Chapter 11

Ethical considerations in pediatric neurology

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Pediatric neurological conditions account for a significant proportion of serious pediatric illnesses, whether acute or chronic, and represent a major cause of impairment and disability. The World Health Organization (WHO) identified perinatal complications that lead to cerebral palsy, mental retardation, blindness, deafness, and some epilepsies as the most prevalent disorders of the nervous system (Murray and Lopez, 1996). This reality results in part from enhanced survival and longevity of patients with acute and chronic nervous system conditions. This evolution has paralleled advances in technology and changes in cultural perceptions of the child in society, of disease and disability, relationships among family, physicians and other professionals involved in care, and more generally the role of physicians. Pediatric neurologists are entrusted with considerable responsibility at multiple levels. This includes planning and implementation of advanced and complex investigations and therapies, individual and family counseling, longitudinal follow-up from fetal life throughout childhood and adolescence, shepherding the transition to adult care, and societal advocacy on behalf of populations with special needs. These responsibilities have brought about a host of new ethical challenges. In this chapter, we address ethical and moral issues that may guide pediatric neurologists. We limit the discussion to contemporary ethical perspectives and focus on a few general ethical themes that pediatric neurologists need to consider. Other related ethical topics can be found in the monograph “Ethics in Pediatric Neurology” (Shevell, 2002).

CURRENT ETHICAL CHALLENGES

Physicians are entrusted to make daily ethical clinical decisions based on contemporary principles of morality. In the last decades, biomedical ethics has undergone a dramatic evolution exploring many untested grounds.

Evidence-based medicine

As in every other medical field, practicing evidence-based medicine and maintaining continuing medical education have become professional ethical responsibilities for pediatric neurologists. Practicing evidence-based medicine requires clinical expertise as well as proficiency in retrieving, interpreting, and applying the results of scientific studies to patients in order to use current best evidence in everyday practice. The greatest challenge posed by evidence-based medicine lies precisely in the application of evidence obtained from research into clinical practice. For example, despite the growing number of good studies of antiepileptic treatment, individual therapeutic decisions are rarely univocal. This approach must thus be included in clinical decision trees, in a rational and critical manner. It must be borne in mind, however, that sound evidence is still lacking in most domains of pediatric neurology and clinical experience must not be overlooked.

Clinical practice and research

The scientific responsibility of pediatric neurologists may also create confusion between two distinct roles that may at times be conflicting – namely the tension between the pediatric neurologist’s healthcare duties toward individual patients and their obligations as scientists to contribute to knowledge. Both roles are fully justified and important, but it is essential that the neurologist as well as the patient and family know which role is being adopted at any specific moment, especially when decision-making is involved. Being treated “blindly” as

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part of a study (i.e., not knowing which treatment is being administered), or undergoing procedures that are not proven essential for individual care, are acceptable options only as part of clear approved research protocols that comply with ethical rules (including informed consent). It is, of course, essential to conduct such research for the advancement of medicine and patients’ healthcare – this is part of the ethical responsibility of pediatric neurologists. But the patient’s right to best available management is inalienable and must take precedence over engagement in research if there is a conflict between the two roles.

**Technological imperative**

Major technological advances have pushed the limits of both diagnostic and management possibilities to such an extent that clinical practice and research have been completely reshaped and society has developed new expectations and demands of medicine (Dan and Abramowicz, 2009). These are largely related to a concept known as the “technological imperative,” which is sometimes taken to imply a reduction of physicians’ responsibility toward their actions (Newell, 2006). However, doctors cannot accept any imperative that would release them from their responsibility to develop, implement, assess, and then adopt or banish technology in healthcare based on the results of sound evidence (Hofmann, 2002). On the contrary, the enhanced possibilities provided by technology do actually result in increased responsibility. Therefore, technology should rather be seen as promoting a moral imperative, in particular, an imperative to undertake proper assessment (Hofmann, 2002) of new technologies (i.e., deep brain stimulation in children). When confronted with the persistent question “What ought to be done for the patient?” doctors should avoid the automatic assumption that if something can be done, it must be done. These challenges are illustrated by the example of the increasing demand for questionable genetic testing or arguably futile interventions.

