The cancer patient: communication and morale

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Good communication in any serious or potentially serious situation is a complex and difficult art, full of paradox. Many of those who are best at it never analyse what they do, let alone write about it. Some think that the subject cannot be taught, being dependent only on personality and experience, perhaps fostered by example. As with leadership, the essence of a good relationship between doctor and patient or nurse and patient tends to evaporate as soon as any attempt is made to put it into cold print. Warmth, concern, sincerity, and spontaneity, all so important, are inevitably diminished by anything savouring of tactics or technique. With cancer there are additional difficulties due to deep-seated fears of a special kind not encountered in any other disease (or, more correctly, group of diseases), even when closely matched in terms of symptoms and prognosis.

Many of those who have given their views have been psychiatrists or social workers—external assessors, so to speak, with all the advantages and disadvantages that this implies. Others have written only of the dying patient. Those of us directly concerned with the treatment and long-term follow-up of many patients with cancer of different kinds (some curable, some in relapse, some in remission) have had much less to say. One thing is certain. Whoever writes on this subject is walking into a minefield of misunderstandings. Some will always be determined to label him (on the basis of selective quotation) as one who "believes that patients should be told the truth" or as one who "believes that they should not." We are all supposed to belong to one school or the other. Yet most of us have learnt that there are important exceptions to every generalisation and that, as Bernard Shaw said in another context "the only golden rule is that there are no golden rules." Every time we say "some patients" or "most doctors," we want to add "but by no means all" and to give examples. Oversimplification and apparent contradictions are inevitable. This is also a very emotional subject. Strong objections raised are as likely to be due to dislike of the words or phrases used (no matter how liberally we sprinkle them with apologetic quotation marks) as to genuine disagreement with what is done.

But there is one overriding reason for not keeping silent—the importance of the subject. To anyone interested in the whole patient (as we are all taught to be from our earliest days as medical students) good communication is far from being just a fringe benefit. Sometimes it is more important than anything else. And it need not always take up a lot of time. Some authors seem to think that little can be done without fairly long interviews. Many of the rest of us, unable or unwilling to allot so much precious time to this particular aspect of our work, except with occasional patients (and by no means convinced that a long formal interview is always the best thing), are constantly impressed by the difference that a few words of the right kind at the right time can make to the morale of a frightened or depressed patient.

Background communication

Patients who feel they are "not being told enough" are often suffering from a feeling of insecurity due, not to insufficient frankness about their exact diagnosis or their long-term prognosis, but to lack of sustained professional interest in their symptoms, lack of good care, or lack of information about what is going on and what to expect in the intermediate future. It is important always to have a plan and to tell the patient what it is. In the advanced case, if there is a reasonable chance of achieving one or more short-term objectives (less pain, easier breathing, a better night's sleep), this needs to be explained to the patient in a suitably positive and optimistic way. Seldom, if ever, is it true to say that "nothing can be done."

Being a good listener need not necessarily take more than a few minutes. The main thing is to be interested, not only in all current symptoms (whether or not they make sense or seem relevant), but also in the patient as a person in his own right, who—to use Cicely Saunders's phrase—"happens to have cancer." If he is weak or elderly, this sort of respect for the patient, with a brief word or two about his past life or his present opinion about what is going on in the world, is especially important, as it counteracts the indignity that so often accompanies serious illness and, combined with technical efficiency, helps to reassure him that he is in good hands.

Some valuable forms of communication depend on good timing and on the personality of the doctor or nurse for their success. A sense of humour (which Sir Robert Hutchison described as "the same thing as a sense of proportion") has remarkable power to reassure, encourage, and give a feeling of security. Equally useful is irrelevant small talk about nothing in particular—the weather, football, weddings, grandchildren. This might seem quite out of place in a serious situation,
Adapting to different situations

Sometimes communication with the cancer patient is discussed as if there was only one prognosis (hopeless from the start) and only one kind of patient (male, middle-aged, with “affairs to settle,” and asking for full details of his diagnosis and prognosis). Many patients with cancer feel and look well. Such patients may have a good, poor, or 50-50 chance of escaping recurrence either within the next two years or within the next 20 years. The variation in prognosis is considerable. Much misunderstanding arises when the layman believes that the doctor always knows what is going to happen. If recurrence occurs, it may be surprisingly helpful to assure the patient and his relatives that nobody “knew” this was going to occur; it had been hoped, but was not so.

