

Closing the Gap

Youth Transitioning to Adult Care in BC



A Policy Paper by BC's Physicians
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The BCMA Council on Health Economics and Policy (CHEP) reviews and formulates policy through the use of project-oriented groups of practicing physicians and professional staff.

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Executive Summary

Successful transition from pediatric to adult care is the provision of uninterrupted, coordinated, developmentally appropriate, and psychologically sound health care. This paper explores several issues in youth transition, including the importance of successful transition; issues faced by patients, parents, and providers; and successes and opportunities for improvement.

Michael was born in the early 1970s with cystic fibrosis. For most of his childhood and youth, pediatricians with expertise in cystic fibrosis gave him the grim prognosis of an early death. However, as time progressed and medical technology advanced, Michael's physicians could manage his condition better, and his predicted life expectancy increased. Now married and in his early 40s, Michael is one of the first cystic fibrosis patients of his generation to live so long. However, the biggest problem in his adulthood has not been managing his cystic fibrosis, but rather finding health care providers with the skill set, knowledge, and equipment to treat an adult with what has been, until recently, a pediatric condition.

For a physician, there are few greater joys than successfully extending the life of a child or youth with a chronic condition like Michael's. Having the opportunity to add years of healthy living to the life of one so young speaks to physicians' most basic desires for entering medicine, and thanks to advances in medical technology, that opportunity has become a reality for many. Today, physicians can more successfully manage chronic conditions in youth—not only cystic fibrosis, but also HIV/AIDS, type 1 diabetes, and some neurological conditions. Indeed, advances in medical technology now mean that approximately 90% of children and youth with complex or chronic illness can expect to reach age 20.

This profound success in extending the life of these youth into adulthood has created, however, an unanticipated problem: how best to transition pediatric patients to an adult care system that never expected to care for them. The challenge extends beyond access to care. The transition between pediatric and adult care systems occurs at the same time as young patients simultaneously leave the school system, enter adulthood, and take on other responsibilities. Managing their health and navigating a complicated health care system is an additional burden during an already-complicated stage of life. Moreover, because these patients have a significant risk of accelerated mortality and morbidity, a successful transition into adult care can be a matter of life and death.

The challenges of managing transitioning patients affect providers, too. Pediatricians without the financial support to care for patients over the age of 18 report that they are nonetheless unable to transfer their patients to appropriate adult care providers as there are so few with the skill set, knowledge, or equipment required to provide the appropriate care. At the same time, the general practitioners of these patients may have limited contact with them after they have been referred to pediatric care until they “age out” of that system. Adult care providers may not feel that they have the resources or adequate training to take on these patients. Finally, for the medical team preparing youth patients for adult care, there are few transition-planning resources or rigorously evaluated programs to which they can refer.

In this policy paper, we define successful transition as the provision of uninterrupted, coordinated, developmentally appropriate, and psychologically sound health care to young adult patients as they move out of pediatric care and into the care of an adult health care provider. We outline the population at risk and the dangers associated with poor transition. We also explore several transition frameworks, including the system navigator, self-management, and individualized transition models. Finally, we examine BC's demonstrated success in transitioning youth from pediatric care using an individualized transition model, and build on previous work from the Ministry of Health and nine other ministries in the provincial *Transition Protocol for Youth with Special Needs*. In an effort to expand on these successful efforts, we offer 10 recommendations and 10 commitments for the realization of successful transition for young patients with complex or chronic illness. Among the most significant are:

1. Pediatric patients with complex and chronic illness should have, in addition to pediatric care providers, a family physician from birth.
2. Pediatric patients graduating from pediatric care should have individualized transition plans.
3. A method for the identification and ongoing tracking to evaluate successful transition and long-term health outcomes should be developed.

Both the government and the BCMA have embraced the Institute for Healthcare Improvement's Triple Aim framework as a mechanism for both implementing and evaluating progress. Specifically, the framework articulates the system-wide goals that will lead to more coordinated, integrated, and comprehensive patient care: reduced health care expenditure, better mental and physical health of a defined population, and a better patient/provider experience. The recommendations offered in this paper were developed with these goals in mind, and it is our view that successful youth transition programs will contribute to their achievement.

