BIOETHICS AND THE SPIRITUAL

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IT IS PERHAPS IN THE FIELD OF BIOETHICS that contemporary philosophy is found to be most wanting. The Anglo-American tradition with its emphasis on argument developed from rational principles and its neglect of anthropology cannot be sufficiently attentive to questions of meaning and spirituality – questions which necessarily attend our experiences of birth, suffering and death. Stressing objective knowledge at the expense of subjective understanding has yielded a moral framework which has no space for moral imagination and cannot deal with the moral significance of the emotions.

Failure to deal satisfactorily with matters of life and death has prompted many to seek alternative ways to think about these matters and there has been a revival of interest in Aristotelian approaches, sometimes called 'virtue' or 'character' ethics. The focus of such reflection is the character of the moral agent. Although the nature of the action and its consequences are seen as important it is suggested that these elements are not sufficient to capture all that concerns us in moral evaluation. Consideration of the character of the moral agent also requires definition of the purpose of human life and what might be considered 'good' or worth striving towards. Such an orientation has also revived an interest in natural law and the suggestion that a narrative tradition in which the telling of the story itself serves to preserve the moral import of the action. The first element has forced an extension of bioethics beyond the narrow frame of medical ethics and reflects the modern scientific view of the world as a complex web of interrelated elements rather than being composed of disparate and isolated entities. The second allows the description of ethical problems to go beyond technical stylized language which permits only analysis, and stimulates an attempt to integrate rational and emotional cognitive processes. In short, a more holistic approach to bioethical dilemmas is developing.

Possession, stewardship and the phenomenon of life

The origins of the current interest in bioethics are, according to most commentators, to be found in the annals of theological debate. A great

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proportion of those engaged in the discipline of bioethics in the United States have primary degrees in theology – people such as Stanley Hauerwas, Paul Ramsey, Richard McCormick SJ and Karen Le Bacqz. The advance of medical science and the astonishing capacity to intervene in matters of life and death require us to think afresh about the meaning of human life, suffering, diminishment and death. Questions about how much and what sort of control we may properly exercise have come to the fore – we can keep someone alive indefinitely on life-support machines, but should we? We can create families in all sorts of new ways, but should we? We can not only alleviate suffering, we can eliminate it, but should we?

As those engaged in the academic discipline of bioethics became increasingly drawn into the clinical situation, new themes began to emerge in their writing. Initially, the concern was to try to arrive at decisions which could be rationally and dispassionately defended. However, as the theologians encountered the dilemmas at the bedside, it became clear that it was important not only to make right and good judgements but to make meaningful decisions. The way in which patients understood the meaning of their illness within the context of their lives came to be seen as critically important. Reflection on the experience of ill health or disability led these thinkers to explore the realities of finitude and limits in human life. Like it or not, the human condition is marked by all sorts of breakdown and loss. There is clearly a call to join in the healing ministry of Jesus, and to alleviate suffering where possible, but there is no realistic prospect of eliminating suffering from human life. The advent of HIV/AIDS has shown us emphatically that we are not even able to eliminate infectious disease. The dream of a pain-free existence seems doomed.

If the clinical encounter teaches us in bioethics that there are inescapable limits to selfhood, so our purview of the ecosystem shows us that we are stewards rather than the source of life. Over and over we are pressed in our reflection to see that our efforts to harness energy and to eliminate disease are thwarted by even more powerful forces. The destructive power of the atom, the defiance shown by bacteria to antibiotics and the environmental hazards associated with a rising standard of living are all testament to a common dream in which ambition dwarfs ability and blinds us to consequences.

Issues of ownership and control are central to many claims about human life and death and are curiously linked to our thinking about how we exploit the world around us. We wonder whether we should use gene technology to design our own offspring in the same way in

which we have improved crops and herds. We consider raising embryos, human and transgenic, to supply tissue for transplant. We patent DNA, the code of life, to permit a few of us to own the inheritance of all of us. Further exploration of these dilemmas reveals a difference between invention and discovery, and raises the question about the extent to which we should attempt to exercise control over the world about us. For instance, the European Community has just drafted guidelines to regulate gene technology. The document is an attempt to strike a balance between views which hold that the earth is primarily there to be exploited in any way at all and those who think that scientific progress contains the seeds of unmitigated disaster.

