

Commentary

Children with medical complexities: Addressing the gaps in respite care during transition from paediatrics to adult health care in Ontario

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Abstract

Respite care is one integral component of the transition process from paediatric to adult health care, and is of particular importance to individuals with medical complexities. Numerous gaps that exist within the current system limit a child and family's ability to access quality respite care during a time when it is often most needed. Identifying and addressing these gaps in a systematic and collaborative way presents an opportunity to improve the quality of life for this vulnerable, ever growing population and their families.

Keywords: *Disabled children; Chronic disease; Respite care; Family; Transition to adult care.*

WHY IS RESPITE CARE IMPORTANT DURING TRANSITION FROM PAEDIATRIC TO ADULT HEALTH CARE?

Transition from paediatric to adult care has long been recognized as an important milestone in the context of a child's life. Transition has been defined as the 'purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care' (1). This process requires planning long before the age of transition, and continues well into early adulthood. Currently, there are numerous guidelines and best practice models that outline how transition from paediatric to adult care can be done well (2–5).

Respite care (defined as alternative care arrangement for persons with disabilities that allows their carers a short break from care commitments (6)) is an integral component of this transition. In paediatrics, families caring for children with medical complexities (CMC) (7) identify the need for respite as an essential component of family-centred care (8,9). The term CMC refers to a group of medically fragile paediatric patients with intensive care needs, often as a result of a congenital or acquired multisystem disease, a severe neurologic condition with marked functional impairment and/or technology dependence for activities (7). Family-centred service provision is considered best practice in paediatric rehabilitation. It embodies the belief that processes and outcomes of health care are optimized through care that encompasses the child, family and the environment where the child lives, learns and plays (8). Older children may have increased medical and physical needs as well as larger body size.

These burdens are compounded when considering aging caregivers, who may develop their own health concerns which can impact their care giving abilities.

In addition, transition to adult care is typically a busy time for children and their families as they have the added stress of navigating new health and education systems, acquainting with new physicians and care providers, and learning the different pathways for funding and social supports. Even a short overnight stay can provide a much needed break for families during challenging times (10).

Respite programs can also become a positive opportunity for children and their families to practice important transition skills. These include the chance to exercise their advocacy skills (if developmentally appropriate) regarding personal and medical care, and to have exposure to expanded recreational and even vocational programming (11). It is also an opportunity for families to gain a better appreciation for how other care providers may become involved to support their child.

Paradoxically, this time period when respite may be of greatest benefit, is also the time when it can be the most difficult to obtain.

WHAT ARE THE CURRENT GAPS IN THE TRANSITION FROM PAEDIATRIC TO ADULT SYSTEMS WITH RESPECT TO RESPITE CARE?

Young adult graduates of the paediatric system face numerous obstacles in accessing respite care in the adult world. Most of the medically focused

transition programs utilize a 'shared management model' with the focus on an early therapeutic alliance between children/youth, families and health care providers that enables young people with chronic conditions to develop into independent, healthy and functioning adults. There is an emphasis on a gradual shift in responsibility and leadership from the health professional to the parent and ultimately to the youth (2–5). The significant limitation to this model is that it often does not apply to, or fully address the needs of more complex patients, or patients with significant developmental disabilities.

The SickKids 'Good to Go' transition program recognizes this limitation and publishes a concurrent Complex Care Transition Resource Guide (4). This offers general information in a chart format about adult support services, funding and transition planning for Ontario families supporting adolescents with complex needs. However, even with this guide, a family would need to consider tapping into a dozen different organizations in order to get the necessary supports regarding respite, home health care, assistive devices, tax credits and education. In addition, there is no process for health care providers supporting the transition to properly assess and appreciate an individual caregiver's needs during this time. This is an identified weakness based on other quality reviews of the current transition models (12,13).

With respect to respite services, funding arrangements are often fragmented during transition. Differences in funding opportunities in the adult system compared to the paediatric system are not always clear. Services may be withdrawn based on age and there is often confusion about the different arrangements that may be available going forward (14). In Ontario, there is a centralized website which lists regional respite options; however this list is alphabetical by organization rather than by type of service provision, medical need or target population (15). The lack of well organized, easy to use and practical information creates unnecessary work for families.

Once a child transitions to the adult respite system, there is a general deficiency of equivalent respite care services available to meet the needs of medically complex patients. This may be due to a lack of medical training and understanding about the unique needs of this population, in addition to a lack of resources both fiscal and human (13).

For young adults with medical complexities who are lucky enough to secure adult respite opportunities, there is a paucity of developmentally appropriate care. Some of the respite placements are in residential facilities which are geared toward care of the elderly (16). Many families are reluctant to leave their young adult children in a place where there will be no opportunity for peer to peer socialization and no recreation options appropriate for their developmental stage (12).

HOW CAN WE BEST ADDRESS SOME OF THE IDENTIFIED GAPS?

Acknowledging the gaps in the current system with respect to accessing adult respite care in general, but more specifically for CMCs, is the first step in creating the opportunity for change and, ultimately for solutions. A central component of this change stems from increasing the collaboration between adult and paediatric respite care systems.

1. Funding and budget: The creation of a joint funding or continuing funding package during the critical transition years may alleviate some of the problems that exist in the current system. Flexibility in how this funding can be utilized for respite care is important, (e.g., home care versus out of home respite) in order to best meet the needs of the individual family and young adult. A designated liaison, or identified expert for transitions between the two respite programs may be invaluable in supporting families as they navigate the transition.
2. Lack of medical supports and lack of developmentally appropriate care: The respite care system needs to build capacity to accommodate the growing population of children with medical complexities

surviving into adulthood. This should be done by increasing training and education opportunities for adult care providers, for both medical and recreational supports. For example, the system could designate special 'young adult' respite bed spaces or 'young adult weeks/week-ends' in residential or long term care facilities. This can help ensure that care providers designated to work with medically complex young adults have the required medical expertise to properly address their needs, and have an understanding of developmentally appropriate recreational opportunities that can be provided. This capacity can be built through collaborative efforts, with paediatric and adult colleagues sharing information and educating one another about their respective systems, and how best to support this unique group.

3. Assessing and understanding caregiver needs: Caregiver needs (particularly in the population of families caring for CMC's), should be highlighted as an essential component of any transition plan program, with respite opportunities as one central component of caregiver well-being. Increased training, and formalized assessment models could allow health care providers to become better at identifying, assessing and addressing caregiver needs (17). We may build our understanding by involving individual families or family councils in planning stages.

Finally, we need to formalize quality improvement by evaluating the effect of change, and soliciting direct and regular feedback from patients and families regarding the impact of any changes implemented to the system (18).

Accessing quality respite care from childhood into adulthood for individuals with medical complexities is a growing issue in Ontario. As paediatricians and health care providers, we have a duty to advocate for changes in the current system to support unmet needs for this vulnerable population. By doing so, we have the potential to improve the quality of life for children, adolescents, young adults and their families throughout the lifespan.

Conflict of Interest

None declared.

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