

Patient autonomy – what does it mean for clinical decision-making in children and adolescents?

Thor Willy Ruud Hansen

Abstract: Autonomy implies the right of a competent patient to make decisions about their own health care. To exercise autonomy a patient must receive an explanation of his/her condition. True autonomy presumes intellectual understanding, the ability to translate theoretical ideas into real-life concepts, and emotional connectedness to the situation.

Children may not be able to understand or process information about treatment choices. Therefore, responsibility for decision-making is vested in the parents. In Norwegian law, this lasts until the child is 12 years old, though the child must be informed and involved commensurate with intellect and maturity. From the ages of 12 until 16, the youngster should increasingly be heard and involved, and from the age of 16 years a youngster is considered medico-legally competent.

Parents who face serious illness in a child are in a life crisis. Yet in spite of this, decision-making competence is often assumed. Decisions with life-or-death or lifetime implications will profoundly influence the life of the family. The best interest of the sick child may not necessarily be compatible with the needs of the family as a unit. As medical caregivers we should be cautious about assuming that our insight into such family realities is adequate. We must sensitively, yet critically, consider decision-making competence, while at the same time supporting the parents' efforts to cope and make the best decisions possible. However, we must never lose sight of the fact that our primary responsibility is towards the sick child.

IeJSME 2016 10(1): 3-9

Key words: Bioethics; Autonomy; Children and adolescents; Decision-making competence; Best interest; Parental authority; Emancipation of children

In the history of medicine, paternalism has until quite recently been the rule of decision-making. It was

axiomatic that the physician knew best, and the patient must do as she or he was told. Children belonged to the parents, and in all matters pertaining to their children, the parents' right and duty to decide was largely unquestioned. However, in medical matters once again the physician was master. This role for the physician assumed that he was acting from benevolent motives, albeit admittedly from a paternalistic understanding.

Patient autonomy – a brief background

It seems reasonable to see the idea that patients had a role to play in decisions pertaining to their health, at least for medicine as practiced in Western countries, as a "child of democracy". American writers have argued that the concept of autonomy comes from the Bill of Rights, the Declaration of Independence, and the U.S. common law tradition¹. It is far beyond the scope of the present paper to discuss the history and philosophy of autonomy, suffice to state that the book on bioethics by Beauchamp and Childress was seminal in establishing autonomy as a core concept². This concept has been incorporated into the health care laws of several countries, including my own³. (As my own arena for the practice of medicine and bioethics is Norway, I shall for reasons of personal knowledge and convenience make occasional reference to rules and laws from that country. However, this does not imply that these rules and laws are superior to the rules and laws of other countries.)

The idea of patient autonomy has received some criticism, specifically the practice of informing the patient, then leaving the decision entirely in the patient's hands in a way that may border on abandonment⁴. Many would argue that for autonomy to truly serve a patient's best interest, the physician's role must be to *enable* the patient to make autonomous decisions⁴. Enabling a patient to exercise his/her autonomy involves giving an explanation of his/her condition and the prognosis, as well as the (professionally sound) treatment options which are available, then engaging in a sensitive and respectful dialogue with the patient, permitting her/him to develop their thinking on the issues.

Department of Neonatal Intensive care, Division of Paediatric and Adolescent Medicine, Oslo University Hospital, and Clinical Ethics Committee, Oslo University Hospital, and Institute of Clinical Medicine, Faculty of Medicine, University of Oslo, NORWAY

Address for Correspondence:

Thor Willy Ruud Hansen, MD, PhD, MHA; Department of Neonatal Intensive Care, Division of Paediatric and Adolescent Medicine, Oslo University Hospital, P.O.B. 4950 Nydalen, 0424 Oslo, NORWAY
Email: t.w.r.hansen@medisin.uio.no

This is challenging for many physicians, as it involves taking into consideration the patient's intellectual, educational, and cultural background, and tailoring, as much as possible, the explanation to the recipient. In essence, the explanation must be couched in such terms that the patient is able to understand it to the extent that he/she is able to say "this is what the choices and the decisions I must make will mean for my life". In other words, true autonomy presumes not only intellectual understanding and the ability to translate theoretical ideas into real-life concepts, but also an emotional connectedness to the situation. Clearly, this very often cannot be adequately achieved by handing out a standardized information sheet or reciting a rote speech. There is reason to suspect that many patient information sessions fail at this stage.