Implementing these and the other seven recommendations in the paper requires concerted action by government and health authorities. However, it also requires action by physicians themselves. Therefore, in addition to the recommendations offered in this paper, the BCMA also offers ten commitments that the Association will undertake to achieve improved youth transitions. Underlying all of these commitments is a dedication to the collaborative processes supported in the current Physician Master Agreement, most notably the various joint Ministry of Health and BCMA committees (e.g., General Practice Services Committee, Specialist Services Committee, and the Shared Care Committee). These collaborative structures, which have demonstrated the ability to increase access and improve the quality of care for specific patient populations, will play a central role in achieving the goals of this paper.

1. Recommendations

Recommendation 1

- a) All pediatric patients with complex and chronic illness should have, in addition to pediatric care providers, a family physician from birth.
- b) Health authorities should ensure that transitioning patients are matched to an appropriate specialist adult care provider one year prior to graduation to adult care.

Recommendation 2

Care programs should include an individualized transition plan for each pediatric patient expected to graduate from pediatric care. This plan should be based within a framework of an established and evidence-based transition model that also reflects both disease and individual patient-specific needs.

Recommendation 3

The BC Ministry of Health and health authorities should develop a method for the identification and ongoing tracking of youth patients with complex and chronic illness to evaluate successful transition and long-term health outcomes.

Recommendation 4

Health authorities should provide ongoing resources and support for specialist and family practitioners to develop appropriate skills and to manage the care of pediatric patients who transition into their care.

Recommendation 5

Health authorities should provide ongoing resources to individual pediatric care programs to maximize the support to young adult patients in preparation for their transition.

Recommendation 6

Individual care programs should include collaborative processes that aggregate resources and provide support between and within pediatric care programs with patients transitioning to adult care.

Recommendation 7

In the case of patients with unique needs for which no specialist adult care provider is available, the Ministry of Health should ensure that support can be provided in order for a pediatric specialist to provide ongoing care until appropriate adult care can be identified.

Recommendation 8

The needs of transitioning pediatric patients with primary mental illness should be investigated further by the Ministry of Health, such as that specified in the Integrated Primary and Community Care framework.

Recommendation 9

Specific benchmarks defining the successful transition of pediatric patients should be developed by individual care programs, health authorities, and the Ministry of Health.

Recommendation 10

Systematic analyses of youth transition data should be conducted including, but not limited to, health outcomes and individual patient experience. Analyses should be conducted at the care program, health authority, and provincial levels.

2. Commitments

Commitment 1

- a) The BCMA, in collaboration with the joint committees, family physicians, and other stakeholders, will support initiatives to ensure all pediatric patients with complex and chronic illness have a family physician from birth.
- b) The BCMA will support efforts by specialist adult care providers, health authorities, and other stakeholders to ensure that transitioning patients and appropriate specialists are matched one year prior to graduation to adult care.

Commitment 2

The BCMA will support the development of individualized transition plans for each pediatric patient graduating from pediatric care. These plans will be based on established and evidence-based transition models that reflect disease and individual patient-specific needs.

Commitment 3

The BCMA will work with the Ministry of Health, health authorities, and other stakeholders to determine how an identification and ongoing tracking method can be implemented for youth patients while also reflecting specific priorities including, but not limited to, patient consent and maximum patient privacy.

Commitment 4

The BCMA will support the work of the joint committees and health authorities to provide practice support and training opportunities for specialists and family practitioners to develop appropriate skills and to manage the care of pediatric patients who transition into their care.

Commitment 5

The BCMA will work with health authorities and other care providers to maximize the support individual care programs can provide to young adult patients in preparation for their transition.

Commitment 6

The BCMA will support physicians in their work with individual care programs to aggregate resources and provide support among respective pediatric care programs with patients transitioning to adult care.

Commitment 7

In the case of patients with unique needs for which no specialist adult care provider is available, the BCMA will support pediatric specialists in collaboration with the Ministry of Health and health authorities to identify necessary supports for these patients or provide ongoing care until appropriate adult care is identified.

Commitment 8

The BCMA will support physician participation in the government's Healthy Minds, Healthy People: A Ten-Year Plan to Address Mental Health and Substance Use in British Columbia.

