-term outcomes. Youth who were verbal discussed interests but were unsure how to meet goals. Priorities of parents: overarching theme was to create a safe environment promoting a high quality of life. Protecting health was a priority. Youth encouraged to take on increasing responsibility by few would be completely about to manage

			<p>African Americans (15%), Asians (20%), Latinos (7%), more than 1 (10%); Parents: African Americans (12%), Asians (16%), Latinos (5%), and more than 1 (4%).</p> <p>Condition/needs: Chronic physical health condition and developmental disability; medications, assistive technologies, assistance with ADLs; 48% of youth verbal. All lived with family except for 6 who live in community settings</p>	<p>condition. Parents expected providers to delay transition.</p> <p>Safety and security including housing, financial security, legal protection, personal safety, and freedom from exploitation. Parents agonized about findings appropriate housing. Some wanted to live at home while others did not. Some youth could make decisions on their own while others could not and required formal legal arrangements for decision-making. Cost was a barrier to setting up these arrangements.</p> <p>Meaningful post-high school activities were important, including stimulating educational, employment, or activity programs. Working with chronic health challenges difficult. Unknown whether educational goals would be met. Search for appropriate activities was a challenge for parents.</p> <p>Social relationships were also a priority, but many parents acknowledge the difficulties youth had in this area. Safety was also a concern: knowing who is a friend or not; sexuality. Socialization opportunities were scarce.</p>
<p>Reiss et al. (2005)</p> <p>Location: Florida, United States</p>	<p>Exploratory study to document the transition experience of those involved in health care transition</p>	<p>Qualitative approach; narrative analysis (Riessman, 1993); focus groups</p>	<p>Recruitment from hospital and community settings N= 49 young adults, 44 family members, 50 providers Age (young adults) - 13-19 years: n=25 - 20-29 years: n=19 - 30-39 years: n=5 Gender: Youth: 24 male and 25 female; Parents: 8 male and 36 female; Provider: 9 male and 41 female Ethnicity: white (57%), black (39%), mixed/other (4%) Conditions/needs:</p>	<p>Factors that affect transition: cognitive ability of the young adult and the progressive nature of condition.</p> <p>Three stages of transition. Envisioning the future began when disability or health care need was identified and consisted of asking questions about future education, independence, employment and health care and starting transition planning early. Age of responsibility involved transfer of self-care responsibility. Age of transition consisted of adolescence and young adulthood. Transition usually associated with age but also with maturity and experience.</p> <p>Differences in pediatric and adults systems. Aging out of treatment prompted transition. Insurance and funding were a concern related to Title V programs and Medicaid. Adult provider knowledge, experience, and training questioned by participants. Care organized differently between pediatric and adult system. Little communication between pediatric and adult providers.</p>

			Varied diagnoses; multiple provider involvement; included young adults with technology dependence	Transition narratives provided background information, insight into relationships with pediatric providers, and changes after moving to adult providers. For relationships with pediatric providers, knowledge and trust were highlighted. A distinctly negative experience with adult providers was described. Lacked knowledge of their condition.
<p>Schultz (2013)</p> <p>Location: Texas, United States</p>	To explicate the process that parents of adolescents with epilepsy and cognitive impairments undergo as they help their adolescent transition from pediatric to adult care.	Grounded theory underpinned by symbolic interactionism	<p>Theoretical sampling: purposive sampling of participants in a transition case management parent-to-parent service; snowball, criterion, and maximum variation also used N= 7 parents Age (young adults): 20-33 (mean 23) Education: All parents have at least some college, over 50% had bachelors or masters Ethnicity: White (4), African American (2), Asian (1) Condition: Epilepsy with severe or profound cognitive impairment; anywhere from seizure-free on medication to multiple seizures a week</p>	<p>Grounded theory: Journey of Advocacy</p> <p>Crisis sparks transition: a crisis related to age, health issue, or insurance forced transition.</p> <p>Parents in turmoil: expressed feelings of fear, rejection, and uncertainty. Changes are scary; rejection from providers; uncertainty of where to receive health care or source of insurance.</p> <p>Parents as advocates: being in turmoil led to advocacy. Had to fight for services, find information on their own, and assume a coordinating, or 'quarterback' role. No agency would do it for them.</p> <p>Web of information: difficulty locating information and understanding the information. Had to differentiate between information and misinformation. Nobody knew what was going on.</p> <p>Captive waiting: waiting for answers from agencies before they could move forward. Often did not have a source of coverage.</p>
<p>Sonneveld et al. (2012)</p> <p>Location: Netherlands</p>	Rooted in a larger evaluation study of a transition program called 'On your own feet ahead!'	Evaluation study: Quantitative descriptive design; Structured survey "Mind the Gap" instrument or other (non-validated) survey	<p>All program participants who met the inclusion criteria N=138 adolescents; 181 parents; 19 providers Age (adolescents): mean age 16.1 (2.2) Sex/Gender: adolescents 58.7%</p>	<p>Significant difference between adolescent and parent satisfaction with providers working together, provision of information to support needs, assistance with planning for the future, display of health-related information in waiting room.</p> <p>Significant difference between current care and perceived best care across all provider-related characteristics, transition care delivery an management of environment for adolescents and in most areas for parents.</p>