**Broadening of guiding principles**

Another change has been brought about by a sociocultural shift from sanctity of life, i.e., right to life, toward participation (WHO, 2001) and quality of life as guiding principles of medical practice. The latter concepts (Ronen et al., 2011) now help define the child’s best interest as the major objective of health outcomes and care. Current bioethical thinking has thus incorporated multiple dimensions from autonomy (e.g., with the use of informed consent), to the Hippocrates-inspired concept of non-maleficence (i.e., the imperative to avoid harm from both the physician’s and patient’s perspectives), to that of beneficence (i.e., doing good from the patients’ perspectives) and justice (i.e., by defining and taking account of the patient’s rights).

**Societal role**

Society has accorded physicians, including neurologists, a level of privileged trust, thereby imposing additional ethical and social obligations. Examples of our broader professional duties include (1) advocacy regarding social equality, (2) support of lay patient organizations, (3) education of the public including knowledge translation for many audiences, (4) provision of evidence-based guidance to the courts and public policy makers, (5) monitoring the quality of the ever-growing but often uncritical medical news stories, (6) interacting in a constructive and accountable engagement with journalists and news media to ensure objective communications (Macilwain, 2010; Wilson et al., 2010), (7) anticipating the social impact of potential new technologies, and (8) whistle-blowing regarding neglect or abuse of vulnerable populations with disability. Physicians are not immune to political pressure and personal ambition and must remain vigilant for threats arising from the state, religious organizations, scientific bodies, and commercial or economic interests and pressures (Ronen et al., 2009).

**PHYSICIAN–PATIENT RELATIONSHIPS: BENIGN PATERNALISM AND RESPECT FOR AUTONOMY**

A major clinical and philosophical debate involves achieving the right balance between the traditional benign paternalistic approach of the clinician who, on the one hand “knows best what the patient needs,” and on the other hand more recent calls for respect for the patient’s and family’s autonomy (a fundamental ethical principle). The latter approach entails the establishment of a less hierarchical physician–patient relationship that allows for shared decision-making in a partnership.

Another issue, which is specific to the pediatric population and particularly to patients with severe neurological impairments, is that decisions for such patients are usually made by physicians and guardians, or by other proxy decision-makers, without clear advance directives from the patient (Mori and Basauri, 1999). This is referred to as surrogate decision-making and is commonly assumed by parents on behalf of their child as part of the societal notion that the parents know what is best for their child. The American Academy of Pediatrics (2007) has thus recommended that pediatricians engage in a relationship with parents based on collaboration and shared decision-making so that they feel and become more competent. Rosenbaum et al. (1998) have articulated these ideas as part of the “family...
centered services’ framework. Clearly adequate medical information is a prerequisite for meaningful and active participation in decision-making. Clinicians should recognize that the decision-making process takes place within a system centered on the child and family, which comprises parents, other family members, physician(s), and other health professionals as well as varied information resources including the internet. Nevertheless, clinicians are encouraged to reduce their paternalistic attitudes for the individual patient even when they recognize potential limitations of cognitive and informational constraints or limited willpower of the patient.

These considerations can be better understood by expanding our professional view of health and disability beyond the traditional biomedical perspective to explore and address the patients’ values and perceptions of their personal well-being. By adopting the concepts of the International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) and valuing the concepts inherent in “quality of life” that incorporate the patients’ aspirations, the physician will better appreciate the fundamental importance of promoting children’s actual and perceived health dimensions (Ronen et al., 2011). By developing a partnership with the patient and family one can more easily discuss realistic goals of management and care in order to avoid futile professional decisions and the pursuit of unrealistic goals. Doing so will make it easier to communicate bidirectionally on sensitive and complex issues. This approach may also empower the patient and family to make informed personal choices regarding their own health and take a more active role in deciding on their own future.

