Parental consent to publicity

Richard Barry Jones *Retired Paediatrician*

Abstract

The problems presented by the use of named child patients and their medical histories in television, radio and newspapers are discussed. It is suggested that it is not acceptable to regard this as comparable to their participation in non-therapeutic research, and that no one, not even the parent has the authority to give consent to such use.

(*Journal of Medical Ethics* 1999;25:379–381)

Keywords: Child patients; parental consent; television; radio; newspapers; publicity

In recent years it has become increasingly common for the medical details of individual, named patients to be discussed in the media. The reason may be associated with the welfare of the patient, for example to add urgency to an appeal for an organ donor, to publicise an advance in medical treatment, or, to publicise a particular hospital or unit, a reason likely to become more common as hospitals compete for patients and the associated revenue, or frankly as a source of entertainment. I was, for example, recently contacted by a researcher from a programme about unexplained mysteries and asked to give an opinion on the phone, without knowing anything about the patient, whether a miraculous unexplained restoration of sight could be explained on the basis that the original loss was hysterical. If the patient is a competent adult, and has given informed consent to the programme going ahead, there is presumably no ethical problem, although, even here, it is difficult to square this with the concept of doctor-patient confidentiality. However, if the patient is not competent, by virtue say, of being too young, or of being in a permanent vegetative state (PVS), the validity of parental consent must be questioned.

It is generally agreed that for children too young to give valid consent to medical treatment themselves, their carer, usually the parent, is able to give consent for them, although, as Alderson says, their views should be sought.¹ She points out that even children as young as five can understand the implications of very complex treatment². As Dickenson points out however,³ even following the Gillick judgment,⁴ parental consent can over-

ride the views of the child even if Gillick-competent, particularly if the child is refusing permission and the parents giving it, although this does not in the opinion of the Medical Defence Union require the doctor to act, but only empowers him or her to do so.⁵

There is less agreement on the validity of parental consent to allow children to be used as subjects in non-therapeutic research, which perhaps more closely resembles their use in publicity. Ramsey is quite unequivocal in stating that parental consent in such a situation is never valid, and quotes from his own book, *The Patient as Person*, in support of this: "To attempt to consent for a child to be made an experimental subject is to treat a child as not a child. It is to treat him as if he were an adult person who has consented to become a joint adventurer in the common cause of medical research. If the grounds for this are alleged to be the presumptive or implied consent of the child, that may simply be characterised as a violent and a false presumption."⁷ Since it is difficult to see how any of the above reasons save possibly the first, can be of personal benefit to the child, one could apply the same strictures to non-beneficial publicity. Ramsey does, however, explore an alternative. If it is imperative that the research be done, if medicine is to progress, and it can only be done on children, then it would be as immoral not to do the research as it would be to use children unable to consent, so that he suggests, the researcher must "sin bravely".⁷ If in the case of publicity, using the child makes it considerably more likely that a donor will be found, so that the child will live rather than die, then it could be argued that there is sufficient personal benefit to justify using the child. Would it be justified, however, to "sin bravely" if the result was not to benefit the child personally, but to publicise the unit and enhance its chance of survival for the benefit of others? Alternatively, it could be argued that by allowing programmes in which the treatment of children is shown, not only are the public made aware of good practice, but also the children are given a voice in a world from which they are, perhaps increasingly, excluded. I do not believe that either of these points is valid. Other ways can be found to publicise good practice, and children can have a

voice without confidential details about them being publicised without their proper consent.

McCormick,⁸ discussing non-therapeutic research on children, differentiates between research that carries no significant risk or discomfort to the child, and that which does carry significant risk or discomfort. He argues from a natural law position "that there are certain identifiable values that we ought to support, attempt to realise, and never directly suppress because they are definitive of our flourishing and wellbeing".⁹ He claims that non-therapeutic research with no significant risk is such a value, so that parental consent for the child to take part in it is valid because it is something the child ought, as a citizen, to do. Participation in research which carries a significant risk he sees as a supererogatory act of charity which no one is required to undertake, and therefore parental consent is not valid in this circumstance. The question is, do any of the reasons for using children in publicity constitute such values?

Three questions

It has been suggested that one way in which the dilemma could be resolved would be to treat publicity in the same way that research is treated. No research project, whether it involved children or not would be allowed to proceed until it had been considered by an ethics committee. Should, therefore, a request to use patients in publicity, particularly child patients, also have to be considered by such a committee? This suggestion raises three questions which need to be addressed. Is publicity ever of personal benefit to the patient? Is publicity ever of value to the community at large, either by enhancing their understanding of disease, or by enhancing their chances of themselves receiving treatment? Does such activity constitute an identifiable value in McCormick's sense, and even if it does, ought people to participate in it for that reason? Data on the first question would, I think, be hard to come by. It is becoming commonplace for prominent people in society, show business or sport, with the support of the treating hospital, to appeal for say, bone marrow donors to save the life of a named sick child, and they are often filmed with the child, but although potential donors may come forward as a result of this there is little evidence that this affects treatment in the individual child or that it increases the number of donors overall. Only if this evidence were available could the argument of personal gain be used, and publicity be seen as equivalent to non-therapeutic research.

