

THE FIVEFOLD ROOT OF AN ETHICS OF SURGERY

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ABSTRACT

Surgical ethics have generally been framed as general medical ethics applied to surgical contexts. This model is helpful, but may miss some of the special features of the surgical process and relationship. It is suggested in this paper that there are five categories of experience and relationship which are especially important in surgery – rescue, proximity, ordeal, aftermath and presence. The sense of rescue, the feeling of relational proximity, the ordeal and the aftermath of surgery are things which the patient experiences. Understanding these experiences allow surgeons to understand what may be asked of them in an ethical sense. Recognition of the reality and validity of each category in the surgical process highlights the importance of presence, the acts by which the surgeon demonstrates that he is present to the patient throughout the surgical process and its aftermath. While the teaching of communication skills may never compensate for insensitivity, the ideal of presence as virtue and duty can be taught by precept and example.

INTRODUCTION

McCullough, Jones and Brody have examined the scope of surgical ethics.¹ They define it by the ways in which the procedural nature of surgery and its capacity for bodily and psychic damage modify general ethical considerations such as virtues, consequences, rights, justice and equality. They recognise the primacy of principle-based ethics, and stress the need for a determinedly consequentialist element in any specifically surgical

¹ L.B. McCullough, J.W. Jones, et al., eds. 1998. *Surgical Ethics*. New York. Oxford University Press.

ethics. This is realistic, given the nature of surgical outcomes, both good and bad. McCullough and colleagues use conventional ethical modes to examine specifically surgical contexts. Thus, they have chapters on informed consent, confidentiality, advance directives, emergency situations, death and dying, and so on. These are the ingredients of other texts on medical ethics generally.² Their thesis seems to be that the ethics of surgery is a special case of the general ethics of medicine.

Yet there is clearly something distinctive about surgery. The current sociological enthusiasm for postmodernist deconstruction yields a particularly unattractive model of 'the surgical'. It is conceived, for example, by Fox as a contest for authority over the body of the patient.³ He describes the surgical operation as an arena in which surgeon and anaesthetist contend for supremacy. Whether we agree with Fox's picture or not, the specialty of surgery – its knowledge, its technical manoeuvres, its mystery, its powers – carries with it a potency that seems to resist deconstruction. People in Western societies still depend on surgery for many benefits, and the image they hold of surgery still retains an element of awe. There remains something special about the surgeon's capacity to enter our lives and to violate the surface of our bodies during moments of almost magical unconsciousness. Surgeons make new ways into the body, unlike endoscopists who proceed *per vias naturales*.

Surgical ethics is not, therefore, differentiated from a general medical ethics by appeals to special kinds of principlism, virtue ethics, rights and duties, nor by special context within micro- and macroethics.⁴ Instead, it is most sharply set apart by five categories within the moral domain of the surgical relationship, which I identify from a number of sources: our work at the Centre for Values, Ethics and the Law in Medicine (see

² T.L. Beauchamp, and J.F. Childress. 1964. *Principles of Biomedical Ethics*. Oxford. Oxford University Press; A. Campbell, M. Charlesworth, et al. 1997. *Medical Ethics*. Oxford. Oxford University Press; B. Gert, C.M. Culver, et al. 1997. *Bioethics: A Return to Fundamentals*. New York. Oxford University Press; I. Kerridge, M. Lowe, et al. 1998. *Ethics and Law for the Health Professions*. Katoomba, NSW. Social Science Press.

³ N.J. Fox. 1992. *The Social Meaning of Surgery*. Buckingham. Open University; N.J. Fox. 1998. Postmodernism and 'health'. In *Health Matters: A Sociology of Illness, Prevention and Care*. A. Petersen and C. Waddell, eds. Sydney. Allen & Unwin: 9–22.

⁴ P.A. Komesaroff. 1995. From bioethics to microethics: ethical debate and clinical medicine. In *Troubled Bodies: Critical Perspectives on Postmodernism, Medical Ethics, and the Body*. P.A. Komesaroff, ed. Melbourne. Melbourne University Press; Komesaroff, P. A., Ed. (1995).

Appendix) with the narratives of cancer patients and the medical staff who care for them: the details of this work have been reported elsewhere;⁵ my own personal experience as a surgeon and as a patient; and from various published accounts of surgical illness.⁶ These are categories which have elements of the ethical, the relational, the existential and the experiential. They are

1. Rescue
2. Proximity
3. Ordeal
4. Aftermath
5. Presence.

Rescue, proximity, ordeal and aftermath are categories which the patient experiences. That much is descriptive. The surgeon's presence to the patient throughout these experiences is the ethical response which best fits the patient's needs. Presence is thus ethically normative.

