Communication in Medicine

How should we talk about acute leukaemia to adult patients and their families?

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Abstract

Problems of communication with patients with acute leukaemia and their families were explored by interviewing the next of kin of 26 patients, six of whom were still alive. In all but two cases the diagnosis had been disclosed to the relatives before the patient, but almost one-third of the relatives were not entirely satisfied with the way in which the diagnosis was presented. Medical prognostications at these initial interviews were, on the whole, regarded as being realistic by the relatives. Nine patients learnt of their diagnosis at an early stage, but relatives were undecided whether patients should be told of the diagnosis in explicit terms. Patients often established complete dependence on the hospital and its staff and had difficulties in relating to their own general practitioners while at home during their illness. Social chats were preferred by the relatives rather than regular progress reports from the doctors.

Introduction

"'You're the boy with leukaemia, aren't you?' the nurse asked as she routinely took my TPR. These seven words hit me like the edge of a blunt instrument." Thus wrote Robert Millington describing the way in which he learnt of his diagnosis in a poignant essay published recently after his death.¹ One wonders how often this type of disaster occurs, an overheard remark by a laboratory technician, an open pathology request form, or casual chatter in the queue at the haematology clinic. We smugly imagine that these disasters occur in other people's units and not in our own.

For the patient or relatives there can be no more terrifying ordeal than to learn that he is suffering from leukaemia; a diagnosis that they will almost certainly equate with death in a few weeks. Yet we as doctors rarely discuss how much we should talk about acute leukaemia to patients and their families. We receive many recommendations from the professional communicators, who are heavy with words of advice and singularly light in their personal experience. Unhappily, little is really known about attitudes and reactions to acute leukaemia. Because of this we embarked on a retrospective study to learn something of our own communications with patients and their families.

Patients and relatives: methods of inquiry

The basis of this survey was 60 consecutive adolescents and adults who had survived more than one week after the diagnosis of acute leukaemia and who were treated by one physician (PJT) in Nottingham over eight years. Of these 60 patients, 20 were unsuitable as they had no relatives or because the next of kin lived so far from Nottingham that communication was impracticable. From the hospital notes 40 patients appeared to be suitable for the survey as they were recorded as having first-degree relatives or next of kin living in the East Midlands. One of us (PJT) initially attempted to contact the kinsmen of this group of 40 patients either directly by telephone or by letter explaining the purpose of the survey and the proposed arrangements for subsequent interviews. At the bottom of each letter was a tear-off slip that could be returned to say whether or not the addressee agreed to be interviewed. Of the 40 relatives, 26 agreed to be interviewed and three refused. Five letters were returned, four relatives having moved away from the district and one having died. We did not get replies from six addressees but reminder letters were not sent as it was thought that in most cases failure to reply implied a refusal. Although forgetting to reply is common, we thought that this was unlikely to be so in this study in which the subject was a matter that had seriously affected all those concerned, usually bringing tragedy into their lives. On such a sensitive topic we were particularly anxious not to cause worry, nuisance, or distress unnecessarily. Fortunately, although less than half of the potential relatives were actually interviewed, this sample proved representative in its age, sex, and social class distribution.

All interviews were performed by HG and all except three were at the relatives' homes. Six patients in the group of 26 patients were still alive and of these six patients two remained present during the interviews. All but one of those interviewed agreed to a tape recording being made. A structured inquiry with 64 questions was put to each relative or next of kin as part of a wider study of the impact of acute leukaemia on families.²

Responses to the inquiry

HOW THE DIAGNOSIS WAS PRESENTED TO RELATIVES

Nearly all the relatives had been told of the diagnosis before the patients. There were two exceptions, one aggressive young man (a descriptive term used by both his wife and the medical team) demanded to know the diagnosis as soon as he was told he needed to be admitted to hospital, and a young woman who had guessed her diagnosis immediately and asked before her husband could be told.

Although all but one of the relatives had been glad to know of the diagnosis at the earliest possible stage, about one-third had not been entirely satisfied with the way in which it had been presented to them. Two relatives thought that they were given far too many details initially and were quite incapable of absorbing them at that stage. In contrast, two other relatives considered that they needed to have more particulars of what they might expect. Two relatives had been told that the patients would probably die but, in fact, both patients remain in complete remission some years later. Understandably, both relatives resented the initial pessimism and would have appreciated more hope. One wife had been told that the doctor wished to see her when she was expecting little more than a social

chat. The news she had received was so utterly unexpected that she collapsed. Later she suggested that at such interviews the hospital should always ensure that a companion was present to give support and to act as an escort home. One wife wished that she had not been told of the diagnosis as she was completely unable to cope with the knowledge and to communicate with her husband, who himself was unaware of the diagnosis.

