

# RESPONSIBILITIES AND RELATIONSHIPS : SOME PERSONAL REFLECTIONS

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Personal reflections

As any of you will know, it is several years since I retired from active surgical work at the end of December 1984. The break with my surgical past was clear cut and complete; the decision planned, not capricious, possibly the neatest incision I ever made. For this reason, I am already too far away from the cutting edge of our speciality to be able to demonstrate a completely new technique of surgical reconstruction or to report progress on some original surgical research.

Instead, I would like to share with you a few personal reflections on some of the responsibilities that we must recognise and accept as doctors, whatever our speciality, and the inter personal relationships that will help us discharge those responsibilities.

My interest in these facts of medical care was kindled during my medical student days, lasted throughout my professional life and was re-awakened when shortly after my retirement I was accepted as a post-graduate student in the Department of Philosophy at University College, Cardiff to read for a M. A. degree in Philosophy and Health Care. I was immediately introduced to a completely new pattern of thinking, a greater respect for honest doubt and an insight into the construction and subsequent demolition of intricately woven arguments. The director of the course was one of the most stimulating teachers I

have ever known. So too was my supervisor, a young senior lecturer half my age, who showed remarkable patience as he unearthed the fallacies in some of my thinking and exercised a restraining hand when he felt my writing strayed from the philosophical path and became contaminated with what he termed "too much unsupported moralising."

For those of us who were medical students in the late 1930's and the early years of the war, the terms health and health care as used today had little meaning. Our clinical teaching was concerned almost exclusively with the diagnosis of diseases, the treatment of illnesses and injuries and, where possible, their cure. From our clinical teachers in the Leeds general Infirmary, distinguished and colourful characters though they were, we gained virtually no insight into the social, economic, industrial and environmental background of the patients we saw on the wards or in the out patient clinics, or the part that it could play in the aetiology and outcome of the illnesses or diseases. The only teacher at the infirmary with a strikingly different approach was C.W. Vining, in charge of the paediatric department. Yet even his official title was Professor of the Diseases of children, not Professor of Child Health.

There were few specific and effective medical remedies, most treatment being supportive, empirical or symptomatic. Surgery, sometimes brilliantly successful and often dramatic, carried a disturbingly high morbidity and mortality due more often to poor anaesthesia and the surgeon's failure to appreciate the lethal effect of uncorrected blood loss and unrecognised fluid depletion rather than the magnitude of the operation itself.

In the days when few infants could be expected to reach adolescence without repeated exposure to life threatening illnesses and adults fared little better, it is hardly surprising that doctors came to be invested with almost divine status, and whether they liked it or not, assumed a God like role in the eyes of those who sought their help. Small wonder too that mother nature, admittedly with the help of some excellent nursing, was often the real architect of survival - though rarely given the credit - and various interpretations of God's will were invoked to ease the pain and distress caused by death.

However, during the student days and the years that came immediately after, three sets of experiences made me realise how unsatisfactory it

was to view the condition of our patients solely in terms of the medical concept of disease and how difficult it was to define health using the same model:

1. The first occasion arose when, by good fortune, six of us were sent as students to St. James's Hospital to do our clerkships in obstetrics and gynaecology. This was an enormous municipal hospital of over 200 beds which by its statute had to accept all patients referred to it who lived within the city boundary. Leeds had some of the worst housing in the North east of England and this hospital was right in the middle of this area of deprivation and decay. Here we were taught by doctors who had a quite different approach to medical care. We were encouraged to develop a sense of social awareness and see our patients problems in the context of poor housing, overcrowding, malnutrition, poverty and appalling conditions at work. Did we not know, for instance, that juvenile rickets in the north east was known as the Leeds Disease? : that cutaneous anthrax in wool sorters was called Bradford Disease and that grinders rot in the cutlery industry was nicknamed Sheffield Disease? There doctors were all full-time salaried staff employed by the city health department. Their skill and competence was obvious; so too was the way in which they worked very closely and amicably with ancillary staff, some of whose duties were unfamiliar to us : such as orthoptists, speech therapists, remedial gymnasts; splint and surgical boot makers and almoners. We had often noticed that the longest queues in the Infirmary's out patient department were those outside the almoner's office; now we understood why. We heard talk of such things as positive health, social medicine, even 'socialist medicine' and began to realise that really effective preventive medicine was far more exciting than the public health section in our medical school syllabus.

