

The Transition to Adulthood for Children With Cerebral Palsy

What Do We Know About Their Health Care Needs?

Nancy L. Young, PhD, MSc, BScPT

There have been significant changes in the clinical management of cerebral palsy (CP) during the past 2 decades. Gastrostomy tubes and nutritional supplements have been paramount in enhancing the life expectancy of those with CP. The literature shows that as many as 90% of children with CP can now expect to live to adulthood.¹⁻⁴ As a result, CP is no longer considered to be a condition limited to childhood. However, emerging populations pose new challenges to those who provide health care support.

This article presents an overview of what we know about the health care needs of adults with CP. When these children began living into their later teens in larger numbers, the existing pediatric services were able to support their needs. But entering adulthood poses many unique challenges, and the adult health care system has not been able to support their needs.⁵⁻⁷ To address this apparent gap, we need to understand the health care needs of adults who have CP and the factors that influence their access to appropriate care and use this knowledge to guide the development of adult-oriented health care services for those with CP.

This article explores what we know about the health care needs of adults with CP. It also explores some of the key factors that may pose challenges to accessing appropriate adult-oriented health care services.

HOW MUCH HEALTH CARE AND WHAT TYPE OF HEALTH CARE DO ADULTS WITH CP REQUIRE?

There is very little information available on the health care needs of adults with CP. The most common source of information on health care for adults with CP is from case series reported in the medical literature. Some of these reports are written by small groups and present the perspectives of several physicians and/or surgeons who have extensive clinical experience with the population. Other authors have tried to improve the science by using formal consensus

methods and thus present a consensus of clinical knowledge from large groups of clinical experts. There are, however, only a few key articles that provide an empirical examination of the needs of adults with CP. From this body of literature, it is apparent that many of the health issues that originated in childhood continue into adulthood. These include impairments in mobility and dexterity, as well as difficulties with spasticity, communication, and swallowing. In addition, new health issues emerge in adulthood. These include early-onset arthritis and osteoporosis,⁶ gastroesophageal reflux,⁸ fractures,^{9,10} and progressive spasticity.¹¹ This information suggests that despite the fact that growth has ceased at the end of adolescence, the need for health services remains high and is likely similar to that of youth. Even with similar needs for care, the case series and clinical consensus literature highlight a lack of services for adults with CP.

A third source of information, administrative data analysis, may be a useful empiric method for exploring the needs of adults with CP. Administrative data are collected by hospitals and ambulatory care clinics to track general trends in health care use and provide financial reimbursement to providers. These data have also been analyzed to examine the types of services used by adults with CP. All 3 approaches are important. If case series, clinical consensus literature, and administrative data studies all show a common pattern, then we can be reasonably certain that we have a comprehensive understanding of the key needs of adults with CP.

What do the administrative data tell us? In 2000, I began a pilot study in conjunction with a multidisciplinary group of scientists and clinicians to examine health care use by adults with CP, spina bifida, and acquired brain injuries in Toronto.¹² The pilot data showed that these adults had admission rates 9.0 times that of the general population.

A second more comprehensive study was initiated in 2003, from which patterns of health care were reported for 587 youth and 477 young adults with CP. We found that both youth and young adults frequently accessed the health care system.¹³ For example, annual hospital admission rates for youth and adults with CP that were 10.6 and 4.3 times higher, respectively, than that of age-matched peers. Furthermore, youth with CP visited physicians on an outpatient basis 2.2 times more often than their age-matched peers, and adults with CP had rates 1.9 times higher than their age-matched peers.

Within the outpatient visit patterns, we found a clinically important discrepancy with respect to visits to

From the Laurentian University, Sudbury, Ontario; The Hospital for Sick Children, Toronto, Ontario; and The Institute for Clinical Evaluative Sciences, Toronto, Ontario, Canada.

Dr Young is supported by a Canadian Institutes of Health Research Canada Research chair.

Reprints: Nancy L. Young, PhD, MSc, BScPT, Laurentian University, 935 Ramsey Lake Road, Sudbury, Ontario P3E 2C6, Canada. E-mail: nyoung@laurentian.ca.

Copyright © 2007 by Lippincott Williams & Wilkins

specialists. Specialists (not including pediatricians) provided 28% of youth visits, but only 19% of adult visits. We reviewed similar information collected by a mail-administered survey from a subset of this population and found a similar pattern with respect to specialist visits. The survey results showed that 79% of youth and 50% of adults with CP had seen a specialist in the previous year.¹⁴ These data raise questions of why adults have fewer specialist visits.

