

The Dunedin Summer Seminar: widening the scope



Herman H. van der Kloot Meijburg, Director of the Department for Health Care Ethics of the Federation of Health Care Organisations in The Netherlands

Introduction

For me the Third Summer Seminar, organised by the Bioethics Research Centre in Dunedin, was truly a learning experience. So, when Alastair Campbell invited me to put some of my observations and reflections down on paper I gladly accepted.

In the book about New Zealand, which the Centre gave to me as a farewell present, the author characterises the New Zealand people as "an articulate people with a deep sense of politics and rightness". Taking the remark for what it stands for, I am tempted to make a comparison with Dutch society. Both countries belong to a category of (smaller) nations in the world who are very sensitive to the overall quality of their society in relation to the well-being of their citizens. Their efforts are directed at building a democratic and participatory society and they may discover, often to their surprise, solutions to certain issues large countries do not seem to manage that well. One of the reasons may be that countries like New Zealand and The Netherlands are more homogeneous in their thinking than other countries.

Examples that come to my mind are the way we cope with issues relating to the environment, the prevailing health care systems, cross-cultural perspectives and the like. The book also mentions that the New Zealand people like to debate these issues at great length before making a decision. That reminds me of The Netherlands too. The ongoing debate on euthanasia for instance started some 25 years ago and as far as I can see there is no end to it yet. Consequently when people fuss about odd "bits and pieces" it may well be related to fundamental notions about the kind of society people ultimately want to live in. The debate about health care delivery may very well be related to these fundamental notions at work in the undercurrent of society. Whatever is said about cost restraints and health care reforms, at the end people perceive health care as a collective good, costly perhaps, but worth preserving.

Others may feel differently about this interpretation but it made me feel quite at home among the participants attending the conference about developments regarding the prevailing health care system; a conference so well planned and organised by the staff of the Bioethics Research Centre in Dunedin. In looking back I will present my observations and reflections in the form of three themes which need, in my opinion, further consideration.

1. Globalization of health care.

We have become quite accustomed to the fact that advancements in the medical sciences and technology pervade health care in all corners of the planet. The standard of care for haemophilia patients in The Netherlands may well be set in New Zealand. New techniques, like laparoscopic surgery, developed in the United States, affect hospital surgery worldwide. We are also accustomed to the worldwide testing of new pharmaceutical drugs. Today clinical trials often involve different clinical centres all over the world. In

the field of health care policy we see the same phenomenon. When physicians in Italy decided that psychiatric patients are better off outside health care institutions, it had enormous effects on ideas about the care for psychiatric patients in countries like Norway and the United States. Likewise the Oregon-model has had an enormous impact on health care reforms in New Zealand. Ideas about introducing market mechanisms in health care delivery have haunted the prevailing health care systems in Europe after they had been introduced in the United States. It took health care policists in The Netherlands eight years to understand that leaving health care delivery to the market would not solve the problems related to the care of the elderly or the mentally retarded. Since then notions of accessibility, solidarity and the deeper meaning of care have come back in the debate. Globalization of health care policies is one thing, the practice of this globalization needs our constant attention and must be debated extensively before we embrace these global concepts nationally. These global outlooks may

Globalization of health care policies is one thing, the practice of this globalization needs our constant attention and must be debated extensively

not always fit the insights of a particular society, on the contrary they may even contribute to feelings of cultural unsafety within that society. I will come back to that later.

2. The medical perspective

My point of view, as stated above, is that the practice of health care has become a very complicated business, causing complicated dilemmas in the realm of patient care. Interestingly enough however, these dilemmas in health care delivery are always presented as treatment dilemmas. Here is this patient in need of help, but at the same time we, practitioners, have to cope with limited resources and cost restraints. What to do? The individual patients will suffer because

