Who Cares About Young Carers?

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“I can’t remember the first time I helped my mom take care of my two younger brothers, William and Jonathan. They both have cerebral palsy and a severe developmental delay. I’m 16 now, and I love my brothers with all my heart, but I find it difficult to have to look after them every time I’m at home. Because I spend so much time caring for my brothers, it’s a challenge for me to hand in all my school assignments on time. Sometimes, I feel exhausted and I wish I could just be a normal teenager. ” This story, Emma’s story, is a story that is too often left untold. Emma (fictional name) is a patient I saw in clinic for depressive symptoms and alcohol addiction. More importantly, Emma is part of a large, yet unrecognized group of Canadians: Young Carers.

Young Carers are children, teenagers or young adults who provide significant care to a family member (parent, grandparent, sibling, etc.) because of illness, disability or other challenges. The caring tasks they perform go beyond the scope of what is expected of young people of the same age, and can include physical care, emotional support, household chores or helping with medical treatments or appointments. Young Carers are found in every community. While Canadian research is still extremely limited, it is estimated, based on national and international research, that there are likely tens of thousands, if not hundreds of thousands of Young Carers in Canada. However, in many cases, Young Carers don’t recognize themselves as such, and are too often invisible even to their peers, as well as to the adults who could potentially help support them.

Why should we, as future paediatricians, care about Young Carers? The costs of not recognizing and supporting Young Carers are immense, both for society and for Young Carers themselves. Research from other industrialized countries shows that Young Carers are less likely to do well at school and have higher drop-out rates than more typical peers. Other harmful consequences of undersupported Young Carers can include: rejection by peers, exhaustion and lack of sleep, physical strain, mental health problems including anxiety, depression and suicidal thoughts, turning to alcohol, drugs or tobacco for relief, and a general feeling of imprisonment and loss of childhood. By not supporting Young Carers, Canada is failing to honor its commitment to the United Nations’ Convention on the Rights of the Child, which states that every child has the right protection from all forms of violence, injury, abuse, neglect or maltreatment (article 19), the right to a quality education (article 28) and the right to play and rest (article 31). Canada is also falling behind other countries that are taking concrete measures to support Young Carers.

Not all aspects of young caring are negative. For instance, when adequately supported, providing care to a family member can allow the caregiver to develop important life skills, a sense of responsibility, and positive qualities such as empathy and compassion. Young carers may also have a special and enriching relationship with the person they care for.

Many countries, such as the UK, Australia and New Zealand, have taken concrete measures to provide support for Young Carers. Some examples are having a National Young Carers Day, respite services for Young Carers, caring allowances, community-based support groups and workshops in schools.
Unfortunately, only three local organizations in Canada (two in Ontario and one in British Columbia) are dedicated to supporting Young Carers and their families.

As health care professionals, the first and easiest steps to take are to get informed and spread the word about Young Carers. Raising awareness will allow Young Carers to come forward and self-identify, while helping more Canadians to understand Young Carers’ needs and their important contributions to society. There is also a need for quality data and research to gain a better understanding of the demographics and characteristics of youth caregiving in Canada. Most importantly, any initiative aiming to support Young Carers should adopt a multisector approach: paediatricians can’t do it alone. We must convince allies from the health, education, youth protection, government and non-government sectors to join our efforts.

Want to read more? Visit www.homeworkorcare.ca to find more information about Young Carers. Read a recent report from the Action Canada Task Force on Young Carers entitled *Who Cares about Young Carers? Raising Awareness for an Invisible Population.*