RESCUE

Surgery conveys power, the power to enter the body of another by cutting into it. That power is socially endorsed, and may be reinforced by the surgeon's individual charisma,⁷ but as with all power it must be constantly renewed and re-validated.⁸ In

⁵ M. Little, C.F.C. Jordens, et al. 2001. *Surviving Survival: Life After Cancer*. Marrickville. Choice Books; M. Little, C.F.C. Jordens, et al. Liminality: A major category of the experience of cancer illness. *Social Science & Medicine* 1998; 47: 1485–1494; M. Little, C.F.C. Jordens, et al. Face, honor and dignity in the context of colon cancer. *Journal of Medical Humanities* 2000; 21: 229–243; M. Little, C.F.C. Jordens, et al. Approval and disapproval in the narratives of patients with colorectal cancer and their carers. *Health* 1999; 3: 451–467; M. Little, K. Paul, et al. Vulnerability in the narratives of patients and their carers studies of colorectal cancer. *Health* 2000; 4: 499–514; C.F.C. Jordens, M. Little, et al. Life disruption and generic complexity: a social linguistic analysis of narratives of cancer illness. *Social Science & Medicine* 2001; 53: 1227–1236.

⁶ M. Allbrook, ed. 1997. *Songs of Strength*. Sydney. Macmillan; A. Broyard. 1992. *Intoxicated by My Illness*. New York. Fawcett Columbine; S. Buchanan. 1994. *I'm Alive and the Doctor's Dead*. Grand Rapids, Michigan. Zondervan Publishing House; A.W. Frank. 1991. *At the Will of the Body*. Boston. Houghton Mifflin Co; B. Stone. 1994. *Cancer as Initiation: Surviving the Fire*. Chicago and La Salle, Illinois. Open Court; B.L. Zaret. 1987. *Trauma. In When Doctors Get Sick*. H. Mandell, ed. New York. Plenum Publishing: 405–411.

⁷ H. Brody. 1993. *The Healer's Power*. California. Stanford University Press.

⁸ M. Foucault. 1980. *Power/Knowledge: Selected Interviews and Other Writings 1972–1977*. London. Harvester Press; M. Foucault. 1982. The subject and power. In *Michel Foucault: Beyond Structuralism and Hermeneutics*. H. Dreyfus and P. Rabinow, eds. Chicago. University of Chicago Press.

surgery, that renewal and re-validation is derived from surgery's *techné* (its technical capabilities), its *epistémè* (its knowledge base), and its *phronesis* (practical wisdom or judgement).⁹ These are the sources of the surgeon's Aesculapian power.¹⁰ It is not productive to see power solely as domination.¹¹ Foucault writes:

Power must be analysed as something that circulates, or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are always also the elements of its articulation. In other words, individuals are the vehicles of power, not its points of application.¹²

This formulation of power enables us to distinguish at least four different types of power that the surgeon may have. The first is *power-over*, the crudest kind of power that enables one person to make another do his or her will. Surgeons have this power insofar as it derives from the exigencies of the illness or threat which compels the surgical consultation. The second is *power-to* do certain things which the patient cannot do for himself. This is the power that derives from the nature of the surgeon as the patient's agent for improvement. Third is *power-with*, the power that derives from partnerships, be they between patient and doctor, surgeon and anaesthetist, surgeon and nurse. The fourth is *power-within*, the power that can only be exerted within the structures of systems and institutions. Alone, the surgeon has knowledge and skills, but they are of little use unless there is a system in which they can be deployed.

Patients have no choice but to acknowledge these powers when they consult a surgeon. Since normal people do not normally submit themselves to such domination willingly, there is always an element of surrender in the surgical relationship. But it is a surrender that presupposes *rescue*, not a surrender that pre-

⁹ E. Annandale. 1998. *The Sociology of Health and Medicine: A Critical Introduction*. Cambridge. Polity Press: 47–48; Fox 1992; Fox 1998, *op. cit.* note 3.

¹⁰ Brody, *op. cit.* note 7.

¹¹ M. Foucault. 1980. *Power/Knowledge: Selected Interviews and Other Writings 1972–1977*. London. Harvester Press: 78–108.

¹² *Ibid.*, p. 98.

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supposes annihilation. Ben, 57 years old and without a colostomy, recalls the moment when his surgeon tells him he has colonic cancer and will need surgery:

When he said, 'Oh you are going to have to have an operation', I thought 'Let's get on and do it as fast as we can'. And I didn't sort of think, 'Let's see if we can do something else' – none of that. I was very happy to go into hospital, as soon as possible.

Mark, 39 years old without a colostomy, similarly registers his desire for rescue from what he recognises as a life-threatening diagnosis of colorectal cancer. At the same time, he surrenders a significant degree of autonomy to his surgeon:

He [the surgeon] says, 'You are going to get two options. You either keep your bowel, keep the rest of your bowel, or the whole lot will have to go and you'll have a bag for the rest of your life'. And I said, 'Well whatever the case may be, as long as you keep me alive'.