2. The second event was the publication in November 1942 of the Beveridge Report. The title "Social Insurance and Allied Services" was innocent enough; its content was explosive. Sir William Beveridge, a former director of the London School of Economics had been invited by the wartime coalition government to head a commission to study the need for a comprehensive scheme of provision of social insurance. Sweeping recommendations were made to eradicate what

Beveridge termed "The Five Giant Evils of Ignorance, Disease, Squalor, Idleness and Want". His proposals included :

- a) A complete re-casting of social insurance services to provide protection from want due to unemployment, sickness, disablement and old age.
- b) A completely new system of children's allowances.
- c) An "all-in" health service to provide specialist medical care to the whole population.
- d) A constructive policy for full employment.

The message of the Beveridge Report was perfectly clear. Ill health and its treatment could not be divorced from the economic and social background in which people lived and worked. The significance of this close association was not lost on that other visionary, the late Aneurin Bevan who, after the war was able to "weave the variegated provision of medical services that existed at the time into a comprehensive system of health care for everyone, from the cradle to the grave. It was a system to be financed and therefore regulated by the State based on the principle that every citizen had an equal right to the best medical care available which he helped to pay for when he was well (through his taxes) and which he received free when he was sick and therefore least able to pay". (Rt. Hon. Barbara Castle : Nye Bevan memorial Lecture 1975).

3. The third experience was of personal involvement in World War II in which civilian and service men/women at home and abroad soon learned by trial and error the effectiveness of the collective will in existence, rescue and survival.

As a very young doctor in the army you could find yourself on your own as medical officer to a West African Infantry unit, with others in a British or Indian General Hospital, on a hospital ship, as a transfusion officer attached to a Forward Surgical Unit or as a graded surgeon in a Casualty Clearing Station. Not all your duties would necessarily be medical. You learnt to accept discipline, to work under stress and occasionally real danger and to realise perhaps for the first time the true meaning and exhilaration of team work with others whose experience of life was often far wider and deeper than your own. These completely unstructured lessons in communication and personal relationships were really an education for life. The essence of this experience was described very movingly by Sir Benjamin Rank in his

semi-autobiographical book "Heads and hands; an era in plastic surgery".

".....any hospital, the world over, is a social entity in itself, often supercharged with all the crudities as well as the subtleties of human emotion and behaviour. To have to work and live with people one might or might not like on first impression is one of the personal and educational compensations of army life. The close proximity of daily living, circumstances of stress and subsequent relaxation disclose many aspects of differing personalities and incompatibilities of attitude as well as common interests when people become necessary and valuable complements to each other. A shrewd knowledge of the darker shadows as well as the lighter aspects of character and reaction make for ease of social intercourse rarely available between those who meet in more circumspect conditions in mature years...."

There were many other lessons to be learnt, for as civilians or as serving soldiers you could never escape noticing the terrible legacies of a major world war in the campaigns in which you had taken part or in the countries through which you had passed.

3. The appalling loss of life among civilians and servicemen alike. Many years later a Soviet surgeon of my own age told me how before the war fifteen members of his family would sit down to lunch every weekend. After the war, only five remained and this, he reminded me, was not an isolated incident.

4. The physical and psychological damage to the surviving civilians and the combatants; the emaciated survivors of the concentration and extermination camps; the prisoners of war in the far east, liberated after the capitulation of the Japanese, their subsequent psychological problems yet to appear.

5. The immediate political aftermath of the war; the territorial readjustments; the emergence of new political groupings in former colonies and overseas possessions; the jockeying for position and spheres of influence by the major powers illustrated by the way in which urgently needed aid might be promptly given or withheld.

