Adolescent patients with chronic health conditions transitioning into adult care

What role should family physicians play?

Roger Chafe PhD Rayzel Shulman MD PhD Astrid Guttmann MD CM MSc Kris Aubrey-Bassler MD MSc CCFP

Between 15% and 18% of adolescents have a chronic health condition that they will continue to have as an adult.[1] Common diseases include asthma, attention deficit hyperactivity disorder, autism spectrum disorder, and other mental health problems, but many other conditions such as juvenile arthritis, cerebral palsy, inflammatory bowel disease, diabetes, and complex neurologic issues also require ongoing care. Some of these conditions are single chronic diseases, others are complex chronic health conditions that require technological supports and multiple specialists. When these patients are younger, it is common for a pediatrician to follow them for their chronic condition, with their family physician seeing them for their other primary care needs. Yet these patients one day reach an age at which it is no longer appropriate for them to be followed within the children's health care environment. While it might be clear and is often regulated that they should no longer be seen by a pediatrician, it is frequently less clear who is the most appropriate provider to take over the lead of their care and what the model of disease management should look like once these patients enter adulthood.

The proper care environment for any patient will depend on his or her individual circumstances. Guidelines around transition often highlight a role for family physicians in providing more of the care previously provided by pediatricians,[2,3] but there is little guidance on how this can be done effectively.[4] In some cases, it is recommended that family physicians take on primary responsibility for managing these patients' chronic conditions.[5,6] Other models, sometimes referred to as a *shared care model,* recommend an expanded role for the family physician as part of a wider team or program looking after these patients.[7,8] In this article, we examine the opportunities and issues these patients might raise, concerns family physicians might have, and what facilitators need to be in place for family physicians to better support young adults with chronic conditions transitioning into adult care.

There is often a distinction made between *transfer,* which is the actual point when a patient's care is moved to a new provider, and *transition,* which includes the longer process of preparing adolescents for their move to adult care. While family physicians can certainly play a role in supporting transition, and there is evidence that they positively affect patient outcomes when they do,[9] in this article we are mostly focused on the role of family physicians accepting greater responsibility for these patients after transfer.

Why family physicians?

There are a number of reasons why family physicians can play a key role for patients transitioning into adult care. First of all, there are a growing number of patients with chronic conditions who need to be accommodated in the adult care system. There is often limited capacity within adult specialty clinics, with many clinics already having lengthy waiting lists. While many of these young adults still require follow-up by a physician, they might have their conditions well under control and be at relatively low risk of serious complications. In short, while they have medical issues that might require multidisciplinary teams to support or specific medical knowledge to manage, they might not need to be seen by a non–family physician specialist on an ongoing basis. Some patients might have a range of comorbidities, which would benefit from being seen in primary care, given its more holistic health focus. Similarly, new models of primary care delivery being employed in Canada—team-based approaches, which better incorporate multiple types of health professionals; blended capitation; pay-for-performance models; or a combination of these—can be well suited to supporting these patients.[10,11] In rural areas, a family physician is sometimes the only available option for patients. Although few cost-effectiveness studies have been conducted, following young adults with chronic conditions in the community is likely more cost effective than in specialized settings.[12]

For patients, seeing their family physicians for follow-up is often more convenient than arranging an appointment with another specialist. Transferring more care to one's family doctor helps keep at least some continuity during the period of early adulthood. It can also help ensure that patients are not lost to follow-up, and that they have a physician familiar with their medical history to whom they can turn if needed. Patients who see a pediatrician for their primary care require concurrent transition of both primary and other specialty care, which might increase the risk of poor transfer outcomes.[13] For these patients, transitioning most of their care to a single primary care setting might be beneficial. Taking more responsibility for managing young adults with chronic conditions is often desired by family physicians who, depending on the condition, see it as a learning experience. The fact is that many young adults with chronic conditions already see their family physicians for many of their health issues.

A recent systematic review and our own review of the literature found few rigorous intervention or even

observational studies on the role of primary care providers in care transition.[4] One area in which there has been some work published is the care of survivors of childhood cancer. Because of the effects of cancer and its treatment, two-thirds of the survivors of childhood cancer will have some late side effects and are at a lifelong elevated risk of a number of health conditions, including the development of a secondary cancer.[14] Nathan et al found that only 14.6% of these survivors of childhood cancer received follow-up care in a cancer centre once they reached adulthood, with most receiving care in the community.[5] In a study from the Netherlands, family physicians following survivors of childhood cancer under a shared care model sent an annual update form to the pediatric oncology program that originally treated the patient. Most (90%) of the participating family physicians returned patient updates to the cancer program. Of 1275 survivors followed in primary care during the 2-year study period, 84 (6.6%) cancer survivors had a second cancer, and 56% of these secondary cancers were initially identified by the patient's family physician.[15] This study illustrates the important role that family physicians can play in the care of these patients when proper supports are in place.

