

Finding the way — meeting the needs of adults with childhood-acquired illnesses

One of the great medical success stories of the last 25 years is the taming of many serious childhood diseases that previously killed children only a generation ago. Adults with cystic fibrosis (CF) were rare in the 1980s — yet now the median survival for CF in Canada is well over 30 years. Childhood leukemia is no longer a death sentence — with over 80% of children with acute lymphoblastic leukemia going into long-term remission, and even those with acute myelogenous leukemia now have a survival rate of over 50%. Most babies born at 26–28 weeks' gestation now survive. Many infants with serious congenital malformations have these diagnosed in utero with care maps planned out before delivery. Often the serious heart defect, gastrointestinal problem or renal anomaly can be managed, modified or corrected.

As these survivors of serious childhood diseases move into adulthood, new problems are emerging that are sometimes related to the disease (diabetes in adult patients with CF) or to sequelae of the treatment of the disease (second malignancies in childhood cancer survivors). In response to these needs, clinics for adults with congenital heart disease or CF are becoming increasingly common, as are follow-up clinics for adult survivors of childhood cancer. Of note, many of these clinics sprang up because these adult patients demanded that their care move out of the pediatric centre into the adult milieu, with care provided by experts in their disease area. These savvy adults knew only too well that disease-specific multidisciplinary expert care does make a big difference in survival and in quality of life. Although transition to adult care settings has not always been smooth, the expectation for most young people with CF, congenital heart disease or cancer is that they will grow up and receive their disease care in an adult-specific program.

Not all adults with serious health problems extending from childhood are so fortunate. There are regional differences in access to adult-specific care programs tailored to meet the needs of childhood disease survivors, as well as lack of specific programs for some conditions. For example, adults with cerebral palsy and serious developmental disabilities often remain marginalized in the adult health care system. Interrelated problems such as poor nutrition, hip dislocation, chronic pain, muscle spasms, contractures, recurrent pneumonias, physical abuse and communication difficulties are addressed in a disconnected fashion, with attention focused on a single problem, rather than in a multidisciplinary coordinated manner. In some instances, problems — such as abuse — are not recognized at all or are ignored. Although

pediatric multidisciplinary clinics have led to improved survival and improved quality of life for these children and youth, “graduation” to an integrated multidisciplinary expert adult health care program is rarely possible, as few such clinics even exist. These proposed adult multidisciplinary tertiary care programs would serve as a resource for the family physicians who provide continuing primary care for this population. As more and more of these children and youth grow into adulthood, this issue has become more urgent.

The plight of adults with cerebral palsy and severe developmental delay highlights the following conundrum: on the one hand, we need to provide health care for the common problems of adulthood and of aging for all, yet on the other hand we need very specialized multidisciplinary care for subpopulations of adults with complex health backgrounds for whom “standard adult care” is inadequate. How do we achieve a balance between these competing needs, especially when a group cannot advocate for themselves, namely, the developmentally delayed adult with cerebral palsy?

Because both human and physical resources are limited, rationing and priority setting has often emphasized the needs of the masses and/or the vocal, for example, adults waiting for joint replacement.

How can we parcel the resources out in a fashion that is more equitable and humane? Who should make these decisions and by what criteria? There is a need for new thinking here, for a more transparent process where relevance, cost-effectiveness and impact on quality and quantity of life are taken into account. The evidence for the choices selected needs to be made clear.

Canada's health care system is based on the notion of the collective good, that is, an effort is made to ensure quality care in a reasonable timeframe for all, such that the individual is not left out, forgotten or bankrupted due to the high costs of his/her health care. The needs of those who are marginalized in society, especially those who do not have a voice such as adults with cerebral palsy and developmental delay, must not be forgotten when health care rationing and priority-setting decisions are being made.

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This article has been peer reviewed.