Special Article

ETHICS AND MANAGEMENT OF ADVANCED CANCER*

BY

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Advanced cancer, in all cases—as Sir Stanford Cade (1955) says—implies extension of the disease beyond its site of origin to adjacent tissues and organs, and always in the end to a multiplicity of symptoms due to metastatic spread. I presume that it is my role in this symposium to describe what can be called the general medical supportive measures in the management of this condition—measures which one presumes will be going on coincidentally with others, such as surgery, radiotherapy, chemotherapy, and hormonal therapy; all contributing to the palliation of the disease. To my mind the management of these cases—once certain preliminaries have been completed—is the responsibility of the family doctor. They comprise some of his most difficult cases, yet, strangely enough, they can also be some of his most rewarding.

I believe that all cases of advanced cancer should be thoroughly investigated and assessed in hospital before being transferred to domiciliary care. This has many advantages: it enables the doctors in hospital to assess the prognosis and to advise such treatment as may be deemed helpful; it also introduces the patient to a specialist who may well be needed later to consult with the family doctor in the patient's home. The advantage to the family doctor is that he can use the patient's stay in hospital for two purposes: to arrange the home environment suitably for the long-term care of a patient who is unlikely to recover, and to speak to the relatives and prepare them for their role in the care of the patient.

Home Arrangements

To deal first with the arrangements of the home: obviously, even in these days of a Welfare State, the doctor's suggestions must be geared to a certain extent to the home background and the financial status.

Ideally, the patient's bedroom should be transferred to the ground floor. A bathroom with lavatory on the same floor is a tremendous help, but is not essential. More necessary is the hire of a hospital type of bed with a pulley or hoist to assist in the nursing care. Steps should be eliminated if necessary.

Even though a diagnosis of incurability may be made on a patient of mine with cancer, I always adopt and maintain a positive programme of aggression towards the disease. I do not allow the word "can't" to enter either the patient's or the relatives' thoughts until such time as I realize that the actual stage of dying is reached. It is essential in these cases that when the diagnosis is made the doctor's interest in and visits to the particular case should increase and not decrease—this in itself proclaims a suggestion that the patient has still something left to live for (as indeed he has) and encourages him to effort which otherwise he might not feel worth taking. Nothing can so demoralize a patient with

incurable disease as the falling off of visits and therefore, by inference, of interest by the family doctor; if the doctor is defeated, or—because there is no hope—he shows that he has lost interest, relatives, nurses, social workers, and friends round the patient are placed in a position of disadvantage which they least deserve. Throughout the remainder of the life of this patient the theme of care must be played in a major key, of which the dominant note is hope (Gibson, 1957).

In arranging the environment, therefore, the doctor is seen to be assuming that the patient will be leading an active life for as long as possible—and an active life can be led from a bed as well as from a chair or in a normal routine daily operation. Encouragement must be given to the patient to do as much as possible for himself, whether in the way of dressing, bathing, feeding, or work in the house or elsewhere. There are other reasons for this besides the need for maintaining morale—not the least of which is to discourage contractures and stiffness of soft tissue, bed-sores, and the like; help can and should be obtained here from the physical medicine department of the hospital.

Sympathetic Help

Nevertheless, although independence is to be encouraged for as long as possible, one has also—and from the very beginning of care—so to arrange the environment of the patient that the maximum weight in the management of his care is taken from his immediate household. This, again, is not only done because an appreciation of the length of time for which care may be required makes it vastly necessary that mental and physical fatigue on the part of near relatives should not be carried to the pitch when the strain on them causes home care to break down; but also because—and this particularly applies to homes in which there are young people—the existence of a chronically ill patient in the house must not be allowed to cast a gloom over the entire family and control their lives so that they virtually rotate day and night around approaching death.

Fortunately it should be easy for the family doctor to help in this respect. First, through regular visits by district nurses and health visitors. (I would stress how helpful the attachment of nurses and health visitors to particular partnerships has proved to be in the management of this type of patient. Where all those responsible for looking after a patient are members of one team it stands to reason that the care must be more sympathetic and all-embracing.) Secondly, by means of help from the Home Help Service, the Red Cross, and others—not excluding the Meals-on-Wheels Service if necessary. All these helpers soon enable the doctor to gear the household to long-term care of the patient.

