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## Contemporary Themes

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### Couples facing death

#### I—Psychosocial aspects

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##### Abstract

Forty-one couples facing the prospect of separation by death were followed up from the time of admission to a continuing care unit through death of the patient to an interview with the bereaved spouse. Half the patients were found to have anxiety or depression or both, usually as a result of failure to cope with specific difficulties. These fell into four groups: unsatisfactory communication, direct effects of illness and treatment, failure to adjust lifestyles to changing circumstances, and pre-existing marital and family problems.

This paper examines in detail the problems in the second and third groups. Support was offered to the patient and family in an attempt to help them to adjust and make the best use of their resources. The responses obtained suggest that some of the suffering of terminal illness can be relieved when psychosocial problems are recognised and appropriate help is given.

##### Introduction

The death of a husband or wife is one of the most stressful events in human life.<sup>1</sup> Much has been written about morbidity after bereavement<sup>2,3</sup> but very little about the effects of a terminal illness on a couple before death. What difficulties do they face and how do they cope with them? Can attention to

their psychosocial problems relieve their suffering more fully? This study explored these questions by following up 41 couples from the first admission of the patient to a continuing care unit, through death, to a follow-up interview with the surviving spouse.

##### Patients and methods

In 1979 and 1980 I assessed and treated when necessary 41 married patients while working as a regular part-time psychiatrist at Sir Michael Sobell House, Oxford. This is a 20-bedded continuing care unit in the grounds of Churchill Hospital, to which patients are referred from other hospitals and from home by their general practitioners. Like other hospices, it is an autonomous unit in many respects, but its work is closely integrated with that of the local hospitals and particularly the oncology services. The emphasis is on developing and using clinical skills to control as completely as possible the symptoms of malignant disease, and to offer medical, social, and psychological support to the patient and to the family. Admissions take place not only in the terminal phase of illness but also earlier if symptoms are not being adequately controlled elsewhere. Some patients go home for long periods; some are readmitted several times, some come back for terminal care, and others die at home.

The patients in this study fell into three groups. Twenty-nine patients were referred by other staff members for various reasons (table I) because their problems were not responding to the usual care given in the unit. Since patients aged under 40 seem to be particularly distressed by terminal illness, it has been the policy in the unit for some years to refer them routinely; 10 of the 29 were in this age group and only one had no obvious problems at the time of referral. Ten patients were designated in order to provide a sample of older patients and those who did not require referral. Every tenth married patient admitted was designated by the research nurse as a potential research case and was included if not referred within a week. Finally, two exceptional patients were selected on the assumption that as much may be learned from success as from failure.

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Once the study began, however, the designated and exceptional groups were found to be too small to study separately. Furthermore, at least four "designated" patients had problems that would have led to referral had they been recognised earlier. The exceptional couples lived up to their name, and three others (2 referred, 1 designated) also coped unusually well with at least some of the problems confronting them. In the end the groups were amalgamated for the purposes of description.

### Assessment and management

Patients were interviewed using a standard form designed for this research. After an initial discussion a detailed history of the illness was taken, concentrating on what was said about it, by whom and to whom, and how the patient and others felt. Details of the immediate family were recorded and an assessment made of who were the most supportive figures and who were perceived as dependent. The mental state was assessed and a diagnosis of psychiatric illness made or excluded. Hallucinations were asked about specifically as they are common in terminal illness and are often concealed by the patient.

At the end of the interview a list of problems was compiled, often with the co-operation of the patient, and further action planned, such as further exploration of the problem with the patient and the giving of more information if he required it, arranging interviews with other family members separately or together or both, and recommending changes in treatment.

The spouse was then seen and the history taken in a similar form, new problems being added to the list if necessary. The spouse was asked how much the daily life of the family was affected by the illness. Often husband or wife or both were asked about previous life crises, such as death of parents or serious illness, to understand how they usually coped with trouble. An impression of the quality of the marriage emerged here.

The results of initial assessment were discussed with medical and nursing staff so that a co-ordinated plan of management could be made. Goals were set out on the problem sheet. The psychiatrist continued to meet the patient and family members as often as necessary and progress was followed until death. Some patients were discharged home for weeks or months, and eight died there, cared for by their general practitioner and his team, usually with the support of the home care sister from the unit. At the end of two years all but two of the patients had died, and 35 of the 39 bereaved spouses had been interviewed. Those interviews, which took place about a month after the death, included an assessment of how the spouse and family were now coping and a review of the whole management.

Nineteen patients were men and 22 women with ages from 25 to 77, evenly distributed. The duration of marriage ranged from two years nine months to 54 years. Occupations varied, from university don to unskilled worker. All but one had malignant disease. The duration of illness from first symptom to death ranged from three months to 12 years: about half the patients had an illness lasting six months to two years.

