When parents refuse a sick teenager the right to give informed consent: the nurse's role

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ABSTRACT

Objective
To outline the case for child patients who are minors to be allowed to participate in the medical decision-making process and make significant choices.

Setting
The paediatric oncology department of a major teaching hospital in Israel.

Subject
A 15-year-old boy from a strictly religious Jewish family was diagnosed with acute myeloblastic leukaemia. Relying on their rabbi's advice, the parents agreed to a chemotherapy protocol but refused an immediate bone-marrow transplant using a central vein access device to ease suffering and increase safety and rejected extracting and freezing some of the boy's sperm (the chemotherapy would cause sterility). They refused to let the boy take part in the discussions with the medical staff, or even to know he had cancer.

Primary Argument
The authors consider that two principles are decisive - the patient's best interest and informed consent. A teenager who has emotional maturity and understanding is entitled to a doctor-patient relationship based on mutual trust; on their right to know; and their capacity for autonomy (to be judged in light of the severity of the treatment required).

The nurse's role is to bring the parents to acknowledge their child's rights; to identify where information is needed; to help the parents express their needs and wishes to the medical staff; to act as case manager and patient advocate; and coordinate between all care-givers. An ethical-problem-solving worksheet is offered to nurses.

Conclusions
Nurses must be specifically trained for this mediating role and be appropriately represented on local ethics committees. Systematic decision-making protocols are needed.

INTRODUCTION

The case study

A 15-year-old boy from a strictly religious Jewish family was diagnosed with acute myeloblastic leukaemia. The physician, a nurse from the paediatric hemato-oncology unit and a social worker gave the parents as much clinical data as was available, discussed possible treatments and made three recommendations: (a) a known chemotherapy protocol common in all Israeli hospitals; (b) a bone-marrow transplant, including examining the boy's five siblings for donor compatibility (a bone-marrow transplant is a relatively innovative treatment involving some risk, yet carries a good chance of recovery; it was suggested that the boy have an immediate transplant using a central vein access device (Port-A-Cath) to ease suffering during treatment and increase safety); and (c) that some of the boy's sperm be frozen, since the aggressive treatment he was about to receive would almost certainly cause sterility. The physician suggested inviting the boy to take part in the discussion.

The parents' reaction was total shock and the first thing they requested was: *"Don't tell the boy anything"*. After a while they turned to the nurse and asked her for clarification concerning the treatment: *Where will it take place? For how long? Will he lose his hair?* After the urgency of treatment had been made clear to the parents, they left for consultation.

Three days later the parents arrived for a second appointment with the physician without the boy. They announced their consent to the chemotherapy and also to an alternative treatment but, having consulted their rabbi, refused consent to the PAC transplant and freezing his sperm. On the bone-marrow transplant and examining their other children, they asked for more time for consultation. They would not sign a consent form for the treatment they had agreed to until all their consultations were complete.

Thus a 15-year-old boy, able to be party to a doctor-patient relationship, was denied this by his parents. The parents refused consent to treatments proposed by the boy's physicians; chose to withhold information from their son; and imposed this decision on medical staff. Relying on their rabbi's advice, they refused the transplant using a Port-A-Cath, raising arguments such as: '*It will always remind him that he is ill*'. They were against 'useless surgery' and everyone knowing the boy had cancer. As for removing and freezing his sperm, the parents also refused, claiming their son was too young (they were informed of a commonly used technique for taking sperm donations from young people). They refused to let the boy know the seriousness of his disease. The word cancer was not to be mentioned. According to the parents, the rabbi they consulted had already talked to the boy, who had agreed to abide by whatever his parents told him to do.

Literature Review

Today, the almost universal approach to minors' consent emphasizes the need to find ways to consider their wishes (Carmi 1998) but there is more than one approach to locating the right level of consideration. The extreme approach of the movement for child emancipation argues that children should have all the autonomy of adults. A more conservative approach sets a fixed age limit, beyond which the child is able to take responsibility and enjoy adult privileges. An intermediate approach would decide each case on its own merits, looking for an optimal balance between the child's maturity and ability to take rational decisions and current legal statements and restrictions on his decision-making rights. Many Israeli hospitals take this approach (Morag 2005; Almog 1997).

Another approach bases competence to give informed consent on the gravity of the patient's state of health and the severity of the treatment required. The competency test is made increasingly stringent as the potential results of treatment become more severe (Pahlman et al 1996; Case 1988).

That parents have the right to give consent to their minor children's medical treatment is an almost universal norm. Few national legal systems recognize the minor's right to decide independently of the parents (Frizler 1994). Nonetheless, Zohar (1998) and Langham (1984) claim that parental consent to medical treatment negates one of the most important values of medical ethics - patient autonomy. A second danger is that, in claiming that the child 'belongs' to the parents, an 'ownership' notion is established, enabling the parents to act according to their own interests as parents and not according to the child's best interest. Brody (1976) questions the source of informed consent, (who is the patient?) and the tendency of health care systems is to see the parent as the customer or patient. It is the parent who is given information about the illness and its treatment, its dangers and probabilities and who makes the final decision. But Brody and Aronson (1978) argue that the patient has three fundamental rights - to receive the best treatment; to know about their condition; but also not to know. Golan (2004) concurs, stating it is an adolescent's primary right to know that their parents, doctors and nurses will never lie to them and never exploit their weakness relative to doctors and parents. Decisions concerning a child's treatment must not be made by adults alone.