We must also remember here one important additional advantage attached to these members of the team: apart from carrying out the duties for which they were trained they can also be of tremendous help to the doctor in what must be called the compassionate side of the management of the patient—in guiding the relatives through each succeeding stage of the illness and even in preparing them for the next stage, and in comforting and encouraging the patient.

There is no time to dissertate on the various types of families with which the doctor may have to deal: they range from those of such an intelligence or level of indifference that home care is virtually impossible, to

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those in which love for the patient is so dominant a factor in the life of the home that difficulty is found in persuading them to accept any outside help at all.

In all types of families the most difficult problem is the arrangement of night care. I can still offer no positive solution to this problem, for it seems that the provision of night care by the local authorities is not only physically impossible but also financially undesirable in these days when householders' rates are already soaring—but the absence of cover at night can more frequently than anything else cause the breakdown of home care. Even the help of a friend or the Red Cross for one or two nights a week can make a great difference, and one has to be content to arrange night care for one's patient on a sort of *ad hoc* basis.

A Problem

One of the first problems the family doctor has to face once the diagnosis is made is whether the patient should be told and, if so, at what stage in his illness the information should be given to him. It is essential, therefore, for the doctor to have a preliminary talk with relatives while the patient is in hospital. Here a knowledge of the family—such knowledge, in fact, as only the family doctor can have—is of great value, for, while it is obviously necessary for the family to be told at once, it is best to choose the method of telling very carefully—either one particular member should first be told and then asked to pass the message on, or the whole family must be drawn together and told at the same time. I am averse to either patient or relatives being told the diagnosis in hospital by a house doctor or a nurse, neither of whom can possibly know the family well enough to have sufficient experience to embark upon such a delicate procedure without expert backing. If the consultant in charge of the case decides to take this step he is wise if he confers first with the family doctor to decide not only the best method of approach but also on its continuity once the patient has left hospital.

Dr. George Abercrombie (1955) says: "Many surgeons cannot bring themselves . . . to tell the patient the truth about his malady, and thus they place the general practitioner at a great and lasting disadvantage. That would not matter if the patient were at ease in mind, but all too often he is not. 'They tell you nothing in hospital, sir. What is it? What is the matter with me?'"

Apart from the fact that Dr. Abercrombie describes a family doctor as a general practitioner, I am in entire agreement with his remarks. The impact on patient and family alike in having to wait until he is discharged from hospital before a definite picture is drawn of his disease—no matter what the picture may be—is too calamitous for description. I would say "sadistic" were it not for the fact that I appreciate that the unkindness is not intentional. There is to-day, thank goodness, more humanism in hospitals than there was in past generations, yet patients still find it impossible to talk to the great men in whose charge they are. They long to ask them questions, to have a tiny little personal conversation with them; but it seems—perhaps up to a point through their own fault, or because so many patients have to be seen in so little time—that all too often this small wish cannot be granted. So out they come—back to their homes—and the family doctor is left to cover up the seeming indifference of his hospital

colleagues, or to enlarge upon or modify the story given to the patient by a sympathetic and comforting ward sister or nurse. No patient with advanced cancer should ever be discharged from hospital without a covering note being sent immediately to the family doctor which either says that the patient has *not* been told of the diagnosis or states what he has been told. Otherwise the home doctor is placed in a most untenable position.

But, as I have said, ideally—by close consultation at all stages and by the family doctor visiting his patient in the hospital—the situation need not arise and the whole process of "telling" can be carried out in unison; gently, kindly, and step by step with as little mental trauma as possible to patient and family.

The Doctor's Dilemma

Having passed this faint criticism on, now let me turn to this vexed question of "Should a doctor tell?" I suppose I have read as much and talked as much as anyone—with the possible exception of Dr. C. J. Gavey—on this subject. Whenever the substance of a talk hinges even remotely on approaching death the question is always asked: "When and how should a doctor tell?" The fact that no paper that I have read has ever given a clear answer points to the complexity of the question.

