Transitioning from paediatric to adult centred care: A review of the research on transition interventions for adolescents and young adults with chronic conditions

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December 2013

A thesis submitted to McGill University in partial fulfillment of the requirements for the degree of Master of Social Work

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Abstract

Thanks to medical advances of recent decades, increased life expectancy for adolescents and young adults with chronic illnesses has created a need for transitional support for patients moving into adult healthcare systems. It is well documented that transitional support is a beneficial part of healthcare for adolescents who are chronically ill. However, the impact of these programs on this population is not well articulated in existing research. The goals of this study are to review and assess the body of literature pertaining to the effects of transitional care, to understand the methods used for measuring outcomes of transitional programs, and to ascertain areas for future study and directions for improved quality of care for adolescents and young adults with chronic conditions. A scoping review of the transition research literature was performed in three diagnostic groups: cystic fibrosis, diabetes, and sickle cell disease; non-categorical studies were also captured and assessed. A database search produced 825 abstracts. Duplicates (232) were excluded and initial and strict screening questions were applied to the remaining 593 articles. During successive screening rounds, 345 studies and 244 studies were respectively removed, leaving four studies for analysis. The main reason for exclusion was a lack of scientific rigor in empirical studies. Despite the small number of rigorous studies produced, the scoping review process did reveal some valuable insights about the current state of transition research. Studies on diabetes-specific interventions were the most common. Researchers are faced with barriers to producing useful evidence of effective transition. More attention should be paid to the importance of interdisciplinary care and the integration of both psychosocial needs and medical needs of young people with chronic conditions.

Sommaire

Grace aux progrès médicaux des dernières décennies, l'espérance de vie des adolescents et jeunes adultes atteints de maladies chroniques a augmenté et a créé un besoin de soutien transitoire pour les patients qui se dirigent vers les systèmes de soin de santé pour adultes. Il est démontré que le soutien transitoire a un rôle bénéfique sur la santé des adolescents qui souffrent de maladies chroniques. Cependant, l'impact de ces programmes sur les personnes dans cette population n'est pas bien cerné dans la recherche actuelle. Les objectifs de cette étude sont d'examiner et d'évaluer l'ensemble de la littérature portant sur les effets des soins de transition, de comprendre les méthodes utilisées pour mesurer les résultats des programmes de transition, et d'établir, en s'appuyant sur cette documentation, des domaines d'études et de l'orientation afin d'améliorer la qualité des soins pour les adolescents et les jeunes adultes atteints de maladies chroniques. Un examen de la littérature a été réalisé sur trois types de groupes diagnostique: la fibrose kystique, le diabète du type 1 et la maladie drépanocytaire; des études non - catégoriques ont également été saisie parmi les données et évaluées. Un total de 825 sommaires ont été extrait à la suite d'une recherche dans une base de données. Les doublons (232) ont été exclus et une première série de questions rigoureuse et approfondies a été employées pour les 593 articles restant. Au cours d'examens successifs, une première série de 345 études puis une seconde de 244 ont été éliminées, n'en laissant que quatre pour l'analyse. La raison principale de cette exclusion était un manque de rigueur scientifique. Malgré le nombre limité d'études rigoureuses évaluées, un examen de ces dernières a quand même révélé des points importants sur l'état actuel de la recherche de transition. Les interventions spécifiques portant sur le diabète dominent la recherche. Les chercheurs continuent d'affronter des obstacles à la production de preuves utiles de transition efficace. Une attention supplémentaire devrait être accordée à l'importance de la prise en charge interdisciplinaire et l'intégration des besoins psycho-sociaux et médicaux des jeunes souffrant de maladies chroniques.

Acknowledgements

I would like to extend my appreciation to who those were instrumental in the completion of this thesis. I acknowledge my supervisor Dr. Lucyna Lach for her support, time, patience and guidance throughout this endeavor. I would also like to thank Lilian Iannone, graduate student affairs coordinator, for her assistance.

I am grateful to McGill University's Student Services and Scholarships & Student Aid for their support. I would especially like to express my thanks to Frederic Fovet, Jana Zuker, Dr. Lisa Travis and Cara Piperni and staff for their patience, assistance, and advocacy. I acknowledge my family (Monica, Dayton and family, Walter & Christine, Sholley, Valrie, Kaylee, Wendy and Family) and close friends for their encouragement and all manners of support offered throughout this process. My gratitude extends to Wendy & family, Keith, Nicole and Yvonne for their encouragement and support. I am indebted to Allana Mayer for the expertise, time, and effort she invested well beyond her duty. I acknowledge the library staff of the McLennan and Life Sciences libraries of McGill University for sharing their guidance, expertise and respect for their craft: in particular, Marilyn Fransiszyn, Angela Lambrou, Yvonne Mattocks, Avril, and Jennifer. I acknowledge Dr. Pluye, Dr. Quesnel-Vallée, and Dr. David Rothwell for graciously sharing their resources and expertise. I would like to acknowledge my unofficial and official educators from past and present, for their time, friendship and wisdom. Thank you, Mrs. Kernan, Elaine Tulley, Pat Anderson, professors John Batertscher, Suzan White, and Bob Kennedy.

This thesis is dedicated to the memory of the late Professor Peter Leonard.

Introduction

Advancements in pharmacology and medical technology have enabled more individuals diagnosed with childhood diseases to live well into their adult years (Blum, 1993; Claster & Vichinsky, 2003; Dyson, Atkin, Culley & Dyson, 2007). As a result, there is an emerging population of young adults living with chronic conditions (Betz & Redcay, 2002; Beresford, 2004). The number of adolescents and young adults (AYA) presenting with chronic conditions has increased significantly, over the last thirty years (Blum, 1992; American Academy of Pediatrics, 2002; Amaria, Stinson, Cullen-Dean, Sappleton, & Kaufman, 2011). As a result, many chronic conditions formerly known as childhood illnesses are now recognized as conditions of childhood onset (Rosen, 1995; Madge & Byron, 2002). The increase in life expectancy has resulted in what Palmer and Boisen (2002) call a paradigm shift, which recognizes that many people diagnosed with disease in childhood are living well into middle age. It has also brought about the need for professionals who provide medical and psychosocial service to this population in the best possible manner (Stein, 1993; Bent et al., 2002; Palmer & Boisen, 2002). Making the transition from adolescence to adulthood is in itself a trial. Adding the challenges of managing chronic health conditions makes the transition all the more complex (Conway, 1998; Green & Green, 2005). Some centres have developed transition interventions to facilitate this and social workers are well positioned to lead and participate in the development and implementation of such programs. It is therefore incumbent on social work practitioners to obtain a thorough understanding of the research on transition practices. This review deals with the current literature on transition interventions. Specifically, it will look at transition literature pertaining to adolescents with chronic health conditions as they move from the paediatric-centred care (PCC) system to adult-centred care (ACC).

How is transition being discussed in the research? What is known about interventions that specifically address the transition of adolescents with chronic conditions to adult-centred care?

What is the role of social work in the interventions highlighted in the research? The objective of this thesis is to systematically review studies evaluating programs and interventions that address transition of adolescents with chronic conditions moving from paediatric-centred care (PCC) to adult-centred care (ACC). Using the scoping review process, a search for relevant studies was conducted, specifying three chronic illnesses.

Identifying three diagnoses helped to focus the search, since the term "*transition*" covers a very broad spectrum of definitions and connotations, which produced large numbers of studies in unrelated subject areas. In this thesis, the three specific diseases are cystic fibrosis, type 1 diabetes (T1D), and sickle cell disease. These diseases were chosen because they each represent a different type of chronic disease. Cystic fibrosis is a disease that involves complex physical impairment. Both cystic fibrosis and sickle cell disease are genetic disorders; diagnoses of sickle cell disease include a high proportion of people of African descent, which adds a dimension of diversity to the care and experience for this group. Diabetes is more prevalent than cystic fibrosis and sickle cell disease, and can be viewed as an invisible chronic condition. Knowledge gained from a thorough undersatnding of evaluated transition program will provide us with a better understanding of the ingredients of best practices as well as what the potential role of social work is or can be in the development and implementation of transition interventions.

Transition, categorical and non-categorical transition models, the experience of chronic illness, and adolescent development will be among the topics discussed in this scoping review. A review of this nature will help to build a transition vernacular that can be understood in interdisciplinary transition research, provide direction for future studies on transition of adolescents with chronic conditions, and contribute to a scholarship that emphasizes the importance of viewing the institutional and life-stage elements of transition in a synergistic manner.

Problem Statement

Coming of age is a difficult time for most adolescents. For the population of young people with childhood-onset chronic conditions, the challenges are more complex. Young people diagnosed with a chronic condition must also learn to cope with the complications their condition may have on their changing biology, sexuality, education, employment, social environment and psychological well-being (Breakey, Blanchette, & Bolton-Maggs, 2010). Though the challenges of transition are many for this population, there are few formal health-care support systems in place to help bridge the worlds of adolescence and adulthood. Betz and Faan (2004) state that “[t]ypically, there is no standardized portal of exit for youth who grow out of their paediatric care services” (p. 685). Therefore, the leap from paediatric- to adult-centred care is both vast and sudden. The transitional shift in social environment takes place simultaneously with the shift in health-care systems. The move from dependence on parents to increased autonomy “requires a re-positioning in relationships” with parents or guardians (Brooks, Bunn, & Morgan, 2009, p. 302). Since parents and guardians play a significant role in managing the health of their children or wards, this adds another dimension of adjustment for AYA and their families.

In traditional health-care settings, the culture of the paediatric health system is significantly different from that of adult-centred systems (Rosen, 1995). PCC tends to be family- and team-oriented, with much emphasis placed on education and support to both the child and the child’s family, while ACC encourages autonomy, privacy and independence (Wang, 2010). The culture of care in adult medicine has been perceived as less attentive to the developmental and behavioural struggles of young adults with chronic health conditions as practitioners operate under the assumption that these struggles have been surpassed during childhood development and learning appropriate behavioural strategies are no longer a primary concern (Anderson & Wolpert, 2004).

It has been suggested that paediatricians tend to be more attentive to the developmental needs of their young patients, including education, sexual health and emotional well-being, compared to physicians in ACC (Fulginti, 1992; Rosen, 1995). This is not to say that adult practitioners are not concerned with the well-being of their patients. Rather, the emphasis is on diagnostic and medical care. It is assumed that developmental issues and expectations have already been addressed by a paediatrician; adult care is primarily concerned with treatment of illness. The adult systems differ structurally, with referral to specialists or consultative services, while the PCC system operates on a more coordinated care model to offer both patient and family access to wrap-around care, likely in the form of a care team.

There is increasing awareness for the need to recognize this "twilight" stage, the period between adolescence and adulthood, as a unique life stage associated with its own consistent developmental behaviours and tasks (Arnett, 2000; Betz, 2004). Adolescence is the time when most self-care behaviours are being fortified (Anderson & Wolpert, 2004), whereas young adulthood is when they are consolidated. The young adult period that follows adolescence, however, is a focus in neither paediatric nor adult medical settings. As a result, there is uncertainty about the existence of a comprehensive body of empirical research on care and education during this transitional phase (Anderson, 2004). "Adolescence" itself is a term subject to varying definitions. For the purposes of this study, "adolescence" and "adulthood" were not given specific age definitions. Age parameters for the study scope are defined by the databases where the searches were conducted, and will be further discussed in the methodology.

According to Erikson's (1950) theory of development across a lifespan, adolescence is a crucial period of identity formation. For children who grow up with chronic conditions, there must be some accommodation of the condition in their identity formation, as their perceptions of illness influence their self-regulation and coping strategies (Leventhal et al., 1992). Developmental tasks at the young adult stage include adjusting to the demands of economic independence, building social networks, and acquiring vocational education and training (Arnett, 2000). For most AYA with special health care needs, these tasks can detract from a focused commitment to chronic disease management, placing a patient's health at risk (Anderson & Wolpert, 2004). Making the shift from adolescence to adulthood in the context of the healthcare system can also pose risks, in that patients can get lost in follow-up. Adolescents and young adults with chronic conditions, such as T1D, who do not follow up with primary health care providers at least once per year after transferring to ACC, have higher hospitalization rates and are at increased risk of health-related complications (Pacaud, 2005). Therefore, while most adolescents are preparing to transition from low autonomy to increased autonomy, for those with complex health issues, autonomy in health care management takes a slightly different form as it must incorporate a balanced relationship with primary care givers and health-care systems to mitigate health risks in adult life.

However, there are gaps in the health-care system which can make finding this balance difficult. Okumura et al. (2008) found that patients with rare and chronic diseases as old as forty were still being treated in PCC. Okumura et al.’s (2010) follow-up study on this phenomenon found that internists in the United States generally had low comfort levels with rare and uncommon childhood onset illnesses. This finding represents one plausible explanation toward the gaps in transitional health care support. There remain, however, a number of unanswered questions about gaps in transitional care.

What is Already Known

We know that the health risks, mortality rates, risk of isolation, and vulnerability to mental health issues are magnified for this growing population if they do not maintain a connection to health-care systems after they transition to adult life stages (Roberts, Goldcare & Neil, 2004;

Bowen, Henske, & Potter, 2010). We also know the possibility of getting lost in follow-up in health-care after transition poses a serious health risk for AYA with chronic conditions (Peters & Laffel, 2011). Therefore, the need for transitional health-care services to be accessible to this population has been well established (Blum, 1993). What is not evident in the research is the form and structure of such interventions. What patterns exist in the types of interventions provided to this particular group of AYA? What constitutes a transition program or intervention? Before approaching these questions, a clear working definition of what it means to transition from paediatric to adult health-care with a chronic condition needs to be established.

Before establishing what "transition" is, I will first distinguish it from what it is not. For instance, it is not synonymous with medical transfer. Transition literature has historically focused on the transfer of medical information from one system to another (Crowley, Wolfe, Locke, & McKee, 2011, p. 549). Pai and Schwartz (2010) highlight this as a common misinterpretation of the term, stating that "transfer, often confused with transition, refers to the actual act of moving to a new health-care setting, provider, or both" (p. 1). How then do we define "transition" if it is not the transfer of health information? Blum (1993) defines it as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems" (p. 570). This has been adopted in the literature as the accepted description of adolescent health-care transition and will be used here as a starting point in understanding the concept.

Because this working definition is specific to health-care systems, there must also be an appreciation for the demands of living with a chronic condition. "Chronic condition" will be understood here as a concept describing what it means to be ill, rather than a diagnosis (Stein et al., 1993). The main distinction between understanding illness as a concept, compared to a diagnosis, is that the concept of chronic conditions places greater emphasis on recognizing the consequences of illness, rather than taking inventory of a disease and its symptoms (Stein et al., 1993). For the purpose of this study, "chronic condition" will be viewed according to Stein at al.'s (1993) theory of non-categorical disease, also known as the "generic disease model." This model considers the efforts made by AYA to actively participate in daily living, including managing their medical conditions, integrating with social environments and achieving appropriate developmental tasks. It can be argued, however, that this model does not speak to the demands of managing specific types of diseases or conditions. To help frame discussions of the nuances between different illnesses, the literature uses sub-categories of both generic and disease-specific approaches to health care transition. For this review, a generic approach to chronic conditions will also be used to observe the differences between interventions (Sawyer, 2007, p. 1483).