In reality, there are limitations to this approach. While some studies have reported improvement in physical and psychological health and in quality of life by adopting this approach, others have found that detailed information might result in higher levels of parental anxiety, which can adversely influence medical management decisions (Schattner, 2002). Autonomy may be hard to attain. Physicians are faced with the dilemma of real tensions between their respect for the patient’s autonomy on the one hand and their “responsibility to act in the patient’s best interest” on the other. Furthermore, as is illustrated by a very large body of opinion and research clinicians should strive not to disclose all facts hurriedly, or communicate difficult information in an inappropriate setting or without addressing the individual’s needs and fears. Physicians are recommended to start from the assumption that patients and families are able to cope with the facts and reserve any potential nondisclosure to situations where harm is expected to result from telling the truth: “Truth should be offered, but not forced” (Rodriguez-Osorio and Dominguez-Cherit, 2008).

For example, we often struggle with how and when to inform young people with new onset epilepsy and their families of the risk of sudden unexpected death in epilepsy (SUDEP) while minimizing the emotional burden and concern of the issue (Morton et al., 2006; Ramachandrannair et al., 2012). The proper amount of information to disclose at any one time varies from person to person. Culture also plays a role in this complex relationship. New immigrants, for example, may not be familiar with the healthcare system and the way medicine is practiced in their adopted country. Language and cultural issues may impinge on our ability to forge a partnership and lead to misunderstanding at different levels. An excellent illustration is portrayed in the book The Spirit Catches You and You Fall Down by Ann Fadiman (1998), where a Hmong family recently arrived in California from Laos was caught between their spiritual belief and western medicine’s concerns over their child’s newly developed epilepsy.

As already indicated, in pediatric neurology we regularly require partners as surrogate decision-makers for individuals who cannot express their own preferences. Surrogate decision-makers should be individuals who have only the patients’ own interests at heart. In most countries, the patient’s family takes this role with the assumption that the family has the ability to know the patient’s preference and values. In reality the level of agreement between child and parent when rating the child’s quality of life is estimated to be around 0.4–0.5, which accounts for only about 20% of the variance (Verhey et al., 2009). Situations of overt conflict between the views expressed by children and parents may occur. The American Academy of Pediatrics Committee on Bioethics (1995) suggests ways of resolving these conflicts. For example, further medical consultation and counseling may present options that were not previously discussed. If this fails to provide an avenue that would be acceptable to all sides, a second opinion may be sought in order to protect the best interests of the child. Institutional ethics committees should be consulted for guidance, education, and advice regarding unusual or complicated ethical problems that involve the care and treatment of children (American Academy of Pediatrics Committee on Bioethics, 2007; Fisher, 2008).

A benign paternalistic approach (one which does not impose significant burden on individual liberties) can play an important role in promoting population health. Examples include laws for mandatory report of suspected nonaccidental injuries or of the presence of active epilepsy in individuals approaching driving age; requirements to wear motorcycle helmets; and immunizations against poliomyelitis. All are based to a considerable extent on acceptable evidence that promotes health benefits and personal safeguards, and allow policy makers
to direct funding for other health programs. However, it is up to the public and their policy makers to enforce such rules. The clinician’s role is to engage in constructive discussions with their patients or the wider public to promote individual and population health (Gostin and Gostin, 2009).

**CLINICAL MANAGEMENT OF SPECIFIC CHALLENGING CONDITIONS**

A number of pediatric neurological conditions (i.e., spinal muscular atrophy, Duchenne muscular dystrophy, neuro-metabolic, neuro-inflammatory and neurodegenerative disorders as well as neuro-oncological conditions) raise specific, complex ethical questions that arise from genetic implications and from management decision. To illustrate the setting in which ethical questioning takes place in clinical practice, we focus here on a few selected illustrations.