Even patients with advanced cancer (perhaps with distant metastases) often remain in good health for many months or even years, especially in certain kinds of cancer (breast, prostate, kidney, lymphoma, and so on) and especially if there is no weakness or loss of weight. Others are obviously incurable again, but new patients should be described as “dying.” Some would be better described as “probably dying” or “possibly dying.” Surprises are quite common. Finally, many patients are elderly and have other medical problems which may be just as likely as their cancer to reduce the duration of their old age.

So much for the disease. What of the patient? Most doctors will regard it as part of the art of being a good doctor that they do not hand out to every patient the same “take it or leave it” policy when they comment on their or prognosis to any patient. They consider whether they can, to his personality and background and to what seems to be going on in his mind. They want to get on the same wavelength. They cannot give maximum help unless they do. This is not easy. We cannot read the patient’s thoughts. Sometimes a word with husband, wife, or close friend may be very helpful, but quite often, even in a close and happy marriage, the marriage partner is as much in the dark on this point as the doctor. Even the patient himself is sometimes not sure exactly what he fears, or what he already knows, or suspects, or wants to know, about the seriousness of his condition.

Doctors with psychiatric training often advise direct questions, inviting patients to say what they are afraid of, or how serious they think their condition is. Rightly or wrongly, many of us without such training are reluctant to do this routinely. We have known occasions where such questions were exactly what was needed, but in many cases we fear we may do more harm than good. Often it seems to us slightly impertinent; robbing the patient of some of his self respect, treading where we have no right to tread, perhaps knocking down fragile defence mechanisms as we go. We also feel that the patient’s answer to a direct question is often a poor guide to the best way of helping him.

THE PATIENT’S ATTITUDE

Any classification must be very crude, but at least five different situations are commonly encountered.

(1) The patient desperately hopes for reassurance that he or she has not “got cancer”; or that the outlook is not hopeless.

(2) Aggressively cheerful optimism. Clearly the patient will be deeply upset, or angry, or both, if he is bluntly given a diagnosis or prognosis that he is striving to reject.

(3) Apparently he wants “the full facts,” as given to relatives. If the prognosis is bad, seven need not be asked, but there are several special reasons why this patient needs to have bluntly spelt out to him the worst that could happen. Will he be able to distinguish between such very different meanings as possible survival for five years as the case may be) to live, and probably only a few months (or years) to live? To many patients there is little difference; both are a death sentence. Finally, is he likely to accept guarded optimism or to despise it?

(4) The patient does not want to discuss diagnosis or prognosis. She is often living from day to day, perhaps cheerful, perhaps sad, but reasonably philosophical and relaxed, confident that everything possible is being done; may be frail and ill; maybe frail and elderly; often not wanting to regard this particular illness as different from any other; and above all, far more concerned with immediate needs and fears than with diagnostic labels or long-range forecasts.

(5) Tense and suspicious that they are being kept in the dark, some patients badly need more information. This must be recognised and dealt with, but it is a mistake to think that such patients must be told everything or they will continue to worry. This may be so, but it is often not so. Sometimes morale may be dramatically restored by limited explanation (anatomical rather than pathological) and encouragement. In suitable cases, show the patient his x-rays; explain to him, as to a medical student, how (for example) enlarged hilar nodes are preventing air from getting into one of his lungs and how it is hoped (by radiotherapy or chemotherapy) to get the lung working again and thus reduce his shortness of breath.

Although the dilemma is sometimes very real and it is difficult to know what to do for the best, in many of these situations there is scarcely any choice, unless we are to be exceedingly heartless, or unless we use so many technical words or so many euphemisms that our information on patients who do not seem to want it? Sometimes a vital clue is not the patient’s first question, but his second question (or the absence of a second question), after we have begun to give him some explanation of what is going on, watching to see how he takes it. The patient, in fact, often guides us as to what we should say. It may be difficult for some to appreciate quite what this means, but with experience its essential truth becomes clear.