Transition is a complex term which can incorporate transition as a concept, transition services and transition practices (Betz & Faan, 2007). It represents a multifaceted process that happens over time (Betz & Faan, 2007). It involves many intersecting variables such as an individual's health and his or her interaction with the systems that help maintain or improve health, as well as all other relevant social environments. It is difficult to fully appreciate the complexity of transition while trying to isolate it from any of the aforementioned intersecting factors. Bringing together the medical aspects with the life-stage and development aspect is the framework that will be utilized in this review.

It is in appreciation for this complexity that I will approach this study using an ecological lens. The foundation of the ecological model rests on the notion that an individual's behaviour cannot be separated from the setting in which he or she exists: therefore, to change the behavior, it is also necessary to change the setting in which it occurs (Jakes & Brookins, 2004; Bronfenbrenner, 1993). For the purpose of this study, the ecological perspective will be used to understand the impact of the transitional care interventions on the health outcomes for this study population. The ecological model provides a frame of reference to examine the literature with regard to the intersecting issues that impact adolescents with chronic conditions, including their psychosocial development, their environment, the health-care system, and the practitioners that function within it.

Biopsychosocial theory provides a framework to accommodate both the medical and psychosocial needs of adolescents with various kinds of chronic disease. The theory "recognizes that illness and one’s experience of illness occurs through a dynamic interaction among biologic, psychologic, social and environmental factors, all of which overlap as potential causes and maintenance factors of symptoms associated with illness” (Armstrong, 2006, p. 17). Nicassio and Smith (1995), citing Haynes and O’Brien's (1990) functional analysis, illustrate the relationships between psychosocial factors and health outcomes. Illustration 1 demonstrates how high social support can help reduce disease activity.

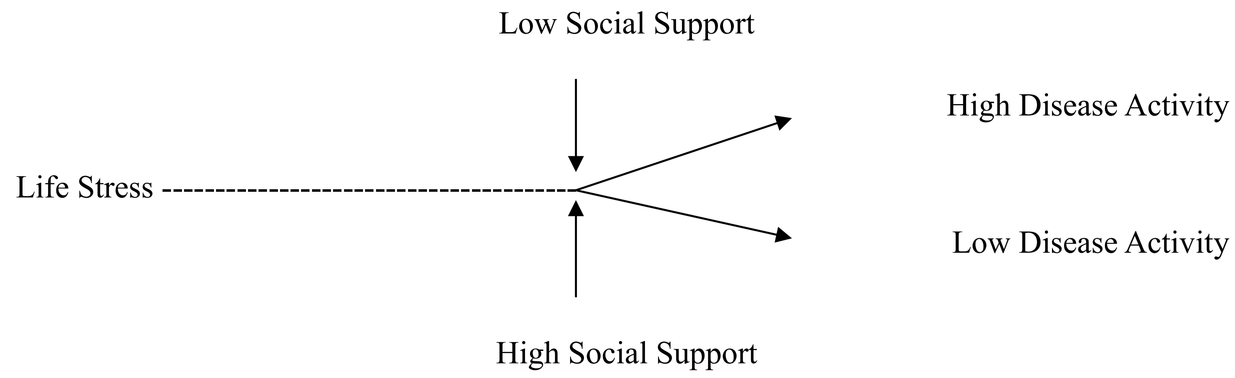

Illustration 1: Mechanisms of action: Examples of moderating effects of psychosocial process on health outcomes (Haynes & O’Brien, 1990, as cited in Nicassio & Smith, 1995, p. 11).

Maintaining social networks increases social contact and the potential for monitoring. Inversely, low social support can result in isolation and increased risk of adverse health. For youth with chronic conditions, maintaining social support can be difficult. As adolescents seek social acceptance from peers, they are simultaneously seeking some autonomy from parents and other forms of authority while trying to process the need to develop and maintain relationships with health care systems (Arnett, 2000).

Literature Review

There are many ways in which the term “transition” is understood and interpreted, and many of the various examples of transition are of interest to health-care professionals. However, for the purposes of this study I will look to Blum et al. (1993) who define transition as “the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems” (p. 570). To help conceptualize intervention research I will look to the description provided by Hawe and Potvine (2009) where they define intervention research as the means of learning from the actions implemented to address the phenomenon we seek to understand in analytic health research.

Transfer of medical information from paediatric to adult health services is among the more recognized interpretations of transition in health care (McDonagh, 2006; Rapley & Davidson, 2009). It involves the movement of medical information: between practitioners, facilities, and departments within an institution, or between the institution and community service or dwelling (Kennedy, 2007; Rapley & Davidson, 2009). Although medical transfer is an important aspect of the transition process, it represents only a part of it, and is therefore not synonymous with transition (Wang, 2010, p. 506). Medical transfer refers to an event, while transition represents a process made up of many components: there is a complexity of psychosocial life-stage facets that intersect with the biomedical aspects of transition for adolescents with chronic conditions (Robertson, 2006). Transfer of a patient and his or her health information from one care facility to another has its own challenges embedded in the process. The reference to medical transfer here serves as a means of distinguishing the terms and clarifying any confusion brought about by past use of terms like transfer and transition interchangeably in the literature. For this scoping review, the focus of intervention is not only on medical transfer but on the transition of the young adult with a chronic condition as a whole entity.

Transition as a concept is evolving to encompass multiple components of biological health and psychosocial development (Blum, 2002). Transition literature is slowly moving away from looking at these components in isolation, and toward understanding how they intersect and function within an individual's environment. This marks a significant shift in transition thinking, moving from medical transfer to a more holistic view of health outcomes (Blum et al., 2002; Stewart et al., 2007). The shift builds on a theoretical model, which merges the medical and psychosocial aspects of health care outcomes.

Early socio-medical theory emerging from theorists such as Foucault and Engle integrated *objective* properties of the medical model and the *subjective* experience of illness (Wang, 2010). Bronfenbrenner (1979) refined these theories into what is known as "ecological theory." It extends the structure of biomedical health to include the behaviors and interactions that will increase the chance of obtaining the best possible health outcomes. Ecological theory functions as a framework which focuses attention on the multiple environments relevant to an individual's health, development and identity (Wang, 2010). The ecological model offers some contingence for gaps between medical models which focus on the individual, the social systems in which they live, and the impact of both of these on the individual. The ecological model provides a means to analyze the impact of systems' environments on the individual. When trying to understand specific populations, there is the temptation to look mainly at the individuals within that population and the microsystems around them. Ecological theory challenges us to look beyond the microsystem and consider all of the social forces that impact intervention planning. For example, the family environment can be very important to the way that children adjust to chronic illness: a child's reliance on family to manage his or her care, and the ability of the family to respond to demands, dictates the quality of that child's and the family's life (McCarthy & Gallo, 1992).

In keeping with Schwartz, Tuchman, Hobbie and Ginsberg's (2011) use of the ecological model, it will function here as a "systems approach that goes beyond just patient knowledge and behavior to include barriers, facilitators and the contributions of multiple stakeholders" (p. 890). Within this model, Bronfenbrenner (1993) organizes social levels of influence on behaviour into micro-, meso-, exo- and macrosystems of influence and demonstrates how they intersect with one another. While the microsystem represents face-to-face influences in specific settings such as families and intimate relationships, the mesosystem refers to interrelations among the various settings in which the individual is involved, such as schools or religious communities (Bronfenbrenner, 1979; McLeroy, Bibeau, Steckler, & Glanz, 1988). The exosystem refers to the forces within the larger social system in which the individual is embedded, such as unemployment rate or inflation; the macrosystem refers to the cultural beliefs that influence all levels (Bronfenbrenner, 1979; McLeroy, Bibeau, Steckler, & Glanz, 1988). Thus an ecological perspective "implies reciprocal causation between the individual and the environment" (McLeroy, Bibeau, Steckler, & Glanz, 1988, p. 354). The ecological lens will be used here, in keeping with McLeroy, Bibeau, Steckler, and Glanz's (1988) perspective that ecological models are similar to systems models, in that they look at how social groups and individuals interrelate. Ecological models extend this by viewing patterned behaviour of individuals or groups as the outcomes of interest.

Chronic conditions, by their persistence, can become incorporated into an adolescent's sense of identity, lifestyle and relationships (Palmer & Boisen, 2002; Anderson, 2002; Benson & Elder, 2011). Treatment of diseases such as childhood cancer, for example, can result in permanent physiological changes which may have implications in adult life: some cancer therapies cause infertility, which can affect how a young individual navigates choices about family and social networks later in life (Hobbie & Ogle, 2001; Grinyer, 2009).

There is growing acknowledgement that focus on medical information alone is not enough for effective transition (Dovey-Pearce et al., 2007). However, what constitutes an appropriate protocol on transition is still widely debated in the literature (Santelli et al., 2003; McDonagh, 2003; Beresford, 2004). Whether or not transition models should be age-related or disease-focused reflects one of the tensions in protocol discussions in transition literature. Most health transitions are based on age-focused models where a specific age, generally the legal age of majority, dictates the point at which primary health-care moves from paediatric-centred care (PCC) to adult-centred care (ACC). A consensus report from PCC and ACC professionals indicates age 18 is a reasonable age for transfer of all young people (Berg Kelly, 2011). The arguments indicate that it is the age of majority when parents lose their legal rights; there are societal expectations and demands of young people at this age which in turn influence a young person's need for active self-management (Berg Kelly, 2011). This contradicts earlier transition discussions that saw a flexible age for transfer as the best option (Rosen, 1995; Berg Kelly, 2011). Some argue that the age of a patient is not an accurate indicator of his or her psychosocial preparedness for transition (Arnett & Galambos, 2003). Nor do age-focused models speak to an adolescent's access to resources or to the process involved in supporting an adolescent through to adulthood (Mosley, 2000). Furthermore, age-focused models do not encompass external variables such as diverse cultural values (Anderson & Wolpert, 2004). Cumsille, Darling, Flaherty, and Loreto Martinez (2009) have highlighted how cultural norms and values, rather than age, have a greater impact on the time at which certain developmental events occur. Age-focused models do not emphasize mitigating factors, such as the impact of chronic health issues on identity, which can influence developmental expectations in the various life stages (Charmaz, 2002). For AYA with chronic illness it can accelerate maturity in some areas and delay development in others. Living with chronic conditions may cause rapid development in terms of personal identity, forcing young people to deal with concepts of loss and mortality at an age normally associated with health and vitality (Dovey-Pearce, Doherty, & May, 2007). Young people living with chronic conditions also have to contend with the possibility of needing to rely on others for support at an age where their peers are moving towards independence, especially in health-care costs. The impact a chronic condition may have on employability, education or training may delay life-stage events like independent living. A position statement, composed by Pinzon and Harvey (2013) for the Canadian Paediatric Society, reported that youth with chronic conditions often had problems with school attendance, vocational planning, economic support, and physical activity: for example, to the extent of having a 30% reduction in school attendance compared with their healthy peers. Pless, Cripps, Davies, and Wadsworth (1989) found the impact to be most significant if the childhood chronic condition intersected with a lower family income. Suris, Michaud and Viner (2004) address what long-term impact educational difficulties have: those in lower classes had significantly lower lifelong income (p. 940). Suris et al. (2004) go on to suggest that these effects can be mitigated with better professional health-care support.

There are some fundamental differences between PCC and ACC. The paediatric setting involves family and support networks made up of specialists and tertiary care teams. Adult health-care systems tend to focus on privacy and autonomy and are often managed by general practitioners who may or may not specialize in a particular disease or chronic illness (Tuchman, 2008; Betz 2010; Peters & Laffel, 2011). Children lack the capacity to make decisions about their own health and care, but as they go through adolescence, they develop self-awareness and a desire for an identity separate from that of their parents (Kennedy, 2007). This can have an impact on conflicting perceptions about health status, ability to function, and quality of life (Sawyer, 2007). Thus, one of the problems with age-focused transition models is that the approaches in adult-centred care, compared to paediatric care, can appear to have competing interests for AYA, their families, and their practitioners.

The concept of "transition readiness" focuses on a patient's preparedness for independence. It assumes individual autonomy, which includes acquisition of life skills, education about illness, ability to establish and maintain relevant relationships, and having a competent care team in place (Betz, 2010; Van Staa, 2011). Transition readiness can potentially fill cultural gaps where appropriating specific tasks to stages of development may differ between cultural regions (Arnett & Galambos, 2003; Arnett, 2003). However, incorporating a "transition readiness" approach requires systemic restructuring to address resource issues such as funding, staffing, and issues surrounding health insurance (Betz, 2010).

There is another school of thought which emphasizes focus on the illness as the path to optimal transitional care for AYA with chronic conditions. While much of the transition studies are published around a specific condition, such as cystic fibrosis, they tend to focus on issues which transcend the illness itself and instead deal with the experience of disease. Disease-focused models appear to be subdivided into two prominent schools of thought: disease-specific transition and generic model transition. Disease-specific models incorporate specific health management strategies into transfer care planning (Mosley, 2000). However, in transition literature, there is much overlap in terms of the impact of illness and interventions and little contingency for the financial and departmental constraints around implementing such a framework (Mosley, 2000). Furthermore, this model tends to lack the recognition of the developmental process for AYA with chronic illness (Anderson & Wolpert, 2004). Alternatively, generic models create a space where multiple diseases can be observed simultaneously, allowing for comparisons and cross-references to be made between groups (Sawyer, 2007, p. 1483). The generic approach to transition can be adapted and used in different sub-populations, such as adolescents. However, this strength can also be a weakness, in that modification to subgroups lends itself to inconsistencies in definitive criteria

(Stein et al., 1993). Although the two models have different guiding principles, they are not mutually exclusive.

Stein et al. (1993) refer to the generic approach as a means of identifying children with chronic illnesses. The framework contains a checklist designed to help researchers and practitioners identify whether or not a child can be classified as having a chronic condition. The checklist draws on three major markers of chronic health conditions. The first is to establish if the condition is biological, psychological or cognitive in symptomology. Second, chronic conditions last or are expected to last beyond one year (Stein et al., 1993; Luft & Koch, 1998; Social Care Institute for Excellence, 2004). Third, chronic conditions produce limitations on functioning, in comparison with healthy peers. These limitations will require dependency on medical, pharmacological, dietary, technological, psychosocial or other related support services to minimize the effect of limitations on functions, activities or social roles (Stein et al., 1993).