**Fetal neurology**

Evaluation of the fetus has undergone a revolution with the refinement of a number of antenatal examination procedures. Among these, imaging techniques such as fetal ultrasonography and MRI have extended possibilities for exploring brain structure (and perhaps function, as proposed in 4D-ultrasonographic studies of fetal movements). The availability of this information raises the need for counseling and decision-making in a period of the child’s and family’s life compared to earlier times when much less information was available to parents and clinicians. As a result, pediatric neurologists find themselves more and more involved in these processes, often in the setting of a multidisciplinary team that may include obstetricians, radiologists, geneticists, social workers, psychologists, neonatologists, and other pediatricians.

Pediatric neurologists are often unprepared to deal with many of these issues. Although the questions from parents that they are expected to answer resemble those of their usual clinical practice, they cannot rely on the full scale of information they are used to having available. Direct developmental history and clinical examination, which provide the crucial elements that help individualize clinical reflection, are very limited. Furthermore, maturation is by definition at an early developmental stage, limiting the picture of either physiological or pathological brain organization. Deprived of direct clinical and electrophysiological elements clinicians are thus left with the literature to help them with counseling and decision-making. For many situations, useful data from the literature are still limited. Some early studies were biased precisely because of variation in attitudes between different centers (e.g., as regards live outcome in centers where termination of pregnancy was encouraged based on detection of brain abnormalities seen on imaging). It is critical that pediatric neurologists involved in cases of this sort review available data in a systematic and comprehensive manner. They need to review direct evidence personally (e.g., look personally at the neuroimaging in addition to reading others’ reports). They need to consult with the other specialists involved in order to reach a collegial understanding of the situation, and must appreciate the sociocultural background of the family before proceeding with counseling. This process can be arduous. It requires rigor and humility and constitutes an intense experience of articulating one’s degree of expertise and partnership, both within a team of professionals and with parents. Non-traditional approaches such as fetal surgery or pregnancy termination should only be based on clear-cut, convergent data with a high degree of certainty. With increasing experience of multidisciplinary teamwork and numbers of outcome studies, pediatric neurologists can become more assured in integrating available information as well as dealing with and sharing uncertainty. They may thus take a leading role in broadly orienting options in the ethical issues associated with antenatal counseling. This role may be expected to acquire new dimensions in years to come with the growing field of fetal intervention.

**Neonatal encephalopathy**

In the last few decades, progress in obstetrical and neonatal care has resulted in increased survival of neonates who require intensive care. This has concerned in particular very low birth weight infants as well as newborns with specific life-threatening conditions such as cardiac or other malformations, severe skin disorders, or selected metabolic disorders. The decrease in neonatal mortality is often accompanied by an increase in neurological morbidity, particularly in the spectrum of intellectual disability, cerebral palsy, and epilepsy. There has also been welcome progress in evaluation of newborn infants. In addition to technological advances, particularly in the field of neuroimaging, there has been continuing progress to improve the prognostic value of observational clinical assessment. Using these tools in a single or multimodal approach has definitely contributed to better outlining groups at risk and outcome subcategories.

In practice, however, there remains much uncertainty regarding biomedical outcomes at the individual level. This gives rise to complex ethical challenges that affect patients and their families, health care professionals, and society at large. As mentioned above, the level of participation of parents in decision-making processes varies widely across different countries and even across different settings in the same country. In addition, in case of
emergency life-or health-threatening situations when parents’ consent cannot be obtained for urgently required treatment, physicians should act on the basis of their own presumption of the child’s best interest. As always, involvement of parents with provision of adequate information is central to the ethical question. This information should include probable outcome, associated risks, and implications of a proposed treatment plan as well as those of alternative options. The pediatric neurologist often occupies a central place for determining and discussing diagnosis and prognosis. This implies a central role in the collaboration with parents along the decision-making process as well as support of parents throughout that emotionally extremely difficult period.

