


Ethics in Health Care Services for Young Persons With Neurodevelopmental Disabilities: A Focus on Cerebral Palsy

Journal of Child Neurology
26(10) 1221-1229
© The Author(s) 2011
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/0883073811402074
http://jcn.sagepub.com


Danaë Larivière-Bastien¹ and Eric Racine, PhD^{1,2,3}

Abstract

In this article we review and discuss some of the key ethical and social challenges that young persons with cerebral palsy face in health care delivery. We identify and explain these challenges, some of which are rarely discussed in contemporary medicine and biomedical ethics, partly because they are not considered genuine “ethical” challenges per se. Most of these challenges are heavily shaped by broader social context and institutional practices, which highlights the importance of nonbiological aspects of the care of young persons with cerebral palsy from an ethics standpoint.

Keywords

cerebral palsy, health care, neuroethics, disability, autonomy, confidentiality

Received September 17, 2010. Received revised December 21, 2010. Accepted for publication February 6, 2011.

Cerebral palsy is the most common cause of physical disability in children.^{1,2} In 2003, the lifetime costs generated by the management of cerebral palsy have been estimated to be over \$11.5 billion (expected for persons born in 2000 with cerebral palsy and including income lost) in the United States³ and in excess of \$380 million each year in Canada.¹ Despite the prevalence and impact of cerebral palsy on individual persons, families, and collectivities, there are still a number of important medical uncertainties regarding the pathological processes of cerebral palsy, the varied effects of rehabilitation treatments, the potential effectiveness of innovative interventions such as stem cells and acute neuroprotective strategies, and the validity of diagnostic tools.⁴⁻⁶ Currently, no interventions can “cure” cerebral palsy, but some treatments are offered in order to improve the functional status of patients.

Because of the nature of cerebral palsy as a health condition and the broader scientific and contextual aspects of health care delivery for cerebral palsy, health care can be a context in which young persons with cerebral palsy are confronted with important ethical and social challenges. These challenges include communication issues,⁷⁻⁹ exposure to non-evidence-based alternative treatments,^{10,11} and inequalities in access to basic services (eg, preventive and routine care).^{12,13} Even though clinics specialized in the care of adult survivors of this childhood disease are surfacing, adults with cerebral palsy are often marginalized within health care.¹⁴ Access of young persons with cerebral palsy to health services drops dramatically with the end of school attendance.^{15,16} Fair access to services

may be particularly compromised during the transition from the pediatric to the adult milieu.^{17,18} Persons with cerebral palsy, like other children living with a disability, also experience negative attitudes in health care services. They can be confronted with disrespect toward their person and their dignity¹⁹ or to stereotypes that undermine respect for their autonomy because providers think they cannot participate in decision making.¹² Denial of their right to confidentiality and to independence has also been reported.^{8,20} The ethical and social issues faced by young persons with cerebral palsy therefore merit further scrutiny. In this paper, we review and discuss available literature on this topic from the standpoint of ethics with a focus on adolescence as a period of change and transition. We call for greater attention to the nonbiological aspects of health care for cerebral palsy that have important ethical and medical consequences.

¹ Neuroethics Research Unit, Institut de recherches cliniques de Montréal, QC, Canada

² Department of Medicine and Department of Social and Preventive Medicine, Université de Montréal, QC, Canada

³ Departments of Neurology and Neurosurgery, Medicine and Biomedical Ethics Unit, McGill University, Montréal, QC, Canada

Corresponding Author:

Eric Racine, PhD, 110 avenue des Pins Ouest, Montréal, QC H2W 1R7, Canada
Email: eric.racine@ircm.qc.ca

Methods

To our knowledge, no perspective or review papers on ethical issues in health care for cerebral palsy patients with a focus on adolescents have been published. To gather relevant literature, we used different databases and search engines (PubMed, Google Scholar, and PsychInfo) to identify articles published in English or in French. Articles specifically discussing ethical aspects of cerebral palsy in adolescents and young adults were very rare. Therefore, we extended our searches to other physical neurodevelopmental disorders and disabilities as well as related issues. For example, we included papers discussing related issues such as the transition from pediatric to adult health care services, access to health care services, attitudes of health care professionals toward persons with cerebral palsy, and literature on bioethics and disability. We reviewed primary studies such as qualitative and quantitative studies as well as review papers and governmental publications. No paper published before 1983 was retrieved. Most papers were published in the past decade. The vast majority of papers were in English.

Ethical and Social Issues in Cerebral Palsy

Our review of the literature allowed us to identify several important ethical and social challenges that cerebral palsy patients face or are likely to face (Table 1). These challenges were found mainly in articles reporting on the perspectives of patients with similar conditions (eg, chronic conditions or diseases, developmental disabilities) and could be experienced as well by patients with cerebral palsy. One caveat is that cerebral palsy involves a unique combination of motor or language deficits with often preserved cognitive functions. Table 1 also proposes relevant action items to address these challenges.

