

The ethics of withdrawal of care and limitation of care in children – a statement of the principles that should guide decisions

Joint statement of the Ethics Group of the European Academy of Paediatrics

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Abstract: The decision to withhold or withdraw care from a child can be one of the most difficult, emotionally and ethically, made by a paediatrician. There is little literature available that can guide us through the considerations that need to be addressed, especially as our society becomes increasingly multicultural. The ethics group of the European Academy of Paediatrics comprises paediatricians from across Europe, many with years of experience in developing ethical frameworks in their own countries. This group has compiled a statement of principles that is intended to act as a guide to colleagues faced with these complex decisions.

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Introduction

In 2001 the ethics working group of the Confederation of the European Specialists of Paediatrics (CESP), itself the predecessor of the European Academy of Paediatrics (EAP), published a statement concerning the withholding or withdrawing of life support in children¹. It is now almost 10 years since that work was undertaken, and November 2010 marks the 21st anniversary of the UN adoption of the 'Convention on the Rights of the Child'²; it therefore seems an appropriate time to review the recommendations made.

The key purpose of this document is to acknowledge suffering in children, and recognise that such suffering may exceed any future prospects that can be envisaged for that child. In such a situation, the duty of those caring for the child is to consider whether palliative support should take precedence over therapeutic intervention. Sometimes that discussion may be very acute, and continuing care may be considered futile or unbearable. In others, the prognosis may be more long term and so much more difficult to predict. In such cases the balance of opinion may need to be more cautious. In many circumstances these decisions should be undertaken as part of a comprehensive discussion about end of life planning³.

In recognising this the original statement emphasised the obligation of a paediatrician to protect the dignity of a dying child, and set out 12 specific guidelines for those involved in such situations. Since then there have been a number of publications looking at this issue in both adult and paediatric or neonatal practice⁴⁻⁹.

These have all emphasised the importance of a multi-disciplinary approach to such discussions, and the involvement of families and patients in any

discussions, but they have also emphasised the differences in attitude that still exist between different communities. These differences vary from practical issues of how different professional and carers are actively involved^{9,10} to issues such as the active hastening of death in severely ill neonates¹¹. There are also substantial legal and cultural differences between countries and communities and in the way in which they approach death, particularly when that involves a child. In such circumstances it would be inappropriate to set out detailed guidelines on how such situations should be handled. Rather, we believe that all paediatricians are able to (and should) advocate on behalf of their patients, and that the ethical foundations for the care of such children contain many commonly shared principles that can be made explicit.

In this position statement, we have set out those principles that underpin our approach to the setting of therapeutic limits.

Fundamental Principles^{9,12}

Partnership of Care. Granted the compelling presumption in favour of life, there is a general duty of care with the primary intention of sustaining life and restoring patients to health. Whether or not a child can be restored to health, there is an absolute duty to comfort and to cherish that child and to prevent pain and suffering.

Healthcare professionals and parents therefore form a partnership, whose function is to serve the best interests of the child. This also involves respecting the wishes and views of the child in the light of their knowledge, understanding and experience. Children should participate as fully as possible in decision making, but the age at which maturity permits such involvement is very variable.

Respect for Children's Rights The United Nations

Convention on the Rights of the Child (1989)², sets out fundamental principles which govern how children should be treated. These affirm the right of a child to the highest obtainable standards of health (article 24), the right to receive and express information (article 13), to have those views given weight (article 12) and to have their 'best interests' as a primary consideration (article 3).

Axioms on which to base practice

From these fundamental principles flow a number of general axioms which may govern practice. These are:

The duty of care is not an absolute duty to preserve life by all means. There is no obligation to provide life sustaining treatment if the benefits of that treatment no longer outweigh the burden to the patient.

Optimal ethical decision-making concerning children requires open and timely communication between healthcare professionals and the child and family, respecting their values and beliefs.

The wishes of a child who has obtained sufficient understanding and experience in the evaluation of treatment options should be given substantial consideration in the decision making process. The antecedent wishes and preferences of the child, if known, should also carry considerable weight given that conditions at the time for action match those envisaged in advance.