Although the generic model includes conditions with a psychological or cognitive basis in its framework, there appears to be a clear professional divide in transition literature. That is, life-stage development remains the domain of psychology and psychiatry, while biomedical needs and psychosocial issues stay in the domain of nursing and social work. This segregation also transcends into chronic condition typology. Chronic mental health conditions fall into a separate category from conditions that manifest physiologically and are therefore not treated in the same manner (Betz & Faan, 2007). Currently, there is no framework within the generic model that would allow for the examination of both physical health issues and mental health issues in the same framework.

In early transition literature, Blum (1993) introduced the “systems approach,” which recognized that health transition facilitates progression in areas of life other than biomedical (p. 573). His efforts highlighted the importance of transition health care, and brought it to forums of public policy. Blum helped forge an expanded view of clinical transfer that validates a interdisciplinary approach to health transition (Blum, 1993; Bent et al., 2002; Klaasen, 2009). Since its introduction, there has been increased awareness of the value of incorporating the perspectives and needs of system users into transition research (Betz, 2010). There is growing recognition that systems approaches need to incorporate evaluation of program effectiveness (Telfair, 2005; Schers et al., 2002). Because young adults with chronic illness are an emerging population, there is a need for an increase in effectiveness research to offer stability to systems approach models of transition.

With the many changes that have developed over recent decades in the perception, definition, and approach to transition, a re-evaluation of the subject will provide a clear picture of transition intervention research and thereby direct research toward improved, effective support.

Methodology

The rapid developments in medical, pharmacological and technological treatments have increased the lifespan of people diagnosed with childhood onset diseases and chronic illnesses (Claster & Vichinsky, 2003; Telfair et al., 2007). Yet there are questions about whether the psychosocial services for this population are adequate, given that more young adults are entering adult stages with chronic conditions. For these young adults, the context of transition intervention is particularly important. This scoping review will focus on health and medical aspects of transition from paediatric to adult care. Intervention studies emphasizing the movement from one setting to another will be the primary focus.

The aim of this study is to gain a deeper understanding of the types of interventions pertaining to transition that have been evaluated and to assess the role that social work has played in the delivery of transition programs and its documentation. With these objectives in mind, the study will employ Arksey and O'Malley's (2005) framework for scoping reviews. This is a process that begins with identifying the research, followed by a study search within designated databases. The third step involves selecting the studies to be reviewed. The fourth step is charting and summarizing the data, followed by the fifth step of reporting the results (Arksey & O'Malley, 2005). The Arksey and O'Malley (2005) framework includes a sixth stage that relates to knowledge transmission which involves communicating the research with stakeholders. It also provides an opportunity to extract themes from a diverse body of evidence (Davis et al., 2009; Levac, 2010). The value of exploring relationships and links across a body of evidence is that it provides a vantage point from which to develop theories that move beyond the descriptive (Davis et al., 2010). The methodology employed in this scoping review is described in the following stages:

1. Identifying the Research Question

The first step of identifying the research involves outlining the objective of the study and/or the research question (Arksey & O'Malley, 2005). The research objective for this review is to obtain a systematic understanding of the interventions that deal with the transition of adolescents from paediatric to adult care settings.

2. Identifying Relevant Studies

Keyword searches on the topic of transition to adult health care were conducted in the following databases:

- Cumulative Index of Nursing and Allied Health Literature (CINAHL),
- Ovid Medline,
- PsycINFO,
- Social Work Abstracts and citation database,
- EMBASE.

Face validity for chosen databases was based on relevance established by consultation with social work practitioners and health science library technicians. Keywords were selected to generate the first set of abstracts.. The eligibility criteria employed key terms in the initial screening such as *transition, continuity of care, adolescen**, *teen**, *young adult, cystic fibrosis, sickle cell disease, diabetes*.

Search Strategy

With the guidance of a health sciences librarian, an initial search strategy was used to create a search template. The template was initially run through Ovid Medline, then used in the additional databases. This template was revised and adjusted according to the characteristics and parameter of each database and therefore represents an example of the terms used for searches in databases other than Ovid Medline. The search template can be found in Appendix 1

Grey literature, such as reports, recommendations, and policy papers, was not included in the scoping review but was used as general or background reference. Grey literature was excluded because the search terms generated large amounts of irrelevant literature (this is discussed further in Discussion: Limitations).

This search strategy generated 825 abstracts from the various databases searched.

3. Study Selection

Study selection involved two phases: initial screening and strict screening.

a. Initial Screening

Titles and abstracts generated using the search template were reviewed using initial screening inclusion/exclusion criteria. Selected citations and abstracts were uploaded to an Endnote library and duplicates were removed. Abstracts were reviewed using the following questions:

1. Is this an empirical study?
2. Is this about adolescents/young adults with cystic fibrosis, sickle cell disease, or diabetes?
3. Is this about transition or continuity of care?

If the answer to each of these questions was “yes,” the abstract was included and moved to the next stage of analysis. If the answer to any of the questions was “no,” the abstract was excluded from further analysis. If the answer to any of these questions was “unclear” the abstract proceeded to the next phase of analysis.

b. Strict Screening

During the strict screening phase, inclusion/exclusion criteria were applied to full text articles. Each article was read and coded yes, no, or unclear in response to the following questions:

1. Is this a quantitative study, defined as a study that presents a question, hypothesis or study objective that is analyzed quantitatively?
2. Is the target population of the study adolescents with chronic illness (e.g. versus parents or siblings of adolescents with chronic conditions)?
3. Is “health transition” the focus of the study?
4. Is this an intervention study?

If the answer to each of these questions was "yes" and/or "unclear," the article proceeded to the next phase of data extraction. If any of the answers was "no," the article was excluded. Studies that evaluated systems (as opposed to patients), that referred to medical transfer from one unit to another within the same institution, from inpatient to outpatient services, or from hospital to home were excluded. Mixed method studies were excluded (this is discussed further in Discussion: Limitations).

Based on recommendations from the Evidence for Policy and Practice Information and Coordination Centre, two additional independent reviewers were recruited to review each article for inclusion criteria (EPPI Centre, 2007). Any discrepancies were discussed between the primary researcher and these reviewers, achieving 100% consensus on all articles.

A hand search was done to locate additional studies, which included an online search of intervention websites and a search of the reference lists of relevant articles. Steps for the hand search will be further detailed in the following chapter.

4. Data Extraction for Charting

Using the template outlined by Arksey and O’Malley (2005), information from the selected articles was organized according to the general charting categories as follows:

- Author(s), date of publication, location of study
- Use of theory (identify theory guiding the study)
- Intervention type (i.e. studies with disease specific and non-categorical disease focus, longitudinal studies, interventions with developmental, behavioral or psychosocial component)
- Study population
- Goals of the study
- Method
- Outcomes
- Limitations

The presence of a social work perspective in the intervention or authorship was also noted. Selected studies were read in entirety and charted by the primary researcher.

5. Reporting

Data extracted from selected studies are summarized and reported below.

Results

This chapter documents the results of each stage of the review process.

Initial screening

Using the search terms and databases identified in the previous chapter, a total of 825 abstracts were generated: n = 318 from CINAHL, n = 351 from Medline, n = 64 from PsycINFO, n = 4 from Social Work Abstracts, and n = 88 from EMBASE. Duplicates (n = 232) were removed, leaving n = 593 for review using the screening questions. After applying initial screening questions, n = 248 studies remained; n = 345 were removed for the following reasons:

n = 3 were not a study
n = 20 were not about adolescents/young adults with cystic fibrosis, sickle cell, diabetes
n = 322 were not about transition or continuity of care

Strict screening

Full-text articles were used at this stage of the review process. Each of the remaining n = 248 articles was read to respond to the strict screening questions as identified in the previous chapter. The screening was done by the author as well as two independent reviewers in order to ensure inter-rater reliability. The reviewers were briefed about the research question, design, and selection criteria. Although not directly used in this study, a variation of the Mixed Methods Appraisal Tool (Pluye et al., 2011) was used to train reviewers on the criteria and the selection process. The role of the reviewers involved reading n = 248 full text articles against the inclusion/exclusion criteria. Folders were made in EndNote where all 248 references and their corresponding PDFs were uploaded and stored. Each of the articles was grouped in one of three categories: “included,” “excluded,” or “unclear.”

All studies which had been categorized as “unclear” were discussed between the two reviewers and the primary researcher until a consensus was reached. Table 1 summarizes results by each reviewer.

Table 1: Classification of all studies by reviewers and researcher (n = 248)

Reviewer	**Included**	**Excluded**	**Unclear**	**Studies voted to advance**
1	34	169	45	79 (34 + 45)
2	39	186	23	62 (39 + 23)
Researcher	42	185	21	63 (42 + 21)

Based on these results, the kappa coefficients were calculated using the following formula:

$$\kappa = \frac{\Pr(a) - \Pr(e)}{1 - \Pr(e)},$$

where *Pr(a) stands* for proportion of units for which the raters agree and *Pr(c) is* proportion of units for which agreement is expected by chance (Stemler, 2001). Results ranged from 0.67 to 0.82; see Table 2.

Table 2: Inter-Rater Reliability Calculations

	Studies voted to advance	Percent agreement - Pr (*a*)	Kappa score (Pr(*e*) = 0.33 based on 3 choices for classification of studies)
Reviewer 1	34 + 45 = 79	Researcher to Reviewer 1: 63/79 = 0.8	$\frac{.8 - .33}{1 - .33} = \frac{.47}{.67} = 0.7$
Reviewer 2	39 + 23 = 62	Reviewer 2 to Researcher: 62/63 = .98	$\frac{.98 - .33}{1 - .33} = \frac{.55}{.67} = 0.82$
Researcher	42 + 21 = 63	Reviewer 2 to Reviewer 1: 62/79 = .78	$\frac{.78 - .33}{1 - .33} = \frac{.45}{.67} = 0.67$

All studies identified by reviewers as meeting inclusion/exclusion criteria were discussed among the three reviewers again, and consensus was reached about the inclusion of each one. Reviewers agreed to include n = 44 articles; n = 204 articles would be excluded for the following reasons:

n = 156 were not peer-reviewed studies (i.e. discussion papers, guidelines and protocol, government-commissioned reports)

n = 27 were qualitative studies

n = 3 were outside age parameters (did not deal with adolescents or young adults)

n = 1 was not within date range

n = 1 did not deal with transition

n = 4 were systematic reviews

n = 5 were mixed-method studies

n = 3 studies did not address the prescribed diagnostic groups

n = 4 studies dealt with inter-agency transition or transition from one care facility to another (i.e. post-operative transition, transition from hospital facility to home)

Following data extraction of 44 selected studies, it was identified that a majority of the selected studies did not clearly measure outcomes or effectiveness of intervention. An additional 40 studies were excluded by the researcher for the following reasons:

n = 17 studies did not measure outcome/effectiveness of intervention

n = 9 studies were reviews of program activities, service, practice methods or protocol

n = 4 studies focused on family perspectives (not considered interventions)

n = 9 studies measured relationships or correlations that were specific to interventions

n = 1 study was a dissertation

Four studies remained matching the pre-test/post-test criteria (Cadario et al., 2009; Van Walleghem, MacDonald & Dean, 2008; Van Walleghem, MacDonald, & Dean, 2011; Vidal et al., 2004). It was determined upon closer inspection that Van Walleghem et al. (2011) was a follow-up article to the 2008 study by the same authors. The same data set was used for both; thus Van

Walleghem et al. (2008) was used for the purposes of the scoping review and the 2011 article was used for reference, as it expanded and elaborated upon some details missed in the 2008 article.

A hand search was done to locate additional studies, which included a search of the reference lists of the four included articles. A hand search of the *CanChild* website was conducted by entering the term "transition to adult" in the website search engine. The search produced 32 results, four of which matched the initial screening criteria (Law, 2006; Reiss, 2012; Stewart, 2006; Young et al., 2006). Three of the four were excluded as they were not studies, and one was excluded because it was a qualitative study. However, the reference lists of these four articles were searched. The reference list of the qualitative study by Young et al. (2006) referenced *Physical and Occupational Therapy 26*(4), which published an issue devoted to adolescent transition. From that issue of *Physical and Occupational Therapy*, one study matching the criteria was identified (Evans, McDougall, & Baldwin, 2006) and was included.

The references for the four included studies are listed below:

1. Cadario, F., Prodam, F., Bellone, S., Trada, M., Binotti, M., Allochis, G., ... & Aimaretti, G. (2009). Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach. *Clinical endocrinology*, *71*(3), 346-350.
2. Evans, J., McDougall, J., & Baldwin, P. (2006). An Evaluation of the "Youth En Route" Program. *Physical & Occupational Therapy in Pediatrics, 26*(4), 63-87.
3. Van Walleghem, N., Macdonald, C. A., & Dean, H. J. (2008). Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with type 1 diabetes. *Diabetes Care, 31*(8), 1529-1530.
4. Vidal, M. et al. (2004). Impact of a special therapeutic education programme in patients transferred from a paediatric to an adult diabetes unit. *European Diabetes Nursing 1*(1), 23-27.

Data extracted from these four articles were charted in Appendix 2.

Findings from Hand Searched Studies

Publication

The time frame for study selection was a 13-year period between 1996 and 2012. However, there was no publication activity prior to 2004. The earliest study was published in 2004 (Vidal et al., 2004), followed by one published in 2006 (Evans, MacDougall, & Baldwin, 2006) one study in 2008 (Van Walleghem, McDonald, & Dean, 2008), and another in 2009 (Cadario et al., 2009). This trend marks a slow but growing emergence of literature evaluating transition programs.

Sample and Recruitment

Of the four studies that were included, two were from Canadian cities: London, Ontario and Winnipeg, Manitoba (Evans et al., 2006; Van Walleghem et al., 2008). The other two were based in Europe: one in Spain (Vidal et al., 2004) and one in Italy (Cadario et al., 2009). All four studies used convenience samples recruited from the centres where the intervention was implemented. Three out of four study samples were recruited from tertiary care facilities specializing in diabetes (Cadario et al., 2009; Van Walleghem et al., 2008; Vidal et al., 2004). The study by Evans et al. (2006) was a secondary care facility specializing in children's rehabilitation.

Van Walleghem et al. (2008) created a database in 2002 to follow two cohorts of patients, a younger one (18 years of age) who were graduates from paediatric care at the Diabetes Education Resource for Children and Adolescents (DER-CA) program in Winnipeg, Manitoba between August 2002 and August 2004 (n=84), and an older cohort (19-25 years of age) who were graduates from the DER-CA program between January 1995 and July 2002 (n=164). This older group was transferred before the Maestro Project was created but was later enrolled in August 2002, up to seven years after transfer to adult care had already taken place. Sixty-four out of 84 participants from the younger cohort were used in the analysis; 101 out of 164 were used in the analysis from the older cohort. These numbers represent the files for which there was complete data related to the nature of medical and educational follow-up. A subsample of seventeen records was audited (eight male, nine female). Mail surveys were completed by 14% of participants in the database. The reason for the low number of record audits was due to very few participants providing consent to access their medical records. The poor response rate on the mail survey was also a disappointment to the research team as considerable effort was made to follow-up by email and telephone. No other demographic information was provided on the sample. Van Walleghem et al.'s (2008) sample came from various parts of Manitoba; however, other than age and condition, no other demographic information was reported.

