

ETHICS & MEDICINE

AN INTERNATIONAL CHRISTIAN
PERSPECTIVE ON BIOETHICS

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Agneta Sutton, Managing Editor

Comment

When, if ever, is it right to withhold medical treatment from a patient? This was the issue addressed at the conference organised by the Centre for Bioethics and Public Policy (CBPP) on 7 May at St Thomas' Hospital. The unequivocal answer given to the question whether it is ever right to withhold treatment was: Yes. By contrast, the question concerning the circumstances under which it is justified to withhold treatment, received no unanimous answer.

The May conference was entitled '*A TIME TO DIE? Ethical, legal and clinical perspectives*'; and, as the title indicates, the question of treatment and non-treatment decisions was debated from different points of view.

Judging by the response of the audience (who was asked to fill in an assessment form), the speech that went straight to their heart was that by Dr John Wyatt, Consultant Neonatal Paediatrician at University College London. Speaking about the care of handicapped newborns, he said that the most likely situations in which intensive care treatment of infants may be regarded as futile are when the child suffers from catastrophic and generalised brain injury and, secondly, when it is affected by a life-threatening and uncorrectable congenital malformation.

Talking of the emotional stresses and sorrows associated with the care for severely handicapped babies, he emphasised that, in his experience, 'the vast majority of paediatricians and parents recognise a clear ethical and intuitive distinction between the withdrawal of intensive support which is futile and intentional killing or euthanasia'.

In keeping with the Judaeo-Christian and Hippocratic tradition of thinking, he commented, most parents accept that the doctor should not seek to keep their child alive at all costs; and they would not want a dying child to undergo treatment that would merely prolong the process. Likewise, he added, most parents would consider it cruel and pointless to treat a child if the burdens of the treatment would outweigh its possible benefits.

But he also emphasised that it is one thing to forego treatment, and quite a different thing to forego nursing care. 'The withdrawal of intensive support does not imply withdrawal of all care, and all newborns deserve a minimum of loving care, including analgesia, food and fluids, and tender loving care'. He also stressed the importance of supporting the family and of allowing them to get to know their dying baby, hold it and take pictures of it if they so wish.

Apart from the newly born, other categories of patients that were discussed were those in the persistent vegetative state and the extremely elderly.

There were two papers on the legal aspects of non-treatment decisions. One was by Judge Christian Byk from France. A former bioethics adviser to the Council of Europe, he spoke about the debate on the Continent. The other paper was by Dr John Keown, CBPP's Vice-Chairman, who spoke on the concept of the sanctity of life versus the concept of quality of life in the law. Having written extensively on the issue of euthanasia, Dr Keown brought home the importance of maintaining legal categories which neither allow the concept of the sanctity of life to be lost sight of nor blur the distinction between the concept of quality of life and that of sanctity of life.

The general feeling at the end of the conference was that the issue of treatment and non-treatment decisions deserves to be further debated. And will be. The CBPP is organising a follow-up conference on palliative care, on 14 November 1997, when Dame Cicely Saunders will speak about her pioneering work in the establishment of Hospice treatment. Other speakers will address current clinical and moral issues. If we do not openly debate these things and invite the public to listen, there is the risk that the public will come to favour euthanasia for fear of medically prolonged and painful dying.

Dr. Ann Bradshaw, Oxford

The Ethics of Nursing Care

Introduction

Although I was born in England I feel very close to the Dutch. It is not only that I have been on holiday twice in the Netherlands, but more particularly because I am the daughter of German Jewish refugees. Both my mother and father fled to England in 1939. My mother was sixteen, my father was twenty. They did not know each other and met

only after the war. My father, from a village near Freiburg was himself in a camp before getting his release papers. My mother had grown up in a little village which is now in Poland, but her family moved to Berlin in order to try to blend into a big city and become less noticeable as Jews. My mother and father managed to escape, my mother by what was called 'kindertransport'. Their parents, my grandparents, could not get out in time. They perished in the

death camps of Auschwitz and Gurs. My parents always told me how very good the Dutch were to the Jews, helping and hiding many of them. Unsurprisingly, I grew up with a very strong feeling for Anne Frank, who was my mother's age, and looked very like my mother. And when I was young my parents took me to see her house in Amsterdam, which made a lasting impression on me.

I grew up in England in a liberal Jewish family. When at eighteen I decided to train as a nurse this was not thought of as a good job for a Jewish girl. Nevertheless I went ahead and became a student nurse. During my training I saw much suffering, and I particularly remember two people who moved me very much. The first person was a young boy of seven who had a deformity for which he needed plastic surgery. I cared for him and became very attached to him.

The other person was a middle-aged woman with cancer of the jaw. She had most of her jaw removed and needed plastic surgery to make a false jaw. She could not eat and sloppy food trickled out of her mouth. She had a constant flow of saliva dripping on to a pad under her mouth. How could this happen to her? Where was my God for these two non-Jewish people? This experience left me with many questions and gradually I became a Christian, or rather a Jewish Christian.

I gained experience as a staff nurse. I worked on medical wards, on surgical wards, on the district, and caring for the elderly. I married, moved to London and began working in a Roman Catholic hospice before the hospice movement had become famous. In fact the hospice I worked in, St Joseph's, was the one that Cicely Saunders had worked in before she founded St Christopher's. I learnt there, by watching the nuns, the art of compassion and care for the dying and the chronically sick.

Changing the philosophy of nursing

I left nursing in 1975 to bring up a family, and returned in the mid-1980s. I decided to do a refresher course, and by chance was taken on as a student in an academic nursing course at a polytechnic. Here I learnt of the enormous changes that had occurred in British nursing since I left. I was very surprised, particularly at the theories that were now being used to justify practice. These theories were all coming from North America. It was as if the British nursing tradition had never existed.

Worse still, it was assumed that the nursing of previous generations was quite defective. Nursing leaders were now ashamed of the past and were striving to make nursing an academic profession. Nursing writers were writing revisionist histories of nursing, describing nurses as oppressed workers, and rejecting the traditional concept of the nurse as dedicated and self-effacing. Sacrifice was over. Nurses were taught to be assertive and empowered (see for example, Salvage, 1985).

The content of the theories of this new 'academic' nursing gradually began to worry me. For each nurse theorist had a different idea about the nature of nursing, what constituted a human being and what response the nurse should make to this human being. These theorists drew insights from psychologists and sociologists to support their ideas. But it was particularly in the realm of 'the holistic' care of the patient and regarding 'spiritual care'

that my worry was greatest. I listened to lecturers who taught that now, because of the work of such theorists, nurses were for the first time able to bring holistic care to patients; whole patient care, that addressed not only physical needs, but also social, psychological and spiritual needs.

I remembered my own training where I had been taught to give my patients what was called 'total patient care'. I found my old nursing textbook, which by the time of its 1967 edition had been published seventeen times since the 1930s. It was a classic, standard textbook used by most student nurses. And I saw there, in the first introductory chapter, the whole ethos of nursing as offering the patient care which encompassed physical, social, emotional and spiritual needs. 'Holistic care' was not a new invention, it had been the basis of nursing through generations.

What was different, however, was how 'spiritual care' was now perceived. In previous generations it was assumed to be about a relationship to a creator and redeemer God. But in the era of the 'new' academic nursing, it was about the person's self-development. Often drawing on the humanistic psychology of Abraham Maslow (1987), modern nursing writers were suggesting that the person's spiritual needs lay at the top of a pyramid. At the lower levels were basic physical needs, moving up through the pyramid into social and emotional needs. At the top of the pyramid were the 'spiritual needs' which Maslow calls 'self-actualisation'. He sees these being reached often through arts and aesthetics, after the preceding needs are satisfied.

But I wondered how Maslow's analysis corresponded with the views of another psychologist, who was also commonly drawn on by nursing writers. Victor Frankl (1978, 1987) believed that the spiritual nature of the human being is his search for meaning. He had formulated his theory in the concentration camp where he was a prisoner. He saw that even in the midst of the most appalling suffering, deprivation and squalor, the human spirit could survive if the person had a meaning in life. Frankl believes that this meaning can be different for everyone, although he also notes that for most people it is connected with the traditional understanding of God. As for himself, when he was released from the concentration camp he fell to his knees and recited a sentence (possibly from Psalm 18): 'At that moment there was very little I knew of myself or of the world—I had but one sentence in mind—always the same: "I called to the Lord from my narrow prison and He answered me in the freedom of space" ' (Frankl, 1987:90).

It was this wondering that led me into further study, into finding out what the traditional understanding of spiritual care was in nursing, and how it was understood at the present time. I wanted to find out what philosophies and ideas had influenced present understandings, and what theological ideas had influenced nursing tradition in the past. Above all I wanted to find out how these different ideas would affect the practical care of patients by nurses. My husband, a clergyman, was teaching at a theological college. From this college I was able to gain tuition in philosophy and theology. This work resulted in a doctoral thesis which I was fortunate to publish as *Lighting the lamp*.

This is the path I have taken. My perspective is naturally about British nursing. I am afraid I know very little about how nursing has developed in the Netherlands. But nurs-

ing is nursing wherever it is carried out. And the essence of nursing, I believe, does not change. In fact, modern British nursing was begun by Florence Nightingale, and it was her model that influenced North America. Nightingale herself began her own training in Germany, in Kaiserswerth am Rhein, as a student of a Lutheran minister, Pastor Fliedner. It is this Nightingale tradition which has become so disparaged in Britain, and which, I would argue, needs to be revived, because it is the moral heart of care.

I have come to realize that the spiritual dimension of care is inextricably tied to the ethic of nursing. The spiritual dimension is not a separate aspect of care but it is the root from which 'care' springs. Hence I would argue that the spiritual care given by the nurse is different from the care given by the religious minister. Spiritual care for the nurse, I believe, is the fundamental expression of care. It is not so much talked about but lived out. It is the reason for care, and it is the basis for the kind of care given. In the past it was considered to be a calling from God, a vocation, which inspired care for the weak and sick. From this spiritual calling the nurse derived strength and compassion. The ethics of care were not so much spoken as lived out. They were about the kind of person the nurse was.

The traditional nursing ethic

The tradition of care in western society grew out of the Judaeo-Christian tradition and the ethical imperative to love one's neighbour as oneself. As Cicely Saunders (1986), who revived a tradition of care for the dying by founding the modern hospice movement, has written, the values underpinning such care historically and traditionally were those expressed in two verses in Matthew 25: 'I was hungry and you gave me food, I was thirsty and you gave me drink, I was a stranger and you welcomed me, I was naked and you clothed me, I was sick and you visited me, I was in prison and you came to me.' The second verse was this: 'As you did it to one of the least of these my brethren you did it to me.'

And nursing as the care of the sick embodied these values. This was precisely the same tradition of values revived by Nightingale in the middle of the last century (Nightingale, 1946). For her, the care of the patient depended on the moral quality of the nurse. Although it was important, no amount of education could produce this quality because it came from inside. It is what the nurse *is* that counts. Hence she was against any form of certification or registration. A good nurse could not be certified like a steam boiler. As she articulated it in a paper delivered in Chicago in 1893, nursing was a calling, not a money-getting profession. It was not about book-learning and lectures (although it included this), but an apprenticeship—a workshop practice. The qualities needed were moral qualities: method, self-sacrifice, watchful activity, love of the work, devotion to duty, 'that is, the service of the good', courage and coolness, tenderness, and absence of pride. (Nightingale in Hampton, 1949:33–4).

Nightingale believed passionately in the moral character of the nurse developed through a relationship with God. She constantly reiterated this theme in letters to probationers at the Nightingale School at St Thomas's Hospital. 'The

free woman in Christ obeys, or rather *seconds* all the rules, all the orders given her, with intelligence, with all her heart, and with all her strength, and with all her *mind*.' And again: 'She who rules best is she who loves best: and shows her love not by foolish indulgence to those of whom she is in charge, but by taking a real interest in them for their own sakes, and in their highest interests' (Nightingale, 1914:11 and 77).

And if one dips into nursing textbooks and nursing periodicals of the first half of the twentieth century, we see that such values emanating from these highest interests, were the basis of nursing. We see this clearly in the *Nursing Times* (The Probationer's Page) in 1912, which covered the topic of nursing ethics in three issues (July 27:769; August 24:862; September 14:929). In the first article the anonymous author writes that the atmosphere of the hospital is determined by the moral character of those in charge. And every nurse is herself part of creating that atmosphere. 'The kind of nurse she will make will depend not alone on what is taught her during the training period, but on the inner qualities of heart and life which she brought with her' (*Nursing Times*, 1912:769). This moral character was ultimately not trained by words but caught by example and inspiration.

'Can a nurse be trained to be kind if she is naturally thoughtless and inconsiderate? Under certain circumstances she can—not by any course of instruction, but under the power of example. Character is caught rather than taught. The character of the ward sisters and the matron will be more potent in the development of the spirit of kindness and the repression of what is sometimes termed "mechanicalism," than any other factor' (*Nursing Times*, 1912:769).

As the final article of the series makes clear, nursing ethics is about the moral ethos of the nurse's life underpinning her every action and activity of care. 'If we are going to teach ethics at all, let us teach it in a practical way, so that nurses will realise that it enters, or may enter, into every act which they as nurses perform. It enters into the giving of medicine, the making of beds, into the giving of baths and treatments, into our conversations in the sick-room, in the corridors, and outside, into our unspoken attitude toward the institution and those in authority in it' (*Nursing Times*, 1912:929).

The best way to teach care was by practical example. Nurses were inducted into a tradition of care by virtue of the fact that the whole profession shared the same values. (Incidentally these were also shared by doctors and almoners). What was important was that these values of care were not essentially talked or written about. The values underpinning care were lived out as a service of the good. What comprised the 'good' was understood by all. Hence the ethics of nursing were concerned not with 'what should I do?', but rather 'what should I be?'. Above all else this meant developing the kind of character that would make possible the good care of patients. This involved obedience, humility, self-discipline, punctuality and loyalty. And the basis and derivation for all these qualities was to be found in *agape*, charity or Christian love. We love because he first loved us. Hence, we see, it was no accident that the revival of nursing as altruistic care that occurred with Nightingale, was directly connected to the evangelical revival of faith in the nineteenth century.

But we should not imagine a romantic or sentimental picture. Writing in the last century, a doctor, Octavius Sturges, demonstrates for us the absolute dedication required of nurses who worked with the most underprivileged members of society. Nurses were involved in an endless round of caring for extremely ill people and experienced 'the ingratitude of many patients, the actual violence of some; of the careful tending of those who have reached the very bottom of social degradation, and whose wounds and diseases are the direct result of their depravity. All this the hospital nurse endures week after week, with small money remuneration, limited prospect of promotion, scanty share in any credit which may accrue, and prompted only by a motive which, however it may find expression, is of the highest and noblest kind. The dignity of such service seems to me quite unequalled' (Sturges, 1880:1091).

Underpinning this dedication then was *agape*, costly, self-giving Christlike love, the covenant response of relationship. The nurse freely entered into it, not out of cold duty, but as a free response, recognizing not the law but the spirit. In conforming to the pattern of love she let go of her own will, but in so doing became more truly herself. In fulfilling her calling, her vocation, she actually became what she was born for, what she was meant to be. Paradoxically, she found herself in losing herself. If *agapeic* love is not cold duty it is also not the kind of love that depends on reciprocation. It hopes for return but does not depend on it. God continues to love even if his love is rejected, because his covenant is binding. Such love then is not an arbitrary emotional response but the ground of human relationality.

To use the example of the Good Samaritan: the Samaritan gave succour to a person who he knew would regard him with disdain. What was significant was that he was not part of the same family or culture. He was a stranger. Despite this he gave his love without condition. The nurse then gave all she could to help the patient, building a relationship with a stranger who was neither family nor friend, without regard to that person's status or state, in all humility, making no demands for recognition, and able to sever the relationship when it was no longer needed.

We are offered a picture of this tradition in a reminiscence of a nurse who began training in 1935. Before being accepted for training references were needed not only from the prospective nurse's headteacher and doctor, but also from her church minister 'to say I was of sound moral character'. The probationer nurse learned rules and regulations. She was examined in theory and practice. She needed to answer questions not only on the constituents of the blood, the rules for pouring out medicines and the avoidance of cross infection, but 'the qualities of the good nurse'. But before she was allocated to her ward the senior tutor was clear: 'Never forget to care. Throughout the years of your training you will no doubt see many changes in both technology and medicine which you will learn to apply to the benefit of your patient. But I want you to remember that it is every bit as important that you should turn the pillow and find time for a friendly word as it is to give him his medication. You must never forget to care' (Baker, 1996:50-51).

Clear vocational values underpinned nursing (albeit unspoken) until the 1960s. It is true that at times these values became attenuated and nursing became mechanicalised or task orientated, but there were always nursing voices to

urge nurses to remember the tradition (for example Pearce, 1953,1963,1969). What changed in the 1960s was the growth of humanistic atheism among a new generation of increasingly influential nurses, together with what seems to have been a loss of confidence among those who held traditional values. For whatever reason, values became personal and private rather than communal. They were no longer shared.

An example of this is provided by the bedpan. In 1963 an editorial in the *Nursing Times* entitled 'The Bedpan Round' suggests that 'Many older nurses will recall being exhorted to "Carry that bedpan to the Glory of God"; if that is unacceptable to the humanists, then can we appeal to them to "Carry that bedpan to the dignity of man"?' But the question is whether the values that enabled the nurse to perform such tasks as carrying bedpans full of human excreta, not only enabled her but gave her joy in doing so, can remain without the values that underpinned it. How long can humility, service before self, self-denial, *agapeic* 'love' remain if their root is cut away?

How relevant is the tradition today?

But in our western society of the 90s should we, indeed, can we, look backwards to the past? As society changes so the values of society change to meet the new world order. Modern commentators argue that we need to find new nursing values. The concept of 'care' itself is now subject to debate, analysis and theoretical thought. Numerous empirical studies are being carried out to find out what 'care' is. But it may be, as the Dutch theologian, Hendrikus Berkhof, writes, that what is really happening is that the gospel fruit is being picked off the gospel tree. Our society claims the fruit but rejects its origins. Nursing theorists write learned treatises on the theories of 'care', but now base their analysis on the abstruse ideas of philosophers such as Heidegger. The problem is clear. How long can the fruit of 'care' remain if the tree from which it is plucked is cut down? Will the tradition of care remain the same in the future; or will its very meaning change if the tree from which it originates is gone? Can the same kind of commitment to care remain if the values of care change?

Certainly nurses throughout the twentieth century have been very worried about the change in the ethos of nursing. In many ways there has been a battle, expressed often in the pages of nursing journals, between nurses who believed that the vocational tradition was a crucial basis for nursing, and those who wanted to modernize nursing, turn it into a profession and remove any vestiges of the 'angel' image. Mirroring society, there has been a profound philosophical change in the ethos and culture of nursing, as traditional vocational values have no longer become acceptable, even as an option.

Writing in 1978, in his review of the National Health Service 1948-1974, Brian Watkin suggested that in the 1970s nurses were reluctant to speak of their work as a vocation. He does not believe this signals any less commitment on the part of nurses, but the fact that changes in society and in nursing itself meant the nurse spent less time on nursing, and hence 'it was easier for her to regard nursing as just another job, a way of making a living, rather than as something rather special, calling for dedication out of the

ordinary, and a measure of self-sacrifice' (Watkin, 1978:128-129).

Hence, nursing in England has become increasingly pre-occupied with developing the profession and expanding the role of the nurse and increasing the status of nursing as a primary interest. The change in nursing education in the 1980s was fundamental to the changing role of the nurse. The mid-1980s saw three highly influential reports from the main British nursing bodies responsible for the education and regulation of the profession. These were the Royal College of Nursing Commission on Nursing Education (the Judge Report, 1985), the English National Board Proposals (1985) and the United Kingdom Central Council for Nursing Midwifery and Health Visiting (UKCC) Project 2000 (1986a). All three looked to nurse education in higher education and the student nurse having supernumerary and student status. No longer should she learn through apprenticeship or as the Judge report puts it, be over-worked 'Pairs of hands', whose own learning needs are secondary because they 'march to the drumbeat of service' (Judge, 1985:8-9 para 1.6).