Equitable Access to Health Care

Several studies have shown that complex needs of persons with cerebral palsy are not always being adequately met. This is the case with general health care and dental care,²¹⁻²⁷ basic needs during periods of hospitalization,²⁸ community care, primary care,²⁹ rehabilitation, prevention, assistive equipment provision, social services,³⁰⁻³² coordination of care (eg, communication among providers),³³ health information,³⁴ and counseling (for psychosocial and mental health problems).^{13,35} Generally speaking, health care providers may be unaware of some of the special needs of persons with cerebral palsy and may lack knowledge on how to adjust to care for them,^{28,33} which could result in “inappropriate and inadequate care,” as reported in a study on hospitalized adults with cerebral palsy.²⁸ Unfortunately, this situation may contribute to the deterioration of the health status of persons with cerebral palsy.^{12,28,29,33,36-46} For example, adult patients with cerebral palsy reported in a study that it was difficult to obtain the help of health care providers for meals or other needs when they were hospitalized.²⁸ In the United States, young adults with disabilities are often uninsured, which leads to unmet needs and barriers to health care access. In the United States and elsewhere, health care is often considered to be “primarily focused on people with acute health care needs, and not persons with recurring or chronic

health problems.”³³ Unfortunately, this comment also applies (although perhaps to a lesser extent) to other health care systems, including public health care systems, that structurally underfund care for chronic illnesses and neurological and mental health.⁴⁷⁻⁵⁰

Access to health care may also be compromised when young persons with cerebral palsy do not receive sufficient preventive and routine care.⁵¹ This situation is not uncommon for young persons with a disability.^{18,33} Moreover, health care professionals tend to selectively focus on the disability to the detriment of other basic health needs. Symptoms related to another health problem are sometimes confused with symptoms related to the condition or disability, namely, diagnostic overshadowing.^{12,13} This is a frequent source of dissatisfaction among persons with disabilities, including persons with cerebral palsy.

Another explanation for the lack of preventive and routine care is that young patients with a disability or chronic condition are believed to be closely followed in the health care system. Health care professionals may therefore wrongly assume that they do not need routine procedures (eg, immunizations, dental care, screening process) given through schools or as part of other health care services.¹³ As a result, there is a range of unmet health care needs in this population.^{13,52} Persons with disabilities certainly have special needs, but they also face the same age-related health problems as nondisabled persons.¹² The situation is similar for adolescents with a chronic disease.^{29,53} The prevalence of some common health care problems is higher in disabled patients (eg, visual impairment found to be 10 times higher in disabled patients than in nondisabled persons).^{12,52} For that reason, adolescents with cerebral palsy need to be probed about traditional adolescence issues^{13,18,54} (eg, acne; puberty; sexuality; use of alcohol, drugs, and tobacco), and particularly disease-prevention issues. Later, health care professionals must be aware of potential problems often associated with cerebral palsy, such as visual or hearing impairments and pain.

Other barriers may affect the health care experience of young patients with disabilities and cerebral palsy.³³ Young patients with physical disabilities are sometimes more sensitive to characteristics of the hospital environment, such as needles and medical equipment, and to the prospect of painful and intrusive examinations.^{12,52} Persons with physical disabilities are also at risk of experiencing environmental barriers that may compromise their access to health care. For example, the geographic location of a health service may prevent these persons from accessing comprehensive services. These environmental barriers can also be created by restrictions in the hospital environment (eg, lack of “appropriate seating” and “limited access in bathrooms and bedrooms,”²⁸ “inaccessible provider facilities and equipment,” delays in the repair of wheelchairs).⁴⁶ Other barriers include insufficient length of time for appointments,^{8,12,20,33,46} insufficient availability of health care providers,⁴⁶ social isolation, and difficulty in obtaining health information.⁵⁵ These examples show how the specificity of disabilities (beyond the generic recognition of disability as a category) must be taken into consideration when patients use

