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# 37 paediatric and adolescent cases discussed in a clinical ethics committee

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## MEDICAL ETHICS

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Cases concerning children and adolescents are brought before clinical ethics committees when healthcare personnel find the value choices they face to be particularly challenging. In this article, we describe experiences from discussions of 37 such cases in a clinical ethics committee at

a hospital over a ten-year period. Restricting life-prolonging treatment, patient and parent autonomy, the best interests of the child principle, and disagreement about decisions were all key topics of discussion.

A growing emphasis on patient autonomy has led to an increased complexity in many issues relating to paediatric and adolescent medicine. Parents are tasked with managing their child's needs because they are assumed to have the child's best interests at heart (1). When this is called into question, healthcare personnel have a statutory duty to protect the child's safety and rights (2). This can present challenges and lead to conflicts.

All Norwegian health trusts have clinical ethics committees to help patients, families and practitioners navigate a path towards ethically acceptable decisions (3). The main purpose of prospective discussions in such a committee is to contribute to a good decision-making process in which the doctor has ultimate responsibility for medical decisions. An ethically sound decision must always be based on the patient's perspective and interests. Many committees therefore include a patient representative (4), and some invite the patient or one of their family members to be present during prospective discussions on matters that relate to the patient (5).

Given that the committees are in a position to influence medical decisions, it is important to describe how they deal with complex issues (6). We reviewed all the paediatric and adolescent cases that were processed by a clinical ethics committee at a university hospital over the ten-year period 2006–2015. The aim was to identify which cases had been ethically challenging and to form a picture of how the committee worked.

## Method

The hospital served by this clinical ethics committee previously consisted of two hospitals with national functions in several complex and rare paediatric and adolescent diseases. Since 2006, the hospitals have had one committee with +/- 12 members representing different categories of healthcare personnel and employees. The secretary and chair of the committee hold part-time positions. The discussion of a case starts with a presentation of the facts in the case, followed by a discussion on aspects related to ethics and values. After the discussion, the secretary prepares a report, which is initially reviewed by the chair followed by all the meeting participants until a final version is ready. The reports are stored on a secure server and do not contain any names or personal identification numbers.

Full transcripts of all cases involving patients under the age of 18 in the period 2006–2015 were reviewed by the authors individually. Both were committee members during the period of the study; one was a chairperson and the other was an external ethics consultant. The following information was noted: patients' age and sex, the stated ethical dilemma, whether the patients' parents and/or other family members had been invited and/or were present during the committee discussion, what advice or analyses the committee had provided, as well as other comments that appeared relevant to understanding the case and the discussion.

After an initial independent review of the reports, the authors discussed differences in interpretation. After six months, we repeated this procedure and clarified necessary adjustments.

## Findings

We identified 37 paediatric and adolescent cases, which corresponds to around 60 % of the cases discussed in our committee during the decade in question. All but two of the discussions were prospective, meaning that they took place before final decisions on treatment were made. Three cases were discussed as anonymous cases of principle. The 37 cases were discussed in 40 meetings. Fourteen of the patients were less than one year old (37.8 %), but only three were infants younger than three months. Nine children/adolescents were over the age of ten (24 %). Twenty-three (62.2 %) of the patients were boys. In 13 cases (35.1 %), one or both parents were not of Norwegian ethnicity. Five cases were referred from other hospitals.

#### DISAGREEMENT ABOUT THE DECISION

In 22 cases (63 %), there was disagreement about the best choice of action, either between healthcare personnel and the parents (16 cases) or internally among the staff (6 cases). In 27/40 (67.5 %) of the discussions, the parents were invited to take part in the committee meeting. Four of these did not wish to participate, however the committee chair spoke to two before the meetings and one couple agreed to be represented by a trusted nurse. In the 23 discussions with parental participation, one or both parents were present, and additional accompanying persons were also in attendance at five of these meetings.

The dominant theme at the meetings (35/40) was restriction of treatment, mainly in relation to questions about a shift of focus from intensive care to palliative care. The conflicts between parents and healthcare staff were linked to this. In most such cases, the parents refused to accept restriction of life-prolonging treatment. However, in three cases, the parents rejected life-prolonging treatment that the medical team believed would be in the best interest of the child.

Autonomy was an important theme in seven of the cases. Relevant issues were therefore the restricting of parents' exercising of autonomy and the emphasis on and respect for adolescents' increasing autonomy rights. In only one of the cases concerning autonomy did the committee advise the practitioners to overrule parental autonomy in order to treat a child under the best interests of the child principle (7). The committee supported the parents' right to refuse the proposed treatment in one case and to withdraw ongoing treatment in another. In two other cases, the committee advised against applying pressure or coercion to treat the adolescents against their will. One patient was over the age of 16 and thus legally entitled to exercise his/her autonomy. The second young patient was in the age group 10–12 years. Administering treatment would have been met with strong resistance and would probably not have been possible without extensive coercive measures. The prognosis and expected treatment outcome were extremely poor for both patients.

The main theme in four discussions was the child's best interests based on a risk-benefit assessment. Two discussions focused on whether experimental interventions were permissible for patients with incurable diseases when no other treatment was available, while one case involved the use of coercion to administer treatment.

#### DISCUSSION OUTCOMES

In 21 of the 35 prospective cases, agreement was reached and the committee's conclusion with regard to further processing was upheld. In 11 discussions, no common understanding was agreed between the parents and the practitioners. In one of these cases, the committee's analysis was subsequently supported by court rulings. In another case, the committee's assessment was upheld despite the parents' dissent. We do not have verified information about the outcome of six cases.

