Setting up terminal care units*

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SUMMARY. From my experience the main problems found by developing terminal care units have been: initial acceptance from existing medical disciplines; communication difficulties and misunderstandings because of them; mistakes in planning and design, possibly due to lack of experience or attention to detail; occasionally, the appointment of staff that have proved unsuitable; problems in the siting of a unit, usually due to shortage of available land. The ideal site is centrally placed in the community it serves and easily accessible to public transport.

Introduction

I FIRST became interested in the problems of setting up terminal care units about three years ago. At that time I was asked to join the Medical Advisory Committee of the Dorothy House Foundation in Bath as the general practitioner representative. In 1976 the Foundation had great plans and ideas for the future, but in practical terms it consisted of one nurse who was caring for terminally ill patients in their own homes. Now, we have a comprehensive home care service and a five-bed in-patient unit opened in September 1979. The problems have been innumerable but the results most rewarding. I personally have learnt a lot during this time and as a result feel more competent to deal with my own dying patients.

During the past year I have been extremely fortunate that with the help of an Upjohn Fellowship I have had the opportunity to visit some of the other units, both established and developing, in the United Kingdom. There is a great variety in the methods of their development and also in what they have set out to offer. They have all had teething problems and have solved them in different ways. I have attempted in rather general terms to record some of the experience gained and lessons learned.

The concept of a terminal care unit, whether it be called a 'hospice', 'continuing care unit', 'after care unit', or 'symptom control centre', seems fairly straightforward. The idea of 'the best of all possible care' for the dying patient would be accepted by all people, but great difficulties are encountered when trying to put this into practice.

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Factors affecting the development of terminal care units

Early in 1979 there were 43 separate units functioning in the British Isles, and many more in the embryonic stage of development. The progress of each individual unit has been moulded by several factors, the most important of which are as follows:

1. The type of community served, whether inner city, suburban, provincial city, or rural.
2. The vision of the individual or the steering committee setting out to provide the service.
3. The financial resources available.
4. The availability of a site for development or buildings for conversion.
5. The encouragement, or otherwise, of other established medical and nursing services.

New developments

London

New developments are taking place within the city of London, where until recently the old established hospices such as St Luke's in Bayswater and St Joseph's in Hackney were the only places specializing in terminal care. In 1968, Dr Cicely Saunders opened St Christopher's Hospice in Sydenham, and laid the foundation stone of a whole new concept of terminal care. She set out to look scientifically at symptom control and to face all the needs of the dying patient. Most of the units which have developed since then have followed in her footsteps.

The Royal Marsden Hospital in London has recently converted a ward exclusively for terminal care. This ward is used when active curative treatment is no longer possible. The pace of this ward is quite different from those in the rest of the hospital, and the aims are no longer to cure but to ensure a peaceful end for the patient. The Department of Health and Social Security

is at present looking into ways of promoting better terminal care in the large general hospitals, particularly the teaching hospitals, by considering the setting up of similar wards. The Department is also looking into the development of better education for nurses and medical students in the care of the dying in order to increase their awareness of the special needs of these patients.

In the East End of London, Dr Richard Lamerton, of St Joseph's Hospice, saw the need for a home care service and has developed what can be described as a 'first-class primary health care team specializing in terminal care'. This team includes doctors, nurses, a physiotherapist, and a social worker. I spent a week with this team and cannot speak too highly of the service they are providing. The development of high-rise flats has isolated many families and broken up communities. General practice in this area is difficult, visiting almost impossible, and many of the doctors have lock-up surgeries and are not available after 17.00 hours. Once a patient has been accepted by Dr Lamerton's team, he or she is visited as necessary and is able to call for help which is always available at any time of the day or night. Once a general practitioner has referred a patient he no longer has to take a further part in the care of that patient. This I found sad, but it was easy to understand why this happened: a good deal of time could be spent driving through heavy traffic, and waiting in traffic jams to get from patient to patient, and parking was often difficult or almost impossible. Knowing that these patients were being well cared for, the general practitioner could spend his time with other problems. I felt that in this part of London there should be many more units like the St Joseph's Home Care Unit, as there must be many more patients in need of this quality of terminal care.

Smaller towns

Units in the smaller cities and towns and those in rural areas work more closely with general practitioners. In most cases the general practitioner makes a personal referral to the medical director of the unit and often they go on a domiciliary visit together to decide on the management of the patient. Where there is a home care service it is often possible to keep the patient at home. However, where this does not exist referral by the general practitioner usually signifies the patient's need for inpatient hospice care.