Commitment 9

The BCMA will support the development of specific benchmarks to define successful transition of pediatric patients.

Commitment 10

The BCMA will support the systematic analysis of youth transition data conducted on, but not limited to, health outcomes as well as individual patient and provider experience.

3. Problem Statement

As a result of advancements in medical technology and innovation in treatments, greater numbers of youth with chronic illnesses are surviving childhood and aging into adulthood. Given the significant health and financial impacts of unsuccessful transition, and the growing population in need, barriers to transition must be addressed.

Michael was born in the early 1970s with cystic fibrosis. At that time, the only advancements in cystic fibrosis treatment were in diagnosing patients and creation of patient registries. His doctors could recommend few treatments other than a high-fat diet, and the prognosis was bleak. There was little comfort for his parents who were warned to prepare themselves because Michael would not outlive his childhood. Their hopes were buoyed in the 1980s when the trans-membrane conductance regulator gene was discovered. With this advancement, treatments abounded and doctors began prescribing mucolytic Pulmozyne and gene replacement therapies. Michael's physicians were able to manage his condition better, and his predicted life expectancy increased. Now married and in his early 40s, Michael is among the first CF patients to live so long. However, these rapid changes in treatment and survival rates did not mean that Michael's care always improved. As he was "aging out" of pediatric care just as treatments were changing, Michael faced many challenges. His biggest problem in adulthood has not been managing his cystic fibrosis, but rather finding health care providers with the skill set, knowledge, and equipment to treat an adult with what was a pediatric condition.

As has happened with cystic fibrosis, advancements in medical technology and innovation in treatments of other diseases have resulted in Canadian youth with chronic illnesses surviving childhood and aging into adulthood more frequently. Despite achievements in increased life expectancy, these patients are still at significant risk of accelerated mortality and morbidity when the transition into adult care is unsuccessful (Scal & Ireland, 2005; Viner, 1999). Young patients receive long-term pediatric care that is specifically tailored to their individual needs at BC Children's Hospital (BCCH) and from pediatricians across BC (Sawyer, Blair, & Bowes, 1997).

Unfortunately, these services may not prepare young adult patients for the shift in culture between pediatric and adult care systems. The purpose of a specified youth transition process is to provide uninterrupted, coordinated, developmentally appropriate, and psychologically sound health care to young adult patients as they age out of pediatric care and into the care of an adult health care provider (Adolescent Health Committee, 2007).

In addition to the usual challenges faced by all young adults who are making the transition into adulthood once they reach age 18, youth patients in BC with complex or chronic illness must leave a familiar and family-focused pediatric system and enter a dramatically different adult care system. Just as with adults who learn to work within a care system over the long-term, youth with complex or chronic illness become familiar with the pediatric care and become accustomed to navigating it successfully (Geenen, Powers, & Sells, 2003). An unsuccessful transition to adult

care may occur for a number of reasons: an inappropriate or ineffective transition, lack of appropriate adult care providers, poor communication between providers, differences in service models, or other unique needs (Blum, 2002). When patients depart from pediatric care without the early implementation of an effective transition plan, they may suffer from treatment failure and a subsequent sense of poor self-reliance. Research suggests that patients who develop a strong sense of self-reliance and confidence in their skills to navigate the adult care system have better health outcomes (van Staa, van der Stege, Jedeloo, Moll, & Hilberink, 2011).

Youth patients aging out of pediatric care need a bridging system that can support them by fostering the communication skills and self-reliance necessary to coordinate their own care to their maximum abilities. Given the current trends in improved diagnoses and advancements in medical technology and treatment, the number of youth patients transitioning is likely to increase. Currently, there is no consistent policy or model to support young adults aging out of pediatric care in BC. Given the significant health and financial impacts of unsuccessful transition to adult care, the barriers to care must be addressed.

4. Youth Transition

Every year about 1,700 youth with chronic complex health care needs are discharged from British Columbia Children’s Hospital when they turn 18. Many of these patients may continue to receive pediatric care as adults because of inappropriate or unavailable adult care services. The causes and effects of unsuccessful transition form a complicated series of relationships. These relationships affect and influence patients, parents, and providers as well as the larger health care system.

