A NURSE'S VIEW OF ETHICAL PROBLEMS IN INTENSIVE CARE AND CLINICAL RESEARCH

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The subject of medical ethics has been a long-standing problem for all concerned with sick people and it is still the most potentially controversial in our health care system. At present many terminally ill patients are condemned to long suffering whilst others with a more hopeful prognosis are unable to receive the medical attention which they need and to which they are entitled. This affects adversely both the patients and those caring for them. The word "caring" needs to be emphasized to avoid misinterpretation when suggesting an apparently more ruthless approach towards some medical attitudes.

The problems are partly related to the rapidity with which the United Kingdom National Health Service has expanded, with questionable benefit, by the use of machinery, organ transplants and increased drug therapy. This apparent policy of life at all costs, regardless of quality, raised new ethical problems, some of which overlap unanswered questions on older attitudes.

MISUSE OF MEDICAL SKILLS

Most nurses are able to recount experiences of caring intensively for patients with a poor prognosis. As a nurse trained in intensive care, I have had the experience of seeing, and helping with, the most tragic misuse of medical and technical skills leading ultimately to the abuse of human dignity. It has even been my experience to nurse, for legal reasons, over a prolonged period, an artificially ventilated, dialysed patient with consecutive flat e.e.g.'s receiving massive blood transfusions and highly intensive care, whilst other patients with a more hopeful prognosis suffered for want of dialysing equipment and beds pace.

Most intensive care nurses are familiar with those patients who have undergone cardiothoracic surgery and who have no hope of survival but who are kept alive artificially by vigorous treatment which sadly but inevitably results only in the loss of human dignity. Too many such procedures are common practice. They may be well intentioned but they are cruel to the patients, to their relatives and to those waiting for treatment. As long as there is a limit to the resources any service can offer, a decision must be made about the appropriate use of these resources when compared with the functional result.

These examples, whilst accurate, are emotive. Although I appreciate fully—indeed I am advocating—the need for a more clinical attitude, it must be remembered that we are meant to help patients, not to dehumanize them. It is supposedly because of caring for humanity that medicine has advanced. The doctor, who was once described as the midwife of death, has now in some instances become the indiscriminate champion of life and we are all in danger of losing our objectives and of forgetting our obligations to those we treat but cannot cure.

Religious attitudes

Such decisions have religious as well as other considerations, and the churches from time to time provide some guidance; for example, an "allocutio" from the Vatican in 1958 reaffirmed its theological position by stating that there is no moral obligation to continue to use extraordinary means of support when a patient has reached an irreversible state (Pope Pius XII, 1958). However, it must be recognized clearly that the differentiation between the ordinary and the extraordinary must be redefined regularly, as medicine develops. There are special difficulties, too, particularly when children are involved, with some minority religious groups who are opposed to certain medical procedures, such as blood transfusions.

Ethics of intensive care

Many of these ethical problems were raised during a recent symposium on the Management of the Acutely Ill (Payne and Hill, 1977), and it became obvious during the debates that many of the clinicians present were greatly worried about the increasing ethical problems presented by modern
It was pointed out that many such problems have been highlighted by the development of organ transplantation and by the need to harvest the appropriate organs. In this respect the lack of criteria for cessation of treatment and the definition of brain death posed further difficulties in relation to the potential donor. To some extent this situation has been made easier for the clinician by a recent statement from the Conference of Medical Royal Colleges and their Faculties in the United Kingdom which listed conditions for considering the diagnosis of brain death (Statement, 1976).

One of the contributors to the symposium, Professor L. E. Morris, spoke in detail of the ethical considerations of intensive care (Morris, 1977):

"Intensive care units are now recognised to be of considerable value, and in fact their services are in such demand that it is necessary to establish criteria for admission, appropriate levels of care, and a basis for discharge. The number of patients who can be accommodated will be limited by the number of beds in an intensive care unit. Therefore, there must be some discretion and judgement in the selection of patients who will benefit by admission to such a unit. Who has the right to intensive care? It is unreal to expect that everyone will be a prospective recipient for organ transplants. It is just as unreal to expect a successful cardiopulmonary resuscitation in all patients. At some points, we must make medical judgements and decide whether to initiate intensive care in a given patient, whether to continue it . . . or whether to discontinue it. We must learn to differentiate between the prolongation of useful life and the delaying of death. . . . If there is a right to live it must be equated also with a right to die."

At present each doctor uses his own criteria, but with the increasing frequency of medico-legal problems such as those resulting from the Quinlan case (Comment, 1975) in the U.S.A., clinicians need support beyond their personal beliefs to ensure their professional integrity and security. Vital decisions should not depend, as they often do at present, on the personality and conviction of individual doctors and nurses. Such questions as abortion on demand, the management of badly deformed babies at birth, the patient's right to know his diagnosis, the right of relatives to be involved, and the vexed problem of euthanasia for the terminally ill are much influenced at present by the personality of the clinician. The persistence of these problems implies a degree of apathy among clinicians both to their own needs and to those of their patients.