		for providers; pre- and post- surveys with calculated gap scores	female; parents 85.1% female Condition/Needs: JRA, Diabetes, Neuromuscular disease with chronic mechanical ventilation	<p>Significant difference between adolescent and parent perceptions of current care related to all transitional care delivery processes and provider-related characteristics.</p> <p>Parents of adolescents with neuromuscular disease with chronic mechanical ventilation were less satisfied about opportunities to be seen in clinic alone and provider's interpersonal skills. Also lower satisfaction in this group related to provider knowledge of condition. Adolescents with neuromuscular disease were more critical of providers' knowledge.</p>
<p>Young et al. (2009)</p> <p>Location: Ontario, Canada</p>	To examine the issue of clinical transition from the perspectives of individual patients with mild, moderate, and severe CP, SB, and ABIC and their parents, to better understand the scope of this issue and to assist with the development of evidence-based health care transition programs.	Qualitative using semi-structured interviews (no specific methodology stated)	<p>Purposive sampling from participants of a previous large scale study; recruitment from CTCs across Ontario.</p> <p>N= 30 (15 youth and 15 adult); 30 parents</p> <p>Age: youth age 14.8-19.6 and adults age 24.8-32.8</p> <p>Urban/Rural: 20% rural, 10% small cities, 27% large cities, and 43% metropolitan cities</p> <p>Conditions/Needs: Cerebral Palsy, Spina Bifida, Acquired Brain Injury (33% severe)</p>	<p>Four barriers: lack of access, lack of professional knowledge, lack of information provided, uncertainty about the transition process. Two solutions: more information throughout the process and more support throughout the process</p> <p>Lack of access to a variety of health professionals; loss of long-term trust relationship in pediatrics; Lack of professional knowledge of adult providers related to CP, SB, and ABIC; Lack of information provided about transition process and adult services; Uncertainty regarding process in terms of what to expect and what happens after transition.</p> <p>More information wanted by youth and adults, would have been helpful if more information provided; More support needed, suggested a coordinator for transition, becoming an advocate.</p> <p>Many parents of youth with ABIC lacked insights into challenges they might face; young people and parents from northern areas more vocal about lack of access; no parents of youth spoke of advocacy, only those who were parents for adults spoke of advocacy.</p>

Appendix C: Templates for Critical Appraisal

Table 1: Framework for Critiquing Qualitative Research

<u>Criterion</u>	<u>Score</u>
<u>Phenomenon of Interest and Purpose</u> 1. What is the phenomenon of interest and is it clearly stated? 2. What is the purpose of the study? 3. What is the projected significance to nursing? 4. What is the justification for using qualitative methodology?	/1.5
<u>Method</u> 1. Is the method used compatible with the purpose of the research? 2. Is the method adequate to address the phenomenon of interest? 3. What are the philosophical underpinnings of the research method? 4. If a particular approach is used to guide inquiry, is the study completed according to the processes described?	/2
<u>Sampling</u> 1. What type of sampling is used? Is it appropriate? 2. Are the informants chosen appropriate to inform the research?	/1.5
<u>Data Collection</u> 1. Is the data focused on human experience? 2. Does the researcher describe data collection strategies? 3. Is protection of human participants addressed? 4. Is saturation of data described?	/2
<u>Data Analysis</u> 1. What strategies are used to analyze the data? 2. Has the researcher remained true to the data? 3. Does the reader follow the steps described for data analysis?	/2
<u>Credibility</u> 1. Do the participants recognize the experience as their own? 2. Has adequate time been allowed to fully understand the phenomenon?	/2
<u>Auditability</u> 1. Can the reader follow the researcher's thinking? 2. Does the researcher document the research process?	/2
<u>Fittingness</u> 1. Are the findings applicable outside the study situation? 2. Are the results meaningful to the individuals not involved in the research? 3. Is the strategy used for data analysis compatible with the purpose of the study?	/2

<u>Findings</u> 1. <i>Are the findings presented within a context?</i> 2. <i>Is the reader able to apprehend the essence of the experience from the article?</i> 3. <i>Do the researcher's conceptualizations accurately reflect the data?</i> 4. <i>Are the results placed in context of what is already known about the phenomenon?</i> 5. <i>Does it fit with existing literature?</i>	/2
<u>Conclusions</u> 1. <i>Do the conclusions, implications, and/or recommendations give the reader a context in which to use the findings?</i> 2. <i>How do the conclusions reflect the study findings?</i> 3. <i>What are the recommendations for future study? Do they reflect the findings?</i> 4. <i>How has the researcher described the significant to practice, theory, or research?</i>	/2
<u>Utility to Practice (added)</u> 1. <i>How do the study findings help me understand my relationship with patients (and families) and how to provide care?</i>	/1

[Adapted from LoBiondo-Wood, G., & Haber, J. (Eds.). (2013). *Nursing research in Canada: Methods, critical appraisal, and utilization* (3rd ed.). Toronto: Elsevier.]