Population

Approximately 1,700 youth with chronic complex health care needs are discharged annually from BCCH when they reach 18 years of age. Anecdotally, it is estimated that as many as 1,000 additional patients may continue to receive care at BCCH because of inappropriate or unavailable adult care services. Estimates suggest that this number represents 6-7% of BC youth who continue to receive care (Tonkin, Murphy, Lee, Saewyc, & Society, 2005). Moreover, the number of youth patients transitioning from pediatric to adult care is increasing. As result of improved treatment and care, it is now estimated that 90% of pediatric patients with complex or chronic illness reach age 20 (Gortmaker & Sappenfield, 1984; Whitehouse & Paone, 1999). Table 1 illustrates compelling examples of developments of various diseases and conditions.

Table 1: Changes in the Number of Pediatric Patients Transitioning to Adult Care

Disease/Condition	Impact
Cystic fibrosis	Cystic fibrosis was once considered a disease that children did not survive, but patients now live well into their 40s. In the United States more than half of cystic fibrosis patients are adults (Tuchman, Schwartz, Sawicki, & Britto, 2010).
HIV/AIDS	Advancements in treatment with antiretroviral drugs for HIV/AIDS patients during pregnancy and labour have reduced the risk of in utero or peripartum HIV transmission, and fewer pediatric HIV patients are born in Canada (Government of Canada, 2010).
Diabetes	The increasing incidence of type 2 diabetes in youth compounds the growth of overall population of adolescents with diabetes, (Price et al., 2011; Van Wallegghem, MacDonald, & Dean, 2006), challenging young diabetic patients who struggle to manage blood sugar levels. The stress of physical and emotional management of their diabetes puts these patients at particular risk for non-adherence and severe health impacts near the time when they transition to adult care (Fleming, Carter, & Gillibrand, 2002). Overall, improved care has resulted in increased life expectancy of pediatric diabetes.

Table 1: (cont'd)

Disease/Condition	Impact
Neurological conditions	Neurological conditions present a unique challenge to adolescents graduating into adult care, particularly when developmental age differs from chronological age (Camfield & Camfield, 2011; Camfield, Gibson, & Douglass, 2011). Eighty-nine percent of youth with chronic health conditions are classified as mildly disabled (Tonkin, et al., 2005). Patients with developmental disabilities that overlap with complex or chronic illness have different needs, abilities, and strengths that contribute to their capacity to manage their own care independently. Patients with developmental disabilities and their parents face these additional challenges as they work with their care providers in a new adult care system and adapt to a new legal framework, which includes guardianship issues.

Risks Associated with Unsuccessful Transition from Pediatric to Adult Care

Pediatric tertiary care is patient- and family-focused in BC, but upon graduating from the pediatric care setting, young adult patients must adapt to adult care, which has a much different orientation defined by illness, care provision program, and developmental age. Already vulnerable, this change puts these patients at serious risk of developing complicating health issues and further affecting their health.

Researchers have identified depression, social problems, and higher levels of stress with regard to death, body image, school, and the future as additional complications to their chronic illness. These young adults are also more likely to be involved in school violence (Tonkin, et al., 2005). Youth patients with mental illness are at particular risk (Poa, 2006; Tonkin, et al., 2005). The roller coaster of emotions, common among all young adults, makes youth who are transitioning to adult care particularly vulnerable to losing focus on their health. Transition programs are an integral part of supporting these adolescents in developing the self-confidence and emotional health necessary to successfully manage their health during a challenging time (Lugasi, Achille, & Stevenson, 2011).

The relationships between unsuccessful pediatric patient transfer to adult services, the deterioration in health status, and the acceleration of mortality have been identified by researchers (Fredericks, 2009). Increased morbidity may be the result of a decrease in follow-up visits after the patient transfers to adult care (Adolescent Health Committee, 2007). For instance, in patients with diabetes, non-adherence to an adult care provider is associated with poor blood sugar control, which may be manageable in the short term but can also lead to neurological and microvascular problems in the long term (Fleming, et al., 2002). These issues may be more significant among patients who appear asymptomatic through young adulthood. For example, young adult patients with HIV may feel better when they stop taking medications, but this significantly affects viral load and health outcomes (Fair, Sullivan, & Gatto, 2011). Other conditions may be diagnosed in childhood but only be considered problematic and manifest more seriously later in adulthood. For example, children diagnosed with neurofibromatosis 1 may present with minor issues, but develop complications including sarcomas and renal failure in adulthood (Camfield & Camfield, 2011). Such patients have serious health risks, and young adult patients may not know the extent of their need for an engaged adult care provider who offers appropriate health stewardship.

