



The Elephant in the Room: *Young Carers in Canada*

Audrey Miller

At some point in our lives, regardless of age, most of us will experience being a carer. We will support a family member, a neighbour or a friend who, without our help, could not manage due to illness, frailty, disability, mental health or substance misuse problems. We will take on caregiving tasks such as cooking, shopping and driving,

cleaning and grooming, budgeting, managing health services and administering medications. Our commitment will at times be borne from love and/or obligation. Sometimes, being a carer will be exhausting, stressful and overwhelming; at other times, it will be energizing and deeply fulfilling.

Caregiving mostly takes place within and among families and is

largely the purview of adults. In most families, children and youth are expected to take on age-appropriate care-related tasks as capacity allows and in step with established family norms and cultural expectations. Asking a 5-year-old to put dirty clothes in the hamper, expecting a 10-year-old to set and clear the table or including a teenager in the roster of friends and family who drive

Grandma to the doctor are well within the range of responsibilities that make up family life. Typically, families provide space for young people to grow into new responsibilities and acquire the necessary skills along the way, through trial and error.

Caring beyond the norm

In some families, a young person may be required to take on a range and depth of care-related responsibilities well before they might otherwise be expected to or ready for. We refer to these young people as young carers.

Young carers are generally 18 or younger and live in families where the “natural” caregiver – typically a parent – is ill, incapacitated or absent. Young carers play a vitally important role in their families and communities. Their contributions, however, often go unnoticed. Partially because of their age and their position in families already marginalized by circumstance, young carers have been largely absent from the discussion of family caregiving in Canada.

Young carers provide primary care

Young carers stand apart from their peers by virtue of the role they play as primary caregivers within the family. In times of family emergency, young carers may be thrust into a caregiving role quickly and unexpectedly, without the benefit of the necessary practice, knowledge or support.

Young caregiving may be intermittent and ongoing or episodic and short-lived. In the case of chronic illness, it may span an entire childhood. The care requirements may be intense and all-consuming or more easily accommodated. Whatever the context, young caring is typically unpredictable and can be highly demanding. These early caregiving responsibilities have the potential to disrupt what may otherwise

be perceived as “normal” life course development for an average adolescent.

Young caring is not an uncommon experience

The largely private and often hidden nature of young caregiving makes it hard to identify the exact number of young carers in Canada. The apparent stigma associated with being a young

carer and with being part of a family that needs young people to take on caregiving roles means that few youth come forward and identify themselves as young carers. Parents are typically even less likely to admit that they have to rely on their child(ren) to help support them and the family (Charles, Marshall and Stainton, 2010).

Keen to get a feel for the number of young people actually providing primary care, a group of researchers from the University of British Columbia recently surveyed high school students in Vancouver and found that 12% self-identified as being primary caregivers, meaning they answered yes to the question: “Do you spend any time taking care of an adult in your family because they cannot care for themselves?” (Charles, Marshall and Stainton, 2010). This number cut across gender and ethnicity lines, with almost equal parts male and female youth identifying as caregivers. The mean age of the young carers in the study was 14 and just over two-thirds were providing care to either a parent or a grandparent.

Clearly, a small but significant number of young people are carers,

and yet they remain largely invisible in their schools and in their communities. Why don't we know more about such an important group of Canadian youth? The UBC team is leading the charge to answer this question in Canada. They liken the subject of young caring to “the elephant in the room.” Few people ask about it; most families that depend on it feel secrete,

12% of students surveyed in a Vancouver high school reported caring for an adult in the family.

ive, ashamed or fearful; and most of the family caregiving research has focused on pressing issues facing adult caregivers.

Our ability to better support young carers and their families requires breaking the silence. This means developing a better understanding of the pathways into and out of young caring and the varied experiences – both positive and negative – that punctuate the journey.

Young caring brings challenge and opportunity

For many young carers, childhood and adolescence are overshadowed by early caregiving responsibilities. When hanging out with friends or spending time alone gets replaced by care-related obligations, young carers risk missing out on age-appropriate activities at a time when circumstances are asking them to grow up too fast.