What is yielded up is some degree of autonomy.¹³ The yielding up, if it is voluntary and not demanded in an emergency, requires that trust exist between patient and surgeon.¹⁴ The patient's motto might read 'I yield that I may be free.' The purpose of the surgical relationship – at least in the presence of serious illness – is to restore as much autonomy as possible, and so to rescue the patient's present and future identity. The rescuing powers of surgery are thought to be very great by many people. The mystery of the act of surgery can over-ride rationality. For me, the most distressing request has always been 'Can't you operate? I don't care what you do' from a patient with inoperable disease. To understand this relationship of rescue is a first step toward a creation of an ethics of surgery. Accepting rescue as a legitimate principle privileges respect for dependence in the surgical relationship. Campbell has argued persuasively that this principle should hold for medicine at large, not just for surgery.¹⁵

¹³ J.M. Little. The potential contribution of autonomy to a calculus of clinical benefit. *Theoretical Surgery* 1994; 8: 221–226; J.M. Little and S. Leeder. Logic, hermeneutics and informed consent. *European Journal of Surgery* 1996; 162: 3–10; M. Little. 1995. *Humane Medicine*. Cambridge. Cambridge University Press: 122–140.

¹⁴ M. Little and M. Fearnside. On trust. *The Online Journal of Ethics* 1997; 2(1): <http://condor.depaul.edu/ethics/ethg16.html>).

¹⁵ A.V. Campbell. 1994. Dependency: the foundational value in medical ethics. In *Medicine and Moral Reasoning*. K.W.M. Fulford, G. Gillett and J.M. Sosskice, eds. Cambridge. Cambridge University Press: 184–192.

To translate the understanding into action needs gentleness and tact. To distinguish the 'relative' rescue of palliation from the 'absolute' rescue of cure requires sensitive negotiation. Both cure and palliation are rescues, but palliation may not be what the patient really seeks. For these reasons patients and their families and doctors may be disappointed in one another. This is particularly true for those patients who incur permanent disability, such as a colostomy or ileostomy, or an amputation.¹⁶ It is equally true when the two sides of the surgical relationship hold different views about the scope and nature of the rescue. But it is possible to hold modest views of rescue and yet retain the connection between doctor and patient. Jim, a colorectal surgeon in his mid forties, recounts the story of a 'modest' rescue:

A guy who we did a few weeks ago, he had a cancer of his lung which was not operable, he had a cancer of his prostate which was not operable, and he came in with an obstructing cancer of his colon. The respiratory doctors asked us to see him because they said that he had a good quality of life for 18 months left. ... I said to him, 'Look, you have got this cancer, your chances of getting through surgery are not very good, what do you want us to do?' He said, 'I want you to operate', and I said 'Fine, okay'. So we operated on him. ... As it turned out he did very well, and recovered quite well from the surgery and is quite happy. He left hospital, was still very short of breath and sitting around at home and not doing very much, but you know, I don't see that as being a big problem.

It is not hard for surgeons to understand the need for rescue. They confront that need in their work every day. They also at times themselves need help and rescue from colleagues when they have troubles with diagnosis, management or operations. The category of rescue is available as a realm of shared understanding for both surgeons and their patients. It is a category that needs to be acknowledged and negotiated between patient and surgeon. It is the first pillar of a surgical ethics.

¹⁶ J.M. Little, D. Petritsi-Jones, et al. Vascular amputees – a study in disappointment. *Lancet* 1974; i: 793–795; G.P. Rubin and H.B. Devlin. The quality of life with a stoma. *British Journal of Hospital Medicine* 1987; 38: 300–303, 306; M.A.G. Spranger, B.G. Taal, et al. Quality of life in colorectal cancer: Stoma vs nonstoma patients. *Diseases of the Colon and Rectum* 1995; 38: 361–369.

PROXIMITY

Surgery is an act of proximity like no other. To operate on another is to be within them, to be privy to the sight of the secret body, a sight denied even to the owner. This is the extremity of the 'medical gaze'.¹⁷ Toombs tells us what it is like to encounter the medical gaze which sees right through the person, renders them transparent in the interests of seeing the disease:

For the physician *qua* physician, then, the fundamental entity is the body-as-scientific-object. As such the patient's body represents simply an exemplar of 'the' human body (and indeed of the human cadaver) which may be explicated wholly in terms of the concepts of natural science. For the patient, however, the fundamental entity is the body 'painfully-lived'. The body 'painfully-lived' represents not only the immediate experience of bodily disruption at the pre-reflective level but the apprehension of 'uncanniness' at the reflective level.¹⁸

Broyard, diagnosed with advanced prostate cancer, tells us what he understands by proximity in the medical relationship:

Now that I know I have cancer of the prostate, the lymph nodes, and part of my skeleton, what *do* I want in a doctor? I would say that I want one who is a close reader of illness and a good critic of medicine. I cling to my belief in criticism, which is the chief discipline of my own life. I secretly believe that criticism can wither cancer. Also, I would like a doctor who is not only a talented physician, but a bit of a metaphysician, too. Someone who can treat body and soul. There's a physical self who's ill, and there's a metaphysical self who's ill. When you die, your philosophy dies along with you. So I want a metaphysical man to keep me company. To get to my body, my doctor has to get to my character. He has to go through my soul. He doesn't only have to go through my anus.¹⁹

This proximity that the patient wishes makes special ethical demands of the surgeon, of which he is frequently unaware, or if

¹⁷ G. Canguilhem. 1988. *Ideology and Rationality in the History of the Life Sciences*. Cambridge, Massachusetts. MIT Press; G. Canguilhem. 1991. *Le Normal et le Pathologique*. New York. Zone Books; M. Foucault. 1975. *The Birth of the Clinic – An Archaeology of Medical Perception*. New York. Vintage Books.