Cadario et al. (2009) conducted a chart review of patients discharged from the Paediatric Diabetes Services (PDS) to the Adult Diabetes Services (ADS) at Maggiore della Carita Hospital, between the years 1994 and 2004. Between 1994 and 1999, patients underwent an unstructured transition; this group comprised n=32 patients. From 2000 to 2004, a structured program was implemented; this latter group comprised n=30 patients. All patients were contacted by the PDS nurse to respond to a set of questions. Eighty-four percent of the unstructured and 100% of the structured group responded. All patients were either 18 or 20 years of age at the time of transition. The structured transition plan was implemented in 1999.

Age range for the study evaluating the Youth En Route (YER) program by Evans et al. (2006) was 16 to 29 with an average age at pre-test of 22 years, 3 months. The sample comprised thirty-four young people with multiple disabilities who had completed secondary school and were enrolled in the Youth En Route (YER) program at the Thames Valley Children’s Rehabilitation Centre in London, Ontario. This was the only study that provided data on participants who did not complete the study.

Of the thirty four participants, 24% had cerebral palsy, 27% had spina bifida, 49% had various other conditions (for example, acquired brain injury). Of the entire sample, 44% reported limitations in mobility, 38% had learning or cognitive limitations, 18% had vision limitations, 12% had limitations in communication, 9% had limitations in hearing, and 12% reported limitations that were listed as “other” (Evans et al., 2006). The study did not specify whether there were adolescents with sickle cell, diabetes, or cystic fibrosis in the 49% with various other conditions. However, some of the sample characteristics describe the functional challenges faced by adolescents with these conditions. A decision was therefore made to include this study in the analysis.

Once registered in the program, registrants were then contacted by telephone by a research assistant and asked if they wanted to participate in the study. Registrants who indicated an interest over the phone were scheduled for a pre-test interview by the research assistant. The study reported 0% as in school full-time, 8% in school part-time, 5.9% working full-time and 41% working part-time. Evans et al. (2006) recorded 64.7% of participants living with parents, 26.6% living independently and 8.8% living in a supported environment. Seventy-seven percent lived in London. The remaining 23% lived in the counties of Elgin, Middlessex, or Perth.

Vidal et al. (2004) recruited a convenience sample of n=80 young adults with type 1 diabetes who transferred between 2000 and 2002 from a paediatric care unit (Sant Joan de Dieu) to an adult care centre (Hospital de Clinic I Universitari de Barcelona) in Barcelona. All of those who transferred between 2000 and 2002 were included in the study. Those lost due to attrition, address change, or other factors were not followed up in adult care. Seventy-two patients (n=39 female, n=33 male) completed the program. The mean age of participants in the study conducted by Vidal et al. (2004) was listed as 19 +/- 1.3 years.

All four studies listed the gender distribution of their samples. The total number of participants across all four studies was n=193 with a relatively even gender distribution: n=93 female and n=100 male.

Study Objectives

The objectives of all four studies were to evaluate the impact of an intervention or approach to transition. Their objectives differed in the way in which they went about doing this. Three out of four studies (Evans et al., 2006; Van Walleghem et al., 2008; Vidal et al., 2004) evaluated how the transition program would change outcomes for those who participated; the fourth study (Cadario et al., 2009) evaluated how one approach/intervention differed from another.

Type of Intervention

Three of the four studies were disease-specific interventions relating to diabetes (Cadario et al, 2009; Van Walleghem et al., 2008; Vidal et al, 2004). One study used a non-categorical disease approach (Evans et al., 2006). These same three studies focused on altering care provision in the tertiary setting while the latter was a stand-alone program attended by the adolescent and his or her family.

The Maestro Project by Van Walleghem et al. (2008) used a systems navigator to support patients as they transitioned from paediatric to adult diabetes care. The person in the role of systems navigator was responsible for maintaining a comprehensive website, a bi-monthly newsletter, and a monthly evening drop-in group, and providing participants with opportunities to both network and socialize at educational events. These events were attended by patients as well as diabetes educators, endocrinologists, researchers, and other service providers and were designed to facilitate relationship-building between patients, their peers, and care providers. Participants were contacted by the systems navigator by telephone every six months to collect information about medical- or disease-related concerns, educational visits, chronic complications, hospitalizations for diabetic ketoacidosis, and barriers to accessing disease-related care in the adult care system. The care team included two diabetes nurse educators, two dieticians, a social worker, three paediatric endocrinologists, and five support staff. Specific duties of the care team were not listed. The systems navigator "works closely with community based health centres in all Manitoba Regional Health Authorities to promote community links and communication" (Van Welleghem, MacDonald, & Dean, 2011, p. 10). Little detail is given regarding specific duties of the person with this title and no information is provided about the frequency with which events were held and the extent to which these were attended. No information is provided about family involvement.

The study by Vidal et al. (2004) used a Therapeutic Education Program (TEP) which included: coordinated transfer visits with endocrinologist and nurse; an initial patient evaluation by diabetes adult care staff; and a patient and family assessment during the first visit. Time planned for each first visit was 90 minutes. Diabetes staff was expected to perform three to six visits in three to six months (average of one visit per month). The content of the TEP was explained and a leaflet was given to each subject. At each visit, an explanation was provided about what could be done during the visit and patients were asked what aspects of the presentation they wanted to cover. Participants were offered four group sessions, two hours each, plus three to six individual visits during the three to six month period.

The study by Cadario et al. (2009) consisted of a structured and unstructured transition program. The structured program, implemented in 1999, had a specialized healthcare team at both paediatric and adult care sites. The team was made up of a paediatrician who acted as transition coordinator and an adult endocrinologist who followed patients through the transition process. The transition process would be discussed by the paediatrician during the last year of paediatric care. At the second to last visit in PDS, a letter with a description of events during the year was given to the patient by the paediatrician. During the last visit in paediatric care, patient was seen by the endocrinologist and paediatrician together at which time the transfer and patient’s condition were discussed. Parents were not included in this last clinic visit. Continuous individual support was guaranteed to patients in the structured program (no description of the individual assistance was provided). Patients were informed that if they were not satisfied with the outcomes in adult care they would be given the opportunity to return to paediatrics. The unstructured program, in place from 1994 to 1999, used a letter summarizing a patient's clinical history and included a fixed appointment for adult care services.

In the study by Evans et al. (2006) the intervention was a regional support program for youth and young adults ages 16 to 29 with various disabilities who had completed secondary school. It was provided to AYA who had chronic health conditions that involve multiple functional limitations related to mobility, communication, vision, hearing, learning and cognition and other daily activities such as self-care. The program had three main components: self-discovery (interpreted as self- knowledge, self-evaluation, information-gathering, planning and goal setting); skill development (through life skills, employment skills); and community experience (through job training, community involvement, accommodations). There were no specific details about how the components were implemented or by whom. The average duration of this intervention was ten months with some variation according to individual goals.

Two of the four studies included family in the intervention (Evans et al., 2006; Vidal et al, 2004). The former study provided families of study participants with information about support and invited them to be involved in the planning process so that they were better prepared to help AYA become more self-determined and participate in the community (Evans et al., 2006). Family involvement reflected the family-centred service delivery model, underpinned by the study. This approach will be discussed further in the section on theoretical approaches used in interventions. Vidal et al. (2004) included the participant’s family in the pre- and post-evaluation. They were included in the initial assessment of participants and their families by a paediatric nurse and endocrinologist. The description does not specify whether the families were included in the four, two-hour group sessions attended by the participants. However, it does allude to family presence for the visits, as visits were adjusted according to a participant or family's need to improve disease management control.

Use of Theory

Two out of four studies made reference to a theoretical framework or guiding principle for the intervention (Evans et al., 2006; Van Walleghem et al., 2008). Only one study (Evans et al., 2006) explicitly stated incorporating the family-centred model of support which they describe as a "family-centred, client-driven service that offers a flexible multi-faceted approach to adolescent transition" (p. 68). Evans et al. (2006) maintained the family-centred model into the adult care setting which, compared to the paediatric care setting, traditionally operates on a more individualistic and autonomous model. Vidal et al. (2004) also included family in the initial assessment of participants in their study and it appears as if they too were intended to be part of the Therapeutic Education Plan in supporting the participant's self-management skills (p. 25). However, it is not definitive in what in way they were instructed to assist with self-management.

The study by Evans et al. (2006) was based on the philosophy of self-determination and self-efficacy as it relates to independence and health management. They define self-determination as the autonomous beliefs and behaviors that ultimately lead to personal choice (Evans et al., 2006, p. 66). Self-determination theory is an approach to human motivation that highlights the importance of an individual's inner resources for personality development and self-regulation (Ryan & Deci, 2000). Self-efficacy refers to a person's "assessments of their effectiveness, competence and causal agency" (Gecas, 1989, p.291). In this study, self-determination theory was used as a mechanism to facilitate autonomy and self-regulating behaviors (Evans et al., 2006). Evans et al. (2006) also used the family-centred model of support. Based on the framework developed by the CanChild Centre for Childhood Disability Research, family-centred model of care is:

> …made up of a set of values, attitudes and approaches to services for children with special needs and their families. Family centred service recognizes that each family is unique; the family is constsant in the child's life and they are the expert on the child's abilities and needs. The family works together with service providers to make informed decisions about services and supports the child and family receive. (Law et al., 2003, as cited in King, Teplicky, King, & Rosenbaum, 2004, p. 79).

There are few theories associated with health transition that would make the presence of a theoretical model in transition literature self-evident to the reader.

Van Walleghem et al. (2008) based the study on the "patient navigator" model originating from a cancer care follow-up model. This is a client-centred model that focuses on tracking and follow-up care of patients after they leave the facility following diagnosis. The original study (Van Walleghem et al., 2008) does not provide much description of the model itself, but a later editorial (Van Walleghem et al., 2011) explains it as a program arising from the cancer care literature. The patient navigator model is described as being created in 1990 in Harlem, New York, to help low-income women overcome barriers to breast cancer screenings and follow-up (Van Walleghem et al., 2011). The editorial describes common functions of the patient navigator as assisting clients' access, coordinating services, identifying individual barriers to care, and providing emotional support and advocacy (Van Walleghem et al., 2011). It was used in the Maestro Project as a means helping young adults with T1D navigate through a complex health care system.

There was no reference to a theoretical framework in the remaining two studies.

Methods and Design

Of the four studies, three were longitudinal (Evans et al., 2006; Van Walleghem et al., 2008; Vidal et al., 2004). Only one study was cross-sectional (Cadario et al., 2009). Two of the studies used a single group (Evans et al., 2006; Vidal et al., 2004); two used two cohorts (Cadario et al., 2009; Van Walleghem et al., 2008). However, they used them in different ways. Cadario et al. (2009) used one cohort to compare against another while Van Walleghem et al. (2008) combined the two cohorts. Cadario et al. (2009) used a cross-sectional retrospective design to document information obtained from patient records and telephone or in-person interviews. For this study, two cohorts were compared: one had received a structured intervention and one had not. The latter was a naturalistic group that was part of the Diabetes services until December 1999; the former were seen after that. Evans et al. (2006) used a longitudinal design to follow a single group using pre- and post-test self-report measures that were standardized. Van Walleghem et al.'s (2008) study was longitudinal but used patient records and a self-report survey. Vidal et al. (2004) was also a longitudinal study employing pre-test and post-test measures of a single group and used a combination of medical records and standardized self-report measures.

Two of the four studies used standardized measures (Evans et al., 2006; Vidal et al., 2004). The standardized measures used by Evans et al. (2006) were the ARC Self-Determination Scale with seventy-two items divided into four subscales of autonomy, self-regulation, psychological empowerment, and self-realization (Wehmeyer & Kelchner, 1995, as cited in Evans et al., 2006). Scoring of the ARC Self-Determination Scale involves determination of raw scores from all domains and subdomains, calculation of a total score, and interpretation of the raw scores based on conversion tables (Wehmeyer, 1995). Raw scores are converted into percentile scores for comparison with sample norms and to determine the percentage of positive responses. For autonomy, participants responded to each statement using a four point Likert Scale ranging from "never" to "all of the time" (Wehmeyer, 1995). The section on self-regulation consisted of two subdomains where participants were required to write or dictate answers. The first section involved story-based answers where the participant identified what he or she considered the best solution to a problem. Responses were scored on a scale of 0 to 2 based on the effectiveness of the solution to resolve the problem (Wehmeyer, 1995). Higher scores on the ARC represented higher levels of achievement on each of these subscales (Wehmeyer, 1996, as cited in Evans et al., 2006). The ARC was validated on a sample of 400 adults with developmental disabilities (Wehmeyer, 1996, as cited in Evans et al., 2006).

Participants' perception of control over their lives was measured in Evans et al. (2006) using the Nowicki-Strickland Locus of Control Scale (NSLC; Nowicki & Strickland, 1973). This is a 40-item scale that uses a "yes" or "no" response format with higher scores representing an external locus of control and lower scores representing an internal locus of control. According to descriptions of the original instrument, scoring for the NSLC scale is done by adding up the number of items that are scored correctly (Fischer & Corcoron, 1994). Concerning reliability, the NSLC scale has only fair internal overall consistency with split half reliabilities increasing with age: .68 for grades 6 through 8; .74 for grades 6 through 11 and .81 for grade 12. Stability of the NSLC scale is fair with six-week test/re-test correlations of .66 for the seventh grade and .71 for tenth grade (Fischer & Corcoron, 1994). With respect to validity, the NSLC has been shown to correlate with numerous academic and non-academic behaviours although race, socio-economic level, and sex tend to mediate some of those findings (Fischer & Corcoron, 1994). To generate "norms," the NSLC was developed in a series of studies involving 1,000 male and female children from the third to the twelfth grade. The students were predominantly white from all socio-economic levels. Means for males and females range from 11.01 to 18.80 with students' responses becoming more internal with age (Fischer & Corcoron, 1994).

