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## The role of patients in European clinical ethics consultation

Ainsley J Newson, Gerald Neitzke, Stella Reiter-Theil (2009)

Clinical ethics committees and consultation services have existed in many European countries for over two decades. Many different modes of operation have emerged, each reflecting a particular health and socio-political context.

As additional clinical ethics services become established, the role of patients and their relatives is attracting increased attention. In North America, patient involvement has been theoretically lauded and recommended by policy, but nevertheless is often neglected in practice.<sup>1</sup> In Europe, this issue has not yet received a great deal of attention, although the importance of listening to the patient's voice has been recognized for some time.<sup>2</sup> Despite this, patients have diverse involvement in European clinical ethics support. Patients or their relatives can, for example: be members of a clinical ethics committee; be notified when an ethics consultation is requested; or be involved in ethical deliberation to the same extent as clinicians.

At the 4th International Conference on Clinical Ethics and Consultation,<sup>3</sup> Professor Stella Reiter-Theil convened an expert panel to discuss: 'Whether and how to involve patients and relatives in clinical ethics support'. Panellists from across Europe<sup>4</sup> used the case in Box 1 to engage in a lively and interactive discussion on the different approaches to patient involvement in clinical ethics consultation.

### Box 1 A request for consultation by the husband of a 67-year-old patient

Mrs W has been on dialysis for 20 years. She had a kidney transplant eight years ago, but this failed a few years later. She has now been hospitalized for several months with an idiopathic abdominal infection not resolved by surgery. Her husband is dismayed at her lack of progress, stating: 'This was our last chance, now we know she is going to die'. Mrs W is conscious but very weak. She finds it hard to speak or move, is being fed via a nasogastric tube and is in pain. Mr W has informed the treatment team that his wife wishes to die, as she cannot tolerate further suffering. He is concerned that the clinicians are not listening to him, but they report that Mrs W appears to be consenting to their treatment. They state that Mrs W is grateful for the care they are giving but Mr W replies that his wife would never dare refuse treatment. She instead expects her husband to act as her advocate. Mr W approaches the clinical ethics service seeking help to execute his wife's wishes for withdrawal of treatment. The treatment team are worried that withdrawing dialysis would be tantamount to killing Mrs W on request.

Substantive issues notwithstanding, this case raises important issues about the nature and purpose of patient involvement in ethics consultation in Europe – not least of which is whether ethics consultation exists to benefit clinicians in their work, or to facilitate a more 'ethical' health-care environment for all. Questions arising include whether a referral should be taken from a relative and, if so, whether the (still-conscious) patient should be informed of or involved in this process. How real is the risk of misuse of ethics consultation by relatives? How should and could the risk of harm be minimized?

Our experiences of responding to requests for clinical ethics support from patients or their relatives suggest that the challenges arising are different from those in academic or inter-professional discourse. Specific skills and virtues of counselling are required that may be less familiar to clinical ethicists or even some health-care professionals. Training courses for ethics consultation confirm that we should not underestimate the importance of these skills and virtues, especially when ethics consultation is becoming more complex; often comprising consecutive conversations with different participants and in various settings.<sup>1</sup> This also impacts on how we handle confidentiality and consent as well as how we prioritize the goals and needs of those involved.

The specially commissioned papers in this issue provide an initial indication of the position on patient involvement in several European countries. It emerges that patients are involved in clinical ethics support and that the scale of this involvement varies. The purpose and context for according a role for patients is also different; in some settings this has been motivated by political developments and in others by moral considerations.

The papers have been written by members of the patient involvement working group of the European Clinical Ethics Network (ECEN). The ECEN was established in 2005 to bring together experts on clinical ethics to foster collaboration and dialogue. This informal network, whose membership comprises two nominated representatives from most European countries where clinical ethics consultation is available, meets twice a year to discuss a variety of issues including methods of deliberation and evaluation in ethics consultation.

One paper, 'Clinical ethics consultation in Europe: a comparative and ethical review of the role of patients',<sup>5</sup> compares the roles of patients in clinical ethics consultation, from notification, to access, to reporting and recording. Several differences are noted, which are then discussed against a background of the health-care and political context of each country. The authors conclude that despite these differences in approach, each institution is engaging in ethical reflection. It is also imperative that clinical ethics support services reflect on patients' access to and participation in their work.

Several papers reflect on the role of patients in particular settings in greater depth. Eirini Rari and Véronique Fournier discuss the position of patients in a French clinical ethics consultation setting.<sup>6</sup> Here there is significant emphasis on the role of the patient in that no consultation can proceed without the patient being involved. The service aims to treat patients as ethics 'actors' just as much as health-care professionals.

In 'Patient involvement in clinical ethics services: from access to participation and membership', Gerald Neitzke<sup>7</sup> analyses and critiques the points at which patients may become active participants in clinical ethics services. Neitzke's view is that it is both possible and desirable for patients to participate in a range of clinical ethics activities, including active membership of clinical ethics committees.

Ainsley Newson provides a snapshot of the current situation regarding the role of patients in the United Kingdom.<sup>8</sup> A questionnaire-based study reveals low participation by patients in ethical deliberation about their care. The study population, while demonstrating sound knowledge of the possible role of patients in ethics support, expressed mixed attitudes.

Reidun Førde and Thor Willy Ruud Hansen<sup>9</sup> from Oslo review a collection of cases discussed in a Norwegian clinical ethics committee, focusing on the involvement of patients or their relatives. It emerges that in many of these cases the active involvement of patients or relatives assisted all stakeholders to reach an acceptable resolution. Førde and Hansen discuss the remaining difficulties of this approach and query whether involving the patient was appropriate in some cases.

These papers describe and compare the many nuances of patient involvement in clinical ethics consultation in Europe today. They show the differences in how patients are involved and that there is some resistance on the part of health professionals to accord patients legitimacy in ethics consultation. These papers do not demand a European consensus on the role of patients, nor do they highlight one model as superior. But they do provide further reflection on an issue that has until now been analysed rarely in European literature.

The European context and its cultural and social diversity will give rise to many varied mechanisms of involving patients. If it emerges that patient involvement in European clinical ethics support is laudable, then several practical considerations will emerge – for example publicizing a service and establishing consent, participation and recording procedures. What is clear is that clinical ethics consultation without patients and relatives appears to miss an important component of the deliberation: the inclusiveness and participatory character of the effort to find ethically appropriate solutions to the requests of those involved.

### Author Notes

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**Professor Stella Reiter-Theil** is the Director of the Department of Medical and Health Ethics, Medical Faculty, University Hospital Basel, Switzerland. Her degrees include the Habilitation and Venia Legendi in Medical Ethics and a PhD in Philosophy and Psychology. She has been instrumental in building institutions of medical ethics in Europe. Various PhD projects on clinical ethics are part of her research programme as well as a Swiss National Grant project of an evidence-based ethical guideline for clinical practice.

### References and Notes

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- 2) Reiter-Theil S. Voice of the patient. Experiences with the “Patients' Forum Medical Ethics”. *Bull Med Ethics* 1998;135:18–21
- 3) <http://www.clinical-ethics.org/> (last accessed 20 May 2009)
- 4) The panellists were: Ainsley Newson (UK, Chair of Panel), Ana Borovecki (Croatia), Veronique Fournier (France), Cristina Gavrilovici (Bulgaria), Gerald Neitzke (Germany) and Renzo Pegoraro (Italy).
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