¹⁸ S.K. Toombs. 1992. *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*. Dordrecht. Kluwer Academic Publishers.

¹⁹ Broyard, *op. cit.* note 6, p. 40.

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he is aware, rejects or distances as an act of self-preservation. The surgical act of operating causally connects intervention to success or failure in the most concrete way. Proximity carries with it the penalties of closeness, and particularly the pains of failure. Distancing makes failure easier to bear. Understanding the pain caused by that distancing is to understand the needs of the vulnerable patient. Understanding the risks and strains of acknowledging the intimacy is the beginning of an appropriate care of the self,²⁰ but it is possible to enter into relationships of closeness which acknowledge suffering in realistic ways. The surgeon Max, a specialist in colorectal cancer in his early fifties, says:

You greet the patients' suffering. You greet their pain. You greet their insecurity. You love their pain. You love their insecurity. You love their suffering. You open your heart to that, and you do it *naturally*.

A patient looks for a particular kind of proximity in the relationship. The knowledge exchanged between patient and surgeon is intimate in nature, and becomes more so after the operation, when the surgeon knows so much about aspects of the bodily identity of the patient that the patient can never know. This is not the mutual *intimacy* of the lover or close friend, because the intimate knowledge belongs to the surgeon alone. That is why I call it proximity. To deny its existence is neither desirable nor possible. Understanding its nature provides a second underpinning for a distinctive surgical ethics.

ORDEAL

Ordeals are periods of extreme experience, capable of the kind of disruption of our lives which Becker writes about in *Disrupted Lives*.²¹ Ordeals challenge our sense of identity, and require work to restore continuity, or to reconstruct identity in new ways.²² They can be imposed by natural events such as earthquakes (Kobe, Turkey), by historical events such as the Holocaust or the

²⁰ A.W. Frank. Stories of illness as care of the self: a Foucauldian dialogue. *Health* 1998; 2: 329–348.

²¹ G. Becker. 1998. *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley and Los Angeles. California University Press.

²² Becker, *ibid.*; A. Morinis. The ritual experience: Pain and the transformation of consciousness in ordeals of initiation. *Ethos* 1985; 13: 150–174.

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genocides of Rwanda, or as rituals of initiation and rites of passage deliberately constructed by the initiated (ritual circumcision, bastardisation ceremonies).²³ The ancient myth of Quest²⁴ reflects the elements of the ordeal. From a normal life, the initiate (Hero) is called to a Quest (finding the Grail or the Golden Fleece, attaining adulthood). For a period, the Hero suffers dreadful and life-threatening experiences. Various kinds of aid arrive at the hands of divine, magical or wise beings. Ultimately, the hero triumphs, and returns home with a new knowledge and wisdom which makes him or her a Master of Two Worlds.

All medical encounters are ordeals. Patients yield autonomy, acknowledge dependence, place trust, face risk, confront embodiment and mortality, lose control over time and space, experience alienation, pain, fear, discomfort, suffering, boredom. The medical encounter takes place in someone else's system, a system with elements of the Grand Guignol, with its own culture and language of exclusion. Surgical encounters can be especially confronting. Coming into hospital, a 39 year old man with bowel cancer and his wife are horrified by the ward to which he is to be admitted. They notice an elderly, desperately sick man in a chair with a nasogastric tube coming from his nose, drips running, catheter in his bladder. The wife remembers the experience:

And when you walk into the ward, there are all these old people. And we sat down on the bed and we both looked at each other and said 'Let's go – we'll come back later and get this done', because there was one man there we thought, 'This is a dead man sitting up in a chair'. And it was *so frightening*.

Surgery is a private ordeal with something in common with the public ordeals of those victimised by natural disasters or historical events. Prison camp imagery, for example, and metaphors recur in the narratives of patients. Lynn, aged 57, two and a half years after surgery, recalling the low point of her hospital stay after her total colectomy for cancer says:

I was just getting so exhausted. I couldn't sleep in there, because of the noise and the vomiting. And, oh I lost all this weight, I really looked like something out of the horror camp.

²³ A. van Gennep. 1960. *The Rites of Passage*. Chicago. University of Chicago Press.

²⁴ J. Campbell. 1973 (1949). *The Hero with a Thousand Faces*. Princeton NJ. Princeton University Press; J. Campbell and B. Moyers. 1982. *The Power of Myth*. New York. Doubleday.

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Pain, along with nausea and vomiting, is a part of the experience of surgery, part of the ordeal to be endured. The ordeal may be compounded by insensitivity after the operation, when the patient is most vulnerable. Mary, aged 63, 40 months after her colectomy and colostomy for cancer, recalls her experience with one nurse responsible for her care after her surgery:

And this particular male sister, oh, I would ask for a needle, you know, I was in a bit of pain and that, and he would *purposely put the needle in a painful way*. I yelled and I ended up with terrific bruise about this size [indicates an area the size of a closed fist on upper thigh] afterwards.

