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Ethical issues in the daily medical care of children

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Abstract The main ethical imperative of all paediatric actions is the demand to do everything “in the best interests of children”. Relevant guidelines can be derived from the UN Declaration on the Rights of Children, whereupon every child has the fundamental right to life and dignity, and is entitled to optimal medical care. Paediatric care in general includes the responsibility to achieve the highest level of knowledge, consideration of the child-specific somatic, mental and social development, empathic and trustworthy communication with the child and parents, observance of the recommendations of the Charter of the Rights of Children in Hospital, and cooperation with experts in related professions. Good communication is based on respect for the dignity of the child as a person and on the use of child-specific language, recognizing the rights of the child to be involved in consent or assent. Good clinical practice dictates and demands high standards of practice in therapeutics, research and medical interventions involving children. Decision making in extreme situations with regard to continuation, withholding or withdrawing life supporting measures is amongst the most complex and ethically difficult tasks of a doctor. Ethical issues with regard to neglect, maltreatment, abuse and addictions involving children need scrupulous consideration. Paediatricians have a prime responsibility to promote and protect the well being of children.

Introduction

Ethics is the study of the rightness or wrongness of human conduct. Declarations of rights and formulations of laws are, at least in democratic systems, derived from ethical reasoning. The main ethical principle of all paediatric activities is the demand to do everything in the “best interests” of children. The difficulty for doctors is that they can never be entirely certain what the best interests of children are in an individual situation. Article 1 of the General Declaration of Human Rights, accepted by most countries in the world, expresses the basic right of all human beings to be free and equal in dignity and rights [14]. Consequently, there is no doubt that children are entitled to full human rights and to the right of full identity.

Although countries may have cultural and ideological differences, guidelines supporting the approach of paediatricians and other doctors caring for children to the best interests of children and adolescents in the daily practice do exist. They are included in the “Declaration of the Rights of Children” proclaimed by UNICEF in 1959 and approved by the 44th General Assembly of the United Nations in 1989 [13]. Several articles deal with medical and social demands defining the needs of children for a healthy development. They culminate in the demand that the child by reason of his or her physical and mental immaturity needs special safeguard and care including appropriate legal protection before and after birth. Several topics among the 54 articles contain essential ethical requirements from which principles of medical ethics can be derived.

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Basic rights of children

- A child in the European Union is defined as every human being below the age of 18 years.
- The basic right to life has to be respected equally for every child. This corresponds to the article “1” of the General Declaration of Human Rights: “Any human being is born free and equal to dignity and rights” [14].

- No child, irrespective of birth, race, sex, social class, nationality, religion or state of health must be discriminated against or placed at a disadvantage when he or she needs medical care [16].
- Every child shall enjoy special protection to enable him to develop physically, mentally, emotionally and socially in healthy conditions and has the right to obtain preventive measures help and healthcare if ill or injured.
- Disabled children have rights identical to those of all other children. They should receive an optimum protection and developmental support to develop in an emotionally nurturing environment so as to become independent human beings as far as this is possible.
- The health and well being of children should have priority in poorer countries as well as developed countries. The health of children is the wealth of any society.

Paediatric care in general

- Continuous medical education is a professional obligation for each paediatrician. The Confederation of European Specialists in Paediatrics (CESP) has given guidelines on mode and content of paediatric training, and on the structure of an adequate continuous pediatric professional development in the EU countries [2].
- Doctors caring for children follow the somatic, psychic, mental and social development of the child. They should facilitate a healthy parent-child relationship. They should be capable of communicating with children and parents in an empathic and trustworthy manner.
- Every child should have a complete clinical record and a personal health document that should include the health information of the child.
- When a child requires hospital care, recommendations of the Charter of the Rights of Children in Hospital should be implemented by paediatric units [5]. Children's units should provide parental accommodation and a friendly, familiar and child-suitable infrastructure and atmosphere. Children's doctors should be familiar with the age-specific needs of children in different age periods and offer appropriate empathy, knowledge and skills.
- Doctors caring for children should provide advice, care and therapeutic interventions according to the best current scientific evidence [15].
- Children's doctors have a duty to act as children's advocates in the provision of services, child protection, accident prevention, and in promoting best health for children.

Communication with children and parents

The ability to communicate with children and parents includes several practical imperatives. An empathic attitude

forms the basis of each medical communication. Credibility and honesty are preconditions of confidence between the doctor, the child and the parents. The child has a right to respect, information and involvement appropriate to maturity. Good communication encompasses attentive listening as well as talking. Medical communication implies simplicity of speech and understandable information. Children's doctors must have appropriate skills, knowledge and competencies. Children have the right to be told the truth about their conditions, medical interventions and prognostications, but the nature and extent of information given will depend on individual situations and clinical judgement.

Paediatric prescribing

The doctor caring for children has to consider carefully the age-specific peculiarities of physiology, pathology, pharmacokinetics and pharmacodynamics and the increased vulnerability and fears of the child. The doctor should carefully use medications and vaccinations that have been scientifically tested in respect to their efficacy and safety for the respective age. He/she reduces risks and pain by choosing adequate methods for laboratory tests, using small blood sample volumes (micromethods), limiting invasive methods and using appropriate anaesthetic or sedation. Adequate pain relief is essential, especially for neonates and small children. Children need therapeutic research performed by competent researchers. Therefore, child-specific guidelines for good clinical practice and the protection of children have to be followed in paediatric research. Ethics committees evaluating biomedical peculiarities and age specific needs of children involved in research need to be available and properly informed.