These were just a few of the problems that faced the Security Council and the United Nations General Assembly after the war and to deal with them, various agencies, best known by their acronyms, were established. The World health

Organisation, for example, sought general agreement on a definition of health that as adopted as the First Principle of the Constitution of the WHO on its foundation in 1948. Namely "health is a state of complete physical, mental and social well-being and not merely the absence of disease or deformity". The Second Principal of the Constitution went on to declare that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social conditions....". Here then was a blue print for health care on a scale that had never been attempted before. Priorities would be very different in the over-developed and the under-developed areas of the world and, for this reason, the WHO was careful not to make sweeping generalisations and recommendations based on the experiences of only one country, but invited individual countries to work out their own schemes and offered them the appropriate advice and help if this was requested. What could not have been foreseen was:

1. The ease with which the implementation of this concept of health and health care could be compromised, shelved or abandoned completely for reasons that had little to do with medical or social need but a great deal with financial greed, vested interests, political expediency and military confrontation (sometimes, organised deliberately and covertly). As I stand here, before you, on Indian soil, I cannot forget the significance of the words of Mahatma Gandhi, "Earth has enough for every man's need, but not enough for every man's greed..." 2. The mindless and ever increasing damage that would be done by man to the environment. This has produced what might be called a Catalogue of Concern that gives naught for our comfort.

3. The nature, speed and scale of the advances that would be made in the medical and biological sciences, physics, pharmacology and technology, and the profound social, medical, ethical, economic and political implications that would follow. Indeed many people believe that we should examine in greater depth the relevance of philosophical principles to our thought and practice in the planning and delivery of health care, particularly the principles of autonomy,

beneficence, non-maleficence and distributive justice.

The principal of autonomy affirms the rights of the individual to take decisions and determine his or her own actions. The principle of beneficence asserts the obligation to take positive steps to do good. The principle of non-maleficence insists on the positive principle of not doing harm. The principle of distributive justice emphasises the point that those in greatest need should have those needs met first but realises that under conditions of scarcity and competitive need its importance (and its great danger) is in the fair allocation of resources.

Other considerations are inextricably woven into these four cardinal principles. Such as the need to tell the truth; the confidentiality of the doctor-patient relationship; respect for the dignity of the individual and the quality of life. Indeed the need to make a distinction between "having a life" and "being alive".

The surgeon by virtue of his calling occupies a position of unusual authority and omniscience in the eyes of the general public and his patients. Because any surgical consultation may lead to an incisional "assault", any encounter between the surgeon and the patient is likely to be far more tense and emotionally charged (with apprehension, disbelief, sheer relief, and even joy) than say a visit to the family doctor or dentist. The realisation that a part of your anatomy - possibly even your life - is literally in someone else's hands only accentuates the extraordinary imbalance between the power of the professional and the vulnerability of the victim.

Now that television producers and camera crews can get unlimited (even deliberately invited) access to our operating theatres, we realise that what Lord Moynihan once regarded as "the ritual of a surgical operation" has become a "surgical soap-opera" or T.V. spectacular in which in the surgeon fields him left type-cast as a miracle worker who in the nick of time produces order out of chaos, salvages tissues and organs that seem irretrievably damaged and saves lives that were almost lost.

One of the dangers of being cast in this role is that the surgeon may forget that his patients are human beings rather than pieces of mal-functioning or missing anatomy, that patients

have feelings too and that something precious is lost in the doctor-patient relationship if patients feel that occasionally unfair advantage is being taken of the excellence of the surgical results to enhance the kudos of a particular surgeon, department or hospital, or to produce advertising copy for promotional literature for manufacturers and suppliers of surgical instruments and dressings that may reproduce identifiable clinical photographs for which their permission was never sought or granted. Some patients can be distressed, particularly in the field of aesthetic surgery if flippant terminology is used to describe operations as "nose jobs", baggy eyelids as "money bags" and inflatable breast implants as "boob busters" - a tactic that the unscrupulous surgical extrovert may introduce jokingly to colleagues at clinical meetings. It is a regrettable practice that demeans the surgeon as much as it affronts the sensitive yet grateful patients.