4. Youth Transition (cont'd)

Issues for Patients

Like their healthier counterparts who are challenged when they move out of the school system and enter adulthood, adolescents with complex health issues carry the additional burden of managing their own health and learning to navigate a complicated health care system. Young adults with chronic conditions have unique needs beyond their health. They are more likely to have social problems and mental health issues, neglect “due process,” increasingly use emergency care, and experience deteriorating health (Tonkin, et al., 2005).

Mental health status, in particular, is an important component that contributes to readiness for transition to adult care services and can be a significant confounding factor for patients with mental illness (Poa, 2006). Failure to transition into adult care successfully leaves all patients susceptible to poor health outcomes, but patients with mental illness are at particularly vulnerable (Poa, 2006). Successful transition to an adult care provider can ensure that young patients overcome barriers to optimal care for young patients (Kelly, Kratz, Bielski, & Rinehart, 2002).

Although young adult patients graduating to adult care need a service model that recognizes their unique challenges, they face an adult service model that delivers care in a dramatically different way. For instance, due to the mortality risks of eating disorders in youth, the minimum diagnostic requirements are lower for adolescents than adults (Adolescent Health Committee, 2011). This can appear shortsighted, as patients may no longer meet the diagnostic criteria for admission to the adult program once they turn 18. Successful transition to an adult care provider can help young patients overcome this kind of barrier to optimal care (Kelly, et al., 2002).

The success of youth transition can be evaluated at a systems level by morbidity/mortality outcomes and by patient perception (Lugasi, et al., 2011). For example, from the patient's viewpoint, age is a contributing factor to his or her sense of being prepared to transfer to adult care, and achievement is identified by good communication and sufficient information on the process (Rutishauser, Akré, & Suris, 2011). As well, patients have stated that successful transition plans include being able to take part in discussions of shifting to adult care, having a sense of self-reliance, and feeling a sense of autonomy (Lotstein et al., 2009; Lugasi, et al., 2011). Finally, patients report that effective long-term care requires reciprocal relationships of trust with their providers (Reiss, Gibson, & Walker, 2005). Young adult patients with complex or chronic illness need time to build a trusting relationship with a new care provider after having that opportunity over years with their pediatric care team.

Issues for Parents and Guardians

From a patient perspective, developmental age and mental health contribute to their sense of preparedness for transfer to adult care (Rutishauser, et al., 2011). Research indicates that there is a high rate of agreement between parents and adolescents on the subject of transition preparedness. Parents and guardians, however, have their own needs unique to those of the patient. A transition plan that addresses the needs of patients alone will not likely meet specific needs of parents, which may impact its effectiveness.

There are three related issues. First is a legal issue. Pediatric medicine is traditionally, and appropriately, family oriented. Until a patient turns 18, parents have legal authority over their child's care and have legal access to their child's health information. This situation changes when the patient turns 18 when parents lose their right to knowledge about their child's health. Even after a patient turns 18, many families report seeing themselves as

having an ongoing role in the care plan because they have important knowledge about their child's health that affects any care plan (Reiss, et al., 2005). The system currently does not effectively recognize the importance of the parental role. Second, the collaboration between patients, families, pediatricians, and adult care providers is a component that contributes to both the patient's and family's perception of transition success (Reiss, et al., 2005). Finally, patients and parents report that achieving transition over the long term requires reciprocal relationships of trust with their providers (Reiss, et al., 2005).

All these issues become more complex for parents of patients who, along with complex or chronic illness, have developmental disabilities that affect their decision-making capacity.

Issues for Care Providers

Both pediatric and adult care providers face challenges in the transition process. From the care provider's perspective, successful transition occurs when the provider has sufficient training and education to manage the care of a new patient (Peter, Forke, Ginsburg, & Schwarz, 2009).

