The Centre for Values, Ethics and the Law in Medicine
Miles Little and Ian Kerridge

Miles Little was the Foundation Professor of Surgery at the new Westmead Hospital Campus in 1977. He started the forerunner of the Centre for Values, Ethics and the Law in Medicine in 1995, with the help and encouragement of Les Bokey and the Department of Surgery. The idea emerged from Little's long-standing interest in medical philosophy, bioethics and the humanities. He spent six months of sabbatical leave in 1995 learning about the philosophy of medicine and its relationship to public policy, particularly with Uffe Juul Jensen in Aarhus, Denmark, and Robin Downie in Glasgow, Scotland. He ‘retired’ officially in 1996, and became the first Director of the Centre.

Stephen Leeder, as Dean of the Faculty of Medicine, strongly supported the development. With his help, the Department of Surgery found three offices and a salary for an Administrative Officer. Little raised money from a variety of sources to pay three research salaries, and recruited a voluntary ‘Core Group’ from interested people of many disciplines – including medicine, philosophy, ethics, law, theology, sociology and anthropology. The Centre was officially recognised by the University in 1996.

From the start, the Centre proposed to fill five major functions – research (predominantly qualitative) and research supervision; advanced education for graduates; consultation on issues beyond those normally tackled by Research Ethics Committees; an intellectual forum for researchers working in areas of wide social interest; and a source of community education.

The Centre’s activities developed rapidly along all lines, which are strongly interconnected.

Research and research supervision

The first research project examined the different values and understandings brought to medical management by major stakeholders: patients, their family carers, clinical staff, business people, policy makers and people from the media. The research used stakeholder narrative as its raw data, and the original research group – Miles Little (clinical surgeon), Chris Jordens (graduate in philosophy and public health), and Kim Paul (anthropologist) – developed appropriate techniques of narrative analysis, based largely in Grounded Theory. The work quickly led to new insights into the misunderstandings that arise between the stakeholders. It also opened a new field of study into
the experience of people surviving cancer, and this work is now widely recognised and taught. It was originally coordinated by Emma-Jane Sayers, a law graduate and cancer survivor, and is now run by Catherine McGrath, also a law graduate and cancer survivor.

A further development from this work led Chris Jordens to explore the potential of social linguistics as an analytic tool for narrative research. His PhD used this approach, and his work remains a landmark in the field of illness and clinician narrative.

Advanced education

Members of the Centre provide much of the ethical teaching for the University of Sydney Medical Curriculum, but its main emphasis is on postgraduate education.

The Centre combines its research and educational functions by offering supervision to master’s and PhD students. Four PhD students are currently working in the Centre.

It also provides advice to other students on matters of study design and qualitative analysis and will contribute to two new master’s courses that will be offered by the University of Sydney in 2006.

Consultation

Some issues fall outside the usual scope of Research Ethics Committees, such as advance directives, religious medical schools and direct-to-consumer advertising. The Centre offers consultative services to government departments, area health services, medical colleges and policy making bodies in matters that are complex, are disputed, and have broad social implications. It makes use of the skills of its Core Group to provide the broadest base of skills and knowledge.

Intellectual forum

Each month, the Core Group meets to hear and discuss a paper given by one of its members or by someone invited from outside the Centre. Each meeting lasts for about 90 minutes. Speakers may present research in progress, analyses of major social or ethical issues, or their current thinking on philosophical issues that influence health care.
3. Education: beyond the medical program

Community education

The main general educational effort has been directed toward cancer survivors and their family carers. The Cancer Survival group have constructed a series of workshops using their own research and the skills of a number of other professionals, including psychologists and actors. These workshops have achieved national and international recognition by Cancer Councils, forums on illness experience and cancer support organisations. A teaching package, supported by the Cancer Council of New South Wales and the Leukaemia Foundation, will be made available to Cancer Councils around Australia, and to cancer support groups. They are at present teaching their material through the Continuing Education Centre's extension program at the University of Sydney.

Development of the Centre

By 1997, the Centre consisted of four research staff assisted by Lindy Gaze as Administrative Assistant; she was the only salaried staff member. Little raised money for the other staff through grants and donations. The Core Group, usually numbering between 20 and 30 people from many disciplines, has remained at much the same size, although its membership has changed over the years. In 2002 the Faculty of Medicine decided that the Centre had sufficiently established its credentials, and approved the appointment of Ian Kerridge to a full-time salaried Director.

Throughout its short history, the Centre has invited visiting scholars, who have spent time working, lecturing and teaching in the Centre and beyond. Several regular visitors have been made Associate Members to recognise their long-term help, advice and supervision. Others have come from US, Europe and Canada.

The Centre collaborates closely with the History and Philosophy of Science Unit in the Faculty of Science, and with the Department of Linguistics and Faculty of Law at Macquarie University.

Future plans

Like many other Centres and Departments, the Centre for Values, Ethics and the Law in Medicine struggles for money. The majority of the staff are paid from grants and donations; there is a constant battle to maintain funding. This difficulty is compounded by the priority naturally given to biomedical research. Qualitative research is still poorly understood by medical scientists, and
its importance is underestimated. Securing longer-term funding remains a high priority, and preparing grant applications unfortunately takes up a large proportion of staff time.

As the Centre’s work has been recognised and acknowledged, however, biomedical researchers have shown increasing interest in using the staff’s distinctive skills in ethics and values to supplement their own research. An indication of the possible future for this kind of collaboration is given by the project entitled ‘Interdisciplinary clinical and health ethics research and training to improve outcomes in immunosuppressed haematology patients’, which is a well-funded study involving staff from the Centre with the Haematology and Infectious Diseases Department at Westmead Hospital. This kind of interdisciplinary work has been pioneered by the Centre, and perhaps offers great promise for the future.

The Centre for Values, Ethics and the Law in Medicine has existed for only a few years, but it has established a remarkable national and international reputation. It has evolved distinctive ways of conducting qualitative research, and developed great expertise in collecting and analysing narratives. It has grown from very small beginnings to the point where it has outgrown its available office space. Its publication output has been remarkable. Over the next few years, it will need to find a more secure funding base. Whatever happens, however, its short career has demonstrated that its presence is needed in today’s medical environment. That need is likely to become more marked as biotechnology develops along paths still barely comprehensible to scientists and ethicists alike.