Persistent vegetative state

The patient in a persistent vegetative state provides another illustration of ethical challenges for the pediatric neurologist. This clinical condition of complete unawareness of the self and the environment is accompanied by sleep–wake cycles, with complete or partial preservation of hypothalamic and brainstem autonomic functions, persisting for more than 1 month. Patients show no reproducible or purposeful behavioral responses to stimuli, have no language comprehension or expression, and have urinary and fecal incontinence. Persistent vegetative state may be caused by bilateral multifocal or diffuse brain injury that can be acquired, whether traumatic or nontraumatic, or occur in the context of central nervous system neurodegenerative disorders, inflammatory, congenital or developmental conditions. It is of utmost importance to evaluate the child very carefully in order to detect evolution from persistent vegetative state to minimally conscious state, in which minimal but definite behavioral evidence of self or environmental awareness can be identified. In this context, subtle reactions may be significant (Shewmon et al., 1999). This evolution may carry positive implications as regards possible recovery, at least if favorable evolution continues in the first year or so. Here, ethical questions will focus primarily on judgments about the reversibility of the condition and the level of cognitive functioning in children who evolved from vegetative state to minimally conscious state.

ADVOCACY AND PUBLIC ROLE

Pediatric neurologists who choose to serve the greater public may face unfamiliar challenges and responsibilities, and spend a great amount of time at the cost of primary professional demands (and private commitment to their own family and friends). In itself, this reality represents an additional ethical challenge. In keeping with their implicit responsibilities toward society, pediatric neurologists should facilitate access to appropriate and effective pediatric services and challenge treatment-authorization policies that delay or deny needed treatments (American Academy of Pediatrics Committee on Bioethics, 2007). Concerning advocacy, the primary role of physicians relates to protection of individual patients from any harm whether from inside or outside of the medical profession. Clearly this duty is multileveled, complex, and may require civic courage. Physicians in various specialties have been increasingly requested to play this role in settings outside their core medical practice.

In this context, interaction with parent support and advocacy groups deserves a special mention. These groups have become an important healthcare resource, and some of them can actually constitute preferred resources for patients and families over physicians for many aspects of healthcare (Ferguson and Frydman, 2004). Some professionals may therefore view these resources as challenging their medical role in engaging in valid practice and counseling, or may choose to ignore them altogether. A distinctive feature of family support groups typically is organization based on equality between group members in sharing the same problems, contrasting with the implied hierarchy between the helper and the persons being helped that characterizes the conventional relationship between the professional and the patient’s family. The autonomy gained by patients and families through support and advocacy groups constitutes definite empowerment. But this does not imply independence from medical professionals. Rather, it may contribute to redefining the partnership, consistent with the notion of the expert patient (Wilson, 2001), which needs to be reconciled with professional understanding of disease.

Collaboration with support groups is based on mutual confidence and respect. Within these programs, pediatric neurologists should provide technical advice on health and safety aspects of services, serve as a source of professional information for families, and learn from these programs how best to contribute to the healthy development of children, families, and communities (Dan, 2008). For example, pediatric neurologists: (1) participate in conferences relating to specific themes and questions, e.g., communication, feeding, epilepsy, orthopedic issues, schooling issues, leisure, transitions, or projections into the future; (2) help disseminate information at the clinical and academic levels; (3) help create or reinforce networks linking parents and professionals (e.g., in institutions) in order to promote the exchange of opinions and good practice; (4) advocate the need for clinical and basic research; (5) inform patients and families that by participating in research studies they can help answer important questions that could lead to further improvement on the currently offered level.
of care; (6) help set up scientific boards; and (7) provide scientific answers to health-related questions put forward by board members and evaluate research funding applications. In addition, pediatric neurologists are in a critical position to advocate for patients’ and families’ rights, including at the political level.

It is critical that in this advocacy role neurologists do not act as patients’ physicians in order to avoid confusion of roles. It requires from them a readiness to be humbly receptive, question previous notions and consider this collaboration as potentially useful (or even necessary) for the quality of their work. Within the group, they may develop tools that allow caregivers to better understand professional jargon and relevant medical and scientific notions. Discussion, exchange, and participation in common projects with parents are likely to change their attitude toward patients, caregivers, disease, and health. Support and advocacy groups represent a model of informal education. Collaborating with them is likely to contribute to the pediatric neurologist’s own continuing education, particularly in communication skills and issue perception (emphasizing family-oriented perspectives).