Table 1. Summary Table With Action Items

Ethical and Social Issues	Description in the Literature	Action Items
Equitable access to health care	<ul style="list-style-type: none"> - Decrease in the use of health care services when leaving school - Gaps in the provision of preventive and routine care - Environmental barriers limiting access to health care (eg, fear of the hospital environment; lack of health information) - Complex health needs not always met (eg, dental and community care) 	<ul style="list-style-type: none"> - Do not presume access to routine health services and actively probe for unmet needs - Become familiar with the specific needs of persons with cerebral palsy and features of cerebral palsy - Acknowledge gaps in chronic health care services - Develop or sustain access programs for persons with disability - Recognize the specificity of the impact of disabilities on issues of care and access
Transitional challenges from pediatric to adult health care services	<ul style="list-style-type: none"> - Difficulties in finding a primary care physician or specialist in the adult care system - Gaps in the continuity of care - Health care professionals' lack of experience with pediatric diseases in adult system - Scarcity of efficient transition programs 	<ul style="list-style-type: none"> - Acknowledge the detrimental health impact of difficult transitions - Develop or sustain programs to prepare early pediatric-adult transitions - Recognize the experiential and relational implications of transition - Train providers in dealing with transitioning patients
Respectful and efficient communication and health information	<ul style="list-style-type: none"> - Difficulties of patients to be understood by health care providers - Health information often directed to the parents leading to feelings of exclusion of the relationship - Reluctance in discussing sensitive topics in the presence of the parents and novel issues arising with adolescence - Need for health care professional training on specific communication issues with these persons 	<ul style="list-style-type: none"> - Acknowledge the consequences of challenged communication - Train and support providers to use specialized communication devices - Be sensitive to the potentially facilitating and impeding role parents can play in communication - Employ appropriate language levels and communication styles - Commit to honesty and transparency
Respect for confidentiality and privacy	<ul style="list-style-type: none"> - Many of the same needs for confidentiality and privacy as persons without cerebral palsy - Concerns for privacy and confidentiality change with adolescence 	<ul style="list-style-type: none"> - Acknowledge and accommodate the sensitivity of persons to large teams in conversations on sensitive topics - Provide opportunities to discuss alone with adolescents in absence of parents
Respect for autonomy and informed consent	<ul style="list-style-type: none"> - Specific issues related to autonomy for persons with disabilities (eg, overprotection by parents; difficulties in promoting autonomy because of pre-existing barriers) - Issues of informed consent and capacity for persons with cognitive disability and for young persons who want to take part in treatment decisions 	<ul style="list-style-type: none"> - Recognize the active role providers can play in empowering autonomy - Accept that autonomous choices may contradict standard care or clinical recommendations - Provide balanced and tailored information, understandable to the individual
Trustful provider-patient relationships	<ul style="list-style-type: none"> - Stereotypes and misconceptions of health care professional (eg, physically impaired persons misperceived as cognitively disabled; negative attitudes caused by ignorance or fear) - Importance of health care professionals' attitudes for young patients with disabilities (eg, honesty; sensitivity to their condition; competency) 	<ul style="list-style-type: none"> - Recognize the importance of trust for communication and decision making - Acknowledge and correct implicit or unconscious negative attitudes often held toward adolescents - Recognize and correct the existence of stereotypes and attitudes like infantilization or lack of consideration caused by ignorance toward disability and fear - Recognize and correct implicit biases in matters of quality of life and disability - Realize the importance of nonbiological, nontechnical aspects of care for patients

Table 2. Barriers in the Transition of Persons With Disabilities From Pediatric to Adult Care Identified in the Peer Review Literature

Finding a physician or a specialist physician ^{32,57}
Lack of continuity and coordination of care ^{18,32,51,61-63}
Negative perception of the quality of care in the adult health care system ^{32,51,62-64}
Adult health care provider's lack of experience, expertise, training, and knowledge about traditionally pediatric diseases and conditions ^{18,32,51,57,62,64}
Poor adult health care physician/patient relationship and communication ^{18,57}
Loss of a trusting relationship with the pediatrician ^{18,32,51,57,62,64}
Lack of preparation to the transition of young persons ^{18,62-64}
Lack of integrated health care and multidisciplinary teams in adult-centered settings ^{18,51,57,64}
Need for transitional programs ^{13,18,32,51,57,61-69}

health care services. The issue of access likely needs to be addressed at the beginning of a patient-provider relationship, even if health care professionals may not feel comfortable asking questions directly about such difficulties.²⁸ This issue is important from an ethical and clinical perspective, since barriers in the care of patients with disabilities may result in detrimental consequences that can be social, psychological, physical, economic, and functional in nature.⁴⁶

Transitional Challenges From Pediatric to Adult Health Care Services

The literature shows that there are problems created by the lack of support for the transition from pediatric services to the generally underfunded adult health care for persons with cerebral palsy. Adolescence and the beginning of adulthood is a period of intense change in all spheres of life, and it is equally true of health care for adolescents with disabilities.^{56,57} Key transitional challenges are listed in Table 2. The literature indicates that the transition is particularly difficult for persons with cerebral palsy.⁵⁷⁻⁶¹

Not only do these young persons have to transition to the adult health care system, but they are also leaving behind typically well-structured care offered through the education system. Afterward, as young persons with cerebral palsy cease attending school, there is a significant decrease in their use of health care services,^{16,35,36} including those from general practitioners as well as specialists, but also from other health care professionals (eg, physiotherapists, occupational therapists, speech therapists, social workers).^{16,35,36} Many choose to cease some of their treatments such as physiotherapy because they become tired of them.^{16,35,36} However, the health needs of these patients do not disappear with the end of schooling, especially in the case of cerebral palsy, which, as a nondegenerative but lifelong condition that evolves over time, requires ongoing health care and attention. Adolescents and young adults with cerebral palsy have important health needs that may become even more complex as they mature.⁵⁷ Although the support for

pediatric services has been a great victory, the difficulty of the transition to the adult health care system jeopardizes the previous integration of persons with cerebral palsy into society and raises fundamental issues of justice in the structure of health care systems.