Competence/mental capacity for exercising autonomy

It will be evident from the preceding discussion that there may be patients who are not competent (have the mental capacity) to make decisions on their own behalf⁶. Such competence must be assessed specifically for each situation, as both timing and situation specifics may impact on capacity. For example, an elderly patient with moderate dementia may have adequate mental capacity to consent to a blood test, but not to decide on a prolonged and invasive therapy with uncertain outcome. Simple tools have been created to assist clinicians in evaluating mental capacity^{6,7}.

There is another danger in a legalistic approach to patient autonomy. Thus, if informing the patient is followed by leaving the patient to decide without further input, physicians may abdicate their professional responsibility for the choices the patient makes. Then, if things do not turn out well, or in fact go very wrong, it may be easy to blame the patient – "you made the choice, now you must accept the consequences".

It is increasingly understood that patient autonomy for adult, competent, patients involves the right to say no to any treatment we might offer, including e.g. blood

transfusions for Jehova's Witnesses. However, choices may occasionally involve therapeutic alternatives which are not equivalent, and such alternatives may not infrequently be brought to the fore by the patient. Physicians should not offer to provide an alternative therapy which they do not believe to be scientifically sound. If asked about such alternatives, they must make it very clear that they *i*) do not recommend that therapy, and *ii*) cannot be responsible for carrying out that treatment. The patient has a right to make that choice, however ill advised the physician may consider it, but the physician is not under any obligation to provide it.

Autonomy for children and adolescents

It will be clear from the preceding discussion that a certain intellectual capacity as well as emotional maturity is needed for patients to properly exercise their autonomous rights. Children may, depending on their age and developmental status, possess neither the intellectual capacity nor the emotional maturity to understand or process information about treatment choices. Therefore, in most settings responsibility for decision-making for children is vested in the parents. In Norwegian law, such responsibility rests with the parents until the child is 12 years old³. From the ages of 12 until 16, the child should increasingly be heard and involved in important decisions, and from the age of 16 years a youngster is considered medico-legally competent (although in general law, the age of emancipation is only reached at 18 years). Even before the age of 12 years, however, the law demands that the child be informed and involved to the extent possible considering the child's intellect and maturity.

The age at which children/youngsters become capable of exercising health care autonomy is not a fixed number of years. Weithorn and Campbell compared the decisions made by children/youngsters aged 9, 14, 18, and 21 years relative to *i*) evidence of choice, *ii*) reasonable outcome, *iii*) rational reasons, and *iv*) inferential understanding⁸. They found that children in the 9-year-old group were less competent than

adults relative to the higher standards of understanding. But they still tended to make similarly logical decisions as those of adults. The 14-year-old group showed the same level of competency as the 18 and 21 year olds, and made more or less the same choices. Others have made largely similar findings⁹. However, as for adults, both cognitive ability and emotional maturity may vary between children and adolescents of the same age. Thus, for each child/youngster and indeed each specific situation, individual assessments must be made.

Child and adolescent autonomy in the law

The age of emancipation varies between countries, but for most countries appears to be in the 18-20 years range¹⁰. However, in several countries youngsters may, in certain circumstances (e.g. marriage, military service) be emancipated at ages down to 16 years¹¹. The particulars of such rules regarding “mature” or “emancipated” minors vary both between and within countries¹².