Let me look at the diversity of situations or personalities with which a doctor may be confronted. In the first place, the preliminary consultation with the patients' family may have clearly directed the doctor to the approach he should make, and as a general rule this family decision is helpful and decisive. On the other hand, the advice or instructions given by the family may be completely contrary to the doctor's own convictions in the particular case—they may, for example, be based on religious convictions, on cowardice, indifference, or a completely disordered approach to and unintelligent understanding of the disease or its likely prognosis. What is the doctor's attitude to be in this type of situation? Worst of all, the family may give no advice at all; with pathetic trust in their family physician, they may say, "We leave it to you, doctor—we are sure you know best." This means that the doctor is left on his own and must—with the help of his team of nurses and health visitors—make his own decision and risk, by so doing, breaking up the last weeks or months of happiness in a family and losing the confidence of his patient.

Again, take the patient. I have read that the doctor's decision must be based on factors which include the intelligence, the social status, the Christian faith, the personality of the patient. He is, presumably, to allot marks for each and according to the result tell or not tell. A family doctor of only one year's experience would throw this method away with no more than a single thought.

I have known the most intelligent patients from the top shelf of our social cupboard who appear to remain in complete ignorance of their disability—yet until their lives have ended I have never known whether this ignorance was real or simulated in order to save embarrassment or unhappiness to their family and their doctor. Then there is humility, which causes a patient to accept the disease without question: into this category I would place those whose faith in their Heavenly Father and trust in their earthly physician is such that the diagnosis and the prognosis are of little importance to

them. Fear seen in the eyes of a patient is a sufficient reason for not unnecessarily delving into details of an illness; a cheerfulness and a buoyant attitude which imply, "Tell me doctor, I can take it," but which, in fact, conceals a dread of being told. On the other hand, truculence and even animosity call for action, for they bring with them mental unrest to the patient and unhappiness to the family. These latter are the patients for whom the doctor should turn for help to the consultant in whose charge they originally were in hospital: between you, round the bedside, the full story can be told and the patient reassured that everything humanly possible has been and is being done for him; the needs for a patient to bring his personal and family affairs up to date and the attitude of his employers must be considered. Again, the age of a patient must influence the doctor—his problem surely must vary with different age-groups. An elderly patient may expect to die; a child certainly will not.

I have said enough, I hope, to prove that this is no easy problem that I am discussing. Now let me add that some authorities state dogmatically that a doctor must not lie to his patient. I would cite, for example, the American theologian, Joseph Fletcher (1955), who says that the truth about himself belongs to the patient—the doctor has no right to keep it from him. Sir William Jenner said that the doctor must be honest, he must be dogmatic, he must be kind. I would disagree absolutely with this school of thought. To me, telling or not telling the patient that he has incurable cancer is part of the treatment of his illness; and in the same way that some patients with pain will require sedatives and others will not, so some patients with advanced cancer will require to be told and others will not. No rigid rule can be applied, and it would be a dreadful thing for any textbook to dictate to a doctor that part of the treatment of advanced cancer in every case is that the patient should be told that he has it.

I may have been more fortunate than some in my contact with this type of case, but I think I can fairly say that, except in a bare minority of cases, I have not been troubled with this problem. I believe it exists mainly on paper only. Dr. Dulake (1955) says: "A day comes when something in the handclasp, in the expression of the patient, implies acceptance of a hopeless situation. From then on, doctor, patient, and close relations often find it easier to play a gentle game of 'make-believe.' Human understanding bridges many gaps." I am quite sure he is right. With compassion, sympathy, and understanding the patient, his family, and his doctor, I submit, can go along together day by day, accepting and explaining each situation as it arises until the time arrives when no further earthly care is needed. But I would qualify this by saying once again that inherent in this concept is the necessity for frequent visits from the doctor, for full co-operation from the nursing services, and for a positive attitude of encouragement from all those surrounding the patient.