Respectful and Efficient Communication and Health Information

For young persons with cerebral palsy, communication can be a very important challenge and a nexus of several difficult situations in which conflicts of values surface and in which the goal of respecting the patient as a person becomes compromised.⁵⁷ Difficulties in communication can complicate every aspect of the care of an individual with cerebral palsy and affect the overall quality of health care services offered.⁷ This situation can be very difficult for patients with communication problems because some may be poorly understood (if at all) by health care professionals or unable to obtain the attention of health care providers when in need of help.⁷ A study has shown that even when patients with cerebral palsy used communication devices and provided written information to help the hospital staff to communicate, health care professionals did not try to use these devices and information and simply tried to "guess" what patients wanted to say. For these patients, this communication problem led to a range of unmet needs, such as insufficient time and resources allotted for treatments and consultations resulting from a lack of communication at the moment of admission in hospitals, or delays in the provision of basic needs such as meals and hygiene.²⁸

Another crucial issue reported by young patients and that more directly pertains to their decisional autonomy is that very often, information and questions about treatment and health status are directed to their parents. As a consequence, young patients can feel excluded and that their opinions, perceptions, desires, or rights are neglected.^{8,9,12,13} Another possible implication of this focus on parents is that young patients may be reluctant to talk about sensitive topics like sexuality and illicit drug use in the presence of their parents.^{8,9,12,13} Therefore, adolescents and young adults need health care professionals with very good communication skills and who are sensitive to these new issues arising in the transition period.⁹ Unfortunately, the experience and the knowledge of health care providers on how to care for patients with communication problems appear to be deficient. Young patients with such difficulties have reported health care providers' lack of time, patience, and willingness to understand the particularities of their condition, to actively listen to them and to try to use their communication devices.²⁸ Communication with adolescents in itself can be challenging for health care professionals, and when these adolescents have a communication problem, it can become overwhelming.^{9,20} Still, these patients want their feelings, preferences, and opinions to be taken into account when discussing personal health-related matters. Like everyone, they want to be considered as persons, rather than be approached through the defining lens of their condition or health status, especially

when the condition is life long, like cerebral palsy. Consultations can be made in a way that young patients can understand, with the appropriate language level (eg, avoiding medical or technical jargon) and attention to what they are ready to know about their condition.^{8,20} Honesty with these patients implies that health care professionals will fully disclose their health status, talk directly, be consistent in messages conveyed, that they will not try to protect them by giving false reassurances, and of course, that they will tell the truth.⁹ Studies suggest that young patients with a disability like cerebral palsy want full and direct disclosure of their health status.^{13,20}

Clinical communication can certainly be a challenge, but in the health care context, communication is integral to the pursuit of good outcomes and to the adherence to treatment. Patients with a disability may be affected by the experience of stress and anxiety related to communication that is compounded by speech disabilities.⁷ Communication is facilitated if the patient knows the physician. Developing a genuine relationship with patients (eg, relating to the adolescent more as a peer, maintaining a sense of equality in the relationship) is an approach that has proven useful in improving the quality of communication.⁸ Although no magic bullet will solve all communication difficulties, such approaches can help diminish feelings of disempowerment or inferiority that young persons could otherwise entertain.⁸ Studies have also shown that specific training aimed at improving the efficiency of verbal exchanges could be an effective way to address this gap in the preparation of health care professionals.^{7,28,33} Independent of the quality of the relationship with health care providers, there will remain some subjects that young patients would prefer not to discuss. In some cases, patients with serious conditions may not be ready to hear bad news concerning their future. Or it may be that they fear disapproval from their physician about lifestyle choices or noncompliance with treatment.⁸

In summary, when young persons with cerebral palsy need to communicate with health care professionals, they must feel respected, not patronized or excluded. Unfortunately, the literature and experience of young persons with disabilities suggest that this is exactly what is not happening on a broad scale. There is a clear need for additional clinical and ethical muscle in this area.⁸

Respect for Privacy and Confidentiality

Privacy and confidentiality are obligations that are articulated in the deontological codes of clinicians of all professions. These ethical constructs also reflect expectations of adolescents and young adults.⁸ For instance, young persons who have been treated for a long time may prefer to meet health care providers without their parents.^{8,9} Others, especially those with a serious condition, may still need parental presence.²⁰ Research has underscored that young persons are sensitive to the presence of other medical staff, such as medical students, during the consultation.⁸ Another factor that may inhibit a trustful, open relationship is the fear that health care professionals will not

respect their obligation to confidentiality when young persons need to reveal behaviors that are generally not approved of by parents or adults.⁸ Principled approaches that incorporate the need (if any) for parental assistance with the right to privacy and confidentiality can be promoted by ensuring time for the adolescent alone with the health care provider.