Finally, either the prognosis, or the attitude of the patient, or both, may at any time change completely, so that the doctor may be confronted by a situation quite different from the one he faced initially. Communication of diagnosis and prognosis is not a dilemma to be faced once and then forgotten. It is a matter for continuous care and sensitivity in changing circumstances.

Hope and “denial”

The subtleties and paradoxes of communicating with the patient with cancer cannot be understood—and his fears cannot be handled sympathetically—without some insight into the gradient formed by varying degrees of hope, optimism, and denial. Each may be slight or considerable and, as in normal life, may vary from day to day and from month to month. “Denial” (not a very satisfactory word, but the best we have) is when a person takes a less serious view of what is happening to him than he would do if it was happening to somebody else; “forgets” what he has been told about his diagnosis or prognosis; or “denies” some unpleasant possibility. Opinions will always differ as to how common this is. It depends on whether slight denial, perhaps affecting only some of the patient’s unhelpful, is included or not. Failure to recognise denial may lead to costly mistakes, with needless damage to morale. Some patients can accept blunt talk about a bad prognosis, provided they have “not got cancer.” Others are exactly the opposite. They can accept that they have a kind of cancer, but cannot tolerate a bad prognosis. Thus diagnosis may be denied and prognosis accepted or vice versa.

The doctor needs to be sensitive to such alternatives and to conflicts in a patient’s mind arising from occasional or sustained use of this useful, perhaps essential, protective mechanism, which may be quite fragile (easily upset by a chance remark; a newspaper article about cancer; the death of another patient) or more deep seated. Sometimes a patient “knows” and sometimes he does not. Perhaps when he is with one person he seems to know; when he is with another
he seems not to know. He may know; but not want to think about it. His mood changes. Perhaps he accepts probable death, but can still plan for possible recovery or remission. ‘He may suspect,’ wrote Barlow, ‘that in his mind he is building castles in the air—and why not—to some extent he has done all his life.’ He may have no illusions, but not want to talk about it. We all know how much it can hurt to have something said aloud that we have suspected for some time. Something that we know deep down, but not superficially—in other words we ‘already know’ it. Finally, there arises an extent that friends and relatives can scarcely credit it; and those looking after him, perhaps unwilling to accept the concept of denial, may attribute such ‘lack of insight’ to brain metastases.

Hospital stays sometimes say a lot about patients. ‘He is not stupid, he must know the score perfectly well.’ But denial is not related to intelligence. Nor to knowledge; it is quite common in doctors who develop cancer. In some ways it can be thought of as the opposite to excessive anxiety—for example, fear of flying, perhaps following some frightening incident. Such fears have little to do with knowledge or intelligence. The ambivalent feelings we all have about these things are shown clearly when on the one hand we talk of ‘wishful thinking’ or ‘self-deception,’ as if this were always unhealthy or a sign of a weak character; and when on the other hand we admire optimism and ‘heroic’ responses, even in those who are ‘guilty’ of committing such a ‘crime’ as for pessi-mistic statistics and gloomy expert opinions) as a sign of strength, resilience, and courage. It has been said that denial in serious illness is just as common, perhaps even more common, in those with a strong personality who have led successful lives.

**OPTIMISM OR “ACCEPTANCE” ?**

We may feel more humble and better able to understand the optimism and denial of some of our patients (and their doubts about the wisdom of asking for more information) if we reflect on the situation that we all face in the last quarter of the twentieth century. Suppose we are asked to say—publicly or in the presence of younger members of our family—what we believe to be the present state of our society. Would we describe the chances of dying within the next 20 years from violence (nuclear or otherwise) as (a) very small; (b) appreciable; or (c) more likely than not? The question is a fair one, objective and dispassionate, but we are quite likely to be annoyed by it and to refuse to take it seriously, a sure sign that we do might disturb our protective defence mechanisms, or those of others (whom we do not wish to hurt). If we are asked about some even more unpleasant possibility, such as hunger or starvation, our unwillingness to discuss the matter will be even greater, although observers from another planet would see nothing fanciful in such a question. Like our patients with cancer who fear possible recurrence and death, we are likely to feel that since there is little we can do about it, and since it may never happen, it is foolish to dwell on the matter and pointless to ask for more information. Much better to get on with living our lives and forget about it.