The arguments about the introduction of human genes into the genome of the pig, in order either to accelerate growth and reduce the fat content of pork, or to render the animal organs more suitable for transplant to a human, show precisely how our views as to what constitutes human life are critical to the debate. Those who oppose such applications of genetic technologies do so on a variety of grounds. Some hold that we ought not use animals in this way, that to do so is disrespectful of their rights as sentient beings. Others see species boundaries as definitive and wonder whether the incorporation of human genes into pigs renders the eating of pork an act of cannabilism. Similarly, this latter group may think that transplanting the heart of a genetically modified pig to a human in some way diminishes the humanity of the recipient. Often such people also imply that to interfere with natural boundaries in this way is an over-stepping of our role in the universe: they say things like 'we ought not play God'.

For those who see species boundaries as rather arbitrary, the ways in which we exploit genetic technology give rise to few ethical quandaries. Subjugation of the earth seems to them to be part of our responsibility to control and direct development. Fundamental to these differing appraisals of the same act is the anthropology underpinning the interpretation of the meaning of life and our place in the universe. It is these basic commitments which have received all too little attention in the bioethical literature because they introduce aspects of humanity, like spirituality, which have been seen as beyond the realm of ethics. On the other hand, an anthropology which excludes consideration of a spiritual dimension in human life is too impoverished to be helpful at the bedside.

Clinical situations inevitably raise for us questions of meaning and how to promote human flourishing. It is in facing death that we recognize the prevailing condition of all life, that tomorrow is promised

to no one. The barn builder of the Gospel, who dreams of material security, is exposed as bent on a futile pursuit. Likewise, the shattering of plans by sickness or accident reminds us how tenuous is our hold on life, let alone any idea of control. Listening to those with a tragic and fatal diagnosis bargaining with God for just enough time to achieve particular goals brings home again how resistant we are to accepting the limits imposed by our life cycle. The futility of the struggle is underscored by the figures which reveal that the largest part of our health expenditure goes to treatment administered in the last months of life.

As we search for ways in which to promote human flourishing, questions of justice emerge. If our work in science and technology is to serve the common good, how can we ensure that this is so? And even more crucial, how are we to define the 'good'?

The good

In trying to determine how best to proceed we must come to some agreement about what constitutes the good. The anthropological and metaphysical questions must be addressed. We cannot know what is good for us without some notion about what it is to be human – and how we can know these things? All too often we conduct our conversation about ethical matters as if our knowing comes only through rational analysis. To constrain reality in this way is counter-productive. Much of our knowledge derives from our interactions with others or through imagination, and is signalled by our feelings. Emotions are of moral significance and to ignore them puts our very humanity at risk. Too great a reliance on the tangible and the objective could direct us to thinking of what is good for human beings in solely material terms. Our object then is to justify our decisions rather than to find what is best. The search for what will really promote human flourishing is complex and requires the integration of all our ways of knowing.

Interrelationships

The bioethicist thinking about the appropriateness of our technical interventions in controlling and changing organic processes sees complex webs of interdependence operating. Intervention at one point creates a ripple of effects which might not have been foreseen. The underlying interconnectedness which the physicists describe grounds reality in an inescapable way and the changes in ecosystems reflect this eloquently. Witness the damage wrought by acid rain, the lowering of the water table in irrigated areas and the developing hole in the earth's

protective ozone layer. Similarly, the advent of HIV/AIDS shows us, among other things, how vulnerable we are to infection. We can protect national boundaries against invasion but we cannot regulate the entry of bacteria and viral infections, especially if their presence is not detectable until some time after infection. The epidemiologists tracking the spread of disease write for us a commentary on our inter-relationships in a new and startling way. Our commonality is underscored. No one can pretend to immunity. Our very humanity makes us all vulnerable to attack by unseen micro-organisms.

In times of infirmity those close to the patient are also reminded forcibly of their own fragility. As we engage with the one who is sick we recognize our own frailty and this, paradoxically, is empowering. As the words of T. S. Eliot ('the wounded surgeon plies the steel') and Henri Nouwen (*The wounded healer*) suggest, it is precisely the possibility of identification with the debilitated which confers genuine healing power. In a similar way, amongst environmentalists, it is identification with the rest of the natural order which alerts us most cogently to the dangers of a quest for power beyond our reach. We recognize that in harming the forest or the ocean we are initiating our own demise because our destiny is inextricably linked with the welfare of all that surrounds and supports us.