This was no doubt a positive attempt to redress inequalities and inadequacies in nurse training in the past, and it is obvious that a nurse's knowledge and technological understanding and capability must change and develop to meet the growing health care demands. The question arises not only as to whether this was revolution rather than reform, but perhaps more importantly, in whose interests the revolution was intended. Baroness Warnock, for example, questioned the movement of nursing away from the apprenticeship model at a time when it was being asked whether teacher training should be moving towards it (Fleming 1985:54). And Dingwall et al. (1992) wonder if the Royal College of Nursing commission, chaired by an educationalist, was primarily interested in providing students to fill higher education places.

Certainly it was not considered that the lay person (and potential patient) would welcome such change. The Royal College of Nursing Commission report is itself aware that lay persons will not want change. As the report notes, nurses may be undervalued and under-rewarded but patients will be confident in the quality of practical nursing. They will ask if the system of training is wrong why the products were so good, and will eschew fancy notions or theories of 'Education'. 'He will be sceptical of any attempts to move the training of nurses from its present base. He will, if pressed, want his bedside nurse to be trained and practical rather than educated and questioning. He will certainly not wish to be cared for after an operation by an amateur psychologist or (still worse) sociologist. Told that nurses learn their craft by being engaged from the beginning in the delivery of care, he will grunt his heartfelt approval' (Judge, 1985:7). Neither does it seem to have been correct that nurses themselves wanted radical change. Surveys of nursing opinion, (SCPR, 1971a and 1971b; MacGuire, 1961 and 1966; UKCC, 1986b) show that nurses themselves were not in favour of radical change.

During this period of rapid change even progressive forward looking nurses were worried about the loss of nursing values. One of the first nursing researchers, Doreen Norton (1965), reflected that more and more qualified nurses talked of and about nursing but no longer did it. She

believed that there was a danger in the development of any profession struggling for recognition of the gradual distortion of its basic concepts, so that it was no longer doing what it set out to do. The traditional understanding of nursing was in conflict with the kind of nursing now being proposed. The very act of advancing the status of a profession bred attitudes which so changed the character of the profession that it no longer lived by the basic values from which it sprang, although it continued to pay homage to them. This, Norton argued, was happening to the nursing profession.

As nursing education moved away from apprenticeship and into colleges so the nursing profession changed and developed, becoming strongly influenced by the social rather than the biomedical sciences. The North American study by Fred Davis (1975), in the mid-1970s now seems to ring true in Britain. In this study Davis found that nurses at the beginning of their training held to a broadly Christian-humanitarian ethic of care, but as their training progressed they increasingly imbibed the prevailing ideology of the institution. This he calls a process of 'doctrinal conversion' by which the nurse becomes 'socialized' into the profession and absorbs 'professional rhetoric'. He sees this as a result of 'the massive infusion of recent years of psychotherapeutic, educationist, and social science terms' into the working vocabulary of the North American nursing profession (Davis, 1975:128).

Davis's description of the values of new student nurses is very revealing. 'Intimately infused with this common-sense version of instrumentalism, there exists a somewhat amorphous, though nonetheless deeply felt, Christian-humanitarian conviction that love, care and a desire to help others constitute a sufficient motivational wellspring in themselves to assure the moral efficacy of the nurse's ministrations and to shield her from the transgressions that an unmitigated instrumentalism might entail' (Davis, 1975:120).

During her course of training she imbibed the 'institutionally approved' imagery of the school, which had three emphases. Firstly, she was taught to consider nursing as having wider scope than confronting sickness, as dealing with a much wider area of 'health problems'. Secondly, she was taught to objectify the nurse-patient relationship and see it in problematic terms, as an object of scrutiny, analysis and manipulation. Thirdly, rather than acquiring technical proficiency as the essence of the student's performance, emphasis was placed on learning 'principles of nursing care' upon which skills could be based. Technical mastery was assumed to be acquired through repeated exposure to situations, and because nursing techniques and procedures were always changing, the focus was not on a rote-like application of 'why it's done' but rather on 'how it's done' (Davis, 1975:121).

In the UK we have followed North America. In the last decade nursing training has moved out of the hospitals and into colleges of both new and old universities, and nurses have become inducted into the various ideas and ideologies which they taught. While as individual nurses we might silently and privately hold traditional values as a basis for the care we give, it becomes increasingly difficult to maintain such beliefs without support and encouragement, and when we are part of a system where traditional values of

care are increasingly devalued and replaced by the philosophical theories of the 'new profession'. Indeed the sea-change in nursing means that while twenty years ago many of the leaders of the nursing profession had a specific Christian faith and commitment, this is no longer true today.

A prophetic voice?

Here, the philosopher, Alasdair MacIntyre, reminds us why this happened, and what it means. The situation in nursing mirrors the much wider situation in society. Cut off from our tradition, the concepts of that tradition lose their meaning. Only in the post-theological age can the concept of *the meaning of life* appear and flourish. Just as the question 'What is the meaning of life?' fills the space left vacant by the question 'Does God exist?', so the concept of *what we care about* becomes important in our culture that has lost its public theory of the good (MacIntyre, 1982). What is happening in nursing is a symptom of what is happening more generally in society. And what forms the opinions in nursing is the same intellectual force that forms the opinions in society.

In Britain eminent people are anxious at the implications for a society that loses its shared values. In education the chairman of the National School Curriculum and Assessment Authority talked of his 'deep concerns about the way our civilisation is going' and argued that the spiritual dimension, as inseparable from its traditional moral underpinnings, needed to be rekindled as a bulwark to this breakdown (Dearing, 1996:1). The chief executive of this authority has also discussed the importance of giving children a moral and spiritual framework. He has suggested that the moral and spiritual development of pupils is inseparable from the moral and spiritual development of society. He believes that traditionally education and government saw their role as the promotion, the development of what Tate calls 'a virtuous society', and the function of government was 'the maintenance of virtue' (Tate, 1996:3).

In medicine there is worry too at the loss of human values. In November 1994 representatives from all areas of the British medical profession met to consider what should be regarded as the 'core values' of the profession in the next century. At about the same time a Human Values in Health Care Forum was set up by members of the medical profession concerned to study those factors in society which may influence for good or ill the standards of practice and ethical behaviour in what they describe as 'the professions and vocations' concerned with health care. (Human Values in Health Care Forum, 1995).

Dr J. Stuart Horner, chairman of the Medical Ethics Committee of the British Medical Association, argued that it was a mistake to equate medical ethics with bioethics, that rather ethics concerns human values. And he pointed to medical tradition to argue that ethics is actually all about relationships. But as he went on he raised the question as to whether, in view of the wide variety of values in society, it is possible to achieve a consensus view, although on this issue he did not agree that we live in a multicultural society. Rather he argued, ours is a unicultural or perhaps bicultural

society: those who believe in some sort of God and those who do not. Horner suggested that those who believe in God as the basis for common core values should be able to express this. Indeed, studies in Britain have shown that a majority of people still believe, however vaguely, in the traditional Judaeo-Christian conception of God (Davie, 1994; BBC, 1995; ITC, 1994).

Maybe this is true for you in the Netherlands. In the British newspaper, *The Times*, recently (September 19, 1996), the Dutch Queen, Queen Beatrix, is reported as staking out the moral high ground, reminding the Dutch of the strong national streak of Calvinist thinking, and the need to articulate some older conservative virtues. But this is the real issue. Should the Christian view be part of this debate? And if it should, how should it be expressed?

In my experience it has often been Christians themselves who have been reluctant to express the Christian viewpoint for fear that they would be accused of imposing their views. Rather keep our views to ourselves, they argue. Keep the faith quietly. Yet, if we remain silent and say nothing our tradition may well die out. As the philosopher, Edmund Burke, has said, evil prospers if good men do nothing. For people like Nightingale, Pastor Flidner, Elizabeth Fry, Lord Shaftesbury and in our day Cicely Saunders, the answer was clear. Christians needed to be involved in the structures of society to preserve, or indeed awaken, the values of care.

I mentioned Berkhof's view earlier. It seems to me that the nursing profession, in my country, cut off from its roots, is now no longer sure of what it is. At a meeting recently a non-nurse asked for a short definition of 'nursing' for a dictionary she was writing. Six nurses were present, and no-one could give a satisfactory answer. The debate centred on whether Virginia Henderson's definition from the 1960s could still be used to describe the registered nurse in the 1990s.

Henderson's famous premise was adopted by the International Council of Nurses and revised in 1969. She stated: 'The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge. And to do this in such a way as to help him gain independence as rapidly as possible' (Henderson, 1969:4).

It is important to note the origins of her definition. Her biographer, James Smith (1989), observes that Henderson was brought up in a strongly religious Protestant home, and, as she tells him, this had a profound influence on her. Probably it was a biblical insight (from Job chapter 29 verse 15) that inspired her description of the nurse on the following page: 'She is temporarily the consciousness of the unconscious, the love of life for the suicidal, the leg of the amputee, the eyes of the newly blind, a means of locomotion for the infant, knowledge and confidence for the young mother, a "voice" for those too weak or withdrawn to speak, and so on' (Henderson, 1969:5).

And this question of 'what is a nurse' and 'what is nursing?' is constantly being asked. The governing body of British nursing, the United Kingdom Central Council of Nursing Midwifery and Health Visiting, is currently trying to decide what might constitute 'advanced nursing prac-

tice' and 'specialist nursing practice', but even 'ordinary nursing practice' is no longer clear. As one nurse manager commented, you have to 'articulate' nursing if you are going to sell it to managers. This seems amazing to me. Do we really have to persuade hospitals to buy nurses? At the same time as nursing is seeking to justify itself there is a recruitment problem (Recruitment, 1995)

But the reason for this is perhaps not so strange. For it may be that as boundaries change between the health care professions and as nursing seeks to 'advance' itself, nursing will itself need to be redefined. Henderson's definition is considered to be no longer adequate. The person who often attends to the basic human needs of the patient is now not a registered nurse at all but a minimally trained health care assistant. Such a person is cheaper to employ than a registered nurse and may increasingly be the norm. But will nurses then have redefined their own role. Will nursing become a totally new profession? And who will be the genuine nurses then?

In my view nursing will not be nursing if it is no longer concerned with compassion and practical care of the most basic kind. In my present post I have had to fight quite hard to remain for a proportion of my time in clinical practice caring for the elderly as an 'ordinary' nurse. I have had to argue that if nursing is anything at all it is lived out in the simple practicalities as much as in the complex techniques. For me it is a tremendous privilege and responsibility to share the life of another human being when they are sick and at their most vulnerable. And it is washing the patient, shaving his growth of beard, cleaning his dentures so that his mouth feels fresh, that makes me a 'real' nurse. It is in the cup of tea, and the time spent talking or listening. It is in holding his arm to help him walk, it is in cleaning away his diarrhoea. Real nursing is in these apparent simplicities just as much as it is in being competent to administer intravenous fluids, give complex drugs, or carry out complicated procedures.

Much of nursing is not easy or glamorous work. There is no status attached. It can be very difficult and frustrating. Perhaps the patient is rude and demanding. Perhaps he has just been settled and made comfortable when he is incontinent again, and all his clean clothes so carefully adjusted need to be removed. But this building of a relationship does not depend on one's own personal feelings, whether one instinctively likes the patient, or whether one does not. It is looking into his eyes and seeing a person made in the image of God. This has traditionally been the power and strength that made nurses what they were. And it is in this sharing of a patient's and his family's life for a time, however brief, which makes nursing what it is.

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Primary Vaginal Cancer in Pregnancy: Difficulty in the Ethical Management

Introduction

Primary vaginal cancer is an unusual malignancy seen most commonly in the post-menopausal patient population. Its occurrence in pregnancy is even more unusual. When diethylstilbestrol (DES)-exposed women began to reach the age of reproduction, there was an increase in the incidence of vaginal cancers in pregnancy.¹ But even then, there were few cases of vaginal or cervical cancer during pregnancy in that period of time that were directly related to the use of DES. Those vaginal cancers seen with DES were of the clear cell type. The most common cell type seen in typical vaginal cancers is that of squamous cell carcinoma. In the world's literature, there have been only twelve reported individuals with the diagnosis of squamous cell carcinoma of the vagina in pregnancy.^{2,3} The authors are reporting a primary cancer of the upper third of the vagina diagnosed concomitantly with a 14-week intrauterine pregnancy (IUP) and the ethical and medical judgments that went into its management.

Case Report

M. W. is a 33 year old married white female who was in her usual state of health when she was diagnosed with a normal intrauterine pregnancy and subsequently seen by her obstetrician. At her initial evaluation, with a 10-week pregnancy, she underwent a routine pap smear. The patient's smear suggested a high grade abnormality of the cervix consistent with severe dysplasia. She had a colposcopy by her physician which showed a pre-malignant lesion called carcinoma-in-situ, confirmed by biopsy. At this point, the patient was referred to the gynecologic oncologists to evaluate further and make recommendations. The lesion on the cervix was seen and a repeat biopsy of the cervix was not performed since the lesion did not appear worse than at the previous biopsy. The remaining examination was normal and no other abnormalities were visualized. The patient was asked to return in one month for re-evaluation and to check for progression of the cervical abnormality. It must be noted that no treatment for carcinoma-in-situ of the

cervix was offered in early pregnancy since it is standard care to follow these pre-malignant lesions closely in pregnancy and not treat when the entire lesion is visible and the pap smear and colposcopic examination do not suggest a more aggressive abnormality.

In one month's time (14-week IUP), the patient returned and had a repeat examination. The cervix appeared unchanged but the rest of the examination revealed a new abnormality. Posterior to the cervix was a one by one centimetre area that was slightly exophytic and clearly visible. A biopsy was obtained and the patient was diagnosed with at least micro-invasive squamous cell carcinoma of the vagina. She was then taken to the operating room for an examination under anesthesia and deeper biopsies. The final diagnosis at that time was a two by two centimetre rapidly growing stage I squamous cell carcinoma of the vagina. The lesion was posterior and left and came within five millimetres of the cervix but was not touching it. Further evaluation did not reveal any other areas in which the tumour had spread.

The choices left at this point, to the physicians and to the patient, were to treat versus no treatment. Treatment by either of the two acceptable methods would be deleterious to the infant and result in the loss of life. The authors will discuss these arguments later. The patient opted for radiation treatment and this was performed in the following fashion: the patient had whole pelvic radiotherapy given in two parts. The external beam was delivered with a two-field A-P technique administering 4500 cGy to the pelvis. External beam was delivered in 25 fractions at 180 cGy per session. During the external beam, at approximately 900 cGy, the pregnancy was viable as expected and continued to have some growth with the uterus. The mother opted to have a dilatation and evacuation at this juncture and therefore terminated the pregnancy. This pregnancy loss was followed by the remainder of the treatment with external beam. Two weeks after the external beam treatment, the patient had one internal placement of cesium. The use of a tandem and vaginal rings to deliver high dose brachytherapy at a dose of 3500 cGy to the mucosal surface of the vagina was then performed.

The patient finished treatment and had a complete clini-

cal response with no evidence of residual disease. She is presently being followed in routine follow-up to monitor for recurrence.

Discussion

Vaginal cancer is the least common cancer of the female genital tract.⁴ Less than one to two thousand cases occur in a given year in the United States. Most of these patients are post-menopausal at the time of diagnosis. Cases involving pregnancy are exceedingly rare. To date, according to the literature search, the authors are aware of only twelve previous squamous cell cancers of the vagina that have been seen during pregnancy.^{2,3}

The treatment of the vaginal cancer depends predominantly on the location of the lesion and the stage of the cancer. Vaginal cancer is clinically staged; meaning the physician performs a pelvic examination and depending on the size of the cancerous lesion, treatment is tailored to the situation.⁵ The predominance of all vaginal cancers are treated with primary radiotherapy.⁶⁻⁹ When a cancer involves the upper third of the vagina as in this case, radiation or a radical hysterectomy with radical upper vaginectomy would be the two possible treatment approaches. Either sequence of events would lead to the loss of the pregnancy. Given the size of the lesion in this case, at two by two centimetres, and its somewhat lateral location, the treatment of choice was believed to be radiation. The effects of ionizing radiation on the embryo or fetus include lethality, congenital anomalies, growth retardation, carcinogenesis, sterility, and genetic effects.^{10,11} Significant factors of importance regarding the frequency and severity of these effects include the radiation dose and stage of gestation at which exposure occurs. Lethality can be induced by relatively small doses in the early embryo. However, large therapeutic radiation doses required to cure pelvic malignancies in pregnant women are uniformly fatal to all stages of embryonal intrauterine development. This is analogous to whole-body irradiation in the post-natal human being where doses as low as 300 cGy can be lethal to the hematopoietic syndrome, inducing bone marrow failure.¹² Knowing this placed the physicians in a difficult situation, since the patient had no other children, would lose this pregnancy, and would lose all future fertility after the treatment for the cancer.

It must be noted that all the physicians involved in the care of this patient were pro-life and had not been involved in performing elective abortions. However, they were all faced with the dilemma on the treatment of this cancer with the inevitable loss of life. Given this perplexing situation, several ethical questions were asked: (1) Can offering this individual the option of waiting for the pregnancy to deliver be entertained? (2) How does a physician approach a case in which choices for life and choices for death are simultaneously made? (3) What is the approach for the family involved as far as choosing for the infant or the wife?

1. In answer to question number one, no data have been published that would allow the physician to know if waiting is an option. Similar information is known on the progression of cervical cancer in pregnancy. Since

the behaviour can be similar between the two cancers, some deduction may be allowed. In series by Duggan et al. and Sorosky et al., they both published accounts of eight separate patients that were pregnant with cervical cancer that opted to wait until viability with the pregnancy before treatment.^{13,14} The mean delay of treatment was 144 and 109 days respectively and the outcomes were all favourable in these series. Does this mean that delay could be considered in this patient? It is difficult to interpret this information in the light of our case being vaginal and not cervical cancer. Even though as stated, there may be some similarities in these cancers, there are also some noted differences in the behaviour of these two cancers. Spread patterns vary in vaginal cancers depending on the location of cancer within the vagina whereas many cervical cancers behave in a more consistent manner. In this case, with the cancer being located in the upper third of the vagina, it probably would behave similarly clinically to a cervical cancer. But this cannot be known with any great certainty. So translating survival information from this type of cancer to another may be a little risky as far as basing life and death decisions is concerned. This information was however shared with the patient, but in its proper light. As is noted from the case history, the patient opted for treatment. The authors believe that this was the more prudent 'choice', given our lack of knowledge about this cancer in pregnancy.

2. In answer to question two about making choices for life and death, this poses a difficult dilemma. No physician wants to be placed into this type of scenario. Very rarely do physicians have to choose between two individuals. Examples might be in the separation of Siamese twins or the obstetrical literature choosing between the mother and the child when the mother has a life threatening medical problem. In obstetrics, situations arise with diseases like preeclampsia or severe cardiac disease in which choices have to be made. If the underlying disease process is allowed to go unabated to the time of viability for the pregnancy, the mother may succumb to the disease process, killing both her and the infant. The physician must ask an honest question as to what will happen if one waits until viability in the infant. The question can never be answered with certainty because no physician can know absolutely the ultimate outcome of a disease process if it is left untreated for 'a time'. But obviously latitude for reasonable medical judgment must be allowed. In this cancer case, the authors believed that with the rapid growth shown over four weeks by the tumour, the patient had a reasonable possibility of having metastatic disease if therapy were delayed by a significantly prolonged period of time. If this were to occur, then the patient would almost certainly die from the disease since metastatic squamous cell cancer of the vagina is very difficult to cure. If, of course, the cancer progressed rapidly during the pregnancy the patient could conceivably die with the pregnancy *in utero* thus resulting in the loss of two lives (although this type of accelerated growth pattern would not be expected). Also it is possible that the infant could have had a metastasis from the malignancy as has been reported in some fifty other non-vaginal cancer cases in

the world's literature.¹⁵ So in making this 'choice' by the physician, honest questions and answers must be entertained and answered looking at the multiple different scenarios. Only then can the physician make the 'best choice' in decisions for life and death.