we have to make these terrible (treatment) decisions on behalf of this patient. As health care professionals they regard it their moral obligation to provide the patient with the best available treatment available. But is it reasonable Grant Gillett would ask? "Reasonable" from what perspective I would like to add? The perspective of "individual need" argues Gillett in his recent book about reasonable care. But who in fact decides what is necessary to meet this need? Is the physician the only person in authority and should the treatment perspective dominate the decision? I believe that many of the cases presented to the public today are no longer doctors' dilemmas in the strict sense. We have long gone beyond that point. During the conference it became evident that these cases are often so complicated not because of the medical point of view only, but also because of all those other interests involved. Policy decisions, the technology available, cost constraints, the level of the quality of care, notions about what care is all about in a decent society, interact with personal beliefs and professional commitments. The arguments have become familiar and often sound reasonable enough. It seems to me, that trying to solve the problem of individualised need along medical lines will only become an increasingly a frustrating business. Perhaps individual need should be related to values such as the capacity of human beings to participate in society normally. This notion expresses a deep concern we have towards each other. We hope we are all able to participate in our societies in a way that it satisfies our needs and aspirations. At least that is what the Dunning Commission has suggested in The Netherlands when we were debating the goals of medicine. I advocate that communication about the multi-dimensional nature of health care decisions be stimulated and integrated into the decision making process. It would not only involve the attending physician, but also other professionals who represent one of these other dimensions in health care. Perhaps a multi-dimensional approach could help us to understand the needs of the individual against the needs of other individuals better. In the debate these individualised others are generalised and become anonymous. Thus their needs may easily be neglected. This puts them in an awkward position. The interests of these generalised, anonymous others

hover over the interests of the individual and this can no longer be ignored. I believe that the two should be connected and be made part of the decision making process. Within the hospital, for instance, the dimension of the health care institution (representing the interests of the "generalised other" as over and above the interests of the "individualised other") could well be represented by the CEO. Perhaps a representative from the community at large could contribute by sharing an insight or offering an alternative that would ease the pain of not doing all that is

Do we understand the meaning of care better by looking separately at the ethics of research or at the ethical dilemmas in the practice of health care delivery?

medically possible, because that would otherwise burden others. It will be a trying exercise and at first we could use more "hypothetical ones" about what "fairness" in health care delivery is all about. But at the end the model should be put to work in practice too.

3. Cross cultural concerns.

During the conference I have become very much aware how present developments in health care affect culturally determined needs. I was greatly impressed by the way the Maori people stood up for their culturally determined needs and I realised that a disregard of those needs is experienced as threatening and very uprooting. Already within a homogeneous culture developments in health care have caused for a considerable amount of unsafety. For instance developments in predictive medicine have created considerable commotion among the handicapped in The Netherlands. To them the acceptance of prenatal diagnosis implies not only that certain handicaps (the illness as such) can and should be avoided, but it also implies that one questions the sheer existence of people who have that particular handicap. They might as well not have been there (and burden society). When in Dunedin I checked out some information about homosexuality/transsexuality in Polynesian culture, especially the position of the fa'a'afi. I discovered that the Polynesian people were rather at ease about this phenomenon and used it in a very practical way, in case there was a

shortage of either men or women. It must have astonished them to discover that with the coming of western culture homosexuality and transsexuality were identified as eccentric deviations of mankind. What was accepted as quite normal in Polynesian culture has become problematic in another cultural setting. These and similar experiences may very well help create the cultural unsafety Maori people talk about in New Zealand society. During the conference they voiced their concerns very well. In The Netherlands we used to label these specific concerns as belonging to minority groups within Dutch society. Part of Dutch policy has been to respect these minorities and their traditions as such. Respect and the acceptance of plurality have been the key

words. But today we realise that this is not enough to create a sustainable and participatory society for all. What we see today is that in reaction to this policy, some of these minority groups have become very rigid about maintaining their cultural background to an extent that they would never do so in their home countries. This development however isolates them from the main stream of life in The Netherlands, thus creating even more cultural unsafety for them. For representatives of the dominant culture it is a tremendous task to force themselves to understand the underlying motives behind the demands from people belonging to other cultural backgrounds. Sometimes they leave the Dutch quite puzzled. Perhaps there is nothing so difficult to understand as different cultural notions and morals about well being. But it should not cause us to turn away, because what concerns them should concern us: what kind of society do we ultimately want to live in. A society that permits developments in health care which sustain one group and make another group feel uncomfortable will no doubt become an unsafe place to be for both groups. It raises the question about what care in that society is ultimately all about.