Respect for Autonomy and Informed Consent

The autonomy of adolescents and young adults is a broad and complex issue in itself, especially in the context of fascinating neuroscience on adolescent decision making.⁷⁰ Respect for the autonomy of adolescents and young adults with a disability involves some rather distinct challenges. Sometimes young persons cannot advocate for their own preferences, values, choices, and beliefs themselves, and health care professionals must help them achieve this goal.¹³ Health care providers may therefore be in a position in which they have to facilitate a young patient's personal autonomy even though the patient does not express the need for it or does not seem to want it, and, more challenging, when it contradicts a health care provider's professional opinions or personal beliefs. During adolescence, there is a risk of parental overprotection, which may interfere with the normal process of development of individual autonomy and decision-making capacity.⁷¹ In relevant studies, adolescents have expressed their desire to take part in their own care and the wish that their own opinions and concerns be taken into consideration.^{9,32} Consultations without the parents may be jeopardized by the possible communication problems of persons with cerebral palsy, but it is still a reasonable approach, when feasible, to increase their independence and autonomy by allowing some time alone with the physician. Of course, one must not completely or systematically exclude the parents, who may have useful information about the health status of their child.¹³ The question of independence can become an issue in most, if not all, types of health care services. For example, if hospitalized, persons with cerebral palsy may need assistance from a family member or other caregiver, but they still deserve respect for their autonomy and independence. Obviously, the question of informed consent arises in cases of cognitive disability, but also for children growing into adolescence and adulthood. Adolescents and young adults with disabilities want to make choices and make decisions regarding their treatment, and they should have this possibility. As usual in matters of informed consent, however, it is essential that these patients have the necessary information needed for the decision, that they understand the detailed information, and that they know all the options offered to them.¹³

Trustful Patient-Provider Relationships

Trust, like autonomy, confidentiality, and genuine communication, is an essential component of sound ethical and clinical approaches to health care in cerebral palsy. However, one of the most enduring stereotypes experienced by physically disabled persons, like many with cerebral palsy, is to be

misperceived as cognitively disabled. This misunderstanding severely jeopardizes trust in patient-provider communication and relationships. This conflation happens more frequently when persons have major communication difficulties, for example, when only parents are able to fully comprehend their speech.¹² Another factor that could mislead health care professionals is the lower social status sometimes attributed to adolescents.⁸ Research has demonstrated the existence of a range of unfortunate stereotypes, misconceptions, misunderstandings, biases, and negative attitudes that could be held by health care professionals and that could be caused by many different factors. These causes include ignorance, apprehension, fear, communication problems, hostility, lack of appropriate training,^{72,73} lack of knowledge of the patient's specific needs, or the physicians' belief that these consultations will take a lot of time and energy and may be difficult on a personal level.^{12,28,72} Further, male medical students have been reported to show less positive attitudes and more misconceptions than female medical students.^{72,73} These perceptions also include the attribution of a reduced value granted to the life of a person with cerebral palsy.⁷² An example of a negative attitude may be a physician who hesitates to treat a non-life-threatening problem (eg, correction of teeth alignment with braces) because he does not see the benefits or the importance of it for an individual whose life is not, in his view, a contributive one.¹² One of the consequences is that health care professionals may act in a patronizing way because of the distorted perceptions they have about this particular group of persons.⁸ Cerebral palsy is often the target of false beliefs in society in general,⁷⁴ and the health care community is no exception.⁷² Negative attitudes of health care professionals toward persons with cerebral palsy may have far-reaching detrimental consequences for the patients, for their self-esteem as well as for their care.^{72,73} As a result, health care professionals may spend less time with these patients or be less likely to advocate for their rights.⁷² Resource allocation may also be negatively affected when people perceive persons with cerebral palsy as less valuable than other patients.^{72,73} This perception may inadvertently lead policy makers to allocate less funding to services for people with cerebral palsy. Fortunately, one study has shown that people who have a good knowledge of cerebral palsy have a more positive general attitude toward persons with cerebral palsy.⁷⁵

Personal characteristics of health care professionals and patients have an impact on the relationship of care. For young patients with a chronic condition, personal characteristics of their physicians are as important, and sometimes more important, than technical qualifications. More specifically, honesty is the quality that adolescents have ranked the highest in qualitative studies that sought the perspectives of adolescents or young adults with cerebral palsy or other chronic illnesses. Young patients with chronic conditions and disabilities also want health care providers to have experience and knowledge about their condition, to pay attention to their pain,⁹ and to be patient with them.²⁸ A study on nondisabled adolescents similarly shows that the style and behaviors of health care providers influence satisfaction with the care received; the way

providers interact with them is more important in their eyes than the content of the consultation.⁷⁶ However, the competency of health care providers remains crucial for patients with cerebral palsy. Studies show that they are confronted with a lack of knowledgeable health care providers on cerebral palsy, which could result in a decrease in their trust and satisfaction with the care they are receiving.²⁸