The more young carers feel able to determine or direct their caregiving, the more likely they are to view the experience as positive. Similarly, the more support a young carer receives both from the care recipient and other

people, the more likely there will be positive outcomes. The less the young person's experiences are validated and the less support he or she receives, the higher the likelihood of adverse consequences.

Among the greatest challenges a young carer faces is the social and physical isolation that may come with being overburdened by care responsibilities. Stress is among the most debilitating of the common consequences of being a young carer (Butler and Astbury, 2005). Worry and anxiety are never very far behind, exacerbated by the often unpredictable nature of their lives and of the well-being of the care recipients.

Without the same opportunity to have what might be seen as an age-appropriate life, young carers report feeling "different" from their non-caregiving peers (Charles, Marshall and Stainton, 2010). Often afraid of being judged or rejected, young carers report keeping their concerns and circumstances hidden from their peers, cutting themselves off from possible support and camaraderie (Armstrong, 2002).

Despite the very real potential for negative outcomes, it is equally possible, under the right circumstances, for young carers to derive something very positive from their caregiving experiences. Adult participants in a recent retrospective study of the impacts of young caring noted that their early caregiving experiences allowed them to develop empathy and a heightened sensitivity to the needs of others (Charles, Marshall and Stainton, 2010). Young carers may also enjoy a heightened closeness with the person for whom they are providing care and derive a great deal of satisfaction from their ongoing commitment to another

person in need. Performing caregiving tasks typically reserved for adults can also have the benefit of lending young carers a sense of maturity and trustwor-

thiness. It can be very powerful to know that one's actions are helping keep a family together.

Supporting families

Adolescence is a time when youth should be connecting to peers, developing new ways of interacting in relationships and building a sense of mastery, independence and confidence in their ability to transition into adulthood. Young carers often bypass this important training ground, compelled by circumstances to remain focused inward and on their family. And, whereas some young carers thrive in their roles, others suffer the pain of isolation, stress and overwork.

Addressing the needs of young carers means also addressing the overall care needs of families. The first step in supporting young carers is identifying them. The next steps, after recognition, are to provide resources, guidance and support. And, while we are still in the early days, trailing behind our counterparts in other countries, the dialogue has begun and awareness is building.

Enhancing this momentum means encouraging awareness and participation

among communities, organizations and corporations involved in developing or providing family-based care to families with members who are aging, ill, disabled

Some young carers thrive in their roles, others suffer the pain of isolation, stress and overwork.

or incapacitated. It also means magnifying the voices and experiences of young people, both carers and non-carers. The contributions these young people are making to their families and their communities are an essential component of family caregiving in Canada. With an aging population, it stands to reason that more and more young Canadians will be called on to step in as primary caregivers within their family networks.

Audrey Miller MSW, RSW, CCRC, CCLCP is the Founder and Managing Director of Elder Caring Inc. (www.eldercaring.ca) and a partner in the CareGiverProject.

To magnify the voices of young carers and their families and to raise awareness of the risks and opportunities unique to their experiences, the CareGiverProject and the Vanier Institute for the Family have created a video about young carers for YouTube (<http://www.youtube.com/watch?v=9pJGAQ69T3o&feature=youtu.be>). The result is a powerful, moving and poignant rap video highlighting the musical talents of Tricky P, a hip-hop artist and young caregiver himself (see p.10 for more information).

REFERENCES

Armstrong, C. (2002). "Behind closed doors: Living with a parent's mental illness." *Young Minds Magazine*, 61, 28-30.

Butler, A.H., and G. Astbury (2005). "The caring child: An evaluative case study of the Cornwall Young Carers project." *Children & Society*, 19(4), 292-303.

Charles, G., S. Marshall and T. Stainton (2010). "Demographics profiles and initial results from the British Columbia Young Carers study." *Relational Child and Youth Care Practice*, 23(4), 64-67.