Notions of care

It looks like whether many of our ethical endeavours in the realm of health care are only there to protect and to safeguard facets of the health care enterprise rather than making us more knowledgeable about the nature

of care as such. Do we understand the meaning of care better by looking separately at the ethics of research or at the ethical dilemmas in the practice of health care delivery? Do we come to a better understanding of the significance of care to the people of a society by looking at the way the interests of different cultural groups are being respected and provided for? It may be part of the exercise but it may just not be enough. During the conference I became more aware of the need to relate our endeavours to the concept of care that sits in the back of our minds. Speaking about care is

talking about how the public, how health care officials from the government, from the hospitals, how the professionals themselves, how the patient, but also how representatives from the sciences and industry, interact and relate to each other. What we are basically talking about in health care ethics are the ethics of all sorts of transactions and relationships in health care. In my experience the Dunedin Summer Seminar was a real eye-opener in this respect and one might wonder whether in time this will need a follow up. In addition I would also like to raise

the question in what kind of cultural context we perform all these care activities. I come back to my initial question how is care perceived in society and how it should function? As long as we take that particular aspect for granted attending to different ethical issues in health care on a one to one basis will leave us behind with these slight feelings of frustration. Perhaps we solved the problem at hand but we may have neglected the more fundamental issues at stake. What is care all about?

Utrecht, April 1996.

At the Centre

The major event at the Centre to report in this issue (as those of you who have read our guest editorial will realise) is the departure of Professor Alastair Campbell at the middle of July. Alastair's appointment to an inaugural chair of the ethics in medicine at Bristol Medical School is recognition of his status as one of the leading international figures in his field. While everybody at the Centre is very pleased for Alastair we are all in a period of denial about his imminent departure.

Centre staff are busy working on the ethics components of the new "Patient Doctor and Society" module of the second and third medical years. The new module is an exciting event for our ethics teaching. In recognition of the increased awareness of young physicians having sufficient training for their relationships with patients, their role as physicians and wider societal issues this module has been made a major part of medical students preclinical years. One of the hopes of this new module is that the ethics components are fully integrated with the other subjects they study and they are thereby able to have more opportunity to consolidate their ethical skills.

The Proceedings from the Summer Seminar should be out within a month or so. Reading over the articles in the Proceedings I realised how fortunate we were to have input from such informed people through out New Zealand. The Proceedings are a good record of the bioethical issues topical at this time. They are being produced by the University of Otago Press and will be an attractive volume. We haven't finalised what price they will be. However all those who are interested in getting copy of the Proceedings should contact John McMillan at the Centre.

Barbara Nicholas and Sara Gordon have been hard at work on the euthanasia resources for community discussion. The resource package has grown out of Sara's HRC funded Summer Studentship. It is a resource for community groups who wish to organise their own events to discuss euthanasia. Material is provided for workshops of 2 or 3 hours, or 3 x 2 hour sessions. The resource package is now available at a cost of \$25 by prepayment. This price includes postage and packaging within New Zealand.

The Centre has again been treated to visits from a number of prominent bioethicists. Professor Robin Gill, Advisor on ethics to the Archbishop of Canterbury, visited in early May. While here he gave two presentations, both of which were well attended and received. He spoke on "Euthanasia After Tony Bland" at a public lecture and "Post-Modernism, Church Leaders and Bioethics" at a Centre Seminar.

Professor Max Charlesworth, Emeritus Professor Deakin University, visited here during May. He spoke on "The Rights of the Terminally Ill: Recent Developments in Australia". Professor Charlesworth is co-author, along with Professors Campbell, Gillett and Jones, of the new edition of *Practical Medical Ethics* (forthcoming).

Raanan Gillon is a name that people with any familiarity with the Bioethics literature will know. Professor Gillon, editor of the *Journal of Medical Ethics*, was here during May and spoke on "The Ethics of Rationing High Cost Pharmaceuticals".



**Bioethics
Research
Centre**

Box 913, Dunedin, New Zealand

ISSN 1173-0110