It is important to recognize that patterns of service use are only a surrogate measure for health care needs. It is possible that their use of services is much less than optimal. Lack of physicians to provide services, lack of access to existing services (eg, due to age restrictions), and frustration with or rebellion against the health care system are potential factors that may reduce use rates. In contrast, it is also possible that a shortage of appropriate services may lead to inefficient use of services, which may, in turn, result in use rates that are higher than would be required under optimal conditions. Hence, some critical research needs to be done to determine what constitutes optimal health care for adults with CP.

WHY ARE THERE DIFFERENCES BETWEEN YOUTH AND ADULT PATTERNS OF HEALTH CARE UTILIZATION?

If we accept that many of the health issues related to CP in youth continue into adulthood, then the different patterns may reflect differences in access to services rather than differences in needs. One possibility is that the transition from pediatric to adult health care is responsible for differential access to services and consequently to different patterns of use.

The pediatric and adult health care systems are structured differently, and the transition to the adult health care sector is forced to occur around 18 or 19 years old. This cut point is not based on their ability to direct their own care but is based on age alone. Age is a poor marker of readiness for adult health care services for persons with CP. Thus, most make the transition to adult-oriented care at a time when they are not yet ready for adult-oriented health care services.

WHAT DO WE KNOW ABOUT THE TRANSITION TO ADULT-ORIENTED HEALTH CARE?

In comparison to the dearth of literature on the health care needs of adults with CP discussed earlier, there is more information available on the issue of transition to adult health care for youth with special health care needs,¹⁵⁻²² including proceedings from 3 international symposia on this topic.²³⁻²⁵ Transition is defined as the "purposeful movement of adolescents and young adults with chronic conditions from child-centered to adult-centered care."¹⁵

The main message from the transitions literature is that the process of moving from one health care system to another is challenging for a variety of clinical groups (eg, those with cystic fibrosis, congenital heart disease) but is particularly difficult for those with CP.^{18,26,27} There are several reasons why the transition to adult health care is challenging for adults with CP. To begin with, we must recognize that change is difficult for many people. The changes associated with

the transition to adult health care involve leaving familiar providers and settings and venturing into new territory. Furthermore, those with both physical and cognitive challenges may have far fewer resources and reserved capacity to assist them in coping with challenging circumstances.

An additional problem is that the adult-oriented health care system does not necessarily provide the same types of services as the pediatric system. For example, we know that health care for children with CP is most effective when it is delivered by integrated health care teams^{28,29} who have specific expertise in CP. In North America, expert teams most commonly deliver services to children with CP through tertiary care pediatric hospitals and children's rehabilitation centers. In these institutions, teams of physicians, therapists, nurses, and other allied health care providers work together to deliver comprehensive and essential health care services under one roof. Multidisciplinary teams and one-stop services are rarely found in the adult-oriented health care sector. Furthermore, the literature suggests that there is little expertise and/or interest in chronic illnesses of childhood within the adult sector.^{25,30,31} Consequently, adults with CP must navigate a new and ill-prepared adult health care system.^{32,33}

WHY DO ADULTS HAVE FEWER VISITS SPECIALISTS COMPARED TO YOUTH?

There are several hypotheses as to why specialist access is less common among adults. It is possible that the reduced rates demonstrate a real reduction in need for these types of services. However, the higher rate of outpatient physician visits among adults when compared with youth suggests that this is unlikely. It is also possible that there are few specialists available today because adult-oriented physicians in current practice were not trained to care for adults with CP, because CP was a condition primarily limited to childhood at the time of their training. Persons with CP were not expected to live into adulthood, so any training related to CP was not particularly salient to physicians training for adult specialties.

WHY HAVE SOME PHYSICIANS NOT STARTED TO SPECIALIZE IN THE CARE OF ADULTS WITH CP?