Evans et al. (2006) also used the Community Integration Questionnaire (CIQ; Wilier, Ottenbacher, & Coad, 1993), which was designed to be used with people with brain injuries. It was used here to measure participants' levels of community integration and consisted of four items using a three-point response scale (never, one to four times per month, and five times per month or greater) to measure frequency of activities such as shopping, leisure activities, visiting friends or relatives, and volunteering (Evans et al., 2006). An additional three items were added to assess participants' school and employment situation (full time, part time, etc.) and the extent of travel outside the home (daily, weekly, seldom, never) (Evans et al., 2006). Given that the original scale was altered, and no reliability or validity information is provided in Evans et al. (2006), it is not possible to make any claims about its properties. Scores can range from 0 to 29 points where high scores represent greater independence and community integration dived between: Home integration (possible 10 points); Social interaction (possible 12 points); and Productive activity (possible 7 points) (Rehabilitation Measures Database, 2013). Two versions of the CIQ questionnaire are available: one for patients and one to be used with families (Rehabilitation Measures Database, 2013). It can be self-administered or administered over the phone.

The Client Satisfaction Questionnaire (CSQ) was an additional test administered during the post-test period in Evans et al.'s (2006) study. It is an eight-item standardized measure and uses a four-point Likert scale to measure overall satisfaction with services (Larsen, Attkisson, Hargreaves, & Nguyen, 1979). It has high internal consistency and adequate concurrent validity (Evans et al., 2006, p. 73). Regarding correlates of satisfaction, relationships were tested between the CSQ and numerous variables (such as education, two ethnic categories [white and non-white], employment status, outpatient visits) using chi-square statistics and correlations. In the chi-square tests, CSQ scores were collapsed into three levels: low, 18-20; medium, 21-26; and high, 27-32 (Larsen et al., 1979). It is scored by adding the individual item scores to produce a range of 8 to 32 with higher scores indicating greater satisfaction (Fischer & Corcoron, 1994). The CSQ rates excellently in internal consistency with an alpha range from .86 to .94. Test and re-test correlations were not reported (Fischer & Corcoron, 1994). It has very good validity. For this the scores are correlated with clients' ratings of global improvement and symptomology and the therapists' ratings of clients' progress and likeability (Fischer & Corcoron, 1994).

In their study of the Therapeutic Education Program (TEP), Vidal et al. (2004) used the Diabetes Knowledge Questionnaire (DKQ2; Lennon, Taylor, Debney, & Bailey, 1990) and the Diabetes Quality of Life test (DQOL; The Diabetes Control and Complications Trial Research Group, 1996).

The DKQ2 was used to assess knowledge of type 1 diabetes and disease management. The DKQ2 was created by Lennon et al. (1990), an expanded version of their original Diabetes Knowledge Questionnaire 1. In the study by Lennon et al. (1990), several other tests were administered, including a test of attitudes and blood glucose control. The DKQ2 specifically measured technical skills related to self-care (e.g. insulin injections, diet and blood glucose testing). The DKQ2 questionnaire comprised 16 items; reliability was determined with Cronbach's α coefficient ($\alpha = 0.83$) and an item difficulty of $P = 0.61$ (Lennon et al., 1990). Technical skills were assessed using a short test of insulin injection technique (5 points maximum), diet (4 points maximum), and blood sugar testing (1 point maximum). Reliability and validity were not conducted on this portion due to the nature of the test. However, the test served as a measure of external validity for the knowledge questionnaires (Lennon et al., 1990).

The Diabetes Quality of Life (DQOL; Diabetes Control and Complications Trial Research Group, 1996) was used by Vidal et al. (2004) to measure general satisfaction and preoccupation with diabetes. The DQOL is a multiple-choice assessment designed to be used with both adults and adolescents. Items do not identify specific types of treatment, such as an insulin pump or self-monitoring blood tests, so that it can be administered to patients using varied types of diabetes management (Diabetes Control and Complications Trial Research Group, 1988). It has four primary scales (15 items on satisfaction, 20 items on impact, 4 items on diabetes worry, 7 items on social/vocational worry), with a total of 46 core items for use in all patients. Responses to question are rated on a 5-point Likert scale (Diabetes Control and Complications Trial Research Group, 1988). Satisfaction is rated from 1 (very satisfied) to 5 (very dissatisfied). Impact and worry scales are rated from 1 (no impact and never worried) to 5 (always impacted and always worried). In addition to the core items there are 16 questions in the DQOL that assess education and family relationship for patients living with parents. Validity of the DQOL was assessed using three instruments: The Symptom Checklist-90-R (SCL), The Bradford Affect Balance Scale (ABS) and the Psychosocial Adjustment to Illness (PAIS) (Diabetes Control and Complications Trial Research Group, 1996). These instruments were chosen because they measure related aspects of quality of life and thereby provide an estimate of convergent validity (Diabetes Control and Complications Trial Research Group, 1988). Two forms of reliability were assessed for the total score and the four scales of the DQOL: internal consistency with Cronbach's α; and test-retest by use of Peason product-moment correlations. All validity testing indicated that the DQOL was valid.

The DKQ2 and DQOL took approximately ten minutes to complete and were administered both pre- and post-intervention. Information was also apparently collected regarding vocational planning, lifestyle (drugs and alcohol), sexual health, psychosocial support and other health behaviors. However, no description is provided about how they were evaluated or what the results were.

Two studies used telephone interviews as a method for collecting data. Van Walleghem et al. (2008) stated that they collected information every six months by telephone about disease-related educational visits, chronic complications, hospital admissions and emergency room visits for acute complications, and barriers to accessing disease-related care in the adult system. However, it is unclear how many data collection points there were and whether this information was collected solely by telephone interview or by chart review as well. This information was entered into their database for later analysis. In the study by Cadario et al. (2009) participants were asked questions regarding the general experience of the transition process by a nurse from the paediatric service. It is not clear what the questions were and whether they were linked to satisfaction and compliance. In both cases, the questions used in the telephone interviews were designed specifically for the study. In neither case were the variables created from those interviews and later reported or rendered explicit and clear.

The same two studies (Van Walleghem et al., 2008; Cadario et al., 2009) performed audits of medical records as a means of gathering data. A similar method was used by Vidal et al. (2004). It appears that Van Walleghem et al. (2008) used the medical records to validate what patients had reported in their interview by telephone. Cadario et al. (2009) gathered information on the following seven areas: 1) medical care during transition, 2) insulin prescriptions, 3) frequency of physical examinations, 4) assessment of glycaemia tests, 5) retinal and foot screening, 6) number of HbA1c determinations and micro albumin urea over a one year period, and 7) recent changes in insulin therapy (proposed by physician, endocrinologist or self-administered). Clinic attendance rate in the Paediatric Diabetes Services (PDS) and in the first year in the Adult Diabetes Services (ADS) was also obtained from medical records. Cadario et al. (2009) measured metabolic levels at date of first admission to adult care as well as any changes in glycated haemoglobin between paediatric and adult care. However, the duration between the two points is not stated. They also measured the rate of clinical attendance in paediatric and adult service. Vidal et al. (2004) obtained information from the medical record about diabetic diet, including intake of carbohydrates, protein and fat, body weight, metabolic control (HbA1c levels), number of hypoglycaemic episodes and insulin modification and intake. Van Walleghem et al. (2008) sent out a survey of participant experience to n=248 patients and received a response back from only n=35, a response rate of 14%.

Patient experience or patient satisfaction was considered in two of the studies (Cadario et al., 2009; Evans et al., 2006; Van Walleghem et al., 2008). In the study by Cadario et al. (2009) patient satisfaction was measured by participants' evaluation of their care as good, sufficient or bad. Although satisfaction was measured by the DQOL in Vidal et al.'s (2004) study, it referred to satisfaction with life rather than satisfaction with the program.

Evans et al. (2006) compared pre- and post-test participant scores to norms of those without disabilities, norms of individuals with mental retardation, and norms with learning disabilities, to obtain effect size. Participants were contacted twelve months after the start date of the program and a post-test interview was conducted in mostly the same manner as the pre-test interview. In this post-test interview, Evans et al. (2006) added the use of the previously mentioned CSQ.

Analysis

Cadario et al. (2009) used chi-square analysis to examined the relationship between two groups (structured vs. unstructured) and whether they received follow-up by a specialist or a general practitioner, the extent to which they were engaged in self-monitoring (yes/no), and experiencing an interruption in clinical or laboratory examination (yes/no). Chi-square was also used to examine the relationship between group and satisfaction. T-tests were used to examine group differences in relation to the following dependent variables: time between last visit in PCC and first visit in ACC; change in HbA1c levels between paediatric and adult care; and between arrival to and one and three years after entering adult care, clinical attendance, and compliance.

Evans et al. (2006) similarly used chi-square tests for descriptive categorical variables and t-tests for subscale and total scores for each measure. Scores on the ARC Self-Determination Scale are compared to normative scores for individuals with mental retardation, learning disabilities and no condition. However, no tests of significance are conducted.

Van Walleghem et al. (2008) documented the proportion of each cohort that was engaged in medical and/or educational support before and after involvement the Maestro Project. Analysis was conducted separately for each cohort. The rest of the results are purely descriptive with no group differences examined. The rates of diabetic ketoacidosis both before and after the Maestro Project are documented; these are again reported separately for the two cohorts. Although no information is provided about the type of statistical test conducted, we are told that the differences are not significant.

Vidal et al. (2004) uses chi-square tests to examine the relationship between time (pre vs. post), percentages of carbohydrate, protein and fat intake, and percentage self-adjusting their insulin. T-tests are used to examine the relationship between time (pre vs. post) and insulin modification, weight, diabetes knowledge, and quality of life indicators.

Dosage of intervention was only prescribed by Vidal et al. (2004). It was the only study to offer a breakdown of dosage or number of hours dedicated to a component of the intervention. The study by Evans et al. (2006) explains duration of the total intervention as being ten months; however, there is no information provided on the number of hours attended to the components of the intervention. The only study to conduct power analysis was Evans et al. (2006).

Results

The study by Cadario et al. (2009) provides support for a structured approach to transition. Comparing results from analysis of the structured group versus the unstructured group, Cadario et al. (2009) reported that the unstructured group was less likely to receive specialist follow-up, were more likely to have prescriptions for insulin refilled by a general practitioner, and were more likely to have a break in clinical or lab exams. The time between discharge from paediatric to being seen in adult care was shorter for the structured group. Metabolic control in the structured group improved more than in the unstructured group during the transition from paediatric to adult care. One year after the transition, metabolic control in the structured group was better than in the unstructured group; this difference disappeared after three years. However, three years after the transition, the structured group were attending clinic more often than the unstructured group.

Van Walleghem et al.'s (2008) study provides support for the use of the systems navigator model. They reported positive results stating that the intervention helped the older group re-connect with adult care services and helped the younger group reduce first-year fall-out rates after transfer from paediatric to adult care. Forty percent of the older group dropped out of adult medical care compared to only 11% of the younger group who used the assistance of the navigator to transfer care. Both cohorts (older and younger) had similar rates of hospital admissions and emergency room visits for acute complications. This study reported a low response rate (14%) to the patient survey. Of those who responded (n=35), almost half of the respondents from both cohorts reported a period without medical care for >1 year. Most of those participants agreed that there was a need for a transition service and that the Maestro project had been helpful to them in managing their diabetes.

Overall, the study by Vidal et al. (2004) found that the Therapeutic Education Program provided moderate support for its use. Little or no change was reported in meal plan composition after follow-up, with a tendency toward carbohydrate-counting improvements. Participants showed decreases in glycated haemoglobin at the end of the study. Knowledge-of-disease scores increased from 71% to 82%. There were no differences reported in terms of total daily insulin dose. However, an increase in the proportion of rapid-acting insulin at the end of the follow-up was noted compared to the beginning (52% compared to 23%). There was an increase in the proportion of subjects who performed readjustments of insulin doses considering self-measurement of capillary blood glucose after three or four days of monitoring (to 48% after twelve months, from 13% initially). Quality of Life (DQOL) test scores showed little or no change from pre-test to post-test. The conclusion was that improvement in metabolism was accomplished without a decrease in quality of life.

Evans et al. (2006) reported that their intervention yielded overall improvement in total self-determination, autonomy, self-regulation and self-realization. Improvement in locus of control was also statistically significant. Hours spent in work/volunteer activities, community leisure activities, and transportation activities increased over time. However, while these improvements were statistically significant, only changes in hours spent in work/volunteer activities and community/leisure activities were clinically meaningful. The proportion of participants living independently increased from 14.7% to 26.6%. The proportion of participants working part-time increased from 17.6% to 41.2%. A majority of youth were highly satisfied with the program. This study compared the pre-/post-test means of the study participants with the ARC norms for adolescents and young adults with mental retardation, learning disabilities and those with no disabilities. Results showed self-regulation post-test scores for participants were higher and therefore better than all three of the other groups. In terms of self-realization, both pre-test and post-test scores for participants were also higher than all three groups. For psychological empowerment, post-test scores of participants were lower than pre-test scores but slightly higher than those with mental retardation and lower than those with learning disabilities and no disabilities. The total ARC scores of participants in post-test were higher than all three groups. Although no tests of significance were conducted, when compared to Canadian norms, participants were dedicating more time to personal care, less time to domestic chores, education, and work/volunteer activities; more of their leisure time was spent at home.

Limitations

Limitations have been described throughout this chapter. The following highlights additional limitations. None of the studies used detailed process measures to establish program fidelity which would evaluate whether each patient received the same intervention and the same amount of the intervention. The exception to this was the study by Vidal et al. (2004) which specified the number of sessions, both individual and group, that were offered. Furthermore, the descriptions of the interventions in all studies make it difficult to replicate any of them. Van Walleghem et al. (2008) published limitations to the study in a supporting document (Van Walleghem et al., 2011). Within this publication they acknowledged a number of limitations relating to bias and generalizability listing three primary limitations as:

1. The patient navigator charged with collecting data for the database also held a non-professional position of advocacy with the participants. Thus, there may have been recall bias in the information provided by participants.
2. Participation in the Maestro project was voluntary, leading to potential selection bias.
3. The rate of response to the survey was low and therefore not generalizable to all adults with type 1 diabetes.

This survey was a self-report participation survey subject to low validity and reliability. They discuss the transient nature of the young adult population and the impact on the high rates of attrition. The short duration of the intervention prevented exploration into cause and effect relationships between participation and chronic complications. The study had no control group (Van Walleghem et al., 2011).

Evans et al. (2006) also had no control group making it difficult to conclude whether the outcomes were a result of the intervention or if participants would have achieved those outcomes regardless of the intervention. The authors suggested that it was not possible to use a control group or random assignment for ethical reasons and time related to the period for which they received government funding for the study. As such, “comparable clients in other geographic regions could not be requested as this would create a demand for service which they did not have the budget resources to provide” (Evans et al., 2006, p. 69). None of the studies accounted for age or other sociodemographic characteristics and the potential role they could play in outcome.

