

Psychosocial issues in palliative care

The quality of life for patients and the manner of their dying is sometimes more influenced by psychosocial factors than by physical status.



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Ever since the original concept of total pain, with its physical, emotional, social and spiritual components, the demands of palliative care have been met by expanding expertise. Palliative care is a team effort and its impact is unique in that it results from a combination of skills. It includes every approach that assists patients and their families to find their own strengths for a journey that is unique to each person.

'Helping people discover life while losing it, is the day to day stuff of palliative care.' —
David Oliviere¹

There is a psychosocial dimension to the work of all involved in palliative care and understanding this will strengthen the practice of any professional working in this area. It is far less clear cut than working strictly in physical care. The very nature of the work entails ambivalence and uncertainty, with the results of the interventions less immediate and often intangible.

FAMILY

'Cancer can affect a family in much the same way as it affects a body – causing deterioration if left untreated.' — Colin Murray Parkes²

Intrinsic to palliative care is the recognition of the family as the unit of care and their support and education are vital. A patient is treated not only as an individual with problems and symptoms but also as a family member whose reactions interlock with the support system. Losses suffered by the patient will be experienced in parallel by the family. Despite the fact that family members come from the same unit with the same cultural, spiritual and psychosocial background, they each have their own needs, expectations and rights.

As such, it is important to give time to family members to talk as individuals as well as in a group.

The close connection between the family, the patient and the disease is depicted in Fig. 1.³

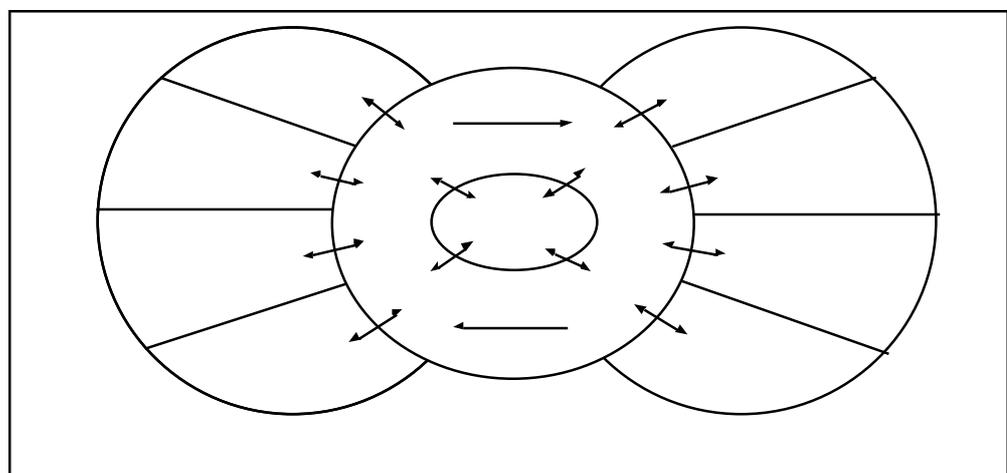


Fig. 1. The close connection between the family, the patient and the disease.

MAIN TOPIC

In palliative care, the creation of a safe space for families to talk is important. Communication becomes constricted as members try to protect one another from painful feelings. Families need help as the patient either withdraws, or wants constant attention.

Three major issues emerge even in well-functioning families:

- acquiring information
- concealing feelings
- coping with helplessness.

Neutrality is important and at all times practitioners should be sensitive and aware of their role within the family. Monroe⁴ warns: 'If the family finds balance only with, and in your presence, you have become part of the problem, rather than helping them find a solution.'

The diagnosis of terminal illness is traumatic for everyone and knowledge and understanding of the crisis is important as everyone's realities change within seconds. All that was once certain becomes uncertain and the emotional and physical resources of the entire family are threatened. In addition, referral to a palliative care service, even when actively sought, is experienced as a major crisis.

Note: In palliative care 'family' often means more than blood ties with the patient. It stands for those relationships that are significant for the patient — a network of attachments existing within a social and cultural context. Thus friends, neighbours and work colleagues may be equally important and equally affected by the diagnosis of terminal illness.

