When chronic care youth age out: Transition planning

The journey from adolescence to adulthood can be a stressful time for young adults as they assume the responsibilities of life traditionally taken care of by their parents. For young adults with chronic health conditions and disabilities, this transition can be especially challenging.

With medical advancements, a new generation of youth with pediatric chronic health conditions and disabilities such as cystic fibrosis and congenital health disease are now surviving to adulthood. This means that approximately 1700 youth are currently aging out of the pediatric system in BC annually, and this number is increasing.

The issue: Poor health outcomes for transitioning youth

For youth with chronic health conditions and disabilities, the failure to attach to adult primary and specialist care in transition from BC Children's Hospital presents a number of risks. Lack of transition planning and preparation, combined with ad hoc systems for transfer, can have the following negative impacts:

- Measurable adverse outcomes including increased mortality, morbidity, and poor long-term prognosis and quality of life.[1-3]
- Increased risk factors including a decline or cessation of medical care leading to secondary disease or illness.
- Inappropriate use of emergency services and expensive use of the adult health care system.

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Successful transition is defined 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."

Closing the gap

In 2011 a provincial workshop hosted by Doctors of BC and Child Health BC brought pediatric and adult specialists together with family physicians to address transition issues for youth with chronic health conditions and disabilities. A policy paper, *Closing the Gap,* was developed as a result in December 2012. In the paper, successful transition is defined 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."[4]

In alignment with the policy paper, a Doctors of BC/Ministry of Health Shared Care Youth Transition Initiative was introduced to address three of the policy paper's 10 recommendations:

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 should be developed to identify and track youth transitioning to adult care, to evaluate successful transition and long-term health outcomes.

Developing the approach

From 2011 to 2014, the Shared Care initiative engaged a number of divisions of family practice as prototype sites to develop approaches for successful planning, preparation, and transfer of youth with chronic health conditions and disabilities from pediatric to adult care. An important component was to ensure the continuous attachment of young adult patients to primary and specialist physicians.

The triple-aim approach—to improve patient and provider experience and maintain cost and improve health outcomes—provided a framework to guide the development of effective transition protocols and tools.

Results

Through discussions with family physicians and specialists, the following tools and processes were developed:

- Medical transfer summary: To provide a relevant summary of the youth's pediatric history, guidance for anticipated future care, and pertinent psychosocial information. This transfer documentation can be electronically submitted to physicians' EMRs through provincial transcription services.
- Expedited referral process: To attach youth transitioning from BC Children's Hospital to appropriate community care (i.e., clinic, family

physician, specialist).

- Fee code recommendations: To appropriately reimburse family physicians and specialists to improve communication practices to support continuous primary care for youth with chronic health conditions and disabilities.
- Algorithm for tracking and evaluation: To identify transitioning patients at BC Children's Hospital as a step toward creating a regionally articulated provincial data set.

The Youth Transition Initiative has now established the foundation to bridge the gaps in transition for youth from BC Children's Hospital to adult community care. These processes and tools are now available to be implemented in other communities across the province.

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