### RESULTS

The reasons for referral are shown in table I; some patients were referred for two or more reasons.

TABLE I—Reasons for referral in 29 patients

Difficult relationships with family (and occasionally staff) ..	10
Persistent or severe depression .. .. .	8
Persistent or severe anxiety .. .. .	5
Spouse unusually distressed .. .. .	5
Persistent anger of patient or family .. .. .	5
Diagnostic—eg ? dementia .. .. .	4
Unusually tragic or vulnerable circumstances .. .. .	3
Total	40

Table II lists the psychiatric diagnoses. A specific diagnosis was made in over half the cases; the morbidity was greater in referred patients. The diagnosis was based on clinical assessment unsupported by formal ratings. Depression was missed in two designated patients; the staff were aware that the other two had organic brain syndrome

TABLE II—Psychiatric diagnoses. (Percentages in parentheses)

	Referred (n = 29)	Designated and exceptional (n = 12)	Total (n = 41)
Depression	11 (38)	2 (17)	13 (32)
Anxiety state	6 (21)	1 (8)	7 (17)
Organic brain syndrome	3 (10)	1 (8)	4 (10)
Personality disorder	1 (3)	—	1 (2)
No psychiatric illness	11 (38)	8 (66)	19 (46)
	32*	12	44*

\*Two diagnoses were made in three patients.

and an anxiety state, respectively, and felt competent to manage them without additional help.

Much of the work done by the psychiatrist was concerned with the alleviation of distress caused by problems that were not strictly psychiatric. Five patients presented no problems for intervention. They and others were encouraged to talk about difficulties they had encountered and handled either by themselves or with the help of others before admission. The patients who coped best were not necessarily the ones with the least problems, but rather those who were most supported by others or who had the resources to overcome their difficulties alone.

The problems presented by the 36 other patients have been divided for the sake of a more orderly presentation into the four groups set out in table III. The number of problems presented by an individual ranged from one to eight.

TABLE III—Problems presented for intervention by 36 patients

1 Problems in communication about the illness with:	
(a) Unit staff .. .. .	5
(b) Spouse .. .. .	11
(c) Other specified relatives .. .. .	15
2 Adjustment reactions to effects of disease and treatment .. .. .	34
3 Adjustment reactions to enforced role change .. .. .	8
4 Independent marital and family problems .. .. .	14
Total	87

Problems in communication with spouse and family (group 1 (b) and (c)) do not necessarily reflect the serious underlying difficulties of group 4. Some of them are caused by mismanagement and respond to quite brief intervention, whereas communication difficulties arising in patients in group 4 have to be treated in the setting of the unsatisfactory relationship. There is inevitably some overlap of these groups.

So much material about communication emerged from this study that it is contained in the second half of this article. To write about the problems of patients in group 4, which undermine satisfactory coping in any illness, would present a task well beyond the scope of a single article. The remainder of this paper will therefore be concerned with the understanding of management of the adjustment reactions in groups 2 and 3.

### Adjusting to the effects of terminal disease and its treatment

Table IV lists the problems directly related to the terminal disease. By the time patients came to the unit most had undergone operations such as mastectomy or colostomy and had adjusted well—a tribute to their own resilience and to good preoperative and postoperative care. Most had received radiotherapy or chemotherapy or both, and many accepted hair loss or the effects of steroids on their appearance as a lamentable but nevertheless tolerable price to pay for treatment that enabled them to go on living. They reported that they were helped by realising that physical change had not in any way alienated them from their families. Five patients in the study were still distressed by such side effects. These were less secure women who thought that a good appearance was essential to maintain their husband's interest; some expressed a new possessiveness or jealousy with regard to any contact the husband had, however innocent, with other women. The husband's failure to understand this response led to deterioration in the relationship. Helping them to recognise their

wives' increased need for reassurance and affection brought about improvement.

The issue of whether or not to continue with treatment came up with six couples. The doctor has to take care that his therapeutic enthusiasm is not influenced by his reluctance to acknowledge that his treatment can no longer be beneficial. Patients also have mixed motives. To continue treatment that has serious side effects and almost no hope of benefit may reflect a genuine wish of a young parent to fight until the end, but it may also be motivated by fear of death or guilt at abandoning the family. When a patient decides to stop fighting it may be more than just resignation. It can be a positive choice, knowing that symptomatic treatment may enable him to feel reasonably well at least for a short time and to do a few things that are important to him and his family. Thus he rounds off his life more satisfactorily, and his relatives often have some good memories of the terminal illness that help to ease the pain of the loss.