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Table 2: Framework for Critiquing Quantitative Research

<u>Criterion</u>	<u>Score</u>
<u><i>Problem Statement and Purpose</i></u> 1. What is the problem explored in, or the purpose of, the research study? 2. Does the statement about the problem or purpose express a relationship between two or more variables? If so, what is the relationship? Is it testable? 3. Does the statement about the problem or purpose specify the nature of the population being studied? What is it? 4. What significance of the problem has the investigator identified?	<i>/1.5</i>
<u><i>Review of the literature and theoretical framework</i></u> 1. What concepts are included in the review? 2. Does the literature review make the relationships among the variables explicit or place the variables within a theoretical or conceptual framework? 3. What gaps or conflicts in knowledge of the problem are identified? How is the study intended to fill the gaps? 4. Are the references cited mostly primary or secondary sources? 5. What are the operational definitions of the variables? Do they reflect the conceptual definitions?	<i>/1.5</i>
<u><i>Hypotheses or Research Questions</i></u> 1. What hypotheses or research questions are stated? Are they appropriately stated? What are the variables? Is the hypothesis statistical or research? 2. Are research questions used in addition to hypotheses or to guide an exploratory study? 3. Are the hypotheses testable?	<i>/1</i>
<u><i>Sample</i></u> 1. How was the sample selected? What type of sampling method is used? Is it appropriate? 2. Does the sample reflect the population as identified in the purpose? 3. Is the sample size appropriate? How is it substantiated? 4. To what population may the findings be generalized?	<i>/2</i>
<u><i>Research Design</i></u> 1. What type of design is used? What is the rationale for the design? 2. Does the choice of design seem logical?	<i>/2</i>
<u><i>Validity</i></u> 1. Discuss the threats to internal validity in the study. 2. Does the design have controls at an acceptable level for the threats to internal validity? 3. What are the limits to generalizability in terms of external validity?	<i>/2</i>
<u><i>Research Approach and Methods</i></u> 1. Does the research approach fit with the purpose of the study? 2. What are the data collection methods? Are they similar for all participants? 3. How have the rights of participants been protected?	<i>/2</i>

<u><i>Instruments (Questionnaires)</i></u> 1. <i>What is the type or format of the questionnaires? Are they consistent with the conceptual definitions?</i> 2. <i>What type of reliability is reported to each instrument? Is the level of reliability reported acceptable?</i> 3. <i>What type of validity is reported? Does it seem adequate?</i>	/2
<u><i>Data Analysis</i></u> 1. <i>What level of measurement is used to measure each major variable?</i> 2. <i>What descriptive or inferential statistics are reported? Are they appropriate for the hypothesis?</i> 3. <i>Does the author report the level of significance set for the study?</i> 4. <i>Do the tables supplement and economize the text, have precise titles and headings, and do not repeat the text?</i>	/2
<u><i>Conclusions, Implications, Recommendations</i></u> 1. <i>If hypothesis testing was done, were the hypotheses supported or not supported?</i> 2. <i>Are the results interpreted in the context of the problem or purpose, hypothesis, theoretical framework, or literature reviewed?</i> 3. <i>What are the limitations discussed?</i> 4. <i>What relevance for nursing practice is identified?</i> 5. <i>Are the generalizations within the scope of the findings or beyond the scope of the findings?</i> 6. <i>What re the recommendations for future research?</i>	/2
<u><i>Applications and Utilization</i></u> 1. <i>Does the study appear valid? (Do the strengths outweigh the limitations/weaknesses?)</i> 2. <i>Do other studies have similar findings?</i> 3. <i>Is direct application of the findings feasible?</i> 4. <i>How and under what circumstances are the findings applicable to nursing practice? Should they be applied to nursing practice?</i> 5. <i>Would it be possible to replicate this study in another practice setting?</i>	/2

[Adapted from LoBiondo-Wood, G., & Haber, J. (Eds.). (2013). *Nursing research in Canada: Methods, critical appraisal, and utilization* (3rd ed.). Toronto: Elsevier.]

Appendix D: Concept Map