## Discussion

Advanced medical treatment of children and adolescents entails challenging ethical dilemmas, including issues relating to the best interests of the child, the wishes and hopes of the child/their parents, and the healthcare personnel's opinions on what constitutes professionally sound and compassionate treatment. Setting limits for treatment is a challenge, and the growing emphasis on patient autonomy has not made it easier. Garnering the views of parties who are not directly involved with the treatment, such as a clinical ethics committee, is sometimes considered useful.

In the study period, 60 % of the cases affected children and adolescents, the same as in a previous ten-year period at one of the two merged hospitals (8). Only one in every four beds at the hospital are allocated to children and adolescents. These cases are therefore overrepresented in the committee. Findings in other studies vary; while some find high numbers of paediatric and adolescent cases in clinical ethics committees (8), others find the opposite (9,10).

There is evidence to suggest that medical personnel who face ethical dilemmas view newborn babies differently to how they view older children and adults (11). This seems to be the case regardless of culture, politics or religion (11). One explanation for only three infants below the age of three months being discussed by the committee may be that fewer conflicts arose in relation to these patients because practitioners take more notice of parents' views on the treatment of young babies. Local factors, such as the clinical ethics competence of staff, may contribute to the varying levels of paediatric cases dealt with by the committees and also to differences in the age distribution of cases (12).

The boys were in the majority in the cases discussed (62 %). This cannot be attributed to culture or ethnicity since the gender balance was the same for children and adolescents of foreign-born parents as for those with parents born in Norway. In other studies of gender in paediatric cases in committees, three out of four found an overrepresentation of boys, but this was not as pronounced as in our findings (13,10).

Our committee has more experience than most with involving patients and/or their families directly in meetings (5). Everyone who is invited to such meetings receives written information in advance. The parents' presence in the discussions adds an important dimension to the committee's understanding and gives patients' families a direct insight into the ethical arguments. Medical facts often come to the fore that may not have been understood by the families, or sometimes not even conveyed to them (14). In an interview survey of ten parents who attended such meetings, all parents agreed that it had been important for them to be present, and no one felt that participation had been too much of a burden (14).

There seems to be a lack of literature on patient/families' participation in committee meetings, and indeed the practice is sometimes considered controversial (10,15,16). In some cases, the primary need is to clarify the basis for disagreement among the staff, as in six of our cases. It may therefore be appropriate to deal with this first, before considering involving the parents. However, if a committee discussion plays a role in changing the treatment goal, we believe that participation gives parents better insight and understanding, while transparency enhances mutual trust (14). In general, our experience over the years is that having the parents present in the discussions gives the committee members a better opportunity to get to know the child as an individual and to learn about the situation from the family's perspective (5).

There are advantages and disadvantages attached to families bringing someone for support to a meeting. Those who feel insecure can find strength in the presence of someone they trust. Sometimes the person supporting the family is there to champion a particular solution, which can be even more apparent when the family brings a lawyer. This can prevent them from viewing the case from more than one perspective – a basic essential for ethical discussion – thereby escalating the conflict.

In an earlier review by the same committee, approximately one-third of the cases were retrospective (8), whereas only two of 37 cases were retrospective in the latest study. This may indicate that the committees are increasingly being perceived as an aid in ongoing cases, and that the content of the discussions can be used in the decision-making process. The majority of the discussions concerned restricting life-prolonging treatment, in line with findings in several other studies (9,10,17,18). 'Giving up' seems to be increasingly unacceptable, not only for the patients and their families, but sometimes also for healthcare personnel. Restricting treatment may seem particularly difficult to accept in Norway, where resources are sometimes regarded as unlimited. It is therefore not surprising that disagreements arose between parents and practitioners in almost half of the paediatric and adolescent cases concerning restriction of treatment. Disagreement is a common reason for consulting the committees (2,13,15,16,19)(19–21). Although most disagreements concerned parents arguing to continue active treatment, there were also cases where the parents rejected treatment, with potentially serious consequences for the children. Such cases are particularly challenging for healthcare personnel. In some cases, there was no real disagreement, but a large degree of uncertainty among practitioners and parents alike about what was the best solution from an ethical perspective. In such cases, the committee was able to contribute to a structured discussion on values and ethics without necessarily giving clear advice.

There may be different views on whether a committee discussion should aim for a consensus (10,16,22). We argue that agreement is primarily of value if it is the result of an open exchange of views where divergent opinions are welcome. Ethical dilemmas can and should always be considered from more than one perspective. It is then the committee's task to throw light on these views and explain the ethical (and moral) values they represent. Choosing between these values is not something that the committee does in isolation, it also involves a respectful dialogue between the patient and/or their representative together with the doctor responsible for the patient's care and other healthcare personnel.

Our study has strengths and weaknesses. Both authors have been members of this committee throughout the period under review and thus had a good insight into all of the cases. This may also have limited the possibilities for considering new perspectives. However, carrying out two separate reviews of the data six months apart ought to have provided an opportunity for more perspectives to emerge. The patients are not representative of a general Norwegian hospital population due to the special role that the hospital in the study plays in the Norwegian public health service. Nevertheless, there is reason to believe that the issues raised are also relevant at other hospitals.

## CONCLUSION

Paediatric and adolescent cases formed the bulk of the cases in our clinical ethics committee at a national referral hospital. Most cases concerned the restriction or withdrawal of treatment, and particularly life-prolonging treatment. Parental involvement in committee meetings ensures that the focus is on the patient as an individual and not solely on ethical issues. Parents gain an insight into the ethical arguments and can express how they view the situation. A discussion in the committee can lead to a consensus in many cases, but even in cases where no agreement is reached, a discussion can provide clarification by making choices and values clearer and more understandable.

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