The laws also appear to differ with respect to the status of children as independent subjects and as wards of the parents. Interestingly, some differences may relate to the financing of health care. Thus, writers in the U.S. have argued that because parents often bear the burden of the decisions made for (or by) their children, including the financial costs of providing treatment which may be very significant and impact on the lives of the entire family unit, the parents should have authority to decide¹³. In Norway, health care coverage is universal, and therefore the ability of the parents to pay for treatment was not a factor in the discussions that concerned emancipation of 16 year olds in health care law¹⁴.

The role of parents

Parents have extensive duties and rights relative to their children. This probably applies in most countries whether determined by law, culture, religion, or social mores. The duties of parents are usually thought to include providing love and care, food, clothing, a home, as well as opportunities for learning and education.

The rights include making decisions for the child and the family, as well as raising the child according to their beliefs and philosophy. Salter states that “The presumption of parental authority in decision-making rests on a few key claims, including the claim that parents generally have the best knowledge of their child’s current interests and well-being, the claim that parents are naturally motivated to protect these interests, and the claim that because they are generally the bearers of decisional consequences, parents have a right to assume decisional control”^{13,15}. Parental authority is also based on the assumption that they want what is best for their child, that they are capable of distinguishing the child’s needs from their own and able to prioritize the child when this seems right, that they possess competence as far as the life of their family, and that they will obtain whatever information and knowledge they need in order to make decisions.

Fortunately, these assumptions are most often proven right. But occasionally there are exceptions, as shown in cases of child abuse, neglect, lack of parental competence, or use of children as “weapons” in divorce cases and custody battles. Thus, health care workers who care for children need to maintain awareness for those situations where signs point to conflicts of interest between the child and the parents.

Further, even in cases when both the will and the ability to care for the child are present, society will occasionally intervene to safeguard a child’s wellbeing or vital interests. Thus, in many countries parents will not be permitted to prevent their child from receiving lifesaving therapy because of their religious or philosophical views. The role of society in this context is sometimes referred to as *parens patriae*, meaning that the state intervenes to act as the parent of any child or individual who is in need of protection¹⁶. The law in this respect has evolved over time, from granting parents almost absolute authority over their children to the present-day situation, where child protective services have significant discretion as far as intervening to protect the wellbeing of children, even in matters unrelated

to health. On the other hand, neither adherents of anthroposophy nor certain religious groups are, in most countries, forced to immunize their children. Thus, the balance between the rights of parents and the perceived duty of society to protect the health and wellbeing of children has shifted, and there is no reason to think that the question has been settled. Indeed, there appear to be differences between countries in respect to this area, and debates occasionally flare up even in countries where a significant role for society is largely accepted. In Norway, a public debate about immunization recently surfaced following breakthrough cases of pertussis and measles. Proponents of immunization argued that vaccination now ought to be compulsory and enforced in order to ensure sufficient herd immunity, while opponents decried vaccines as “unnatural”, lauded the purported beneficial effects of acquiring immunity through natural infections, and pointed to the side effects of vaccines.

Best interest

The concept of “best interest” has undoubtedly played an important role in the developments described in the previous section. A key document in this context is the UN Convention on the Rights of the Child¹⁷, which was adopted by the UN General Assembly on November 20th, 1989 and has subsequently been ratified (although with some stated reservations or variations in interpretation) by all the members of the UN except the USA, which has signed, but not ratified the convention¹⁸. For many, the key phrase of the convention is found in Article 3: “In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration”. This principle has since been incorporated, both in laws and in declarations by public bodies and professional organizations. It is also referred to in influential ethics books, such as e.g. later editions of Beauchamp’s and Childress’ *The Principles of biomedical ethics*¹⁹.