Discussion

The findings in this scoping review indicate that there is a scant but emerging body of studies evaluating transition interventions. Only four studies met the inclusion, so this development is modest at best. The presence of transition research literature, though relatively small, seems to indicate that transitional care is slowly shifting from establishing a need for transitional support to implementing and evaluating transition as a valid intervention. Few transition studies met the standards set out by the Centre for Evidence Based Medicine for higher levels of evidence, which would qualify studies as having the necessary components to be consistently applied to other settings (OCEBM Levels of Evidence Working Group, 2013).

Sample and Recruitment

The samples in the final four studies were all convenience samples. It is difficult to ascertain if sample sizes were adequate. Typically a power analysis is performed to determine a statistically meaningful sample size; only one study (Evans et al., 2006) performed this analysis. Their minimum required sample size was thirty five participants; their study had thirty four. The study claims to have “came close" to the calculated minimum effect size but did not achieve the minimum (Evans et al., 2006, p. 71). The remaining three studies did not use power analysis to calculate an appropriate sample size. Recruitment of adequate sample sizes is challenging, particularly when studies are not formally funded and adequate resources cannot be allocated to this function. Only one of the studies was funded (Evans et al., 2006). It was in fact, the only intervention that was offered outside of standard care and required additional ‘attendance’ at a structured program per se.

There are a number of ways to ensure adequate sample size for transition studies. One method increasingly being used is that of recruitment via Twitter or Facebook. Similarly, interventions are increasingly being offered online. For example, David Nicholas from the

University of Calgary, has investigated the use of web-based support groups (Nicholas et al., 2012). Nicholas et al. (2012) reported online support as an important resource for clinical practice as it reduced isolation and facilitated coping for fathers of children with brain tumours. Similarly, findings illustrated by Nicholas et al. (2009) revealed that accessibility, ease of communication and connection with peers were among the benefits of an online support network for adolescents with chronic kidney disease. These results are further supported by Marziali and Garcia (2011) who found that both patients with dementia and their caregivers showed improvements in self-efficacy and a decline in distress following post-test examination of participation in web-based interventions.

Some concern was expressed in one of the studies about whether randomized control trials are "ethical" and therefore feasible (Evans et al., 2006). Withholding a potentially beneficial treatment is cited as the concern. Although understandable, in such cases a quasi-experimental cross-over design could have been used. This allows those who are initially in the control group to receive the treatment after the intervention group have received theirs. It facilitates comparison of an intervention to those who receive treatment as usual, thereby allowing attribution to be made to the intervention and not time alone (Sibbald & Roberts, 1998).

Samples were obtained from adult care facilities (Cadario et al., 2009; Van Walleghem et al., 2011; Vidal et al., 2004) as well as a paediatric tertiary care centre (Evans et al., 2006;). Transition programs are shown to be most effective when they are initiated during the paediatric care phase rather than after the transition has already occurred to adult care (Stewart et al., 2009). Although the samples obtained via adult care were convenience samples for the purpose of evaluation, transition programs ideally require collaboration between paediatric and adult sites (Bolton-Maggs, 2007; Berg Kelly, 2011; Stewart et al., 2009).

There is limited information about the demographic characteristics of those who participated in the studies. Mean age and age range was provided; all of the selected studies documented gender of their sample group. None of the studies used age or gender to understand intervention effectiveness. Beyond that, little is known about participants' socioeconomic status, such as their ethnocultural or immigrant status, family structure, and whether they were living in urban or rural centres. One study (Evans et al., 2006) provided a breakdown of the chronic conditions and types of impairments represented in their sample, but only did so for 51% of the sample. The other 49% was referred to as “various other conditions” (Evans, et al. 2006, p. 70). In summary, it appears that not much attention is being given to the uptake of these programs for youth from different socioeconomic backgrounds. Future research should take into consideration factors such as age, language, cultural beliefs regarding engagement with health care professionals in intervention programs as beliefs about chronic conditions and disabilities are not homogeneous (Davies & Vander Stoep, 1997; Stewart, Law, Rosenbaum & Willms, 2002). These types of issues can potentially impact the effect of an intervention and introduce additional barriers (Rueda et al., 2005; Trainor, 2008).

Disease-Specific vs. Non-Categorical Approaches

The results from this review reflect a strong emphasis on Type 1 Diabetes in the transition literature. This is in keeping with the findings of Crowley, Wolfe, Lock and McKee (2011) who found that “most studies evaluating transitional care have been for patients with diabetes mellitus” (p. 548). Berg Kelly (2011) describes it as a well-defined serious disease where follow-up in adult centered care is needed. Transition is equally as challenging for those with other chronic conditions such as cystic fibrosis and sickle cell disease. The sample size of this scoping review is too small to draw significant conclusions about the emphasis on diabetes, but the trend is worth noting and reflecting upon.

Another important observation is that only one of the studies was non-categorical. On the one hand, disease-specific interventions do have some advantages, in that they consider the needs of transitioning adolescents that are unique to their condition. Fear of self-injecting, for example, has been associated with poor glycaemic control in adolescents with T1D (Berlin et al., 1997). Female adolescents with T1D are at higher risk of poor glycaemic control related to diet, because of higher instances of anxiety related to body image (Trigwell & Jawaad, 2007). Being part of a community of people who share similar experiences based on a condition may provide a sense of inclusion for young people. While disease-specific interventions account for the nuances and special considerations for any particular condition, institutions would be challenged to implement individual transition programs for each condition. Perrin et al. (1993) argue that "this approach fosters thinking about chronic conditions as discrete entities and discourages considerations of the collectivity of chronic conditions as a whole" (p. 787). There may be a benefit to implementing transition programs that address issues that are common to adolescents and their caregivers such as the 'experience of the condition', its impact on peer relationships, sexuality, employment, continuing education, housing, etc. If all adolescents and their families must make a plan for the next developmental phase, they theoretically could do so together.

The Intervention

All of the studies set out to evaluate the impact of an approach to transition. Three of the programs were delivered in the context of care-as-usual by altering what was considered the 'typical' health care encounter. Evans et al. (2006) required attendance in a separate program. While little has been developed regarding standard protocols for transition to young adulthood, some have started to identify best practices and recommendations. The CanChild Center for Childhood Disability Research at McMaster University published an evidence-based model and best practice guidelines for the transition of youth with disabilities. The model identifies six main themes emerging from discussions and professional consensus from a panel of field experts entitled the “Best Journey to Adult Life” Model. The six main elements for healthy transition include:

1. collaborative initiatives and policies are necessary supports for the transition
2. building capacity of people and communities will enhance the transition process
3. the role of a “navigator” within communities facilitates capacity building
4. information and resources are accessible to all involved in the transition process.
5. education is a critical component of any transition strategy
6. ongoing research and evaluation provides the evidence needed for success (Stewart et al., 2009)

A joint consensus statement of “critical first steps” was published by a number of professionals associations, regarding the transition process for young people with special health care needs (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002). This was the result of an invitational planning committee consisting of field experts who organized to collaborate on a policy statement representing consensus around the responsibilities of service providers to young people with special health care needs and their families transitioning through the health system. They developed six critical first steps necessary for optimal transition support which include the following points:

1. an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health care planning
2. identify the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special health care needs and make them

part of training and certification requirements for primary care residents and physicians in practice

3. prepare and create up-to-date medical summary that is portable and accessible
4. create a written health care transition plan by age 14 together with the young person and family
5. apply the same guidelines for primary and preventive care for all adolescents and young adults, including those with special health care needs, recognizing that young people with special health care needs may require more resources and services than do other young people to optimize their health
6. ensure affordable, continuous health insurance coverage for all young people with special health care needs throughout adolescence and adulthood. This insurance should cover appropriate compensation for 1) health care transition planning for all young people with special health care needs, and 2) care coordination for those who have complex medical conditions. (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002)

Using these standards, Table 3 analyzes the extent to which the programs reviewed reflected principles identified in these ‘best practice’ checklists.

Table 3: Best Practices

	Cadario, et al., 2009	**Evans et al., 2006**	**Van Walleghem et al., 2008**	**Vidal et al., 2004**
Collaborative initiatives and policies (between pediatric and adult services and practitioners)		✓		
Capacity building of people and communities		✓		
“navigator” within communities facilitates capacity building.			✓	
Information and resources are accessible to all involved in the transition process			✓	

	Cadario, et al., 2009	**Evans et al., 2006**	**Van Walleghem et al., 2008**	**Vidal et al., 2004**
Education is a critical component of any transition strategy				✓
Ongoing research and evaluation provides the evidence needed for success				
Identify health care professional Who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health care planning.			✓	✓
Identify the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special Health care needs and make them part of training and certification requirements for primary care residents and physicians in practice				
Prepare and create up-to-date medical summary that is portable and accessible	applied this after age 18		✓	✓
Create a written health care transition plan by age 14 with the young person and family.	applied this after age 18			
Apply the same guidelines for primary and preventive care for all adolescents and young adults, including those with special health care needs, recognizing that young people with special healthcare needs may require more resources and services than do other young people to optimize their health.				
Ensure affordable, continuous health insurance coverage for all young people with special healthcare needs throughout adolescence and adulthood. This insurance should cover appropriate compensation for 1) health care transition planning For all young people with special health care needs, and 2) care coordination for those who have complex medical conditions.				

This analysis reflects that there are significant gaps in each of the approaches. None of the studies indicated that research was ongoing. Similarly, there was no indication that these programs were applied at the primary and preventive levels, or that they were made into universal programs. All articles were silent on the issue of health insurance coverage. In the Canadian context, coverage for transition planning is provided for through universal health care programs. Although this does not ensure access (as there are other barriers), in principle, provincial funding is the source by which transition plans can be implemented. The following addresses the extent to which each of these components were reflected in the four studies.

Collaboration between paediatric and adult care was evident in three studies: in Cadario et al. (2009) and Vidal et al. (2004), paediatric health practitioners collaborated with an adult endocrinologist to facilitate the transfer process; the rehabilitation specialists in Evans et al. (2006) collaborated with an adult community agency who could provide follow up support after the program was over. It is possible that the systems navigator in Van Walleghem et al.'s (2008) study provided a link between paediatric and adult diabetes care services, but this is not explicitly stated. This type of collaboration ensures continuity of the care plan, accuracy of information transfer, and begins to build a relationship between the young adults and their future care providers.

Capacity building was an explicit focus of the Evans et al. (2006) study where the emphasis was on building skills of self-determination and autonomy which in turn promote healthy decision making and empowerment. These skills are particularly as they are associated with patient's ability to manage their diabetes (e.g. with diet or self-care), to actively participate in the community, and to make healthy life choices. The study concentrated largely on helping participants enhance their capacity to be self-directive and exert control over their own health and well-being. As well, it highlighted the importance of building capacity in the community by a deliberate attempt to make connections with community organizations and participants. Through these connections, community members gain awareness about the strengths and assets offered by young adults. Wynn et al. (2006) describe one of the components of capacity building as "asset mapping" where people in the community take inventory of its own assets. Through this process, they can address the challenges that impede on maximizing the development of those assets (p. 94). The process also encourages a shift in focus from "problems" and "needs" to strengths and potential (Wynn et al., 2006). Further to the benefits of capacity building, it helps agencies foster a sense of accountability among agencies and institutions which can motivate development of appropriate resources, tools and mechanisms to make an organization or institution more relevant to its AYA users (Wynn et al., 2006).

A navigator was successfully used in the study by Van Walleghem et al. (2008) to assist participants with the transition process. There are numerous barriers to accessing follow-up care after transition that a navigator may help to negotiate. Barriers such as systems that are ill-prepared to determine transition readiness, the different developmental capacities of adolescents and young adults, health care professionals who have not received adequate training in the unique developmental needs of emerging adults (Peters & Laffel, 2011) can be addressed by navigators who are familiar with how to deal with such issues. Incorporating a patient navigator helps reduce the risks associated with young people with chronic conditions being lost in follow-up care during or after transition (DiMatteo, 2004). The navigator is also useful in supporting patients with accessing resources and information. However, the study by Van Walleghem et al. (2008) focuses mainly on the participants as individuals rather than the participants and their families.

The extent to which information and resources were available to both the patient and his or her family also varied. Families were included in the studies by Evans et al. (2006) and Vidal et al. (2004). Family involvement is considered an important component of the transition process (Laffel et al., 2003). Families of adolescents working with a care team had better metabolic outcomes than those receiving standard care and the families and were more likely to maintain or increase family involvement in the care plan (Laffel et al., 2003). For young people with chronic conditions parents have often been involved in their health since diagnosis in the paediatric care setting as parents are a significant part of managing health care for the young person. After transition to adult care where the culture of team and family support is abruptly reversed into a patient-centred model, parental involvement suddenly becomes precarious, uncertain and is often not supported. Future interventions and their evaluation should include families in the planning process.

Education is another principle identified as a best practice for successful transition of young people with chronic conditions. Education about transition was not an explicit component of any of the four studies; however, it was an implicit in each of them. The engagement of patients, their families, health care providers and community agencies would, de facto, increase knowledge about transition. In order to have a true impact on the transition experience, numerous parts of the participant's ecological environment must be engaged. This is consistent with intervention approaches in social work that draw on multisystemic principles. An important aspect of the multisystemic approach is identifying factors within each system or subsystem that promote negative outcomes. Using this information, a treatment plan is developed that integrates interventions within and between family, peers, school and community systems (Henggeler et al., 1996). In doing so, the multisystemic approach aims to provide the individual and their family with complete care addressing both micro and macro (internal and external) barriers (Henggler et al., 1996).

Medical summaries distill a lengthy medical history into its most salient features allowing adult practitioners to focus their efforts on where the patient left off in paediatric care. It appears that such a summary was used by Cadario et al. (2009) as part of their unstructured intervention. In the structured program, a summary letter was just a small part of a more interactive, collaborative transfer process.

The studies provide little direction regarding the duration of the intervention as this varies considerably. Vidal et al. (2004) utilized three to six coordinated visits, each visit lasting ninety minutes over a three to six month period. They reported that approximately twelve to fifteen hours were devoted to each subject and about half of these hours were group sessions. Informal group gatherings were also used by Van Walleghem et al. (2008), although no information is provided on duration, dose, nor content. The program evaluated by Evans et al. (2006) was ten months in duration. Although the total number of visits in Cadario et al.'s (2009) study was not specified, they did note whether or not patients attended and how long it took them to make an appointment in adult care. The study by Van Walleghem et al. (2008) collected data on medical and psychosocial status every six months over a two year period but did not specify or focus on the degree or duration of contact. No conclusion can therefore be drawn regarding how much of an intervention should be received and over what time period.