Trust in the relationships as well as stereotype-free attitudes of health care professionals are essential to ensure adequate, respectful, and equitable care for patients with disabilities, including young persons with cerebral palsy. Clearly, it appears that in some cases, health care providers still tend to view the needs of persons with disabilities as less important than those of persons without disabilities, which, again, could lead to dissatisfaction and a decrease in the quality of care they receive.²⁸

Several limitations of the perspectives put forward in this paper should be taken into account. First, the literature review supporting our analysis is based on relevant papers, but we found, *stricto sensu*, no review or perspective papers published specifically on ethical aspects of cerebral palsy. We therefore extended our searches to capture relevant literature and issues common to disability more generally. Second, few if any studies have examined qualitatively how adolescents and young adults experience ethical challenges in health care delivery. There is therefore a gap in the literature, which clearly calls for primary research on ethics in cerebral palsy.

Conclusion

In this paper, we reviewed and discussed some key ethical and social challenges experienced by persons with cerebral palsy, the most frequent cause of physical disability in children but nevertheless a health condition rarely discussed from the standpoint of ethics. Cerebral palsy is a nonprogressive, chronic condition, but the clinical manifestations observed can change over time and can be improved or exacerbated by social and medical support or lack of appropriate support. These facts point to the synergetic interaction of good health care with good ethical practices; respecting the patient as a person is contiguous with the goal of providing evidence-based care. Thus, further attention should be given within clinical care to the ethical and social challenges faced by adolescents and young adults growing up with cerebral palsy. Also, further research should examine the perspective of these persons throughout the lifespan to help integrate their voices and recommendations within health care delivery.

Acknowledgments

We would like to thank members of the Neuroethics Research Unit for feedback on previous versions of the manuscript.

Author Contributions

Both authors designed the project, realized the review of papers, organized the results, analyzed the results, drafted and wrote the articles, and revised the final paper.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research and/or authorship of this article. Support for the conduct of this research comes from the Institut de recherches cliniques de Montréal (E.R.), the Social Sciences and Humanities Research Council (E.R.), the Canadian Institutes of Health Research (E.R.), the Programmes de bioéthique of Université de Montréal (scholarship to D.L.-B.), and the NeuroDevNet (E.R.).

Ethical Approval

Not applicable.