Meaning/purpose

As we are drawn into the circle of care and concern in response to suffering and infirmity, it becomes ever clearer that our decisions matter. Our humanity is defined by the way in which we evaluate the balance of burden and benefit in trying to decide which of those things we can do we ought do. In powerful contradiction to the common view that 'anything goes', our serious reflection about action and judgement reveals that our choices condition our future. The narrative each of us writes of our own life must be coherent. We do make decisions which we think will be for the best, and whilst that depends on our willingness to name the good, we also seek a sense of meaning and continuity. The capacity to retain a coherence in the unfolding story of the self was, according to Victor Frankl, the critical difference between those who survived the horrors of the Holocaust and those who succumbed to its brutal fatality. It is important that we traverse the terrain of illness and diminishment in a manner consistent with the way we have tried to live. Especially at the end of life, it is vital to honour the story of the person we accompany by entering into their decision-making on their own terms.

In approaching decision-making this way, bioethical reflection has more in common with a process of discernment than a rigorous, rationally defined, analytical exercise. The outcome of reflection will be the sense that the best way to proceed is to take specific actions, but the focus is on the feeling of coherence and peace rather than the framing of a watertight, objective justification. There is no sense of emerging as 'right', only of being somehow in right relationship with the deepest elements of the self. The basis for that peace may well be that this moral discernment is a process of gradual conformity to the ways of God. Our good is found quite palpably in this equilibrium and accompanying sense of wholeness, often made all the more startling because it occurs in the midst of stress, pain and loss. We know deeply that sorrow and despair are not the same, that hope may survive the exigencies of the here and now. It is in this experience of limits that we come to know the expansiveness of God. It is in the loss of what we thought defined us that we see, finally, who we are and know ourselves for the first time. In the experience of vulnerability we see ourselves as vulnerable. As we admit an inability to control and direct our lives we see that in a deep sense our lives were all along in the hands of another. It is both humbling and freeing. Although choices matter, in a radical way we are freed of responsibility. We are after all children of God.

Experience and encounter

The stories of therapeutic relationships indicate that self-awareness is fundamental to the practice of healing and health care. Competence is of course critical to clinical efficacy but it is exposed as arid and provides no comfort in the absence of a true other-centredness. A powerful illustration of what I mean is found in a case told by a self-reflective paediatrician.[1] He speaks of the experience of caring for a seven-year-old boy who was suffering from mucolipidosis, an inherited, debilitating, disfiguring progressive disease which is usually fatal within the first decade of life. The little boy was grotesque to look at and resistant to attention. One evening, by chance, the physician happened upon the little boy talking with his young, single mother. The physician saw first-hand how the child was transformed by his mother's love and was forced to explore the quality of his own interactions with the little boy. He says:

> When this mother gazed at her bloated, dying son, she physically saw a person I had never seen. Transformed by her eyes' willingness to see the child beyond the disease, Blake had become a different being, an individual no longer diseased and distorted, but a frightened child visibly changed by his mother's love.[2]

He likens the effect of the mother's gaze on her son to Jesus' way of seeing people, and says:

> The wonder of Jesus' way of seeing people is that it is a transforming vision that reaches into the essential character of the person and alters that character at its core. It is, miraculously, a way of seeing that is accessible to all of us and one that transforms not only the person seen, but also the person seeing.[3]

It is the experience of encounter and the readiness to reflect on it that permits physicians like Boyce to become truly caring practitioners. Blake was beyond cure, as all of us will be some day, but he was well within the compass of care. What Boyce's reflections suggest is that it is a concern for what constitutes care which must provide the frame within which clinical ethics is pursued.

The diminishment which Blake suffered actually informed the way in which Boyce approached the patient. The retrieval of Blake as a person was achieved for Boyce by Blake's mother. In turn Boyce's engagement with Blake was changed, the kind of care he administered was different. The perspective of the health-care professional necessarily informs the practice and creates the parameters of the ethical framework which cannot be independent of the nature of the clinical relationship. Rejection by the practitioner of diminishment and finitude will result in construing terminal illness as hopeless and death as failure. There is something in the experience of illness which lets us know how tenuous our hold on independence is, and for both patient and carer there is a sharing of this precarious reality.

In Dr Boyce's story it becomes clear that it is not the possession of particular attributes which identifies us as persons. The truth is that we endow with personhood those we elect to treat as persons. It was that which differentiated Blake's mother and the physician. It was that choosing to give the other respect which characterized Jesus as an enlightening teacher and empowering healer. Boyce is right: each of us can exercise this transforming choice of seeing others as fellow-travellers. Jesus will not turn away from the prostitute in Simon's house because she has no right to be there. As another being endowed with life she has as much right to be present as anyone else. The choice of inclusion or exclusion is ours and the basis arbitrary.