Because the life expectancy for children with CP has consistently extended into adulthood for the past 2 decades, adults with CP are not truly a new population.⁴ So why have specialist services not developed to meet their needs? There is limited literature to draw from in this area. However, several ideas have been put forward by our multidisciplinary group of researchers and clinicians. Most of these focus on the challenges presented in working with this population. For example, some adults with CP lack a degree of social and cognitive maturity, which pose additional challenges to health care providers who are not accustomed to working with adults who have developmental delay. Communication, memory, and problem-solving deficits common to CP^{6,28,34} make it extremely difficult for these adults to effectively access, communicate with, and use the adult health care

system where a traditional one-to-one relationship between the health care provider and the recipient is expected.^{30,35} In such relationships, the support of parents or attendants is necessary, but the presence of others is not always accepted by the health care providers in the adult system.

It is also worth considering that there are several aspects of CP that make the clinical relationship less enticing for many health care providers. First, adults with CP have a progressive illness with no opportunity for cure. This is in many ways similar to palliative care. However, unlike palliative care, there are multisystem challenges and complex interpersonal interactions to accommodate. The cumulative effect of multidomain handicaps is far more challenging than the effect of a single isolated deficit.^{26,32} Second, fee-for-service reimbursement systems for health care providers do not adequately compensate clinicians for the time and effort involved in caring for these adults. Third, there is often little or no allied health care support for this group (eg, funding for physical therapy or occupational therapy). This lack of team support may be a deterrent to getting physicians to take on care for adults with CP. An alternative hypothesis may be that the lack of specialized services may be due to the relatively small size of the adult CP population.

DISCUSSION

Clearly, there are some suggestions from case series, consensus statements, and administrative data studies regarding the transition to adult-oriented health care for adults with CP. All of these sources report challenges associated with the transition. The challenge is now widely recognized, and the desire among clinicians to improve the transition to adult-oriented health care is growing. This has been the impetus for the development and implementation of “transition programs” that are intended to bridge the gap between the pediatric and adult health care systems.^{18,26,27,30,36} Unfortunately, these programs have been developed on an idiosyncratic site-by-site basis³⁷ and documented plans for transition are not yet part of standard clinical practice.^{20,38} Furthermore, most programs focus on the transition to independent living, with little attention to the medical transition.

New solutions are needed to support the medical transition. Some of these will need to focus on preparing youth with CP and their parents for this medical transition. Other solutions must be directed toward the development of expert providers within the adult-oriented health care system, because the responsibility for the health care of this population must now be passed on to them. The key adult health care providers are expected to be internal medicine, family practice, and physical medicine physicians, along with their allied health counterparts. More education and appropriate reimbursement plans will be important in this shift in care. Education and funding must also be directed at the allied health care sector to prepare other members of the multidisciplinary team for their roles. These solutions may be derived by merging the best principles from the pediatric system with the realities of the adult care sector.

The development of new knowledge will be essential to guide the development of real world solutions for adults with

CP, because the health care needs of adults with CP is uncharted territory. Thus, we must continue to study the health and patterns of health care use in this population over time, so that we might improve our understanding of their health care needs.

It will take time and support for the adult-oriented health care sector to build up expertise among adult providers. Some of this expertise may be learned from pediatric specialists, but the issues unique to adulthood will only be learned through time and experience. There is hope that, over time, these solutions will be developed and that some specialists may begin to focus on this small orphan population of adults with CP. The subsequent steps must focus on implementing these solutions and measuring their effectiveness.