Our hospice in Bath is unusual in not having a medical director, but the nurses and volunteers work with the general practitioner in looking after the patient. This has worked extremely well up to now, but problems may arise when we open our inpatient unit.

Services offered

What in fact are the services offered by the 43 units now functioning in Great Britain? These range from total inpatient care with support for the family to an outpatient advisory service for patients at home. The care is always rather special care and can be divided into four categories:

1. Physical care

This is the care of a body, the nursing of the sick patient, the control of his symptoms, dressing his wounds and generally making him as comfortable as possible.

2. Emotional care

This means not only treating the patient's anxieties and depressions but allowing him the chance to express his fears and to ask questions, and even to talk about death if he should so wish.

3. Social care

This includes care of the patient's family, assessment of the patient's home and job, and his financial and material needs.

4. Spiritual care

This is tailored to the individual patient's own wishes and beliefs.

As it takes time to give this kind of care, a very high ratio of staff to patients is required in these units.

Care at home

More and more units are developing a home care service. This is not only less expensive than inpatient care but enables more patients to be looked after. If possible, most patients would prefer to die at home and most families would prefer to look after them; with enough support, they are often able to do so. With the move towards more home care there is also a move towards more family care with support for the patient's family not only during the terminal illness but immediately after bereavement and occasionally through long-term follow-up.

Family care can include such things as simple practical help with housekeeping or children, a laundry service, home nursing, nightsitters, the loan of equipment, writing letters for patients, arranging transport to hospital and many other services. Care immediately after the bereavement can mean just someone to talk to, or helping with funeral arrangements, attending the funeral, and may extend to 'family social evenings' in the following weeks, or in many cases a card of remembrance sent on the anniversary of the death. The need for bereavement follow-up varies from family to family but is invaluable in some cases.

Setting up a hospice

NHS Funding

Most of the units in Great Britain have been conceived by the inspiration and enthusiasm of one individual. In

many instances this has been a doctor, but in others nurses, clergymen and laymen have provided the initial impetus. Their reasons for this range from deeply held religious convictions to other, very personal reasons, most commonly a distressing experience of death where, had the circumstances been different, this might have been less painful. Having been convinced that a project was possible, other enthusiasts have become involved and in most cases steering committees have been set up to investigate the feasibility of forming a unit. Early in the development of a hospice decisions have had to be made within the steering committees of how funds should be raised. Most units have felt the need for the security of NHS backing. Application for funds from the NHS are made either to the district management teams or to the area health authorities. In some cases local authorities have also been approached for joint funding with the NHS. Where the project has appealed to the district management teams or area health authorities, sums have been granted fairly readily, but often, owing to a shortage of funds, acrimonious arguments have ensued. Discussions about where priorities should lie and whether terminal care should take money away from acute services are common causes of contention. The ease with which a unit has developed, and the time it has taken, have depended largely on the relationships between the various allies and antagonists of the scheme.

Funds from other sources

Some units have been set up wholly within the framework of the NHS and others have had only partial NHS backing. Many of the units have started independently and almost all of them help in some way towards their running expenses. Most steering committees have registered as charities at a very early stage and many also have registered as companies. As these units have an emotional appeal, raising money by public subscription is often easier than with other charities. However, it still requires devoted volunteers to organize functions such as coffee mornings, flag days or fêtes. The need is a continuing one and therefore fresh ideas continually have to be sought for repeated fund raising. Public appeals can be made on television and radio, and in some cases a professional appeal director has been brought in to help with money raising. These appeals and publicity can be costly in themselves. In almost every area local charitable organizations such as Rotary, Round Table, Women's Institute or local schools have all played a part. Local firms have given donations or financed part of the equipment needed. Any gift of money which continues year after year, such as the sponsorship of a bed or a covenant, is particularly valuable. Apart from donations of money, many professional people have also given their services free of charge; they include solicitors, architects, accountants, and insurance brokers.

National Society for Cancer Relief

Of all the many charities which have helped in the setting up of terminal care units, one which must be mentioned especially is the National Society for Cancer Relief. This Society has helped, and is continuing to help, many new units to become established and also helps individual patients in time of need. The Society is also drawing together the various units throughout the country by organizing seminars whereby representatives from the developing units can meet to discuss progress. The older established hospices also arrange seminars, and more recently several weekend and week-long courses have taken place to discuss the various aspects of terminal care. I have attended day seminars at St Luke's Hospice in Sheffield, St Christopher's Hospice in Sydenham, and St Joseph's Hospice in East London. I have also been able to attend a weekend course arranged by the National Society for Cancer Relief at the University of Reading, and a week's course in Oxford on 'Symptom Control in Terminal Care'.