If a patient soon denies what he has been told,10 does this mean that it would have been better to handle his case differently? I think it often does. A period of shock and depression, followed by denial because the patient has been told that he has cancer, may be a period of unnecessary distress that could have been avoided. Nobody has benefited. Either the patient has been wrongly assessed, or his peace of mind has been deliberately sacrificed, perhaps in the name of some over-rigid dogma or rule of thumb, based on the idea of “always being honest”; perhaps we have the hope of ultimately reducing public fear of certain words; perhaps for real or imagined medicolegal reasons. Much has been written about patients moving gradually from denial towards “acceptance,” but it is also quite common to see a change in the opposite direction, from acceptance to denial; and this may be seen both in patients who in good faith have been, and in patients, a 50-year-old unmarried teacher, who said she had no religious faith. But this is not common. Similarly, situations where husband and wife both accept and discuss freely with each other (and perhaps even with their friends) the expected forthcoming death of one of them can occasionally work well and be touching and ennobling. But, once again, such an approach for months on end seems to suit only a few. Attempts to achieve such acceptance in unsuitable cases can damage the relationship between doctor and patient and lead to considerable distress, at least until a more fruitful approach is found. Patients may present themselves and mercifully heal the pain and feeling of hopelessness that they encounter. Even in dying patients, Hinton11 found complete acceptance in only five out of 60 of those he interviewed.

The evidence of certain kinds of inquiry (for example, asking healthy people if they would like to be told if they were dying; or asking patients with cancer if they approve of having been told the full facts) needs to be treated with the greatest reserve. Understandable pride, self respect, and concern not to seem cowardly are likely to distort the findings to such an extent that such studies cannot be taken too seriously. In a more hopeful sense, the fact that we bereaved relatives of 785 patients were interviewed by independent observers,12 only 2%, definitely considered that it would have been better if those who did not appear to know the probable outcome of their illness had survived.12 Kubler-Ross in her carefully detailed and sensitive study of dying patients goes so far as to say that “even the most accepting, the most realistic patient, left the possibility open for some cure… they showed the greatest confidence in the doctors who allowed for such hope—realistic or not—and appreciated it when hope was offered in spite of bad news.”

**Diagnosis**

Most of us like to think of ourselves as robust personalities, calling a spade a spade, not afraid to tell the truth, however unpleasant, and not afraid to hear it. The doctor wants to have a reputation for speaking freely and frankly. The man in the street likes to feel that if he ever has cancer, he would welcome this approach. The reality is rather different. Sometimes blunt talk is refreshing and valuable, but if the other times to be silent about all or part of the truth is essential if we are not to cause pointless distress. To be considerate is to be discreet. Euphemisms are a part of life, and of good manners, and plain language may be offensive. Most of us enjoy being “fed” by the flesh of dead animals and drinking their blood, so long as both are cooked first. But we do not express it like this to our host or hostess.

It is often the same with the word “cancer.” Taboos and attitudes change. Discussion is less inhibited than it was 20 years ago. But there are still a lot of patients in every walk of life (and probably in every country) who cannot cope emotionally with “having cancer” in the way that they cope with having, say, heart disease of roughly equivalent seriousness. For them it is a cruel and painful word, suggesting a horrible incurable disease (‘we don’t know the cause, it could happen to anyone’) is often useful reassurance), probably incurable and certainly incompatible with a normal life unless speedily and totally eradicated. Immediate use of the word cancer is to some (not all) patients as unfortunate as bluntly telling others that they have epilepsy, or schizophrenia, or that they will be crippled for life, when they are quite unprepared for such harsh, blunt words.