The issue of Consent compels us to respect the autonomy of the patient. In a nutshell, it means saying YES to a proposition; but as our legal colleagues gently remind us, the proposition must be properly "put".

**Implied :** The very act of going to a doctor's surgery or to a hospital indicates a willingness of intention to seek medical help or guidance.

**Expressed :** Usually obtained by the doctor or the nurse as a response to such propositions as "let me listen to your chest" or "I will just check your blood pressure" or "we will have an X-ray of your chest". Consent to such a proposition is usually verbal but may be visual - a nod or shake of the head. When faced with such propositions as "let's take a sample of your blood" the patient may want to know why and may well refuse if there are potential medico-legal implications as in the determination of blood alcohol levels. The ethical implications of mass screening of random sampling of patients' blood samples to check their HIV status and the risk of developing AIDS, without their knowledge and consent, have been highlighted in recent years by the decision of insurance companies to compel clients seeking cover to state on their application form whether they have had blood tests for AIDS and to insist that their family doctor should disclose to the insurance company what he or she knows or even suspects of their patient's marital history and life style.

**Written :** This is the form with which patients and doctors are most familiar. It is important because it requires a deliberate action on their part, unlike implied or expressed consent. A carefully worded operation consent form correctly dated, properly completed and signed legibly gives documentary proof that a proposition was "put" to the patient or parent. The name and purpose of the operation or investigation must be stated and the doctor who countersigns the form must confirm that this explanation was given by him personally. Such a document is a crucial part of the surgical case notes; its loss or its deliberate alteration at any time after the operation can have serious medico-legal implications and consequences. Nevertheless, such a form of consent gives no guarantee whatever that the information provided to the patient or parent was necessarily accurate, complete, intelligible or properly understood. Indeed did the doctor who sought consent really understand the nature of the operation himself? Did it differ, for example, from the explanation given by the surgeon to the patient in the outpatient clinic or on the Ward round? Was anything specifically said about any inherent complications or risks? It has been suggested by those who fear lawsuits for malpractice that "check lists" of every possible complication - a kind of inventory of potential disasters - should be compiled and each item ticked off by the surgeon and countersigned by the patient; a practice more appropriate to the quarter-master's stores that a hospital ward. The need for informed consent applies with even greater force to healthy volunteers recruited in experimental research work and to patients who are included in control or randomised clinical trials. Respect for ethical principles in the protocol and conduct of experimental research and clinical trials is now demanded by all reputable clinical research institutes, by assessors of academic research submitted for higher degrees and insisted upon by editors and referees as a condition of their acceptance of manuscripts submitted for publication. As was pointed out by Sir Austin Bradford Hill (not a clinician himself) "...it is very easy to be wise (and critical) after the event; the problem is to be wise (and ethical) before the event". Doctor H.K. Beecher, a former Professor in Anaesthetics at Harvard in a paper entitled "Consent in Clinical Experimentation; Myth and Reality" was equally critical.

“Most codes of practice dealing with human experimentation start out with the bland assumption that consent is ours for the asking. This is a myth.”

“Patients will, if they trust their doctor, accede to almost any request he makes (my doctor would not ask anything of me that was not for my good). This too, in many cases, is a myth.”

“A particularly pernicious myth is the one that depends on the view that the ends justify the means. A study is ethical or not at its inception; it does not become ethical merely because it turned out valuable data.”

We can easily overlook the large amount of epidemiological or observational research involved in the daily task of history-taking and documentation. Yet its importance may be as great as any laboratory work. In our field of plastic surgery we could cite:

1.The accurate recording of any history of illness, acute infectious disease, anaesthetic anoxic episode, smoking, drug or alcohol abuse, medical treatment given or supplied during the early days or weeks of pregnancy in our search for possible aetiological factors in the production of congenital abnormalities.

2.The collection of detailed information on the precise history of burns and scalds sustained at home and at work, the time of day, the ages of victims, the treatment given and outcome. without this information, it is difficult to mount intelligent schemes for accident prevention and improve the quality of care for the victim to enable his survival and rehabilitation. This is a field in which the Plastic Surgical and burns Associations have done

so much pioneering work particularly here in India and the United Kingdom.