Although it is possible that medical programmes do benefit society at large, since they have the potential to de-mystify medicine and

make it more accessible and less frightening, it is difficult to see why the participation of named identified patients is necessary to achieve this end other than to add a voyeuristic element which might encourage people to watch.

Obligations to society

Even if there is no personal benefit, is McCormick right in suggesting that a child, although not competent to give valid consent, has a duty to fulfil obligations to the society in which it lives? Ought she to take part in publicity, if it is agreed that there is such an obligation? Vandever, in the context of non-therapeutic research, suggests not, on the grounds that the child has not voluntarily partaken of the benefits of the research, so has no duty to contribute to it.¹⁰ An equally strong case could be made against participation in publicity. As Vandever states, the criterion must be the best interest of the child.

The assumption that everything that passes between doctor and patient during a consultation is confidential, and will only be divulged to a third party with the full permission of the patient is central to the doctor-patient relationship. In my opinion the use of patients in any form of medical publicity is a violation of that relationship unless full, informed and freely given consent is obtained. This cannot be obtained from a child who is not Gillick-competent, (although, a case could be made that one who is so competent, even technically still a minor could give such consent) and the evidence that the child derives personal benefit from the publicity comparable to the benefit of treatment may be too slim to warrant allowing parental consent. A telephone counsellor for one of the major medical defence organisations was unable to see why this situation should not be treated in the same way as any other disclosure of confidential medical information, say to a teacher to explain how a child's visual impairment might influence learning, for which parental consent would be valid. The answer might lie in the possibly apocryphal story of the woman who, while looking through one of her medical student daughter's books, found a full frontal naked photograph of herself as a child. Even if this did not actually occur, it could have, and the distress caused to the adult, could not justify her parental action in giving permission for the photograph to be used in the first place. How much more distress could be caused by publicity, not in the restricted medium of a technical book, but on the front page of a tabloid newspaper, or in a television programme, with its potential for later re-use? In my opinion, publication of medical details of children in the public media is an invasion of private

and a breach of confidentiality which no one, not even the child's parent, has the authority to permit unless the strongest possible case can be made that it is in the child's personal interest in that it will positively affect the outcome of her treatment.

Richard Barry Jones, FRCP, FRCOphth, FRCPCH, is a retired Consultant Paediatrician.

References

- 1 Alderson P. Out of the darkness. *Health Service Journal* 1991;Oct 3: 22-4.
- 2 Alderson P. In the genes or in the stars? Children's competence to consent. *Journal of Medical Ethics* 1992;18:119-24.
- 3 Dickenson D. Children's informed consent to treatment: is the law an ass? *Journal of Medical Ethics* 1994;20:205-6.
- 4 Gillick v West Norfolk & Wisbech AHA. 1985. 3 All ER 402-437.
- 5 Gilberthorpe J. *Consent to treatment*. London: The Medical Defence Union Ltd, 1997.
- 6 Ramsey P. The enforcement of morals: non-therapeutic research on children. *Hastings Center Report* 1976;6:21-30.
- 7 See reference 6: 21.
- 8 McCormick RS. Proxy consent in the experimentation situation. *Perspectives in Biology and Medicine* 1974;18:2-20.
- 9 See reference 8: 11
- 10 Vandever D. Experimentation on children and proxy consent. *The Journal of Medicine and Philosophy* 1981;6:81-93.

News and notes

Second World Congress of Philosophy and Medicine

The theme of the Second World Congress of Philosophy and Medicine is Human Healthcare - Sciences, Technologies, Values. The conference will take place in Cracow, Poland from August 24 - 26, 2000.

Abstracts should be sent and registration completed by February 1, 2000.

For more information please contact: Professor Doctor Henk ten Have, secretariat ESPMH, Department of Ethics, Philosophy and History of Medicine, Faculty of Medical Sciences, Catholic University of Nijmegen, PO Box 9101, 6500 HB Nijmegen, the Netherlands. Fax: 024 - 3540254; from abroad: ++ 31 - 24 - 3540254.

News and notes

Human Genetics and Bioethic Laws

The XVIth Conference of the European Association of Centres of Medical Ethics, entitled Human Genetics and Bioethic Laws, will be held in Marseille, France from the 14th to the 16th of October 1999.

For further information please contact: Professor J F Mattei-Cerem, Departement de Genetique Medicale, Hopital d'Enfants de la Timone - 13385 Marseille Cedex 5, France. Tel: 33(0)4 91 38 79 67; fax: 33 (0)4 91 49 41 94.