**PRESERVING PROFESSIONAL INTEGRITY AND AVOIDING CONFLICTS OF INTEREST**

The relationship of physicians to the pharmaceutical and technology industries also poses special ethical challenges. As noted by Brody “There must be some reasonable balance between the physician self-interest and the commitment to serve the patient, and just how much to draw the line of ‘reasonableness’ is highly contentious” (Brody, 2007). Ideally, clinicians, scientists, and the industry should work together to advance and promote health, without any interfering motives. Many physicians construct their sense of what is ethical through their everyday practices in the clinic in relation to the needs of the industry and their own business bottom lines (Fisher, 2008). As public trust in these industries has plummeted, the close connection between professional leaders such as neurologists, epileptologists, and other brain specialists and the pharmaceutical and technological industries, once a sign of progress for the profession, is now cited as a potential sign of corrupt influence (Freedman et al., 2009). The media increasingly criticize physicians for having financial ties to or receiving gifts and rewards from industry (including free drug or device samples) and for taking part in activities sometimes disingenuously claimed by these industries to constitute objective education. There is a genuine risk of confusion of physicians’ own personal interest with that of the industry when doctors endorse a certain drug, medical device, or manufacturer, or choose to prescribe drugs before attempting to offer other modes of management or prevention. By endorsing the industry and breaching the trust of their patients, doctors may indeed be involved in a conflict of interest, though they might not perceive it. As noted by Brody (2007) “When we can make more money by deviating from our strict professional obligations, we have a very strong tendency to judge our own motives in the kindest possible light and to imagine the deleterious consequences of our actions to be minor or nonexistent.” Furthermore, clinicians may misuse the phrase “conflict of interest” to suggest that the two competing forces drawing the physician in different directions are of equal moral weight, when in fact the physician’s professional duty is to care for and protect the patient, and not to represent the interests of the industry. This pattern of behavior is likely to have further consequences, such as increasing prescription usage, raising the price of medications, or boosting insertions of neurostimulators. These unethical practices may occur when nationally respected experts take part in consensus statements but are potentially biased by their ties with the industry. These practices may also prompt the public to refuse to trust other members of the profession. Similarly, individuals entering clinical trials need to be informed in detail about any financial incentives and potential conflicts of interest that involve the researcher or the recruiting clinician. We now need to assume a new responsibility of protecting our patients from conflicts of interest in the selection of their treatment (Freedman et al., 2009). Evidently, the financial interests may cause some ethical breaches. However, it has been argued that they can also motivate physicians to conduct studies ethically and insist on upgrading the safeguards of scientific journals for full disclosure and prevention of misreporting or incomplete reporting of data (Lewis et al., 2006; Fisher, 2008). Above all, professional integrity demands trustworthiness, and trustworthiness demands behavior that would convince even skeptical onlookers of one’s good faith (Brody, 2007).

As physicians pediatric neurologists can take advantage of their privileged status in society by embracing moral leadership to preserve public trust in our profession. For example, we can make a difference by openly opposing any collaboration with industry in questionable marketing practices of emerging drugs or medical devices where “evidence” is presented that demonstrates only what the industry wants us to believe. Academic leaders, professional societies, and patient advocacy groups could regain public trust by adopting a higher level of moral responsibility and accountability, by developing a culture of transparency and circumspection for our profession’s collaboration with industry,
including the clear separation of academic clinical missions from industry marketing even by risking withdrawal of funding (Insel, 2010).