Although the use of ‘best interest’ is so common as to make the concept behind it appear almost intuitive and

self-evident, Salter has recently offered a very thoughtful critique, elements of which should be kept in mind when considering, in concrete cases, the balance between parental rights and duties and the emerging autonomy of a child/adolescent¹³. First, Salter points out that ‘best interest’ is commonly understood as exclusively patient focused, in other words individualistic. In the case of a child/adolescent, this understanding can be taken to exclude both parental, familial, and broader societal interests. Second, Salter argues that there are in fact many different versions of the best interest standard, which differ i.a. with respect to how and if they incorporate the interests of others. Salter also argues that a narrow application of the best interest standard in the case of children fails to respect the family unit. As an example: a very expensive new therapy may help a child, and thus be in his/her best interest. However, the expense and practicalities necessitated by administering the drug might require moving the family away from their home, relocate siblings and potentially deprive them of their future opportunities for schooling and health care, and remove the parents from their source of income and health insurance, thus eliminating the possibility of paying for the expensive treatment. Could it not then be argued that the best interest of the individual vs the family unit are incompatible? A further discussion of Salter’s critique is beyond the scope of this paper, but the brief points mentioned above seem worthy of consideration.

Challenges to autonomy encountered by child/youth health care workers

Parents object to plans for treatment

A number of questions need to be addressed in this scenario. Is the planned treatment both effective and indicated, e.g. will it prevent death or significant loss of future health and function? Does the treatment involve significant risks, and if so, what is the balance between risks and potential benefit? Have the parents been sufficiently well informed, and was the information

understandable, given the parents' emotional situation and intellectual resources? Do they understand the possible consequences of not treating? Are the parents competent to make a decision, and do both parents agree? Do both have (shared) legal custody of the child/youngster? What is the child's/youngster's age, and how do health care workers assess the young person's maturity as well as current emotional and cognitive state? Has the child/youngster been informed and has she/he voiced an opinion? Most, perhaps all, of these questions will need to be addressed carefully and thoughtfully in a respectful dialogue. If an agreement or a common understanding can be reached, that is a significant achievement.

The parents demand complementary/alternative treatment for the child

It is crucial to search for information about the proposed/requested treatment. If the requested treatment is certain to be innocuous, objecting to it is likely to cause blocks in communication and do more harm than good. However, not infrequently there is lack of documentation of both effects, side effects, and possible interactions with medical treatment. If such interactions are possible, and could weaken the effect of ongoing, well-documented, medical therapy, or increase the risks of side effects of the same, this needs to be carefully explained. As always, listening carefully to the parents and allowing them the time they need to explain their thinking, is of the utmost importance. But in the end, a physician cannot be party to a course of action which does not, in carefully considered medical judgment, constitute "sound medical practice"²⁰.

The parents demand treatment which in medical judgment is futile

Examples of this might be one more round of cytostatic drugs with no potential for slowing down tumor growth, surgery with no real prospect of palliation (much less cure), or "resuscitation" or ventilator treatment of someone who has been shown to be brain dead. However, futility is a term that may be very value laden, so before

one uses the term, one should engage the parents in a real dialogue as far as what goal (utility) they would be aiming for with the treatment in question²¹. It may turn out that the "utility" we are thinking of, is not the one the parents are looking for. Relevant issues to think about might be: Does (or might) the child/youngster have opinions of his/her own? Is there a price to be paid for the proposed treatment, such as increased or prolonged suffering for the child, occupying therapeutic resources which might do more good for another patient, or increased cost for the hospital? Another "price", often not considered, is whether an unremitting focus on ever more treatment steals attention from the fact that a life is drawing towards its end. Preparations for death might include expressions of mutual love, thank-yous, forgiveness and reconciliation, celebrations of a life well lived, and religious rites. Such actions may play an important role in the subsequent work of grief.

However, apparently futile care might on occasion possibly yield benefits, such as time to develop acceptance, time for a loved one to reach the sick-bed, and time for final good-byes. It may be wise, before embarking on this course, to state certain terms clearly. It seems imperative that increased pain or suffering for the child/youngster cannot be accepted. There must be a clear agreement on time limitations, and increasing intensiveness or invasiveness of care is almost always unacceptable.