Use of Theory

While discussion of transition models is evident in the literature, two out of four of the selected studies made reference to a theoretical framework used as a guiding principle for the intervention. One study (Van Walleghem, MacDonald, & Dean, 2011) was based on the "patient navigator" model originating from a cancer care follow-up model. This is a client-centred model that focuses on tracking and follow-up care of patients after they leave the facility following diagnosis. It was developed as a strategy to improve health outcomes in vulnerable populations by reducing barriers to timely diagnosis and treatment of cancer and other chronic diseases (Freeman & Rodriguez, 2011). It was designed to address disparities in access such as financial, communication, cultural, systems and emotional barriers experienced by patients (Freeman & Rodriguez, 2011). Van Walleghem et al. (2008) did not present details on which aspects of this model were modified to be suitable for young adults transitioning with T1D; the concept does address the issues and problems concerning AYA getting lost to follow-up care during or after transition. Illustration 2 depicts the "patient navigation" model concept (see page 64).

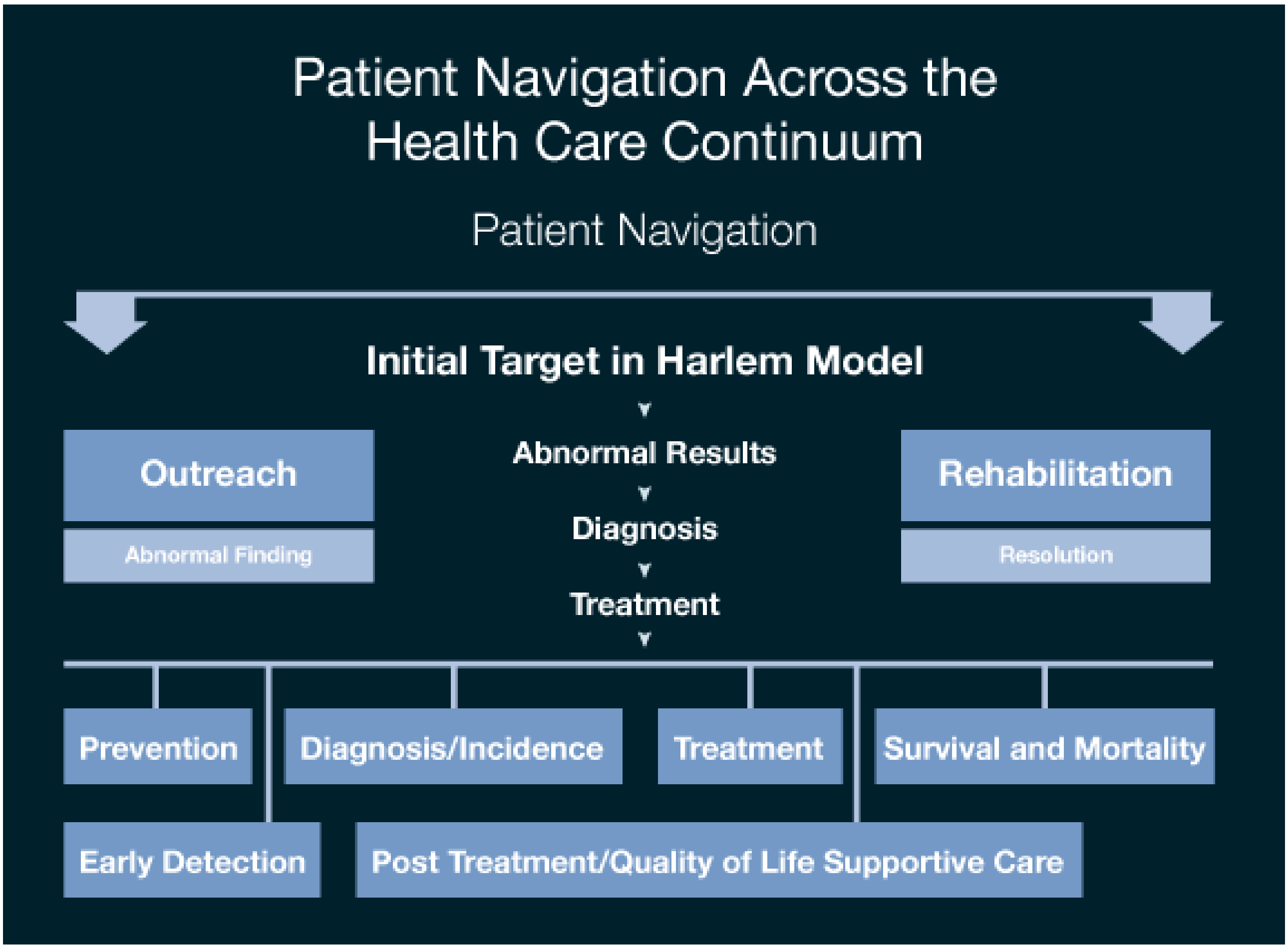

Illustration 2: Patient Navigation model (Harold P. Freeman Patient Navigation Institute, 2013)

The second theory used was based on the philosophy of self-determination and self-efficacy as it relates to independence and health management. Self-determination theory was used as to conceptualize the importance of autonomy and self-regulating behaviors (Evans et al., 2006). The same study also used the *family-centred* model of support. Family centered care has been described as both a philosophy and an approach to practice (King, King, Teplicky, & Rosenbaum, 2004). “Family centered care involves ensuring that parents have ultimate control over decision making, treating parents respectfully and supportively and providing parents with needed information” (King, King & Rosenbaum, 1996, as cited by King, King, Rosenbaum, & Goffin, 1999, p. 41). It is considered to be a best practice model for early intervention and paediatric rehabilitation (King,

King, Teplicky, & Rosenbaum, 2004) and is suited to the multi-layered service generally provided in paediatric care settings.

Although it is recognised and widely used in paediatric care settings, it is seldom embraced in adult care settings which tend to emphasize privacy, autonomy and self-agency. A patient in an adult care setting is generally expected to be responsible for facilitating the desired networks of care perhaps with the assistance of their general practitioner but rarely does family influence care except where legal proxy is granted. For adolescents with chronic and childhood onset diseases transitioning to adult care is made more complex by the differing cultures of paediatric and adult centered care (Blum et al., 1993; Reiss, Gibson, & Walker, 2005). Parent and family involvement may need to be extended beyond transition to adult care as parents have in depth experience with their young person's condition and care outside of the clinical setting. This needs to be balanced with a young adult's desire to find a way to affirm their independence and to develop and maintain various caregiver networks.

There was no reference to a theoretical framework in the remaining two studies. More foundational theoretical discussion is needed on the subject of transition for young people with chronic conditions, as theoretical frameworks will help structure various transition models.

Methodology

None of the studies used a control group. On the one hand, the state of knowledge is such that future studies should follow a cohort over time or that one approach should be compared to 'treatment as usual'. However, until a controlled study is conducted, it will be difficult to ascertain if a transition program results in desirable outcomes. The most often cited barrier to conducting a randomized control trial is that of ethical concerns. To some extent, this is true insofar as withholding a potentially beneficial treatment is ethically problematic. However, one of the ways of addressing this concern is to use a quasi-experimental cross-over design, as has been discussed. Granted, this could only be used over a short period of time as age would remain a concern. However, it would provide some level of assurance that outcomes were a function of the program and not just of time.

Outcomes/Results

There is increasing awareness of the benefits of integrating bio-medical health indicators with systems and psychosocial well-being appearing in transition intervention literature. The extent to which outcomes reflect integration of physical health indicators (e.g. disease management), psychosocial well-being, and systems cooperation or collaboration (e.g. access to care) varies between studies. As a retrospective study analyzing existing programs, Cadario et al. (2009) focused on the medical and systems aspects of transition comparing structured and unstructured interventions. The study by Evans et al. (2006) emphasized psychosocial well-being in terms of participation in community and family involvement. They draw significant attention to collaboration between the participant and social services with a focus on improvement in psychosocial outcomes. Van Walleghem et al. (2008) focused on health care surveillance emphasizing the importance of maintaining connections between participants and health system to reduce the risk of medical complications and hospital admissions. They make an effort to link the importance social networks to disease management through use of web based interaction and informal discussion groups. The study by Vidal et al. (2004) appeared the most comprehensive in terms of outcomes reflecting integration of health indicators, systems and psychosocial well-being as investigated the effects of therapeutic education on glycemic control in young adults with T1D. Throughout their investigation they aim to strengthen ties between health care professionals, young adults and their environment (i.e., family) making connections between health care system, the young adult's behavior, the young adult's environment and their medical outcomes concerning glycaemic control.

Integration of health indicators and psychosocial aspects of wellness are integral components of the biopsychosocial intervention model. Emerging on the cusp of the ecological model (Bronfenbrenner, 1979), the biopsychosocial model was developed as an alternative to the medical model and deemed to be more effective in producing positive health outcomes, as it shifted focus from the physician's ability to impart care to the role the patient and their environment play on incorporating care. Research has consistently affirmed the value of the biopsychosocial perspective and demonstrated how biological, psychological and social process operate together to affect physical outcomes (Suls & Rothman, 2004). In terms of transition interventions the biopsychosocial model helps to facilitate balance between the complex interactions of young adults, their health care systems, and their social environment, to achieve the best possible health outcomes as they move into adulthood.

Limitations

The process of analyzing transition research is not without challenges. Establishing appropriate search terms and parameters proved difficult due to inconsistencies across the databases, resulting in large numbers of irrelevant studies and "analysis fatigue." Terms such as "transition" and "chronic" produce different results with various databases. Some terms were not recognized at all within a database. In particular, search terms as well as age parameters varied in meaning between social science databases, such as SocioIndex, and health science databases, such as MEDLINE. Schwartz et al. (2011) acknowledged that "[t]he literature fails to present a consistent use of transition-related language with authors using transition readiness, transfer to adult care and other transition-related terms interchangeably" (p. 885). Databases which are dedicated to health research and literature have tried to address this by providing a space to store research, methodologies and tools on various health topics. Such databases can be used to help develop a consistent vernacular for transition research.

One example is the Cochrane Library, a collective database of research, methodologies, and tools on health and health interventions. It brings together rigorous and current research on the effectiveness of treatments and interventions, making evidence literature readily available and accessible to professionals, students and researchers. While databases such as the Cochrane Library have helped to make relevant studies readily available, recommendations for future research ought to include informing databases such as Cochrane about the gaps in technologies and review processes.

A second challenge in the process of this thesis was found in defining illness parameters. Despite looking at specific conditions as a means of narrowing the search, it became evident that health-care transition is discussed as a process for both disease-specific and non-categorical groups. Although disease-specific research does dominate the literature, the search captured literature from categorical and non-categorical disease groups.

A third and over-arching limitation was the apparent lack of overlap or collaboration between health research review methods and social science review methods. A majority of the studies came from health-related databases, while databases related to social sciences produced very few health-related research articles. If the need for integrated care and intervention models is to be truly recognized, then this ought to be reflected in the research, not only through integrated models of interventions but integrated research and review methods that incorporate the importance in sharing data across the disciplines. More interdisciplinary training is needed to make data accessible across the disciplines and support systemic collaboration.

The scope of this study was limited to quantitative studies because of time and resource constraints. Because transition health has yet to generate its own vernacular, there are few topic-specific terms that could be used in the search strategy. Combinations of terms like "transition," "adolescent," "chronic disease," etc. generate large numbers of studies not related to transition interventions. Excluding grey and qualitative studies made the analysis manageable for a researcher working alone. Although using quantitative studies allowed for an analysis of more rigorous studies, it did so at the exclusion of a larger spectrum of issues that could be considered. Future research should include mixed-method reviews that systematically analyze qualitative, quantitative, and mixed studies to gain a more accurate picture of the types of interventions and their impact on the AYA population at risk.

Role of Social Work

None of the studies included in the review referred to a social worker being involved or to a social worker being part of the research team. This was a tremendously disappointing finding insofar as social work is well-positioned to develop and implement transition programs. Given their role in paediatric and adult settings as ‘discharge planners,’ as well as their systems-level training, it is surprising that they were not mentioned. This may be due to the fact that some of the studies were outside of North America (Italy and Spain), where the social work role may be either nonexistent, of defined differently.

On a similar note, social workers have the training and expertise to develop an evaluation framework for such programs. Anecdotally, social workers are actively involved in transition programs. It appears that the problem is that social workers are not documenting the impact of their practices using well-established research methods.

Conclusion

Implications for Future Research and Practice

In spite of an abundant amount of literature documenting the need for transition programs, surprisingly little has been documented and evaluated. No studies were found that evaluated transition programs specifically in youth with sickle cell or cystic fibrosis. Although these conditions are not highly prevalent, youth diagnosed with those conditions face disease-specific challenges that warrant special attention. Given the small sample size in this study, it cannot be established whether programs for these youth do not exist, or whether they simply have not been evaluated quantitatively. One of the key recommendations emerging from this review is the need for more research evaluating the impact of transition interventions on youth with a variety of conditions. In addition, more current research which considers employment, agency, and other quality of life variables in adulthood is needed, and would provide a better picture of the impacts of transition intervention for this population.

Other variables to consider may include organizational and non-health factors (e.g. economic status, ethnicity) and their complex relationships with health outcomes. In particular, more studies that track this population longitudinally would provide a better picture of variable impact on the population. Research in this area will help guide structural improvements.

This review provides some direction regarding future research.

1. Given that youth diagnosed with these conditions come from diverse ethnocultural backgrounds, we need to ensure that they are represented in research. This will allow us to obtain a better understanding of their and their family’s experiences of transition

interventions.

2. The development and evaluation of transition programs should involve both paediatric and adult care centres. The culture of care in PCC settings compared with adult care settings operates under differing principles which are at odds: where paediatric settings tend to emphasize "wrap-around" support and education for both patient and family, adult settings are client-focused with an emphasis on privacy and autonomy. Though not necessarily exclusive, the shift in philosophy of adult care settings compared to paediatric care often results in "care culture shock" and can increase stress for young adults and their families. The difference in philosophies can also be a challenge for health professionals as it can impede communication and collaboration. Practice models that transcend the two care cultures are needed to reduce these challenges.
3. Evaluation of transition programs should incorporate both medical and psychosocial indicators of outcome.
4. Transition programs should be guided by theoretical models that help us to understand the complexity of this phenomenon as well as the treatment approach. One such model would be the social-ecological model of AYA readiness for transition (SMART; Schwartz et al., 2011). While best-practice principles and consensus statements have been established around transitioning AYA with special health care needs, a specialized theoretical paradigm is yet to be developed. With greater understanding about the necessity of incorporating psychosocial aspects of care with medical needs, a paradigm shift would go far in structuring research and practice in health care transition for AYA with special health care needs.
5. Social workers should become more active in documenting the contribution they are making to transition programs and documenting the impact of such programs on the well-being of

their participants.

6. Though specific chronic conditions have unique care needs, more research is required on the effectiveness of non-categorical transition interventions. Future research should focus on designing and evaluating programs that are accessible to a wider group of young adults with various conditions. A cost/benefit analysis should be embedded in that evaluation to determine if the costs of running such programs are outweighed by the benefits accrued to individuals, institutions, and society.

