

- 18 Freeman WL. The role of community in research with stored tissue samples. In: Weir R, ed. *Stored tissue samples: ethical, legal, and public policy implications*. Iowa City, IA: University Iowa Press, 1998.
- 19 National Health and Medical Research Council of Australia. *Guidelines on ethical matters in Aboriginal and Torres Strait Islander health research*. Canberra: NHMRC, 1991. (found at www.health.gov.au/nhmrc/ethics/astipdf)
- 20 Medical Research Council (MRC), Natural Science and Engineering Research Council (NSERC), Social Sciences and Humanities Research Council (SSHRC). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Ottawa: Public Works and Government Services Canada; 1998. (www.mrc.gc.ca/ethics/english/index.htm)
- 21 Association of Canadian Universities for Northern Studies. *Ethical principles for the conduct of research in the north*. Ottawa: ACUNS, 1997. (www.yukoncollege.yk.ca/~agraham/ethics.htm)
- 22 American Indian Law Center. *Model tribal research code*. 3rd ed. Albuquerque: American Indian Law Center, 1994. (www.ihs.gov/NonMedicalPrograms/Research/irb.htm)
- 23 Wax M. The ethics of research in American Indian communities. *American Indian Q* 1991;15:431-56.
- 24 Willms D, Singer SM, Adrien A, Godin G, Maticka-Tyndale E, Cappon P. Participatory aspects in the qualitative research design of phase II of the ethnocultural communities facing AIDS study. *Can J Public Health* 1996;87(suppl 1):S15-32.
- 25 Entwistle VA, Renfrew MJ, Yearley S, Forrester J, Lamont T. Lay perspectives: advantages for health research. *BMJ* 1998;316:463-6.
- 26 Quigley V, Sanchez V, Handy D, Goble R, George P. The success of participatory research strategies in nuclear risk management for Native communities. *J Health Communication* (in press).
- 27 Daniel M, Green LW, Marion SA, Gamble D, Herbert CP, Hertzman C, et al. Effectiveness of community-directed diabetes prevention and control in a rural Aboriginal population in British Columbia, Canada. *Soc Sci Med* 1999;48:815-32.
- 28 Fisher B, Neve H, Heritage Z. Community development, user involvement, and primary health care. *BMJ* 1999;318:749-50. (Accepted 19 August 1999)

Partnerships with children

Mary Dixon-Woods, Bridget Young, David Heney

Department of Epidemiology and Public Health, Faculty of Medicine and Biological Sciences, University of Leicester, Leicester LE1 6TP
Mary Dixon-Woods
lecturer in health policy

Bridget Young
lecturer in health psychology
Children's Hospital, Leicester Royal Infirmary NHS Trust, Leicester LE1 5WW

David Heney
senior lecturer in paediatric oncology
Correspondence to: M Dixon-Woods
md11@le.ac.uk

BMJ 1999;319:778-80

Earlier this year a 15 year old girl had her decision to refuse a heart transplant overruled by the High Court,¹ highlighting the issue of partnership with children. The case is the latest of several² that have shown how children's participation in decision making and recognising their autonomy and rationality^{3,4} can conflict with the need to protect them from making decisions that are not in their long term interests.⁵

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.⁶ Professional bodies and others concerned with children's wellbeing seem to have accepted many of these principles,⁷⁻¹⁰ 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 consultations^{8,11} 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

Summary points

Child partnerships have been debated largely in the context of discussions about children's rights or high profile court decisions

Many obstacles to forging partnerships with children could be overcome with better evidence from research

Parents, health professionals, and others need good quality evidence to reassure them that partnership with children will not produce adverse effects in the long term and to guide them about how to manage partnership

Evaluation of outcomes of childhood interventions needs encouragement from government bodies together with promotion of quality in information for children

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,⁶ 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 paternalism, 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 conceptualisations more aptly.¹⁷ These methods need to be used more extensively to study ill children, whose experiences may facilitate the development of competencies beyond their chronological age. More appropriate 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 evidence about how to design information materials for children. How far methods for evaluating adult materials, 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 making may raise many sources of potential conflict. Shifting coalitions and complex forms of role switching may occur, professional-child alliances might undermine 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



Children's views should be included in assessing outcomes of health care. These paintings by a child with cancer show how effectively children can express their feelings

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 sophisticated 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 evaluation of health services and in planning research agendas 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)? *J R Soc Med* 1998;91:457-61.
- 3 Hart C, Chesson R. Children as consumers. *BMJ* 1988;316:1600-3.
- 4 Rylance G. Making decisions with children. *BMJ* 1996;312:794.
- 5 Ross LF. Health care decision-making by children. Is it in their best interest? *Hastings Cent Rep* 1997;27:41-5.
- 6 Alderson P, Montgomery J. *Health care choices: making decisions with children*. London: Institute for Public Policy Research, 1996.
- 7 United Nations. *Convention on the rights of the child*. Geneva: United Nations, 1989.
- 8 House of Commons Health Committee. *The specific needs of children and young people*. Vol 1. London: Stationery Office, 1997.

- 9 American Academy of Pediatrics, Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 1995;95:314-7.
- 10 Royal College of Paediatrics and Child Health. *A children's health service*. London: RCPCH, 1998.
- 11 Silverman D. *Communication and medical practice: social relations in the clinic*. London: Sage, 1987.
- 12 Mayall B. The changing context of childhood: children's perspectives on health care resources including services. In: Botting B, ed. *The health of our children. OPCS decennial supplement*. London: HMSO, 1995.
- 13 House of Commons Health Committee. *Hospital services for children and young people*. London: Stationery Office, 1997.
- 14 Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in children with asthma. *Qual Life Res* 1996;5:35-46.
- 15 Shucksmith J, Hendry LB. *Health issues and adolescents: growing up, speaking out*. London: Routledge, 1998.
- 16 Brewster AB. Chronically ill hospitalized children's concepts of their illness. *Pediatrics* 1982;69:355-62.
- 17 Oakley A, Bendelow G, Barnes J, Buchanan M, Husain OAN. Health and cancer prevention: knowledge and beliefs of children and young people. *BMJ* 1995;310:1029-33.
- 18 www.discern.org.uk

(Accepted 11 August 1999)

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

Cathy Charles, Tim Whelan, Amiram Gafni

Department of
Clinical
Epidemiology and
Biostatistics,
McMaster
University,
Hamilton, Ontario,
Canada L8N 3Z5

Cathy Charles
associate professor
Amiram Gafni
professor

Department of
Medicine, McMaster
University
Tim Whelan
associate professor

Correspondence to:
C Charles
charlesc@fhs.
mcmaster.ca

BMJ 1999;319:780-2

For many decades, the dominant approach to making decisions about treatment in the medical encounter has been one of paternalism.¹⁻⁷ 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.²⁻⁸⁻¹³ 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 health care; and small area variations in doctors' practice patterns that seem unrelated to differences in health status.⁷ 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 care¹⁴; patients with similar clinical problems may receive different treatments from different doctors, due in part to systematic variations in practice patterns across geographical areas.¹⁴⁻¹⁵

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,^{6,7} 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