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Partnerships with children

Mary Dixon-Woods, Bridget Young, David Heney

Earlier this year a 15 year old girl had her decision to refuse a heart transplant overruled by the High Court, highlighting the issue of partnership with children. The case is the latest of several9 that have shown how children’s participation in decision making and recognizing their autonomy and rationality4 can conflict with the need to protect them from making decisions that are not in their long term interests.3

Court cases dramatically show the problems of involving children in decision making, but they tend to deal with extreme and unusual examples and have led to uncertainty and anxiety about routinely involving children in decision making. Away from the courts a movement is growing to promote children’s rights. Proponents have argued from a position of moral obligation and have called for a code of practice which would emphasise children’s rights to information, to express views, and to give or withhold consent provided the child is considered competent by a doctor.2 Professional bodies and others concerned with children’s wellbeing seem to have accepted many of these principles,4,10 which are based on ethical and moral principles of autonomy, free will, choice, and compassion and have the laudable aim of allowing children’s opinions to be voiced, heard, and acted on wherever possible.

However, the evidence suggests that partnership with children enjoys only limited success. Children are given little voice in medical consultations11 and are rarely consulted as partners in the evaluation and planning of health services.12 13 The aspirations of the children’s rights movement will have little chance of being realised until there is more research based evidence about the outcomes of shared decision making, how the competence of children can be assessed, how information can be shared with children, and how shared decision making should be managed in practice.

Outcomes

An important source of resistance to extending the ideals of patient partnership to children is lack of good evidence about the outcomes. Clinicians, parents, and others need to be reassured about the effect on children’s wellbeing and about issues such as how families, perhaps with the benefit of hindsight, assign responsibility for “wrong” decisions. In assessing the outcomes of partnership, it is vital to include children’s perspectives and to be sensitive to how these may change as children develop. Recent developments in methods for assessing child based outcomes have been encouraging. For example, measures of quality of life in children have begun to move away from using parents as proxies and treating children of all ages as having the same concerns. Instead they ask children directly for their views and are developmentally sensitive.14 The recent use of qualitative approaches is also hopeful.15 Use of these developments for longitudinal assessment of outcomes of different forms of shared decision making should be a research priority.

Competence

A key anxiety in creating partnerships with children is uncertainty about children’s competence and how it
can be assessed in different ages and abilities. Despite
the suggestion that children should be assumed to be
competent unless demonstrably incompetent,8 it is
easy to assume that children are competent only if they
make the decisions doctors want them to make. The
children's rights movement might see this as paternal-
ism, but it also reflects the fact that our knowledge of
children's ability to understand and act on medical
information is incomplete. Better understanding of
children's conceptualisation of health and illness would
help to resolve some of the legal and ethical debates
about whether children of different ages and
intellectual abilities can give informed consent.

Traditionally, however, research into children's
ideas about health and illness has been dominated by
an overly rigid Piagetian perspective.16 Recent work
using methods such as "draw and write" has broadened
its focus and begun to demonstrate children's conceptu-
alisations more aptly.17 These methods need to be
used more extensively to study ill children, whose
experiences may facilitate the development of competen-
cies beyond their chronological age. More appro-
priate methods also need to be developed for
investigating older children and adolescents, perhaps
using in depth interviews. Another priority is better
methods for assessing the competence of children of
different intellectual abilities, including those who have
learning disabilities. These methods should be useful in
clinical settings as well as research projects.

Providing information
Children's ability to participate competently in
decision making and give informed consent might be
improved by well designed information materials.
Although excellent examples do exist, many materials
are directed at parents or do not take account of the
different needs of different ages. The development of
new materials to support evidence based choice by
children is hampered by fundamental problems with
the quality of the evidence about many common
paediatric interventions.7 There is also a scarcity of evi-
dence about how to design information materials for
children. How far methods for evaluating adult materi-
als, such as the DISCERN instrument,18 apply to
children of different ages and intellectual abilities
needs to be determined. The newly established
National Institute for Clinical Excellence and the
Centre for Health Information Quality could have a
role in this.