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Appendix 1: Search Template

1. diabetes.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
2. cystic fibrosis.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
3. sickle cell.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
4. 1 or 2 or 3
5. transition.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
6. delivery of health care.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
7. continuity of care.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
8. 5 or 6 or 7
9. limit 8 to ("adolescent (13 to 18 years)" or "young adult (19 to 24 years)")
10. limit 9 to "young adult and adult (19-24 and 19-44)"
11. limit 10 to (english language and humans and (case reports or classical article or comparative study or controlled clinical trial or evaluation studies or guideline or historical article or journal article or meta-analysis or multicenter study or "review" or twin study or validation studies)
12. limit search to studies conducted between 1996 and 2012, inclusive

Appendix 2: Data Analysis

Author, title	**Goal of study**	**Population/ sample and recruitment**	**Use of theory**	**Intervention type/model**	**Method**	**Outcomes/results**	**Limitations**
Cadario, F., Prodam, F., Bellone, S., Trada, M., Binotti, M., Trada, M., Allochis, G., et al. 2009 Transition process of patients with Type 1 Diabetes (T1dm) from paediatric to the adult health care service: A hospital-based approach. *Clinical Endocrinology, 71,* 346-350	To compare health outcomes associated with structured versus unstructured transition plans from paediatric to adult diabetes services at Maggiore della Carita` Hospital, Novara, Italy	n = 62 AYA patients with type 1 diabetes discharged from paediatric diabetes service to adult diabetes service (within the same hospital) between 1994 and 2004 Convenience sample 34 male 28 female mean age of entire sample 19 +/- 2.8 years n=32 in unstructured group (27/32 responded to request for information) – Group A n=30 in structured group (all responded to request for	None identified	Unstructured intervention consisted of a summary letter of condition; this was given to patient for adult care services with little/no additional support/supervision; this was the practice until December 1999 Structured intervention consisted of a transfer planned with paediatric and adult endocrinologists; paed. specialist prepared adolescent; parents were excluded from last visit when both specialists were present; patients were given the	Retrospective survey of patient records and phone or in-person interview regarding transition experience Major outcomes: Date of first admission into adult sector Metabolic control – change in glycated haemoglobin (HvA1c) between paediatric and adult care duration of transfer clinical attendance	Unstructured group was less likely to receive specialist follow-up and only see their general practitioner to have prescriptions for insulin refilled; this group was also more likely to have a break in clinical or lab exams than the structured group The time between discharge from paediatric to being seen in adult care was shorter for the structured group. One year after transfer, greater proportion were seen by an adult specialist in the structured group Metabolic control in the structure group improved more than in the unstructured group during the transition from paediatric to adult care One year after the transition, metabolic control in the structured group was better	No information about how they were assigned to these groups – potential for selection bias No process measures of program fidelity that would evaluate whether each patient received the same intervention and the same amount of the same intervention No standardized measure of satisfaction was used Psychological effects of a structured program could not be assessed because it was a retrospective study

Author, title	**Goal of study**	**Population/ sample and recruitment**	**Use of theory**	**Intervention type/model**	**Method**	**Outcomes/results**	**Limitations**
		information) – Group B		opportunity to return to paediatrics if they did not like the outcomes in adult care. During the last visit in paediatric care patient was visited by the endocrinologist and the paediatric specialist together.	rate in paediatric and adult service satisfaction and compliance	than in the unstructured group; this difference disappeared after 3 years 3 years after the transition, the structured group were attending clinic more often than the unstructured group	
Evans, J., McDougall, J., & Baldwin, P. 2006 An evaluation of the "Youth En Route" program *Physical & Occupational Therapy in Pediatrics* 26(4), 63-87	To measure levels of self determination, sense of personal control over life choices and community involvement prior to and 1 year following involvement with the Youth En Route (YER) program To determine the impact of self-determination,	n = 34 youth with multiple disabilities. Youth with chronic health conditions that limit mobility and/or function 24% - cerebral palsy 27% - spina bifida, and 49% - various other conditions (e.g., neurological disorders, acquired brain injury) 44% reported having limitations in	Program based on philosophy of self-determination and self-efficacy Family-centred model, client driven service and multi-faceted approach to transition Ecologically-based intervention that utilizes strength based coaching	Program is government funded and implemented through Thames Valley, a children's rehabilitation centre, and Hutton House (a community agency for adults with disabilities) Both agencies are located in London, Ontario - partnership model Intervention is regional support program for youth and young adults	Information about school, employment and support was collected pre-test and post-test Single group; pre-test/post-test ARC Self-determination scale (Wehmeyer & Kelchner, 1995); 72 items divided into 4 subscales: autonomy, self-	Intervention yielded overall improvement in total self-determination, autonomy self-regulation and self-realization Improvement in locus of control; clinically meaningful/significant Time spent in community leisure activities increased but not clinically significant Hours spent in work/volunteer activities, community leisure activities and transportation activities increased; former two were clinically meaningful	No control group; therefore cannot conclude that the changes were due entirely to their involvement in the program. Cited ethical reasons for lack of control group as: government funding requires them to be accountable to provide services to all clients within a specified time frame. As such,

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	sense of personal control, and community involvement on health outcomes	mobility; 38% had limitations in the learning/cognition; 18% vision impairment; 12% limitations relating to communication; 9% hearing limitations; 12% reported having “other” limitations All were participating in Youth En Route Program at a children’s rehabilitation centre in London Ontario, Canada Convenience sample N=51 met inclusion criteria N=5 did not complete pre-test N=46 completed pre-test N=12 completed pre-test only	and support strategies Conceptualization of individual’s health and functioning reflects the World Health Organization’s (2001) views of health and functioning which views diagnosis as distinct from disability (p. 70 of article) - ICF Model	ages 16 to 29 with multiple disabilities, who have completed secondary school Program includes three components: 1) Self-discovery (interpreted as self-knowledge, self-evaluation, information-gathering, planning and goal setting) 2) Skill development (i.e. life skills, employment skills) 3) Community experience (i.e. job training, community involvement, accommodations) Families of AYA involved are provided information about supports and invited to be involved in the planning process so that they are better prepared to help	regulation, psychological empowerment and self-realization Nowicki – Strickland Locus of Control Scale (Nowicki & Strickland, 1973) 40-item yes or no format with higher score representing an external locus of control Community Integration Questionnaire (Willer et al., 1993); 3-point scale to measure frequency of following activities: (shopping, leisure activities, visiting friends or relatives and volunteering); additional 3 items: school situation, employment	while latter was only minimally so. Proportion of participants living independent increased from 14.7% to 26.6% Proportion of participants working part-time increased from 17.6% to 41.2% Vast majority of youth were highly satisfied with the program Comparing the pre/post-test means of the study participants with the ARC norms for AYA with mental retardation, learning disabilities and AYA with no disabilities findings revealed: Self-regulation - post-test scores for participants were higher than all three of the of the other groups Self-realization – both pre-test and post-test scores were higher than all three groups Psychological empowerment -	“comparable clients in other geographic regions could not be requested as this would create a demand for service which they did not have the budget resources to provide” (p. 69). No treatment manual No process measures; cannot conclude that all participants received the same amount of the intervention or that they received the same intervention Some of the measurement tools may not be suitable for use in youth with multiple disabilities

Author, title	Goal of study	Population/ sample and recruitment	Use of theory	Intervention type/model	Method	Outcomes/results	Limitations
		N=6 excluded - dropped out of program after pre-test; n=3 found study too difficult and deemed inappropriate; n=1 too busy to complete study; n=2 did not complete post-test N=34 completed pre-test and post-test Average age at pre-test 22 years and 3 months n = 17 males n = 17 females 73% lived in London, Ontario 23% lived in the counties of Elgin, Middlessex and Perth, Ontario power analysis indicates that sample size is adequate to detect statistically significant differences		AYA become more self-determined and participate in the community Skills development is interwoven into the youth/young adult's choice of community participation and is specific to the experience gained in participation. Average duration of the program was 10 months with some variation due to the individual's goals	situation, extent of travel outside the home Client Satisfaction Questionnaire: measures overall satisfaction of services with high internal consistency and adequate concurrent validity Independent Variables: Time (Pre and post-test) Group (student participants, norms without disabilities, norms with mental retardation, and norms with learning disabilities)	post-test scores of participants were dropped from pre-test scores but slightly higher than those with mental retardation but lower than those with learning disabilities and no disabilities The post-test for the total ARC scores were higher than all three groups Averages of time spent doing different activities pre-test to post-test, compared with the general Canadian population, shows: a decrease in the time spent at home and watching TV from pre-test to post-test (participants were lower than the general Canadian population) A significant increase in the post-test hours spent volunteering (lower than general Canadian population)	

Author, title	**Goal of study**	**Population/ sample and recruitment**	**Use of theory**	**Intervention type/model**	**Method**	**Outcomes/results**	**Limitations**
Van Walleghem, N., MacDonald, C.A., & Dean, H. J. 2008. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with Type 1 Diabetes. *Diabetes Care, 31(8),* 1529-1530. Follow-up analysis for feasibility: Van Walleghem, N., MacDonald, C.A., & Dean, H.J.	Primary objective: to evaluate feasibility and acceptability of transition program (Maestro project) Secondary objective: to evaluate effectiveness of Maestro project on medical and educational follow up and on medical outcomes; also, to identify barriers to care for AYA in the adult diabetes system	Young adults 18-25 with type 1 diabetes who were followed by the Diabetes Education and Resource Centre, a paediatric care program in Winnipeg, Manitoba, Canada Convenience sample of participants, all of whom were enrolled in the Maestro Project 2 cohorts enrolled in Maestro Project: An older group (n=164) aged 19-25 who graduated from the Diabetes Education and Resource for Children and Adolescents (DER-CA) between January 1995 and July 2002, before the Maestro project was in place; complete information available for n=101; A younger group	Patient navigator concept derived from cancer care follow-up model (Freeman & Rodriguez, 2011).	Systems Navigator Service (Maestro Project) to aid transfer through frequent telephone and email contact, bi-monthly newsletter, monthly drop-in group to increase social interaction and maintain connection to peers, educators and clinical care providers The project uses several methods of services delivery designed to encourage socialization with peers and facilitate relationships with diabetes educators, endocrinologists, researchers and other service providers	Both cohorts received access to intervention Pre/post-test x 2 cohorts; Evaluation was completed in 2005 comparing the year before the Maestro Project was created to the year after the project was in place for each cohort separately Participants were contacted by phone every six months to collect information about medical or disease-related educational visits, chronic complications, hospitalization for diabetic ketoacidosis and barriers to accessing disease	The model helped the older group re-connect with care services and helped the younger group reduce first year fall-out rate after transfer from paediatric to adult care; therefore, improved medical surveillance In the older cohort, 40% were not attending regular medical care prior to transfer; only 5% of younger cohort were not attending regularly prior to Maestro; after Maestro, 11% of the younger cohort dropped out of regular adult medical care Navigator Model showed improvements in continuity of care: helped older group reconnect with adult care services and reduced dropout rate for younger cohort after their first year of transfer In both cohorts, no significant differences in hospital admissions or emergency room visits for acute complications before and after Maestro	No comparison group who did not receive Maestro; therefore, changes could be related to maturation Not clear how data collected every 6 months was used in analysis no t-tests or chi-square tests conducted (at least no evidence of such); therefore claims of greater benefit to younger cohort not tested Very low response rate in the patient surveys (14%) Long term complications could be a function of age and not exposure to Maestro Limitations:

Author, title	**Goal of study**	**Population/ sample and recruitment**	**Use of theory**	**Intervention type/model**	**Method**	**Outcomes/results**	**Limitations**
2011 The Maestro Project: A patient navigator for the transition of care for youth with Type 1 Diabetes. *Diabetes Spectrum, 24(1)*, 9-13.		(n=84) 18 years of age; complete information available for n=64 Chart audit of n=8 males n=9 females Between the ages of 22 and 29 Database of sample created for the purpose of the study			related care in the adult care system Assessed 2 cohorts using 3 different methods of data collection: database, audit of hospital records and patient self-reporting survey.	Older cohort reported long term medical complications whereas younger cohort did not Almost half of respondents surveyed from both groups reported a period without medical care	1) Patient navigator who had a non-professional advocacy role with participants, collected data for the database. There may have been recall bias in the information provided by the young adults. 2) Participation in the Maestro Project was voluntary leading to potential selection bias. 3) Low response rate to survey.
Vidal, M., Jansa, M., Anguita, C., Torres, M., Giménez, M., Esmatjes, E., Levy, I., & Conget, I. 2004	To evaluate the impact of a specifically designed therapeutic education program (TEP) on glycemic control, self-management and quality of life 12 months after the	n = 80 young adults with type 1 diabetes who transferred (2000-2002) from a paediatric care unit (Sant Joan de Deu) to an adult care center (Hospital de Clinic I Universitari de Barcelona in Barcelona Spain	None stated	Subjects participated in a TEP which included coordinated transfer visits (visit with endocrinologist and a nurse), initial evaluation by diabetes adult care staff (this first visit included subject and family assessment).	Single group, pre/post-test Outcomes: Self-adjustment of metabolic control (HbA1c) Diet, weight, number of hypoglycaemic	Little or no change in meal plan composition; tendency toward improvement in carbohydrate counting Decrease in HbAlc (which means in improvement in metabolic control); increase in % of sample performing re-adjustments (13% vs. 48%; $p < 0.001$)	No comparison group; therefore improvements can be due to maturation TEP requires approximately 1 visit per month with a clinician in order to complete the whole program; this

Author, title	**Goal of study**	**Population/ sample and recruitment**	**Use of theory**	**Intervention type/model**	**Method**	**Outcomes/results**	**Limitations**
Impact of a special therapeutic education programme in patients transferred from a paediatric to an adult diabetes unit. *European Diabetes Nursing, 1(1)*, 23-27.	transfer of AYA from paediatric diabetes unit to adult unit in; both are hospital based programs in Barcelona	Convenience sample n=72 completed the program n=39 female; No other gender noted the assumption is that the remaining 33 are male		Time planned for each visit was 90 minutes. Patients could influence education topics. An agreement to set goals and adapt insulin therapy program was established by care provider and recipient. 4 2-hour group sessions plus 3-6 individual visits during a 3 to 6 month period. 12-15 hours dedicated to each subject, 50% of which were group sessions.	episodes Insulin modification (daily insulin dose, rapid acting insulin) DKQ2, DQOL, Satisfaction, social preoccupation, diabetes preoccupation Patient evaluation and files regarding transition were reassessed one year following discharge	Decrease in # of hypoglycaemic episodes No change in insulin dose; increase in rapid acting insulin (23% vs. 52%; $p < 0.001$.) Significant increase in weight Significant increase in knowledge of disease scores No significant change in DQOL scores; improvement in metabolism was accomplished without decrease in quality of life	represents a minor inconvenience to the adolescent/young adult