3.The legislation to make the wearing of seat belts and crash helmets compulsory to reduce the appalling number of major cranio-facial injuries, death from head injuries and permanently brain damaged survivors was only reluctantly accepted by parliament after years of painstaking documentation by neurosurgeons, plastic surgeons, thoracic surgeons and the police and rescue services. Because such observational studies do not demand any invasive techniques and possibly no contact with the patient or victim, little thought may be given to the fact that this activity can itself be invasive. Unrestricted access to confidential and personal information including photographs and correspondence may easily allow sensitive and highly personal material to fall into the hands of unauthorised persons and agencies without the knowledge or consent of the patient, or the parent or even the appropriate hospital specialists. Some of the questions asked in questionnaires may be so intimate or personal that “merely asking” is invasive, for example, in the counselling sessions widely used in the investigation of infertility; in the prolonged physical, social and psychological work-up required in the treatment of those seeking gender reassignment by hormonal or surgical means or in the investigation and proof of child sexual abuse. The ethical implications are particularly serious if audio-visual recordings are made of such interviews without the consent of the parties involved and are used later in court proceedings. To justify such a breach of confidentiality on the grounds that it may provide invaluable teaching material or help provide proof in court invites

health professionals to take part in a confidence trick in which the autonomy of both the health worker and victim has been violated and the storage of the material which may later prove to be inaccurate (in parts or in whole) could lead to prosecution under the Data Protection Act. How reliable are questionnaires? Some questions may be so badly phrased or incomprehensible that an unscrupulous scrutineer may be tempted to add "ticks" to boxes that may have been left blank by the research assistant. unfavourable findings can easily be "sanitised" or discarded as insignificant. Encouraging signs of success may be seized upon and given wide publicity, ignoring other factors that might have well have been responsible for the apparent surgical success. The list of papers on the healing of leg ulcers using certain creams, dressings or pressure support shows what a rich hunting ground the lower leg can offer.

Nearly all our new cleft lip and palate infants are seen within 24-36 hours of birth by the surgeon, the orthodontist or both. These meetings with both parents are probably the most crucial in laying down the foundation for a sound trusting relationship that will carry you, the parents and the child through into adolescence, if not further. The process will demand caring and effective treatment by every member of the team along agreed lines of unit policy. This policy is not immutably fixed; it may need reappraisal and modification in the light of experience as we have seen in the timing of the various stages of the surgical and non-surgical treatment. At all times the advice given to the patients must be consistent and truthful. If there is no language or cultural barrier on either side, the establishment of a sound personal relationship will be easy. In Nigeria, where many infants presented with a bewildering array of gross

congenital defects or with appalling facial destruction caused by cancrum oris the regional dialects were so numerous that often no one, even the official interpreters, could help translate simple questions and answers. The verbal barrier was complete and one had to rely on simple drawings and clinical photographs and a good deal of mime to give some idea of what was surgically feasible. The parents were only too grateful that something could be done, but in no way could their assent be regarded as informed consent and never once in the whole three and a half years I spent in Ibadan did experience the kind of empathy that I needed just as much as they did.

In south Wales, the incidence of neural tube defects was very high indeed and at one stage during the early 1960's we were asked by the paediatricians if we would consider helping them in the very early surgical closure of these defects, using the same policy that was being tried out in Sheffield by Zachary and Sharrard; the paediatric and orthopaedic surgeons to the Children's Hospital. My chief said he would only consider this if all the surgery was done at Chepstow within six hours of birth. This was such an impossible stipulation that mercifully the scheme was abandoned; mercifully because the later reports of the sheffield report showed very disquieting features in the protocol and conduct of their trials. According to John Lorber, who was the paediatrician to the Sheffield Unit, the agreed policy started in the early 1960's was ".... to offer total care to all infants irrespective of their degree of handicap with all available medical and surgical means.... Infections including ventriculitis were energetically treated and collapsed infants were resuscitated on the operating table. On the children's wards cardiac massage was practised in

cases of cardiac arrest. Patients with Complications of shunt surgery were all operated upon even if the child had severe intellectual or physical defects".

