Editoriale. Dall’etica al reparto di pediatria

*Editorial. From the Ethics to the pediatric ward*

**Melania Manco**
MD, Ph.D FACN, Area di Ricerca per le Malattie Multifattoriali, Ospedale Pediatrico Bambino Gesù, Roma

As physician, I have been working for a long time with adult patients. In 2006, since my strong scientific interest for pediatric endocrinology, I moved to the Bambino Gesù Children’s Hospital, one of the largest hospitals in Europe for high-standard care and research in Pediatrics. At that time I had to learn how to communicate with young patients with no or limited decisional autonomy and, more and more demanding to me, with parents. I started to cope with practical and ethical issues I never thought about before. The fundamental ethical principles of autonomy, beneficence and confidentiality assisted me in understanding, negotiating and navigating these issues but the clinical practice in the pediatric ward made them shedding novel light. Seventy percent of in- and out-clinic patients referred to our Institution are affected by major conditions (often inborn diseases) that limit seriously expectancy and quality of life, i.e. genetic abnormalities and rare diseases often complicated by mental retardation; conditions that require single or multiple organ transplants; various neoplasia. Any disease is expected to carry some pain and discomfort. Acceptance of suffering and even death or limited quality of life, however, can be handled and somehow better tolerated when they involves an adult individual. It seems impossible to handle these conditions when they affect a child. We would never give young patients and parents ominous information about the children health.

The June issue of the Journal deals with modalities of medical communication and therapeutic engagement of pediatric patients and their parents. Physicians and health care professionals from different Italian Institutions report their experience in communication to young patients and parents about diagnosis, therapy and prognosis in very challenging conditions. Experts in Ethics and social sciences provide updated insight about and discuss critically about family and society emerging challenges related to the child’s disease, i.e. including the role of media. Continuous advances in the medical science enable the earlier diagnosis of several inborn diseases and the more effective treatment of several conditions, hence improving life quality and expectancy. However, as for many other examples of “technological progresses”, novel ethical issues and concerns rise. With the spreading of the prenatal diagnosis of several inborn conditions, parents must be informed and decide about a baby that they never met. The newborn has not decisional autonomy. Who will decide on the child’ behalf? The physician? The Institutions? The parents? What will be the basis of such a decision? The case of Baby Doe tells that, sometimes, even trained health professionals provide biased information. Parents, who are not adequately informed, may become more and more scared about their own child condition taking an unfair decision. Baby Doe parents’ resolution was based on the expectation of a “poor quality of life”. However, the notion of quality life is limited by hazy boundaries. Now days, patients like Baby Doe have a longer life expectancy with most of the life-threatening co-morbidities effectively treated and are socially involved. A very sensitive issue is about the diagnosis and therapeutic interventions in newborns with ambiguous genitalia and disorders of the sexual development.

The daily experience in the clinical ward suggests us how determinant in terms of effectiveness of the treatment is to provide an effective informed support to parents. Once they learn about a poor diagnosis, parents behave differently. Some of them refuse it, some are scared of being inadequate about parenting or of social stigmatization; some of them
feel guilty; some others stay apart or, on the contrary, become hyperactive willing to do “something” and to offer the child the best care they can. Parents may live different phases along the “mourning” process. As for an expected “death”, sadness and anger can be common feelings. The emotional elaboration and acceptance of the child’s disease is, however, fundamental for the parents to act as efficient caregivers. The parental attitude can be part of the therapeutic process. The health professional must inform parents in a way that make them able to communicate in turn to the child. The effectiveness of the parents’ communication plays a pivotal role to help the patient to accept the disease and to be active player in the therapeutic process. In this issue, the readers will find practical examples of the need to involve the patient’s family in the treatment process toward a very effective relationship with the patient himself, i.e. in the treatment of anorexic and, at the extreme of the spectrum, obese patients. On the other hand, the health professional must inform also the young patient in a way that is tailored to his ability of understanding and cognitive capacities to make effective an intervention, in many case empowering him to be active player in the therapeutic process. In this issue, the readers will find practical examples of the need to involve the patient’s family in the treatment process toward a very effective relationship with the patient himself, i.e. in the treatment of anorexic and, at the extreme of the spectrum, obese patients. On the other hand, the health professional must inform also the young patient in a way that is tailored to his ability of understanding and cognitive capacities to make effective an intervention, in many case empowering him to be active player in the therapeutic process as it happens for the therapeutic education of obese adolescents.

In Italy as well as in many other countries, in the clinical practice parents of patient under 18 years of age are informed and must consent. Once the patient is able of verbal communication, the doctor will inform the child with the support of a psychologist by using simple words and colored cartoons about the disease but more importantly about what will be the diagnostic and therapeutic procedures. This is particularly important if such procedures are invasive and/or will cause pain and discomfort. This kind of assent is required usually in preschoolers and children in the early school age. Older children and adolescents are required to sign a document, which is similar to the parents’ consent form. If the written information must be provided to the patient and parents with the simplest words, verbal and non-verbal communication to the adolescent about the disease must be in keeping with his emotional and cognitive capacities. Some adolescents are able to fully understand their condition and express their williness. Hence, the autonomy is the ability of self-determination, meaning the competency of the pediatric patient to understand the disease status and the right to choose among treatment options and refuse any unwanted medical interventions varies from null in the newborn to the full competence of some adolescents. At the extreme of such spectrum, the health care provider may face very challenging situations that require high skills, extreme fairness to ensure the patient the best therapeutic option to maximize outcomes in terms of health and psychosocial well-being. As to the continuous support to parents and family members to meet their psychological requirements, there is also need to solve practicalities and overcome the sensation of bewilderment that they often feel at their admission to a hospital. As part of the treatment, great attention must be paid to family and the family services can be a precious resource. Professionals, who are trained to care for the whole family, contact the family and familiarize before the admission, “welcome” them at the time of the admission and watch over the family for as long as required, until the discharge and even after. Giving the sensation of being cared for enables the family to focus on the only thing that matters: their child’s health.

Finally, the discussion about the living donation is an extraordinary opportunity to critically revise the major principles of the Bioethics in pediatrics.

We would like to conclude this editorial reminding some statements of the Ethics Committee of the American Board of Pediatrics: “Medical decision making for pediatric patients should be based on the child’s best interest, which is determined by weighing many factors, including effectiveness of appropriate medical therapies, the patient’s psychological and emotional welfare, and the family situation. When there is legitimate inability to reach consensus about what is in the best interest of the child, the wishes of the parents should generally receive preference”. “Certain classes of children, such as emancipated or mature minors, may provide consent to their own medical care. Physicians should give pediatric patients the opportunity to participate in decision making at a developmentally appropriate level. The physician should seek the patient’s assent, or agreement, by explaining the medical condition, its clinical implications, and the treatment plan in ways that take into account the child’s cognitive and emotional maturity and social circumstances. The physician should provide a supportive environment and encourage reluctant parents to discuss their child’s health status with the patient, in private themselves or with the physician”.

References