**OTHER OPPORTUNITIES TO BE INVOLVED IN BIOETHICS**

When pediatric neurologists meet to consider ethical issues, they tend to discuss topics related to the right to die or refuse treatment, or dilemmas that emerge from advanced biomedical technology. Many of these philosophical discussions have been inspired by cases appearing before the courts. The recent shift from the linear biomedical model of disability, which focused on impairment, disability, and handicap (WHO, 1980), to a broader social perspective (WHO, 2001) has opened many new avenues for pediatric neurologists to participate actively in social questions related to our patient population and their families. For example, a potential task could be to clarify cultural and political understanding of the way disability is perceived within society. Other areas in need of bioethical scrutiny include the similarities rather than the differences perceived within society. Other areas in need of bioethical scrutiny include the similarities rather than the differences between people with disabilities and the general population in spite of the former’s “special needs.”

Much remains to be learned about the place of dependency, dignity, autonomy, and opportunity among individuals with neurodisability (Ronen and Rosenbaum, 2013). As a group the population with impairment and disability could benefit from a collaboration between pediatric neurologists, ethicists, and other professionals in fostering dialogues in society and legislatures on topics such as how to think about impairments and disabilities, how to improve attitudes toward this population, and the need to evaluate legislation that intends to protect the rights of this population. Neurologists can explore many of these issues by becoming involved in discussions about habilitative care, long-term care, home care, and respite care. Clinicians need to listen to individuals with impairments and their families to achieve a firsthand disability perspective. Only by including neurologists and the stakeholders themselves in these social roundtable discussions will an ethical consensus be built on a firmer, more broadly based foundation (Kuczewski, 2001). By entering the world of people with neurological impairments and disabilities and by trying to understand disabilities, neurologists can become directly involved in societal advocacy, in promoting new health service policies to enhance strategies that affect people where they live.

**CONCLUSION**

Societal and technological changes have brought about a host of new challenges for pediatric neurologists. These changes have considerably broadened their multiple roles as clinicians, researchers, and advocates. There has been a welcome tendency toward less paternalism on the part of doctors, paralleling the increase in patients’ autonomy. Pediatric neurologists need to adapt to the fact that, like other physicians, they are more scrutinized than in the past, resulting in an increase in the number of litigation and medical scandals reported in the media. As regards technological changes, pediatric neurologists have a duty to promote continuing advances. They need to strive for improvements in therapeutic benefits and to addressing expectations (including quality of life) of patients, parents, and allied professionals more effectively. Ethical questioning should be a central part of professional training, competency, and clinical judgment. Ultimately, ethics is an inalienable responsibility of each pediatric neurologist.

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Consideration of scarce resource allocation for children and young adults raises unique and vexing ethical challenges. A broad spectrum of chronic neuromuscular disorders affects both children and adults. The practice of pediatric neurology demands a high level of responsibility at multiple levels. These include listening carefully to people’s stories in order to assess each situation, planning and implementing investigations and therapies, individual and family counseling, longitudinal follow-up from fetal life throughout childhood and adolescence, organization of transition to adult care, and societal advocacy.

In this chapter, we address ethical and moral issues that may help guide pediatric neurologists with regard to a number of specific challenges. These include physician-patient relationships that are based on benign paternalism with respect for autonomy and promoting quality of life, practicing evidence-based medicine, and the technological imperative. Pediatric neuropsychology (paediatric in the UK) is a sub-speciality within the field of clinical neuropsychology that studies the relationship between brain health and behaviour in children. Many pediatric neuropsychologists are involved in teaching, research, supervision, and training of undergraduate and graduate students in the field. In the United States undergraduate and graduate psychology programs generally do not offer a “track” in pediatric neuropsychology, per se. Specific supervised Ethics Pediatrics Children Subpart D International guidelines Extrapolation Component analysis Equipoise Risk assessment Choice of control group Placebo Minor increase Scientific necessity Minimal risk Direct benefit Parental permission Child assent. Roth-Cline M., Gerson J., Bright P., Lee C.S., Nelson R.M. (2011) Ethical Considerations in Conducting Pediatric Research. In: Seyberth H., Rane A., Schwab M. (eds) Pediatric Clinical Pharmacology. Handbook of Experimental Pharmacology, vol 205.