TABLE IV—Problems directly related to terminal disease and treatment

Hair loss or Cushingoid appearance or both	5
Decisions about radiotherapy or chemotherapy	6
Paralysis	2
Personality change	2
Boredom and weariness	2
Prolonged anger	4
Plans not made—eg, a will	2
Fears:	
of going mad	6
of unexpected death	2
of being drugged	1
of becoming an addict	1
that cancer is contagious	1

The decision to abandon treatment needs to be questioned, however. The patient may be making an informed choice, but an unconscious wish may be present to escape from an intolerable situation unrelated to the illness. Thus one young mother refused chemotherapy quite early in the course of her disease. In other circumstances she might have attempted suicide, but she knew that her cancer would provide a way out. When help was given with her family problems she accepted more treatment.

Two wives had personality change due to cerebral secondaries, and their husbands found it painful and perplexing to relate to a familiar person who responded in unpredictable ways. We thought we were justified in keeping these women in the unit even though their physical condition might have indicated home care.

Prolonged anger about what the patient saw as delayed or inadequate treatment, or about the illness itself, was regarded as a problem if it stopped the patient from making the best of what was left of his life. Such anger may be displaced on to nurses or family, making the patient unpopular and alienating him from those whose care and affection he most needs. He may then say, "My family don't seem to care any more" or "The staff like other patients better than me," and then be labelled paranoid. Psychotherapy may correct the displacement and solve the problem.

Dying patients have many fears, which they express to staff only if a close and trusting relationship has developed. The fear that dying will be intolerably painful is probably the commonest of all, but it did not feature much in this study because it was handled successfully by others. Fear of insanity is also common, and patients often conceal hallucinations. When a patient recognises, in a confusional state or the early stages of personality change or dementia, that he is "not his usual self" he becomes frightened. Psychotherapy can help people maintain a separation between the concepts of "myself" and "my illness." They respond with great relief to reassurance such as, "Whatever odd things your brain tumour makes you say or do, I still know that you yourself are all right."<sup>24</sup>

Many dying patients' fears are about their loss of control, and they are helped when they share in decisions about their management. A fear of unexpected sudden death sometimes troubles people early in the illness, when it is not appropriate. One such patient slept very badly at night, fearing he might slip away with no attempt being made to rescue him or comfort him.

Fear that their cancer may be contagious sometimes causes patients to deny themselves a whole range of intimate contact—from sexual intercourse to giving a kiss to a grandchild—the lack of which impoverishes their lives and contributes to isolation and depression. This fear also responds to reassurance, unless it is part of a serious depressive illness.

## Adjustment reactions to change in role

Almost every patient spoke of occasions when they had to accept that the illness was forcing them—and their partners—to make major changes in their way of life. Most managed this fairly smoothly, and some couples even felt they were drawn closer. Others failed to adapt. For instance, different couples spoke of their reaction to the realisation that the husband could no longer drive the car and that the wife should learn to do so. Usually the husband felt angry and frustrated that his wife was taking over something he had always enjoyed. If he became able to accept this both took pride in her new skill and recognised that she was better prepared for widowhood. If his resentment persisted she was likely to become discouraged and give up the attempt.

Changes in the level of dependency are difficult to make smoothly. A few of the younger patients remained defiantly independent almost up to death, whereas others accepted the suggestion that they had put up a good fight and that they might get more out of the life that remained if they relaxed and let others help them. At the other extreme there were those who gave up too soon. Occasionally the spouse may impose the sick role on the patient. One husband, when told that his wife had breast cancer, assumed that she would live longer and feel better if he took over all the housework and let her rest. She then felt redundant and useless at home; they needed help to work out a better way to share the tasks. Conversely, denial of the seriousness of the illness leads to rejection of the sick role by patient or family. A mother in this study became exhausted in her struggle to maintain standards, and the family complained that she did not do as much for them as usual. She deliberately concealed her feelings from the family in order to spare them suffering; then she blamed them for not seeing how ill she was. At follow-up, her husband was very angry that she had denied him the opportunity to comfort her during her last months.

As death approaches some patients prepare for separation by withdrawing. They no longer want to hear news, and ask for visits to be less frequent. Some families feel rejected and wonder what they have done to cause this change in attitude. They need to be told that it is part of the preparation for death and not a sign that they have caused offence. Other patients seem to appreciate the comfort of the family with them right to the end, and are at their most peaceful when someone they love is quietly by their side.

Occasionally the husband or wife becomes distressed because the patient turns to his or her parents in preference to the spouse. Parents may be helped to understand the extra suffering their child's spouse is experiencing, and may agree to share the care. Sometimes the patient is obviously more content with parents alone, and the therapist can do little except support the rejected spouse.

## Discussion

Mention must be made of the place of psychotropic drugs in this setting, where they are used not only for their specific effects but also as antiemetics, co-analgesics, and muscle relaxants. Any attempt to assess the contribution of these drugs to the overall improvement that many of the patients showed is beyond the scope of this paper.