3. The final question dealing with how the family 'chooses' who will possibly live and who will possibly die in a cancer situation is more important than what the physicians chooses, since the final choice lies with the family. The family wrestles between the 'permanent' relationship between the husband and wife and their need and desire to continue this marriage and the future relationship with the child. In analysing this difficult decision, the family must consider the difference between these two relationships in light of the probability of death of the spouse if the pregnancy is allowed to continue. The one marriage relationship should be considered 'permanent' since vows are given until death do them part. Does this mean that the husband should counsel his wife that this may be the 'death due them part' and encourage against treatment? The authors would not agree with this idea and believe that if reasonable treatment can be offered to potentially cure the patient that this should be the encouraged route by the husband. The other relationship between the parents and a future child is biblically a temporary one since a child is commanded to 'leave and cleave', thus ending this direct, in the home parent-child relationship. It is a fine line though, since we never really break the relationship with our children, we just change the roles. As the authors see it, it is the physician's role not to make the choice but to give the patient and their family the information to work with to allow them to make an informed choice. But the best choice would seem biblically mandated towards preserving the 'permanent' marriage relationship.

Conclusion

This is a difficult case for physicians who hold the pro-life position. We were torn between keeping an oath to preserve and care for life while simultaneously taking a life. A non-enviable situation to be sure and yet one that is made all over this country and in the world everyday. In

this situation, the patient had a complete response to treatment and should have a 90% probability of a five-year survival. The patient lost the pregnancy and also future fertility in exchange for a real option of life. A chance that her physicians are elated about and yet at the same time can only hope that they made the right 'choices'.

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Bioethics and the Future of Medicine

A Christian Appraisal

Editors, John F. Kilner, Nigel M. de S. Cameron, and David L. Schiedermayer

While abortion is a vital aspect of the exploding bioethics agenda so are issues such as euthanasia, genetic engineering, health care rationing, assisted reproduction. The 23 essays in this book deal with the practice of medicine; the ethical underpinnings of medicine; the evolving abortion crisis; and the expanding bioethics agenda.

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'The Least a Parent Can Do': Prenatal Genetic Testing and the Welcome of Our Children

Recently I had an experience which brought home to me the extent to which prenatal testing is already affecting the experience of parenthood, and the kinds of subtle pressures it can exert on the way we view our offspring. My wife and I are both physicians in our mid-thirties, and we were expecting our second child. Because of my wife's age our obstetrician recommended an ultrasound plus amniocentesis to look for the abnormalities of which our child would be at special risk. We declined the amniocentesis on the grounds that it would reveal nothing that would change our decision to carry the pregnancy to term, and that it posed a risk to both mother and child. We did, however, consent to the ultrasound, because it was harmless and it potentially could show something that would be useful to know, like an obstructed kidney or hydrocephalus that needed prenatal shunting or a neural tube defect that would indicate cesarean section.

On the appointed day we were shown into the ultrasound suite by a pleasant young technician. She, we soon discovered, had recently had a baby herself, and she seemed thoroughly to enjoy giving us our first visual contact with our child. For the next half-hour she flashed the transducer across my wife's abdomen with smooth, efficient strokes, regaling us with shot after shot of our new, lovely child. She had a wonderful knack for moving the transducer at just the right speed and in just the right line to give the image that appeared on her screen a real-time, three-dimensional appearance. Our baby was twenty-two weeks old, eleven inches long, and had a skull barely two inches in diameter. Everything appeared perfect. We watched our baby yawn, rub its eyes, roll over and stretch. It was an intensely intimate and moving experience. Our child was all glory in miniature, and we welcomed it wholeheartedly into our lives. All too soon the technician announced she was finished, and reluctantly we prepared to go. 'Oh', she said, 'you're not finished yet. Before you go we need a physician to go over the shots—but don't worry, it's just routine.'

We were only too happy to comply—we were glad to get a few more peeks. Soon the doctor was with us. She was only a little older than the technician—our age, in fact—but she seemed utterly lacking in her colleague's joy. For the next hour she ploughed through her exam with single-minded intensity. She took shots from every aspect and angle, reminding us again and again that she couldn't guarantee that our 'fetus' wouldn't have Down's—even though everything looked good; the sensitivity of the ultrasound

for that sort of thing was only 50%. Didn't we want an amnio? Hmm . . . just so we understood that we couldn't really rely on the ultrasound. . . .

The exam with the physician was different from the first: less enjoyable. Technically, she was a marvellous ultrasonographer—the pictures she took were even clearer and more detailed than the technician's. It was just that her view of what was going on in that suite was so entirely different from ours. We saw ourselves as the welcome wagon. She viewed herself as quality control.

The view that medicine—and parents in partnership with it—should be in the business of controlling the quality of the offspring delivered has become increasingly prevalent in recent years, fuelled by the growing availability of prenatal testing and genetic testing. Consequently, new questions have been raised regarding our proper roles as parents and the nature of our relationships with our children. Furthermore, as diagnostic advances have surged ahead of comparable advances in treatment, parents have increasingly been faced with difficult and painful decisions regarding their own reproduction and the treatment of their developing children—decisions which have proved especially difficult for those who believe that developing life is sacred, and that the bearing of children is heavily freighted with symbolic, spiritual, and sacramental meanings.

In this article we will examine some of the questions raised by the growing availability of genetic and prenatal testing, and we will seek to determine the implications of the various potential answers both for our understanding of the family and the place of reproduction in human life.

Genetic Testing and Genetic Abortion

Prenatal testing is usually offered in one of several situations. First, when parents are known to be at special risk of carrying a disease gene, usually because they are members of an ethnic group known to be at high risk for certain diseases; because they have a previous child or a relative with genetic abnormalities; or because they have had multiple previous miscarriages. Second, when maternal age is 'advanced'—usually age 35 or over. Third, when routine maternal blood screens such as the serum alpha-fetoprotein level yield an abnormal result. Prenatal testing may begin with relatively non-invasive procedures such as ultrasonography or maternal peripheral blood sampling,

but it often progresses to involve the use of more invasive tests like amniocentesis or chorionic villus sampling, which require instrumenting the uterus to obtain samples of fetal tissues. Such tests carry risks for the termination of pregnancy of between 0.3 and 4.5 percent.¹

The information gathered through such procedures may be used in a variety of ways. Several of these uses are widely considered to be morally uncontroversial, even by those categorically opposed to abortion or destruction of embryos. It may be used simply to allay the fears of prospective parents, to prepare them for giving birth to a child with special needs, or to allow for special precautions at the time of delivery. If, for example, a mother were shown soon after the third month of pregnancy to have an abnormally high alpha-fetoprotein level, an ultrasound could be performed which might reveal the presence of a neural tube defect such as spina bifida or meningomyelocele which would render her fetus susceptible to trauma during normal labour, and an elective cesarean section could be scheduled instead. Such information may also be used to help carriers of disease-causing genes make decisions regarding marriage or reproduction. Evangelical theologians John and Paul Feinberg have written: '[I]t is hard to argue that early detection of those who will get a [genetic] disease so as to treat it or discovery of carriers of a recessive gene so that they may make informed decisions about marriage and reproduction are immoral uses of genetic screening.'²

In contrast to such uses, the information gathered from prenatal testing may also be used in ways which generate profound moral controversy, as in decisions to abort genetically abnormal fetuses or to destroy genetically abnormal *in vitro* fertilized embryos. Indeed, the promise of such uses has frequently been offered as one of the primary justifications for the Human Genome Project, usually under the rubric of 'disease prevention'. As Evelyn Fox Keller has noted: '[P]revention means preventing the births of individuals diagnosed as genetically aberrant—in a word, it means abortion.'³ Keller supports her contention by citing one scientist who extolled the benefits of the Genome Project as follows: 'Pointing to schizophrenia, which he claimed currently accounts for one-half of all hospital beds, Charles Cantor, the former head of the Human Genome Center at the Lawrence Berkeley Laboratory, recently argued in a lecture that the project would more than pay for itself by preventing the occurrence of just this one disease. When asked how such a saving could be effected he could only say: "by preventing the birth" of schizophrenics.'⁴ Ruth Schwartz Cowan notes similarly that, 'We need to be very clear about what therapy is currently available for most diseases or disabilities that can be diagnosed prenatally: none. The only recourse for patients whose fetuses are diagnosed as having Down's syndrome, or spina bifida, or Turner's syndrome, or Tay-Sachs disease, or sickle cell anemia, or one of the thalassemias is abortion, a process that can hardly be described as therapeutic. This means that, for the foreseeable future, the ethical and social implications of the human genome project are going to be inextricable from the ethical and social implications of abortion'⁵.

Although the right to obtain an abortion has not been legally prohibited in the United States for over twenty

years, abortion is still usually regarded as a moral issue even by those (such as Cowan) who believe the procedure justifiable. This is particularly true in the case of abortions which are obtained for genetic reasons, which for ease of usage will be referred to as 'genetic abortions'. Indeed, it is rare to find anyone, either in the professional literature or in a public policy forum, who denies that there are serious moral considerations concerned with this issue. While a variety of justifications have been offered for the practice of genetic abortion, I will focus on three which are most frequently given.

First Justification: Fetal Benefit

The first and most common means of justifying genetic abortion is by pointing to the benefit it gives to the fetus. According to this line of thinking, since fetuses with severe genetic disorders are destined to have lives of such poor quality, the most merciful thing one can do for them is prevent their birth. In his recent book *The Lives to Come*,⁶ philosopher Philip Kitcher provides a typical argument of one who holds such views, and of the ways in which the lives of those suffering from severe genetic defects may be viewed as being of poor quality.

According to Kitcher, an individual's quality of life can be measured along three axes.⁷ The first of these axes reflects the individual's ability to form a sense of what is valuable and important to him or herself as a person. According to Kitcher, an individual must be able to form such a sense of values in order to attain the status of 'personhood' which is required for membership of the human moral community. In employing this criterion, Kitcher follows a line of thought which originated with Immanuel Kant. According to Kant, human dignity is a product of the human capacity for autonomy or moral self-legislation, a capacity belonging solely to rational creatures. By virtue of this capacity, rational beings are creatures 'of infinite worth' and 'deserving of respect'. For Kant this meant that a rational being must be regarded only as 'an end in itself' and never simply as a 'means'. Kant referred to rational beings as 'persons', while he called non-rational beings 'things'.⁸ Only the former were considered 'objects of respect' and hence deserving of protection from 'arbitrary use'. Kitcher uses similar arguments in setting standards which he believes any human life must meet in order to be considered even minimally valuable. For Kitcher, any individual who, as a result of genetic disease, is destined never to attain this state of personhood, may justifiably be aborted. Kitcher gives the example of Tay-Sachs. 'Doctors, parents, even many religious leaders agree on the permissibility of terminating pregnancies when the fetus is diagnosed as positive for Tay-Sachs, not because the baby will suffer pain—that can relatively easily be avoided—but because neurodegeneration will start before the distinctive life of an individual person can begin.'⁹

The second of Kitcher's quality of life axes reflects the extent to which an individual's autonomously chosen values and desires are satisfied. According to Kitcher, there are certain genetic disabilities which, though they may not affect an individual's ability to form a system of values, inevitably prevent their realization of goals which are

typically regarded as of central importance to most human lives. As such, quality of life is diminished, often to the point where that life may be considered not worthwhile. In this regard Kitcher cites as paradigmatic disorders which result in severe immobilization and dependence, though he also implies that disorders resulting in infertility or shortened life span may similarly deprive life of worth.

Kitcher's third quality of life axis reflects the balance of pleasure and pain which are expected to occur in an individual's life. His typical examples include Tay-Sachs disease, which results in an early onset of painful neurological degeneration, and Lesch-Nyhan syndrome, which results in painful, compulsive self-mutilation.

According to Kitcher, when faced with a developing fetus who is known to have a genetic defect which we believe will cause it to have a life of poor quality, it is morally permissible, and in fact even morally commendable, to abort that fetus. Most contemporary bioethicists agree. Others go even farther, calling such abortions morally obligatory. Philosopher Margery Shaw has even charged that parents who knowingly give birth to a seriously impaired child are guilty of negligent child abuse, and has urged that courts and legislatures develop standards by which parents should be held accountable for the genetic health of their children.^{10,11}

Though the near-consensus among secular thinkers that quality of life considerations are sufficient justification for genetic abortion is not entirely unexpected, what *is* perhaps surprising is the apparent acquiescence to this view among a number of religious groups which have traditionally been strongly opposed to abortion. Such groups include the Greek Orthodox and Roman Catholic churches in Cyprus and Sardinia where beta-thalassemia is rampant, and certain Orthodox Jewish communities afflicted with a high incidence of Tay-Sachs disease. While we might expect the leaders of such communities to agree with secular thinkers that children affected by severe genetic disabilities are destined to a quality of life which we would not willingly *choose* for them, we might expect them to oppose the premise that we are therefore justified in taking their lives through genetic abortion.

Even if we set aside our concerns about abortion in general, we should still be troubled by the fact that the quality of life criteria which Kitcher adduces could equally well be used with to justify the killing of severely handicapped infants, and mentally impaired children and adults. Such criteria could also be used to justify abortion for sex selection—a practice almost universally condemned by western bioethicists—especially in countries such as India and China where there are clear differences in expected quality of life for male and female children, and where females can be highly restricted in their ability to form and fulfil their own sets of values. Indeed, such subjective third-party assessments of quality of life are unavoidably elastic, capable of being stretched to accommodate whatever concerns or biases the assessor might have. Such considerations should give us pause, and lead us to wonder whether Leon Kass was perhaps right in claiming that the principle ‘“Defectives” should not be born’ is a principle without limits.¹²

There are other reasons to question both the validity and wisdom of this first type of justification; but as they apply

equally to the two justifications we have yet to consider, they will be dealt with below.

Second Justification: Societal Benefit

The second kind of justification commonly offered for genetic abortion is that it increases the well-being of the society as a whole, and of future generations in particular. Those with genetic diseases, it is argued, consume a large quantity of limited societal resources which yield only a limited benefit to themselves and no benefit whatsoever to the rest of society. These resources, it is claimed, could better be used to fund immunizations, disease prevention, or biomedical research which could ultimately benefit millions. Philip Kitcher provides a characteristic argument along these lines: ‘To the extent that funds for social programs are tightly limited, support for [children born with severe disabilities] diverts money that could be used to improve the quality of the lives of many others.’¹³ What should be the proper response to this fact on behalf of parents? Kitcher answers: ‘[B]ecause reproductive decisions do not occur in social vacua, responsible reflections must recognize that new lives impose demands. If everybody acted as we are inclined to, what would be the effect on the well-being of other children and adults in our society?’¹⁴

Kitcher's arguments are predicated on a number of claims whose validity he seems to assume but which others may be inclined to doubt. First, his claim that genetically handicapped children will deprive others of scarce and costly medical resources is predicated on the premise that the total amount of money available for the care of the ill is somehow gravely limited—a claim which, however often repeated, is lacking in factual support. The actual quantity of money that will be available for such purposes—especially in the affluent societies of the West—will be an indication of the value which the citizens of those societies place upon such uses. As such, a better response to a shortage of funds would be to explain both the inherent value and the neediness of our handicapped citizens and to appeal to the public at large for their support. Arguing as Kitcher has done will only increase societal prejudice against handicapped persons, implying as it does that their births were somehow the result of selfish or even anti-social acts. Such prejudice can only decrease the public's willingness to assist the handicapped.

Kitcher's arguments are also predicated on the claim that genetically disabled persons can confidently be known to consume more societal resources than their non-disabled counterparts. While this claim seems to have greater relevance for some disorders than others, it would be hard to demonstrate its accuracy for any known disorder. As Leon Kass has pointed out, ‘Many questions can be raised about [such an] approach. First, how accurate are the calculations? Not all the costs have been reckoned. The aborted “defective” child will in most cases be “replaced” by a “normal” child. In keeping the ledger, the costs to society of his care and maintenance cannot be ignored—costs of educating him, or removing his wastes and pollutions, not to mention the costs in nonreplacable natural resources that he consumes. Who is a greater drain on society's precious

resources, the average inmate of a home for the retarded or the average graduate of Berkeley? I doubt that we know or can even find out.¹⁵ There is additionally the hidden cost to society which the 'normal replacement' child has if he or she is a carrier for a recessive genetic disease and subsequently passes that disease gene on to subsequent generations—something which the handicapped person him or herself will most often be unable to do. Indeed, there is actual empirical data to suggest that for certain kinds of disorders, genetic testing as it is currently practised actually has the 'dysgenic' effect of raising the frequency of disease alleles that are passed on to subsequent generations. Marc Lappé has written that 'the process of aborting a fetus with a deleterious recessive disease and then compensating for the loss of the expected child by trying to have more children ultimately results in a subtle increase in frequency of the recessive gene over many generations. This is true because with reproductive compensation, two-thirds of all of the live children will be carriers of the recessive gene at issue, instead of the one-half normally expected without prenatal diagnosis.'¹⁶ A similar effect can be expected with X-linked disorders also.

Perhaps the strongest objection to such societal good arguments is that we have powerful reasons for doubting the claim that our society's good is to be found in the intentional killing of any of its members. Even without appealing to divine standards of justice, we should remember that our society has been founded on the notion that all human beings possess an 'unalienable right' to life, and that all of us have been created equal; not equal in every respect, of course—not equal in talents or capacities or intellectual abilities—but equal in the politically important sense that we possess an 'unalienable right' to life, simply by virtue of our membership of the human community.¹⁷ Once this membership ceases to be awarded to each and every individual simply on the basis of his or her descent from human parents—once, in other words, it is awarded only to those possessing certain abilities or capacities—the guarantee of 'unalienable rights' that has been the backbone of our democracy will be formally meaningless, and human rights will belong only to those who are beloved by the powerful. It is for this reason more than any other that all people in our society—whether believers in the divinely ordained value of human life or not—should be highly suspicious of any purported societal good which requires the abandonment of our society's belief in the moral equality of all human beings.

Third Justification: Familial Benefit

The third justification for genetic abortion is that it benefits the family into which the defective child would otherwise be born. Severely defective infants, it is argued, place such great demands upon a family that they significantly reduce the quality of the lives of the other family members. Philip Kitcher again provides a typical example of such an argument when he urges that we take account of such facts when we think about genetic abortion. He bases his argument upon the oft-recited contemporary claim that human beings, until they attain the status of autonomous persons, are devoid of any intrinsic value, and as such, any value

which they possess as non-persons must be conferred upon them by others. When an essentially worthless prenatal life poses a great threat to the quality of already existing lives it is only reasonable to abort it. Kitcher expresses this view in the form of a paraphrase of Ronald Dworkin: 'Liberals about abortion take the value of human lives to arise as the result of human investment in lives. In consequence, they view the continuation of some pregnancies as greatly diminishing the value of lives—the lives of parents, children already born, others who are affected—in which there has already been substantial human investment, and see this diminution of value as a far greater loss than the cessation of a human life that has not yet "begun in earnest".'¹⁸

Even if we ignore the question of whether a fetus has any intrinsic value, we may still question the apparent confidence of Kitcher and Dworkin that they can know in advance what sorts of events would or would not be good for 'families' as such. While many families have no doubt experienced considerable grief and disruption after the birth of a handicapped child, many others have found the experience deeply enriching. Author Pearl Buck, for example, has written movingly of the experience of having a daughter gravely retarded from PKU: 'A retarded child, a handicapped person, brings its own gift to life, even to the life of normal human beings. That gift is comprehended in the lessons of patience, understanding, and mercy, lessons which we all need to receive and to practice with one another, whatever we are. My feelings can be summed up, perhaps, by saying that in this world, where cruelty prevails in so many aspects of our life, I would not add the weight of choice to kill rather than to let live.'¹⁹ Another Nobel Prize-winning novelist, Kenzaburo Oe of Japan, has written extensively of his and his family's enriching experience of raising a mentally handicapped child. In his recent memoir *A Healing Family* he writes: 'Twenty-five years ago, my first son was born with brain damage. This was a blow, to say the least; and yet, as a writer, I must acknowledge the fact that the central theme of my work, throughout much of my career, has been the way my family has managed to live with this handicapped child. Indeed, I would have to admit that the very ideas that I hold about this society and the world at large—my thoughts, even, about whatever there might be that transcends our limited reality—are based on and learned through living with him.'²⁰ This birth was for Oe 'a case of "perfect timing," an immensely important event that occurred at a vital moment in my life',²¹ and he can say of it now that 'My greatest source of pride these days is the fact that my brain-damaged son is a decent, tolerant, trustworthy human being who also happens to have a good sense of humor. And his strength of character has had no small influence on our family. In the course of living with him, I have come to know many disabled people, their families, and those who help with their rehabilitation, and I have seen how each shoulders his or her own burden. The signs of this suffering are clearly visible on the faces of the handicapped, even when they have reached the stage of acceptance; and those around them are no doubt similarly marked. But I believe there is another sign that all these people share: their common decency.'²²

Leon Kass captures well the difficulties of the view that familial hardship is inevitably harmful: 'It is not entirely clear [in any family] what would be good for the other

children. In a strong family, the experience with a suffering and dying child might help the healthy siblings learn to face and cope with adversity. Some have even speculated that the lack of experience with death and serious illness in our affluent young people is responsible for their immaturity and lack of gravity, and their inability to respond patiently and steadily to the serious problems they encounter in private or community life. Doubtless many American parents have unwittingly fostered childishness by their well-meaning efforts to spare their children any confrontation with harsh reality.²³ Christians especially would seem to have reason to challenge this unquestioning desire to avoid suffering, even at the cost of another's life, and the low value which contemporaries ascribe to the sacrificial care of the helpless. This is not to make light of the very real sufferings which those who give birth to handicapped children experience, but it is an attempt to do justice to the very real value which suffering may sometimes have in human life, and to question those who pretend to know in which direction the good for a family inevitably lies.