**The right to die**

It is not only in this country that the problems caused by such paternalism are under discussion. In Canada, in the Provincial Parliament of Ontario, a private member's Bill which gives patients the right to refuse treatment if they are terminally ill had a second reading before being lost by the dissolution of Parliament (Toronto Star, 1977). The basis of the Canadian Bill was respect for the right of the individual to determine his treatment when terminally ill. The form of words proposed was as follows:

"I . . . . . . . . being of sound mind, wilfully and voluntarily direct that all life-sustaining procedure be withheld or withdrawn if at any time I should be in a terminal condition and where the application of life-sustaining procedures would serve only to artificially prolong the moment of death. It is my intention that this direction be honoured by my family, physicians and medical staff as the final expression of my legal right to refuse medical and surgical treatment and to die naturally."

It was the intention of the sponsors that the document would be endorsed by two witnesses, neither of whom would stand to gain by the patient's death. In addition, it would be necessary for two independent physicians to agree that the illness was terminal. California had previously enacted such legislation in the United States and several other American states have followed with similar legislation.

**ETHICS AND CLINICAL RESEARCH**

It must be emphasized, however, that medical ethics are not confined to the management of the care of the sick. They assume particular importance in clinical research and, although medicine cannot advance without clinical investigations, few nurses have become involved deeply with research. As more clinicians seek the opportunity to utilize their day-to-day routine to accumulate knowledge of specific aspects of medicine, it is inevitable that nurses will become more involved and will have to accept greater responsibility. Some awareness of this responsibility has been shown by the Royal College of Nursing in that it has published a booklet entitled "Ethics Related to Research in Nursing" (Booklet, 1977). Unfortunately, however, it barely
contributes to the subject as most of the major problems are avoided, no doubt because of the traditional attitude that it is not for nurses to make, or even suggest, policies in matters concerning the treatment of patients.

Declaration of Helsinki

Unlike the position in intensive care medicine, the ethics of human experimentation have been widely debated and, in 1964, the Helsinki Declaration was drawn up by the World Medical Association and is still the only International Code of Ethics in medicine which provides guidelines on the conduct of research (Declaration of Helsinki, 1964). However, it is limited in that it only covers clearly defined situations concerned solely with human experimentation. Its basic principles are as follows:

1. Clinical research must conform to the moral and scientific principles that justify medical research, and should be based on laboratory and animal experiments or other scientifically established facts.

2. Clinical research should be conducted only by scientifically qualified persons and under the supervision of a qualified medical man.

3. Clinical research cannot legitimately be carried out unless the importance of the objective is in proportion to the inherent risk to the patient.

4. Every clinical research project should be preceded by careful assessment of inherent risks in comparison to foreseeable benefits to the subject or to others.

5. Special caution should be exercised by the doctor in performing clinical research in which the personality of the subject is liable to be altered by drugs or experimental procedure.

In this country various organizations including the Medical Research Council and the Royal Colleges have based their advice on this declaration. In general, the guidelines emphasize that the patient's rights both legally and morally within the doctor–patient relationship must always be considered in clinical research. More particularly, written witnessed consent for invasive investigations is advised, and consent for minor, non-invasive procedures should be obtained after ascertaining both the mental and physical suitability of the patient. This is not only for the obvious humane considerations but also for the legal protection of the doctors and assistants involved. It is further emphasized that investigations must always be carried out with utmost care and any risks must be minimized. All staff, both medical and technical, involved with the patient during the investigations should be aware of the trust and responsibility they must assume on the patient's behalf. Non-therapeutic investigations should be abandoned if the patient reacts adversely. In cases of therapeutic research the risks should be balanced carefully against the benefits likely to result as compared with other methods of investigation. Careful follow-up examination should always be carried out, both for clinical and psychological reasons. The last consideration not only serves to create good relationships which will benefit both patient and doctor, but also will remind them of their mutual dependence.

Special chronic units

Finally, since there are reasonably well-defined guidelines in clinical research, would it be possible for similar provision in the field of intensive care? Perhaps it is time that all professional bodies concerned with patient care were prepared to discuss jointly the needs of their patients and to have the courage to acknowledge their limitations. In particular, the time is long overdue for the United Kingdom National Health Service to move towards the provision of a more realistic form of terminal care. Special chronic units could provide an answer to the financial problems and to staff difficulties and, most important, could offer more humane treatment to the terminally ill. A high standard of basic nursing care could be maintained without the need for the expensive monitoring equipment which is almost standard in most intensive care units. This would prevent "blocking" of much needed equipment from which another patient could benefit. Relatives and friends could be welcome at all times, without being exposed to the oppressive environment inevitably associated with an intensive care unit. Such units could be staffed mainly by ancillary nurses, supervised by a limited number of State Registered nurses. Some nurses prefer, and have much to contribute to, terminal nursing, whereas the morale of intensive care nurses is, as all units know to their cost, both fragile and vulnerable to a poor survival rate. A few units such as the St Christopher Hospice provide this type of service, but many more are needed. A reassessment of the use, or misuse, of our highly specialized units is long overdue. We need to utilize our resources more fully and to care in a more humane manner for those whom we cannot cure. In this connection the nurse's
acceptance of death and her attitude to the loss of all hope for her patient's recovery form a vital part of her relationship with her patient and his family. To know that the team of which she is a part has exhausted its expertise would appear to leave nothing to offer. This is wrong: nurses not only follow instructions, they also provide the link between the patient and his alien environment. Thus this very human involvement gives us the unique privilege of being able to give, and to maintain, reassurance and equanimity up to the moment of death.

REFERENCES
Toronto Star, April 15, 1977.