In families with grown-up, even married, children in all but two cases the older children and grown-up sons and daughters had been told of their parent's diagnosis at an early stage. The children in the main, though saddened by the news, were said by older members of the family to have been subsequently helpful and considerate. Teenage children tended to act differently. One became difficult and was described by his mother as becoming wild; another started a frantic search for publications on new treatments and possible cures; another teenage son became extremely aggressive towards his mother after his father's death. None of the very young children were told of their parents' diagnoses, but they seemed to adapt well after the deaths of the parent. One confidently said at interview "My mummy's going to get a new daddy, you can buy them at Sainsburys."

SHOULD THE PATIENT BE TOLD?

It was not the usual medical policy on this unit to tell every patient he or she had acute leukaemia unless they specifically asked questions. Nevertheless, it was thought essential that some should be told, particularly those with family or financial responsibilities. No particular decisions were made in relation to sex, race, religion, or intelligence.

Of the 26 patients with acute leukaemia, nine actually knew of the diagnosis but the circumstances of its discovery varied considerably. Three were told when they had entered remission, and two patients had already guessed the diagnosis before being told. One patient was told because his job gave him access to medical books so that he would quickly have made the diagnosis himself. One patient was told but did not realise leukaemia was a fatal disease, another demanded to know, and another learnt the diagnosis "by mistake" from a relative.

The patients with leukaemia had had very varied responses on being told the diagnosis. The two patients who had guessed the diagnosis and asked accepted the diagnosis calmly and were grateful for being told. The remainder reacted with varying but considerable grief. The young man who demanded to know was very upset when told and gradually withdrew from his children. Although he continued to work and was able to talk freely with his wife, he could not bear to see his children, knowing that he would not see them grow up. One woman, after months of being told that she had anaemia, became very angry at being told of the diagnosis when she had entered remission. She thought that at that stage she did not want to know the diagnosis and was bitter with her family and with the hospital for not having told her earlier.

Although all but one of the relatives wished to know the diagnosis themselves, more than half were pleased that the patient did not know. Four of the relatives (all spouses) of patients who were not told were subsequently unsure that this had been the right decision. They all mentioned that it made it difficult to talk to their partners and that after years of marriage it was unpleasant deceiving them in this way. One woman considered that it was an insult to her husband's intelligence.

EXPECTATIONS AND REALITIES DURING TREATMENT

The extensive coverage of a disease such as acute leukaemia in newspapers, magazines, television, and films ensures that most people have a fairly accurate idea of its sinister nature. Of our group of 26 relatives, the expectations at the time of diagnosis had usually been pessimistic; nine relatives thought that there was virtually no hope, 11 thought that there was little hope of a cure and that the treatment would just slow down the illness, three had no ideas at all, while three hoped for a miraculous cure. Unfortunately, in this study those relatives hoping for a miraculous cure had never come to accept that the patient might die and when he did so they were extremely shocked.

Given that rather more optimistic predictions were made about younger patients with acute lymphoblastic leukaemia, the doctors' initial predictions were on the whole fairly accurate. Exactly half of the relatives thought that the doctors' predictions at the onset of the disease had been entirely realistic, whereas just over a quarter re-

garded them as being too pessimistic and just under a quarter as being too optimistic. A considerable group of relatives thought that a leaflet or booklet explaining the disease would have been helpful.

Although 20 of the 26 patients died, often after extremely unpleasant treatment with disagreeable side effects, almost three-quarters of the relatives thought that the treatment was worth while. Most were grateful for the extra months of life it had provided, and many were heartened and encouraged by the remissions. This was not always the case, however, and three relatives admitted that the patient's death came as a relief and that they were pleased that he had not lived and suffered for longer. Some regarded the treatment as the only source of hope, albeit a slim one. One young wife was told that the treatment was no longer having an effect, and it was suggested it might be stopped. She was completely against this, particularly as her husband knew the diagnosis and could not have tolerated "sitting waiting to die." Similar responses had come from other adult patients who had known the diagnosis. All had been anxious to "try anything" when it was apparent that conventional drugs were not working.

When patients were unaware of the diagnosis themselves it was sometimes difficult to persuade them to continue with the treatment, which was often described as frightening as well as being extremely unpleasant. Adolescents in particular were not keen to receive treatment. Most did not know the diagnosis, and although they were aware they were ill they did not realise how seriously ill they were. Five relatives reported difficulty in persuading these youngsters to visit hospital but were convinced that it would have been wrong to pressure them by disclosing the true diagnosis. The younger patients complained to their relatives about the depressing effect of the old patients with other diseases in the ward, many of whom were admitted in a critical state to the acute medical wards. Some patients who had had cranial irradiation reported that the masks they wore were extremely claustrophobic and for one patient formed the most terrifying part of all the treatment.