Each of the three putative justifications for genetic abortion which we have discussed contain additional difficulties in their thinking about the family, the most fundamental of which involve misunderstandings of the ultimate purposes of parenthood and of the relationship between parents and children. It is to an examination of these misunderstandings that we will now turn, and since we are seeking the sources of misunderstandings in predominantly secular thought, we will begin by examining the ideas which are most characteristic of contemporary secular views of the family.

Secular Views of the Family

Aristotle was perhaps the first secular philosopher seriously to address one of the most fundamental questions regarding the nature of the family: why parents desire to have children. In *De Anima* he wrote: 'For this the most natural function of living creatures . . . namely to make another thing like themselves . . . so that in the way that they can they may partake in the eternal and the divine. . . . Now the living creature cannot have a share in the eternal and the divine by continuity, since none of the mortal things admits of persistence as numerically one and the same, but in the way that each creature can participate in this, in that way it does have a share in it . . . and persists not as itself but as something like itself. . . .'²⁴ For Aristotle, then, the desire to procreate is tied up with the deepest desires of the soul: the desires for immortality and transcendence. In his *Nicomachean Ethics*, Aristotle says further of the relationship between generations that parents love their children as 'a part of themselves'—an offshoot, as it were—'for one's offspring is a sort of other self in virtue of a separate existence'.²⁵

Contemporary philosopher David Heyd expands further on the topic of parental desires, revealing both their positive and negative aspects: 'It is a universal cultural fact that human beings desire to have children and that they raise them more or less "in their own image". Empirical research enumerates a wide variety of motives for having children: economic need (children as work force), security

(for old age), status, power, psychological stimulation, expression of primary group ties (love), companionship, self-realization, the preservation of lineage, the continuation, multiplication, or expansion of the self, a religious or moral duty (to God or society), even simple fun. This long list indirectly supports a generocentric view of procreation, as the list conspicuously does not consist of "altruistic" motives, that is, those concerned with the good of the future child. The decision to have children is one of the most selfish of human choices, and parentocentric motives guide not only the positive choices (to create another happy child), but also the negative (refraining from begetting a handicapped child). For as a matter of psychological fact, we rarely face a case in which the parents wish to have a (handicapped) child but decide to assign an overriding weight to the "interests of the child" not to be born. It is the parents who do not want a suffering child. . . . We want to have children for our own satisfaction; we want them, therefore, to be of a particular nature (identity), that is, sufficiently similar to us; and we want them to be of a certain number, such that we can maintain that kind of quality of life (for us and for them) which would secure that satisfaction.'²⁶

Thus, in the contemporary view of the parent-child relation, children are not only *from* the parents, but also *for* the parents, and their existence is to be valued only in so far as it furthers parental aims or pleasures. This view is behind the following claim of H. Tristram Engelhardt that pre-rational children are a form of parental possession: 'One also owns what one produces. One might think here of both animals and young children. Insofar as they are the products of the ingenuity or energies of persons, they can be possessions. There are, however, special obligations to animals by virtue of the morality of beneficence that do not exist with regard to things. Such considerations, as well as the fact that young children will become persons, limit the extent to which parents have ownership rights over their young children. However, these limits will be very weak, at least insofar as they can be made out in general secular terms, with regard to ownership rights in human zygotes, embryos, and fetuses that will not be allowed to develop into persons, or with regard to lower vertebrates, where there is very little sentience.'²⁷

The view that parents possess absolute rights over their offspring is not, of course, new. Historically it was embodied in the Roman law of *patria potestas* which gave absolute power over the life and death of children to their father, and with only slight modification this has been the controlling principle in parent-child relations in most cultures throughout most of history. Such views, however, began to be questioned in the West, from about the seventeenth century. At that time the rights of parents over their children came to be viewed as being analogous to the rights of kings over their subjects—rights which at that time were beginning to come under heavy fire.

Nowhere was this subject more keenly debated than in England. Thomas Hobbes and his contemporary Robert Filmer were the most powerful defenders of the old order. Hobbes argued in his book *Leviathan* that based on their relations in the state of nature, parents have no fundamental obligations to their children. Their primary duty rather is to protect themselves, which entitles them to keep their

children in a state of submission by threat or, if need be, by violence. For Hobbes, the war of all against all extended even into the family. Filmer echoed Hobbes in claiming that parents—or rather fathers—possess absolute authority over their children. For Filmer, this power is given by God: divine in origin, and in authority.²⁸ Through procreation, the father becomes owner of his children. He made them, and they are his property to do with as he will. His authority is absolute and unlimited, extending to the right of life or death over his children.

Later in that same century, John Locke argued that such views are fundamentally unsound. Locke based his argument on the fact that such views are incompatible with the Bible's teaching that each individual is fundamentally equal in the eyes of God, and that parents are given power over their children by God solely for the children's benefit. According to Locke, 'The power . . . that parents have over their children arises from the duty which is incumbent on them to take care of their off-spring during the imperfect state of childhood. . . .'²⁹ Since man is not the maker of his children but God, children are not man's property; rather, they belong to God. For Locke, the child does not exist to serve the wishes of the family, but the family to serve the child. Jacob Joshua Ross has summarized Locke's views by saying that, 'This Lockean conception demotes parents from their status as absolute monarchs and turns them into trustees whose children are temporary wards and whose actions are subject to constant . . . divine scrutiny'.³⁰

Locke's view has been extremely influential in subsequent western thought, and in many ways it still forms the theoretical basis for many of our laws governing the relations of parents and post-natal children. However, as the divine command upon which Locke's argument was based has lost its authority in our increasingly secular culture, the child-centred view of human procreation which it embodies has become increasingly rare. Indeed, we have now reached the point where pre-natal fetuses and 'defective' infants are viewed as having no intrinsic value but only such value as is conferred upon them by their parents—a value which is usually assessed according to the extent to which the child is seen as furthering parental goals and desires. In consequence, it is now largely among religious communities that views of the human family such as Locke's can be found. Indeed, the views which these communities espouse are frequently even richer than the largely fiduciary image of trusteeship presented by Locke, for they incorporate additional teachings from the Bible regarding the nature of the human family. It is to such teachings that we will now briefly turn to see what guidance they can offer for our understanding of the family and our attitudes toward the new genetic technologies.

Biblical Views of the Family

The Bible clearly teaches, both in Old and New Testaments, that there is tremendous spiritual significance to the fact that God has chosen to give each of us physical life through a particular pair of human parents—situating us in a particular family, and giving us a particular genetic, cultural, and spiritual heritage.³¹ He has created both parents and children with the capacity to love each other—a capacity

which is of equal or even greater importance than the sense of obligation cited by Locke in forming the basis of their relationship. The Bible also teaches that the relationship between human parent and child has been ordered by God to represent his relationship to his earthly children; as such, our care for our children is intended to be both an imitation of and a thanksgiving for God's gracious care for us. The Bible explicitly endorses the notion that parents have duties to their children, which include, among other things, nurturance and kindness,³² love,³³ and the provision of basic necessities.³⁴

This biblically inspired view of the family, and the parent-child relationship in particular, stands in marked contrast to those contemporary secular understandings which view parental rights as superseding absolutely those of the pre-natal, or even pre-rational child. Put quite simply, the biblical understanding of the family, which incorporates a fundamental obligation to the sacrificial service of the needy child, could not be more at odds with those new and darkly utilitarian visions of the family which would justify the sacrifice of the needy child for the happiness of the powerful parent.

Conclusions

How, then, should those who are persuaded of the relevance of this biblical view of the family respond to the availability of the new genetic technologies which we have been considering? Should they avoid the use of such technologies as unpardonable incursions into areas of divine prerogative? Should they seek testing before marriage, like many Orthodox Jewish communities, and abstain from marriage to those with whom they would be at high risk of giving birth to a child with a severe genetic disability? Should they marry but refrain from reproduction? Or should they make use of prenatal testing and pursue an abortion when a severe genetic defect is detected?

Responding first to the last of these questions, for those religious communities which hold that all human life is sacred—even prenatal human life—the practice of genetic abortion has usually been regarded as an unwarranted usurpation of a divine prerogative. Even within those communities, however, certain voices have been calling for a loosening of such prohibitions in the case of certain genetic disorders which carry particularly grim prognoses. Religious ethicist Allen Verhey, for example, said recently: 'There are, I think, genetic conditions which justify abortion. There are conditions like Tay-Sachs which consign a child not only to an abbreviated life, but to a life subjectively indistinguishable from torture; and there are conditions like trisomy 18 which are inconsistent not only with life but with the minimal conditions for human communication. Prenatal diagnosis and abortion, I think, can be used responsibly.'³⁵

Certainly those who are committed to a biblical view of the family will be sympathetic to Verhey's desire to minimize the suffering of infants born with such conditions (even if, like Philip Kitcher, we are not so pessimistic about the possibility of relieving the conscious suffering of those afflicted with disorders such as Tay-Sachs). Such persons, however, must also notice the extent of Verhey's departure

from traditional Christian belief regarding the impermissibility of intentionally taking innocent human life. It is important to note in considering Verhey's recommendations that his arguments must either entail an acceptance of other life-taking practices such as infanticide or euthanasia, or the devaluation of prenatal human life. If intense suffering and the inability to communicate are regarded as sufficient justifications for taking human life, then voluntary euthanasia of the intensely suffering and involuntary euthanasia of the comatose, vegetative, or severely retarded would seem to be countenanced. Indeed, if termination of life under such circumstances is regarded as beneficial and appropriate for the unborn, it would only seem cruel to deny them to those already born. Take, for instance, the case of Tay-Sachs. If we feel justified in aborting a fetus diagnosed with Tay-Sachs, should we not equally feel justified in euthanising a year-old infant who is just beginning to develop symptoms? or even a day-old newborn who can expect several months of pre-symptomatic existence—a time which will most probably only increase its parents' eventual suffering? If not it must be only because we believe that pre-natal life is somehow inherently less valuable than post-natal life. There is simply no way around the fact that if we believe we are justified in taking a particular human life, we must either reject outright the belief that innocent human lives *as such* must not taken, or we must believe that the particular life in question is of insufficient worth to merit protection under the general prohibition. Either way such a view would carry tremendous implications both for our understanding of the inherent worth of human life, and for our treatment of the unborn and the infirm. Surely we must think carefully about such implications before adopting Verhey's recommendations; otherwise it is not only possible but highly likely that we will be led into evil by our desire to do good.³⁶

How else might we respond to Verhey's quite legitimate desire to minimize the suffering caused by genetic disorders without resorting to genetic abortion? One way is by preventing the conception of children with severe genetic diseases through a programme of adult genetic screening and counselling in which couples who are found to be at high risk of giving birth to children with severe genetic defects could be given the option of foregoing reproduction. Would such a programme be consistent with the kind of biblical view of the family presented above? While this point is not beyond dispute, I believe that it would. Such a practice seems consistent with many Protestant understandings of our mandate as beings created in the divine image to use our creative powers to introduce back into a fallen creation God's own standards of compassion for the suffering. Such a practice will, of course, require sustained reflection on the part of each couple involved as to precisely which genetic diseases are severe enough to warrant such action; Lesch-Nyhan syndrome, with its tendency to produce painful and disfiguring self-mutilation in addition to mental retardation, would seem a likely candidate, as would Tay Sachs disease, Fragile X-chromosome syndrome, and a variety of syndromes resulting from stable genetic translocations which lead to shortened life span and the early onset of severe mental disabilities. But what about cystic fibrosis? Sickle cell anemia? Huntington's disease? Familial Alzheimer's disease? Hemophilia? All of these

disorders are now compatible with years of potentially enjoyable life. Are the health problems faced by those with these disorders severe enough to warrant avoidance of reproduction by their parents? Such questions are extremely difficult to answer, and are probably best left to the individual consciences of those involved. Given, however, the growing availability of prenatal testing, such questions will inevitably have to be addressed, and we would do well to address them in advance of any attempt on the part of the government to form any national policy guidelines on such issues.

I would like to address two potential objections to this policy. The first is that any attempt to prevent the birth of genetically handicapped children—no matter how effected and irrespective of motives—will inevitably lead to discrimination against other handicapped persons. Such efforts, it is claimed, inevitably carry the message that we view such lives as not worth living, and that we wish such persons had never been born. These arguments are admittedly powerful when directed against efforts to prevent the birth of severely handicapped children because such children are a strain on their families and society. Such arguments would appear especially powerful against efforts that employ abortion to take lives which have already begun. Such arguments, however, would appear to be less powerful when directed against efforts which are motivated by a concern for the plight of the potential persons themselves who could be affected by handicaps, especially when such efforts embody a respect for the inviolability of such lives once they have begun, and a willingness on the part of parents to forego the pleasures of reproduction for the benefit of others. Indeed, in a community where persons would be freely willing to forego their opportunities to reproduce—and possibly even their unconstrained choice of marital partners—for the sake of their potential offspring, an other-centred attitude would be fostered which would create a view of human relationships that placed a high value on caring for the needs of others. Such an attitude would only increase the community's concern for the needs of the handicapped. It would also lead to a new and truer understanding of 'quality of life' as measured not according to the possible quality attainable to some mythical 'normal' child, but as the best quality available to each individual child.

The second objection is that a growing acceptance of such practices will usher in an increasingly mechanistic and production-oriented view of human reproduction—that procreation will be undertaken with a specific end or kind of product in mind, and that such a practice is invariably dehumanizing. As with the previous objection, such a complaint seems apt when directed against the kind of practice in which decisions to abort or refrain from reproduction are based mostly on parental desires to give birth to a particular type of offspring; but it seems less apt against those efforts which are motivated by a sincere interest to avoid causing harm another individual. In the latter case, procreative decisions are motivated by parental love for their potential offspring, which would seem to affirm rather than deny the humanity of the procreative process.

How then should we respond to the growing availability of prenatal genetic testing? and what implications will such testing have for the relations between parents and their

children? Several options are available. Certain of these options are predicated on the belief that not every human conceptus should be carried to term, but only those which meet certain standards: freedom from genetic defects; ability to fulfil parental desires or expectations; capacity to develop rational thought and 'personhood'; and likelihood of living free of significant suffering. To those who meet such standards, family membership is given; to those who fall short, it is denied. Parental choice is absolute, at least until late in gestation: they made it, they own it, they may do with it what they will.

Another option is based on the notion that each human conceptus is a unique and valuable individual, and is as such fully invested with the rights and liberties belonging to human beings. Though these individuals are of us, by us, and from us, they are not 'ours' in the sense of property, to do with as we will. Rather they are members with us of one great family whose children we are and whose father is God. He is our maker, and he alone holds the rights of ownership over all humankind; and though Scripture teaches that he has invested us with extensive powers of stewardship over all creation, it has never taught that those powers extend to our deciding which innocent human beings may be deprived by us of his sovereign gift of life.

Our responsibility as parents and stewards of the life God has given through us is, while more limited, no less divine. Ironically, this responsibility has perhaps never been stated more eloquently than by that great modern herald of human isolation, Franz Kafka, who wrote in his *Letter to His Father*: 'The least that a parent can do for a child is to welcome it when it arrives.' May we all give our children such welcomes.

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2. John S. Feinberg and Paul D. Feinberg, *Ethics for a Brave New World* (Wheaton, Illinois: Crossway Books, 1993), p. 265.
3. Evelyn Fox Keller, 'Nature, Nurture, and the Human Genome Project', in *The Code of Codes*, p. 296.

4. *Ibid.*, p. 296.
5. Cowan, in *The Code of Codes*, p. 246.
6. Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (New York: Simon and Schuster, 1996).
7. *Ibid.*, p. 289.
8. Immanuel Kant, *Grounding for the Metaphysics of Morals*, James W. Ellington, trans. (Indianapolis: Hackett, 1983) see esp. pp. 35-6 (*Akademie* 428).
9. Kitcher, *The Lives to Come*, p. 288.
10. Margery W. Shaw, 'The Potential Plaintiff: Preconception and Prenatal Torts', in *Genetics and the Law II*, Aubrey Milunsky and George J. Annas, eds. (New York: Plenum, 1980) pp. 225-232.
11. This proposal bears many resemblances to the German 'Law for the Prevention of Genetically Diseased Offspring', enacted in July, 1933.
12. Leon R. Kass, *Toward a More Natural Science: Biology and Human Affairs* (New York: The Free Press, 1985) p. 89.
13. Kitcher, *The Lives to Come*, p. 298.
14. *Ibid.*
15. Kass, *Toward a More Natural Science*, p. 92.
16. Marc Lappe, 'Eugenics: Ethical Issues', in *The Encyclopedia of Bioethics*, Warren T. Reich, ed. (New York: Macmillan, 1995) p. 773.
17. See Kass, *Toward a More Natural Science*, p. 84.
18. Kitcher, *The Lives to Come*, p. 229.
19. Pearl Buck, as quoted in Kass, *Toward a More Natural Science*, p. 93.
20. Kenzaburo Oe, *A Healing Family* (New York: Kodansha International, 1996) p. 44.
21. *Ibid.*, p. 28.
22. *Ibid.*, p. 52.
23. Kass, *Toward a More Natural Science*, p. 95.
24. Aristotle, *De Anima* (London: Penguin Classics, 1986) II: 4, p. 165.
25. Aristotle, *Nicomachean Ethics* (London: Penguin Classics, 1976) p. 279.
26. David Heyd, *Genethics* (Berkeley: University of California Press, 1992) pp. 199-200.
27. H. Tristram Engelhardt, Jr., *The Foundations of Bioethics*, 2nd Ed. (Oxford: Oxford University Press, 1996) p. 156.
28. It was Filmer, in fact, who coined the well-known phrase 'the divine right of kings'.
29. John Locke, *Second Treatise of Government* (Indianapolis: Hackett, 1980) p. 32.
30. Jacob Joshua Ross, *The Virtues of the Family* (New York: Free Press, 1995) p. 140.
31. A particularly helpful discussion of the biblical teachings on the human family (as interpreted by the Family Life Committee of The Lutheran Church, Missouri Synod) can be found in Oscar E. Feucht, ed. *Family Relationships and the Church: A sociological, historical, and theological study of family structures, roles, and relationships* (St. Louis: Concordia, 1970).
32. See, e.g., Ephesians 6:4 Colossians 3:21.
33. See, e.g., Titus 2:4.
34. See, e.g., 2 Corinthians 12:14.
35. Allen Verhey, Transcript of a talk given at *The Christian Stake in Genetics* conference, July 1996.
36. See, e.g., the apostle Paul's discussion of performing an action evil in itself with the aim of producing the greatest of all goods—i.e., the glorification of God—in Romans 3:8.