Surgery is a particular kind of ordeal. It is not usually voluntarily sought. The structuring of the ordeal is in the hands of surgeons and their teams. The surgeon Max recognises the extent of the ordeal as he describes what he sees among his postoperative patients:

It's a difficult time, because you are meeting people at their most vulnerable. They have been slashed. They have been mutilated. They have been humiliated. They are put in a strange *bed*, in a strange *house*, in strange *pyjamas*. Their bodily fluids are around them. They have got nursing staff, you know, who may or may not appear to care for their needs. Doctors who may or may not appear to be concerned about their needs. Food that smells bad, tastes bad, looks bad. Trolleys. People coming in and out, cleaning the machines. Interns who walk in and out, sucking blood out of them, puncturing their veins. Oncologists talking about recurrent cancer; people next door vomiting, farting, shitting; showers that are shared by four different people – it's like a *zoo*. And in the middle of that, you are trying to establish a rapport which basically evolves around trying to get a human rapport in difficult circumstances. A four bedded cubicle, shared by men and women, pull the curtain around and talk to someone who has been mutilated. Now on top of that there is a thing in your arm feeding you morphine that confuses your brain. So the hospital experience is for many a nightmare.

The ideal of rescue and the power of surgery balance the fear of the pain, loss of autonomy, degradation, alienation and suffering involved. When the outcome is seen as redemptive, the ordeal is seen as tolerable, a worthwhile initiation ceremony. Bert, a man

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aged 79, 12 years after his colectomy and permanent colostomy for cancer, says:

I just got on with my life ... went back to the surf, and played a bit of golf ... You've got it [the colostomy] ... but it's not the end of the world.

But the outcome is not always redemptive, or not so redemptive as was hoped. The colostomate may wonder whether the 'rescue' was worthwhile. Says Bill, a man of 74 years, six years after his colectomy and permanent colostomy:

But I wasn't prepared for a) the trauma that I would have to go through, the surgical trauma, and b) the restrictions it placed on my life afterwards ... The restrictions I am talking about are physical restrictions. For instance, I don't go swimming for fear of infection ... I can't dance. I can't play any sport ... These are the sort of restrictions I have got on my life. You know, I used to love my swimming. I used to love playing golf. I used to love playing table tennis. ... I've been used to it all my life ... So you've got to then look for other avenues of, outlets, physical outlets to compensate for your sedentary occupation ... I'm just now tinged with regret for what I have had to put up with, and there is just nothing on the horizon, there is nowhere I can turn for the future ... And on reflection I think maybe, maybe with what's happened with my restricted life-style since – maybe I shouldn't have had it [the operation]. Maybe I should have said 'No, let's go home and die and be done with it.'

The immediate and obvious ordeal of the surgery itself is often not the end of the ordeal. The cancer diagnosis, in particular, is never over, even for long-term survivors.²⁵ Survival brings its own difficulties, rather than mastery of other worlds. Surgeons observe and participate in the lives of patients with 'deep illness',²⁶ and cannot help observing and sometimes sharing their tribulations. Understanding the ordeal of the surgical episode and the sustained ordeal of adaptation to survival can help surgeons to help their patients. It is a third pillar of surgical ethics, a recognition that the surgical episode is an extreme experience, and that to survive is not necessarily to survive unscathed.

²⁵ M. Little, C.F.C. Jordens, et al. *op. cit.* note 3.

²⁶ A. W. Frank. 1999. Personal communication.

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AFTERMATH

Serious illness leaves physical and psychic residue. Surgery leaves physical and psychic scars.²⁷ Particularly when embodiment is changed, surgery modifies lives.²⁸ Colostomies, amputations, changed bowel habits, diminished exercise tolerance, tender or ugly scars, persistent deformity – all change our relationships to our bodies and the expression of our embodiment in daily living. They may also render visible mortality and bodily frailty. We have elsewhere shown how the diagnosis of cancer is adherent, usually for life.²⁹ Even those who deny that they still feel themselves to be cancer sufferers commonly observe the anniversary of their surgery. Robert, for example, an 88 year old retired surgeon, who plays down his status as a cancer survivor, takes his surgeon to dinner each year on the day of his colectomy 25 years after the operation. Even Ben, a 57 year old man without a colostomy, who tells us that his life is unchanged by his bowel cancer operated more than six years before, says:

I suppose, even now, I sometimes think, all those people that have got cancer – ‘*The poor things*’, and suddenly it hits. ... I have forgotten at one level *that I have had it*. And I think, well you have had it too!! And I completely forget that I have sort of had it. I don’t consciously think all the time. I hear other people dying with cancer and having horrible things, and I think, ‘I’m glad *I’m not one of them*.’ And then something hits me – ‘*But you have had it too*.’

More typical is the response of Jean, a 71 year old woman 5 years after colonic resection for cancer and restoration of bowel continuity:

Of course, I think if I get a pain now ‘Where is it [the recurrent cancer]? Is it there? Or is it there?’