There are relevant recommendations, such as the ICH Topic E11, the EU Directive 2001/20RC and the publication of the Ethics Working Group of CESP [6, 7, 8].

Informed consent/assent

Every child and family are entitled to receive full information about the medical procedures and interventions intended at a pace and a level they can comprehend [3]. They will use that information to make a voluntary choice as to whether to undergo a proposed procedure. Children reach the stage of adult capacity for abstract thoughts at the age of 14–16 years. Younger children should be informed in a language suitable to their age. Informed consent of the legal representative of the child, or of the competent child, is a process that emphasizes the quality of partnership, mutual understanding, respect and trust which are essential for the doctor-patient and doctor-family relationship [4]. The doctor has a responsibility to determine the ability and competence of the child to give his or her consent or assent under the conditions of national laws.

Neglect, maltreatment and abuse of children

Doctors caring for children have a duty and responsibility to respect the rights of children, to participate in child protection in its broadest sense, and to recognise child abuse if/when it occurs. The doctor's first duty is to be appropriately educated and informed in the recognition and management of child physical abuse, child sexual abuse, child neglect and deprivation, and child misuse (as in forced labour). Doctors should have a pivotal role in clinical diagnosis of child abuse, in child protection procedures, and in the functioning of multidisciplinary child protection teams. Doctors have a moral and, in some jurisdictions, legal responsibility to report episodes of child abuse to the competent authorities, including police and social services. While it is usual practice to attempt to return a child to his/her family there will be instances when alternative short term or long term care arrangements will need to be made. Most EU countries now have established codes of practice in child protection issues. The doctor's responsibility is to correctly and thoroughly document medical evidence of abuse, to present that evidence to case conference or legal proceedings, and to advocate for the best interests of the child.

Alcohol and drug addiction

Children's lives are often blighted by parental abuse of alcohol, and/or other drugs with associated risk for congenital physical anomalies, limitations of psychomotor development as well as child neglect, physical abuse and severe environmental deprivation. Parental smoking constitutes risks for adverse influence in the foetus and newborn and for airway diseases in children. Paediatricians have a pivotal role in identifying children who live in such conditions. The doctor's role is furthermore to cooperate and collaborate with other care services in recognizing such children and make efforts to improve their lives.

Use and abuse of alcohol and drugs by adolescents merit increased paediatric interest and involvement.

Decision making in extreme situations

Most practising paediatricians other than those in neonatal intensive care, or very specialised units, e.g. oncology, are unlikely to be involved in the ethical issues surrounding continuing or withdrawing treatment in extreme situations. This topic however has been covered in previous CESP ethics group documents [9–11].

Practising paediatricians may be involved in ethical therapeutic issues involving handicapped children at home and in institutions. Such issues would include treatment of pneumonia in a severely handicapped child, continuation of intravenous or nasogastric feeding in a child in a vege-

tative state, relieving pain and suffering in terminally ill children. The broad ethical guidelines of consulting and listening to parents/guardians, of involving all members of the caring team, of offering optimum palliative care, and of maintaining dignity and quality of life should prevail. Active intentional ending of the life of a child is not acceptable to paediatricians in most EU states. Legislation permitting euthanasia in children under very restricted conditions exists in the Netherlands. Enabling and allowing children to die with dignity, pain relief and minimal suffering should be the paediatrician's goal. Appropriate religious, cultural and counselling support should be offered.

Advocating for the rights of children

Where and when possible paediatricians should advocate for respect and action concerning the right of children expressed in the UN Declaration and accepted by all of the world's countries (except the USA) [13].

Difficult paediatric ethical issues

Paediatricians involved in genetics, molecular biology, perinatal medicine, antenatal diagnosis, stem cell research, and other areas of innovative research and practice are, and will be, increasingly confronted with complex ethical issues beyond the remit of this paper [1, 12]. These could include ethical discussion and argument concerning:

- Abortion for handicapping conditions of childhood (Down's Syndrome, neural tube defects, inborn errors of metabolism, etc.)
- Use of "spare" embryos for research purposes
- Cloning techniques

Discussion points

- (a) Do paediatricians have an ethical responsibility to children in general or to a specified group of children in the context of prevention of child abuse?
- (b) Is it ethically acceptable to withdraw nasogastric feeds in a seriously handicapped child who is unresponsive and has no suck/swallow reflex?
- (c) How do we define paediatricians ethical duty of care with regard to children whose parents are deemed to be providing inadequate care for chronic conditions, e.g. not giving anticonvulsants regularly for epilepsy, failure to return for review at diabetes clinics, etc?
- (d) Do paediatricians have an ethical duty to campaign when children are being deprived of what is seen as a basic or essential health care service, e.g. if government economic "cutbacks" or rationing cause service withdrawal or service reduction below an acceptable level?

Paediatricians should encourage and advocate in the interests of individual children and children in general

- Breast feeding
- Child friendly hospitals initiative
- Access to immunisations shown to be safe and effective
- Accident prevention initiatives
- Children in Hospital Charter
- Good nutrition/education
- Growth monitoring
- Strategies to eliminate child poverty
- Provision of children's commissioner, ombudsman or minister for children by central Government

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