Finally, it becomes clear in the story of Blake and his mother that it is in the here and now, the mess of disease and distortion, that we encounter the depths of ourselves and each other. It is precisely in this limited embodied state which tells us of diminishment, finitude and

dependence that we encounter God. Certainly this is on terms we have not chosen, but that presence is tangible in the love the young mother has for her grotesque, suffering and doomed little boy. Her love can surmount the limits: even in the midst of an alienating setting like a hospital she attends to her child. Her little boy is known for who he is: she is not misled by appearances. It is in this moment of revelation that we see that the truth of this embodied existence is spiritual. There is no separation of flesh and spirit: we are known as we are. How else are we to understand the impact of the mother's gaze on the boy who now floats, supported and relaxed, in a way closed to him in the routine of the scheduled visits of professionals, whose calibrating eyes are trained to take in only the quantifiable? Surely here Boyce is right to identify that transformation as mysterious in origin, and to draw a parallel with the way in which Jesus looks at people, at us.

In illness we are vulnerable and dispossessed. The most confident are stripped of all that they can usually depend upon. We are at sea in a strange and intimidating setting. The future is uncertain. We are no longer active agents. The effect is profoundly disturbing. We are disoriented, perhaps mute and alienated from ourselves and from each other. In some sense it dawns on us that this is the truth of our existence: we are radically dependent and not at all self-made. Mastery over life is now seen as illusory. Now we must relate in a situation of radical inequality and so begin to recognize that our dignity does not reside in our abilities but in our fundamental being. Acknowledging dignity by according rights to self-determination is now exposed as a shallow misrepresentation of what it means to be human. Paradoxically, in my dependence I can at last see the basis of my dignity, which is the holding in common with those who care for me a human nature. For those who care for the dispossessed there is the unavoidable possibility of the tables being turned. The health-care professional must know more deeply than most that 'there but for the grace of God go I'. Oddly too, it is in this state of dispossession that the possibility of encounter with God as the ground of my being is realized. As God may be recognized in ecstasy, so too will that presence be palpable in the void of loss and terror.

Against the claim that reality is of our own making, in illness we are faced with limitation and suffering. Elemental experiences show us most clearly the parameters of humanity and will not permit self-delusion. Finding ourselves so constrained only points up the truth of our condition, a truth we are generally shielded from by health and apparent independence and self-direction. Under these conditions we

can come to believe that we have invented and made ourselves, but in diminishment against which we have no defence we see that we are not self-creating to quite the extent we would like to be.

The experience of suffering, diminishment and death can render life absurd, but only if we have misunderstood life all along as possession rather than gift. The truth of the Christian story is that however lowly our birth or demeaning our death, we are known, loved and accompanied by God. It is the task of the Christian community to make tangible this truth, to be the companions who will not abandon any in their need, to be those who know sorrow but not despair.

Conclusion

It is in the vulnerability of illness that both patient and carer are confronted with the radical interdependence and finitude which marks all forms of life. It is in this situation that we see ourselves as we are, social beings with limited prospects for control over matters of life and death. We also see that our decisions reflect specific perspectives and tell the story of who we are. Our real commitments are made visible in action, and however hard we may try to take refuge in doubt we will finally be confronted with the truth that our lives are shaped by what Taylor[4] has called 'inescapable frameworks'. Reflection on these experiences in the course of the practice of health care has forced us to acknowledge the spiritual dimension in human life. Religious traditions can illuminate the ways in which we evaluate the balance of burden and benefit of medical intervention in a milieu of suffering and alienation. Once acknowledged, the process of ethical deliberation which must integrate both affective and intellectual components of our response is clearly going to be more akin to discernment than rational analysis. The recovery of these insights in the field of bioethics has the prospect of reinstating care and compassion to the heart of health care. It may also dispose us to emphasize our relationships with each other and the environment rather than defining ourselves by difference and separation.

NOTES

[1] W. T. Boyce, 'Beyond the clinical gaze' in S. S. Phillips and P. Benner (eds), *The crisis of care* (Washington DC: Georgetown University Press, 1994), pp 144–148.
[2] *Op. cit.*, p 146.
[3] *Op. cit.*, p 147.
[4] C. Taylor, *Sources of the self* (Harvard University Press, 1989), pp 3f.