When parents insist that the child/youngster not be told of a poor prognosis

Earlier I have stated that the parents are the "experts" on their family and its members. They know their child, her/his personality and foibles, and they are aware of the, often complex, interrelationships between the members of their family unit as well as their extended family. Caregivers may get to know some families quite well, perhaps better than some parents recognize, but can never approach the depth of understanding that (most) parents have. Thus, if the treatment team believe that parents' wish to keep the child/youngster ignorant must

be overruled, careful evaluation must precede such a decision, and the arguments must be strong, recognizing that violating the parents' wishes may irreparably damage their relationship with the medical team and cause deep distrust¹⁵.

First, an extensive, but sensitive, discussion between the parents and trusted members of the medical team is necessary. Understanding their reasons for wanting to withhold information from their child is a basic requirement. A common reason for such thinking is a desire to spare the child the anguish of thinking about death. Parents often do not recognize that children who are severely ill usually understand much more about their situation than adults perceive²². Indeed, when a child understands what is happening, yet recognizes that parents and caregivers are holding back, the child may feel isolated and alienated²³. The child, recognizing the pain and grief of the adults, will try to spare them by feigning ignorance, increasing his/her feelings of isolation and preventing him/her from articulating his/her feelings, thoughts and fears¹⁵. Such issues should be explored with the parents through regular conversations. Building a trusting relationship between parents and caregivers is of great value, and frequent changes of team members will most likely hinder this process.

Secondly, it is not an uncommon experience that when everybody except the patient knows, at some point someone will unintentionally "spill the beans". This will reveal the deceit in the prior communication, and further increase distrust and alienation. Further, parents should be told early on that if the child/youngster asks a staff member a direct question, that staff member will not lie, but answer the question truthfully. Finally, being denied the right to prepare for what is coming, particularly if what is coming is death, could be seen as the ultimate betrayal. Therefore, it is important that the parents be given every opportunity to discuss and consider the implications of their desire to not inform the child.

Abstaining from autonomy

Though autonomy is a right, it is questionable whether it is a duty. Thus, it is still not unusual for elderly patients, when faced with a healthcare decision, to say: "Doctor, I want you to decide what you think is best". In such a situation, the patient delegates her/his healthcare autonomy to another person, under the assumption that the other person will weigh the arguments carefully. Whether that proxy decision-maker is to use 'substituted judgment', 'best interest', or some other tool from the ethics toolbox, may or may not be specified. It is perfectly permissible to use one's autonomy to transfer the responsibility for decision-making to someone else.

In my experience, parents who are faced with life-or-death decisions also occasionally choose to defer to the attending physician. For some, thinking that they have been in some way "responsible" for a decision that ended the life of their child is too much to bear. Caring physicians will accept this responsibility, and may, depending on the legal situation, be able to point to legal precedent. Thus, as an example, Norwegian healthcare law specifically states that the responsibility for "medical" decisions rests with physicians²⁰.

Conclusions

Autonomy is increasingly seen as a basic right of patients. Children and adolescents, too, have such rights. Parents are responsible for the autonomous rights of young children, but as children grow and mature, they should increasingly be heard and eventually decide for themselves. The age at which young people are considered competent decision-makers with respect to healthcare, is in part determined by law. If healthcare laws do not specify age limits, the legal age of general emancipation must be assumed also to be the age at which individuals can, and usually should, assume responsibility for healthcare decisions.

There appear to be sound arguments why children should be informed and heard, and that their voice in decisions should be commensurate with cognitive

and emotional maturity. Healthcare workers need to be in continued dialogue with both the parents and the child/youngster, and be sensitive to signs of lacking competence. Although the best interest of the child is an important consideration, the specifics of the situation and the needs of the family as a unit should also be weighed carefully. Occasionally, it may be advisable to enlist the help of resources outside the core medical team. Such resources may include, but may not necessarily be limited to, psychologists/psychiatrists, social workers, religious advisers, and extended family and friends. In cases of medical disagreement, involving someone from the outside for a second opinion may be advisable. Finally, clinical ethics committees or ethics consultants may help to analyze and clarify the values and choices.