It is revealing that even doctors who are most anxious to use the word cancer initially in the interest of “complete honesty,” will seldom use it subsequently, unless the patient particularly seems to want it. Which fact undermines many criticisms of the use of euphemisms (not all) that they are used to mislead patients, or that “the cancer is getting on?” than is his colleague who has avoided using the word from the start. Many patients find that if they use the word too freely their friends are embarrassed and avoid them. MacIntosh1 observed during prolonged observation of patients with cancer in hospital that most of those who “knew” or “probably knew” preferred to use euphemisms when talking to each other. To complicate matters further, when we speak of “having cancer,” “having a curable kind of cancer,” “having a small tumour,” or “having a growth,” there are significant differences in the way we use these words and this may be much less frightening than another, although all may be true. Because of this, and because of varying degrees of denial, the very same phrases that insult the dignity and intelligence of one patient (he would prefer blunt language) may bring valuable comfort and encouragement to another. Again, suppose a patient with a cancer that carries a good chance of cure—a small early malignant melanoma perhaps, or a carcinoma confined to the cervix—asks if she has got cancer.” The problem now may be not so much “should the truth be told,” but what exactly is “the truth”? If this patient is terrified, having firmly believed all her life that to have “cancer” is to have had disease, disgrace, and hopelessness, it is usually just wishful thinking for the doctor to imagine that he can eradicate at a stroke the convictions of a lifetime by giving a brief enlightened account of the facts. It follows that it may be true and not false to assure the patient (speaking to her in language, not ours) that she does not have cancer, but that we advise...
Avoiding extremes

Between the extremes of cold or excessively pessimistic "honesty" on the one hand, and what is sometimes called the "bluff" category of deception on the other, lies a complex range of various more civilised and generally preferable options. Some are a blend of bluntness and cautious optimism. Some are based on talking to the patient in such a way that he is, in effect, given the choice of either denial or acceptance of the diagnosis, and many patients preferring to be "told" in this way, rather than to have everything spelt out to them. Some rest on the fact that, although many patients are grateful to have someone looking after them who is not afraid to discuss cancer, death, and dying, many others prefer their doctors to talk about the disease in a more restrained way.

Each option, whether applied to diagnosis or to prognosis, is infinitely flexible. As doctors, concerned only with doing our best for each patient, we should take full advantage of this fact. To do so need not in any way compromise our integrity. It is sometimes wise to be much more blunt about diagnosis than about prognosis; and sometimes vice versa. With some patients optimism carries more conviction when salted with some unpallatable facts and possibilities. With others, especially if they are frail and elderly, to do this, or even to hint at percentages and survival statistics is clumsy and thoughtless. Some patients, for various reasons including old age, deafness, and extreme anxiety, are especially prone to misinterpret or misquote what we say. When we talk to them it may well be that the fewer words we use and the simpler our message the better, otherwise what we say may increase rather than relieve their anxiety.

It may seem unduly paternalistic, even arrogant, to make arbitrary decisions of this kind, calculated to emphasise the more hopeful aspects of a situation or to protect the patient from the full rigours of "the truth." But are we really at least equally "arrogant" if we insist, often to the dismay of the relatives, that we have a duty to be blunt and to give full information, whether the patient seems to want this or not? What right have we, if the outlook is bleak, to conceal elements of doubt about the diagnosis, extent of spread, or prognosis, on the grounds that to speak of them might "raise false hopes"? It can be very encouraging for a patient to be told that there are few certainties in medicine. Is it not inevitable that we are selective and arbitrary to some extent, not only in our choice of words, but in emphasis and manner? Have we the right in a serious situation to do it at all. In 1940 Winston Churchill began one of his wartime radio talks to the British people with the simple, emphatic, and incredibly blunt words: "The news from France is very bad." Yet because of the way he said it and because of his personality, the morale of those of us who heard him rose rather than fell, and confidence in him (and in ourselves) grew before he had said another word.

Although in some ways such situations differ from that of advanced cancer, it seems to help medical students, young nurses, and trainee social workers (some of whom feel that it must surely be the doctor's duty to tell every patient the full facts) if we discuss with them problems of leadership and morale in a non-medical context. Suppose a plasterer, working in an isolated area where the chance of ever being found is remote and where every aspect of the situation is as bad as it can be. The "honest" leader, who considers that every survivor, whatever his age or condition, has a right to know that there is "no hope" (and who advises acceptance of a slow and certain death, rather than "pretending" otherwise) will not be very popular. Few will have any confidence in him. Morale will suffer. Many will want to choose a new leader. Equally unfortunate for most people would be the leader who, hoping to improve morale in the short term, uses false optimism to tell the patient the truth, but that the situation is not serious. Often the best leader is the one with the strength of character to keep his worst fears to himself and who says, "We are in a very tough spot, there is no doubt about that; I can promise nothing, but I think we have a chance, in fact, I know we have," and who then outlines a plan of action, calculated to take full advantage of whatever small chance exists.
to describe what has already passed between patient and staff (unless something striking or unusual has happened) may only encourage an undesirably rigid idea that the problem has been dealt with.