References

- Tator C, Bray G, Morin D. The CBANCH report—the burden of neurological diseases, disorders, and injuries in Canada. *Can J Neurol Sci.* 2007;34:268-269.
- Surman G, Hemming K, Platt MJ, et al. Children with cerebral palsy: severity and trends over time. *Paediatr Perinat Epidemiol.* 2009;23:513-521.
- Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment—United States, 2003. *MMWR Morb Mortal Wkly Rep.* 2004;53:57-59.
- Cahill AG, Stout MJ, Caughey AB. Intrapartum magnesium for prevention of cerebral palsy: continuing controversy? *Curr Opin Obstet Gynecol.* 2010;22:122-127.
- Msall ME, Limperopoulos C, Park JJ. Neuroimaging and cerebral palsy in children. *Minerva Pediatr.* 2009;61:415-424.
- Harris DT. Cord blood stem cells: a review of potential neurological applications. *Stem Cell Rev.* 2008;4269-4274.
- Balandin S, Hemsley B, Sigafos J, Green V. Communicating with nurses: the experiences of 10 adults with cerebral palsy and complex communication needs. *Appl Nurs Res.* May 2007;20:56-62.
- Beresford BA, Sloper P. Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *J Adolesc Health.* 2003;33:172-179.
- Britto MT, DeVellis RF, Hornung RW, DeFries GH, Atherton HD, Slap GB. Health care preferences and priorities of adolescents with chronic illnesses. *Pediatrics.* 2004;114:1272-1280.
- Oppenheim WL. Complementary and alternative methods in cerebral palsy. *Dev Med Child Neurol.* 2009;51:122-129.
- Weisleder P. Unethical prescriptions: alternative therapies for children with cerebral palsy. *Clin Pediatr.* 2010;49:7-11.
- Doostan D, Wilkes M. Treating the developmentally disabled. *West J Med.* 1999;171:92-96.
- Michaud PA, Suris JC, Viner R. The adolescent with a chronic condition. Part II: healthcare provision. *Arch Dis Child.* 2004;89:943-949.
- MacDonald N. Finding the way—meeting the needs of adults with childhood-acquired illnesses. *Can Med Assoc J.* 2006;175:717, 719.
- Andersson C, Mattsson E. Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol.* 2001;43:76-82.
- Ng SY, Dinesh SK, Tay SK, Lee EH. Decreased access to health care and social isolation among young adults with cerebral palsy after leaving school. *J Orthop Surg (Hong Kong).* 2003;11:80-89.
- Bailey S, O'Connell B, Pearce J. The transition from paediatric to adult health care services for young adults with a disability: an ethical perspective. *Aust Health Rev.* 2003;26:64-69.
- Binks JA, Barden WS, Burke TA, Young NL. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabil.* 2007;88:1064-1073.
- Blumberg L. The personal and the political. Medical attitudes toward disability. *Health PAC Bull.* 1993;23:35-37.
- Britto MT, Slap GB, DeVellis RF, et al. Specialists understanding of the health care preferences of chronically ill adolescents. *J Adolesc Health.* 2007;40:334-341.
- Bourke LF, Jago JD. Problems of persons with cerebral palsy in obtaining dental care. *Aust Dent J.* 1983;28:221-226.
- Ferguson FS, Berentsen B, Richardson PS. Dentists' willingness to provide care for patients with developmental disabilities. *Spec Care Dentist.* 1991;11:234-237.
- Finger ST, Jedrychowski JR. Parents' perception of access to dental care for children with handicapping conditions. *Spec Care Dentist.* 1989;9:195-199.
- Russell GM, Kinirons MJ. A study of the barriers to dental care in a sample of patients with cerebral palsy. *Community Dent Health.* 1993;10:57-64.
- Schultz ST, Shenkin JD, Horowitz AM. Parental perceptions of unmet dental need and cost barriers to care for developmentally disabled children. *Pediatr Dent.* 2001;23:321-325.
- Waldman HB, Perlman SP. Dental care for individuals with developmental disabilities is expensive, but needed. *J Calif Dent Assoc.* 2002;30:427-432.
- Al Agili DE, Roseman J, Pass MA, Thornton JB, Chavers LS. Access to dental care in Alabama for children with special needs: parents' perspectives. *J Am Dent Assoc.* 2004;135:490-495.
- Buzio A, Morgan J, Blount D. The experiences of adults with cerebral palsy during periods of hospitalisation. *Aust. J Adv Nurs.* 2002;19:8-14.
- Carroll G, Massarelli E, Opzoomer A, et al. Adolescents with chronic disease. Are they receiving comprehensive health care? *J Adolesc Health Care.* 1983;4:261-265.
- Doyle Y, Moffatt P, Corlett S. Coping with disabilities: the perspective of young adults from different ethnic backgrounds in inner London. *Soc Sci Med.* 1994;38:1491-1498.
- Stevens SE, Steele CA, Jutai JW, Kalnins IV, Bortolussi JA, Biggar WD. Adolescents with physical disabilities: some psychosocial aspects of health. *J Adolesc Health.* 1996;19:157-164.
- O'Connell B, Bailey S, Pearce J. Straddling the pathway from paediatrician to mainstream health care: transition issues experienced in disability care. *Aust J Rural Health.* 2003;11:57-63.
- Kroll T, Neri MT. Experiences with care co-ordination among people with cerebral palsy, multiple sclerosis, or spinal cord injury. *Disabil Rehabil.* 2003;25:1106-1114.