Palliative Measures

The family doctor's share in the management of these patients also includes the treatment of the unpleasant symptoms which may accompany or result from the advance of the cancer. The first of these to be considered must be pain. Obviously one must start with the simple sedative. Personally I find that pot. brom. 5 gr. (0.32 g.), codein. phosphat. $\frac{1}{8}$ gr. (8 mg.), with mist.

aspirin is a most useful standby, or mist. A.P.C. (with 10 gr. (0.65 g.) of aspirin, 3 gr. (0.2 g.) of phenacetin, and 1 gr. (65 mg.) of caffeine) is an alternative, and phenazone 5 gr. (0.32 g.) t.d.s. a possible next step. For the night I use amylobarbitone sodium or "tuinal." I still use "nepenthe" and find it one of the best drugs—10 min. (0.6 ml.) in combination with 10 gr. (0.65 g.) of aspirin takes a lot of beating. From these drugs I proceed to methadone hydrochloride and pethidine (in that order), leaving hyperdoric morphine or heroin until the last. It is surprising how very rarely one seems to have to resort to these latter drugs. I will do no more than mention in passing such items as nerve-blocking, nerve-root resection, and leucotomy. But they must be remembered by the family doctor as examples of help which his specialist colleagues can give to him in his domiciliary care.

One must, of course, make a special mention of chlorpromazine. To my mind this drug has proved to be a most useful addition to our armament. Alone or in combination with others it can change the whole picture of pain and anxiety in a patient and in the household. I am also interested to note that it is nearly always the nurses' favourite drug—which in itself proves its value.

Next comes anaemia—either through loss of blood or as a result of toxic absorption. I would not hesitate to ask for a blood transfusion here if necessary. It may seem an absurd thing to say in a paper such as this but one is all the time attempting to help the patient to feel well, so that he can be best able to cope with his disability. For this reason, therefore, there is no justification for allowing him to become weak through an increasing anaemia.

The same applies to cachexia. It is, of course, difficult to persuade these patients to take nourishment—but such additions to diet as "complan" and glucose, with as high a fluid intake as possible and injections of "parentrovite," certainly help.

Attempts should be made to control infection round a tumour by the use of antibiotics. To cope with this as well as the disease itself is an unnecessary insult added to injury.

Conclusion

Finally, a paper on this subject would be incomplete if it did not include a word on the spiritual comfort. I often feel ashamed that in so many cases I fail to speak to patients at the right time about the possibility of doctor and priest joining together in the last stages of treatment. This has meant that the patient or his relatives have been left to approach me first on the subject, and so often—again to my shame—they are reluctant to do this for fear of causing offence to the doctor. Although there is a great deal to be said against the doctor and the priest each individually visiting the patient and tending to "treat" him within the boundaries of their own calling, and, worse still, of unwittingly overlapping into the other's province, too much cannot be said on the benefits resulting from a close collaboration of the two round the patient's bed. In fact, the absence of the priest from the team of helpers means automatically that the management of the patient is incomplete and doctors should therefore be the first to solicit the help of the family parson.

Finally, may I say what we all know to be true. Death is not a dreadful or a hopeless thing. It is only the methods by which patients die and their fears of

what is to happen to them in each succeeding stage of their dying that need concern us. Therefore our care of these patients is infinitely worth while.

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SOCIETY FOR SOCIAL MEDICINE

[FROM A SPECIAL CORRESPONDENT]

The Society for Social Medicine held its sixth annual meeting at the Welsh National School of Medicine, Cardiff, from September 27 to 29.

The introductory session on Epidemiology in South Wales was opened by A. L. COCHRANE (Welsh National School of Medicine), who outlined methods evolved by the M.R.C. Research Units to study social and medical problems in random samples drawn from the populations of the Rhondda and the Vale of Glamorgan. He also presented some of the results of a recent pilot study of juvenile delinquency. J. O. ROBINSON (M.R.C. Social Psychiatry Research Unit) described how tests of neuroticism had been given to a random sample of the Rhondda population and to a group of out-patients with diastolic blood-pressures of 100 mm. Hg or more. The out-patients achieved significantly higher scores than the random sample but the correlation between blood pressure and neuroticism in the random sample was low. He suggested that this might be explained by a tendency among general practitioners to refer to hospital only those hypertensives who had high neuroticism scores. P. D. OLDHAM (M.R.C. Pneumoconiosis Research Unit) discussed some pitfalls in follow-up studies, pointing out how, when the difference between first and second measurements was related to first measurement, spurious correlation might obscure a real relationship or introduce an apparent relationship when none was present. The only safe device was to use the mean (or sum) of the two measurements and their difference. To conclude the opening session, A. R. CULLEY (Welsh Board of Health) gave an account of the epidemic of smallpox in South Wales earlier this year and discussed some of its puzzling epidemiological features.