Even routine follow-up reiteratively reminds cancer sufferers of their mortality. Helen, a 40 year old woman with no colostomy four years after her colectomy says:

²⁷ D. Lupton. 1994. *Medicine as Culture: Illness, Disease and the Body in Western Societies*. London. SAGE Publications: 88–89.

²⁸ H. Bronheim. Psychotherapy of the medically ill: The role of object relations in body image and grief. *Journal of the American Academy of Psychoanalysis* 1996; 24: 515–525; H. Bronheim, J.J. Strain, et al. Psychiatric aspects of head and neck surgery: II. Body image and psychiatric intervention. *General Hospital Psychiatry* 1991; 13: 225–232.

²⁹ M. Little, C.F.C. Jordens, et al. *op. cit.* note 3.

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When you had to go for your check ups ... I couldn't plan any more than to that check up ... I couldn't think past that.

There are other difficulties with surgical aftermath. The experience of serious illness is incommunicable because words cannot create the sufferings endured in those who listen. Professor George Wilson in 1847 wrote a letter of gratitude to James Young Simpson, discoverer of chloroform. In it he described the experience of undergoing a difficult and tedious Syme's amputation of the foot, without anaesthesia, at the hands of Syme himself:

Of the agony it occasioned, I will say nothing. Suffering so great as I underwent cannot be expressed in words, and thus fortunately cannot be recalled. The particular pangs are now forgotten, but the black whirlwind of emotion, the horror of great darkness, and the sense of desertion by God and man, bordering close on despair, which swept through my mind and overwhelmed my heart, I can never forget however gladly I would do so.³⁰

Wilson points to a major problem. He cannot communicate the nature of his Ordeal. Words (fortunately) cannot recall for him, let alone for his readers, the extremity of his pain. Metaphors must serve to give us the merest glimpse of the nature of his suffering. They are vivid and disturbing, but we cannot really say that we know what it was that Wilson actually experienced. We cannot experience what he cannot forget. In a simpler and more direct way, Lynn, the 57 year old woman with an ileostomy two and a half years after colectomy for cancer says, in tears, of her family:

You don't want to dwell on it, that it's been a bad experience ... but [with great emphasis] *sometimes you just want them to understand ... and they can't.*

Lynn points to an unfortunate truth. The fullest understanding can only come from those who have had similar experiences. There must always be at least some feeling of alienation from those who have not shared the subjective experience.

These three problems – adherence of diagnosis, awareness of bodily and mortal limits, and communicative alienation – comprise liminality, an existential state which seems to persist for the lives of cancer patients, and probably for the life-times of others with serious and chronic illness.³¹ Surgical ethics must

³⁰ G. Wilson. 1956. Quoted in *Surgeons All* by H. Graham. London. Rich and Cowan: 314.

³¹ M. Little, C.F.C. Jordens, et al. *op. cit.* note 3.

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accommodate and live with this creation in particular and vivid ways. And when death approaches our patients, we must remember, not deny, our own mortality. The colorectal surgeon Max gives us an indication of how we may do this:

I will sit down with the patient, and I will *sit* down, rather than *look* down on the patient, and I usually do it in my office with the patient's relatives. And I say 'We have operated on you, and at the time of operation we found that you had cancer of the liver or in the lungs or etc. etc.'. And they say 'What does this mean?' And I say, 'this means that you have got advanced cancer'. And then they usually – there is some tears. And I usually put my arms around them, or I sit down and hold their hands, which is the most natural thing to do. And then they say 'What about chemo, what about this, what about that', and I say 'Yep, all of these options are available. I can send you to the best in town for an opinion, but my advice to you is that we probably are going the wrong way there.' And 'Anyway,' I say 'all of our lives are insecure'. And as soon as I say that, something happens in the conversation. And then I usually follow by saying, 'I don't know how long I have got to live. I could be here today, gone tomorrow, I don't know what is inside me'. And then they start to think a little bit. And then I introduce them to the concept of what is life anyway? You know I generally say, words to the effect of 'You know, we're born and we have a period on earth and beyond that there could be some marvellous things, you know? It may well be that our tired old bodies just cannot hold us any more. We are only made of skin and bits of bowel and bits of livers and things, we need to free ourselves of our bodies at times and death allows us to do that. It will probably take us to a state of mind that is not held down by pain and discomfort and bed pans and bags and so on and so forth ...' People imagine that the average patient is incapable of thinking that way, that this is the sort of talk for philosophers and educated people. And it is bullshit. You know the most humble person, who cannot read or write, is able to comprehend all of that, and probably comprehend it a lot more than the bloke who has written and read a lot more.

Such an approach takes courage and a sense of personal security. It would not suit everyone, neither patients nor surgeons. But it does suggest that surgeons are in a good position to understand the existential threats that their patients experience, the sense of mortality and bodily frailty they live with, and the difficulty of explaining extreme experience to others. Surgeons tend to live

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with repeated extreme experience, at least vicariously. They can, if they choose, in some small part be there for their patients in their extreme experience. They can usually share some of the frustration of being unable to communicate the nature of their work and their lives to others. Patient and doctor share a knowledge of the work and commitment required for the particular rescue played out between them. Max's experience also suggests that opening oneself to the mortality and boundedness of patients can be sustained without loss of objectivity, without compromising the professional relationship. It suggests that a recognition of the difficulties of the aftermath of surgical acts can be confronted and alleviated as an ethical act. This is the fourth pillar of surgical ethics.