Lorber's observations on the outcome on the consecutive series of 270 infants with spina bifida treated in this way forced him to conclude that the policy adopted "probably resulted in more harm than good."

In an impressive paper in 1973 on "Moral and Ethical Dilemmas in the special Care Nursery" Duff and Campbell of Yale University Medical School stressed some of the dangers of precipitate action when their paediatric units also adopted the Sheffield Plan of Management of spina bifida. Some of the appalling difficulties that can arise when the role of communication between experts and parents is ignored are clearly illustrated in the following extracts from the Yale paper:

"... Parents routinely signed permits for operations though rarely had they seen their children's defects or had the nature of the management plans clearly explained to them. Some physicians believed that parents were too upset to understand the nature of the problems and the options for care. Since they believed informed consent had no meaning in the circumstances, they either ignored the parents or told the parent that the child needed an operation on the back as the first step in correcting several defects. As a result, parents felt completely left out while the activities of care proceeded at a brisk pace. However, when maximum treatment was viewed as unacceptable by families and the physicians in the unit, there was a growing tendency to seek early death as a management option."

"Closer study of this change in attitude revealed mixed motives. Among the physicians they found some who believed that allowing death as an option was euthanasia and must be stopped "for fear of setting a poor example." Yet many admitted that if they were the parents of severely handicapped infants, they would go for the euthanasia option. Others feared the risk of personal prosecution or loss of research funding if their centre took the "non-treatment option". Some physicians even put forward the unbelievable argument that the training of professionals for the care of defective children in the future and "the advancing state of the art" would be compromised by the loss, through death, of, "Valuable teaching material". As for the parents, some requested that their children should be allowed to die to obtain relief from the high cost of keeping a handicapped child alive and the tensions produced by suffering. Others were afraid that by being kept alive, their children were in danger of becoming "experimental subjects" a fear that in more recent times is by no means groundless. From this point it is only a short step to treating the grossly deformed neonate as a donor source of transplant material on the assumption that parents might accept such a policy so that "some good to mankind might come from their personal tragedy".

In the same issue of the New England Journal of Medicine that published Duff and Campbell's paper, Dr. Franz J. Ingelfinger wrote an inspired editorial "Bedside Ethics for the Hopeless Case":

"... the one most entitled to advise doctors on treatment is he who has himself treated. The same principle holds for non-treatment. Those who like



Duff and Campbell describe the agony of identifying infants who have the right to die, have the necessary credentials; they may be amateur philosophers, but they have endured the fire....”

“This is the heyday of the ethicist in medicine. He delineates the rights of patients, of experimental subjects, of foetuses, of mothers, of animals and even doctors. His insights are often astute and prescient. yet his precepts are essentially the products of arm-chair exercise and remain abstract and idealist until they have been tested in the laboratory of experience. Some philosophers, to be sure, promulgate fairly rigid rules of ethical, professional behaviour, but the practitioner appears to prefer the principles of individualism. As there are a few atheists in fox holes, they tend to be few absolutists at the bed side. Some institutions have established committees of persons with imposing credentials in theology, jurisprudence and the humanities, as well as in medicine, but such a court is formal and distant, a surrogate for abstract ethics. It's deficiencies are epitomised by the sobriquet used by at least one house staff “the God squad”. So when Duff and Campbell ask “who decides for the child?, the answer is YOU”.

As I come to the end of this keynote address, what conclusions can be reasonably draw from the personal reflections that I have placed before you on the responsibilities and inter-personal relationships that should influence and underpin our professional thought and practice? Let us go back to the important paper by H.K. Beecher, to which reference has already been made. he asked, “Is, then, the patient without hope, for honest responsible care? Not at all. His greatest safeguard in experimentation as in therapy, is the

presence of a skillful, informed, intelligent, honest, responsible, compassionate physician.”

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