The medical staff's ethical responsibility to a minor patient derives from the same obligation society imposes on parents. All have a duty to provide the child with the best care possible. Yet, when the child is ill, the physician may be thought to be more capable of providing for the child's needs. Toward the parents, the physician has an obligation to pass on all necessary information and receive their consent to the treatment proposed, but the physician also has a direct commitment and duty to the child (Truman and Bran 1984).

A particularly problematic issue that physicians face, especially in paediatrics, is around experimental treatments. In the field of oncology, the borders between experimental and conventional treatment are often unclear (Van Eys 1987). Many treatments are based on protocols that are still under experimental study. It is beyond question that obtaining informed consent to innovative treatment requires the physician to give not only a detailed explanation of the treatment but also of the study's design and goals.

DISCUSSION

When parents and medical staff disagree

When parents and medical staff disagree, complex philosophical, ethical, and legal problems are confronted. To what extent is it possible to scrutinize the 'way devoted parents should act' when discussing a boy ill with cancer and at high risk both from the disease and the proposed treatment? Are there standard criteria at all? The solution to these complexities can perhaps be found in the concept of the patient's best interest. This is the standard that must guide the course of the entire treatment. Brody, Golan, Aronson and others argue that the first and principal right of a juvenile with cancer is the right to know. He has the right to be told the truth by physicians, nurses and parents. Decisions concerning him should not be made only by adults. A second guiding principle is the principle and values of informed consent (Tabak 1993). Together, the two principles should establish the nature and goal of the relationship between nurse, patient and the family.

Who is the patient? In current Israeli law, the parents are the staff's partners in the informed consent process and they are the child's representatives. In practice, it is the child who will or will not, receive treatment and therefore they are the patient. The clinicians' role is always to acquire the patient's trust and such trust can only be based on integrity and not on the withholding of information. A teenager who has emotional maturity, clear understanding and the competence to make choices should be entitled to all the rights of an adult. The doctor-adolescent patient relationship must stand on the two pillars of mutual trust and the adolescent's capacity for autonomy (judged on the severity of the treatment required).

The contemporary approach is to take each case on its individual merits and look for the optimal balance between the child's ability to take decisions and current legal restrictions on his right to do so. If this means asking adolescents to cope with long-term and life-threatening data and situations, then this is their right. Cancer and chronic disease bring minors into maturity far earlier than their healthy peers, to the point that they are mature enough certainly to share in making, if not to make alone, the necessary hard choices.

Parental rights over their children are not absolute but subject to: a) the child's growing up and b) society's developing understanding of children's rights and abilities. Both children and parents need to know the limit of a parent-guardians' rights and responsibilities. In this case the limits are set by two key concepts - the minor's best interest and the norms and values of society. After all, the concepts involved in this controversy - the rights and obligations of minors and parents and a patient's best interest - all stem from society's ruling values and these values develop over time. Society clearly has a legitimate voice in the argument and doctors and nurses represent that voice (as do hospital ethics committees and the law courts). In refusing to acknowledge their son's right to a significant degree of autonomy the parents themselves open the door for society to intervene. At age 15, it is to be presumed, until demonstrated otherwise, that an adolescent can think for himself. Of course, one of the problems of this case is that not one but two sets of societal norms are in competition: those of the larger society and those of the strictly orthodox community to which the boy and his family belong. But even in Jewish law, the boy came to manhood at bar-mitzvah (age 13 years) and as such, has the personal responsibility of any Jewish adult for obeying Jewish law.

The parents cannot protect their son from the disease so they try at least to protect him from the news. Yet, health professionals who take care of the child see the situation differently: The child is on the verge of becoming an adult and being prevented from realising his rights and interests. In the present, he is denied the basic right to know and decide and the right to enjoy a better quality of life during his illness. As for the future, by refusing freezing of his sperm, the boy is potentially prevented from procreating. Sperm donation and freezing is a relatively simple and safe procedure which however made the parents feel uneasy and required them to share the information they have been given with their child. They derive their right to refuse from the religious authority their rabbis represent. The question arises as to whether the boy's subordination to his parents - in this specific case - is in his best interest.

Another relevant issue tends to the same conclusion. The parents report that their son has agreed to abide by his parents' wishes and guidance - presumably either without knowing or having been misled as to the implications of his illness. If the child has indeed chosen not to know there is a clash between his best interest and his right not to know and in such cases the decisive weight is given to his best interest.