The exceptional couples in this study, and many others, adapted well to changing circumstances. They reported periods of stress to which they responded by mutual support, recognising the nature of their problems and working out ways of solving them. Many spoke of the help they had received before admission from their general practitioner and other professionals, and from family or friends. Other couples responded in inappropriate ways that increased their suffering. Psychotherapy helped them considerably. Many were resilient and capable of change even in the last weeks of their lives. When they were shown how they could help themselves and each other they did so, and discovered new strengths and closeness. Others could go on coping only in familiar ways. Here the focus of therapy was with the family, helping them to understand the patient and accept him as he was. This also brought about some resolution of conflict and contributed to a peaceful death.

Among the couples in this study those most at risk were the under-40s, especially those whose children and parents both

needed them. Marital problems, isolation or estrangement from the extended family, poor communication, and underlying personality disorder all increased a couple's difficulties. It is part of human nature to be able to cope with death and bereavement. When coping fails we should not turn away or offer only symptomatic treatment. Rather we should look for a cause, and help the couple to overcome it, relieving unnecessary suffering so that the natural adjustment can proceed and equilibrium be restored.

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# The Six Diseases of WHO

## Lymphatic and other filariases

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The three parasites, *Wuchereria bancrofti*, *Brugia malayi*, and *B timori*, all of which produce disease in the lymphatic vessels, are the most widespread and abundant of all the human filarial worms.

### Epidemiology

Well over 250 million people dwelling in the tropics are exposed to infection with these parasites. By far the greatest numbers of patients with *W bancrofti* are found in India, but the disease is also found in many other Asian countries (Sri Lanka, Bangladesh, Burma, Thailand, Malaysia, Indonesia, China, Philippines, and New Guinea); in tropical parts of Africa and adjacent islands; in Egypt; in many Pacific islands; and to a less extent in parts of Central and South America and the West Indies. Infections with *B malayi* are more restricted. They are most numerous in Indonesia (where *B timori* also occurs) as well as in Malaysia, India, China, Thailand, Vietnam, Philippines, and South Korea.

Although a high proportion of infections may be clinically silent, there are many millions of people with patent microfilaraemia, who are capable of spreading the parasite, and probably almost as many who suffer intermittently or permanently from some pathological manifestation of the parasite—acute and subacute manifestations of adenolymphangitis and filarial fever or chronic manifestations of hydrocoele, elephantiasis, chyluria, etc.

The immature and adult worms of all three species (4-10 cm long) live in the lymphatic vessels and nodes and are responsible for almost all the pathology of the infection. They produce microfilariae that invade the blood and which, when ingested by appropriate mosquitos, may develop over 10-12 days to infective larvae, transmissible when the insect bites again. The microfilariae are not normally pathogenic, but their sudden death in large numbers at the onset of chemotherapy may cause fever; and their presence in the lung of sensitised individuals may be

responsible for the condition known as tropical pulmonary eosinophilia.

*W bancrofti* exists in two main forms. The nocturnally periodic (largest number at night, few if any during the day) form is most widespread, having microfilariae that appear in the peripheral blood at night. It is transmitted in rural environments mainly by *Anopheles* mosquitos and in urban areas, where it is becoming an increasing problem, by *Culex* mosquitos. In the more easterly Pacific islands the microfilariae are diurnally subperiodic (largest number during the day and an appreciable number during the night) and the vectors are day-biting *Aedes* mosquitos. Many of the epidemiological features of the infection vary from place to place according to the habits of the particular vector mosquito.

*B malayi* also occurs in two forms. One is a nocturnally periodic infection confined to man and spread by anophelines and *Mansonia* mosquitos. The other is the nocturnally subperiodic form, which has an animal reservoir, and is transmitted by *Mansonia* mosquitos.

### Clinical features

Acute manifestations may occur at any age after the first or subsequent inoculation of infective larvae. They may be more severe in people first exposed in adult life, such as short-term visitors to the tropics, and they may appear as early as three months after the person is bitten by infective mosquitos. They are characterised by recurrent episodic attacks of fever and adenolymphangitis, usually in a superficial lymph node and its vessels. The lymphangitis is typically retrograde, and there may be considerable oedema of the limb or part affected. Bancroftian filariasis affects especially the lymphatics in the spermatic cord and testis giving rise to funiculitis, epididymitis, and orchitis; or it may affect the legs or arms. In Brugian filariasis the inguinal region is most affected, the arms to a less extent, and the genitals are spared.

Recurrent acute attacks, with the residual swelling subsiding less and less each time, may eventually lead on to hydrocoele, elephantiasis, chyluria, etc. Such manifestations are becoming increasingly rare as a result of earlier treatment of the acute manifestations. They are likely to be encountered only in people born, bred, and living for a long time in the endemic area.

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