34. Nieuwenhuijsen C, van der Laar Y, Donkervoort M, Nieuwstraten W, Roebroek ME, Stam HJ. Unmet needs and health care utilization in young adults with cerebral palsy. *Disabil Rehabil.* 2008;30:1254-1262.
35. Cathels BA, Reddihough DS. The health care of young adults with cerebral palsy. *Med J Aust.* 1993;159:444-446.
36. Bax MC, Smyth DP, Thomas AP. Health care of physically handicapped young adults. *Br Med J (Clin Res Ed).* 1988;296:1153-1155.
37. Williams MH, Bowie C. Evidence of unmet need in the care of severely physically disabled adults. *Br Med J.* 1993;306:95-98.
38. Iacono T, Humphreys J, Davis R, Chandler N. Health care service provision for country people with developmental disability: an Australian perspective. *Res Dev Disabil.* 2004;25:265-284.
39. Thomas A, Bax M, Coombes K, Goldson E, Smyth D, Whitmore K. The health and social needs of physically handicapped young adults: are they being met by the statutory services? *Dev Med Child Neurol Suppl.* 1985;50:1-20.
40. Young NL, Gilbert TK, McCormick A, et al. Youth and young adults with cerebral palsy: their use of physician and hospital services. *Arch Phys Med Rehabil.* 2007;88:696-702.
41. Young NL, Steele C, Fehlings D, Jutai J, Olmsted N, Williams JJ. Use of health care among adults with chronic and complex physical disabilities of childhood. *Disabil Rehabil.* 2005;27:1455-1460.
42. Callahan ST, Cooper WO. Access to health care for young adults with disabling chronic conditions. *Arch Pediatr Adolesc Med.* 2006;160:178-182.
43. Beatty PW, Hagglund KJ, Neri MT, Dhont KR, Clark MJ, Hilton SA. Access to health care services among people with chronic or disabling conditions: patterns and predictors. *Arch Phys Med Rehabil.* 2003;84:1417-1425.
44. Dauvergne F, Eon Y, Gallien P, et al. Disabilities, access to medical care, and way of life of adults with cerebral palsy. APIB study: initial results [in French]. *Ann Readapt Med Phys.* 2007;50:20-27.
45. Bingham SC, Beatty PW. Rates of access to assistive equipment and medical rehabilitation services among people with disabilities. *Disabil Rehabil.* 2003;25:487-490.
46. Neri MT, Kroll T. Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disabil Rehabil.* 2003;25:85-96.
47. Feasby TE. Is the Canadian health care system better for neurologic care? *Neurology.* 2006;67:1744-1747.
48. NeuroScience Canada. *The Case for Canada's Increased Investment in Neuroscience Research.* Montreal: NeuroScience Canada; 2006.
49. World Health Organization. *The World Health Report 2001. Mental Health: New Understanding, New Hope.* Geneva, Switzerland: World Health Organization; 2001.
50. World Health Organization. *Neurological Disorders: Public Health Challenges.* Geneva: World Health Organization; 2006.
51. Tiffreau V, Schill A, Popielarz S, Herbau C, Blanchard A, Thevenon A. Transition in health care from youth to adulthood for disabled people [in French]. *Ann Readapt Med Phys.* 2006;49:652-658.
52. Messinger-Rapport BJ, Rapport DJ. Primary care for the developmentally disabled adult. *J Gen Intern Med.* 1997;12:629-636.
53. Blum RW. Transition to adult health care: setting the stage. *J Adolesc Health.* 1995;17:3-5.
54. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health.* 2003;33:309-311.
55. Centers for Disease Control and Prevention (CDC). Environmental barriers to health care among persons with disabilities—Los Angeles County, California, 2002-2003. *MMWR Morb Mortal Wkly Rep.* 2006;55:1300-1303.
56. Marn LM, Koch LC. The major tasks of adolescence: Implications for transition planning with youths with cerebral palsy. *Work.* 1999;13:51-58.
57. Young NL. The transition to adulthood for children with cerebral palsy: what do we know about their health care needs? *J Pediatr Orthop.* 2007;27:476-479.
58. Reiss J, Gibson R. Health care transition: destinations unknown. *Pediatrics.* 2002;110:1307-1314.
59. Blum RW. Introduction. Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. *Pediatrics.* 2002;110:1301-1303.
60. Scal P. Transition for youth with chronic conditions: primary care physicians' approaches. *Pediatrics.* 2002;110:1315-1321.
61. Ko B, McEnery G. The needs of physically disabled young people during transition to adult services. *Child Care Health Dev.* 2004;30:317-323.
62. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics.* 2005;115:112-120.
63. Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child.* 1999;81:271-275.
64. Dommergues JP, Alvin P. Transition from pediatric to adult care in severe chronic diseases in children [in French]. *Arch Pediatr.* 2003;10:295-299.
65. Stevenson CJ, Pharoah PO, Stevenson R. Cerebral palsy—the transition from youth to adulthood. *Dev Med Child Neurol.* 1997;39:336-342.
66. Bates K, Bartoshesky L, Friedland A. As the child with chronic disease grows up: transitioning adolescents with special health care needs to adult-centered health care. *Del Med J.* 2003;75:217-220.
67. Chamberlain MA, Kent RM. The needs of young people with disabilities in transition from paediatric to adult services. *Eura Med-icophys.* 2005;41:111-123.
68. Lewis-Gary MD. Transitioning to adult health care facilities for young adults with a chronic condition. *Pediatr Nurs.* 2001;27:521-524.
69. Soanes C, Timmons S. Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *J Child Health Care.* 2004;8:102-112.
70. Steinberg L. Should the science of adolescent brain development inform public policy? *Am Psychol.* 2009;64:739-750.

71. Turnbull AP, Turnbull HR, 3rd. Developing independence. *J Adolesc Health Care*. 1985;6:108-119.
72. Martin HL, Rowell MM, Reid SM, Marks MK, Reddihough DS. Cerebral palsy: What do medical students know and believe? *J Paediatr Child Health*. 2005;41:43-47.
73. Tervo RC, Azuma S, Palmer G, Redinius P. Medical students' attitudes toward persons with disability: a comparative study. *Arch Phys Med Rehabil*. 2002;83:1537-1542.
74. Westbrook MT, Legge V, Pennay M. Attitudes towards disabilities in a multicultural society. *Soc Sci Med*. 1993;36:615-623.
75. Sillanpaa ML. Public awareness of and attitudes toward cerebral palsy in a nation-wide adult population. *Acta Paediatr Scand*. 1990;79:1105-1111.
76. Freed LH, Ellen JM, Irwin CE Jr, Millstein SG. Determinants of adolescents' satisfaction with health care providers and intentions to keep follow-up appointments. *J Adolesc Health*. 1998;22:475-479.