Medical social workers and others, seeing a patient for the first time after being informed that he knows his diagnosis and prognosis, are often puzzled to find that this does not appear to be the case. The cause is twofold. Firstly, when doctors talk of “telling” or “not telling” the patient, they differ considerably as to what they mean by these phrases. Many British doctors, for example, believe that in the United States “they tell all their patients.” Yet it was recently claimed in an American medical journal that 90% of American doctors “usually do not tell.” Secondly, the denial mechanism and a preference for euphemisms may have already come into play, and perhaps the patient totally suppresses part of what was said to him and emphasises another part.

Sometimes it is suggested that the best solution to this problem is to leave all such discussion to the family doctor, who probably knows the patient, his family, and his responsibilities better. But there are serious objections to this. Firstly, the specialist has first-hand knowledge of all the benefits and side effects experienced by many other patients in a similar situation. The patient senses this and realises that he is not just getting a second-hand opinion or a view based on a fairly small experience of his particular problem. Secondly, to delay until the patient sees his own doctor can cause unacceptable anxiety. Thirdly, the hospital doctor, particularly if he specialises in cancer, has a far better chance than the family doctor of being able to provide valuable encouragement by telling of a similar patient who responded well to treatment; perhaps of one who recently attended for a checkup, who is back at work and enjoying life. A specialist in a large centre, unlike the family doctor, may refer to such cases without risk of breach of confidence.

Conclusion

“It is fear that I stand most in fear of,” wrote Montaigne nearly 400 years ago, “in sharpness it exceeds every other feeling.” So we must try to relieve this particular form of suffering, just as we try to relieve pain; and good communication can often do this better than any drug. We must communicate both efficiency and kindness; and we must not confuse diagnosis with prognosis. Whatever the outlook, our main objective is to maintain morale and to help the patient to achieve maximum courage, equanimity, and peace of mind, but not in a shortsighted way which will create difficulties later on. Most of us prefer to be pragmatic, in the best sense of the word, rather than to follow some set dogma; to assess as best we can

(pREFERABLY WITH THE HELP OF RELATIVES AND NURSING STAFF) the immediate and late effects of what we have said or not said, modifying accordingly our future policy in similar circumstances, and trying to learn from our mistakes, just as we do in any other aspect of patient care.

Central to the art of good communication is firstly to try to get the amount of information and explanation about right. Lack of information can greatly increase anxiety and stress (knowledge is the antidote to fear, said Emerson)—but so can too much of it. Secondly, whether the outlook is good or bad, to give appropriate reassurance and encouragement. There is always something to reassure the patient about and nearly always something to be positive and optimistic about, even if this is only the prospect of symptom relief. Thirdly, to be watchful and flexible, especially if there is a change (as there often is) either in the prognosis, in the patient’s attitude, or in his threshold for anxiety and depression. And finally—sometimes directly in serious conversation, sometimes indirectly, by word or by manner, by humour or by friendship—to remind the patient whose outlook is serious, but not hopeless, that few things in this world are certain and that the difference between the uncertainties that he faces and those faced by others his age may be only a matter of degree. We are all travelling the same road.

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What is the monetary value of a human life?

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Summary

The resources available to the health service are limited and so the amount the NHS can spend on saving human life is also limited. Rational allocation of resources

requires a decision theory model, which in turn demands some monetary valuation of human life. Each of three approaches discussed—basing value on productive capacity, the NHS’s implied values, or individuals’ values—rests on an underlying set of non-monetary values. Choice of the underlying value will determine the method to be used in placing a monetary value on life. As the Health Service implicitly places certain values on life already, a means of making this valuation more rational and explicit can only improve the quality and quantity of health care.

Introduction

Even in the early days of the NHS it was recognised that a comprehensive health service could not be provided for every