Dignity and Dying

A Christian Appraisal

Editors, John F. Kilner, Arlene Miller and Edmund D. Pellegrino

In this book twenty leading experts in the bioethics debate address a number of basic clinical and ethical issues from a Christian perspective. They show how humans can confront the realities of suffering and dying with true compassion and a God-given dignity, without killing the sufferer. Demonstrating the Christian meaning of terms such as compassion, mercy, self-determination and dignity, the book will be welcomed both by believers and thoughtful unbelievers who are concerned about the development of a 'culture of death'.

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Jim Leffel

Engineering Life: Defining 'Humanity' In A Postmodern Age

'Has existence significance at all? [This is] the question which will require a couple of centuries even to be completely heard in all its profundity'

—Fredrich Nietzsche, *Joyful Wisdom*.

The fact that God could create free beings vis-à-vis of Himself is the cross which philosophy could not carry, but remained hanging therefrom'

—Soren Kierkegaard, *Aphorisms*

Signs of the Times

- An actively heterosexual Russian female athlete is informed that she cannot compete in the Olympic games as a woman, because she is genetically a man.
- A New Jersey family takes their doctor to court for allowing the 'wrongful birth' of their Down's Syndrome child. Over 300 similar suits have reached the courts in recent years. Today, as in an earlier time, we hear of 'life unworthy of life'.
- A child is conceived in California for the purpose of serving as a bone marrow donor for an older sibling. The cells are harvested and her sister lives. It is not only possible, but legal to create human life for 'spare parts'.
- An embryo conceived in a Louisiana laboratory is protected by state law. But as soon as it is implanted into the mother, it can be aborted by another constitutionally protected right.
- Researchers at Harvard and Stanford Medical Schools uncover over 200 cases of genetic discrimination. Based on 'pre-existing conditions', insurance companies have denied coverage to people who carry genetically transmitted diseases.

Each of these incidents illustrates the complexities genetic technology introduces. The ethical dimension is of obvious concern. How *should* we treat fellow human beings? Then there are legal questions about what should be prohibited or sanctioned in human genetic research. But a more basic and all too often ignored question must also be explored. What is a human person? Indeed, without an answer to this question, moral and legal reflection is almost pointless. How, for example, can we speak of protecting human rights without identifying the bearer of those rights?

Recognizing human rights has always been explosive business. In the 19th century, the issue was to whom do the constitutionally protected 'inalienable rights of men'

apply? This question so divided our republic that it was resolved only by civil war. In recent historic experience, we can turn to the death camps of Auchwitz or one of the thousands of 'family planning centres' in America for further evidence of the scale of this question's lethality—and, tragically, of social ambivalence to it.

Citing a lengthy bibliography of current scholarly works on the meaning of 'personhood', psychologist and social critic Kenneth Gergen observes,

One of the most interesting aspects of this work is that it exists at all, for only under particular cultural conditions would the question be considered worthy of such attention.¹

What are these 'particular cultural conditions' to which Gergen refers? Both in academia and in popular culture, we are experiencing a sweeping ideological shift. It is the decline of Enlightenment assumptions that have guided western civilization for the past 250 years, and the emergence of a 'postmodern' cultural consensus. This shift in thought has been extensively documented in public opinion² and in more scholarly work.³ However, little critique has been given to the practical implications of postmodernism for the pressing biomedical issues of our day. As postmodern language and concepts become an increasingly significant part of the public discussion in medical ethics, I think it is essential that Christians understand the thinking that lies beneath the rhetoric and formulate compelling responses to it.

This paper is an attempt to turn the discussion in that direction. We consider the meaning of personhood as it is conceived by postmodernists and its implications in an age of genetic technology. We conclude that a biblical view of humanity uniquely provides moral guidance through the turbulent waters of our postmodern era.

From Modern to Postmodern Anthropology

Comparing Anthropologies

Modernism	Postmodernism
Autonomous	Social
Rational	Subjective

Let's step back for a minute to define our terms. Outside of academia, 'postmodernism' is not in common use, though

we all encounter it in its various forms.⁴ In a word, postmodernism is a rejection of the modern, or Enlightenment thought, that has dominated intellectual life for over two hundred years. To understand what is at stake with current issues surrounding genetics, we need to consider two crucial points of conflict between the modern and postmodern concepts of human personhood.

First, for modernists, *man is rational by nature*. French philosopher René Descartes is often considered the father of modern philosophy. Parting company with medieval thought that sought to root reason in the soil of Christian belief,⁵ Descartes attempted to develop a method of discovering truth independent of external sources of authority. He began inwardly, with his rationalistic deduction, 'I think, therefore I am'. Descartes' first certainty was that 'I exist as a thinking thing'. The concept of man as rational by nature became the hallmark of Enlightenment thought. Descartes, and many who followed him, believed that it was possible to discover ultimate truths through the exercise of reason alone, and to develop a comprehensive, rationalistic world view. Reason was thus the guiding light of the Enlightenment.

Second, the subtle assertion underlying Cartesian method is that *the self is autonomous*. By autonomous, we mean that there exists an individual self (the 'I' that 'thinks') who transcends, or stands above environment and biology. Descartes based his theory of an autonomous self on mind/body dualism—the idea that an immaterial mind stands over and apart from nature. Later philosophers rejected Cartesian dualism and the theism it presumed, but for more than two hundred years, most maintained the belief in an autonomous self and confidence in the rational objectivity it made possible. The autonomous, rational self became the foundation for Enlightenment humanism and its liberal political theory, free market economics and radical individualism.⁶

Postmodernism is a direct assault on the entire Enlightenment enterprise. At the heart of it, postmodernists deny the possibility of rational objectivity because they reject the view of the self that modernism presupposes. Rather than seeing humanity as an ocean of autonomous rational selves, as modernists held, postmodernists think of humans as an extension of culture and deny the individual self altogether. Kenneth Gergen notes,

With the spread of postmodern consciousness, we see the demise of personal definition, reason, authority . . . All intrinsic properties of the human being, along with moral worth and personal commitment, are lost from view . . .⁷

The self stands under 'erasure' for postmodernists, meaning they deny all transcendent categories, including essential human personhood, reason and human value. There is no Cartesian 'I' that thinks any more than there is a computer 'self' beneath its programming. Postmodern anthropology is based on the idea that humans are 'social constructs', or socially determined beings. We cannot have objective access to reality, because there is no neutral context from which to think. We have no individual personhood, because we are the product of culture.

Despite much of its 'politically correct' rhetoric, postmodernism is anti-essentialist and anti-humanist.⁸ There is no universal human essence, no stable personal identity,

and consequently, no inherent human value. Humans derive a sense of individual identity and value as persons from the arbitrary mores of a given culture. So one's identity, value, and civil rights are an accident of cultural origin, not some property intrinsic to human nature.

Postmodern Antihumanism and Genetic Technology

Postmodern antihumanism and the contemporary genetics industry are two powerful currents that form a potentially menacing rip tide against which proponents of human dignity must struggle. We consider key forces directing genetic research and the genetics industry, and how postmodern anthropological assumptions increasingly encroach on bioethics and biopolitics.

Scientists are for the most part extremely antagonistic to postmodernism because of its assault against reason and the postmodernists' accusations that science is a tool of western cultural imperialism.⁹ However, naturalistic materialism, the dominant view among secular scientists, shares in postmodernism's antihumanism, creating a dangerous consensus among intellectuals today. Consider the remarks of Robert Haynes, president of the 16th International Congress of Genetics,

For three thousand years at least, a majority of people have considered that human beings were special, were magic. It's the Judeo-Christian view of man. What the ability to manipulate genes should indicate to people is the very deep extent to which we are biological machines. The traditional view is built on the foundation that life is sacred. . . . Well, not anymore. It's no longer possible to live by the idea that there is something special, unique, even sacred about living organisms.¹⁰

Whether biological machines or cultural constructs, naturalism and postmodernism strip humanity of all intrinsic value and leave postmodern culture with no meaningful frame of reference to address the pressing bioethical issues of our day.

One assumption driving the frenzy to map the human genome is that all human behaviour is of genetic origin. Things that in previous times were attributed to environment or moral choice are now being attributed to genetics. High profile scientists exploiting front page journalism have claimed to have discovered the genetic basis for a host of controversial behaviours and characteristics, including alcoholism, homosexuality, promiscuity, IQ and violence. Serious scientific doubt about these claims is commonly given little attention, leaving the public with the impression that science is on the verge of solving some of society's greatest problems.

Aside from these more explosive social issues, there are areas of research and technology where individuals may feel a more personal stake. This is where postmodern constructivism is particularly dangerous. For example, as genetic screening becomes more of an option for potential parents, we can expect to see further erosions in the value of human personhood. Dr. Harvy Lodish of the Whitehead Institute for Biomedical Research in Cambridge, Massachusetts states,

By using techniques involving in vitro fertilization, it is already possible to remove one cell from the developing embryo and characterize any desired region of DNA. Genetic screening of embryos, before implantation, may soon become routine.¹¹ Beyond 'reproductive consumerism', economic and social pressure may well turn the possibility of genetic screening into a social obligation. After all, some will be prepared to argue, 'If we can prevent another alcoholic from wasting valuable economic resources, it seems that we ought to'. Or, some may ask, 'Who wants the trauma of raising a homosexual child if it could be avoided?'

Important market forces are also at work in the genetics research industry. Billions of dollars can be gained through the commercial marketing of genetic material. And scientists have been quick to seize the opportunities. Since 1971, corporations have put on a no holds barred legal battle to patent human life. In that year, General Electric researcher Ananda Mohan Chakrabarty sought a patent for a microbe synthesized in the lab for the purpose of cleaning large oil spills. After nearly a decade of legal argument, the United States Supreme Court sided with Chakrabarty. Life forms could be considered 'human inventions', thus patentable by the US Patent and Trademark Office (PTO). This case began a slippery slope toward the inevitable patenting of human life.

In 1987, the PTO widened patent rights to include all life-forms on earth, including animals.¹² Human beings were exempt from the ruling, citing the Thirteenth Amendment of the Constitution prohibiting slavery. However, the ruling had significant shortcomings. Kimbrell notes, '... under the PTO's 1987 ruling, embryos and fetuses, human life-forms not presently covered under Thirteenth Amendment protection, are patentable, as are genetically engineered human tissues, cells, and genes'.¹³ Corporate America won the right to own, use and sell all multicellular creatures, including human.¹⁴ While a storm of pro-life protest resulted in the withdrawal of NIH requests for public funding for the use of human embryos in genetic research, it is still legal. Human life has now become a commercial commodity as billions of dollars enter into the global genetics market. The PTO is now flooded with applications for patents on hundreds of human genes and gene lines. Kimbrell warns, '[a]s patenting continues, the legal distinctions between life and machine, between life and commodity, will begin to vanish'.¹⁵

Human genetic engineering has been suggested for all kinds of medical and social applications. But as practical demand for human tissue increases, the value of human personhood in a postmodern culture experiences a corresponding decrease. As of 1990, there were over three hundred law suits against doctors by parents or children claiming a new species of injustice with strange constructivist language: 'wrongful life' and 'wrongful birth'.¹⁶ Translated, these euphemisms mean that life is protected not by an unalienable right, but by arbitrary decisions based upon socially acceptable characteristics. Along these lines, noted ethicist H. Tristram Engelhardt uses the expression, 'injury of continued existence',¹⁷ a disturbingly similar notion to the Nazi concept of 'life unworthy of life'. In today's world of genetic mapping and gene therapy, we hear terms such as the 'commodification of life', and 'the human body shop industry'.¹⁸

We are witnessing the depersonalization of human bio-science language:

As body parts and [genetic] materials are sold and patented, manipulated and engineered, we also are seeing an unprecedented change in many of our most basic social and legal definitions. Traditional understandings of life, birth, disease, death, mother, father, and person begin to waver and then fall.¹⁹

In depersonalizing language, scientific and legal jargon obscures important moral distinctions. The consequence is that genetic research and technology appear more neutrally scientific than deeply ethical and human. So while questionable research goals and methods and clearly unbiblical anthropological assumptions sometimes drive the genetics industry forward, sociological data shows that most Americans don't really understand what's going on.²⁰ And those who do understand, but oppose public funding for gene research on human embryos, are called 'uneducated' and 'ignorant' by research professionals.²¹ But such *ad hominem* responses will continue to have a hollow ring until scientists and biopolicy makers offer some meaningful distinction between what they *can* do and what they *should* do.

At a time when few people can articulate a meaningful defence of human dignity, we are left open to the increasing influence of postmodern anti-humanists. David Hirsch raises a daunting problem:

Purveyors of postmodern ideologies must consider whether it is possible to diminish human beings in theory, without, at the same time, making individual human lives worthless in the real world.²²

There are important indications that Hirsch's fears are now being realized. In recent public opinion surveys, a substantial majority favour genetic screening for a wide range of genetically transmitted disorders.²³ Abortion as a therapeutic option is, of course, in view. But it is not merely serious or fatal diseases that are being singled out. For example, in a recent survey taken in New England, eleven percent of couples polled said they would abort a child genetically predisposed to obesity.²⁴ We need to call these sentiments what they are: *eugenic*.

This popular opinion is also reflected in the medical community. Between 1973 and 1988, the percentage of geneticists who approve of prenatal diagnosis for sex selection rose from 1 percent to 20 percent.²⁵ In a broader study of gender-selected abortion, physicians were asked to respond to the following scenario:

A couple with four healthy daughters desires a son. They request prenatal diagnosis solely to learn the fetus' sex ... They tell the doctor that if the fetus is female, they will abort it. Further, they say that if the doctor will not grant their request for prenatal diagnosis, they will have an abortion rather than risk having a fifth girl.²⁶

In this case, 62% of American doctors said they would either perform the diagnosis or refer them to a physician who would. Civil rights activists have rightly condemned abortion based on gender around the world and we should be equally outraged by the blatant misogyny this study suggests.

Back to the Future?

Postmodernists themselves recognize the potential cost of their anti-humanistic denial of objective human value. Kenneth Gergen concedes,

Postmodernism has often been viewed as morally bankrupt because it fails to profess any fundamental values or principles. More forcefully put, postmodernism fails to offer arguments against Nazism or any other forms of cultural tyranny.²⁷

Gergen's point is grossly understated. In point of fact, there are dangerous historical and conceptual connections between postmodern antihumanism and fascism.²⁸

Comparing Worldviews

Fascism	Postmodernism
Humans as social constructs	Humans as social constructs
No objectivity, appeal to the pragmatic	No objectivity, appeal to the pragmatic

Having illustrated postmodern sentiment and language in current discussions of genetics, we now turn to a brief analysis of the commonality between postmodern anthropology and *folkism*—the ideological basis for German fascism.

In his sobering and timely essay, 'Biological Science and the Roots of Nazism',²⁹ George Stein states,

German philosophic romanticism was a xenophobic . . . reaction against the idea of 'man' as a species. Rather, 'men' participated in life or had their being through a unique natural and cultural identity. Folkism was established as both a philosophical ideology and as a political movement.³⁰

For folkism, human value and human rights were associated with cultural identity just as it is for contemporary postmodernism. There simply are no inalienable rights, because there is no universal human essence. And individualism was also a myth for folkism in much the same way it is for contemporary postmodernists. Again citing Stein,

Man is a social species. Individualism is an illusion . . . each individual is subordinate to the social body of which he is a member.³¹

Individuals, therefore, possess value as they take their place in culture. This raises two questions. First, what is 'culture'; and second, what does it mean to have a place in culture? Early fascists found the question of culture easy enough to define: Aryan folkism. And in the post World War I era, when Germany was searching for some way to regroup, folkism provided the rallying point. As to what it meant to have a place in folkish society, that was another matter. Stein points out,

Without human essentialism, folkish standards came to define normative humanity at the exclusion of other

racess, and even many within the race. [German social darwinist Ernst] Hackel and others were thus willing to argue that we must assign a totally different value to their lives.³²

Ideology alone could not accomplish the folkish ideal of the German Aryan state. But what if folkish romanticism and Aryan superiority were *scientifically* true? This was the claim of the German social darwinists and the basis for the Nazi eugenics programme. It was a scientific application to what postmodernists today call 'social constructivism'. Social undesirables—those who did not fit the folkish ideal—were considered genetically inferior. As such they had a responsibility to die. As Haeckel states, 'Hundreds of thousands of incurables—lunatics, lepers, people with cancer—are artificially kept alive without the slightest profit to themselves or the general body'.³³

A growing number are expressing concern that the same ruthless pragmatism can easily be cultivated in today's multi billion dollar genetics revolution. Arbitrarily assigning value to human life and scientific justification for social engineering is not merely a folkish matter. As we have seen, Americans today have shown some of the same tendencies. And as economic and social pressures merge with various prejudices, postmodern constructivism provides a compelling basis for weeding out or altering so-called 'undesirable traits' of the gene pool. Some have considered proposals to treat medically people who carry the alleged 'violence gene',³⁴ since reform is considered unlikely. *The Bell Curve*, written by two widely respected scientists (one a Harvard researcher), argues for a social policy that curbs efforts to educate many poor people based on their presumed limited genetic potential.³⁵ In a disturbing and woefully underreported trend, corporations are showing an increased willingness to do genetic screening on their employees to identify factors that might make them less productive or expensive to insure.³⁶

We are entering into a new age in the struggle for human rights. The secular world view, rooted in naturalism and postmodern constructivism has little room for the inherent dignity of man. It is a culture without anchor, adrift in what Gergen has called 'the tyrannies of rhetoric'.³⁷ Apart from the image of God in all people, there is little reason to resist the current momentum toward social engineering. Christians must take a stand as we did with abolition and child labour, and as many continue to do against abortion, as humanists in the rich, biblical sense of the term.

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1. Kenneth Gergen, *The Saturated Self* (New York: Basic Books, 1991), 272.
2. George Barna, *The Barna Report: What Americans Believe* (Ventura: Regal Books, 1991), 112.
3. See Lynne Cheney's report to congress as Chair of the National Endowment for the Humanities, 1992.
4. For an introduction to postmodern thought and its affects on a wide spectrum of contemporary society, see Dennis McCallum, Ed., *The Death of Truth* (Minneapolis: Bethany House Publishers, 1996).
5. Medieval epistemology can be summarized in Anselm's dictum, 'I believe so that I may understand'.
6. For an excellent discussion of American individualism, see Robert Bellah, et. Al., *Habits of the Heart* (Berkeley: University of California Press, 1985).