Challenges to transferring care

While many family physicians might already be managing young adults with chronic conditions, there are challenges that need to be addressed. A recent systematic review in the United States found that some of the common barriers to successful transition were related to patients not wanting to leave pediatric care, difficulties finding a new provider, gaps in health insurance, limited patient knowledge about how transition is supposed to occur, and limited ability to self-manage their conditions.[16] While some of these issues can be addressed within pediatric settings, others will require wider system changes.

Because some chronic conditions are rarely seen in family practice, family physicians might be unfamiliar with the appropriate management of these conditions and their treatment schedules. When concentrated in a single clinic, there might be sufficient numbers to justify developing in-depth knowledge. But spread across all of the family physicians in a region, patient populations can be quite small. Increases in prevalence of chronic conditions in young adults are largely driven by increases in diagnosis of intellectual, behavioural, and mental health conditions. These conditions can be more difficult to manage in some primary care settings because of the need for other professional support and the added time for clinic visits.[17]

Transfer to adult care is often poorly coordinated, and many children's hospitals and pediatric specialists lack good transition programs.[18,19] This might mean that family physicians have limited access to hospital records for patients they are now responsible for or have limited opportunities to discuss patients with the pediatric providers who diagnosed and treated them. There is also little evidence regarding the most appropriate model for integrating family physicians in the care of patients with specific conditions.[4]

Better supporting a shared care model

In their review of family physician involvement with follow-up care for survivors of childhood cancer, Singer et al recommended a well-organized transition program and giving the family physician a summary of the treatments the patient received, a care plan, and education on specific aspects of care for survivors as important elements of a successful shared care model.[20] These elements would likely be beneficial for the transition of any emerging adults with chronic medical conditions. Easy-to-use mechanisms for family physicians to access subspecialty consultations or efficient processes for referring patients when required need to be in place. More research is needed to allow us to determine what models of care transition work best for family physicians, and to determine the barriers that family physicians and their patients see to improving transition care.

Although not previously identified in the literature, there seems to be 2 approaches that can be used for patients with chronic conditions in primary care. In one approach, primary care physicians see young adults with chronic conditions who happen to be in their practices (ie, cases of a specific condition are diffused across all family physicians in an area). In a more concentrated model, a family physician might take on the role of seeing patients with a specific condition, so that his or her clinic has a sufficient number of patients to justify developing increased knowledge about a disease, with other family physicians in an area taking on a similar role for patients with different conditions. While we recognize that this type of specialization for part or all of a family physician practice might be at odds with the model of comprehensive care, it might be the most effective model in areas with a low supply of non–family physician specialists. We need to research further the implications of both approaches, and what the appropriate level of compensation for providing this type of expanded service would be. We also need to explore which new models of primary care delivery, including multidisciplinary care teams, are best able to support young adult patients with ongoing health care needs. Models of transition and adult care will undoubtedly need to be tailored to the complexity of the health care needs.

Conclusion

In Canada, approximately 70 000 emerging adults transfer annually out of pediatric care but still require ongoing care or follow-up. Transition causes a great deal of concern for families with children with chronic health conditions. While it is not appropriate to transition all of these patients directly into primary care, family physicians, if correctly supported, can play a vital role in the

lives of many of these patients, helping to ensure that their transfer to adult care is a positive step in their lifelong journey with their disease.

Dr Chafe is Associate Professor at Memorial University of Newfoundland in St John's. **Dr Shulman** is a staff physician at the Hospital for Sick Children in Toronto, Ont, Scientist Track Investigator at the SickKids Research Institute, and Adjunct Scientist at ICES. **Dr Guttmann** is a staff physician and Senior Associate Scientist at the Hospital for Sick Children, Senior Scientist and Chief Science Officer at ICES, and Professor of Paediatrics and Health Policy, Management and Evaluation at the University of Toronto. **Dr Aubrey-Bassler** is Associate Professor and Director in the Primary Healthcare Research Unit at Memorial University of Newfoundland.

Competing interests
None declared

Correspondence
Dr Roger Chafe; e-mail **roger.chafe@med.mun.ca**

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