Acknowledgement

This paper was presented as a plenary lecture at the 2nd International Conference on Bioethics and Professional Practice, International Medical University, Kuala Lumpur, Malaysia, 18 – 19 November 2015.

REFERENCES

- Annas GJ, Grodin MA. The Nazi Doctors and the Nuremberg Code. Human Rights in Human Experimentation. New York and Oxford: Oxford University Press, 1992.
- Beauchamp TL, Childress JF. Principles of biomedical ethics, 3rd edn. Oxford and New York: Oxford University Press, 1989.
- Lov om pasient- og brukerrettigheter. <https://lovdata.no/dokument/NL/lov/1999-07-02-63>. Accessed: 21 October 2015.
- Entwistle VA, Carter SM, Cribb A, McCaffery K. Supporting patient autonomy: the importance of clinician-patient relationships. *J Gen Intern Med* 2010; 25: 741-5. doi: 10.1007/s11606-010-1292-2.
- Buchanan A. Mental capacity, legal competence and consent to treatment. *J R Soc Med* 2004; 97: 415–20. doi: 10.1258/jrsm.97.9.415
- Etchells E, Sharpe G, Elliott C, Singer PA. Bioethics for clinicians: 3. Capacity. *CMAJ* 1996; 155: 657-61.
- <http://www.jcb.utoronto.ca/tools/documents/ace.pdf>. [accessed 10-19-2015]
- Weithorn L A, Campbell SB. The competency of children and adolescents to make informed treatment decisions. *Child Devel* 1982; 53: 1589-99.
- Dickey SB, Kiefner J, Beidler SM. Consent and confidentiality issues among school-age children and adolescents. *J School Nurs* 2002; 18: 179-86.
- Michaud PA, Berg-Kelly K, Macfarlane A, Benaroyoa L. Ethics and adolescent care: an international perspective. *Curr Opin Pediatr* 2010; 22: 418–22.
- Coleman DL, Rosoff PM. The legal authority of mature minors to consent to general medical treatment. *Pediatrics* 2013; 131: 786-93. doi:10.1542/peds.2012-2470
- AAP Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 1995; 95: 314-7.
- Salter EK. Deciding for a child: a comprehensive analysis of the best interest standard. *Theor Med Bioeth* 2012; 33: 179–98. DOI 10.1007/s11017-012-9219-z
- OT prp nr.12 (1998-99) Lov om pasientrettigheter. <https://www.regjeringen.no/no/dokumenter/otprp-nr-12-1998-99-/id159415/>. Accessed: 21 October 2015.
- Salter EK. Should we tell Annie? Preparing for death at the intersection of parental authority and adolescent autonomy. *Narr Inq Bioeth* 2013; 3: 81–8.
- Wadlington W. Medical decision making for and by children: tensions between parent, state, and child. *Univ Ill Law Rev* 1994; 311-36.
- <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>. Accessed: 21 October 2015.
- <http://indicators.ohchr.org/>. Accessed: 21 October 2015.
- Beauchamp TL, Childress JF. Principles of biomedical ethics. 6th ed. New York: Oxford University Press, 2008.
- Lov om Helsepersonell <https://lovdata.no/dokument/NL/lov/1999-07-02-64>. Accessed: 21 October 2015.
- Burns JP, Truog RD. Futility – a concept in evolution. *Chest* 2007; 132: 1987-93.
- Sahler O J, Frager G, Levetown M, Cohn F G, Lipson MA. Medical education about end-of-life care in the pediatric setting: Principles, challenges and opportunities. *Pediatrics* 2000; 105: 575–84.
- Beale E, Baile W, Aaron J. Silence is not golden: Communicating with children dying from cancer. *J Clin Oncol* 2005; 23: 3629–31.