A competent child is ethically able to refuse life sustaining although this would generally be expected to occur in the context of a wider agreement about that child's 'best interests'.

Parents may ethically decide on behalf of children who are unable, for whatever reason, to express preferences, unless they are clearly acting against the child's best interest or are unable, unwilling or persistently unavailable to make decisions on behalf of their child.

In general, resolution of disagreement should be by discussion, consultation and consensus.

Changing the emphasis of care from life sustaining treatment to palliation can be entirely consistent with the best interests of a patient.

The withdrawal of procedures designed to alleviate pain or promote comfort should only ever be undertaken at the express and rational direction of the child.

It follows that use of medication and other treatments which may incidentally hasten death may be justified if their primary aim is to relieve suffering.

The importance of language

Discussions about limiting care frequently occur at a time of great stress for the family. The importance of introducing discussion about end of life issues needs to be balanced by an awareness of the effect of that discussion on families.

Limiting care should never imply lack of care.

Language used by staff must emphasise the balance between 'cure' and 'care' for a patient. Phrases such as withdrawing or withholding care may be taken to imply that a patient will be left without any support.

All those involved in a decision on care limitation need to have a clear understanding of the details of that decision, which should be recorded in the notes and copied to the carers. In particular there should be clarity over what supportive care will be offered (eg oxygen, suction, analgesia). This recognises that every such decision is individual and specific to the patient concerned^{13,14}. In some units, the phrase Do Not Resuscitate (DNR) has been considered too blunt and the use of alternative phrases (such as Allowing a Natural Death (AND)) have been proposed¹⁵.

Decisions often vary with time, and may need to be rediscussed at intervals. Decisions made at a time of acute illness may be reconsidered after recovery, and the environment (eg hospital, respite care, home) may also influence decisions. These changes in opinion and plan are entirely acceptable and appropriate, but must be explicit and documented.

Training staff to handle end of life discussions is essential. At present such training is limited and mostly experiential¹⁶. New methods to teach ethical issues to healthcare professionals may need to be developed (R Ross Russell, personal communication).

In some institutions, clinical ethical committees exist who can offer advice. There is some data to support this approach^{17,18}, but there is a lack of evidence about their effectiveness¹⁹.

Dealing with conflict

Despite best intentions, it is inevitable in such emotional situations that disagreements can arise²⁰. Such issues may involve those directly associated with the child, or at some distance, such as spiritual leaders or senior family members. It is important that clinicians have established a procedure to deal with such situations and that this is in place prior to discussions. On some occasions there may also be conflict between two carers. It is important that engagement with all such parties occurs, and that attempts are made at a consensus. Previous studies have shown that disagreement between clinicians and parents is the most common issue and usually relates to problems with spiritual beliefs or communication²¹, although within-team conflict (usually about the accuracy of the prognosis) may also occur^{18,21}. They may be resolved by facilitated discussion, by external independent opinion or by time^{9,22}. External opinion may be from independent professionals, from mediators or from clinical ethical committees⁹. It is important that every effort is made to avoid bias in the decision making, and that all areas of uncertainty are clearly and openly debated²³. As a last resort legal opinion may be necessary. However it is rarely important that

decisions are made quickly, and a period of time that allows a family to reflect on the advice they have been given is frequently beneficial.

Bereavement support

There is some evidence to suggest that continued support beyond the point of death can be beneficial to families²³. Where possible, opportunities for families to meet trained staff to discuss any issues that may still concern them should be arranged. Recommendations for the structure of such meetings have been published²⁴.

Summary

Dealing with major clinical decisions, when those decisions involve the possible death of a child, is an emotional and difficult time. It can be easy to allow one's passion to obscure good decision making, but equally easy to lose one's sensitivity to a situation in trying to reach objective decisions. We offer these principles that we believe are generic to all the major cultural and religious groups, and hope that they may guide clinicians and carers in this difficult area.

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