Managing the consultation
A further barrier to creating partnerships with
children is uncertainty about how to manage shared
decision making in the context of a complex
relationship involving not only the doctor and child
but also parents, other family members, and a range of
healthcare professionals. The process of decision mak-
ing may raise many sources of potential conflict. Shift-
ing coalitions and complex forms of role switching
may occur, professional-child alliances might under-
mine the parent-child relationship, and there is a risk
that shared decision making could be mistakenly seen
as sanctioning the delegation of responsibility to
children. Moreover, children of different ages require
very different forms of partnership and different kinds
of support for those partnerships.

Examples of shared decision making in child
health can be found, but the rules that govern them
need to be explicit and formalised, perhaps through
empirical observation and analysis by social scientists.
These rules need to be complemented by more sophisti-
cated theory on issues around responsibility for
decision making in situations involving children. In
particular ideas around the role of "agency," in which
children, parents, and professionals might all delegate
responsibility to an informed agent, need to be
developed. Models for including children in decision
making need to move away from individually based
models towards collective models and to recognise that
situations involving children require a family oriented
perspective.

Conclusion
Patient partnership may benefit children and should
ideally include participation in the planning and evalu-
ation of health services and in planning research agen-
das as well as participation in decision making.
However, children have special needs and we owe a
duty of protection to them. Systems need to be put in
place to support partnership, including information materials. Perhaps more urgently, research is needed to show the effect of involving children in decisions and to indicate how partnership can be managed in practice.

We thank Professor Mike Silverman for comments on earlier drafts of this paper.

1 Dyer C. English teenager given heart transplant against her will. BMJ 1999;319:209.
2 Lansdown R. Listening to children: have we gone too far (or not far enough)? JR Soc Med 1998;91:457-61.
18 wwwdiscern.org.uk (Accepted 11 August 1999)

What do we mean by partnership in making decisions about treatment?

Cathy Charles, Tim Whelan, Amiram Gafni

For many decades, the dominant approach to making decisions about treatment in the medical encounter has been one of paternalism. In recent years this model has been challenged by doctors, patients, medical ethicists, and researchers who advocate more of a partnership relation between doctors and patients. The reasons for this challenge have been described in detail elsewhere and include the rise of consumerism and the notion of consumer sovereignty in healthcare decision making; the women’s movement with its emphasis on challenging medical authority; the passage of legislation focusing on patients’ rights in healthcare; and small area variations in doctors’ practice patterns that seem unrelated to differences in health status. Though the first three factors are seen as either contributors to or facilitators of patients’ participation in making decisions about health care, the fourth highlights the imprecision or the “art” of medical care, patients with similar clinical problems may receive different treatments from different doctors, due in part to systematic variations in practice patterns across geographical areas.

The call for doctor-patient partnerships opens up options beyond paternalism for approaching the task of making decisions about treatment. But it also raises new complexities. Because a partnership between patient and doctor can take different forms, it is not intuitively apparent what this model would look like. The Oxford English Dictionary (1995) defines a partner as “a person who shares or takes part with another or others.” This definition leaves several important questions unanswered. For example, does the concept of a partnership imply that both doctor and patient need to share all parts of the decision making process? What is it that both parties are sharing, and to what degree? Who is responsible for determining if a partnership is possible and for initiating the first steps?

Summary points

Doctor-patient partnerships in making decisions about treatment can take different forms

Three theoretical treatment decision making models are the paternalistic, the shared, and the informed

Most clinical consultations use elements of these theoretical models, and these may change as the interaction unfolds

Doctors need to be aware of and be able to identify and explain the treatment options available

If doctor-patient partnerships are to be promoted in clinical practice, current disincentives such as time and funding constraints will need to be restructured

Is there room for variation in patients’ and doctors’ roles while still retaining the concept of a partnership? What are the clinical contexts within which a doctor-patient partnership is most needed? Drawing on our earlier conceptual papers, this article identifies and describes different types of partnerships that can be developed between a doctor and patient in the context of making decisions about treatment.

Theoretical models

In the figure, treatment decision making is broken down into different analytical steps or stages (though in