The Nurse's Role

The medical staff's role is to bring the parents to acknowledge their child's rights over his present and future. Within the hospital team nurses have the right to autonomy of judgement and decision and in conflicted situations, such as the one described here, they have specific roles to fill. But these roles must be performed within an institutional context and within a multidisciplinary team of doctors, nurses, social workers and other carers. The nurse is required to behave rationally and professionally so that patients benefit optimally from her decisions. As in every service profession, the nurses' first duty is not to cause harm or allow harm to be caused by others.

Nursing can solve problems only within an inter-disciplinary framework of mutual dependence. In a case like that presented in this paper, doctor, nurse, social worker, psychologist, rabbi and legal advisor are all involved. In such a scenario, one role of the nurse is to act as the coordinator between all these care-givers, act as case manager and keep the balance between the physicians' and parents' authority and minor's best interest.

The nurse's particular position gives her more opportunity than others to play a mediating, coordinating role between all parties. In a conflict situation as described here, when informed consent is not forthcoming, Case (1988) stresses the nurse's important role in working for an alternative decision.

The nurse can help the parents understand the situation; ensure they appreciate the consequences - positive and negative, short-term and long-term - of their decisions and actions; and show them what parental obligation is and is not and how to give the child the information he ought to have. The nurses is able to take the time to sit with the parents and set out in detail the context and consequences of their choices and of the alternative choices, and assist them to a rational decision (Rotenberg 1988). The nurses' role is to identify where information is needed and help the parents express their needs and wishes to the medical staff.

Another role of the nurse is that of 'patient advocate', professionally assessing a patient's maturity and competence to understand and cope with hard decisions and then defend their autonomy against the authority of physicians and parents.

The nurse owes a duty also to her profession's own code of ethics. In Israel this code makes no mention of the patient's age: in other words, to adults and minors alike the nurse owes the same duty to give the best possible care and show respect for the patient's rights and dignity (Israel Nurses Association 1994). In such problematical, complicated situations as outlined in this case study, the nurse is expected to modify her response as she evaluates the inputs from all the many participants. This decision-making duty is a key element of her emotional and behavioural burden. Situations and disputes like the one described here are bound to be stressful and the nurse has a first choice to make between two opposing modes of action, to accept others' decisions or to intervene to modify them. Clearly, the authors consider the nurse has a duty to intervene.

There is great importance in the socialisation of nursing to this role of mediating and balancing between the parties and it is a role requiring special training and understanding to help cope with the resulting clash and stress. Clash of interest and worldview between the professionals, the child patient and the alternative decision-maker have been mentioned (Rushton 1993). Another clash may occur between the nurse's obligations toward the patient and her loyalty to the physician.

The authors offer the following work sheet to help nurses cope in such situations:

The Central Issue	**Telling the truth to a minor - his right to make a free choice.**
The Specific Problem	Telling the truth to an adolescent before performing experimental treatment, going against the parent's demands to withhold information from their son and their opposition to freezing his sperm.
Nurses' Beliefs	Personal belief - a 15-year-old boy in today's society has the capacity to understand and it is his right to be part of the decision-making process over his body. He must be part of the informed consent process together with his parents. Professional belief (nurses' ethical code) - "The patient has the right to receive information concerning the diagnosis, the treatment and its consequences, including the risks, the chances of success, and alternative treatments." Creating a basis for informed consent is one element in the quality of care.
Patient's Free Choice	The patient has the right to reject experimental treatment and is free to make decisions concerning all aspects of his treatment.
Alternative courses of action for nurses in this case	1. Withhold information; 2. Reveal true information about the treatment; 3. Limit the parents' authority: decide according to the child's best present and future interest; 4. Appeal to the courts against the parent's authority; 5. Weigh the child's best interest against his rights.
Decision	Give the child true information for his best interest and in order to obtain his consent to donate sperm for freezing; Set up an interdisciplinary team to work with the parents and secure their cooperation.
Points for discussion	Children's rights, child's best interest, protecting the child.

CONCLUSIONS

When Israeli nurses are confronted with a complex ethical dilemma their usual practice is to meet together and use a problem-solving model to try to reach a solution. They set out the problem and, making explicit the distinctions between their personal and professional codes, suggest a range of possible solutions. Each suggestion is analysed for its advantages and disadvantages. After general discussion the best option is chosen for action and the relevant physicians are informed of the nurses' choice. At the end of such a decision-making process the nurses usually try to generalise from the particular dilemma so the results of their discussion can serve them in similar future difficulties. In the specific case reported here, the problem-solving model brought the nurses to the conclusion they should try to persuade the boy's parents to bring their rabbi to discuss the case with the head of the Paediatric Oncology department.

RECOMMENDATIONS

Nurses need to learn and develop the skills needed in obtaining informed consent, in removing obstacles, resolving conflicts and building up understanding.

The nurse's advocacy role should be promoted by devising and applying systematic decision-making protocols and by making the appropriate modifications to the nurse training syllabus and professional ethics. To achieve this end, nurses need to be appropriately represented on local ethics committees and nursing-policy-making bodies.

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