The site

The site of a hospice depends largely on the facilities available at the time. Units which develop within the grounds of a general hospital benefit from the facilities the hospital has to offer and can in many ways provide the broadest spectrum of care. Michael Sobell House, in the grounds of the Churchill Hospital at Oxford, is an excellent example. Patients often develop such complications as pathological fractures, paraplegia, intestinal obstruction, and haemorrhage and therefore the availability of radiology, pathology, surgery, and radiotherapy are important. A terminal care unit cannot work in isolation and needs the availability of acute medical services. In some cases land has been available within the grounds of specialist hospitals, for example, psychiatric or geriatric hospitals, and has been used for building a unit. An example is the Countess Mountbatten Home in Southampton. In some cases buildings are available for conversion as in Bath and Bristol. In other places sites have been donated or offered at peppercorn rents for purpose-built units. Some units have been exceptionally lucky in having beautiful buildings and situations; others have had to make do with lesser facilities but one thing they all seem to have in common is an atmosphere of cheerfulness and calm, combined with homeliness, a quality often sadly lacking in a busy general hospital.

Purpose-built units

The steering committees of purpose-built units can all relate unending stories of problems with planning permission, planning appeals, building contractors, building regulations, building materials and escalating costs. They can also relate difficulties with delays in every stage of development and rarely have units been able to open at the time originally planned. Having completed the building, problems have arisen with furnishing and

equipment. One lesson that has been learnt by all is that every item should be chosen with care; mistakes have been made with such things as the type of floor covering to be used in a ward and replacement can be very expensive. The sharing of experience through seminars intended to help those who wish to set up hospices will save much time, money, and discussion.

Setting goals

The early years of development of a hospice are difficult. There are so many things to get right. An enormous amount of energy and dedication is needed. It is essential to be able to accept criticism, to re-think ideas and to be prepared to start again. Staff must be taught how to accept the concept that the patient must be allowed to remain dignified until death, and that even the most difficult patient must be understood and respected. They must accept the fact that however hard they work in the end most of the patients are going to die. I say most, because all hospices relate stories of incorrect prognosis, or diagnosis, and some patients who have been referred to them for terminal care are still alive many years later. Recovery therefore not being expected, there are the smaller goals of keeping the patient comfortable or helping him to sleep through the night. Provided the goals set are to a certain extent attainable, the staff will not lose heart.

Acceptance

One of the biggest problems that has to be overcome is the acceptance of a new unit within an area. The fact that it has been conceived of at all is perhaps a criticism of the type of care that is at present being provided, and some existing medical and nursing services feel very strongly about this. Some general practitioners wish to continue to care for their own patients in their own way and will have nothing to do with the unit. District nurses may feel threatened when their patients are visited by a hospice nurse. Consultants do not always see the need for a terminal care unit, and the general public would often rather turn a blind eye to the fact that people are dying in their community. If units are to be accepted they must work with the existing services and be felt to be an asset by all those in health care.

To establish a terminal care unit requires hard work, tact, and diplomacy from those working for and within the unit. In the initial stages, particularly, they must prove their value and show that they have a service to offer. In most of the units I visited acceptance has been the big problem and the resistance from existing medical and nursing disciplines one of the biggest hurdles. Acceptance is also needed from patients and patients' families and this is made easier if the family can be introduced to the service by being offered help in small practical ways before the patient is in a terminal state of illness.

The time and method of referral is of the utmost importance. All units prefer to make contact with the patient at pre-terminal stage, at the time when active curative treatment is ceasing to be a possibility. In this way there is time to develop a relationship with that patient. Most units insist, quite rightly, that the source of referral should be the patient's general practitioner, and most units prefer the general practitioner to maintain his involvement and interest.

One factor which has to be very carefully considered is the language used in publicity literature. The brochures and pamphlets produced for patients by different units explaining how they function and what they are trying to achieve take many hours of careful preparation. Some brochures, by trying to avoid the word terminal, have never quite managed to explain clearly their aims and function. It is very difficult to put into words what terminal care entails without evoking a certain amount of anxiety. Appeals and publicity brochures must therefore be extremely carefully worded. On occasions badly worded reporting in a newspaper has caused considerable upset and distress to a unit struggling to get off the ground, and also distress to existing services who have been reported as "not coping".