PRESENCE AS VIRTUE AND DUTY

Rescue, proximity, ordeal and aftermath are categories of experience which patients undergo. Sensitivity to them and understanding of them will help sensitive and virtuous surgeons to be ethically attuned to the experiences of their patients. There is, however, another important virtue to consider. Pellegrino and Thomasma have stressed the importance of *beneficence* and *fidelity to duty* as virtues for the practice of medicine.³² They are clearly important for the surgeon, but there is something else required. The patient undergoing surgery, particularly major surgery, wants the surgeon to be *present* to him at all phases of the surgical encounter. Whenever rescue, ordeal and aftermath are active categories of experience in the context of surgical illness and its follow-up, patients look for more than a nominal proximity. They want the surgeon's presence. That presence is at best a real, physical, cognitive and engaged presence; at least a delegated presence in which junior doctors and nursing staff express the surgeon's engagement and concern. It is the fifth pillar of surgical ethics.

Not everyone has the personal attributes of charisma, confidence, energy and empathy which draw trust from patients and staff. But most surgeons have – almost by definition – the stamina and cognitive ability to be present to their patients. The regular morning round, the registrar's reassurance that the surgeon is informed and directing treatment, telephone messages to patients, words to their families – all these things stand for the surgeon's presence.

³² E.D. Pellegrino and D.C. Thomasma. 1993. *The Virtues in Medical Practice*. New York. Oxford University Press.

Our own work in the Centre for Values, Ethics and the Law in Medicine confirms these hypotheses.³³ Perhaps surprisingly (particularly given the critiques of sociologists) patients generally respected their surgeons, but were distressed by their surgeons' absences. For several patients, the programme of treatment was dictated by impending overseas trips to be undertaken by surgeons. The narrative of Mary, 63 years old, three and a half years after her colectomy and colostomy for colon cancer, is typical:

[My doctor] found the growth, the tumour, *very low, very low*, and then he rushed, I will admit he rushed around like anything to get me to see Professor X, because he was going overseas to America.

After undergoing pre-operative radiation therapy, Mary returns to Professor X for her surgery:

And then I came in for the operation, once again Professor X was going overseas, and it was a real rush job. Everyone was rushing around like mad, he is trying to fit in all his patients before he went and everything.

For others, the need to be taken to another hospital for complications of previous surgery posed a profound threat to the continuity of their illness care. Mark developed intestinal obstruction some months after his colectomy. At a strange hospital, he signals his need for the presence of his original surgeon:

I said 'Well, the only person that is going to stick a knife into me, I said, is Professor B because he knows what is in there.'

Presence needs to be emphasised as virtue and duty in surgical education. Those for whom relationships come easily need to be encouraged to use that ability as a virtue which will prompt their presence for their patients. Those who need to protect themselves, or who cannot easily relate to others in distress, need to cultivate the duty of presence. I question whether we can make people sensitive to the needs of others when they lack sensitivity. I question, as do Randall and Downie,³⁴ whether we can teach communication skills as if the performance of a protocol could stand in the place of personal insight and warmth. The category

³³ *Op. cit.* note 3.

³⁴ F. Randall and R.S. Downie. 1996. *Palliative Care Ethics: A Good Companion*. Oxford. Oxford University Press.

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of presence, however, can be taught. Each surgeon will manage it in a different way. Presence can be taught by precept and example. It is the tangible expression of a recognition of the elements of the surgical relationship, the categories of rescue, proximity, ordeal and aftermath. The surgeon's presence is required in each.

SURGICAL ETHICS

Testing and negotiating the reality of the category of rescue, negotiating the inherent proximity of the relationship, revealing the nature of the ordeal and offering and providing support throughout its course, and being there for the other³⁵ in the aftermath of the surgical encounter, are ideals on which to build a distinctively surgical ethics. It is time, in other words, to begin a modest reconstruction of surgery, eschewing the Cutler Walpole and Lancelot Spratt paradigms of the past, made famous by Bernard Shaw in *The Doctor's Dilemma* and by Richard Gordon in *Doctor in the House*, and distinguished by their crass insensitivity. Such a reconstruction would concentrate on what is discernible within the good surgical relationship, and what should be present in every surgical relationship. It would be thus both a descriptive and normative project.

Undergoing major surgery is an extreme experience, which changes people's lives. Surgeons are therefore repeatedly involved in the extreme experiences of others. This in itself is also a form of extreme experience, which changes their own lives. The grounds of understanding between patient and surgeon are therefore created by the nature and the acts of surgical practice. Surgeons are distinctively placed among health care professionals to understand the experiences of their patients. They have only to open themselves to the stories of their patients and to their own stories in order to develop a relevant ethics of surgical care.