7. Kenneth Gergen, *The Saturated Self* (New York: Basic Books, 1991), 228, 229.
8. See David Michael Levin, *The Opening of Vision: Nihilism and the Postmodern Situation* (New York: Routledge, 1988), 405–08.
9. See Jim Leffel, 'Postmodernism and the Myth of Progress', in Dennis McCallum ed, *The Death of Truth* (Minneapolis: Bethany House Publishers, 1996), 45–57.
10. Andrew Kimbrell, *The Human Body Shop: The Engineering and Marketing of Life* (San Francisco: Harper San Francisco, 1993) 233,4.
11. Harvey Lodish, 'Viewpoint: The Future' in *Science*, 267:1609.
12. U.S. Patent and Trademark Office, *Animals-Patentability* (Washington, D.C.: U.S. Patent and Trademark Office, April 7, 1987), cited in Kimbrell, 199.
13. Kimbrell, *The Human Body Shop*, 199.
14. Kimbrell states, 'It is important to note that, as described in the last two chapters, current U.S. patent law makes patenting human embryos perfectly legal'. *The Human Body Shop*, 223.
15. Kimbrell, *The Human Body Shop*, 212.
16. Cited in Andrew Kimbrell, *The Human Body Shop*, 127.
17. H. Tristram Engelhardt, Jr, in Marvin Kohl, ed., *Beneficent Euthanasia* (Prometheus Books, 1975).
18. Kimbrell uses these terms to describe both the rhetoric and the emerging biopolicy surrounding genetic research and technology.
19. Kimbrell, *The Human Body Shop*, 228.
20. Kimbrell, *The Human Body Shop*, 290.
21. William Ryan, 'Poll Shows Strong Opposition to Embryo Research Funding', *United States Catholic Conference News*, July 25, 1995.
22. David Hirsch, *The Deconstruction of Literature: Criticism after Auschwitz* (Hanover: Brown University Press, 1991), 165.
23. Kimbrell, *The Human Body Shop*, 290.
24. Kimbrell, *The Human Body Shop*, 124.
25. Gina Kolata, 'Fetal Sex Test Used as Step to Abortion', *New York Times* (December 25, 1988), A1.
26. Cited in Kimbrell, *The Human Body Shop*, 123.
27. Gergen, *The Saturated Self*, 231.
28. See Gene Edward Veith, *Today's Fascism* (St. Louis: Concordia Press, 1993).
29. George Stein, 'Biological Science and the Roots of Nazism', *American Scientist*, 76:50–58.
30. Stein, 'Biological Science and the Roots of Nazism', 53.
31. Stein, 'Biological Science and the Roots of Nazism', 56.
32. Stein, 'Biological Science and the Roots of Nazism', 55.
33. Cited in Stein, 'Biological Science and the Roots of Nazism', 54.
34. The brochure for a conference dealing with violence, sponsored in part by the NIH, but cancelled after substantial protest, states: 'Researchers have already begun to study the genetic regulation of violent and impulsive behaviour and to search for genetic markers associated with criminal conduct. Their work is motivated in part by the early success . . . on the genetics of behavioral and psychiatric conditions like alcoholism and schizophrenia. But genetic research also gains impetus from the apparent failure of environmental approaches to crime—deterrence, diversion and rehabilitation—to affect the dramatic increases in crime, especially violent crime that this country has experienced over the last 30 years. *Genetic research holds out the prospect of identifying individuals who may be predisposed to certain kinds of criminal conduct . . . and of treating some predispositions with drugs and unintrusive therapies*'. (Italics added). Cited in Kimbrell, *The Human Body Shop*, 258.
35. See Charles Murray and Richard Herrnstein, *The Bell Curve: The Reshaping of American Life by Differences in Intelligence* (New York: Free Press, 1994).
36. Kimbrell cites an Office of Technology Assessment survey that indicates that 20% of Fortune 500 companies may use genetic screening over the next five years. *The Human Body Shop*, 248. See U.S. Congress, Office of Technology Assessment, *Genetic Monitoring and Screening in the Workplace*, OTA-BA-445 (Washington, D.C.: U.S. Government Printing Office, October 1990), 17–178. Also, see Committee on Government Operations, *Designing Genetic Information Policy: The Need of an Independent Policy Review of the Ethical, Legal, and Social Implications of the Human Genome Project*, sixteenth report (Washington, D.C. Government Printing Office, 1992), 19–21.
37. Gergen, *The Saturated Self*, 229.

Jerome R. Wernow Ph.D., R.Ph.

Confronting the Pine Box with the Ballot Box: A Critical Appraisal of Oregon's Attempt to 'do' Medical Ethics by Public Ballot

By using Orwellian 'doublespeak' we might be letting ourselves in for procedures and conclusions which we do not fully comprehend at the time of decision-making. On the other hand, perhaps euphemisms allow people to come to grips with brutal facts which, stated another way, would be repugnant.¹

Derek Humphry

On November 8, 1994, thirty-four percent of the registered voters of Oregon approved an initiative entitled the Oregon 'Death With Dignity Act', otherwise known as Measure 16.² It was an effort by 'medicide' advocates to establish physician-assisted suicide policy via public ballot.³ Three issues

at stake include (1) the affirmation of a mitigated patient autonomy by means of physician-assisted suicide codification (2) a peaceful efficient death or as stated in the Act a death with dignity and (3) a precedent of establishing medico-ethical policy making through macro level politics. In retrospect, little analysis or reflection can be found which addresses the appropriateness of using public referendums like Measure 16 in establishing medico-ethical policy. This presentation will address such appropriateness through a short critical appraisal of the first two issues at stake: autonomy and safety of suicide. I will analyse both what the

proponents were asking the public to consent to in Measure 16 and the safety of their proposal. Our appraisal will lead to a concluding concern regarding the ramifications of accepting the ethic behind the application of informed consent criterion assumed appropriate for voter consent as practised in the public campaign upon the application of informed consent criterion for future patient choice in assisted suicide.

At the outset it may seem strange or unhelpful to employ the phase 'informed consent', as understood in medical decision making, to describe insufficiently reflective voting habits of the populace. To aid in my association I use the simple definition of informed consent by Thomas Shannon. He states: 'informed consent is the knowledge of and consent to a particular form of treatment before that treatment is administered.'⁴ The *micro* level use of this notion, that of patient-physician, is being applied paradigmatically to the *macro* or public policy level.⁵ In our context the public serves as the agent that is both **informed** and that gives or denies **consent** to a particular form of treatment, before the treatment is administered, that treatment being death with dignity or, less euphemistically put by Dr. Kevorkian, prescription medicine. By this I mean the proponents of medicine disclose the information of the policies, procedures, risks, and benefits of the treatment to the public in order that the public may choose or reject the treatment option on behalf of themselves as society.

The Issue of Disclosure of Route of Drug Administration

The route of administration of a lethal drug was key to Measure 16's public acceptance and safety. Oral routes of administration are accompanied with greater public confidence in individual control and a voluntary peaceful death. When other routes of administration were considered, like injection, public acceptance of the lethal act was diminished.⁶ According to some medicine advocates involved in the crafting and advocacy of the measure, the 'Oregon Death with Dignity Act' was based upon euphemisms which veiled the issue of route of administration for the sake of political expediency.⁷ They suggested that the avoidance of clear language regarding the route of administration in the wording was deliberate, in order that the voting majority would accept the concept of physician assisted suicide and not have to deal with repugnant facts behind it.⁸ For instance, a Roper Poll funded by *ERGO!* intimated that the use of straight-forward language about lethal injection in the initiative would probably lead to the Measure's defeat, as had happened previously in the states of Washington (1991) and California (1992).⁹ The use of well crafted euphemisms, on the other hand, would lead to its probable acceptance, according to the poll.¹⁰

Indeed, route of administration was the major point of contention at a Eugene Oregon debate between medicine purist Derek Humphry and moderate Eli Stutsman. As Thomas Bates, writer for the *Oregonian*, comments on the debate:

From the outset, the big question was whether to go with an oral prescription or a lethal injection bill. Even before the writing started, Stutsman felt it should be the former.

When word of his position leaked out, Humphry, who favored a 'two-handed bill' allowing for lethal injection, invited him to Eugene for a debate.¹¹

Reflecting upon the rejection of his proposal to use clear rather than ambiguous language, *ERGO!*'s founder Derek Humphry said, 'The euphemisms won.'¹²

The result was the use of language which avoided disclosing precisely what actions were involved in the treatment policy as well as the risks associated with the actions. Nowhere is this more evident than in Section 3.14 ('Construction of the Act'). This section reads:

Nothing in this Act shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing, or active euthanasia. Actions taken in accordance with this Act shall not for any purpose constitute suicide, assisted suicide, mercy killing or homicide, under the law.¹³

At first glance these statements seem to militate against both lethal injection and administration of medication by secondary agents; however, a closer examination of the text reveals that neither this statement nor others found in the document clearly preclude the possibility of the patient's self-administration of a prescription drug for lethal injection or inhalation. It appears only to exclude 'any other person' from those actions. Furthermore, if the patient and physician fulfil the requirements of the Act, then they appear to be permitted to utilize all prescription medications within the bounds of the semantical field of the word 'drug' without being implicated in legal remedies attached to suicide, assisted suicide, or mercy killing.¹⁴ Thus, multiple routes and the agents needed to execute the administration of those routes, the lethal act, appear permissible.

This interpretation might seem to be speculative except that medicine advocates, Oregon pharmacy task force members, and the Oregon District Court agreed on the broader interpretation of the lethal act to include lethal injection.¹⁵ For instance, in an interview with Ted Koppel, the attorney of Dr. Jack Kevorkian, Geoffrey Feiger, suggested that there was nothing in the new statute which prevented the patient from utilizing a device delivering a lethal intravenous injection such as that used by Kevorkian. Oregon Right to Die medicine advocate, Peter Goodwin, agreed with Feiger's assessment, stating, 'if the patient had a gadget similar to that that Dr. Kevorkian used and wanted to do it that way, it's my belief that that would not be excluded as long as the patient had full responsibility.'¹⁶

Goodwin's statement contradicts his earlier assessment on what actions the referendum did and did not permit. In the pre-election brochure endorsed by Goodwin, 'lethal injection' and 'Kevorkian style suicide machines' were expressly prohibited.¹⁷

Issues of Disclosure, Safety, and Efficacy

Questions over adequate disclosure were raised not only by literature used to inform the public but in politically spun campaign advertisements. A political advertisement repeatedly aired on television and printed in the *Oregon Voter's Pamphlet* gave a compelling account of the supposedly successful suicide of a proponent's daughter. A late

pre-election account in the *Oregonian* uncovered a very different account, a 'botched' attempt. The oral medication did not work, necessitating a frantic attempt at lethal injection. The *Oregonian* recounts the advertisement in the following citation.

In the television commercial, the spokeswoman for measure 16 tells the story of how her cancer-stricken daughter 'slipped peacefully away' after taking a lethal dose of pills. But in a talk to a national conference on euthanasia two years ago, Patty A. Rosen of Bend, told a different story. The assisted suicide seemed to backfire so badly that a family member nearly put a pillow over her daughter's head to hasten the death. In the end, Rosen, a registered nurse, said she 'hit a vein,' suggesting a lethal injection was used to supplement the pills.¹⁸

The essential point is that statements made by some of the advocates and crafters could easily lead one to believe that the Measure was crafted in a manner which made it appear to be limited to oral ingestion, but could easily be broadened to lethal injection after the election. In fact, such a broadening would have been necessary to substantiate the voter's belief in a safe, efficient, and 'dignified' death. As Humphry stated after the measure passed, 'The Oregon law, which forbids injections, could be disastrous.'^{19,20} He was aware of the problem of lingering deaths and lack of efficacy of minimizing physician-assisted suicide to oral ingestion.²¹ The potential disaster stated by Humphry should not be under-estimated. Lingering deaths from barbiturate overdoses have been recorded as resulting in such adverse effects as toxic psychosis, pulmonary abscess, pulmonary embolization, renal failure, gross muscle necrosis, and/or coma.²²

Can an assertion be sustained that Measure 16 was designed with an emphasis on appealing to the public's political voting sentiments rather than on the pragmatics of public safety in the lethal act? On the one hand, the Roper Poll commissioned by *ERGO!* gives that impression. On the other hand, crafters like Stutsman adamantly reject any such assertion stating that 'It (the Roper Poll) was interesting but had no influence'.²³ Interestingly, an interview with Measure 16 drafter Mark Trincherio by *Oregonian* reporter Thomas Bates suggests that voter surveys contributed to the choice of wording in the document.²⁴

Whether the Roper Poll was included remains unclear. What is clear is that the use of euphemisms in the language of Measure, like 'death with dignity', are common to the wording most favoured by the public in that poll. Derek Humphry and his close colleague Cheryl Smith make it very clear that initiatives crafted in terms of euphemism may lead to questionable public policy, but are useful in securing their political objective. Smith, who crafted the first draft of Measure 16, made a statement which resounds with the underlying pragmatic utilitarian ethic operative in the movement's approach: 'We wanted to know what works.'²⁵

Reflections on 'doing' Medical Ethics through Macro Politics

The foundational feature of Measure 16, a person's ability to exercise self-determination as an informed decision

maker, be it on the *macro* level as a voter or the *micro* level as a patient, rests upon, among other things, informed consent. Our analysis raises questions surrounding the meeting of this criterion in *macro* politics. Put crudely, the objective of information dissemination at the political level is on 'what works' to get the vote. What worked in Oregon, and had not been tried in California (1992) or Washington (1991) was the use of euphemisms to veil, as one proponent put it, 'the repugnant facts' of medicide. What worked was clever, even rather brilliant, campaigning which politically spun information in the voters' pamphlet, leading the public to believe that groups like the Oregon State Pharmacy Association and Oregon Hospice did not oppose the referendum.²⁶ What was absent was disclosure about the nature of the lethal act and the practical risks of the referendum to the consenting community. Admittedly, approaches placing a 'positive spin' on controversial policies may be acceptable to many in the sphere of astute politics. They are questionable, however, when trying to inform the consenting agent or 'doing' medical ethics in a manner established by medico-ethical community.

The precedent set in the Oregon referendum raises questions about 'doing' bioethics at the *macro* level. Did the public receive sufficient information about risks, safety, and practice to make an informed decision on Measure 16? Can the public be informed adequately to meet the criterion of informed consent? Do they possess sufficient expertise to direct medical practitioners to change their medico-ethical practice policies? Can politicians 'do' successful health care policy formation and medical ethics concomitantly? Our analysis of the disclosure of information regarding the lethal act casts doubt on a positive answer to the first question. It is not patently clear whether the proponents of Measure 16 either carelessly overlooked or purposely withheld facts needed for informed public consent in this case. Whatever the case, injection was shown to be both necessary for a safe execution of the lethal act and unacceptable as far as the public were concerned. A positive answer to the second question is doubtful as well. The lack of awareness of the necessity of lethal injection to insure a successful death by even the 'neutral' experts analyzing these issues on the public's behalf brings into question the ability of the less informed and educated general public to understand those issues.²⁷

Reflections on 'doing medical ethics' by Public Ballot

All this is not to say that positive contributions are lacking from the Measure 16 experience. If little else, Measure 16 contributes to the understanding of the interaction, compatibility, and consequences of two institutional structures: politics and medicine. Politics are structured in such ways that policy makers are enabled to promote their agendas and disclose information in the best light while attempting to minimize or remain silent about risks. In contrast, medicine in general and medical ethics in particular, are structured to weigh the information in light of proportional risks and benefits. The juxtaposition and interaction of these two structures uncovered issues and raised questions which are certain to visit us again in the near future. These questions

are pertinent not only to Oregon and the United States. Nor are they limited to the issues of medicide and public policy. These questions point to something greater in the western medical industrial complex. Will and should medicine be absorbed into the confines of politics on a grand scale? Measure 16 serves as an example and an opportunity to reflect on the question of medicine 'done' through politics. It causes one to pause and consider that perhaps the current nature of public politics may not really serve as the best venue for crafting health care policies which facilitate sufficiently informed ethical decision making at the patient level. Deeper reflection upon the acceptance of the use of political euphemisms in ethical health care policy making, leaves me haunted, haunted by a question which I leave with you the reader. If the public continues to be placed in the role of medical ethical decision maker at the *macro* level, and informed consent need not be adequately met at the ballot box, what then is their guarantee that it will be met when they are confronted with the pine box?

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1. Humphry, Derek: *What's in a word? The results of a Roper Poll of Americans on how they view the importance of language in the debate over the right to choose to die.* (Euthanasia Research and Guidance Organization (ERGO): August, 1993) p. 1.
2. Keisling, Phil (Secretary of State): *Official Abstract of Votes General Election.* (State Elections Division, Salem, Oregon; November 8, 1994) pp. i, 54. The fact that only thirty-four percent (627,980) of the total number of registered Oregon voters (1,832,774) approved the referendum casts doubt on the argument that the passing of this initiative was a clear indication of the 'will of the people' as touted by some Hemlock Society members.
3. Medicide is a term introduced by Dr. Jack Kevorkian to describe 'an application of medical science for the purpose and intent of hastening the death of a person'. The reason for the choice of this word over terms like 'euthanasia' or 'death with dignity' will become apparent as the article develops. At this point I contend that 'medicide' describes the practice more accurately than the two other terms.
4. Shannon, Thomas: *An Introduction to Bioethics.* (New York: Paulist Press, 1979) p. 28.
5. I am using the terms '*micro* and *macro* levels' of medico-ethical treatment decision making in a manner elaborated by Singer, Pellegrino, and Siegler in their discussion addressing Ethics committees and consultants. cf. Singer, Peter; Pellegrino, Edmund; and Siegler, Mark: 'Ethics Committees and Consultants', *The Journal of Clinical Ethics.* (Winter, 1990) v.1 no. 4, pp. 263-267.
6. cf. Humphry, Derek: *What's in a word? The results of a Roper Poll of Americans on how they view the importance of language in the debate over the right to choose to die.* (Euthanasia Research and Guidance Organization (ERGO): August, 1993) p. 2.
7. This was stated by one of the Hemlock Society representatives at a pharmacy task force implementation meeting December 15, 1994 in Salem, Oregon.
8. Humphry states: *By using Orwellian 'doublespeak' we might be letting ourselves in for procedures and conclusions which we do not fully comprehend at the time of decision-making. On the other hand, perhaps euphemisms allow people to come to grips with brutal facts which, stated another way, would be repugnant.* cf. Humphry, Derek: *What's in a word? The results of a Roper Poll of Americans on how they view the importance of language in the debate over the right to choose to die.* (Euthanasia Research and Guidance Organization (ERGO): August, 1993) p. 2.
9. ERGO! stands for the 'Euthanasia Research & Guidance Organization' founded by Derek Humphry after leaving the Hemlock Society, which he also founded.
10. Humphry, Derek: *op. cit.*, p. 2.
11. Bates, Tom: 'Write to Die', *The Oregonian.* (December 18, 1994) section A, p. 30. This exposé gives a concise account of the background of those associated with the measure and its crafting.
12. *IBID.* In this article Stutsman adamantly denies any effect of the Roper poll on the referendum's drafting. Mark Trincherro suggests voter's polls were used in the drafting. Humphry suggests the poll's purpose was conducted so as to remove the debate over the most acceptable right to die language from 'personal decision to as wide as public platform as possible'. cf. Humphry, Derek: *op. cit.*, p. 2.
13. Keisling, Phil: *op. cit.*, p. 123.
14. Oregon Revised Statutes (ORS) 689.005 (28), 1993-52-4. The statute reads: 'Prescription' or 'prescription drug order' means a written or oral direction, given by a practitioner for the preparation and use of a drug. When the context requires, 'prescription' also means the drug prepared under such written or oral directions. There, 'prescription' is defined in terms of the word 'drug'. The Oregon Statutes signification of 'drug' is as follows: 'Drug' means all medicines and preparations for internal and external use of humans, intended to be used for the cure, mitigation or prevention of diseases or abnormalities, which are recognized in any United States Pharmacopoeia or National Formulary, or otherwise established as a drug. Oregon Revised Statutes 677.010 (6). Drug was further defined by ORS 689.005 (10) as: Articles recognized as drugs in the official United States Pharmacopoeia, official National Formulary, official Homeopathic Pharmacopoeia, other drug compendium or any supplement to any of them; (b) Articles intended for the use in the diagnosis, cure, mitigation, treatment or prevention of disease in a human or other animal; (c) Articles (other than food) intended to affect the structure or any function of the body of humans or other animals . . .
15. An initial legislative change was sent to Dr. Grant Higginson, Acting State Health Officer by a working group of the pharmacy task force. The December 6, 1994 text read: 'Prescription for Medication' means drugs in all doses, dosages forms and routes of administration prepared and dispensed by a licensed pharmacist for the purpose of self-administration to end life in a humane and dignified manner. The citation comes from closed task force implementation sessions and the identity of the participants involved are confidential. The veracity of the text can be substantiated by contacting the Oregon State Pharmacy Association. It should be noted that this recommendation was modified into meaninglessness at a following meeting of this task force and was never brought before the Oregon legislature for approval. cf. also United States District Court for the District of Oregon: Gary Lee et al. v State of Oregon et al, (Civil No. 94-6467-HO), August 3, 1995, pp. 16-17. It (Measure 16) provides that the attending physician may prescribe drugs, but does not limit that prescription to drugs which must be ingested. A prescription may be taken intravenously or a physician may establish a device for releasing the drug by a switch or gas mask. These possibilities subject a vulnerable person to potential abuse at the hands of others, and without the person's knowledge and consent.
16. cf. ABC News Nightline text#3533 (December 7, 1994) pp. 2-3.
17. Under the rubric 'What the Oregon Death with Dignity Act Does Not Allow' the statement reads in bold: 'The Oregon Death with Dignity Act does not authorize lethal injection, mercy killing or active euthanasia.' cf. Goodwin, Peter (ed.): *What Health Care Professionals Need to Know About the Oregon Death With Dignity Act.* (Authorized by Oregon Right to Die, No Date) inside panel 3.
18. O'Keefe, Mark: 'TV ad on assisted suicide leaves out part of story', *The Oregonian.* (November 4, 1994) section C, p. 1.
19. Humphry, Derek: 'Letter to the Editor', *New York Times,* (December 3, 1994) p. 14. Humphry suggests he has data substantiating his opinion, saying: *In October Dutch television aired a documentary showing the death of Cornelius van Wendel de Joode from injections of barbiturates and curare. This voluntary euthanasia was swift, painless and sure. Here is where the Oregon law, which forbids injections, could be disastrous. In a controlled study in the Netherlands, 90 people were given, at their request, nine grams of barbiturates by mouth. Sixty-eight died quickly—within two hours. The rest lingered as long as four days; In 15 instances the doctor gave a lethal injection because the oral drugs were causing protracted suffering to the patient, the family and himself.*
20. Humphry in all likelihood is alluding to the Admiraal Study where the author suggests that assisted suicide limited to oral ingestion is an unsafe medical practice cf. O'Keefe, Mark: 'Dutch researcher warns of lingering deaths', *The Sunday Oregonian.* (December 4, 1994) p. 1. Admiraal, a Dutch expert in medicide, is cited as describing 25 percent of those attempting suicide using the oral route lingering two days or longer. He intimates that Oregon's law is a first step, but is uncivilized in its current form because of the unpredictability of outcomes after oral ingestion.
21. Maas, P.J. van der; J.J.M. van Delden; and Pijnenborg L.: *Euthanasia and other Medical Decisions Concerning the End of Life.* (Elsevier: Amsterdam, 1992) v. 2, p. 47. Humphry's opinion is substantiated not only by Admiraal's apparent study but is also recorded in the Rammelink Report after attempted medicide and assisted suicide. Out of a sample of one-hundred and eighty-six persons, twenty-eight lingered between one hour and one day, eight lingered between one day and one week, and one

lingered for up to four weeks. There is a difference between the resolution of these lingering deaths in the Netherlands' Experience and that in Measure 16 that should not be understated. The Netherlands clearly permits lethal injection.