Patient needs dictate the composition of the care team that may include various specialists in addition to a family physician. Many adult care providers, however, do not feel confident in adopting these patients, as they may feel that they have not received adequate training to take on their unique needs (Peter, et al., 2009). From the perspective of a pediatrician, successful transition occurs when there is an appropriate adult care provider to offer appropriate medical support for the patient (Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002). There are few adult care providers with the skill set, knowledge, or equipment to provide appropriate care for youth with complex or chronic illness. Consequently, transition is difficult for pediatricians, many of whom do not have the financial support to care for patients over the age of 18 (Adolescent Health Committee, 2007). This is further complicated by the increased demand for care from a growing number of patients with complex or chronic illness transitioning to adult care.

Family physicians also face multiple barriers to transitioning young adult patients. When these patients come back into the care of a family physician, that care may be compromised if medical information is not transferred in a timely manner from the pediatrician (Reiss, et al., 2005). Family physicians may have referred their patients to pediatricians years earlier but may not have received updates or reports on their patients until they graduate out of the pediatric system. Despite being optimally positioned to provide continuity of care to adolescent patients, family practitioners have historically faced a lack of the training, support, or timely access to specialists necessary to optimize care for their patients.

The physical location of patients and providers can also pose a challenge. Transition may fail because there is a lack of adult specialists or family physicians with the appropriate skills in the patient's region or health authority. Young adult patients who live outside major urban centres may also need the services of adult specialists outside of their health authority. In these cases, both the general practitioner and patients may find it difficult to develop a strong relationship with other members of the care team.

5. Transition Models

A series of transition models have been developed, including a system navigator model, a self-management model, and an individualized transition model. These models frequently serve as frameworks for different specialties that adapt them for specific patient or specialty needs. To date, there has been no formal evaluation of these transition models.

Transition Model Research

There is no shortage of research supporting the relationship between successful transition of youth to adult care and optimal health outcomes. There is also a great deal of information available on various transition models. There is no agreement, however, on whether transition models should be focused at a systems or program/illness level.

Weissberg-Benchell, Wolpert & Anderson (2007) recommended that transition protocols should be defined by the illness of the youth transitioning to adult care, and a literature review suggests this perspective is widely accepted. As a result, there has been a splintering of the literature, with a number of symptom-specific transition models. Thus, the research and results are as varied as each program because of their focus on the specific needs of their patients.

While often specialty-specific, most models fall within broad profiles (Davis & Sondheimer, 2005). Individual transition programs may share some attributes, but they are primarily focused on parameters defined by illness or disease. Once the transition program is developed, variations may depend on the developmental age of the patient. In general, individual programs use only a few high-level models as frameworks and then adapt their programs to suit the needs of their patients.

System Navigator Model

System navigator models have been successfully applied in Canada to target and alleviate potential barriers to youth patients obtaining treatment in the adult care setting. This model is founded on preventing the primary reasons identified for patient dropout such as challenges in scheduling appointments, failure to establish relationships with new care providers, feeling overwhelmed by the new system, and a lack of perceived value of adult care (Van Wallegghem, et al., 2006). In this model, one person, the system navigator, acts as an administrative project coordinator who maintains contact with each patient to provide support and assistance in overcoming these difficulties. In some instances the navigator works with various resources (e.g., educational tools) to ensure that the patient follows provider instructions and attends referral appointments.

Self-Management Model

Self-management models have been developed and evaluated in Canada and have been applied to patients with cystic fibrosis and lupus erythematosus (Grant & Pan, 2011). The model focuses on helping young patients develop the necessary skills and knowledge to advocate for themselves successfully, maintain health-promoting behaviour, and use adult health care services. This model aims to build an alliance among youth, families, and health care providers early in the process, followed by a gradual shift as the adolescents adopt more responsibilities themselves.

Youth participating in self-management programs are encouraged to participate, at a developmentally appropriate level, from the age of diagnosis. This includes encouraging patients to take “ownership” of their medical condition. The model emphasizes success both at the individual patient and family level.

Individualized Transition Model

The individualized transition model is designed to meet the unique physical and cognitive abilities of young adults and their families. With this model, the onus of successful transition is focused on the pediatric care providers. These providers may work with allied health professionals to identify and maximize each patient’s abilities.