Organizing a unit

Staff

Once a terminal care unit is completed and begins to function, what may have started as an emotional ideal becomes a practical reality. An increasingly large number of people are needed to look after the functioning unit. These will include a medical director or in some cases a medical advisory committee, consultants to deal with specific problems, and doctors to help run the unit; these may include local general practitioners, rotating senior house officers, general practitioner trainees, and in some cases medical students on attachment. Both day and night nurses are needed for the inpatient beds, and domiciliary nurses for a home care service. It is generally agreed that these nurses need special training and provision has to be made for them to attend training courses at the established hospices. Auxiliary nurses, secretaries, social workers, occupational therapists, physiotherapists, cooks and cleaners are also needed. From the moment of employment of the first staff, such administrative matters as contracts, superannuation, and car allowances come into play and the question of union membership also has to be considered.

Volunteers

Volunteers provide a valuable workforce but in order to use this efficiently a volunteer organizer is essential. Volunteers can be numerous at the start but a well organized volunteer course will often identify those people who have a genuine intention to help.

Problems of design

The patients by definition will be extremely ill, often with bed sores, incontinent, or with fungating wounds.

Their mobility will be restricted and all these factors must be taken into account in the design and planning of the hospice. Specially engineered equipment is available, for example, water beds, extractor fans with built in deodorizer, flushing commodes, and many other aids. The screening of beds, removal and storage of bodies, access of undertakers particularly in the smaller units without several entrances, are all problems that have to be overcome.

The starting of a new unit is the ideal opportunity of doing things right from the start. There is the chance to design good systems for storing and recalling data, and developing systems for coping with enquiries and donations.

Keeping people informed

Enquiries about the hospice should always be answered and donations, however small, should be acknowledged. Keeping people informed is also important and very often the distribution of newsletters is helpful. Successful units have considered all these facts; others have made mistakes by overlooking one or more of them.

Role of religion

Something I feel I must mention, as it is so very important, is the place that religion plays in terminal care units. Many are Christian Foundations but in these units I have met staff of all types of beliefs and many with none at all. Prayers are often said at the hospices and services are available for those who wish to attend. However, I have never found any patient who has felt any pressure put upon him to alter his own beliefs or has been embarrassed by the beliefs of those around him. Prayers are more often silent than spoken, and I have been greatly impressed by this aspect of the care, and also by the fact that the staff are chosen for themselves rather than for their religious beliefs. I am sure that no-one need feel any fear of religious persuasion. Most units have a chaplain or a priest available if the patient should wish to see one, but no pressure is put on the patient to do so.

Role of the psychiatrist

Units which have included a psychiatrist as a member of their team have found him or her to be valuable not only in advising patients and relatives but also in helping the staff with their problems. The staff of hospices are not immune from such feelings as distress, anger, and occasionally even a dislike of a patient or task they have to do. Often they feel guilty at not being able to rise above these feelings, and being able to discuss this with a psychiatrist can be of great benefit.

Education

With the vast increase in the number of units being set up education is becoming an important factor in this work. Many new units are finding that within the first year or so they are being asked to train staff. All units already functioning are finding educative work a much larger task than they had anticipated. They are having to teach while they themselves are still learning. As well as the teaching of professionals, there is lecturing to the public and the teaching of volunteers. Doctors and nurses with an ability to speak well may find that they are being asked to lecture time and time again. This can be exhausting, but it is also invaluable because it helps to train more and more people towards giving better care. St Christopher's Hospice now has a large Education Centre and undertakes a great amount of teaching on terminal care. Students and visitors come from all over the world to the study days and there is also a large comprehensive library from which literature is easily available.

Conclusion

The hospice movement is one of the rapidly developing facets of health care at present. In recent years physicians have been appointed as consultants in terminal care and by the careful monitoring and control of symptoms a subtle change is taking place whereby the art of caring for the terminally ill is developing into a science. I am sure that with the trend towards better education, the sharing of new ideas in symptom control, and a more open approach to the problems of dying, many more patients are going to benefit from the hospice movement.

Acknowledgements

It has been a great privilege to be able to visit the various units and to meet the people involved in running them. The feeling one gets within the hospice movement is that of joining an ever-increasing family. I would like to thank all those people who have been so kind in showing me their units and discussing their problems. I would also like to thank Upjohn for giving me the opportunity to develop this interest.

Life events and illness

The relationship between life events and the onset of organic physical illness has been studied in a group of women in the general population. The link between severe events and the onset of organic illness, which held only for women of 50 years or younger, was not a direct causal association but mediated by an intervening psychiatric disturbance of an affective kind, all occurring within a six-month period. The findings are discussed in the light of the high psychiatric morbidity found in physically ill patients.

Reference

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