22. Moeschlin, S.: 'Clinical Features of Acute Barbiturate Poisoning', in *Acute Barbiturate Poisoning*, edited by Matthew Henry (Amsterdam: Excerpta Medica, 1971) pp. 118-127. The ineffectiveness of barbiturates has long been recognized. For example, Moeschlin comments that barbiturates are probably the most 'agreeable' and at the same time the most 'uncertain' method of taking one's life. One wonders if professionals practising with this awareness violate practice 'in good conscience' as well as current Oregon Statute. e.g. the practising of 'unprofessional conduct-through the use of unproved or unscientific treatments' ORS 677.190c.

23. Bates, Tom: *op. cit.*, p. 30.

24. *IBID.* He reports that Mark Trincherio, a telecommunications lawyer who was in on the drafting from the start, says the committee was able to draw upon

voter surveys and even raised money for surveys of its own.

25. Bates, Tom: *op. cit.*, p. 30.

26. These organizations were listed under the categories of 'Arguments in Favor' even though neither of the organizations gave permission for the use of their name, and in the end they opposed the measure. cf. Keisling, Phil: *op. cit.*, p. 126. On October 6, 1994 the Board of Oregon State Pharmacists Association voted unanimously to oppose Measure 16. This led to the sending of a letter of protest by their executive director, dated October 11, 1994, to Oregon Right to Die 'expressing strenuous objection to the using of their name without permission'.

27. The lack of clarity in these two statements led influential panel members of the Oregon State Extension Service to interpret the 'Act' as prohibiting 'lethal injection' and 'mercy killing'. The ambiguity of Section 3.14 leaves the accuracy of this interpretation in question. cf. Hare, J.; Gregerson, D.; Pratt, C.; Campbell, C.; Kliever, David; Bruce, J.: *The Oregon Death with Dignity Act*. EM 8569, August 1994.

Book Reviews

The Christian Virtues in Medical Practice

Edmund D. Pellegrino and David C. Thomasma
Washington D.C.: Georgetown University Press, 1996
ISBN 0878405666, 176 pp., hardcover \$27.95

I have had the distinct pleasure of reviewing Drs. Pellegrino and Thomasma's new book, *The Christian Virtues in Medical Practice*. For many authors, a book's success is measured in how their work changes their readers; for medical ethics this change might take place either in the process or the content of ethical reflection. In this reviewer's case, Drs. Pellegrino and Thomasma have certainly written a success.

The Christian Virtues in Medical Practice is a sequel to Pellegrino and Thomasma's book, *The Virtues in Medical Practice* (New York: Oxford University Press, 1995; reviewed here, 11[3], pp. 68-69). Pellegrino and Thomasma lay out their approach to a Christian virtue ethic fairly early in their book: 'First, any comprehensive Christian medical moral philosophy ought to be grounded in the nature of medicine itself . . . Second, a Christian perspective begins, but does not end, with this internal morality . . . Third . . . certain practical moral choices are clearly more consistent with the virtue of charity than others' (p. 30). These eminent authors feel they have previously clarified, through the nature of medicine, a medical moral philosophy (e.g. *The Philosophical Basis of Medical Practice* [New York: Oxford University Press, 1981] and *The Virtues in Medical Practice*). They base their theory of Christian virtue on this medical moral philosophy, additionally building from the works of St. Augustine, St. Aquinas, Scripture, and Pope John Paul II, as well as adding a principle based framework.

Pellegrino and Thomasma do feel that certain moral activities are inconsistent with a Christian virtue ethic: 'the health professional cannot cooperate formally or directly with an intrinsically evil act. There is the obligation to decide whether to withdraw respectfully or, if the harm being done—e.g., active euthanasia, grossly incompetent surgery—is sufficiently great, to intervene directly' (p. 78). However, Pellegrino and Thomasma do not specifically deal with these intrinsically evil acts in this current work. The difference Christianity makes to virtue ethics is the transformation of a profession to a vocation thereby raising 'the profession to a level of grace' (p. 4). *The Christian Virtues in Medical Practice* places in perspective the Christian physician specifically as he or she relates to the virtues in medical practice, viz. 'the Christian physician is not just a physician who happens to be a Christian. He is, at once, a Christian and a physician, one who is competent, but one whose competence is practiced within the constraints of Christian ethics' (p. 2).

Charity is pivotal to the Christian virtues, 'it is the ordering virtue of the Christian life, the source of resolution of internal conflict as well as the rectification of the passions, directing them to their proper ends' (p. 19) and 'illuminates a central dilemma of philosophical ethics: why, and to what degree, are some rules and principles are morally imperative and others not, and which among the possible sources of morality should take precedence?' (p. 72). To Pellegrino and Thomasma this focus on charity establishes an 'agapeistic ethic', which 'should therefore dispose the physician to decisions that would advance the good of the patient, but in a way informed by charity' (p. 73). Pellegrino and Thomasma link Christian virtue theory with principle based ethics in a unique way, through charity and their agapeistic ethic. However, a principle based approach is insufficient: 'what the virtue of charity adds is a special way in which these principles are to be lived and applied in concrete situations. From this religious perspective, charity "informs" these principles' (p. 74). Charity in an agapeistic ethic also provides a framework from which to judge the principles when in conflict. Therefore, 'each of the principles of medical ethics is thus subject to tests of conformity with normative sources of moral validation—Scripture, the tradition or teaching of an official church, the example of Jesus' (p. 74).

Pellegrino and Thomasma have a deep and rich sense of the virtues of the Christian physician. He or she is an individual who has answered a calling to practise the vocation of medicine. A Christian physician believes and practises an agapeistic ethic where, 'charity is for him "the root of all good"' (p. 127). His or her view of justice is also transformed where, 'justice is ultimately grounded in love—a charitable justice rendering to others their due, in which "due" is not only what is legally owed but what is called for by love' (p. 128). This Christian vocation of medicine 'imposes a standard of commutative and distributive justice weighed heavily in the direction of benevolence and beneficence even at the expense of inconvenience, cost, and some personal danger to the physician' (p. 131). For Pellegrino and Thomasma, physicians should treat HIV patients, shun the pursuit of profit in health care and strive to eliminate the inequalities of distributive justice in the health care system; all actions supported by their agapeistic ethic. Christian physicians should be 'self-effacing', although that self-effacement should be balanced with responsibilities of family, church, and friends. Therefore, 'the Christian virtues seek to define the kind of person the physician ought to be to fulfill his or her calling both as a physician and as a Christian' (p. 154).

In the last few pages of this book, Pellegrino and Thomasma speak of the patient's responsibility: 'patients, therefore, owe a

debt to the community' (p. 124). Patients also do not have *carte blanche* when it comes to demands on the physician: 'the patient cannot, in the name of the absoluteness of autonomy, demand that the physician become the unquestioning instrument of the patient's will' (p. 123). It would seem that the practice of virtue is not the domain solely of the physician. Patients also have some responsibility for their care and relationships. Does the patient have a responsibility to exhibit the virtues in the patient-physician relationship, and what about the Christian patient? I would still like to see a work explicating the medical moral philosophy of the virtuous patient. This would be a very interesting sequel to Pellegrino and Thomasma's series, *The Virtues in Medical Practice* and *The Christian Virtues in Medical Practice*.

The major problem I see in this work relates to Pellegrino and Thomasma's insistence that physicians must be neutral with respect to their patients' values. They have upheld this concept in previous works, stating, for example, that 'justice would require that neither physician nor patient impose her values on the other' (*The Virtues in Medical Practice*, p. 97). So it comes as no surprise when they state in this new volume, 'some fear that too overt a commitment to Christian ethics would lead to imposition of the doctor's beliefs on the patient. . . . It is distressing even to think that a physician would exploit a patient's illness to proselytize' (p. 1).

Christian physicians, however, should not be silent about their values in the public debate on health care and medical morality: 'to be silent about one's beliefs is to impoverish this debate and to lose it by default. To suppress the religious perspective means tacitly to accept secular and civic religion as the final determinants of morality' (p. 2). This is a seeming contradiction. In the patient-physician relationship physician values should not be verbally expressed, yet publicly we have an obligation to express these same values. To Pellegrino and Thomasma the vulnerability of the patient requires a 'value neutral' physician.

For these authors the 'best way to evidence one's Christianity is by genuine commitment to the sick and the poor' (p. 114) and 'the way we engage with even the hostile opponent reveals more about the veracity of our message than our logical arguments' (p. 114). Yet, if one believes that being a follower of Christ is 'the way, the truth and the life' (John 14:6 NAS) and the only way to the soul's salvation, why would that person be silent in the setting of illness? Shouldn't illness, above all other situations, be where we would share our faith, not only in action but verbally as well? Is a person's body of more import than their soul and if we are healers, are we not healers of the soul also? Pellegrino and Thomasma, seemingly have forgotten what the early Church fathers had to say concerning the importance of the soul's salvation. In the Orthodox Church Christian saints who were physicians are recognized and honoured. These physicians treated patients for free and enjoined them to become Christians. They felt that conversion was part of the healing process. Saints Comas and Damian are described thus: 'they sought no reward for their work, only urging the sick to faith in Christ the Lord' (St. N. Zelmimirovic [1986], *The Prologue from Ochrid: The Lives of the Saints*, vol. 3, translated by Mother Maria ([Birmingham England: Lazarica Press], p. 5). Saint Cyrus, the holy un-mercenary physician, is described in the same work in this way: 'discovering that illness came upon people mainly through sin, he always told them to cleanse their souls from sin by repentance and prayer, that they might be restored and strengthened in body' (vol. 1, p. 116). It seems hard to imagine that these physicians would stand by, allowing patients to make the wrong choice without hearing the true alternative, i.e., Christ and his church. The inconsistency of Pellegrino's and Thomasma's position seems, at least to me, difficult to reconcile. That Drs. Pellegrino and Thomasma are devout Catholic Christians who believe in the expression of their faith in both word (outside the patient-physician relationship) and deed is beyond doubt. Yet, why would the setting of the doctor-patient relationship be without that same devotion, in both word and deed? If, as Pellegrino and Thomasma seem to feel, our responsibility to a patient's bodily illness is profound enough to disallow us

to refuse to treat, how much more our responsibility to their souls?

Drs. Pellegrino and Thomasma seem to be embracing the position of physician value neutrality (PVN). This position, it seems to me, is without any warrant and does not deserve a place in any Christian view of the patient-physician relationship (See Peppin JF. [1995], 'Physician Values and Physician-Value Neutrality?' *Journal of Religion and Health*, 34, 287-299; and Peppin JF. [1995]. 'Physician Neutrality and Patient Autonomy in Advanced Directive Decisions.' *Issues in Law and Medicine*, 11, 13-27). PVN considers a physician's values, especially religious values, to have no place in the patient-physician relationship. It has deep roots in the liberal political philosophy of Rawls, Dworkin and others, and stresses unconstrained patient autonomy (Rawls J. [1971], *A Theory of Justice*. [Cambridge Mass.: Harvard University Press], and Dworkin R. [1978], 'Liberalism,' in *Public and Private Morality*, Hampshire S. ed. [Cambridge Mass.: Cambridge University Press]). In the setting of illness the patient is more vulnerable to suggestion and manipulation, therefore a physician should be especially wary of possible influence through syntax and language. This would be a violation of that patient's ability to seek his or her own concept of the moral 'good' in their medical care.

Obviously the authors of *The Christian Virtues in Medical Practice* feel that the ministrations of the physician say more than any verbal profession of faith ever could and perhaps this is true. Certainly our physical ministrations, i.e., our works, are of great import in our Christian witness. However, could this type of ministration itself be a violation of PVN? It would seem to me that values can be imposed in ways other than verbally. Does body language, clothing and the exhibition of Christian charity also impose values on the patient? Why would the profession of one's faith verbally be any less manipulative than the ministrations to the body in Christian charity? The sociologic literature supports communication in ways other than verbal: e.g., body language and clothing can transmit certain underlying beliefs and values (see Milgram S. [1974], *Obedience to Authority*). If this is true, then this same body language and clothing can express Christian values and beliefs, which is exactly what Pellegrino and Thomasma wish for, e.g., 'the best way to evidence one's Christianity' (p. 1).

Pellegrino and Thomasma seemingly have also forgotten that our ministrations to the sick and poor are done as a command as a witness of the truth of Christ and God's love for mankind; 'For by this all men shall know that you are my disciples' (John 13:35 NAS). We are trying to share Christ with our patients by showing them God's love through our actions. This seems to be an 'imposition' of the physician's values into the patient-physician relationship as much as verbal proselytizing. I make this point not to forbid body language, Christian charity, or other ways in which physicians may express their values, but rather to show the inconsistency of not allowing verbal ministrations when extolling ministrations to the body. Both are imposing values, and very rich values, into the patient-physician relationship.

Pellegrino and Thomasma's book is essential reading for individuals interested in medical ethics, but especially for those Christian physicians who wish to investigate the blending of medicine and Christianity. Pellegrino and Thomasma have challenged me personally to act with more charity and humility. They have challenged me to seek new ways to care for the poor and those without medical insurance or means to pay. I must confess that I had decided not to treat AIDS patients once I left residency, couching this in medical terms, i.e., I was not qualified enough to treat these types of cases and thus should refer them on to specialists in this area. However, perhaps this was just an excuse, a way of neglecting Christian charity in the guise of medical expediency and personal safety. Although Pellegrino and Thomasma may not have clearly spelled out the extent of the verbal Christian witness in the patient-physician relationship or dealt with the issue of value neutrality, they have still written a powerful work that will challenge the reader. This is one of those few books you will re-read. It is one of an even smaller subset that

will change the way you see your relationship to your patients.

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The DNA Mystique: The Gene as a Cultural Icon

Dorothy Nelkin and M. Susan Lindee
New York: W.H. Freeman and Company, 1995
ISBN 0-7167-2709-9, x + 276 pp., paperback \$12.95

According to sociologists Dorothy Nelkin (New York University) and M. Susan Lindee (University of Pennsylvania), the human genome has not only scientific importance, but also crucial social meaning and significance. *The DNA Mystique* chronicles and assesses popular beliefs about the role of genetics in contemporary culture. The authors' research draws from a wide range of sources. They interviewed students, political ideologues, scientists, business people, housewives and others. They reviewed popular journalism, television, and cinema. They attended meetings hosted by a myriad of professional organisations and groups interested in, and concerned about, the nature and use of genetic information. Their conclusion: The gene is emerging as a defining icon of contemporary culture.

Nelkin and Lindee are wary of the privileged social status accorded genes. Yet, unlike many contemporary sociologists and historians of science who look for cultural lenses that inhibit scientific objectivity, the authors focus on the interpretations given to genetics in popular culture. Ideology, not science, is their primary concern: 'We suggest that the powers attributed to heredity in both the historical and contemporary contexts reflect cultural and social agendas more than they do the state of scientific knowledge' (p. 21). By distinguishing between science and scientism, the authors offer a balanced and insightful account of the renewed emphasis given to genetics in relation to human identity, social ethics and public policy.

The authors' central concern is the widespread social acceptance of genetic essentialism. Genetic essentialism, 'reduces the self to a molecular entity, equating human beings, in all their complexity, with their genes' (p. 2). Nelkin and Lindee observe that this model of personhood has replaced the biblical soul in popular culture. It does this in three ways. First, genes provide the meaning of human uniqueness. 'The genome appears as a "solid" and immutable structure that can mark the borders and police the boundaries between humans and animals, man and machine, self and other, "them and us" ' (p. 43). Second, DNA has an immortal quality. Its structure, which makes a thing what it is, will survive long after the body. It can be resurrected, as in Michael Crichton's *Jurassic Park*, or preserved in one's progeny. Finally, 'DNA explains our place in the world: our history, our social relationships, our behavior, our mortality and our fate' (p. 57). As popularly conceived, genes sovereignly dictate personality and direct human destiny. Genes are said to explain our intelligence, virtues and vices, sexual predilections, and so on.

What elevated DNA to the status of cultural icon? Nelkin and Lindee identify various social agendas they think contribute to the widespread acceptance of genetic essentialism. According to the authors, the genetics research community is a primary source of public opinion. They supply two reasons for this. First, in the competition for limited research grants, some scientists in the behavioural genetics field have turned to the media as a way to cultivate public interest in their work. 'Indeed, many of the values and assumptions expressed in popular representations of genes and DNA draw support from the rhetorical strategies of scientists—the promises they generate and the language they use to enhance their public image' (p. 6).

Also, geneticists too often employ misleading reductionistic

language and images to explain their work to a lay public. Sometimes this is done to heighten awareness of the biological contribution to public health concerns. At other times, however, reductionist language conveys many scientists' bias toward genetic essentialism. The authors note, for example, that geneticist Walter Gilbert introduces his public lectures on gene sequencing by 'pulling a compact disk from his pocket and announcing to his audience: "This is you" ' (p. 7). This reductionism is particularly disconcerting for Nelkin and Lindee in the case of politically committed scientists such as gay activist Simon LeVay or *The Bell Curve* authors, Herrnstein and Murray. These researchers use the elevated social status of science as a means of advancing their ideologically driven interpretations of research data.