CHILDREN

'We live in a culture that prefers children to be seen, but not sad.' — Julie Stokes⁵

Care offered to the patient and family is incomplete without con-

sidering the children, for whom parents usually require extra support and reassurance.

Monroe⁴ tells us that children learn to mourn and to grieve healthily by observing others and that there is usually no choice about whether or not to communicate with them because:

- they read emotions around them
- they respond to body language
- they are aware of changes in routine.

Parents must be treated as colleagues — after all they know their children best. When talking to children:

- information has to be clear and truthful and to proceed at the children's pace
- children facing death need reassurance about their own continuing care and will be enormously relieved when these issues are openly discussed
- children need support not protection in their sadness and have a surprising capacity to deal with the truth.

Teenagers appreciate time alone with the practitioner. They should be encouraged to speak out rather than act out.

LOSS

'There is only one obvious lesson to learn about other people's grief — to believe what they say about it.' — Polly Toinbee⁶

An understanding of loss, grief and bereavement is necessary for all who work in palliative care. The journey through life-threatening disease is marked by losses — some come early and others later in the disease process. Grief is the reaction to loss and if patients and their families are helped to express this, they usually cope more effectively with the disease process.

Dealing with loss takes time. Grief

is not linear and often it is a matter of two steps forward and one back. Some will continue to hope and expect to get better. For this group, denial is a powerful coping mechanism — not necessarily abnormal or pathological — allowing time to come to terms with a new reality. There is usually little to be gained from forcing the issue. Indeed, by shattering even unrealistic hope, we run the risk of stripping individuals of ways of coping.

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We should rather listen to patients and families — to their grounds for hope and reasons for holding on to it, and assist them in identifying new hopes when they are ready.

How can we help those who will never accept this situation? Perhaps only by understanding and acknowledging the need.

Examples of loss

- Loss of 'big' world
- Loss of strength and physical function
- Loss of independence
- Loss of body image
- Loss of role in family, workplace
- Loss of self-esteem
- Loss of sense of control
- Loss of future

'Fear is the psychological reaction to danger. The list of physical symptoms

that can be caused by fear is long, ranging from the physiological effects of disturbance of the autonomic nervous system, to the secondary effects of over-breathing. When they occur in people who are already physically ill, the resulting tangle of physical and psychosomatic symptoms is not always easy to unravel. — Colin Murray Parkes⁷

Many problems arise from fear. Time is needed to create the trust in a relationship that is important to help patients and family feel safe enough to talk to us about them. We may need to invite the questions by showing that we are unafraid to speak about the ‘unspeakable’.

Fear often builds fear and a regular consultation with a trusted professional can often break this vicious circle. Honest reassuring discussion, normalising fear, is usually sufficient.

Examples of fears

- Fear of separation from loved ones
- Fear of isolation
- Fear of loneliness
- Fear of being a burden/helplessness
- Fear of pain or other symptoms
- Fear of leaving unfinished tasks
- Fear of dying

SEXUALITY

Professionals working in palliative care must be prepared to help patients and their partners with their sexual needs. This whole area is thought of as being a particular specialty but in fact the same communication skills are required as for any sensitive topic.

People often have questions about the sexual side of life but practitioners usually need to encourage

discussion of sexuality and to respond to cues with a reasonable degree of comfort. More than anything, couples need to know that this is an acceptable subject. Graded open questions often help, for example, ‘has your illness changed your life as a couple?’

As with any other component of care, fears should be anticipated, expectations explored and problems normalised. It is important to remember that couples need to be seen separately as well as together. Most couples do not expect all the answers but appreciate a warm, sympathetic straightforward approach. A sense of humour assists with any difficult moment and is greeted with relief!

SPIRITUALITY

‘The Gods were arguing about where to hide the secret of life so that men would never find it Bury it under a mountain, said one God Put it in the ocean, said one God Put it inside them, a third God said They will never think of finding it there. The gods agreed’⁸ — Dossey⁸

Many people regard religion and spiritual as interchangeable terms but an appreciation of the difference is important when working in the palliative care setting. Leonard Lunn⁹ tells us that ‘a foundational principle of effective spiritual care is to recognise that it is much broader than religious concerns. Religion might be seen as the corporate, organised outward expression of a belief system. The spiritual dimension is common to us all and is concerned with a search for meaning.’