REFERENCES

- Hemming K, Hutton JL. Long-term survival for a cohort of adults with cerebral palsy. *Dev Med Child Neurol.* 2006;48:90–95.
- Hutton JL, Cooke T, Pharoah PO. Life expectancy in children with cerebral palsy. *BMJ.* 1994;309:431–435.
- Strauss DJ, Shavelle RM, Anderson TW. Long-term survival of children and adolescents after traumatic brain injury. *Arch Phys Med Rehabil.* 1998;79:1095–1100.
- Evans PM, Evans SJ, Alberman E. Cerebral palsy: why must we plan for survival? *Arch Dis Child.* 1990;65:1329–1333.
- Darrah J, Magil-Evans J, Adkins R. How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disabil Rehabil.* 2002;24:542–549.
- Klingbeil H, Baer HR, Wilson P. Aging with a disability. *Arch Phys Med Rehabil.* 2004;85:S68–S73. [quiz S74–S75].
- Rapp CE Jr, Torres MM. The adult with cerebral palsy. *Arch Fam Med.* 2000;9:466–472.
- Bottos M, Feliciangeli A, Sciuto L, et al. Functional status of adults with cerebral palsy and implications for treatment of children. *Dev Med Child Neurol.* 2001;43:516–528.
- Gajdosik CG, Cicirello N. Secondary conditions of the musculoskeletal system in adolescents and adults with cerebral palsy. *Phys Occup Ther Pediatr.* 2001;21:49–68.
- Murphy KP, Molnar GE, Lankasky K. Medical and functional status of adults with cerebral palsy. *Dev Med Child Neurol.* 1995;37:1075–1084.
- Overeinder JC, Turk MA. Cerebral palsy and aging: a framework for promoting the health of older persons with cerebral palsy. *Top Geriatr Rehabil.* 1998;13:19–24.
- Young NL, Gilbert TK, McCormick A, et al. Youth and Young Adults with Cerebral Palsy: The Use of Physician and Hospital Services. *Archives of Physical Medicine and Rehabilitation.* In Press.
- Young NL, McCormick A, Mills W, et al. The transition study: a look at youth and adults with cerebral palsy, spina bifida and acquired brain injury. *Phys Occup Ther Pediatr.* 2006;26:25–45.
- Owen JL. *The use of professional health care providers by youth and young adults with complex conditions [thesis].* Toronto, Ontario, Canada: University of Toronto; 2006.
- Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health.* 1993;14:570–576.
- Lotstein DS, McPherson M, Strickland B, et al. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics.* 2005;115:1562–1568.
- McPherson M, Weissman G, Strickland BB, et al. Implementing community-based systems of services for children and youths with special health care needs: how well are we doing? *Pediatrics.* 2004;113:1538–1544.
- Reiss J, Gibson R. Health care transition: destinations unknown. *Pediatrics.* 2002;110:1307–1314.

19. American Academy of Pediatrics Committee on Children With Disabilities. The role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. *Pediatrics*. 2000;106:854–856.
20. Scal P, Ireland M. Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*. 2005;115:1607–1612.
21. White PH. Access to health care: health insurance considerations for young adults with special health care needs/disabilities. *Pediatrics*. 2002;110:1328–1335.
22. Rosen DS. Between two worlds: bridging the cultures of child health and adult medicine. *Adolesc Med*. 1995;17:10–16.
23. American Academy of Pediatrics, American Academy of Family Physician, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110:1304–1306.
24. Centers for Disease Control and Prevention. *Healthy People 2010 Disability and Secondary Conditions*. Washington, DC: US Public Health Services, US Department of Health and Human Services; 2000.
25. Blum R. Summary of conference recommendations. *J Adolesc Health*. 1995;17:6–9.
26. Blum RW. Introduction. Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. *Pediatrics*. 2002;110:1301–1303.
27. Scal P. Transition for youth with chronic conditions: primary care physicians' approaches. *Pediatrics*. 2002;110:1315–1321.
28. Cooley CW. Providing a primary care medical home for children and youth with cerebral palsy. *Pediatrics*. 2004;114:1106–1113.
29. King S, Teplicky R, King G G, et al. Family-centered service for children with cerebral palsy and their families: a review of the literature. *Semin Pediatr Neurol*. 2004;11:78–86.
30. Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child*. 1999;81:271–275.
31. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics*. 2005;115:112–120.
32. Sawyer SM, Collins N, Bryan D, et al. Young people with spina bifida: transfer from paediatric to adult health care. *J Paediatr Child Health*. 1998;34:414–417.
33. Rosen D. Transition of young people with respiratory diseases to adult health care. *Paediatr Respir Rev*. 2004;5:124–131.
34. van der Dussen L, Nieuwstraten W, Roebroek M, et al. Functional level of young adults with cerebral palsy. *Clin Rehabil*. 2001;15:84–91.
35. Bent N, Tennant A, Swift T, et al. Team approach versus ad hoc health services for young people with physical disabilities: a retrospective cohort study. *Lancet*. 2002;360:1280–1286.
36. McDonagh JE. Growing up and moving on: transition from pediatric to adult care. *Pediatr Transplant*. 2005;9:364–372.
37. Anderson DL, Flume PA PA, Hardy KK, et al. Transition programs in cystic fibrosis centers: perceptions of patients. *Pediatr Pulmonol*. 2002;33:327–331.
38. Lam PY, Fitzgerald BB, Sawyer SM, et al. Young adults in children's hospitals: why are they there? *Med J Aust*. 2005;182:381–384.