It was during the treatment of the illness that many relatives thought they would have liked to have met the doctors more often, just for a social chat at visiting time. The availability of a doctor on a casual basis was required much more than formal interviews to report progress. While the patients were at home the relatives were greatly comforted that they could telephone the hospital at any time to obtain advice. When ill and in trouble at home most of the patients preferred to contact the hospital rather than their general practitioners. Nearly half of the relatives seemed dissatisfied with the general practitioner's role as he often seemed reluctant to become concerned with a patient undergoing regular treatment and surveillance at hospital. With complex modern regimens of chemotherapy this reluctance is not perhaps surprising. Four patients were reported as actually preferring to be in hospital. They had been so frightened by their symptoms that they felt secure only in hospital.

Discussion

Although dozens of papers have been written on the treatment of acute leukaemia little has been said concerning the problems of doctor/patient/relative communication. While recognising that our own survey might have been biased and unrepresentative, and also dealt with only a small population, we believe it represents the first inquiry of this kind in acute adult leukaemia.

Several studies have been made in the more common forms of malignant disease.³⁻⁵ With various forms of cancer relatives are very likely to be told much more about the disease than the patient though rarely are they given any idea as to how long the patient might survive.⁶ Why close relatives are readily recognised as having a right to detailed information that is denied the patient is uncertain, but this pattern of communication was largely reproduced in our own group with acute leukaemia. Obviously there are commonsense reasons why relatives must know the diagnosis, such as domestic and family arrangements, acceptance of long periods of hospital care, and the understanding of complex and frightening therapeutic regimens. Nevertheless, one wonders if our anxious, and perhaps unconscious, reasons for earlier discussions with relatives rather than with patients include a need to forestall later indignant and hostile reactions when the patient fails to improve or dies.

Why then should we be so reluctant to tell our patients that

they have fatal illnesses? In a study from a cancer ward less than one-third of patients suspecting themselves of having malignant disease wished to have it confirmed, and even fewer wanted information about their prognosis.⁶ Nevertheless, in another group of patients who had cancer, and knew it, 81% thought that doctors should disclose the diagnosis.⁵ In contrast doctors often seem reluctant to tell patients that they have cancer or are dying.^{4, 7}

In many ways problems of communication with patients with acute leukaemia are different. Though a rare disease, leukaemia is often publicised by books and the media, and its rapidly fatal course is well known. The combination of the terms "blood disease," "bone marrow examinations," and "treatment by injections" are quickly translated by most alert patients into a diagnosis of leukaemia. As a result it may not be necessary to make a decision whether to tell an adult patient; he will already know. Such was the pattern in several of our own patients with leukaemia. In those in whom the diagnosis has not suggested itself to the patient already the harrowing and prolonged nature of treatment makes disclosure of the diagnosis mandatory. Certainly few would agree to such measures unless they knew that their lives were at stake. There are, nevertheless, some patients with acute leukaemia who do not wish to have the diagnosis confirmed or who may be too ill throughout their illness to ask about it. Whether we should tell such patients just for the sake of being truthful is uncertain. Undoubtedly management is easier for doctors and nurses when the patient knows the diagnosis, but it is uncertain whether the patient is happier in knowing the diagnosis. "I don't want to go through all that wretched treatment again if I am likely to die a few months hence" said one patient who did, in fact, have a short but happy remission. Sometimes a know-

ledge of the diagnosis does bring peace of mind and acceptance, but if the diagnosis is disclosed prematurely, casually, or uncritically it may bring unnecessary grief for one who needs only comfort.

The results of our survey of our own patients have taught us that there can be no standard answer for the standard patient and relative with a standard disease. We believe that relatives must know the diagnosis and are obviously entitled to more hope than perhaps was given in the past. We have learnt that it is as important to listen to relatives as to talk to them. One relative, a general practitioner, was told by one of the doctors, "There's nothing to be said, is there?" Although she did not need information, she did need someone just to talk to. She felt deserted and left on her own to cope. The social chats that may seem trivial to us are comforting and reassuring to frightened and bewildered relatives.

References

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Today's Treatment

Clinical Pharmacology

Plasma protein binding of drugs

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Binding to plasma proteins is both a help and a hindrance to the distribution of drugs through the body. Transport in the bloodstream by binding to albumin helps the drugs to reach regions remote from the site of administration. Because bound drug cannot readily leave the capillaries, however, the rate of distribution of drug into the tissues will be controlled by the concentration gradient produced by the concentration of unbound unionised drug. Usually, it is the unbound drug concentration that is considered to be pharmacologically and toxicologically active. The fraction of unbound drug can also influence the rate of drug elimination. Binding does, therefore, affect both the duration and intensity of drug action.

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The binding and transport of endogenous and exogenous substances is one of several important functions of the plasma proteins (figure). The endogenous substances include bilirubin,

Protein binding and drug disposition.