In one example of this model, the youth patients are introduced to the program in early adolescence and trained in the stages of transition. Each stage has various components, and patients and families work with health professionals to master the different components. After each stage, the clinician meets with the patient or family to discuss the various components of the previous stage, both those that were mastered and those that were not, before the patient graduates to a new stage.

Nurse clinicians or other support providers may work as care coordinators as the patient transitions to adult care. The patient education is begun early and is designed to ensure that the patients maximize their potential in self-management.

Common Themes in Different Transition Models

Common themes have been identified in successful transition models or programs. These include communication, increased patient self-esteem, and bridging with the help of current providers or external resources (Crowley, Wolfe, Lock, & McKee, 2011; Kelly, et al., 2002; Van Wallegghem, et al., 2006; While et al., 2004). Despite the extensive similarities between the models, there is a lack of evidence to support one model over another or the use of patient-specific models (Hamdani, Jetha, & Norman, 2011; Scal, Evans, Blozis, Okinow, & Blum, 1999; Watson, Parr, Joyce, May, & Le Couteur, 2011). Of note, while it has not been formally evaluated, the perceived success of these models is often dependent on a multidisciplinary care team, whose members become knowledgeable in transition processes.

From a systems view, many successful facets of each program or model have been used to create a framework or series of “good practices” that become a foundation from which illness or patient-specific models can be tailored (Grant & Pan, 2011; Kelly, et al., 2002; While, et al., 2004). Such practice supports the literature, which suggests that a successful program must address issues for each individual, parent/carer, and providers involved in the transition (Grant & Pan, 2011; While, et al., 2004).

6. Youth Transition in BC

BC has some demonstrated success in transitioning youth from pediatric care through inter-ministry collaboration, the development of clinical pathway tools, and specialty-level initiatives at BC Children's Hospital. There remains, however, no effective and overarching provincial program that addresses barriers to access for patients as a result of provincial geography, economic climate, and isolation between health authorities.

Successes

BC has demonstrated some success in transitioning youth from pediatric care with specific initiatives.

- In 1998 an individualized transition model was developed that used a clinical pathway tool to guide transition planning and identify each patient's achieved tasks or skills (Paone, Wigle, & Saewyc, 2006). The documents are permanent health care records maintained for patient follow-up but also include input and notes from the patient and other care providers. The program is supported by a nurse clinician as care coordinator and existing subspecialty teams that have long-term working relationships with their patients. The program has not been formally evaluated; however, anecdotally, the challenge in province-wide adoption of the program was that it was "too bulky" and there was insufficient training time for care providers to educate themselves on the use of the tools. Regardless, various elements and features of the program have been integrated into 14 pediatric subspecialty multidisciplinary teams at BCCH (Grant & Pan, 2011). The program has support from the BC Ministry of Health and the BC Medical Association through the Shared Care Committee, which identified financial support for the navigation model in late 2011.
- In 2007 the Division of Nephrology at BCCH implemented a multidisciplinary transition clinic. The transition program is specifically designed for pediatric nephrology patients who will eventually transfer to an adult nephrologist. Using educational, behavioural, and social support strategies, the family-centred program is designed to improve patient adherence to adult care and deliver developmentally appropriate interventions. The program was evaluated in 2010 with respect to patient and allograft survival, and a preliminary economic feasibility assessment was also conducted (Prestidge, Romann, Djurdjev, & Matsuda-Abedini, 2012). While researchers were not able to identify statistically significant results due to the small sample size, improved health outcomes were identified in the intervention group. The researchers were also unable to identify significant cost savings as a result of the small sample size and limited results (Prestidge, et al., 2012).
- The Ministry of Health and nine other ministries have supported the importance of transition by signing off on the Transition Protocol for Youth with Special Needs. Other initiatives suitable for transitioning youth are also available through nursing services within each health authority and at the individual community level. In addition to the transition resources provided in pediatric care, these services meet other important needs of transitioning youth.