Spiritual support:

- elicits the awareness of the inner journey of the soul
- is a response to a patient’s individuality

- enhances the sharing of beliefs and values
- seeks to give permission to the expression of anger
- assists the patient to be at peace with the inexplicable and not try to answer the unanswerable.

It is to be involved with respectful listening, a response of acceptance, an openness to individuality. . .to be a presence.

CULTURE

‘In order to understand patients and families you need to understand where they are in their culture.’ — David Oliviere¹⁰

The goal in providing culture-sensitive care is to be sensitive and aware of the beliefs, values, traditions and practices of others and to respect them when providing care even if they are quite different from your own. People tend to categorise and/or generalise to make sense of other cultures but it is important to avoid becoming rigid and unrealistic. For example, not every Jewish person keeps Kosher or every Catholic wants to say the rosary. While every culture may have its tendencies, many people are subject to several cultural influences.

Association with a particular cultural, ethnic or religious group may influence:

- expression and meaning of pain and suffering
- attitude towards disclosure and awareness
- beliefs about the cause and meaning of illness
- choice of healer and treatment regimen
- attitude towards death and dying
- beliefs about the afterlife
- the value of human life and the body
- expressions of loss and grief

MAIN TOPIC

- death rituals including preparation for burial, funeral practices or memorial services, customs for disposing of the body and mourning rites.

The desire to tell or know the truth about illness or death is clearly a Western cultural value. People have the same right not to know as they have to know. For example, death as understood in the African tradition is not seen as the end of life, but as a physical separation from other human beings.

Helpful points about African culture:¹¹

- The community is holistic and religion permeates all aspects of life.
- There are different perceptions within each ethnic group resulting from westernisation, evangelism and urbanisation.
- The broader understanding of the concept of home as different from the ordinary residential place plays an important role in the approach to death and dying.
- Healing is also holistic, seen at different levels, and sometimes consists of preparation for death.
- Death is a rite of passage from the physical to the spiritual world.
- Death should occur in a home where the original community of the dying person and his or her family reside.
- When someone is dying, those who will be left behind are gathered together to hear the dying person's last wishes.
- There is wariness of a post-mortem examination as it results in an incomplete human being making the journey to the spiritual world.
- It is important for the dying to know that they are leaving a harmonious family group behind. There is a definite preference to

create the setting for this out of the hospital environment.

FINANCIAL ISSUES

No effective work can be carried out if patients and families are worrying about the loss of income. Identifying financial needs is essential, particularly with families who have to deal with poverty, unemployment and poor housing. The role of the palliative care professional in this area is mainly one of referral. For example, knowing where to refer for poverty alleviation programmes and state grants is very important. Discussing a will is often a difficult subject for patients and families — but once completed, this concern is easily put aside. Patients feel far more in control and less of a burden to others if their financial affairs are in order.

CONCLUSION

Patients who have a short life expectancy face loss at every level — physical health, independence, career and status, normal family life, predictability and future, motivation and meaning.

The journey from life to death is different for each person and family, and in the end death is still a very personal and individual event.

The journey from life to death is different for each person and family, and in the end death is still a very personal and individual event. It is my firm belief that illness and loss represent more than simply a

crisis for patients and families — they also present a remarkable opportunity for self-awareness, change and growth.

No article of this nature would be complete without my thanking the patients and families with whom I have been privileged to work, for allowing me into their lives to bear witness to their courage.

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FURTHER READING

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IN A NUTSHELL

There is a psychosocial dimension to the work of all professionals involved in palliative care.

Patients with life-threatening illness experience a series of losses as the illness progresses.

Patients' symptoms and families' reactions are not unrelated and addressing both aspects is healthier for both.

Never underestimate the therapeutic value of listening empathetically to 'the story'.

By shattering even unrealistic hope, we run the risk of stripping the ability of patients and family to cope.