The media also have a crucial role in perpetuating genetic essentialism. Nelkin and Lindee point out that journalism and advertising thrive on the sensational and have little patience for more balanced assessments of scientific research. This cultivates naive and simplistic notions about human behaviour. 'Imagologues', as the authors call them, influence public opinion through careless use of genetic imagery and language. Such images are found across the spectrum, from blue jeans commercials ('thanks for the genes, Dad') to sitcoms, science fiction, and soap operas. Even serious news magazines provide high profile to the claims of some behavioural geneticists, while grossly underreporting qualifications, limitations, contrary interpretations, and even counter-proofs of these controversial claims. The book identifies the alleged genetic basis for IQ, homosexuality, alcoholism, and violence as clear examples of this kind of journalistic distortion.

Nelkin and Lindee point out that a key reason why popular culture readily accepts genetic essentialism is its search for easy answers to complex social problems. At a time when many Americans feel threatened by urban violence, rising addiction rates and intractable poverty, genetic essentialism provides a convenient means of absolution. Society should not be blamed for nature's misfortunes. On genetic essentialist grounds, '... if individuals are not malleable—and in the political imagination a genetic trait is a trait that cannot be affected by environmental forces—the efforts to change the social environment may be irrelevant' (p. 129). Simply put, '[p]eople with problems become, in effect, problem people. . . . Genetic deviance, a property of individuals and their DNA, relieves state and society of collective responsibility for the social conditions that foster violence' (p. 129). Such thinking gives little reason to continue supporting expensive social welfare programmes that target 'at risk' populations.

The authors express concern that genetic explanations of social problems may lead to public policy aimed at population control and other encroachments of human rights. Chapter nine, 'Genetic Futurism', explores several related ideas along these lines. Two ideas are particularly significant. First is a belief that the quality of the human gene pool is compromised by undisciplined reproductive practices of the poor. The economic 'underclass' is regarded by many as genetically inferior. That is why, they aver, poverty seems to follow family lines. By controlling the reproductive patterns of the poor, we can prevent their increased threat to the domestic economy and public safety. Such thinking has made the racist pronouncements, like those of *The Bell Curve*, plausible to many. As economic pressures mount, genetic essentialism will, Nelkin and Lindee think, make reproductive control of the poor a more serious consideration. They also raise the spectre of a Malthusian approach to foreign policy with impoverished nations.

A second disturbing idea entertained in 'Genetic Futurism' is that some lives are simply not worth living. The authors argue from a variety of examples in popular entertainment that public sympathy for congenital deformity is changing. They conclude, '... disabilities today are often seen in terms of their cost implications for the state. When disabilities are understood as economic burdens for the larger society, whether or not to bear a potentially imperfect child becomes a social as well as individual choice' (p. 176). Social pressure as much as public policy may lead to the

expectation of prenatal genetic screening and, where the developing child fails to 'meet the grade', abortion.

Nelkin and Lindee offer a sobering assessment of a society in which the gene has become a cultural icon: 'Infused with cultural meanings, the gene has become a resource that is too readily appropriated, too seldom criticized, and too frequently misused in the service of narrow or socially destructive ends' (p. 199). Christians concerned for social justice will find *The DNA Mystique* a troubling barometer of public sentiment. Unfortunately, the authors provide little direction for how to think ethically and constructively about the new genetics revolution. Perhaps this is because Nelkin and Lindee appear to lapse into the same kind of reductionism that characterizes genetic essentialists. For the authors, 'nature' and 'nurture' seem to be the only alternatives in defining human personhood. I suggest that a return to a view of humans made in the image of God uniquely captures our intuitive knowledge of human dignity and provides a moral framework to address a more complicated millennium that awaits us.

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The Sterilization Option: A Guide for Christians

David B. Biebel, ed.

Grand Rapids: Baker Books, 1995

ISBN 0-8010-5267-X, 102 pp., paperback \$8.99

My wife and I recently had our third child. While adjusting to the day-to-day realities of caring for these blessings from God, our thoughts have often turned to the number of children God wants us to have. The topic of sterilisation soon arose, specifically my having a vasectomy, since it was 'my turn' to go through some reproductive pain! Yet something other than fear of the 'knife' left me less than enthusiastic about this option. Discussions with other Christians, including some physicians, were usually met with something along the line of 'What moral issue?' In the midst of searching for biblical resources addressing my dilemma, Biebel's book arrived on my desk to be reviewed.

At last! Someone else acknowledging that sterilisation involves spiritual issues which deserve much prayer, reflection and discussion. *The Sterilization Option: A Guide for Christians* is written 'to assist couples who are considering permanent sterilisation to make a medically informed, theologically sound, ethically defensible, morally acceptable choice' (p. 12). The six short essays by different authors excellently review the main issues that should concern Christians. Each essay is clearly and concisely written for those without professional training in medicine, theology, or ethics. Each chapter concludes with questions suitable for personal reflection or group discussion.

In the first essay, Biebel, Dean I. Youngberg, and Judy Youngberg relate the stories of some couples considering sterilisation. That of Biebel and his wife particularly struck a chord with me. Here was someone else who for some reason was morally uneasy about sterilisation, but couldn't quite figure out why. We hear about another engaged couple who never want to bring children into this kind of a world. And yet another couple are considering reversing a tubal ligation in the belief that it was against God's will for them to have had the procedure in the first place. Based on the authors' experience, Christians needing biblical guidance in these situations are often told that sterilisation is just a matter of couples deciding what they prefer.

The next two essays focus on the medical aspects of sterilisation. Joe S. McIlhane, Jr. (an obstetrician/gynaecologist) writes on female sterilisation, and Charles K. Casteel (a urologist) writes on vasectomies. The anatomical and procedural details are articulated well, with helpful diagrammes suitable for those without medical training. Statistical details cover the main reasons for sterilisation, the failure rates, side effects, and chances of reversing

the procedures. An interesting point, not commented on in the book, is that while McIlhane thinks it better that the woman be sterilised, Casteel believes the man should undergo the procedure. Nevertheless, these essays provide valuable information for making informed medical decisions.

The last three essays address the ethical, theological and moral issues. Robert Orr honestly admits that he has frequently sterilised married couples without reflecting on the ethical or spiritual issues involved. He accepted the secular ethic that all that mattered was patient autonomy and informed consent. In this chapter, he provides an excellent overview of medical ethics, and contrasts secular and Christian approaches. His set of Christian guidelines and principles would prove helpful in working through any ethical issue. He then reviews the positions on sterilisation of the Roman Catholic Church and the major Protestant denominations. In contrast to the former's unwavering position that 'direct sterilization is intrinsically evil' (p. 54), most Protestant ethicists see the decision as one of individual conscience. Most evangelical groups, including medical organisations, are either permissive on this issue, or silent.

John Jefferson Davis returns to many of the points made by Orr, expanding on some. While sometimes repetitious, the additional detail is helpful, particularly in understanding the unwavering Roman Catholic position. Davis then reviews many of the biblical texts referred to in these discussions. While showing that some of these, particularly those dealing with eunuchs, have little direct application today, he makes important points about the call to be fruitful, God's consistently favourable view of children, and the fact that our bodies are a trust from God, not ours to do with as we please.

Dave Biebel's concluding essay on morality looks at the ethical and theological issues in light of social beliefs. Biebel laments that many Christians seem to have adopted the views of secular society on this issue, not Scriptural principles. Looking at some of these biblical principles already raised in other essays, and adding others, Biebel concludes that many reasons used to justify sterilisation are inappropriate for Christians. 'Christian couples who choose childlessness for reasons of selfishness, personal convenience, finances, or to pursue a career unhindered, are rejecting something God views as a heritage, a reward, a gift, or a blessing. To view something as a liability which the Lord holds in such positive esteem seems to be not very spiritually discerning' (p. 81). None of the authors suggests that this means Christians should have as many children as possible. Even a literalistic interpretation of the command to be fruitful (Gen. 1:28; 9:1, 7) would require only three children for every couple.

The discussion raises questions as to whether temporary or permanent means of limiting fertility are ethically different. Biebel sees them as different because permanent sterilisation requires surgery (and hence higher risks), the long-term risks are poorly understood, and the motivations are different. Inherent to becoming permanently sterilised is the decision to take 'complete' control of your child-bearing possibilities. I was disappointed that only one page was given to discussing this important distinction. Much more needs to be said on this, but at least Biebel has offered something to get the discussion started.

Other relevant biblical issues deserved further discussion, such as the balance between God's sovereignty and technological control, stewardship and world population, and why anyone should have any children. The authors frequently admitted that this is an area over which committed Christians will have differing opinions. This should not eliminate discussions, but makes the need for these conversations more urgent. The fact that this has not been occurring, even among evangelicals, is disturbing.

However, as an introduction to the issue, and a resource for non-professionals, this book should be welcomed. Any couple wondering about how many children God wants them to have should read *The Sterilization Option* together and pray about the issues it raises. In my own life, this book has brought me comfort

in knowing that others are struggling with these same issues. The book does not give definite positions on the issue, except in certain situations and with some motivations. However, the concluding sentence of the book has helped me realize that right now I cannot proceed with permanent sterilisation: *'The procedure should only be performed if a couple shares the settled belief, perhaps reached with the assistance of trusted advisors, that under no circumstances would God want them to have another child'* (p. 89, emphasis original).

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Bioethics and The Future of Medicine: A Christian Appraisal
Edited by John F Kilner, Nigel M de S Cameron and David L Schiedermayer.

Carlisle: Paternoster Press, 1995
ISBN: 0-85364-674-0, 309pp., paperback

The book is divided into four parts. The first part has to do with the practice of medicine. So firstly Nigel Cameron examines what is implied by the coining of the new term 'bioethics' which coincided with the collapse of the Judaeo-Christian view of the value of human life. The term bioethics (instead of medical ethics) takes the moral decision making in medicine away from doctors. In its place, lay, commercial and utilitarian values are used in the application of medical science. Bioethics signifies the change in ideas of what it means to be human in an era which has repudiated Christian values. There is bound to be a divergence of opinion in those who hold Christian values and those whose starting point is the repudiation of those values. He proposes a dissident medicine, active and well grounded in biblical and Christian tradition to counter these effects. Continuing the theme, Henk Jochemsen and colleagues note that medical practice is dominated by an approach in which the leading metaphor for the human body is the machine, scientific theory is accepted as *the* reality and not just a model to describe certain phenomena, and science and technology are seen as instruments to control existence and solve all our problems. Thus health and even salvation are seen as available from medical science and the place of medicine in the welfare of mankind becomes vastly overrated. This approach to medicine is neither financially nor ethically sustainable and Christians need to point out the pretensions of such a system.

Loreen Herwaldt reflects that God has given the world an absolute foundation for ethics. When Christians choose to disobey God if their immediate ambitions or survival in the world seem to be in jeopardy, they are prostituting themselves to the gods of this world. She compares the biblical examples of David and Saul and observes from C. S. Lewis that it is possible to turn into dragons while we are (spiritually) asleep. Like Eustace, the nasty little boy in *The Voyage of the Dawn Treader*, who found that 'Sleeping on a dragon's hoard with greedy, dragonish thoughts in his heart, he had become a dragon himself'.

John Peppin tackles physician values and the nonsense of value neutrality. It is impossible for *any* person to act without values affecting his or her decisions. What Christian physicians are being asked to do, is to accept all value systems as valid and in that acceptance, to relinquish their own. He proposes that value non neutrality and sharing, not imposing, one's faith and values is both truthful and admirable.

From findings from Systematic Reviews and Valence Reviews of the mental and physical health literature David Larson and Mary Greenwold observe that religion as a function affecting patients' health has not been validly studied, even though nearly three quarters of the American population claims to base its entire approach to life on its spiritual beliefs.

The final chapter in this section is an interesting essay on the ethics of physician income.

The second part of the book is about the ethical underpinnings of medicine.

As a Catholic and a medical practitioner, Allen Verhey's chapter on Luther's 'Freedom of a Christian' and a patient's autonomy gave me a lot of food for thought. Protestants have a lively tradition of refusing to submit to arbitrary despotism. Protestant moral theologians noting the new powers of medicine, protested against the depersonalising effects of medical powers and insisted on respect for patients as agents. However, freedom means different things to different people and Protestants have a responsibility to say where and how the notion fits Protestant tradition and where it does not.

The next chapter handles the problem of how to justify decisions not to pursue medical interventions which would only prolong dying without being accused of making quality of life (utilitarian) decisions. Since Christians and atheists have entirely different concepts of the purpose of human life, that is to say whether it is holy or not, they are bound to disagree on notions of 'quality of life' depending on whether the term conveys to them spiritual or utilitarian dimensions.

Nietzsche, a man who lived in the last century, had strong views on medical ethics. In a work of his entitled 'A moral code for physicians' he begins: 'The invalid is a parasite on society'. Commencing thus Stephen Williams outlines Nietzschean ideas in his chapter on 'Bioethics in the shadow of Nietzsche' and discusses whether present day thinking has been influenced by them.

Ben Mitchell discusses the rôle of the church in bioethics in the light of Christ's offices as prophet, revealing the truth, priest, reconciling man to God, and king, ruling over and protecting his people, functions which all Christians as Christ's body collectively and individually take part—or should take part. The next chapter again rings with the same theme, that Christians should not be leaving bioethics to secular debate. Robert Orr, on Christian and secular decision making, attributes the burgeoning medical ethics debate to advances in technology, changes in the doctor-patient relationship and cost containment. I do not think that that is so. The basic problem is the general abandonment of religion and with it a true awareness of man's rôle and destiny. However, he develops ground rules for medical decision making and compares attitudes of Christians and secularists.

Denis Hollinger's chapter on 'doing bioethics' teases out three strands for ethical debate. The sources from which we understand Christian ethics, these ethics applied to individuals (pastoral care) and to society (public policy).

The second half of the book deals with specific ethical problems, part three with aspects of the abortion crisis: post abortion syndrome, abortifacient vaccines, the legal status of the unborn, a discussion on what it means to be an 'image of God' and finally the moral betrayed of women who are presented with abortion as the way out of their difficulties. In part four, the expanding bioethics agenda, focuses on surrogate mothers genetic engineering, advance directives, the right to die, Christian care of the dying and resource allocation in health care.

It is not surprising that as a doctor I found those parts written by doctors very much easier to read. I suppose that this comment contains a plea that theologians and philosophers should make their ideas simpler to layfolk, particularly those who need to digest information fairly rapidly. This may be one of the reasons why Christian views have not found their way, as they should, in ethical debates. The ideas are not put across simply enough. Perhaps in talking across the divide to those in different disciplines we should all endeavour to explain things as we would to an intelligent child of three! Even so, I found the book informative, thought provoking and useful and well worthwhile wrestling with the philosophical bits.

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Books Received

Brends Almond (ED) (1996): *AIDS; A Moral Issue. The Ethical, Legal and Social Aspects* (2nd edition)

[Macmillan Press, Macmillan Distribution, Houndmills, Basingstoke, Hants, RG21 6XS, England]

ISBN 0 333 63344 X

x + 162pp, Pb, £15.99

R. J. Berry (1996): *God The Biologist: Faith at the Frontiers of Science* [Apollos, 38 de Montfort Street, Leicester LE1 7GP, UK]

ISBN 0 85111 446 6

ix + 143pp, Pb, £12.99

Peta Bowden (1996): *Caring: Gender-sensitive Ethics*

[Routledge, 11 New Fetter Lane, London EC4P 4EE, UK]

ISBN 0 415 13384 X

vii + 224pp, Pb, £12.99

Gunnar Brober and Nils Roll-Hanse (Ed) (1996): *Eugenics and the Welfare State: Sterilization Policy in Denmark, Sweden, Norway and Finland*

[Michigan State University Press, East Lansing, Michigan 48823-5202, USA]

ISBN 0 87013 413 2

ix + 294pp, Hb

Michael D. Calabri (1996): *Florence Nightingale and Greece*

[State University of New York Press]

ISBN 0 7914 3116 9

x + 163pp, Pb, \$14.95

Catholic Bishops' Joint Committee on Bioethical Issues (1996): *Genetic Intervention on Human Subjects*

[Linacre Centre, 60 Grove End Road, London NW8 9NH, UK]

ISBN 0 9520923 1 X

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[Institut Borja de Bioetica Fundacion Mapfre Medicina, Llasares 30, 08190 Sant Cugar del Valles (Barcelona), Spain]

ISBN 84 87621 52

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John Keown (1996): *Euthanasia in the Netherlands: Sliding Down the Slippery Slope?*

[CBPP, 58 Hanover Gdns, London SE11 5TN, UK]

ISBN 09574760 X

36pp, Pb £2.00

Rudolf Klein, Paricia Day and Sharon Redmayne (1996): *Managing Scarcity: Priority Setting and Rationing in the National Health Service*

[Open University Press, Celtic Court, 22 Ballmoor, Buckingham, MK18 1XW, UK]

ISBN 0 335 19446 X

viii + 161pp, Pb,

Daryl Koehn (1994): *The Ground of Professional Ethics*

[Routledge, 11 Fetter Lane, London EC4P 4EE]

ISBN 0 415 11667 8

xi + 224pp, Pb, £11.99

Robin Levin Penslar (Ed) (1995): *Research Ethics. Cases & Materials*

[Indiana University Press, UK Distributor, Open University Press, Celtic Court, 22 Ballmoor, Buckingham, MK18 1XW, UK]

ISBN 0 253 20906 4

xii + 278pp, Pb

James D. Mallory (1996): *Ending the Battle of the Sexes*

[Crossway Books, 38 Montfort Street, Leicester LE1 7GP, UK]

ISBN 1 85684 156 1

188pp, Pb, £5.99

Pete Moore (1996): *Trying for a Baby: What You Need to Know About Fertility Treatment*

[Lion Publishing Services, Sandy Lane West, Oxford OX4 5HG, UK]

ISBN 0 7459 3421 8

192pp, Pb, £6.99

David S. Oderberg and Jacqueline A. Laing (1997): *Human Lives: Critical Essays on Consequentialist Bioethics*

[Macmillan Press, Macmillan Distribution, Houndmills, Basingstoke, Hants, RG21 6XS, England]

ISBN 0 312 16099 2

vii + 244pp, Hb, £40.00

Gillian Paterson (1996): *Love in a Time of AIDS*

[WWC Publications, World Council of Churches, PO Box no. 2100, 150 route de Ferney, 1211 Geneva 2, Switzerland]

ISBN 2 8254 1191 4

xv + 130pp, £&.25, \$11.50

Drucilla Scott (1996): *Michael Polanyi*

[SPCK, Holy Trinity Church, Marylebone Road, London NW1 4DU]

ISBN 0 281 05017 1

v + 215pp, Pb

Rod Sheaff (1996): *The Need for Healthcare*

[Routledge, 11 New Fetter Lane, London EC4P 4EE]

ISBN 0 415 10112 3

xi + 228pp, Pb £13.99

Marco Ventura (1994): *Procreer Hors la Loi*

[Cerdic Publications, 11 rue Jean Sturm, F-67520 Norheim, France]

ISBN 2 85097 052 2

348pp, Pb, FF 200

Vernon White (1996): *Paying Attention to People*

[SPCK, Holy Trinity Church, Marylebone Road, London NW1 4DU, UK]

ISBN 0281 04988 2

vii + 199pp, Pb

Book from earlier lists which we still wish to be reviewed:

Peter Doherty (Ed) (1995): *Post-Abortion Syndrome. Its Wide Ramifications*

[Four Courts Press, Kill Lane, Blackrock, Co Dublin, Ireland]

ISBN 1 85182 159 7

120pp, Pb

John Keown (Ed) (1995): *Euthanasia Examined: Ethical, Clinical and Legal Perspectives*

[CUP, The Pitt Building, Trumpington Street, Cambridge CB2 1RP]

ISBN 0 521 45141 8

xv + 340, Hb

David Short (1995): *The Medical Consultation: A Practical Guide for the Hospital Specialist*

[Quay Books Division of Mark Allen Publishing Ltd, Jesses Farm, Snow Hill, Dinton, Salisbury, Wilts SP3 5HN, UK]

ISBN 1 85642 118 X

xiii + 129, Pb