In addition to these transition-specific initiatives, the British Columbia Medical Association and the BC Ministry of Health collaborate to improve patient care and increase physician satisfaction in BC through the joint committees and other initiatives. While not specifically targeted to youth transitioning to adult care, the General Practices Services Committee (GPSC) programs are well positioned to support general practitioners who take on these patients:

- The “Practice Support Program” offers various training sessions for physicians to help improve practice efficiency and support enhanced delivery of patient care, including a module on chronic disease management.
- The “Full-Service Family Practice Incentive Program” offers compensation for complex care patients, including patients with diabetes.
- The Community Healthcare and Resource Directory (CHARD) database provides health care providers with comprehensive and up-to-date listings for various community health care referral resources.

Challenges

The unique system of tertiary care provision in BC delivers focused and age-appropriate pediatric services throughout the province. The system is well recognized for its child- and family-focused service delivery, advancements in research and technology, and dedication of its staff. Youth patients in BC are privileged in the care that they receive, although this can make navigating an adult-oriented care system even more challenging.

As there are few tertiary care centres in BC, many patients travel to Vancouver or other major urban centres for pediatric care and specialist referrals. Travel and care are supported at the provincial level by the Provincial Health Services Authority (PHSA). Upon graduation from centralized pediatric care, patients face a number of challenges. Some patients may return to communities far from their tertiary care centre, which may prevent pediatric providers from developing relationships with adult care providers outside their health authority or region. The financial burden of travelling to urban centres for treatment is a significant barrier to care and may be a challenge for patients and their families.

The lack of a provincial network between pediatric physicians and adult care providers has contributed to the lack of collaboration at the program level. While research has been focused on the development of program-specific transition programs, poor interdepartmental cooperation means a failed opportunity to share finite resources. Given the current economic climate and the small population of BC, it behooves researchers and care providers to collaborate on and support the implementation and evaluation of transition models across care programs as small sample sizes are a limitation to identifying results.

Further, individual budgets at the health authority level are a challenge to identifying financial success. Pediatric care, at a time when transition programs should usually be implemented, falls within the PHSA budget. Successful transition programs are designed to reduce emergency room visits, maintain continuity of care, and increase patient-physician attachment, all of which can reduce costs to adult care. Adult care is, generally, overseen by other health authorities where efficiencies of PHSA initiatives may be realized. However, the failure to identify or track transitioning patients significantly limits long-term evaluation of young patients. Successful transition programs contribute to cost savings, improved health outcomes, and individual patient experience, and success should be shared across the continuum of pediatric and adult care systems.



7. Conclusion

Youth graduates of transition programs are able to achieve their maximum potential and can become stewards of their own care. Youth patients who have successfully transitioned to adult care reap the benefits of improved health and increased self-esteem, providers benefit from reduced complications and the ability to collaborate, and the system experiences reduced emergency visits and improved economic benefits. As youth successfully transition to adult care, the benefits are transferred to all.

The transition from adolescence to adulthood is a unique time of life. Reaching adulthood comes with the expectation of adopting independence, personal responsibility, and navigating a complex world. Some adults, including parents and care providers, perceive adolescents as irresponsible, emotional, and erratic. As youth enter adulthood and leave school, taking on more responsibility and trying to make their way in an adult-oriented world, it is natural to feel overwhelmed and frustrated. For youth with chronic health issues, these feelings are coupled with the additional burden of self-management of care and an abrupt departure from the patient-centred pediatric care environment. Despite an identified need for greater support to maintain good health, youth with complex or chronic illness are faced with additional barriers to achieving independence and self-reliance. As a society, we have the responsibility to ensure that youth with the greatest need for support have the skills and resources necessary to succeed.

Youth graduates of transition programs are able to achieve their maximum potential and can become stewards of their own care. In an adult care system where patients navigate and advocate for themselves, it is appropriate to encourage all patients to achieve developmentally appropriate independence. Patient readiness to transition does not occur naturally upon approaching age 18. Young adult patients require support to develop the skills to navigate a complex adult system, and it is the role of pediatric and adult care systems to create the infrastructure and supports to guide them.

Youth patients who have successfully transitioned to adult care reap the benefits of improved health and increased self-esteem (van Staa, et al., 2011). Likewise, providers benefit from reduced complications and the ability to collaborate (Reiss, et al., 2005). The system experiences reduced emergency visits and improved economic benefits. As youth successfully transition to adult care, the benefits are transferred to all.

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