X Rays and Leukaemia

The second session was concerned with malignant disease and the leukaemias. B. MACMAHON (Harvard School of Public Health) summarized the results of the 11 studies so far published of the relationship between prenatal x-ray exposure and childhood cancer. The best estimate of the relative risk (incidence in exposed divided by that in non-exposed) from these studies was 1.4. He demonstrated that in the United States the peak of mortality for childhood leukaemias at 4 years of age was not due to a recent increase at this age but to a decline in mortality among younger children. A. M. STEWART (Oxford) described a survey designed to study the possible relationship between diagnostic x-rays and the adult leukaemias, which had been modelled on her earlier survey of childhood leukaemias. She concluded

that about 8% of leukaemias other than lymphatic leukaemias were related to diagnostic x-raying of the chest and abdomen (see *Journal*, October 6, p. 882). J. A. H. WATERHOUSE and K. W. CROSS (Birmingham) described methods of computing cancer prevalence from data in the Birmingham Regional Cancer Registry and discussed the underlying assumptions involved.

Sex Ratio, Malformations, and "Cot" Deaths

The third session was devoted to the sex ratio, malformations, and infant death. R. A. M. CASE (Chester Beatty Research Institute) presented data on the secular change of the male/female live-birth ratio in England and Wales. In 1841 the secondary sex ratio was 1.05, falling steadily to about 1.03 in 1890, since when it had shown a rising trend with a very high peak (1.06) in 1919. He suggested that the initial decline might in part be due to incomplete reporting of female births in the early years after the introduction of birth registration, and that the peak in 1919 could have been due to the influenza pandemic, which might have altered the intrauterine death ratio to the disadvantage of the female foetus. He was followed by J. M. DAVIES (Chester Beatty Research Institute), who examined by means of Cohort Life Tables, which largely remove the effects of war and migration, the way in which the male/female ratio in the general population had changed in relation to age over the same period (1841-1960). Until about 1906-11 females outnumbered males from the end of the first year of life onwards. Since then the age of "switch over" from a male to a female preponderance had risen progressively until at the present time it takes place at age 35-39. I. M. LECK and E. L. M. MILLAR (Birmingham) had examined the incidence of malformations among Birmingham births between 1957 and 1961 for evidence of secular change. They had found formally significant variations with maxima in 1958 for cleft palate, hypospadias, and reduction deformities of the radii and thumbs, and a significant increase in 1960-1 of reduction deformities affecting both arms or legs. The combined incidence of cleft lip, oesophageal atresia, anal atresia, and exomphalos increased markedly after the influenza epidemics of 1957, 1959, and 1961. R. G. CARPENTER (Cambridge) had analysed sociological data on sudden "cot" deaths in infancy, collected by coroners' officers and health visitors in London and Cambridge, to explore the possible contribution of infection, suffocation, and anaphylactic reaction. If the conclusions he drew from his survey are valid, it would appear that half the present "cot"-death rate (600 deaths a year) is associated with soft pillows and bottle-feeding.

Methodological and Operational Research

The fourth session had a methodological focus. E. G. KNOX (Durham) pointed out that an epidemic might be demonstrated either as a concentration in time over a small area or a geographical concentration over a short period of time. With rare diseases the selection of a sufficiently small section of one of these dimensions so reduced the concentration of events that the concepts of prevalence and wave-form broke down, and he discussed a computer method for overcoming this difficulty. E. D. ACHESON (Oxford) described the identification of documents in the Oxford Record Linkage Study, which was at present concerned with birth certificates, hospital in-patient summaries,