Surgical ethics must therefore recognise these five particularities. Principlism may help us in our dyadic and microethical relationships with patients.³⁶ Virtue ethics reminds us of beneficence and fidelity to duty.³⁷ Our rights and duties are those of all our colleagues. Our macroethics remind us of the constraints that our society places upon us because of scarcity of

³⁵ E. Levinas. 1989. Ethics as first philosophy. In *The Levinas Reader*. S. Hand, ed. Oxford. Blackwell: 84.

³⁶ T.L. Beauchamp and J.F. Childress. 1989. *Principles of Biomedical Ethics*. Oxford. Oxford University Press.

³⁷ Pellegrino and Thomasma, *op. cit.* note 32.

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resources.³⁸ These things, however, do not really distinguish surgery as having or needing a special ethics. They are the stuff of medical ethics generally. The special relationships that exist, at least in potential, between patient and surgeon can *only* be understood through the stories of those who endure and deliver surgical care. The surgical history – the medical history generally – conceals the nature of experience, by constraining the kind of evidence it will allow. Individual values tend to vanish in the formal structure and selective editing that distinguish the medical and surgical histories. On the other side, surgeons make a virtue of coping behaviours which do not permit the telling of personal biography in ways which allow deep values to be expressed. Given the chance to talk, however, surgeons tell stories of great complexity and moral richness. They also reveal a profound understanding and recognition of patient experience and suffering, as the surgeon Max's narrative confirms. Their proximity to patients seeking rescue, facing ordeal and experiencing the aftermath of surgery presents them with a great challenge, which they can meet best by a determination to be present for each patient throughout the surgical encounter.

APPENDIX – METHODOLOGY OF THE RESEARCH PROJECT

Over a period of 18 months, we conducted narrative interviews with patients who have had colorectal cancer, with their medical carers, and with other stakeholders in health management and outcomes. The aim of the project has been to compare the value-bases which the various stakeholders bring to the health and medical systems. Ethical and research approval was obtained from both the University of Sydney and the hospital at which the research has been carried out. Signed consent to the interview and subsequent publication of material from interviews was elicited before each interview. Transcripts were typed by an

³⁸ J. Butler. 1999. *The Ethics of Health Care Rationing*. London. Cassell; J. Butler. The modern doctor's dilemma: rationing and ethics in healthcare. *Journal of the Royal Society of Medicine* 1999; 92: 416–421; M. Little. 2000. Ethics and resource allocation. In *Surgery, Ethics and the Law*. B.J. Dooley, M.R. Fearnside and M.W. Gorton, eds. Carlton South. Blackwell Scientific: 53–62; M. Little. Ethnomomics – the ethics of the unaffordable. *AMA Archives of Surgery* 2000; 135: 17–21; M. Little. Increased capability, diminished possibility. *Medical Journal of Australia* 2000; 173: 39–40; M. Little. Healthcare rationing: constraints and equity. *Medical Journal of Australia* 2001; 174: 641–642; M. Little. 2001. Utopia as wilderness: Medicine in the latter half of the twentieth century. In *Matters of the Mind: Poems, Essays and Interviews in Honour of Leonie Kramer*. L. Jobling and C. Runcie, eds. Sydney. University of Sydney: 101–112.

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expert transcriber, and edited for emphasis and other signals by the interviewer. Each transcript was then given to each of three workers (ML, CFCJ and KP) for detailed analysis using immersion/crystallisation, thematic analysis, editing techniques, and the technique of 'reading-for' particular emphases, such as power or approval/disapproval.³⁹ Each transcript has been discussed in detail by workers accredited to the project, and discussion has continued until discrepancies have been resolved. Data has been de-identified and securely stored.

For this part of the study, we have interviewed 13 patients and three of their lay carers, three surgeons, an oncologist, a specialist in palliative care, a clinical psychologist, a stomal therapist, a nursing unit manager, a social worker, a radiologist and a general practitioner. Each narrative addresses the generic prompt 'How did you come to be where you are now?' Narratives have been allowed to unfold with minimal further prompting. The interviewers have taken the stance of 'empathic witnesses'.⁴⁰ Most interviewees took about an hour to tell their story, and transcripts varied in length from 20 to 40 pages.

The narratives have been examined to elucidate the perceptions that patients and other health care workers have of surgeons, and the perceptions that surgeons have of themselves and of their relationships with their patients. Some of the publications from this project are listed in footnote 5.

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³⁹ L.M. Brown, M.B. Tappan, et al. 1989. Reading for self and moral voice: A method of interpreting narratives of real-life moral conflict and choice. In *Entering the Circle: Hermeneutic Investigations in Psychology*. M. Packer and R. Addison, eds. New York. State University of New York Press: 141–164; E.G. Mishler. Models of narrative analysis: A typology. *Journal of Narrative and Life History* 1995; 5: 87–123; M. Stewart, F. Tudiver, et al., eds. 1992. *Tools for Primary Care Research*. Newbury Park. SAGE Publications: 209–220.

⁴⁰ A. Kleinman. 1988. *The Illness Narratives – Suffering, Healing and the Human Condition*. USA. Basic Books: 54.